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Inquiry into end of life choices

Final Report

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Committee functions

The Legal and Social Issues Committee (Legislation and References) is established under the Legislative Council Standing Orders Chapter 23 – Council Committees, and Sessional Orders.

The committee's functions are to inquire into and report on any proposal, matter or thing concerned with community services, gaming, health, law and justice, and the coordination of government.

The Legal and Social Issues Committee (References) may inquire into, hold public hearings, consider and report on other matters that are relevant to its functions.

The Legal and Social Issues Committee (Legislation) may inquire into, hold public hearings, consider and report on any Bills or draft Bills referred by the Legislative Council, annual reports, estimates of expenditure or other documents laid before the Legislative Council in accordance with an Act, provided these are relevant to its functions.

Government Departments allocated for oversight:

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- Department of Justice and Regulation
- Department of Premier and Cabinet

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This report is available on the Committee's website.

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Terms of reference

Inquiry into end of life choices

On 7 May 2015 the Legislative Council agreed to the following motion:

That pursuant to Sessional Order 6 this House requires the Legal and Social Issues Committee to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

Chair's foreword

Death and taxes, the two certainties of life. Little has changed since this saying was coined several hundred years ago.

What has changed, however, is our understanding of death.

To past generations, death was familiar. Now it is often out of sight and shrouded in mystery.

Recent generations have been the beneficiaries of remarkable medical advances, so that illness and disease that once resulted in death, are now routinely treated, managed or cured.

We are living longer, fewer young people die and we have an expectation, sometimes falsely, that appropriate medical intervention can cure virtually all serious conditions.

For many of us, this has resulted in death being rarely seen, little understood and rather than occurring in the family home as once was the norm, is now removed to a hospital, nursing home or other medical facility.

Although most Victorians express a wish to die at home, only 14 per cent do.

When death is confronted, it is often too late to enable the patient's end of life choices to be clearly communicated and implemented. This needs to change.

Communication is a two way street and it is clear that as medicine has become more specialised, with often no single practitioner having responsibility for overall patient care, difficult discussions about a person's likely trajectory towards death may be avoided. This needs to be addressed.

We need to have conversations about how we envisage our own end of life taking place and then communicate those with loved ones, our GP and relevant health practitioners. The sooner these conversations take place, the better.

A person's wishes must also carry legal weight. That is why advanced care plans should be legally binding for future, and not just current, medical conditions. The medical substitute decision making framework should also be centralised and streamlined.

An advanced care plan should also record the person's values to inform the nature and extent of treatment when the person is no longer competent.

To increase the use of advanced care plans, certain conversation trigger points should be nominated, such as entry to residential care, as part of over-75 health assessments, or when it is clear to the medical professional that an individual is likely to die within 12 months.

Palliative care has improved significantly in the last 20 years. In the vast majority of cases (but not all), pain and suffering can be treated to the satisfaction of the patient.

However, while palliative care has improved, its provision can be inconsistent, particularly in rural and regional areas. The ageing of the population will only increase the pressure for additional services. Further resourcing will be necessary into the future.

Victoria is lucky to have so many amazing community palliative care volunteers, providing respite, comfort and understanding. The Committee met with volunteer groups from across Victoria including Geelong, Colac, Warrnambool, Portland, Hamilton, Shepparton and Gippsland. We are lucky to have them all and we owe them a vote of thanks for their care and compassion.

For doctors, helping patients who are at the end of life can be difficult. It is important they have clear legal protection to enable them to provide the care that patients need. That is why the common law doctrines of double effect and withdrawal of futile treatment should be codified to improve clarity and certainty for health practitioners.

Continuous palliative sedation is widely accepted as an appropriate way to relieve suffering for someone at the end of life. However, unlike some jurisdictions, its use is not centrally recorded, the extent of its use is unknown, and no guidelines exist to regulate it. This should change to provide direction for doctors and to improve transparency.

Laws regarding providing assistance to die are inconsistent. On one hand, doctors, on a patient's request, can withdraw life sustaining treatment with death the certain outcome, while they can also deliver lethal doses of morphine and other drugs, as long as the intent is to relieve pain. On the other hand, a loving husband who assists his frail, suffering and near death wife to die could be guilty of murder, while a person near death and in unacceptable pain, cannot receive help to end their own suffering.

The legal system in Victoria understands these inconsistencies. Despite significant examples of death taking place in the shadows of the law, prosecutions are rare and the penalties applied are generally so light as to risk undermining the law. Indeed, in the case of *DPP v Rolfe*, Justice Cummins said to Bernard Rolfe, after he pleaded guilty to manslaughter and received a two year suspended sentence, 'your actions do not warrant denunciation; you should not be punished; there is no need to deter you from future offences ...'.

However, while the law can show great flexibility in dealing with such cases, it does not mean the status quo serves Victorians well. With a lack of end of life choices, many older members of the community are taking their own lives, often in horrific circumstances. While some argue that the needs of such people can be addressed with appropriate palliative care and mental health services, the

Coroner said, ‘people who have invariably lived a long, loving life surrounded by family die in circumstances of fear and isolation’ and that, ‘The only assistance that could be offered is to meet their wishes, not to prolong their life.’

As former Supreme Court Judge John Coldrey said, ‘these cases don’t sit comfortably in a court setting. The person goes out into society labelled a murderer when their motive has been compassion and love ... I’d like to see a regime where people who act in this way are not put at risk of criminal charges.’

While the shortcomings of the current system in Victoria were apparent, the Committee was also concerned about the risk posed by change, both to individuals and the impact on institutions over time. We were warned against change on the basis of what, purportedly, has occurred in jurisdictions that have legalised assisted dying. To evaluate these claims, five members of the Committee travelled to the Netherlands, Switzerland, Canada and the US State of Oregon in late March to early April 2016. We met with academics, regulators, health care professionals, supporters and opponents of the different legalised assisted dying frameworks.

While these jurisdictions differ significantly in their assisted dying models, what they all have in common is robust regulatory frameworks that focus on transparency, patient-centred care and choice. We found no evidence of institutional corrosion or the often cited ‘slippery slope’. Indeed, the regulatory framework has been unchanged in Oregon, the Netherlands and Switzerland for many years.

Given the conflicting evidence regarding practices and occurrences in these jurisdictions, the trip was very important for developing an understanding of the facts about how these systems work.

In recommending an assisted dying framework for Victoria, the Committee has sought to adopt the best elements of these jurisdictions and mould them to the Victorian context. The proposed model contains several significant checks and balances that seek to protect individuals from exploitation, while facilitating choice in certain limited circumstances.

The Committee has sought to strike an appropriate balance between respecting the end of life choices of Victorians while recommending a sufficiently robust eligibility framework for competent adults that protects against abuse.

Like in other jurisdictions, the Committee anticipates that while a comparatively small number of Victorians will die using the assisted dying framework (approximately 0.4 per cent of all deaths in Oregon and Switzerland), many others will take comfort from its existence, knowing that another option exists.

The Committee recognises that assisted dying is contentious, that is why there should be no legal, moral or ethical compulsion on any individual or institution to participate in any part of this process, including through referral.

The Committee is indebted to all those who made submissions to this Inquiry and from whom the Committee received evidence. We were fortunate to benefit from the knowledge of a range of eminent experts in end of life care. We were deeply moved by those who, despite suffering serious illness, had the courage to tell their personal stories.

The Committee was very fortunate to have such a dedicated team who worked extremely hard to help table this Report within the time stipulated by the Legislative Council's resolution. In particular, I would like to pay tribute to Lilian Topic, Committee Secretary, for her dedication and leadership, and to thank the Secretariat of Joel Hallinan, Matt Newington, Caitlin Grover and Esma Poskovic for their commitment to the work of the Committee on this Inquiry.

Finally, I would like to thank my parliamentary colleagues on the Committee for the way they have worked together over the past 10 months to respond to challenging terms of reference.

I commend the Report to the House.



Hon Edward O'Donohue MLC
Chair

Executive summary

Chapter 1

Chapter 1 of the *Inquiry into end of life choices — Final Report* provides an overview of the Inquiry methodology and key issues raised in the Report.

The Legal and Social Issues Committee received the terms of reference for the Inquiry into end of life choices from the Legislative Council on 30 May 2015. The Report is a culmination of the Committee's extensive research and consultation process.

During the Inquiry the Committee received 1037 submissions, 925 from individuals in a private capacity and 112 from organisations. The overwhelming majority of individual submissions discussed assisted dying. Only a small number focused solely on palliative care.

The Committee also conducted an extensive program of site visits and public hearings around Victoria between July 2015 and February 2016. The Committee held 17 days of public hearings and heard from 154 witnesses.

In addition, the Committee travelled to the Netherlands, Switzerland, the Canadian province of Québec, Canada and Oregon, United States to speak to stakeholders about their jurisdiction's assisted dying framework. Each of these jurisdictions has a unique legal framework permitting assisted dying.

Key findings

The Committee has identified a number of key themes, issues and concerns that were raised during the Inquiry. They are also common themes in reviews that have been conducted internationally.

The key findings of the Report are:

- As a society, we are hesitant to talk about death, which is considered a taboo subject. This inhibits planning for end of life care, and may result in a person's end of life wishes not being followed.
- Although most people in Victoria wish to die at home, in reality most of them will die in hospital.
- Demand for palliative care is steadily increasing, and is expected to continue to do so. At the same time, palliative care patients' diseases and needs have increased in complexity. As such, Victoria's palliative care sector is overburdened and needs better support from government.
- Despite Victoria having good palliative care services available, those who could benefit the most often receive care too late.

- Carers and the volunteer workforce are integral to Victoria's palliative care system.
- Although the advance care planning process has proven benefits, there are low awareness and implementation rates for advance care plans in Victoria and Australia.
- Existing end of life care legislation is confusing in many ways, and causes uncertainty, particularly for health practitioners.
- The legal framework for advance care planning spans several Acts and some legal issues may rely on common law rulings. Substitute decision making provisions are confusing and poorly understood by doctors. In addition, the law does not provide certainty that a person's wishes detailed in an advance care plan will be carried out when they lose capacity.
- Prohibition of assisted dying is causing some people great pain and suffering. It is also leading some to end their lives prematurely and in distressing ways.
- Instances of assisted dying are rare, even in jurisdictions where it is legal. Assistance in dying is, in the vast majority of cases, provided to people in what would otherwise be the final weeks of their lives.
- Government support and funding of palliative care has not declined when assisted dying frameworks have been introduced.
- Courts invariably impose lenient penalties without jail time on people who assist a loved one to end their life. This is true in Australia and in similar overseas jurisdictions.
- Everyone's end of life care needs differ. It is important that Victoria has a system in place to cater for the needs of individuals, whilst ensuring that there are safeguards in place to protect vulnerable people.

Core values

The Committee has defined a set of shared core values for end of life care. These provide an understanding of the beliefs that underpin the Committee's approach to this subject.

These are intended to assist in providing the reader with an understanding of areas of broad agreement that provided guidance for our discussions and for the drafting of this Report. These values are based on what the Committee has learned throughout the Inquiry process.

Box 1.1: Core values for end of life care

Every human life has value

Every individual person has inherent value.

Open discussion about death and dying should be encouraged and promoted

Death is an inevitable and natural part of life. It is human nature to fear death, however by acknowledging our own mortality through open discussions with health practitioners and family we can plan for our death.

People should be able to make informed choices about the end of their life

An adult with capacity has the right to self-determination. This is a fundamental democratic principle which should be respected. Information on end of life choices must be clear and accessible.

End of life care should be person-centred

The focus of medical treatment has shifted in recent times from a 'doctor knows best' mentality to patient-centred care. End of life care should be no different.

End of life care should address the needs of families and carers

The end of a person's life is a very stressful time for their families and carers, and can take a toll on their physical and mental health. End of life care services should extend to and provide assistance to families and carers during this difficult time.

Pain and suffering should be alleviated for those who are unwell

Not all treatment is beneficial for those at the end of life. Treatment provided to a 20-year-old may not be appropriate for an 80-year-old. The goal of end of life care should be to minimise a person's pain and suffering.

Palliative care is an invaluable, life-enhancing part of end of life care

Palliative care provides much needed pain relief for people during the end of their life, and provides comfort to their loved ones and carers. Palliative care often prolongs life.

High quality end of life care should be available to all people in all settings

People should be able to plan for death in their preferred setting.

Each person should be entitled to core rights in end of life care

All forms of discrimination in end of life care should be ended as far as possible, whether based on geographical location, physical condition, ethnicity or wealth.

Vulnerable people should be supported and protected

End of life care should focus on relieving pain and suffering. Safeguards need to be in place to ensure that vulnerable people are not pressured or coerced into making decisions that they do not want to.

The law should be coherent and transparent

Health practitioners and patients should be fully aware of their legal rights and responsibilities in end of life care.

The law should be followed and enforced

The purpose of end of life legislation should be to provide for end of life choices for patients and protection for doctors. Breaches of laws should be penalised appropriately.

Chapter 2

Chapter 2 discusses current approaches by governments to palliative care, including the policy and legislative framework for the sector at local, Victorian and national levels. It also briefly discusses the Victorian Government's review of the state's end of life care framework, which was conducted simultaneously with the Inquiry.

Palliative care is a multi-disciplinary approach to managing a person's illness. This includes both pain relief and symptom management for the person themselves, and support for their family and carers.

Demand for palliative care in Victoria has steadily increased in recent times. This is forecast to continue.

The majority of palliative care services are provided by non-government organisations. According to a 2015 review of Victoria's hospital capacity, of the 23 128 contacts of palliative care provided in Victoria in 2014–15, 16 442 were provided by non-government organisations and community health services.

Community palliative care is an essential part of Victoria's palliative care services. It provides comfort to patients, their family and carers, and allows people to die in their place of choice. It also provides a financial benefit to the health system. Community palliative care services include in-home care, day hospices for respite care and after-hours support. Support is also provided to carers through respite, counselling services and bereavement support.

Victoria's palliative care professional workforce is predominantly female and most of the workforce are nurses. Most work part-time and most are employed in inpatient or consultancy settings.

Volunteers provide a significant contribution to the Victorian palliative care workforce, to patients, their families and to the Victorian health system as a whole. The combined hours worked by these volunteers amounts to 30 per cent of the paid full-time equivalent workforce. Volunteers are predominantly older, female, and work mostly in community palliative care. The vast majority are retired or work part time.

Governance of the Victorian palliative care sector is provided at state, regional and Commonwealth levels. Palliative care is primarily the responsibility of state and territory governments. Regional groups provide input on local practices and issues, and the role of the Commonwealth is to provide guidance to ensure some consistency of practice between the states.

The Department of Health and Human Services is the lead agency of the Victorian palliative care sector and coordinates service provision across the state. Coordination at a regional level for Victoria's palliative care sector is provided by regional consortia. The Commonwealth Government provides support and guidance to the sector through national guidelines and funding as part of subacute care services.

Chapter 3

The evidence that the Committee heard on palliative care generally dealt with our ageing population which is resulting in an increased demand on palliative care, discussed the need to improve existing standards of palliative care and highlighted various opportunities for improvement.

The Committee recommends improvements to Victoria's palliative care sector which if implemented would assist it to move towards a community-based approach to providing end of life care.

Victorian services provide a high standard of palliative care to patients. These services benefit a large number of Victorians and the community in general. However, increased demand in recent times, caused by an ageing population and changing disease profiles, has put a strain on the system. This has created a number of challenges for the palliative care workforce.

There are gaps in quality and provision of palliative care in Victoria. Palliative care services are not easily accessible for people living in rural and regional areas. Aged care facilities are a common and well-suited site for palliative care provision. However, there is a considerable variation in the quality of end of life care provided by Victorian facilities.

In addition, there are particular challenges in providing palliative care to specific groups of people, which results in their underrepresentation in palliative care. These include Aboriginal and Torres Strait Islanders, culturally and linguistically diverse people, and people with a disability.

The type of illness a patient suffers can be a factor in the palliative care a patient receives, particularly as an increased focus is required for patients with diseases other than cancer. Palliative care provision is fragmented between services and at times poorly integrated with the rest of the health system. Inadequate community palliative care results in increased avoidable hospital admissions and greater pressures on emergency departments, which often end up providing end of life care. With this comes increased cost for acute patient care in hospitals.

Community palliative care services currently lack the capacity to sufficiently and effectively care for patients in their place of choice. This includes those who wish to be cared for and die at home, in a hospice, or aged care facility. As such, patients are being cared for and dying away from their place of choice. Obstacles to caring for and allowing people to die in their place of choice include location, lack of after-hours service and poor access to medication.

The Committee also heard extensive evidence that health practitioners need to be trained in:

- identifying when end of life care options should be discussed
- communicating about end of life care matters
- making referrals to palliative care services
- providing palliative care.

Family and carers of patients near the end of life play an extremely important role. They put their own lives on hold in order to care for a loved one as they die. Carers take on an incredible burden and risk ‘burning out’ while caring for a person if they cannot cope with the intensity of the role.

A variety of palliative care concepts and practices may be affected by end of life law. These include:

- the doctrine of double effect
- continuous palliative sedation
- protection for doctors withholding or withdrawing futile treatment.

The law surrounding them is based in common law rulings, and these concepts are not always properly understood by health practitioners, let alone patients. The Committee also heard disagreement about whether some of these concepts and practices constitute assisted dying.

Through proper support and awareness of Victoria’s palliative care services the Committee believes it is possible to improve the number of people who die in their place of choice.

Chapter 4

Chapter 4 discusses the role of advance care planning in end of life care. It also analyses the legislative framework for advance care planning in Victoria and other Australian jurisdictions.

Advance care planning is the process for an individual to plan for their medical treatment preferences in the event they become too unwell to make the decisions themselves. The process is used to communicate a person’s values and desired health outcomes to help guide medical practitioners, family members and others to make medical decisions in their best interests. Advance care planning is undertaken by people of all ages and levels of health.

Substitute decision makers are an important aspect of advance care planning. ‘Substitute decision maker’ is a generic term for a person who has been appointed or identified as having authority over medical treatment decisions when a patient lacks capacity. They may be appointed by the patient in advance or a nominated authority under legislation.

Victoria’s advance care planning laws have lagged behind other Australian jurisdictions and have seen little change since their introduction in 1988. Currently, a refusal of treatment certificate is the only legally-binding advance care plan a person can make to specify their future treatment wishes. The refusal of treatment certificate is also limited to current medical conditions.

Victoria’s legislative framework for substitute decision makers is convoluted and difficult to interpret. This can lead to problems and disputes when end of life care decisions need to be made on a patient’s behalf.

Although common law rulings in Australia have upheld individuals' advance care plans, there is some uncertainty about whether this would apply in Victoria due to provisions of Victoria's framework for substitute decision makers.

Victoria's health services provide support and resources to patients to prepare and document advance care plans. Despite this, the uptake of advance care planning is relatively low in Victoria and Australia-wide.

Chapter 5

Chapter 5 recommends legislative reform to simplify and strengthen Victoria's advance care planning system. In particular, it proposes introducing instructional health directives that include legally binding provisions and that cater for future medical conditions. The chapter also makes recommendations to streamline Victoria's medical substitute decision making framework.

Approximately 85 per cent of Australians will die after a chronic illness, not a sudden event and up to 50 per cent will be incapable of making their own decisions at the end of life. Despite the foreseeability of the dying process and the benefits of advance care planning, very few people have advance care plans.

As a community, our unwillingness to talk about dying is a major obstacle to advance care planning. Proper community education is essential to encouraging people to plan for their death. An overwhelming majority of people who create an advance care plan choose to receive palliative care at the end of life rather than life-prolonging measures.

Research shows that patients expect their doctors to initiate advance care planning conversations. Many doctors, however, find such conversations difficult and have inadequate training in advance care planning and end of life care communication. Doctors and medical professionals need proper education and support to initiate difficult conversations about dying with patients and their relatives.

Accessibility of advance care plans is one concern that relates to a broader problem that take-up of advance care planning needs to be improved in Victoria. An advance care plan is useful only insofar as it is accessible at all points along the treatment spectrum, from the general practitioner, to the palliative care specialist, the oncologist and the emergency department.

Victoria's advance care planning legal framework, particularly substitute decision making provisions, needs to be simplified through reform to provide legal certainty for doctors and patients.

Chapter 6

Chapter 6 discusses the current legal framework for assisted dying in Victoria. It describes how courts are invariably lenient on people who assist a loved one to die. It also notes that no doctor has yet been charged for crimes related to assisted dying.

Assisted dying is illegal in Victoria. Inciting suicide and aiding and abetting suicide are also illegal. Despite this, the Police, the Office of Public Prosecutions, and the judiciary are reluctant to pursue harsh penalties for those who assist loved ones to die.

Although the particular circumstances of a case may meet the legal requirements of a murder or manslaughter charge, those accused of assisting another person to die are invariably charged with lesser offences.

While these outcomes may appear just on a case-by-case basis, the reliance on individual discretion to achieve just outcomes rather than the systematic implementation of the law threatens to undermine public confidence in the administration of justice and bring the law into disrepute. It also suggests that the law as it stands does not align with the community's views of reprehensibility.

There have been no prosecutions in Australia of doctors for assisting a patient to die, despite evidence that they do so in unlawful circumstances. Criminal law institutions have no way of identifying end of life medical cases that ought to be investigated. Police and prosecuting authorities are reluctant to pursue suspected cases of doctors performing assisted dying. In addition, there are also serious evidentiary obstacles in proving that a doctor intended to hasten the death of a patient in administering treatment.

In this Chapter the Committee notes evidence from the Victorian State Coroner that between January 2009 and December 2013, there were 2879 suicide deaths in Victoria. Of these, 240 were people who were experiencing an irreversible deterioration in physical health due to disease. Within this group, the highest frequency was for those aged 65 years and over.

Chapter 7

Chapter 7 examines how Victoria's legal framework relating to assisted dying is affecting people at the end of their life. It shows that the nature of dying under Victoria's end of life legal framework for people with a serious and incurable condition can be difficult and sometimes harrowing for individuals, their families and communities.

Family members, the Coroners Court of Victoria and Victoria Police gave evidence about how people experiencing an irreversible deterioration in health are taking their own lives in desperate but determined circumstances.

Decisions are made each day on the hospital floor to alleviate suffering where a patient is at the end of life. This may be through withdrawal or refusal of treatment, continuous palliative sedation, or intensified alleviation of pain, even if this may unintentionally cause death. These are standard practices.

While the existing legal framework is not an obstacle to good medical practice for most people at the end of life, it does not accommodate the needs of all.

The effect of the end of life legal framework on the lives of Victorians and on the practice of medicine and the law signifies that it does not reflect our contemporary society's values.

The objective of the recommendations in the Report are to not only enable patients' end of life wishes to be respected, but also to protect patients, particularly vulnerable people, from abuse and coercion.

The recommendations also aim to increase transparency around end of life medical practice and to improve clarity on end of life law so that health practitioners can be confident knowing where the boundaries of legal medical practice lie.

The Committee is of the view that the existing end of life legal framework needs reform.

Chapter 8

Chapter 8 recommends a legislative framework for assisted dying in Victoria. The proposed framework is a result of consideration of the advice provided to the Committee during an extensive research and consultation process.

The Chapter discusses the Committee's reasons for making these recommendations.

While several submissions suggested that all pain and suffering can be alleviated through the provision of better palliative care, the Committee heard from health practitioners that not all pain can be alleviated. Palliative care cannot always be the solution to managing pain and suffering at the end of life.

The Committee considered three options for addressing the issues of Victoria's current end of life care legal framework:

1. maintain the status quo
2. enforce the current legal framework
3. change the law.

The Committee rejects maintaining the status quo as an inadequate, head-in-the-sand approach to policy making and the plight of the Victorians discussed in this Report. The Committee also heard next to no evidence in favour of increasing efforts to enforce the current law. Accordingly, the Committee believes that the end of life care legal framework must be changed.

The Committee's research in Victorian and international jurisdictions has satisfied it that the methods used in assisted dying are medically sound and help that small cohort of patients who want this option to achieve a peaceful death. The evidence is conclusive that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not.

The Committee chose not to focus solely on the arguments for and against legalising assisted dying. These are well known and have been addressed in many different reports and research papers, both in Australia and internationally. The arguments put forward in evidence to the Inquiry reflected these and were consistent with arguments the Committee examined during its research process.

The Committee's recommended assisted dying framework allows for adults with decision making capacity who are at the end of life, and suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable to request assisted dying.

The framework also includes a robust oversight, review and reporting structure, including:

- an Assisted Dying Review Board
- End of Life Care Victoria, a new entity established to work with existing health entities to champion end of life care, and provide information and guidance on end of life care to health services, practitioners and the Victorian community
- the academic position of Chair in End of Life Care, to conduct ongoing research into end of life care in Victoria.

Appendices

Further information that informed the Committee's deliberations and recommendations can be found in the appendices.

- Appendix 1: A list of submissions
- Appendix 2: A list of public hearings and meetings
- Appendix 3: A summary of assisted dying frameworks in international jurisdictions
- Appendix 4: A comparative chart of legislation in jurisdictions that allow assisted dying
- Appendix 5: A comparative chart of Australian Bills on assisted dying
- Appendix 6: A summary of submission evidence
- Appendix 7: A summary of arguments for and against legalising assisted dying.
- Appendix 8: Recommendations from the Victorian Law Reform Commission's *Guardianship Report* (2012)

Recommendations

3 Towards a community based approach to palliative care

RECOMMENDATION 1: That the Victorian Government develop a holistic, evidence-based funding framework for the palliative care workforce that includes targets to meet the current shortfall and growing demand for palliative care services.....53

RECOMMENDATION 2: That the Victorian Government support an interdisciplinary approach to end of life care that focuses on continuity of care for the patient through the implementation of measures to encourage the efficient organisation and exchange of information with all parties. This includes patients, substitute decision makers, general practitioners, nurse practitioners, community nursing services, Aboriginal health services, home care workers, and managers of community and residential aged care facilities.55

RECOMMENDATION 3: That the Victorian Government encourage integration of palliative care with other health services by:

- incorporating palliative care principles into care for patients with chronic conditions
- ensuring timely referral of patients to palliative care (see also Recommendation 37)
- encouraging timely advance care planning conversations through a dedicated Medicare item number (see also Recommendation 34)
- ensuring staff are trained to communicate and facilitate appropriate advance care planning and end of life care.....55

RECOMMENDATION 4: That the Victorian Government prioritise integrating patient data systems and improve information sharing options for communicating with palliative care services, including information technology.....55

RECOMMENDATION 5: That the Victorian Government increase access in rural and regional communities to community palliative care services by:

- identifying health and community organisations that provide best practice community palliative care and enabling them to expand their services and/or guide the development of similar services in other rural and regional areas
- providing funding for administrative support to community palliative care organisations, so that they can focus on providing frontline palliative care services, such as respite for carers
- increasing funding to community palliative care services in rural and regional Victoria
- implementing incentive programs to attract palliative care expertise to rural and regional Victoria
- providing increased local training opportunities for palliative care staff in rural and regional Victoria
- increasing focus on telehealth projects connecting palliative care patients with health practitioners so patients may remain in their own home with the support of community palliative care services
- fostering community-academic partnerships to promote research and education that contributes to local education and understanding
- investigating targeted funding programs to help people in rural and regional Victoria access allied health palliative care services such as social workers and bereavement counsellors. 61

RECOMMENDATION 6: That the Victorian Government work to reduce inequities in the provision of palliative care by ensuring consistent palliative care services across residential aged care facilities. 62

RECOMMENDATION 7: That the Victorian Government work to prevent unnecessary emergency department presentations from aged care facilities and reinvest any savings into palliative care. 62

RECOMMENDATION 8: That the Victorian Government support programs, such as the workshops provided by Palliative Care Victoria, to increase the visibility and highlight the benefits of palliative care to Aboriginal and culturally and linguistically diverse Victorians, through initiatives specifically targeting these communities. 65

RECOMMENDATION 9: That the Victorian Government provide support to carers from groups that are less likely to have access to palliative care, including Aboriginal and culturally and linguistically diverse groups. 65

RECOMMENDATION 10: That the Victorian Government work with the Commonwealth Government to incorporate the National consensus statement: *Essential elements for safe high quality end of life care* into the National Safety and Quality Health Service Standards. 68

- RECOMMENDATION 11:** That the Victorian Government establish standards of care to clearly discern criteria for referral to specialist palliative care and the expectations of palliative care knowledge and capability for generalist health care providers. This should include referral of patients who:
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 - are currently underrepresented in palliative care
 - would benefit from palliative care.....68
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- RECOMMENDATION 13:** That the Victorian Government provide support to community palliative care services so people who wish to can receive end of life care at home, and choose where to die. 80
- RECOMMENDATION 14:** That the Department of Health and Human Services model the potential budget savings of an increase in palliative care patients dying at home, as compared to dying in hospital. Such modelling should include budget outcomes for the current percentage of patients dying at home and incremental increases in the rate of home death for palliative care patients. 80
- RECOMMENDATION 15:** That the Department of Health and Human Services model the budgetary impact on the hospital system of a stronger community palliative care system, in particular the impact on intensive care and emergency department costs that could be avoided with an increase in capability and availability of community palliative care..... 81
- RECOMMENDATION 16:** That the Victorian Government, recognising the value of community palliative care and informed by its investigations as stated in Recommendation 14 and Recommendation 15, increase support and funding to community palliative care services..... 81
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- RECOMMENDATION 19:** That the Victorian Government increase availability of reliable respite services for carers, particularly in rural and regional areas.87
- RECOMMENDATION 20:** That the Victorian Government, in consultation with key stakeholders, design a strategy to ensure an appropriate level of high quality palliative care curriculum content in medical, nursing and allied health degrees, including how to have conversations on end of life care with patients.96

RECOMMENDATION 21: That the Victorian Government investigate expanding programs such as the MedeSims and virtual clinical setting programs offered at Deakin University School of Medicine, to better educate medical students in communication skills, particularly around difficult end of life conversations.....	96
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Improving advance care planning

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• allocation of high needs home care packages	
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• to use as core documentation for transfer of care	
• to develop a system of alerts and triggers that indicate a person has an advance care plan and how it can be accessed across health services.	155

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RECOMMENDATION 44: That health services prioritise the implementation of advance care planning and meet all the Department of Health and Human Services' data collection and reporting requirements..... 155

RECOMMENDATION 45: That the Department of Health and Human Services improve its advance care planning reporting to better understand the level of uptake. 155

RECOMMENDATION 46: That the Department of Health and Human Services, working with experts and stakeholders, develop and distribute an advance care directive form to allow patients to record their values and preferences as detailed in Recommendation 48. 161

RECOMMENDATION 47: That the Victorian Government, as part of legislating to reform advance care planning, standardise the definition of medical treatment across Victorian statutes. 167

RECOMMENDATION 48:

Repeal relevant legislation

That the Victorian Government repeal the *Medical Treatment Act 1988* and repeal health substitute decision making provisions in the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*.

New legislation — the Future Health Bill 2016

That the Victorian Government introduce legislation providing for:

- instructional health directives, which will replace the refusal of treatment certificate. This should specify:
 - refusal of or consent to a particular medical treatment will be taken to be a binding provision, which can apply in limited circumstances
 - all other provisions of an instructional health directive, such as value statements, are non-binding provisions
- the ability to refuse or consent to treatment in relation to future conditions
- protection for ambulance officers when they act in good faith in reliance on an instructional health directive
- substitute decision makers, with the equivalent of an enduring power of attorney (medical treatment), to be able to refuse medical treatment..... 167

8

Victoria should legalise assisted dying

RECOMMENDATION 49: That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report in Annex 1, Assisted Dying Framework Summary. ... 213

Annex 1: Recommendation 49

Assisted Dying Framework Summary

The Government should introduce legislation to allow adults with decision making capacity, suffering from a serious and incurable condition who are at the end of life to be provided assistance to die in certain circumstances.

This should include amending the *Crimes Act 1958* to provide the exemptions necessary to protect health practitioners who act within the provisions of assisted dying legislation.

Any assisted dying legislation should include an 18-month period between Royal Assent and operation, to allow appropriate time to prepare for implementation on a practical and clinical level.

1.1 Activity being regulated

Assisted dying should in the vast majority of cases involve a doctor prescribing a lethal drug which the patient may then take without further assistance.

The singular exception is where people are physically unable to take a lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.

1.2 Conscientious objection

No doctor, other health practitioner or health service can be forced to participate in assisted dying.

1.3 Eligibility criteria and assessment

Assisted dying is intended to provide an option that can limit suffering at the end of life, not a way to end life for those who are otherwise not dying.

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition. Each doctor must independently judge whether the person's request satisfies all of the criteria outlined below.

The exception to this is the suffering component. It is essential that the patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which they deem tolerable. This is fundamental to patient-centred care, and is a subjective measure judged by the patient themselves.

The person	<p>An adult, 18 years and over, with decision making capacity about their own medical treatment.</p> <p>Patients whose decision making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.</p> <p>Ordinarily resident in Victoria and an Australian citizen or permanent resident.</p>
The condition	<p>At the end of life (final weeks or months of life).</p> <p>Suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.</p> <p>Suffering as a result of mental illness only, does not satisfy the eligibility criteria.</p>
The request	<p>Must come from the patient themselves.</p> <p>Cannot be included in an advance care directive.</p> <p>Must be completely voluntary, free of coercion.</p> <p>Must be properly informed. The primary and secondary doctor must each properly inform the patient:</p> <ul style="list-style-type: none"> • of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results • of palliative care and its likely results • that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time • of the probable result and potential risks of taking the lethal drug. <p>Must be repeated three times:</p> <ul style="list-style-type: none"> • an initial verbal request • a formal written request, which must be signed by two independent witnesses • a final verbal request. <p>Must be enduring. The primary and secondary doctors must be independently satisfied that the patient's request is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of a lethal drug. In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely trajectory. The primary and secondary doctors must also assess the reasonableness of the request. This is to ensure that the patient truly understands and appreciates the nature and consequences of the decision to request assisted dying, as well as the alternatives to assisted dying, and that the patient's request is not ambivalent.</p> <p>Patient may withdraw their request at any time. Once withdrawn, the request becomes void, and the primary and secondary doctor must assess any subsequent request from the beginning.</p>

1.4 Implementation Taskforce

There are clinical and practical implementation issues in establishing an assisted dying framework that require further investigation. The Government should establish an Implementation Taskforce of experts and health practitioners to investigate and advise on the best approach to these issues before the assisted dying framework commences.

1.5 Oversight, review and reporting

1.5.1 Assisted Dying Review Board

The Assisted Dying Review Board is to review each approved request for assisted dying.

Membership of the Assisted Dying Review Board:

- a representative of End of Life Care Victoria
- a doctor
- a nurse
- a legal professional
- a community member.

The function of the Board will not be to approve or reject requests from patients to access assisted dying. That is the role of the primary doctor and independent secondary doctor in each case. Neither will the Board hear appeals from patients whose requests to access assisted dying have been rejected.

The purpose of the Board is to ensure that doctors are complying with requirements of the assisted dying framework.

If the Board finds a breach of the assisted dying framework, it should forward its report to the appropriate authority. Depending on the nature of the breach, this may be Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency. Those bodies will then determine whether to investigate the case further.

The Board should report to Parliament on the operation of the assisted dying framework, including any trends it identifies and recommendations for improvement. For the purposes of increased transparency and accountability, during the first two years of operation these reports should be every six months. Following that the Board should report annually.

1.5.2 End of Life Care Victoria

The Government should establish a new entity to champion end of life care, and provide information and guidance on end of life care to health services, practitioners and the Victorian community. End of Life Care Victoria will work closely with palliative care and other end of life care health practitioners and services to enhance and support the excellent work already being done in the Victorian health system. End of Life Care Victoria will aim to increase engagement with end of life care in the community and the health sector as a whole.

End of Life Care Victoria will not only provide policy and strategic direction on all aspects of end of life care, it will also serve as a point of entry for health practitioners and ordinary Victorians looking for information on end of life care issues, including assisted dying. This will help to address the existing poor levels of understanding of end of life care issues within health professions and the broader Victorian community.

This also reflects the Committee's view that these are all part of the continuum of end of life care.

Functions of End of Life Care Victoria will include:

providing policy and strategic direction for end of life care in Victoria	developing and maintaining a register of doctors who are willing to provide assisted dying
gathering, analysing and reporting data on end of life care practices including palliative care, advance care planning, continuous palliative sedation, and assisted dying	maintaining a hotline for health practitioners seeking advice on end of life care issues, with a particular focus on assisting health practitioners in rural and regional areas who have limited access to end of life care specialists
providing administrative and research support to the Assisted Dying Review Board	providing information to the public on end of life care issues
developing and maintaining a register of advance care plans and directives to provide a single location for doctors and health practitioners	providing education and training programs in end of life care for health practitioners, including case support workers
counselling for health practitioners involved in assisted dying	maintaining a relationship with the Chair of End of Life Care at a Victorian-based University.

1.5.3 Chair of End of Life Care

The Government should establish and fund the research position of Chair of End of Life Care at a Victorian-based university. The Chair should be established through a Government expression of interest process. The Chair should perform comprehensive research on end of life care and choices in Victoria. This will produce information that will help determine the needs of people at the end of their lives and how the Government can better provide end of life care.

While the Chair should have independence to determine the direction of research, the Chair should consult with End of Life Care Victoria to ensure their research functions are complementary.

1.5.4 Five-year review

Review of the assisted dying framework by a parliamentary select committee of members from both Houses after five years of operation.

The will to live is a strong psychological force within all humans, to fight for survival — particularly in the face of hardship or illness. The Committee heard many times during this Inquiry about just how passionately people wish to live notwithstanding age and illness.

However death is not an event that can be avoided, and every one of us would like to die well when the time comes.

An open discussion about what this means to the community is essential to ensuring we have the best possible systems in place to care for people at the end of their lives and to respect individuals' preferences, if possible, about how they wish to die. If medical and legal systems are not in place to respect end of life preferences, we risk abandoning those who are most vulnerable.

Current end of life law is complex and lacks clarity for patients, their families, health practitioners, prosecutors and the Courts. Victoria's legislative framework is causing pain and distress to some people facing death, and to their families. The Committee heard during the Inquiry that some Victorians with irremediable pain and suffering, many of whom were frail and elderly, will die in brutal circumstances by their own hands. The Committee believes that this needs to be addressed through significant reform.

This Report is a culmination of an extensive research and public consultation program. It is one of many reviews into end of life choices that has been conducted over the last decade, both in Australia and internationally. Evidence provided to the Committee shows that concerns about end of life issues are creating challenges for many jurisdictions.

The Report deals with three broad themes: the role and provision of palliative care, the need for advance care planning and legalisation of assisted dying.

This Report makes a number of significant, and consequential, recommendations. The Committee acknowledges that some of these are controversial. However, the evidence was overwhelming that the current legal system and medical approach in Victoria is not adequate to deal with the pain and suffering that some people may experience at the end of life. So too was the evidence that Victoria's legislative framework must be reformed to reflect society's values rather than relying on legal contortions to achieve just outcomes.

The Committee strongly believes that the reforms recommended in this Report will strengthen end of life care in Victoria.

1.1 Terms of reference

On 7 May 2015 the Committee received the terms of reference for an Inquiry into end of life choices from the Legislative Council. The terms of reference required the Committee to inquire into, consider and report on the need for laws in Victoria to allow citizens to make informed decisions about their own end of life choices. In particular, the Committee was asked to:

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.¹

The Legislative Council required the Committee to report by 31 May 2016.

The terms of reference emphasise the need for investigation of current laws to determine whether individual preferences about their end of life care can be met in Victoria. Given the importance of palliative care and advance care planning in end of life care the Committee resolved to consider these areas in depth, alongside a careful examination of the relevant law.

During the course of the Inquiry, the Victorian Government announced development of a statewide end of life care framework. The Government sought input through a public consultation process.²

Inevitably there was some overlap in the process that the Government commenced with that of the Committee's work, given the respective terms of reference and subject matter being addressed. The Committee dealt with issues of overlap in its interim Report, tabled on 10 November 2015.³

1.2 Inquiry process

The Committee conducted an extensive research and consultation process in preparing this Report. The Committee was guided by a review of academic literature and reports from similar inquiries that have been conducted both in Australia and internationally. The Committee also called for submissions from the public and heard from witnesses at public hearings.

¹ Victoria, Legislative Council 2015, *Debates*, vol. 6, p. 1278.

² Department of Health and Human Services, *Greater say for Victorians: Improving end of life care*, Victorian Government, Melbourne, 2015.

³ Standing Committee on Legal and Social Issues, *Inquiry into end of life choices: Interim report*, Victorian Parliament, Melbourne, 2015.

In addition, the Committee held briefings with representatives from the Department of Health and Human Services and conducted site visits to health services providing end of life care. The Committee wishes to acknowledge funding from the Department for a research position for the Inquiry.

In 2016 the Committee met with stakeholders in international jurisdictions that allow, or will soon allow, assisted dying.

The Committee was overwhelmed by the extent of public interest in this Inquiry. The Committee heard from many individuals and organisations holding strong views on end of life care.

Hundreds of recommendations have been suggested to the Committee. Areas of interest included assisted dying legislation, advance care planning, palliative care, community palliative care, support for medical staff and carers, and many other issues.

The Committee is immensely grateful to the many stakeholders who gave up their time to provide information to the Inquiry, whether through written submissions, providing evidence at public hearings, briefings and discussions or site visits. Their evidence and advice based on both expertise and experience has been invaluable in guiding the Committee's discussions and in developing the Report's recommendations.

1.2.1 Submissions

The Committee issued a call for submissions on 30 May 2015. Submissions formally closed on 31 July 2015, however given the ongoing public interest in the terms of reference the Committee continued to accept submissions throughout the course of the Inquiry.

The Committee received 1037 submissions. Of these, 925 were from individuals in a private capacity, and 112 from organisations.

Submissions were received from a very broad range of individuals and organisations, emphasising the breadth of concern in the community on the subject of end of life care. Each submission was reviewed extensively.

A number of individuals requested that their submissions remain confidential or that their names be withheld from publication. These requests were determined by the Committee on a case-by-case basis.

The Committee was particularly moved by the number of individuals who made a submission to the Inquiry. While most of the individual submissions were from metropolitan and rural and regional Victoria, the Committee also heard from people in other Australian and overseas jurisdictions. These individual submissions came from a wide range of people, including individuals currently facing their own death. Others included:

- a range of health practitioners, including general practitioners, nurses, medical specialists and allied health workers, many with first-hand experience in managing end of life care
- retired and former health practitioners
- medical law and other legal experts
- palliative and aged care specialists
- academics with expertise in end of life issues, from Australian and international jurisdictions
- current and retired religious and faith-based organisation leaders
- general members of the public who wished to provide their opinions and experiences to the Inquiry.

The overwhelming majority of individual submissions discussed assisted dying. Only a small number focused solely on palliative care.

Many individuals who made submissions detailed their personal experiences in end of life issues. Some spoke about their experience of the illness or death of their patients or loved ones. A number of submissions disclosed involvement in another's suicide or in assisted dying.

About 6 per cent of individual submissions disclosed that the author is facing their own imminent death.

People wrote at length about the irreversible conditions that they were experiencing or had witnessed others go through.

The Committee respects the compelling contribution made by these individuals which provided invaluable insight into what people experience at the end of life.

The remaining 112 submissions were provided by a range of organisations, including:

- advocacy groups
- health services
- professional associations
- religious and faith-based organisations
- academia
- law bodies
- government
- community groups, including the residents of retirement homes, residential aged care facilities and hospices.

The majority of organisations discussed assisted dying, often alongside palliative care. Some focused solely on palliative care.

The Committee appreciates the system-wide view that these groups brought to the analysis of end of life care in Victoria. Their contributions were critical in shaping the Committee's recommendations on improving the structure of end of life care service provision in the State.

In the submissions that discussed legalising assisted dying, there were many recurring themes. These are represented in word clouds in Figures 1.1 and 1.2 below. The terms shown in the word clouds represent themes identified in submission to the Inquiry. The font size of each term represents how many submissions raised the corresponding theme.

Figure 1.1 Themes from submissions supporting assisted dying



A full list of the submissions accepted by the Committee can be found in Appendix 1. A quantitative analysis of submissions is provided in Appendix 6.

Figure 1.2 Themes from submissions opposing assisted dying



1.2.2 Public hearings, site visits and briefings

The Committee conducted an extensive program of site visits and public hearings around Victoria between July 2015 and February 2016. These were held at the following locations:

- Melbourne, at Parliament House
- Warrnambool
- Geelong
- Bendigo
- Shepparton
- Traralgon
- Mornington.

The Committee held 17 days of public hearings and heard from 154 witnesses. Many busy people gave up their time to provide evidence to the Inquiry. These included representatives of the Department of Health and Human Services, the Office of the Public Advocate, the Victorian Coroners Court, Victoria Police and other government agencies. The Committee also heard from health practitioners, health service providers, palliative care and hospice services, religious and faith-based organisations, academics, advocacy groups, lawyers and individuals in a personal capacity.

People gave evidence to express their concerns about a range of issues related to the terms of reference. Many individuals told us their stories, many were deeply personal. The Committee listened to all the evidence very carefully.

The Committee's visits to regional areas gave members an insight into the unique end of life care issues that are faced by rural and regional health services.

The Committee was provided with a number of briefings from departmental experts on end of life care and government plans in this area.

In June 2015 Michael Bramwell, Chair and Odette Waanders, Chief Executive Officer of Palliative Care Victoria provided a private briefing to the Committee. Later in June the Committee met with Professor Cameron Stewart, Pro Dean and Professor of Health Law and Ethics at the University of Sydney.

I suppose I could say that I am like the elephant in the room here: I am the person this discussion is about — and the choices that I want to make in relation to how my life will end and that it will end with some sort of dignity with the least amount of suffering for my family. But it is like all this discussion is going on around me, not with me, which concerns me a little.

Suzanne Jensen, public hearing,
16 September 2015.

In July 2015 the Committee visited Barwon Health and the Warrnambool and District Community Hospice.

In August 2015 the Committee visited Austin Health's Olivia Newton-John Cancer and Wellness Centre in Heidelberg. During the site visit the Committee met with palliative care doctors and nurses, and representatives from Austin Health's advance care planning team for a roundtable discussion of end of life issues. This provided a valuable insight into how Austin Health and health services generally deal with end of life issues on the hospital floor.

In March 2016 the Committee met with professors Ben White and Lindy Willmott from the Australian Centre for Health Law at the Queensland University of Technology. Professors White and Willmott provided the Committee with advice on end of life law in Australia.

During the Inquiry, many witnesses provided evidence at hearings of their personal experiences in end of life care or of their own illness. At times this was very difficult for them to recount. The Committee commends these witnesses for their courage in describing their experiences and concerns, which have helped to inform this Report.

A full list of the Committee's site visits and public hearings, including a list of witnesses, can be found in Appendix 2.

1.2.3 Overseas research

In 2016 a five-member delegation of the Committee visited five overseas jurisdictions where assisted dying is allowed. The assisted dying frameworks in these jurisdictions were discussed in evidence throughout the Inquiry process. The Committee considered it important to see how the frameworks operate and to test the criticisms made of them by some stakeholders.

The Committee's focus in investigating the assisted dying frameworks in international jurisdictions was on the role and development of assisted dying in the context of palliative care, safeguards and review processes and qualification criteria.

The Committee visited 5 jurisdictions in 4 countries:

- Netherlands
- Switzerland
- Canadian province of Québec
- Canada
- Oregon, United States.

Each of these jurisdictions has a unique assisted dying legal framework. Some key differences include:

- whether the schemes require a patient to take lethal medication themselves, or whether a doctor can assist
- whether the patient must be an adult
- how people with mental illness are treated
- legislative safeguards in place, including:
 - the number of health practitioners required, including referrals for psychiatric evaluation
 - how the requests must be made (e.g. verbally or in writing), and how many times the request must be repeated
 - cooling off periods between when a request is made and a drug can be administered
- mandatory referral requirements for health practitioners who do not wish to be involved in providing assisted dying to the patient
- reporting requirements, oversight and review of the schemes.

A detailed summary of these legislative frameworks is provided in Appendix 4.

The Committee met with many stakeholders and experts to hear their views on their jurisdiction's assisted dying framework. These included:

- representatives from government departments and agencies
- academics with internationally-regarded expertise in end of life care policy, law and practice
- critics of assisted dying frameworks, including people who had previously worked in organisations that monitor assisted dying
- doctors, nurses and health practitioners
- advocacy groups for assisted dying and the rights of patients
- end of life care groups, including hospice and palliative care workers
- representatives of committees and taskforces that have developed assisted dying frameworks.

A full list of these stakeholders and organisations is listed in Appendix 2.

The Committee heard about the robustness of the medical systems in place where assisted dying is legal. Each framework has rigorous safeguards to protect patients from potential abuse.

In each jurisdiction, a relatively small number of total deaths each year are attributed to assisted dying:

- In the Netherlands there were 5516 reported cases of assisted dying in 2015, amounting to 3.9 per cent of all Dutch deaths in the year. Of these, in 5277 cases a doctor administered the medication, 208 were patient self-administered and the remaining 31 were a combination of both.⁴
- An analysis of assisted suicide deaths of Swiss residents found that there were 300 cases in 2009 (0.48 per cent of total deaths).⁵ Dignitas, an organisation that provides foreigners with assistance to die under Swiss law, recorded 222 cases in 2015.⁶
- In Oregon, United States 218 people received prescriptions for lethal medication in 2015. In the same year, there were 132 deaths as a result of people taking the medication (0.39 per cent of total deaths).⁷
- No official figures have been released in the Canadian province of Québec. At the time of publication, however, it has been reported in the media that approximately 50 people have received assisted dying since a framework was implemented in December 2015. This is in the context of the Québec annual death rate (approximately 63 000 in 2014).⁸

4 DyingForChoice.com, 'Netherlands — 2015 euthanasia report card', viewed 18 May 2016, <www.dyingforchoice.com>.

5 Swiss Federal Statistical Office, 'Cause of death statistics 2009 — Assisted suicide and suicide in Switzerland', viewed 18 May 2016, <www.bfs.admin.ch>.

6 See 'Accompanied suicide of members of Dignitas by year and by country of residency 1998–2015, from Dignitas, 'Statistics', viewed 18 May 2016, <dignitas.ch>.

7 Oregon Health Authority, *Oregon Death With Dignity Act: 2015 data summary*, Oregon Health Authority, 2016, p. 3.

8 See Société Radio-Canada, 'Une cinquantaine de Québécois ont reçu l'aide médicale à mourir', viewed 18 May 2016, <ici.radio-canada.ca>. (Note, webpage is in French).

The Committee is immensely grateful to all those who shared their experiences and what they have learnt in the context of their own robust medical systems and assisted dying frameworks that have been in place for many years.

1.3 Report structure

This Report looks at the key issues in end of life care in Victoria. The Committee decided it was important to look at all elements of end of life care together to ensure the best possible outcomes for people. Accordingly, the Report comprises eight chapters which examine aspects of the full continuum of end of life care.

This Report states that palliative care has proven benefits for a person's end of life. According to one study, Australia ranks second worldwide, as a place to die a good death.⁹

However, there is much more that can be done to improve the prevalence of palliative care and how it is provided.

The Report also states that advance care planning is an essential tool in a patient-centred end of life care framework.

A key message of this Report is that for a small number of Victorians, the current law inhibits good medical practice, and leads to outcomes that do not align with community values.

In preparing the Report, the Committee chose not to focus solely on the arguments for and against legalising assisted dying. The Committee believes that the recent international reports from jurisdictions such as Canada, the United Kingdom and Québec have adequately canvassed these issues. This is discussed further in Chapter 8. However, the Committee gave in-depth consideration to these during its deliberations and has provided a summary of arguments for and against legalising assisted dying in Appendix 7.

1.3.1 Chapter outline

Chapter 1 provides an overview of the Inquiry methodology and key issues of the Report.

Chapter 2 discusses current approaches by governments to palliative care, including the policy and legislative framework for the sector at local, Victorian and national levels. It also discusses the Victorian Government's review of the State's end of life care framework, which was conducted simultaneously with the Inquiry.

⁹ The Economist Intelligence Unit, *The 2015 Quality of Death Index — Ranking palliative care across the world*, Lien Foundation, London, United Kingdom, 2015.

Chapter 3 analyses issues relating to palliative care that the Committee heard from Inquiry stakeholders. It also recommends improvements to Victoria's palliative care sector to move towards a community-based approach to providing end of life care.

Chapter 4 discusses the role of advance care planning in end of life care. It also analyses the legislative framework for advance care planning in Victoria and other Australian jurisdictions.

Chapter 5 recommends legislative reform to simplify and strengthen Victoria's advance care planning system. In particular, it proposes introducing instructional health directives that include legally binding provisions and that cater for future medical conditions. The Chapter also makes recommendations to streamline Victoria's medical substitute decision making framework.

Chapter 6 discusses the current legal framework for end of life in Victoria. It describes how courts are invariably lenient on people who assist a loved one to die. It also notes that no doctor has yet been charged for crimes related to assisted dying.

Chapter 7 examines how Victoria's assisted dying framework is affecting people at the end of their life. It describes how people are living and dying with irremediable pain, and how others are determined to end their life instead. It also details how decisions are made each day on the hospital floor to alleviate suffering where a patient is at the end of life. This may be through withdrawal or refusal of treatment, continuous palliative sedation, or intensified alleviation of pain, even if this may unintentionally cause death. These are standard practices.

Chapter 8 proposes a legislative framework for assisted dying in Victoria for capable adults in certain circumstances. The proposed framework is a result of the Committee's extensive research and consultation process during the Inquiry. The Chapter discusses the Committee's reasons for making these recommendations.

1.4 Why an inquiry into end of life choices?

Dying well is important to all of us. In Victoria and Australia we are facing an ageing population and more prolonged chronic illness and death. The end of life legal framework in Victoria has also remained largely unchanged since the *Medical Treatment Act 1988* was introduced. Since then, there have been many changes in medicine, how medical care is provided, and how people want to receive treatment. The Committee believes that society's expectations for autonomy and patient-centred care have increased.

There is pressure for [assisted dying] to be considered more thoroughly through law reform commission bodies. Debate and further proposals to legalise voluntary euthanasia and assisted dying are likely to increase in future.

Professor Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014.

The following sections provide a summary of some key issues that influenced this Inquiry and the Committee's development of recommendations.

1.4.1 How we die is changing

In its report *Dying well* (2014), the Grattan Institute noted that how we die has changed dramatically over the past century. As a result of advances in medicine, people are now far more likely to die in old age of chronic and degenerative disease. Death is more predictable and often extends over a longer period of time. At the same time, the average life expectancy has increased, but a person's maximum life span has not changed.¹⁰

These changes to the way we die have required changes to the way a person is cared for at the end of their life. People are more often cared for and die outside of their home in Victoria, and their families and loved ones experience and observe death far less than they did in the past. Death can be highly medicalised as well as hidden from view.

The changing prominence of diseases has shifted the focus from curing a disease to managing a person's illness and providing them comfort and pain relief as they die. These factors have also resulted in an increase in demand for palliative care, putting pressure on this sector.

The medical community has also seen a paradigm shift from a more paternalistic approach to an approach based on patient-centred care.

1.4.2 Palliative care

Palliative care is an emerging field and a relatively new approach to providing end of life care. As a result, there are general misunderstandings in the community about palliative care — in particular when palliative care can be provided and who can receive it. Palliative care is a valuable approach to improving a patient's quality of life and can provide comfort to those at the end of life, their carers and loved ones. Palliative care can assist patients who are also receiving curative treatment, and the Committee heard that patients can be discharged from palliative care.

Victoria has high quality palliative care services, however increased demand has caused a strain on the system. There are gaps that have emerged, particularly in rural and regional areas. In addition, palliative care service provision is somewhat fragmented between organisations, and at times is poorly integrated with the broader health sector.

As demand for palliative care increases, it is important that governments provide adequate support and guidance to ensure that appropriate service levels are maintained.

¹⁰ Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014, p. 5.

1.4.3 People want genuine choice

Assisted dying is a controversial subject. However, Australian public opinion polls over the past 25 years show varying but consistent support for reform to introduce assisted dying laws.¹¹ This is the case in international jurisdictions as well.¹²

People also want to plan for their death, and have assurance that their wishes will be respected if they are unable to make medical decisions themselves. Through the course of the Inquiry the Committee heard about the value of advance care planning. This is where an individual discusses or documents their wishes for medical treatment and care in the event that they lose the ability to make or communicate their decisions. This issue is an important concern in end of life care. Although health services have processes for advance care planning, awareness and completion rates remain very low.

In addition, Victoria's only legally-binding advance care plan — a refusal of treatment certificate — has limitations that need to be addressed. The refusal of treatment certificate can only be used for a current condition. There are also concerns that a patient's refusal of treatment certificate may not be binding in some circumstances, due to Victoria's substitute decision making legal framework.

I would submit that doctors and other health professionals are not always in tune with the thinking of their patients. A few years ago I took part in a large survey carried out in Queensland of the views of doctors and their patients about end-of-life decisions:

- 57% of general practitioners believed their patients would prefer to leave such decisions to the doctor; only 14% of the public held this view
- 62% of patients were in favour of assisted dying compared to 30% of doctors
- 65% of patients felt the law should be changed to allow the process ...

There is little doubt that a substantial majority of the public is in favour of measures to permit assisted dying ... our professional resistance is one of its strongest obstacles. Is our opposition really justified?

Sir Raymond Hoffenberg, 'Assisted dying', *Clinical medicine*, vol. 6, no. 1, 2006.

1.4.4 Assisted dying is occurring in Victoria

Assisted dying is illegal in all Australian jurisdictions. However, increasingly there have been a number of highly publicised cases of doctors providing patients with drugs that will end the patient's life, upon their request. These doctors have not been prosecuted.

¹¹ Douglas, R, et al., *The right to choose an assisted death: Time for legislation?*, Australia21 and Queensland University of Technology Health Law Research Centre, Canberra, 2013.

¹² See Udo Schüklenk, et al., 'End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making', *Bioethics*, vol. 25, no. s1, 2011.

Research also shows that assisted dying is occurring in Victoria and Australia.¹³ Without criteria to gauge a request for assisted dying, there may be no accounting for its voluntariness or the capacity of the person making the request.

Police are reluctant to and have difficulty in pursuing charges against health practitioners and others, often loved ones, who assist a person to end their life. Courts are also reluctant to penalise these people, and have invariably imposed suspended sentences or good behaviour bonds in lieu of harsher penalties. This indicates that the law for assisted dying is not being enforced. It also shows that the acts committed by people who assist someone to die in these situations do not reflect community attitudes of reprehensibility.

It is important that laws are applied and enforced, but for assisted dying, in an effort to achieve just outcomes, this is not occurring. The Committee heard next to no evidence that a lack of prosecutions for assisted dying is a failure of the current legal system.

1.4.5 Frameworks are being implemented overseas

This is not the first review into end of life issues, nor would the assisted dying framework recommended by the Committee be the first to be introduced in the world. Assisted dying is legal in a number of jurisdictions.¹⁴

An increasing amount of evidence has become available from overseas jurisdictions which have implemented frameworks for provision of assisted dying.¹⁵ Many submissions and witnesses at public hearings also referred to these frameworks. The Committee drew on the experience of these jurisdictions and other reviews similar to this Inquiry in developing the recommendations in its Report.

The Committee's extensive evaluation of material from other jurisdictions included the following reports:

- 'The current legal status of assisted dying is inadequate and incoherent ...' Report of the UK Commission on Assisted Dying (2011)
- 'End-of-life decision-making in Canada: The report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making' (2011)
- 'How should Australia regulate voluntary euthanasia and assisted suicide?' (2012)

¹³ Christina A Stevens and Riaz Hassan, 'Management of death, dying and euthanasia: attitudes and practices of medical practitioners in South Australia', *Journal of medical ethics*, vol. 20, no. 1, 1994; Peter Baume and Emma O'Malley, 'Euthanasia: attitudes and practices of medical practitioners', *The Medical Journal of Australia*, vol. 161, no. 2, 1994; Helga Kuhse, et al., 'End-of-life decisions in Australian medical practice', *Medical Journal of Australia*, vol. 166, no. 4, 1997; Charles D Douglas, et al., 'The intention to hasten death: a survey of attitudes and practices of surgeons in Australia', 2001; Rurik Löfmark, et al., 'Physicians' experiences with end-of-life decision-making: Survey in 6 European countries and Australia', *BMC medicine*, vol. 6, no. 1, 2008.

¹⁴ For example, see: Lindy Willmott, et al., '(Failed) voluntary euthanasia law reform in Australia: Two decades of trends, models and politics', *University of New South Wales Law Journal*, vol. 39, no. 1, 2016.

¹⁵ See Australian and New Zealand Society of Palliative Medicine, 'Position statement — Benchmark number of specialists in palliative medicine', viewed 15 March 2016, <www.anzspm.org>. The Society's 2009 position statement calculates, based on 2007 data, that the ratio is 0.44 full time equivalent palliative care specialists per 100 000 Victorians.

- The report of the Québec Select Committee on Dying with Dignity (2012)
- Provincial-Territorial Group on Physician Assisted Dying, Canada (2015)
- *Medical assistance in dying: A patient-centred approach* — Report of the Special Joint Committee on Physician-Assisted Dying, Canadian Parliament, including a dissenting report (2016).

In addition, the Committee carefully considered the assisted dying frameworks in place in Oregon, the United States; Québec, Canada and the Netherlands. The Committee also considered Canada's assisted dying legislation, which was introduced in the Canadian Parliament in April 2016.

Although there are many differences between the frameworks, the Committee saw benefits in aspects of each. The framework recommended in this Report is based on those elements which the Committee considered best practice as well as an appropriate cultural fit in the context of Victoria's medical and legal systems and culture.

1.4.6 A note on terminology

Throughout this Report, the Committee uses the term 'assisted dying' to describe assistance to die provided in a medical context.

When referring to frameworks in overseas jurisdictions, the terms 'assisted suicide' and 'voluntary euthanasia' are used. In these instances, 'assisted suicide' refers to the practice of a doctor providing a patient with the means to end their life. 'Voluntary euthanasia' refers to medical assistance to die which is administered by a doctor (such as through a lethal injection).

1.5 Key findings

The Committee has identified a number of key themes, issues and concerns that were raised during the Inquiry. They are also common themes in reviews that have been conducted internationally.

The key findings of the Report are:

- As a society, we are hesitant to talk about death, which is considered a taboo subject. This inhibits planning for end of life care, and may result in a person's end of life wishes not being followed.
- Although most people in Victoria wish to die at home, in reality most of them will die in hospital.
- Demand for palliative care is steadily increasing, and is expected to continue to do so. At the same time, palliative care patients' diseases and needs have increased in complexity. As such, Victoria's palliative care sector is overburdened and needs better support from government.
- Despite Victoria having good palliative care services available, those who could benefit the most often receive care too late.

- Carers and the volunteer workforce are integral to Victoria's palliative care system.
- Although the advance care planning process has proven benefits, there are low awareness and implementation rates for advance care plans in Victoria and Australia.
- Existing end of life care legislation is confusing in many ways, and causes uncertainty, particularly for health practitioners.
- The legal framework for advance care planning spans several Acts and some legal issues may rely on common law rulings. Substitute decision making provisions are confusing and poorly understood by doctors. In addition, the law does not provide certainty that a person's wishes detailed in an advance care plan will be carried out when they lose capacity.
- Prohibition of assisted dying is causing some people great pain and suffering. It is also leading some to end their lives prematurely and in distressing ways.
- Instances of assisted dying are rare, even in jurisdictions where it is legal. Assistance in dying is, in the vast majority of cases, provided to people in what would otherwise be the final weeks of their lives.
- Government support and funding of palliative care has not declined when assisted dying frameworks have been introduced.
- Courts invariably impose lenient penalties without jail time on people who assist a loved one to end their life. This is true in Australia and in similar overseas jurisdictions.
- Everyone's end of life care needs differ. It is important that Victoria has a system in place to cater for the needs of individuals, whilst ensuring that there are safeguards in place to protect vulnerable people.

1.5.1 Core values

The members of the Committee hold different views on the subject of assisted dying, views which align in some cases on some subjects but not on others. Some believe that assisted dying should be available more broadly, others believe that it should be available but that eligibility criteria should be extremely strict and others are simply opposed. For some Committee members their views have changed since the outset of this Inquiry.

Nevertheless, the Committee has defined a set of shared core values for end of life care. These provide an understanding of the beliefs that underpin the Committee's approach to this subject.

These are intended to assist in providing readers with an understanding of areas of broad agreement that provided guidance for the Committee's discussions and for the drafting of this Report. These values are based on what the Committee has learned throughout the Inquiry process.¹⁶

¹⁶ Ibid.; The Commission on Assisted Dying, *"The current legal status of assisted dying is inadequate and incoherent..."*, Demos, London, 2011.

Box 1.1: Core values for end of life care

Every human life has value

Every individual person has inherent value.

Open discussion about death and dying should be encouraged and promoted

Death is an inevitable and natural part of life. It is human nature to fear death, however by acknowledging our own mortality through open discussions with health practitioners and family we can plan for our death.

People should be able to make informed choices about the end of their life

An adult with capacity has the right to self-determination. This is a fundamental democratic principle which should be respected. Information on end of life choices must be clear and accessible.

End of life care should be person-centred

The focus of medical treatment has shifted in recent times from a 'doctor knows best' mentality to patient-centred care. End of life care should be no different.

End of life care should address the needs of families and carers

The end of a person's life is a very stressful time for their families and carers, and can take a toll on their physical and mental health. End of life care services should extend to and provide assistance to families and carers during this difficult time.

Pain and suffering should be alleviated for those who are unwell

Not all treatment is beneficial for those at the end of life. Treatment provided to a 20-year-old may not be appropriate for an 80-year-old. The goal of end of life care should be to minimise a person's pain and suffering.

Palliative care is an invaluable, life-enhancing part of end of life care

Palliative care provides much needed pain relief for people during the end of their life, and provides comfort to their loved ones and carers. Palliative care often prolongs life.

High quality end of life care should be available to all people in all settings

People should be able to plan for death in their preferred setting.

Each person should be entitled to core rights in end of life care

All forms of discrimination in end of life care should be ended as far as possible, whether based on geographical location, physical condition, ethnicity or wealth.

Vulnerable people should be supported and protected

End of life care should focus on relieving pain and suffering. Safeguards need to be in place to ensure that vulnerable people are not pressured or coerced into making decisions that they do not want to.

The law should be coherent and transparent

Health practitioners and patients should be fully aware of their legal rights and responsibilities in end of life care.

The law should be followed and enforced

The purpose of end of life legislation should be to provide for end of life choices for patients and protection for doctors. Breaches of laws should be penalised appropriately.

Government approaches to palliative care

In Australia, between 60 and 70 per cent of people wish to die at home, yet only about 14 per cent do. Approximately 54 per cent die in hospitals and 32 per cent in residential care.¹⁷ Of those who have a life-limiting illness, 90 per cent wish to die at home.¹⁸ In countries such as New Zealand, the United States, Ireland and France twice as many people die at home.¹⁹

It is the Committee's belief that through proper support and awareness of Victoria's palliative care services we can increase the number of people who die in their place of choice.

In this Chapter, the Committee examines the Government's approach to palliative care at state and federal levels. It also discusses the Victorian Government's plans for change to our palliative care sector through development of a statewide end of life care framework.

2.1 What is palliative care?

Palliative care is a multi-disciplinary approach to managing a person's illness. This includes both pain relief and symptom management for the person themselves, and support to their family and carers.²⁰

Palliative care is often misunderstood in the general community. In many cases palliative care can increase an individual's lifespan. For some palliative care can lead to periods of recovery and be accessed again later on during an illness trajectory. Palliative care is an important and measured approach to manage a person's pain or suffering and provide them comfort during the end of their life. It encompasses medical, physical, mental and spiritual comfort for not only patients, but also their relatives, carers and friends.

People think that palliative care is about dying. If we are going to achieve anything out of this, we have really got to achieve a much greater community awareness around what palliative care can offer and what it stands for.

... palliative care is not just about dying. It is about quality of life, it is about how we live with our illness, it is about choices, and it is about where we want our care, who we want to be involved in our care and how we bring all that together.

Annette Cudmore, Clinical Nurse Consultant, West Hume Palliative Care Consultancy Service, public hearing
13 August 2015

¹⁷ Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014, p. 2.

¹⁸ Victorian Government, *Submission*.

¹⁹ Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014, pp. 2, 4.

²⁰ The term 'carer' refers to a person providing unpaid care to a patient, excluding volunteers who work in the palliative care sector. Carers are typically family members, friends or acquaintances of the patient.

Australia, through the national palliative care strategy (see section 2.4.3) has adopted the World Health Organization definition of palliative care, which is as follows:

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.²¹

Although there is no consensus on the definition of ‘end of life care’, the Australian Commission on Safety and Quality in Health Care uses the following definition:

[End of life care] includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient’s body after their death.

People are ‘approaching the end of life’ when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and co-existing conditions that mean that they are expected to die within 12 months
- existing conditions, if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.²²

²¹ World Health Organization, ‘WHO definition of palliative care’, viewed 18 February 2016, <www.who.int>.

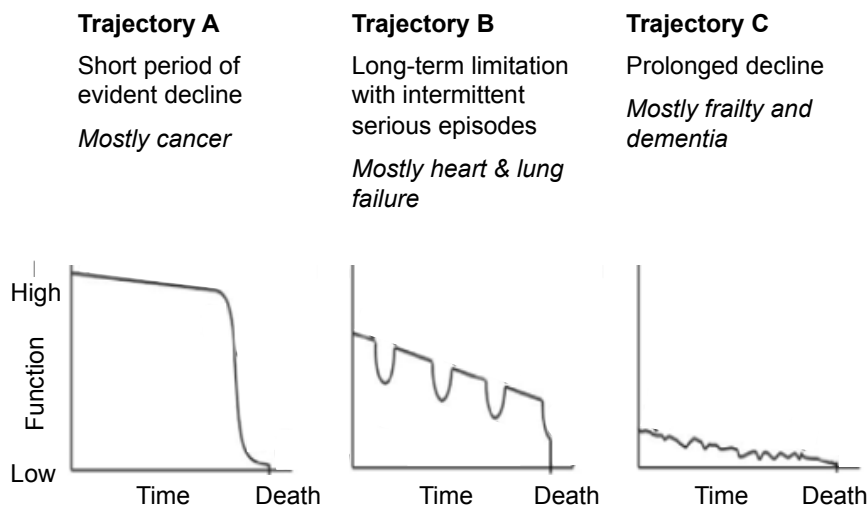
²² Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements from safe and high-quality end-of-life care*, Australian Government, Sydney, 2015, p. 33.

Around 63 per cent of people who receive palliative care in Victoria are over 70 years old, with the average age of referral to palliative care in Victoria being 76.²³ Approximately 36 per cent of recipients are aged 25–69, and only about 1 per cent are under 24 years.²⁴

Historically, palliative care has primarily been provided to cancer patients. This is still the case — Palliative Care Victoria estimates that over 75 per cent of palliative care recipients in Victoria are receiving treatment for cancer.²⁵ However, over the last decade palliative care has been increasingly accessed by people with chronic and life-limiting illnesses other than cancer. These include motor neurone disease; HIV/AIDS; end-stage heart, lung or kidney disease; and advanced dementia.²⁶

Life-limiting illnesses have differing ‘illness trajectories’ that affect the patient’s health and functionality. As a result, each illness requires a different approach to palliative care provision and services. Figure 2.1 below illustrates how illness trajectories differ in chronic diseases.

Figure 2.1 Disease trajectories of typical illnesses leading to death



Source: Joanne Lynn and David M Adamson, *Living well at the end of life: Adapting health care to serious chronic illness in old age*, RAND Corporation, Santa Monica, California, 2003, p. 8, cited in Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014.

Palliative care provision also extends to carers, who are usually family or friends of the patient and often untrained in palliative care. Carers are more at risk of mental health problems and more likely to suffer declines in their physical health than other people of the same age.²⁷ Palliative care services provided to carers include after-hours support, respite care and bereavement support.

23 Victorian Government, *Submission*, p. 2; Palliative Care Victoria, *Submission*, p. 62.
24 Palliative Care Victoria, *Submission*, p. 62.
25 Ibid.
26 Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 1.
27 Victorian Auditor-General, *Carer support programs*, Victorian Auditor-General's Office, Melbourne, 2012, p. 2.

Palliative care service providers can be classified into three categories based on the type of service they provide:

- community services
- inpatient wards
- consultancy services.²⁸

In addition, the Victorian palliative care service sector is supported by various statewide service and research programs. Each type of service is discussed in detail in section 2.2.

Palliative care inpatients are classified into four phases based on the care they require. These are: stable, unstable, deteriorating and terminal. The phases indicate the level of care required and the complexity of the patient's care needs, with stable being the least complex and terminal the most complex.²⁹

Demand for palliative care in Victoria has steadily increased in recent times, with an average increase of 4.9 per cent per year in the last 10 years. According to the Victorian Government, forecasts up until 2018–19 show demand to continue to grow on average by 4 per cent per year.³⁰ The Department of Health and Human Services attributed this to '[Victoria's] growing and ageing population, the prevalence of chronic progressive diseases and people's preferences about care'.³¹ This is consistent with international trends.³²

In its submission, the Victorian Government noted that the complexity of palliative care patient phases is increasing. In 2011–12, stable phases accounted for 31 per cent of inpatient palliative care activity, and the remaining phases accounted for 69 per cent. In 2014–15, the proportion of stable phases decreased to 26 per cent, and the remaining phases accounted for 74 per cent of palliative care activity.³³

Similarly, stable phases in community palliative care accounted for 43 per cent of activity in 2011–12, and the remaining phases accounted for 57 per cent. By 2014–15 the proportion of activity had changed to 33 per cent stable phase and 67 per cent remaining phases.³⁴

In addition, the Victorian Government noted that the following key groups are underrepresented as palliative care recipients:

- culturally and linguistically diverse communities
- people living in aged care facilities and disability residential care

²⁸ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 2.

²⁹ Victorian Government, *Submission*, p. 4.

³⁰ *Ibid.*, p. 2.

³¹ Department of Health and Human Services, *Greater say for Victorians: Improving end of life care*, Victorian Government, Melbourne, 2015, p. 3.

³² Worldwide Palliative Care Alliance, *Global atlas of palliative care at the end of life*, World Health Organisation, London, 2014, p. 4.

³³ Victorian Government, *Submission*, p. 4.

³⁴ *Ibid.*

- people living in rural and remote areas
- Aboriginal and Torres Strait Islander groups.³⁵

2.2 Palliative care services in Victoria

In Victoria, palliative care services are provided by a range of health services and non-government organisations. These services are largely funded by the Department of Health and Human Services and provided through a range of service models and settings.

Victoria's palliative care services are well-regarded. Professor Rohan Vora, then President of Palliative Care Australia and President elect of the Australasian Chapter of Palliative Medicine gave evidence to the Senate Community Affairs References Committee's 2012 inquiry *Palliative care in Australia*. He considered Victoria's palliative care service and governance model was of 'gold standard' and should be applied to other Australian jurisdictions.³⁶

The majority of palliative care services are provided by non-government organisations.³⁷ According to a 2015 review of Victoria's hospital capacity, of the 23 128 contacts³⁸ of palliative care provided in Victoria in 2014–15, 16 442 were provided by non-government organisations and community health services.³⁹

In Victoria, 21 palliative care services provide 289 palliative care beds: 75 in regional Victoria and 214 in metropolitan Melbourne. There are 31 community palliative care services in rural Victoria and 7 community palliative care services in metropolitan Melbourne.⁴⁰

Palliative Care Victoria is the peak body for palliative care services in the State. Its responsibilities are to:

- provide advice to the Department of Health and Human Services on significant issues affecting the sector
- improve community awareness of palliative care
- provide information to palliative care services, the public and other key stakeholders
- provide the 'focal point' for all palliative care services and those with an interest in palliative care in Victoria

³⁵ Ibid., p. 5.

³⁶ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012.

³⁷ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 2; Palliative Care Victoria, *Submission*, p. 57; Department of Health, *Palliative care workforce study — Volunteers and employees*, Victorian Government, Melbourne, 2013, p. 26.

³⁸ For the definition of 'contact', see Department of Health and Human Services, *Victorian Integrated Non-Admitted Health (VINAH), minimum dataset manual: Section 2 — Concepts and derived items*, Victorian Government, Melbourne, 2015, p. 9.

³⁹ Douglas G Travis, *Travis review — Final report*, Victorian Government, Melbourne, 2015, p. 42.

⁴⁰ Victorian Government, *Submission*, p. 7.

- maintain and develop strategic partnerships and links
- lead and manage specific palliative care strategies.⁴¹

Palliative Care Victoria is also a member of Palliative Care Australia, the national peak body for Australian palliative care services.

Carers of palliative care patients in the State are represented by Carers Victoria. Its focus includes:

- being the 'voice' of carers
- raising awareness of carers and caring in communities
- being the place to go for all carers and information about carers
- providing services and programs to support the needs of carers and people they care for
- creating services and products to meet needs and service gaps of carers and people they care for
- other research, policy development and advocacy.⁴²

Carers Victoria is a member of Carers Australia, the national peak body representing carers from all health sectors in Australia.

2.2.1 Inpatient palliative care services

Inpatient palliative care is provided in designated palliative care beds and by specialist consultancy services. Palliative care beds in Victoria are located within acute hospitals, in subacute units and in stand-alone services. A number of private hospitals and other private services also provide inpatient palliative care.⁴³

Palliative care beds are used in a variety of ways for caring with patients who have complex needs. They can also be used in coordination with community palliative care services to stabilise the patient and enable them to return home for ongoing care.⁴⁴

Palliative care services provided by inpatient wards include symptom management, end of life care, planning for patient discharge and respite. Inpatient palliative care services may be accessed when families can no longer care for a person at home, in particular during the last days of life.⁴⁵

⁴¹ Department of Health, 'Palliative care decision making groups: Peak body — Palliative Care Victoria Inc', viewed 18 February 2015, <www2.health.vic.gov.au>.

⁴² Carers Victoria, *Strategic plan*, Carers Victoria, Melbourne, 2015, p. 3.

⁴³ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 18.

⁴⁴ Ibid.

⁴⁵ Ibid.

2.2.2 Community palliative care services

The majority of Victoria's palliative care is provided in community settings by non-government providers.⁴⁶ Around 56 per cent of community palliative care referrals are received from non-palliative care health services and 21 per cent from general practitioners, specialists and psychiatrists. The remaining referrals are from:

- palliative care health services (8.4 per cent)
- community-based agencies (5.5 per cent)
- the patient themselves, a relative, carer or friend (4.2 per cent)
- residential aged care facilities (1.7 per cent)
- other sources (3 per cent).⁴⁷

Community palliative care services include in-home care, day hospices for respite care and after-hours support. Support is also provided to carers through respite, counselling services and bereavement support.

In-home care

'In-home care' refers to care provided in a patient's home or home-like setting, such as aged care and disability residential facilities. In-home care is provided by a number of different services, including:

- health services
- community palliative care staff
- general practitioners
- the Royal District Nursing Service
- community hospices
- home community care services⁴⁸
- not-for-profit organisations.⁴⁹

Day hospices

A day hospice is a community palliative care service which allows a patient to spend a day away from home. Patients attend the hospice for a day and are provided with various types of palliative care and support services. There are four day hospices in Victoria, at Sunshine, Caulfield, Kew and Bendigo.

⁴⁶ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 18.

⁴⁷ Department of Health and Human Services, Correspondence to Standing Committee on Legal and Social Issues secretariat, 10 March 2015.

⁴⁸ For example general services for the elderly and people with disabilities.

⁴⁹ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 2.

The focus of day hospices is to provide psychological, social and spiritual support to patients. They provide programs such as music therapy and fatigue management and are also used as respite for carers. Day hospices may also provide patients with access to consultations with palliative care health practitioners.⁵⁰

After-hours care

Provision of after-hours support has been a requirement for community palliative care service providers since 1997.⁵¹ 'After-hours' is defined as all times outside of business hours (between 7.00 am and 4.30 pm, Monday to Friday, excluding public holidays).⁵² The minimum level of service required for after-hours support is defined in the Department of Health and Human Services policy and funding guidelines and includes:

- telephone advice to carers and families, primarily for symptom management advice
- a nursing visit, if the service assesses that a visit is required and it is safe for staff to do so.⁵³

An audit into palliative care conducted in 2015 by the Victorian Auditor-General noted that after-hours support provided in Victoria fell into variations of three main models of service:

- a regional nursing telephone triage service provider supporting several community palliative care services
- a local hospital after-hours manager providing telephone triage to the local community palliative care service
- an individual palliative care service or local district nursing service that provides after-hours telephone triage support to the local community.⁵⁴

Respite care

Respite care refers to support provided to carers to enable them to take a break from caring for a person in palliative care. Respite care includes informal care provided by family, friends or neighbours and formal care provided by respite services.⁵⁵ In addition, there are times that beds in inpatient wards are used for respite.

50 Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 20.

51 Department of Health, *After hours palliative care framework*, Victorian Government, Melbourne, 2012, p. 1.

52 Department of Health and Human Services, *Policy and funding guidelines 2015*, Victorian Government, Melbourne, 2015, p. 243.

53 Department of Health, *After hours palliative care framework*, Victorian Government, Melbourne, 2012, p. 1.

54 Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 36.

55 My Aged Care, 'Respite care', viewed 18 February 2016, <www.myagedcare.gov.au>.

At a public hearing, Tam Vistarini, hospice manager at Warrnambool and District Community Hospice told the committee of the range of respite provided by that organisation:

It can be going in and just staying with the patient while the carer goes, has a haircut, does some shopping, whatever. But it could be a whole range of things: it could be talking to the families; it could be hanging out the washing; it could be washing their hair; it could be cooking a cake; or it could be assisting them in bed, to turn the patient over. It could be staying there. We have a shift from 10 o'clock at night until 7 o'clock the next morning, so the carers can just go to bed and get a sleep and not have to worry that the patient is going to have a fall or wake up in pain. They can ring the 24-hour palliative care number if there is an emergency and they can support the family.⁵⁶

Formal respite services in Victoria include the four day hospices across the State and in-home support provided by volunteers or community services.⁵⁷

2.2.3 Consultancy services

Victoria's 2004–09 palliative care policy (see section 2.4.1) introduced a requirement for health services to develop palliative care consultancy services. The number of consultancy teams in Victoria has since increased from four in 2004 to 18 in 2015.⁵⁸

Palliative care consultancy services provide symptom management and discharge planning for patients in acute hospital wards, and outpatient services for community palliative care services.⁵⁹

Consultancy services provide advice and support to treating teams in hospitals and in the community. They also provide direct clinical care, assessment and advice for clients and carers with complex needs.⁶⁰

Consultancy services provide specialist advice and support to services in community settings. This includes at community palliative care services and residential facilities, enabling them to meet very complex needs for clients that might otherwise require admission to hospital. Consultancy services also provide education and training to other clinicians.⁶¹

⁵⁶ Tam Vistarini, Hospice in the Home Manager, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 26.

⁵⁷ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 37.

⁵⁸ *Ibid.*, p. 28.

⁵⁹ *Ibid.*, p. 2.

⁶⁰ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 19.

⁶¹ *Ibid.*

Each metropolitan health service (excluding the Royal Women's Hospital and the Royal Victorian Eye and Ear Hospital) has a palliative care consultancy service. Each of the five Victorian regions also has a regional palliative care consultancy service to support rural health services.⁶²

2.2.4 Research and other statewide services

The Victorian Government funds a number of statewide palliative care services that provide specialist advice on particular diagnoses or groups. Key services include:

- HIV/AIDS Consultancy Service
- MND Victoria
- Peter MacCallum Cancer Centre
- Statewide Specialist Bereavement Service, operated by the Australian Centre for Grief and Bereavement
- Very Special Kids
- Victorian Paediatric Palliative Care Program.⁶³

Palliative care research in Victoria is primarily conducted by the following institutions, with assistance from the Department of Health and Human Services:

- Centre for Palliative Care, part of St Vincent's Hospital and a collaborative centre of the University of Melbourne. The Centre's research focus is on family-centred palliative care, psychosocial care, symptom management and service delivery.
- Chair in Palliative Medicine, Monash University and Southern Health. Research focus is on palliative care policy, service delivery and symptom management.
- Palliative Care Unit, La Trobe University. Research focus is on public health, pastoral care, sociological studies and supportive care.⁶⁴
- Vivian Bullwinkel Chair in Palliative Care Nursing, in clinical partnership with Peninsula Hospice Service, Royal District Nursing Service and Peninsula Health and funded by Monash University. Research focus includes service evaluation, palliative care policy, cultural issues and education.
- Department of Pain and Palliative Care and Department of Nursing and Supportive Care, Peter MacCallum Cancer Centre. Research focus is on supportive care and pain management.⁶⁵

⁶² Victorian Government, *Submission*, p. 7.

⁶³ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, pp. 20–21.

⁶⁴ Department of Health and Human Services, 'Statewide palliative care services', viewed 9 March 2016, <www2.health.vic.gov.au>.

⁶⁵ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 24.

2.3 Workforce demographics

2.3.1 Professional workforce

Victoria has a small, occupationally-diverse palliative care workforce. A 2013 study of the workforce conducted by the former Department of Health indicated a composition of around 63 per cent nurses, 11 per cent medical staff and 8 per cent allied health professionals. Other workforce roles include psychosocial care, grief and bereavement services, spiritual care and health promotion.⁶⁶

Workforce highlights:

- 86% are women
- 63% are nurses
- 72% work part time
- Most work in inpatient or consultancy settings

Approximately 86 per cent of palliative care employees are female. The average age of employees is around 47.8 years for females and 46 years for males.⁶⁷

Most palliative care doctors work in inpatient or consultancy settings. A smaller proportion are based in community and statewide services.⁶⁸

In 2014–15, 63 per cent of palliative care contacts involved nurses, 23 per cent doctors, 20 per cent allied health professionals and 21 per cent psychosocial support staff.⁶⁹

Victoria's palliative care sector employees are predominantly employed part-time. In 2013, the sector was comprised of approximately 72 per cent part-time workers, 24 per cent were full-time and the remaining 4 per cent were employed on a casual basis.⁷⁰

Palliative care sector employees typically work across a number of organisations, which has increased over time from an average of 1 organisation per worker in 2007 to 1.4 organisations for each worker in 2013.⁷¹

2.3.2 Volunteer workforce

Formal volunteers — as distinct from carers — make up a substantial part of Victoria's palliative care workforce. There are approximately 2000 trained palliative care volunteers in the State.⁷² The former Department of Health workforce study reported that the number of hours volunteers work in

⁶⁶ Department of Health, *Palliative care workforce study — Volunteers and employees*, Victorian Government, Melbourne, 2013, p. 26.

⁶⁷ Ibid.

⁶⁸ Ibid., p. 3.

⁶⁹ Victorian Government, *Submission*, p. 6. Note that contacts often involve multiple medical practitioners.

⁷⁰ Department of Health, *Palliative care workforce study — Volunteers and employees*, Victorian Government, Melbourne, 2013, p. 3.

⁷¹ Ibid.

⁷² Palliative Care Victoria, *Submission*, p. 58.

palliative care is equivalent to 30 per cent of paid full-time employees.⁷³ The study indicated that around two-thirds of them contribute directly to supporting the quality of life of patients and their carers.

Volunteers in Victoria's palliative care sector are predominantly female and on average are 64 years old. Approximately 65 per cent are retired and 18 per cent work part-time. The average palliative care volunteer spends between one and four hours per week volunteering, however more than 20 per cent work more than four hours.⁷⁴

The study also found that about 80 per cent of volunteers work within community settings. Approximately 17 per cent work in inpatient palliative care, and about 1 per cent work in day hospices or statewide palliative care service respectively.⁷⁵

Around 44 per cent of volunteers provide in-home patient support, with 20 per cent providing inpatient and bereavement support respectively. The predominant form of palliative care provided by volunteers is companionship and others include emotional support, respite support and assistance with transport.⁷⁶

The Committee acknowledges the significant contribution that volunteers make to the palliative care workforce, to patients, their families and to the Victorian health system as a whole. It can be a very stressful time for relatives and carers when a patient enters palliative care, and the support provided by volunteers is integral to helping them through this difficult stage of their lives.

2.4 Governance and leadership

Governance of the Victorian palliative care sector is provided at state, regional and Commonwealth levels. Palliative care is primarily the responsibility of state governments. Regional groups provide input on local practices and issues, and the role of the Commonwealth is to provide guidance to ensure some consistency of practice between the states.

The framework for palliative care is complex and incorporates aspects of many different policies, standards, strategies, and guidance documents at each governance level. The sections below provide an overview of the framework at each level.

⁷³ Department of Health, *Palliative care workforce study — Volunteers and employees*, Victorian Government, Melbourne, 2013, p. 13.

⁷⁴ *Ibid.*, pp. 2–13.

⁷⁵ *Ibid.*, p. 7.

⁷⁶ *Ibid.*, p. 17.

2.4.1 Statewide

The Department of Health and Human Services is the lead agency of the Victorian palliative care sector and coordinates service provision across the State. The Department is also responsible for developing policy and guidance, setting targets, providing funding and determining service priorities for the sector.⁷⁷

Policy framework

Victoria's palliative care policy is detailed in *Strengthening palliative care: Policy and strategic directions 2011–2015*. The policy was developed by the former Victorian Department of Health and replaced the initial version of Victoria's palliative care policy, which was developed in 2004 and expired in 2009.⁷⁸ The policy was launched in August 2011, with Government allocating \$34.4 million over four years to 'meet growing demand and address gaps in service delivery'.⁷⁹

Due to the expiration of the palliative care policy at the end of 2015, there is no current palliative care policy in operation. The Victorian Government announced a review of its approach to palliative care in October 2015, including development of a new framework. The Government released a discussion paper inviting input from the public to guide the review. The review is discussed in detail in section 2.5.

The 2011–2015 policy details seven strategic directions to improve state palliative care services. These are:

1. Informing and involving clients and carers
2. Caring for carers
3. Working together to ensure people die in their place of choice
4. Providing specialist care when and where it is needed
5. Coordinating care across settings
6. Providing quality care supported by evidence
7. Ensuring support from communities.⁸⁰

The focus of these strategic directions is consistent between the 2004–2009 and 2011–2015 policy documents which have been developed by successive governments.

Within the seven strategic directions there are 23 priority areas, each containing their respective required actions and impacts.

⁷⁷ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 4.

⁷⁸ Department of Health, *Strengthening palliative care: A policy for health and community providers 2004–09*, Victorian Government, Melbourne, 2004.

⁷⁹ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015 — Implementation strategy*, Victorian Government, Melbourne, 2011, p. 1.

⁸⁰ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 11.

The policy is supported by an implementation strategy which details the required agency actions, timeframes and performance measures of each strategic direction.⁸¹ In addition, the policy contains a service delivery framework that identifies service expectations and describes how services should be provided across the State.⁸²

The policy forms part of Victoria's broader health plan, the *Victorian health priorities framework 2012–2022*. The framework details the planning and development priorities for health services across the whole Victorian health care system by the year 2022.⁸³ It also identifies seven priority areas for Victorian health system reform.

In September 2015 the Victorian Government announced development of Health 2040, a health service and infrastructure plan which will replace the existing statewide framework. Development of Health 2040 was a result of a statewide review of Victoria's public hospitals. It is intended to provide a 20-year view for the Victorian health sector, with a sharper focus on the first five years.⁸⁴

Progress of the Victorian Government's 2011–2015 palliative care policy was reported in 2011–12 and in 2012–13 by the former Victorian Department of Health. Both reports identified that the policy had beneficial impacts to the sector, and that a number of initiatives were implemented under the strategy.⁸⁵

A Victorian Auditor-General's audit into palliative care examined the impact of the policy's seven strategic directions and discussed the effective provision of palliative care in the State. The audit described the strategic directions as 'ambitious but relevant goals for palliative care'.⁸⁶

Victoria's palliative care policy framework also includes a number of other guidelines and standards, including:

- *Strengthening palliative care: Palliative care volunteer standards* (2007)
- *Strengthening care for children with a life-threatening condition* (2008)
- *Disability residential services palliative care guide: End-of-life care for residents of disability residential services* (2010)
- *After-hours palliative care framework* (2012)
- *Bereavement support standards for specialist palliative care services* (2012)
- *Advance care planning; have the conversation: A strategy for Victorian health services 2014–2018* (2014)

81 Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015 — Implementation strategy*, Victorian Government, Melbourne, 2011.

82 Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, Appendix 1

83 Ibid., p. 2.

84 Douglas G Travis, *Travis review — Final report*, Victorian Government, Melbourne, 2015, p. 40.

85 Department of Health, *Strengthening palliative care: Policy and strategic direction 2011–2015 — First year report 2011–12*, Victorian Government, Melbourne, 2012; Department of Health, *Strengthening palliative care: Policy and strategic direction 2011–2015 — Second year report 2012–13*, Victorian Government, Melbourne, 2013.

86 Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 12.

- *Supporting people with dementia and their families and carers: Victorian dementia action plan 2014–18* (2014).

The role of carers is formally recognised in law under the *Carers Recognition Act 2012*. The Act outlines a set of principles for respect and recognition of carers, and obligations of carer support organisations that are funded by the Victorian Government.

Clinical leadership

Clinical leadership for the Victorian palliative care sector is provided by the Palliative Care Clinical Network. The network was established in 2010 by the former Victorian Department of Health and its goals are:

- overseeing clinical service improvement projects
- convening forums to provide an opportunity for workers to enhance their practice regarding key palliative care issues
- promoting consistent practice across the State
- maintaining links with regional clinical advisory groups, other clinical groups and research networks.⁸⁷

The Palliative Care Clinical Network is supported by an Endorsement Standing Sub-Committee. The sub-committee coordinates the endorsement process for clinical guidelines and strategies and makes recommendations to the Palliative Care Clinical Network to incorporate them into statewide clinical practice improvements.⁸⁸

The Palliative Care Clinical Network is also supported by a number of other working groups to help execute its work plan.⁸⁹

Monitoring and data collection

The Department of Health and Human Services collects data from palliative care organisations through a number of compulsory and voluntary reporting methods. These are summarised in Table 2.1 below:

⁸⁷ Department of Health and Human Services, 'Palliative Care Clinical Network', viewed 18 February 2016, <www2.health.vic.gov.au>.

⁸⁸ Ibid.; Victorian Palliative Care Clinical Network, 'Translating local strategies into state-based clinical practice improvements: The work of the Victorian Palliative Care Clinical Network Endorsement Standing Sub-committee', Paper presented at the *Australasian Clinical Networks Conference*, Sydney, 22-23 November, 2012.

⁸⁹ For examples, see Victorian Palliative Care Clinical Network, 'Translating local strategies into state-based clinical practice improvements: The work of the Victorian Palliative Care Clinical Network Endorsement Standing Sub-committee', Paper presented at the *Australasian Clinical Networks Conference*, Sydney, 22-23 November, 2012.

Table 2.1 Palliative care data collection methods

Dataset	Compulsory/voluntary	Information collected	Health services
Victorian Admitted Episodes Dataset	Compulsory	Clinical and administrative data	Inpatient services
Victorian Integrated Non-Admitted Health Minimum Dataset	Compulsory	Clinical and administrative data Patient-centred data	Community palliative care services Hospital consulting services
Policy Implementation Audit Tool	Compulsory	Survey data on policy implementation	Inpatient services Community palliative care services Hospital consulting services Regional consulting services Day hospices
Palliative Care Outcomes Collaboration (National)	Voluntary	National benchmarking data on patient outcomes	Inpatient services Community palliative care services
National Standards Assessment Program (National)	Voluntary	Accreditation against national quality improvement standards	Inpatient services Community palliative care services Hospital consulting services
Victorian Palliative Care Satisfaction Survey	Compulsory for health services to provide to patients and carers. Completing the survey is voluntary	Survey responses on palliative care services	Inpatient services Community palliative care services

Source: Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 8.

Funding

Victorian palliative care services are largely funded by the Department of Health and Human Services.⁹⁰ Funding for 2015–16 is illustrated in Table 2.2 below.

Table 2.2 Funding for palliative care services in 2015–16

Service	Funding (\$ million)
Inpatient services	62.5
Community services	43.1
Consultancy services	11.2
Training and development	2.1
Regional palliative care consortia	1.1
Total	\$120.0

Source: Victorian Integrated Non-Admitted Health data provided to the Standing Committee on Legal and Social Issues by Department of Health and Human Services.

90 Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. ix.

Approximately 35 per cent of Victorian palliative care funding goes to community palliative care services.⁹¹ These services are block funded, based on a tender process conducted in 1998. In 2005 and 2011 additional growth funding was allocated to community services based on population growth and needs.⁹²

Inpatient palliative care is funded using an activity based funding model, which was introduced in 2013–14. This funding approach applies daily payments according to the patients' phase of care — stable, unstable, deteriorating and terminal — during their hospital stay.

Funding for hospital palliative care consultancy has been provided as part of acute inpatient activity since 2013–14. Funding for statewide palliative care consultancy teams is provided as a block grant.

Funding for regional palliative care consultancy teams is also provided as a block grant. This funding covers aged and disability link nurses and is recognised as recurrent.⁹³

In Geelong the Committee heard that the Government's approach to funding may not always lead to positive outcomes. At a hearing at Grace Mackellar House in July 2015 the Committee discussed this issue with representatives of Barwon Health:

Ms FITZHERBERT — Just one last question: when was that new ward actually completed? My understanding is that it is completed, but it is just that beds are not funded, so it cannot be used. When was it completed?

Dr MARTIN — At the end of May.

The CHAIR — Dr Martin, can you clarify from whom you are seeking the funding for those beds that are not yet funded?

Dr MARTIN — The state government.

Ms JONES — We put a proposal in in September last year.⁹⁴

The facility later opened as an acute palliative care unit in May 2016. However, the Committee highlights that it is crucial that the Victorian Government ensures that timely recurrent funding is available to coincide with the completion of new capital projects so that resources can be fully utilised.

⁹¹ Ibid., p. 18.

⁹² Ibid., p. 4.

⁹³ Department of Health and Human Services, *Policy and funding guidelines 2015*, Victorian Government, Melbourne, 2015, p. 70.

⁹⁴ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 54; Julie Jones, Chair, Barwon South Western Region Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, p. 54.

Programs

There are a number of statewide programs providing services, education and training for palliative care in Victoria. Key programs are as follows:

- The Victorian Palliative Medicine Training Program is run by the Centre for Palliative Care with a focus on workforce development and education and training in Victoria's palliative care sector. The program is funded by the Department of Health and Human Services.⁹⁵
- The Department of Health and Human Services in partnership with the Victorian Aboriginal Community Controlled Health Organisation administers the Victorian Aboriginal Palliative Care Program. The program was established in 2008 to increase awareness of and access to palliative care services for the Aboriginal community and to provide culturally appropriate care.⁹⁶
- The Victorian Palliative Care Nurse Practitioner Collaborative is administered by the Centre for Palliative Care with funding from the Department of Health and Human Services. The program was initiated in 1998 for development, support and mentorship of palliative care nurse practitioners. The Department also offers scholarships to nurses who are completing Masters (Nurse Practitioner) programs.⁹⁷
- The Victorian Paediatric Palliative Care Program is administered by the Royal Children's Hospital, Very Special Kids and Monash Health and is funded by the Department of Health and Human Services. The program is a consultation-liaison team comprised of specialist doctors, a case manager/social worker, occupational therapists and nurses. The team does not provide direct patient care — services provided include:
 - care coordination
 - communication assistance between specialist hospital care and community care providers
 - patient management advice
 - educational activities for staff of hospital and community agencies.⁹⁸

The Department of Health and Human Services also administers a number of programs provided under the National Palliative Care Program. The program is discussed in section 2.4.3.

⁹⁵ Centre for Palliative Care, 'Victorian Palliative Medicine Training Program Advisory Committee — 2013 terms of reference', viewed 18 February 2016, <centreforallcare.org>.

⁹⁶ Ibid.

⁹⁷ Centre for Palliative Care, 'Victorian Palliative Care Practitioner Collaborative', viewed 17 February 2016, <www.centreforallcare.org>.

⁹⁸ Better Health Channel, 'Victorian Paediatric Palliative Care Program', viewed 24 February 2016, <www.betterhealth.vic.gov.au>.

2.4.2 Regional

Coordination at a regional level for Victoria's palliative care sector is provided by regional consortia. Eight palliative care regional consortia were established in 2004 across the State with the following key roles:

- undertaking regional planning in line with departmental directions
- coordinating palliative care service provision in each region
- advising the Department of Health and Human Services about regional priorities for future service development and funding
- in conjunction with the Palliative Care Clinical Network (see section 2.4.1):
 - implementing the Victorian palliative care policy's service delivery framework
 - undertaking communication, capacity building and clinical service improvement initiatives.⁹⁹

Membership of palliative care consortia comprises:

- one representative from all department-funded palliative care services in the region
- a representative from any public hospital in the region
- regional departmental staff
- consortium manager
- representatives from various other health, community and aged care providers.¹⁰⁰

Each consortium is run independently of the Department of Health and Human Services. The Department monitors consortia performance through their annual reports.¹⁰¹

Regional consortia are also required to establish clinical/practitioner advisory groups, whose roles and responsibilities are described as:

- ensuring decisions by the consortium are made on evidence-based clinical practice
- developing and assisting to implement resources that promote evidence-based clinical practice
- advising the consortium on clinical issues in the region

⁹⁹ Department of Health, *Strengthening palliative care: Policy and strategic directions 2011–2015*, Victorian Government, Melbourne, 2011, p. 15.

¹⁰⁰ Department of Health, 'Palliative care decision making groups — Palliative care consortium', viewed 29 January 2015, <www2.health.vic.gov.au>, p. 2. Membership may include representatives from Medicare, integrated cancer services, primary care partnerships. Non-voting membership may be given to clinical representatives and other government stakeholders.

¹⁰¹ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 22.

- providing a forum for clinicians to discuss and resolve clinical issues
- identifying clinical issues to be escalated to the Palliative Care Clinical Network.¹⁰²

In addition, regional consortia may establish an advisory/reference group to provide input into policy and strategic planning in the region and communicate this to service providers. Consortia may decide to combine the function of an advisory/reference group into the clinical/practitioner group or strategic planning consultation group.¹⁰³

2.4.3 Commonwealth

Although palliative care service provision is the responsibility of state and territory governments, the Commonwealth Government provides support and guidance to the sector. This is through national guidelines to ensure service consistency between jurisdictions and funding for national and state palliative care programs. The Commonwealth Government also provides funding for palliative care to the states and territories as part of funding for subacute care services.¹⁰⁴

National oversight of the palliative care sector is provided by the Commonwealth Government Department of Health. In addition, the Commonwealth Government is responsible for palliative care services provided by general practitioners and residential aged care services.¹⁰⁵

The objectives of Victoria's palliative care strategies and those expressed in the Commonwealth policy framework broadly align.

National palliative care strategy

The national policy framework for palliative care is detailed in *National palliative care strategy 2010: Supporting Australia to live well at the end of life*. The strategy identifies four goal areas to meet increasing demand in palliative care in Australia:

- awareness and understanding
- appropriateness and effectiveness
- leadership and governance
- capacity and capability.¹⁰⁶

¹⁰² Department of Health, 'Palliative care decision making groups — Palliative care consortium clinical/practitioners group', viewed 29 January 2015, <www2.health.vic.gov.au>.

¹⁰³ Department of Health, 'Palliative care decision making groups — Palliative care consortium advisory/reference group', viewed 29 January 2016, <www2.health.vic.gov.au>.

¹⁰⁴ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 22.

¹⁰⁵ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 10.

¹⁰⁶ Department of Health, *National palliative care strategy 2010: Supporting Australia to live well at the end of life*, Australian Government, Canberra, 2010, p. 8.

Each goal area is further defined with sub-goals, actions and measures of success.

The national Palliative Care Working Group¹⁰⁷ is responsible for implementing the national strategy.¹⁰⁸ The working group was established in 1998 as a forum that aims to ensure a consistent approach to palliative care across Australia. It comprises one representative from each state and territory government department responsible for palliative care. The working group was incorporated into the committee structure of the Australian Health Ministers' Advisory Council in 2011.¹⁰⁹

Other guidelines

Other key national guidelines relating to palliative care include the following:

- *Guidelines for a palliative approach in residential aged care* (2006). These guidelines target health professionals providing palliative care in residential aged care facilities. This includes nurses, care workers and general practitioners.
- *Guidelines for a palliative approach for aged care in the community setting: Best practice guidelines for the Australian context* (2010). These guidelines were developed as a companion to the 2006 guidelines, and are aimed at health practitioners providing palliative care to older people in community settings.¹¹⁰
- *Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples: Resource kit*. The Commonwealth Government provided funding to the Wodonga Institute of TAFE to develop the resource kit. The kit is provided for palliative care services to deliver culturally appropriate palliative care to Aboriginal and Torres Strait Islander people.¹¹¹
- *National carer strategy* (2011). This details how governments, business, professionals and the community should respond to the changing needs of carers through support and services. It details six priority areas for long-term policy directions. The strategy gives effect to the principles of the *Carer Recognition Act 2010* (Cth) under the broader national carer recognition framework.¹¹²

¹⁰⁷ Previously the Palliative Care Intergovernmental Forum, which is referenced in the national strategy.

¹⁰⁸ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 3.

¹⁰⁹ Department of Health and Ageing, *Submission*, no. 96, Inquiry into palliative care in Australia, Standing Committee on Community Affairs (References Committee), Australian Parliament, p. 2.

¹¹⁰ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 9.

¹¹¹ Department of Health, 'Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander Peoples: Resource kit', viewed 11 March 2016, <www.health.gov.au>.

¹¹² Department of Families, Housing, Community Services and Indigenous Affairs, *National carer strategy*, Australian Government, Canberra, 2011, p. 7.

At the time of writing, the Commonwealth Department of Health is reviewing the 2006 and 2010 guidelines. In 2015 the Department engaged Nous Group (a management consulting and leadership development firm) to conduct a feasibility study — including a survey on public awareness and perceptions of the guidelines — to inform the review.¹¹³

In addition, Palliative Care Australia has developed the following standards and guidelines for palliative care service provision. These are intended to be considered complementary to existing standards and guidelines. Compliance with these guidelines and standards by palliative care service providers is not mandatory.¹¹⁴ The standards are:

- *Standards for providing quality palliative care for all Australia* (2005)
- *A guide to palliative care service development — A population based approach* (2005)
- *Palliative care service provision in Australia — A planning guide* (2003).

In 2014, Palliative Care Australia initiated a review of these three standards. This included a consultation paper and a public submission process.¹¹⁵ At the time of writing, Palliative Care Australia expects to release a set of revised standards during 2016.

The Senate Community Affairs References Committee's 2012 inquiry into palliative care in Australia heard that the standards being voluntary results in inconsistent application. The Committee recommended 'that the Australian Commission on Safety and Quality in Healthcare ... consider the proposal to implement a national standard linked to accreditation, noting that reforms should not result in increased regulatory burden or complexity'.¹¹⁶

National consensus statement for end of life care

The Australian Commission on Safety and Quality in Health Care published the *National consensus statement: Essential elements for safe and high-quality end of life care* in 2015. The statement is aimed at clinicians and contains recommended practice for providing end of life care services.

The consensus statement is not part of the *National safety and quality health service standards* (see below) and is therefore not part of the associated health accreditation scheme. The Committee also notes that the Commonwealth Government does not enforce the consensus statement, and it is up to state and territory governments to implement its objectives.

¹¹³ Leading Age Services Australia — Victoria, 'Survey: Informing review of palliative care guidelines', viewed 11 March 2016, <www.lasavictoria.asn.au>.

¹¹⁴ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 10.

¹¹⁵ Palliative Care Australia, 'Communiqué on the review of *The standards for providing quality palliative care for all Australians*', viewed 29 January 2016, <palliativecare.org.au/>.

¹¹⁶ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 19.

The consensus statement describes 10 essential elements which are required in systems to ensure safe and high-quality end of life care. The essential elements are as follows:

1. Patient-centred communication and shared decision-making
2. Teamwork and coordination of care
3. Components of care
4. Use of triggers to recognise patients approaching the end of life
5. Response to concerns
6. Leadership and governance
7. Education and training
8. Supervision and support for interdisciplinary team members
9. Evaluation, audit and feedback
10. Systems to support high-quality care.¹¹⁷

Essential elements 1–5 relate to end of life care processes. Elements 6–10 relate to organisational structures and workforce needs. Each element contains a number of actions to assist implementing the consensus statement.

The consensus statement also contains 15 guiding principles for providing end of life care. These are detailed in Box 2.1 below.

Box 2.1: National consensus statement: Essential elements for safe and high quality end-of-life care — Guiding principles

1. Dying is a normal part of life and a human experience, not just a biological or medical event.
2. Patients must be empowered to direct their own care, whenever possible. A patient's needs, goals and wishes at the end of life may change over time.
3. Providing for the cultural, spiritual and psychosocial needs of patients, and their families and carers is as important as meeting their physical needs.
4. Recognising when a patient is approaching the end of their life is essential to delivering appropriate, compassionate and timely end-of-life care.
5. The prognosis and the way that people respond to medical treatment will vary between individuals. This means that there is potential for ambiguity and uncertainty at the end of life. This must be honestly and openly acknowledged, and discussed with patients, substitute decision-makers, families and carers.
6. Safe and high-quality end-of-life care is patient and family-centred. Whenever possible, it should be aligned with the values, needs and wishes of the individual, and their family or carers. Such care should consider the patient's expressed wishes regarding the circumstances, environment and place in which they wish to die.

¹¹⁷ Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements from safe and high-quality end-of-life care*, Australian Government, Sydney, 2015, p. 7.

Box 2.1: National consensus statement: Essential elements for safe and high quality end-of-life care – Guiding principles (continued)

7. Safe and high-quality end-of-life care requires the availability of appropriately qualified, skilled and experienced interdisciplinary teams.
8. Safe and high-quality end-of-life care requires effective communication, collaboration and teamwork to ensure continuity and coordination between teams, within and between settings, and across multiple episodes of care.
9. Care of the dying is urgent care. Timely recognition of a patient's transition to the terminal phase of life must be documented and communicated to patients, families, carers and other health professionals by the interdisciplinary team. The care plan must be specifically revised to meet the unique needs of the patient, family and carers during this phase.
10. End-of-life decision-making should be shared between the interdisciplinary team and the patient. Substitute decision-makers, families and carers should be involved, in accordance with the patient's expressed wishes and/or jurisdictional legislation.
11. The interdisciplinary team has a responsibility to:
 - provide timely and accurate information regarding the patient's clinical condition and its severity or stage, the expected disease trajectory, the available treatments, and the likelihood of response to such treatments
 - clearly communicate information to support patients (or substitute decisionmakers, families and carers) to make decisions about care, and to check that they understand the implications, consequences and risks associated with such decisions
 - invite patients to participate in the process of advance care planning, and create opportunities for patients to make decisions and to communicate their values, goals and wishes regarding their end-of-life care
 - offer support, expert opinion and advice so that patients (or substitute decisionmakers, families and carers) can participate in fully informed, shared (or supported) decision-making
 - identify existing advance care plans and provide care in accordance with the patient's expressed wishes
 - document, communicate and hand over the agreed plan of care and any limitations of medical treatment to other clinicians involved in the patient's care
12. For ethical reasons, it is important not to harm patients approaching the end of life by providing burdensome investigations and treatments that can be of no benefit.
13. Patients have the right to refuse medical treatments. Decisions regarding treatment may be made in advance and remain valid unless the patient (or substitute decision-maker, family and carers) state otherwise.
14. Unless required by law, doctors are not obliged to initiate or continue treatments that will not offer a reasonable hope of benefit or improve the patient's quality of life.
15. Care of the deceased person, and care for families and carers extends to the period after the patient has died.

Source: Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements from safe and high-quality end-of-life care*, Australian Government, Sydney, 2015, pp. 4–5.

The Committee believes these guiding principles are well-articulated and important for health services when providing palliative care.

The consensus statement notes that the scope of the statement may not apply to situations where a patient is being provided with palliative care led by a specialist palliative care doctor or team. In these situations, it refers to the standards developed by Palliative Care Australia for patient-centred palliative care services. The statement further recommends that palliative care standards are also considered to ensure a collaborative approach between palliative care and end of life services.¹¹⁸

National safety and quality health service standards

The *National safety and quality health service standards* are a set of national standards used for accreditation of health service organisations. All hospitals and day procedure services must be accredited to the standards. Accreditation requirements for private health services are determined by state level health departments.¹¹⁹

The standards were developed by the Australian Commission on Safety and Quality in Health Care in 2011, and mandatory accreditation was introduced in 2013.

The primary aims of the standards are to ‘protect the public from harm and improve the quality of health service provision’.¹²⁰

Each standard contains:

- an outline of the intended actions and strategies to be achieved
- a statement of intent, which describes the intended outcome
- the context of the standard
- a list of key criteria, each with a series of required items and actions needed to meet the standard.

The standards include criteria relating to advance care planning. This is discussed further in Chapter 4.

¹¹⁸ Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential elements from safe and high-quality end-of-life care*, Australian Government, Sydney, 2015, p. 3.

¹¹⁹ Australian Commission on Safety and Quality in Health Care, ‘Information for health service organisations’, viewed 18 February 2016, <www.safetyandquality.gov.au>.

¹²⁰ Australian Commission on Safety and Quality in Health Care, *National Safety and Quality Health Service Standards*, Commonwealth of Australia, Sydney, 2011, p. 3.

National Palliative Care Program

The Commonwealth Government provides funding to palliative care projects through the National Palliative Care Program.¹²¹ Funding under these areas is provided to a number of palliative care programs and collaboratives, local groups, health and aged care providers, and church and charitable organisations.¹²²

Funding is provided to initiatives in four areas:

- support for patients, families and carers in the community
- increased access to palliative care medicines in the community
- education, training and support for the workforce
- research and quality improvement for palliative care services.¹²³

Examples of initiatives under the four areas of the program include:

- grants for community palliative care services
- coordination of multi-site drug trial and applications for funding for palliative medications through the Australian Pharmaceutical Benefits Scheme
- research and quality improvement initiatives
- education and training programs.¹²⁴

Palliative Care Australia receives funding from the Commonwealth Government through the National Palliative Care Program.¹²⁵

After-hours care

The Commonwealth Government funds Decision Assist, which includes a 24-hour telephone-based advice service which provides support to general practitioners and aged care staff. Callers are connected to a specialist palliative care or advanced care planning operator. Decision Assist aims to 'enhance the provision of palliative care and advance care planning services to the aged nationally'.¹²⁶ It is managed by a consortium of national health and aged care organisations.¹²⁷

¹²¹ See Department of Health, 'Palliative care', viewed 26 May 2015, <www.health.gov.au> for a full list of programs funded in 2015–16.

¹²² Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 31.

¹²³ Department of Health and Ageing, *Submission*, no. 96, Inquiry into palliative care in Australia, Standing Committee on Community Affairs (References Committee), Australian Parliament, p. 6.

¹²⁴ Australian Commission on Safety and Quality in Health Care, *Safety and quality of end-of-life care in acute hospitals: A background paper*, Australian Government, Canberra, 2013.

¹²⁵ Department of Health and Ageing, *Submission*, no. 96, Inquiry into palliative care in Australia, Standing Committee on Community Affairs (References Committee), Australian Parliament, p. 19.

¹²⁶ Decision Assist, 'About Decision Assist', viewed 9 March 2016, <www.caresearch.com.au>.

¹²⁷ Ibid.; Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 36.

Carers

As part of its 2015–16 budget, the Commonwealth Government announced development of the Integrated Plan for Carer Support Services. The plan will replace the National Carer Strategy, which was developed in 2011.

The plan includes establishing Carer Gateway, which is a national website, phone service and service finder to help carers access information and support.¹²⁸

Other Commonwealth support programs and services provided to carers include:

- Young Carers Respite and Information Services
- Young Carer Bursary Programme
- Respite Support for Carers of Young People with Severe or Profound Disability Program
- Mental Health Respite: Carer Support
- MyTime Peer Support Groups for Parents of Young Children with Disability.¹²⁹

2.5 Victorian Government's new end of life care framework

In September 2015 at the national Australian Palliative Care Conference the Victorian Minister for Health announced the Government's intention to develop a new end of life framework.¹³⁰ A public consultation process was announced in October 2015.¹³¹

The Government intends to release the framework in June 2016.

In its submission to the Inquiry, the Victorian Government stated that the framework will include four priority areas:

- improving the capacity of, and access to, specialist palliative care
- better matching what people want and what is provided
- improving integration across service delivery
- increasing knowledge about end of life care amongst all clinicians and services.¹³²

¹²⁸ Department of Social Services, 'Carers', viewed 11 March 2016, <www.dss.gov.au>.

¹²⁹ Ibid.

¹³⁰ Kym Peake, Secretary, Department of Health and Human Services, *Transcript of evidence*, 25 November 2015, p. 2.

¹³¹ Minister for Health, *Victorians to have their say on end of life care*, media release, Victorian Government, Melbourne, 28 October 2015.

¹³² Victorian Government, *Submission*, p. 10.

2.5.1 Conduct of the review

In October 2015 the Victorian Government announced a public consultation process to develop the new end of life care framework.

This included releasing a discussion paper, holding 24 public forums throughout Victoria and establishing the website <www.betterendoflife.vic.gov.au/>. The website allowed users to submit short comments as part of an online consultation.

The discussion paper outlined five feature areas for consideration:

- enabling genuine choice — there is no legally-binding way for a person to state their treatment wishes for future conditions. The Government intends to introduce legislative reforms to include advance care planning in law.
- supporting individuals, families and carers
- responding to diversity
- helping people to die well
- supporting the workforce.¹³³

It also noted five key challenges to Victoria's end of life care system:

- growing demand for palliative care and advance care planning
- increasing patient complexity
- access to services, particularly by culturally and linguistically diverse communities, those living in aged care and disability residential care services, people from rural and remote areas, and Aboriginal and Torres Strait Islander people
- workforce issues, including the professional workforce adapting to changing demand and expectations and upskilling the generalist health workforce
- community expectations.¹³⁴

Submissions to the discussion paper closed on 18 December 2015.¹³⁵

The consultation process also included 24 public forums held in various metropolitan and regional locations from 4 November to 11 December 2015.¹³⁶

The Committee notes that many contributors to the website addressed the issue of assisted dying. This is despite the lack of explicit reference to that topic on the website.

¹³³ Department of Health and Human Services, *Greater say for Victorians: Improving end of life care*, Victorian Government, Melbourne, 2015, p. 1.

¹³⁴ *Ibid.*, p. 3.

¹³⁵ betterendoflife.vic.gov.au, 'Discussion paper', viewed 11 March 2016, <www.betterendoflife.vic.gov.au/>.

¹³⁶ betterendoflife.vic.gov.au, 'Forums', viewed 27 January 2016, <www.betterendoflife.vic.gov.au/>.

The Secretary of the Department of Health and Human Services advised the Committee that the Government was also reviewing the publicly available submissions made to the Legal and Social Issues Committee Inquiry.¹³⁷

2.5.2 Overlap with the Committee's Inquiry

At the time of writing this Report the Victorian Government's review was being conducted separately, although concurrently, to the Committee's Inquiry. As the Committee noted in its interim Report, there will inevitably be some overlap between both reviews.¹³⁸

At a public hearing, representatives from the Department of Health and Human Services also clarified the differences. Simone Corin, Director, Health Programs Branch, acknowledged there was overlap but stated that the Government's review provided a forum for clinicians to comment on practical issues:

I think there is clearly overlap ... But we are certainly not seeking to duplicate in terms of seeking duplicate submissions. We are saying they are noted as having been provided to you. But I think the opportunity that our consultations provide is that there are then those clinicians able to work within a similar group within the regional area where the discussion does get to that practical level about what is the approach that might work within your region. How might you actually work with other health services to deliver? What might be the referral pathways? What are the governance-type considerations that might need to be made? I think that is a slightly different conversation because it is a conversation between clinicians and health services to inform us at a practical level about what needs to be considered in the framework.¹³⁹

Kym Peake, the Department's Secretary, added that the Government's review was focused on the shorter term:

The other point I would make is that I would certainly envisage that some of your recommendations will have more of a medium and longer term effect. While we are trying to have a broad framework for how to think about this, we are very focused on what are the very practical short-term actions that can be taken and how to organise for those.¹⁴⁰

It is the Committee's hope that the Victorian Government considers this Report, in particular the rich material provided in the many submissions made to the Inquiry and by the witnesses who gave evidence at public hearings. The Committee believes this evidence is invaluable for decision makers developing policy on end of life care and hopes that the Government can consider this Committee's and the community's contribution when developing the new end of life framework.

¹³⁷ Kym Peake, Secretary, Department of Health and Human Services, *Transcript of evidence*, 25 November 2015.

¹³⁸ Standing Committee on Legal and Social Issues, *Inquiry into end of life choices: Interim report*, Victorian Parliament, Melbourne, 2015.

¹³⁹ Simone Corin, Director Health Programs Branch, Department of Health and Human Services, *Transcript of evidence*, 25 November 2015, p. 7.

¹⁴⁰ Kym Peake, Secretary, Department of Health and Human Services, *Transcript of evidence*, 25 November 2015, p. 7.

3

Towards a community based approach to palliative care

3.1

Introduction

Palliative care is an important part of health care in Victoria. It benefits a large number of Victorians directly, and the Victorian community generally.

The Committee was struck by the dedication of the health practitioners and volunteers that make up Victoria's palliative care workforce, and was privileged to be able to meet and learn from so many of these people, whose expert care of their patients in a time of great need is exemplary.

The Committee heard extensive evidence on the role of palliative care services in end of life care. Much of this evidence came from health services that shared their experiences in delivering palliative care. These included palliative care service providers, hospices, aged care facilities and hospitals.

Various health professional associations also made submissions to the Inquiry. Additionally, evidence on the topic of palliative care was received from academic institutions, the Victorian Government and some statutory bodies, such as the Victorian Auditor-General's Office. Religious and faith-based organisations and advocacy groups also contributed their views on palliative care.

The Committee also heard from sick and dying Victorians, and the relatives of deceased Victorians, about their experiences with palliative care. Many of these brave people are currently unwell but found the time to contribute to the Committee's Inquiry. For this, the Committee is very grateful.

The Committee heard evidence that there are shortfalls in community palliative care services, including that community palliative care services currently lack the capacity to sufficiently and effectively care for patients in their place of choice. This includes those who wish to be cared for and die at home, in a hospice, or aged care facility. As such, patients are being cared for and dying away from their place of choice, often in a hospital emergency department.

... palliative care is not just about dying. It is about quality of life, it is about how we live with our illness, it is about choices, and it is about where we want our care, who we want to be involved in our care and how we bring all that together.

Annette Cudmore, Clinical Nurse Consultant, West Hume Palliative Care Consultancy Service, public hearing
13 August 2015

The Committee heard from many sources,¹⁴² such as the Grattan Institute in their report *Dying Well*, that although 70 per cent of Australians wish to die at home, only about 14 per cent do so.¹⁴³ Further to this, Victorian Government Department of Health and Human Services statistics show that from 2012–13 through 2014–15, approximately 50 per cent of people in community palliative care who want to die at home¹⁴⁴ do so. Approximately 90 per cent of people in community palliative care who want to die in hospital do so.¹⁴⁵

Apart from these statistics showing people's desires are not being met, the Committee heard that inadequate community palliative care results in increased avoidable hospital admissions and greater pressures on emergency departments, which often end up providing end of life care. With this comes increased costs for acute patient care in hospitals.

The evidence that the Committee heard on palliative care generally dealt with our ageing population which is resulting in an increased demand on palliative care, discussed the need to improve existing standards of palliative care and highlighted various opportunities for improvement. The need for better funding was a common theme in the evidence, particularly to address specific issues that are discussed throughout this Chapter.

3.1.1 A note on terminology — palliative care and end of life care

The Committee heard throughout the Inquiry process that palliative care and end of life care are not the same thing. However, the way in which they are similar or different was often confusing for patients and the general community, and the terms were not always used the same way by health practitioners.

Palliative care can be seen as a subset of end of life care, in that it is one part of how medicine can help patients near death. End of life care can be seen as a subset of palliative care, in that it aims to achieve many of the same outcomes of palliative care, but is focused particularly on the very end of life.

Many of the issues described in this chapter relate both to palliative care and end of life care, and some witnesses used the terms in different contexts than others.

For this reason, this Chapter will not strictly delineate what is palliative care and what is end of life care, but rather focus on what issues arose during the Inquiry process, and how patient experience can be improved.

Despite this, one particular point that the Committee believes important to note is that palliative care need not be associated with death. While dying patients often benefit from palliative care, patients can receive palliative care away

142 Robyn Hayles, Chief Operating Officer of Community Health, Rehabilitation, Palliative and Aged Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 7; Palliative Care Victoria, *Submission*, p. 13; Catholic Archdiocese of Melbourne, *Submission*, p. 9; Public Health Association of Australia (Vic), *Submission*, p. 2; Council of the Ageing, *Submission*, p. 13; Australian Catholic Bishops Conference, *Submission*; Office of the Public Advocate, *Submission*, p. 30.

143 Grattan Institute, *Submission*, p. 1.

144 For the purposes of these data home includes private residences, retirement villages, and caravans.

145 Department of Health and Human Services statistics provided to the Committee.

from an end of life setting, including for conditions that are not immediately life-threatening. Indeed, some patients recover to a point where they no longer require palliative care. As Carmel Smith, Executive Manager of Goulburn Valley Hospice Care Service put it:

People do not realise, but we do actually discharge patients from palliative care ... They actually get discharged when they are well, and that tends to be more our non-malignant palliative cares, and we are getting more and more of them on the books now.¹⁴⁶

3.1.2 A note on recommendations — End of Life Care Victoria

In Chapter 8 of this Report the Committee will recommend the Government establish End of Life Care Victoria, with functions regarding palliative care that include those currently undertaken by the Department of Health and Human Services. Throughout this Chapter, the Committee will make recommendations that may be addressed by the Department of Health and Human Services, with the understanding that, should End of Life Care Victoria be established, those recommendations will be transferred to that entity.

3.2 Benefits and limitations of palliative care

Evidence to the Committee acknowledged the benefits, or potential benefits, of palliative care for people who are suffering, particularly from life-limiting illnesses. Palliative Care Victoria, for example, discussed meeting the needs and wishes of people at the end of their lives through well-resourced palliative care services:

Appropriately resourced palliative care will provide the best care possible to improve the quality of life of people with a life-limiting illness, to respond to their needs and preferences, and to support them to die with dignity and in comfort.¹⁴⁷

Cabrini Health also noted this point, and highlighted the benefits of specialist palliative care provided in hospitals:

Research demonstrates that specialist palliative care services improve the quality of life of patients and their families, as well as providing more effective and efficient use of health resources.¹⁴⁸

Palliative care means so much to every life it touches because in the end it is about time. Time to share in the comfort and company of loved ones, time to die with dignity and care, and yet time to truly be alive for the last time possible.

Jacquie Page, Palliative Care Consultant at Western District Health Service, public hearing 30 July 2015

¹⁴⁶ Carmel Smith, Executive Manager, Goulburn Valley Hospice Care Service, *Transcript of evidence*, 13 August 2015, p. 26.

¹⁴⁷ Palliative Care Victoria, *Submission*, p. 12.

¹⁴⁸ Cabrini Health, *Submission*, p. 6. This point was also made by Professor David Kissane, Head of Psychiatry, Monash University, *Transcript of evidence*, 15 October 2015, p. 39.

This was expanded upon by Dr Natasha Michael, Director of Palliative Care at Cabrini Health:

We have demonstrated since the inception of modern palliative care in the 1960s, started off by Dame Cicely Saunders, that through the application of rigorous research, training and scholarship and the judicious use of pain medications and other interventions — that is both pharmacological and non-pharmacological — the ability to improve the quality of end-of-life care for patients and their families through the attention to physical, psychological, psychosocial and existential factors. More recently scientific evidence has demonstrated the improved survival and quality of life of those exposed to palliative care early in their illness trajectory, thus promoting the development of services within acute hospital environments and ambulatory care.¹⁴⁹

In addition to highlighting the benefits of palliative care for patients, the Centre for Palliative Care pointed out the public health and social benefits of palliative care:

Palliative care has established benefits for patients with advanced cancer including improved symptom relief, quality of life, and communication around health care goals. These benefits extend to the patient's family, enhancing caregiver quality of life and bereavement outcomes after the patient's death. Public health benefits have also been reported, with survival gains demonstrated for spouses of patients who received palliative care. Benefits also extend to health care utilisation and therefore costs, with reduced aggressive and futile care at the end of life, reduced hospitalisation and presentation to emergency department, and greater likelihood of death at home for those patients who receive palliative care.¹⁵⁰

Associate Professor Peter Hunter, Chair, Victorian Clinical Leadership Group on Care of Older People in Hospital further elaborated on the benefits to palliative care patients. He stressed that palliative care should not be seen as giving up and that active treatment can continue to occur in conjunction with palliative care:

In fact I think we need to reimagine palliative care. Palliative care is often thought about as giving up, but actually palliative care is a form of escalation of care. It is as much of an escalation of care as someone going to intensive care. We know now that palliative care does not divorce someone from having active treatment at the same time, so this idea that palliative care is giving up is wrong. It is its own form of escalation, and by escalating people to appropriate care you get to relieve a lot of the worries that people have.¹⁵¹

Professor Hal Swerissen of the Grattan Institute explained an additional benefit, longer life:

Paradoxically, palliative care often leads to longer periods of life than acute interventions, something which the literature clearly shows.¹⁵²

149 Dr Natasha Michael, Director Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p. 7.

150 Centre for Palliative Care, *Submission*, p. 2.

151 Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 51. This point was also made by Professor David Kissane, Head of Psychiatry, Monash University, *Transcript of evidence*, 15 October 2015, p. 39.

152 Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 14.

The Committee heard of the many benefits of palliative care, an area of medicine which has advanced significantly over the last decade. However, palliative care does have limitations, as described by Palliative Care Victoria, who explained that palliative care can sometimes be ineffective at relieving all suffering:

In most cases, specialist palliative care teams are able to address the person's physical pain and other symptoms and to respond to their psycho-social, emotional, spiritual and cultural needs so that they are able to live and die well with dignity.

However, a small minority of patients experience refractory symptoms such as agitated delirium, difficulties breathing, pain and convulsions.¹⁵³

Dr Michelle Gold, Director of Palliative Care at Alfred Health, made similar comments:

We can provide really excellent or very good levels of comfort for the majority of patients we care for. I could not honestly pretend to say that we are successful 100 per cent of the time; I acknowledge that. We cannot do a perfect job at this stage, but I think, nonetheless, a strong palliative care network to provide care for the most vulnerable people in our community is a really critical foundation for excellence in end-of-life care.¹⁵⁴

This concern was echoed in a number of other submissions and hearings, especially in the context of discussions about assisted dying.

3.3 Challenges for the palliative care workforce in Victoria

As discussed in Chapter 2 of this Report, the Committee heard from many sources that the demand for palliative care is growing, and that our ageing population and changing disease profiles, including a rise in chronic diseases, are driving the rise in demand.¹⁵⁵

The Health Issues Centre explained the impact of an ageing population as follows:

At the same time, it is a reality that with longer life comes the increased likelihood of chronic disease and disability. The end of life trajectory will depend on the condition(s), but for at least some Victorians this will mean slower decline with sporadic episodes of serious illness, or a long period of comparatively low quality of life.¹⁵⁶

¹⁵³ Palliative Care Victoria, *Submission*, p. 14.

¹⁵⁴ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55.

¹⁵⁵ Victorian Government, *Submission*, p. 2; Mercy Health, *Submission*, p. 2; Melbourne City Mission, *Submission*, p. 3; Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 1; Eastern Palliative Care Association, *Submission*, p. 4; Australian Christian Lobby, *Submission*, p. 3; Royal Australasian College of Physicians, *Submission*, p. 2; FamilyVoice Australia, *Submission*, p. 4; Cabrini Health, *Submission*, p. 6; Cancer Council Victoria, *Submission*, p. 10; Irene Murphy, Regional Nurse Practitioner Mentor, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 5; Jenny Turra, Palliative Care Nurse Practitioner, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 29; Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, pp. 4,8,47; Helen Ridgeway, Positive Ageing Officer, Mornington Peninsula Shire Council, *Transcript of evidence*, 29 October 2015, p. 9; Christopher McCormick, Nurse Unit Manager, Palliative Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 16.

¹⁵⁶ Health Issues Centre, *Submission*, p. 2.

Rebecca Bartel, Chief Executive of the Australian Centre for Health Research outlined some of the factors that are increasing demand on the palliative care system and in particular the capacity of the system to provide for diversity and choice:

... an ageing population; changing disease patterns; case mix changes — we are moving from an acute to a chronic state; rising expectations and patients actually making choices, and more informed choices; groups with diverse needs — dementia, CALD (culturally and linguistically diverse) populations and Aboriginal populations who need entirely different kinds of care; residential aged care — there is a whole new growth in what palliative procedures should be occurring in residential care; and rocketing health expenditure, where we have now been asked to do much more with a lot less. Obviously things have got to change if we are going to achieve some choice.¹⁵⁷

This demand has an effect on entry criteria for inpatient palliative care, as explained by Dr Grant Davies, Health Services Commissioner:

Entry criteria into inpatient palliative care due to high demand are getting higher, and this creates a burden on relatives and carers. I have spoken to a number of relatives and carers who are really stressed about trying to get some inpatient palliative care needs met. Linked with that is the availability of community-based palliative care.¹⁵⁸

Dr Davies went on to say:

I think transfer to alternative care is also problematic. Demand is outstripping supply of inpatient palliative care, necessitating the need to transfer into other residential care.¹⁵⁹

Throughout this Inquiry the Committee heard that, despite funding growth over recent years, the palliative care workforce in Victoria is struggling to meet the growing demand for this service.

Melbourne City Mission stated that funding constraints forced it to decline referrals, even though it saw increased referrals each year.¹⁶⁰ The Eastern Palliative Care Association similarly shared that it would have to soon cut some services and place people on waiting lists because of insufficient funding to meet demand.¹⁶¹

While the Committee heard from the Victorian Government that the palliative care workforce has grown,¹⁶² it also heard the workforce needs to increase further to meet the demands of an ageing population.¹⁶³ The palliative care workforce

¹⁵⁷ Rebecca Bartel, Chief Executive, Australian Centre for Health Research, *Transcript of evidence*, 21 October 2015, p. 10.

¹⁵⁸ Dr Grant Davies, Health Services Commissioner, Office of the Health Services Commissioner, *Transcript of evidence*, 18 November 2015, p. 12.

¹⁵⁹ Ibid.

¹⁶⁰ Melbourne City Mission, *Submission*, p. 2.

¹⁶¹ Eastern Palliative Care Association, *Submission*, p. 7.

¹⁶² Victorian Government, *Submission*, p. 6. And see Chapter 2 for more.

¹⁶³ Palliative Care Victoria, *Submission*, p. 14; Australian Christians, *Submission*, p. 1; Australian Family Association, *Submission*, p. 3; Knights of the Southern Cross Victoria, *Submission*, p. 6; HOPE: Preventing Euthanasia & Assisted Suicide, *Submission*, p. 21; Cancer Council Victoria, *Submission*, p. 11.

falls well below the ratio of 1.0 full time equivalent palliative medicine specialists per 100 000 people (as recommended by the Australian and New Zealand Society of Palliative Medicine)¹⁶⁴. In this regard, Melbourne City Mission summed up:

Victoria has less than half the recommended number of palliative medicine specialists, and more are required to meet the anticipated growth in need for palliative care. Gaps in these services contribute to avoidable hospital admissions, difficulties in accessing advice after hours, and diminished access to expert advice for GPs involved in end of life care.¹⁶⁵

The Australasian College for Emergency Medicine also pointed out that better resourcing of primary care providers would increase end of life care planning and reduce presentations in emergency departments for end of life care.¹⁶⁶

The Committee recognises that the palliative care workforce in Victoria has not reached the numbers recommended by the Australian and New Zealand Society of Palliative Medicine. The Society recommends 1.0 full time equivalent palliative medicine specialists per 100 000 people, and according to the Society's 2009 position paper, data from 2007 shows we employ 0.44 full time equivalent palliative medicine specialists per 100 000 Victorians.¹⁶⁷

RECOMMENDATION 1: That the Victorian Government develop a holistic, evidence-based funding framework for the palliative care workforce that includes targets to meet the current shortfall and growing demand for palliative care services.

3.4 Fragmentation of care

The Committee heard that medical care in general and in particular at end of life can be fragmented, leading to negative outcomes for patients.¹⁶⁸ Associate Professor Daryl Jones, of Austin Health, told the Committee:

In cases where there are multiple teams involved in one patient's care due to the complexity of patients, there is often no one team taking ultimate responsibility for having the difficult end-of-life care discussions.¹⁶⁹

¹⁶⁴ See Australian and New Zealand Society of Palliative Medicine, 'Position statement — Benchmark number of specialists in palliative medicine', viewed 15 March 2016, <www.anzspm.org>. The Society's 2009 position statement calculates, based on 2007 data, that the ratio is 0.44 full time equivalent palliative care specialists per 100 000 Victorians.

¹⁶⁵ Melbourne City Mission, *Submission*, p. 3.

¹⁶⁶ Australasian College for Emergency Medicine, *Submission*, p. 3.

¹⁶⁷ Australian and New Zealand Society of Palliative Medicine, 'Position statement — Benchmark number of specialists in palliative medicine', viewed 15 March 2016, <www.anzspm.org>.

¹⁶⁸ Dr Alistair Mah, Chief Medical Officer, Chief of Barwon Health End of Life Care Steering Committee, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 7; Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 16; Rebecca Bartel, Chief Executive, Australian Centre for Health Research, *Transcript of evidence*, 21 October 2015, p. 12.

¹⁶⁹ Associate Professor Daryl Jones, Medical Director Critical Care Outreach, Austin Health, *Transcript of evidence*, 5 August 2015, p. 6.

The Centre for Palliative Care and others¹⁷⁰ stressed the need for the healthcare system to better integrate palliative care within different areas of practice:

To manage the complexity and burdens – enabling good advance care planning (ACP) and good end of life care (EOLC) – our system needs to be much more responsive to complex care needs. This requires earlier integration of palliative care practices across health care settings, with staff trained to communicate and facilitate appropriate ACP and EOLC, and modelling capacity to share care between areas of practice. For example, primary disease specialists, primary GP care and specialist palliative care working cooperatively to support urgent/complex care in the home of the imminently dying patient.¹⁷¹

Professor Hal Swerissen of the Grattan Institute highlighted some problems existing in a system where palliative care and end of life care are not integrated into wider health care.¹⁷² He also spoke about the necessity of integration early in patient care:

The idea that you go from treatment to palliative care is the wrong idea. You need to have the two combined early on in the process. One of the things that is important in advance care planning is to say to people that it is not either/or; they can do both.¹⁷³

Professor Swerissen also suggested general practitioners take a greater role in ensuring a patient's end of life and palliative care is integrated with other aspects of their care:

The critical place for coordination to occur ideally is with general practice. In a sense over a long period of time we have de-emphasised the role of general practice in actually helping to manage these sorts of processes. Often specialists end up taking responsibility for care, so a cardiologist or an oncologist will typically end up with the responsibility for people who are very seriously ill with the GP as a kind of adjunct to the process and what is going on.¹⁷⁴

Professor David Kissane spoke to the Committee at length about the need to assess patients for depression and other mental health conditions and to include 'psycho-oncology' support as an essential element of end of life care:

While palliative care has developed substantially in Victoria over the past two decades, considerable deficits still exist, especially in psychosocial care provision. Early intervention is central to improving our quality of care. There is so much we can do to reduce suffering, treat depression, relieve existential distress, help family conflict, assist where there is communication breakdown and support people who have a fear of dying.¹⁷⁵

170 Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 2; Dr Arup Bhattacharya, Divisional Clinical Director Medical, Goulburn Valley Health *Transcript of evidence*, 13 August 2015, p. 12; Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 52; Rebecca Bartel, Chief Executive, Australian Centre for Health Research, *Transcript of evidence*, 21 October 2015, p. 10.

171 Centre for Palliative Care, *Submission*, p. 3.

172 Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, pp. 17,21.

173 *Ibid.*, p. 17.

174 *Ibid.*, p. 21.

175 Professor David Kissane, Head of Psychiatry, Monash University, *Transcript of evidence*, 15 October 2015, p. 36.

Professor Kissane advocated for early referral of patients to ‘psycho-oncology’ practitioners and believes that:

... many patients who seek to hasten their death have undiagnosed psychiatric disorders, such as clinical depression or adjustment disorders with demoralisation, which can underpin their suicidal thinking. These disorders often go unrecognised, so psychiatry has a major role to play in diagnosing and treating these patients.¹⁷⁶

The Committee proposes the following recommendations based on the evidence and advice presented during hearings and in submissions that a less fragmented care model would lead to better care at end of life.

The recommendations borrow from the approach of the *National Consensus Statement: Essential elements for safe and high-quality end of life care 2015* endorsed by the Australian Commission on Safety and Quality in Health Care.

RECOMMENDATION 2: That the Victorian Government support an interdisciplinary approach to end of life care that focuses on continuity of care for the patient through the implementation of measures to encourage the efficient organisation and exchange of information with all parties. This includes patients, substitute decision makers, general practitioners, nurse practitioners, community nursing services, Aboriginal health services, home care workers, and managers of community and residential aged care facilities.

RECOMMENDATION 3: That the Victorian Government encourage integration of palliative care with other health services by:

- incorporating palliative care principles into care for patients with chronic conditions
- ensuring timely referral of patients to palliative care (see also Recommendation 37)
- encouraging timely advance care planning conversations through a dedicated Medicare item number (see also Recommendation 34)
- ensuring staff are trained to communicate and facilitate appropriate advance care planning and end of life care.

RECOMMENDATION 4: That the Victorian Government prioritise integrating patient data systems and improve information sharing options for communicating with palliative care services, including information technology.

The Government’s work in this area would be well supported by consultation with Barwon Health. Dr Martin described their processes to the Committee:

The model we have here is an integrated model where one provider offers a whole range of services. Just to recap: that would be services to support, in the hospital, bedded palliative care services, community services and subregional support. The advantage for patients and carers is that these transitions are quite different from services that are run by different organisations. We have the ability to look at an integrated program. Health professionals can follow patients and carers to make those transitions more seamless. That creates some efficiencies as well. What we have really tried to articulate more recently is a range of services that are customised for the needs of the patients and carers. Whether that is that they need to be in the

¹⁷⁶ Ibid., p. 34.

hospital because they might need some specialist pain interventions and they are still getting chemotherapy, whether that is they need to come to a subacute environment place where we can link with our aged-care and rehabilitation colleagues, whether they go home with a package of care or whether they go to a residential aged-care facility that Barwon Health run that we can have a much bigger input with, as well as a range of these kinds of outpatient services. That has been set up, as well as supporting our subregional colleagues in the likes of Colac and Bellarine. Whilst there are some challenges in some of the resource issues and some of the transitions, I think we are able to provide that kind of linkage and continuity of care that is harder to do in other parts of the health system.¹⁷⁷

3.5 Unequal access to palliative care services

A wide variety of health services, and other organisations stressed the need to address inequity in access to palliative care services in Victoria.¹⁷⁸ Melbourne Health described the problem as follows:

Within Victoria there is evidence of inequitable access to these services, including waiting lists to access urgent palliative care services, inadequate resourcing of palliative care (including at The Royal Melbourne Hospital; with aged and poorly constructed and not suitable for purpose ward facility and restricted bed access), barriers to medication access, equipment for care at home, other medical aids including wound dressings, home oxygen provision and care after hours.¹⁷⁹

Dr Jenny Hynson, Head of the Victorian Paediatric Palliative Care Program at the Royal Children's Hospital expressed her concern that variable service levels across community palliative care means that not all patients and families receive the same high level of care:

... we are very blessed in Victoria in that the community palliative care service network is very strong and something to be proud of, but it is inequitable in the sense that not all services provide the same constellation of services or the same level of service. Because we see all of our patients engaged with the various services, I worry that some families do not get the same level of service as other families.¹⁸⁰

The Committee heard that specific groups are underrepresented in palliative care. These include indigenous people, migrant communities, people living in aged care or disability care services, children, and adults with non-malignant life-limiting illnesses.¹⁸¹

¹⁷⁷ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, pp. 2–3.

¹⁷⁸ Mercy Health, *Submission*, pp. 2,5; Melbourne City Mission, *Submission*, p. 2; Christian Medical and Dental Fellowship of Australia, *Submission*, p. 2; Southern Cross Care Victoria, *Submission*, p. 2; Health Services Commissioner, *Submission*, p. 3; Knights of the Southern Cross Victoria, *Submission*, p. 6; Medicine with Morality, *Submission*, p. 2; Australian and New Zealand Society of Palliative Medicine, *Submission*, p. 4; Health Issues Centre, *Submission*, p. 4; Council of the Ageing, *Submission*, p. 12; Cabrini Health, *Submission*, p. 6; Catholic Social Services Victoria, *Submission*, p. 3; Centre for Palliative Care, *Submission*, p. 2; Port Macquarie Dying With Dignity NSW, *Submission*, p. 1; Cancer Council Victoria, *Submission*, p. 11; Irene Murphy, Regional Nurse Practitioner Mentor, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 5.

¹⁷⁹ Melbourne Health, *Submission*, p. 2.

¹⁸⁰ Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 53.

¹⁸¹ Palliative Care Victoria, *Submission*, p. 13; Royal Australasian College of Physicians, *Submission*, p. 3; Melbourne Health, *Submission*, p. 2; Victorian Government, *Submission*, p. 5.

A number of factors were brought to the Committee's attention as indicators of inequity in access to palliative care services:

- living in rural and regional Victoria
- type of illness (for example, non-cancer related)
- cultural and linguistic diversity
- disability
- living in residential aged care facilities

3.5.1 Living in rural and regional Victoria

The Committee frequently heard that palliative care services are not easily accessible for people living in rural and regional areas.¹⁸² This is not unique to Victoria. During its research into international jurisdictions,¹⁸³ the Committee heard from health practitioners and others providing palliative care services in rural and regional locations that they face the same challenges as rural and regional services in Victoria. For example, in many Canadian provinces, and in Oregon in the United States (a state similar in size to Victoria) there are difficulties providing quality services to remote areas.

Judy Sommerville, a community palliative care volunteer with Western District Health Service in Hamilton, related the plight of a rural farmer dying on a farm in a remote area:

This man was dying. He said ... I was born on the land, grew up on the land and b[r]ought up a family on this land. I have battled the pests and the elements, and I have managed to grow food for my country, but here I am dying and there is no guaranteed support system available for me to die on my land should my family require help'.¹⁸⁴

This issue was echoed across evidence the Committee heard at hearings in regional Victoria. For example, in Traralgon, Melissa Marr, Carer Mentor with Gippsland Carers Association Inc. told the Committee:

For many rural Victorians, when they are at home it is quite a distance to get service providers or assistance out there, and that can be a real challenge. It can also be a challenge if they decide to be in a palliative care facility. Being so rural and so far out, that means a lot of distance and a lot of time spent and a lot of cost.¹⁸⁵

¹⁸² Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, pp. 3,7; Marlene Connaughton, Manager Integrated Services, Strat-Haven Aged Care, *Transcript of evidence*, 12 August 2015, p. 26; Doctors for Voluntary Euthanasia Choice, *Submission*, p. 1; Australian Family Association, *Submission*, p. 3; Knights of the Southern Cross Victoria, *Submission*, p. 6; Catholic Archdiocese of Melbourne, *Submission*, p. 8; Royal Australasian College of Physicians, *Submission*, p. 3; Melbourne Health, *Submission*, p. 2; HOPE: Preventing Euthanasia & Assisted Suicide, *Submission*, p. 22; Cancer Council Victoria, *Submission*, p. 10.

¹⁸³ For details, see Appendix 3.

¹⁸⁴ Judy Sommerville, Community Palliative Care Volunteer, Western District Health Service, *Transcript of evidence*, 30 July 2015, p. 47. See also Usha Naidoo, Manager, Care Coordination, Hamilton, Western District Health Service, *Transcript of evidence*, 30 July 2015, p. 48.

¹⁸⁵ Melissa Marr, Carer Mentor, Gippsland Carers Association, *Transcript of evidence*, 9 September 2015, p. 16.

In Bendigo, Catherine Kemp, Palliative Care Coordinator at Swan Hill District Health repeated the challenges faced in rural areas:

Due to our rural and regional location, preferences for end-of-life care are limited, due to geographical reasons. The Manangatang client may have no carer or may have a frail, aged carer who is unable to support them to die at home, even if this is their preference. This is due to a lack of community support, community services. Inpatient palliative care is available at Mildura, Bendigo and Echuca, all requiring travel and accommodation for families and carers.¹⁸⁶

One aspect of the issue is in appropriately staffing palliative care services outside of metropolitan centres. The challenge of attracting and retaining appropriately trained specialist staff to rural areas was highlighted in the Barwon Region by Dr Peter Martin, Regional Director, Palliative Care at Barwon Health:

One of the things for all of us in terms of the struggle regionally is that we might have some core disciplines of nursing and medicine, but when we look at getting access to allied health, particularly specialist psychology, counselling and bereavement support, there is a variation depending on where you are in this region and on what is available and whether that can be offered in a timely manner.¹⁸⁷

Jane Robertson, Community Nurse Manager, Colac Palliative Care Services made a similar point:

I am sitting in three roles at the moment, so we just stretch and stretch and stretch. It is difficult. Because it is such a highly specialised area we need to be able to not only recruit them and retain them but we also need to make it very attractive and worthwhile.¹⁸⁸

An inability to access allied health workers, as well as counsellors, social workers, and bereavement specialists was a recurrent theme in regional hearings.¹⁸⁹ The Committee also heard that any training necessary can be a challenge, as it typically involves travel to a metropolitan centre.¹⁹⁰

The Government provided the Committee with information about its palliative care training programs for nurses and doctors in rural and regional Victoria.¹⁹¹

The Committee also heard of the advantages to receiving palliative care in a small rural hospital, where such services can become an extension of the sense of community fostered in rural areas.

¹⁸⁶ Catherine Kemp, Palliative Care Coordinator, Swan Hill District Health, *Transcript of evidence*, 12 August 2015, p. 20.

¹⁸⁷ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 47.

¹⁸⁸ Jane Robertson, Community Nurse Manager, Colac Palliative Care Services, Barwon South Western Regional Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, p. 52.

¹⁸⁹ Jenny Turra, Palliative Care Nurse Practitioner, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 30; Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015, p. 62.

¹⁹⁰ Fiona Heenan, Director of Primary and Community Health, Portland District Health Service, *Transcript of evidence*, 30 July 2015, p. 33; Lynn McCarter, Manager, Complete Care, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, p. 30.

¹⁹¹ Victorian Government, *Submission*, p. 5.

Associate Professor Tim Baker, Director of the Centre for Rural Emergency Medicine at Deakin University explained:

This is something that many small rural hospitals do very well. Palliative care is a large part of what they provide the community, and people get to die in their home town near family and friends.¹⁹²

The Ballarat Health Service shared its experience in caring for patients living in regional areas outside of specialist palliative care units, when the patients' needs were not complex:

Palliative care training has been the domain of the specialist palliative care practitioner but many of those who die in the health service do not have complex palliative care needs when they are dying. They can be managed by a care team who has had some palliative care training to ensure that they have the skills and confidence to discuss palliative care with patients and their loved ones. We have introduced the Care of the Dying Management Plan (CDMP) which is a document based on the Liverpool Care Pathway but customised in response to feedback after the trial of the LCP. The CDMP aims to enable best practice evidence-based terminal care to be delivered in clinical settings outside a specialist palliative care unit. The challenge has been in having time allocated for the Palliative Care specialist staff to train and support the clinical workforce to use the CDMP and to manage other aspects of end of life care delivery including referral.¹⁹³

This highlights the benefits of supporting palliative care in rural and regional communities and the need for government to ensure that regional Victorians can stay in their community when they are unwell at the end of their life.

Case Study 3.1

The Committee notes the services provided by Goulburn Valley Hospice Care Service as a particular example of a program providing high quality palliative and end of life care in a rural and regional setting.¹⁹⁴ Dr John Hetherington, President, Committee of Management, Goulburn Valley Hospice Care Service described the Service's origin and work:

The service is an autonomous, freestanding organisation. We had a grassroots origin 25 years ago — well, we have been going for 26 years now, so 27 years ago a grassroots group of people realised that there was a need for palliative care in this area. Too many patients were coming to the end of their treatable disease in hospital and basically being sent home to die in the arms of their relatives. This was not appropriate, so a small group got together and it gradually increased its size and its abilities, and we are now at a situation where we have about 60 per cent of our funding from the government and 40 per cent from fundraising, public donations and public subscriptions. So we regard ourselves as a thoroughly grassroots community organisation.

...

¹⁹² Associate Professor Tim Baker, Director of the Centre for Rural Emergency Medicine, Deakin University, *Transcript of evidence*, 30 July 2015, p. 37.

¹⁹³ Ballarat Health Service, *Submission*, p. 6.

¹⁹⁴ See also 3.6.4.

Case Study 3.1 (continued)

We have six nurses in our employ ... We also have a coordinator of volunteers, because we have volunteers acting in several different modes. We have what we call patient volunteers, who are trained members of the community who are able, after training and with supervision, to go into the home and help the family and help the patient in just about any legal way you can think of. That is a very demanding job, but every time one of those volunteers spends an hour with a family, that is an hour that we have got of nurses pay instead.

Ms Carmel Smith, Executive Manager of Goulburn Valley Hospice Care Service further explained:

I think one of the strengths of our service is that we are a stand-alone service — we are able to dictate and do what we want to do out in the community, and we do it very well. We have an 85 per cent home death rate against a state average of 21, so we are actually doing something very good out there, and I still believe we are one of the few services now that still do our own 24-hour on call.

So after hours when patients and families ring, or on weekends, it is one of the nurses they know who takes that call. The beauty of doing that is that because you know the family unit so well, and we all work very closely with all of our patients, you know if it is carer fatigue and — we have had children looking after parents who have psychiatric problems — you can pick the triggers and you know the family so well. So often we can avert a hospital admission by being able to go out and do a visit as needed overnight or on a weekend. I believe that is one of the main reasons that our patients are able to stay at home to die at home in the care of their family, and I think that we do that very well.

We are very proactive in planning that end-of-life care, so we have the drugs in place weeks before they are needed, we have the orders in place and we have very strong support in our community from our GPs. That enables us to do that.

Ms Smith also described the relationship Goulburn Valley Hospice Care Service has with local general practitioners and Goulburn Valley Health and with Shepparton Private Hospital that allows a continuity of care that greatly benefits their patients:

We are very lucky that we have had over the years — because we have been here so long — a great relationship with Goulburn Valley Health and with Shepparton Private Hospital. Up until this new innovation with the palliative beds coming on — and this is all very new for all of us — our service agreement credentials all of our nurses to actually come into the hospital, see our patients while they are in there, write in their notes, have discussions with the doctors and that. That allows great continuity of care with our families and our carers ...

The Committee recognises the exceptional work of Goulburn Valley Hospice Care Service, its committee of management, staff, and volunteers. The Service provides care in the Goulburn Valley region that, if replicated across rural and regional Victoria, would greatly benefit the lives of many sick and dying people, and their families.

RECOMMENDATION 5: That the Victorian Government increase access in rural and regional communities to community palliative care services by:

- identifying health and community organisations that provide best practice community palliative care and enabling them to expand their services and/or guide the development of similar services in other rural and regional areas
- providing funding for administrative support to community palliative care organisations, so that they can focus on providing frontline palliative care services, such as respite for carers
- increasing funding to community palliative care services in rural and regional Victoria
- implementing incentive programs to attract palliative care expertise to rural and regional Victoria
- providing increased local training opportunities for palliative care staff in rural and regional Victoria
- increasing focus on telehealth projects connecting palliative care patients with health practitioners so patients may remain in their own home with the support of community palliative care services
- fostering community-academic partnerships to promote research and education that contributes to local education and understanding
- investigating targeted funding programs to help people in rural and regional Victoria access allied health palliative care services such as social workers and bereavement counsellors.

3.5.2 Living in residential aged care facilities

The Committee heard that residential aged care facilities were a common and well-suited site for the provision of end of life care.¹⁹⁵ However, it was also observed that there was considerable variation in the quality of end of life care provided by residential aged care facilities.¹⁹⁶ Dr Peter Martin, Regional Director of Palliative Care at Barwon Health made this point, and noted that residential aged care facilities need more help with end of life care:

Residential aged care has a huge variation between the services that are very well set up and others, but in general they need more help to essentially deliver more and more end-of-life care as frailer people with more complex illness end up there, often sooner than they used to.¹⁹⁷

This point was touched on by Mercy Health, Southern Cross Care Victoria and Eastern Palliative Care Association. They stressed the need to employ and train residential aged care facility staff in the provision of end of life care.¹⁹⁸

¹⁹⁵ Southern Cross Care Victoria, *Submission*, p. 3; Australasian College for Emergency Medicine, *Submission*, p. 2.

¹⁹⁶ Southern Cross Care Victoria, *Submission*, p. 3; Barwon Health, *Submission*, pp. 3–4.

¹⁹⁷ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 2.

¹⁹⁸ Mercy Health, *Submission*, pp. 5–6; Southern Cross Care Victoria, *Submission*, p. 3; Eastern Palliative Care Association, *Submission*, p. 7.

Vicki Doherty, of the Gippsland Region Palliative Care Consortia told the Committee that training of aged care staff in end of life care is currently available through the Department of Health and Human Services, but there is still work to do:

We have a lot of people moving into aged-care facilities, and that is another issue in itself. Through the Department of Health and Human Services we have been trying to upskill staff in residential aged care to provide a palliative approach for their clients. I think Victoria is leading the way in the country as far as that is concerned. There have been a lot of resources and commitment by the government to building capacity in aged care. There is still a long way to go, though.¹⁹⁹

The Committee heard about the important role residential aged care facilities can play in preventing unwanted transfers to hospitals.²⁰⁰ However, the Australasian College for Emergency Medicine observed that emergency department presentations from residential aged care facilities were increasing.²⁰¹ The Committee believes that further work is needed by government and the facilities themselves to identify the reasons why this is the case.

Ian Patrick, General Manager Clinical and Community Services, Ambulance Victoria advised the Committee that Ambulance Victoria takes patients out of nursing homes into hospitals for relatively minor procedures, something they are trying to rectify:

I think this is about proper care planning and availability of the resources. We take patients to hospital in the middle of the night to get a catheter changed. We have arrangements with locums now that we will get the doctor to come or we will get a continence nurse, in some places, to come. We are trying to set up referral pathways to connect these people so they do not have to be taken out of the nursing home.²⁰²

RECOMMENDATION 6: That the Victorian Government work to reduce inequities in the provision of palliative care by ensuring consistent palliative care services across residential aged care facilities.

RECOMMENDATION 7: That the Victorian Government work to prevent unnecessary emergency department presentations from aged care facilities and reinvest any savings into palliative care.

3.5.3 Type of illness

The Committee heard that the type of illness a patient suffers can be a factor in the palliative care a patient receives, particularly as an increased focus is required for patients with non-cancer diseases. As Dr Michelle Gold, Director of Palliative Care at Alfred Hospital told the Committee:

¹⁹⁹ Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 5.

²⁰⁰ Southern Cross Care Victoria, *Submission*, p. 3; Australia and New Zealand Society for Geriatric Medicine, *Submission*, p. 1; Australasian College for Emergency Medicine, *Submission*, p. 2. For more on this see section 3.6.3.

²⁰¹ Australasian College for Emergency Medicine, *Submission*, p. 2.

²⁰² Ian Patrick, General Manager Clinical and Community Services, Ambulance Victoria, *Transcript of evidence*, 18 November 2015, p. 34.

... I think the palliative care sector could be strengthened and expanded in some ways to have a greater presence in areas of medicine outside oncology. We do really well with a lot of our oncology groups but not so well in the non-malignant sector. I think a strong representation at acute hospitals is really important — obviously that is where I sit, so I might be biased — but we also need to fill some gaps in the community.²⁰³

Dr Gold went on to say:

I think we have a lot of areas we could improve on in how we provide palliative care for people with non-malignant diseases. There is little bit of work going on around that in the college of physicians in training of the doctors, but it is just starting, so there is going to be quite a lead time before those people are out and practising in the community.²⁰⁴

Dr Gold sees some progress with regard to referrals to palliative care for non-malignant diseases, but also notes the extra pressure this puts on palliative care services:

I think more importantly we are starting to get more referrals from the non-malignant sector and are seeing people with chronic diseases — respiratory diseases or cardiac diseases — and they tend to have a much longer period of being quite frail or needing a lot of care and a lot of symptoms support.²⁰⁵

This problem was echoed by Jason Franklin, who suffers from Hirschsprung's, a congenital bowel disease. Mr Franklin told the Committee:

I would also like to touch on the palliative care system. I feel it needs to go a lot further than just patients being terminal, especially in a situation like mine where I frequent hospital every six weeks to have IV pain relief administered, but once I go home I am back to the same problem. My pain is exactly the same; it is just totally out of control. I have had three palliative care assessments, and they have said because I am not terminal there is nothing that could help me in the home rather than having to frequent hospital or the emergency department if needed.²⁰⁶

Mr Franklin pointed out that he 'falls through the cracks in the system':

I have had three assessments from palliative care, I have spoken to the head of Palliative Care Victoria. They even said that I fall between the cracks in the system, basically. They said, 'Because you are not terminal, you cannot be administered any IV pain relief in the home'.²⁰⁷

Recommendation 11 in section 3.5.6 addresses the issue of making palliative care more accessible by those suffering from non-cancer and chronic illnesses.

²⁰³ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55.

²⁰⁴ *Ibid.*, p. 56.

²⁰⁵ *Ibid.*

²⁰⁶ Jason Franklin, *Transcript of evidence*, 18 November 2015, p. 28.

²⁰⁷ *Ibid.*, p. 29.

3.5.4 Cultural and linguistic diversity

The Committee heard advice about the particular challenges in providing palliative care to culturally and linguistically diverse (CALD) patients, including indigenous patients. Dr Grant Davies, Health Services Commissioner highlighted some of these challenges, and how they relate to communication:

Some of the recommendations that I would make in relation to mitigating some of these issues would include better training throughout a clinician's career on good communication and the process of end-of-life care and in particular in CALD communities. I think they are particular challenges, not just in terms of language and understanding but also in terms of cultural needs. I know that some cultures, for example, do not talk about dying, do not want to talk about dying, do not want to acknowledge dying, so that can be very difficult in a care setting. I know Palliative Care Victoria has run some workshops in 10 communities, and they have highlighted this need.²⁰⁸

The workshops Dr Davies refers to were also raised by Melbourne City Mission's Palliative Care Manager Tracey Mander:

What a few of us from Melbourne City Mission did last year was take part in a project with Palliative Care Victoria, which was around engaging with CALD communities. I talked to a Muslim community about palliative care and got them to translate palliative care into their own language. Then they would go out to their communities and say, 'Look, here are the services'. Often they have a picture of what death and dying is like wherever they have come from, for whatever reason, and they are not aware of the palliative care services here. So there was a huge project done around that, engaging with different CALD communities and raising the profile of palliative care.²⁰⁹

The cultural taboo around dying expressed by the Health Commissioner can extend to families not wanting their dying relative to know that they are dying.²¹⁰

A further challenge put to the Committee was that some culturally and linguistically diverse communities can be reluctant to access services that are offered, possibly due to a cultural expectation that it is a family's duty to provide all of a patient's care.²¹¹

Carolyn Hargreaves, After-Hours Hospital Manager at Goulburn Valley Health explained the particular challenge of using an interpreting service, or family member when treating patients who do not speak English:

First of all, how we support families that are of a non-English-speaking background: we really have interpreters over the phone. We can always access them, but it certainly is not great. Often we are reliant on family members who can speak English.

208 Dr Grant Davies, Health Services Commissioner, Office of the Health Services Commissioner, *Transcript of evidence*, 18 November 2015, p. 12.

209 Tracey Mander, Manager Palliative Care, Melbourne City Mission, *Transcript of evidence*, 14 October 2015, p. 47.

210 Rosemarie Draper, Deputy Chair, Peninsula Care Planning Group, *Transcript of evidence*, 29 October 2015, p. 25; Carolyn Hargreaves, After Hours Hospital Manager, Goulburn Valley Health, *Transcript of evidence*, 13 August 2015, p. 3.

211 Lynn McCarter, Manager, Complete Care, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, p. 30.

That is very difficult. As you are going from one department to the next department, especially in those initial phases, that can create some really big issues. Family members are great as interpreters, but you cannot be assured that what the family is receiving is exactly what is being said. That is challenging, and at the moment a big thing in those initial phases is using phone hook-ups.²¹²

Despite all the challenges, the Committee heard success stories in palliative care for culturally and linguistically diverse patients, for example from Carmel Smith of the Goulburn Valley Hospice Care Service:

A few years ago Rumbalara in the Aboriginal community got the funding to build an aged-care facility in Shepparton. It is a fantastic facility. We have a palliative care room on the end of that, and it has a smoking area out the back and everything. That is going really well. The staff there now [is] getting better at end-of-life care with our education and our support, and often now they will just need to ring us for management of a symptom that is not going well. They have got their own amazing belief systems. Some of them want to die at home, and some of them do not — the same as any of us.²¹³

The Committee also heard from the Government about the Victorian Aboriginal Palliative Care Program, which aims to improve access to, and enable, palliative care services to provide culturally appropriate care.²¹⁴

RECOMMENDATION 8: That the Victorian Government support programs, such as the workshops provided by Palliative Care Victoria, to increase the visibility and highlight the benefits of palliative care to Aboriginal and culturally and linguistically diverse Victorians, through initiatives specifically targeting these communities.

RECOMMENDATION 9: That the Victorian Government provide support to carers from groups that are less likely to have access to palliative care, including Aboriginal and culturally and linguistically diverse groups.

3.5.5 Disability

The Committee heard from Professor Teresa Iacono, Professor of Rural and Regional Allied Health at La Trobe University and a researcher with the Living with Disability Research Centre that people with intellectual and developmental disabilities:

... may be experiencing palliative care, but that is more through luck than good planning. Few are offered choices or supported to make choices, even about their everyday life — who they live with, what they eat, let alone how they are going to die or where they are going to die.²¹⁵

...

²¹² Carolyn Hargreaves, After Hours Hospital Manager, Goulburn Valley Health, *Transcript of evidence*, 13 August 2015, p. 3.

²¹³ Carmel Smith, Executive Manager, Goulburn Valley Hospice Care Service, *Transcript of evidence*, 13 August 2015, p. 27.

²¹⁴ Victorian Government, *Submission*, p. 5.

²¹⁵ Professor Teresa Iacono, Professor of Rural and Regional Allied Health, Latrobe University, *Transcript of evidence*, 12 August 2015, p. 44.

People with [intellectual and developmental disabilities] are also dying in disability support accommodation cared for by staff who have goodwill but who lack experience and skill in supporting older people with [intellectual and developmental disabilities], let alone those who may have a terminal illness.²¹⁶

Professor Iacono further expanded her comments:

Disability staff are often distrustful of mainstream systems, including palliative care. They feel that these services, or the people who work in them, lack an understanding of [intellectual and developmental disabilities] — and they are probably right — or they do not understand their particular needs.²¹⁷

Professor Iacono's advice was that:

We need to build a strong nexus between disability services, aged care, dementia care and palliative care to address support for people with [intellectual and developmental disabilities] who are ageing or seriously or terminally ill and, finally, to build an understanding of supported decision-making for these people so as to educate and guide families, disability support staff, advocacy workers and mainstream services in the process and to include people in decisions about the end of their lives.²¹⁸

The Office of the Public Advocate also explained the challenges faced by those with a disability during end of life care, and health care in general:

There are cases where it is patently wrong to make judgments about a person's quality of life and OPA [Office of the Public Advocate] raises here a concern in relation to the risk of discrimination in treatment options for those people for whom OPA has particular responsibility.

OPA has anecdotal experience of discrimination against people with disability in end of life scenarios. This also relates to treatment of people with disability within the health system more broadly.²¹⁹

This includes the issue of 'diagnostic overshadowing':

OPA has also seen cases where the concept of 'diagnostic overshadowing' – the phenomenon where symptoms or conditions are wrongly attributed to the person's primary disability, rather than to a separate medical condition – have been applied. This has been a significant issue within the healthcare system for many years.²²⁰

3.5.6 Palliative care standards

The Health Services Commissioner, the Public Health Association of Australia and the Centre for Palliative Care supported the idea of standard-setting within the field of palliative care so as to improve the accessibility and quality of

²¹⁶ Ibid., p. 45.

²¹⁷ Ibid.

²¹⁸ Ibid.

²¹⁹ Office of the Public Advocate, *Submission*, p. 26.

²²⁰ Ibid., p. 27.

palliative care. The standards called for related to quality of service and referral and entry criteria for palliative care services, particularly as admission criteria for palliative care services varied widely.²²¹

Dr Grant Davies, Health Services Commissioner, told the Committee that standardisation of entry criteria to inpatient palliative care and consistent quality of community palliative care is critical. He stressed the importance of seamless transfer between inpatient and community care:

Standardised entry into inpatient palliative care services should be established. I think as demand increases the availability will become increasingly difficult. Of course greater availability of inpatient palliative care is important. Equity of access and greater availability to high-quality community-based palliative care is important as well.

...

The availability of inpatient palliative care with a standardised set of entry criteria would be critical. Having a consistent quality and availability of community-based palliative care across the state is critical, and a seamless transfer between those two environments would be important as well.²²²

National Seniors Australia suggested the need for mandatory standards for palliative care service providers:

Palliative care must have the sole purpose of caring for the patient and there should be a Code of Practice or set of standards for providers. The Council of Palliative Care Australia sets out 13 standards for providing quality palliative care for Australians but these remain voluntary.

Further work by government is required to introduce mandatory standards as a basis for accreditation. All providers should be required to report against the standards including such matters as length of time in palliative care, pain management and family/carer engagement.²²³

Dr Karen Detering, with the Respecting Patient Choices Program at Austin Health highlighted that national standards had helped in the related field of advance care planning:

We have the national quality and safety standards [National Safety and Quality Health Service Standards], and that has been an enormous enabler in terms of getting some buy-in from the hospitals, in terms of some systems in place and all sorts of other things. Those things are really helpful.²²⁴

Advance care planning is discussed in detail in Chapters 4 and 5 of this Report.

²²¹ Health Services Commissioner, *Submission*, p. 3; Public Health Association of Australia (Vic), *Submission*, p. 2; Centre for Palliative Care, *Submission*, p. 3.

²²² Dr Grant Davies, Health Services Commissioner, Office of the Health Services Commissioner, *Transcript of evidence*, 18 November 2015, pp. 12,13.

²²³ National Seniors Australia, *Submission*, pp. 7–8.

²²⁴ Dr Karen Detering, Respiratory Physician and Clinical Ethicist, Respecting Patient Choices Program, Austin Health, *Transcript of evidence*, 5 August 2015, p. 12.

Dr Natasha Michael, Director of Palliative Medicine at Cabrini Health recommended accreditation for end of life care, mentioning the *National Consensus Statement: Essential elements for safe high quality end of life care* produced by the Australian Commission on Safety and Quality in Health Care:

... making sure that quality end-of-life care becomes part of national accreditation is absolutely mandatory. The current Australian Commission on Safety and Quality in Health Care program is...calling for expressions or commentary on version 2 of the NSQHS [National Safety and Quality Health Service] Standards that we are all contributing to.²²⁵

Dr Michael also made the point that standards can help ensure high quality care, no matter the setting:

Sixty per cent of Australians die in hospital. I always say we cannot have the lack of parity of services — that you get first-class care if you die in an inpatient palliative care unit, second-class care if you die in an acute hospital that happens to have a palliative care team, and third class care if you die in the community. We need to ensure that there is parity in quality of care, and quality standards are an important way of moving that forward.²²⁶

RECOMMENDATION 10: That the Victorian Government work with the Commonwealth Government to incorporate the National consensus statement: *Essential elements for safe high quality end of life care* into the National Safety and Quality Health Service Standards.

RECOMMENDATION 11: That the Victorian Government establish standards of care to clearly discern criteria for referral to specialist palliative care and the expectations of palliative care knowledge and capability for generalist health care providers. This should include referral of patients who:

- have chronic or non-terminal illnesses
- are currently underrepresented in palliative care
- would benefit from palliative care.

3.6 Community palliative care

Community palliative care services include in-home care, day hospices for respite care and after-hours support. Support is also provided to carers through respite, counselling services and bereavement support. For a more detailed explanation of community palliative care services in Victoria see Chapter 2 of this Report.

This section will explore evidence the Committee heard surrounding community palliative care, including place of care, and place of death.

Professor Hal Swerissen, Grattan Institute Fellow, focused on the need for expansion of community based palliative care in the community. He told the Committee:

²²⁵ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 11.

²²⁶ Ibid.

More competent, comprehensive and coordinated home and community-based services are needed for people who are dying if we are going to support them at home. Much of what is required is well-coordinated personal care to relieve pain and symptom management, as well as counselling, respite care and so on. It needs to be available seven days a week, 24 hours a day in order to work. Only a fraction of our estimate of \$5 billion worth of care in the last year of life is spent on community-based support, which is only a tiny fraction. Around Australia it is probably less than \$200 million.²²⁷

The Committee heard from stakeholders in the sector that not only was community palliative care the community's preference in most cases, but that there is also the peripheral benefit that community palliative care is more cost-effective than inpatient palliative care. Aside from enabling patients to die in their place of choice and freeing up inpatient services, the Grattan Institute suggested that replacing hospital and residential care with community based palliative care would deliver greater savings for the State. For this reason, it contended that more investment in community palliative care services is required:

The total estimated cost of public hospital, residential aged care and community-based aged care services for the last 12 months of life for older people is at least \$5 billion ... Only two per cent of identified expenditure is spent on community care packages. We estimate that the average cost of community based care for the last three months of life for community aged care packages is about \$6000. The costs of supporting individuals to die at home are therefore lower than hospital and residential care, but to achieve overall savings hospital and residential care would have to be replaced by community based services.²²⁸

Professor Hal Swerissen expanded on this point at a hearing:

... savings from hospital and residential care would offset the cost of extending those services [community palliative care] to all of the people who would want them. It is not an expensive exercise in doing that; it actually reduces the cost. The last hospital admission alone, if it were saved, would pay for that care. We think there is room for a significant expansion of community-based palliative care.²²⁹

The idea that community care is less expensive than hospital care was also supported by evidence at regional hearings in Geelong, Warrnambool and Traralgon²³⁰ and by Peter Hunter, Associate Professor, Geriatrician and Director of Aged Care at Alfred Health.²³¹

²²⁷ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 16.

²²⁸ Grattan Institute, *Submission*, p. 24.

²²⁹ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 16.

²³⁰ Jacqui White, Community Palliative Care Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 31; Lynn McCarter, Manager, Complete Care, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, p. 31; Deidre Bidmade, Vice-President, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 25; Cr Dale Harriman, Coordinator, Gippsland Carers Association, *Transcript of evidence*, 9 September 2015, p. 21.

²³¹ Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 54.

3.6.1 Place of care and place of death

The Committee heard evidence that there are shortfalls in community palliative care services. According to this evidence, community palliative care services currently lack the capacity to sufficiently and effectively care for patients in their place of choice. This includes those who wish to be cared for and die at home, in a hospice, or aged care facility. As such, patients are being cared for and dying away from their place of choice.

The Grattan Institute and others²³² referred the Committee to the report *Dying Well*, which found that although 70 per cent of Australians wish to die at home, only about 14 per cent do so. This compares to 54 per cent who die in hospitals, and 32 per cent in residential care.²³³

A caveat to this statistic was raised by Vicki Doherty, Director of the Gippsland Region Palliative Care Consortium:

... I just wanted to mention data and outcomes. There has been a very big focus on whether people are dying in their site of choice. That is very easy to collect, but also it does not give us a really good indication of whether people are being cared for in the site they want to. Often people can see it as a failure — that their loved ones have died, maybe in hospital, even though they have provided all that care for them right up until towards the end. With data and outcomes we just need to be mindful that if people die in their place of choice, it does not always mean that they had a good death. It is also about collecting process outcomes around that.²³⁴

The Committee learned during its research into international jurisdictions²³⁵ that the statistics in other jurisdictions can be much different to those in Victoria.

In Oregon, approximately 28 per cent of people die in hospital, 39 per cent die at home, and 28 per cent die in nursing homes, residential institutions and hospices.²³⁶

In Canada, approximately 64 per cent of people die in hospital, while 35 per cent of people die in non-hospital settings, including private homes, health care institutions such as nursing homes and other long-term care facilities, nursing stations and other short-term care facilities and other health care facilities not licensed to operate as hospitals.²³⁷

²³² Robyn Hayles, Chief Operating Officer of Community Health, Rehabilitation, Palliative and Aged Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 7; Palliative Care Victoria, *Submission*, p. 13; Catholic Archdiocese of Melbourne, *Submission*, p. 9; Public Health Association of Australia (Vic), *Submission*, p. 2; Council of the Ageing, *Submission*, p. 13; Australian Catholic Bishops Conference, *Submission*; Office of the Public Advocate, *Submission*, p. 30.

²³³ Grattan Institute, *Submission*, p. 1.

²³⁴ Vicki Doherty, Director, Gippsland Region Palliative Care Consortium, *Transcript of evidence*, 9 September 2015, p. 3.

²³⁵ For details, see Appendix 3.

²³⁶ Oregon Health Authority, *Oregon vital statistics annual report 2014 — Volume 2*, Oregon Health Authority, Portland, 2014, pp. 6–147.

²³⁷ Statistics Canada, 'Table 102-0509 — Deaths in hospital and elsewhere, Canada, provinces and territories', viewed 20 May 2016, <www5.statcan.gc.ca/>.

In the Netherlands, approximately 33 per cent of people die in hospital, 29 per cent of people die at home, 25 per cent die in nursing homes, and 12 per cent in care homes.²³⁸ The Committee notes research from the Netherlands that found when a patient's general practitioner knows their preferred place of death, 80 per cent of patients die in that preferred place.²³⁹

The Committee heard that patients were often unable to die at home because of inadequate community based palliative care services.²⁴⁰ Cancer Council Victoria, for example, stated that current limitations in community palliative care services prevented patients from being cared for in their homes at the end of their lives:

Gaps in community palliative care services hamper the ability of inpatient palliative care services to facilitate complex care discharges to home, and also to implement the safe and timely transfer of patients to home with handover to community services. Clinicians also identified that community palliative care services are not able to meet current demands due to a lack of beds. This is compounded by a lack of consultants and training registrars with available hours to work in the community, with general practitioners, and with patients in their homes.²⁴¹

Professor Hal Swerissen of the Grattan Institute told the Committee:

We have a big mismatch between what people want and what actually happens. Currently services for people who want to die at home are inadequate, and as a result they have little option but to die in hospital or in residential care if they need significant support.²⁴²

The Committee further heard that in addition to fulfilling the wishes of the dying person, dying at home can have wider, positive effects:

It also often happens that if people are able to procure good care for their loved ones in their home, it has some good implications for bereavement. We are talking about the health of populations here that extrapolate into good societies.²⁴³

Dr David Sykes, General Manager of Learning and Development at Alzheimer's Australia Vic. made it clear that dying in hospital can be particularly bad for people with dementia:

²³⁸ 2006 figures from Statistics Netherlands via Eburn Abarshi, et al., 'General practitioner awareness of preferred place of death and correlates of dying in a preferred place: A nationwide mortality follow-back study in the Netherlands', *Journal of Pain and Symptom Management*, vol. 38, no. 4, 2009, p. 58. In the Netherlands 'care homes' provide basic care, with residents retaining their general practitioner. Nursing homes offer more comprehensive care, and specialist doctors take over care for residents. In 2003 the figures from Statistics Netherlands were 33 per cent at home, 25 per cent in hospital, 20 per cent in nursing homes. See Statistics Netherlands, 'One in three people in the Netherlands die in hospital', viewed 20 May 2016, <www.cbs.nl>.

²³⁹ Eburn Abarshi, et al., 'General practitioner awareness of preferred place of death and correlates of dying in a preferred place: A nationwide mortality follow-back study in the Netherlands', *Journal of Pain and Symptom Management*, vol. 38, no. 4, 2009, p. 54.

²⁴⁰ Alfred Health, *Submission*, p. 4.

²⁴¹ Cancer Council Victoria, *Submission*, p. 11.

²⁴² Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 16.

²⁴³ Irene Murphy, Regional Nurse Practitioner Mentor, Gippsland Region Palliative Care Consortium, *Transcript of evidence*, 9 September 2015, p. 5.

The evidence unfortunately is very strong that hospitals are the worst places for people living with dementia or dying with dementia. They have incredibly adverse outcomes in that context.²⁴⁴

...

People want to die around the people they love in an environment they are comfortable in. That is more commonly the home, but even if it is in a residential aged-care facility and they have lived there for a while, that can equally be far more supportive than potentially going into a very strange environment at that very final stage of your life.²⁴⁵

Inquiry stakeholders suggested that greater investment in community palliative care services is required to increase access to such care, thus allowing more people to die where they want to.²⁴⁶

3.6.2 Obstacles to people dying where they want

The Committee heard that there are obstacles to people being cared for and dying in their place of choice, particularly when that place is outside of hospital. These obstacles include:

- location
- lack of after-hours services
- poor access to medication.

Location

Getting adequate support to die in your place of choice, particularly at home, involves the same difficulties in rural and regional areas as receiving palliative care.²⁴⁷

Jacquie Page, Palliative Care Consultant at Western District Health Service in Hamilton highlighted this difficulty through the story of a 47-year-old woman living on a farm about 30 kilometres from Hamilton:

She has asked to die at home, but I have no district nurse to provide personal care this far out, so it would be nearly impossible. I do not tell her that. If she lived within the Hamilton boundary, she would be able to access three-days-a-week personal care. Even for those people within that boundary with little family support, that is inadequate for someone dying who is bedbound.²⁴⁸

²⁴⁴ Dr David Sykes, General Manager Learning and Development, Victoria, Alzheimer's Australia, *Transcript of evidence*, 14 October 2015, p. 25.

²⁴⁵ *Ibid.*, pp. 25–6.

²⁴⁶ Mercy Health, *Submission*, p. 5; National Seniors Australia, *Submission*, p. 8; Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 4; Alfred Health, *Submission*, pp. 8–9; Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 3.

²⁴⁷ For more see section 3.5.1

²⁴⁸ Jacquie Page, Palliative Care Consultant, Western Health District Service, *Transcript of evidence*, 30 July 2015, p. 44.

Andrea Janes, a registered nurse with South West Healthcare, highlighted the availability of 24-hour care as the main obstacle to dying at home in rural areas:

We could provide all the equipment, but in terms of care provision — the main barrier is if you do not have someone who can care for you 24 hours at home, the likelihood of you being able to achieve your last wish is very minimal in the rural setting.²⁴⁹

After-hours services

The Committee heard that palliative care services that support patients in their home during the day are often not available after hours,²⁵⁰ particularly in rural and regional areas.²⁵¹ This leads to unwanted emergency department presentations and hospital admissions.²⁵² Annette Cudmore, Clinical Nurse Consultant for Palliative Care with West Hume Palliative Care Consultancy Service highlighted this problem:

We need to be able to strengthen our capacity to care for people. People do not get sick Monday to Friday. People get sick seven-days-a-week, and things are harder and worse at 2 o'clock in the morning than at lunchtime on a Wednesday when you have got access to support. If we are going to support home deaths, we need to be real about how we are going to do that and how we are going to support people.²⁵³

Lisa Mitchell, a geriatrician, told the Committee the problem is not limited to people living at home, but also in residential aged care facilities:

People who live in Residential Aged Care facilities also have limited access to medical review and emergency medications in the event of a sudden deterioration, particularly if this occurs after hours. In some cases this means that older people from Residential Aged Care Facilities must be transferred to acute hospitals to die, or, alternatively, receive less symptom management than they might have otherwise.²⁵⁴

Recommendation 18 in section 3.7.2. addresses the issue of after-hours services.

Access to medication

The Committee heard that a significant obstacle to people being cared for and dying at home is the inability of carers and volunteers to administer necessary medications. Witnesses told the Committee that the legislation around this is unclear, resulting in poorer care for patients. The inability of carers and volunteers to administer certain drugs in these situations results in an increase in emergency department presentations and hospital admissions (discussed below in section 3.6.1).²⁵⁵

²⁴⁹ Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 11.

²⁵⁰ Lisa Mitchell, *Submission*, p. 1; Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 3.

²⁵¹ Marlene Connaughton, Manager Integrated Services, Strat-Haven Aged Care, *Transcript of evidence*, 12 August 2015, p. 26.

²⁵² For more on this issue, see section 3.6.3

²⁵³ Annette Cudmore, Clinical Nurse Consultant Palliative Care, West Hume Palliative Care Consultancy Service, *Transcript of evidence*, 13 August 2015, p. 14.

²⁵⁴ Lisa Mitchell, *Submission*, p. 1.

²⁵⁵ For more on this issue, see section 3.6.3

Dr Peter Martin, Regional Director of Palliative Care at Barwon Health summarised the problem:

We know from the evidence that the single biggest reason people end up in [the emergency department] that is preventable is having drugs that they need for the common symptoms that arise out of the blue ... We have had to do some workarounds when people run out of a key medication as to how they get it from one part of the system to another. It is very complicated and a very long policy, and I am not sure that is in anybody's interests. That is just simply to provide an obvious medication for somebody's care. We have done a workaround for that regionally, but it might mean a relative driving up to our palliative care unit, picking up a box of drugs and driving them back.²⁵⁶

This is an issue, not only for people living in their own home, but also in residential aged care facilities.²⁵⁷ Dr Martin again:

Medication management is a particular issue in residential care, whether they are getting the care they need, but then when they need to get a drug, they have to be able to give it to themselves, and if they are frail the person in the residential facility is not legislatively entitled to give them that painkiller which would easily keep them in that facility.

There is this terrible thing of if we just had someone who could give them their as-needed medication they could stay there, but because they are not entitled in terms of the qualifications the whole system falls apart. We might have somebody who needs painkillers once or twice a night. If it works, they can stay where they want to be, but the system does not enable that through some of the issues — for example, if they are a patient care worker they are not medication endorsed, so there are some real issues around that.²⁵⁸

Dr Martin told the Committee that part of the problem is a lack of clarity in legislation about who can give medication:

There is the legislative lack of clarity, so I think there is no reason that I can see frankly why it makes sense that a patient care worker should not be giving a medication that a family member can. It seems very odd to me, and it seems odd that we would be putting that sort of pressure on giving the correct medication to the right person. I think that could be made clearer, and would probably enhance patient care.²⁵⁹

Joy Leggo, Chief Executive Officer of Multicultural Aged Care Services Geelong echoed this view:

We sought legal advice, specialised legal advice, and it came back to us that it is a grey area and will probably need to be tested, but we would have to make sure that it was really clear and agreed with the family as to what we were doing, and all parties need to be in agreeance with the carer delivering the drops or whatever,

256 Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 48.

257 Marlene Connaughton, Manager Integrated Services, Strat-Haven Aged Care, *Transcript of evidence*, 12 August 2015, p. 27; Lisa Mitchell, *Submission*, p. 1.

258 Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, pp. 48–49.

259 *Ibid.*, p. 51.

and then specialised training would need to be given and some form of accredited course would need to be taken. But it was still considered to be quite a risk for an organisation to do it at a personal care level, when you are talking about someone with a base training of a certificate III with some specialised palliative care.²⁶⁰

Jacqui White, Community Palliative Care Coordinator with Barwon Health highlighted how this affects families her organisation supports:

... one of the hugest barriers for us in providing care for people right through their terminal phase at home is the issue about the delivery of medications — PRN medication, [medication as needed]. Certainly when we had introduced the idea of whether we could look at putting in an overnight carer to families, it was like. ‘What is the point if you are going to have to wake me anyway to give the medication?’. So there were lots of barriers from the family’s perspective in terms of accepting that sort of assistance.

...

Families can be educated, and if they are willing they are able to give those medications, and we certainly have a range of mechanisms that we have in place in terms of our medical record so that families can record what they have given. Generally, though, those medications are drawn up by a nurse, labelled appropriately, stored appropriately in the home for that purpose, but we do need to have checks and balances. But generally, certainly from a paid carer’s perspective, those medications essentially need to be given by a nurse.²⁶¹

Lisa Mitchell, a geriatrician, told the Committee that access to medicine is also a factor in residential aged care facilities:

People who live in Residential Aged Care facilities also have limited access to medical review and emergency medications in the event of a sudden deterioration, particularly if this occurs after hours. In some cases this means that older people from Residential Aged Care Facilities must be transferred to acute hospitals to die, or, alternatively, receive less symptom management than they might have otherwise.²⁶²

The Committee also heard that there are limits to the medications nurses can administer. Dr Ric Milner, a general practitioner working in the Western Victoria Primary Health Network explained:

When I leave here today I will be seeing this lady. I will go and see her. I write a script when she first comes home for a bucketload of narcotics and other drugs to be kept in the house — a range of them. If I go to another palliative care person, I will write another bucket full, so there are bucketloads of these drugs all around the place, mostly not being used, because the palliative care nurses are not allowed to carry the drugs. If the palliative care nurses had a bucket full of a bigger range of drugs, they could then ring us if they needed to alter doses and things. They used to do it many years ago, but there was a palliative care nurse who was using narcotics herself,

260 Joy Leggo, CEO, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, p. 31.

261 Jacqui White, Community Palliative Care Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 32.

262 Lisa Mitchell, *Submission*, p. 1.

so they just wiped it. That sort of protecting the organisation structure just causes discomfort and harm to patients. That would be an easy thing to fix — to just make it that they can and should.²⁶³

Several other health practitioners discussed this problem in evidence given to the Committee in Geelong. They pointed out that there are carers who would be enthusiastic about being trained to administer medication, but that there is uncertainty about precisely what training requirements and other guidelines need to be met, and difficulty in finding the time necessary to train those who want it.²⁶⁴

The Committee recognises the issues raised surrounding access to medication. Any solution to ensure greater access to medication may not be straightforward. There are some possible solutions which the Victorian Government may consider investigating. For example, requiring residential aged care facilities to employ staff able to administer appropriate palliative care medication, and/or amending legislation or regulation to increase the ability of nurses, carers, and patient care workers to administer appropriate palliative care medication. However, these or other measures require further investigation, including targeted consultation with key stakeholders.

RECOMMENDATION 12: That the Victorian Government update the regulations regarding the storage of and access to medications at home and in residential aged care facilities for palliative care patients so that unnecessary barriers to treatment and pain relief are removed, while mitigating the risk of potentially dangerous and addictive medications being accessed inappropriately.

3.6.3 Pressure on emergency departments

One result of inadequate after-hours care and community palliative care in general is increased hospital admissions and greater pressures on emergency departments in hospitals, which often end up providing end of life care.²⁶⁵ The Australasian College for Emergency Medicine told the Committee:

... the emergency department is now routinely being utilised as the default provider for end of life care, and in some cases palliative care, for elderly patients and those with a terminal illness. Residents from aged-care facilities are now comprising a significant proportion of emergency department presentations.²⁶⁶

There are a number of reasons why an individual at the end of their life might end up in a hospital. The Committee often heard that hospital admissions can be the result of caregivers having too much to handle when caring for a patient at home:

²⁶³ Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 38.

²⁶⁴ Julie Jones, Chair, Barwon South Western Region Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, pp. 51–52; Karlie Keck, Coordinator Community Nursing and Support Program, Bellarine Palliative Care Services, Barwon South Western Region Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, pp. 51–52; Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, pp. 51–52; Jane Robertson, Community Nurse Manager, Colac Palliative Care Services, Barwon South Western Regional Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, pp. 51–52.

²⁶⁵ Barwon Health, *Submission*, p. 2; Australia and New Zealand Society for Geriatric Medicine, *Submission*, p. 1.

²⁶⁶ Australasian College for Emergency Medicine, *Submission*, p. 2.

... that admission into hospital comes, in a lot of cases, for that very reason; they [the caregiver] are just burnt out and they have not got the supports. So that then drains the system by putting a person into a bed when somebody medically needs to be in that bed. We feel the benefits from a hospital perspective as well, with freeing up hospital beds for people who are dying, and who do have medical needs, so we feel it is a win-win all around.²⁶⁷

The Victorian Health Services Commissioner suggested there was a need to expand existing community palliative care services to meet the wishes of patients wanting to die at home and to free up inpatient palliative care services:

The demand for inpatient palliative care could be mitigated by the availability of community based palliative care. There will always be a need for specialist inpatient palliative care services but, with people increasingly wishing to die at home, specialist community based palliative care is also important and complementary. Transfers to aged care facilities are likely to decrease with appropriate home based care. At present, some community based palliative care and domiciliary nursing services undertake this role, particularly after hours but the coverage is patchy. The needs of palliative care patients often increase as they move closer to death and have specialist care needs. This requires specialist skills and knowledge. There is great variability in the way domiciliary nursing services engage and work with local palliative care services in Victoria. The model can be quite different depending on where you live and die. This is a source of frustration and confusion for carers and families. This raises questions of equity of care because it should not matter where you live in accessing and receiving quality community based palliative care.²⁶⁸

Eastern Palliative Care Association shared its experience in providing care to terminally ill patients in their homes. It pointed out that a number of factors may be at play when death does not occur at home, such as the disease process, lacking a carer, the patient living alone, unexpected deaths during periods in hospital and social circumstances where it may not be safe for a patient to be at home.²⁶⁹ Recognising that patients wishing to die at home may require hospital treatment on occasions, Eastern Palliative Care Association stressed the need for hospitals and specialist community palliative care services to work together:

The collaboration between hospitals and specialist community palliative care services is essential and needs to go above and beyond the goodwill of individuals to be a requirement of the system in order for client choice to be acted on. Returning clients home after hospitalisation also needs to be an expectation, not an option. Many clients are reluctant to go to hospitals because they feel they will not get an opportunity to be home again, when in fact a short hospital stay may improve their quality of life. EPC (Eastern Palliative Care) constantly keeps in touch with hospitals when clients are admitted to ensure that they know we are involved and the services we can provide. Many hospitals believe that complex care can only be provided in hospital ignoring the choices of the client and their families.²⁷⁰

²⁶⁷ Deidre Bidmade, Vice-President, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 27.

²⁶⁸ Health Services Commissioner, *Submission*, p. 3.

²⁶⁹ Eastern Palliative Care Association, *Submission*, p. 2.

²⁷⁰ Ibid.

Ian Patrick, General Manager Clinical and Community Services at Ambulance Victoria told the Committee of the pressure placed on ambulance services and emergency departments:

The other thing is that that patient now goes into an emergency department, where we have ambulances — 10 ambulances, maybe — sitting outside there waiting to clear. Now we are taking another person in there who cannot sit in the waiting room, cannot be unsupervised and has to be attended to. A blocked catheter can become a major problem. So it is a complete system-wide bottleneck, and if you have 50 of these a day it is a lot.²⁷¹

Some hospital admissions for palliative care patients are appropriate, but others might not be. Tracey Mander, Manager of Palliative Care at Melbourne City Mission explained:

I had a look at our hospital admissions for our patients, and all of them experienced between 1 and 10 inpatient admissions. Many of those were appropriate, and they came out again; but 20 of those died within two days of admission, so I am wondering, if we had had some resources at that time, could they have been supported to die at home?²⁷²

Ms Melissa Weaver, Care Manager at Strath-Haven Community, which provides aged care in the Bendigo region, explained that sometimes emergency department presentations are the result of not having the necessary medications:

If we feel that we need medications and we cannot get medications, because maybe the GP has not ordered them or they have not been in to review, and somebody is very ill, we need to send them up to the emergency department at Bendigo Health. We sent somebody up yesterday, and they said, 'You'll be going knowing that you will be sitting behind 10 other ambulances. That is probably an issue as well. We could not get the medication we needed for this lady. She chose, and her family chose, to go up to the ED to be reviewed, and in order to get medications that is probably a process that we have been through, because we have not been able to get drugs to support our residents.'²⁷³

Apart from adding pressure to the health system, unwanted emergency department visits close to end of life have negative impacts on patients and their families:

Having to send somebody to an emergency department close to the end of their life because we have no alternative is heartbreaking for all concerned, and that is a real challenge.²⁷⁴

The Central Hume Primary Care Partnership described to the Committee a system that allows NSW Ambulance paramedics to manage a patient's symptoms in their home, rather than bringing them to an emergency department:

²⁷¹ Ian Patrick, General Manager Clinical and Community Services, Ambulance Victoria, *Transcript of evidence*, 18 November 2015, p. 35.

²⁷² Tracey Mander, Manager Palliative Care, Melbourne City Mission, *Transcript of evidence*, 14 October 2015, p. 45.

²⁷³ Melissa Weaver, Care Manager, Strath-Haven Aged Care, *Transcript of evidence*, 12 August 2015, p. 27.

²⁷⁴ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 8.

The NSW Ambulance Authorised Care Plans system assists medical professionals to be aware of and honour informed decision making about end-of-life care and choices.

In consultation with the patient and their family, a GP may elect to complete a NSW Ambulance Authorised Adult or Paediatric Palliative Care Plan. Once endorsed by NSW Ambulance, this plan specifically authorises NSW Ambulance paramedics to deliver individually tailored treatment based on the medical practitioner's orders as documented in the plan. In the event of Triple Zero (000) call-out by the patient, the NSW Ambulance Authorised Adult / Paediatric Palliative Care Plan is initiated, and may include administration of medications and other actions to relieve and manage symptoms in the home.²⁷⁵

Chapter 5 includes Recommendation 47 which deals with the need to ensure that ambulance officers are protected for care decisions that are made for patients at the end of their life.

3.6.4 Programs helping people to die in their place of choice

While overall the demand for people to die at home or another place of preference is not being met, there are specific programs that are helping patients to die in their place of choice.

Carmel Smith, Executive Manager of Goulburn Valley Hospice Care Service reported that the service has an excellent home death rate:

We have an 85 per cent home death rate against a state average of 21, so we are actually doing something very good out there ...²⁷⁶

Ms Smith explained how the service is able to achieve this:

I still believe we are one of the few services now that still do our own 24-hour on call. So after hours when patients and families ring, or on weekends, it is one of the nurses they know who takes that call ... So often we can avert a hospital admission by being able to go out and do a visit as needed overnight or on a weekend. I believe that is one of the main reasons that our patients are able to stay at home to die at home in the care of their family, and I think that we do that very well.²⁷⁷

In particular, Ms Smith highlighted that Goulburn Valley Hospice Care Service works with general practitioners to have appropriate medications available in advance:

We are very proactive in planning that end-of-life care, so we have the drugs in place weeks before they are needed, we have the orders in place and we have very strong support in our community from our GPs. That enables us to do that. But I work closely with the other NGOs [non-government organisations] in Melbourne, the bigger services, and I know one of the biggest issues they have that does not allow patients to die at home is that their GP will not prescribe the drugs that we need to

²⁷⁵ Central Hume Primary Care Partnership, *Submission*, p. 2.

²⁷⁶ Carmel Smith, Executive Manager, Goulburn Valley Hospice Care Service, *Transcript of evidence*, 13 August 2015, p. 25.

²⁷⁷ *Ibid.*, p. 26.

keep the patient comfortable after hours — if they cannot do that and if the doctor will not sign the death certificate — they are all things that we work on with the family very closely in the weeks leading up to the death of the patient.²⁷⁸

Dr Jenny Hynson, head of Victorian Paediatric Palliative Care Program at the Royal Children's Hospital reported that around half of children in the program die at home, and half in hospital:

We are very fortunate that the community-based palliative care services have been very willing to take children, even though I am sure at times it is pretty scary when we call them to ask if they could help us with the care of a six-month-old baby with a really rare genetic condition. Their willingness to help in those circumstances has been extraordinary. Over the 15 years we have been working together, they have all gained more experience in the care of children and have been very responsive. We now have the capacity to care for children at home, which you can imagine for families is very important, with the help of those services. I would say about half the children we are involved in caring for would die at home and about half in a hospital, with a handful who die at the Very Special Kids hospice.²⁷⁹

The Committee also heard from representatives of Multicultural Aged Care Services in Geelong that their 'invisible walls' model was allowing patients to move smoothly between various palliative care services:

The beauty of MACS [Multicultural Aged Care Services] is that we have this sort of invisible walls model of care, where people can come in at independent living, go to supported care, then go into residential and community packages as well, so they can go through the whole system. One of the things we have developed with Barwon Health and the Hospice Foundation is illustrated by one particular case where we had a lady who was on a palliative care package with the Hospice Foundation. Her condition improved so that we could not continue with the Hospice Foundation, but our community program was then able to step in, offer her a commonwealth-funded package, and we were able to keep that support. So we sort of have this lovely, seamless process happening, and we call it 'invisible walls'; people can move in and out of it as they need to. We think that is a model that can be replicated.²⁸⁰

RECOMMENDATION 13: That the Victorian Government provide support to community palliative care services so people who wish to can receive end of life care at home, and choose where to die.

RECOMMENDATION 14: That the Department of Health and Human Services model the potential budget savings of an increase in palliative care patients dying at home, as compared to dying in hospital. Such modelling should include budget outcomes for the current percentage of patients dying at home and incremental increases in the rate of home death for palliative care patients.

²⁷⁸ Ibid., pp. 25,26; Ibid.

²⁷⁹ Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 52.

²⁸⁰ Joy Leggo, CEO, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, p. 33.

RECOMMENDATION 15: That the Department of Health and Human Services model the budgetary impact on the hospital system of a stronger community palliative care system, in particular the impact on intensive care and emergency department costs that could be avoided with an increase in capability and availability of community palliative care.

RECOMMENDATION 16: That the Victorian Government, recognising the value of community palliative care and informed by its investigations as stated in **Recommendation 14** and **Recommendation 15**, increase support and funding to community palliative care services.

RECOMMENDATION 17: That the Department of Health and Human Services provide detail on palliative care service provision and expenditure as part of its annual reporting, including a breakdown of funding sources and the value of the volunteer workforce contribution.

3.7 Family and carers

Family and carers of patients near the end of life play an extremely important role. These are people who are putting their own lives on hold in order to care for a loved one as they die. They take on an incredible burden, and give enormous benefit to the quality of life of their loved one as their life ends. Jacquie Page, Palliative Care Consultant with Western District Health Service succinctly summarised how essential carers are, and how they need to be supported:

Give me a family support worker to assist the family and focus completely on the carer's needs, because if you look after the carer then the carer can look after the patient. Once the carer goes down then everything goes down.²⁸¹

The Committee received extensive evidence discussing the role played and challenges faced by carers.²⁸² This evidence shared concerns about carers 'burning out' while caring for a person at home and not coping with the intensity of the role. In light of these issues, many called for greater recognition and support for carers, suggesting that carers need practical hands-on assistance as well as respite options.²⁸³

²⁸¹ Jacquie Page, Palliative Care Consultant, Western Health District Service, *Transcript of evidence*, 30 July 2015, p. 45.

²⁸² The term 'carer' refers to a person providing unpaid care to a patient, excluding volunteers who work in the palliative care sector. Carers are typically family members, friends or acquaintances of the patient.

²⁸³ Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 4; Eastern Palliative Care Association, *Submission*, p. 3; Catholic Archdiocese of Melbourne, *Submission*, p. 9; Barwon Health, *Submission*, p. 1; Anam Cara House Colac, *Submission*, p. 1; Australia and New Zealand Society for Geriatric Medicine, *Submission*, p. 2; FamilyVoice Australia, *Submission*, p. 5; Centre for Palliative Care, *Submission*, p. 5; Carers Victoria, *Submission*, p. 3; Office of the Public Advocate, *Submission*, p. 34; Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015, p. 63; Jacquie Page, Palliative Care Consultant, Western Health District Service, *Transcript of evidence*, 30 July 2015, p. 45; Deidre Bidmade, Vice-President, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 21; Tam Vistarini, Hospice in the Home Manager, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 23; Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 31; Professor David Kissane, Head of Psychiatry, Monash University, *Transcript of evidence*, 15 October 2015, p. 41; Tracey Mander, Manager Palliative Care, Melbourne City Mission, *Transcript of evidence*, 14 October 2015, p. 48.

Jacqui White, Community Palliative Care Coordinator at Barwon Health highlighted the importance of tailoring carer support to individual needs:

For our patients who do have carers, we have also looked at an audit fairly recently at what their needs are, and what that has demonstrated to us is that although there are a lot of similarities in carer needs across our population, they are not a homogenous group; they have really varied needs. So we need to be thinking about what sort of packages and what sort of care we can provide, and that is across a gamut. We need to be creative and we need to be innovative around that. It has to be flexible.²⁸⁴

Empowering and educating carers to be confident in carers for their loved ones is a priority for community palliative care services, as explained by Andrea Janes of Southwest Healthcare:

Our Lismore campus just provides primary and community health services. They have identified that carer support and education is a priority for their area. They need to educate their carers so that they are confident on their own, especially because they do not have the after-hours support, so they are trying to teach their carers and educate them the best they can to provide the care.²⁸⁵

The Committee also heard of the financial consequences of taking on caring responsibilities, especially where carers do not have enough carers leave.²⁸⁶ Carers Victoria explained the issue:

Nearly 40 per cent of all carers are between the prime working ages of 45–64 years, and the ratio is even higher for female carers at 46.2 per cent. When caring is protracted, many carers feel they have little choice but to drop out of the workforce with significant consequences for family income during and after caring and reduced capacity for former carers to re-enter the workforce.²⁸⁷

In this regard, Mercy Health provided insight into how it supports carers in dealing with the financial impacts:

We also recognise that managing a terminal illness can significantly impact on people's financial resources. As a result, two years ago the Mercy Health Foundation established an endowment fund named the Urgent Need Appeal. Family members who become carers have limited leave entitlements and are often faced with difficult decisions, such as leaving their employment or seeking unpaid leave so they can continue to care for their loved one. Other financial stresses include the cost of medication, medical fees, travel and increased utility costs for heating, cooling or using additional equipment ... Providing this sort of financial assistance is a largely unmet need in Australia.²⁸⁸

²⁸⁴ Jacqui White, Community Palliative Care Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 28.

²⁸⁵ Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 10.

²⁸⁶ Mercy Health, *Submission*, p. 5.

²⁸⁷ Carers Victoria, *Submission*, p. 3.

²⁸⁸ Mercy Health, *Submission*, p. 5.

3.7.1 Respite care

Witnesses throughout the Committee's inquiry repeated that the value of respite care to families and carers. The Committee heard again and again the benefits of respite care go beyond the specifics of the care provided. The Committee heard that just knowing respite care is coming gives families and carers increased confidence and ability to provide care²⁸⁹ and that respite care prevents carer burnout and therefore hospital admissions.²⁹⁰

The Committee heard that respite care that is planned ahead of time is particularly beneficial. Barwon Health explained that families can care better for patients with regular respite care:

Families often take on more intense caring roles if they are offered booked regular respite. Knowing there are periods of respite available helps them with the knowledge and confidence that they will cope with the responsibilities. Without respite care being available, carers/families are often torn between Residential Aged Care Facilities (RACFs), which in itself is a stressful process of placing their family member in a palliative care unit for longer periods. This raises uncertainty and causes distress about how families/carers will manage. It may also have significant financial impacts on carers who have limited access to carer leave.²⁹¹

This was supported by Vicki Doherty, Manager of Gippsland Region Palliative Care Consortium:

In palliative care we need access to planned respite so that carers know when they are going to be able to get that relief.²⁹²

From the perspective of a palliative care service provider, the Eastern Palliative Care Association described its challenges in supporting carers during intense periods, and the requirement for planned and emergency respite care:

Ensuring understanding at all levels of Government as to what 'caring' means is essential. Certain supports need to be planned and put in place ahead of time but some assistance and resources are needed quickly almost as an emergency either when the stress of caring becomes too much or the person's condition changes. This is where [Eastern Palliative Care Association] experiences limitations in the services we can offer. We do not have the resources to put a registered nurse into the home to provide care and support at night when the carer needs to rest. In home support and assistance particularly overnight respite, may allow the carer to take a short break (even just a night or 2 of sleep) so they can continue to care.²⁹³

²⁸⁹ Deidre Bidmade, Vice-President, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 27; Jacquie Page, Palliative Care Consultant, Western Health District Service, *Transcript of evidence*, 30 July 2015, p. 45; Irene Murphy, Regional Nurse Practitioner Mentor, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 4.

²⁹⁰ Lynn McCarter, Manager, Complete Care, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, pp. 29–30; Julie Jones, Chair, Barwon South Western Region Palliative Care Consortium, *Transcript of evidence*, 29 July 2015, p. 50.

²⁹¹ Barwon Health, *Submission*, p. 1.

²⁹² Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 3.

²⁹³ Eastern Palliative Care Association, *Submission*, p. 3.

Respite care can take many forms, it might be providing care for a night, so families and carers can sleep, or even just for a couple of hours, so they can do the shopping, visit with friends, or just relax.²⁹⁴ Tam Vistarina, Hospice in the Home Manager at Warrnambool and District Community Hospice gave examples of respite care the Hospice provides:

It can be going in and just staying with the patient while the carer goes, has a haircut, does some shopping, whatever. But it could be a whole range of things: it could be talking to the families; it could be hanging out the washing; it could be washing their hair; it could be cooking a cake; or it could be assisting them in bed, to turn the patient over. It could be staying there. We have a shift from 10 o'clock at night until 7 o'clock the next morning, so the carers can just go to bed and get a sleep and not have to worry that the patient is going to have a fall or wake up in pain. They can ring the 24-hour palliative care number if there is an emergency and they can support the family.²⁹⁵

Availability of respite care

The Committee heard that respite care is not available to everybody who needs it. This has an effect on family and carers ability to provide ongoing care, which in turn results in more emergency department presentations, hospital admissions, and pressure on inpatient palliative care services.

Rural and regional health services particularly told the Committee that providing respite care is a challenge:

In our region there are limited resources for respite. Planned respite can often go awry because if it is for an inpatient unit, then a patient who has got more pressing needs will take precedence, so they will get bumped ... There is a huge impact on the client and the carer if they want to die at home and we cannot provide that respite.²⁹⁶

... there are very limited respite services available, and most of it is depending on where the patient lives. In Warrnambool City Council there are aged-care facilities which provide limited respite services in an inpatient setting. In terms of in-home respite, it is very difficult to facilitate in Warrnambool and in the wider region and community.²⁹⁷

In some cases, no palliative care respite beds are available, only inpatient palliative care beds:

Respite is very limited, and in our palliative care beds there are no designated respite beds as such. It is all inpatient, so at the moment we cannot actually tweak to say, 'Can someone come in for respite?'. We are not sure — that is a bit of a grey area.²⁹⁸

²⁹⁴ Damian Goss, Board Member, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 24; Tracey Mander, Manager Palliative Care, Melbourne City Mission, *Transcript of evidence*, 14 October 2015, p. 47; Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 13. Lynn McCarter, Manager, Complete Care, Multicultural Aged Care Services, *Transcript of evidence*, 29 July 2015, pp. 29–30.

²⁹⁵ Tam Vistarini, Hospice in the Home Manager, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 26.

²⁹⁶ Tracey Mander, Manager Palliative Care, Melbourne City Mission, *Transcript of evidence*, 14 October 2015, p. 45.

²⁹⁷ Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 6.

²⁹⁸ Ibid.

Elizabeth Loughnan, Acting Manager, Loddon Mallee Regional Palliative Care Consultancy Service highlighted the gap in respite care for those under 65 years of age, as well as gaps relating to location:

We certainly have gaps for respite under 65. Our youth and anybody between 25 and 55 really do not have many options. Our community team run a day respite program, which is run three days a week. It badly needs extra funding. It does not even have a permanent site. We rely on volunteer assistance, and volunteer assistance is fine, but if you want to grow a program it is difficult.

...

There is not a lot of respite. Say with oncology — breast cancer — in this region, there is the Otis Foundation, which have places for women with breast cancer and their families to recover. We need something similar for youth. Our day respite program provides taxi vouchers for them to come. That really only services people in the immediate Bendigo area. If you live out at Newbridge, it is too far out for us to be providing that. So there is really not a lot to reach out to them.²⁹⁹

Dr Jenny Hynson, Head of Victorian Paediatric Palliative Care Program at the Royal Children's Hospital told the Committee about the limited availability of respite in paediatric palliative care:

I feel very passionately about respite in paediatric palliative care. I feel passionate about the need for meaningful respite. By that I mean serious hours from a skilled person. Parents of sick children are at home running ventilators, changing tracheostomy tubes and putting their children through extremely painful dressings many times a week. They are using powerful medicines and they are managing seizures, and they do this for years and years. They get very limited access to paid carers, but almost no access to nursing respite in the home. I think it has all sorts of ramifications for families, putting them through that.³⁰⁰

3.7.2 After-hours services

The Committee heard that palliative care services support to patients in their home are often not available after hours,³⁰¹ and that this lack of after-hours care is not meeting community expectations.³⁰²

The Committee also heard that some after-hours palliative care programs do not have the resources to make home visits and are therefore limited to telephone contact.³⁰³ Andrea Janes from South West Healthcare told the Committee:

²⁹⁹ Elizabeth Loughnan, Acting Manager, Loddon Mallee Regional Palliative Care Consultancy Service, Bendigo Health, *Transcript of evidence*, 12 August 2015, p. 15.

³⁰⁰ Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 53.

³⁰¹ Lisa Mitchell, *Submission*, p. 1; Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, p. 3. Especially in rural and regional areas, see section 3.6.

³⁰² Jenny Turra, Palliative Care Nurse Practitioner, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 30.

³⁰³ Elizabeth Loughnan, Acting Manager, Loddon Mallee Regional Palliative Care Consultancy Service, Bendigo Health, *Transcript of evidence*, 12 August 2015, p. 18.

Our current community service works Monday to Saturday and after-hours contact is done through the after-hours nurse managers of our subacute campus. There is no longer a facility to go into homes after hours ... I believe that leaves carers high and dry.³⁰⁴

If a carer needs more than can be provided by telephone, the only option may be attending an emergency department. Dr Peter Martin from Barwon Health stated:

There is out of hours, and then there is out-of-hours nursing, and there is a variation. At some places you will get a community nurse who can rapidly respond. In other areas there will be no community nursing available, and the only alternative is if we cannot fix it up by remote control, they will have to do attend an emergency department, which is often what nobody wants — the patient, the carer or the health service.³⁰⁵

Similarly, he noted that where a person lives can mean their only option for after-hours care is to go to hospital:

I talked about the generalist out-of-hours provision — for instance, just up the road here there is a pocket where there is no after-hours care and we have to completely plan differently for that person rather than for somebody 10 or 15 kilometres down the road. ‘There are pockets’, we will say to such and such patient, ‘which means we are not going to be able to rely on after-hours general care.’³⁰⁶

Michelle Clancy, of the Royal District Nursing Service, told the Committee that the service provides after-hours calls, but is restricted by limited funding, and must also service generalist health care.³⁰⁷

Dierdre Bidmade, Vice President of Warrnambool and District Community Hospice suggested a dedicated after-hours end of life care phone service for families and carers:

Some other solutions that we see is bringing the public, the private and the volunteer providers in the community all together to work as one, and the provision of a dedicated end-of-life phone line to help families and carers and to help with the continued growth of hospice in home, supporting families, particularly overnight and on the weekends.³⁰⁸

This was supported by Tara Szafraniec, who told the Committee the story of the death of her father Ray Godbold:

We did often call up the district nurse. But again a palliative care specialist number or something you could call — and I do not know if it exists to be honest — where you could get that particular advice would be really useful.³⁰⁹

³⁰⁴ Andrea Janes, Project Worker, Improving Care for Older Persons Initiative, South West Healthcare, *Transcript of evidence*, 30 July 2015, pp. 3,7.

³⁰⁵ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 48.

³⁰⁶ Ibid. See also Judy Sommerville, Community Palliative Care Volunteer, Western District Health Service, *Transcript of evidence*, 30 July 2015, p. 46.

³⁰⁷ Michelle Clancy, Team Leader Palliative Care, Royal District Nursing Service, *Transcript of evidence*, 29 October 2015, p. 23.

³⁰⁸ Deidre Bidmade, Vice-President, Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p. 21.

³⁰⁹ Tara Szafraniec, *Transcript of evidence*, 29 October 2015, p. 4.

The Victorian Auditor-General's Office reported on respite care in its 2015 report, *Palliative Care*, and made a number of recommendations for improvement. The Committee endorses these recommendations made to the Department of Health and Human Services, detailed below:

- Conduct a systematic review of respite and carer support provision
- Develop clear expectations for health services to support carers
- Review and improve the after-hours model for community palliative care services across Victoria
- Review system-wide palliative care performance measures to improve how hospitals and palliative care services document and deliver patient- and carer-focused services.³¹⁰

Further to these recommendations the Committee believes that the Government should to take the action expressed in the recommendations below.

RECOMMENDATION 18: That the Victorian Government, as a priority, work with palliative care services to increase awareness of existing telephone support services, including after-hours support, to the community.

RECOMMENDATION 19: That the Victorian Government increase availability of reliable respite services for carers, particularly in rural and regional areas.

3.8 Knowledge and skills within health professions

3.8.1 Palliative care education

The Committee heard extensive evidence that health practitioners need to be trained in:

- identifying when end of life care options should be discussed
- communicating about end of life care matters
- making referrals to palliative care services
- providing palliative care.

Many witnesses accordingly proposed that palliative care and communication skills should form a greater part of medical undergraduate, postgraduate and continuing professional development training,³¹¹ including the Health Services Commissioner:

³¹⁰ Victorian Auditor-General, *Palliative care*, Victorian Auditor-General's Office, Melbourne, 2015, p. 41.

³¹¹ Palliative Care Victoria, *Submission*, p. 13; Mercy Health, *Submission*, p. 5; Social Responsibilities Committee of the Anglican Diocese of Melbourne, *Submission*, p. 13; Southern Cross Care Victoria, *Submission*, p. 4; Health Services Commissioner, *Submission*, p. 2; Very Special Kids, *Submission*, p. 1; Australian and New Zealand Society of Palliative Medicine, *Submission*, p. 9; Health Issues Centre, *Submission*, p. 6; Barwon Health, *Submission*, p. 5; Council of the Ageing, *Submission*, p. 15; Centre for Palliative Care, *Submission*, p. 4; Ballarat Health Service, *Submission*, p. 4; Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 56; Monsignor Anthony Ireland, Episcopal Vicar for Health, Aged Care and Disability Care, Catholic Archdiocese of Melbourne, *Transcript of evidence*, 18 November 2015, p. 17.

Communication skills both at undergraduate and postgraduate and as part of CPD], or continuing professional development, in the education of all clinicians is critical. There is not the checking in and clarifying by which people really understand what has been told to them. Certainly that sort of process in a continuous way throughout people's careers would be really important.³¹²

This suggestion was not just directed at palliative care specialists, it was extended to other health practitioners as well.³¹³ Southern Cross Care, for example, stated in its submission:

The importance of education of health professionals, both as undergraduates and practitioners, about palliative and end of life care continues to be a critical issue; whatever the nature of clinical practice or specialty. End of life care is everyone's business.³¹⁴

Fiona Heenan, Director of Primary and Community Care at Portland District Health Service highlighted the importance of skills general practitioners have in providing palliative care:

... GPs are often at the front line and are quite pivotal, so they need to be confident and competent in provision of palliative care and also with prescribing medications, Niki pumps, and knowing their technology and setting those up and so forth.³¹⁵

Southern Cross Care Victoria further suggested training in palliative care was particularly important for emergency department staff in light of the number of palliative care patients attending emergency units in hospitals.³¹⁶ Speech Pathology Australia also discussed the need for speech pathologists to be trained in palliative care, so that they are better able to assist patients who struggle to swallow and/or communicate.³¹⁷

Health practitioners themselves told the Committee that medicine would benefit from a greater focus on education around end of life issues and communication. Dr Michelle Gold of the Alfred Hospital told the Committee she sees an imbalance in the way palliative care is taught:

As I understand it, there is no mandated curriculum or minimum curriculum. We know that everybody is going to die, and yet there is far greater training in obstetrics and gynaecology than there is in palliative care. Most practitioners will not really have anything to do with a delivery once they leave medical school, so the balance is wrong.³¹⁸

³¹² Dr Grant Davies, Health Services Commissioner, Office of the Health Services Commissioner, *Transcript of evidence*, 18 November 2015, p. 13.

³¹³ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55; Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network, *Transcript of evidence*, 12 August 2015, p. 37.

³¹⁴ Southern Cross Care Victoria, *Submission*, p. 4.

³¹⁵ Fiona Heenan, Director of Primary and Community Health, Portland District Health Service, *Transcript of evidence*, 30 July 2015, p. 33.

³¹⁶ Southern Cross Care Victoria, *Submission*, p. 3.

³¹⁷ Speech Pathology Australia, *Submission*, p. 5.

³¹⁸ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 56.

Associate Professor Peter Hunter, Chair, Victorian Clinical Leadership Group on Care of Older People in Hospital also thought palliative care needs more focus at medical school:

The amount of teaching around palliative care, for example, at Melbourne and Monash is minuscule. When I taught at Melbourne University, there was a two-week block of palliative care training in five years of medical training, and it is one of the most fundamental issues. It has never been thought to be particularly important.³¹⁹

Associate Professor Hunter also highlighted the importance of educating doctors in communication, including breaking bad news. He emphasised that ‘one-off’ training is not adequate, it needs to be done regularly. He also stated that hospitals as well as medical schools need to focus on this, so senior doctors who were not trained at medical school can be positive role models for junior staff.³²⁰

The importance of teaching communication skills in medicine was echoed by Dr Ranjana Srivastava, of Monash University:

Even today, if you look at a medical curriculum, there is often token interest paid to the teaching of better communication, the teaching of, say, palliative care, and there is still a lot of emphasis on things like anatomy, physiology. And that is understandable too because, after all, a doctor needs to understand medicine to treat patients. But I think it is a source of dismay to many of us that better communication and teaching doctors about humanity and about empathy and compassion is not more of a core in the curriculum. It is kind of considered to be taken that if you enter medicine, of course you must be nice and compassionate because, after all, you enter medicine to make a difference. But I argue in this book that I read from and in many other places that communicating well with patients is a learned skill, much like suturing is and much like surgery is.³²¹

Maree McCabe, Chief Executive Officer of Alzheimer’s Australia Vic. said that education around providing a good death is particularly needed for those treating patients with dementia:

There is a whole piece of work and education that really needs to occur around ensuring people have a good pain-free death, and also in pain management, particularly in the area of dementia where people are unable to express that pain.³²²

Witnesses also suggested specific ideas for increased continuing professional development on breaking bad news³²³ and how to teach and examine emergency medicine trainees on end of life decision making.³²⁴

³¹⁹ Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 52.

³²⁰ *Ibid.*, pp. 51,52,53.

³²¹ Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 16.

³²² Maree McCabe, Chief Executive Officer, Victoria, Alzheimer’s Australia, *Transcript of evidence*, 14 October 2015, p. 4.

³²³ Dr Brian McDonald, Clinical Director Palliative Care, Peninsula Health, *Transcript of evidence*, 9 September 2015, p. 12.

³²⁴ Associate Professor Tim Baker, Director of the Centre for Rural Emergency Medicine, Deakin University, *Transcript of evidence*, 30 July 2015, p. 40.

The Committee notes the ‘virtual clinical setting’ and ‘MedeSims’ programs used at Deakin University’s School of Medicine. The virtual clinical setting program puts students in a safe environment that mimics a medical workplace. Students learn clinical and communication skills by assessing and communicating with faculty or trained simulated patients.³²⁵ The MedeSims program has students complete four interactive online simulations (MedeSims) based on real scenarios in order to improve their end of life communication skills. The MedeSims program has been received positively by medical students, including desire for use of the program for practice after they have completed their assessment.³²⁶

These programs provide benefit to medical students, in addition to their standard rotations through various medical fields, including palliative care. Deakin’s innovative programs allow students greater access to learning clinical and communication skills, particularly around end of life communication in the case of MedeSims, in preparation for their future role as doctors.

3.8.2 Late referral to palliative care

The Committee heard that a factor in some patients missing out on palliative care is that they are not referred to palliative care services soon enough. Jenny Turra, palliative care nurse practitioner at Latrobe Community Health Service in Morwell explained the benefit of a timely referral to palliative care:

I guess what the literature tells us is that palliative care, if we can get in early and build relationships with people — if they are referred in a timely manner — then we can get supports in place. We can have those discussions about what it is that people are wanting, what their values are — discussions around end of life — when they are reasonably well. That is something that as a service we have really focused on and spent a lot of time promoting within the hospital, with GPs, doing education sessions, providing guidelines for when is an appropriate time to refer to palliative care, and as a result our numbers have grown significantly and we have increased the palliative care stable population on our books as well.³²⁷

Several Inquiry participants expressed concern that many people did not benefit from palliative care because they had not been referred to palliative care, or referred too late.³²⁸ Mercy Health, for example, stated:

While palliative care is accepted as best practice for end of life care, many people do not have their symptoms and pain adequately managed and their human dignity honoured as they approach the end of their lives. We sadly have witnessed instances where people are referred for palliative care too late or not at all.³²⁹

³²⁵ www.simulationaustralasia.com/newsarticle/the--virtual-clinical-setting--at-deakin-school-of-medicine--victoria accessed 20 April 2016.

³²⁶ Personal communication, Sharyn Milnes, ‘Use of E-Simulation (Virtual World) to Teach Communication Skills in Final Year Medicine’, Paper presented at the *Innovations in Medical Education: Transforming Health Professions through Innovation*, University of Southern California, 2013, p. 25.

³²⁷ Jenny Turra, Palliative Care Nurse Practitioner, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 30.

³²⁸ Melbourne City Mission, *Submission*, p. 3; Very Special Kids, *Submission*, p. 1; Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55; Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 2; Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 3.

³²⁹ Mercy Health, *Submission*, p. 2.

Some submissions suggested that health practitioners were failing to refer patients to palliative care services because of a misconception that palliative care was only for people with cancer or people very close to death.³³⁰ Alfred Health provided insight into this misconception:

Some clinicians believe palliative care is relevant only in the last days of life. This is not the case: palliative care teams can assist with symptom management and provide opportunities for patients and their loved-ones to discuss their fears and concerns. For many patients, involvement of the palliative care team occurs concurrently with active and even life-sustaining treatment in conjunction with other medical teams. Palliative care focuses on quality of life, holistic care and meticulous symptom management. Greater education on the role and benefits of palliative care is of paramount importance.³³¹

The Ballarat Health Service shared a similar view:

The area that remains a challenge for referring clinical staff is that palliative care is not just terminal care. It is for people who have a life limiting illness who need excellent symptom assessment and management ... There is however, a tendency for the treating medical teams to wait until the person is actively dying before a referral is made to the specialist palliative care team.³³²

Dr Peter Martin, Regional Director of Palliative Care at Barwon Health explained some of the possible reasons behind late referrals to palliative care:

Some of it is about the reticence to have the tough conversation that their illness is progressing. I do not think it is out of gatekeeping or malice. I just think there is sometimes a reticence and a reluctance to have what is a difficult conversation around where their illness is heading and what choices there are. Sometimes I think there are some assumptions made about what choices they wish, which may not be truly reflective.³³³

As well as the consequences:

... now there is a growing body of literature to suggest that seeing us [palliative care providers] earlier would have a range of outcomes around terms of quality of life, survival and symptom burden.³³⁴

And offered some possible solutions:

Some countries have changed the name to supportive care or symptom control or other things that reflect the breadth of what we do. Yes, end-of-life care is a core part of what we do, but also in terms of symptom support, planning and helping them.³³⁵

Recommendation 11 in section 3.5.6 addresses the issue of appropriate referral to palliative care.

³³⁰ Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 31.

³³¹ Alfred Health, *Submission*, p. 3.

³³² Ballarat Health Service, *Submission*, p. 7.

³³³ Dr Peter Martin, Regional Director Palliative Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 5.

³³⁴ *Ibid.*

³³⁵ *Ibid.*

3.8.3 Communicating about death and palliative care

The Committee heard that there is a trend for health practitioners to avoid having conversations about death with patients:³³⁶

No one likes to talk about death, and doctors do not like talking about death either.³³⁷

This was largely seen as a barrier for patients and their families to accept and prepare for death, and to explore available options for end of life care (including palliative care).³³⁸ Some also warned that such communication failures often lead to administration of burdensome or futile medical treatment.³³⁹

A particularly troublesome theme the Committee heard was that doctors can find it easier to treat a patient, whether it is the best course of action or not, than have a difficult discussion about death. Dr Jason Fletcher, Bendigo Health Staff Intensivist, Advance Care Planning Clinical Lead described the situation. He discussed why patients die in hospital when they want to die at home, including a systemic reason he sees behind the problem:

... I do think the biggest driver is a lack of understanding of patients of where they are in their disease trajectory, and I think that is potentiated by the fact that it is harder for a doctor to have that discussion than it is to provide treatment. It is a lot more time consuming, so it is easier for me to write a script or do a test than to sit down and have a discussion about, 'What are the goals of treatment? What can you reasonably expect in the next 3, 6 or 12 months of your life?'. So I think it is primarily in education.

Just the way the system is set up at the moment, a lot of it is volume-based medicine, so clinicians lack the time to have those discussions. And they are hard discussions. It takes a lot of courage to be able to say to someone, 'Actually, you are in the last 3, 6 or 12 months of your life'. I think it is less of a palliative care issue but more about that patient-doctor interaction.³⁴⁰

The Coroners Court of Victoria stated in its submission that it dealt with many cases where relatives of a deceased person were not advised to expect death, even though the death was medically expected.³⁴¹ Coroner Caitlin English added at a hearing that:

... we see time and again, from the medical records that it does not look like the difficult conversations have been had between the medical staff and the family, often, or it has been left to junior medical staff — just those hard conversations to have about prognosis, the viability of treatment and what is ultimately medically expected.³⁴²

³³⁶ Mercy Health, *Submission*, p. 2; Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 2; Health Issues Centre, *Submission*, p. 6; Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 24.

³³⁷ Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 55.

³³⁸ Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 2.

³³⁹ Grattan Institute, *Submission*, p. 20; Council of the Ageing, *Submission*, p. 15.

³⁴⁰ Dr Jason Fletcher, Advance Care Planning Clinical Lead, Bendigo Health, *Transcript of evidence*, 12 August 2015, p. 3.

³⁴¹ Coroners Court of Victoria, *Submission*, p. 2.

³⁴² Coroner Caitlin English, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, pp. 7–8.

This was echoed by other witnesses,³⁴³ including the Health Services Commissioner, who noted that poor communication lay at the root of most complaints he received:

With most of the complaints received in the OHSC [Office of the Health Services Commissioner], poor or miscommunication lies at the core of the grievance. In end of life care, communication problems can be very distressing for the consumer and their family.

For example, one family did not understand their relative was being transferred into palliative care and did not understand how rapidly their relative was deteriorating. Part of the complaint to the OHSC centred on the level of shock they experienced when their relative died.³⁴⁴

The Committee heard that it can be difficult to have discussions about death,³⁴⁵ with one reason being that doctors feel torn between the need to have the discussion about death and to provide hope to a person dealing with terminal or chronic illnesses.³⁴⁶ This is particularly so for paediatricians:

It is extremely challenging for a paediatrician to sit with a devastated and desperate family and talk to them about the fact that there is no effective cure, or you have come to the end of your options in terms of being able to cure an illness. I think a lot of families come to a hospital like ours expecting that we can fix everything. It may mean that that conversation does not happen or happens very late, and that then has flow-on effects for the care of the child. Also people feel the need to do something, and they equate doing something with doing more treatment, even if the burdens are very great and the chances are very low.³⁴⁷

Complicating this is what Dr Ranjana Srivastava described to the Committee as a 'death-denying' culture on the part of the broader community, including patients:

I think doctors face a dilemma. On the one hand, we are often blamed for not communicating with our patients, not explaining to people exactly what they are undergoing and what is happening. On the other hand, it is clearly evident that we have a culture that is death denying, that does not wish to necessarily engage with bad news, that does not want to hear it.³⁴⁸

And that this contributes to a disincentive for doctors to discuss death with their patients:

... there is some interesting data that shows that although many people feel that many patients feel that they value honesty in a doctor and they want to be told the truth — and certainly this is my lived experience too — telling the truth does not make you a popular doctor. In fact there is evidence to suggest that oncologists who

³⁴³ Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 14; Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 22.

³⁴⁴ Health Services Commissioner, *Submission*, p. 1.

³⁴⁵ Alfred Health, *Submission*, p. 3; Cancer Council Victoria, *Submission*, p. 10; Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 3.

³⁴⁶ Grattan Institute, *Submission*, p. 15; Coroners Court of Victoria, *Submission*, p. 2; Council of the Ageing, *Submission*, p. 15; Cancer Council Victoria, *Submission*, p. 10.

³⁴⁷ Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 52.

³⁴⁸ Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 15.

tell their patient the truth about their diagnosis and about their dire prognosis are often ranked poorly on their communication skills because people do not like hearing the truth.

If you are a young doctor who has been graded poorly by a patient or treated poorly by a patient because you have tried to sit down and tell them the truth, that has a great impact on the rest of your career, and you can imagine why a doctor may then wish to avoid these difficult conversations, thinking, ‘Well, what good did that do?’. If we want to be a society where we truly value honest and open discussions, then we have to take the good with the bad.³⁴⁹

While recognising the challenges, submission and hearing evidence stressed the need for health practitioners to be better equipped to have conversations about end of life matters,³⁵⁰ and to recognise these conversations as an important part of their job.³⁵¹ Very Special Kids described the importance of good communication as follows:

We have found that once families engage in the palliative process with clarity they are able to help their child to live as richly as possible in the remaining time available to them. This engagement with life in the face of death enables families to feel more acceptance of the death when they are subsequently grieving the loss of their child.³⁵²

The Victorian Clinical Leadership Group on Care of Older People in Hospital also pointed out the role of better communication in addressing fears about death:

In order to alleviate the angst about dying in our culture and to be able to have a “good death”, there needs to be opportunities to talk about and plan for it. In planning, clinicians need to recognise that their patients are entering a terminal phase of their illness where end of life issues need to be the focus.³⁵³

3.8.4 Providing a good death

The Committee heard that doctors would benefit from increased focus on patient-centred care. Associate Professor Charlie Corke, Intensive Care Specialist at Deakin University told the Committee that while medical students learn patient-centred care, the hospital environment can degrade these skills:

I am interested that I do a lot of teaching for medical students who get patient-centred care and shared decision-making and making decisions with the patient based on what is important to the patient, but we see that disappear as they move into the hospital environment, and the pressures of work and the medical model makes them less effective. So we need to protect that and work on it.³⁵⁴

Associate Professor Corke also gave evidence of a lack of patient-centred note-taking in oncology treatment:

³⁴⁹ Ibid., p. 16.

³⁵⁰ Dr Natasha Michael, Director Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p. 8; Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 18.

³⁵¹ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 22.

³⁵² Very Special Kids, *Submission*, p. 1.

³⁵³ Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 2.

³⁵⁴ Professor Charlie Corke, Intensive Care Specialist, Barwon Health, *Transcript of evidence*, 15 October 2015, p. 6.

We did a survey of the oncology patients at Barwon Health and looked for any patient-centred words in the notes — any comment in the notes about what mattered to the patient, not about their white cell count, not about the tumour size, not about that, but about what mattered to them. Five per cent had any sort of patient-centred comment in the notes.³⁵⁵

The Committee heard that one aspect of patient-centred care doctors could improve at is transferring focus from saving life, to providing a good death. Associate Professor Tim Baker, Director of the Centre for Rural Emergency Medicine at Deakin University highlighted how this can be a challenge in medicine:

We face the problem that we tend to want to focus on resuscitations and treatment, and sometimes it can be very hard to switch from going all-out to save someone's life to swapping to then provide a good death without that seeming like a failure, which of course it is not. There is absolutely no doubt that providing a good death is absolutely the core of what we should be doing.³⁵⁶

Dr Jason Fletcher of Bendigo Health explained the steps that go into this process:

We need to make the diagnosis of dying. We need to be frank when that happens and tell people that, 'Actually you're dying and that process has begun', and then need to focus on a relief of symptoms.³⁵⁷

Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care agreed, saying that we want doctors to act in the patient's best interest by better diagnosis of dying as well as stopping unnecessary investigations.³⁵⁸

The Committee heard that this change, from a focus on disease and cure at all costs to a more patient-centred model is a cultural issue in medicine.³⁵⁹ However, the Committee also heard that sometimes it is patients and their family who are pressuring doctors into treatments that are not effective:³⁶⁰

... most doctors want to do the right thing. They absolutely want to do the right thing, and they want enough evidence to help them to feel comfortable that they are doing the right thing ... Most doctors are comfortable to not put people through stuff which they know to be arduous if people do not want it. Inevitably we want to treat people who want to be treated and people who want to be treated to get better and go home, or try to, and those who want to be comfortable we want to make comfortable.³⁶¹

³⁵⁵ Ibid.

³⁵⁶ Associate Professor Tim Baker, Director of the Centre for Rural Emergency Medicine, Deakin University, *Transcript of evidence*, 30 July 2015, p. 39.

³⁵⁷ Dr Jason Fletcher, Advance Care Planning Clinical Lead, Bendigo Health, *Transcript of evidence*, 12 August 2015, p. 2.

³⁵⁸ Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 65.

³⁵⁹ Dr Simon Fraser, Chief Medical Officer, Latrobe Regional Hospital, *Transcript of evidence*, 9 September 2015, p. 40; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 38.

³⁶⁰ Professor Charlie Corke, Intensive Care Specialist, Barwon Health, *Transcript of evidence*, 15 October 2015, p. 9.

³⁶¹ Ibid., p. 8.

Dr David Sykes, General Manager of Learning and Development at Alzheimer's Australia Vic. told the Committee that focusing on what is best for the patient is particularly challenging for patients with dementia:

There are a whole lot of ramifications around sometimes the lack of understanding of dementia in the context of the medical area, which means that you really get some incredibly adverse outcomes that are unnecessary and are often driven by some other pressures that are not focused on what that individual needs.³⁶²

RECOMMENDATION 20: That the Victorian Government, in consultation with key stakeholders, design a strategy to ensure an appropriate level of high quality palliative care curriculum content in medical, nursing and allied health degrees, including how to have conversations on end of life care with patients.

RECOMMENDATION 21: That the Victorian Government investigate expanding programs such as the MedeSims and virtual clinical setting programs offered at Deakin University School of Medicine, to better educate medical students in communication skills, particularly around difficult end of life conversations.

RECOMMENDATION 22: That the Victorian Government develop an education package for residential aged care workers on end of life care.

RECOMMENDATION 23: That the Medical Board of Australia include end of life care elements in periodic revalidation for any health practitioner who is likely to manage patients with end of life care needs, including continuing professional development.

RECOMMENDATION 24: That the Victorian Government require that health services adopt palliative care training modules in orientation programs and annual competencies for clinical staff.

3.9 Community education

The Committee heard extensive evidence discussing the need to raise public awareness about a wide range of end of life care issues. These include the role of palliative care, the limitations of medicine, and existing end of life choices.³⁶³

³⁶² Dr David Sykes, General Manager Learning and Development, Victoria, Alzheimer's Australia, *Transcript of evidence*, 14 October 2015, p. 4.

³⁶³ Palliative Care Victoria, *Submission*, pp. 10, 13; Mercy Health, *Submission*, p. 6; Melbourne City Mission, *Submission*, p. 3; Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 4; Christian Medical and Dental Fellowship of Australia, *Submission*, p. 1; Southern Cross Care Victoria, *Submission*, p. 6; Speech Pathology Australia, *Submission*, p. 6; Australian and New Zealand Society of Palliative Medicine, *Submission*, p. 7; Grattan Institute, *Submission*, p. 2; Melbourne Health, *Submission*, p. 2; Council of the Ageing, *Submission*, p. 15; Centre for Palliative Care, *Submission*, p. 5; Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network, *Transcript of evidence*, 12 August 2015, p. 37; Dr Arup Bhattacharya, Divisional Clinical Director Medical, Goulburn Valley Health *Transcript of evidence*, 13 August 2015, p. 11.

3.9.1 Palliative care

The Committee heard that there was often a misconception or poor understanding of the purpose of palliative care services among patients and the community. Many associated it exclusively with dying.³⁶⁴

Annette Cudmore, a Clinical Nurse Consultant at West Hume Palliative Care Consultancy Service expressed concern that the community does not understand the difference between palliative care and end of life care:

One of the big things for me is that we still have not got the community awareness and the recognition and understanding of palliative care versus end-of-life care. People think that palliative care is about dying. If we are going to achieve anything out of this, we have really got to achieve a much greater community awareness around what palliative care can offer and what it stands for.

...

palliative care is not just about dying. It is about quality of life, it is about how we live with our illness, it is about choices, and it is about where we want our care, who we want to be involved in our care and how we bring all that together.³⁶⁵

It was also noted that many people equate palliative care with ‘giving up’.³⁶⁶ Dr Michelle Gold, Director of Palliative Care at Alfred Hospital spoke about the community’s conception of palliative care:

I think community understanding of palliative care certainly needs to be improved. It is changing, but at a very glacial pace. I see many families who do not want to meet me. I am really not that scary, but they want to pursue every last second of existence on this planet, and they are incorrectly worried that if they agree to meet with me or with my team that that would be perhaps seen as an indication that they might be willing to let go and to give up.³⁶⁷

Alfred Health and the Cancer Council Victoria further warned that such misconceptions can compromise the quality of life and support that patients receive at the end of their lives.³⁶⁸ To this point, Dr Ranjana Srivistava told the Committee that a good understanding of end of life choices is associated with better outcomes for patients:

³⁶⁴ Australian Nursing and Midwifery Federation (Vic), *Submission*, p. 5; Eastern Palliative Care Association, *Submission*, p. 7; Catholic Archdiocese of Melbourne, *Submission*, pp. 3, 10; Public Health Association of Australia (Vic), *Submission*, p. 2; Australasian College for Emergency Medicine, *Submission*, p. 5; HOPE: Preventing Euthanasia & Assisted Suicide, *Submission*, p. 17; Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 2; Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 32; Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015, p. 62; Mary Hocking, Physiotherapist in palliative care, *Transcript of evidence*, 15 October 2015, p. 31; William Darby, Chairperson, Peninsula Advisory Committee for Elders, *Transcript of evidence*, 29 October 2015, p. 41.

³⁶⁵ Annette Cudmore, Clinical Nurse Consultant Palliative Care, West Hume Palliative Care Consultancy Service, *Transcript of evidence*, 13 August 2015, p. 8.

³⁶⁶ Alfred Health, *Submission*, p. 3; Cancer Council Victoria, *Submission*, p. 8.

³⁶⁷ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55.

³⁶⁸ Alfred Health, *Submission*, p. 3; Cancer Council Victoria, *Submission*, p. 8.

... there is evidence that if people understand their choices more, if they are more health literate and if we can help them understand their health issues, they make better decisions for themselves. They are more compliant with treatment, they have less chances of having aggressive treatment or choosing aggressive treatment, they have less chances of ending up in hospital sometimes, they are more likely to die at home or in a hospice, they are less likely to be admitted to hospital and this raft of issues stems from better doctor-patient communication.³⁶⁹

The need for the community to be better informed about the services available, and what their rights and options are for end of life care was echoed by other witnesses.³⁷⁰

In addition, some evidence identified a need to educate the public about overly-burdensome treatment and the right to refuse treatment.³⁷¹

One aspect of community understanding of palliative care and other end of life medical options raised was unrealistic community expectations about the limits of medicine, and the need to address that.³⁷² Dr Karen Detering of Austin Health stated that helping people to understand what medicine can and cannot do will help them to make informed decisions:

A further barrier is around patient and community expectations — some people get it, but I think we need to be working in that space a little bit as well and help our population understand the limits of modern medicine and what can and cannot be achieved, and help them to then be able to make an informed decision about what is reasonable for them.³⁷³

3.9.2 Talking about death

Witnesses told the Committee that, as a culture, we avoid talking about death.³⁷⁴ Professor Hal Swerissen of the Grattan Institute put it like this:

We have professionalised, hidden and pushed away the notion of death to somewhere else, and so people do not want to deal with it. So we need campaigns which really get people just to think that this is something they do have to think about.³⁷⁵

³⁶⁹ Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 17.

³⁷⁰ Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 3; Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 33; Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015, p. 63.

³⁷¹ Victorian Clinical Leadership Group on care of older people in hospital, *Submission*, p. 4; Christian Medical and Dental Fellowship of Australia, *Submission*, p. 2; Catholic Archdiocese of Melbourne, *Submission*, p. 10; Catholic Social Services Victoria, *Submission*, p. 3; Cancer Council Victoria, *Submission*, p. 7.

³⁷² Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 51; Associate Professor Daryl Jones, Medical Director Critical Care Outreach, Austin Health, *Transcript of evidence*, 5 August 2015, p. 5; Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 24.

³⁷³ Dr Karen Detering, Respiratory Physician and Clinical Ethicist, Respecting Patient Choices Program, Austin Health, *Transcript of evidence*, 5 August 2015, p. 11.

³⁷⁴ *Ibid.*, p. 15; Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 24; Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015, p. 62; Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 29.

³⁷⁵ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 22.

Dr Ranjana Srivastava's experience is that patients' unwillingness to talk about death creates a barrier to important discussions:

As an oncologist — and I have extensive palliative care experience — I consider difficult conversations part of my job and part of my obligation. I am very willing to have them, and I feel that I have sufficient training to have them. Yet the barrier that I face is not my willingness to have them but the patient's unwillingness and the family's unwillingness.³⁷⁶

Annette Cudmore, Clinical Nurse Consultant at West Hume Palliative Care Consultancy Service crystallised the issue from both a patient and medical practitioner point of view:

... we need to be comfortable with our own mortality, and we need to be comfortable with supporting people to discuss their mortality.³⁷⁷

The Committee heard that people are open to discussing death and end of life care if it is raised sensitively. They are particularly prepared if they are deteriorating or dying. As Dr Neil Orford of Barwon Health put it:

People are prepared to talk about their end-of-life care as they are deteriorating and dying, because they have got skin in the game. It matters and they want to talk about it ... I think people are prepared to talk about it if it is done sensitively.³⁷⁸

Luke Williams, Clinical Lead at Latrobe Community Health Service in Morwell explained that people who are dying are thankful for the opportunity to talk about their options, perhaps because our society ignores death in general:

... we do not talk about this as a society — death is often ignored. Going into someone's house, as I do a lot, and talking about death and what they want for end of life, they are often thankful for having that opportunity, because we ignore it as a society.³⁷⁹

Dr Michelle Gold, Director of Palliative Care at Alfred Hospital told the Committee that she sees death and the dying process as misleadingly bleak and frightening in the public mind, where her experience is that the end of life can be a time for important experiences, goodbyes, and shared memories with loved ones:

... I am concerned that the community narrative on end-of-life care is very skewed. It seems that there is an overly bleak picture of death and dying that has come into the public mind and context that death is always frightening. I think that is quite misleading. It seems to be something that by definition must be painful, undignified, ghastly, and if that is your impression, then of course it is no surprise that people want to avoid death at all costs — which I can assure you is not possible — or to exert some sort of control over it.

³⁷⁶ Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 18.

³⁷⁷ Annette Cudmore, Clinical Nurse Consultant Palliative Care, West Hume Palliative Care Consultancy Service, *Transcript of evidence*, 13 August 2015, p. 14.

³⁷⁸ Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, pp. 22–23, 24.

³⁷⁹ Dr Luke Williams, Clinical Lead, Morwell, Latrobe Community Health Service, *Transcript of evidence*, 9 September 2015, p. 29.

My experience as a palliative care professional is really that death and in fact the whole end-of-life process can be something quite different. Even when a death is not wished for, which is the vast majority of the time, it can be a peaceful and meaningful process, and those last phases of life can contain many opportunities for important interactions, fulfilment of wishes and really crucial goodbyes. Many precious memories are created when people have an opportunity to confront imminent death with support, information and expert care.³⁸⁰

Many experts, including the Council of the Ageing, Palliative Care Victoria, Public Health Association Australia, Australasian College for Emergency Medicine, and the Office of the Public Advocate called for public education on death generally in order to challenge social taboos on talking about death.³⁸¹

In Chapter 5 the Committee recommends a public awareness campaign to increase understanding of advance care planning. This should include information about palliative care, what it means and its importance in the health sector and to the community.

RECOMMENDATION 25: That the Victorian Government introduce a coordinated approach to disseminating information on palliative care and associated health services.

3.10 Palliative care and end of life law

The Committee heard about a variety of palliative care concepts and practices that may be affected by end of life law. These concepts and practices are used in palliative care in Victoria. The Committee heard that the law surrounding them is based in common law, and that they are not always properly understood by health practitioners, let alone patients.

The Committee also heard disagreement about whether some of these concepts and practices constitute assisted dying.³⁸²

The concepts and practices include:

- the doctrine of double effect
- continuous palliative sedation
- protection for doctors withholding or withdrawing futile treatment.

This section provides an overview of these practices and concepts, including any disagreement on their use the Committee heard.

³⁸⁰ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 54.

³⁸¹ Council of the Ageing, *Submission*, p. 15; Palliative Care Victoria, *Submission*, p. 9; Public Health Association of Australia (Vic), *Submission*, p. 3; Australasian College for Emergency Medicine, *Submission*, p. 5; Office of the Public Advocate, *Submission*, p. 34.

³⁸² For more see the footnotes to section 3.10.1

3.10.1 Doctrine of double effect

What is the doctrine of double effect?

The doctrine was first explicitly stated as a common law doctrine applicable to medical practice in *R v Adams*, by Lord Devlin:

If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he took *might* incidentally shorten life.³⁸³

The doctrine of double effect (sometimes called the principle, or rule of double effect) is described by White, Wilmott and Ashby:

The essence of the doctrine of double effect is that an act performed with good intent can still be moral despite negative side effects. In the context of palliative care, this can arise when four conditions are met:

1. Administering palliative medication is not, in itself, immoral;
2. The intention is to relieve pain, not to hasten the patient's death;
3. The relief of pain is not achieved through causing the patient's death; and
4. Proportionally, the need to relieve pain is such that it warrants accepting the risk of hastening death.³⁸⁴

The researchers go on to describe the defence provided by the doctrine:

... in brief, the doctrine of double effect provides a defence to a criminal charge where it is alleged that a doctor has caused the death of a patient as a result of the provision of medication if the intention of the doctor in providing that medication was to relieve pain rather than to hasten the patient's death.³⁸⁵

This applies, even when a foreseeable result of the doctor's action is that the patient dies, as explained by Professor Paul Komesaroff, Director for Ethics in Medicine and Society at Monash University:

... the acceptance that one can provide whatever treatment is needed to relieve the suffering of a patient, even in circumstances in which the unintended but foreseeable outcome is that person's death.³⁸⁶

A qualitative study that involved interviewing 18 Australian palliative care specialists, found that palliative care doctors, in particular, see maintaining a certain intention as described by the doctrine of double effect as part of their role:

³⁸³ Andrew McGee, 'Double effect in the Criminal Code 1899 (Qld): A critical appraisal', *Queensland University of Technology Law and Justice Journal*, vol. 4, no. 1, 2004, p. 46.

³⁸⁴ Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 2.

³⁸⁵ *Ibid.*, p. 5.

³⁸⁶ Professor Paul Komesaroff, Director for Ethics in Medicine & Society, Monash University, *Transcript of evidence*, 23 July 2015, p. 3.

In contrast to their colleagues in acute medical practice, these Australian palliative care specialists were almost unanimously committed to distinguishing their actions from euthanasia. This commitment appeared to arise principally from the need to maintain a clear professional role, and not obviously from an ideological opposition to euthanasia.

While some respondents acknowledged that there are difficult cases that require considered reflection upon one's intention, and where there may be some 'mental gymnastics,' the nearly unanimous view was that it is important, even in these difficult cases, to cultivate an intention that focuses exclusively on the relief of symptoms.³⁸⁷

The Committee acknowledges that the doctrine of double effect is used in palliative care practice in Victoria.³⁸⁸

The doctrine of double effect in Australian and Victorian law

The doctrine of double effect's legal status in Australia is (in most states) based on English case law.³⁸⁹ The doctrine has also been accepted as law in the United States³⁹⁰ and Canada.³⁹¹ Three Australian states (Queensland,³⁹² Western Australia,³⁹³ and South Australia³⁹⁴) have incorporated the doctrine of double effect in legislation. In doing so however, specialists in medical law have argued that they have limited the doctrine as it stands at common law.³⁹⁵

The Committee heard contending views on the doctrine of double effect; particularly whether the practice it describes is a form of assisted dying.³⁹⁶

³⁸⁷ Charles D Douglas, et al., 'Narratives of 'Terminal Sedation', and the Importance of the Intention-Foresight Distinction in Palliative Care Practice', *Bioethics*, vol. 27, no. 1, 2013.

³⁸⁸ Palliative Care Victoria, *Submission*, p. 16.

³⁸⁹ Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 3.

³⁹⁰ *Vacco v Quill*, USSC 75; 117 S Ct 2258, [1997].

³⁹¹ *Rodriguez v British Columbia (Attorney General)* [1993] 3 SCR 519, 1993.

³⁹² *Criminal Code 1899 (QLD)* s 282A.

³⁹³ *Criminal Code Act Compilation Act 1913 (WA)* section 259(1).

³⁹⁴ *Consent to Medical Treatment and Palliative Care Act 1995 (SA)* sections 17–18. Though whether the common law still applies despite codification in South Australia is unclear Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 6.

³⁹⁵ *Ibid.*, pp. 6–7. For further investigation of this effect, see 3.10.5

³⁹⁶ Dan Flynn, Victorian Director, Australian Christian Lobby, *Transcript of evidence*, 16 September 2015, pp. 18, 20; Dr Katrina Haller, Chief Executive Officer, Right to Life Australia, *Transcript of evidence*, 18 November 2015, p. 61; Professor Paul Komesaroff, Director for Ethics in Medicine & Society, Monash University, *Transcript of evidence*, 23 July 2015, p. 3; Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p. 55; Neil Francis, DyingForChoice.com, *Transcript of evidence*, 21 October 2015, p. 28; Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 15; Professor Loane Skene, Director of Studies, Health and Medical Law, University of Melbourne, *Transcript of evidence*, 23 July 2015, p. 27; Dr Ken Harvey, Member, Doctors for Voluntary Euthanasia Choice, *Transcript of evidence*, 15 October 2015, p. 44; Steven A Trankle, 'Decisions that hasten death: Double effect and the experiences of physicians in Australia', *BMC Medical Ethics*, vol. 15, no. 1, 2014, p. 26; Udo Schüklenk, et al., 'End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making', *Bioethics*, vol. 25, no. s1, 2011; Julian Savulescu, Uehiro Chair in Practical Ethics, Oxford University, *Transcript of evidence*, 19 August 2015, p. 5; Dr Jenny Hynson, Head, Paediatric Palliative Care Program, Royal Children's Hospital, *Transcript of evidence*, 14 October 2015, p. 52; Mark Staaf, Professional Officer, Australian Nursing and Midwifery Federation, *Transcript of evidence*, 18 November 2015, p. 45; Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 65; SA Fohr, 'The double effect of pain medication: Separating myth from reality', *Journal of Palliative Medicine*, vol. 1, no. 4, 1998.

The Committee is less concerned with the ethical differences presented to it than with the practical effect the doctrine of double effect's place in Victorian law is having on patient access to adequate palliation. For more on this see section 3.10.4.

3.10.2 Continuous palliative sedation

What is continuous palliative sedation?

Palliative Care Victoria³⁹⁷ pointed the Committee to a definition of palliative sedation from the European Association of Palliative Care:

Therapeutic (or palliative) sedation in the context of palliative medicine is the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering in a manner that is ethically acceptable to the patient, family and health-care providers.³⁹⁸

The word 'continuous' refers to sedation that continues until a patient's death. The Committee notes that it has heard various phrases to describe this practice, including 'palliative sedation', 'therapeutic sedation', 'continuous sedation', 'continuous deep sedation', 'terminal sedation', 'controlled sedation', 'end of life sedation', 'total pharmacological sedation', and 'sedation for intractable distress in a dying person'. It is not always clear which terms are used to describe sedation that continues through to the patient's death, and which are used for intermittent sedation close to death. The Committee will use the term 'continuous palliative sedation' to describe sedation which is intended to continue through to the patient's death.

Dr Rodney Syme, Vice-President of Dying with Dignity Vic. offered this description:

In people suffering from what they call refractory symptoms, which others might call intolerable and unrelievable suffering, palliative care can provide continuous delivery of analgesics and sedatives by titration — that means the slow and incremental increase — without the provision of hydration, to slowly induce over some days a deep continuous sedation which can only result in death.³⁹⁹

One confronting example of a non-clinician's view of continuous palliative sedation was provided by Ian Wood, National Coordinator of Christians Supporting Choice for Voluntary Euthanasia:

... putting a person into a coma until they starve to death. That is essentially what the procedure is.⁴⁰⁰

³⁹⁷ Palliative Care Victoria, *Submission*, p. 15.

³⁹⁸ Nathan I Cherny, et al., 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care', *Palliative Medicine*, vol. 23, no. 7, 2009, p. 1.

³⁹⁹ Dr Rodney Syme, Vice President, Dying With Dignity Victoria, *Transcript of evidence*, 14 October 2015, p. 25.

⁴⁰⁰ Ian Wood, National Convenor, Christians Supporting Choice for Voluntary Euthanasia, *Transcript of evidence*, 15 October 2015, p. 24.

Dr Syme raised a point that further complicates the practice of continuous palliative sedation, providing hydration and nutrition. Palliative Care Victoria⁴⁰¹ referred the Committee to the 10-point framework for the ethical use of sedation recommended by the European Association for Palliative Care, which states:

The decision about artificial hydration/nutrition therapy is independent of the decision about sedation itself. Whether artificial hydration/nutrition therapy is performed should be individually decided through comprehensive evaluation of the patient's wishes and the estimated benefits/harms in light of the treatment aim (palliation of suffering).⁴⁰²

The Australian Medical Association (Victoria) Ltd. told the Committee that 'there are no official guidelines for the use of palliative sedation in Victoria.'⁴⁰³

The literature shows research into how various guidelines in other jurisdictions compare, including in the terminology they use.⁴⁰⁴

During its research into international jurisdictions⁴⁰⁵ the Committee learned that continuous palliative sedation and guidelines for its use were very clear to the Dutch medical profession and notes that comprehensive guidelines have been published by the European Association for Palliative Care in the academic journal, *Palliative Care*.⁴⁰⁶

The Committee also notes some literature suggests what is meant by continuous palliative sedation is not consistent in the minds of doctors.⁴⁰⁷ Research from Belgium found that:

... unlike euthanasia, the concept of palliative or terminal sedation covers a broad range of practices in the minds of physicians. This ambiguity can be a barrier to appropriate sedation practice and indicates a need for better knowledge of the practice of palliative sedation by physicians.⁴⁰⁸

A systematic review of nurses' attitudes and practices around continuous palliative sedation in Belgium, Canada, Japan, the Netherlands, Norway, the UK, and the United States found:

⁴⁰¹ Palliative Care Victoria, *Submission*, p. 15.

⁴⁰² Nathan I Cherny, et al., 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care', *Palliative Medicine*, vol. 23, no. 7, 2009, p. 587.

⁴⁰³ Australian Medical Association (Vic) response to question on notice, March 2016, p 1.

⁴⁰⁴ Ebun Abarshi, et al., 'Towards a standardised approach for evaluating guidelines and guidance documents on palliative sedation: Study protocol', *BMC Palliative Care*, vol. 13, no. 34, 2014, p. 34.

⁴⁰⁵ For details, see Appendix 3

⁴⁰⁶ Nathan I Cherny, et al., 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care', *Palliative Medicine*, vol. 23, no. 7, 2009.

⁴⁰⁷ For more on this, and health professional views on continuous palliative sedation, see Jane Seymour, et al., 'Using continuous sedation until death for cancer patients: A qualitative interview study of physicians' and nurses' practice in three European countries', *Palliative Medicine*, vol. 29, no. 1, 2014; Kasper Raus, et al., 'Continuous sedation until death: The everyday moral reasoning of physicians, nurses and family caregivers in the UK, The Netherlands and Belgium', *BMC Medical Ethics*, vol. 15, no. 1, 2014; Judith AC Rietjens, et al., 'Approaches to suffering at the end of life: The use of sedation in the USA and Netherlands', *Journal of Medical Ethics*, vol. 40, no. 4, 2014; Sam Rys, et al., 'Continuous sedation until death with or without the intention to hasten death — A nationwide study in nursing homes in Flanders, Belgium', *Journal of the American Medical Directors Association*, vol. 15, no. 8, 2014.

⁴⁰⁸ Jef Deyaert, et al., 'Labelling of end-of-life decisions by physicians', *Journal of Medical Ethics*, vol. 40, no. 7, 2014.

In general, nurses had a positive but cautious attitude toward the practice of PS [palliative sedation]. Most saw it as a last resort treatment for relieving suffering and refractory symptoms, and its practice was often influenced by their level of education, expertise, and the roles they played per setting.⁴⁰⁹

Further, doctors take differing approaches to continuous palliative sedation, including how deeply and quickly sedation should be administered.⁴¹⁰

Continuous palliative sedation is practiced in Victoria

The Committee heard from Palliative Care Victoria⁴¹¹ and multiple medical practitioners that continuous palliative sedation is practiced in Victoria. Dr Brian McDonald, Clinical Director of Palliative Care at Peninsula Health told the Committee:

We do provide terminal sedation quite frequently, where we render the patients unconscious. I talk to families, and I will talk to the patient if they are aware enough to talk to, because people seem to understand the medically induced coma.⁴¹²

The Committee also heard from Dr Natasha Michael, Director, Palliative Medicine, Cabrini Health:

Continuous deep sedation is sometimes instituted in people where we feel they have intractable pain that we just cannot manage. You have to be very clear in your mind around the issues of intent. I cannot be somebody else's moral compass; you can only be your own moral compass.⁴¹³

Michelle Clancy, team leader of palliative care at the Royal District Nursing Service stated:

There is a lot of controversy between terminal sedation and what euthanasia means. There is a clouding amongst that. We do practice terminal sedation, and there have been various papers written on it. In some cases we are practising terminal sedation.⁴¹⁴

Dr Brian McDonald, Clinical Director of Palliative Care at Peninsula Health told the Committee that he considers there to be a difference between euthanasia and continuous palliative sedation, but he is not sure the families of his patients think the same:

⁴⁰⁹ Ebun A Abarshi, et al., 'The complexity of nurses' attitudes and practice of sedation at the end of life: A systematic literature review', *Journal of Pain and Symptom Management*, vol. 47, no. 5, 2014.

⁴¹⁰ Siebe J Swart, et al., 'Considerations of physicians about the depth of palliative sedation at the end of life', *Canadian Medical Association Journal*, vol. 184, no. 7, 2012.

⁴¹¹ Palliative Care Victoria, *Submission*, p. 15.

⁴¹² Dr Brian McDonald, Clinical Director Palliative Care, Peninsula Health, *Transcript of evidence*, 9 September 2015, p. 12.

⁴¹³ Dr Natasha Michael, Director Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p. 10.

⁴¹⁴ Michelle Clancy, Team Leader Palliative Care, Royal District Nursing Service, *Transcript of evidence*, 29 October 2015, p. 22.

Often the argument in terms of what I do and with terminal sedation is: what is the difference? I have been commenting for many years that there is a difference, but is it a big difference? Occasionally we will still hear the expression 'slow euthanasia', so 'isolate patients, allow them to die'. If we do not provide them with nutrition and hydration, we know they will die.

Another comment I sometimes make is that I wonder how many of the families who walk out of the inpatient unit think that we have provided euthanasia. I think it is probably quite a substantial number: 'making them comfortable' may be interpreted by the family as basically saying that is euthanasia. I do not believe it is from a legal perspective, and from a medical ethics perspective it is not. We are providing symptom management, we are providing relief from distress and that at the moment is our mission in life. If euthanasia were legal, would I do it? I do not know. It is hypothetical. I do not know.⁴¹⁵

Conceptions of continuous palliative sedation,⁴¹⁶ and its moral/ethical equivalence to or distinction from assisted dying are contested in academic literature.⁴¹⁷

The Committee heard differing views on the subject. Professor Hal Swerissen of the Grattan Institute told the Committee that there is a fine line between continuous palliative sedation and assisted dying.⁴¹⁸

While Dr Katrina Haller, Chief Executive Officer of Right to Life Australia told the Committee that continuous palliative sedation allows a patient to die from their underlying condition:

Right to Life Australia would just ask that in end-of-life choices people be offered proper palliative care, pain relief — the first duty of a medical practitioner is to relieve pain, even if it shortens their life — and that they can have palliative sedation on the individual level.

...

We think people have to have their pain relieved. That is the first duty of medical practitioners. There might be a rare case where that is not possible under current palliative care regimes. That person may be given palliative sedation — but that they not be given a lethal jab, they be allowed to die from whatever fatal condition they have. They die because of the condition; they are not given an active jab.

...

⁴¹⁵ Dr Brian McDonald, Clinical Director Palliative Care, Peninsula Health, *Transcript of evidence*, 9 September 2015, p. 13.

⁴¹⁶ This review uses the term continuous palliative sedation to mean sedation until death. The practice is also termed terminal sedation, sometimes conflated or confused with palliative sedation or intermittent palliative sedation. Note, however, there is some controversy surrounding the equivalence or otherwise of these terms.

⁴¹⁷ For a brief overview of the difficulties with the term and the practice see Johannes JM van Delden, 'Terminal sedation: Source of a restless ethical debate', *Journal of Medical Ethics*, vol. 33, no. 4, 2007. See also Henk ten Have and Jos VM Welie, 'Palliative sedation versus euthanasia: An ethical assessment', *Journal of Pain and Symptom Management*, vol. 47, no. 1, 2014; Samuel H Lipuma, 'Continuous sedation until death as physician-assisted suicide/euthanasia: A conceptual analysis', *Journal of Medicine and Philosophy*, vol. 38, no. 2, 2013; Joseph A Raho and Guido Miccinesi, 'Contesting the equivalency of continuous sedation until death and physician-assisted suicide/euthanasia: A commentary on LiPuma', *Journal of Medicine and Philosophy*, vol. 40, no. 5, 2015; Torbjörn Tännsjö, *Terminal sedation: Euthanasia in disguise?*, Springer, 2004; Marco Maltoni, et al., 'Palliative sedation for intolerable suffering', *Current Opinion in Oncology*, vol. 26, no. 4, 2014.

⁴¹⁸ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 15.

So you can alleviate the suffering of a person by getting rid of the person, or you can alleviate the suffering of the person by pain relief or palliative sedation, and they die because of their fatal condition. They die because of their kidney failure, or they die because of their lung failure.⁴¹⁹

The Committee's view is that, as it has been advised by medical experts, continuous palliative sedation has a place in appropriately-administered end of life care. However, the current lack of clarity and consistency around its administration in the mind of doctors is problematic. This issue combined with a lack of data about the extent or circumstances of its use contributes to a lack of accountability and transparency that the Committee sees as undermining high quality patient-centred care.

RECOMMENDATION 26: That the Victorian Government establish a taskforce to create appropriate guidelines for the administration of continuous palliative sedation to address the existing absence of data on continuous palliative sedation which undermines transparency.

RECOMMENDATION 27: That the Victorian Government establish a requirement for all cases of continuous palliative sedation to be reported to the Department of Health and Human Services, and for the Department to include this data, de-identified, in its annual report.

3.10.3 Protection for doctors withholding/withdrawing futile treatment

Futile treatment in Australian and Victorian law

Doctors in Victoria are protected at common law from liability for withholding or withdrawing futile treatment.⁴²⁰ Lindy Willmott, Ben White, and Jocelyn Downie set out the situation in a 2013 article in the *Journal of Law and Medicine*:

The cases to date have concluded that there is no obligation to provide futile treatment either because it is not in the patient's best interests to receive it or because a failure to treat in these circumstances will not breach the relevant criminal law duty. As will be shown, the current law grants doctors a very high degree of autonomy in this area as they have the power to determine that treatment is futile and such an assessment (unless successfully challenged in the courts or tribunals) removes the obligation to treat. This means in Australia (the position is less certain in New Zealand) that there is no obligation at common law to obtain a patient's consent or the consent of her or his loved ones before making this decision. This power is referred to here as one to 'unilaterally withhold or withdraw potentially life-sustaining treatment' as the doctor herself or himself has lawful authority to make this decision. Consent is not required and neither is authorisation from any other source such as a court, tribunal or statute.⁴²¹

⁴¹⁹ Dr Katrina Haller, Chief Executive Officer, Right to Life Australia, *Transcript of evidence*, 18 November 2015, p. 60.

⁴²⁰ *Messiha v South East Health* [2004] NSWSC 1061. Described in Lindy Willmott, et al., 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand', *Journal of Law and Medicine*, vol. 20, no. 4, 2013.

⁴²¹ *Ibid.*, p. 3.

Although a determination of what is in the patient's best interests ultimately rests with the court, legal challenges to a doctor's assessment of futility have generally not succeeded.⁴²²

The duty to provide the necessities of life is the source of criminal responsibility for those involved in decisions to withhold or withdraw potentially life-sustaining treatment. Within this framework, where medical treatment is not a 'necessary of life', the duty imposed by the criminal law does not arise:

At common law in Australia, a person who voluntarily assumes responsibility for another who is unable to care for themselves due to mental or physical incapacity, has a duty to provide that other with the necessities of life. This common law duty operates in the Australian Capital Territory, New South Wales, South Australia and Victoria. An equivalent duty is imposed in the jurisdictions of the Northern Territory, Queensland, Tasmania and Western Australia that are governed by Criminal Codes.⁴²³

Willmott, White, and Downie also describe the civil law element:

So far as the civil law is concerned, in Australia at least, a doctor is required by the general law of negligence to use reasonable care and skill when making treatment decisions in relation to her or his patient. What a doctor must do in a particular case to discharge the duty of care will depend on all of the circumstances. Where medical treatment is needed to keep a patient alive, reasonable care will often require that treatment be provided. Thus, withholding or withdrawing potentially life-sustaining treatment can give rise to a breach of this civil duty if doing so falls short of exercising reasonable care and skill.⁴²⁴

Willmott, White, and Downie note that court cases in Australia and New Zealand have consistently concluded there is no duty to provide futile treatment:

There are only a few cases in Australia and New Zealand where a decision to withhold or withdraw treatment has been litigated, and where the issue of futile treatment has been raised. The courts have been consistent in concluding that there is no duty to provide treatment that is futile. These cases have been resolved in one of two ways: determining that treatment is not in the patient's best interests, or deciding that not treating does not breach the criminal law.

...

Of note ... is that a number of the cases also made specific reference to the fact that treatment for the patient was futile as part of determining that it was not in the patient's best interests and so need not be provided.⁴²⁵

Note that Australian cases challenging an assessment of futility have involved only patients that lack capacity, but the English Court of Appeal has concluded that patients cannot demand treatment if doctors are of the view that it was 'not clinically indicated'.⁴²⁶

⁴²² Ibid.

⁴²³ Ibid., p. 4.

⁴²⁴ Ibid., p. 5.

⁴²⁵ Ibid., p. 7.

⁴²⁶ *R (Burke) v General Medical Council* [2006] QB 273 [301-302].

Willmott, White, and Downie reach four conclusions for the situation under the common law in Australia:

there is no general duty on doctors to provide treatment that they consider to be futile⁴²⁷

...

doctors do not need consent from the patient or a substitute decision-maker, or other authorisation from the courts or elsewhere, to withhold or withdraw treatment they consider to be futile. In other words, withholding or withdrawal of treatment can be done unilaterally by the treating doctor. Indeed, at least as a matter of law, they may do this despite the objections of others who are requesting treatment

...

the determination of futility is in the first instance made by doctors. They are the decision-makers as to when their duty to treat ends as they are responsible for determining when treatment is futile.⁴²⁸

...

while [the] determination as to futility is capable of being challenged before a court or tribunal, there is no obligation on the part of the treating doctor to facilitate the resolution of a dispute in this way. The onus rests on the family or other party objecting to the treatment being withheld or withdrawn⁴²⁹

The Office of the Public Advocate, in its submission to the Committee, explained that the *Medical Treatment Act 1988* preserves the right of patients to include their perception of their quality of life in decisions about their medical treatment:

... it is clear from the wording of the Medical Treatment Act that a patient can make decisions about their medical treatment based on their perception of their quality of life. The Medical Treatment Act does this in two ways. It sets out a process by which a person can refuse medical treatment for a current condition. Further, it states that the Act does not affect any right of a person under any other law to refuse medical treatment.⁴³⁰

This ability to include quality of life as a consideration in decisions about medical treatment is extended to an enduring power of attorney (medical treatment) appointed by a person under the *Medical Treatment Act 1988*, which states that an agent or guardian may only refuse medical treatment on behalf of a patient if:

... there are reasonable grounds for believing that the patient, if competent, and after giving serious consideration to his or her health and well-being, would consider that the medical treatment is unwarranted.⁴³¹

⁴²⁷ Lindy Willmott, et al., 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand', *Journal of Law and Medicine*, vol. 20, no. 4, 2013, pp. 9–10.

⁴²⁸ *Ibid.*, pp. 10–11.

⁴²⁹ *Ibid.*, p. 11.

⁴³⁰ Office of the Public Advocate, *Submission*, p. 24.

⁴³¹ *Medical Treatment Act 1988*, 41 of 1988. section 5B(2).

3.10.4 Working with end of life law

The need to provide legal certainty for health practitioners working in end of life care was flagged by a number of submissions, and by witnesses at hearings. Issues raised as unclear include the doctrine of double effect, the withdrawal of futile treatment, substitute decision makers, advance care plans,⁴³² and patients' right to refuse medical treatment.⁴³³ Avant Mutual Group Head of Advocacy Georgie Haysom put it succinctly:

I think it is fair to say — and I know the committee has heard from a lot of the legal academics and other practitioners — that they are uncertain about their legal obligations.⁴³⁴

Ms Haysom highlighted some of the difficult situations doctors are required to navigate:

Often calls will relate to who is the appropriate substitute decision-maker in a particular instance when a patient lacks capacity. Often there are several family members involved or there is conflict between the clinicians and family members about what is appropriate treatment.⁴³⁵

The Australian Centre for Health Law Research and Cancer Council Victoria referred the Committee to empirical data that many medical practitioners were not aware of or did not fully understand the law surrounding end of life care, finding it too complex.⁴³⁶ Bill O'Shea of the Law Institute of Victoria gave evidence on a survey about doctors' knowledge of the law around end of life procedures:

There was a recent survey done by a group in Queensland that looked at doctors' knowledge of end-of-life procedures, and they gave them seven questions to answer. The average score was about three and a half out of seven, including doctors who specialise in end-of-life care, who just find the whole topic totally confusing — and you cannot blame them for that. It is just not clear enough.⁴³⁷

The Public Advocate, Colleen Pearce, explained further:

We commonly come across situations where the medical practitioners, hospital staff are unaware of the law, and if they are aware of the law, say, 'I'm making my own decisions anyway'. I think it is really imperative that whatever the committee comes up with there is a focus on education for the health sector. It is really critical.⁴³⁸

⁴³² For more see Chapter 5. Cross reference to ACP chapter.

⁴³³ National Seniors Australia, *Submission*, p. 7; Southern Cross Care Victoria, *Submission*, p. 4; Alfred Health, *Submission*, p. 5; Health Issues Centre, *Submission*, p. 6; Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*; Australasian College for Emergency Medicine, *Submission*, p. 5; Cancer Council Victoria, *Submission*, p. 6.

⁴³⁴ Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 10.

⁴³⁵ Ibid.

⁴³⁶ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, pp. 2–3; Cancer Council Victoria, *Submission*, p. 6.

⁴³⁷ Bill O'Shea, Member, Health law and elder law committees, Law Institute of Victoria, *Transcript of evidence*, 18 November 2015, p. 9.

⁴³⁸ Colleen Pearce, Public Advocate, Office of the Public Advocate, *Transcript of evidence*, 18 November 2015, p. 54.

The importance of legal certainty was highlighted by the Australian Centre for Health Law Research, which illuminated the legal role taken on by health practitioners when providing end of life care:

While medical professionals play a critical clinical role in the provision of medical treatment at end of life, they also play a significant legal role in the process. For example, doctors must assess whether a patient has capacity to make a treatment decision, determine who an authorised decision-maker is if the patient lacks capacity, and know whether a patient's previously expressed wishes comprise a valid advance directive.⁴³⁹

The Committee heard that uncertainty about the law leads health practitioners⁴⁴⁰ to fear prosecution⁴⁴¹:

We need to get the doctors also not being scared of prosecution. I have had times when GPs do not prescribe the morphine because they think that because the patient may die a bit sooner than they would otherwise, they are at risk of prosecution.⁴⁴²

The Australian Medical Association (Victoria) Ltd., the Health Services Commissioner, and others⁴⁴³ suggested a fear of prosecution amongst medical practitioners may make them hesitant to provide pain management that could have a secondary effect of shortening life.⁴⁴⁴ In this regard, the Australian Medical Association (Victoria) Ltd. observed:

In Australia there is no case law directly on point relating to the double effect doctrine. Although some legal commentators argue that there seems little doubt that the double effect principle at common law forms part of Australian law due to its acceptance in other jurisdictions, the legal recognition has been widely criticised as being inconsistent with criminal law principles. Medical practitioners who follow current best practice by providing whatever care is needed to alleviate pain and distress cannot be confident that they would be protected from criminal law prosecution for murder, manslaughter or aiding and abetting suicide.⁴⁴⁵

Similarly, the Australian Centre for Health Law Research stated:

Despite the protection provided by the doctrine of double effect, there is some anecdotal evidence that some health professionals are reluctant to administer palliative care due to concerns about legal repercussions such as civil litigation, criminal prosecution or disciplinary action where a patient's death results from the pain relief provided. These concerns have been identified in Australia as a factor in the under-treatment of pain.⁴⁴⁶

⁴³⁹ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 2.

⁴⁴⁰ Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 57.

⁴⁴¹ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, pp. 2–3; Australian Medical Association (Vic), *Submission*, p. 3.

⁴⁴² Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 65.

⁴⁴³ Eastern Palliative Care Association, *Submission*, p. 8; Alfred Health, *Submission*, p. 5; Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, pp. 2–3; Australasian College for Emergency Medicine, *Submission*, p. 5.

⁴⁴⁴ Health Services Commissioner, *Submission*, p. 4.

⁴⁴⁵ Australian Medical Association (Vic), *Submission*, p. 3.

⁴⁴⁶ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 6.

Inadequate pain treatment as a consequence of health practitioners' uncertainty about the law was a repeated theme:

... that there are some practitioners who might be terrified of legal ramifications for easing suffering. Most people who do it a lot are not, but some people are, and that can result in increased suffering and distress for people with end-of-life problems.⁴⁴⁷

...

I think it is fair to say that doctors do feel very uncomfortable proceeding on the basis of refusal of treatment, and having some reassurance that they are not going to be prosecuted or have some sort of adverse implication would be of some comfort, and it also means that the patient's wishes are going to be respected, which is the most important thing, I think.⁴⁴⁸

The Committee also heard legal uncertainty can lead to conflict between doctors and nurses:

... practitioners also expressed concern about the doctrine of double effect. They do express concern about pain relief and they often have conflict with nursing staff about that too, so the nursing staff may be concerned about providing pain relief where they think it might hasten death and sometimes there is conflict between the nursing staff and the practitioners about whether that is appropriate or not.⁴⁴⁹

The Committee heard personal stories from witnesses who have cared for loved ones, that health practitioners, including residential aged care facility staff, were reluctant or afraid to administer pain medication for fear of legal ramifications. Dr Ric Milner, a general practitioner working in the Western Victoria Primary Health Network told the Committee:

This committee has already heard about doctors and nurses being afraid to provide sufficient pain relief medication to dying patients, and that was my experience.⁴⁵⁰

Tom Valenta told the Committee about the death of his wife, Marie, in 2009:

When Marie was in a nursing home in a semi-vegetative and then a vegetative state, there were times when she was clearly in pain or distress. Professional staff agreed with me that her facial and body contortions indicated her distress, and yet they were reluctant — very reluctant — to administer additional pain medication for fear of her dying and the potential loss of accreditation for the nursing home.

Doctors who I consulted, and there were three, were also initially reluctant to increase her pain medication for fear of being embroiled in a coronial inquiry. One doctor said to me, 'It only takes one person to complain, and I can't be looking after my other patients because I've got a coroner's inquiry to be attending'.

...

⁴⁴⁷ Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 37.

⁴⁴⁸ Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 11.

⁴⁴⁹ Ibid.

⁴⁵⁰ Graeme Lovell, *Transcript of evidence*, 15 October 2015, p. 18.

What kind of system is so inhumane that it deters health care professionals from administering appropriate levels of pain relief for fear of a bureaucratic or a legal backlash? Surely we can amend, streamline, update current laws and regulations to cover this kind of situation.⁴⁵¹

3.10.5 Legislative enactment of end of life common law

The Committee notes the evidence above that health practitioners are uncertain about various aspects of end of life law. This includes the doctrine of double effect, the withholding and withdrawal of futile or burdensome treatment, substitute decision makers, advance care plans, and patients' right to refuse medical treatment. The Committee also notes that this can result in negative consequences for patients, such as insufficient pain relief.

As a solution to this uncertainty, the following witnesses recommended legislating to enact protection or at least clarifying protection, afforded to doctors by the doctrine of double effect:

- Australian Centre for Health Law Research⁴⁵²
- Council of the Ageing⁴⁵³
- Australian Medical Association (Victoria) Ltd.⁴⁵⁴
- Social Responsibilities Committee of the Anglican Diocese of Melbourne⁴⁵⁵
- Professor Paul Komesaroff, Director for Ethics in Medicine and Society at Monash University⁴⁵⁶
- Ian Wood, National Convenor of Christians Supporting Choice for Voluntary Euthanasia⁴⁵⁷
- Health Services Commissioner⁴⁵⁸
- Australasian College for Emergency Medicine.⁴⁵⁹

⁴⁵¹ Tom Valenta, *Transcript of evidence*, 29 October 2015, p. 15.

⁴⁵² Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 1.

⁴⁵³ Council of the Ageing, *Submission*, p. 20.

⁴⁵⁴ Australian Medical Association (Vic), *Submission*, pp. 3–4. Note the Australian Medical Association (Victoria) Limited supports the South Australian *Consent to Medical Treatment and Palliative Care Act 1995*. Note the Australian Medical Association (Vic) Ltd. identified continuous palliative sedation as a practice that is likely to fall under the doctrine of double effect, and an area which should be clarified: Australian Medical Association (Vic) response to question on notice, March 2016, p. 1.

⁴⁵⁵ Social Responsibilities Committee of the Anglican Diocese of Melbourne, *Submission*, p. 12.} Note the Social Responsibilities Committee of the Anglican Diocese of Melbourne's phrasing was that 'it would be wise to clarify [protection afforded by the doctrine of double effect] in Victorian law'.

⁴⁵⁶ Professor Paul Komesaroff, Director for Ethics in Medicine & Society, Monash University, *Transcript of evidence*, 23 July 2015, p. 4.

⁴⁵⁷ Ian Wood, National Convenor, Christians Supporting Choice for Voluntary Euthanasia, *Transcript of evidence*, 15 October 2015, p. 26.

⁴⁵⁸ Health Services Commissioner, *Submission*, p. 4. Note the Health Services Commissioner's phrasing was 'Consideration should also be given to clarifying a medical practitioner's legal position under the 'doctrine of double effect' ... Some reluctance to giving adequate pain relief may be related to a medical practitioner's perceived legal vulnerability in providing it.'

⁴⁵⁹ Australasian College for Emergency Medicine, *Submission*, p. 5. Note the Australasian College for Emergency Medicine's phrasing was 'ACEM therefore encourages the introduction of legislation that protects practitioners in situations in which a decision has been made that prolonging life is no longer the primary aim, and optimising the [quality of life] of the patient is the only significant and/or realistic goal.'

Not all witnesses were supportive of legislation. The Australian Catholic Bishops Conference prefers education on the current common law rather than any legislative change, stating:

If evidence emerges during the inquiry that this [legal uncertainty for doctors prescribing pain relief that may unintentionally hasten death] is a concern for medical professionals, education on the protection offered by the current common law would be more effective than blunt legislative change.⁴⁶⁰

Some witnesses also recommended legislating to include the law around withdrawal of futile or burdensome treatment in statute:

- Australian Medical Association (Victoria) Ltd.⁴⁶¹
- Office of the Public Advocate.⁴⁶²

Alfred Health stopped short of recommending putting in statute the common law around futile treatment, but did ask that legislation continues to support an approach consistent with the current common law.⁴⁶³

The Australian Medical Association (Victoria) Ltd. put their position like this in their submission:

While double effect and non-provision of futile care are ethically acceptable practices by the medical profession, many medical practitioners are concerned that they are not adequately protected by the law. As such, many patients may not be receiving the care they wish to have at the end of life because medical practitioners fear prosecution.⁴⁶⁴

Dr Anthony Bartone, President of the Australian Medical Association (Victoria) Ltd. expanded on this point:

Protection should relate to measures directed at maintaining or improving the comfort of the person who is or would otherwise be in pain and distress, and there should be no civil or criminal liability if these measures are performed in accordance with good medical practice and with the intent of relieving pain and suffering.

Introducing such legislation in Victoria should effectively address doctors' main uncertainties. In providing greater reassurance and confidence to medical practitioners, patients can also be sure that doctors are focused on providing good end-of-life care instead of reacting to the fear of legal consequences. It is clearly desirable that seriously ill patients in terminal stages of their lives are able to have their pain or distress properly managed so they can remain as comfortable as possible for the time they have left.⁴⁶⁵

⁴⁶⁰ Australian Catholic Bishops Conference, *Submission*, p. 11.

⁴⁶¹ Australian Medical Association (Vic), *Submission*, pp. 3–4. Note the Australian Medical Association (Victoria) Limited supports the South Australian *Consent to Medical Treatment and Palliative Care Act 1995*.

⁴⁶² Office of the Public Advocate, *Submission*, p. 5.

⁴⁶³ Alfred Health, *Submission*, p. 8.

⁴⁶⁴ Australian Medical Association (Vic), *Submission*, p. 2.

⁴⁶⁵ Dr Anthony Bartone, President, Victoria, Australian Medical Association, *Transcript of evidence*, 24 February 2016, p. 13.

Dr Bartone further highlighted how important respecting patient choices and values is when dealing with these issues:

The issue of futile care is a very personal one and an individual one. Each patient will have a different view on what treatment they do or do not want to receive. It is incumbent on the doctor to ensure that they are effectively communicating with the patient to ensure that they are aware of the realistic outcomes that could be achieved through any treatment. It is also important that the doctor is aware of the patient's wishes and goals for their care.

For one patient with end-stage cancer, a last dose of chemotherapy that gives them an extra few weeks may be extremely important, because they want to spend as much time with their family as possible or make it to a certain event, like a wedding. For another patient in the same position, the relief of their pain and suffering may be more important to them than an extra few weeks of life. It is about ensuring personal choices and values are respected at all times.⁴⁶⁶

Litigation concerning end of life issues

Georgie Haysom, Head of Advocacy at Avant Mutual Group told the Committee there have not been many cases litigated around end of life law:

No, there are not many. It is kind of curious and interesting. I have reflected on that from time to time as to why that is the case. Certainly as far as I am aware, there has not been very much civil litigation in this area. In fact the civil litigation rates have dropped off significantly since the tort reforms that came in the early 2000s, so the civil litigation anyway has gone down against medical practitioners. Perhaps as a consequence of that, there has been an increase in professional conduct complaints and complaints to the regulator, such as AHPRA — a slightly side issue. There is one case that I am aware of in New South Wales, which involved some self-represented litigants who were at odds with their father's wishes about the treatment of their mother. That was a case called Lane, and that was around the conflict that happened, but other than that I am not aware of any cases, and it is curious.

On one view, you can say that doctors deal with it very well. When I have said that to doctors, they say, 'I don't think we necessarily deal with it very well', so it is curious. The cases that have been around have related more perhaps to who is the appropriate decision-maker when someone has lost capacity, or alternatively where a hospital is unsure about what their obligations are and feel that they need to go to the court for a declaration that withdrawing treatment or complying with a patient's wish to refuse treatment is an appropriate course to take because they are concerned that it does not have the court's sanction.⁴⁶⁷

Dr Anthony Bartone, President of the Australian Medical Association (Victoria) Ltd. told the Committee he was not aware of any prosecutions, but noted the uncertainty around these issues exists despite that fact:

⁴⁶⁶ Ibid.

⁴⁶⁷ Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 13.

I am not currently aware of any doctors that have had to submit to prosecution under those situations, but the uncertainty and the lack of clarity around the lack of legislation exists. While there have been opinions offered by various legal minds, it still leaves that potential for risk and uncertainty. While that uncertainty exists, it must form a potential barrier to providing the best quality of care.⁴⁶⁸

Codified doctrine of double effect in other Australian states

Queensland,⁴⁶⁹ Western Australia,⁴⁷⁰ and South Australia⁴⁷¹ have codified the doctrine of double effect in legislation.⁴⁷²

Benjamin White, Lindy Willmott and Michael Ashby, writing in the *Internal Medicine Journal* in 2011, noted that legislating to include the doctrine of double effect in statute in Queensland, Western Australia, and South Australia had altered its operation:

While the common law is largely consistent with the doctrine of double effect as an ethical principle, this is not the situation for the legislative excuses. These defences are of a different nature, particularly in relation to the required standard of medical care and consent.⁴⁷³

Standard of medical care

White, Willmott and Ashby write that codification in Queensland and South Australia has added a required standard of medical practice doctors must comply with to rely on the doctrine of double effect as a legislative defence, making criminal acts less difficult to prove:

Generally, criminal responsibility for careless medical practice is imposed only where the conduct of the doctor is so grossly negligent that it should be regarded as a crime against the State and therefore worthy of punishment. By contrast, the legislative defences to criminal charges in Queensland and South Australia are available only if a higher standard is met: doctors must comply with good medical practice or proper professional standards of palliative care respectively.

This is significant not only because a higher standard of practice is required but also because legal exposure for doctors is increased by making criminal acts less challenging to prove. At common law, the focus is on a doctor's subjective intention. This is notoriously difficult to establish, particularly beyond reasonable doubt as is required in the criminal law setting. Fewer difficulties arise in proving a failure to

⁴⁶⁸ Dr Anthony Bartone, President, Victoria, Australian Medical Association, *Transcript of evidence*, 24 February 2016, p. 16.

⁴⁶⁹ *Criminal Code 1899* (QLD) s 282A.

⁴⁷⁰ *Criminal Code Act Compilation Act 1913* (WA) section 259(1).

⁴⁷¹ *Consent to Medical Treatment and Palliative Care Act 1995* (SA) sections 17–18. Though whether the common law still applies despite codification in South Australia is unclear Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 6.

⁴⁷² The ACT also has legislation around the doctrine of double effect, but it has very limited scope, and does not remove criminal liability. The ACT legislation is not be examined in this Report. For more see . Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011

⁴⁷³ Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 9.

comply with an objective and measurable standard of practice. The probable outcome is that the State, when prosecuting a doctor, is likely to focus on demonstrating that the standard of care was inadequate, as that is easier to prove than criminal intent.⁴⁷⁴

Consent

White, Willmott and Ashby go on to write that patient consent is not required under the common law doctrine of double effect defence. The legislation in South Australia, and possibly Queensland and Western Australia, includes a consent component, restricting the defence that would be available under the common law:

In relation to consent, the legislative defences again offer less protection than at common law. Whereas consent from a patient or someone authorised to consent on his or her behalf is not required under the common law defence, it is if relying on the South Australian legislation and possibly also in Queensland and Western Australia. The effect is that a doctor could potentially be subject to criminal liability for unlawfully causing death due to a failure to obtain consent for otherwise appropriate palliative care.

While this may be less problematic in South Australia if the defence at common law is also available, this is of concern in Queensland and Western Australia where the legislative provisions provide the sole defence.⁴⁷⁵

White, Willmott, and Ashby reach the conclusion that:

The nature of medical decision-making at the end of life gives rise to legal risk. Although criminal prosecutions are rare, interaction with the legal system can have significant consequences for those involved, even if their actions are vindicated. It is therefore vital that doctors are aware of these local legislative changes, particularly in Queensland and Western Australia where the defence is the only one available. Legal obligations in these jurisdictions will not be satisfied simply by acting in accordance with what the doctrine dictates as an ethical principle. Recent Western Australian case law makes clear that, at least in that State, protection depends on the terms of the legislative defence and not double effect.⁴⁷⁶

The Committee heard evidence at hearing on the impact of doctrine of double effect legislation in other Australian states. Professor Paul Komesaroff, Director for Ethics in Medicine and Society at Monash University gave his view:

It is my understanding that all of these approaches have been favourably received. The South Australian act is perhaps the most advanced, but it is limited deliberately and implicitly to the setting of palliative care, the significance of which is not completely clear and suggests that such actions may be restricted to people who have particular expertise in palliative care. We believe that we need to address the broader setting of end-of-life care generally.⁴⁷⁷

⁴⁷⁴ Ibid., pp. 9–10.

⁴⁷⁵ Ibid., pp. 10–11.

⁴⁷⁶ Ibid., p. 11.

⁴⁷⁷ Professor Paul Komesaroff, Director for Ethics in Medicine & Society, Monash University, *Transcript of evidence*, 23 July 2015, p. 4.

Georgie Haysom, Head of Advocacy at Avant Mutual Group did not take a position on legislating for the doctrine of double effect, but mentioned the South Australian legislation in advocating for consistent terminology in end of life law across Australia:

We have mentioned the South Australian legislation and, whilst we are not necessarily endorsing that is the framework that should be adopted, the fact that they are using terminology that is consistent with the national framework and is used in other jurisdictions is helpful to practitioners.⁴⁷⁸

Legislated protection for withholding/withdrawing futile treatment in other Australian states

Willmott, White, and Downie (2013) consider whether legislative reform in Queensland⁴⁷⁹, South Australia,⁴⁸⁰ Western Australia,⁴⁸¹ and New South Wales⁴⁸² has altered the situation under the common law, described above. They conclude that this has occurred in Queensland only:

... the preferable interpretation of the legislation in New South Wales, South Australia and Western Australia is that the common law is not altered regarding the ability of a doctor to unilaterally withhold or withdraw treatment that he or she considers to be futile. Queensland legislation, on the other hand, expressly alters the common law by requiring that consent from a substitute decision maker (or some other authorisation) be obtained before a doctor can withhold or withdraw futile treatment from an adult who lacks capacity.⁴⁸³

Willmott, White, and Downie describe the situation in Queensland:

Section 79 of the *Guardianship and Administration Act 2000* (Qld) makes it an offence for a health provider to carry out 'health care' for an adult with impaired capacity unless the appropriate consent (or some other authorisation) is obtained. 'Health care' is defined to include withholding and withdrawal of a life-sustaining measure '*if the commencement or continuation of the measure ... would be inconsistent with good medical practice*' ... This means that a potentially life-sustaining measure that is considered futile would fall within that definition.

Accordingly, unless some other authorisation is available, consent must be obtained from either the adult's advance health directive or, more commonly, from a substitute decision-maker to withhold or withdraw a futile potentially life-sustaining measure. This means that doctors do not have unilateral power to make decisions not to provide such treatment they regard as futile, and indeed, a substitute decision-maker can insist on that treatment being given. In 2009, the Queensland State Coroner considered the above interpretation of the *Guardianship and Administration Act*, and concluded that 'the patient or a person authorised under the [*Guardianship and Administration Act*] must consent to the withholding of life-sustaining measures'.

⁴⁷⁸ Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 11.

⁴⁷⁹ *Powers of Attorney Act 1998* (Qld) and *Guardianship and Administration Act 2000* (Qld).

⁴⁸⁰ *Consent to Medical Treatment and Palliative Care Act 1995* (SA) section 17.

⁴⁸¹ *Guardianship and Administration Act 1990* (WA) sections 110ZJ and 110ZL.

⁴⁸² *Crimes (Administration of Sentences) Act 1999* (NSW) section 72A.

⁴⁸³ Lindy Willmott, et al., 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand', *Journal of Law and Medicine*, vol. 20, no. 4, 2013, p. 12.

While the above represents the starting point for decisions about withholding or withdrawing futile treatment, the legislation does contain mechanisms for challenging the decision of a substitute decision-maker who refuses to consent to the withholding or withdrawal of treatment. In an appropriate case, a decision to withhold or withdraw may be made by the Adult Guardian, the Queensland Civil and Administrative Tribunal or the Supreme Court.⁴⁸⁴

Willmott, White, and Downie conclude:

The broad position, then, is that unilateral decision-making power is generally accorded to doctors to determine that treatment is futile, which then relieves them of the obligation to provide that treatment. Questions can and should be asked as to whether this is the best legal model. Because of the significance of these decisions, it is important that careful consideration be given to determining the appropriate decision-maker and the criteria they should apply.⁴⁸⁵

Dr Anthony Bartone, President of the Australian Medical Association (Victoria) Ltd. does not foresee any unintended consequences in legislating to include the doctrine of double effect and protection for withholding or withdrawing futile treatment in statute:

As long as the principles of good medical practice are followed, and that I think is clearly spelt out in the South Australian legislation, I do not see any issues with following that kind of legislation. The principles are very clear and talk about the principles that we value — it is about communication; it is about understanding the wishes and desires and being clear in the expectations, likely or not likely, through treatment. So I think that really if we follow those principles of good medical practice, and remembering they are at the heart of what our regulators suggest as a code of conduct for us, there cannot be a situation where there would be unintended consequences.⁴⁸⁶

The Committee's view on the doctrine of double effect is that there is evidence that patients may be receiving sub-optimal care because of fear on the part of health practitioners about their legal position.

RECOMMENDATION 28: That the Victorian Government enact in legislation the common law doctrine of double effect to strengthen the legal protection for doctors who provide end of life care.

RECOMMENDATION 29: That the Victorian Government legislate to enact the protection doctors currently have under the common law regarding withholding or withdrawing futile treatment. In this regard the Committee recommends Government give consideration to the South Australian *Consent to Medical Treatment and Palliative Care Act 1995* section 17.

⁴⁸⁴ Ibid., p. 13.

⁴⁸⁵ Ibid., p. 19.

⁴⁸⁶ Dr Anthony Bartone, President, Victoria, Australian Medical Association, *Transcript of evidence*, 24 February 2016, p. 15.

4 Government approach to advance care planning

Numerous examples were presented to the Committee illustrating why advance care planning is important.

The Committee heard many times that patients who have planned for their medical care and expressed their wishes save themselves and their loved ones a great deal of stress during difficult times.

At a meeting with Professor Charlie Corke from Barwon Health, Committee members experienced first-hand what is involved in making and expressing decisions about end of life care. It can be a confronting process but is also enormously worthwhile, and the Committee was grateful for this opportunity.

In Victoria we have resources available for advance care planning but poor rates of uptake. The Legal and Social Issues Committee believes that we need to do a better job of relaying the importance of advance care planning to the community.

4.1 What is advance care planning?

Advance care planning is the process for an individual to plan for their medical treatment preferences in the event they become too unwell to make the decisions themselves. The process is used to communicate a person's values and desired health outcomes to help guide health practitioners, family members and others to make medical decisions in their best interests. Advance care planning is undertaken by people of all ages and levels of health.

The process may be informal, such as conversations with relatives or doctors, or result in production of 'advance care plans' or 'advance care directives'. Note that the use of this terminology is not standardised and differs between health services and jurisdictions. In addition, the terms are often used interchangeably.⁴⁸⁷ Further, neither term appears in Victorian legislation; however references to each appear in various Victorian Government documents.

This report uses definitions for 'advance care plan' and 'advance care directive' as detailed in the Commonwealth Government's *A national framework for advance care directives*. Definitions in the Victorian Government documents are consistent with those used in the national framework.⁴⁸⁸

The national framework defines advance care plans as follows:

⁴⁸⁷ Other terms, such as 'living wills' are also used.

⁴⁸⁸ Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 92.

Advance care plans state preferences about health and personal care and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.

There are many ways of recording an advance care plan including oral and written versions. They may be made by, with or for the person.⁴⁸⁹

Advance care directives are defined as:

... one way of formally recording an advance care plan. An ACD [advance care directive] is a type of written advance care plan recognised by common law or authorised by legislation that is completed and signed by a competent adult. An ACD can record the person's preferences for future care and appoint [another person] to make decisions about health care and personal life management. ACDs are focused on the future care of a person not on the management of his or her assets.⁴⁹⁰

Table 4.3 in section 4.5 outlines the terminology used in Australian jurisdictions for advance care directives and the statutory instruments through which they are enforced.

In Victoria, advance care directives recognised under statutory law include refusal of treatment certificates and legally-appointed substitute decision makers. These are discussed in detail in sections 4.2.5 and 4.2.7 below.

4.2 Legal framework

The statutory framework for 'advance care planning' in Victoria comprises four Acts:

- *Medical Treatment Act 1988*
- *Guardianship and Administration Act 1986*
- *Powers of Attorney Act 2014*
- *Charter of Human Rights and Responsibilities Act 2006*.

These are discussed below.

4.2.1 *Medical Treatment Act 1988*

The *Medical Treatment Act* sets out a person's legal right to refuse medical treatment through completing a refusal of treatment certificate. The specific purposes of the *Medical Treatment Act* are to:

- clarify existing common law rights of patients to refuse medical treatment
- establish a procedure for clearly indicating a decision to refuse medical treatment

⁴⁸⁹ Australian Health Ministers' Advisory Council, *A national framework for advance care directives*, Australian Health Ministers' Advisory Council, Melbourne, 2011, pp. 9–10.

⁴⁹⁰ *Ibid.*, p. 10.

- enable an agent to make decisions about medical treatment on behalf of an incompetent person.⁴⁹¹

The Act was developed in response to recommendations made by the Victorian Parliament's Social Development Committee in its final report on the *Inquiry into Options for Dying with Dignity* (1987).⁴⁹²

4.2.2 ***Guardianship and Administration Act 1986***

The *Guardianship and Administration Act* contains provisions for substitute decision makers, which are discussed in detail in section 4.2.7. The Act also establishes the position of the Public Advocate. Among other functions, the Public Advocate may be appointed by the Victorian Civil and Administrative Tribunal (VCAT) as a patient's substitute decision maker.

4.2.3 ***Powers of Attorney Act 2014***

The *Powers of Attorney Act* allows for a person to appoint someone else as their enduring power of attorney to make legal decisions on their behalf. Under the Act, a person may allow their enduring power of attorney to consent to medical treatment on their behalf. The Act also contains a definition of capacity for people to make decisions relating to enduring powers of attorney.

Further, the Act introduced supportive attorneys, a position with particular focus on assisting people with disabilities. Supportive attorneys can provide support to make and give effect to a person's decisions.

4.2.4 ***Charter of Human Rights and Responsibilities Act 2006***

The *Charter of Human Rights and Responsibilities Act* sets out general human rights that the Victorian Parliament seeks to protect and promote. A number of sections of the Charter are relevant in the context of advance care planning.

Section 10(c) of the Act states that a person must not be 'subjected to medical or scientific experimentation or treatment without [their] full, free and informed consent'. In addition, Section 13(a) states that a person has the right 'not to have his or her privacy ... unlawfully or arbitrarily interfered with'. In this context, 'privacy' is understood to extend to privacy of the body, bodily integrity or autonomy.

The Act imposes an obligation on all public authorities — including public health services — to comply with the human rights set out in the Act.

There is also an accepted principle under common law that an adult with capacity has the right to decide whether or not to consent to medical treatment. Many Australian courts have reaffirmed this right and extended it to advance care plans

⁴⁹¹ *Medical Treatment Act 1988*, 41 of 1988, section 1.

⁴⁹² Social Development Committee, *Inquiry into options for dying with dignity — Second and final report*, Victorian Parliament, Melbourne, 1987.

made outside of statutory law. However there is some uncertainty regarding whether common law advance care plans would be valid under Victorian law. This is discussed in detail in section 4.2.8.

4.2.5 Refusal of treatment certificate

A refusal of treatment certificate is a type of advance care directive that allows a person to refuse medical treatment for a 'current condition'. It is a legal document provided under section 5 of the *Medical Treatment Act*.

A refusal of treatment certificate must be certified by a registered medical practitioner and signed by another witness.⁴⁹³ It is also a requirement under the Act for the board or proprietor of a hospital or nursing home to take 'reasonable steps' to submit a copy of the certificate to VCAT within seven days of completion.⁴⁹⁴

'Current condition' relates to an illness that has already been diagnosed. In addition, it may not cover illnesses that may arise as a result of the current condition, such as pneumonia. Consequently, a refusal of treatment certificate cannot be used in anticipation of illnesses or injury.⁴⁹⁵

A medical practitioner who knowingly provides medical treatment that contravenes a refusal of treatment certificate commits an offence of medical trespass.⁴⁹⁶ However, this does not include treatment by non-practitioners, such as ambulance officers, nurses or allied health workers.⁴⁹⁷

A refusal of treatment certificate must be completed by a person when they are still competent and must relate to a patient's current condition.⁴⁹⁸ Refusal of treatment certificates may also be completed by a person with enduring power of attorney (medical treatment) over the patient under substitute decision making provisions (discussed in section 4.2.7).

Refusal of treatment certificates cannot be used to refuse palliative care, which the *Medical Treatment Act* defines as:

- (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or
- (b) the reasonable provision of food and water⁴⁹⁹

In this context, artificial provision of food and water is considered a medical treatment and not palliative care.⁵⁰⁰

⁴⁹³ *Medical Treatment Act 1988*, 41 of 1988, section 5.

⁴⁹⁴ *Ibid.*, section 5E.

⁴⁹⁵ Lindy Willmott, et al., 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)', *Journal of Law and Medicine*, vol. 18, no. 4, 2011, p. 17.

⁴⁹⁶ *Guardianship and Administration Act 1986*, 58 of 1986, section 6.

⁴⁹⁷ Bill O'Shea, Member, Health law and elder law committees, Law Institute of Victoria, *Transcript of evidence*, 18 November 2015, p. 2.

⁴⁹⁸ *Medical Treatment Act 1988*, 41 of 1988, section 5.

⁴⁹⁹ *Ibid.*, section 3.

⁵⁰⁰ See *Gardner; Re BWV*, VSC, [2003].

4.2.6 Capacity and consent

The legal concepts of capacity⁵⁰¹ and consent are important aspects of advance care planning.

Capacity refers to a person's ability to make a decision on their own behalf. Any person over 18 years old is presumed to have decision making capacity unless it can be proven otherwise.

A person's loss of capacity to make decisions about medical treatment is the trigger to activate their advance care plan. This may include their refusal of treatment certificate or activation or appointment of a substitute decision maker to make a decision on their behalf.⁵⁰²

The definition of capacity under the *Powers of Attorney Act* is as follows:

a person has capacity to make a decision ... if the person is able to—

- (a) understand the information relevant to the decision and the effect of the decision; and
- (b) retain that information to the extent necessary to make the decision; and
- (c) use or weigh that information as part of the process of making the decision; and
- (d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.⁵⁰³

Similarly, the *Guardianship and Administration Act* defines when a person lacks the capacity to consent to medical treatment:

... a person is incapable of giving consent to the carrying out of a special procedure, a medical research procedure or medical or dental treatment if the person—

- (a) is incapable of understanding the general nature and effect of the proposed procedure or treatment; or
- (b) is incapable of indicating whether or not he or she consents or does not consent to the carrying out of the proposed procedure or treatment.⁵⁰⁴

It is the role of the medical practitioner to determine whether or not the patient has capacity to consent to the treatment.⁵⁰⁵

If the person is considered to lack capacity under the Act, they are unable to consent to medical treatment. In this case, a substitute decision maker must consent on behalf of the person before any medical treatment can take place.⁵⁰⁶

⁵⁰¹ The term 'competence' is also used interchangeably with 'capacity'.

⁵⁰² Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 55.

⁵⁰³ *Powers of Attorney Act 2014*, 57 of 2014, section 4(1).

⁵⁰⁴ *Guardianship and Administration Act 1986*, 58 of 1986, section 36(2).

⁵⁰⁵ Office of the Public Advocate, 'Medical consent', viewed 8 March 2016, <www.publicadvocate.vic.gov.au>.

⁵⁰⁶ *Guardianship and Administration Act 1986*, 58 of 1986, section 37.

A person's consent for treatment is not required in emergency situations. The *Guardianship and Administration Act* allows for a medical practitioner to provide medical treatment without a patient's consent:

- to save their life
- to prevent serious damage to their health
- to prevent them from suffering or continuing to suffer significant pain or distress.⁵⁰⁷

If a person is incapacitated, consent is also not required for:

- non-intrusive examinations for diagnostic purposes (such as visual examinations of the mouth, throat, nose, eyes or ears)
- first aid
- administering a prescription or self-administered drug within recommended dosages.⁵⁰⁸

Nevertheless, it is still an offence for a medical practitioner to knowingly provide treatment that contravenes a person's refusal of treatment certificate, even in emergency situations.⁵⁰⁹

4.2.7 Substitute decision maker

Substitute decision makers are an important aspect of advance care planning. Advance care plans and the substitute decision maker's decision making powers are triggered when the patient loses capacity.

'Substitute decision maker' is a generic term for a person who has been appointed or identified as having authority over medical treatment decisions when a patient lacks capacity. There is no central statutory location to define how and when a substitute decision maker can be appointed and the extent of their legal power. Substitute decision makers may be appointed under the *Medical Treatment Act*, *Guardianship and Administration Act* or *Powers of Attorney Act*.

There are several types of substitute decision makers. They may be appointed by the patient in advance or be a nominated authority under legislation. The *Guardianship and Administration Act* details the hierarchy of substitute decision makers for medical treatment. This is summarised in Table 4.1 below.

Ultimately, the highest person on the hierarchy who is *available and willing* can make the decision whether or not to consent on the patient's behalf.⁵¹⁰

⁵⁰⁷ Ibid., section 42A(1).

⁵⁰⁸ Ibid., section 3.

⁵⁰⁹ Ibid., section 41.

⁵¹⁰ Ibid., section 37(1).

Table 4.1 Substitute decision maker hierarchy under the *Guardianship and Administration Act 1986*

Substitute decision maker	Act appointed under	Known as
A person appointed by the patient as enduring power of attorney (medical treatment)	<i>Medical Treatment Act</i>	Agent
A person appointed by VCAT to make decisions about the proposed treatment	<i>Guardianship and Administration Act</i>	Guardian
A person appointed by VCAT as the patient's guardian with the power to make decisions about medical treatment	<i>Guardianship and Administration Act</i>	Guardian
A person appointed by the patient as: <ul style="list-style-type: none"> an attorney for personal matters under an enduring power of attorney an enduring guardian with health care powers under enduring power of guardianship 	<i>Powers of Attorney Act</i> (from 1 September 2015) <i>Guardianship and Administration Act</i> (before 1 September 2015)	Attorney
The last person appointed in writing by the patient to make medical decisions on their behalf (must relate to the proposed procedure or treatment)	<i>Guardianship and Administration Act</i>	Person responsible
The patient's spouse or partner	<i>Guardianship and Administration Act</i>	Person responsible
The patient's primary carer (not including paid carers or service providers)	<i>Guardianship and Administration Act</i>	Person responsible
The patient's 'nearest relative', according to the following hierarchy: <ul style="list-style-type: none"> children parents siblings grandparents grandchildren uncle or aunt nephew or niece. If two or more people are on the same tier of the nearest relative hierarchy, the eldest person is selected.	<i>Guardianship and Administration Act</i>	Person responsible

Source: *Guardianship and Administration Act*, 85 of 1986, sections 3; 37(1); Office of the Public Advocate, 'When a patient cannot consent to treatment', viewed 16 February 2015, <www.publicadvocate.vic.gov.au>.

Substitute decision makers may consent, not consent or refuse medical treatment on a patient's behalf. This differs depending under which Act their substitute decision making powers are provided.

The only substitute decision makers who can refuse treatment on a patient's behalf are:

- an agent with enduring power of attorney (medical treatment), appointed under the *Medical Treatment Act*
- a guardian, where VCAT has granted them the power to refuse treatment.⁵¹¹

⁵¹¹ *Medical Treatment Act 1988*, 41 of 1988, section 5A(1)(b).

This is achieved by the agent or guardian completing a refusal of treatment certificate on the patient's behalf. The agent or guardian can only refuse treatment if:

- the treatment would cause unreasonable distress to the patient
- there are reasonable grounds to believe that the patient, if competent, would consider the treatment unwarranted.⁵¹²

The remaining substitute decision makers may either consent or not consent to treatment on the patient's behalf.

If the substitute decision maker does not consent to the treatment, a medical practitioner may apply to VCAT to overturn their decision. The practitioner must believe on 'reasonable grounds' that the treatment is in the best interests of the patient.⁵¹³ This process is rarely utilised.⁵¹⁴

The *Guardianship and Administration Act* also requires medical practitioners and substitute decision makers to consider the patient's best interests. These include:

- the patient's wishes
- the wishes of the patient's family
- the consequences to the patient if they do not receive the treatment
- alternative treatments available
- the risks associated with the treatment or alternative treatment
- whether the treatment is only to promote and maintain the patient's health and well-being.⁵¹⁵

4.2.8 Common law provisions

Although common law rulings in Australia have upheld individuals' advance care plans, there is some uncertainty about whether this would apply in Victoria. The reason for this uncertainty relates to the substitute decision maker provisions under the *Guardianship and Administration Act*.

In its submission to this Inquiry, the Office of the Public Advocate noted that the legal status of common law advance care plans has not been resolved by the High Court of Australia and has not been tested in Victoria.⁵¹⁶ In its report on Victorian guardianship laws in 2012, the Victorian Law Reform Commission also raised concerns about their legal status, stating:

⁵¹² Ibid., section 5B(2).

⁵¹³ *Guardianship and Administration Act 1986*, 58 of 1986, section 42L.

⁵¹⁴ Office of the Public Advocate, *Submission*, p. 41.

⁵¹⁵ *Guardianship and Administration Act 1986*, 58 of 1986, section 38.

⁵¹⁶ Office of the Public Advocate, *Submission*, p. 47.

... it is unclear whether a common law advance directive is binding on a substitute decision maker or is merely one of the matters that must be taken into account in determining the best interests of the patient.⁵¹⁷

Similarly, the Law Institute of Victoria stated in its submission to the Inquiry:

While assertions are made that Victorian law extends to support a common law Advance Care Directive, it is probably more accurate to say that advance care planning documents being promoted administratively, particularly in the form of a 'statement of choices', assist decision makers to make ... health care decisions consistent with the individual's choice without ascribing rights to any person.⁵¹⁸

Researchers Willmott et al. discussed four reasons why common law advance care directives may be overruled by the substitute decision maker provisions in the *Guardianship and Administration Act*:

1. The Act requires a substitute decision maker to take the patient's views into account, but they are not bound to make a decision that consents with these views.
2. Neither the *Guardianship and Administration Act* nor the *Medical Treatment Act* state that the common law right to refuse treatment remains despite the enactment of the substitute decision making regime.
3. The *Guardianship and Administration Act* gives substitute decision makers authority as if the patient had capacity.⁵¹⁹ Since an adult with capacity can override their advance care directive, a substitute decision maker could also do so.
4. The *Guardianship and Administration Act* states that a medical practitioner must not contravene a refusal of treatment certificate. By only referring to refusal of treatment certificates and not common law, it could be argued that a common law advance directive would not prevail over the Act's substitute decision making provisions.⁵²⁰

Nevertheless, Willmott et. al consider that common law rights still apply, and that advance care directives should be recognised in Victoria. They believe:

- There is a legal assumption that express words or an implication is required for an Act to negate previously held common law rights. Neither is present in the *Guardianship and Administration Act*.
- The *Medical Treatment Act* is legislation that specifically deals with refusal of medical treatment. It also states that the rights of a person under 'any other law'⁵²¹ are not affected — a reference that could be viewed as referring

⁵¹⁷ Victorian Law Reform Commission, *Guardianship report (Report no. 24)*, Victorian Law Reform Commission, Melbourne, 2012, p. 213.

⁵¹⁸ Law Institute of Victoria, *Submission*, p. 5.

⁵¹⁹ *Guardianship and Administration Act 1986*, 58 of 1986, section 40.

⁵²⁰ Lindy Willmott, et al., 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)', *Journal of Law and Medicine*, vol. 18, no. 4, 2011, p. 777.

⁵²¹ *Medical Treatment Act 1988*, 41 of 1988, section 4.

to common law rights. As the *Guardianship and Administration Act* deals with guardianship issues, the legal principle that the specific should prevail over the general would apply.⁵²²

The need for legislation that will expand the degree to which advance care plans are recognised under statutory law is discussed further in section 4.6.

4.3 Policy overview

4.3.1 Victorian policy framework

The Victorian Government's advance care planning policy direction is outlined in *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*. The policy was prepared by the former Department of Health and is intended for use by health services. It aims to 'promote consistent practice and inform the development of processes, policies, guidelines, training, governance and quality structures that support advance care planning'.⁵²³

The strategy is directed at health services to improve their advance care planning by:

- establishing robust systems so that organisations can have the conversation
- ensuring organisations have an evidence-based and quality approach to have the conversation
- increasing organisational workforce capability to have the conversation
- enabling the person being cared for to have the conversation.⁵²⁴

Each of the four areas relates to criteria within the *National safety and quality health service standards* (discussed previously in Chapter 2).

The Government's strategy documents eight best-practice standards to guide clinical approaches to developing and activating advance care plans. The best-practice standards are based on principles contained in the national framework for advance care directives, which is discussed in detail in section 4.3.2.⁵²⁵

The strategy forms part of the broader *Victorian health priorities framework 2012–2022* (discussed previously in Chapter 2). The Victorian Government's focus in advance care planning is related to broader Victorian health priorities. Information about the strategy's four priority action areas and how they relate to the health framework's seven priority areas can be found in the framework's introduction.⁵²⁶

⁵²² *Generalia specialibus non derogant*.

⁵²³ Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 5.

⁵²⁴ *Ibid.*

⁵²⁵ *Ibid.*, p. 19.

⁵²⁶ *Ibid.*, p. 6.

Another relevant document is *Advance care planning: Resource for doctors and health professionals*, which aims to assist practitioners to:

... ‘have the conversation’ with patients about end of life decision making, engage patients in decisions about their care, and help them to undertake advance care planning.⁵²⁷

The document covers the Victorian legal framework for advance care planning; consulting with patients and developing advance care plans; implementing a patient’s advance care plan; advance care planning in the workplace, and advance care planning in a mental health context.⁵²⁸

The Advance Care Planning Implementation Advisory Group provides advice to the Department of Health and Human Services and other stakeholders. The group comprises members from the following organisations within government:

- Office of the Public Advocate (including the group’s Chair)
- Ambulance Victoria
- Council of the Ageing
- Networking Health Victoria
- Commonwealth Department of Health
- Health Issues Centre
- various health services and support organisations.⁵²⁹

Victorian health services conduct a range of programs for advance care planning. These have a varied focus, including training and resources for health practitioners, community engagement and research projects. The Victorian and Commonwealth health departments provide support and funding to these programs.

Recent programs in Victoria include the following:

- The *Respecting Patient Choices* model for health services to provide advance care planning. The program was initiated in 2002 by Austin Health and has since been introduced in many health and residential aged care services in Victoria and nationally. The Committee heard from several stakeholders who considered the model to be a best-practice initiative.
- A scoping survey led by Austin Health, to investigate the progress of health services implementing the Government’s advance care planning strategy.
- MyValues, led by Barwon Health, an online survey that allows users to create a profile for their end of life choices based on their personal values.

⁵²⁷ Australian Medical Association and the Department of Health and Human Services, *Advance care planning: Have the conversation — Module 1: The facts*, Victorian Government, Melbourne, 2015.

⁵²⁸ Department of Health and Human Services, ‘Advance care planning: Resource for doctors and health professionals’, viewed 8 February 2015, <www2.health.vic.gov.au>.

⁵²⁹ Department of Health and Human Services, ‘Advance Care Planning Implementation Advisory Group’, viewed 10 February 2016, <www2.health.vic.gov.au>.

- System Wide Advance Care Planning, led by Networking Health Victoria, supporting regional consortia to improve awareness and uptake of advance care planning in their local areas.
- An options paper led by Austin Health, to investigate transferability of advance care plans across different organisations.
- Resources to support health practitioners, led by the Australian Medical Association.
- Having difficult conversations factsheet, led by Northern Health.
- Guidelines to support conversations when caring for very sick children, led by the Royal Children's Hospital.
- Can community dwelling older adults complete a person based Advance Care Directive to provide useful information to substitute decision makers? A research project led by Alfred Health.
- Diverse cultural groups and advance care planning, led by Northern Health.
- Developing resources for consumers, led by the Health Issues Centre.
- Developing resources for consumers from different cultural groups, led by Ethnic Communities' Council of Victoria.⁵³⁰

4.3.2 National policy framework

A national framework for advance care directives is a best practice guide for providing advance care planning. It is intended for use by regulators — including governments and parliaments — and administrators of advance care planning programs.

The national framework was prepared by a working group of the Australian Health Ministers' Advisory Council. The stated objectives of the Advisory Council are described below.

- Greater use of advance care planning will assist the community to recognise the limits of modern medicine and the role of health-promoting palliative care.
- Mutual recognition of advance care directives across all states and territories will be facilitated through harmonisation of formats and terminology.
- Growing numbers of Australians will contemplate their future potential loss of decision-making capacity, and will appreciate the benefits of planning where and how they will live and be cared for, and of communicating their future life and care choices in advance.
- Advance care directives will be well established across Australia as a means of ensuring that a person's preferences can be known and respected after the loss of decision-making capacity.
- Decisions by substitute decision makers chosen and appointed under advance care directives will be respected and will reflect the preferences of the person.

⁵³⁰ Department of Health and Human Services, 'Advance care planning implementation: Greater say for dying patients — July 2015 update', viewed 8 March 2015, <www2.health.vic.gov.au>; Department of Health and Human Services, 'Advance care planning initiatives', viewed 16 February 2016, <www2.health.vic.gov.au>.

- Advance care directives will be readily recognised and acted upon with confidence by health and aged care professionals, and will be part of routine practice in health, institutional and aged care settings.
- Clinical care and treatment plans written by health care professionals will be consistent with the person's expressed values and preferred outcomes of care as recorded in their advance care directive.⁵³¹

These objectives reflect the view of health practitioners that the Committee heard in many locations — that advance care planning should be routinely undertaken and widespread in uptake.

The national framework includes a code for ethical practice and a set of best practice standards.

The code for ethical practice contains 15 directions to guide practice in services where advance care directives are used. These are illustrated in Box 4.1 below.

Box 4.1: The code for ethical practice for advance care directives under *A national framework for advance care directives*

1. Advance care directives are founded on respect for a person's autonomy and are focused on the person
2. Competent adults are autonomous individuals and are entitled to make their own decisions about personal and health matters
3. Autonomy can be exercised in different ways according to the person's culture, background, history or spiritual and religious beliefs
4. Adults are presumed competent
5. Directions in advance care directives may reflect a broad concept of health
6. Directions in advance care directives can relate to any time in the future
7. The person decides what constitutes quality of life
8. The substitute decision maker has the same authority as the person when they were competent
9. The substitute decision maker must honour residual decision-making capacity
10. The primary decision-making standard for substitute decision makers is substituted judgement
11. A substitute decision maker should only base his or her decision on best interests when there is no evidence of the person's preferences on which to base substituted judgement
12. An advance care directive can be relied upon if it appears valid
13. A refusal of a health-related intervention in a valid advance care directive must be followed, if intended by the person to apply to the situation

⁵³¹ Australian Health Ministers' Advisory Council, *A national framework for advance care directives*, Australian Health Ministers' Advisory Council, Melbourne, 2011, p. 1.

Box 4.1: The code for ethical practice for advance care directives under *A national framework for advance care directives* (continued)

14. A person, or their legally recognised substitute decision maker, can consent to treatment offered, refuse treatment offered, but cannot demand treatment
15. A valid advance care directive that expresses preferences or refusals relevant and specific to the situation at hand must be followed.

Source: Australian Health Ministers' Advisory Council, *A national framework for advance care directives*, Australian Health Ministers' Advisory Council, Melbourne, 2011, pp. 14–15.

These best practice standards describe how services should help develop and use advance care directives. The standards cover the following topics:

- substitute decision making, including a pathway for substitute decision makers when acting on a person's behalf
- core standards for law and policy
- core standards for guidelines and forms
- completing advance care directives
- activating advance care directives
- making decisions under advance care directives
- problem solving.

Quality assurance standards for health services providing advance care planning are detailed in the *National safety and quality health service standards*. Advance care planning-specific criteria are listed in Table 4.2 below.

Table 4.2 *National safety and quality health services standards* criteria relating to advance care planning

Measure		Actions Required	
Standard 1 — Governance for safety and quality in health service organisations			
Patient rights and engagement			
1.18	Implementing processes to enable partnership with patients in decisions about their care, including informed consent to treatment	1.18.4	Patients and carers are supported to document clear advance care directives and/or treatment-limiting orders
Standard 9 — Recognising and responding			
Communicating with patients and carers			
9.8	Ensuring that information about advance care plans and treatment-limiting orders is in the patient clinical record, where appropriate	9.8.1	A system is in place for preparing and/or receiving advance care plans in partnership with patients, families and carers
		9.8.2	Advance care plans and other treatment-limiting orders are documented in the patient clinical record

Source: Australian Commission on Safety and Quality in Health Care, *National safety and quality health service standards*, Commonwealth of Australia, Sydney, 2011.

4.4 Advance care planning programs in Victoria

4.4.1 Health services

Health services provide support and resources to patients to prepare and document advance care plans.

At a public hearing, Dr Karen Detering, a doctor from Austin Health who works on the *Respecting Patient Choices* program, detailed the advance care planning process from her health service's perspective: The process involves detailed consultation with patients:

When we have an advance care planning discussion, we are aiming to do a number of things. The first thing we are really trying to do is to work out how decisions will be made if that person becomes unable to make their own decisions, so we will try to find out how they would like this to occur. We do not tell them how the decisions will be made, but rather discuss with them how they can be made, obviously if the person is able to make their own decisions, we are going to go and talk to them.

Then we need to work through what will these decisions be. How will they be worked out? There are a number of factors that need to be considered. We need to think about the individual's goals, values, beliefs and what they consider to be a reasonable outcome ... We need to find out what information the person, their family and others might need to facilitate and assist with this. They may not know what is wrong with them. They may not understand that they have an eventually fatal condition. They may want some further information. They may want to understand what dying is going to look like if they have the surgery versus if they do not. They may have some very specific views about treatments they do not want.⁵³²

Jill Mann, coordinator of Barwon Health's Respecting Patient Choices program, provided a similar account:

I would say the majority of our advance care planning conversations do not end up in a refusal of treatment. It is usually about what is important for that person to live well, based on their values. And it is more about, 'In certain situations what sort of things would you want to have happen? What is paramount for you, and what matters most? What is the thing that matters most to you of all things at that time?'. Those are the sort of things we try to capture. It is not just about not having a certain intervention.⁵³³

Ms Mann also provided specific details about Barwon Health's advance care planning service. She explained the importance of initiating and facilitating advance care planning in general practice, which has a high success rate:

Skilled, trained advance care planning clinicians from our service — from Barwon Health — are provided to general practice through an outreach model, and it continues to have a very high referral rate from general practice. The uptake to document completion is very high in that cohort of 90 per cent. That is compared

⁵³² Dr Karen Detering, Respiratory Physician and Clinical Ethicist, Respecting Patient Choices Program, Austin Health, *Transcript of evidence*, 5 August 2015, p. 7.

⁵³³ Jill Mann, Respecting Patient Choices Program Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 13.

with other health referral areas of around 50 per cent or 60 per cent. It has been demonstrated through our model that when advance care planning is initiated and facilitated in general practice through routine processes — for example, over 75 health assessments — and in the absence of acute illness, in a trusted environment individuals are more likely to engage in that process. Our average referrals for the year 2014–15 have been around 120 a month, and about 95 of those go on to complete documents.⁵³⁴

In 2014, the Department of Health and Human Services conducted a survey of health services on their progress against measures in the Victorian Government's advance care planning strategy. In its submission, the Victorian Government noted key findings of the survey:

- sixty-five per cent of services had developed or were developing an organisation-wide advance care planning policy
- ninety-five per cent had resources available to patients and families about advance care planning
- sixty-four per cent had developed or were developing a process where managers and clinical leaders assessed results of advance care planning quality audits
- eighty-five per cent had developed or were developing education and training for staff about advance care planning.⁵³⁵

Frances Diver, Deputy Secretary, Health Service Performance and Programs from the Department of Health and Human Services, detailed further findings of the survey:

... 70 per cent of health services have resources to support advance care planning; 40 per cent of services have an electronic alert system, which is fantastic; where there is not an electronic alert system, 45 per cent of services also have a paper-based alert. That just means something on the front of the medical record that would indicate that there is an advance care plan. Forty-three per cent are using best practice standards.

...

... Seventy per cent of services have a nominated clinical leader. Clinical champions for these kinds of programs are obviously crucial, and these programs are best led clinically. Seventy per cent of health services are focusing on delivering advance care planning for key patient groups, so making sure that culturally and linguistically diverse groups or particularly vulnerable groups are able to access these services.⁵³⁶

⁵³⁴ Ibid., p. 10.

⁵³⁵ Victorian Government, *Submission*, p. 8.

⁵³⁶ Frances Diver, Deputy Secretary, Health Service Performance and Program, Victoria, Department of Health and Human Services, *Transcript of evidence*, 23 July 2015.

4.4.2 Prevalence and awareness of advance care planning in the community

Despite the benefits associated with advance care planning, the Committee heard that the uptake of advance care planning was relatively low in Victoria and Australia-wide.

In its submission to the Committee, the Council of the Ageing stated there was ‘varying’ awareness of advance care planning from participants at its *Dying to talk* seminars.⁵³⁷ Similarly, Professor Hal Swerissen, an academic from LaTrobe University and fellow with the Grattan Institute involved in the publication of the report *Dying Well*, told the Committee:

The reality is that advance care plans and directives are very poorly used at the moment, and very few people have them in place. Very few people have medical powers of attorney in place. Even in nursing homes and residential care facilities very few people have them in place, yet 90 per cent of permanent residents in nursing homes or residential care facilities will die in the residential care facility.⁵³⁸

Professor Swerissen’s comments highlighted that even those in facilities where they are likely to die do not understand the nature of advance care planning.

Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care, raised a related issue. He told the Committee that medical practitioners are often unaware of a patient’s advance care plan. He also stated that copies of refusal of treatment certificates are often not provided to VCAT as required under the *Medical Treatment Act*.⁵³⁹

The Law Institute of Victoria also expressed similar concerns, based on feedback received from an advance care directives forum:

In 2012, the LIV co-hosted a forum on advanced care directives with the [Australian Medical Association] (Vic). Participants at the forum, who included medical and legal practitioners, discussed practical issues arising from the complexity of the current law. Participants reported that [refusal of treatment certificates] ... are rarely made. Participants further stated that there appears to be widespread non-compliance with aspects of section 5E of the [*Medical Treatment Act*], which requires a copy of a [refusal of treatment certificate] to be placed on the patient’s record, given to the chief executive officer of the hospital or aged care home and given to the principal registrar of VCAT within seven days after the certificate is completed.

Forum participants also noted anecdotal feedback from hospital emergency physicians that patients are only very rarely admitted with any type of advance care directive (usually a ‘statement of choices’) on their person and, where this does occasionally occur, it is rarely relied upon because often the document is unclear and poorly written.⁵⁴⁰

⁵³⁷ Council of the Ageing, *Submission*.

⁵³⁸ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 15.

⁵³⁹ Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, pp. 65–66.

⁵⁴⁰ Law Institute of Victoria, *Submission*, p. 9.

According to a survey conducted by White et al., around 13.4 per cent of Victorians have formalised a refusal of treatment certificate. This was reasonably consistent with completion of advance care directives generally in Australia (14.4 per cent).⁵⁴¹

Respondents from Queensland and South Australia were more likely to have prepared an advance care directive than the remaining states or territories. Nationally, respondents were more likely to have an advance care directive if they had already completed a will or had appointed a financial enduring power of attorney. Respondents were also more likely to have a directive if they were single or not in a legally recognised relationship.⁵⁴²

The authors noted that there is little national data available on the prevalence of advance care directives. They concluded that more research is needed to understand why the uptake of advance care directives in Australia is low.⁵⁴³

In summary, various health services have invested to develop ways to engage with their patients. Whilst there currently exists a government framework for engagement, more needs to be done to inform and work with patients to see their wishes fulfilled.

4.5 Overview of advance care directives in other Australian jurisdictions

All Australian jurisdictions — apart from New South Wales and Tasmania — have enacted legislation for advance care directives. New South Wales and Tasmania recognise advance care directives under common law.

As noted previously, the terminology of advance care directives differs in Australian jurisdictions. Table 4.3 below lists the advance care legislation and terminology used in each state and territory.

Table 4.3 Advance care directive law in Australian jurisdictions

Jurisdiction	Legislation	Terminology used
ACT	<i>Medical Treatment (Health Directions) Act 2006</i>	Health direction
NSW	Recognised at common law	-
NT	<i>Advance Personal Planning Act 2013</i>	Advance consent decision
Qld	<i>Powers of Attorney Act 1998</i>	Advance health directive
SA	<i>Advance Care Directives Act 2013</i>	Advance care directive
Tas	Recognised at common law	-
Vic	<i>Medical Treatment Act 1988</i>	Refusal of treatment certificate
WA	<i>Guardianship and Administration Act 1990</i>	Advance health directive

Source: Compiled by the Standing Committee on Legal and Social Issues.

⁵⁴¹ B P White, et al., 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, vol. 44, no. 10, 2014.

⁵⁴² Ibid.

⁵⁴³ Ibid.

In addition, all Australian jurisdictions have legislative arrangements for substitute decision makers.

Provisions for advance care directives differ greatly between jurisdictions. Some key provisions where jurisdictions take different approaches include:

- scope for advance care directives (e.g. limitations for future conditions; when a directive can be activated)
- decisions that substitute decision makers can make
- powers and scope of the Public Advocate
- provisions for a medical practitioner to override an advance care directive or substitute decision maker
- recognition of advance care directives and substitute decision makers from other jurisdictions
- witness requirements for advance care directives and appointing substitute decision makers
- legal protection for medical practitioners acting according to an advance care directive
- legislated requirement to act in the ‘best interests’ of the patient
- recognition of advance care directives made under common law.

A detailed comparison can be found in Appendix 1 of the document *A national framework for advance care directives*.⁵⁴⁴

The Senate Community Affairs References Committee noted inconsistency between jurisdictions regarding advance care directives in its *Inquiry into Palliative care in Australia* in 2012. The report stated that this creates a difficulty for legal recognition of advance care directives from other jurisdictions.⁵⁴⁵ In addition, Palliative Care Australia in its submission to the Senate inquiry claimed that jurisdictional differences hinder further uptake of advance care plans.⁵⁴⁶

4.6 Statutory recognition of advance care plans

At the time of writing this Report the Victorian Government was reviewing the State’s end of life framework. Feature area 1 of the review’s discussion paper focuses on changes to advance care planning.

⁵⁴⁴ See Australian Health Ministers’ Advisory Council, *A national framework for advance care directives*, Australian Health Ministers’ Advisory Council, Melbourne, 2011. Note: South Australia and the Northern Territory have introduced new legislation on advance care directives since the framework was published. This inquiry’s report reflects these changes.

⁵⁴⁵ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 202.

⁵⁴⁶ Palliative Care Australia, *Submission*, no. 98, Inquiry into palliative care in Australia, Standing Committee on Community Affairs (References Committee), Australian Parliament.

In evidence to the Committee, Kym Peake, Secretary of the Department of Health and Human Services, explained advance care planning aspects of the review. She confirmed that the Government is looking broadly at advance care planning and related elements of decision making at end of life:

... the department is reviewing existing Victorian legislation to examine overlaps and differences between the *Medical Treatment Act*, the *Powers of Attorney Act* and the *Guardianship and Administration Act*. We have also commenced discussions with the Office of the Public Advocate, the Law Institute of Victoria, Health Issues Centre, clinical practitioners involved in the subacute peak body and the health services commissioner ...⁵⁴⁷

The review's discussion paper states that the Victorian Government 'is committed to strengthening end of life care planning through legal reform that enshrines advance care planning in law'.⁵⁴⁸ The paper also refers to treatment for future conditions.⁵⁴⁹ Both of these aspects were features of the Victorian Government's 2014 election platform.⁵⁵⁰

The discussion paper sought comments on two 'questions to consider':

- How do we ensure that people with a life-limiting illness are involved in, and have genuine choices, about decisions regarding their medical treatments and care for both current and future medical conditions?
- How do we ensure people have options regarding where they want to be cared for, where they want to spend the last days of their life and where they want to die?⁵⁵¹

⁵⁴⁷ Kym Peake, Secretary, Department of Health and Human Services, *Transcript of evidence*, 25 November 2015, p. 3.

⁵⁴⁸ Department of Health and Human Services, *Greater say for Victorians: Improving end of life care*, Victorian Government, Melbourne, 2015, p. 5.

⁵⁴⁹ Ibid.

⁵⁵⁰ ALP Victoria, 'Platform 2014', viewed 17 February 2016, <www.viclabor.com.au>, p. 39.

⁵⁵¹ Department of Health and Human Services, *Greater say for Victorians: Improving end of life care*, Victorian Government, Melbourne, 2015, p. 5.

5

Improving advance care planning

The Committee makes a number of recommendations in this Chapter relating to advance care planning to help give effect to the choices of Victorians at the end of life.

The first part of this Chapter focuses on policy changes to increase and encourage participation in advance care planning.

The second part focuses on legislative change that is necessary to allow individuals to identify and record their future health preferences in a legal document.

5

5.1 The value of advance care planning

Advance care planning plays an integral role in better patient outcomes in end of life care.⁵⁵² The Committee received evidence to support this from a broad range of people involved in end of life care.

It involves clarifying a patient's understanding of their illness and treatment options, understanding their values, beliefs, and goals of care and identifying their wishes.

Research shows that doctors and family members are poor predictors of patient preferences for end of life care,⁵⁵³ often electing to perform treatment and interventions that patients themselves do not want.⁵⁵⁴

The Committee believes that patients with advance care plans are more likely to receive treatment that reflects their wishes and reduces the likelihood of invasive medical interventions, which in turn helps to reduce anxiety for patients and family.⁵⁵⁵

⁵⁵² B P White, et al., 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, vol. 44, no. 10, 2014, p. 974.

⁵⁵³ Richard F Uhlmann, et al., 'Physicians' and spouses' predictions of elderly patients' resuscitation preferences', *Journal of Gerontology*, vol. 43, no. 5, 1988, p. 120.

⁵⁵⁴ Rebecca S Allen and John L Jr Shuster, 'The Role of Proxies in Treatment Decisions: Evaluating Functional Capacity to Consent to End-of-Life Treatments within a Family Context', *Behavioural Science Law*, vol. 20, no. 3, 2002, p. 6; Grattan Institute, *Submission*, p. 16.

⁵⁵⁵ Karen M Detering, et al., 'The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial', *British Medical Journal*, vol. 340, no. 7751, 2010, p. 1.

An overwhelming majority of people who create an advance care plan choose to receive palliative care at the end of life rather than life-prolonging measures.⁵⁵⁶ Palliative care improves patient symptoms and mood and prolongs life of a higher quality.⁵⁵⁷

People with advance care plans are also far more likely to die in their preferred location, which is a key indicator of what is described as a good death.⁵⁵⁸

Conversely, patients whose preferences for medical treatment are not known by doctors or family members are more likely to receive unnecessary or unwanted treatment, which causes increased anxiety and uncertainty for patients and their families.⁵⁵⁹

Unless we fully embrace advance care planning we will always fall short of good and effective palliative care because we will not know what our patients have wanted.

Dr Arup Bhattacharya, Divisional Clinical Director, Medical, Goulburn Valley Health, public hearing 13 August 2015

If you do not know what to do, you can treat at all costs, but once you get onto that treatment treadmill, it is very difficult to stop.

Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network, public hearing 12 August 2015

5.2 A case study of advance care planning

Approximately 85 per cent of Australians will die after a chronic illness, not a sudden event and up to 50 per cent will be incapable of making their own decisions at the end of life.⁵⁶⁰

Despite the foreseeability of the dying process and the benefits of advance care planning, very few people have advance care plans.

A 2010 study found that only 13.4 per cent of Victorians had completed a binding advance care plan, known as a refusal of treatment certificate.⁵⁶¹

Programs that guide people through the advance care planning process have successful completion rates well above the broader community level of uptake.

⁵⁵⁶ Austin Health, *Final evaluation of the community implementation of the Respecting Patient Choices Program*, Austin Health, Melbourne, 2006, p. 5.

⁵⁵⁷ Ian A Scott, et al., 'Difficult but necessary conversations — The case for advance care planning', *Medical Journal of Australia*, vol. 199, no. 10, 2013, p. 663.

⁵⁵⁸ Grattan Institute, *Submission*, p. 11.

⁵⁵⁹ AA Wright, et al., 'Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment', *Journal of the American Medical Association*, vol. 300, no. 14, 2008, p. 2.

⁵⁶⁰ Austin Health, *Final evaluation of the community implementation of the Respecting Patient Choices Program*, Austin Health, Melbourne, 2006; *Ibid.*; Advance Care Planning Australia, 'Why is advance care planning important?', viewed 20 May 2016, <advancecareplanning.org.au>.

⁵⁶¹ B P White, et al., 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, vol. 44, no. 10, 2014, p. 979; *Ibid.*

One such program, *Respecting Patient Choices*, was initially implemented in 17 residential aged care facilities in Melbourne. Of those who were introduced to the program, 52 per cent documented their choices concerning future medical treatment.⁵⁶²

Of those who completed advance care plans, 90 per cent indicated a preference for palliative care rather than life-prolonging measures at the end of life.⁵⁶³

This is significant in several respects. Firstly, palliative care is fundamental to good end of life care. It improves quality of life through relief from pain, provides psychological support for patients and their carers and improves communication between care providers, the patient and the family.⁵⁶⁴ Secondly, palliative care reduces the likelihood of aggressive non-beneficial treatment and hospitalisation, which doctors are inclined to initiate when people's preferences are not clear.⁵⁶⁵

Evaluation of the initial implementation of *Respecting Patient Choices* found that 100 per cent of residents with an advance care plan had their medical wishes respected at the end of life and 85 per cent received end of life care in their residential aged care facility.⁵⁶⁶ Residents who had not identified treatment preferences were between 64 and 80 per cent more likely to die in hospital.⁵⁶⁷

A subsequent study also found that surviving relatives of patients who participated in the program experienced significantly reduced anxiety, depression and post-traumatic stress disorder symptoms than non-participants.⁵⁶⁸ Dr Karen Detering, author of this study and a physician at Austin Health who worked on the *Respecting Patient Choices* program, expanded on this at a public hearing:

When I last checked the medical research, we are more likely to die than to have our house burn down. We all have house insurance yet we do not have advance care planning.

Associate Professor William Silvester,
President, International Society of Advance
Care Planning and End of Life Care, public
hearing 23 July 2015

When we get the death wrong, not only is it bad for the person themselves, but it is bad for everyone else who hangs around after them. In the study, where the patient received advance care planning, the surviving family members were much more satisfied with the quality of the patient's death and they had improved psychosocial outcomes, so less risk of post-traumatic stress disorder anxiety and depression.⁵⁶⁹

⁵⁶² Austin Health, *Final evaluation of the community implementation of the Respecting Patient Choices Program*, Austin Health, Melbourne, 2006, p. 5.

⁵⁶³ Ibid.

⁵⁶⁴ World Health Organization, 'WHO definition of palliative care', viewed 18 February 2016, <www.who.int>.

⁵⁶⁵ Grattan Institute, *Submission*, p. 17.

⁵⁶⁶ Austin Health, *Final evaluation of the community implementation of the Respecting Patient Choices Program*, Austin Health, Melbourne, 2006, p. 6.

⁵⁶⁷ Ibid.

⁵⁶⁸ Karen M Detering, et al., 'The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial', *British Medical Journal*, vol. 340, no. 7751, 2010, p. 7.

⁵⁶⁹ Dr Karen Detering, Respiratory Physician and Clinical Ethicist, *Respecting Patient Choices Program*, Austin Health, *Transcript of evidence*, 5 August 2015, p. 8.

The difference in outcomes for patients with and without advance care plans illustrates how increasing the level of advance care planning is critical to improving end of life care.

The Committee heard from many witnesses in submissions and at hearings that a number of improvements are needed to our advance care planning framework in Victoria.

5.3 Policies to improve advance care planning

Despite advances in recent years, very few people are making advance care plans and where advance care plans have been made, they are often unclear.

The Committee believes that it is important to improve community understanding of advance care plans and their importance to receiving preferred medical treatment. The Recommendations made in this Chapter have been made to support this finding.

As a society, up until now, we do not really talk about death that much. It is not in our media; it is not on our television. Everyone survives cardiac arrests in soap operas. But I think people are prepared to talk about it if it is done sensitively.

Dr Neil Orford, Divisional Director, Intensive Care Unit, Barwon Health, public hearing 29 July 2015

The importance of improving community awareness of advance care planning was highlighted by health groups, statutory authorities, religious and faith-based organisations, and individuals in evidence to the Committee.⁵⁷⁰

The Committee heard that a major obstacle to advance care planning is an unwillingness to talk about death and dying.

Dr Jane Fischer of Calvary Health Care Bethlehem, in Melbourne, observed 'We are quite a death-denying society. People do not want to talk about it.'⁵⁷¹

Talking about death and dying is an important precursor to discussing treatment options and preferences at the end of life and yet these conversations are not taking place, even where a person is seriously ill. Cabrini Health noted:

We are frequently told by families that they have not had a conversation with their loved one about his/her end of life wishes, despite the health, social and/or other physical disabilities that have led to the requirement for residential care.⁵⁷²

Dr Ric Milner, a general practitioner, observed that end of life care is less distressing where families have had the conversation about preferred treatment:

⁵⁷⁰ Council of the Ageing, *Submission*, p. 20; Mercy Health, *Submission*, p. 6; Melbourne City Mission, *Submission*, p. 3; Central Hume Primary Care Partnership, *Submission*, p. 3; Commissioner for Senior Victorians, *Submission*, p. 3; Australia and New Zealand Society for Geriatric Medicine, *Submission*, p. 2; Australasian College for Emergency Medicine, *Submission*, p. 5; Australian Catholic Bishops Conference, *Submission*, p. 11; Palliative Care Victoria, *Submission*, p. 10; Kathleen Puls, *Submission*, p. 12.

⁵⁷¹ Dr Jane Fischer, Chief Executive Officer, Medical Director, Calvary Healthcare Bethlehem, *Transcript of evidence*, 9 September 2015; *Ibid*.

⁵⁷² Cabrini Health, *Submission*, p. 5.

The conversation with the patient is important, but the conversation with the patient, their family, their loved ones and their carers is vital because that reduces end of life distress for their families. It is bad enough having your loved one going through terrible illness, but if the decisions have been pre-discussed, you have much less chance of two warring factions of children or relatives fighting over the decision that the person has made.⁵⁷³

Critically, once these conversations take place, a person is more likely to receive the type of end of life care they want. Rebecca Bartel, Chief Executive Officer at the Australian Centre for Health Research observed:

We know from research and evidence already that conversation makes a significant difference. There is greater alignment between patient preferences and the care they receive; higher patient quality of life; improved satisfaction; less use of aggressive or non-beneficial life-sustaining interventions; greater use of hospice care; increased likelihood that people will die at home or at least in a comfortable setting of their choice; reduced family distress, anxiety and depression; reduced stress amongst doctors, nurses and other caregivers; and improved resource use and cost efficiencies.⁵⁷⁴

Community education is essential to starting these conversations within the community, as the Grattan Institute noted in its 2014 study *Dying Well*:

A program of public education about the end of life is needed to combat misperceptions and to encourage people to realistically discuss their preferences for end of life care and to put in place plans to ensure they are met.⁵⁷⁵

This is supported by a review of advance care planning models by La Trobe University which found that ‘education interventions are regarded as a central aspect of [advance care planning] promotion.’⁵⁷⁶

The Committee believes that the Victorian Government should undertake work towards improving community awareness of end of life choices, particularly the importance of advance care planning. The Government should consider doing this in a targeted way which ensures that important groups in the community, such as citizens over 75, will receive this message.

The Committee recommends that the Government achieve this through a statewide community awareness campaign. The Committee notes that successive governments have lead similar campaigns — such as the Transport Accident Commission and DonateLife — which have resulted in successful changes.

Given the significant work being undertaken on advance care planning in Victoria, it is important that community awareness is driven at a state level.

⁵⁷³ Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 47.

⁵⁷⁴ Rebecca Bartel, Chief Executive, Australian Centre for Health Research, *Transcript of evidence*, 21 October 2015, p. 10.

⁵⁷⁵ Grattan Institute, *Submission*, p. 22.

⁵⁷⁶ Annette Street and Dr Goetz Ottman, *State of the science review of advance care planning models*, La Trobe University, Melbourne, 2006, p. 45.

RECOMMENDATION 30: That the Victorian Government undertake a community awareness campaign to improve understanding of end of life choices, particularly advance care planning.

Notwithstanding the role of the State Government, the Committee also believes that national action is required to improve community awareness of advance care planning.

A national public awareness campaign on advance care planning would strengthen any similar measures implemented in Victoria and has been recommended by the Grattan Institute⁵⁷⁷ and Carers Victoria⁵⁷⁸ to improve levels of advance care planning.

Several Commonwealth parliamentary committees have recommended a national information campaign to raise awareness about advance care directives, including the Standing Committee on Family, Community, Housing and Youth in 2009⁵⁷⁹ and the Senate Community Affairs References Committee in 2012.⁵⁸⁰ The Committee endorses the need for such an initiative.

RECOMMENDATION 31: That the Victorian Government through COAG Health Council or the Australian Health Ministers' Advisory Council lobby the Commonwealth Government to undertake a national public awareness campaign on advance care planning to reinforce state efforts in this regard.

Dying to Know Day is an annual day of action that promotes advance care planning and aims to initiate conversations around death, dying and bereavement within the community.

Recognising Dying to Know Day was supported by the Australian Centre for Health Research⁵⁸¹ and Kathleen Puls.⁵⁸²

RECOMMENDATION 32: That the Victorian Government support the recognition of Annual Dying to Know Day on 8 August.

The Victorian Government should ensure that policy reflects the need for advance care planning to be implemented while individuals have capacity and are in good health. This will mean that Victorians do not find themselves in crisis situations without having made their wishes formally known and understood.

Hospital emergency departments and intensive care units are locations where complex treatment is being undertaken and decisions are being made quickly by doctors. The Committee has heard that there is often not time to make fuller

⁵⁷⁷ Grattan Institute, *Submission*, p. 25.

⁵⁷⁸ Carers Victoria, *Strategic plan*, Carers Victoria, Melbourne, 2015, p. 6.

⁵⁷⁹ Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Australian Parliament, Canberra, 2009, p. 113.

⁵⁸⁰ Senate Community Affairs References Committee, *Palliative care in Australia*, Australian Parliament, Canberra, 2012, p. 214.

⁵⁸¹ Australian Centre for Health Research, *Submission*, p. 27.

⁵⁸² Kathleen Puls, *Submission*, p. 12.

inquiries about what patients would like to include in their wishes for their health care when they no longer have capacity. Making an advance care plan for the first time in such a situation can be stressful for patients and their families.

As discussed below, implementation, monitoring, and review of advance care plans is best conducted by an individual in consultation with their general practitioner.

Although there is no dedicated Medicare Benefits Scheme item number for advance care planning, the use of some item types for advance care planning activity in general practice was endorsed by the Commonwealth Department of Health in 2015. This includes general consultations, health assessments and telehealth.⁵⁸³

The Committee believes that advance care planning needs to be implemented systematically for the benefits to be realised across the population and to ensure that best practice is achieved and sustained.⁵⁸⁴

Providing incentives for advance care planning by creating a Medicare Benefits Scheme item number would considerably increase its uptake. It would enable people to discuss their preferred end of life care with their general practitioner, who is best placed to assist in the process given their longstanding, trusted relationships with patients.⁵⁸⁵

Witnesses and submissions to the Committee strongly supported this idea.⁵⁸⁶

The Committee believes that this could occur within the context of the current Medicare Benefits Schedule Review being conducted by the Commonwealth Government.⁵⁸⁷

The Barwon Health *Respecting Patient Choices* program has successfully engaged with general practitioners and the Barwon Medicare Local through providing advance care planning clinics in the region. This outreach service, which involves trained staff facilitating planning with patients who are referred by

⁵⁸³ Decision Assist, 'Advance care planning in general practice: Guidance on use of MBS items', viewed 16 February 2015, <www.caresearch.com.au>, p. 1.

⁵⁸⁴ Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 2.

⁵⁸⁵ Ian A Scott, et al., 'Difficult but necessary conversations — The case for advance care planning', *Medical Journal of Australia*, vol. 199, no. 10, 2013, p. 665; Colleen M Cartwright and Malcolm H Parker, 'Advance care planning and end of life decision making', *Australian Family Physician*, vol. 33, no. 10, 2004, p. 817.

⁵⁸⁶ Central Hume Primary Care Partnership, *Submission*, p. 3; Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 6; Adjunct Associate Professor Ranjana Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University, *Transcript of evidence*, 19 August 2015, p. 19; Jill Mann, Respecting Patient Choices Program Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 10; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 38; Catherine Kemp, Palliative Care Coordinator, Swan Hill District Health, *Transcript of evidence*, 12 August 2015, p. 21; Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network, *Transcript of evidence*, 12 August 2015, p. 36; Professor Charlie Corke, Intensive Care Specialist, Barwon Health, *Transcript of evidence*, 15 October 2015, p. 6; Dr Rod Stephenson, *Submission*, p. 3; Dr Anthony Bartone, President, Victoria, Australian Medical Association, *Transcript of evidence*, 24 February 2016, p. 14.

⁵⁸⁷ Department of Health, 'About the Medicare Benefits Schedule review', viewed 26 April 2016, <www.health.gov.au>.

their general practitioners, has a high rate of engagement with 90 per cent of patients completing the documentation.⁵⁸⁸ This supports the idea that general practitioners are well placed to engage people in advance care planning.

Robyn Hayles, Chief Operating Officer of Community Health, Palliative Care, Rehabilitation and Aged Services at Barwon Health explained how the *Respecting Patient Choices* program worked:

What we have found has worked well is having skilled-up staff that have visited clinics in regular times so that the GP can commence discussion, evolve the discussion a bit and then, when people are ready, have a resource — an educated, trained, in our case nursing, staff, who have those conversations in more detail and take people into the legislative framework of advance care planning et cetera if and when that is appropriate.⁵⁸⁹

RECOMMENDATION 33: That the Victorian Government propose that the Commonwealth Government consider creating a Medicare Benefits Scheme item number for advance care planning to provide incentive for increased uptake.

RECOMMENDATION 34: That the Victorian Government provide education to health practitioners about the option of using existing Medicare Benefits Scheme item numbers for advance care planning.

The Australian Centre for Health Research suggested remunerating general practitioners for having advance care planning conversations with people at the 75-year-old health assessment, patients with newly diagnosed dementia and residents of aged care facilities.⁵⁹⁰

The Victorian advance care planning strategy identifies priority groups who would benefit from support to articulate their wishes for future treatment and care. These include:

- aged or older people who are frail
- people of any age with chronic progressive and life-limiting conditions
- people approaching end of life
- people with multiple comorbidities and/or at risk of conditions such as stroke or heart failure
- people with early cognitive impairment.⁵⁹¹

Establishing trigger points for conversations about end of life choices would make it easier for doctors to have these conversations with patients.

⁵⁸⁸ Jill Mann, Respecting Patient Choices Program Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 10.

⁵⁸⁹ Robyn Hayles, Chief Operating Officer of Community Health, Rehabilitation, Palliative and Aged Care, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 6.

⁵⁹⁰ Australian Centre for Health Research, *Submission*, p. 27.

⁵⁹¹ Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 12.

Using the 75-year-old health assessment as a trigger for an advance care planning conversation was supported by the Grattan Institute,⁵⁹² Associate Professor William Silvester of the International Society of Advance Care Planning and End of Life Care,⁵⁹³ and the Australian Centre for Health Research.⁵⁹⁴

Other stakeholders recommended that people admitted to residential aged care facilities⁵⁹⁵ and hospital in-patients who are likely to die of a chronic condition in the next year⁵⁹⁶ should also be engaged in end of life discussions, including the development of advance care plans.

Victoria's advance care planning strategy also recommends using these triggers for advance care planning conversations.⁵⁹⁷

RECOMMENDATION 35: That the Victorian Government include measures in its end of life care framework to ensure that end of life discussions and planning occurs. This should include nominating trigger points for conversations about end of life preferences between general practitioners and patients, such as:

- over-75 health assessments
- entry to residential aged care
- allocation of high needs home care packages
- discharge plans for those likely to die within 12 months.

Only around 13.4 per cent of Victorians have formalised a refusal of treatment certificate. This is reasonably consistent with completion of advance care directives generally in Australia (14.4 per cent).⁵⁹⁸

Some academic evidence suggests that in the United States of America, approximately 70 per cent of older Americans have completed an advance care directive.⁵⁹⁹ This figure, however, may include people who have completed a Durable Power of Attorney for Health Care, which only appoints a substitute decision maker, so is not directly comparable with the 13.4 per cent of Victorians who have completed a refusal of treatment certificate.⁶⁰⁰

⁵⁹² Grattan Institute, *Submission*, p. 27.

⁵⁹³ Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 66.

⁵⁹⁴ Australian Centre for Health Research, *Submission*, p. 22.

⁵⁹⁵ Dr Rodney Syme, Vice President, Dying With Dignity Victoria, *Transcript of evidence*, 14 October 2015, p. 6; Australasian College for Emergency Medicine, *Submission*, p. 3; Grattan Institute, *Submission*, p. 28; HOPE: Preventing Euthanasia & Assisted Suicide, *Submission*, p. 11.

⁵⁹⁶ Grattan Institute, *Submission*, p. 28; Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 66.

⁵⁹⁷ Department of Health, *Advance care planning: Have the conversation — A strategy for Victorian health services 2014–2018*, Victorian Government, Melbourne, 2014, p. 4.

⁵⁹⁸ B P White, et al., 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, vol. 44, no. 10, 2014. The authors conceded that there is little national data available on the prevalence of advance care directives. They concluded that more research is needed to understand why the uptake of advance care directives in Australia is low.

⁵⁹⁹ JM Teno, et al., 'Association between advance directives and quality of end-of-life care: A national study', *Journal of the American Geriatrics Society*, vol. 55, no. 2, 2007; MJ Silveira, et al., 'Advance directive completion by elderly Americans: a decade of change', *Journal of the American Geriatrics Society*, vol. 62, no. 4, 2014.

⁶⁰⁰ Karen Detering and MJ Silveira, 'Advance care planning and advance directives', viewed 8 March 2016, <www.uptodate.com>.

However, the Committee believes the Victorian Government should encourage people to engage in advance care planning discussions, and believes a target figure can assist in efforts to do this.

RECOMMENDATION 36: That the Victorian Government establish a voluntary target to measure and encourage improvements in the level of advance care planning across Victoria.

5.3.1 Health practitioner education

This section looks at ways in which we can improve health practitioner understanding of advance care planning and substitute decision making in Victoria. The recommendations made relate to this concern.

Research shows that patients expect their doctors to initiate advance care planning conversations.⁶⁰¹ Many doctors, however, find such conversations difficult and have inadequate training in advance care planning and end of life care communication.

The Committee heard this many times during the Inquiry, where it was widely reflected in the evidence of witnesses and submissions. For example, Vicki Doherty of the Gippsland Region Palliative Care Consortium observed:

I think one of the major issues in planning for end of life care is the capacity for clinicians to actually have difficult conversations. There is lots of documentation around about how to complete an advance care plan, but it is actually starting that conversation with the clients and carers about what it is that they want. We know not all clinicians have good communication skills, but they can be taught and they can be learnt.⁶⁰²

Developing the skills of health practitioners in facilitating these conversations is essential.

The Australian and New Zealand Society of Palliative Medicine,⁶⁰³ the Public Health Association Australia (Vic Branch),⁶⁰⁴ the Australasian College for Emergency Medicine,⁶⁰⁵ and the Council of the Ageing⁶⁰⁶ noted the importance of training health practitioners to communicate and facilitate advance care planning.

How conversations with patients become treatment decisions is an important part of the process, as the Health Issues Centre observed:

⁶⁰¹ Karen M Detering, et al., 'The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial', *British Medical Journal*, vol. 340, no. 7751, 2010, p. 1.

⁶⁰² Vicki Doherty, Director, Gippsland Region Palliative Care Consortia, *Transcript of evidence*, 9 September 2015, p. 4.

⁶⁰³ Australian and New Zealand Society of Palliative Medicine, *Submission*, p. 9.

⁶⁰⁴ Public Health Association of Australia (Vic), *Submission*, p. 2.

⁶⁰⁵ Australasian College for Emergency Medicine, *Submission*, p. 3.

⁶⁰⁶ Council of the Ageing, *Submission*, p. 20.

Health professionals need to assist the person to translate their values and priorities into specific treatment decisions.⁶⁰⁷

RECOMMENDATION 37: That the Victorian Government undertake a health practitioner education campaign to improve understanding of advance care planning and how to facilitate this process with patients.

In undertaking this work the Government should be guided by programs that are currently in place in Victoria, such as the initiative described by Associate Professor Daryl Clarke from the Austin Hospital:

CLEARx decisions [is a program] which stands for Consultant Leadership in End-of-life care Advance care planning and treatment decisions. This is a program whereby a group of very senior clinicians on the senior medical staff association executive have developed some guidelines and guiding principles and then gone and promulgated those to the senior medical staff of the hospital. The idea is not to be prescriptive and tell clever people what to do, but to give some guiding principles about what we would like them to do in their area and their acting as local champions.

We are educating clinicians, particularly doctors, and we are starting this in medical school, that comfort care is not failed care, that a good death in a patient who is always going to die is actually a success. That is something we stress in the intensive care unit when we make the switch from curative care to comfort care. We are trying to improve communication skills and emphasising starting the conversation as early as possible in the course of a patient's decline so that there are no surprises.⁶⁰⁸

Communication difficulties are a barrier to advance care planning and can reduce a person's ability to participate in decision making processes about their end of life care.

Speech Pathology Australia recommended developing and implementing guidelines and resources for health practitioners to support advance care planning and end of life conversations with individuals with communication difficulties.⁶⁰⁹

RECOMMENDATION 38: That the Victorian Government implement guidelines and resources for health practitioners to support advance care planning and end of life conversations with patients with communication difficulties.

Improving levels of advance care planning also requires health practitioner education on the end of life legal framework and substitute decision making.

⁶⁰⁷ Health Issues Centre, *Submission*, pp. 4–5.

⁶⁰⁸ Associate Professor Daryl Jones, Medical Director Critical Care Outreach, Austin Health, *Transcript of evidence*, 5 August 2015, p. 6.

⁶⁰⁹ Speech Pathology Australia, *Submission*, p. 6.

The Committee heard that health practitioners do not understand the legal framework. This makes it difficult to identify substitute decision makers and to determine whether advance care plans are legally binding, particularly when they are disputed by substitute decision makers.

The Office of the Public Advocate observed, ‘the law concerning substitute medical consent is complex, confusing and is not well understood by medical professionals, much less the general public.’⁶¹⁰

This is supported by *Medical Journal of Australia* research which found that many doctors cannot identify a legally valid advance care directive and do not know whether they are obliged to follow one that conflicts with their clinical judgment.⁶¹¹

In a test on the validity of advance care directives and the law on substitute decision makers, Victorian doctors scored an average of 3.17 out of a possible 7. This compared to an aggregate score of 3.26 for all doctors (from New South Wales, Victoria and Queensland).⁶¹²

These findings have serious consequences for end of life care, as Alfred Health noted:

Poor knowledge among medical staff (and other health professionals) around relevant legislation relating to end of life can lead to scenarios where they may persist with or institute treatments that are no longer of benefit.⁶¹³

This point was reiterated by Kathleen Puls, who made a submission in a private capacity, observing:

Medical practitioners who are confused about the legality of advance care directives and the authority of substitute decision-makers or who are unaware of the wishes of the patient, may choose active treatment that would have been refused had the patient had capacity.⁶¹⁴

RECOMMENDATION 39: That the Victorian Government lobby the Australian Medical Council to examine the adequacy of compulsory teaching in medical schools about substitute decision making and substitute medical consent.

RECOMMENDATION 40: That the Postgraduate Medical Council of Victoria ensure that medical interns are adequately trained on the subject of substitute decision making.

RECOMMENDATION 41: That the Victorian Government require doctors and nurses to undertake continuous professional development on advance care planning.

⁶¹⁰ Office of the Public Advocate, *Submission*, p. 11.

⁶¹¹ Ben P White, et al., ‘Doctors’ knowledge of the law on withholding and withdrawing life-sustaining medical treatment’, *Medical Journal of Australia*, vol. 201, no. 4, 2014.

⁶¹² Sarah Colyer, ‘End-of-life legal warning’, *MJA InSight*, 11 August 2014, viewed 15 February 2016, <www.mja.com.au>; Professors Ben White and Lindy Willmott, Correspondence to Standing Committee on Legal and Social Issues secretariat, 19 May 2016.

⁶¹³ Alfred Health, *Submission*, p. 5.

⁶¹⁴ Kathleen Puls, *Submission*, p. 11.

5.3.2 Health system strengthening

Several health practitioners expressed concern to the Committee that advance care plans cannot be accessed as required.⁶¹⁵

Accessibility is one concern that relates to a broader problem that take-up of advance care planning needs to be improved in Victoria. This Report makes Recommendations which the Committee believes would assist in improving adoption rates.

Critically, an advance care plan is useful only insofar as it is accessible at all points along the treatment spectrum, from the general practitioner, to the palliative care specialist, the oncologist and the emergency department.

Dr Natasha Michael, the Director of Palliative Care at Cabrini Health, illustrated this point, noting:

People must need to know where the documents are kept, families need to know what they say and health systems must have procedures in place for these documents to be accessible. That is probably one of the greatest areas that we need to work on in terms of systems implementation.⁶¹⁶

Access to advance care plans is complicated by the nature of the health system and geographic mobility, as Dr Karen Detering of the *Respecting Patient Choices* program at Austin Health observed:

We work in fragmented health services. People move all over the place and come backwards and forwards and do not even go to the same emergency department in the same hospital, particularly in big, busy places like Melbourne but also they come from the country down to Melbourne and they come from interstate, so it is quite fragmented. Thus it is difficult to make sure advance care directives are available.⁶¹⁷

Several submissions suggested establishing an electronic register to address these issues of accessibility, including the Grattan Institute,⁶¹⁸ the Central Hume Primary Care Partnership,⁶¹⁹ Alfred Health,⁶²⁰ Cancer Council Victoria,⁶²¹ as well as several individuals.⁶²²

⁶¹⁵ Dr Ewa Piejko, Medical Adviser, General Practitioner, Murray Primary Health Network, *Transcript of evidence*, 12 August 2015, p. 35; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015; Jason Trethowan, Chief Executive Officer, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 41; Ian Patrick, General Manager Clinical and Community Services, Ambulance Victoria, *Transcript of evidence*, 18 November 2015, p. 33.

⁶¹⁶ Dr Natasha Michael, Director Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p. 10.

⁶¹⁷ Dr Karen Detering, Respiratory Physician and Clinical Ethicist, Respecting Patient Choices Program, Austin Health, *Transcript of evidence*, 5 August 2015, p. 11.

⁶¹⁸ Grattan Institute, *Submission*, p. 19.

⁶¹⁹ Central Hume Primary Care Partnership, *Submission*, p. 2.

⁶²⁰ Alfred Health, *Submission*, p. 10.

⁶²¹ Cancer Council Victoria, *Submission*, p. 12.

⁶²² Kathleen Puls, *Submission*, pp. 5–6; Jill Mann, Respecting Patient Choices Program Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 12; Lindsay Doig, *Submission*, p. 4; Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 65.

This is supported by research which has established that shared health records improve coordination and communication in end of life care and using electronic information significantly increases the uptake of advance care plans.⁶²³

The Commonwealth Government My Health Record, previously known as the personally controlled health care records, can be used to develop, record and activate advance care plans.⁶²⁴ As such, it presents an opportunity to improve the accessibility of advance care plans, thereby enabling doctors to give effect to patients' wishes, as well as improving the level of uptake.

The National Lead Clinicians Group has noted that the My Health Record can enable advance care plans to be easily accessible across hospital, community and residential aged care settings. Using the My Health Record for advance care plans allows for the development of a system of alerts that indicate to health staff and ambulance officers when an advance care plan exists and how it can be accessed.⁶²⁵

The Commonwealth My Health Record may be the place to embed advance care plans, however, the Committee did not hear evidence that there is a high uptake.

The Committee recognises that the My Health Record has its limitations, however, it is currently the most viable existing option, given the cost and complexity in establishing a stand-alone electronic register solely for advance care plans.

The Committee also notes the advance care plan hotline registry model used in Oregon which allows emergency medical services to access a patient's advance care plan by phone. The Physician Orders for Life-Sustaining Treatment (POLST) registry hotline received 1583 emergency calls in 2015, with a patient's advance care plan registered in 38.5 per cent of cases.⁶²⁶

With low levels of uptake of the My Health Record, the Committee recommends that the Department of Health and Human Services investigate the possibility of a similar hotline for Victoria, whilst considering integration of the My Health Record into standard medical practice.

⁶²³ Isabelle Skinner and Cathy Smith, 'Realist review to inform development of the electronic advance care plan for the personally controlled electronic health record in Australia', *Telemedicine and e-Health*, vol. 20, no. 11, 2014, p. 1042.

⁶²⁴ Department of Health and Human Services, *Advance care planning: Resource for doctors and health professionals — Module 5: Record — How to document the conversation*, Victorian Government, Melbourne, 2015, p. 1.

⁶²⁵ Department of Health and the National Lead Clinicians Group, *Queensland forum report of outcomes — Transfer of care: Advance care planning*, National Clinicians Network, Brisbane, 2013, p. 2.

⁶²⁶ Oregon Physician Orders for Life-Sustaining Treatment Registry, *2015 annual report*, Oregon Physician Orders for Life-Sustaining Treatment Registry, Portland, 2015, p. 6.

RECOMMENDATION 42: As part of its longer term strategy in this policy area, that the Victorian Government implement a long-term systemic approach to integrating the My Health Record (including appropriate Information Technology infrastructure) into standard medical practice for the following purposes:

- to record advance care plans
- to use as core documentation for transfer of care
- to develop a system of alerts and triggers that indicate a person has an advance care plan and how it can be accessed across health services.

RECOMMENDATION 43: That the Victorian Government, through End of Life Care Victoria recommended in this Report as part of the assisted dying framework, establish a registry hotline to improve access to advance care plans for emergency medical services.

A related but overarching concern is that of maintaining good health records for advance care planning. The Victorian Auditor-General reported on this need in the 2015 Report, *Palliative care*, and made a number of recommendations for improvement. The Committee endorses these recommendations, detailed below:

RECOMMENDATION 44: That health services prioritise the implementation of advance care planning and meet all the Department of Health and Human Services' data collection and reporting requirements.

RECOMMENDATION 45: That the Department of Health and Human Services improve its advance care planning reporting to better understand the level of uptake.

5.4 Legislative reform to improve advance care planning

The Committee believes that the complex end of life care legal framework in Victoria needs to be simplified and clarified.

There are several aspects to the end of life care legal framework in Victoria that are confusing, unclear and need to be updated. In particular the enforceability of advance care plans, the limitation in refusal of treatment certificates to current conditions and the substitute decision making framework.

The *Medical Treatment Act 1988* was introduced in response to the Social Development Committee's final report on the *Inquiry into options for dying with dignity* (1987), nearly 30 years ago.

A refusal of treatment certificate was favoured at the time due to concerns that allowing for treatment decisions relating to future conditions would lead to uninformed decisions.⁶²⁷

⁶²⁷ Victorian Legislative Council 23 March 1988, *Debates*, vol. 390, p. 704., cited in Deborah Porter, 'Advance directives and the persistent vegetative state in Victoria: A human rights perspective', *Journal of Law and Medicine*, vol. 13, no. 2, 2005, p. 263.

The narrow scope of the *Medical Treatment Act 1988*, however, has since become apparent, with concerns that the Act does not adequately support the community's belief in the principle of individual autonomy and the human right to self-determination.⁶²⁸ As Palliative Care Victoria noted in its submission:

It would be appropriate to review the Act given community aspirations to have a stronger voice in determining the future medical care they may receive, both for current and future conditions.⁶²⁹

The Committee has identified options for legislative reform that will reduce the risk that a patient's wishes are not upheld and clarify the legal obligations of health practitioners in Victoria. These include:

- providing for binding advance care plans
- allowing for planning for future conditions
- simplifying substitute decision making in new legislation
- introducing supplementary legislative reforms.

The Committee will recommend repealing the *Medical Treatment Act 1988* and introducing new legislation to provide for binding advance care plans, planning for future conditions and substitute decision making. This will require repealing health substitute decision making provisions in the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*.

5.4.1 Enforceable advance care plans

As discussed in Chapter 4, the enforceability of common law advance care plans is unclear as neither the High Court nor the Victorian Supreme Court has considered the matter. Victoria's current statutory advance care directive mechanism, the refusal of treatment certificate, only allows for treatment to be specified in relation to a current condition. It also only allows for advance refusal of, and not consent to, treatment.⁶³⁰

Several submissions by religious and faith-based organisations, advocacy groups and individuals supported the role of advance care plans as indicators of a patient's wishes rather than legally binding instruments.⁶³¹

The Social Responsibilities Committee of the Anglican Diocese of Melbourne, for example, stated the following concerns about enforceable advance care plans:

- advance care plans may not be based on informed consent
- interpretation may be difficult
- advance care plans may conflict with the patient's best interests.⁶³²

⁶²⁸ Deborah Porter, 'Advance directives and the persistent vegetative state in Victoria: A human rights perspective', *Journal of Law and Medicine*, vol. 13, no. 2, 2005, p. 264.

⁶²⁹ Palliative Care Victoria, *Submission*, p. 18.

⁶³⁰ *Medical Treatment Act 1988*, 41 of 1988, section 5.

⁶³¹ Australian Catholic University, *Submission*, p. 1; HOPE: Preventing Euthanasia & Assisted Suicide, *Submission*.

⁶³² Social Responsibilities Committee of the Anglican Diocese of Melbourne, *Submission*, pp. 9–10.

Similarly, the Australian Christian Lobby stated:

Any move towards further regulation of written directives should be part of a holistic approach towards advanced care planning that not only includes patient choices but also includes good health care principles. [Australian Christian Lobby] does not believe that making directives legislatively binding will assist towards that goal.⁶³³

Giving evidence in a personal capacity, Mary Hocking, who holds medical power of attorney for her husband who has early onset dementia, observed:

I know the man my husband used to be, and I know he would not want to be the man that he is today; however, he is happy as he is the man he is today, which brings me to another difficulty with advance care plans, which is: whose version do we hold with or think is more valid?⁶³⁴

In contrast, the Committee heard arguments from other stakeholders that advance care plans should be enforceable under legislation. Key issues are discussed below.

Providing legal certainty

Evidence presented to the Committee indicated uncertainty about the enforceability of common law advance care plans exposes health practitioners to legal liability. This in turn undermines the likelihood that a patient's wishes will be fulfilled.

Alfred Health is one of many health bodies that believes that health practitioners are at risk of legal liability in the current system:

There is also no immunity provided to health professionals who follow the instructions of an [advance care plan]. Health professionals can face threats of legal action from family members who disagree with a patient's [advance care plan].⁶³⁵

The Law Institute of Victoria believes that making advance care plans enforceable would resolve this question of liability:

We think the best way to protect health workers, be they doctors, nurses, whoever, when they are faced with an advance care plan, is to make the advance care plan enforceable; in other words, force them to follow the plan subject to a number of possible exclusions. That gives them protection, it gives them immunity, as does the current refusal of treatment certificate.⁶³⁶

⁶³³ Australian Christian Lobby, *Submission*, p. 15.

⁶³⁴ Mary Hocking, Physiotherapist in palliative care, *Transcript of evidence*, 15 October 2015, pp. 29–30.

⁶³⁵ Alfred Health, *Submission*, p. 4.

⁶³⁶ Bill O'Shea, Member, Health law and elder law committees, Law Institute of Victoria, *Transcript of evidence*, 18 November 2015, p. 4.

This position was supported by Melbourne Health:

Legislation to support the delivery of Advance Care Planning and Refusal of Treatment Certificates should be strengthened to allow further clarity in a legal sense for people's decisions to be respected, particularly when they are no longer in a position to be able to voice these for themselves.⁶³⁷

Although there is no evidence to suggest that health practitioners will be prosecuted under the current system, it is nevertheless important that they are expressing these concerns.

Recognising patient choices

In assessing the end of life legal framework in Victoria, Willmott et al. favoured recognising common law advance directives because of the greater weight this would give to individual autonomy.⁶³⁸

This reflects the position of Vicki Davidson of National Seniors Australia, who observed:

... we are strongly supportive of advance care directives that are binding on family members and health professionals. Such directives would give legal force to the right of individuals to control what does happen to their bodies.⁶³⁹

The ethicist Professor Julian Savulescu similarly said that 'people ought to know that their wishes either will or will not be respected in that situation.'⁶⁴⁰

In evidence provided to the Committee, a range of statutory authorities, health bodies, advocacy groups, professional bodies and individuals also supported enacting legislation to make advance care plans enforceable.⁶⁴¹

Among these was Jill Mann, Coordinator of the *Respecting Patient Choices* program at Barwon Health:

Based on our extensive experience, we believe that the act is a little bit remiss in that it does not often acknowledge the frail and elderly who may wish to exercise their autonomy to refuse treatments in all circumstances but actually may not have a current condition diagnosed.⁶⁴²

⁶³⁷ Melbourne Health, *Submission*, p. 2.

⁶³⁸ Lindy Willmott, et al., 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)', *Journal of Law and Medicine*, vol. 18, no. 4, 2011, p. 791.

⁶³⁹ Vicki Davidson, Committee Member, National Seniors Advisory Group, *Transcript of evidence*, 21 October 2015, p. 2.

⁶⁴⁰ Julian Savulescu, Uehiro Chair in Practical Ethics, Oxford University, *Transcript of evidence*, 19 August 2015, p. 6.

⁶⁴¹ Law Institute of Victoria, *Submission*, p. 13; Office of the Public Advocate, *Submission*, p. 6; Australian and New Zealand Society of Palliative Medicine, *Submission*, p. 10; National Seniors Australia, *Submission*, p. 3; Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 4; Victorian Law Reform Commission, *Guardianship report (Report no. 24)*, Victorian Law Reform Commission, Melbourne, 2012. cited in Cancer Council Victoria, *Submission*, p. 12; Dr Jason Fletcher, Advance Care Planning Clinical Lead, Bendigo Health, *Transcript of evidence*, 12 August 2015, p. 2; Melbourne Health, *Submission*, p. 2; Grattan Institute, *Submission*, p. 25; Australian Nursing and Midwifery Federation (Vic), *Submission*, p. 7; Janine Truter, *Submission*, p. 2; Alan Shell, *Submission*, p. 1; David Shuttle, *Submission*, p. 1; Jan Lacey, *Submission*, p. 1; Tom Valenta, *Transcript of evidence*, 29 October 2015, p. 16; Kathleen Puls, *Submission*, p. 6; Bourne and Associates, *Submission*, p. 14.

⁶⁴² Jill Mann, Respecting Patient Choices Program Coordinator, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 11.

South Australia, Queensland, Western Australia, the Northern Territory and the Australian Capital Territory allow for statutory advance care plans. In New South Wales common law plans have been upheld in the Supreme Court. Foundation Professor of Aged Services at Southern Cross University Colleen Cartwright noted that making advance care plans enforceable would give Victorians the same opportunities as other Australians in preparing for end of life.⁶⁴³

The Committee supports statutory enactment of binding advance care plans as this will enable Victorians to plan for their future with greater certainty. It will also clarify the legal obligations of health practitioners.

The Committee notes that this was previously recommended by the Victorian Law Reform Commission in its *Guardianship Report* (2012).⁶⁴⁴

Substitute decision makers overruling advance care plans

The Victorian Law Reform Commission's *Guardianship Report* highlighted another complication associated with common law advance care plans: are they binding on a substitute decision maker or are they merely one of the matters that must be taken into account in determining the best interests of the patient?⁶⁴⁵

This issue was raised by the Australian College of Nursing, which believes that appointed substitute decision makers and health practitioners can overrule a common law advance care plan.⁶⁴⁶

The Council of the Ageing noted that participants in its *Dying to Talk* events expressed concern that their wishes reflected in advance care plans could be ignored where doctors and substitute decision makers choose to overrule them.⁶⁴⁷

The Office of the Public Advocate notes that the relationship between common law plans and substitute decision making is unclear as it has not been resolved by the High Court and is untested in Victoria.⁶⁴⁸

Willmott et al. suggest that a common law advance care plan would prevail over a contrary direction by a substitute decision maker,⁶⁴⁹ as discussed in Chapter 4. However, they suggest the prevailing confusion demonstrates the need to reform the end of life care legal framework in Victoria to provide greater clarity and certainty.⁶⁵⁰

⁶⁴³ Professor Colleen Cartwright, *Submission*, p. 1.

⁶⁴⁴ Victorian Law Reform Commission, *Guardianship report (Report no. 24)*, Victorian Law Reform Commission, Melbourne, 2012, p. 222.

⁶⁴⁵ *Ibid.*, p. 213.

⁶⁴⁶ Australian College of Nursing, *Submission*, p. 2.

⁶⁴⁷ Council of the Ageing, *Submission*, pp. 12–13.

⁶⁴⁸ Office of the Public Advocate, *Submission*, p. 47.

⁶⁴⁹ Lindy Willmott, et al., 'The legal role of medical professionals in decisions to withhold or withdraw life-sustaining treatment: Part 3 (Victoria)', *Journal of Law and Medicine*, vol. 18, no. 4, 2011, p. 777.

⁶⁵⁰ *Ibid.*

Combined binding and advisory directives

South Australia, Queensland, Western Australia, the Northern Territory and the Australian Capital Territory have in place binding statutory advance care plans that also provide for ‘advisory statements’.⁶⁵¹ This enables people to create binding or advisory directives (or both) according to their own values and beliefs.

Binding directives include consent to or refusal of medical treatment in a specific set of circumstances, such as refusal of cardiopulmonary resuscitation where a patient is permanently unconscious.

Advisory statements are broad descriptions of values, wishes and health goals that provide guidance to substitute decision makers and health practitioners in determining whether or not to perform or withdraw medical treatment. For example, where a person has indicated that personal autonomy is more important to them than survival at all costs, a doctor may decide against performing life-prolonging treatment where the patient will subsequently be dependent on carers to be washed, dressed and fed.

People who choose to create a binding directive can also create an advisory statement to provide further guidance to decision makers.

The distinction between binding directives and advisory statements has legal implications for health practitioners who follow them. To provide medical treatment that had been refused, such as through a refusal of treatment certificate, would amount to battery and medical trespass. However, allowing a person to die in hospital when they said they wanted to die at home would not cause legal liability.⁶⁵²

Nonetheless, a health practitioner is required to take into account advisory provisions in determining appropriate medical treatment.

Each jurisdiction has developed tools to assist health practitioners to identify their legal responsibilities in a given situation.

Figure 5.1 and Figure 5.2 below of South Australia’s Advance Care Directive Form illustrate the type of matters that can be addressed in advisory statements and binding directives and how these can be recorded together in that jurisdiction.

This model enables people to address each element of advance care planning in one form: a binding directive, an advisory statement and appointing a substitute decision maker.

At the moment we allow people to opt out of treatment in hospital provided that they understand the repercussions of those decisions, and I think that should extend to people in the community for a potential illness.

Dr Jason Fletcher, Staff Intensivist, Advance Care Planning Clinical Lead, Bendigo Health, public hearing 12 August 2015.

⁶⁵¹ Although New South Wales does not have statutory provisions enforcing advance care plans, the Supreme Court of New South Wales has found that common law advance care plans are legally binding; *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88.

⁶⁵² Department of Health, ‘Advance Care Planning: Frequently Asked Questions’, viewed 30 March 2016, <www.dpp.grampiansml.com.au>.

Enabling people to identify their end of life choices in regards to binding directives, advisory statements and substitute decision makers in one form is the Committee's preferred model. This would improve consistency in end of life planning and completion rates. It would also facilitate better access to records.

The Committee believes that guidance from the Department of Health and Human Services in relation to what an ideal form would look like would be welcomed by many practitioners and health services, and recommends that one be developed by the Department. This does not preclude health services customising forms to suit their culture. Forms should not be prescribed in legislation.

Establishing a standard advance care planning form would provide certainty for doctors and patients when completing and making decisions based on an advance care plan. This also reflects the experience of other jurisdictions such as Queensland, where the State is moving from a less-prescriptive model to a single form.

The Committee also highlights the need for doctors to communicate well with patients about the implications of completing advance care plans, particularly binding provisions. Advance care planning is a process that requires full and careful consideration of an individual's medical treatment wishes.

RECOMMENDATION 46: That the Department of Health and Human Services, working with experts and stakeholders, develop and distribute an advance care directive form to allow patients to record their values and preferences as detailed in Recommendation 48.

Figure 5.1 South Australian advance care directive form — Values statement

The image shows a screenshot of the 'Advance Care Directive Form' with a blue header. The form is divided into two main sections. The left section, titled 'Part 3', contains instructions and a list of bullet points: 'What is important to you', 'Outcomes that you would want to avoid', 'Health care you prefer', 'Where you wish to live', 'Other personal arrangements', and 'Dying wishes'. It also includes a note about where to find more information and a warning to draw a diagonal line across the section if not filled. The right section, titled 'Part 3: What is Important to me – my values and wishes:', contains the text 'When decisions are being made for me, I want people to consider the following:' followed by a large, empty rectangular box for the user to write their values and wishes.

Source: South Australian Government, 'Advance care directive form', accessed 30 March 2016, <www.advancecaredirectives.sa.gov.au>.

Figure 5.2 South Australian advance care directive form — Binding refusal of health care

Advance Care Directive Form

For more information about writing down your refusal(s) of health care and some suggested statements see page 8 of the Guide.

If you did not fill in this Part please draw a line diagonally across this Part.

I make the following binding refusal/s of particular health care:
(If you are indicating health care you do not want, you must state when and in what circumstances it will apply as your refusal(s) must be followed, pursuant to section 19 of the Act, if relevant and applicable).

Source: South Australian Government, 'Advance care directive form', accessed 30 March 2016, <www.advancecaredirectives.sa.gov.au>.

5.4.2 Current/future conditions

The *Medical Treatment Act 1988* currently provides for refusal of treatment certificates in relation to current conditions only.⁶⁵³

Maintaining the restriction in refusal of treatment certificates to current conditions was supported by several submissions and witnesses.

The Catholic Archdiocese of Melbourne stated:

The progress of illness is often unpredictable and it is unlikely that the patient will have enough information on a future health condition to give fully informed consent in advance.⁶⁵⁴

Similarly, the Australian Family Association observed 'to refuse treatment for a future condition when the future is unpredictable and the surrounding circumstances unknown is unwise.'⁶⁵⁵

In evidence to the Committee, Dr Katrina Haller of Right to Life Australia stated:

⁶⁵³ *Medical Treatment Act 1988*, 41 of 1988, section 5(1).

⁶⁵⁴ Catholic Archdiocese of Melbourne, *Submission*, p. 10.

⁶⁵⁵ Australian Family Association, *Submission*, p. 7.

You do not know what is going to happen in the future. It is better to have a document that you can consider and make a decision about in calmness and time and space to make a properly considered decision.⁶⁵⁶

However, a range of submissions and witnesses at hearings told the Committee that advance care plans should allow for people to specify treatment in relation to future conditions.

Cancer Council Victoria,⁶⁵⁷ the Office of the Public Advocate⁶⁵⁸ and the Law Institute of Victoria⁶⁵⁹ supported recommendations by the Victorian Law Reform Commission in its *Guardianship Report* (2012).⁶⁶⁰ They advised that the refusal of treatment scheme should be replaced with statutory advance care directives that can be made in respect of future and current conditions.

Broadening the scope of health care planning to provide for future conditions was also supported by other stakeholders in evidence presented to the Inquiry.⁶⁶¹

It was also noted by the Law Institute of Victoria that ‘Victoria is the only state that is saddled with the current condition rider in its *Medical Treatment Act*.’⁶⁶²

As discussed in Chapter 4, the Victorian Government has committed to statutory recognition of advance care plans as stated in its submission and end of life discussion paper.

The Committee believes that enabling Victorians to specify medical treatment in relation to future conditions reflects our community values of autonomy and the right to self-determination.

5.4.3 Substitute decision makers

Confusing and complex legislation

As discussed in Chapter 4, whether a substitute decision maker may consent, not consent or refuse medical treatment on a patient’s behalf depends on whether they have been appointed as:

- an agent or guardian with power to refuse treatment on the patient’s behalf under the *Medical Treatment Act 1988* (enduring power of attorney [medical treatment])

⁶⁵⁶ Dr Katrina Haller, Chief Executive Officer, Right to Life Australia, *Transcript of evidence*, 18 November 2015, p. 59.

⁶⁵⁷ Cancer Council Victoria, *Submission*, p. 13.

⁶⁵⁸ Office of the Public Advocate, *Submission*, p. 12.

⁶⁵⁹ Law Institute of Victoria, *Submission*, p. 2.

⁶⁶⁰ Victorian Law Reform Commission, *Guardianship report (Report no. 24)*, Victorian Law Reform Commission, Melbourne, 2012.

⁶⁶¹ Kathleen Puls, *Submission*, p. 5; Dying For Choice, *Submission*, p. 6; Barwon Health, *Submission*, p. 6; Bradley Lawyers, *Submission*, p. 11; Associate Professor William Silvester, President, International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, p. 66.

⁶⁶² Bill O’Shea, Member, Health law and elder law committees, Law Institute of Victoria, *Transcript of evidence*, 18 November 2015, p. 2.

- a guardian or person responsible under the *Guardianship and Administration Act 1986*
- an attorney for personal matters with enduring power of attorney under the *Powers of Attorney Act 2014*.

Professors Lindy Willmott, Ben White and Julian Savulescu noted that the difference between these provisions is a fine one unlikely to be understood and complied with by many Victorian health practitioners.⁶⁶³

Many submissions and witnesses called for simplification of substitute decision making legislation, including the Law Institute of Victoria,⁶⁶⁴ the Office of the Public Advocate,⁶⁶⁵ Cancer Council Victoria,⁶⁶⁶ the Commissioner for Senior Victorians,⁶⁶⁷ Professors Lindy Willmott, Ben White and Julian Savulescu,⁶⁶⁸ and Alzheimer's Australia,⁶⁶⁹ amongst others.⁶⁷⁰

The Committee believes that clarifying substitute decision making for health is essential to support a robust end of life legislative framework.

The Law Institute of Victoria's submission highlighted confusion about the difference between the ability of persons responsible to withhold consent to medical treatment under the *Guardianship and Administration Act 1986* and to refuse medical treatment under the *Medical Treatment Act 1988*.⁶⁷¹

It further noted that:

... the distinctions between refusing treatment and withholding consent and the relationship between the GAA [*Guardianship and Administration Act 1986*] and the MTA [*Medical Treatment Act 1988*] are unreasonable and confusing for both the general community and health professionals.⁶⁷²

The Health Issues Centre noted substitute decision makers need considerable support to identify and advocate for a person's wishes within the existing complex legal framework.⁶⁷³

⁶⁶³ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 3.

⁶⁶⁴ Law Institute of Victoria, *Submission*, p. 12.

⁶⁶⁵ Office of the Public Advocate, *Submission*, p. 11.

⁶⁶⁶ Cancer Council Victoria, *Submission*, p. 12.

⁶⁶⁷ Commissioner for Senior Victorians, *Submission*, p. 2.

⁶⁶⁸ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 177.

⁶⁶⁹ Dr David Sykes, General Manager Learning and Development, Victoria, Alzheimer's Australia, *Transcript of evidence*, 14 October 2015, p. 3.

⁶⁷⁰ Law Institute of Victoria, *Submission*, p. 12; Office of the Public Advocate, *Submission*, p. 11; Kathleen Puls, *Submission*, p. 4; Avant Mutual Group, *Submission*, p. 2; Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 177; Commissioner for Senior Victorians, *Submission*, p. 2; Cancer Council Victoria, *Submission*, p. 12; Palliative Care Victoria, *Submission*, p. 18; Dr David Sykes, General Manager Learning and Development, Victoria, Alzheimer's Australia, *Transcript of evidence*, 14 October 2015, p. 3.

⁶⁷¹ Law Institute of Victoria, *Submission*, p. 12.

⁶⁷² *Ibid.*, p. 8.

⁶⁷³ Health Issues Centre, *Submission*.

Options for simplifying legislation

Several submissions made specific recommendations on how to simplify the law on substitute decision making in Victoria.

Professors Lindy Willmott, Ben White and Julian Savulescu suggested that all substitute decision makers should be granted power to refuse treatment. They also considered all substitute decision making should be covered by a single statute by incorporating and adapting the relevant aspects of the *Medical Treatment Act 1988* into the *Guardianship and Administration Act 1986*.⁶⁷⁴

Similarly, the Law Institute of Victoria and the Office of the Public Advocate submitted the following suggestions outlined in Table 5.1 to streamline substitute decision making legislation.

Table 5.1 Recommended changes to substitute decision making legislation from the Law Institute of Victoria and the Office of the Public Advocate

Act	Recommended change
<i>Powers of Attorney Act 2014</i>	Both the Law Institute of Victoria and the Office of the Public Advocate recommended extending the enduring power of attorney for personal matters to include decisions to refuse medical treatment
<i>Guardianship and Administration Act 1986</i>	Both the Law Institute of Victoria and the Office of the Public Advocate recommended that: <ul style="list-style-type: none"> an enduring personal guardian should be empowered to refuse medical treatment provision should be made for the automatic (statutory) appointment of a substitute decision maker.
<i>Medical Treatment Act 1988</i>	<p>Law Institute of Victoria: remove the power of attorney (medical treatment) as per Recommendation 201 of the <i>Guardianship Report</i>.^(a)</p> <p>Office of the Public Advocate: only enduring power of attorneys and guardians appointed by VCAT with health decision making powers should have power to refuse medical treatment where death is a likely result (i.e. not enduring personal guardians).^(b)</p>

(a) Victorian Law Reform Commission, *Guardianship report* (Report no. 24), Victorian Law Reform Commission, Melbourne, 2012, p. 291.

(b) Office of the Public Advocate, Submission, p. 6.

Source: Compiled by the Standing Committee on Legal and Social Issues.

Another cause of confusion for health practitioners is the different definitions of medical treatment in existing legislation.

Medical treatment in the *Mental Health Act 2014* includes pharmaceutical drugs and palliative care. The *Guardianship and Administration Act 1986* excludes pharmaceutical drugs and includes palliative care, whereas the *Medical Treatment Act 1988* includes pharmaceutical drugs and excludes palliative care, as shown in the Table 5.2 below.

The Committee notes that these inconsistencies complicate the substitute decision making process and the delivery of health care. The Committee believes that the Victorian Government should address these inconsistencies through advance care planning legislative reform.

⁶⁷⁴ Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 4.

Table 5.2 Comparison of the definitions of ‘medical treatment’ in Victorian legislation

<i>Guardianship and Administration Act 1986</i>	<i>Mental Health Act 2014</i>	<i>Medical Treatment Act 1988</i>
<p><i>medical or dental treatment</i> means—</p> <ul style="list-style-type: none"> (a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by, or under, the supervision of a registered practitioner; or (b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a registered practitioner; or (c) any other treatment not referred to in paragraphs (a) and (b) that is prescribed by the regulations to be medical or dental treatment for the purposes of this Act— <p>but does not include—</p> <ul style="list-style-type: none"> (d) a special procedure; or (da) a medical research procedure; or (e) any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears); or (f) first-aid treatment; or (g) the administration of a pharmaceutical drug for the purpose and in accordance with the dosage level— <ul style="list-style-type: none"> (i) if the drug is one for which a prescription is required, recommended by a registered practitioner; or (ii) if the drug is one for which a prescription is not required and which is normally self-administered, recommended in the manufacturer's instructions or by a registered practitioner; or (h) any other kind of treatment that is prescribed by the regulations not to be medical or dental treatment for the purposes of this Act; 	<p>In this Act, <i>medical treatment</i> means—</p> <ul style="list-style-type: none"> (a) medical treatment (including any medical or surgical procedure, operation or examination and any prophylactic, palliative or rehabilitative care) normally carried out by, or under, the supervision of a registered medical practitioner; or (b) dental treatment (including any dental procedure, operation or examination) normally carried out by or under the supervision of a registered dental practitioner; or (c) the administration of a pharmaceutical drug for which a prescription is required; or (d) any other treatment that is not referred to in paragraph (a), (b) or (c) and is prescribed by the regulations to be medical treatment for the purposes of this Act— <p>but does not include—</p> <ul style="list-style-type: none"> (e) a special procedure or medical research procedure within the meaning of the Guardianship and Administration Act 1986; or 	<p><i>medical treatment</i> means the carrying out of—</p> <ul style="list-style-type: none"> (a) an operation; or (b) the administration of a drug or other like substance; or (c) any other medical procedure— <p>but does not include palliative care;</p> <p><i>palliative care</i> includes—</p> <ul style="list-style-type: none"> (a) the provision of reasonable medical procedures for the relief of pain, suffering and discomfort; or (b) the reasonable provision of food and water;

Note

Part 4A of the **Guardianship and Administration Act 1986** applies to the carrying out of a special procedure or medical research procedure on persons who are incapable of giving consent to that procedure.

- (f) any non-intrusive examination made for diagnostic purposes (including a visual examination of the mouth, throat, nasal cavity, eyes or ears); or
- (g) first-aid treatment; or
- (h) any treatment for mental illness or the effects of mental illness.

Source: Compiled by the Standing Committee on Legal and Social Issues.

RECOMMENDATION 47: That the Victorian Government, as part of legislating to reform advance care planning, standardise the definition of medical treatment across Victorian statutes.

5.5 Recommended legislative reform

5.5.1 Substantive legislative reform

Substantive legislative reform is necessary to update and simplify the advance care planning legal framework to reduce the risk that a patient's wishes are not upheld and to clarify the legal obligations and protections for health practitioners in Victoria.

This can be done by amending the *Medical Treatment Act 1988*, the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*. In light of the confusion about substitute decision making in the existing legislation, however, the Committee believes that further amendments will only serve to exacerbate existing complications.

As such, the Committee recommends the introduction of new legislation that encompasses each of these elements of advance care planning, including substitute decision making. This will require repealing the *Medical Treatment Act 1988* and repealing the health substitute decision making provisions from the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*.

RECOMMENDATION 48:

Repeal relevant legislation

That the Victorian Government repeal the *Medical Treatment Act 1988* and repeal health substitute decision making provisions in the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*.

New legislation — the Future Health Bill 2016

That the Victorian Government introduce legislation providing for:

- instructional health directives, which will replace the refusal of treatment certificate. This should specify:
 - refusal of or consent to a particular medical treatment will be taken to be a binding provision, which can apply in limited circumstances
 - all other provisions of an instructional health directive, such as value statements, are non-binding provisions
- the ability to refuse or consent to treatment in relation to future conditions
- protection for ambulance officers when they act in good faith in reliance on an instructional health directive
- substitute decision makers, with the equivalent of an enduring power of attorney (medical treatment), to be able to refuse medical treatment.

5.5.2 Supplementary legislative reform

The Committee believes that the Victorian Government should consider appropriate supplementary measures to give effect to the substantive reforms recommended above. The Victorian Law Reform Commission's *Guardianship Report* (2012) details further matters which the Government should consider, including:

- preserving the common law
- recognising existing refusal of treatment certificates
- retaining enduring powers of attorney
- reviewing the offence of medical trespass
- exceptions for emergency treatment
- protection for health practitioners for non-compliance in certain circumstances
- conscientious objection
- psychiatric treatment
- witnessing requirements.

Further information on these measures can be found in Appendix 8.

6

The existing legal framework governing end of life in Victoria

This Chapter examines the existing legal framework in Victoria in areas of the law that relate to the Committee's terms of reference. It focuses on current approaches to the application of the law and areas where the law is problematic.

The Committee has cited a number of cases, below, based on information provided by the Coroner's Prevention Unit and an examination of case law in Victoria. These cases illustrate, as does the statistical evidence from the Coroner, that too many Victorians who experience an irreversible deterioration in their physical health, many of whom are elderly and frail, take drastic and brutal measures to end their lives. Chapter 7 looks further at these cases.

In addition, the Committee highlights comments made by Coroner Jacqui Hawkins in her investigation into the death of Valerie Seeger, a 75-year-old woman who was assisted to die by her friend Dr Claire Parsons, who then took her own life:

It is not the role of a Coroner to comment on the ethical and social issues surrounding end-of-life decisions such as those made by Dr Parsons and Ms Seeger. I understand the Victorian Parliamentary Standing Committee on Legal and Social Issues is currently conducting an Inquiry into end-of-life choices and that their Report is due to be completed on 31 May 2016. My hope is that some of the social and ethical issues raised by the deaths of Dr Parsons and Ms Seeger may be addressed in the Report. For this reason, I forward a copy of my finding to the Standing Committee for their information.⁶⁷⁵

Chapter 7 of this Report looks in more detail at the social and ethical issues raised by the operation of end of life law in Victoria.

6.1 Suicide

6.1.1 The legal history of suicide

Victorian law on suicide has been profoundly shaped by the English history from which it originated.

In 13th century England, suicide was a felony at common law, punishable by forfeiture of property to the King. Attempted suicide was a misdemeanour.⁶⁷⁶ The Court at Common Bench observed in the 16th century that '[suicide] is an

⁶⁷⁵ Coroner Jacqui Hawkins, *Investigation into the death of Valerie Seeger*, Coroner's Court of Victoria, Melbourne, 9 February 2016.

⁶⁷⁶ Jerry Menikoff, *Law and bioethics: An introduction*, Georgetown University Press, Washington DC, United States, 2001, p. 330.

Offence against Nature, against God, and against the King...[T]o destroy one's self is contrary to Nature, and a Thing most horrible.'⁶⁷⁷ Until 1823, English law held that the property of a person who suicided would be forfeited and his body placed at the cross-roads of two highways with a stake driven through it.⁶⁷⁸

The criminalisation of suicide reflects the principle of sanctity of life which resonates throughout English and Australian case law. This doctrine historically 'holds that human life is created in the image of God and is therefore possessed of an intrinsic dignity which entitles it to protection from unjust attack.'⁶⁷⁹

Suicide was decriminalised in Victoria in 1967 by an amendment to the *Crimes Act 1958*, which states that it is no longer a crime for a person to commit or to attempt to commit suicide.

Crimes Act 1958

6A Suicide is no longer a crime

The rule of law whereby it is a crime for a person to commit or to attempt to commit suicide is hereby abrogated.

In his second reading speech, the Hon. Rupert Hamer MLA observed that the law prohibiting suicide 'is open to strong attack on the ground that it is based on factors which do not now apply in a modern society.'⁶⁸⁰

Inciting suicide⁶⁸¹ and aiding and abetting suicide⁶⁸² remain illegal in Victoria.⁶⁸³

Despite decriminalisation, there is no legal right to commit suicide. Section 463B of the *Crimes Act 1958* permits anyone to use such force as may reasonably be necessary to prevent a person from suiciding.

Crimes Act 1958

463B Prevention of suicide

Every person is justified in using such force as may reasonably be necessary to prevent the commission of suicide or of any act which he believes on reasonable grounds would, if committed, amount to suicide.

⁶⁷⁷ *Hales v Petit*, 1 Plowd. Com. 253, 261, 75 1561-1562. quoted in Lois Snyder and Arthur L Caplan, *Assisted suicide: Finding common ground*, Indiana University Press, Bloomington, 2002, p. 160.

⁶⁷⁸ *Rodriguez v British Columbia (Attorney General)*, 3 SCR, 1993, pp. 596-597.

⁶⁷⁹ *Re A (Children)(Conjoined Twins: Surgical Separation)*, 4 All ER [2000]. [999] per Ward LJ, quoted in Julia JA Shaw, 'Fifty years on: Against the stigmatising myths, taboos and traditions embedded within the Suicide Act 1961 (UK)', *Journal of Law and Medicine*, vol. 18, no. 4, 2011, p. 801.

⁶⁸⁰ Victoria, Legislative Council 1967, *Debates*, vol. 286, p. 3135.

⁶⁸¹ *Crimes Act 1958*, 6231 of 1958. section 6B.

⁶⁸² *Ibid.*, section 6B(2)(b).

⁶⁸³ See sections 6.2.2 and 6.2.3 for more.

6.1.2 Coroner must investigate suicide

Under section 15 of the *Coroners Act 2008*, a coroner must investigate the death of a person if it appears that the death is a ‘reportable death’. Suicide is a reportable death under section 4(2)(a), which states a death is reportable if it appears to have been unexpected, unnatural or violent, or to have resulted, directly or indirectly, from an accident or injury.

Coroners Act 2008

4 Reportable death

- (1) In this Act, a death of a person is a “reportable death” if—
 - (a) the body is in Victoria; or
 - (b) the death occurred in Victoria; or
 - (c) the cause of the death occurred in Victoria; or
 - (d) the person ordinarily resided in Victoria at the time of death—
 and the death was a death specified in subsection (2).
- (2) For the purposes of subsection (1), the deaths are—
 - (a) a death that appears to have been unexpected, unnatural or violent or to have resulted, directly or indirectly, from an accident or injury; or
 - (b) a death that occurs—
 - (i) during a medical procedure; or
 - (ii) following a medical procedure where the death is or may be causally related to the medical procedure —

The Coroners Court of Victoria’s submission to this Inquiry outlines research by the Coroners Prevention Unit of suicide cases where the deceased took his or her life after experiencing an irreversible deterioration in physical health. The evidence presented to the Committee by Coroners John Olle and Caitlin English at a public hearing on 7 October 2015 built on the information in the written submission. The Committee received a further submission from the Coroners Court of Victoria on 20 May 2016.

Of 2879 suicide deaths between January 2009 and December 2013, the Coroners Prevention Unit found 240 in which there was evidence that the deceased had experienced an irreversible deterioration in physical health due to disease or injury.⁶⁸⁴ Among these suicides, most of the deceased were suffering from multiple diseases. These included:

- cancer, in approximately 50 per cent of cases
- diabetes, in approximately 10 per cent of cases
- arthritis, in approximately 10 per cent of cases
- cardiovascular diseases, in approximately 8 per cent of cases
- Parkinson’s disease, in approximately 5 per cent of cases
- Huntington’s disease, in approximately 4 per cent of cases.⁶⁸⁵

⁶⁸⁴ Coroner’s Court of Victoria, *Further submission*, p. 4.

⁶⁸⁵ *Ibid.*, p. 3.

Table 6.1 below from the Coroners Court of Victoria's further submission to the Committee details the frequency of suicide methods used by those who were suffering irreversible physical deterioration due to disease and injury.⁶⁸⁶

Table 6.1 Frequency and proportion of suicide methods among suicides of people experiencing irreversible physical deterioration caused by disease and injury, Victoria 2009–13

Suicide method	Disease	Injury	Combined
Poisoning	54	20	74
Hanging	45	19	64
Firearm	29	5	34
Threat to breathing	18	1	19
Motor vehicle exhaust	7	6	13
Rail	7	1	8
Jump from height	7	0	7
Sharp object	4	1	5
Other methods	15	1	16
All	186	54	240

Source: Coroners Court of Victoria, *Further submission*, p. 6.

While overall suicide frequency peaks in middle age,⁶⁸⁷ the highest frequency for people who experienced irreversible deterioration in physical health due to disease was among those aged 65 years and over.⁶⁸⁸

The Coroners Prevention Unit observed that this finding probably reflects that with advancing age there is less ability to recover from the effects of disease. It also stated that over time the symptoms of degenerative disease have a cumulative impact on quality of life.⁶⁸⁹

In response to a question about whether palliative care or other support services could prevent such suicides, Coroner John Olle said:

... the people we are talking about in this small cohort have made an absolute clear decision. They are determined. The only assistance that could be offered is to meet their wishes, not to prolong their life.⁶⁹⁰

⁶⁸⁶ Ibid., p. 6.

⁶⁸⁷ The Australian Bureau of Statistics reports that: 'The median age at death for intentional self-harm in 2014 was 44.4 years for males, 43.6 years for females and 44.2 years overall. In comparison, the median age for deaths from all causes in 2014 was 78.5 years for males, 84.8 years for females and 81.8 years overall.' Australian Bureau of Statistics Catalogue Number 3303.0 Intentional Self-Harm by Age.

⁶⁸⁸ Coroners Court of Victoria, *Submission*, p. 4.

⁶⁸⁹ Ibid.

⁶⁹⁰ Coroner John Olle, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, p. 9.

The following case is an account of a suicide investigated by the Coroners Court of Victoria. It demonstrates the desperate circumstances in which a person experiencing an irreversible deterioration in health may take their own life.

Case 6.1

An elderly man ended his life by intentionally ingesting a fatal dose of medication that he had stockpiled from a previous prescription. At the time of his death, the man was suffering with depression and a variety of physical ailments. His mobility and eyesight were failing and he expressed resentment over his inability to pursue his hobbies. The man openly discussed his views towards assisted dying and believed that a person should have the right to end their own life, instead of suffering through debilitating physical decline. The man discussed his stance on suicide with his doctor, but did not indicate a specific plan to end his life or ask for support in carrying it out.⁶⁹¹

6.2 Killing or assisting another to die

6

Although suicide was decriminalised in 1967, inciting suicide and aiding and abetting suicide remain illegal in Victoria.

Family and friends have been prosecuted for assisting a loved one to die with offences ranging from aiding and abetting suicide to attempted murder.

A consistent theme in case law is the remarkable degree of leniency shown to offenders, even though there is a clear violation of the criminal law.⁶⁹² This pattern of leniency resonates with experiences in other Australian jurisdictions⁶⁹³ and in international jurisdictions.⁶⁹⁴

In Victoria, leniency is demonstrated in the exercise of prosecutorial discretion in accepting guilty pleas to lesser charges and judicial discretion in the imposition of non-custodial sentences.⁶⁹⁵ According to the Committee's review of end of life care law in Victoria, nobody prosecuted for assisted dying has received a custodial sentence.⁶⁹⁶

While the outcome achieved may appear just on a case-by-case basis, the reliance on individual discretion to achieve just outcomes rather than the systematic implementation of the law threatens to undermine public confidence in the administration of justice and bring the law into disrepute.

⁶⁹¹ Coroners Court of Victoria, *Submission*, p. 6.

⁶⁹² Professor Margaret Otlowski, *Voluntary euthanasia and the common law*, Oxford University Press, Oxford, 1997, p. 10.

⁶⁹³ Jocelyn Downie, 'Permitting voluntary euthanasia and assisted suicide: Law reform pathways for common law jurisdictions', *Queensland University of Technology Law Review*, vol. 16, no. 1, 2016, pp. 100–103.

⁶⁹⁴ *Ibid.*, pp. 104–105.

⁶⁹⁵ Professor Margaret Otlowski, *Voluntary euthanasia and the common law*, Oxford University Press, Oxford, 1997, p. 10.

⁶⁹⁶ According to a review of the case law in LexisNexis.

It also suggests that the law as it stands does not align with the community's views of reprehensibility. This analysis is reflected in the judgment of Justice Cummins in *DPP v Rolfe*:

Your actions do not warrant denunciation; you should not be punished; there is no need to deter you from future offences; and you do not require reformation.⁶⁹⁷

Where a finding of guilt does not require performance of these fundamental functions of the criminal law, it must be asked what purpose the law serves.

Further, if such actions are not reprehensible, it is important to determine whether it is reasonable and just that people who assist a loved one to die bear the stigma and opprobrium of prosecution and criminal conviction.

Table 6.2 below is an overview of the reported Victorian cases in which a person has been prosecuted for assisting a loved one to die.

Table 6.2 Victorian cases relating to assisted dying

Case	Year	Charge	Maximum penalty	Sentence
<i>Hollinrake</i>	1992	Attempted murder	25 years' imprisonment	3-year good behaviour bond
<i>DPP v Riordan</i>	1998	Attempted murder	25 years' imprisonment	3-year good behaviour bond
<i>R v Marden</i>	2000	Manslaughter by suicide pact	10 years' imprisonment	2-year suspended sentence
<i>R v Hood</i>	2002	Aiding and abetting suicide	5 years' imprisonment	18-month suspended sentence
<i>R v Maxwell</i>	2003	Aiding and abetting suicide	5 years' imprisonment	18-month suspended sentence
<i>DPP v Karaca</i>	2007	Attempted murder	25 years' imprisonment	3-year suspended sentence
<i>DPP v Rolfe</i>	2008	Manslaughter by suicide pact	10 years' imprisonment	2-year suspended sentence
<i>DPP v Nestorowycz</i>	2008	Attempted murder	25 years' imprisonment	2 years and 9 months suspended sentence
Victor Rijn (unreported)	2011	Inciting suicide	5 years' imprisonment	3-year good behaviour bond
<i>R v Klinkerman</i>	2013	Attempted murder	25 years' imprisonment	18-month community corrections order

Source: Compiled by the Standing Committee on Legal and Social Issues.

⁶⁹⁷ [2008] VSC 528 [25].

Although the particular circumstances of a case may meet the legal requirements of a charge of murder, those accused of helping another to die are invariably charged with lesser offences.⁶⁹⁸ This is due to prosecutorial discretion and the key considerations that shape it:

- (1) is there a reasonable prospect of a conviction; and
- (2) is a prosecution required in the public interest?⁶⁹⁹

There are a range of factors relevant to whether a prosecution is in the public interest. Those that relate to assisting another to die include:

- the seriousness of the alleged offence
- any mitigating or aggravating circumstances
- the characteristics of the accused, the victim and any witnesses (such as age, physical or mental health, or disability)
- the degree of the accused's culpability in relation to the offence
- the level of cooperation of the accused
- the need to maintain confidence in Parliament, the courts and the law
- whether the consequences of any resulting conviction would be unduly harsh and oppressive
- whether the offence is of considerable public concern
- the likely length and expense of a trial.⁷⁰⁰

The practice of prosecuting on lesser grounds than murder for assisting suicide was reflected in the evidence of Victoria Police Acting Commander Rod Wilson in his appearance before the Committee. In describing the case of a nurse who assisted her partner to die, the Acting Commander stated that:

... the OPP [Office of Public Prosecutions] only presented her on aid and abet, not the murder charge — they dropped the murder charge and presented on the aid and abet and she received a bond. So we went through a lot of process at the end of the day for not a lot of outcome in terms of the effort and investigation that went into it.⁷⁰¹

Rather than using discretion to administer lenient punishment to people who assist suicide, former Director of Public Prosecutions and Supreme Court Justice John Coldrey has said that these laws need to be changed:

These cases don't sit comfortably in a court setting. The person goes out into society labelled a murderer when their motive has been compassion and love.⁷⁰²

⁶⁹⁸ Professor Margaret Otlowski, 'Mercy killing cases in the Australian criminal justice system', *Criminal Law Journal*, vol. 17, no. 1, 1993, p. 10.

⁶⁹⁹ Director of Public Prosecutions Victoria, *Director's policy: Prosecutorial discretion*, Office of the Director of Public Prosecutions Victoria, Melbourne, 2014, p. 2.

⁷⁰⁰ Ibid.

⁷⁰¹ Acting Commander Rod Wilson, Crime Command, Victoria Police, *Transcript of evidence*, 7 October 2015, p. 16.

⁷⁰² Justice John Coldrey in Karl Quinn, 'Andrew Denton is back with Better Off Dead, a podcast about the right to die', *Age*, 8 February 2016, viewed 4 April 2016, <www.smh.com.au>.

I'd like to see a regime where people who act in this way are not put at risk of criminal charges.⁷⁰³

Analysis of the case law on family and friends performing assisted dying illustrates a serious discrepancy between the law as it stands in theory and as it is applied in practice. While this may be necessary to achieve just outcomes on a case-by-case basis, it threatens to bring the law into disrepute.

The way in which the law is applied in cases such as those described in this Chapter has serious consequences for the rule of law and public confidence in the administration of justice.

As Professor Margaret Otlowksi observes 'where the administration of the law depends to such a large extent on intangible considerations of sympathy, there is no guaranteed consistency of application.'⁷⁰⁴

Predictability and consistency are central to the rule of law as they ensure the law is applied equally to all persons in like circumstances and help people to assess the lawfulness of their behaviour.⁷⁰⁵

The state of the rule of law is compromised where there is a considerable gap between the law in theory and its application in practice and where justice hinges upon the 'intangible considerations of sympathy' described by Professor Otlowksi above.

Analysis of the case law on family and friends who assisted a loved one to die also raises the question as to whether the law reflects the contemporary values of the Victorian community.

The Committee is concerned that if our law enforcement agencies, those investigating deaths and those presiding over cases, do not believe that a just outcome would be achieved by enforcing the law, then it is time to question the law.

⁷⁰³ Justine John Coldrey in Andrew Denton, 'It can never be perfect, so why try and improve it?', *Better off Dead*, 17 February 2016.

⁷⁰⁴ Professor Margaret Otlowksi, 'Getting the law right on physician-assisted death', *Amsterdam Law Forum*, vol. 3, no. 1, 2011, p. 128.

⁷⁰⁵ David Hume, 'The rule of law in reading down: Good law for the 'bad man'', *Melbourne University Law Review*, vol. 37, no. 3, 2014, p. 621.

6.2.1 Manslaughter by suicide pact

A survivor of a suicide pact who kills another party to the pact is liable for manslaughter and faces up to 10 years' imprisonment under section 6B of the *Crimes Act 1958*.

Crimes Act 1958

6B Survivor of suicide pact who kills deceased party is guilty of manslaughter

- (1) Where upon the trial of a person for the murder of another person the jury are satisfied that the accused caused or was a party to causing the death of that other person by a wilful act or omission but are satisfied on the balance of probabilities that the act was done or the omission made in pursuance of a suicide pact then the jury shall, notwithstanding that the circumstances were such that but for the provisions of this section they might have returned a verdict of murder, return a verdict of manslaughter in lieu thereof.
- (1A) Despite section 5, a person convicted of manslaughter under subsection (1) is only liable to level 5 imprisonment (10 years maximum).
- ...
- (4) For the purposes of this section "suicide pact" means an agreement between two or more persons having for its object the death of all of them whether or not each is to take his own life; but nothing done by a person who enters into a suicide pact shall be treated as done by him in pursuance of the pact unless it is done while he has the settled intention of dying in pursuance of the pact.

Case 6.2

Janetta Rolfe was diagnosed with vascular dementia in 2006. She needed assistance to walk and could no longer communicate. Her husband Bernard Rolfe suffered extreme anxiety and depression. He was particularly concerned that Janetta would need to go into respite care and that they would be separated. Bernard Rolfe promised his wife of 55 years that she would not end up in a home.

Police found Mr and Mrs Rolfe at home in bed, with a propane gas bottle on the floor connected to a hose leading under the blankets. Janetta Rolfe had died and Bernard Rolfe was unconscious. He was resuscitated by paramedics.

Bernard Rolfe pleaded guilty to manslaughter by suicide pact and received a two-year suspended sentence. In sentencing, the judge stated, 'Your actions do not warrant denunciation; you should not be punished; there is no need to deter you from future offences; and you do not require reformation.'⁷⁰⁶

⁷⁰⁶ *DPP v Rolfe*, VSC, [2008].

Case 6.3

Joan Bernice Marden suffered rheumatoid arthritis and experienced constant pain and discomfort despite pain relief medication. She was unable to dress herself and had difficulty walking. Her husband of 48 years, Robert Marden, also had poor health. He developed angina and, after undergoing cardiac surgery, had a pacemaker implanted. Robert Marden was later diagnosed with lung cancer and depression.

Joan Marden was in constant pain and expressed a wish to die on several occasions. Robert Marden also felt he was at the end of his life. The two decided to die together. Robert Marden attempted to electrocute Joan, but the shock was not enough to end her life so he smothered her. He then took assorted pills to end his life and although they ordinarily would have been enough to kill him, his pacemaker kept him alive.

The judge accepted a statement from their son that 'he did what he did to my mother out of the uncompromising love and devotion he had for her.'

Robert Marden received a two-year suspended sentence.⁷⁰⁷

6.2.2 Inciting suicide

A person who incites another person to commit suicide is liable for up to 5 years' imprisonment.

Crimes Act 1958

6B

...

- (2) (a) Any person who incites any other person to commit suicide and that other person commits or attempts to commit suicide in consequence thereof shall be guilty of an indictable offence and liable to level 6 imprisonment (5 years maximum); but if the jury are satisfied on the balance of probabilities that the acts constituting the offence were done pursuant to a suicide pact the jury shall return a verdict of guilty of the indictable offence of being a party to a suicide pact and the convicted person shall be liable to level 6 imprisonment (5 years maximum).

White et al. suggest that it is rare that such a provision would be relevant in the assisted suicide context.⁷⁰⁸ This is supported by the case law, which indicates that people who assist a loved one to die do so as a last resort and, most often, reluctantly.

6.2.3 Aiding and abetting suicide

A person who aids or abets another in committing or attempting to commit suicide faces up to 5 years' imprisonment.

⁷⁰⁷ *R v Marden*, VSC, [2008].

⁷⁰⁸ Ben P White, et al., *Health law in Australia*, Thomson Reuters, Sydney, 2014.

Crimes Act 1958**6B**

...

- (2)(b) Any person who aids or abets any other person in the commission of suicide or in an attempt to commit suicide shall be guilty of an indictable offence and liable to level 6 imprisonment (5 years maximum); but if the jury are satisfied on the balance of probabilities that the acts constituting the offence were done pursuant to a suicide pact the jury shall return a verdict of guilty of the indictable offence of being a party to a suicide pact and the convicted person shall be liable to level 6 imprisonment (5 years maximum).

In describing the crime of aiding and abetting suicide to the Committee, Detective Inspector Mick Hughes of Victoria Police explained, ‘you almost need to be in the room with the person, encouraging, inciting or taking an active part in it.’⁷⁰⁹

The case law on aiding and abetting suicide is limited. In evidence to the Committee, Acting Commander Rod Wilson stated that only five cases of aiding and abetting suicide were reported between 2010 and 2014.⁷¹⁰ Of these, only one was prosecuted.⁷¹¹

6

Case 6.4

Margaret Maxwell was diagnosed with breast cancer in 1994. She researched the disease and pursued a regime of alternative medicines, hoping to not only cure herself but also provide guidance and inspiration for others.

These proved unsuccessful, however, and Margaret underwent a double mastectomy. In 2002, she was diagnosed with massive tumours and, told she had only months to live, decided to take her own life by ceasing to eat.

Margaret’s husband Alexander persuaded her to end her starvation, but she made him promise to assist her to end her life if her health did not improve because she was terrified of becoming comatose as a result of a failed suicide attempt.

Margaret’s health deteriorated, with frequent bouts of vomiting and coughing, breathlessness and insomnia. Unable to wash, dress or feed herself, she asked Alexander to help her die. He complied.

Alexander Maxwell was convicted of aiding and abetting suicide and received a wholly suspended sentence of 18 months imprisonment.⁷¹²

The judge observed ‘You emerge as a person forever prepared to support your wife in her initiatives and to provide whatever assistance she required. One family friend spoke of your absolute love for her.’⁷¹³

⁷⁰⁹ Detective Inspector Mick Hughes, Detective Inspector, Homicide Squad, Victoria Police, *Transcript of evidence*, 7 October 2015, p. 17.

⁷¹⁰ Acting Commander Rod Wilson, Crime Command, Victoria Police, *Transcript of evidence*, 7 October 2015, p. 15.

⁷¹¹ This case is unreported.

⁷¹² *R v Maxwell*, VSC, [2003].

⁷¹³ *Ibid.*, per Coldrey J [5].

6.2.4 Attempted murder

A person who attempts to commit murder faces a maximum penalty of 25 years' imprisonment.⁷¹⁴

Murder and attempted murder

Murder is a crime at common law. It has the following four elements, each of which the prosecution must prove beyond reasonable doubt:

- i. The accused committed acts which caused the victim's death;
- ii. The accused committed those acts voluntarily;
- iii. The accused committed those acts while:
 - a. the body is in Victoria; or
 - b. [if reckless murder has been left to the jury] *knowing that it was probable* that death or really serious injury would result.
- iv. The accused did not have a lawful justification or excuse for those acts (such as self-defence, provocation, duress or sudden or extraordinary emergency).⁷¹⁵

Crimes Act 1958

321M Attempt

A person who attempts to commit an indictable offence is guilty of the indictable offence of attempting to commit that offence.

White et al. observe that an assisted death is more likely to be prosecuted for attempted murder than aiding and abetting suicide where the deceased lacks capacity to form the intent to commit suicide, as in the case of Alzheimer's disease and dementia.⁷¹⁶

In *DPP v Riordan*, the defendant attempted to kill his wife, who suffered advanced Alzheimer's disease. He also attempted to kill himself.⁷¹⁷ In sentencing Mr Riordan to a three-year good behaviour bond, Justice Cummins stated:

Mr Riordan is a decent, compassionate and selfless man who was totally devoted to his wife. He spent his life working hard and caring for his family. He had strong and devoted family values ... He has no prior convictions. Ultimately, in circumstances to which I shall shortly come, he sought to take his wife's life to relieve her of the terrible suffering and indignity she had been undergoing for years and which he daily saw.⁷¹⁸

His Honour cited the analysis provided to the Court by psychologist Mr I Joblin:

In my experience this is one of the most tragic cases one could report ... the offence was not committed because of any violent, aggressive disposition of a malicious nature directed toward his wife. Indeed, on the contrary the offence was committed with compassion under conditions of a depressed and disconsolate psychological

⁷¹⁴ *Crimes Act 1958*, 6231 of 1958, section 321P(1A).

⁷¹⁵ Judicial College of Victoria, 'Criminal charge book', viewed 6 January 2016, <www.judicialcollege.vic.edu.au>, p. 7.2.1.1.

⁷¹⁶ Ben P White, et al., *Health law in Australia*, Thomson Reuters, Sydney, 2014.

⁷¹⁷ *Director of Public Prosecutions v Riordan*, Unreported, 28 November, 1998.

⁷¹⁸ Ibid. quoted in Megan-Jane Johnstone, *Alzheimer's disease, media representations and the politics of euthanasia*, Routledge, Oxon, United Kingdom, 2013.

state ... Through tears Mr Riordan indicated that his wife was his 'mate', his best friend but in particular his ears because he was deaf and thereby his strength ... Mr Riordan reported that some 13 years ago his wife began deteriorating from Alzheimer's disease ... Basically this man's wife deteriorated to the extent that she was living a vegetative existence ... he had planned to take his wife's life and then his own ... The offending, therefore must be placed in the context outlined above ... It was paradoxically representative of the strong love this man had for his wife and his distress over her demise into a vegetative state seen in advanced cases of Alzheimer's ...⁷¹⁹

6.3 Unlawful medical practice

Academic evidence supports the position put by witnesses to the Committee that doctors practice unlawful assisted dying despite its prohibition and despite prospective liability for serious crimes.

For example, a survey of doctors in South Australia in 1991 found that 19 per cent had taken active steps which had brought about the death of a patient.⁷²⁰

A 1993 survey of doctors in New South Wales and the Australian Capital Territory found that almost half of the respondents had been asked to 'hasten death'. Of this proportion, 28 per cent had 'taken steps to bring about death,' and 7 per cent had provided the means for suicide.⁷²¹

Kuhse et al. found in 1997 that assisted dying and ending of a patient's life without the patient's concurrent explicit request were happening in Australia. Of all deaths in Australia, the study showed that:

- 1.8 per cent were euthanasia (including physician-assisted suicide)
- 3.5 per cent were ending of a patient's life without the patient's concurrent explicit request
- 28.6 per cent involved withholding or withdrawing potentially life-prolonging treatment
- 30.9 per cent involved alleviation of pain with opioids in doses large enough that there was a probable life-shortening effect.⁷²²

Similarly, a 2001 study of the attitudes of surgeons to assisted death found that 36 per cent had administered drugs in doses larger than necessary to relieve symptoms with the intention of hastening death.⁷²³

⁷¹⁹ *Director of Public Prosecutions v Riordan*, Unreported, 28 November, 1998. quoted in Megan-Jane Johnstone, *Alzheimer's disease, media representations and the politics of euthanasia*, Routledge, Oxon, United Kingdom, 2013.

⁷²⁰ Christina A Stevens and Riaz Hassan, 'Management of death, dying and euthanasia: Attitudes and practices of medical practitioners in South Australia', *Journal of Medical Ethics*, vol. 20, no. 1, 1994, p. 41.

⁷²¹ Peter Baume and Emma O'Malley, 'Euthanasia: Attitudes and practices of medical practitioners', *The Medical Journal of Australia*, vol. 161, no. 2, 1994, p. 137.

⁷²² Helga Kuhse, et al., 'End-of-life decisions in Australian medical practice', *Medical Journal of Australia*, vol. 166, no. 4, 1997, p. 191.

⁷²³ Charles D Douglas, et al., 'The intention to hasten death: A survey of attitudes and practices of surgeons in Australia', *Medical Journal of Australia*, vol. 175, no. 10, 2001, p. 511.

These findings were echoed in a 2007 study that found 43 per cent of doctors who had treated at least one terminally ill patient had been asked at least once to hasten death by administering drugs. The study also found that 35 per cent of these doctors reported administering drugs with the intention of hastening death at least once.⁷²⁴

A 2008 survey that compared doctors' attitudes and experiences in six European countries and Australia found that 7 per cent of physicians in Australia reported administering, prescribing or supplying drugs with the explicit intention of hastening the end of life on the explicit request of a patient.⁷²⁵

Professor of Health Law and Governance Roger Magnusson has interviewed doctors, nurses and therapists from Melbourne, Sydney and San Francisco who have helped patients to die. This research demonstrates how in some cases assisted dying is performed in the absence of safeguards:

Patients died without having received assessment for depression or dementia, without adequate counselling or palliative care, and without specialist assessments as to prognosis and treatment alternatives.⁷²⁶

What we really want to do is avoid the situation that many people have suggested may well be occurring at present, which is that people are undertaking actions in secret. They are not documenting them because they fear that there may be repercussions. We want to bring this all out into the open. We want to open to public scrutiny the actions that are undertaken.

Professor Paul Komesaroff, Director, Centre for Ethics in Medicine and Society, Monash University, public hearing 23 July 2015

Doctors who act in isolation, without standards and safeguards, may seriously compromise the quality of patient care. In Professor Magnusson's research, nearly 20 per cent of interviewees reported being involved in mismanaged attempts of assisted dying.⁷²⁷ He found that in many cases 'doctors and nurses miscalculated the dosages required to achieve death and resorted in panic to suffocation, strangulation, and injections of air'.⁷²⁸

Professor Magnusson describes the experience of 'Peter',⁷²⁹ a community nurse, who reported the following failed attempt:

The relatives left the room and the doctor and I opened the doctor's case and gave him everything in the case. It didn't work – he was still alive – and the doctor said "if you can get heroin, we'll give him heroin ..."⁷³⁰

⁷²⁴ Dr Neil Orford, Medical Director Intensive Care Unit, Barwon Health, *Transcript of evidence*, 29 July 2015, p. 721.

⁷²⁵ Rurik Löfmark, et al., 'Physicians' experiences with end-of-life decision-making: Survey in 6 European countries and Australia', *BMC Medicine*, vol. 6, no. 1, 2008, p. 8.

⁷²⁶ Professor Roger S Magnusson, 'Underground Euthanasia' and the harm minimization debate', *Journal of Law and Medicine*, vol. 30, no. 5, 2004, p. 488.

⁷²⁷ Roger S Magnusson, 'Euthanasia: Above ground, below ground', *Journal of Medical Ethics*, vol. 30, no. 5, 2004, p. 442.

⁷²⁸ Ibid.

⁷²⁹ Not his real name. Professor Magnusson used pseudonyms in his article.

⁷³⁰ Professor Roger S Magnusson, *Angels of death: Exploring the euthanasia underground*, Melbourne University Press, Melbourne, 2002, p. 205.

Another risk regarding unlawful assisted dying identified by Magnusson is what he refers to as ‘non-consensual’ assisted dying. Some cases involved mentally incompetent patients, where assisted dying was carried out at the family’s request.⁷³¹ In other cases, although the patient had apparently expressed a desire to die to a family member or friend, no independent evidence of this was obtained before hastening the patient’s death.⁷³²

‘Tim’,⁷³³ a general practitioner, performed assisted dying on a patient with a viral infection on the brain who was unable to communicate. As he had not previously met the patient, Tim’s decision to assist in the patient’s death was based on conversations with family members and the unrelenting nature of the patient’s distress.⁷³⁴

Professor Magnusson also reports several instances where interviewees felt coerced into hastening the death of patients they hardly knew.⁷³⁵

‘Gary’,⁷³⁶ a general practitioner, explained how a patient he’d never treated called him and requested an assisted death the following day. He admitted:

... it was difficult to get an appreciation of whether he was depressed or dementing ... I felt I was being pushed, rushed.⁷³⁷

Nonetheless, he complied with the request.⁷³⁸

The practice of unlawful assisted dying raises serious concerns about the protection of vulnerable people in the absence of regulatory safeguards.

Without criteria to gauge a request for assisted dying, there may be no accounting for its voluntariness or the capacity of the person making the request. Together with coercion of doctors, this risks exposing vulnerable people to ‘non-consensual’ assisted dying.

The traumatic treatment of patients subjected to mismanaged attempts of assisted dying is further cause for concern about the implications of unlawful assisted dying on patient care.

Despite facing potential criminal convictions, medical practitioners are openly performing unlawful assisted dying. This is occurring in an unregulated environment, and sometimes in circumstances that compromise patient care.

The Committee heard evidence that some doctors act in ways which may be unlawful, but that this is driven by a sense of obligation to alleviate pain.

⁷³¹ Ibid., p. 222.

⁷³² Ibid., p. 233.

⁷³³ Not his real name. Professor Magnusson used pseudonyms in his article.

⁷³⁴ Professor Roger S Magnusson, *Angels of death: Exploring the euthanasia underground*, Melbourne University Press, Melbourne, 2002, p. 211.

⁷³⁵ Ibid., p. 210.

⁷³⁶ Not his real name. Professor Magnusson used pseudonyms in his article.

⁷³⁷ Professor Roger S Magnusson, *Angels of death: Exploring the euthanasia underground*, Melbourne University Press, Melbourne, 2002, p. 211.

⁷³⁸ Ibid.

Dr Edward Brentnall, MBE, OAM, told the Committee in his submission that he and other doctors act to end patients' lives:

Many doctors have acted to end patients' lives when their suffering is due to an incurable illness. I have certainly done so.⁷³⁹

Professor Hal Swerissen of the Grattan Institute agrees that people are assisted to die all the time:

We currently allow voluntary euthanasia, but we have it hidden. It happens all the time, in fact, that people are assisted to die.⁷⁴⁰

Nurses also told the Committee that assisted dying is practiced in Australian medicine. Mark Staaf, Professional Officer with the Australian Nursing and Midwifery Federation told the Committee that he has seen assisted dying:

The CHAIR — ... Can I ask: do you think that euthanasia is practised at all in our medical system covertly at the moment? Even at the margins?

...

Mr STAAF — The answer is yes to 'Have I seen it?'. Yes, I have, but I do not think the intent is to do anything but give people a peaceful death.⁷⁴¹

So any doctor who is helping a patient to die does risk being prosecuted. It is true that doctors are rarely prosecuted, but the fact is that this is an intentional act, and it makes no difference that the patient has requested it or even that the patient is in the process of dying. It is still a criminal offence.

Professor Loane Skene, Director of Health and Medical Law, University of Melbourne, public hearing 23 July 2015

At present individuals, including doctors, are at risk of prosecution if they intentionally take the lives of any person suffering an irreversible deterioration of physical health.

Acting Crime Commander Rod Wilson of Victoria Police, public hearing 7 October 2015

6.3.1 Doctors are not prosecuted for unlawful medical practice

There have been no prosecutions in Australia of doctors for assisting a patient to die, despite evidence that they do.⁷⁴²

There are several reasons for this. Firstly, criminal law institutions have no way of identifying end of life medical cases that ought to be investigated.⁷⁴³ Police and prosecuting authorities are reluctant to pursue suspected cases of doctors performing assisted dying.⁷⁴⁴

⁷³⁹ Edward Brentnall, *Submission*, p. 3.

⁷⁴⁰ Professor Hal Swerissen, Grattan Institute Fellow, Grattan Institute, *Transcript of evidence*, 23 July 2015, p. 20.

⁷⁴¹ Mark Staaf, Professional Officer, Australian Nursing and Midwifery Federation, *Transcript of evidence*, 18 November 2015, p. 45.

⁷⁴² Professor Margaret Otlowski, *Submission*, p. 5.

⁷⁴³ John Griffiths, 'Euthanasia and assisted suicide should, when properly performed by a doctor in an appropriate case, be decriminalised', in *The criminal law and bioethical conflict: Walking the tightrope*, Rebecca Bennett Amel Alghrani, Suzanne Ost (ed.). Cambridge University Press, Cambridge, 2012, p. 21.

⁷⁴⁴ Ibid.

In evidence to the Committee, Detective Inspector Mick Hughes of the Homicide Squad explained the difficulty in prosecuting such cases:

We have certainly looked for a long time at one particular doctor in Victoria, and certainly my view in recent times is that there is not sufficient evidence to prosecute that person. It is a hard line for me because I think his motivation is probably to assist those who are in difficult situations; however, if I thought there was sufficient [evidence] there to prosecute, I would be duty-bound to prosecute.⁷⁴⁵

There are also serious evidentiary obstacles in proving that a doctor intended to hasten the death of a patient in administering treatment.⁷⁴⁶

The obstacles to prosecuting doctors for providing assisted dying and the lenient treatment of people charged with assisting a loved one to die indicate serious flaws in the end of life legal framework in Victoria.

I don't like invoking the principle of double effect as justification for what I did with that patient ... at all. But, uhm ... I know that I could. I know if someone attacks me in law I would have to use that argument to say that, that I was not responsible for his death ... but I feel responsible.

Jeremy, Palliative Specialist, *Decisions that Hasten Death*

Establishing subjective intention beyond a reasonable doubt in criminal law is notoriously difficult in any context.⁷⁴⁷ This is particularly so in the context of assisted dying.

During this Inquiry the Committee heard that administering high doses of pain relief commonly occurs as a patient approaches the end of life, and this can result in the patient's death.⁷⁴⁸

Doctors can also invoke the doctrine of double effect as a legal defence to any charges relating to a patient's death from excessive pain relief. This is difficult to disprove, even where it does not apply to a particular situation. See Chapter 7 for more information on the doctrine of double effect.

The widely acknowledged fact that members of the medical profession are known to be breaching the law but avoid prosecution may threaten to undermine public confidence in the administration of justice and bring the law into disrepute. It also shows that those in authority do not believe that justice would be served by robust application of the law as it stands.

⁷⁴⁵ Detective Inspector Mick Hughes, Detective Inspector, Homicide Squad, Victoria Police, *Transcript of evidence*, 7 October 2015, p. 16.

⁷⁴⁶ Professor Margaret Otlowski, *Voluntary euthanasia and the common law*, Oxford University Press, Oxford, 1997, p. 147.

⁷⁴⁷ Benjamin P White, et al., 'Palliative care, double effect and the law in Australia', *Internal Medicine Journal*, vol. 41, no. 6, 2011, p. 10.

⁷⁴⁸ Professor Roger S Magnusson, *Angels of death: Exploring the euthanasia underground*, Melbourne University Press, Melbourne, 2002, p. 145.

6.3.2 Implications of unlawful medical practice on patient care

Under the existing legal framework, what is available to patients at the end of life depends on what their doctor may suggest or be willing to do. In the absence of criteria and safeguards, decision making relating to assisted dying depends on the values of individual doctors and their interpretation of a situation.⁷⁴⁹

Professor of Public Health Rob Moodie expressed this view in his submission:

For many doctors their ability to provide adequate end of life care and to relieve intolerable pain and suffering can become an entirely arbitrary situation which depends on the medical practitioner's courage and moral beliefs, on the patient's disease, and on where the patient is based.⁷⁵⁰

Certain patients may gain access to lethal medications or assistance from health practitioners in ending their lives. Others may have the means to travel to a jurisdiction where assisted dying is permitted. These options are far less accessible to disadvantaged groups.⁷⁵¹

Questions of fairness arise where treatment options to end suffering are available to some and not to others for reasons beyond their medical circumstances.

This point was also made by Dr Roger Hunt, Medical Head of Palliative Care at the Queen Elizabeth Hospital in Adelaide in his submission:

The law is also unfair because it doesn't treat people equally. Some people can be helped to die on their own terms as a result of their knowledge and/or connections while some are able to hasten their death by the refusal of life-sustaining treatment. But others do not have access to the means for their life to end.⁷⁵²

The Québec Select Committee on Dying with Dignity observed that unlawful assisted dying 'opens the door to all manner of abuse,'⁷⁵³ and poses a serious threat to the rights of a patient to autonomy and self-determination.

In the absence of regulation, there is the risk of a lack of accountability, transparency, and oversight of medical practices that end in death. As such, there is a risk of inadequate protection of vulnerable people from coercion, no verification that assisted dying is a measure of last resort and no established criteria for assessing the merits of a request for assisted dying.

This point was made clear by Professor Moodie in his submission:

There is almost complete silence within the profession about the end of life practices that do occur, and this lack of transparency actually can open up the possibility of abuse.⁷⁵⁴

⁷⁴⁹ Henk Ten Have and Jos VM Welie, *Death and medical power: An ethical analysis of Dutch euthanasia practice*, Open University Press, London, 2005, p. 17.

⁷⁵⁰ Prof Rob Moodie, *Submission*, p. 1.

⁷⁵¹ Ibid.

⁷⁵² Dr Roger Hunt, *Submission*, p. 5.

⁷⁵³ Select Committee on Dying with Dignity, *Dying with Dignity*, National Assembly of Québec, Québec, 2012, p. 75.

⁷⁵⁴ Prof Rob Moodie, *Submission*, p. 1.

6.4 The right to refuse medical treatment and medical trespass

The right to refuse medical treatment and the prohibition against medical trespass are well established at common law.⁷⁵⁵

The refusal of treatment certificate provided for in the *Medical Treatment Act 1988* enables people to refuse treatment at a time when they no longer have capacity to communicate a treatment preference. This Act addresses concerns raised by the Social Development Committee's final report into the *Inquiry into options for dying with dignity* (1987) which found that doctors were uncertain of their obligations with regard to patient rights.

This was illustrated in the case of John McEwan, a former water-skiing champion who became quadriplegic and dependent on a ventilator after a diving accident.

Mr McEwan asked doctors to withdraw the ventilator that was keeping him alive, however, fearing litigation, his doctor's insurers refused. Dr J Toscano gave evidence that he received legal advice that he could not be charged with assault if he performed treatment to prolong Mr McEwan's life. This advice was contrary to the common law right to refuse medical treatment and the prohibition against medical trespass.

In response to the refusal of his request, Mr McEwan went on a hunger strike and was certified insane after pleading to be allowed to die.⁷⁵⁶ Only when he agreed to end his hunger strike, go on anti-depressant medication and receive counselling was the certification revoked. He was kept on a ventilator and died 10 months later.

The Social Development Committee subsequently recommended that the right to refuse medical treatment and medical trespass be enacted in legislation to clarify the obligations of doctors to respect the rights of patients.

The legislation that was enacted following the Social Development Committee's inquiry and recommendations to the government of the day enabled people with capacity to refuse medical treatment for a current condition through a refusal of treatment certificate.⁷⁵⁷

⁷⁵⁵ *Schloendorff v Society of New York Hospital* 105 NE 92, 93 (1914); *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649; Ben P White and Lindy Willmott, 'Will you do as I ask? Compliance with instructions about health care in Queensland', *Law and Justice Journal*, vol. 4, no. 1, 2005, p. 77.

⁷⁵⁶ Social Development Committee, *Inquiry into options for dying with dignity — Second and final report*, Victorian Parliament, Melbourne, 1987, p. 16.

⁷⁵⁷ Under section 4 of the Act, other legal rights to refuse treatment are not affected. This means that the common law right to refuse treatment is retained.

Medical Treatment Act 1988

5 Refusal of treatment certificate

If a registered medical practitioner and another person are each satisfied—

- (a) that a patient has clearly expressed or indicated a decision—
 - (i) to refuse medical treatment generally; or
 - (ii) to refuse medical treatment of a particular kind—
for a current condition; and
- (b) that the patient's decision is made voluntarily and without inducement or compulsion; and
- (c) that the patient has been informed about the nature of his or her condition to an extent which is reasonably sufficient to enable the patient to make a decision about whether or not to refuse medical treatment generally or of a particular kind (as the case requires) for that condition and that the patient has appeared to understand that information; and
- (d) that the patient is of sound mind and has attained the age of 18 years—

the registered medical practitioner and the other person may together witness a refusal of treatment certificate.

Under the *Medical Treatment Act 1988*, a doctor in Victoria who undertakes or continues medical treatment that is prohibited by a refusal of treatment certificate commits medical trespass and faces a fine of five penalty units.

Medical Treatment Act 1988

6 Offence of medical trespass

A registered medical practitioner must not, knowing that a refusal of treatment certificate applies to a person, undertake or continue to undertake any medical treatment to which the certificate applies, being treatment for the condition in relation to which the certificate was given.

Penalty: 5 penalty units.

There have been no reported cases of medical trespass in Victoria.

6.5 Importing and possessing suicide related material and barbiturates

6.5.1 Using a carriage service for suicide related material

The offence of using a carriage service for suicide related material was enacted by the Commonwealth Government in 2005. This is intended to prevent people, organisations and groups from distributing material detailing how to commit suicide through the internet, radio and television.

Criminal Code 1995 (Cth)**474.29A Using a carriage service for suicide related material**

- (1) A person is guilty of an offence if:
- (a) the person:
 - (i) uses a carriage service to access material; or
 - (ii) uses a carriage service to cause material to be transmitted to the person; or
 - (iii) uses a carriage service to transmit material; or
 - (iv) uses a carriage service to make material available; or
 - (v) uses a carriage service to publish or otherwise distribute material; and
 - (b) the material directly or indirectly counsels or incites committing or attempting to commit suicide; and
 - (c) the person:
 - (i) intends to use the material to counsel or incite committing or attempting to commit suicide; or
 - (ii) intends that the material be used by another person to counsel or incite committing or attempting to commit suicide.

Penalty: 1,000 penalty units.

- (2) A person is guilty of an offence if:
- (a) the person:
 - (i) uses a carriage service to access material; or
 - (ii) uses a carriage service to cause material to be transmitted to the person; or
 - (iii) uses a carriage service to transmit material; or
 - (iv) uses a carriage service to make material available; or
 - (v) uses a carriage service to publish or otherwise distribute material; and
 - (b) the material directly or indirectly:
 - (i) promotes a particular method of committing suicide; or
 - (ii) provides instruction on a particular method of committing suicide; and

Criminal Code 1995 (Cth)**474.29A Using a carriage service for suicide related material (continued)**

- (c) the person:
 - (i) intends to use the material to promote that method of committing suicide or provide instruction on that method of committing suicide; or
 - (ii) intends that the material be used by another person to promote that method of committing suicide or provide instruction on that method of committing suicide; or
 - (iii) intends the material to be used by another person to commit suicide.

Penalty: 1,000 penalty units.

In its 2007 decision on *The peaceful pill handbook*, by Dr Philip Nitschke and Dr Fiona Stewart, the Classification Review Board cited section 474.29 and section 307.3 of the *Criminal Code Act 1995 (Cth)*, amongst others, as grounds for refusing classification.⁷⁵⁸

⁷⁵⁸ Classification Review Board, Decision to classify the publication *The peaceful pill handbook*, by Dr Philip Nitschke and Dr Fiona Stewart, Category 1 – Restricted, 4 February 2007.

6.5.2 Possessing, controlling, producing, supplying or obtaining suicide related material for use through a carriage service

Under section 474.29B of the *Criminal Code 1995* (Cth), a person found guilty of possessing, controlling, producing, supplying or obtaining suicide related material for use through a carriage service is liable for a fine of 1,000 penalty units.

Criminal Code 1995 (Cth)

474.29B Possessing, controlling, producing, supplying or obtaining suicide related material for use through a carriage service

- (1) A person is guilty of an offence if:
- (a) the person:
 - (i) has possession or control of material; or
 - (ii) produces, supplies or obtains material; and
 - (b) the material directly or indirectly:
 - (i) counsels or incites committing or attempting to commit suicide; or
 - (ii) promotes a particular method of committing suicide; or
 - (iii) provides instruction on a particular method of committing suicide; and
 - (c) the person has that possession or control, or engages in that production, supply or obtaining, with the intention that the material be used:
 - (i) by that person; or
 - (ii) by another person;

in committing an offence against section 474.29A (using a carriage service for suicide related material).

Penalty: 1,000 penalty units.

There are no reported cases relating to this offence.

6.5.3 Importing border controlled drugs

It is an offence under section 307.3 of the *Criminal Code 1995* (Cth) to import substances used in assisted dying, such as Nembutal,⁷⁵⁹ with punishment of up to 10 years' imprisonment, a fine of 2,000 penalty units, or both.

Criminal Code 1995 (Cth)

307.3 Importing and exporting border controlled drugs or border controlled plants

- (1) A person commits an offence if:
- (a) the person imports or exports a substance; and
 - (b) the substance is a border controlled drug or border controlled plant.

There is no case law on importing border controlled drugs to be used in assisted dying as these cases have been prosecuted under the *Customs (Prohibited Imports) Regulations 1956* (Cth).

⁷⁵⁹ *Criminal Code 1995* (Cth), 12 of 1995, section 301.4. (Barbiturates are listed as a drug in *Customs (Prohibited Imports) Regulations 1956*, Schedule 4, Item 18).

6.5.4 Importing prohibited barbiturates

Barbiturates such as Nembutal that can be used in assisted dying are listed as a prohibited import under *Customs (Prohibited Imports) Regulations 1956* (Cth), *Schedule 4, Item 18 (Regulation 5)* and a fine of 7,500 penalty units applies.

Both a licence and permit must be issued by the Drug Control Section of the Therapeutic Goods Administration to import Nembutal.

Customs (Prohibited Imports) Regulations 1956 (Cth)

Regulation 5 Importation of drugs

- (1) Subject to subregulations (2) and (2A), the importation into Australia of a drug is prohibited unless:
 - (a) the person importing the drug is the holder of:
 - (i) a licence to import drugs granted by the Secretary or an authorised person under this regulation; and
 - (ii) a permission to import the drug granted by the Secretary or an authorised person under this regulation;
 - (b) the permission referred to in subparagraph (a)(ii), or a copy of the permission, is produced to the Collector;
 - (c) the drug is imported within the period specified in the permission referred to in subparagraph (a)(ii); and
 - (d) the quantity of the drug that is imported does not exceed:
 - (i) except where subparagraph (ii) applies—the quantity specified in the permission referred to in paragraph (a)(ii) in relation to the drug; or
 - (ii) where the Collector has given a certificate or certificates under subregulation (14)—the difference between the quantity specified in the permission in relation to the drug and the quantity specified in the certificate, or, if more than one certificate has been given, the total of the quantities specified in those certificates, in relation to the drug.

There have been several convictions for importing Nembutal. It is important to note, however, that no judgments have been reported.⁷⁶⁰ The following cases have been identified in news media.

In 2007, Caren Jennings was charged with importing Nembutal and being an accessory before the fact to the murder of Graeme Wylie.⁷⁶¹ She pleaded guilty to the importation offence and not guilty to the accessory charge, but was found guilty at trial.⁷⁶² Prior to sentencing, Ms Jennings, who had been suffering from breast cancer, died as a result of taking Nembutal.⁷⁶³

In April 2009, Ann Leith of Victoria was charged with importing Nembutal. She pleaded guilty and was released on a \$500, 12-month bond and ordered to pay \$1000 into the court fund.⁷⁶⁴

⁷⁶⁰ Where importation where has been the only crime prosecuted.

⁷⁶¹ *R v Shirley Justins*, NSWSC 568, [2011].

⁷⁶² *Ibid.*

⁷⁶³ Jonathan Dart, 'Euthanasia advocate ends it', *Sydney Morning Herald*, 19 September 2008, viewed 9 March 2016, <www.smh.com.au>.

⁷⁶⁴ Adrian Lowe and Steve Butcher, 'No conviction for euthanasia drug', *Age*, 16 April 2010.

Lynn Afotey-Otu of Queensland was charged with importing Nembutal in 2014. She was placed on a two-year good behaviour bond and 12 months' probation. No conviction was recorded.⁷⁶⁵

Rupert Ward of Western Australia, a member of Exit International, was also charged with possessing Nembutal in 2014. He pleaded guilty to importing an illegal drug, was fined \$2600 and received a spent conviction.⁷⁶⁶

⁷⁶⁵ Thomas Chamberlin, 'Lynn Afotey-Otu pleads guilty to importing euthanasia drug Pentobarbital', *Courier Mail*, 26 June 2014.

⁷⁶⁶ Mark Bennett, 'Rupert Ward, guilty of possessing euthanasia drug Nembutal, given spent conviction', *ABC*, 29 August 2014, viewed 18 March 2016, <www.abc.net.au/news>.

7

How the existing legal framework shapes end of life experiences

Establishing whether changes to the end of life legal framework are necessary requires examining the effect of the existing legal framework on the lives of Victorians.

In the previous Chapter the current legal framework around end of life was examined in the context of recent legal cases.

This examination, combined with the evidence received in submissions and hearings has raised many questions for the Committee in relation to the current situation in Victoria.

The Committee received compelling evidence that the nature of dying for people with terminal illness and chronic and degenerative diseases under Victoria's existing end of life legal framework can be difficult and sometimes harrowing for individuals, their families and communities and for law enforcement.

People suffering from terminal illness and serious chronic and degenerative diseases gave evidence about the angst and frustration they feel at being unable to choose to end their irremediable pain and suffering, and to die at home surrounded by loved ones.

Some people are choosing to stop having treatment, knowing that this will result in their imminent death.

Others spoke of the trauma of watching seriously ill loved ones refuse food and water to expedite death and finally relieve their suffering.

Family members, the Coroners Court of Victoria and Victoria Police gave evidence about how people experiencing an irreversible deterioration in health are taking their own lives in desperate but determined circumstances.

Research shows that some doctors will do what they consider to be necessary to end a patient's suffering when they are at the end of life. This may be through continuous palliative sedation or intensified alleviation of pain, even if this may unintentionally result in death.

Analysis of the case law in Chapter 6 illustrates a serious discrepancy between the law as it stands in theory and as it is applied in practice. While this may achieve just outcomes on a case-by-case basis, it threatens to bring the law into disrepute, undermining our community's confidence in our legal system.

It also raises the question as to whether the law reflects the contemporary values of the Victorian community.

7.1 The legal framework and peoples' end of life experiences

The Committee heard evidence from health providers that palliative care is effective in alleviating pain and suffering in the vast majority of end of life cases. For those for whom palliative care is effective, it provides comfort and support and improves the quality of life of patients and their families. This is discussed at length in Chapters 2 and 3.

The Committee also heard from patients, carers and health practitioners that there is a proportion of people who continue to experience irremediable pain despite receiving palliative care.

The cases described in this Chapter demonstrate the trauma experienced by patients and their families when palliative care does not provide an adequate solution for their situation.

It is these cases of irremediable pain and suffering that the recommendation in Chapter 8 aims to address.

7.1.1 People with terminal illness

Many people described to the Committee their experiences of terminal illness and irremediable pain. In particular, what they have been told to expect of their illness and the dying process, their fears of dying a bad death and the effect of this on their families and loved ones.

These people bravely wrote or spoke to the Committee about profoundly personal experiences of pain and the terrible choices they face.

Suzanne Jensen was diagnosed with oesophageal cancer in 2009 and underwent major surgery, chemotherapy and rehabilitation and was later diagnosed with lung cancer:

While I am not focussing on what might be, when and if the time comes, I want to be able to determine my own exit with some degree of grace and dignity. An exit that will be peaceful and on my terms with the support and assistance of my family.⁷⁶⁷

Lachlan Smith has glioblastoma multiform brain tumour and has undergone multiple doses of chemotherapy and radiotherapy. He told the Committee 'I have been injected, irradiated and infused with just about everything.'⁷⁶⁸

Mr Smith explained the likely trajectory of his illness to the Committee:

⁷⁶⁷ Suzanne Jensen, *Submission*, p. 1.

⁷⁶⁸ Lachlan Smith, *Transcript of evidence*, 14 October 2015, p. 19.

The end is pretty grim when it happens. I will be victim to a creeping paralysis and increasing loss of cognitive function, until I am paralysed and delirious. There will also be quite a lot of pain from increased intracranial pressure. I will slip in and out of a coma until I die. This process could stretch out for quite some time.⁷⁶⁹

In discussing his end of life options, he observed:

By the time life is not worth living we are going to be in no condition to do anything about it; I am going to be effectively blind and paralysed. So I have the choice: when I am still capable but I start to feel I am declining, do I take action then and deprive myself of what could be a couple more months of limited functionality, or do I roll the dice and hope it does not get any worse? Having some surety that if it does get too bad, someone could do something for me would make a very big difference.⁷⁷⁰

Christine Hamann has end stage lung cancer and a gut problem that pain medication cannot relieve:

My life is intolerable. If I left my cats in such pain, in such a condition I would be in court for neglect and cruelty but because I am a human being it is legal to leave me like this. And I believe this must change. I believe God would not wish what I must live day upon day, night upon night on anyone.⁷⁷¹

I want the peace of mind that the legal option of voluntary euthanasia would give me NOW as my dying process becomes more and more awful. It would be such a relief. Not just to me but to my family who have so often [watched] me crying or screaming with pain.⁷⁷²

Leith Richards has been diagnosed with Stage 4 primary peritoneal cancer:

I have a husband and two sons and the idea of them watching me slowly and painfully waste away and die because there is nothing anyone can do to avert it is emotionally excruciating, almost surreal.⁷⁷³

She further notes:

I have for many years believed that clear thinking adults who are terminally ill should be legally allowed to have the help of a compassionate doctor and drugs to let them end their lives peacefully and painlessly at the time they want to. The alternative may be weeks or months of emotional and/or physical pain and anguish. It would give me enormous peace of mind to know I had some control and that I could hopefully spare them [my family] and myself a little suffering.⁷⁷⁴

⁷⁶⁹ Lachlan Smith, *Submission*, p. 1.

⁷⁷⁰ *Ibid.*, pp. 19–20.

⁷⁷¹ Christine Hamann, *Submission*, p. 1.

⁷⁷² *Ibid.*

⁷⁷³ Leith Richards, *Submission*, p. 1.

⁷⁷⁴ *Ibid.*

7.1.2 People are dying bad deaths

The Committee heard from many people about the traumatic deaths of their loved ones and how they ought to have had more options at the end of life.

Dr Doug Gaze believes that maintaining the current legal framework contributes to painful deaths for a significant number of people:

The vision of a dying patient on a morphine drip surrounded by family and slipping away peacefully is not the reality in a significant proportion of patients. Patients can suffer ... physically, psychologically and existentially for weeks or months and can die in great suffering, often alone in the middle of the night and often in confusion, fear and distress gasping for breath or choking on their own fluids. But for the sake of a small proportion of the community who will not accept a more humane way (including some Doctors) this is how things will continue.⁷⁷⁵

Dr Janet Fitzpatrick wrote of her husband who had cancer of the pancreas, liver and throat and was too ill to nurse at home:

A peaceful death at that stage would have been wonderful. Instead he had 10 days in hospital when he was in pain, his tracheostomy tube was constantly blocked with thickened mucus, he could not communicate or recognise us.⁷⁷⁶

Anne Woodger wrote of her father who suffered motor neurone disease and decided to cease percutaneous endoscopic gastronomy feeding so he would die of starvation and dehydration:

While the law respected his right to decide to end his life, it gave him no help to do it and insisted that he must die slowly of starvation and dehydration ... Mucous solidified in the back of his throat and needed to be regularly prized out with cotton buds, causing him to gag. His mouth was dry and could only be swabbed with water ... He died after 12 days.⁷⁷⁷

Kerri Laidlaw described the protracted death of her sister who suffered breast cancer and a secondary cancer:

She exhibited “Ascites” the build up of fluid between the organs in her body that could only be drained at a rate of litres per week to avoid her body going into shock. The ascites was literally crushing her organs. She suffered vomiting and difficulty breathing ... Her doctor could

The choice is not between life and death but between death in agony and death in peace.

Doris Hart, personal submission

At present in most jurisdictions in this country any person, suffering more than he/she wishes to bear can refuse to accept any treatment and virtually commit suicide. It is surprising that we as a community can watch the patient slowly die but cannot help to bring a swift end to that life ... To me that is not compassion, it is cruelty.

Ranjan Ray, personal submission

⁷⁷⁵ Dr Doug Gaze, *Submission*, pp. 1–2.

⁷⁷⁶ Dr Janet Fitzpatrick, *Submission*, p. 1.

⁷⁷⁷ Anne Woodger, *Submission*, pp. 3–4.

find no chemotherapy that would make any creditable difference to her state. She was dying. She hung on for 8 weeks. [E]very time she awoke from the drugs her eyes would cast around the room and she would breath[e] a heavy sigh, realising she was still alive. When nurses asked would she like anything, she replied “A lethal dose?” It was akin to torture her being kept alive. She wanted to die ... Nothing could be done but she was left to suffer in the name of good medicine.⁷⁷⁸

Dr Geoff Wall described treating a fully paralysed patient with end stage neuromuscular disease who could only communicate through eye movements:

Once he realised he would never get off the ventilator, his mental status deteriorated to extremely fragile and he repeatedly indicated that he wished to die. His eyes would well with tears on mention of his home, family and pets.

The problem with ceasing artificial ventilation was that he would need almost an anaesthetic to overcome the feeling of suffocation as he died ... If artificial ventilation is ceased as strong intravenous sedation is given, causing rapid death, some may believe this to be murder.

... The patient remained on life support for 11 weeks until he died from pneumonia.

I can scarcely imagine what went through his mind, immobilised, staring at the ceiling for months, unable to say where he was hurting, with tubes in his windpipe, arm, stomach and bladder, 24hr machines and alarms, no hope of recovery, begging to end it all and finally an awful septic death.

Current laws failed to protect both this patient’s right to control his own fate, and the medical staff’s freedom to implement his wishes.⁷⁷⁹

7.1.3 People are choosing suicide over dying with irremediable pain

Another troubling issue raised in evidence to the Committee is the desperate and violent nature of death experienced by people with serious and incurable conditions and irremediable pain who feel they have no alternative but to commit suicide.

The Coroners Court of Victoria presented particularly disturbing evidence that around 50 Victorians a year are taking their lives after experiencing an irreversible deterioration in physical health.⁷⁸⁰

Pre-emptive suicide, often by horrendous means, and so-called ‘mercy killings’ are both tragic consequences of the legal status-quo, and are an indictment on a civilised society. Until the law is changed there is a terrible legacy; both for the patient and their loved ones who face a complicated grief process.

Dr Julia Anaf, personal submission

⁷⁷⁸ Kerri Laidlaw, *Submission*, p. 1.

⁷⁷⁹ Dr Geoff Wall, *Submission*, p. 2.

⁷⁸⁰ Coroner John Olle, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, p. 3.

As Coroner Caitlin English described in evidence to the Committee:

These are people who are suffering from irreversible physical terminal decline or disease, and they are taking their lives in desperate, determined and violent ways.⁷⁸¹

The way in which people die in these circumstances is often starkly contrasted with the way in which they lived their lives, Coroner John Olle observed:

People who have invariably lived a long, loving life surrounded by family die in circumstances of fear and isolation.⁷⁸²

The following case studies are accounts of suicide investigations undertaken by the Coroners Court of Victoria and provided as evidence to the Committee.

Case 7.1

A middle-aged man was diagnosed with a metastatic colorectal carcinoma approximately three years prior to his death. During that time, he received chemotherapy, radiofrequency ablation and underwent surgical intervention to try and counter the progression of the cancer. The man's general practitioner observed a steady decline in his mental and physical health despite the various treatments. In the weeks preceding his death, the man expressed suicidal ideation to his family on two occasions indicating that he would rather die than face deteriorating health in hospital. He bought a rope from a hardware store and two days later he hanged himself in a public location, he had left a note to his family at their home.⁷⁸³

Case 7.2

A 93-year-old woman with crippling arthritis and back pain had gone into an aged care facility and smuggled a razor blade into her wallet which she then used, and she died of exsanguination with her arm dangling over the toilet bowl. Her daughter made a very compelling statement about her mother's death. The essence of it is that, from the family's point of view, if only there was a better way, that their loved ones did not have to die in such violent circumstances and alone.⁷⁸⁴

Individual submissions to the Committee further detailed the drastic measures people with serious and incurable conditions and irremediable pain have resorted to in order to end their pain. David Scanlon wrote of his father who, in the early stages of dementia, hanged himself in his garage. Mr Scanlon also described the shock his mother experienced upon finding him:

Things could have been so very different if there were proper processes in place for end of life choices. He could have lived a while longer. He could have enjoyed life, family and friends for a while longer. He could have said proper goodbyes to

⁷⁸¹ Coroner Caitlin English, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, p. 3.

⁷⁸² Coroner John Olle, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, p. 3.

⁷⁸³ Coroners Court of Victoria, *Submission*, p. 6.

⁷⁸⁴ Coroner Caitlin English, Coroner, Coroners Court of Victoria, *Transcript of evidence*, 7 October 2015, p. 7.

his family and friends. He could have consulted with his doctor as to when and how would be the best time to go. He would not have had to face and carry out the decision that he did, alone. His wife wouldn't have had to find him, hanging in the garage, the image forever imprinted on her mind.⁷⁸⁵

Elizabeth Short explained how her father-in-law was diagnosed with an aggressive form of prostate cancer and refused treatment for fear of losing the ability to have any control of his own death. He subsequently placed a plastic bag over his head, tied a sock around his neck to secure the bag and suffocated.⁷⁸⁶

Carol McCrae described how her mother attempted to take her own life using oxycontin and a knife and was subsequently threatened with a psychiatric section and admission to a psychogeriatric locked ward.⁷⁸⁷

Laura Gaal explained how a friend diagnosed with dementia committed suicide by driving head on into a truck.⁷⁸⁸

Debbie Marcius described how her 92-year-old father, suffering from prostate cancer, decided to end his own life:

Now left as a grieving daughter, I have to ask why this amazing man had to end his life by his own hand by himself, when his final time should have been surrounded by those who loved him.⁷⁸⁹

Coralie Richmond wrote of her father who had fluid build-up on his lungs and how pain relief did not ease his suffering:

Mother rang and said "Your father has had a haemorrhage." I raced to her home and found the cause, there was the gun and Father was still alive but in great distress. His brain was a pulp, the body still alive.⁷⁹⁰

Her father died a week later in hospital.

Terri Eskdale described the effects of multiple sclerosis on her partner Mark Brennan who took his own life. She stated his greatest fear was that he would get to a stage where he would not be able to end his life because his hands would not work:

If we had laws that allowed a system where people could choose to end their life on their own terms Mark may still be alive today ... Mark died alone and without a word of goodbye because he had to protect me. That is what upsets me the most, he had to die alone and in an unnecessarily violent way.⁷⁹¹

⁷⁸⁵ David Scanlon, *Submission*, p. 1.

⁷⁸⁶ Elizabeth Short, *Submission*, p. 1.

⁷⁸⁷ Carol McCrae, *Submission*, p. 1.

⁷⁸⁸ Laura Gaal, *Submission*, p. 1.

⁷⁸⁹ Debbie Marcius, *Submission*, p. 1.

⁷⁹⁰ Coralie Richmond, *Submission*, p. 1.

⁷⁹¹ Terri Eskdale, *Submission*, p. 1.

Acting Commander Rod Wilson of Victoria Police described the effect of these violent deaths on first responders:

... the desperation and the will of some people to take their lives have exposed our police to fairly horrific scenes of suicide. I think that the police who attend these events, like ambulance officers and others — our police are only fairly junior and inexperienced and quite young — and I think the impact of dealing with the deceased persons at those horrific scenes, and also having to prepare inquest briefs for the coroner and taking statements from family members who are clearly desperate and frustrated with the system, I would just like to say that that does have some impact on our frontline police officers.⁷⁹²

While it is impossible to know whether people would have availed themselves of the option of assisted dying if it existed, the evidence suggests that decisions to suicide are desperate and occur in the absence of a less devastating alternative.

7.2 Lawful medical treatment at the end of life

People are living longer due to advances in medicine. The process of dying has become increasingly protracted as people are more likely to die from chronic and degenerative diseases that cause a gradual decline in health over long periods of time.⁷⁹³

Modern medicine has evolved to reflect these changes, sometimes focusing on preserving quality of life in the delivery of medical treatment rather than prolonging life at all costs.

Withholding and withdrawing futile medical treatment, providing adequate pain relief, even if this may have the unintended consequence of ending a patient's life, and continuous palliative sedation are regularly employed, lawful medical practices. They are not assisted dying.

The Committee heard that doctors in Australia may potentially shorten a patient's life through conventional medical practice where the alleviation of pain is more important than prolonging life. Doctors told the Committee that this was uncontroversial standard practice where death is imminent and pain is extreme.

Withdrawing and withholding futile medical treatment

Doctors are protected at common law from liability for withdrawing life support without the consent of the patient where the treatment is futile and confers no benefit.⁷⁹⁴

⁷⁹² Acting Commander Rod Wilson, Crime Command, Victoria Police, *Transcript of evidence*, 7 October 2015, p. 15.

⁷⁹³ Professor Hal Swerissen and Stephen Duckett, *Dying well*, Grattan Institute, Melbourne, 2014, p. 5.

⁷⁹⁴ *Messiha v South East Health* [2004] NSWSC 1061.

In the English case *Airedale NHS Trust v Bland*, a hospital sought a declaration that doctors caring for a man in a persistent vegetative state, with no hope of improvement, could remove life support without facing civil or criminal liability.⁷⁹⁵

The Official Solicitor of the English Supreme Court, the patient's guardian, opposed the hospital's declaration. It was contended that the removal of treatment would amount to the crime of manslaughter, if not murder, because by withdrawing the feeding tubes the doctors would be taking active steps to bring about the patient's death.

The House of Lords granted the declaration, finding that there was no duty to treat if treatment was not in the best interests of the patient. Since there was no prospect that the treatment would improve the patient's condition, the treatment was futile and therefore not in his best interests.

The common law legal principle that doctors are not legally obligated to provide futile treatment applies throughout Australia.⁷⁹⁶

Doctrine of double effect

It is also lawful for doctors to provide adequate pain relief, even if this has the unintended consequence of ending a patient's life.

This is known as the doctrine of double effect which, as discussed in Chapter 3, protects doctors who administer pain relief with the intention of relieving pain rather than hastening death.

The Australian Medical Association's Code of Ethics states that doctors should provide treatment for pain and suffering 'even when such therapy may shorten a patient's life.'⁷⁹⁷

Doctors told the Committee that this was uncontroversial standard practice where death is imminent and pain is extreme.

This view was also expressed by Dr Doug Gaze in his submission:

Surely relief of suffering is the highest goal? Why allow intolerable suffering when it is within our power to give people a choice to relieve it? For some the only relief and the greatest kindness and humanity is allowing the choice of a peaceful death ...⁷⁹⁸

⁷⁹⁵ [1993] 2 WLR 316.

⁷⁹⁶ Professor Lindy Willmott, et al., 'Withholding and withdrawal of 'futile' life-sustaining treatment: Unilateral medical decision-making in Australia and New Zealand', *Journal of Law and Medicine*, vol. 20, no. 4, 2013, p. 908.

⁷⁹⁷ Australian Medical Association, 'Code of ethics', viewed 30 March 2016, <ama.com.au>, p. 1.4(c).

⁷⁹⁸ Dr Doug Gaze, *Submission*, p. 2.

Dr John Stanton discussed his experience in treating patients at the end of life:

Over the years, I have helped a number of patients with terminal cancer die a dignified death. This has usually been in the patient's home with support of family, friends and a domiciliary palliative care team. I have learnt to prescribe adequate doses of narcotic analgesia to make a patient comfortable and pain free, even when these doses may speed up the inevitable death.⁷⁹⁹

Continuous palliative sedation

Continuous palliative sedation is another standard medical practice at the end of life to treat irremediable pain and suffering. As discussed in Chapter 3, continuous palliative sedation is the practice of sedating a patient with the intention of continuing that sedation through to their death.

Dr Brian McDonald told the Committee:

We do provide terminal sedation quite frequently, where we render the patients unconscious. I talk to families, and I will talk to the patient if they are aware enough to talk to, because people seem to understand the medically induced coma.⁸⁰⁰

More information on continuous palliative sedation can be found in Chapter 3.

7.2.1

Protecting lawful medical practice of doctors

Advances in medicine that have led to increasingly protracted dying have not been met with corresponding developments of the law. It is the view of this Committee that the subsequent divergence between best practice medicine and the law must be rectified.

Evidence to the Committee suggests that some health practitioners are uncertain about the law relating to the administration of pain relief which may have the unintended effect of ending a patient's life.⁸⁰¹ As a result, some patients may be receiving inadequate pain treatment.

As discussed in Chapter 3, doctors should be able to provide necessary pain relief without fear of potential legal repercussions. This was widely supported in submissions to the Inquiry.⁸⁰² The Committee believes end of life care in Victoria would be improved by legislating the doctrine of double effect, just as Queensland, Western Australia, and South Australia have, as per Recommendation 28.

⁷⁹⁹ Dr John Stanton, *Submission*, p. 1.

⁸⁰⁰ Dr Brian McDonald, Clinical Director Palliative Care, Peninsula Health, *Transcript of evidence*, 9 September 2015, p. 12.

⁸⁰¹ Australian Centre for Health Research, *Submission*, p. 6; Dr Ric Milner, General Practitioner, You Yang, Western Victoria Primary Health Network, *Transcript of evidence*, 29 July 2015, p. 37; Georgie Haysom, Head of Advocacy, Avant Mutual Group, *Transcript of evidence*, 25 November 2015, p. 11.

⁸⁰² Professors Lindy Willmott, Ben White and Julian Savulescu, *Submission*, p. 1; Council of the Ageing, *Submission*, p. 20; Australian Medical Association (Vic), *Submission*, pp. 3–4; Social Responsibilities Committee of the Anglican Diocese of Melbourne, *Submission*, p. 12; Professor Paul Komesaroff, Director for Ethics in Medicine & Society, Monash University, *Transcript of evidence*, 23 July 2015, p. 4; Health Services Commissioner, *Submission*, p. 4; Australasian College for Emergency Medicine, *Submission*, p. 5.

Professor Paul Komesaroff has observed:

[A] genuine and abiding problem with the current legal situation remains unresolved: doctors who follow current best practice by providing whatever care is needed to alleviate pain and suffering cannot be confident that they would be protected from criminal prosecution for murder, manslaughter or aiding and abetting suicide should they be actively involved in the death of their patient.⁸⁰³

This reflects the concerns of many submissions and witnesses that the end of life legal framework puts doctors in an impossible position of having to choose between complying with a patient's request to end their suffering or abiding by the law.

Graeme Lovell, whose personal submission details the death of his wife Susan, supported the need to protect doctors in these circumstances:

They should not be placed in the position of career risk for trying to help dying people to end their lives peacefully.⁸⁰⁴

Dr Roger Hunt, Medical Head of Palliative Care at the Queen Elizabeth Hospital in Adelaide has echoed this view:

Compassionate clinicians can experience enormous pressure to grant a dying person's wish for a hastened death. In these circumstances, I believe clinicians should have protection from prosecution for the most serious crime of murder.⁸⁰⁵

This position was reinforced by law Professor Margaret Otlowski who observed that:

[I]t seems quite inappropriate that a doctor acting bona fide on the request of a patient in providing such assistance should potentially have to face criminal charges for murder.⁸⁰⁶

At a personal level, I suffer from a slowly progressive disease which, if I live long enough, can be reasonably expected to incapacitate me such that I shall no longer be able to walk, stand, and may experience loss of bladder and bowel control. If I ever do get to this stage and if I wish to do so because my life has become unbearable for me I should like to be able to end my life without breaking the law either for myself or for anyone else.

Robert Gunter, personal submission

The evidence the Committee heard makes it clear that doctors make medical decisions regarding the death of their patients every day in hospitals and other health and aged care services, decisions made in the context of complicated end of life care.-

⁸⁰³ Professor Paul Komesaroff, 'A minimalist legislative solution to the problem of euthanasia', *Medical Journal of Australia*, vol. 202, no. 9, 2015, p. 480.

⁸⁰⁴ Graeme Lovell, *Transcript of evidence*, 15 October 2015, pp. 19–20.

⁸⁰⁵ Dr Roger Hunt in Bob Douglas, et al., *The right to choose an assisted death: Time for legislation?*, Queensland University of Technology and Australia21, Brisbane, 2013, p. 24.

⁸⁰⁶ Lorana Bartels and Margaret Otlowski, 'A right to die? Euthanasia and the law in Australia', *Journal of Law and Medicine*, vol. 17, no. 4, 2010, p. 554.

7.3 Implications of the legal framework governing end of life care

The Committee is of the view that the existing end of life legal framework as described in Chapter 6 is untenable.

Under the existing legal framework, Victorians with serious and incurable conditions and irremediable suffering are exposed to the possibility of a traumatic death. Some are driven to suicide.

End of life care can be highly dependent on the individual doctor, and disadvantaged groups are less likely to have access to the same choices as those with the resources to more effectively navigate the healthcare system.

The effect of the end of life legal framework on the lives of Victorians and on the practice of medicine and the law signifies that it does not reflect our contemporary society's values and social needs. The Committee heard this many times during its Inquiry.

Consequently, the Committee considers that there must be reform of the end of life legal framework. The Committee strongly believes that the most suitable option for addressing these concerns is the introduction of a legalised assisted dying framework, which is discussed in detail in Chapter 8.

The objectives of the recommendations made in this Report are to not only enable patients' end of life wishes to be respected, but also to protect patients, particularly vulnerable people, from abuse and coercion.

They also aim to increase transparency around end of life medical practice and to improve clarity on end of life law so that health practitioners can be confident in knowing where the boundaries of legal medical practice lie.

I do not wish to spend my last days in pain and with loss of dignity. I do not wish my doctor or pharmacist to act against his or her religion or conscience. I do want them to be able to provide me with the knowledge, and medication, to end my life at a time of my choosing and with dignity, without fear of prosecution. Without this knowledge I am left with only one alternative – a plastic bag over my head.

Morna Ann Brayshaw, personal submission

8

Victoria should legalise assisted dying

8.1

Introduction

In this Chapter the Committee proposes a legislative framework for assisted dying in Victoria for capable adults in certain circumstances. The proposed framework is a result of the Committee's extensive research and consultation process during the Inquiry. This Chapter discusses the Committee's reasons for making this recommendation, including the specific eligibility criteria, safeguards, and oversight mechanisms included in the framework.

The essential elements of the framework the Committee proposes are included in an Annex to this Chapter at 8.11.

In explaining this framework, the Committee chose not to focus solely on arguments for and against legalising assisted dying. The Committee made this decision for a number of reasons.

First, the various arguments put by supporters and opponents are well known and have been addressed many times in many different reports and research papers, both in Australia and internationally. The arguments put forward in evidence to the Inquiry reflected these and were consistent with arguments the Committee found during its research process.

Concerns raised in arguments against legalising assisted dying — such as the inability to implement and maintain effective safeguards — have not eventuated in jurisdictions where assisted dying is legal. The Committee did not find compelling evidence to support the negative consequences predicted by these claims.

Rather, these jurisdictions highlight the importance of establishing a framework that suits a particular jurisdiction's medical and legal culture and of providing the appropriate safeguards within that framework.

The Committee has provided a summary of arguments for and against legalising assisted dying in Appendix 7. This is drawn from the evidence provided in submissions to the Inquiry.

8.2 The problem

The Committee has considered the wealth of information provided to it directly in evidence to the Inquiry, as well as in existing literature and reviews, arguing for and against legalising assisted dying. The Committee has also considered the evidence of medical practitioners, academics, and other experts describing the way some people are dying under our current legal system.

The evidence presented by the Coroner's Court of Victoria was highly persuasive, and revealed some disturbing examples of the hidden damage that occurs. The evidence highlighted some of the horrific ways people are currently dying under our current law, particularly frail, elderly and vulnerable Victorians. This led the Committee to further investigate this issue, including how the criminal justice system deals with those who break the law.

The Coroner's Court told the Committee that some Victorians are ending their lives in dreadful ways. Many of these people identified by the Coroner are dying alone and in pain. They are often dying earlier than they desire because they believe they must act alone, before they are no longer capable, and so that their loved ones are not implicated in their death.

Palliative care will provide comfort and pain relief at the end of life for most Victorians and, as observed by Monsignor Anthony Ireland, 'palliative care services must be made available to all Victorian citizens.'⁸⁰⁷

While several submissions suggested that all pain and suffering can be alleviated through the provision of better palliative care,⁸⁰⁸ the Committee heard from health practitioners that not all pain can be alleviated.⁸⁰⁹

Palliative care has improved by leaps and bounds and we all hope that it keeps improving, but it is not and never will be the answer to the distress and loss of dignity that the elderly fear and hope to avoid at the last stages of their lives.

Ranjan Ray, personal submission

At a personal level, I suffer from a slowly progressive disease which, if I live long enough, can be reasonably expected to incapacitate me such that I shall no longer be able to walk, stand, and may experience loss of bladder and bowel control. If I ever do get to this stage and if I wish to do so because my life has become unbearable for me I should like to be able to end my life without breaking the law either for myself or for anyone else.

Robert Gunter, personal submission

⁸⁰⁷ Monsignor Anthony Ireland, Episcopal Vicar for Health, Aged Care and Disability Care, Catholic Archdiocese of Melbourne, *Transcript of evidence*, 18 November 2015, p. 17.

⁸⁰⁸ Australian Catholic University, *Submission*, p. 1; Australian Catholic Bishops Conference, *Submission*, p. 9; Australian Family Association, *Submission*, p. 14; Social Responsibilities Committee of the Anglican Diocese of Melbourne, *Submission*, p. 14; Australian Christian Lobby, *Submission*, p. 12.

⁸⁰⁹ Dr Doug Gaze, *Submission*, p. 47; Mark Staaf, Professional Officer, Australian Nursing and Midwifery Federation, *Transcript of evidence*, 18 November 2015, p. 44; Dr Michelle Gold, Director, Palliative Care, Alfred Hospital, *Transcript of evidence*, 23 July 2015, p. 55; Palliative Care Victoria, *Submission*, pp. 14–15.

The Committee endorses better palliative care, however, the evidence is clear that this may not always be the solution to all pain and suffering at the end of life. This is discussed at length in Chapters 2 and 3.

Some Victorians are dying terribly at the end of a terminal illness. They are spending the last days and weeks of their lives in pain which cannot be relieved. They are ready to die. They are determined to end their suffering. Some choose starvation or dehydration as their only option to end their life.

These people want what we all want; a good death. Our current medical and legal system can provide this for most Victorians. But for some, it is out of reach.

Because of the way our medical and legal systems are currently regulated, we do not have the data to see the full picture of how people die in Victoria. Practices are not transparent, nor are they adequately recorded.

Some Victorians are being prosecuted for acts of love and compassion towards their relatives and loved ones that violate our criminal law. However, our criminal justice system is showing extraordinary leniency in dealing with them. Without exception, police, prosecutors and judges have used their discretion to ensure those prosecuted for helping loved ones to die do not face the full effects of the law. Whilst this may be a desirable outcome on a case-by-case basis, it threatens to bring the law into disrepute and undermine public confidence in the administration of justice.

Some Victorians who want to help a loved one to end their life are ending their own life as well, out of fear of prosecution for providing assistance. They may not want to die, but neither do they want to face the prospect of prosecution that exists under our current criminal justice system.

Some Victorians are being assisted to die by doctors. This is happening without regulation, without support, without transparency or accountability, and from the evidence received, sometimes without their consent.

In short, the current legal framework is not serving Victorians well.

The Committee recognises people's suffering and resolved to consider what legislative action, if any, should be taken to best serve Victorians at the most difficult time of their lives.

The community wants this support from health professionals — wants it to be available — but the law lags far behind, leaving health professionals and families in limbo. We should not continue to shirk this issue. We are a mature community, and we can do better. We must provide legal clarity, rather than just sweeping the issue under the carpet.

Vicki Davidson, Group Member, National Seniors Australia, public hearing
21 October 2015

8.3 The options

The Committee believes that there are three options for proceeding, three paths the Committee can take to address the suffering described above:

1. maintain the status quo
2. enforce the current legal framework
3. change the law

8.3.1 Maintain the status quo

The Committee rejects this as an inadequate, head-in-the-sand approach to policy making and to the plight of the Victorians described in this Report. To maintain the status quo risks ignoring the evidence of the harm that occurs within it. In light of the evidence submitted, the Committee has determined that this is not an acceptable outcome.

The status quo is, if not causing, then facilitating or allowing great pain. The Committee does not wish this to continue.

8.3.2 Enforce the current legal framework

The Committee heard next to no evidence in favour of increasing efforts to enforce our current law. The majority of arguments against legalising assisted dying did not engage with the fact that the current law is not being enforced, or indeed why this is the case.

Law enforcement officers working in the field did not suggest that stronger enforcement was appropriate.

The Committee notes the point made in an article by Professor Roger Magnusson, Professor of Health Law and Governance at the University of Sydney about the effect of strictly policing and prosecuting offences in the practice of medicine:

Any attempt to suppress the covert practice of euthanasia by actively investigating suspicions and prosecuting offenders would also require a massive commitment to policing clinical functions. The most common euthanasia recipes consist of overdoses of relatively accessible, therapeutic drugs. A more aggressive policing of analgesics, sedatives, and antidepressants would have a disastrous impact on pain relief and symptom management. The resulting climate of “defensive medicine” would seriously undermine palliative care. Doctors would fear giving adequate levels of pain relief, and chronically ill and dying patients would suffer because of it.

I see doctor-assisted dying as a compassionate and caring approach. People are now kept alive longer and the dying process is protracted. Modern medical technology enables expensive, futile interventions that only put off the inevitable death and may cause unnecessary suffering. It is not about choosing between life and death but about ways of dying.

Susan MacDougall, personal submission

It seems plausible to argue that a policy of aggressive policing would not only fail, but because of its effect on patients, could also lead to renewed calls for PAS/AE [physician assisted suicide/active euthanasia] to be legalised.⁸¹⁰

The Committee has described the existing problem of some doctors' fear and hesitancy in giving adequate pain relief.⁸¹¹ The Committee does not believe an approach that exacerbates this problem benefits our health practitioners, nor the Victorians they serve.

The Committee does not know what the precise outcome of more strict enforcement of Victoria's current laws would be. However, outcomes the Committee can predict with relative confidence include:

- greater certainty of the consequences of breaking the law
- an increased climate of 'defensive medicine' as described by Professor Magnusson above
- incarceration of doctors and loved ones for crimes ranging from inciting suicide to murder⁸¹²
- continued lonely, horrific suicide by people who experience irreversible deterioration in physical health.

The Committee does not see fostering these outcomes as best serving Victorians.

8.3.3 Change the law

The Committee heard extensive evidence supporting legalising assisted dying through regulatory or legislative change. This could be achieved through various legal reforms:

- Prosecutorial guidelines that recognise the criminality of the conduct, but include discretion for the criminal law not to be enforced in appropriate cases. See for example the *England and Wales Crown Prosecution Service Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide*.⁸¹³
- Creating a defence to prosecution of 'benevolent intent' or similar to existing criminal law. See for example the Swiss law on assisted dying.⁸¹⁴
- Creating a new statutory framework to allow and regulate assisted dying under certain conditions. See for example the approach taken in Oregon and other states in the United States, the Canadian province of Québec, the Netherlands and soon Canada.⁸¹⁵

⁸¹⁰ Roger S Magnusson, 'Euthanasia: Above ground, below ground', *Journal of Medical Ethics*, vol. 30, no. 5, 2004, p. 444.

⁸¹¹ See section 3.10 in Chapter 3.

⁸¹² For example, see cases from 1992 to 2013 in Chapter 6.

⁸¹³ The Director of Public Prosecutions, 'England and Wales Crown Prosecution Service policy for prosecutors in respect of cases for encouraging or assisting suicide', viewed 31 March 2016, <www.cps.gov.uk>.

⁸¹⁴ See for a description Appendix 3 and Udo Schüklenk, et al., 'End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making', *Bioethics*, vol. 25, no. s1, 2011, pp. 59–60.

⁸¹⁵ See for a description Appendices 3 and 4, and *Ibid.*, pp. 58–59.

The Committee has considered these approaches carefully, through its examination of experiences of jurisdictions where these approaches exist,⁸¹⁶ and the arguments presented by witnesses and in submissions.

The Committee notes that reform achieved through prosecutorial guidelines or a defence of ‘benevolent intent’ means that assisted dying remains a criminal offence. Further, the Committee’s research in Switzerland indicated that although Swiss law appears to be broadly accepted in that jurisdiction, it would not be a suitable model for Victoria. The Swiss approach does not provide the necessary explicit safeguards, accountability and transparency that the Committee thinks necessary for a robust assisted dying framework in Victoria.

Similarly, creating a defence to prosecution in existing criminal law is an inadequate response to the problems raised in this Inquiry. The Committee does not believe that prosecution of assisted dying is in the public interest, nor does it align with the Victorian community’s values. Further, the existing evidentiary obstacles and reluctance of law enforcement authorities to prosecute doctors as discussed in Chapter 7 would remain. Assisted dying would be no more transparent or accountable if a criminal defence to prosecution was created. Transparency in assisted dying practice is an important goal for the Committee.

While each approach has its advantages and disadvantages to be taken into consideration, any Victorian response must also be tailored to best fit with Victorian culture and values.

Accordingly, the Committee has reached a decision which it believes best addresses the negative outcomes resulting from Victoria’s current law relating to assisted dying. This response takes into consideration the vast evidence provided to the Committee, and provides a positive step forward.

8.4 The Committee’s decision — An assisted dying framework

The Committee has examined a wealth of academic research and other publications investigating assisted dying. Many of these were published by eminent academics in respected journals, some were produced by committees performing inquiries similar to this one. These publications often examined the arguments presented for and against legalising assisted dying, and it was

At present in most jurisdictions in this country any person, suffering more than he/she wishes to bear can refuse to accept any treatment and virtually commit suicide. It is surprising that we as a community can watch the patient slowly die but cannot help to bring a swift end to that life. I find that baffling. To me that is not compassion, it is cruelty.

Ranjan Ray, personal submission

⁸¹⁶ For more see Appendices 3 and 4.

through examining these that the Committee gained a solid understanding of the issues at hand.⁸¹⁷

Recent publications from Canada, the United Kingdom, and here in Australia provided an overview of the issues surrounding assisted dying both from an academic and ethical standpoint, and a practical implementation standpoint.

At the time of writing Canada is considering its own assisted dying legislation. While this is the result of a legal decision by Canada's Supreme Court,⁸¹⁸ it is informed by a body of publications from the past five years that closely investigated assisted dying. These publications include academic papers and reports from:

- the Royal Society of Canada Expert Panel⁸¹⁹
- the Québec National Assembly Select Committee on Dying with Dignity⁸²⁰
- the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying⁸²¹
- the University of Toronto Joint Centre for Bioethics Task Force on Physician-Assisted Death⁸²²
- the External Panel on Options for a Legislative Response to *Carter v Canada*⁸²³
- the Canadian Parliament's Special Joint Committee on Physician-Assisted Dying, including a dissenting report.⁸²⁴

In amongst the 80-year-old contemporaries that I mix with in my retirement village and at the bowls club and Probus clubs where I go now, we 80-year-olds now talk about what is happening and when we see members going off and passing away, but none of us fear death. None of us fear death because when you get to our age you know it is inevitable. When you are your age, you think you are invincible — and I did too. But when you get to our age, you realise you are not, and that one of these days it is going to happen to you. So there is no fear of death. The fear, the real fear, is the manner of death. This is the fear.

We see our contemporaries dying in different ways. Some of them die very peacefully and without any problems at all, others die quickly and some die in terrible circumstances. Another terrible fact is that only 14 per cent of people die at home. The rest do not even die at home. I think legislation can change that.

Hon Rod Mackenzie OAM, public hearing
16 September 2015

⁸¹⁷ See Appendix 7 for a summary of these arguments.

⁸¹⁸ *Carter v Canada (Attorney General)*, BCSC 2012.

⁸¹⁹ Udo Schüklenk, et al., 'End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making', *Bioethics*, vol. 25, no. s1, 2011.

⁸²⁰ Select Committee on Dying with Dignity, *Dying with Dignity*, National Assembly of Québec, Québec, 2012.

⁸²¹ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final report*, 2015.

⁸²² University of Toronto Joint Centre for Bioethics Task Force on Physician Assisted Death, *After Carter v. Canada: Physician assisted death in Canada — Report and recommendations*, University of Toronto, Toronto, Canada, 2015.

⁸²³ Harvey Max Chochinov, et al., *Consultations on physician-assisted dying: Summary of results and key findings — Final report*, External Panel on Options for a Legislative Response to *Carter v. Canada*, 2015.

⁸²⁴ Special Joint Committee on Physician-Assisted Dying, *Medical assistance in dying: A patient-centred approach*, Parliament of Canada, Ottawa, Ontario, Canada, 2016.

In 2011 the UK Commission on Assisted Dying released its report titled ‘The current legal status of assisted dying is inadequate and incoherent...’. The report reviewed the existing legal and policy approach to assisted dying in England and Wales. Led by Lord Falconer, with research from Demos and financial support from Sir Terry Pratchett and Bernard Lewis, the Commission’s report was comprehensive, covering all aspects of the assisted dying debate in the UK.⁸²⁵

It is available in other parts of the world. We have seen that it can be very safely regulated. The predictions of abuse and a slippery slope simply have not been borne out by the evidence that has just been released from the Netherlands, Belgium and Switzerland. This affords people with options that they see as fundamental to controlling their life.

Professor Julian Savulescu, Director, Oxford Uehiro Centre for Practical Ethics, public hearing 19 August 2015

In January 2013 not-for-profit research organisation Australia21 and Queensland University of Technology held a roundtable on the question ‘How should Australia regulate voluntary euthanasia and assisted suicide?’. The roundtable resulted in a report which detailed the differing views of those involved.⁸²⁶ The background paper to the discussion, also titled ‘How should Australia regulate voluntary euthanasia and assisted suicide?’⁸²⁷ was written by Professors Benjamin White and Lindy Willmott of Queensland University of Technology. This paper summarised Australian law on assisted dying, arguments surrounding the issue, as well as laws and data from jurisdictions that allow some form of assisted dying.

The Committee has also focused on describing how medicine and the law shape end of life experience for Victorians, and how this can be improved.

The Committee recognises that there are a number of Victorians who wish to have the option of choosing assisted dying. The Committee’s Inquiry has led it to conclude that this option would reduce the extraordinary suffering they encounter at the end of life, and the toll this takes on loved ones.

Research into Victorian and international jurisdictions has satisfied the Committee that the methods used in assisted dying are sound and help that small cohort of patients who want this option to achieve a peaceful death.

The evidence is clear that assisted dying can be provided in a way that guards against abuse and protects the vulnerable in our community in a way that unlawful and unregulated assisted dying does not. The Committee is satisfied, through its research into international jurisdictions, that assisted dying is currently provided in robust, transparent, accountable frameworks. The reporting directly from such frameworks, and the academic literature analysing them, shows that the risks are guarded against, and that robust frameworks help to prevent abuse.

⁸²⁵ The Commission on Assisted Dying, *The current legal status of assisted dying is inadequate and incoherent...*, Demos, London, 2011.

⁸²⁶ Bob Douglas, et al., *The right to choose an assisted death: Time for legislation?*, Queensland University of Technology and Australia21, Brisbane, 2013.

⁸²⁷ Benjamin P White and Lindy Willmott, ‘How should Australia regulate voluntary euthanasia and assisted suicide?’, *Journal of Law and Medicine*, vol. 20, no. 2, 2012.

The Committee travelled to jurisdictions that allow assisted dying to better understand how it operates in practice. In discussions with experts in the Netherlands, Canada, Switzerland and Oregon, the Committee developed a strong understanding of how and why these frameworks have, for many years, met the needs of those seeking another option at the end of life, in the context of robust medical systems.

The Australian Christian Lobby,⁸²⁸ the Catholic Archdiocese of Melbourne,⁸²⁹ Doctors Opposed to Euthanasia,⁸³⁰ the Australian Catholic Bishops Conference,⁸³¹ and the Australian Family Association,⁸³² amongst others, suggested that safeguards in assisted dying frameworks cannot provide adequate protection for the vulnerable.

The Committee also met with opponents from overseas jurisdictions where assisted dying is legal, who expressed similar concerns.⁸³³

While their concerns about the safety of vulnerable people and the need for them to be protected are valid and should inform the design of any assisted dying framework, the Committee did not find evidence to support these concerns.

The Committee met with doctors, medical and legal experts, palliative care specialists and disability rights groups in jurisdictions where assisted dying is legal and who highlighted the rigorous safeguards, monitoring procedures and high levels of compliance in their jurisdictions.⁸³⁴

Critically, as detailed in Chapter 7, Victoria's existing legal framework on assisted dying does not provide adequate protection of vulnerable people.

The Committee appreciates that there are diverse views on the issues this Inquiry addresses and believes that Victorian law can reflect this diversity. The Committee considers that Parliament is best placed to represent such views and to enact reform to improve the end of life options for Victorians.

The law should enable the small percentage of eligible Victorians who want help to end their suffering to die surrounded by loved ones, without fear of prosecution.

RECOMMENDATION 49: That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report in Annex 1, Assisted Dying Framework Summary.

⁸²⁸ Australian Christian Lobby, *Submission*, p. 7.

⁸²⁹ Catholic Archdiocese of Melbourne, *Submission*, p. 6.

⁸³⁰ Doctors Opposed to Euthanasia, *Submission*.

⁸³¹ Australian Catholic Bishops Conference, *Submission*, p. 3.

⁸³² Australian Family Association, *Submission*, p. 10.

⁸³³ Dr Theo A Boer, Lindeboom Professor of Health Care Ethics, Theological University Kampen; Ms Margaret Dore, Attorney, Choice is an Illusion; Ms Carine Brochier, Project Manager, European Institute for Bioethics Brussels, Belgium.

⁸³⁴ Refer to Appendix 2 (List of overseas meetings).

The framework should be implemented as described in detail in this Report, and summarised in Annex 1 of this Chapter.

The assisted dying framework legislation should include an 18-month period between Royal Assent and operation, to allow appropriate time to prepare for implementation on a practical and clinical level.

Before outlining further details of the proposed framework, two issues need to be addressed:

1. There should be no 'right' to assisted dying.
2. No doctor, other health practitioner or health service should be forced to participate in assisted dying.

8.4.1 No 'right' to assisted dying

The framework should not establish an unencumbered right to assisted dying. Rather, it should make the practice legal if all criteria are met.

There should be no presumption of access to assisted dying. Access will be determined by the careful assessment of a robust set of criteria by those best placed to do so: the person themselves, a primary doctor, and an independent secondary doctor.

Assisted dying should not be an unencumbered right. Rather, it should be made available to those who request it and meet all the relevant criteria.

8.4.2 Conscientious objection

The Committee recognises the right of doctors, other health practitioners and health services to conscientiously object to assisted dying. The Committee appreciates the concerns expressed by providers of palliative care services that neither doctors nor health services should be forced to perform assisted dying.

No one should be forced to facilitate assisted dying.

The codes of conduct and ethics of the medical profession are instructive on this matter.

The Australian Medical Association Code of Ethics states:

- k. Respect your patient's right to choose their doctor freely, to accept or reject advice and to make their own decisions about treatment or procedures.

...

- p. When a personal moral judgement or religious belief alone prevents you from recommending some form of therapy, inform your patient so that they may seek care elsewhere.⁸³⁵

835 Australian Medical Association, 'Code of ethics', viewed 30 March 2016, <ama.com.au/>.

Other health practitioners, such as nurses, have similar statements in their codes of ethics.⁸³⁶

These codes are commendable and it is the Committee's view that whilst the code quoted above refers to 'therapy', others are broader. It is the responsibility of regulatory bodies to provide sufficient guidance to ensure a properly functioning assisted dying framework. Doctors and other health practitioners should continue to be guided by their codes of ethics.

No doctor, other health practitioner or health service can be forced to participate in assisted dying.

8.5 Overview of proposed assisted dying framework

The decision to recommend that Parliament enact an assisted dying framework is not one that the Committee makes lightly.

The Committee has thoroughly investigated the issues and been circumspect in its deliberations. It is profoundly indebted to all who made contributions to this work: every person and organisation who wrote to the Committee, those who sat before the Committee and told their stories and the experts who shared a wealth of knowledge and experience.

A clear and transparent legislative framework is necessary to ensure access to assisted dying for those, and only those, who meet the eligibility criteria. On this point, the Committee supports the statement made in the United Kingdom's Commission on Assisted Dying Report:

While clear eligibility criteria would be an essential feature of robust legislation, we certainly do not suggest that these criteria should be approached as a tick-box exercise. Instead, it would be essential that each criterion was investigated thoroughly as part of an ongoing discussion and dialogue between the individual and their doctor, and where appropriate including other professionals responsible for that person's end of life care.⁸³⁷

It is that person's choice – to be able to pass away peacefully, maybe surrounded by loved ones and at one's own choosing, is the kindest act society could allow for someone in unmanageable pain.

Prue and Max Beck, personal submission

A small proportion of cases fail to obtain relief of pain and distress by those [palliative care] means. Their plea for assistance to die with dignity before the loss of control of bodily functions and when still able to farewell family and friends, requires legal approval.

Halina Strnad, personal submission

⁸³⁶ Nursing and Midwifery Board of Australia, 'Code of ethics for nurses', viewed 19 April 2016, <www.nursingmidwiferyboard.gov.au/>, p. 2.

⁸³⁷ The Commission on Assisted Dying, 'The current legal status of assisted dying is inadequate and incoherent...', Demos, London, 2011, p. 301.

Assisted dying should be incorporated into existing end of life care processes in order to protect and support patients and ensure sound medical practice. Ensuring high standards of patient care requires that health practitioners and regulatory authorities work together in implementing an assisted dying framework.

The Committee's research of jurisdictions that allow assisted dying shows that robust oversight, review and reporting will guard against abuse of the framework. The data from these jurisdictions, the academic literature, and what the Committee learned by meeting with doctors and other experts shows that the concerns about abuse have not eventuated. The eligibility criteria and safeguards are restricting access to only those who qualify, and protecting vulnerable people.

Robust oversight, review and reporting processes will also help to provide more detailed information about end of life experiences so the Victorian Government and the health care sector can provide better outcomes for all Victorians at the end of life, regardless of their treatment preferences.

Finally, the Committee believes that the needs of the patient must be squarely at the centre of an effective framework. Ensuring that the rights of patients are respected depends on the expertise and judgment of those working within the framework, particularly doctors.

In saying this, the Committee supports the words of eminent palliative care specialist Professor Ian Maddocks AM:

Rather than fighting a rear-guard action, I suggest the proponents of palliative care join forces with advocates of assisted dying, and with mutual respect and dialogue ensure that enabling laws are framed with a care and precision that allows no abuse and promotes best outcomes.⁸³⁸

8.5.1 Proposed framework is informed by international frameworks

The assisted dying framework the Committee has developed incorporates the lessons it learned during the Inquiry and reflects the values of the Victorian community at large.

The framework has been significantly informed by the Committee's discussions with stakeholders during its research into international jurisdictions. It incorporates what the Committee considers to be the best aspects of these frameworks in the context of Victorian culture and values.

Giving people the right to choose, or not choose, maintains our dignity and humanity. It allows some to avoid some very, very terrible end of life situations. It is the greatest kindness when facing death.

Alana Hadfield, personal submission

⁸³⁸ Ian Maddocks, 'Letter to the editor', *The Monthly*, viewed 27 February 2016, <www.themonthly.com.au>.

This section will explain how the lessons the Committee learned from its research into international jurisdictions informed the recommended framework. Details of the eligibility criteria and safeguards recommended are below at sections 8.6 and 8.7. Details of the oversight, review and reporting mechanisms recommended are below at section 8.9.

8.5.2 The importance of Victorian culture and values

The Committee's research into international jurisdictions was informative in understanding what safeguards and oversight mechanisms work well and what could be improved. The Committee also observed that an assisted dying framework must reflect the values and culture unique to a particular jurisdiction. Certain elements of each framework are effective precisely because they reflect this uniqueness.

For example, a patient in Oregon can receive a prescription for a lethal drug and choose not to see their doctor again. This is because choosing the level of interaction with a doctor reflects the value of self-determination that is fundamental in American culture. Conversely, the more involved nature of the doctor–patient relationship in the Netherlands renders it untenable that a doctor would not be present when a patient undergoes assisted dying.

The lesson the Committee takes from this is that an assisted dying framework must incorporate the culture and values of the people it serves. While some technical aspects of international frameworks may transfer well to Victoria, some may need refinement to align with the legal and medical values and culture that are essential to Victorians. In recommending a framework, the Committee has attempted to do just that — take the best of current practice, and implement it in a way that is suited to Victoria.

Chapter 1 discusses the core values underpinning the Committee's approach to this Inquiry.

8.5.3 Criteria and safeguards

The Committee's recommended framework allows an adult, with capacity, who is at the end of life and has a serious and incurable condition which is causing enduring and unbearable suffering to request assisted dying.

Where the Oregon, Québec and Canadian models include capacity and adulthood as essential criteria, the broader Netherlands model does not. The Committee firmly believes that Victorian values do not support allowing assisted dying to be provided to those who are yet to reach adulthood, nor those who do not have decision making capacity.

It is essential that the patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which the patient deems tolerable, as the Québec model requires. This is fundamental to patient-centred care and,

while a doctor's advice will be invaluable in assisting patients in their decision, in the shift towards patient-centred medicine the Committee believes it is not for others to decide what is and is not tolerable for a patient.

The Committee notes that its recommended framework includes eligibility criteria and safeguards that will make some people who wish to access assisted dying ineligible, for example those who have lost capacity due to dementia or Alzheimer's disease. The Committee recognises this, but believes the eligibility criteria and safeguards are necessary to guard against potential abuse.

8.5.4 Oversight, review and reporting mechanisms

The Oregon model, which is broadly followed in Washington State, Vermont, and California, requires doctors to report all prescriptions for lethal medications to the Oregon Health Authority. The Oregon Health Authority is responsible for notifying the Board of Medical Examiners of any failures in prescribing or reporting requirements. Data is then reported publicly on an annual basis.

The Committee's recommended framework requires that data on assisted dying in Victoria is similarly reported on an annual basis.

It is the Committee's view that whilst this will provide some transparency, more detailed information is necessary to inform all end of life care, not only assisted dying.

End of life care entity

The Québec model of assisted dying includes a Commission on end of life care. Among other responsibilities, the Commission:

- evaluates the implementation of end of life care legislation
- refers to Government any matter relating to end of life care that requires Government attention or action
- reports to Government on the status of end of life care in Québec
- oversees the application of specific requirements relating to assisted dying.

It is the Committee's view that this innovative approach reflects the increasing importance of end of life care to the community and the need for coordination of health services across the continuum of end of life care. The Committee's recommended framework includes a similar entity, with important adaptations, that reflects the importance of palliative care in Victoria's medical system.

One particular adaptation to note is requiring the end of life care entity to provide, or facilitate, training for nurses to be case support workers for patients whose assisted dying request is approved. The Committee believes support should be available to people who access assisted dying throughout their care, including after their request has been approved, and during the processes and

events that follow. To this end, the Committee's framework includes providing trained case support workers, in addition to the existing support in our medical system.

Assisted Dying Review Board

The Regional Euthanasia Review Committees provide a robust, rigorous examination mechanism for assisted dying in the Netherlands. These committees review each case of assisted dying to ensure doctors have followed all procedures and complied with all requirements. Each committee consists of a doctor, a legal expert, and an ethicist. No further action is taken in cases of compliance, but if criteria have not been met the committee refers the case to the public prosecutor.

The Committee's recommended framework includes establishing a similar statewide review board in Victoria to review cases of assisted dying.

Chair in End of Life Care

The expanse of information on end of life issues in some European countries, particularly the Netherlands, far outstrips that available in Canada, the United States, Australia, and in Victoria. In the Netherlands researchers have undertaken repeated, nationwide studies of all deaths every five years since 1990.⁸³⁹

Engaging academics and providing funding for this comprehensive research has produced invaluable information to help determine the needs of people at the end of their lives and how the government can better provide services such as palliative care. This is particularly pertinent to the findings of this Report on the gaps in data on palliative care and advance care planning in Victoria.

The Committee believes end of life care in Victoria would benefit immensely from a strong evidence base that increased end of life care research would produce. As such, the Committee's recommended framework includes the establishment of an academic Chair in End of Life Care to conduct ongoing research.

8.5.5 Four key components

There are four key components of the framework for assisted dying that the Committee is recommending:

1. **Core elements:** the nature of the activity being regulated, and the eligibility criteria that will apply to all who wish to access it.
2. **Legislative safeguards:** processes to ensure that the eligibility criteria are followed, abuse is prevented, and vulnerable people are protected.

⁸³⁹ See for example Bregje D Onwuteaka-Philipsen, et al., 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: A repeated cross-sectional survey', *The Lancet*, vol. 380, no. 9845, 2012.

3. **Additional guidance for health practitioners and services:** practical, clinical and medical guidelines, separate to legislation or in subordinate legislation. These will ensure best practice among health practitioners providing assisted dying, preferably developed in consultation with regulatory authorities, medical experts and professional bodies.
4. **Oversight, review and reporting mechanisms, including education:** a board to review each death, a systematic review process that monitors the framework's performance and publicly reports its findings. Funding also provided for broader academic research on end of life care and choices to inform health policy, along with public and health practitioner education on the assisted dying framework and end of life care more generally.

8.6 Core elements

8.6.1 Activity being regulated — Assisted dying

Assisted dying should in the vast majority of cases involve a doctor prescribing a lethal drug which the patient may then take without further assistance. The singular exception is where people are physically unable to take a lethal drug.

The Committee believes people should not be prohibited from accessing assisted dying because they are physically unable to take a lethal drug. In this case, a doctor should be able to assist a person to die by administering the drug.

In cases where a person is physically unable to take the medication, the primary and secondary doctor are required to specify and document the nature of the inability and why they concluded that assistance was needed. This would provide further safeguards for patients and ensure that data was collected by End of Life Care Victoria to determine whether inability to take the medication needs further investigation, or only occurs in a very limited number of cases.

It is important to emphasise that the requirement for a patient applying for assisted dying to have capacity refers to legal capacity to make the decision, not physical capacity to take a drug.

I am now almost 86 years old and I want the peace of mind that the knowledge of a legal option of medically assisted dying would give me and my family, if my dying were to become too distressful and prolonged.

Anne Kotzman, personal submission

8.6.2 The person

Age

Assisted dying should be accessible only to adults, 18 years and over.

Capacity

Assisted dying should be accessible only by people with capacity to make decisions about their own medical treatment. Those without legal capacity cannot access assisted dying.

Some people in these circumstances see no point to enduring suffering when death is inevitable and proximate. Currently, they may legally decline medical treatment, refuse food and drink and die of dehydration or be sedated until they die. None of these options end in a dignified death, and none are guaranteed to reduce suffering.

Janine Truter, personal submission

The Committee does not support access to assisted dying through any kind of advance care plan or directive.

Doctors routinely make assessments of capacity. As such, the Committee considers that the same expertise can be applied, with judicious care, to people who decide to request assisted dying. Those who decide to request assisted dying will be conscious that an assessment will need to be made by two doctors, and in cases where the possibility that mental illness is affecting capacity has been raised, by a psychiatrist as well.

Residency

Only a person who is ordinarily resident in Victoria and either an Australian citizen or permanent resident may access assisted dying.

This criterion is designed to prevent people coming from outside Victoria to obtain assisted dying. The responsibility for determining whether a patient is a Victorian resident and Australian citizen or permanent resident lies with the primary and secondary doctors.

The primary and secondary doctors may satisfy themselves that a patient is ordinarily resident in Victoria through their established relationship with the patient, and/or if necessary through documentary evidence. This could include:

- a Victorian driver's licence
- enrolment to vote in Victorian elections
- medical records
- evidence that the patient owns or leases property in Victoria.

The Committee believes that doctors are best suited to determine residency on a case-by-case basis, as occurs in other jurisdictions. There is precedence for this approach being effective in Oregon.

8.6.3 The request

The request must come from the person themselves. A substitute decision maker may not request assisted dying for a person, despite any power granted to them by virtue of their position as substitute decision maker. The person must have capacity. A request cannot be included as part of an advance care plan or directive.

The primary and secondary doctors must be independently satisfied that the patient's request is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of a lethal drug. In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely illness trajectory. The primary and secondary doctors must also assess the reasonableness of the request. This is to ensure that the patient truly understands and appreciates the nature and consequences of the decision to request assisted dying, as well as the alternatives to assisted dying, and that the patient's request is not ambivalent.

The request must be completely voluntary and properly informed.

The voluntariness of the decision, and whether it is free of coercion, will be judged first by the person's primary doctor, and then by an independent secondary doctor. See section 8.7 below for more information.

The primary and secondary doctor must each properly inform the patient:

- of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results
- of palliative care and its benefits
- that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time
- of the probable result and potential risks of taking the lethal drug.

I want the peace of mind that the legal option of voluntary euthanasia would give me NOW as my dying process becomes more and more awful. It would be such a relief. Not just to me but to my family who have so often watched me crying or screaming with pain.

Christine Hamann, personal submission

A patient must make three requests, as detailed below, before a doctor can prescribe a lethal drug, or end a patient's life by administering the drug. The patient must:

- make an initial verbal request
- complete a formal written request in a form outlined for that purpose⁸⁴⁰
- make a final verbal request.

⁸⁴⁰ This form will become part of the record of the assisted death, and be used for oversight and reporting purposes. See for example forms used in Oregon: Oregon Health Authority, *Request for medication to end my life in a humane and dignified manner*, Oregon Health Authority, Portland, 2014. and Vermont: Vermont Department of Health, 'Request for medication for the purpose of hastening my death', viewed 27 April 2016, <healthvermont.gov>.

The written request must be signed by two independent witnesses, with provisions for people who cannot physically sign a request.

The patient may withdraw their request at any time. If withdrawn, the request becomes void, and the primary and secondary doctor must assess any subsequent request from the beginning.

This process ensures that the decision to request assisted dying is well considered, and that the person has a period of time to reflect on it and discuss it with loved ones.

8.6.4 The condition

Assisted dying should be accessible only to those who are:

- at the end of life (final weeks or months of life), and
- suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.

Suffering as a result of mental illness only does not satisfy the eligibility criteria. The Committee did not receive evidence during its Inquiry that compelled it to consider including mental illness alone as part of the eligibility criteria to access assisted dying.

The Committee investigated these criteria extensively, examining laws in jurisdictions that allow assisted dying and discussing how it works in practice with those responsible for overseeing its implementation in the Netherlands, Switzerland and Oregon, and those who will soon do so in Canada.

Each jurisdiction has a different approach to the condition a person must have to access assisted dying. There are various reasons for this, including historical, cultural, legal and political factors.

For example, doctors in Oregon told the Committee that the requirement that a patient be within six months of death to access assisted dying is based not on a medical judgement, but on the fact that federal funding for hospice care is available to Oregonians at that point.

The Committee's view is that assisted dying in Victoria should be provided only to those who are at the end of life, as determined by a primary doctor and an independent secondary doctor. The Committee does not support an assisted

The rise of palliative care in 1998–99 coincided with the start of the Death with *Dignity Act* and I think they work together because we were trying to do right by the patients. I think that we wanted to do our best job by the patients and we wanted to keep the lines of communication open. So that's why I think it's all better because of this, rather than worse.

Dr Jocelyn White, Medical Director of Legacy Palliative and Hospice Care, Legacy Health, briefing 7 April 2016, Portland, Oregon

dying framework that extends beyond this. Assisted dying should provide an option that can limit suffering at the very end of life, not a way to end life for those who are otherwise not dying.

The evidence shows that simply knowing there is an option of assisted dying can be immensely beneficial to a person nearing the end of life, whether or not they choose to use it. In Oregon, approximately 30 per cent of people who are prescribed a lethal drug under the assisted dying framework do not take it.⁸⁴¹ For some the feeling of control such an option provides helps to ease suffering and fear of a painful death. This was reflected in evidence the Committee heard from people who are seriously ill and want another option at the end of life.

Doctors are best placed to assess whether a patient is at the end of life. The Committee trusts the judgement of doctors, specialists and health practitioners in determining whether a patient is at the end of life, according to the nature of their condition and its likely trajectory. The Committee believes that empowering doctors to make this assessment is preferable to allocating an arbitrary time limit based on factors that are not applicable to the Victorian context. For example, the six-month requirement specified in the Oregon framework which is based on access to hospice benefits is not applicable to the Australian context which provides universal health care. The Committee believes that this model would in practice apply to those with weeks or months to live, not years, as is the experience in overseas jurisdictions.

Assisted dying should be made available to adults with decision making capacity who are at the end of life and suffering from a serious and incurable condition, which is causing enduring and unbearable suffering that cannot be relieved in a manner they deem tolerable.

Suffering as a result of mental illness only, does not satisfy the eligibility criteria.

Only Australian citizens or permanent residents who are ordinarily resident in Victoria should be eligible.

We found that once patients even had the prescription in their homes it just gave them a sense of comfort and many of them never even used it.

...

We found it was patients who most feared loss of autonomy or dignity who wanted the PAD [physician assisted dying] option ... Those kinds of patients where having that prescription and knowing they could use it or they have their fear about pain and symptom control alleviated, then they don't want to.

Barb Hansen, Chief Executive Officer, Oregon Hospice and Palliative Care Association and Executive Director of Washington State Hospice and Palliative Care Organization, briefing 7 April 2016, Portland, Oregon

⁸⁴¹ Oregon Public Health Division, *Oregon Death with Dignity Act: 2015 data summary*, Oregon Health Authority, Portland, United States, 2016, p. 2. Of the 1545 patients that have had prescriptions written for a lethal drug since the *Death with Dignity Act* was passed in Oregon in 1997, 991 have filled the prescription and died from ingesting the drug.

Assisted dying should be provided in the form of a doctor prescribing a lethal drug which a person may then take themselves, or in the case of a person being physically unable to take the drug themselves, the doctor administering the drug.

The request to access assisted dying must be completely voluntary, properly informed, and satisfy the verbal request, formal written request, repeat verbal request procedure described above.

8.7 Legislative safeguards

This section outlines the additional legislative safeguards that will reinforce protections in the core elements described in this Chapter to ensure only those who meet all criteria can access assisted dying.

8.7.1 Approval by two or more doctors

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition.

Each doctor must independently judge whether the person is:

- at the end of life
- suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable
- making a voluntary decision, free from coercion
- making a properly informed decision (see section 8.7.2).

In cases where either doctor is concerned that the patient's decision making capacity may be impaired by mental illness, they must refer the patient to a psychiatrist. The psychiatrist should then determine whether the patient is suffering from mental illness that makes them incapable of making informed decisions about medical treatment. It is important to note that the psychiatrist is a third doctor who is independent from the first and second doctors.

To strengthen the scrutiny provided by the second doctor, the Royal Dutch Medical Association established a program called Support and Consultation on Euthanasia in the Netherlands. It provides doctors with a detailed understanding of the assisted dying framework and how to strictly apply safeguards.

Research has shown that a second assessment undertaken by these specifically-trained doctors is more rigorous and comprehensive than in other instances.⁸⁴²

⁸⁴² Marijke Jansen-van der Weide, et al., 'Quality of consultation and the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN)', *Health Policy*, vol. 69, no. 3, 2007, p. 99.

As such, End of Life Care Victoria (see section 8.9.2) may consider implementing a similar program, to enhance the knowledge and compliance of doctors providing assisted dying in Victoria. This is a subject that could be addressed in consultation with the Australian Medical Association. They may wish to address the establishment of protocols and information and education programs for doctors.

Whatever approach is taken by the medical profession, it is essential that the secondary doctor is independent of both the patient and the primary doctor. The secondary doctor must review the patient's record, examine the patient, and provide their assessment in writing. This written assessment will form part of the official record.

While both the primary and secondary doctor have responsibilities under the framework, the responsibility for ensuring compliance with procedural statutory requirements, including reporting requirements, lies with the primary doctor.

To this end, the primary doctor must submit documentation on all formal written requests, whether approved or rejected, to End of Life Care Victoria. For approved requests, this should occur after the patient has died.

Approved requests will be reviewed by the Assisted Dying Review Board and data on approved and rejected requests will be reported publicly by End of Life Care Victoria. For more on oversight, review and reporting see section 8.9.

The Committee considered whether to have a review board assess each assisted dying case before approval. However, the Committee's view is that doctors, rather than a review board, are in the best position to assess whether a patient is eligible for assisted dying.

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be satisfied that the patient is at the end of life, suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable, making a voluntary decision, free from coercion, and making a properly informed decision.

In cases where either doctor is concerned that the patient's decision making capacity may be impaired by mental illness, they must refer that patient to a psychiatrist to determine whether the patient is capable of making decisions about their own medical treatment. Not all cases of mental illness impair a patient's decision making capacity.

8.7.2 Patient must be properly informed

Patients must be properly informed of certain medical and procedural information to make a valid request for assisted dying.

Patients requesting assisted dying must be properly informed:

- of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results
- of palliative care and its benefits⁸⁴³
- that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time
- of the probable result and potential risks of taking the lethal drug.

In closing, I just want to say that Australia and Victoria have world's best practice medical staff, doctors, nurses, medical facilities, and to suggest that they would be somehow coerced or ill-informed about a decision that I might make about what I want to happen to me at the end I think is misinformed. It is almost insulting to their intelligence that you would think that they would not take my thoughts into consideration.

Suzanne Jensen, public hearing
16 September 2015

It will be the role of the primary and secondary doctors to properly inform the patient of the information described above. Each doctor must be independently and separately satisfied that the patient is properly informed.

The Committee highlights the importance of informing the patient of palliative care. As discussed previously, awareness of palliative care, its benefits and the relief it can provide is lower than what the Committee considers is acceptable. There may be instances where palliative care will provide a patient with the relief they seek, and they simply need to be made aware of that option.

A patient must be properly informed of their diagnosis, prognosis, and therapeutic treatment options, including palliative care and its benefits. The patient must also be informed of the probable result and potential risks in taking the lethal drug, and that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time.

All these criteria must be met to the satisfaction of the primary and secondary doctor for a patient to make a valid request for assisted dying.

8.7.3 Request must be properly considered

Throughout the Committee's research, including its research into international jurisdictions, the Committee learned of various approaches to ensuring a patient's request for assisted dying was enduring.

The purpose of this provision in all frameworks is to ensure that patients are not accessing assisted dying without proper consideration.

⁸⁴³ For more information see Chapter 2.

Some jurisdictions, such as Oregon and other states in the United States, prescribe specific waiting or cooling-off periods between an initial request and the provision of a lethal drug.⁸⁴⁴ European legislation is less specific, with wording along the lines of doctors being certain of the ‘durable’ nature of the request, and holding multiple interviews with the patient at reasonable intervals, having regard to the evolution of the patient’s condition.

The Committee recognises the need to guard against impulsive decisions by people experiencing extreme physical and emotional pain in the darkest hours of their lives. The Committee also believes that it is unreasonable to mandate an arbitrary cooling-off period that denies some people who would otherwise qualify to access this option at the end of life. This point was highlighted by doctors working in hospice care in Oregon who explained that many requests for assisted dying come from patients extremely close to death, who then die before the prescribed 15-day cooling-off period lapses.⁸⁴⁵

Doctors routinely assess whether medical treatment decisions are properly considered. As such, the Committee believes the best approach is to allow doctors to determine whether this criterion is established.

The primary doctor is best placed to judge the enduring nature of the patient’s request in the context of the trajectory of their condition. The independent secondary doctor is best placed to act as a safeguard to ensure the judgement of the primary doctor is reasonable. These assessments, combined with the requirement that a patient be ‘at the end of life’, provide the necessary protection to ensure requests are properly considered, while also taking into account a patient’s condition and likely deterioration.

The primary and secondary doctors must be independently satisfied that the patient’s request is enduring, and that a reasonable amount of time has passed between the patient’s initial request, and the provision of a lethal drug. In making this judgement, the primary and secondary doctors must have regard to the particular condition, and likely trajectory of the patient. An enduring request, by its very nature, requires an ongoing and sustained interest over time.

8.8 Implementation Taskforce

Evidence gathered during the Inquiry indicated that there are clinical and practical implementation issues in establishing an assisted dying framework that require further investigation. The Committee believes that a Taskforce of experts and medical practitioners is best placed to investigate and advise on the best approach to these issues.

⁸⁴⁴ In Oregon’s *Death With Dignity Act*, the period is described as ‘No less than fifteen (15) days shall elapse between the patient’s initial oral request and the writing of a prescription ... No less than 48 hours shall elapse between the patient’s written request and the writing of a prescription’ and ‘In order to receive a prescription for medication to end his or her life in a humane and dignified manner, a qualified patient shall have made an oral request and a written request, and reiterate the oral request to his or her primary doctor no less than fifteen (15) days after making the initial oral request.’

⁸⁴⁵ This is also supported in Katrina Hedberg and Susan Tolle, ‘Putting Oregon’s Death with Dignity Act in perspective: Characteristics of decedents who did not participate’, *Journal of Clinical Ethics*, vol. 20, no. 2, 2009, p. 133.

The Taskforce will investigate and recommend the clinical and practical guidelines necessary for the implementation of assisted dying. This will include making recommendations to the Minister for Health for regulations under the Act regulating the assisted dying framework.

The Taskforce's work will include investigating and recommending:

- procedures for recording data on assisted dying requests, whether granted or not
- guidelines for doctors administering assisted dying, including guidelines on what medication to administer to patients
- guidelines for pharmacies and pharmacists in storing, transporting, and filling prescriptions involving drugs for assisted dying
- methods for facilitating patient access to an independent secondary doctor, or to another primary doctor in the case of conscientious objection
- an accountability system for tracking assisted dying medication that has been prescribed to patients
- procedural requirements for the Assisted Dying Review Board (see section 8.9.1)
- procedures for the Assisted Dying Review Board to provide feedback to doctors who have provided assisted dying
- procedures for the Assisted Dying Review Board to refer non-compliant cases of assisted dying to investigative bodies
- any other relevant processes the Taskforce, End of Life Care Victoria or Minister for Health identifies.

Membership of the Taskforce should comprise representatives from key stakeholders in end of life care and assisted dying, including but not limited to:

- End of Life Care Victoria
- Department of Health and Human Services
- Centre for Palliative Care
- Palliative Care Victoria
- medical professional organisations, such as the Australian Medical Association and the Australian Nursing and Midwifery Federation.

The assisted dying framework should include an Implementation Taskforce comprising the necessary expertise to investigate and recommend solutions for clinical and practical issues surrounding assisted dying to ensure the smooth implementation of the assisted dying framework.

8.9 Oversight, review and reporting

The Committee recognises that there are genuine concerns about protecting vulnerable people and ensuring safeguards are followed in an assisted dying framework.

The Committee shares these concerns, and looked to the international jurisdictions that allow assisted dying to discover what oversight, review and reporting mechanisms they use. This included investigating how well mechanisms work, and what changes people working within the jurisdictions would make to improve their own framework.

Accordingly, the Committee's recommended framework includes a robust oversight, review and reporting structure for the assisted dying framework itself, and end of life care more generally.

A theme that emerged during the Inquiry was that reliable and consistent data in current end of life care in Victoria is lacking. The oversight, review and reporting structure the Committee's recommended framework includes is therefore aimed at addressing this, while also providing appropriate oversight of the assisted dying framework itself. This will help to address existing gaps in information on palliative care and advance care planning detailed in this Report, which will in turn provide a strong evidence base to improve the delivery of end of life health care services.

The structure will include:

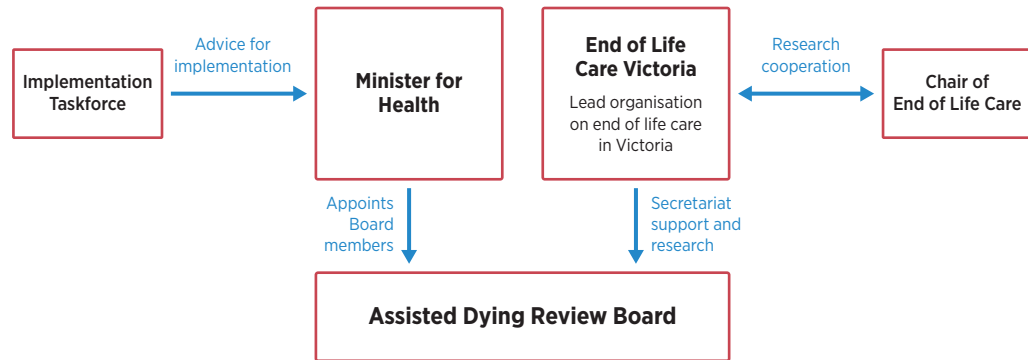
- an Assisted Dying Review Board, to review each approved request for assisted dying
- an entity, End of Life Care Victoria, to:
 - provide policy and strategic direction for end of life care in Victoria⁸⁴⁶
 - gather, analyse and report data on end of life care practices, while also cooperating with the Chair in End of Life Care's research program
 - provide administrative and research support to the Assisted Dying Review Board
 - maintain a hotline for health practitioners seeking advice on end of life care issues, with a particular focus on assisting health practitioners in rural and regional areas who have limited access to end of life care specialists
 - provide information to the public on end of life care issues
 - provide education and training programs in end of life care for health practitioners, including case support workers
 - perform other functions as described in section 8.9.2 below

⁸⁴⁶ This function is currently performed by the Department of Health and Human Services.

- a Chair of End of Life Care, an academic position at a Victorian-based university, established through a Government expression of interest process, to conduct ongoing research into end of life care and choices in Victoria.

The relationship between these bodies is illustrated in Figure 8.1 below.

Figure 8.1 Recommended assisted dying oversight, review and reporting structure



8.9.1 Assisted Dying Review Board

The Committee's investigations of jurisdictions that allow assisted dying and attempted legislation in Australia showed that many assisted dying frameworks include an entity responsible for reviewing cases. Exactly how the entity is constituted and what its role is differs between each jurisdiction.

The Committee's proposed framework has used the Dutch Regional Euthanasia Review Committees model as a basis for case-by-case review. The Committee considers this necessary to ensure a robust assisted dying framework in Victoria. The Committee's recommended framework includes establishing a statewide review entity, the Assisted Dying Review Board.

Administrative support for the Board should be provided by End of Life Care Victoria.

Functions

The Assisted Dying Review Board is to review each instance where a patient's request to access assisted dying has been approved. This should include:

- patients who take the lethal drug prescribed to them, and subsequently die
- patients who are administered a legal drug by a doctor and subsequently die
- patients who receive a prescription for a lethal drug, but do not take the drug, for whatever reason
- patients whose request to access assisted dying is approved, but die before their doctor is able to prescribe the lethal drug.

The function of the Board will not be to approve or reject requests to access assisted dying from patients. That is the role of the primary doctor and independent secondary doctor in each case. Neither will the Board hear appeals from patients whose requests to access assisted dying have been rejected. The purpose of the Board is to ensure that doctors are complying with requirements of the assisted dying framework by reviewing cases of approved requests following the patient's death.

The Board should inform the primary and secondary doctor of its findings once it has completed its review. This should be no later than 90 days after the patient's death.

In the case of administrative, clerical, or minor procedural errors on the part of either doctor, the Board should provide feedback to ensure the doctors involved follow proper procedure in the future.

In the case of breaches, the Board should forward its report to the appropriate authority. Depending on the nature of the breach this may be Victoria Police, the Coroner, and/or or the Australian Health Practitioner Regulation Agency. Those bodies will then determine whether to investigate the case further.

The exact procedures followed by the Board should be included in regulations made by the Minister for Health on the advice of the Implementation Taskforce. See section 8.8 for more.

Membership

The Assisted Dying Review Board should have its membership detailed in legislation, and should consist of the following members, appointed by the Minister for Health:

- a representative of End of Life Care Victoria
- a doctor
- a nurse
- a legal professional
- a community member.

The Committee considered requiring that the Coroner examine each case. However, the Committee believes this is unnecessary because a death that occurs as a result of assisted dying would be reasonably expected and lawful, and therefore would not qualify as a reportable death under section 4 of the *Coroners Act 2008*.

Reporting

The Board should report to Parliament on the operation of the assisted dying framework, including any trends it identifies and recommendations for improvement. End of Life Care Victoria will provide research and administrative support to the Board in preparing the report.

For the purposes of increased transparency and accountability during the initial operation of the assisted dying framework, the Committee's recommended framework requires that the Board report every six months in the first two years of the framework's operation, and annually thereafter. Reports should be published online and be available to the public.

The Board may also report to Parliament in any other circumstance it sees fit to do so.

The assisted dying framework should include an Assisted Dying Review Board as described in this Report.

8.9.2 End of Life Care Victoria

The Committee has determined that establishing End of Life Care Victoria would address several major issues that were raised during the Inquiry and addressed in Chapters 2 through 5 of the Report, including:

- the need for a greater focus on palliative care
- the need to support the move towards community palliative care
- the need for legal reform of the advance care planning framework
- the need for clarification and education on Victoria's advance care planning framework.

End of Life Care Victoria will work closely with palliative care and other end of life care health practitioners and services to enhance and support the excellent work already being done in the Victorian health system. End of Life Care Victoria will aim to increase engagement with end of life care in the community and the health sector as a whole, and to complement the current work being done.

End of Life Care Victoria will not only provide policy and strategic direction on all aspects of end of life care, it will also serve as a point of entry for health practitioners and ordinary Victorians looking for information on end of life care issues, including assisted dying. This will help to address the existing poor levels of understanding of these issues within health professions and the broader Victorian community.

An entity that works to ensure Victorian health services are equipped to provide the best quality palliative care and advance care planning, as well as providing information to the public and health practitioners on assisted dying, reflects the Committee's view that these are all part of the continuum of end of life care. Accordingly, the Committee recommends that End of Life Care Victoria should be provided for in legislation regulating assisted dying.

Transitional functions

Initially, End of Life Care Victoria should be responsible for developing administrative processes to support assisted dying, with advice and guidance on clinical and practical procedures from the Implementation Taskforce (see section 8.8).

Ongoing functions

Ongoing functions of End of Life Care Victoria should include:

- an examination and assessment of the overall functioning of end of life care governance in Victoria
- providing policy and strategic direction for end of life care in Victoria
- collaborating with existing organisations to support and enhance current work on collecting, analysing and reporting data on end of life care practices including:
 - palliative care
 - advance care planning
 - continuous palliative sedation
 - assisted dying (End of Life Care Victoria's data collection function will include analysing statistical data on assisted dying to support the Assisted Dying Review Board's reports to Parliament. This includes data on rejected requests for assisted dying.)
- providing administrative and research support to the Assisted Dying Review Board
- developing and maintaining a register of advance care plans and directives to provide a single location for doctors and health practitioners
- developing and maintaining a register of doctors who are willing to provide assisted dying
- maintaining a hotline for health practitioners seeking advice on end of life care issues, with a particular focus on assisting health practitioners in rural and regional areas who have limited access to end of life care specialists
- providing information to the public on end of life care issues
- providing education and training programs in end of life care for health practitioners
- providing training for nurses to be case support workers for patients whose assisted dying request is approved
- providing counselling for health practitioners who participate in assisted dying
- maintaining a relationship with the Chair of End of Life Care (see section 8.9.3).

The assisted dying framework should include establishing End of Life Care Victoria as described in this Report.

The Committee recognises that establishing a new entity requires a significant amount of resources. However, much of End of Life Care Victoria's proposed work — such as providing support to existing end of life care services, policy effort and governance — is already being done by the Department of Health and Human Services. In addition, based on the experiences of other jurisdictions,

the Committee anticipates that compliance work for assisted dying in Victoria would require only a small amount of resources due to the small number of cases each year.

8.9.3 Chair of End of Life Care

The Committee was impressed with the integration of research undertaken by universities and the provision of health services in the Netherlands. This research provides Dutch policy makers with detailed information about the treatment people receive at the end of life and how health services can be improved.

Repeated cross-sectional surveys of Dutch doctors undertaken every five years are particularly useful as they specify the number of deaths due to all end of life decision making. This includes assisted dying, as well as refusal of treatment, intensified alleviation of symptoms and ending of life without explicit request. The detailed information that is obtained enables health policy makers to target services to better meet the needs of patients and provides greater transparency in all end of life care.

The Committee believes that similar research undertaken in Victoria would help to address the significant gaps in information about end of life care that it found during the Inquiry. Ongoing research into all end of life care, including but not limited to palliative care, advance care planning, continuous palliative sedation and assisted dying would help to develop a strong evidence base as a foundation for end of life care services. As such, the Committee's recommended framework includes establishing the research position of Chair of End of Life Care at a Victorian-based university to conduct ongoing research into end of life care and choices in Victoria. The Chair should be established through a Government expression of interest process.

While the Chair should have independence to determine the direction of research, the Chair in consultation with End of Life Care Victoria should ensure their research functions are complementary.

The assisted dying framework should include establishing and funding a research position of Chair of End of Life Care at a Victorian-based university to conduct ongoing research into end of life care and choices in Victoria. The Chair should be established through a Government expression of interest process.

8.9.4 Five-year review

The Committee recognises that implementing a legislative framework for assisted dying is a significant reform. Accordingly, there should be a review of the framework after an appropriate period of time has passed.

The assisted dying framework that the Committee recommends has originated from a multi-party committee. Any Act based on this Report would be a product of both Houses of Parliament and would also have input from multiple political parties. The Committee is committed to maintaining this multi-partisan

approach and believes an Act providing for assisted dying needs a bicameral review process. The Committee's recommended framework therefore includes that a select committee of Parliament comprising members of the Legislative Council and the Legislative Assembly be established to review any Act regulating assisted dying. The review should occur five years after the Act commences operation.

The Committee should review the provisions of the Act regulating assisted dying and report to the Parliament. In performing its review, the Committee should have regard to the reports published by the Assisted Dying Review Board, End of Life Care Victoria, and research undertaken by the Chair of End of Life Care.

The assisted dying Act and framework should be reviewed by a select committee of both Houses of Parliament, established for that purpose, five years after the Act becomes operational.

8.10 Amendments to other Acts

The assisted dying framework the Committee proposes would conflict with current aspects of Victoria's common law and criminal statute, particularly in the *Crimes Act 1958*. In order to accommodate the assisted dying framework it is necessary to include an exemption to certain offences.

Assisted dying legislation should include consequential amendments to existing legislation to ensure that no health practitioner shall be criminally liable for participating in assisted dying in accordance with the assisted dying framework.

8.11 Annex 1: Recommendation 49

Assisted Dying Framework Summary

The Government should introduce legislation to allow adults with decision making capacity, suffering from a serious and incurable condition who are at the end of life to be provided assistance to die in certain circumstances.

This should include amending the *Crimes Act 1958* to provide the exemptions necessary to protect health practitioners who act within the provisions of assisted dying legislation.

Any assisted dying legislation should include an 18-month period between Royal Assent and operation, to allow appropriate time to prepare for implementation on a practical and clinical level.

1.1 Activity being regulated

Assisted dying should in the vast majority of cases involve a doctor prescribing a lethal drug which the patient may then take without further assistance.

The singular exception is where people are physically unable to take a lethal drug themselves. In this case, a doctor should be able to assist the person to die by administering the drug.

1.2 Conscientious objection

No doctor, other health practitioner or health service can be forced to participate in assisted dying.

1.3 Eligibility criteria and assessment

Assisted dying is intended to provide an option that can limit suffering at the end of life, not a way to end life for those who are otherwise not dying.

A request for assisted dying must be approved by a primary doctor and an independent secondary doctor. Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition. Each doctor must independently judge whether the person's request satisfies all of the criteria outlined below.

The exception to this is the suffering component. It is essential that the patient must be experiencing enduring and unbearable suffering that cannot be relieved in a manner which they deem tolerable. This is fundamental to patient-centred care, and is a subjective measure judged by the patient themselves.

The person	<p>An adult, 18 years and over, with decision making capacity about their own medical treatment.</p> <p>Patients whose decision making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.</p> <p>Ordinarily resident in Victoria and an Australian citizen or permanent resident.</p>
The condition	<p>At the end of life (final weeks or months of life).</p> <p>Suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.</p> <p>Suffering as a result of mental illness only, does not satisfy the eligibility criteria.</p>
The request	<p>Must come from the patient themselves.</p> <p>Cannot be included in an advance care directive.</p> <p>Must be completely voluntary, free of coercion.</p> <p>Must be properly informed. The primary and secondary doctor must each properly inform the patient:</p> <ul style="list-style-type: none"> • of the diagnosis and prognosis of their condition, as well as the treatment options available to them, including any therapeutic options and their likely results • of palliative care and its likely results • that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time • of the probable result and potential risks of taking the lethal drug. <p>Must be repeated three times:</p> <ul style="list-style-type: none"> • an initial verbal request • a formal written request, which must be signed by two independent witnesses • a final verbal request. <p>Must be enduring. The primary and secondary doctors must be independently satisfied that the patient's request is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of a lethal drug. In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely trajectory. The primary and secondary doctors must also assess the reasonableness of the request. This is to ensure that the patient truly understands and appreciates the nature and consequences of the decision to request assisted dying, as well as the alternatives to assisted dying, and that the patient's request is not ambivalent.</p> <p>Patient may withdraw their request at any time. Once withdrawn, the request becomes void, and the primary and secondary doctor must assess any subsequent request from the beginning.</p>

1.4 Implementation Taskforce

There are clinical and practical implementation issues in establishing an assisted dying framework that require further investigation. The Government should establish an Implementation Taskforce of experts and health practitioners to investigate and advise on the best approach to these issues before the assisted dying framework commences.

1.5 Oversight, review and reporting

1.5.1 Assisted Dying Review Board

The Assisted Dying Review Board is to review each approved request for assisted dying.

Membership of the Assisted Dying Review Board:

- a representative of End of Life Care Victoria
- a doctor
- a nurse
- a legal professional
- a community member.

The function of the Board will not be to approve or reject requests from patients to access assisted dying. That is the role of the primary doctor and independent secondary doctor in each case. Neither will the Board hear appeals from patients whose requests to access assisted dying have been rejected.

The purpose of the Board is to ensure that doctors are complying with requirements of the assisted dying framework.

If the Board finds a breach of the assisted dying framework, it should forward its report to the appropriate authority. Depending on the nature of the breach, this may be Victoria Police, the Coroner, or the Australian Health Practitioner Regulation Agency. Those bodies will then determine whether to investigate the case further.

The Board should report to Parliament on the operation of the assisted dying framework, including any trends it identifies and recommendations for improvement. For the purposes of increased transparency and accountability, during the first two years of operation these reports should be every six months. Following that the Board should report annually.

1.5.2 End of Life Care Victoria

The Government should establish a new entity to champion end of life care, and provide information and guidance on end of life care to health services, practitioners and the Victorian community. End of Life Care Victoria will work closely with palliative care and other end of life care health practitioners and services to enhance and support the excellent work already being done in the Victorian health system. End of Life Care Victoria will aim to increase engagement with end of life care in the community and the health sector as a whole.

End of Life Care Victoria will not only provide policy and strategic direction on all aspects of end of life care, it will also serve as a point of entry for health practitioners and ordinary Victorians looking for information on end of life care issues, including assisted dying. This will help to address the existing poor levels of understanding of end of life care issues within health professions and the broader Victorian community.

This also reflects the Committee’s view that these are all part of the continuum of end of life care.

Functions of End of Life Care Victoria will include:

providing policy and strategic direction for end of life care in Victoria	developing and maintaining a register of doctors who are willing to provide assisted dying
gathering, analysing and reporting data on end of life care practices including palliative care, advance care planning, continuous palliative sedation, and assisted dying	maintaining a hotline for health practitioners seeking advice on end of life care issues, with a particular focus on assisting health practitioners in rural and regional areas who have limited access to end of life care specialists
providing administrative and research support to the Assisted Dying Review Board	providing information to the public on end of life care issues
developing and maintaining a register of advance care plans and directives to provide a single location for doctors and health practitioners	providing education and training programs in end of life care for health practitioners, including case support workers
counselling for health practitioners involved in assisted dying	maintaining a relationship with the Chair of End of Life Care at a Victorian-based University.

1.5.3 Chair of End of Life Care

The Government should establish and fund the research position of Chair of End of Life Care at a Victorian-based university. The Chair should be established through a Government expression of interest process. The Chair should perform comprehensive research on end of life care and choices in Victoria. This will produce information that will help determine the needs of people at the end of their lives and how the Government can better provide end of life care.

While the Chair should have independence to determine the direction of research, the Chair should consult with End of Life Care Victoria to ensure their research functions are complementary.

1.5.4 Five-year review

Review of the assisted dying framework by a parliamentary select committee of members from both Houses after five years of operation.

Committee room, 23 May 2016.

Appendix 1

Submissions

A

Abbey, Brian and Jennifer
 Abery, Jillian
 Abetz, Jeremy
 Ackland, M. Leigh
 Action for Life
 Acton, John
 Adam, William
 Agostino, Susan
 Ahern, Eugene
 Aiashi, Trudi and Aiman
 Alcock, William
 Alfred Health
 Allen, Wilma and Grahame
 Alp, Veronica
 Alvaro, Joe
 Alwyn, Meg
 Anaf, Julia
 Anam Cara House Colac Inc.
 Anastasiou, Robyn
 Anderson, Keith
 Anderson, Margaret
 Andrews, Brian
 Anglican Diocese of Melbourne, Social Responsibilities Committee
 Anthony, Kathryn
 Appels, Janis
 Apps, Robyn
 Apthorp, Joan
 Arblaster, Stuart
 Archer, Catherine
 Arena, Franca
 Armstrong, Doris
 Aspinall, Glenn
 Attard, Rita
 Australasian College for Emergency Medicine
 Australian and New Zealand Society for Geriatric Medicine
 Australian and New Zealand Society of Palliative Medicine Inc.

Australian Catholic Bishops Conference
 Australian Catholic University
 Australian Centre for Health Law Research
 Australian Centre for Health Research Limited
 Australian Christian Lobby
 Australian Christians
 Australian College of Nursing
 Australian Family Association
 Australian Health Practitioner Regulation Agency
 Australian Medical Association (Victoria) Limited
 Australian Nursing & Midwifery Federation (Victorian Branch)
 Australian Psychological Society
 Australian Sex Party
 Avant Mutual Group Limited
 Avery, Jennifer

B

Bach, Neil
 Bagguley, Charles and Marianne
 Baker, Donald
 Baker, Louise
 Baker, Richard
 Ballarat Heath Service
 Bamber, Josie
 Barnes, Kay
 Barnes, Louise
 Barnier, Robert
 Barratt, Lynne
 Barrington, Jan
 Barwon Health
 Barnier, Robert
 Basiri, Amir
 Bate, Wendy
 Battova, Brigitte
 Bayley, Donald
 Baynes-Williams, Rupert
 Beattie, Pru
 Beck, Prue and Max

Beehey, J. M.
 Beekmeyer, Stuart
 Bennett, Jim
 Bennett, Lila
 Benson, Simon Michael
 Berg, Sumner
 Beslik, Lydia
 Biasuzzo, Jane
 Bingham, David
 Blackwell, Andrew
 Blair, Nannette
 Blanch, Max
 Bland, Ross
 Blismas, Nick and Natalie
 Boerlage, Coenraad
 Bonavia, Luke
 Bond, Catherine
 Bonwick, Montague
 Borg, Paul
 Boryslawski, Lucien
 Boschen, Ruth
 Bourke, Mark
 Bourne and Associates
 Bowles, Rebecca
 Boyd, Anne
 Boyd, Fiona
 Boyd, Joan
 Boyd, Pamela
 Braby, Robert
 Bradley, Amanda
 Bradshaw, Anthony V.
 Bramich, Fred
 Brandenburg, John
 Branford, Glenn
 Brayshaw, Morna Ann
 Breed, Maria
 Brentnall, Edward
 Britten-Jones, Robert
 Broad, Isabel
 Brolly, Anne
 Bromson, Kerry
 Brown, Gabrielle
 Brown, Jill and John
 Brown, Rhonda
 Browne, Michele
 Bruce, John R.
 Buchanan, John

Buckley, Andrea
 Buegge-Borshoff, Florence
 Bullock, Joe
 Buman, Alison
 Burger, Bruce and Sue
 Burkinshaw, Sam
 Burns, Thomas
 Burnstein, Kate
 Burrows, Rodney
 Burton, Liz
 Butler, Kevin
 Byrne, Greg
 Byrne, Roger
 Byrne, Yvonne

C

Cabrini Health
 Cameron, Denise
 Campbell, Debora
 Campbell, Pauline
 Cancer Council Victoria
 Capper, Sandra
 Carers Victoria
 Carolan, Catherine Mary
 Caroline Chisholm Centre for Health
 Ethics Inc.
 Carroll, John
 Carter, Brad
 Carter, David
 Carter, Irene
 Cartwright, Colleen
 Casanova, John
 Catalano, John
 Catholic Archdiocese of Melbourne
 Catholic Health Australia
 Catholic Social Services Victoria
 Catholic Women's League of Victoria &
 Wagga Wagga Inc.
 Cava, Roberta
 Center, Yola
 Central Hume Primary Care Partnership
 Centre for Palliative Care
 Charles, Owen
 Charnell, Wendy
 Cheesman, Bernadette
 Chevor, Eleanor
 Christian Medical & Dental Fellowship of
 Australia

Christians for Labor
 Christians Supporting Choice for
 Voluntary Euthanasia
 Cipollone, Ettore
 Citroen, Jennifer
 Civil Liberties Australia Inc.
 Clarence, Jodie
 Clark, Frank
 Clarke, Roger
 Cleary, William
 Clegg, Pauline
 Cleigh, W. Carol
 Cleland, Jacquelin Lilian
 Clements, Ken
 Cobain, L.
 Cock, Peter H.
 Cocks, Paul
 Cohealth
 Cohen-Almagor, Raphael
 Coleman, Alan
 Coleman, Peter
 Coleman, Marilyn
 Coles-Rutishauser, Ingrid
 Collier, Mary
 Collins, Joan
 Commissioner for Senior Victorians
 Compton, Helen
 Compton, Roger
 Conlan, Elizabeth
 Connell, John and Helen
 Constantine, Joan
 Cook, Jonathan
 Coombs, Wayne
 Cooney, John
 Cooper, Lee
 Copeland, Paul
 Cora, Dorothy
 Corby, Dora and Max
 Cornelius, Otto
 Coroners Court of Victoria
 Corrigall, Deborah
 Corris, Peter
 Cosstick, Mark
 Costello, Leo and Sally
 Cotching, Daniel
 Coughlan, Brenda
 Council of the Ageing

Cowden, Janet
 Cowen, Rabbi Shimon
 Coyne, Elizabeth
 Cram, Barbara
 Crawford, John
 Cronk, Carol
 Cronk, Oscar
 Crook, Sue
 Cross, Max
 Cross, Richard
 Crump, Sandra
 Cummings, David and Ruth
 Cunningham, John
 Cunningham, Lesley
 Curtis, Linda
 Cutler, David

D

Dakin, Hugh
 Daley, Judith
 Daley, Lois
 Daniel, Lawrie
 Daniels, Norma
 D'Arcy, George and Rita
 Davidson, Rev Warwick
 Davies, Bernadette
 Davis, Charles
 Dawes, Shirley
 Dawson, June
 De Haas, Judy
 de Moulpied, Patricia
 Denton, Andrew
 Dethlefs, Geoffrey
 Devries, Bert and Tina
 Di Lorenzo, Joanne
 Diggins, Ann-Marie
 Dignitas
 Dillon, David
 Ditmarsch, Bill
 Dobson, Paul
 Doctors for Voluntary Euthanasia Choice
 Doctors Opposed to Euthanasia
 Doherty, Kevin
 Doig, Lindsay
 Donegan, Teresa
 Donnelly, Greg
 Donnelly, Matt
 Donohoe, Paul

Doumit, Monica
 Dowsett, Gary
 Drysdale, Graeme
 Duncalf, Barry
 Dying For Choice
 Dying with Dignity ACT Inc.
 Dying With Dignity New South Wales
 Dying with Dignity (NSW) Central Coast Group
 Dying with Dignity (NSW) Port Macquarie
 Dying with Dignity Tasmania
 Dying with Dignity Victoria

E

Eastern Palliative Care Association Incorporated
 Ebert, Kathryn
 Edgar, Sheila
 Elliott, Shan
 Elmes, Rebecca
 Endeavour Forum Inc.
 Eskdale, Terri
 Ethics Committee of the Christian Medical and Dental Fellowship of Australia
 Evans, Len
 Everett, Colin and Josephine
 Eyres, Frances

F

FamilyVoice Australia
 Farrell, Matthew
 Featherston, Julian
 Feeney, Helen
 Ferlin, Fides
 Ferraro, Umberto
 Ferri, Robyne
 Ferwerda, Peter
 Fiddelaers, Carolyn
 Filipovski, Laura
 Fillion, Elaine
 Finn, Christine
 Finter, Derek
 Fisher, William Hayes
 Fiske, Frank and Margaret
 Fitchman, Barbara
 Fitzgerald, Roger
 Fitzpatrick, Janet
 Fletcher, Joy Gwendoline
 Flood, Gerard

Fogarty, F. R.
 Fogarty, Jess
 Ford, Norman
 Foreman, Maria
 Fornito, Tommy
 Forster, David
 Foster, Ralph Reginald
 Franklin, Bertha
 Franklin, Jason
 Franze, Linda
 Fraser, Judith
 Fraser, Lenley
 Fuller, Helen
 Fuller, Virginia
 Furman, Barbara

G

Gaal, Laura
 Gano, Elaine
 Gardner, Valerie
 Garnham, Ken
 Gartrell, Glenda
 Garven, Rhonda
 Gawler, David
 Gawler, Isobel
 Gaze, Doug
 Gear, Rev Spencer
 George, Kuruvilla
 Geschke, Norman
 Geschke, Robert
 Gilbody, Julie
 Gill, Elizabeth
 Gill, John
 Gill, Samuel
 Gilmour, Camille
 Gilmour, Mark
 Gleeson, Marie
 Gleeson, Suzanne
 Glover, Andrea
 Godbold Family
 Godbold, Raymond
 Godbold, Rory
 Godden, Brett and Dianne
 Goldberg, Elizabeth
 Gosbell, Janine
 Graham, Margaret
 Grant, Lidiya
 Grant, Richard and Beverly

Grattan Institute
 Gray, Christine
 Greaves, Earle and Grace
 Green, D.
 Green, Sandy
 Greenhaff, R. W. A
 Greenough, F.
 Greenwood, Beverley
 Griffith, Andrea
 Grigg, Desmond
 Grigg, Lindsay
 Grimstad, Julie
 Grocott, Stephen and Dianne
 Gronn, Kathryn
 Gunter, Robert

H

Hadfield, Alana
 Hallsworth, Sally
 Hamann, Christine
 Hamilton, Tim
 Hannaford, Paul
 Harle, Rob
 Harman, Jennifer
 Harper, Richard
 Harris, David
 Harris, John
 Hart, Doris
 Hartin, Peter
 Harvey, Beverly
 Harvey, Fr. Geoff and Janet
 Harvey, Jim
 Harvey, Stephen
 Harwood, Helen and Kevin
 Hasslacher, Barbara
 Hastie, Liam
 Hatton, Stephen
 Hawkes, Ada and Hubert
 Hawkins, Margaret
 Hawthorn, Alison
 Hawthorn, Kelvin
 Haxell, Phillip
 Hayes, Barbara
 Hayes, John
 Hayes, Mary Anne
 Hayhoe, Brett
 Hayhoe, Paul
 Haynes, Dennis and Pat

Health Issues Centre
 Health Services Commissioner
 Hearn, Joyce
 Hempton, Courtney
 Henderson, Rosemarie
 Hengeveld, Steven, Murna and Tania
 Henke, Hamish and Anita
 Henney, Ronald
 Henry, Reg
 Henry, Douglas M.
 Herman, Rodney
 Herraman, Elice
 Hess, Robert and Shirley
 Hickey, Paul and Helen
 Hickling, Mathew
 Highfield, Lynne
 Higson, Shayne
 Hill, Anna
 Hill, Barry
 Hill, Mary
 Hill, William
 Hitchens, John
 Hocking, Mary
 Hodgson, Robert
 Hogan, Kevin
 Hogan, Bruce and Heather
 Hokin, Allen
 Holliday, Valica
 Honeyman, Julie
 Hont, John
 Hookey, Geoffrey
 HOPE
 Hosking, William
 Houghton, Santhosha Vani
 Howard, Peter
 Hoy, Vikki
 Hoysted, Alan
 Hubbard, David
 Hubbard, Graham
 Hubbard, Paul
 Hughes, Gilian
 Hughes, Therese
 Hum, Steven Istvan
 Humanist Society of Victoria Inc.
 Hunt, Gillian
 Hunt, Roger
 Hurworth, Patricia

Husman, Eduardina

Hutcheson, Marion

I

Iley, John

Isaacs, Sandra

Isocracy Network Inc.

J

Jackson, Dirk

Jago, Arnold

James, Helen

Janson, Vickie

Janssen, Fons and Bronwyn

Jeffries, Shirley

Jensen, Suzanne

Jessiman, Lyn

Jex, Mildred

Johnson, Christopher

Johnson, Paul

Johnson, Philip J.

Johnson, Trish

Johnson, Vivienne

Johnston, Suzanne

Johnstone, Ross

Johnstone, Vicki

Jones, Les and Bev

Jones, Millicent

Jonquiere, Rob

Joseph, Rita

Joy, Kyra Ly

Joyce, Harry

K

Kalotas, Thomas and Susanne

Kastner, Irmgard

Kavanagh, Mary

Keane, Patricia

Keeda, Peter

Keenan, Nigel

Keldoulis, Lilian

Kelly, Bill and Hazel

Kelly, David St Leger

Kelly, Des

Kelly, John

Kelly, Norma

Kemp, Catherine

Kendall, Jan

Kenmar, Doreen

Kennedy, Michael

Kennedy, Rosemary

Kerbone, Richard and Nola

Kerr, Andrew

Kerr, Bruce

Kesbah, Glenn

King, Carolyn

King, Natalie

Kissane, David

Klabbers, Johannes

Knights of the Southern Cross Victoria

Kok, Jereth

Koniuszko, Lidia

Kos, Stefan

Kotzman, Anne

Krietsch, Sylvia

Krins, Tony

Kuhse, Helga

Kumaschow, Lydia

L

La Trobe University, Palliative Care Unit

Lacey, Jan

Lackner, Susan

Ladd, Atala and Elena

Lademan, Eileen

Laidlaw, Kerri

Landvogt, Julie

Lane, Magdalena

Lanham, Anne and Ray

Larcombe, Travis

Large, Anne and Neville

Lastman, Anne

Lau, Michael

Law Institute of Victoria

Leach, Cr Helen

Leake, Peter

Lechner, Henry

Lee, Carolyn

Lee, Edna

Lee, Geraldine

Leeds, Gabrielle

Leitch, Douglas

Lennon, Matthew

Lenzo, Joe

Leschke, John

Leung, Patricia

Lewandowski, Ed

Lewis, Dianne	Mathieson, Eamonn (and signatories)
Lewis, Kenneth	Matthews, Iola
Liberty Victoria	Matthews, Kerryanne
Limb, Jennifer	Matthews, Ron
Lindenmayer, Graeme and Greta	Mavric, Heather
Linnane, Damien	May, Sandra
Lissenden, Jean Valerie	Mayhead, Gerald
Little, Carla	Mazzei, Emilia
Little Sisters of the Poor Aged Care Ltd	McCarthy, Ernest
Littlemore, Chris	McCarthy, Ronda
Lives Worth Living	McCathie, Robert
Lloyd, Alan Murray	McClatchie, Gordon
Lock, Thomas	McCleave, P. J.
Long, Dorothy	McConaghy, Brian
Long, Michael	McCormack, John Francis
Loughlan, Patricia	McCormack, Paul
Lubitz, Karin	McCrae, Carol
Luker, Margaret	McCullagh, Peter
Lushch, Denis	McDonald, Janette
Lynam, Tamplin	McDonald, Lilian
Lynch, Pauline	McDonald, Peter
Lynch, Troy	McDonald, Ronald
Lyttle, Janet	McFarlane, Amy
M	McGarity, Barbara
Maack, Evelyn	McGovan, Bess
MacDougall, Susan	McHardy, Jeanette
Mackenzie, Rod	McInerney, Mary B.
MacLean, Joan	McIntosh, Stephen
MacMillan, Gordon	McIntyre, Beverley
Magree, Brian and Judith	McKay, James
Magree, Terence	McKay, Patrick
Maher, Margaret	McLaren, Ann
Mahony, John	McLaughlan, Mark
Majdali, Kameel	McLennan, Carol
Malicki, Stan	McLeod, Dianne
Mallinson, Gaye	McMahon, Erin
Mangalson, Stan	McNamara, Gary
Manickam, Julia	McPhee, Jodie
Manoy, Robyn	McSweeney, Loretta
Manser, Carol	Meaney, Patricia
Marantelli, Laurie	Mears, Robert
Marcus, Debbie	Medical Oncology Group of Australia Incorporated
Marks, Sheila	Medicine with Morality
Marshall, Jim	Meese, Lesa
Martin, Pamela	Meharg, Bob
Martyres, Raymond	Melbourne Catholic Lawyers Association
Mathai, Anna	

Melbourne City Mission
 Melbourne Health
 Mercy Health
 Metcalf, Flora
 Meyer, Susan
 Middleton, Christopher
 Miles, Judith
 Millar, Graeme
 Millar, Maralyn
 Miller, David
 Miller, James
 Miller, Eliana Freydel
 Milley, Cheryl
 Mills, Gareth
 Mills, Richard
 Minniti, Ashley
 Mitchell, Kahli
 Mitchell, Patricia
 Mitchell, Lisa
 Mitro, Eva
 Moir, Marie
 Monagle, Marisa
 Money, Lawrence
 Moodie, Rob
 Morris, Brian
 Morris, Jane
 Morris-Leonzini, Sandra
 Morrissey, M.
 Morison, Peter
 Morrison, Marty
 Morrissey, John J.
 Morrow, Ann
 Mortier, Tom
 Moseley, Les
 Moynihan, Tracey
 Mummery, Barbara
 Munro, Jane
 Murphy, Jenny
 Murray, Joel
 Murray, Peter
 Murtagh, John
 Musumeci, Joan
 Myers, John
N
 Name withheld (15 name withheld submissions)
 Namow, Tina

National Seniors Victorian Policy Advisory Group
 Navaratne, Rohan
 Naylor, Patricia
 Nerlich, Graham
 Networking Health Victoria
 Newell, Patricia
 Newton, Marie
 Nimon, Joy
 Nitschke, Philip
 Niven, A.
 Nolan, James
 Norwood, Neville
O
 O'Connor, Bill
 O'Connor, Frank
 O'Connor, Margaret
 Oderberg, David S.
 O'Donnell, Bill and Kay
 O'Donnell, Tony
 O'Dwyer, Anne
 Office of the Public Advocate
 O'Hanlon, Paul
 O'Hea, Mary
 Olive, Dorothy
 Oliver, Norma
 Ollerenshaw, David
 O'Loughlin, Carolyn
 Opie, Margaret
 Orchard, Jeremy
 O'Reilly, John
 O'Shea, Barry
 Otlowski, Margaret
P
 Paas, Johannus
 Palliative Care Australia
 Palliative Care Victoria
 Palma, Michael and Maria
 Palmer, Margot
 Parker, G. and S.
 Parker, Yvonne
 Parliamentary Friends of Palliative Care
 Parrott, Barbara
 Pascal, M.
 Paschke, Win and Deidre
 Pask, Sharon

Patterson, Joyce
 Paul, Tony
 Payne, Rachel
 Peake, David
 Pearce, Susanne
 Pearce, Tony and Elizabeth
 Pearson, Beverley
 Pelczynska, Barbara
 Pelczynski, Stanislaw
 Pelletier, Robert
 Perez, Beatriz
 Perrin, David
 Perron, Marshall
 Pestell, Lorraine
 Peters, Robert
 Pfanner, Ruth
 Phefley, Anne
 Phillips, Clare
 Phipps, Graeme and Magda
 Pilcher, Fred
 Pledge, Stephen
 Plunkett Centre for Ethics
 Pollnitz, Robert
 Pollock, Cassandra
 Pollock, Sue
 Ponsford, Caroline
 Pope, Thelma
 Porter, Mary
 Pound, Brian
 Powell, Harley
 Powell, Julia
 Presbyterian Church of Victoria, Church
 and Nation Committee
 Prescott, Bronte
 Price, Mary
 Prichard, Jeremy
 Progressive Atheists Inc.
 Pro-Life Victoria
 Proud, Helen
 Pryor, Lyn
 Pryor, Malcolm and Rosemary
 Public Health Association Australia
 (Victorian Branch)
 Pulitano, Rosa
 Puls, Kathleen
 Purdie, Grant
 Purton, Doug

Q
 Quinn, Bernadette
 Quinn, Peter
R
 Rabinowicz, Dvora
 Rael, Andrew
 Rainier, Marilyn
 Rampertshammer, Alfred
 Ramsay, Belinda
 Rapley, Sylvia
 Raskine, Mikhail
 Rationalist Society of Australia
 Rawlins, Judith
 Rawlins, Judith A.
 Ray, Ranjan
 Reale, Frank
 Redding, Graham
 Regos, Nodda
 Reid, Benjamin Andrew
 Reid, Graeme
 Reid, Margaret and Derek Gordon
 Reid, Judy
 Reiffel, John
 Reilly, Mary
 Renehan, Michael and Jo
 Reti, Paul
 Reynolds, Norm
 Richards, Leith
 Richmond, Coralie
 Riddell, Anne
 Ride, Patricia
 Ridley, Laine
 Riedel, William
 Right to Life Australia Inc.
 Ritchie, Susan
 Roberts, Clyde J.
 Roberts, Debra
 Roberts, Elaine
 Roberts, June
 Roberts, Lyal and Judie
 Roberts, Lyn
 Robertson, Bonita
 Robertson, Melissa
 Robinson, Edward
 Robinson, Susan
 Robson, Graeme

Robson, Dawn
 Rodda, John
 Rodriguez, Charles B.
 Roebuck, Tracey
 Rogers, Kathy
 Rommel, Glenda
 Ronc, Joanna
 Rosenberg, Anna
 Rosenblatt, Jill
 Royal Australasian College of Physicians
 Royal Australian and New Zealand College
 of Psychiatrists
 Royal, Christine
 Rule, Brenton
 Rutnam, Romaine
 Ruys, Paul
 Ryan, Barrie

S

Salt Shakers
 Samman, Michaela
 Scanlon, David
 Scarlett, Maureen
 Scherek, Paul
 Schuklenk, Udo
 Schumann, Angela
 Scott, Lyndal R.
 Scott, Peter
 Shaw, Dawn
 Shaw, Kate (and sisters)
 Shea, Patrick
 Sheahan, Geoff
 Sheehan, Betty
 Shell, Alan
 Sheppard, Nancy
 Sheridan, Bert
 Sheriden, Margaret
 Shorland, Allan
 Short, Bill (and other residents of Cherry
 Tree Grove Retirement Village)
 Short, Elizabeth
 Shuttle, David
 Simcoe-Fitzmaurice, Mark
 Simmons, Gwen
 Simpson, Anne
 Simpson, George
 Simshauser, Cheryl
 Singer, Peter

Sisters of Nazareth—Geraldton
 Community
 Slatyer, David
 Sleeman, Glenys
 Smeaton, Elaine
 Smith, Colin
 Smith, Helen
 Smith, Lachlan
 Smith, Michael
 Smith, Peter
 Smith, Roger
 Snaauw, John
 Sobey, Annie
 Soo, Victor and Crystal
 Souter, Elisabeth
 South Australian Voluntary Euthanasia
 Society
 Southern Cross Care Victoria
 Sparrow, Linda
 Speech Pathology Australia
 Speidel, Rosmarie
 Spicer, John
 Spinks, Julie
 Spiritual Health Victoria
 Spirovska, Nevena
 Stamm, Mort
 Stanley, Alison
 Stanton, John
 Stebbing, Duncan
 Steer, Kay
 Stephen, Paul
 Stephens, Elizabeth
 Stephenson, Rod
 Stevenson, Rhonda
 Stewart, Ian
 Stewart, Joyce Hilda
 Stewart, Maree
 Stewart, Robert
 Still, Peter
 Storm, Caroline
 Strangman, Denis
 Stratis, Sotiria
 Strickland, Susan
 Strnad, Halina
 Stuckey, Phillip and Richard E.
 Sullivan, Marie and Kevin
 Sumpter, Pamela
 Sutherland, Lisa

Sutherland, Max
 Sutton, Peter J.
 Swan, Kate
 Swan Hill District Hospice
 Swanton, David
 Swarbrick, M. L.
 Sweeney, Julianne
 Swinnerton, Neville
 Sykes, Hugh
 Syme, Rodney
 Synnott, David
 Sypkens, Susan

T

Tallott, Jared
 Taylor, Judy
 Taylor, Patricia
 Taylor, Sarah
 Tent, Adriaan and Geertruida
 Tetteroo, John
 Thomas, Bob
 Thompson, Brian
 Thompson, Beverley
 Thorpe, Lea
 Thurbon, Patrick and Yvonne
 Tighe, Margaret
 Ting, Dora
 Tinker, Ross
 Tinsley, Michael P.
 Tiong, Poh Huong
 Tobias, Heather
 Tobin, Judith A.
 Tognetti, K.
 Toohill, Graham
 Toulantas, Jill
 Traill, Joan
 Trautman, Jodie
 Trousdell, Bruce
 Truter, Janine
 Tucker, Cathi
 Tung, Peter
 Turner, Angela
 Turner, Joseph
 Turner, Ken
 Turner, William and Irene

U

Uphill, Ann
 Usher, Keith

V

van Brummelen, Graeme
 van der Horst, Joel David
 van der Linden, Maureen
 van der Straaten, Anne
 Veldman, Hetty
 Valenta, Tom
 Verkerk, Michelle
 Vertigan, Katrina
 Very Special Kids
 Vevers, Sherryn
 Victorian Auditor-General's Office
 Victorian Clinical Leadership Group on
 Care of Older People in Hospital
 Victorian Government
 Victorian Healthcare Association
 Victorian Secular Lobby Inc.
 Villa Maria Catholic Homes
 Voluntary Euthanasia Party (NSW)
 Voluntary Euthanasia Party (VIC)
 Voorendt, Nicolaas

W

Waddington, Margaret and Michael
 Walker, Anne
 Walker, Geoffrey
 Walker, Linda
 Wall, Geoff
 Wall, Joyce
 Walsh, Mary
 Walsh, Sandy
 Wannan, Lynne
 Ward, Belinda
 Ward, Maurice
 Waterman, Mary
 Waterman, Robert
 Watkins, Jo
 Watts, Elaine
 Webberley, Helen
 Weinberg, Sherri
 Welsh, Jim
 Western Australia Department of Health
 — WA Cancer and Palliative Care Network
 Western Health
 Westwood, Barbara
 Wheelhouse, Kevin
 Whelan, Tony
 White, Janet

White, Joan Ann
White, Lynette
White, Michelle
Whitehead, Peter
Wicks, Lyn
Wielechowska, Krystyna
Wignell, Edel
Wilberforce Foundation
Wilce, Robert
Willcocks, Peter
Williams, Carolyn
Williams, Deborah
Williams, Geoffrey
Williams, Jennifer
Williams, Michael
Williamson, Kathie
Wilcox, Dianne
Wilson, Catriona
Wilson, Peter
Wilson, Darryl Raymond
Wilson, Margaret
Wilson, Trent
Wilson, John D.
Wingrove, Lorna
Winship, Brian
Wittick, Alan and Andrea
Wong, Yvonne
Wood, Kamini
Wood, Nancy
Woodger, Anne
Woolf, Kath
Woulfe, John
Wynter, John

X**Y**

Young, John
Young, Terry and Cheryl
Young, Nancy

Z

Zeimer, Mira

Appendix 2

Public hearings, briefings, site visits and meetings

A2.1 Public Hearings

23 July 2015, Melbourne

Name	Title	Organisation
Professor Paul Komesaroff	Director	Centre for Ethics in Medicine and Society
	Faculty of Medicine, Nursing and Health Sciences	Monash University
Professor Hal Swerissen	Emeritus Professor, College of Science, Health and Engineering	La Trobe University
	Visiting Fellow, Health Program	Grattan Institute
Professor Loane Skene	Director of Studies, Health and Medical Law, Faculty of Law and Faculty of Medicine, Dentistry and Health Sciences	University of Melbourne
Ms Frances Diver	Deputy Secretary, Health Service Performance and Programs	Department of Health and Human Services
Ms Jackie Kearney	Project Director, End of Life Care	
Ms Pauline Ireland	Director, Health Review and Regulation	
Dr Michelle Gold	Director, Palliative Care	Alfred Hospital
	Member, Australasian Chapter of Palliative Medicine	Royal Australasian College of Physicians
Associate Professor William Silvester	President	International Society of Advance Care Planning and End of Life Care

29 July 2015, Geelong

Name	Title	Organisation
Dr Peter Martin	Regional Director, Palliative Care	Barwon Health
Mr Paul Cohen	Acting Chief Executive Officer	
Dr Alastair Mah	Chief Medical Officer	
	Chair, End of Life Care Steering Committee	
Ms Robyn Hayles	Chief Operating Officer, Community Health, Rehabilitation, Palliative and Aged Care, and Mental Health	
Ms Jill Mann	Coordinator, Respecting Patient Choices Program	
Mr Mark Arnold	Nurse Manager, Inpatient Rehabilitation Centre	

Name	Title	Organisation
Mr Christopher McCormick	Nurse Unit Manager	Barwon Health
Dr Neil Orford	Medical Director, Intensive Care Unit	
Ms Jacqui White	Coordinator, Community Palliative Care	
Ms Joy Leggo	Chief Executive Officer	Multicultural Aged Care Services, Geelong
Ms Lyn McCarter	Manager, Complete Care	
Ms Karin Bauer	Community Services Manager	
Ms Sue White	Chairperson	Hospice Foundation Geelong
Mr Jason Trethowan	Chief Executive Officer	Western Victoria Primary Health Network
Dr Ric Milner	General Practitioner, You Yangs Medical Clinic	
Ms Julie Jones	Chair	
Ms Karlie Keck	Coordinator, Community Nursing and Support Program	Barwon South Western Region Palliative Care Consortium
Dr Peter Martin	Regional Director, Bellarine Palliative Care Services	
Ms Jane Robertson	Community Nurse Manager, Colac Palliative Care Services	
Ms Helen Hunter	Private capacity	
Ms Helen Newell	Private capacity	

30 July 2015, Warrnambool

Name	Title	Organisation
Ms Andrea Janes	Registered Nurse, Acting Nurse Coordinator, Subregional Palliative Care	South West Healthcare
Mr John Quinlivan	Nurse Unit Manager, Medical/Palliative Care Inpatient Unit	
Dr Emma Greenwood	Medical Director, Palliative Care	
Ms Sue Marsh	Paediatric Unit Manager	Warrnambool and District Community Hospice
Ms Deidre Bidmade	Vice President	
Mr Damian Goss	Board Member	
Ms Tam Vistarini	Hospice Manager	Portland District Health Service
Ms Fiona Heena	Director, Primary and Community Care	
Ms Jeanette Beaglehole	Community Palliative Care Volunteer	
Ms Lyn Smith	Community Palliative Care Volunteer	Deakin University
Associate Professor Tim Baker	Director, Centre for Rural Emergency Medicine	
Ms Usha Naidoo	Manager, Care Coordination	
Ms Jacquie Page	Palliative Care Consultant	Western District Health Service, Hamilton
Ms Judy Sommerville	Volunteer	
Ms Elizabeth Gore	Hospice Coordinator	Anam Cara House Colac

12 August 2015, Bendigo

Name	Title	Organisation
Dr Jason Fletcher	Staff Intensivist Advance Care Planning Clinical Lead	Bendigo Health
Associate Professor Marc Budge	Medical Director, Clinical Rehabilitation and Geriatric Medicine	
Ms Elizabeth Loughnan	Acting Manager, Loddon Mallee Regional Palliative Care Consultancy Service, Bendigo Community Palliative Care Service	
Ms Catherine Kemp	Palliative Care Coordinator, Swan Hill Palliative Care Services	Swan Hill District Health
Ms Melissa Weaver	Care Manager	Strath-Haven Community
Ms Marlene Connaughton	Manager of Integrated Services	
Dr Ewa Piejko	Medical Adviser General Practitioner	Murray Primary Health Network
Councillor Helen Leach	Councillor	City of Greater Bendigo
Professor Teresa Iacono	Professor of Rural and Regional Allied Health, College of Science, Health and Engineering, Living with Disability Research Centre	La Trobe University
Ms Diana Hookey	Private capacity	
Mr Geoffrey Hookey	Private capacity	
Mr Andrew Huntley	Private capacity	
Mr John Carty	Private capacity	

13 August 2015, Shepparton

Name	Title	Organisation
Ms Carolyn Hargreaves	After-Hours Hospital Manager	Goulburn Valley Health
Ms Annette Cudmore	Clinical Nurse Consultant	West Hume Palliative Care Consultancy Service
Dr Arup Bhattacharya	Divisional Clinical Director, Medical, Goulburn Valley Health	
Mr Vin White	Nurse Unit Manager, Intensive Care Unit	Goulburn Valley Health
Ms Carmel Smith	Executive Manager	Goulburn Valley Hospice Care Service
Dr John Hetherington	President, Committee of Management	
Dr Margi Gould	General Practitioner, Yarrawonga Medical Clinic	Central Hume Primary Care Partnership
Mr Ronald Henney	Private capacity	
Mr Dean Walton	Executive Manager, Aged Care Services	Rumbalara Aboriginal Co-operative

19 August 2015, Melbourne

Name	Title	Organisation
Professor Julian Savulescu	Uehiro Chair in Practical Ethics	Oxford University
	Director, Centre for Neuroethics	
	Sir Louis Matheson Distinguished Visiting Professor	Monash University
	Doctoris Honoris Causa	University of Bucharest
	Editor in Chief	Journal of Medical Ethics
Dr Ranjana Srivastava	Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences	Monash University
	Oncologist	
	Columnist	Guardian Newspaper
	Presenter	ABC Television and Radio National

9 September 2015, Traralgon

Name	Title	Organisation
Ms Vicki Doherty	Manager	Gippsland Region Palliative Care Consortium
Ms Irene Murphy	Regional Nurse Practitioner Mentor	
Dr Brian McDonald	Clinical Director, Palliative Care	Peninsular Health
	Consultant	Gippsland Region Palliative Care Consortium
Ms Melissa Marr	Carer Mentor	Gippsland Carers Association Inc.
Councillor Dale Harriman	Coordinator	
Ms Norma Kelly	Private capacity	
Dr Luke Williams	Clinical Lead	Latrobe Community Health Service, Morwell
Ms Naomi Griffiths	Assistant Manager, Ambulatory Care	
Ms Jenny Turra	Palliative Care Nurse Practitioner	
Dr Simon Fraser	Chief Medical Officer	
Ms Amanda Cameron	Acting Chief Executive Officer	Latrobe Regional Hospital
	Director, Nursing, Midwifery and Clinical Services	
Dr Tricia Wright	Physician	
Ms Terri Eskdale	Private capacity	
Mr Owen Charles	Private capacity	
Ms Cheryl Bush	Executive Manager, Clinical and Nursing Services	Gippsland Lakes Community Health
Ms Nicola Gorwell	Palliative Care Nurse Practitioner Candidate	
Dr Jane Fischer	Chief Executive Officer, Medical Director	Calvary Health Care Bethlehem
Mr Tony Paul	Private capacity	

16 September 2015, Melbourne

Name	Title	Organisation
Hon Rod Mackenzie OAM	Former Chair of the Social Development Committee	Parliament of Victoria
Dr Natasha Michael	Director, Palliative Medicine	Cabrini Health
Ms Suzanne Jensen	Private capacity	
Mr Dan Flynn	Victorian Director	Australian Christian Lobby

7 October 2015, Melbourne

Name	Title	Organisation
Coroner Caitlin English	Coroner	Coroners Court of Victoria
Coroner John Olle	Coroner	
Dr Jeremy Dwyer	Manager, Coroners Prevention Unit	
Mr Mick Hughes	Detective Inspector, Homicide Squad	Victoria Police
Mr Rod Wilson	Acting Commander, Homicide Squad	

14 October 2015, Melbourne

Name	Title	Organisation
Ms Maree McCabe	Chief Executive Officer	Alzheimer's Australia Victoria
Dr David Sykes	General Manager, Learning and Development	
Ms Sue Hendy	Chief Executive Officer	Council on the Ageing
Ms Janet Wood	Former President	
	Vice President	International Federation on Ageing
Mr Lachlan Smith	Private capacity	
Ms Lesley Vick	President	Dying with Dignity Victoria
Dr Rodney Syme	Vice President	
Rabbi Dr Shimon Cowen	Director	Institute for Judaism and Civilization
Ms Tracey Mander	Manager, Palliative Care	Melbourne City Mission
Ms Deborah Fewster	Head of Policy, Advocacy and Government Relations	
Dr Jenny Hynson	Head, Victorian Paediatric Palliative Care Program	Royal Children's Hospital

15 October 2015, Melbourne

Name	Title	Organisation
Associate Professor Charlie Corke	Intensive Care Specialist	Barwon Health
Mr Graeme Lovell	Private capacity	
Mr Ian Wood	National Coordinator	Christians Supporting Choice for Voluntary Euthanasia
Ms Mary Hocking	Physiotherapist in Palliative Care	
Professor David Kissane	Head, Department of Psychiatry	Monash University
Dr Ken Harvey	Member	Doctors for Voluntary Euthanasia Choice
Associate Professor Peter Hunter	Chair	Victorian Clinical Leadership Group on Care of Older People in Hospital

21 October 2015, Melbourne

Name	Title	Organisation
Mr Arnold Bates	Chair, Policy Advisory Group	National Seniors Australia
Ms Vicki Davidson	Group Member	
Mr Alan Castleman	Chair	Australian Centre for Health Research
Ms Rebecca Bartel	Chief Executive	
Mr Norman Geschke OBE	Private capacity	
Mr Neil Francis		DyingForChoice.com

29 October 2015, Mornington

Name	Title	Organisation
Mr Rory Godbold	Private capacity	
Ms Tara Szafraniec	Private capacity	
Ms Helen Ridgeway	Positive Ageing Officer	Mornington Peninsula Shire Council
Mr Tom Valenta	Private capacity	
Ms Rosemarie Draper	Deputy Chair	Peninsula Care Planning Group
Ms Michelle Clancy	Team Leader, Palliative Care	Royal District Nursing Service
Ms Lisa Rollinson	Chairperson	Ageing Well Alliance
Ms Mary Waterman	Private capacity	
Mr William Darby	Chairperson	Peninsula Advisory Committee for Elders
Dr Doug Gaze	Private capacity	
Dr Peter Lynch	Clinical Director, Aged Care Medicine	Peninsula Health
Mr David Goldberg	General Counsel	

18 November 2015, Melbourne

Name	Title	Organisation
Mr Bill O'Shea	Member, Health Law and Elder Law Committees	Law Institute of Victoria
Ms Michelle Whyte	Senior Lawyer, Legal Policy	
Dr Grant Davies	Health Services Commissioner	Office of the Health Services Commissioner
Monsignor Anthony Ireland	Episcopal Vicar for Health, Aged and Disability Care	Catholic Archdiocese of Melbourne
Father Anthony Kerin	Episcopal Vicar for Life, Marriage and Family	
Mr Jason Franklin	Private capacity	
Mr Ian Patrick	General Manager Clinical and Community Services	Ambulance Victoria
Mr Mark Staaf	Professional Officer	Australian Nursing & Midwifery Federation
Ms Colleen Pearce	Public Advocate	Office of the Public Advocate
Mr Phil Grano	Principal Legal Officer	
Dr John Chesterman	Director of Strategy	
Dr Katrina Haller	Chief Executive Officer	Right to Life Australia
Mr Andrew Denton	Broadcaster and Producer	

25 November 2015, Melbourne

Name	Title	Organisation
Ms Kym Peake	Secretary	Department of Health and Human Services
Ms Simone Corin	Director, Health Programs Branch	
Ms Jackie Kearney	Project Director, End of Life Care, Health Service Programs	
Ms Georgie Haysom	Head of Advocacy	Avant Mutual Group

24 February 2016, Melbourne

Name	Title	Organisation
Professor Peter Hudson	Director	St Vincent's Hospital and Collaborative Centre of the University of Melbourne
Associate Professor Mark Boughey	Director, Palliative Medicine, and Co-Deputy Director	
Associate Professor Jennifer Philip	Deputy Director, Palliative Medicine, and Co-Deputy Director, Centre for Palliative Care	
Dr Anthony Bartone	President	Australian Medical Association Victoria
Professor John Tobin	Co-Director of Studies, Human Rights Law	University of Melbourne, Melbourne Law School

A2.2 Briefings

10 June 2015, Melbourne

Name	Title	Organisation
Mr Michael Bramwell	Chair	Palliative Care Victoria
Ms Odette Waanders	Chief Executive Officer	

23 June 2015, Melbourne

Name	Title	Organisation
Professor Cameron Stewart	Pro Dean and Professor of Health, Law and Ethics	University of Sydney

24 June 2015, Melbourne

Name	Title	Organisation
Professor Margaret Somerville AM	Founding Director, Centre for Medicine, Ethics and Law	McGill University, Canada

16 March 2016, Melbourne

Name	Title	Organisation
Professor Ben White	Public Health and Health Services	Queensland University of Technology
	Co-Director, Australian Centre for Health Law Research	
Professor Lindy Willmott	Public Health and Health Services	
	Co-Director, Australian Centre for Health Law Research	

A2.3 Site Visits

29 July 2015, Barwon Health, Geelong

Name	Title	Organisation
Dr Peter Martin	Regional Director, Palliative Care	Barwon Health
Mr Paul Cohen	Acting Chief Executive Officer	
Dr Alastair Mah	Chief Medical Officer Chair, End of Life Care Steering Committee	

30 July 2015, Warrnambool and District Community Hospice, Warrnambool

Name	Title	Organisation
Ms Deidre Bidmade	Vice President	Warrnambool and District Community Hospice
Mr Damian Goss	Board Member	

26 August 2015, Austin Hospital, Melbourne

Name	Title	Organisation
Associate Professor Daryl Jones	Intensive Care Specialist	Austin Health
Dr Simon Judkins MBBS. FACEM.	Clinical Director, Emergency Medicine	
Dr Juli Moran	Director, Palliative Care Services	
Dr Karen Detering	Respiratory Physician Clinical Ethicist	
Dr Sarah Charlton	Palliative Medicine Physician	
Ms Kathy Whiteside	President, ACP SIG Committee	
Ms Sharon Neyland	Leader, Austin ACP implementation	

A2.4 Meetings**21 March 2016, Melbourne (via video conference)**

Name	Title	Organisation
Dr Harvey Max Chochinov, MD, PhD, FRCPC	Distinguished Professor of Psychiatry	University of Manitoba
	Director, Manitoba Palliative Care Research Unit	CancerCare Manitoba
	Chair	External Panel on Options for a Legislative Response to Carter v. Canada

29 March 2016, Amsterdam, Netherlands

Name	Title	Organisation
Mr Eric van Wijlick	Senior Staff Member	Royal Dutch Medical Association (KNMG)
	Clinical ethicist	Erasmus Medical Centre
Mr Gert Van Dijk	Medical ethicist	Royal Dutch Medical Association
	Senior ethics advisor	Euthanasia Review Board
Dr Gerrit Kimsma MD	General Practitioner	Scientific Institute for Quality of Health Care, Department for Ethics and Philosophy of Medicine, Radboud University Medical Center
	Associate Professor in Medical Philosophy	

30 March 2016, Amsterdam, Netherlands

Name	Title	Organisation
Dr Marianne Donker	Director, Public Health Department	Ministry of Health, Welfare and Sports
Mr Jim Terwiel	Policy Coordinator and Deputy Head	
	Legal Coordinator, Public Health Directorate	
Ms Sara Dekking	Senior Policy Advisor, Ethics Section	
Mrs Tessa Klitsie	Policy Officer, Health Ethics	Ministry of Security and Justice
Ms Maartje van der Linden	Legal Adviser, Directorate for Legal and Operational Affairs	
Professor Ann Ruth Mackor	Professional Ethics, Faculty of Law	University of Groningen
	Member, Supervisory Board, Code of Practice	Regional Euthanasia Review Committee (Groningen, Friesland and Drenthe and BES Islands)

31 March 2016, Amsterdam, Netherlands

Name	Title	Organisation
Professor Bregje Onwuteaka-Philipsen	End of Life Care, Research Institute for Health and Care Research	VU University Amsterdam
Dr Theo A Boer	Lindeboom Professor of Health Care Ethics	Theological University Kampen
Dr Aycke Smook	Medical Practitioner	Right to Die Europe
	President and Founder	
	Board Member	Euthanasia Research & Guidance Organization, Oregon

1 April 2016, Amsterdam, Netherlands

Name	Title	Organisation
Ms Krista Jansen	Policy Advisor	Dutch Right to Die Society
Mr Rob Jonquiere	Communications Director	

2 April 2016, Zurich, Switzerland

Name	Title	Organisation
Ludwig A Minelli	Secretary General	Dignitas
Mr Silvan Luley	Manager	
Dr Frank Th. Petermann	President	Swiss Medical Lawyers Association
Mr Alexander E Harbaugh	Communications Manager	
Ms Franziska Sutter	Assistant	

4 April 2016, Montreal, Canada

Name	Title	Organisation
Mrs Véronique Hivon	Member for Joliette	National Assembly of Quebec
	Opposition critic for end of life care	
	Opposition critic for justice and legislation	
Ms Pascale Sévigny	Former Vice-Chair	Select Committee on Dying with Dignity
	Secretary Policy, Head of Communications, Office of the Member for Joliette	National Assembly of Quebec

4 April 2016, Ottawa, Canada

Name	Title	Organisation
Dr Karima Velji	President	Canadian Nurses Association
	Member	Provincial-Territorial Expert Advisory Group on Physician Assisted Dying
Ms Anne Sutherland Boal	Chief Executive Officer	Canadian Nurses Association
Ms Carolyn Pullen	Director of Policy, Advocacy and Strategy	
Ms Josette Roussel	Senior Nurse Advisor, Professional Practice	
Professor Jocelyn Downie	Professor of Law	Pierre Elliott Trudeau Foundation Fellow
	Associate Dean, Graduate Studies	Faculty of Medicine, Health Law Institute, Schulich School of Law
	Member, End of Life Experts Panel	Royal Society of Canada (2009-2011)

5 April 2016, Ottawa, Canada

Name	Title	Organisation
Ms Jessica Prince	Senior Policy Advisor, Office of the Minister for Justice and Attorney General of Canada	Parliament of Canada
Mr Sean J. Casey MP	Member for Charlottetown, Parliamentary Secretary for Justice	
Senator Jim Cowan	Senator, Municipality of Nova Scotia	
	Former member, Special Joint Committee on Physician-Assisted Dying	
Ms Shaila Anwar	Acting Deputy Principal Clerk, Senate Committees	
	Former Committee Joint Clerk, Special Joint Committee on Physician-Assisted Dying	
Ms Cynara Corbin	Committee Joint Clerk, Special Joint Committee on Physician-Assisted Dying	
Ms Julia Nicol	Legal and Legislative Affairs Division, Parliamentary Information and Research Service, Library of Parliament	
Ms Marlisa Tideman	Social Affairs Division, Parliamentary Information and Research Service, Library of Parliament	
Ms Caitlin Gropp	Policy Advisor, Senate of Canada	
Ms Barbara Kagedan	Senior Policy Advisor, Senate of Canada	

5 April 2016, Portland, Oregon

Name	Title	Organisation
Senator Elizabeth Steiner Hayward MD	State Senator, District 17	Oregon State Legislature
	Family Physician and faculty member	Oregon Health and Science University
	Director	OHSU Knight Cancer Institute Breast Health Education Program
	Board member	Oregon Academy of Family Physicians
Representative Mitch Greenlick	Chair, House Committee on Health	Oregon State Legislature
Mr Lane Shetterley	Chair	Oregon Law Commission
Mr Bryan Boehringer	Chief Executive Officer	Oregon Medical Association
	Executive Vice President	
Mr Bob Dannenhoffer	Delegate	
Dr Jim Moorhead MD	Former President	
Mr Matt Wittaker	Multi-state Implementation Manager	Compassion and Choices
Dr Leigh Dolin MD	Intensivist	Providence Portland Medical Centre
Ms Sandy Thiele-Cirka	Administrator, House Health Care Committee, Senate Health Care Committee	Oregon State Legislature
Professor Linda Ganzini MD MPH	Professor, Psychiatry and Medicine	School of Medicine, Department of Psychiatry, Oregon Health and Science University
	Director, Geriatric Psychiatry Fellowship Program	
	Director, Division of Geriatric Psychiatry	
	Staff Psychiatrist, Consult-Liaison Psychiatry Service and Outpatient Mental Health	Portland Veterans Affairs Medical Centre
	Director, Health Services Research and Development	
	Director, Interprofessional Fellowship Program in Palliative Care	
Mr Georg Eighmey	President	Death with Dignity National Center
Mr Eli D. Stutsman	Attorney	
Ms Peg Sandeen	Executive Director	

7 April 2016, Portland, Oregon

Name	Title	Organisation
Ms Barb Hansen, MA RN CWON	Chief Executive Officer	Oregon Hospice and Palliative Care Association
	Executive Director	Washington State Hospice and Palliative Care
Dr Jocelyn White	Medical Director, Legacy Palliative and Hospice Care	Legacy Health
Ms Gail Mueller	Manager, Legacy Hopewell House Hospice	
Ms Sharon Vinhasa LCSW	Social Work, Legacy Hospice Services	
Ms Margaret Dore	Chair	
Ms Brenda Ray	Assistant	Choice is an Illusion
Dr Katrina Hedberg MD MPH	State Epidemiologist and State Health Officer, Oregon Public Health Division	Oregon Health Authority

8 April 2016, Portland, Oregon

Name	Title	Organisation
Mr Bob Joondeph	Executive Director	Disability Rights Oregon

13 April 2016, Melbourne (via video conference)

Name	Title	Organisation
Ms Carine Brochier	Project Manager	European Institute for Bioethics (Brussels, Belgium)

Appendix 3

Assisted dying in international jurisdictions

In 2016 a five-member delegation of the Committee conducted international research for this Inquiry. The Committee’s focus was to investigate end of life care frameworks in international jurisdictions, with a particular focus on assisted dying frameworks.

The Committee visited the following jurisdictions:

- Netherlands
- Switzerland
- Canada
- Canadian Province of Québec
- Oregon, United States.

This Appendix gives a summary of the assisted dying frameworks operating in the jurisdictions the Committee’s delegation visited, as well as a timeline describing the path each jurisdiction took in legalising assisted dying.

A3.1 The Netherlands

Table A3.1 Timeline of key events — The Netherlands

Date	Legal mechanism	Event
1973	Case law	Recognised a doctor could lawfully shorten a person’s life to prevent serious and irremediable suffering
1984	Case law	Recognised where a doctor was faced with a request from a patient to die, he or she was entitled to assist the patient to die under the doctrine of necessity
1994–2002	Prosecutorial guidelines	Indicated when a doctor would and would not be charged in relation to ending a patient’s life or assisting a patient to die
2002	Legislation	Doctors could not be prosecuted if they acted with ‘due care’ as defined in the legislation

A3.1.1 Background

While assisted dying was illegal under the Dutch Criminal Code, from 1973–2002 the courts recognised the defence of necessity. A doctor could invoke the defence of necessity when carrying out a patient’s request to die was the only available means to end unbearable and irremediable suffering.

To clarify the scope of assisted dying, the Dutch Government passed the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* in 2002.

Assisted dying, whether through voluntary euthanasia or assisted suicide, remains a criminal offence in principle, however, doctors are not prosecuted if they report to a Regional Euthanasia Review Committee and meet all due care criteria.

Assisted dying is most commonly provided in a patient's own home. Doctors typically administer a barbiturate intravenously, which puts the patient to sleep. This is followed by injection of a lethal neuromuscular blocker.

A3.1.2 Eligibility and safeguards

Eligibility and safeguards are based on a model requiring 'due care' on the part of the doctor assisting a patient to die. Assisted dying is legal only if the 'due care' criteria established in the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* are met.

The attending doctor must:

1. be satisfied that the patient has made a voluntary and well-considered request
2. be satisfied that the patient's suffering was unbearable, with no prospect of improvement
3. have informed the patient about his or her situation and his or her prospects
4. have concluded, together with the patient, that there is no reasonable alternative in light of the patient's situation
5. have consulted at least one other independent doctor who must have seen the patient and given a written opinion on the due care criteria referred to in 1–4 above
6. have terminated the patient's life or provided assistance with suicide with due medical care and attention.

In addition to the 'due care' criteria described above, the framework under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* includes the following elements:

- generally accessible by adults aged 18 and over, but children aged 16–18 can also access assisted dying with parental consultation, as can children aged 12–16 with parental consent
- it applies not only to the terminally ill but also the chronically ill and people with mental suffering
- there is no need for competency at the time of a patient's death — a doctor may provide assisted dying to a patient 16 years or older, where they made the request in writing prior to losing competence

- there is no mandatory mental health assessment, but if a doctor determines that a patient's judgment may be impaired by poor mental health, they may decide the request does not meet the 'well-considered' part of the due care criteria
- there is no residency requirement⁸⁴⁷
- there is no mention of a specified cooling-off period, but the doctor must be satisfied that a request is 'well-considered'.

A3.1.3 Reporting and oversight

Where assisted dying occurs, doctors are required to report the death to the municipal pathologist, who then notifies a Regional Euthanasia Review Committee.

These committees, which consist of a medical doctor, an ethicist and a legal expert, assess whether the doctor has fulfilled the statutory due care criteria.

If the committee concludes that the criteria have been met, the doctor is exempt from criminal liability and no further action is taken.

If the committee finds that the doctor has not acted in accordance with the due care criteria, it reports its findings to the Public Prosecution Service and the Regional Health Inspector. These two agencies then consider what action, if any, should be taken against the doctor.

A3.1.4 Deaths under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*

The table below shows the number of deaths under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* each year since it came into operation in 2002.

Table A3.2 Deaths under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*

Year	Deaths	Year	Deaths	Year	Deaths
2002	1882	2007	2120	2012	4188
2003	1815	2008	2331	2013	4829
2004	1886	2009	2636	2014	5306
2005	1933	2010	3136		
2006	1923	2011	3695		

Source: Compiled by the Standing Committee on Legal and Social Issues.

⁸⁴⁷ Though the Netherlands Ministry for Foreign Affairs has stated that it would be 'impossible' for a non-resident to access assisted dying on the basis that a close doctor-patient relationship is needed for the requirements of the legislation to be met: Netherlands Ministry of Foreign Affairs, *The Termination of Life on Request and Assisted Suicide (Review Procedures) Act in practice, FAQ Euthanasia*, 2010. It is not clear, however, on the face of the legislation as to why a person must be a resident for this to be so.

A3.2 Switzerland

A3.2.1 Background

Swiss assisted dying law primarily resides in the country's *Criminal Code*. Assisted suicide, if done without selfish motives is legal, while assisting or inciting suicide with selfish motives is illegal. Euthanasia is illegal in all cases.

Article 114

Any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request shall be liable to a custodial sentence not exceeding three years or to a monetary penalty.

Article 115

Any person who for selfish motives incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty.

The practical effect is that assisted suicide is only a crime where the following elements are proven:

1. a suicide was committed or attempted
2. a third party encouraged or helped in the suicide
3. the third party acted on selfish grounds
4. the third party acted deliberately, with intent.

A3.2.2 Eligibility and safeguards

Unlike the other jurisdictions described in this Appendix, Swiss law does not contain a statute with a framework of eligibility criteria and safeguards for assisted dying. As such there are none of the usual eligibility requirements such as terminal illness or unbearable and irremediable suffering. Neither is assisted dying restricted to citizens or residents of Switzerland.

Assisted dying in Switzerland need not be performed by a doctor; in fact the vast majority of assisted deaths that take place in Switzerland are not supervised by doctors. A doctor is required, however, if a person wants to use a lethal drug which may only be accessed by prescription. Most deaths take place in a patient's home, or at one of the organisations listed below.

The four most prominent organisations in Switzerland that assist people to end their lives are:

- Dignitas
- Exit — German Switzerland
- Exit — French Switzerland
- Exit International.

A3.2.3 Reporting and oversight

Right to die organisations (see list above) notify the police and coroner when they assist a person to die. The police and coroner investigate to determine if any crime has taken place, in the most part determining whether there were selfish motives, but also examining any doubts about the deceased's competence and the autonomy of their choice. If the police and coroner find no wrongdoing the death is reported as suicide.

A3.2.4 Deaths under the Swiss law

There are no official statistics on the number of assisted deaths in Switzerland. One study investigating the number of deaths assisted by Exit — German Switzerland found that:

Between 1990 and 2000 Exit [German Switzerland] assisted in 748 suicides among Swiss residents (0.1% of total deaths, 4.8% of total suicides).⁸⁴⁸

Another study comparing characteristics of those accessing assisted dying through Exit — German Switzerland and Dignitas found that:

... for the period 2001–2004: 274 (65%) [assisted suicides] were facilitated by Dignitas and 147 (35%) by [Exit — German Switzerland].⁸⁴⁹

The UK Commission on Assisted Dying noted the work by John Griffiths, Heleen Weyers and Maurice Adams in their book *Euthanasia and law in Europe*:

There are no official data in Switzerland on the numbers of assisted suicides that take place each year, as the rate of assisted suicide is not collected centrally. Griffiths et al observe that there are approximately 62,000 deaths in Switzerland each year and academic studies suggest that between 0.3 per cent and 0.4 per cent of these are assisted suicides. This figure increases to 0.5 per cent of all deaths if suicide tourism is included (assisted suicides that involve non-Swiss nationals).⁸⁵⁰

A3.3 Canada

Assisted dying has more recently gained prominence in Canada compared to other jurisdictions listed in this Appendix.

At the time of writing, Québec is the only province in Canada to have introduced a scheme for assisted dying. Legislation to legalise assisted dying in all of Canada was introduced in the Canadian Parliament in April 2016, as required by the Supreme Court's ruling in *Carter v Canada (AG)*, discussed in Table A3.3.

⁸⁴⁸ Georg Bosshard, et al., '748 cases of suicide assisted by a Swiss right-to-die organisation', *Swiss Medical Weekly*, vol. 133, 2003, p. 310.

⁸⁴⁹ S Fischer, et al., 'Suicide assisted by two Swiss right-to-die organisations', *Journal of Medical Ethics*, vol. 34, no. 44, 2008, p. 5.

⁸⁵⁰ The Commission on Assisted Dying, 'The current legal status of assisted dying is inadequate and incoherent...', Demos, London, 2011, p. 295.

Table A3.3 below provides an overview of key events in legislating for assisted dying in Canada and Québec.

Table A3.3 Timeline of key events — Canada and Québec

Date	Jurisdiction	Event
1972	Canada	Suicide is decriminalised in Canada. Assisted dying remains a crime.
30 September 1993	Canada	<i>Rodriguez v British Columbia (AG)</i> Canadian Supreme Court rules 5–4 against Sue Rodriguez, who challenged Canada’s prohibition of assisted dying as unconstitutional. Ms Rodriguez was diagnosed with terminal amyotrophic lateral sclerosis (ALS).
1995	Canada	Special Senate Committee on Euthanasia and Assisted Suicide recommends that euthanasia remains as murder, with a lesser penalty.
2009	Québec	Collège des médecins du Québec publishes a discussion paper on euthanasia. It concluded that under exceptional circumstances, voluntary euthanasia could be accepted as the final step in the continuum of end of life care. The discussion paper was considered a major turning point for the debate on euthanasia in Québec.
2011	Canada	The Royal Society of Canada’s international Expert Panel on End-of-Life Decision-Making releases its report. The report recommended legalisation of assisted dying, and discussed multiple methods for reform to achieve this.
22 March 2012	Québec	Select Committee on Dying with Dignity of the Québec National Assembly tables its final report. The report recommended introduction of legislation to recognise medical aid in dying as appropriate end of life care in certain circumstances.
5 June 2014	Québec	The Québec National Assembly passes <i>An Act Respecting End-of-Life Care</i> , which legalised assisted dying. Québec becomes the first Canadian province to do so.
6 February 2015	Canada	<i>Carter v Canada (AG)</i> Canadian Supreme Court unanimously rules that Canada’s prohibition of assisted dying in certain circumstances is unconstitutional. This overturned the decision in <i>Rodriguez v British Columbia (AG)</i> . The Court ordered the Canadian Government to introduce legislation to legalise assisted dying by 6 February 2016. This was later extended to 6 June 2016 after the Canadian Government sought an extension to the time frame.
30 November 2015	Canada	Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying: Final Report. Expert group of academics and doctors providing non-binding advice to Provincial-Territorial Ministers of Health and Justice.
1 December 2015	Québec	Québec’s Superior Court temporarily suspends <i>An Act Respecting End-of-Life Care</i> until the federal ban on assisted dying is lifted.
10 December 2015	Québec	Although suspended as a result of the Superior Court decision on 1 December 2015, Québec’s <i>An Act Respecting End-of-Life Care</i> comes into effect.
14 December 2015	Canada	University of Toronto Joint Centre for Bioethics Task Force on Physician-Assisted Death publishes <i>After Carter v Canada: Physician assisted death in Canada</i> . The report examined ethical dimensions and implications of implementing an assisted dying framework, and made recommendations to policymakers, legislators and professional groups in Canada.

Date	Jurisdiction	Event
15 December 2015	Canada	External Panel on Options for a Legislative Response to <i>Carter v Canada</i> established by the Canadian Government releases its final report. The mandate of the panel was to engage Canadians and key stakeholders on issues relating to the <i>Carter</i> ruling.
22 December 2015	Québec	Québec's Court of Appeal overturns the Superior Court's suspension of <i>An Act Respecting End-of-Life Care</i>
January 2016	Canada	The Canadian Supreme Court rules that the Québec law still has effect until federal legislation is introduced.
25 February 2016	Canada	Special Joint Committee on Physician-Assisted Dying of the Canadian Parliament tables its report on the review of the report of the External Panel on Options for a Legislative Response to <i>Carter v Canada</i> . The report made recommendations for a legislative framework for assisted dying in Canada.
14 April 2016	Canada	Canadian Government introduces legislation for assisted dying into the House of Commons.

Source: Compiled by the Standing Committee on Legal and Social Issues.

A3

A3.3.1 Background to proposed federal legislation

In February 2015, the Supreme Court unanimously ruled in *Carter* that the prohibition on assisted dying was unconstitutional. The ruling was suspended for 12 months to allow the Canadian Government to enact the constitutional right to assisted dying for consenting adults with intolerable physical or mental suffering.

In July 2015 the then Canadian Government established the External Panel on Options for a Legislative Response to *Carter v Canada*. The panel consisted of three members with expertise in end of life care. It published its final report in December 2015.

In December 2015, the incoming Trudeau Government requested a six-month extension to introduce legislation in response to the *Carter* decision. On 15 January 2016, the Supreme Court granted the Canadian Government a four-month extension to pass assisted dying legislation.

The new Canadian Government established a Special Joint Parliamentary Committee on assisted dying in December 2015 to address the *Carter* decision and to review the report of the External Panel. The Special Committee tabled its report in February 2016 and made recommendations to implement a legislative framework for assisted dying.

The Special Committee recommended eligibility for people who are:

- 18 years old and eligible for public health care⁸⁵¹
- suffering from a 'grievous or irremediable medical condition'
- enduring intolerable physical or psychological suffering that is related to the condition.

⁸⁵¹ i.e. a Canadian citizen or permanent resident.

Although the Special Committee limited eligibility to those over 18 years of age, it also recommended investigating eligibility for ‘competent mature minors’, subject to a study of moral, medical and legal issues.

It also recommended the following legislative safeguards and oversight mechanisms:

- two medical practitioners must confirm the patient’s eligibility
- Canadian health department must table an annual report on assisted dying cases
- mandatory review of legislation every four years by a parliamentary committee.

In its recommendations, the Special Committee did not include a mandatory cooling off period between the request for assisted dying and when it is provided to the patient. It stated that cooling off periods should be flexible, based in part on the progression of the patient’s medical condition.

The Special Committee also stated that individuals should not be excluded from eligibility because they have a psychiatric condition.

A3.3.2 Proposed federal legislation

On 14 April 2016 the Canadian Government introduced Bill C-14: An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying). The Bill aims to legalise assisted dying through amendments to the Criminal Code of Canada.

The provisions of the Bill are narrower in scope than the recommendations of the Special Committee.

A person is eligible for assisted dying if they meet the following criteria:

- they are at least 18 years old and capable of making decisions about their healthcare
- they are eligible, or would be eligible despite any waiting period, for health services funded by a government in Canada
- they are suffering from a ‘grievous and irremediable medical condition’ (see below)
- the request was made voluntarily
- they give informed consent.

A person is considered to have a ‘grievous and irremediable medical condition’ if:

- they have a serious and incurable illness, disease or disability
- they are in an advanced state of irreversible decline in capability

- any of these conditions causes enduring physical or psychological suffering that is intolerable to the patient and that cannot be relieved under conditions that they consider acceptable
- their death is reasonably foreseeable, taking into account all of their medical circumstances, without prognosis necessarily having been made as to the specific length of time that until their death.

Assisted dying may be administered by a medical practitioner or a nurse practitioner.

The Bill provides the following safeguards which must be determined by the practitioner administering assisted dying:

- the patient must meet the eligibility criteria
- the request must be signed after the patient was informed their death is reasonably foreseeable and that they may withdraw their request at any time
- the request must be signed by two independent witnesses
- a second independent practitioner must confirm the patient's eligibility.

Fifteen days must elapse between the time the patient signs the request and when assisted dying is administered. When an administering practitioner prescribes a drug for assisted dying, they are required to inform the pharmacist dispensing the drug of its intended purpose. The administering practitioner must provide the patient with an opportunity to withdraw their request immediately before administering the drug.

The Bill specifies penalties for failure to comply with safeguards, forgery and destruction of documents. In addition, it creates exemptions under the Canadian Criminal Code for practitioners and pharmacists who are involved in assisted dying.

The Bill provides for the Canadian health minister to make regulations to establish monitoring and reporting processes for the assisted dying framework. After five years of operation, the Act is to be reviewed by a joint parliamentary committee.

The provisions of the Bill do not address mature minors, people suffering only from mental illness and advance requests. Rather, the preamble states that the Canadian Government has committed to developing non-legislative measures to deal with these issues. These issues will be referred for consideration to an expert body.

A3.3.3 Québec law

Before the *Carter* decision, Québec was the sole province in Canada to legalise assisted dying. In June 2014 the Québec National Assembly passed *An Act Respecting End-of-Life Care* in response to the Select Committee on Dying with Dignity's final report in March 2012. The Act came into effect on 10 December 2015.

The Act provides for ‘medical aid in dying’ in the form of voluntary euthanasia and assisted suicide for patients who are:

- 18 years of age and capable of giving consent
- at the end of life
- suffering from a serious and incurable illness
- in an advanced state of irreversible decline in capability
- experiencing constant and unbearable physical or psychological pain which cannot be relieved in a manner they deem tolerable.

The Act contains the following safeguards:

- two doctors must be satisfied the request is an informed one, that it is made freely and without external pressure
- the patient must be informed of their prognosis and other therapeutic possibilities and their consequences
- no specified cooling-off period, but a doctor must verify the persistence of suffering and that the wish to obtain assisted dying remains unchanged at reasonably spaced intervals.

The legislation does not specify whether depression or mental illness is a limiting factor for eligibility, however, the patient must be capable of giving consent.

The Québec legislation established a Commission on end-of-life care⁸⁵² to oversee the application of assisted dying.

A doctor who provides assisted dying must notify the Commission within 10 days. The Commission assesses whether the doctor complied with the requirements of the Act.

If at least two-thirds of members of the commission believe the Act was not complied with, the conclusions are forwarded to the institution concerned and to the Collège des Médecins du Québec.

The law was challenged in December 2015, and was temporarily suspended by Québec’s Superior Court until the federal prohibition against assisted dying was lifted. This suspension was later overturned by Québec’s Court of Appeal. In addition, the Supreme Court of Canada ruled in January 2016 that Québec’s assisted dying law can remain in effect until federal legislation is enacted.

Representatives from Canada’s justice ministry noted that Québec’s assisted dying legislation does not conform to the Canadian Charter due to its limitation to terminal patients. As a result of the *Carter* decision, Québec’s assisted dying framework will need to be extended to accommodate those who are not terminally ill.

If passed and assented to, the provisions of Canada’s Bill C-14 would apply to Québec’s medical aid in dying legislation.

⁸⁵² The ‘Commission sur les soins de fin de vie’.

A3.3.4 Deaths under the Québec law

Official statistics on the number of assisted deaths under the Act are yet to be released.

Media outlets have reported that patients have received medical aid in dying.⁸⁵³

A3.4 Oregon⁸⁵⁴

Table A3.4 Timeline of key events — Oregon

Date	Event
1994	<i>Death with Dignity Act</i> , a citizens' initiative, passed by Oregon voters by a margin of 51 per cent in favour and 49 per cent opposed.
1994–97	Implementation of the <i>Death with Dignity Act</i> delayed by a legal injunction. Multiple legal proceedings concerning the Act, including a petition to the United States Supreme Court.
27 October 1997	Legal injunction lifted, <i>Death with Dignity Act</i> comes into operation.
November 1997	Legislature puts question on general election ballot asking Oregon voters to repeal the <i>Death with Dignity Act</i> . Voters choose to retain the Act by a margin of 60 per cent to 40 per cent.

A3.4.1 Background

Assisted dying has been legal in Oregon since 1997, when the *Death with Dignity Act*, a law originating in the state's 'citizen's initiative' procedure, came into operation.

Similar laws have since been passed in Washington, Vermont, and California.

Patients who are approved in Oregon most commonly ingest a lethal barbiturate without the presence of their doctor or other healthcare provider.

A3.4.2 Eligibility and safeguards

In Oregon, only assisted suicide is legalised, not euthanasia. Doctors can prescribe patients who meet certain criteria a lethal medication. Patients who choose to take the medication must do so without assistance.

To be eligible to access a lethal medication under the *Death with Dignity Act*, a person must:

- be 18 years of age or older and 'capable'⁸⁵⁵
- be a resident of Oregon

⁸⁵³ Graeme Hamilton, 'First Quebec euthanasia case confirmed, two others reported', *National Post*, 15 January 2016, viewed March 25 2016, <news.nationalpost.com>; Kate McKenna, 'Doctor-assisted death obtained by Sherbrooke man who starved himself to qualify', *CBC*, 13 April 2016, viewed 25 March 2016, <www.cbc.ca>.

⁸⁵⁴ Similar laws exist in Washington, Vermont, and California.

⁸⁵⁵ Defined in the *Death with Dignity Act* as 'able to make and communicate health care decisions'.

- have a terminal disease from which they will die within six months
- make three separate requests; an initial verbal request, a written request, then a second verbal request. The verbal requests must be separated by a minimum of 15 days.

In assessing and granting a request to access lethal medication under the *Death with Dignity Act*, two doctors must:

- confirm the diagnosis of the terminal disease
- confirm the patient is capable of making and communicating health decisions
- confirm the patient's request is voluntary
- ensure that the patient is making an informed decision, and in doing so inform the patient of:
 - their medical diagnosis and prognosis
 - the potential risks, and probable result of taking the lethal medication
 - the feasible alternatives, including comfort care, hospice care, and pain control.

If either of the two doctors believes the patient's judgement is impaired by a psychiatric or psychological disorder or depression, the patient must be referred for counselling. The patient cannot be prescribed lethal medication unless the counsellor determines the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgement.

A3.4.3 Reporting and oversight

Doctors must document in a patient's medical record information concerning a patient's request for lethal medication. This includes information regarding eligibility as described above, as well as all verbal and written requests for lethal medication made by a patient.

Doctors are required to report all prescriptions for lethal medication to the Oregon Health Authority.

The Oregon Health Authority is responsible for notifying the Board of Medical Examiners of any failures in prescribing or reporting requirements.

Data on activity under the *Death with Dignity Act* is reported annually, and published on the Oregon Health Authority website.

A3.4.4 Deaths under the Oregon law

The table below shows the number of prescriptions for lethal medications written each year and the number of patients who died as a result of taking the medication. The discrepancy in prescriptions and deaths each year is due to people not taking medication, dying of other causes and using prescriptions written during previous years.

Table A3.5 Prescriptions and deaths under the Oregon *Death with Dignity Act*

Year	Prescriptions written	Deaths due to prescribed medicine	Percentage of total deaths
1998	24	16	0.055
1999	33	27	0.092
2000	39	27	0.091
2001	44	21	0.070
2002	58	38	0.122
2003	68	42	0.136
2004	60	37	0.120
2005	65	38	0.120
2006	65	46	0.147
2007	85	49	0.156
2008	88	60	0.194
2009	95	59	0.193
2010	97	65	0.209
2011	114	71	0.225
2012	116	85	0.235
2013	121	73	0.219
2014	155	105	0.310
2015	218	132	0.386

Source: Oregon Death with Dignity Act Annual Report Year 18 – 2015

Appendix 4

Legislation in jurisdictions that allow assisted dying

	Netherlands	Belgium	Luxembourg	Oregon ^(b)	Washington State	Québec	Canada	Switzerland
OVERVIEW OF REGULATION ^(a)								
Name of legislation	Termination of Life on Request and Assisted Suicide Act 2002	Act on Euthanasia 2002	Law of 16 March 2009 on Euthanasia and Assisted Suicide	Death with Dignity Act 1994	Washington Death with Dignity Act	An Act respecting end-of-life care	Bill C-14 An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)	Articles 114 and 115 of the Swiss Criminal Code
Year commenced operation	2002	2002	2009	1997	2009	2015	2016	1942
Nature of activity that is regulated	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide	Assisted suicide	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide and voluntary euthanasia. Voluntary euthanasia is illegal in Switzerland, however a less severe penalty is imposed compared to other homicides. The Swiss penal code contains a long-standing provision that prohibits assisted suicide unless it is provided 'without selfish motives'.

	Netherlands	Belgium	Luxembourg	Oregon ^(b)	Washington State	Québec	Canada	Switzerland
ELIGIBILITY REQUIREMENTS								
Must be an adult?	No 12+ who has a reasonable understanding of own interests (where parents/guardians agree)	No Legislation extends to emancipated minors	Yes	Yes	Yes	Yes	Yes	Uncertain Not expressly prohibited, however 'capacity' becomes an issue. No documented cases of assisted suicide for minors.
Must be competent at time death occurs?	No	No	Yes	Yes	Yes	Yes	No?	Yes
Must person have a terminal illness?	No	No	No Exception: Children seeking assistance in dying must have a terminal illness.	Yes	Yes	No 'an incurable serious illness'	No 'at the end of life' with a 'grievous and irremediable medical condition'. A serious and incurable illness, disease or disability in and advance state of irreversible decline in capability.	No Must have a 'well-documented' illness and have tried every treatment
Is pain and/or suffering required?	Yes	Yes Patient must be in a 'medically futile condition of constant and unbearable physical/mental suffering that cannot be alleviated'	Yes Patient must show 'constant and unbearable physical or mental suffering without prospects of improvement'	No	No	Yes Patient must suffer from an advanced state of irreversible decline in capability and from constant and unbearable physical/psychological pain that cannot be relieved	Yes Condition must cause enduring physical or psychological suffering that is intolerable and cannot be relieve under conditions patient considers acceptable	No

	Netherlands	Belgium	Luxembourg	Oregon ^(b)	Washington State	Québec	Canada	Switzerland
Must be a resident in the jurisdiction?	No	No But doctor must be satisfied of 'durable' nature of patient's request, i.e. must have several conversations over reasonable period of time	No But doctor must have treated patient for some time to ensure the 'persistence' of the patient's suffering and to hold 'several interviews with the patient, at reasonable intervals	Yes	Yes	No But doctor must verify the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged by talking to patient at reasonably spaced intervals	Yes Eligible for health services funded by Canadian Government (Canadian citizens and permanent residents)	No
SAFEGUARDS								
Involvement of health professionals	2 doctors	2 doctors (unless not expected to die in near future — otherwise 3)	2 doctors	2 doctors	2 doctors	2 doctors	2 professionals: Medical practitioners or nurse practitioners	Health care professionals not required
Legitimacy of request	2 doctors must be satisfied that the request was voluntary, well-considered	Doctor to be satisfied that request is voluntary, well-considered and repeated. Must also not result from external pressure.	Doctors must be satisfied that request is made voluntarily, after reflection and, if necessary, repeated. Must also not result from external pressure.	2 doctors satisfied that request is made voluntarily	2 doctors satisfied that request is made voluntarily	2 doctors satisfied the request is an informed one, that it is being made freely and without any external pressure	2 professionals confirm patient is eligible, request is legitimate, satisfied that witnesses and professionals are independent.	Assisted suicide must not be administered for 'selfish motives'
Patient must be professionally informed	Patient informed of the 'situation he was in and about his prospects'	Patient informed about health condition, life expectancy, the possible palliative and therapeutic courses of action and their consequences	Patient informed about state of health and life expectancy, therapeutic and palliative possibilities and their consequences	Patient informed of diagnosis and prognosis, risks and result of taking the medication, and alternative treatment (including comfort care, hospice care and pain control). Patient must be offered opportunity to rescind request before prescription is written	Patient informed of diagnosis and prognosis, risks and result of taking the medication, and alternative treatment (including comfort care, hospice care and pain control)	Patient informed of prognostic and other therapeutic possibilities and their consequences	Patient informed that their natural death has become reasonably foreseeable and that they may withdraw their request at any time.	Not required

	Netherlands	Belgium	Luxembourg	Oregon ^(b)	Washington State	Québec	Canada	Switzerland
Cooling off period	Not specified	Doctor must be certain of the 'durable' nature of request. Doctor must have had 'several conversations with the patient spread out over a reasonable period of time'. And if patient is not expected to die in near future, there must be at least 1 month between the written request and act of euthanasia).	Doctor to 'hold several interviews with the patient, at reasonable intervals having regard to the evolution of the patient's condition'	15 days between initial and verbal requests. 48 hours from signing written request to prescription of medication.	15 days between initial and verbal requests. 48 hours from signing written request to prescription of medication.	Doctor must verify the persistence of suffering and that the wish to obtain medical aid in dying remains unchanged by talking to patient at reasonably spaced intervals	15 days between when request was signed and administration of the drug. Exemptions if both professionals believe death or loss of capacity to provide consent is imminent and it is appropriate in the circumstances.	None
Relevance of depression / mental health issues	Legislation is silent re: depression. However, the request must be 'well-considered'. If depression affects the patient's judgment, this may have an impact on whether the doctor can regard the request as 'well-considered'	Legislation is silent re: depression. However, the patient must be 'competent' to make a request. If depression affects the patient's judgment, he or she may not be regarded as 'competent'	Legislation is silent re: depression. However, patient must be 'capable' to make a request. If depression affects the patient's judgment, he or she may not be regarded as 'capable'	Doctor to refer the patient for counselling if patient may be suffering from psychiatric or psychological disorder or depression causing impaired judgment and, if does, medication cannot be prescribed until counsellor determines patient is not suffering in a way that impairs judgment	Doctor to refer the patient for counselling if patient may be suffering from psychiatric or psychological disorder or depression causing impaired judgment and, if does, medication cannot be prescribed until counsellor determines patient is not suffering in a way that impairs judgment	Legislation is silent re: depression. However, the request must be capable of giving consent to care	Not stated in legislation, however preamble states that Canadian Government has committed to developing non-legislative measures to deal with request from people with mental illnesses	Not stated, however DIGNITAS believes as a general rule that people with mental health issues are entitled to ask for and receive assistance for suicide as much as people suffering for physical health issues

	Netherlands	Belgium	Luxembourg	Oregon ^(a)	Washington State	Québec	Canada	Switzerland
OVERSIGHT OF THE LEGISLATION								
Reporting and strategic review	Doctor to notify municipal pathologist of action; Regional Review Committees have overall responsibility for reviewing notifications	Doctor completes a form for every death and registers it with the Federal Control and Evaluation Commission, and form reviewed by Commission to ensure compliance	Doctor to submit documentation for every death to National Commission for Control and Assessment, and documentation reviewed to ensure compliance	Health care provider who dispenses medication to file a copy of dispensing record with the Department of Human Services; Department to review a sample of records annually; Department also to produce publicly available annual statistical report	Health care provider who writes a prescription or dispenses medication to file documentation with Department of Health; Department to review all records annually; Department also to produce publicly available annual statistical report	Doctor to give notice to council of physicians and end-of-life Commission	Review of Act by joint parliamentary committee in Act's fifth year	The State investigates every assisted suicide

(a) Colombia also has an assisted dying framework.

(b) Vermont and California have laws similar to Oregon's *Death with Dignity Act 1994*.

Appendix 5

Recent Australian legislative attempts for assisted dying frameworks

	ACT	NSW	NT	SA	Tas	Vic	WA
OVERVIEW OF REGULATION							
Name of legislation	Medical Treatment (Amendment) Bill 1997	Rights of the Terminally Ill Bill 2013	<i>Rights of the Terminally Ill Act 1995</i>	Voluntary Euthanasia Bill 2016	Voluntary Assisted Dying Bill 2013	Medical Treatment (Physician Assisted Dying) Bill 2008	Voluntary Euthanasia Bill 2010
Status	Discharged (second reading debate) after <i>Euthanasia Laws Act 1997</i> (Cth) assented to	Defeated (second reading)	Repealed by <i>Euthanasia Laws Act 1997</i> (Cth)	Current as of time of writing (adjourned second reading)	Defeated (second reading)	Defeated (second reading)	Defeated (second reading)
Nature of activity that is regulated	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide Voluntary euthanasia	Assisted suicide	Voluntary euthanasia Unclear from debate whether this was intentional
ELIGIBILITY REQUIREMENTS							
Must be an adult?	18 years	18 years	18 years	'an adult person'	18 years	18 years	21 years
Must be competent at time death occurs?	No	No	No	Yes	Yes	Yes (assisted suicide scheme)	Uncertain, Act refers to medical practitioner using 'reasonable endeavours' to ensure the wishes of the patient are carried out
Must person have a terminal illness?	Yes, terminal phase of illness	Yes	Yes	No	No, however condition must be in advanced stages with no reasonable prospect of permanent improvement	No, may be terminal or advanced incurable illness	Yes

	ACT	NSW	NT	SA	Tas	Vic	WA
Is pain and/or suffering required?	Yes, pain or distress caused by the illness that cannot be controlled by medical treatment or palliative care to the satisfaction of the person.	Yes, severe pain, suffering or distress to an extent unacceptable to the patient.	Yes, pain suffering and/or distress to an extent unacceptable to the patient. Doctor may not assist if they believe there are palliative care options available to reasonably alleviate pain and suffering to levels acceptable by the patient.	Yes, 'unbearable and hopeless suffering'.	Yes, 'not relievable suffering' that is intolerable.	Yes, doctor satisfied that illness is causing 'intolerable suffering'.	Yes, 'pain suffering or debilitation' that is considerable and related to the illness.
Must be a resident in the jurisdiction?	No	Yes, 'ordinary resident'	No	Yes, lived in SA for 6 months	Yes, Tasmanian resident. Examples given are holding a Tas drivers licence or enrolled to vote in Tas state elections.	Yes, settled or usual residence in Vic for 12 months	Yes, 'ordinary resident' of WA for 3 years
SAFEGUARDS							
Involvement of health professionals	2 doctors	2 doctors, 1 psychiatrist. Second must be qualified in patient's illness Primary doctor may also require patient to be assessed by a social worker	2 doctors, second must hold a diploma in psychological medicine or equivalent	2 doctors, psychiatric assessment if either requires it	2 doctors, 1 must have 'special or particular' knowledge and experience in patient's illness	2 doctors Psychiatric and palliative care consultations also required if patient has incurable illness	2 doctors An 'observing doctor' must be present when assisted dying is administered (unclear whether this may be the second doctor)
Legitimacy of request	Primary doctor must be satisfied request was made voluntarily and without inducement or compulsion	Both doctors are satisfied that patient has decision making capacity and decision was made freely, voluntarily and after due consideration	Both doctors are satisfied that patient is of sound mind and decision has been made freely, voluntarily and after due consideration	Both doctors must be of the opinion that patient was not acting under any form of duress, inducement or undue influence	Request must be voluntary. If primary doctor is not satisfied, they must refer patient to counselling	Primary doctor is satisfied that decision has been made voluntarily and after due consideration. Second doctor must be satisfied that decision was made with due consideration and without undue influence.	Both doctors must be satisfied request was made freely and voluntarily and with full knowledge of the consequences

	ACT	NSW	NT	SA	Tas	Vic	WA
Patient must be professionally informed	Primary doctor must inform (and be satisfied they understand) the nature and likely course of illness, treatment available (including palliative care), consequences of treatment and consequences of remaining untreated.	Patient informed of nature of illness, its likely course, medical treatment available, including palliative care, counselling, psychiatric support and measures for keeping the patient alive.	Patient informed of the nature of illness, its likely course, medical treatment available including palliative care, counselling, psychiatric support and extraordinary measure for keeping the patient alive.	Patient informed of diagnosis and prognosis, forms of treatment reasonably available and their associated risks, medical procedures used to administer assisted dying and their associated risks, and any other information required by regulations.	Patient informed of diagnosis and prognosis, process and procedures for making assisted dying requests, assisted dying methods of administration likely to be used and their potential risks, the probable result of assisted dying medical, all other reasonable treatment options available (including palliative care), and other information consider relevant by the medical practitioner.	Patient informed of the nature of illness, its likely course, and medical treatments available (including palliative care).	Patient informed of nature of illness and prognosis, forms of treatment reasonably available and their associated risks, availability of counselling, psychiatric and other support services, forms of palliative care available and their respective risks and side effects. methods used to administer assisted dying and their associated risks, and applicant's ability to revoke request at any time.
Cooling off period	Initial request: 72 hours after patient being informed that their illness has reached the terminal phase 24 hours from request to administration	Patient must orally reiterate request after being informed of treatment options 72 hours between reiterated oral request to signing certificate of request 24 hours from certificate of request to administration Request lapses at any time if the patient indicates otherwise	7 days from initial request to signing certificate of request 48 hours from signing certificate to administration	48 hours from request to administration	48 hours from oral request to written request 7 days from written request to subsequent oral request	For incurable illness: 14 days from psychiatric and palliative care consultations to written request 48 hours from written request to repeated written request	14 days between initial written request and second written request

	ACT	NSW	NT	SA	Tas	Vic	WA
Relevance of depression/mental health issues	Not stated	Not stated	Second doctor must confirm patient is not suffering from treatable clinical depression in respect of the illness	Not stated	Patient must not be suffering from a psychiatric or psychological disorder or depression, to a degree that may cause the judgement of the person to be impaired	Patient's decision must not have resulted from a mental illness, unless a psychiatrist determines that the decision was not a result of the mental illness or treatment of the mental illness is unlikely to alter the patient's decision	2 doctors to determine that the request is not wholly or substantially referable to or a symptom of a state of clinical depression
Conscientious objection	Yes	Yes	Yes	Yes	Yes	Yes; however mandatory referral required	Yes
OVERSIGHT OF THE LEGISLATION							
Reporting and strategic review	Coroner reports annually to the Attorney-General on the number of deaths and the operation of the Act.	Establishes a Voluntary Assisted Death Review Panel. 6-member expert panel as appointed by Minister. Panel review each death as they occur. Reports to Parliament annually, and reports on any breach of the Act.	Coroner reports annually to the Attorney-General on the number of deaths and the operation of the Act.	Minister reports annually on the operation of the Act	Minister-appointed Registrar of Act. Registrar investigates, reports and makes recommendations to Minister on any matter relating to operation of the Act.	Coroner reports annually to Parliament on the nature and frequency of assistance and deaths under the Act. Annual report must be reviewed by a joint 'all-party' committee.	Coroner reports annual to the Minister on the operation of the Act and a statistical report of deaths under the Act. Coroner may also make other reports at any time.

(a) Table based on Lindy Willmott, et al., '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics', *University of New South Wales Law Journal*, vol. 39, no. 1, 2016.

Appendix 6

Submission evidence summary

A6.1 Submissions received

The Committee issued a call for submissions on 30 May 2015. Submissions formally closed on 31 July 2015, however the Committee continued to accept submissions throughout the course of the Inquiry.

The Committee received 1037 submissions. Of these, 925 were from individuals in a private capacity, and 112 were from organisations. This volume of submissions is significant for a parliamentary Committee Inquiry, indicating the importance of end of life choices to Victorians.

A great majority of the submissions to the Inquiry addressed assisted dying. Many addressed both assisted dying and other end of life issues, including advance care planning and palliative care. A small minority dealt exclusively with non-assisted dying issues. While palliative care and advance care planning were discussed in detail in some submissions, these topics were not addressed in a way amenable to quantitative analysis, in the way assisted dying was. Palliative care and advance care planning are discussed in Chapters 2–5.

The Committee is grateful to all those who made submissions, and thanks them for their contribution throughout the Inquiry process.

A6.2 Submission quantitative analysis

The volume of submissions presented a challenge for the Committee; how best to recognise and incorporate so many voices and opinions in its deliberations and final Report.

The Committee benefitted from examining this volume of submissions, and is grateful to those who provided them (submissions are published on the Committee’s website⁸⁵⁶). The arguments, personal stories, and evidence presented in the submissions have informed the Committee’s deliberations.

One way the Committee aims to represent the submissions in this Report is through quantitative analysis and infographics. While each submission is unique, there are repeated and recognisable themes that emerge in many of them.⁸⁵⁷ By gathering, analysing, and presenting these themes, the Committee hopes to give an indication of the overall picture they paint.

⁸⁵⁶ <www.parliament.vic.gov.au/lsic/article/2759>.

⁸⁵⁷ These themes often aligned with themes discussed in reviews similar to the Committee’s Inquiry. For more see Appendix 7.

Important to note is that analysing submissions in this manner necessarily includes a degree of subjectivity. In performing its analysis, the Committee endeavoured to reduce this subjectivity as much as possible.

Also important to note is the source data used in this analysis. Submissions to the Inquiry were not gathered in any kind of scientific manner, and the content of the submissions does not follow any particular format. Further, the content of each submission is not a response to a carefully worded questionnaire, but entirely at the discretion of the author. In gathering data from submissions, the Committee avoided inferring or ascribing any opinion that was not explicitly stated.

All information presented as a result of the Committee's analysis must be seen for what it is: based entirely on the submissions provided to the Legal and Social Issues Committee of the Legislative Council of the Parliament of Victoria during its Inquiry into End of Life Choices. This means any inherent biases in the submissions and the manner of their collection remains in the information presented here.

Finally, the Committee wishes to make it clear that it does not see weight of numbers alone, in any direction, as reason enough to make a particular recommendation. On this point, the Committee notes the position described by Professor Margaret Otlowski:

... public opinion should have a role in shaping the law, indicating, as it does, prevailing morality and the needs of the community. After all, ultimately, the law must serve the community and it must, therefore, be responsive to real social needs. It is widely recognised that if a law is markedly out of tune with public opinion, it will quickly fall into disrepute. Thus, while evidence of community support for legalisation of active voluntary euthanasia is not of itself decisive, it is undoubtedly a relevant factor in determining the appropriateness of legalisation.⁸⁵⁸

A6.2.1 Information gathered from submissions

The Committee set out at first to assess the position of each submission on assisted dying. In addition, the Committee recorded arguments each submission gave in support of its position.

Early analysis revealed that the arguments given in submissions followed reasonably predictable themes (for more see Appendix 7). Using these themes as a guide, along with additional arguments or particular formations of arguments identified in its early analysis of submissions, the Committee was able to gather data on how often various arguments were made across all submissions.

Further analysis yielded a separate theme, particularly in individual submissions — personal stories of a loved ones' death or serious illness. This prompted the Committee to gather this and similar information.

⁸⁵⁸ Professor Margaret Otlowski, *Submission*, p. 13.

For the purpose of its analysis, the Committee gathered the following information from each submission:

- author: individual or organisation
- position for or against assisted dying
- arguments given for or against assisted dying
- whether the author included personal experience of a loved one's serious illness or death
- whether the author is suffering from a serious illness
- whether the author expressed an intention to end their own life, and the situation under which they would do so
- whether the author knows someone who intends to end their own life.

With this information, the Committee was able to produce numbers and infographics which help give an overview of the submissions.

By collecting the themes in arguments given for or against assisted dying in submissions, the Committee has gathered data it can use to give a visual representation of the views expressed to the Inquiry. This representation can be seen in the word clouds in this Appendix. See Figure A6.2, Figure A6.3, Figure A6.5, Figure A6.6, Figure A6.11 and Figure A6.12.

The terms shown in the word clouds represent themes identified in submissions to the Inquiry. The size of each term represents how frequently it was raised in submissions. Multiple themes were identified in many submissions. The terms and associated themes are described in Table A6.1 and Table A6.2 below.

Some of the themes in submissions overlap, or are otherwise very closely related. For example, the themes 'choice' and 'control'⁸⁵⁹ both speak to an argument around autonomy, as well as the idea that legalisation of assisted dying can have a palliative effect, even for patients who do not use it. In gathering arguments into themes, the Committee attempted to strike a balance between recognised arguments present in debate on this issue, and the specific content and terminology in submissions.

As mentioned above, submissions to the Inquiry are not the result of a carefully designed questionnaire. Rather they are people's and organisations' uniquely worded contributions. There is therefore a degree of subjectivity in identifying themes.

A6.2.2 All submissions

Of the 1037 submissions the Committee received, 1023 were included in the analysis. The remaining 14 submissions were received too late to be included.

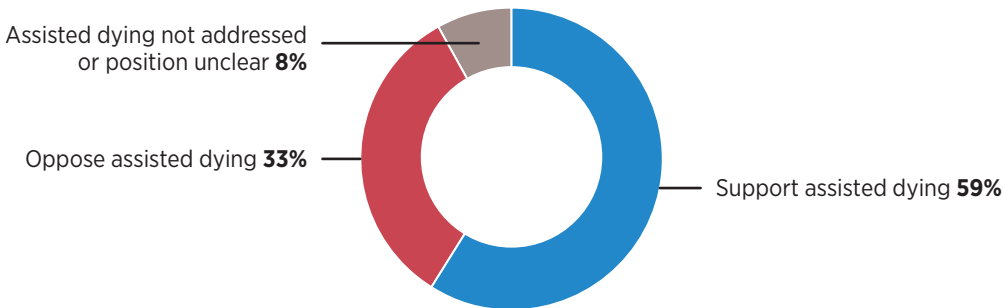
Of those 1023 submissions, 92 per cent expressed a view on assisted dying.

⁸⁵⁹ See Table A6.1.

59 per cent of the total 1023 submissions were supportive of assisted dying and 33 per cent were opposed to assisted dying.

The remaining eight per cent were unclear, inconclusive, or did not engage with assisted dying.

Figure A6.1 All submissions: Position for or against assisted dying



A6

The themes supporting arguments for or against assisted dying identified in all submissions are shown in the word cloud below. Within each word cloud, the font size of each term represents how many submissions raised the corresponding theme.

Figure A6.2 All submissions: Themes supporting assisted dying



Figure A6.3 All submissions: Themes opposing assisted dying



Table A6.1 Description of word cloud terms: Themes supporting assisted dying

Word cloud term	Description of theme
Choice	The manner of a person's death should be completely up to that person. Each person should be able to choose how they die, just as they choose how to live. As such, assisted dying should be legalised.
Relief from suffering	People who are suffering should be able to end their suffering through assisted dying.
Dignity ^(a)	People should be afforded the ability to die with dignity. Assisted dying can help achieve this.
Unwanted prolonging of death	People who are in the dying process and feel 'ready to die' are living when they no longer wish to. Assisted dying can allow people to end their lives when they are ready, and avoid living beyond this time.
Public opinion	Public opinion is in favour of legalising assisted dying.
Control	Having the option of assisted dying would give dying people a feeling of control over their death, and remaining life. This feeling of control has a palliative effect whereby just the possibility of assisted dying would provide relief from fear of suffering and allow people to make the most of their remaining life. This is true even if the person does not end up using assisted dying.
Palliative care not solution for everyone	Palliative care is a good thing, but it is not the path everybody wants to choose. Those who do not wish to use palliative care should have the option of assisted dying. Palliative care also cannot alleviate all suffering.
Pet	We allow assisted dying for pets and other animals that are suffering, but not for people. There would be legal consequences for leaving an animal to suffer the way we let people suffer. This is a cruel and contradictory situation.
Prevent suicides and associated suffering	Some people who currently suicide without assistance would benefit from assisted dying. People who may qualify for assisted dying are currently suiciding alone, often in a horrific manner. Assisted dying would allow people to end their life surrounded by loved ones, and under medical care. This would benefit both the patient and their loved ones.
Loved ones	Assisted dying allows a peaceful death surrounded by loved ones. This includes discussions with family which increase understanding and help with closure. It also avoids family and friends having to watch their loved ones suffer.
Others' morals should not prevent	The morals, religion, and ethics of other people should not affect a personal decision about ending your own life when experiencing irremediable suffering. The law on assisted dying should reflect this.
State should not prevent	The state should not create laws that prevent people being able to choose when and how they die in the context of irremediable suffering. Doctors should be free from legal liability to provide assisted dying.
Regulate practice	Assisted dying is practiced in Victoria unlawfully. Because it is unlawful there are no protections for patients against abuse. Assisted dying should be legalised and regulated properly, and the doctors who participate should be legally protected.
Legal options inhumane	The current options for hastening death, which include the patient refusing treatment, food and water, are inhumane. They subject patients to unnecessary pain and suffering that could be avoided by assisted dying.
Opponents not affected	The rights of opponents of assisted dying will not be adversely affected by a change in the legal framework, whereas the rights of those who want to access these options are adversely affected under the current framework.

(a) See the discussion of the term 'dignity' in Appendix 7.

Table A6.2 Description of word cloud terms: Themes opposing assisted dying

Word cloud term	Description of theme
Coercion	<p>If assisted dying is legalised, people will feel pressure to end their own lives. This could be explicit or implicit, and come from family, friends, or health practitioners.</p> <p>A voluntariness requirement in an assisted dying framework will not be an adequate protection against coercion. Sick, elderly, mentally ill and disabled people will be particularly vulnerable to coercion.</p> <p>Simply legalising assisted dying sends a message to some people that their lives are not worth living, which in turn pressures them to end their lives.</p>
Slippery slope	<p>Legalising assisted dying will create a slippery slope, particularly to involuntary assisted dying, in which safeguards are eroded, either in practice, or by further changes to law. People beyond the initial scope of assisted dying law will die as a result.</p> <p>Once assisted dying is morally acceptable, such extensions will be difficult to resist. Assisted dying should not be legalised because it is impossible to guard against these risks.</p>
Safeguards won't work	No safeguards can protect completely against abuse of an assisted dying framework. No safeguards or oversight can guarantee people will not be killed contrary to their wishes.
Not doctors' role	<p>Assisted dying is incompatible with a doctor's role. Assisted dying is contrary to the doctor's duty to do no harm. Hastening a patient's death is not a legitimate function for a doctor.</p> <p>Doctors should not have to act contrary to their conscience. Even if they are not required to provide assisted dying, they will likely be required to refer the patient to someone who will, and would thus be complicit.</p>
Devalues life	<p>Legalising assisted dying devalues life generally, and can lead to the situations described in the 'coercion' and 'slippery slope' themes above.</p> <p>This argument is sometimes framed from a religious perspective, with a deity being the only agent with the authority to give or remove life.</p>
Odds with palliative care	Legalising assisted dying is contrary to the philosophy and practice of palliative care. Further, legalising assisted dying may discourage funding for palliative care services and development.
Request means health system failed	<p>There is no reason for a person to suffer either mentally or physically as they die in a properly funded and functioning health system.</p> <p>Requests for assisted dying represent a failure on the part of the health system to properly care for the patient. Access to palliative care should be available to all who want it.</p>
Palliative care makes assisted dying obsolete	Improvements in palliative care make the need for assisted dying obsolete.
God	Only God has the authority to give or remove life.

A6.2.3 Individual submissions

925 submissions, the vast majority, came from individuals.

Some of these individuals had special knowledge of medicine. The Committee heard from current and former nurses, specialist physicians, general practitioners, and allied health workers.

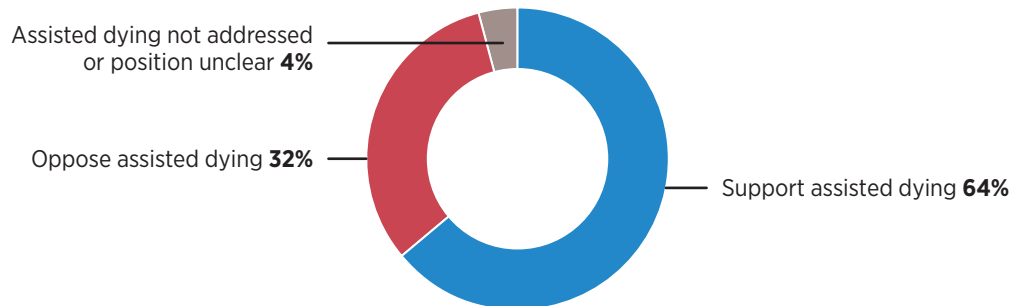
Of the 925 individual submissions the Committee received, 912 were included in the analysis. The remaining 13 individual submissions were received too late to be included.

Of those 912 submissions from individuals that were examined, 96 per cent expressed a view on assisted dying.

64 per cent of the total 912 submissions were supportive of assisted dying and 32 per cent were opposed to assisted dying.

The remaining four per cent were unclear, inconclusive, or did not engage with assisted dying.

Figure A6.4 Individual submissions: Position for or against assisted dying



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The themes supporting arguments for or against assisted dying identified in individual submissions are shown in the word clouds below. Within each word cloud, the font size of each term represents how many submissions raised the corresponding theme.

Figure A6.5 Individual submissions: Themes supporting assisted dying

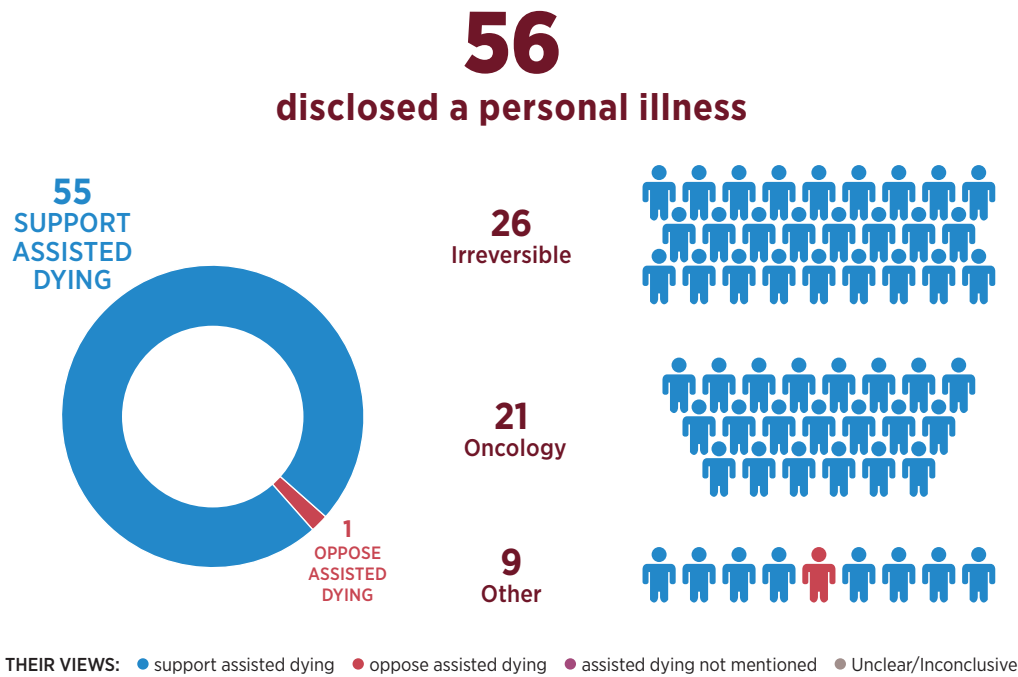


Figure A6.6 Individual submissions: Themes opposing assisted dying



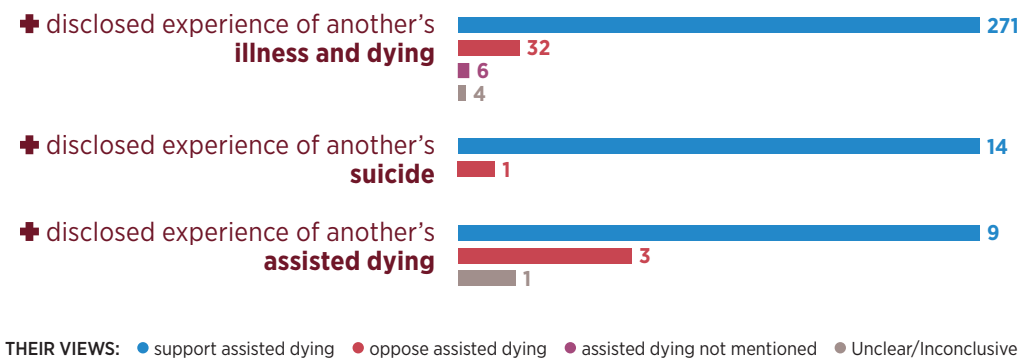
In 56 submissions, the authors disclosed a serious personal illness, the majority being forms or cancer or irreversible conditions. The Committee recognises that the issues this Inquiry addressed are of particular significance to the authors of these submissions.

Figure A6.7 Submissions that disclosed a personal illness



More than a third of all individual submissions, 313 in total, disclosed an experience of someone close to them either dying, or suffering from a serious illness. In some cases, the deaths described could be defined as suicide or assisted dying.

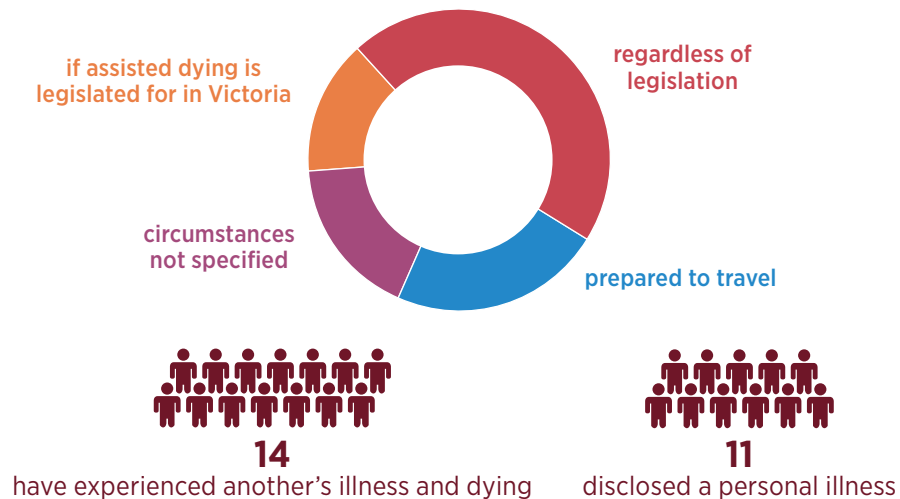
Figure A6.8 Submissions that disclosed another’s illness, death, suicide or assisted death



31 submission authors expressed an intention to end their own life. The situation under which people would do this varied, with some willing to travel to a jurisdiction that allows assisted dying, while others would act if the law was changed in Victoria.

Figure A6.9 Submissions that disclosed an intention to end own life

31
expressed an intention to end their own life at some point



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A6.2.4 Organisational submissions

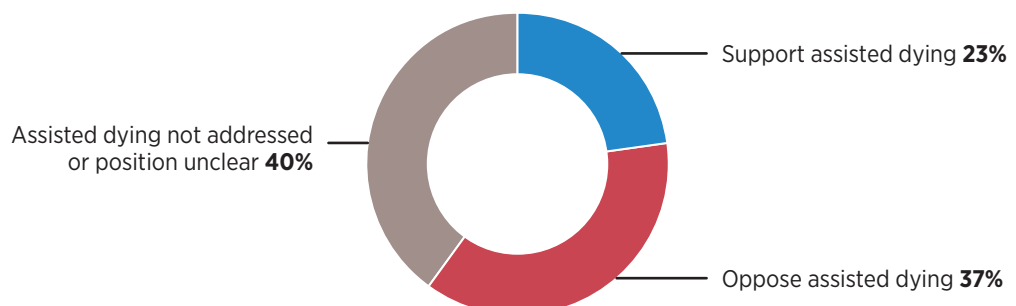
112 organisations made submissions to the Inquiry. Organisations were wide-ranging, including advocacy groups, health services (particularly in palliative care), religious and faith-based organisations, government agencies, academic organisations, and more.

Of the 112 organisational submissions the Committee received, 111 were included in the analysis. One submission in this category was received too late to be included.

Of those 111 submissions, 60 per cent expressed a view on assisted dying.

23 per cent of the total 111 submissions were supportive of assisted dying and 37 per cent were opposed to assisted dying.

The remaining 40 per cent were unclear, inconclusive, or did not engage with assisted dying.

Figure A6.10 Organisational submissions: Position for or against assisted dying

The themes supporting arguments for or against assisted dying identified in organisational submissions are shown in the word clouds below. Within each word cloud, the font size of each term represents how many submissions raised the corresponding theme.

Figure A6.11 Organisational submissions: Themes supporting assisted dying⁸⁶⁰



Figure A6.12 Organisational submissions: Themes opposing assisted dying



⁸⁶⁰ Note the theme 'pet' was raised only once in organisational submissions, resulting in a font size too small to be included here.

Appendix 7

Arguments for and against legalising assisted dying summary

A7.1 Arguments largely consistent on assisted dying

The arguments for and against legalising assisted dying are extensively covered in academic literature, and public and political debate. The Committee learned that these arguments are largely consistent across a variety of jurisdictions.

This pattern was reflected in evidence the Committee received. There were some arguments raised, or formulated in a particular way, in submission and hearing evidence that were not represented as strongly in academic literature. However on-the-whole the submission and hearing evidence the Committee received aligned with the broader arguments on assisted dying.

The arguments are summarised here based on Inquiry submissions and witnesses. They summaries are informed by four recent investigations into assisted dying, described below. This summary is not exhaustive, nor does it offer a critique of the arguments. Rather it shows the most common arguments the Committee encountered through its submission and hearing process and in the academic literature.

A7.2 Four investigations into assisted dying

These reports provided the Committee with a useful basis for understanding the issues relating to assisted dying. They contain summaries and analysis of the issues, as well as insight into how other jurisdictions are confronting these issues.

- **‘How should Australia regulate voluntary euthanasia and assisted suicide?’ Benjamin White and Lindy Willmott (2012):**⁸⁶¹ This background paper produced for Australia21 formed the basis of a roundtable discussion between doctors, lawyers, former parliamentarians, academics and activists in Brisbane in 2013. It outlines the current legal landscape, the arguments for and against assisted dying, as well as options for regulation. It also investigates previous unsuccessful attempts at law reform in Australia and the nature of law reform in jurisdictions where assisted dying is allowed. It was written by Law, Public Health and Health Services academics at Queensland University of Technology’s Faculty of Law.

⁸⁶¹ Benjamin P White and Lindy Willmott, ‘How should Australia regulate voluntary euthanasia and assisted suicide?’, *Journal of Law and Medicine*, vol. 20, no. 2, 2012.

- **Québec Select Committee on Dying with Dignity Report (2012):**⁸⁶² The Québec National Assembly established a Select Committee to explore end of life issues, particularly assisted dying, in 2009. The 2012 report examines the arguments for and against legalising assisted dying and approaches to legal reform and regulation. The Report was prepared by a nine-member Select Committee of the Québec National Assembly.
- **‘The current legal status of assisted dying is inadequate and incoherent...’ Report of the UK Commission on Assisted Dying (2011):**⁸⁶³ The UK Commission on Assisted Dying was established in 2010 to consider whether the existing legal and policy approach to assisted dying in England and Wales was appropriate. The 2011 report examines issues relating to assisted dying and canvasses options for reform. The report was prepared by a Commission led by Lord Falconer, which included a broad range of experts.⁸⁶⁴ Think tank Demos provided research and secretariat support. Sir Terry Pratchett and Bernard Lewis provided financial support.
- **‘End-of-life decision-making in Canada: The report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making’ (2011):**⁸⁶⁵ The Report examines issues relating to end of life care in Canada, including the arguments for and against assisted dying, as well as options for legal reform. The Report was prepared by a group of academics in the bioethics, philosophy, medical ethics, health law and policy, law and ethics, family and community medicine, and political philosophy fields.

A7.3 Dignity — Difficulty in using the term in the assisted dying debate

Before presenting the arguments for and against assisted dying, it is important to note the use of the term ‘dignity’.

Arguments in the assisted dying debate often use the term ‘dignity’ or ‘human dignity’. Submissions to the Inquiry used the term both as an argument for, and an argument against, legalising assisted dying. Academic literature also recognises the difficulty surrounding use of the term.⁸⁶⁶

⁸⁶² Select Committee on Dying with Dignity, *Dying with Dignity*, National Assembly of Québec, Québec, 2012.

⁸⁶³ The Commission on Assisted Dying, *‘The current legal status of assisted dying is inadequate and incoherent...’*, Demos, London, 2011.

⁸⁶⁴ The head of the Academic Unit of Supportive Care at the School of Medicine in the University of Sheffield, Lord Blair (former commissioner of the Metropolitan Police), President of the College of Medicine, an experienced palliative medicine specialist, a doctor with a PhD in disability equality issues, a House of Commons MP who was the founding chairman of both the All Party Parliamentary Group on Life Science and the All Party Parliamentary Group on Choice at the End of Life, an independent life peer trained in medicine and psychiatry, a member of the Committee on Standards in Public Life, an Anglican priest with experience in helping people think about end of life issues, and a Baroness with extensive experience managing health districts in London.

⁸⁶⁵ Udo Schüklenk, et al., ‘End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making’, *Bioethics*, vol. 25, no. s1, 2011.

⁸⁶⁶ See for example Todd TW Daly, ‘Whose dignity? Reflections on a deceptively difficult term in bioethical debates’, *Ethics and Medicine*, vol. 29, no. 3, 2013.

Extracts from two of the reports described above⁸⁶⁷ demonstrate that others investigating these issues have encountered the same phenomenon.

The Report by the Royal Society of Canada Expert Panel on End-of-Life Decision-Making includes a detailed discussion of the term based on historical sources, Canadian Supreme Court decisions, and recent moral philosophy, concluding:

... the same pattern running through all three, namely a tendency to make dignity mean one thing and its opposite, and to cloak potentially controversial moral consideration – individual autonomy on the one hand, and some quality inherent within agents, in virtue of their being human on the other – in the pleasing language of dignity. In light of this conclusion, the Panel asserts it is best that debate about moral issues, such as assisted death, absent discussions of human dignity; rather, the values that lie behind this concept, on both sides of the debate, be explicitly considered.⁸⁶⁸

Australian experts on health law reach a similar conclusion:

Because human dignity is a concept which is potentially relevant to both sides of this debate, it has not been included in the above outline of arguments for and against VE [voluntary euthanasia] and AS [assisted suicide]. Instead, in the arguments supporting reform, dignity is considered in the narrower context as part of the justification for allowing individual choice in decision-making at the end of life. On the other side, dignity is relevant in advancing the argument concerning the sanctity of life, and the need to protect human life.⁸⁶⁹

This Appendix will therefore avoid using the term ‘dignity’ focusing instead on the arguments it is used to espouse, as explained in the extracts above.

A7.4 Arguments for legalising assisted dying

The methodology the Committee used in the Inquiry, including examination of submission and hearing evidence and academic research, allowed it to identify the arguments that were most commonly put forward in the assisted dying debate. These arguments were repeated, to varying degrees, by academics, health practitioners, religious and faith-based organisations, and individuals.

The arguments presented below are a plain synopsis of those encountered by the Committee in submissions, hearings and academic research, particularly the four reports described above.⁸⁷⁰ As far as possible this summary uses the language and terminology presented in evidence.

⁸⁶⁷ See section A7.2

⁸⁶⁸ Udo Schüklenk, et al., ‘End-of-life decision-making in Canada: The report by the Royal Society of Canada expert panel on end-of-life decision-making’, *Bioethics*, vol. 25, no. s1, 2011.

⁸⁶⁹ Benjamin P White and Lindy Willmott, ‘How should Australia regulate voluntary euthanasia and assisted suicide?’, *Journal of Law and Medicine*, vol. 20, no. 2, 2012.

⁸⁷⁰ See section A7.2

In describing these arguments here, the Committee does not assign any particular value or make any critique of them, rather it wishes to provide a brief description of the most common arguments it encountered during the Inquiry.

A7.4.1 Autonomy

Autonomy features prominently in the arguments for legalising assisted dying. This argument states that each person has the right to determine the course of their life in keeping with their values and beliefs, within the limits imposed by the rights and freedoms of others.

This autonomy, or self-determination, is fundamental to liberal democracy and the common law. Further, autonomy is a basic principle of medical ethics. It entitles patients to choose a preferred medical intervention or refuse treatment, and should also give a person the right to choose the time and manner of their own death.

This argument has also been framed by saying the state does not have the right to diminish the individual's autonomy in choosing assisted dying, as it does no harm to others.

Submissions to the Inquiry that included the autonomy argument often used the word 'choice', but sometimes also referred to 'control'. A common argument relating to control is that simply having the option to choose assisted dying has a palliative effect in and of itself by enabling people at the end of life to reclaim control of their situation. For more on this see section A7.4.8.

A7.4.2 Relief from suffering — Patients and loved ones

This argument holds that irremediable suffering is grounds for legalising assisted dying.

Even with more or better palliative care, there are some people whose suffering cannot be alleviated. Certain types of pain can be difficult to alleviate or cannot be controlled completely. Advances in medical practice have helped to prolong life, but for some this means an extended period of suffering. A recurring related argument is that it is cruel and contradictory to allow euthanasia of pets and other animals that are suffering, but not people.

Existing methods of pain relief, such as continuous palliative sedation, may not be viable for those who want to remain lucid or do not want to prolong their suffering.

Also, the existential suffering experienced by people at the end of their lives cannot be palliated in all cases.

People whose suffering cannot be relieved should have access to assisted dying.

Assisted dying enables people to ensure they are surrounded by loved ones at the time of death and have the chance to say goodbye to friends and family. Further, the death is more peaceful than it would otherwise be. This has benefits for the

patient and the family, who can use the certainty around time of death to say final goodbyes, and are spared the trauma of suffering and seeing their loved one suffer.

Associated with this argument was that of people who do not wish to be a burden to their loved ones. This argument holds that if someone does not wish to be a burden on their loved ones, they should be allowed access to assisted dying.

A7.4.3 Preventing suicides and associated suffering

With assisted dying unavailable, people with illness or injury that are suffering, or anticipate suffering, suicide alone, often in violent or disturbing ways. Having the option of assisted dying would allow these people to either end their lives in a more humane manner or let their illness run its course. It would provide them comfort in the knowledge that they could end their life with assistance if they decided to.

A7.4.4 Assisted dying occurs already, and is unregulated

Assisted dying occurs already in Victoria, despite being unlawful. It occurs within and outside of medical settings. The instances that occur within medicine are nearly impossible to police.

As these practices are not regulated, there are no safeguards, and the ongoing unlawful practice of assisted dying brings the law into disrepute.

A7.4.5 Assisted dying is no different to refusing treatment and receiving continuous palliative sedation

There is no moral distinction between refusing or stopping treatment, combined with continuous palliative sedation, and providing assisted dying. This is particularly so when continuous palliative sedation is combined with removing nutrition and hydration.

There is no logical basis for prohibiting assisted dying but permitting the refusal of treatment where the consequences are the same. If the distinction between continuous palliative sedation and assisted dying is ‘intention’, or intended and foreseen consequences, then it is too slight to identify precisely and routinely.

A7.4.6 Benefit to the doctor–patient relationship

Doctor–patient relationships will be enhanced by the openness and honesty that legalising assisted dying will foster.

Discussing whether to stop treatment or administer continuous palliative sedation has not diminished trust between doctors and patients, by the same token an openness around assisted dying will not be harmful, but will be beneficial. Current restrictions on this discussion undermines the doctor–patient relationship, the ability to discuss all end of life options can only enhance it.

A7.4.7 The current law treats people differently

The prohibition on assisted dying affects people differently and is therefore discriminatory. Some individuals have the physical ability to commit suicide, while the physical circumstances of others may prevent them from doing so. Further, some individuals may have the financial resources to travel overseas to jurisdictions such as Switzerland where assisted dying is lawful, while others may not.

A7.4.8 The option of assisted dying is palliative

The option of assisted dying is in itself palliative and gives many peace of mind. Fear of death often stems from the fear of dying badly. Knowing that assisted dying can be accessed eases concern about the prospect of a 'bad death'.

A7.4.9 Public opinion favours legalising assisted dying

There is a long-standing history of strong public support for assisted dying in certain circumstances. In Australia, opinion polls have consistently shown public support for assisted dying.

Table A7.1 Assisted dying opinion poll results referred to in evidence^(a)

Polling body	Year	Result
Essential Media Communications	2015	73 per cent support ^(b)
Fairfax Ipsos	2014	76 per cent support ^(c)
ABC Vote Compass	2014	76 per cent support ^(d)
Australia Institute	2012	greater than 70 per cent support ^(e)
Newspoll	2012	82 per cent support ^(f)
Australia Institute	2011	75 per cent support ^(g)
Newspoll	2009	85 per cent support ^(h)

(a) Note the precise question/s asked varied across polls. All polls national except Vote Compass 2014 (Victoria only) and Fairfax Ipsos poll 2014 (Victoria only).

(b) Essential Media Communications, 'Voluntary euthanasia', viewed 6 April 2016, <www.essentialvision.com.au>.

(c) Julia Medew, 'Fairfax Ipsos poll: 3 out of 4 Victorians support people being given assistance to die if they want to', *The Age*, 14 November 2014, viewed 6 April 2016, <www.theage.com.au>.

(d) Guy Stayner, 'Victorian election 2014: Electorate overwhelmingly back voluntary euthanasia, Vote Compass reveals', *ABC*, 24 November 2014, viewed 6 April 2016, <www.abc.net.au>.

(e) 'Survey shows support for legalised euthanasia', *ABC*, 16 November 2012, viewed 6 April 2012, <www.abc.net.au>.

(f) Natasha Egan, 'Wide support for euthanasia: Poll', *Australian Ageing Agenda*, 6 December 2012, viewed 6 April 2016, <www.australianageingagenda.com.au>.

(g) Adele Horin, 'Euthanasia wins 75% support', *Sydney Morning Herald*, 6 January 2011, viewed 6 April 2016, <www.smh.com.au>.

(h) AAP, '85 per cent support voluntary euthanasia — Poll', *The Australian*, 26 October 2009, viewed 6 April 2016, <www.theaustralian.com.au>.

A7.4.10 Assisted dying is uncommon

Assisted dying will not cause the consequences its opponents fear because it is not something a large percentage of people desire for themselves.

A7.4.11 Opponents to legalisation would be unaffected by change

Opponents to assisted dying will not be affected by a change in law, but those who want assisted dying are adversely affected by the current situation.

A7.4.12 God

God would want us to take a compassionate approach to those who are suffering. Providing assisted dying is a compassionate option.

A7.5 Arguments against legalising assisted dying

The arguments below are presented by the Committee without discussion or analysis. They represent the views that were included in submission and hearing evidence and explored in the four reports described above.⁸⁷¹ The Committee does not assign any particular value or make any critique of the arguments as presented in this Appendix.

A7.5.1 Vulnerable people will become victims

Legalising assisted dying poses a threat to vulnerable members of society. Key to the concern for vulnerable people is the idea that they will be subjected to pressure and subtle coercion to seek assisted dying. Vulnerable people may come to think of themselves as a burden on their families or society and see assisted dying as a solution.

No safeguards or oversight of assisted dying can guarantee vulnerable people will not be killed contrary to their wishes. The risks that assisted dying poses to the vulnerable outweigh any benefits.

Vulnerable people will not seek medical help when it is needed if they are concerned they may be encouraged to end their lives.

Legalising assisted dying will undermine the value of life, particularly lives that some may no longer deem ‘useful’. This will foster negative attitudes towards people with disabilities.

A7.5.2 The slippery slope

Legalising assisted dying will create a slippery slope, particularly to involuntary euthanasia, in which safeguards are eroded and people beyond the initial scope of assisted dying law will die as a result.

⁸⁷¹ See section A7.2

The slippery slope argument overlaps with the concern that vulnerable people will become victims of assisted dying. Both suggest that assisted dying will extend beyond its initial scope, either through further legislative change, or practice outside of legal safeguards, including:

- to people for whom assisted dying is inappropriate, such as children
- to people who lack capacity to make an informed medical decision.

Once assisted dying is morally acceptable, such extensions will be difficult to resist. Assisted dying should not be legalised because it is impossible to guard against these risks.

A7.5.3 Legalising assisted dying devalues life

Legalising assisted dying devalues life generally, and can lead to the situations described in the arguments above concerning vulnerable people, and the slippery slope.

This argument is sometimes framed from a religious perspective, with a deity being the only agent with the authority to give or remove life.

A7.5.4 Instances of assisted dying are increasing where it is legal

Data from jurisdictions that allow assisted dying show that more people are accessing it every year. The numbers are increasing, and are likely to continue to increase.

A7.5.5 Palliative care is the best solution

Palliative care is the best option for most people at the end of life. Improving the quality of and access to palliative care would reduce requests for assisted dying. Having the option of assisted dying may diminish the role of palliative care in end of life care.

High quality palliative care can eliminate any desire for assisted dying. Resources should be directed towards improving palliative care practice and delivery, rather than assisted dying.

Cases where a patient's symptoms are truly unmanageable are rare.

A7.5.6 Incompatible with doctors' duties and conscience

Assisted dying is incompatible with the role of doctors. Assisted dying is contrary to the doctor's duty to do no harm. Hastening a patient's death is not a legitimate function for a doctor.

Doctors should not have to act contrary to their conscience. Even if they are not required to provide assisted dying, they will likely be required to refer the patient to someone who will, and would thus be complicit.

A7.5.7 Assisted dying will undermine the doctor–patient relationship

Legalising assisted dying will compromise the doctor–patient relationship. People will lose trust in doctors if they assist their patients in dying as a matter of routine. Vulnerable people will become anxious and fearful about seeing their doctor.

A7.5.8 Research and investment into palliative care services will diminish

Assisted dying will reduce investment in palliative care practice and development, along with health practitioners' training in palliative care. This reduced focus will hurt patients who would otherwise benefit from quality palliative care.

A7.5.9 Continuous palliative sedation while refusing treatment is different to assisted dying

There is a distinction between continuous palliative sedation while refusing treatment, and assisted dying.

There is a moral difference between actively ending a patient's life and omitting to keep a patient alive. The doctrine of double effect distinguishes continuous palliative sedation from assisted dying.

A7.5.10 Requests for assisted dying are inherently irrational

Requests for assisted dying should not be agreed to because choosing to die is not a rational decision.

The depression people experience during the end of life means a decision to seek assisted dying is a cry for help that should be met with proper medical care, not assistance to die.

A7.5.11 Legislating for a minority

Governments should not adopt laws for exceptional cases. The number of people who would use assisted dying is extremely low, and governments should not make laws for such a small minority.

A related argument is that hard cases do not make good law. The most tragic and heartbreaking experiences at end of life which give rise to a call for assisted dying fall into the category of hard cases upon which law should not be based.

A7.5.12 Assisted dying will traumatise those involved

Bereavement associated with suicide is particularly difficult for loved ones. Family and friends of those who choose assisted dying will be harmed. Further, doctors will be scarred by their participation in assisted dying.

A7.6 Counter-arguments to those against legalising assisted dying

In addition to presenting arguments for legalising assisted dying the four reports described above,⁸⁷² along with submission and witnesses, presented refutations of arguments against legalising assisted dying. These are presented below. The Committee does not assign any particular value or make any critique of the arguments as presented in this Appendix.

A7.6.1 Refuting the slippery slope and risks to vulnerable people argument

The slippery slope has not eventuated in permissive jurisdictions.

The argument refuting the risks to vulnerable people of legalised assisted dying is linked to the argument against the slippery slope. The slippery slope scenario has not materialised. Studies in jurisdictions which permit assisted dying have shown that vulnerable people are not more likely to receive assisted dying and suicide rates have not increased.

The slippery slope argument applies to a full range of issues where public policy and laws are nonetheless made. Accepting this argument would lead to stasis.

Using the slippery slope argument to justify maintaining the status quo overlooks the fact that there are costs and risks in the status quo.

The argument that people with disabilities are vulnerable to coercion is paternalistic. Anyone with capacity should be trusted to make decisions on their own behalf.

An effective legal framework and guidelines can prevent against abuse of assisted dying. Additionally, without the safeguards and monitoring that assisted dying legislation entails, unregulated assisted dying is occurring.

A7.6.2 Refuting the diminished investment in palliative care argument

Legalisation of assisted dying has boosted the development of palliative care in Belgium and the Netherlands. Improving the quality of and access to palliative care was central to support for assisted dying.

⁸⁷² See section A7.2

A7.6.3 Refuting the argument against legislating for a small number of people

History is filled with examples of legislation designed to protect the rights of a minority, such as people with disabilities.

A7.6.4 Refuting the argument that a request for assisted dying is irrational

Patients can make informed, rational decisions to die. A patient asking for assisted dying is no less rational than a patient who refuses treatment. The sadness that accompanies a prognosis of imminent death should not be confused with depression.

A7.7 Counter-argument to those for legalising assisted dying

In addition to presenting arguments against legalising assisted dying the four reports described above,⁸⁷³ along with submission and witnesses, presented a refutation of an argument for legalising assisted dying. This are presented below. The Committee does not assign any particular value or make any critique of the argument as presented in this Appendix.

A7

A7.7.1 Refuting the autonomy argument

Autonomy is not absolute and must be balanced with the inherent value of life. Respect for life prevails over personal autonomy. Autonomy is properly limited by the rule of law, public safety and the fundamental rights and freedoms of others.

The broader social impact of autonomous actions cannot be ignored. Autonomy is no argument for allowing people to make bad decisions.

The individualism fostered by autonomy is a threat to our sense of community and leaves our most vulnerable at risk of abandonment.

⁸⁷³ See section A7.2

Appendix 8

Supplementary legislative reform

A8.1 Recommendations from the Victorian Law Reform Commission's *Guardianship Report* (2012)

A8.1.1 Preservation of common law

New guardianship legislation should provide that the existence of statutory provisions to make an instructional health care directive does not affect any existing common law right to make an advance directive about medical treatment.

A8.1.2 Refusal of treatment certificates

Refusal of treatment certificates made prior to the introduction of new provisions should remain legally valid.

A8.1.3 Retain enduring powers of attorney

An adult with capacity should continue to be able to appoint a person to make decisions for them about personal matters, including medical treatment and financial matters, when they lack capacity to make these decisions in the future.

A8.1.4 Medical trespass

The offence of medical trespass should be extended to apply to a health provider who knowingly provides medical treatment to a person that is contrary to that person's wishes as expressed in an instructional health care directive and that is not otherwise authorised by law.

A8.1.5 Emergency treatment

If emergency treatment is required and the health provider is aware of an instructional health care directive but does not have time to apply to the tribunal to determine if it is valid or if a direction in the directive is operative, and they believe on reasonable grounds that one of the following applies:

- a. circumstances, including advances in medical science, have changed since the completion of the instructional health care directive to the extent that the principal, if they had known of the change in circumstances, would have considered the terms of the direction inappropriate

- b. the instructional health care directive is uncertain
- c. there is persuasive evidence to suggest that the instructional health care directive is based on incorrect information or assumptions then the health provider does not incur any liability, either to the principal or anyone else, if the health provider does not act according to the directive.

A8.1.6 Protection for health providers for non-compliance with instructional health care directives

New guardianship legislation should provide the following protection for health providers:

- a. A health provider is not affected by an instructional health care directive to the extent that the health provider, acting in good faith, does not have actual knowledge that the person has an instructional health care directive.
- b. A health provider who — acting in good faith and without actual knowledge that an instructional health care directive is invalid — acts in reliance on the directive, does not incur any liability to the principal or anyone else because of the invalidity.
- c. A health provider has a duty to determine whether an instructional health care directive is in place by checking the register before providing treatment. A health provider who fails to check the register and provides treatment that is inconsistent with the directive will not be protected from liability by the provisions providing protection for a lack of actual knowledge. A health provider is not required to check the register if emergency treatment is required.

A8.1.7 Conscientious objection

A health practitioner should be required to refer the patient or enduring personal guardian to another health practitioner if their personal views or beliefs prevent them from complying with lawful directions in a valid instructional health care directive.

A8.1.8 Psychiatric treatment

Any directions in an instructional health care directive about psychiatric treatment are not binding if a person becomes an involuntary patient under the *Mental Health Act 1986*.

A8.1.9 Witnessing requirements

An instructional health care directive should be signed and dated by two witnesses who are present at the time the instructional health care directive is made. One of the witnesses must be a person who is authorised to witness an affidavit or a registered medical practitioner. The witnesses must be satisfied that:

- a. the principal is at least 18 years old

- b. the authorised witness has seen appropriate identification documents, which confirm the principal's identity. The Act or regulations should detail what combination of documents is eligible as effective proof of identification
- c. the principal's decision is made voluntarily and without inducement or compulsion
- d. the principal understands the nature and likely effects of each direction in the instructional health care directive
- e. the principal understands that a direction in an instructional health care directive operates only while the principal lacks capacity to make decisions about the matter covered by the direction
- f. the principal understands that they may revoke a direction in the instructional health care directive at any time they have capacity.

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Extracts of proceedings

Legislative Council Standing Order 23.27(5) requires the Committee to include in its report all divisions on a question relating to the adoption of the draft report. All Members have a deliberative vote. In the event of an equality of votes, the Chair also has a casting vote.

The Committee divided on the following questions during consideration of this report. Questions agreed to without division are not recorded in these extracts.

23 May 2016

Recommendation 2

That the Victorian Government support an interdisciplinary approach to end of life care that focuses on continuity of care for the patient through the implementation of measures to encourage the efficient organisation and exchange of information with all parties. This includes patients, substitute decision makers, general practitioners, nurse practitioners, community nursing services, Aboriginal health services, home care workers, and managers of community and residential aged care facilities.

Ms Springle moved, That **Recommendation 2** stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mrs Peulich
Ms Springle	
Ms Fitzherbert	
Mr Melhem	
Mr Mulino	
Ms Patten	
Ms Symes	

Question agreed to.

Recommendation 7

That the Victorian Government work to prevent unnecessary emergency department presentations from aged care facilities and reinvest any savings into palliative care.

Ms Springle moved, That **Recommendation 7** stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mrs Peulich
Ms Springle	
Ms Fitzherbert	
Mr Melhem	
Mr Mulino	
Ms Patten	
Ms Symes	

Question agreed to.

Recommendation 43

That the Victorian Government, through End of Life Care Victoria recommended in this Report as part of the assisted dying framework, establish a registry hotline to improve access to advance care plans for emergency medical services.

Ms Symes moved, That **Recommendation 43**, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Recommendation 48

Repeal relevant legislation

That the Victorian Government repeal the *Medical Treatment Act 1988* and repeal health substitute decision making provisions in the *Guardianship and Administration Act 1986* and the *Powers of Attorney Act 2014*.

New legislation — the Future Health Bill 2016

That the Victorian Government introduce legislation providing for:

- instructional health directives, which will replace the refusal of treatment certificate. This should specify:
 - refusal of or consent to a particular medical treatment will be taken to be a binding provision, which can apply in limited circumstances

- all other provisions of an instructional health directive, such as value statements, are non-binding provisions
- the ability to refuse or consent to treatment in relation to future conditions
- protection for ambulance officers when they act in good faith in reliance on an instructional health directive
- substitute decision makers, with the equivalent of an enduring power of attorney (medical treatment), to be able to refuse medical treatment.

Ms Symes moved, That **Recommendation 48** stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mrs Peulich
Ms Springle	
Ms Fitzherbert	
Mr Melhem	
Mr Mulino	
Ms Patten	
Ms Symes	

Question agreed to.

Recommendation 49

That the Victorian Government introduce a legal framework providing for assisted dying, by enacting legislation based on the assisted dying framework outlined in this Report in Annex 1, Assisted Dying Framework Summary.

Ms Springle moved, That **Recommendation 49** stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Preliminary pages

Ms Patten moved, That the preliminary pages, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Chapter 1

Ms Springle moved, That **Chapter 1**, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Chapter 6

Ms Springle moved, That **Chapter 6**, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Chapter 7

Ms Symes moved, That **Chapter 7**, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Chapter 8

Ms Patten moved, That **Chapter 8**, as amended, stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Appendices 1–8

Mr Melhem moved, That **Appendices 1–8** stand part of the Report.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Tabling of Report

Ms Symes moved, That the final Report, Including chapters 1–8, preliminaries, appendices, bibliography and extracts of proceedings, as amended, be the final Report of the Committee to be tabled on 7 June 2016.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	Mrs Peulich
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Abridged report

Ms Patten moved, That in addition to the final Report, the Committee table an abridged version of the Report, including: Committee membership, Committee staff, Contents, Chair's foreword, Executive Summary, Recommendations, Annex 1.

The Committee divided.

Ayes	Noes
Mr O'Donohue	Mr Mulino
Ms Springle	
Ms Fitzherbert	
Mr Melhem	
Ms Patten	
Ms Symes	

Question agreed to.

Minority reports

End of Life Choices Inquiry: Minority Report – Inga Peulich MLC

As a member of the Legal and Social Issues Committee of the Legislative Council, I submit this minority report opposing several significant recommendations being made by the committee to support the establishment of a regime which allows physical assisted dying in Victoria, and in a narrow range of circumstances, to allow euthanasia.

Terms of Reference

The inquiry into End of Life Choices by the Victorian Legislative Council's Legal and Social Issues Committee was established on 7 May 2015. The Legislative Council agreed to a motion to inquire into, consider and report, no later than 31 May 2016, on the need for laws in Victoria to allow citizens to make informed decisions regarding their own end of life choices and, in particular, the Committee should —

- (1) assess the practices currently being utilised within the medical community to assist a person to exercise their preferences for the way they want to manage their end of life, including the role of palliative care;
- (2) review the current framework of legislation, proposed legislation and other relevant reports and materials in other Australian states and territories and overseas jurisdictions; and
- (3) consider what type of legislative change may be required, including an examination of any federal laws that may impact such legislation.

Background

I opposed the establishment of this inquiry on the basis that Victorians had access to an outstanding program of palliative care available to terminally ill patients, and that the real intent of the motion was to work towards the establishment of a physician assisted dying regime. The Greens had unsuccessfully introduced this into the Victorian Upper House in 2008 which I opposed at the time on, personal, social and moral grounds.

From the outset, this inquiry was expected to deliver the recommendations which are contained in the report due to the strong predisposition of the committee to voluntary euthanasia, from the time of the inquiry's establishment as well as the loading of the inquiry with pro euthanasia submissions.

Overwhelming support for Palliative Care

I am strongly in support of recommendations which seek to improve the operations and funding of our well respected and effective palliative care system.

The management of pain, accessibility, and availability of palliative care, and its access by indigenous and multicultural Victorians are areas where ongoing improvement is occurring. This needs to be supported to ensure that pain is managed effectively and that no terminally ill person dies in pain.

Advance Care Planning

The notion of advance care planning to promote end of life choices being made by Victorians is in principle worthy of support.

I am however concerned that the content and the implementation of advanced care plans can be used as a vehicle for the promotion of physician assisted dying. I am also concerned that advanced care plans may be used to lock in advanced care directives which bind physicians and medical staff to executing wishes which may well be subject to change when a person is confronted by the prospect of death.

No person can predict the psychological disposition of a person, his or her will to live or die, or propensity to change their mind when confronted by death.

Furthermore, if one of the options in advance care planning is physician assisted dying or worse still, euthanasia (involving the administration of a lethal drug by a third person in instances where the patient cannot self-administer), then advance care plans become problematic. This is the reason why I oppose advance care plans if the legal framework in which advance care plans exist include physician assisted dying or a form of euthanasia.

Physician Assisted Dying and Euthanasia

The substantial part of this minority report arises from my strong opposition to physician assisted dying and any form of euthanasia.

Any proposal for a physician assisted dying regime or a form of euthanasia is not only a slippery slope, but people will die as a result of accident, error or misdiagnosis.

Any accidental loss of life – even the loss of one life, means such a regime cannot be justified, just as the loss of life, due to capital punishment, deliberate or due to a possible miscarriage of justice, cannot be justified and was the reason for its abolition.

Furthermore, is it possible to guarantee that a person facing death will not experience a last minute change of mind when staring death in the face?

Worse still, when unable to communicate their wishes on life and death issues, can we be confident that the actions of the medical profession or family members will be genuinely motivated by the best interests of the patient, their wishes and/ or their views? Can ending the life of a person who is unable to give informed consent ever be justified in a modern, democratic and multicultural society?

It is even more disturbing to consider the social impact of state sanctioned assisted suicide. What impact does the promotion of a physician assisted death regime have on our efforts to reduce suicide or youth suicide? This is a most serious social impact that has not been adequately considered by this or any other inquiry of which I am aware.

And lastly, how long will it be before those who have been campaigning for a broadening of eligibility for physician assisted dying to call for a broader set of criteria including those who suffer

experiential pain, mental health sufferers, persons who are inarticulate or even children and babies?

Conclusion

In conclusion, except those who are prepared to take a significant leap of faith to support calls for a physician assisted dying regime, a caring and compassionate society cannot support the taking of life when it is clearly impossible to have safeguards against errors of medical judgement, the accidental taking of human life, let alone the moral arguments which exist against state sanctioned death, no matter what language this is cloaked in.

Consensual physician assisted dying or even consensual euthanasia enshrined in advance care directives can never be a one way ticket to a destination without cases having been prone to manipulation and subjective interpretation. Nor should any scheme ever deny the patient concerned with every opportunity to change his or her mind right up to the very end, should such a regime ever be established.

Through the availability of palliative care, well-funded and accessible, delivered by caring, well trained and compassionate staff with all of the sensitivities required by patients suffering terminal illness and their families, terminal patients can be looked after compassionately.

End of life directives that exclude physician assisted death options, is the only safe and assured way of protecting and safeguarding against unintended deaths due to human error, accident, misdiagnosis or patients unable to express their views, or factor in a possible renewed desire to live at a critical point of any life taking regime.

Many of the arguments presented to the committee in favour of “dying with dignity” were based on a general commitment to principles of personal autonomy and rights.

However, a state legislated regime of physician assisted dying is not just an exercise of personal autonomy. The implications of such a regime for those who legislate, those who administer and those who may be victims of poor implementation, something not uncommon in society or our hospitals, are too severe and the recommendations of this report must be given closer scrutiny and rejected as a response of a compassionate society.

Pro euthanasia advocates claim that life is not devalued by permitting assisted suicide and euthanasia. Given that there can never be a guarantee that a regime will never result in a single accidental death is cold comfort who those who lose a loved one “accidentally” as a consequence of such a regime being in place.

The pressuring of vulnerable and sick people is another dimension which is a risk for which we cannot fully account – prospectively or retrospectively.

Also, is there a risk of creating a society where choosing death becomes an obligation for the patient so as to relieve family of the responsibility and cost of looking after an ill or disabled patient who is consuming resources associated with a continuation of life?

Will a pro death culture be created if we see the ill as being such a burden to society that their death serves to eliminate them or the elderly from our overcrowded hospitals or nursing homes?

Such a culture would undoubtedly be corrosive to the trust patients and families have in the medical profession and our health institutions.

The respect of personal autonomy enshrined in advanced care planning is a means of respecting the wishes of the individual patient who no longer wishes to continue receiving treatment for terminal illnesses.

Any regime which goes beyond that is no longer simply about personal autonomy and raises far too many issues for a compassionate society to contemplate.

Inga Peulich MLC

Member for the South Eastern Metropolitan Region

EXECUTIVE SUMMARY

The Majority Report does not establish the case for the legalisation of assisted suicide or euthanasia. It is mistaken in asserting that it is possible to fundamentally change medical practice in order to help the small minority of people who experience unendurable pain and that no one will be worse off as a result. The facts say otherwise.

The key arguments that will be developed in this report are that:

- It is possible to respect individual autonomy while not empowering health professionals to actively participate in acts of assisted suicide or euthanasia.
- Even if it can be argued that euthanasia or assisted suicide are justifiable in some instances, the negative consequences arising from legalisation far outweigh the benefits arising in that minority of cases.

This report acknowledges that extremely complex situations can arise at the end of life

Not all pain can be effectively managed, whether it be physical or psychological. In the face of unmanageable pain, some people express a clear desire to end their life. For most of us, witnessing great suffering by another person, particularly a loved one, prompts a strong desire to find a way to end that suffering. That is why many of the people who have a desire and willingness to give assistance to these wishes do so out of compassion and love.

The potential for very difficult situations to arise towards the end of life was reinforced by direct evidence provided to the Committee. This evidence was received in both written form and through testimony. All of the people who gave this evidence exhibited great bravery in telling their stories. This report acknowledges the importance of these peoples' experiences.

It is also important to acknowledge that situations involving unendurable suffering are not limited to the end of life. They can arise as a result of non-terminal diseases, accidents or other changes in circumstances that have ongoing negative consequences on a person's quality of life. Cases occurring near the end of life are generally focussed on in the euthanasia and assisted dying debate since these are widely seen to provide the strongest support for the case for intervention to give effect to a person's wish to die.

It is possible to respect individual autonomy without supporting euthanasia or assisted suicide

For many, the importance of respecting individual autonomy underpins the case for euthanasia and assisted suicide. It is almost universally agreed that adults have a right to make informed choices about their medical treatment, including opting for a withdrawal of treatment. This report supports that proposition.

Euthanasia and assisted suicide are different. They are not simply a matter of whether to give effect to an individual's choice about their own treatment. They necessarily involve third parties, usually medical practitioners, in acts that will intentionally result in death.

As such, acts of euthanasia and assisted suicide move from the private realm into the public realm. Public policy questions such as the risk of unintended consequences and proportionality are relevant and must be considered if regulatory intervention is to be justified.

Euthanasia and assisted suicide are a last resort in only a tiny minority of cases

While not all pain can be managed, it can be managed in the vast majority of cases and the proportion of cases in which pain can be managed is constantly increasing.

Experts in palliative care, oncology and related fields almost unanimously agreed that almost all symptoms arising from physical pain at the end-of-life can now be managed. The palliative care and oncology experts who gave evidence also stated that, over long careers, the number of people expressing a desire to have their life shortened was very small.

Even where there is an expressed desire to die, it is critically important to understand the nuances of such requests. Where the person making the request is experiencing depression or a mental illness, which is relatively common, there are usually other treatment options worth exploring. Holistic palliative care and other forms of assistance can often provide effective relief, even if not complete, and can often lead to a reversal in the expressed desire.

In practice, euthanasia and assisted suicide are a disproportionate response that cause far more social harm than good

The number of instances of euthanasia and assisted suicide is growing rapidly in all major jurisdictions where it is legal. This has been occurring for almost two decades in some jurisdictions, with no sign of abatement. The usage of euthanasia and assisted suicide in practice is far out of proportion to the situations that were originally used to justify the practice in these jurisdictions: namely, that small minority of cases where the symptoms of pain are unmanageable.

Moreover, the rapid growth in documented cases of euthanasia and assisted suicide probably materially understates the actual prevalence of the practice. There is a widespread failure of safeguards and procedures across jurisdictions, including low rates of reporting.

While legalisation was supposed to bring what was occurring in the shadows into the light, legalisation has simply pushed the boundary of what is legal out further and may have increased the amount of activity that occurs beyond the sight of regulators.

In countries with legalised euthanasia or assisted suicide, many vulnerable people are being placed in difficult situations in which they have to make irreversible, complex choices under a great deal of pressure. Evidence suggests that it is doubtful that safeguards are working as intended for such people.

CHAPTER 1 – FRAMING THE ISSUE

This report starts from the premise that adults have a right to control what happens to them. This includes a right to decide which medical treatments are administered to them and a right to have medical treatment fully withdrawn should a person decide that the burden of any treatment would outweigh the likely potential benefits.

A patient should be able to convey a desire to have treatment withdrawn either explicitly while conscious or through a clear statement of their preferences that could take effect should a person fall into an indefinite unconscious state. The importance of this right was reflected in the *Medical Treatment Act 1988* and this report concurs with the right to refuse treatment or have treatment withdrawn as critical.

It is important to stress from the outset that, in cases of both euthanasia and assisted suicide, the ethical dimensions are inherently more complex since third parties are necessarily involved. It is not enough to assert a belief in the individual's right to autonomy. Any system of regulated euthanasia or assisted suicide must involve the active participation of members of the health profession and possibly also other regulatory arms of the state.

In addition to considering how to give effect to the wishes of the patient, the role of medical professionals and the health system more generally in actively bringing about the death of patients must be scrutinised in any discussion of active euthanasia or assisted suicide.

The role of professionals in a regulated euthanasia or assisted suicide regime could take a number of forms, including some or all of the following:

- One or more medical professionals providing approval before an individual is granted access to either euthanasia or assisted suicide.
- One or more medical or related professionals providing counselling before either euthanasia or assisted suicide is administered.
- One or more medical professionals (or a chemist, with approval) prescribing the drug/poison to be used in an assisted suicide.
- One or more medical professionals administering euthanasia.
- Medical professionals or others as deemed appropriate witnessing an assisted suicide.
- Medical professionals and others as deemed appropriate monitoring instances of euthanasia or assisted suicide and possibly hearing appeals at different steps of the regulated process.

Because regulating euthanasia and assisted suicide involves the state regulating how medical professionals can take active steps to bring about death, it is not just a question of individual autonomy.

Euthanasia and assisted suicide involve broader policy questions in relation to how the medical system can best work in the interests of individuals who are either terminally ill or in grave physical

or mental distress. Issues such as unintended consequences and whether procedural breaches can be managed lie at the heart of the issue.

In giving evidence to the House of Lords Select Committee inquiry into the Assisted Dying for the Terminally Ill Bill, Professor Alan Johnson, Emeritus Professor of Surgery at the University of Sheffield observed:

... the impression has been given that obeying patients' wishes is the overriding ethical imperative for doctors. Of course it is important, but it is not paramount. If it were, I would have done many unnecessary operations and some harmful operations in my time as a surgeon (Q 165).¹

He cited, as an example of the need to subordinate individual patient autonomy to the interests of the wider patient community on rare occasions, the refusal of doctors to prescribe antibiotics at a patient's request for relatively trivial conditions because to do so would "produce resistance which might have quite a serious effect on people further down the line".²

The Select Committee concluded that: "We are agreed that patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community."³

In the context of euthanasia and assisted suicide, there is arguably a gain from giving effect to some patients' wishes to hasten their death. But this must be weighed against the potential for societal harm through a range of potential negative consequences, including: vulnerable people being pressured into euthanasia or assisted suicide; people having their death hastened without having given proper consent; and a gradual broadening of practices without transparent public consideration. As will be shown below, evidence from jurisdictions that have legalised euthanasia and assisted suicide shows that all of these are real risks.

The House of Lords Select Committee supported this framing of the issue:

... we cannot address the issue of personal autonomy in isolation and ... we must proceed to look at some of the 'real world' issues which have been raised and to try to assess the balance between greater personal choice for some people and increased potential harm for others ...⁴

What is the real choice that we face? It is important to acknowledge that neither current regulatory arrangements nor a world with legalised euthanasia/assisted suicide will be free from unendurable suffering. We are ultimately choosing between two systems in which some suffering will be difficult to treat or manage and in which regulation is difficult to perfectly enforce.

The Majority Report gave considerable weight to the evidence from the Coroners Court of Victoria. This evidence included details of a number of confronting situations in which people committed suicide, often in very distressing ways, in order to end suffering. What the Majority Report doesn't

¹ House of Lords, *Assisted Dying for the Terminally Ill Bill – First Report*, Select Committee on Assisted Dying for the Terminally Ill Bill, Session 2004-05, 3 March 2005, paragraph 45.

² Ibid, paragraph 45.

³ Ibid, paragraph 62.

⁴ Ibid, paragraph 63.

make clear is that many of the instances raised by the Coroners Court wouldn't fall within the scope of its proposed regime. This highlights the difficult choice that we face in practice.

As Table 1 outlines, we do not face a choice between respecting autonomy and bringing dubious actions out of the shadows on the one hand versus an intransigent, knee-jerk protection of the status quo on the other. Rather, we face a choice between two imperfect situations. In neither will the wishes of all people to die be fully complied with. In neither will there be full and transparent compliance with the law.

Rather, the choice as to whether to reform or not should be guided by an informed judgement of the likely consequences for our overall treatment of people in vulnerable situations.

Table 1: Characteristics of current arrangements vs legalised euthanasia/assisted suicide

Current arrangements	Legalised euthanasia or assisted suicide
Harrowing deaths exist - although in the vast majority of cases, physical pain can be managed effectively with modern pain relief and palliative care. These instances are a small and shrinking minority of overall deaths.	Harrowing deaths will still exist – although there will probably be less in the category of deaths explicitly allowed under the euthanasia/assisted dying regime. The degree to which there are less deaths involving unmanageable physical or psychological pain will depend upon the permissiveness of the scheme.
Psychological pain that is difficult to treat exists – although treatment in this sphere is improving.	Psychological pain that is difficult to treat will continue to exist – unless a very permissive regime is introduced, such as in Belgium. Under such a permissive regime, the effectiveness of safeguards will be extremely difficult to ensure.
	The number of instances of euthanasia or assisted suicide will probably rise rapidly and this increase is likely to persist. In foreign jurisdictions with legalised euthanasia or assisted suicide, there has been a rapid and sustained growth in the number of deaths and in no jurisdiction is there evidence that this increase will slow down.
	It is likely that the enforcement of safeguards will be difficult. In jurisdictions with legalised euthanasia or assisted suicide, there is systemic non-compliance with the law. This includes: <ul style="list-style-type: none"> • non-reporting of many instances of euthanasia/assisted suicide; • incomplete awareness by regulators of breaches of the law; and • incomplete enforcement by health regulators and law enforcement of breaches.
The law is currently not fully enforced. This can take a number of forms, including: prosecutorial discretion and sentencing leniency, particularly in relation to cases where people are killed or assisted in their suicide by loved ones.	It is unclear if enforcement of the law will improve at all. In jurisdictions with euthanasia and assisted suicide, it is acknowledged by regulators that considerable activity occurs at the edges of the law and that they are powerless to monitor, let alone prevent, much of this activity.

CHAPTER 2 – ALMOST ALL CASES OF PAIN ARE CURRENTLY MANAGEABLE

In almost all cases where a patient experiences a great deal of pain, including terminal cases, the symptoms of that pain can be managed by current best practice in pain relief and palliative care. It is important to note that the capacity of health practitioners to manage the symptoms of pain is increasing over time.

2.1 Pain relief is effective in almost all cases

A number of expert practitioners in palliative care gave evidence to the Committee in relation to the frequency of cases in which it was possible to manage pain at the end of a patient's life. While it is not possible to put a precise percentage on this proportion, the experts were unanimous in their assessment that it was rare that pain couldn't be managed.

This included the following evidence:

Associate Professor Daryl Jones, Austin Health: "... in 20 years as a clinical practitioner, the number of patients I have seen who die to whom that applies is the overwhelming minority."⁵

Associate Professor Peter Hunter, Alfred Health: "We do know that in almost all patients, if we do a proper assessment and understand that the drugs are available, we can alleviate pain and we can do a good job of that."

"I have never not been able to control anyone's symptoms around pain once you have got them on the right treatment path, be it narcotic analgesia or infusion pumps et cetera, so I think that if anyone dies in pain, that is an absolute travesty because there is capacity to really manage that effectively in this day and age."⁶

Moreover, the proportion of patients for whom pain is manageable is rising. When asked if palliative care techniques had improved, Dr Michelle Gold, Director of the Palliative Care Unit at the Alfred Hospital stated that:

Dr Michelle Gold: There are always new medications available in that sense. We are having increasingly fruitful interactions with some of our interventional colleagues to provide pain relief with various procedures and interventions that are sometimes much better directed than the medications are and hopefully have fewer side effects. It is terrific that there are new techniques – new ways of delivering some of the old medication.⁷

⁵ Associate Professor Daryl Jones, *Transcript of evidence*, 5 August 2015, p24.

⁶ Associate Professor Peter Hunter, Geriatrician and Director of Aged Care, Alfred Health, *Transcript of evidence*, 15 October 2015, p55.

⁷ Dr Michelle Gold, Director of the Palliative Care Unit of the Alfred Hospital, *Transcript of evidence*, 23 July 2015, pp56-57.

2.2 Knowledge about pain relief options can provide considerable comfort

Many health practitioners who provided evidence to the Committee spoke of the considerable potential to provide patients with peace of mind by clearly communicating the pain relief options available to them. For example Ms Deidre Bidmade, Vice-President of the Warrnambool and District Community Hospice, stated that:

Ms Deidre Bidmade: ... in the last 10 years the biggest factor when somebody is dying is how I am going to die. Is my pain going to be out of control? These conversations before somebody is in their last phase of dying is so important, because if you allay those fears and reassess the fact that we have such wonderful drugs out there to ensure that people are not in pain and that we do have things like Niki syringe drivers, so that you can go home with that in situ and that can be titrated to the needs every day, if you can give people peace of mind that they are supported in the journey and that there is no need for acceleration of symptom, that in my experience has been most of the underlying issue.⁸

This view was supported by Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care:

Associate Professor William Silvester: I am amazed by the number of times that I have gone to walk away and some has called me back and said, 'Look doctor, I didn't tell you, but in fact I've been thinking about euthanasia, and now that you've been able to lift such a weight off my shoulders and I can now be sure and confident that I am going to get the care that I want at the end in the way that I want it, I can now concentrate on living as well as possible. I don't have to think any longer about getting Nembutal or saving up all of my prescription tablets or whatever so that I can do something before I lose control, because now I can see that even when I reach a point where I no longer have control, I will still get what I want and I will not get what I do not want.'⁹

2.3 Very few people ask to be killed – especially if they are aware of care options

Dr Ranjana Srivastava recently wrote an internationally acclaimed book, "Tell me the truth" dealing with the meaning of a good life and good death and the ethics of end-of-life interactions. She is an oncologist with considerable experience and adjunct associate professor in the Monash University Faculty of Medicine, Nursing and Health Sciences. Dr Srivastava gave evidence to the Committee in relation to the issue of how often people seek active intervention by a doctor to end their life:

Dr Srivastava: ... from 15 years of experience ... the most informed I can tell you is that in all my career there have been no more than two or three people at most, in the thousands of patients I have seen, who have said, 'I have had enough. I want to die.'¹⁰

⁸ Ms Deidre Bidmade, Vice-President of the Warrnambool and District Community Hospice, *Transcript of evidence*, 30 July 2015, p27.

⁹ Associate Professor William Silvester, President of the International Society of Advance Care Planning and End of Life Care, *Transcript of evidence*, 23 July 2015, pp63-64.

¹⁰ Dr Ranjan Srivastava, Adjunct Associate Professor, Faculty of Medicine, Nursing and Health Sciences, Monash University and Oncologist, *Transcript of evidence*, 19 August 2015, p20.

This was corroborated by other evidence, including from Professor Peter Hudson, Director of Palliative Care at St Vincent's Hospital:

Professor Peter Hudson: We have been collecting data in two large teaching hospitals for about 15 years now, and it shows that less than 1 per cent of patients referred to the palliative care consultation service actually request euthanasia.¹¹

Even where people ask to die or ask to be killed, the subtle nuances in what they are communicating can only be interpreted by an expert:

Dr Natasha Michael: One of the questions I am always asked is: do patients ask you to kill them? The answer is: yes. I do not use the term 'request for euthanasia'; I use the term, 'They express a desire for death'. Many might have heard me use this terminology or expression before.

People say one of three things to me: 'I want to die', 'Let me die' or 'Kill me'. The people who are saying 'I want to die' are people who are saying: my suffering is so unbearable at this point in time, with my pain, my distress or the burden I am placing on my family, death has to be a better option. The answer to that is not injecting them with a drug or providing barbiturates; the answer to that is saying, 'How can I help you with these factors that are making you feel that death has to be the better option?' The 'Let me die's' are saying, 'You know what, I have fought this fight. I have run the course. I am 85 — or I am 63 — I have had six lines of chemotherapy. I have had enough. Let me die'. **The 'Kill me' is from a really, really small minority** [emphasis added]. Most health professionals are not trained to unpick these things. They lump them together in a singular cohort, so you think of the danger you pose when people come to you and express a desire for death when actually what they are saying is, 'My suffering is so unbearable that I just want you to help me'. The risk is phenomenal.¹²

If you have an unskilled practitioner, you do not have the ability to distinguish these complex psychosocial phenomena. The risk is too high ... I have seen too many people express a desire for death when actually all they are asking for is help.¹³

To set up a system in which many GPs face a situation in which they have to interpret complex end-of-life situations will create significant risks particularly given that most GPs do not have training in this specific area of care and will face such situations rarely. As will be outlined below in detail, these risks are further compounded by the inadequacy of safeguards in practice.

¹¹ Professor Peter Hudson, Director, Centre for Palliative Care, St Vincent's Hospital, *Transcript of evidence*, 24 February 2016, p4.

¹² Dr Natasha Michael, Director, Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p9.

¹³ Dr Natasha Michael, Director, Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2015, p10.

2.4 Conclusion: A very small number of cases are problematic under current arrangements

For the vast majority of people, modern pain relief and palliative care can manage physical pain right up to the end of life. If euthanasia or assisted suicide was legalised so as to deal with this type of situation, one would expect to see a small and relatively stable number of cases over time. As will be outlined in the following chapter, the evidence differs markedly from this in every major jurisdiction that has legalised euthanasia or assisted suicide.

Psychological pain is sometimes more difficult to manage. However, once psychological pain is used as a rationale for euthanasia or assisted suicide, difficulties arise as this type of pain is not particularly associated with end-of-life issues. It can therefore be used to justify the extension of euthanasia and assisted suicide regimes to non-terminal situations. Moreover, as will be argued in Chapter 4, allowing euthanasia or assisted suicide in cases involving profound psychological pain is problematic as the patient's condition will likely impact on their capacity to provide consent.

CHAPTER 3 – THE FREQUENCY OF EUTHANASIA AND ASSISTED DYING IS RISING RAPIDLY

3.1 In all jurisdictions where euthanasia or assisted suicide is legal, there has been a sharp, sustained upward trend in the number of deaths – often over long periods of time

In all major jurisdictions where euthanasia or assisted suicide is legal, the number of cases has increased sharply ever since legalisation. This increase has been rapid and sustained. In no major jurisdiction is a plateau in numbers evident.

The majority of this increase is not due to the aging of society or to a growing awareness of end-of-life options. As will be outlined in Chapter 4, it is most likely to due to factors such as:

- An expansion in the categories of people eligible to opt for euthanasia or assisted dying either through formal legislative change or, sometimes less transparently, gradual changes in the interpretation and application of existing provisions.
- A “normalisation” of euthanasia or assisted dying in the medical system and across the broader culture.
- Systemic failures in safeguards.

The Majority Report sidesteps this issue. It provides no attempt to explain either why such persistent growth in cases is occurring or whether the risks associated with this trend can be managed.

3.2 A summary of empirical trends in the number of cases of euthanasia and assisted suicide across major jurisdictions

Over the next two pages, the number of cases of euthanasia and assisted suicide in the major jurisdictions that have legalised either procedure are set out.

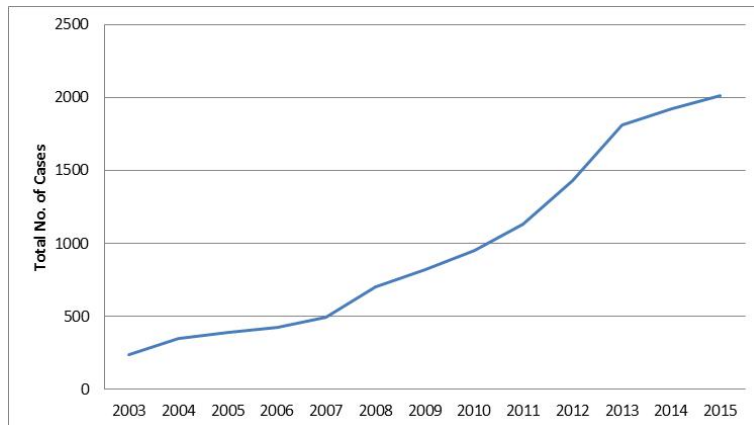
The data from which the graphs and associated growth rates were derived was all obtained from public sources.

The period of data availability varies by jurisdiction, but in three instances, data is available for more than 10 years and in two jurisdictions for more than 15 years.

EUROPEAN JURISDICTIONS

Figures 1 to 3 contain the trend in the total number of cases of euthanasia and assisted dying in Belgium, the Netherlands and Switzerland over the period for which reliable data is available. Data is available for 12 years in the case of Belgium, 7 years in the case of Netherlands and 16 years in the case of Switzerland.

Figure 1: Belgium



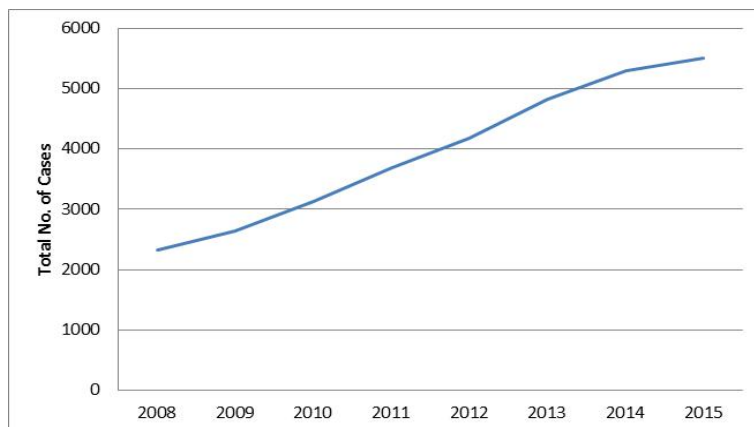
Total Growth 2003-2015:

235 → 2,012

Compound annual growth rate:

19.6%

Figure 2: Netherlands



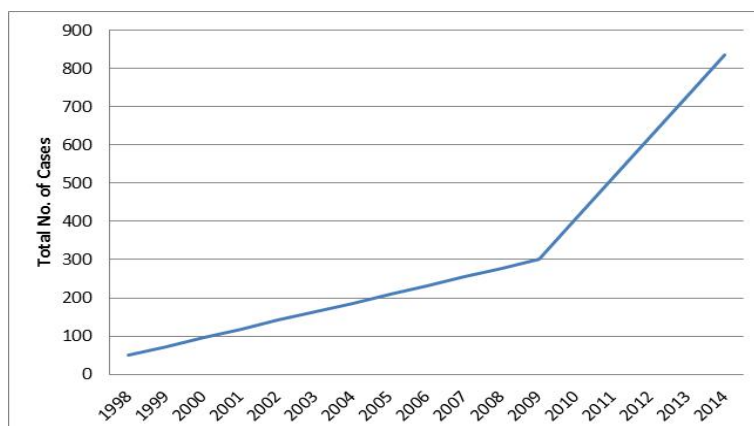
Total Growth 2008-2015:

2,331 → 5,516

Compound annual growth rate:

13.1%

Figure 3: Switzerland



Total Growth 1998-2014:

50 → 836

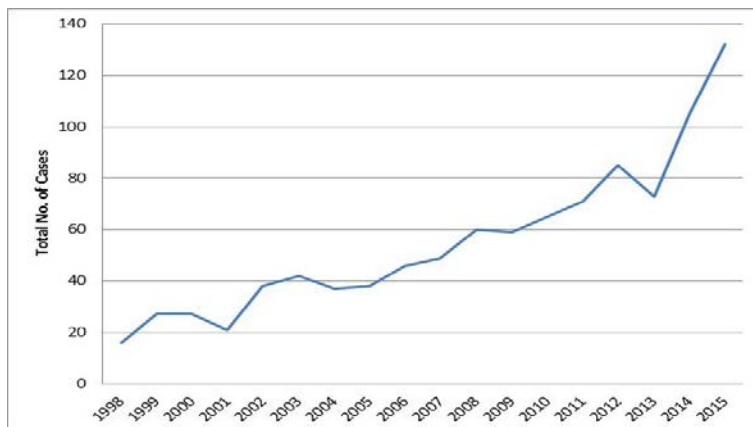
Compound annual growth rate:

19.2%

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Figures 4 and 5 contain the trend in the total number of cases of euthanasia and assisted dying in Oregon and Washington State over the period for which reliable data is available. The data is available for 17 years in the case of Oregon and 5 years in the case of Washington State.

Figure 4: Oregon



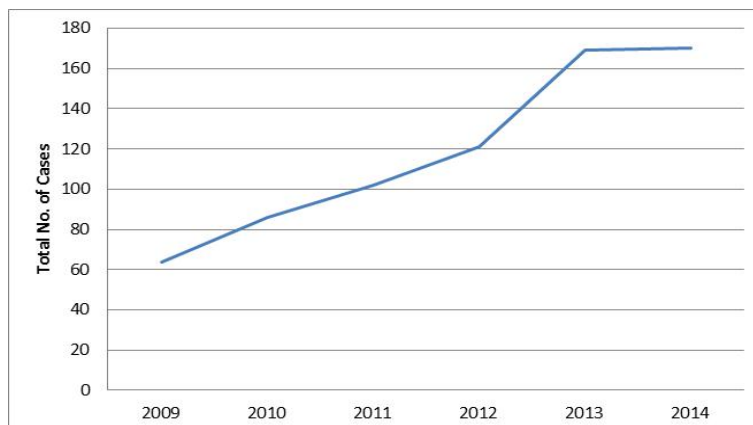
Total Growth 1998-2015:

16 → 132

Compound annual growth rate:

13.2%

Figure 5: Washington State



Total Growth 2009-2014:

64 → 170

Compound annual growth rate:

21.6%

For Belgium, the data was compiled from the official statistics of the Federal Control and Evaluation Commission. These are reported to the Belgian legislature.¹⁴

For the Netherlands, the data is sourced from the Dutch Regional Euthanasia Review Committees.¹⁵

¹⁴ <http://www.lesoir.be/637943/article/actualite/belgique/2014-08-27/euthanasies-ont-augmente-55-en-deux-ans-infographie-for-years-2002-2013>.

For 2014 and 2015, see <http://www.news24.com/World/News/belgian-euthanasia-cases-hit-record-high-20160127> which cites official government statistics.

¹⁵ The Netherlands has five regional euthanasia review committees. The review committees assess whether a doctor who has performed or assisted suicide, euthanasia, has complied with the due care criteria set out in the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act*. An annual report is issued each year by the Dutch Regional Euthanasia Review Committees.

The statistics for Switzerland are derived from a number of sources. Swiss authorities published the first official statistics on assisted suicide in March 2012. According to the Federal Statistical Office, the number of Swiss residents who died from assisted suicide has increased continuously between 1998 and 2009. The Federal Statistical Office reported that, in 2009, approximately 300 assisted suicide deaths occurred (4.8 per 1000 deaths or 0.48% of all deaths) compared with fewer than 50 deaths in 1998.¹⁶ In 2014, the total number of assisted suicide deaths in Switzerland, including deaths at Dignitas and the Eternal Spirit clinic, was around 836.¹⁷

Given the lack of data, Figure 3 is derived by linear interpolation between the data points provided by the Federal Statistical Office for 1998 (using 50 to be conservative in relation to growth rates) and around 300 in 2009.¹⁸ There is a further linear interpolation between the 2009 figure and 836 in 2014.

Recent media articles detailing the number of deaths at individual organisations corroborate this overall trend. It has been reported that the Swiss assisted suicide organisation (EXIT) helped 782 people end their lives in 2015, 199 more than the previous year (583 in 2014).¹⁹ For 2011, it has been independently reported that the right-to-die organisation EXIT assisted 416 deaths, up from approximately 348 deaths in 2010.

In Switzerland, a material number of deaths are from non-residents. The 2011 figure for non-resident deaths reported by the organisation Dignitas was 149.²⁰ *The Atlantic* reported that, in the decade leading up to 2010, over 1,000 people had received assisted suicide at Dignitas.²¹

The data for Oregon and Washington State is sourced from the relevant State Department of Health reports.²²

Source: Dutch Regional Euthanasia Review Committees, Annual Reports, 2012-2015.

¹⁶ Switzerland, Federal Statistical Office (FSO), [Cause of death statistics: Assisted suicide and suicide in Switzerland](#), accessed 11 May 2016.

¹⁷ A Schadenberg, [Switzerland assisted suicides jump 34% in 2015](#), Euthanasia Prevention Coalition, web blog, 3 March 2016.

See, <http://alexschadenberg.blogspot.com.au/2016/03/switzerland-34-increase-in-assisted.html> (Accessed 30 May 2016)

¹⁸ Shariff, M.J., "Assisted death and the slippery slope – finding clarity amid advocacy, convergence, and complexity", *Current Oncology*, 2012, Jun; 19(3): 143-154, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3364764/> (Accessed 30 May 2016)

¹⁹ [EXIT reports jump in assisted suicide numbers](#), Swissinfo.ch, website, 2 March 2016. (Accessed 30 May 2016)

²⁰ Shariff, M.J., "Assisted death and the slippery slope – finding clarity amid advocacy, convergence, and complexity", *Current Oncology*, 2012, Jun; 19(3): 143-154, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3364764/> (Accessed 30 May 2016)

²¹ http://www.theatlantic.com/magazine/archive/2010/03/death-becomes-him/307916/?single_page=true, March 2010, Vol. 305, Issue 2, p68.

²² Oregon State Health Authority, Death With Dignity Act, Annual Report 2014. See <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf> for the most recent report.

See also: Washington State Department of Health, Death with Dignity Act Report, 2014. <http://www.doh.wa.gov/YouandYourFamily/IllnessandDisease/DeathwithDignityAct/DeathwithDignityData>

3.3 The sustained and long-term nature of growth

In all jurisdictions, the increase in the total number of cases has been sharp and sustained. In no jurisdiction is there clear evidence that growth rates are plateauing.

The total number of deaths is higher in the European jurisdictions than the North American jurisdictions, which is to be expected given that the former are more permissive.

To put the current number of deaths in context, in the Dutch speaking part of Flanders, physician-assisted deaths constituted 3.8% of deaths in 2007 and 6.3% of deaths (or 1 in 16) in 2013.²³

A rate of over 6% of all deaths being carried out via physician-assisted deaths - and still rising - can be considered as nothing other than a major shift in practice and culture, particularly given that euthanasia was originally justified in Belgium as a last resort for the tiny minority of people for which palliation could not provide adequate care.

Table 2: Annual growth rate in cases of euthanasia and assisted suicide in selected jurisdictions

Country	% Annual Growth in Total Deaths	CAGR ²⁴ in euthanasia / assisted suicide	No. of years over which CAGR calculated
UNITED STATES	0.5 ²⁵		
Oregon		13.2 ²⁶	17
Washington		21.6 ²⁷	6
EUROPE			
Belgium	0.3 ²⁸	19.6 ²⁹	12
The Netherlands	-0.3 ³⁰	13.1 ³¹	7
Switzerland	0.3 ³²	19.2 ³³	16
AUSTRALIA			
Victoria	1.6 ³⁴		

²³ Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), pp30-31.

²⁴ Compound annual growth rate

²⁵ <http://stats.oecd.org/> - CAGR from 2000-2013

²⁶ Compound annual growth rate: 1998-2015

²⁷ Compound annual growth rate: 2009-2015

²⁸ <http://stats.oecd.org/> - CAGR from 2000-2013

²⁹ Compound annual growth rate: 2003-2015

³⁰ <http://stats.oecd.org/> - CAGR from 2000-2010 (latest data point)

³¹ Compound annual growth rate: 2008-2015

³² <http://stats.oecd.org/> - CAGR from 2000-2103

³³ Compound annual growth rate: 1998-2015

³⁴ ABS 3302.0, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.02014?OpenDocument>, 2004-2014

(Accessed 30 May 2016)

Annual growth rates in the order of 13 – 20 per cent are extremely high. It is worth noting that the impact of cumulative growth rates of this magnitude over the medium term can be deceptive. What appears to be manageable at first can rapidly lead to very large numbers and, in the case of euthanasia and assisted suicide, a very high proportion of overall deaths.

For example, the total number of cases in Belgium has increased by 756% over 12 years and the number of cases in Oregon is 725% higher over the 17 years following legalisation.

Table 3 indicates what would happen in jurisdictions with legalised euthanasia and assisted suicide if currently observed growth rates continue. The final two columns indicate how many multiples of the base year frequency would occur after 10 and 20 years of sustained growth. These are not long periods of time.

For example, if Oregon's observed annual growth rates were applied to a base number of 100 deaths, that number would grow to 350 after 10 years and 1,200 after 20 years. Higher growth rates, such as observed in Washington State, Belgium and Switzerland result in even more dramatic growth. Based on growth rates observed in Washington State, a base number of 100 cases in year 1 would grow to 700 ten years after commencement and 5,000 after 20 years.

It is not at all clear what kind of growth to expect in jurisdictions with legalised euthanasia and assisted suicide over the upcoming 10 or 20 years. However, we cannot rule out continued growth in the order of what we have already observed in jurisdictions such as Oregon and Switzerland.

Table 3: Annual growth rate in the cases of euthanasia and assisted suicide in selected jurisdictions

Country	Observed annual growth rate by jurisdiction	Cumulative growth over 10 year period	Cumulative growth over 20 year period
UNITED STATES			
Oregon	13.2% ³⁵	3.5x	12x
Washington	21.6% ³⁶	7x	50x
EUROPE			
Belgium	19.6% ³⁷	6x	35x
The Netherlands	13.1% ³⁸	3.4x	12x
Switzerland	17.6% ³⁹	5.8x	34x

It is difficult to say, based on available data, why this is happening. Many jurisdictions with legalised euthanasia and assisted suicide do not provide for transparent reporting in relation to case details. The following chapter will outline five possible reasons for the rapid, sustained growth in the number of observed cases.

³⁵ Compound annual growth rate: 1998-2015

³⁶ Compound annual growth rate: 2009-2015

³⁷ Compound annual growth rate: 2003-2015

³⁸ Compound annual growth rate: 2008-2015

³⁹ Compound annual growth rate: 1998-2015

CHAPTER 4 – REASONS FOR THE GROWING PREVALENCE OF EUTHANASIA AND ASSISTED DYING

There are many possible reasons why the number of cases of euthanasia and assisted suicide is rising so quickly and over such a long period of time. Understanding the causes of this growth is critical if we are to be confident that public policy objectives can be achieved through legalisation.

There is considerable evidence that this rapid and sustained rise in numbers is attributable in part to a growth in the scope of the practice, to a normalisation of the practices and to a failure of safeguards.

Box 1: Key public policy considerations

The Victorian Parliament should carefully evaluate evidence which demonstrates that:

- In jurisdictions where it is legal, access to euthanasia and assisted suicide is not being limited to those people experiencing unendurable physical pain, even where this was the original rationale for legalisation.
- Over time, the rapidly growing number of cases of euthanasia and assisted suicide reflects a disturbing normalisation of the practice, even though the original rationale for legalisation usually stressed that it was only intended to be used as a last resort in exceptional cases.
- Safeguards are systemically and routinely failing across a number of jurisdictions. Many of these safeguards are relied upon in the Majority Report without evidence that they will work in practice.

4.1 A greater awareness of rights unlikely to be a sustained driver of growth

Greater awareness of access to euthanasia or assisted dying could possibly have driven a growth in total cases in the months and even years following introduction of each scheme. As can be seen in Figures 1 to 5 however, high growth rates in total numbers have not abated in any jurisdiction, even where data exists for periods of almost two decades. In no jurisdiction is there any indication that growth rates are slowing. This suggests that sustained growth is due to factors other than community awareness.

4.2 An aging demographic contributes only a small share of overall growth

An aging demographic is often put forward as a possible reason why the number of cases is rising.

Aging is not a major factor driving the growth in the number of cases of euthanasia or assisted dying in any of the jurisdictions for which data is available. As Table 2 shows, the total number of deaths over the period 2000-2010 grew at less than 1 per cent per annum in all relevant jurisdictions – and indeed it fell in the Netherlands. The change in the total number of deaths is less than one tenth of the total change in euthanasia and assisted dying cases.

4.3 Scope creep is occurring in at least some jurisdictions

There is a long-standing debate in ethics and jurisprudence as to the nature of the ethical difference (if there is one) between an act and an omission that lead to the same outcome. In the context of medical care, the debate centres on whether there is an ethical difference between a decision to end or withdraw treatment by a health practitioner and that same health practitioner actively taking part in ending someone's life.

Regardless as to one's views on whether there is a meaningful ethical difference between these two situations, the distinction between withdrawing treatment and undertaking a positive action is clearly defined. The logical and philosophical arguments on either side of debate are well developed and have been clearly articulated over centuries.

What is much less clear is the ethical difference between various types of action. For example, if one accepts that euthanasia or assisted suicide can be ethical in some situations, that raises subsequent questions such as whether it should be available only for people with a terminal condition or also for those suffering from a condition that is "unbearable", albeit not terminal. Is physical pain necessary to trigger justifiable action or is psychological pain also sufficient? Is explicit consent required? If euthanasia or assisted suicide is justified only for people suffering from a terminal condition, what does "terminal" mean? Must death be expected within 3 months, 6 months, a year? Should an age limit be placed on consent? And so on.

The reason why the "slippery slope" argument has credibility in this context is that, once euthanasia or assisted suicide is accepted for a limited subset of situations, there is very little by way of logical or philosophical argument to stop the expansion of categories.

- If euthanasia or assisted suicide is permitted for those with a terminal condition in order to alleviate suffering – why not alleviate suffering of the same magnitude in those whose condition is not terminal?
- If consent is critical – then why limit availability to adults if "mature minors" can also give meaningful consent in other contexts such as joining the military.
- If advanced care directives can be used to justify the cessation of invasive and possibly painful medical procedures, why should advanced care directives not also be used to justify active euthanasia?

This is why the limitations included in euthanasia and assisted suicide regimes often come under immediate pressure as soon as these schemes are enacted. This takes two main forms. The first is attempts to explicitly expand the categories of situations in which euthanasia or assisted suicide is legal. The second is to reinterpret existing categories more broadly. As will be outlined below, reinterpretation has been undertaken in practice by both non-legislative and non-judicial bodies.

Often, legislation is passed with limitations that are designed to secure its passage through parliament. Where this "pragmatic" approach is adopted, these limits will almost inevitably be tested once the regime is in place.⁴⁰

⁴⁰ It is widely accepted that in Belgium, at least some of the restrictions contained in the initial legislation were included so as to secure passage of the Bill. Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the

Some would argue that a slippery slope argument is flawed in that it doesn't acknowledge that subsequent changes might be justified on the basis of sound reasoning and policy formulation. That is true. There isn't anything wrong, per se, with legislation that has the potential to change.

The slippery slope argument is less concerned with the merits of each future potential change, and more with the inherent "momentum" in the system. The argument is that, once legalised, there will be a tendency for euthanasia and assisted suicide schemes to expand in scope since the logical and philosophical boundaries between different types of pro-active hastening of death are far weaker than the boundary between omissions and actions.

As will be argued below, the evidence bears this out in a number of jurisdictions.

4.3.1 Scope creep through legislative expansion of categories

Legislative changes have either been implemented or are under active consideration in a number of jurisdictions:

Belgium: euthanasia for children. The original euthanasia legislation in Belgium restricted access to people over the age of 18 years of age. On one reading, children were specifically excluded from the ambit of the legislation as "it was deemed so controversial that including it would have threatened approval of the Euthanasia Bill."⁴¹ In 2014, an amendment was passed that allowed for euthanasia by "mature minors".

Belgium: other changes under consideration by the legislature. In Belgium, a series of other legislative expansions of the euthanasia regime have been submitted to parliament, including:

- Requiring doctors to make referrals, even if it is against their conscience
- Permitting euthanasia for dementia patients
- The use of advanced care directives for people in an unconscious state⁴²

Canada: physician assisted dying for minors. While the *Carter* judgement by the Canadian Supreme Court only applied to competent adult persons, the Provincial-Territorial Advisory Group (PTAG) has already recommended allowing physician assisted dying for minors. Recommendation 17 of the PTAG Final Report is that:

Access to physician-assisted dying should not be impeded by the imposition of arbitrary age limits. Provinces and territories should recommend that the federal government make it clear in its changes to the Criminal Code that eligibility for physician-assisted dying is to be based on competence rather than age.⁴³

Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post---Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p28.

⁴¹ Lemmens, Trudo, The Conflict Between Open---ended Access to Physician---Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post---Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p27 citing Griffiths, John, Heleen Weyers and Maurice Adams, *Euthanasia Law in Europe*, Portland, Hart Publishers, 2008, p328.

⁴² European Institute of Bioethics, *Euthanasia in Belgium: 10 years on*, 2012, p4.

⁴³ Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying, *Final Report*, November 30 2015, Recommendation 17, p34. See: http://www.health.gov.on.ca/en/news/bulletin/2015/docs/eagreport_20151214_en.pdf

4.3.2 *Non-legislative and informal extensions within an existing framework*

Physician-assisted dying in Belgium is an example of informal slippage in the scope of the law. In his expert review for the Canadian Attorney-General, Professor Montero found that:

The Belgian legislator clearly intended to exclude physician-assisted suicide from the scope of the Act on euthanasia. This intention was criticized and debated extensively when the Act was being developed. A number of amendments were introduced to incorporate physician-assisted suicide into the scope of the Act, but they were all rejected to the Conseil d'Etat's astonishment.

After the Act was passed, parliamentarians deemed it necessary to propose bills to amend the Act on euthanasia to include physician-assisted suicide performed under the same conditions as those applicable to euthanasia. To them, it is clear that physician-assisted suicide is not covered by the Act and therefore constitutes an illegal practice within the meaning of the Act as it is currently written.

Therefore, it is surprising that the Commission de controle regularly approves reported physician-assisted suicide cases and has been doing so since its first official report, stating that the practice “falls within the scope of the Act, as it is currently written ...”⁴⁴

Lemmens argues that, in Belgium:

... the vague and open-ended nature of the terms ‘medically hopeless situation’ as well as a very subjective interpretation of the term ‘constant and unbearable physical or mental suffering’ have clearly opened the door to many instances of euthanasia that are controversial if not outright problematic.⁴⁵

The Netherlands Organisation for Health Research and Development (ZonMw) published the second evaluation report on the functioning of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act* in 2012. The report finds that a more liberal approach is emerging in relation to requests from patients from some groups, such as those with mental illness or dementia.

This shift can be seen in medical opinion as well as in the policy position of the regional euthanasia review committees. The evaluation report states that:

... this development does not imply an expansion of the legal requirements: it should be seen as further conceptualisation of the meaning and scope of the requirements, that are formulated rather “openly” in the Act.⁴⁶

⁴⁴ Montero, Professor Etienne, Affidavit to *Lee Carter v The Attorney General of Canada et al*, Supreme Court of Canada, No. 35591, pp52-53.

⁴⁵ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p36.

⁴⁶ Regional Euthanasia Review Committees, *Annual Report 2012*, p3.

As is noted below, the number of instances of people with dementia and mental illness being euthanised in the Netherlands is rising rapidly. This could reflect regulatory creep.

On 7 January 2016, the *Netherlands Times* report that:

The Ministries of Public Health and Security and Justice updated their “guide” on euthanasia to give people suffering from severe dementia the option of euthanasia, even if they are unable to express the wish themselves. This is only possible if the patient wrote a declaration with his wish for euthanasia while he was still clearheaded, broadcaster NOS reports.⁴⁷

The proposed physician-assisted dying regime in the Majority Report will establish an entity responsible for monitoring assisted dying within Victoria. Given the experiences of such entities in other jurisdictions, the risk that a supervisory body in Victoria will unilaterally extend the scope of any assisted dying regime through non-transparent interpretation of legislative provisions is a real risk and of great concern.

⁴⁷ <http://www.nltimes.nl/2016/01/07/euthanasia-okd-for-dementia-patients-who-request-it-when-lucid/> (Accessed 30 May 2016)

4.4 There is evidence of a “normalisation” of euthanasia and assisted suicide

Chapter 3 presents clear evidence of an upward and persistent trend in the number of cases of euthanasia and assisted suicide following legalisation. This section will refer to commentary that relates to a contemporaneous normalisation of the practice.

The term “normalisation” in this context is used to indicate that, once legalised, euthanasia and assisted suicide are increasingly taken for granted and seen to be unexceptional both within the medical profession and more broadly within society.

This is important given that the original rationale for euthanasia and assisted suicide in most jurisdictions, and in the Majority Report, is to deal with a set of circumstances that is extremely rare.

4.4.1 Belgium

Belgium currently has one of the most liberal euthanasia regimes in the world. Carine Brochier of the European Institute of Bioethics reported that one physician had told her:

You are right to say that many euthanasia cases are not [officially] declared. I myself have practiced euthanasia very many times, and I never declared them. It is too personal and a matter between the patient and his doctor. No need to publicise it.⁴⁸

The open-ended regime in Belgium evokes “a culture of normalization of active life-ending interventions by physicians that may have long-term consequences which are hard to predict.”⁴⁹

In Belgium, the number of cases of euthanasia is rising rapidly. One would think that this would mean that a growing number of instances of euthanasia applications are falling into more difficult categories. But a recently published survey of physicians in Flanders found a rise in the proportion of requests granted from 56.3% in 2007 to 76.8% in 2013.⁵⁰ This could indicate a growing level of comfort with physician-assisted dying amongst physicians.

Wim Distelmans, who was Chairman of the Federal Control and Evaluation Commission in Belgium, was interviewed by the *New Yorker* and stated that:

We at the commission are confronted more and more with patients who are tired of dealing with the sum of small ailments – they are what we call ‘tired of life’.

...

⁴⁸ Cook, Michael, “Belgian Euthanasia: not such a big deal?”, BioEdge, 22 February 2013, http://www.bioedge.org/bioethics/bioethics_article/10401 (Accessed 30 May 2016)

See also Cohen-Almagor Raphael, “First do no harm: pressing concerns regarding euthanasia in Belgium”, *International Journal of Law and Psychiatry*, 2013, p5.

⁴⁹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p8.

⁵⁰ see Kenneth Chambaere et al, “Recent Trends in Euthanasia and Other End-of-Life Practices in Belgium”, 2015, 372:12, *New England Journal of Medicine*, p1179.

See in general also the Reports of the Federal Euthanasia Control and Evaluation Commission, which are posted by LevensEinde InformatieForum, online: <http://www.leif.be/professioneel/professioneleids/139-rapportenevaluatiecommissieeuthanasie.html>

If you ask for euthanasia because you are alone, and you are alone because you don't have family to take care of you, we cannot create family.⁵¹

In 2013, Wim Distelmans euthanised a 44 year old transgender man, Nathan Verhelst, because Verhelst was devastated by the outcome of his sex-change operation.⁵²

Lemmens reports on a number of stridently pro-euthanasia physicians in Belgium who publicly argue for a need to widen current practices and who reject basic regulatory requirements such as reporting cases to regulators or consulting a second physician.⁵³

A report by the European Institute of Bioethics warned that euthanasia has become normalised:

Initially legalized under very strict conditions, euthanasia has gradually become a very normal and even ordinary act to which patients are deemed "to have a right". In the face of certain high profile cases, the evident relaxation of the very strict conditions has caused many reactions but also a total absence of any sanctions on the part of the Commission and a very conciliatory silence from the political establishment has given rise to a feeling of impunity on the part of some concerned medical practitioners, and to a feeling of powerlessness in those worried about where things are leading.⁵⁴

4.4.2 The Netherlands

A recent article by a former review committee member in the Netherlands, Theo Boer, notes a shift in the type of patients who seek assisted dying:

... beginning in 2007, the numbers of assisted dying cases started going up by 15 percent each year. In 2014 the number of cases stood at 5,306, nearly three times the 2002 figure.

A shift has also taken place in the type of patients who seek assisted dying. Whereas in the first years the vast majority of patients—about 95 percent—were patients with a terminal disease who had their lives ended days or weeks before a natural death was expected, an increasing number of patients now seek assisted dying because of dementia, psychiatric illnesses, and accumulated age-related complaints.

Terminal cancer now accounts for fewer than 75 percent of the cases. Many of the remaining 25 percent could have lived for months, years, or even decades. In some reported cases, the suffering largely consists of being old, lonely, or bereaved.⁵⁵

⁵¹ Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁵² Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁵³ Lemmens, Trudo, "The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era" (forthcoming in Regis, Catherine, Lara Khoury and Robert Kouri, eds., *Key Conflicts in Health Law*, Cowensville: Yvon Blais, 2016). See discussion on pp32-33.

⁵⁴ European Institute of Bioethics, *Euthanasia in Belgium: 10 Years On*, 2012, p7.

⁵⁵ T de Boer, [Rushing toward death? Assisted dying in the Netherlands](#), *Christian Century*, 28 March 2016.

This normalisation manifests itself in many ways. In 2012, mobile euthanasia clinics began providing lethal injections to people free of charge at their homes in the Netherlands:⁵⁶

The launch of the so-called *Levenseinde*, or "Life End", house-call units – whose services are being offered to Dutch citizens free of charge – coincides with the opening of a clinic of the same name in The Hague, which will take patients with incurable illnesses as well as others who do not want to die at home.

The scheme is an initiative by the Dutch Association for a Voluntary End to Life (NVVE), a 130,000-member euthanasia organisation that is the biggest of its kind in the world.⁵⁷

http://www.cmq.org.uk/CMQ/2015/Nov/dutch_experiences_on_regulating.html (Accessed 10 May 2016).

See also: J Legemaate and I Bolt, [The Dutch Euthanasia Act: Recent Legal Developments](#), *European Journal of Health Law*, 20, 2013.

⁵⁶Connolly, K, "Dutch mobile euthanasia units to make house calls", *The Guardian*, 2 March 2012; <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> (Accessed 30 May 2016)

And see: Holligan, A, "Dutch offered 'euthanasia on wheels'", *BBC News Europe*, 4 March 2012: <http://www.bbc.com/news/world-europe-17230102> (Accessed 30 May 2016)

⁵⁷Connolly, K, "Dutch mobile euthanasia units to make house calls", *The Guardian*, 2 March 2012; <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> (Accessed 30 May 2016)

4.5 A growing number of cases involving vulnerable people

One of key arguments used to support the legalisation of euthanasia and assisted dying is the need to respect peoples' autonomy. The growing number of cases involving very vulnerable people or people who may not have a capacity to provide meaningful consent raises serious questions about the validity of this rationale.

4.5.1 People who feel as though they are a burden

In 2006, Dr Harvey Chochinov undertook a review of the empirical literature related to the psychological, existential and spiritual aspects of patient deaths.⁵⁸ Some key findings cited by Chochinov in relation to this issue were:

- A study of reports from family members of patients in Oregon and Washington State who expressed a wish for hastened death indicated that 59% of patients who did not discuss wanting assisted suicide and 94% of patients who did discuss wanting assisted suicide experienced distress due to feeling like a burden on others.⁵⁹ The study found that: "Data from other studies and from the Oregon Health Division supports that fear of being a burden is common in patients who die by lethal prescription."⁶⁰
- This is corroborated from survey data of caregivers in Japan.⁶¹
- In a study from Northern Ireland, 103 doctors provided case history details of patients who had requested euthanasia. Being a "burden to others" was the second most commonly cited concern of patients, being raised in 54.9% of cases.⁶²
- A study of patients who killed themselves found that many were concerned about being a burden on others: "Multiple vulnerability factors were present simultaneously in all patients. However, the loss of, and the fear of losing, autonomy and their independence and of being a burden on others were the most relevant."⁶³

A 2009 survey of 56 Oregonians who had either requested physician aid in dying (PAD) or contacted a PAD agency sought to explore the motivation for these requests. Respondents were asked to rate each of 29 possible reasons on a scale from 1 to 5 (1 being not very important through to 5 being very important). The most important reasons, with a median score of 5, included "wanting to

⁵⁸ Chochinov, Harvey Max, "Dying, Dignity, and New Horizons in Palliative End-of-Life Care", *CA Cancer Journal for Clinicians*, 2006; 56:84-103.

⁵⁹ Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain Symptom Management*, 2002;24, p315.

Morita T, Sakaguchi Y, Hirai K, et al., "Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care.", *Journal of Pain Symptom Management*, 2004;27:44-52. This was a survey of 500 primary caregivers with a response rate of 290. It found that one of the major reasons for desiring death and for making a request to hasten death was being a burden on others.

⁶⁰ Ganzini L, Silveira MJ, Johnston WS. Predictors and correlates of interest in assisted suicide in the final month of life among ALS patients in Oregon and Washington. *Journal of Pain Symptom Management*, 2002;24:p316.

⁶¹ Morita T, Sakaguchi Y, Hirai K, et al., "Desire for death and requests to hasten death of Japanese terminally ill cancer patients receiving specialized inpatient palliative care.", *Journal of Pain Symptom Management*, 2004;27:44-52. This was a survey of 500 primary caregivers with a response rate of 290. It found that one of the major reasons for desiring death and for making a request to hasten death was being a burden on others.

⁶² McGlade KJ, Slaney L, Bunting BP, Gallagher AG., "Voluntary euthanasia in Northern Ireland: general practitioners' beliefs, experiences, and actions", *British Journal of General Practice*, 2000;50:794-797.

⁶³ Filiberti A, Ripamonti C, Totis A, et al., "Characteristics of terminal cancer patients who committed suicide during a home palliative care program". *Journal of Pain and Symptom Management*, 2001.

control the circumstances of death”, “future poor quality of life”, “future pain” and “loss of independence”. Importantly, another reason that rated very high, with a median score of 4 was “perception of self as burden”.⁶⁴

This corroborated results from an earlier 2001 study of physician-assisted suicide in Oregon reported in the *New England Journal of Medicine* which found that 63% of patients who received a hastened death under the Dying with Dignity Act had expressed a strong sense of being burden and that “the frequency of concern about being a burden to others has increased.”⁶⁵

In the most recent report published by the Oregon Public Health Division, of the 132 deaths for which data was available, 48% listed being a burden on family, friends or caregivers as a concern.⁶⁶

Box 2: Case Study - Kate Cheney, Oregon

“Kate Cheney, an eighty-five-year-old widow, was diagnosed as terminally ill with stomach cancer. Kate wanted the option of assisted suicide in case she was in pain or if the indignities of losing control of her body functions became unbearable. Her daughter Erika, a retired nurse who had come from Arizona to care for her mother, went with Kate when she made her request for assisted suicide to her physician at Kaiser Permanente. Erika described the physician as ‘dismissive’ and requested and received a referral to another Kaiser physician. Kate’s second doctor arrange for a psychiatric consultation, a standard procedure at Kaiser. Although the psychiatrist who visited Kate at her home declined to be interviewed, the family released his report to the *Oregonian’s* reporter. The psychiatrist found that the patient did ‘not seem to be explicitly pushing for assisted suicide’ and lacked ‘the very high level of capacity to weigh options about it.’ Although the patient seemed to accept the assessment, the psychiatrist noted that the daughter became very angry.

Kaiser then suggested that the family obtain a second assessment from an outside consultant. The psychologist consulted noted that Kate had some memory defects and that her ‘choices [might have been] influenced by her family’s wishes, and that her daughter, Erika, [might have been] somewhat coercive’ but felt that Kate had the ability to make her own decision. A Kaiser administrator saw Kate and decided that she was competent and was making the decision on her own. Kate received the lethal drugs, which were put under Erika’s care.

As time went by and Kate ate poorly and became somewhat weaker, Erika and her husband needed a respite and sent Kate to a nursing home for a week. Kate ate well there, but when Erika visited Kate always asked when she would be going home. On the day she returned from the nursing home she told Erika and her husband that something had to be done, given her declining health. She had considered going permanently into a nursing home but decided against it. She told them she wanted to use the pills and asked for their help. ‘When would you like to do this?’ her son-in-law asked. ‘Now’, Kate replied. Grandchildren were contacted, those who lived nearby came over, goodbyes were said, and within a short time, with her family beside her, Kate took the pills and died.”⁶⁷

⁶⁴ Ganzini, Linda, Elizabeth Goy and Steven K. Dobscha, “Oregonians’ Reasons for Requesting Physician Aid in Dying”, *Arch Intern Med*, Vol. 169 (No. 5), March 9, 2009, p491.

⁶⁵ Sullivan AD, Hedberg K, Hopkins D., “Legalized physician-assisted suicide in Oregon, 1998-2000”, *New England Journal of Medicine*, 2001;344:605–607. The percentage of patients with concerns about being a burden on family, friends or other caregivers rose from 2/16 (12%) to 17/27 (63%).

⁶⁶ Oregon Public Health Division, Annual Reports under the Death with Dignity Act: for the most recent report see <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>, p6.

⁶⁷ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, pp156-157.

In the case of Kate Cheney, one can easily see how an elderly person could feel as though they were a burden on their family. The pressure on Kate's family was immense and her daughter and son-in-law were in desperate need of respite. However, it is also true that, as Foley and Hendin observe, "one can readily see how in the best of circumstances frail elderly patients can feel coerced to die."⁶⁸

4.5.2 Depression

Many people experiencing terminal diseases also suffer from depression. This is completely unsurprising. The prevalence of depression in people with terminal conditions raises a significant question as to how that depression interacts with decision-making. It goes without saying that experiencing depression doesn't necessarily make one unable to make sound decisions. But depression can impact on decision-making in a way that raises questions about the effectiveness of safeguards in relation to irreversible choices.

Depression is common amongst those seeking euthanasia and assisted suicide. In a study of 138 cancer patients with an estimated life expectancy of 3 months or less, a strong connection was found between depression and a request for euthanasia. Specifically, a patient was 4.1 times more likely to request euthanasia if depressed than if not depressed.⁶⁹

A study of suicide victims who had suffered from cancer found that depressive syndromes were present in 80 per cent of cases. "Only a small minority of cancer suicides seem to occur in the absence of mental disorders."⁷⁰

In a study of 44 terminally ill patients by Brown et al, 34 had never wished death to come early and ten were either suicidal (3) or desired an early death (7). All ten of the patients who desired an early death were found to be suffering from clinical depressive illness.⁷¹

Ganzini et al, in a broad ranging review of instances of assisted dying in Oregon, found that twenty percent of the patients had symptoms of depression.⁷²

These studies raise questions about what safeguards need to be in place in legalised euthanasia or assisted suicide regimes to protect people from making decisions that might be affected in the short term by a depressive mood that might be manageable or treatable with additional support.

Some argue that euthanasia and assisted suicide are suitable in cases of treatment-resistant depression. Even in these cases, treatment options are often available. A study of the longer-term outcomes for patients with confirmed treatment-resistant depression examined the outcomes between 8 to 34 months following treatment in a specialist in-patient centre. The study included 118 participants. The key result was that the majority of participants (60.2%) were in full remission

⁶⁸ Ibid, p157.

⁶⁹ Van der Lee, Marije, Johanna van der Bom, Nikkie B. Swarte, A. Peter Heintz, Alexander de Graeff and Jan van den Bout, "Euthanasia and Depression: A Prospective Cohort Study Among Terminally Ill Cancer Patients", *Journal of Clinical Oncology*, Vol 23, Number 27, 2005, pp6608-6609.

⁷⁰ Henriksson MM, Isometsa ET, Hietanen PS, Aro HM, Lonnqvist JK., "Mental disorders in cancer suicides", *Journal Affective Disorders*, 1995;36:11-20.

⁷¹ Brown JH, Henteloff P, Barakat S, Rowe CJ., "Is it normal for terminally ill patients to desire death?", *Am J Psychiatry* 1986;143:208-11.

⁷² Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p559.

following specialist care and that nearly half of the total sample (48.3%) maintained full remission for at least 6 months.⁷³

While this does not mean that all cases of treatment-resistant depression can be fully treated, it does suggest that great care needs to be taken where a person is suffering from depression and is seeking either euthanasia or assisted dying. Given the range of treatments currently available and the ever improving prospects for treatment over time, the risk of allowing someone to choose death when realistic treatment options are available is a real one.

A number of studies have shown that physicians find it difficult to diagnose depression in patients with terminal conditions, let alone to determine whether that depression is impairing judgement.⁷⁴ Foley and Hendin argue that the Ganzini et al study cited above of physicians administering lethal injections in Oregon suggests potential difficulties in diagnosis. In that study of 143 cases, 20 per cent were identified as having depression which Foley and Hendin argue is materially well below the more commonly established rate of approximately 60 per cent or more.⁷⁵ This suggests that at, in at least some cases in the survey, depression may have been undiagnosed.

In 2015, *The New Yorker* examined the high profile case of Godelieva De Troyer in considerable detail.⁷⁶ This is a complex case from Belgium involving a woman who had suffered from severe depression over a long period of time. During a period of alienation from her adult children, she was euthanised without their knowledge. This case has achieved a high degree of public attention both within Belgium and internationally as it highlights the particularly complex circumstances that can arise when euthanasia is carried out on a person with a mental health condition.

One of the main reasons that the case has generated public debate is the campaign that was subsequently waged by her son. He has challenged the appropriateness of a person being euthanised without family members being consulted. He argues that it was particularly inappropriate in Godelieva's case given that her depression arose, in part, as a result of estrangement from her family. A reconciliation might have been a key element in her recovery. Issues relating to consultation with family members in cases of mental health care decisions arise more broadly than in cases of euthanasia. But these issues are particularly pronounced in euthanasia given the irreversibility of the decision.

A second issue relating to this case that has caused public controversy is a review of Godelieva's medical file that was undertaken by Dr Georges Casteur, a former president of the provincial council of the doctors of West Flanders. His review found that Godelieva had "struggled to find three doctors who would say that she had an incurable illness, as the law required. One psychiatrist wrote that her desire for euthanasia was 'not mature', because she has 'ups and downs'". According to the reviewing psychiatrist, a second doctor concluded that she could still be helped and that "when

⁷³ Fekadu, Abebaw, Lena Rane, Sarah Wooderson, Kalypto Markopolou and Lucia Poon, "Prediction of Longer-term Outcome of Treatment-Resistant Depression in Tertiary Care", (2012) 201, *British Journal of Psychiatry*, 369. Some other studies show lower rates.

⁷⁴ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, p151.

⁷⁵ Ibid, p151. Foley and Hendin are referring to results from Ganzini et al in the *New England Journal of Medicine*.

⁷⁶ Aviv, Rachel, "The Death Treatment", June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

Godelieva discussed her grandchildren she became emotional and expressed doubts about her decision to die.”⁷⁷

The purpose of raising this case is not to dwell on the particulars of Godelieva’s situation, but rather to highlight the difficulties in diagnosis and treatment in cases involving depression and mental health issues more generally. Jurisdictions such as Belgium and the Netherlands have more stringent safeguards in place where there is a mental health condition, but the effectiveness of these safeguards in practice is not proven.

4.5.3 Mental Illness

This paper will not examine the merits of whether a scheme should permit euthanasia or assisted suicide where a patient is suffering from a mental illness. At the very least, it is worth noting that in such situations additional care should be taken as diagnosis will often be challenging and it will usually be more difficult to clearly establish consent. The growing prevalence of euthanasia and assisting dying for people with mental illness in at least some jurisdictions raises concerns about the effectiveness of safeguards.

The Belgian legislation allows those experiencing mental suffering to access physician assisted dying but includes additional safeguards for people in this category. This includes a detailed consultation with a third physician and a mandatory one month waiting period between the request and the life-ending act.

The proportion of euthanasia deaths involving neuropsychiatric disorders has increased sharply in Belgium over the past decade, from 1.2% of cases in 2004/05 to 2.8% in 2010/11 (58 cases) and 3.7% of cases in 2013/14 (67 cases).⁷⁸ Table 4 contains the number of instances of euthanasia in Belgium over recent years as reported to the Belgian legislature.

Table 4: Number of cases of euthanasia for neuropsychiatric conditions in Belgium⁷⁹

Source	Years covered by report	Number of cases of neuropsychiatric conditions
Second report	2004 and 2005	9 ⁸⁰
Third report	2006 and 2007	13 ⁸¹
Fourth report	2008 and 2009	62
Fifth report	2010 and 2011	105

⁷⁷ Aviv, Rachel, “The Death Treatment”, June 22 2015, *The New Yorker*, <http://www.newyorker.com/magazine/2015/06/22the-death-treatment>

⁷⁸ Lemmens, Trudo, The Conflict Between Open---ended Access to Physician---Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post---Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p39.

⁷⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

⁸⁰ This included three cases of Alzheimer’s disease, one case of Huntington’s disease, one case of Creutzfeldt-Jacob disease and four cases of unyielding depression.

⁸¹ Nine cases of neuropsychiatric conditions (dementia or depression) in addition to four for people with neuropsychiatric conditions for whom death was not expected in the short term.

In the Netherlands, recent data from reports of the Regional Euthanasia Review Committees points to a growing number of cases of euthanasia in cases of mental illness and dementia. Table 5 contains the number of cases of mental illness and dementia over the period 2012-2015.

While the number of cases in each category is coming off a low base, the rapid CAGR rate suggests that number of cases in each category could be very large in the not too distant future. There is no reason to think that growth rates in either category will taper off given what we observe in growth rates in the overall number of cases both in the Netherlands and other major jurisdictions.

Table 5: Number of cases of euthanasia for mental illness or dementia in Netherlands⁸²

Year	Mental Illness (Cases)	Dementia (Cases)
2012	14	42
2013	42	97
2014	41	81
2015	56	109
Growth rate: (CAGR 2012-2015)	59%	37%

As is noted above, when the Belgian Act on euthanasia was being debated and adopted, it was stated repeatedly that patients with psychiatric disorders, dementia or depression would be excluded from the Act.⁸³ However, as in the Netherlands, there has been a rapid growth in this category over recent years.

In 2007, the *Netwerk Depressie Vlaanderen*, a Flemish association that provides support to people suffering from depression, stated that: “The door to euthanasia is open for thousands of depressed and suicidal people to kill themselves legally.”⁸⁴

Dealing with requests for euthanasia or assisted suicide from people with mental illness is particularly challenging for medical practitioners. Kim et al undertook a detailed review of 66 cases of euthanasia and assisted suicide involving psychiatric conditions in the Netherlands between 2011 and 2014. Two senior psychiatrists reviewed reports provided by the Dutch regional euthanasia review committees up to 1 June 2015. They found that:

- Most patients had chronic, severe conditions with histories of attempted suicides and psychiatric hospitalisations.
- A range of conditions were present including: depression; personality disorders; psychotic, post-traumatic stress or anxiety; neurocognitive and eating disorders; as well as prolonged grief and autism.
- 27% (n=18) of patients received euthanasia or assisted suicide from physicians new to them.

⁸² See Dutch Regional Euthanasia Review Committee Annual Reports.

⁸³ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

⁸⁴ Statement made in the article “Qatre cas pour depression majeure irreductible”, La Libre Belgique, 2 February 2007. See translation in Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p51.

- Of the 18 physicians that were new to patients, 14 of these were from the End-of-Life Clinic, a mobile euthanasia clinic.⁸⁵ In 2012, the NVVE (Dutch Association for a Voluntary End to Life) created the End-of-life Clinic and started making “house calls” via mobile euthanasia units that respond to the wishes of patients whose regular doctors have refused to carry out their wishes.⁸⁶

Kim et al conclude that the “granting of their EAS [euthanasia or assisted suicide] requests appears to involve considerable physician judgment, usually involving multiple physicians who do not always agree (sometimes without independent psychiatric input)”.⁸⁷

The difficulty of evaluating suicidal patients with serious medical illness is explored by Hamilton et al. They argue that there are competing paradigms: the traditional model; and the assisted suicide competency model.⁸⁸

In the *Harvard Medical School Guide to Suicide Assessment and Intervention*⁸⁹, Hendin argues that medically ill suicidal patients are no different from other suicidal individuals. “Although physical illness may be a precipitating cause of despair, these patients usually suffer from treatable depression and are always ambivalent about their desire for death.”⁹⁰

Hamilton et al argue that “when it comes to treatment, the approach in this population emphasizes an effort to ‘understand and relieve the desperation that underlies the request for assisted suicide.’ To do so, the clinician must resist assuming the role of ‘gatekeeper’, someone who would focus on issues of competence alone.”⁹¹

This approach, they argue, can be contrasted with the assisted suicide competency model. One example of the alternative approach is contained in Oregon’s assisted suicide guidebook which states that:

The mental health consultation as outlined in the Oregon Act, is a form of a capacity or competence evaluation, specifically focused on capacity to make the decision to hasten death by self-administering a lethal dose of medication.⁹²

In the assisted suicide competency model, there is no obligation to treat depression or mental illness where it is found.

⁸⁵ Kim, Scott Y. H., Raymond De Vries and John Peteet, “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014”, *JAMA Psychiatry*, 2016: 73(4), 362-368.

⁸⁶ <http://www.theguardian.com/world/2012/mar/01/dutch-mobile-euthanasia-units> ; 1 March, 2012.

See also an article from Spiegel re the controversial practice: <http://www.spiegel.de/international/controversy-over-dutch-mobile-euthanasia-teams-in-the-netherlands-a-822484.html> ; March 22, 2012.

⁸⁷ Kim, Scott Y. H., Raymond De Vries and John Peteet, “Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014”, *JAMA Psychiatry*, 2016: 73(4), 362-368.

⁸⁸ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060.

⁸⁹ Hendin, J, “Suicide, assisted suicide, and euthanasia”, *Harvard Medical School Guide to Suicide Assessment and Intervention*, edited by Jacobs DG, San Francisco, Jossey-Bass, 1999, pp540-560.

⁹⁰ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060.

⁹¹ Hamilton, Gregory and Catherine Hamilton, “Competing Paradigms of Response to Assisted Suicide Requests in Oregon”, *American Journal of Psychiatry*, 162:6, June 2005, p1060. See also Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, p152.

⁹² Goy, Elizabeth, Linda Ganzini and Tony Farrenkopf, “Mental Health Consultation”, in Dunn, Patrick et al (eds), *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, 2008 edition, Chapter 9.

The differences between the approach to dealing with patients suffering from depression and mental illness in Oregon assisted suicide consultations (and in similar jurisdictions) as compared to more traditional treatment clinical models is telling. It is potentially problematic in an area where there is still considerable disagreement between experts as to the relationship between depression, mental health issues and competence.

4.5.4 Cases in which explicit consent is not given

One of the difficulties of drawing conclusions in relation to life-ending acts without explicit patient request is the lack of clear data. In a large-scale death certificate survey, Chambaere et al find that “life-ending acts without explicit request are significantly different from those provided in euthanasia and similar to those provided in standard palliative care.”⁹³ This suggests that some of the worst fears that have been expressed in this area are based more on poor reporting than systemic abuse.

However, they also argue that legalisation of euthanasia or physician-assisted dying did not put an end to the practice of non-voluntary or involuntary termination of life (as argued elsewhere in this paper) and that: “we recommend a more nuanced view of life-ending acts without explicit patient request in the debate on physician-assisted dying.”⁹⁴

Some advocates claim that legalisation of either euthanasia or assisted dying will bring practices such as euthanasia without consent into the open. Seale examines end-of-life decisions in the UK and concludes that the rate of this type of end-of-life decision-making is sufficiently low that: “in the UK, this argument cannot be made.”⁹⁵

In contrast, it appears that this type of euthanasia has not disappeared from countries which have legalised euthanasia or assisted suicide, with relatively high rates persisting in Belgium. A study in *the Lancet* by Van der Heide et al undertook surveys in six European countries to contrast end-of-life decision making. It found that ending of a patient’s life without request occurred at rates ranging from 0.06% (Italy) through to 1.50% (Belgium).⁹⁶ Two countries with the highest rates of this type of end-of-life (Belgium at 1.5% and the Netherlands with 0.60%) allowed the practice of euthanasia and assisted dying.

Moreover, as will be argued below, it is clear that wherever the legal line is drawn, activity occurs in the grey area around that line that is difficult to monitor.

⁹³ Chambaere, Kenneth, Jan Bernheim, James Downar and Luc Deliens, “Characteristics of Belgian ‘life-ending acts without explicit patient request’: a large-scale death certificate survey revisited”, *CMAJ Open*, 2(4), 2014, pE264.

⁹⁴ Chambaere, Kenneth, Jan Bernheim, James Downar and Luc Deliens, “Characteristics of Belgian ‘life-ending acts without explicit patient request’: a large-scale death certificate survey revisited”, *CMAJ Open*, 2(4), 2014, pE262.

⁹⁵ Seale, C, “National Survey of end-of-life decisions made by UK medical practitioners”, *Palliative Medicine*, 2006, 20:3-10.

⁹⁶ Van der Heide A., L Deliens, K Faisst, T Nilstun, M Norup, E Paci et al, “End-of-life decision-making in six European countries: descriptive study”, *the Lancet*, 2003, 362, p347.

See also: K. Meeussen, L. Van den Block, N. Bossuyt et al., “Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium” , *BMC Public Health*, 10 (2010), p. 186.

4.5.5 Patients receiving inadequate pain relief or palliative care

Many situations in which a person requests a hastening of death involve pain management or palliative care that fall short of best practice. Before legislating for euthanasia or assisted suicide, it would be appropriate to provide greater support to health care providers dealing with patients at the end of life.

Cases involving inadequate pain management

The Committee received considerable expert evidence that best practice medical treatment and palliative care can now effectively manage pain in almost all cases. Occasionally, best practice is not followed. The best response to the occasional failure to maintain best practice is to provide appropriate resourcing to the health care system – including training for health practitioners - and to ensure that processes to monitor the quality of end-of-life care are adequate.

Dr Natasha Michael, Director of Palliative Care at Cabrini Health argued that, many of the instances of poor end-of-life care that are used to justify euthanasia or assisted suicide reflect practitioners who:

... practice outside of the scope of their training and experience and neither have the knowledge, experience or skill to assist those who suffer. The ongoing under-resourcing of psychosocial support to patients and family needs urgent attention in palliative care and in end-of-life care. The association between the expression of a desire for death and depression, anxiety and demoralisation is well-documented in international research. However, there remains poor availability of key staff in clinical psychology, liaison psychiatry and social work services in our populations.⁹⁷

Cases involving inadequate palliative care: Oregon

In a study published in the *New England Journal of Medicine*, Ganzini, Nelson, Schmidt, et al. reported the results of an extensive survey of physicians eligible to prescribe lethal medications under the Oregon Death with Dignity Act. Of the 2,649 physicians responding (65% response rate), 144 had received a total of 221 requests for prescriptions of lethal medications. Complete information was received for 143 patients, including the final outcome for those patients.⁹⁸

In the case of 68 patients, the treating physician implemented at least one substantive intervention, including: control of pain or other symptoms; referral to a hospice; a mental health, social work, chaplaincy or palliative care consultation; or a trial of antidepressant medication. Of the patients who experienced a substantive intervention, 31 out of 67 (46%) changed their minds about wanting a prescription for lethal medication as opposed to 11 out of 73 (15%) for whom no substantive

⁹⁷ Dr Natasha Michael, Director of Palliative Care, Cabrini Health, *Transcript of evidence*, 16 September 2016, pp7-8.

⁹⁸ Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p557.

intervention was given.⁹⁹ This material difference in outcomes indicates how dangerous it can be if any patients fail to access all best practice treatment interventions when they are in a vulnerable situation and considering suicide or euthanasia.

The 2016 Report of the Oregon Health Division indicates that 28.7% expressed inadequate pain control or a concern about it as a reason for wanting assisted suicide.¹⁰⁰ This was the second least commonly cited reason in 2015.

It would be useful to know, of the 28.7%, what proportion were experiencing unendurable pain at the time the lethal dose was prescribed and administered and what proportion were suffering from an anticipation of future pain. It would also be useful to know, of those patients experiencing unendurable pain at the time the dosage was administered, how many were not benefiting from best practice pain relief of palliative care.

Advocates of euthanasia and assisted dying often point to the potential for legalised regimes to provide people with comfort by providing them with the assurance that they will be able to opt for a painless death if they wish to. Yet how many people under the assisted dying regime in Oregon (and similar regimes) secure access to lethal drugs out of a fear of future unbearable pain only to use those drugs before they have explored best practice palliative care options? Given current reporting arrangements, it is impossible to know with confidence.

Cases involving inadequate palliative care: the Northern Territory

The legalisation of euthanasia in the Northern Territory was accompanied by a number of safeguards that advocates of euthanasia and assisted suicide claim can protect vulnerable people in practice, including that:

- Under the legislation, an opinion from a second medical practitioner was required to verify the existence and terminal nature of the patient's illness. The second medical practitioner was required to have "special expertise in the illness [being experienced by the patient] and qualifications in a medical specialty recognised by fellowship in a specialist college in Australia."¹⁰¹
- If the first doctor did not have special qualifications in palliative care, a third doctor with such expertise and qualifications was required to give information to the patient on the availability of palliative care.¹⁰²
- A psychiatrist was required to examine the patient to certify that he or she did not have "a treatable clinical depression."¹⁰³

The outcomes of this brief episode of legalising euthanasia are highly instructive as it is the only example of legalisation in Australia to date.

⁹⁹ Ganzini Linda, Heidi Nelson, Terri Schmidt, Dale Kraemer, Molly Delorit and Melinda Lee, "Physicians' Experiences with Oregon Death with Dignity Act", *New England Journal of Medicine*, Volume 342, Number 8, p560.

¹⁰⁰ Oregon Public Health Division, *Oregon Death with Dignity Act: 2015 Data Summary*, February 4 2016, p6.

¹⁰¹ Kissane, David, "Deadly Days in Darwin", in Foley K and Hendin H (Eds.) "The Case against Assisted Suicide, For the Right to End-of-Life Care", pp192-209. Baltimore: Johns Hopkins University Press, 2002, p193.

¹⁰² Ibid, p194.

¹⁰³ Ibid, p194.

The experiences of people whose lives ended under the Northern Territory regime casts doubt on the effectiveness of the types of safeguards proposed in the Majority Report. During the 9 months that euthanasia was legal in the Northern Territory (July 1996 – March 1997), seven people made formal use of the Rights of the Terminally Ill (ROTI) Act, four of whom died.¹⁰⁴ All seven patients had cancer, most at an advanced stage.

In a paper by Kissane, Street and Nitschke¹⁰⁵, it was found that three of the seven patients were socially isolated and depressive symptoms were present in four of the seven.¹⁰⁶ Failure of pain management did not appear to be the motivation for the patients. Of the seven patients, four had controlled pain and the remaining three did not have prominent pain.¹⁰⁷ This is in contrast to the way this issue is often framed by advocates of euthanasia and assisted dying.

The requirement that there be a consensus as to whether the patient was terminal was problematic. There was a consensus that the patient was terminal in four cases, a lack of consensus in two cases and the patient was not terminal in one case.¹⁰⁸ In one instance, an oncologist gave a prognosis of 9 months and a dermatologist and local oncologist both judged that the patient was not terminal.

The ROTI Act contained a requirement that a psychiatrist confirm that the patient was not suffering from a treatable clinical depression. “Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to overcome.”¹⁰⁹

To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient’s plight? In case 1, there was important background detail about the death of one child and alienation from another, which was withheld during the psychiatric assessment. These experiences may have placed the patient in a lonely, grieving, demoralised position: an unrecognised depression may have led to suicide.

Four of the seven cases had symptoms of depression, including reduced reactivity, lowered mood, hopelessness, and suicidal thoughts. Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management. PN judged this patient as unlikely to respond to further treatment. Nonetheless, continued psychiatric care appeared warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia. Ganzini and colleagues¹⁷ showed that only 6% of psychiatrists in Oregon, USA, thought that they could be a competent gatekeeper after a single assessment of a patient.¹¹⁰

¹⁰⁴ Kissane, David, Annette Street and Philip Nitschke, “Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia”, *The Lancet*, Vol. 352, October 3 1998.

¹⁰⁵ This paper, which appeared in *the Lancet*, was based upon, inter alia, 18 hours of interviews with Nitschke by Professor David Kissane, a psychiatrist and professor of palliative care and Annette Street, a medical sociologist. In addition, the authors had access to documents from the coroner’s court, public texts created by the patients and other public commentary (eg in the media).

¹⁰⁶ Kissane, David, Annette Street and Philip Nitschke, “Seven Deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia”, *The Lancet*, Vol. 352, October 3 1998, p1098. Two had depressive symptoms (one of whom was on anti-depressants), one had a history of depression and was experiencing suicidal thoughts, and another was suicidal (this person ultimately died as a result of suicide).

¹⁰⁷ Ibid, p1098.

¹⁰⁸ Ibid, p1099.

¹⁰⁹ Ibid, p1101.

¹¹⁰ Ibid, pp1101.

In a follow up article, Professor Kissane examined each of the seven cases briefly summarised above. He found that demoralisation, which could at least partly be managed, played a significant role:

Review of these patients' stories highlighted for me the importance of demoralization as a significant mental state influencing the choices these patients made. It is likely that the mental state of demoralization influenced their judgement, narrowing their perspective about available options and choices. Furthermore, demoralized patients may not make a truly informed decision in giving medical consent.

The prognostic language within oncology that designates 'there is no cure' is one potential cause of demoralization in these patients, a cause that be avoided by more sensitive medical communication with those who are seriously ill.¹¹¹

Kissane also found that other perceptions were common in patients, most of which were manageable through effective medical and palliative care:

... this Australian cohort considered concern about loss of dignity, becoming dependent on others, and potentially being a burden as prominent reasons for the request for euthanasia. ...

Research has repeatedly shown how quality of life is appraised differently by patient, caregiver and clinician. A patient with cancer can adjust to the experience of gradual frailty over time, so long as adequate reassurance is given about the thoroughness of care long the way.¹¹²

The experience of euthanasia in the Northern Territory demonstrates that a regime with what are typically considered to be strong safeguards can fail vulnerable people. In the Northern Territory, people who experienced social isolation, isolation from family, depression and demoralisation were not given the best possible treatment.

4.5.6 Summary of evidence in relation to vulnerable people

There is considerable evidence that many vulnerable people will be put into a difficult position if euthanasia or assisted suicide are choices that become a standard part of the set of treatment options available at the end-of-life.

The House of Lords Select Committee on Ethics came to a similar overall conclusion:

... it would be next to impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law was not abused.

vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death¹¹³

¹¹¹ Kissane, David, "Deadly Days in Darwin", in Foley K and Hendin H (Eds.) "The Case against Assisted Suicide, For the Right to End-of-Life Care", pp192-209. Baltimore: Johns Hopkins University Press, 2002, p203.

¹¹² Ibid, p204.

¹¹³ House of Lords, *Report of the Select Committee on Medical Ethics*, House of Lords Papers Number 21, 1993-94, paras 238-239.

4.6 The widespread failure of safeguards

The Majority Report asserts that the evidence is “clear” that safeguards work in jurisdictions with legalised euthanasia and assisted suicide. A balanced reading of the evidence would lead one to conclude that such an unequivocal statement is not true.

4.6.1 Systemic non-reporting

A requirement to report instances of euthanasia and assisted suicide is seen by some advocates as a key strength of a legalised regime. They argue that it will bring opaque practices more into the open. The experience in Belgium suggests otherwise.

In Belgium, mandatory notification of euthanasia to the Federal Control and Evaluation Commission is a cornerstone of the regulatory arrangements. However, recent reports suggest that around half of all euthanasia cases are not reported.¹¹⁴ In one study, physicians who did not report cases of euthanasia provided the following responses:

- Did not perceive their action to be euthanasia 77%
- Too much of an administrative burden 18%
- That legal due care requirements had not been met 12%
- That euthanasia is a private matter 9%
- Possible legal consequences 2%¹¹⁵

The high rate of non-reporting and the reasons given are a matter of serious concern and raise doubts about the effectiveness of official oversight.

While the rate of non-reporting is falling in the Netherlands, it appears to be of a similar magnitude to that found in Belgium.¹¹⁶

A low rate of reporting could potentially lead to serious consequences. A cross sectional analysis of reported and unreported euthanasia cases provided evidence that unreported cases were generally dealt with less carefully than reported cases. Specifically, in unreported cases: a written request for euthanasia was more likely to be absent; independent physicians and caregivers specialising in palliative care were consulted less often; the life ending act was more likely to be performed with opioids or sedatives; and the drugs were more often administered by a nurse, not a physician as required.¹¹⁷

¹¹⁴ T. Smets, J. Bilsen, J. Cohen, M.L. Rurup, L. Deliens, “Legal euthanasia in Belgium: Characteristics of all reported euthanasia cases”, *Medical Care*, 48 (2), 2010, February, pp. 187–192.,

T. Smets, J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

¹¹⁵ Multiple answers are possible, which is why the various categories sum to more than 100 per cent. Smets T., J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

¹¹⁶ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002.

¹¹⁷ Smets T., J. Bilsen, J. Cohen, M.L. Rurup, F. Mortier, L. Deliens, “Reporting of euthanasia in medical practice in Flanders, Belgium: Cross sectional analysis of reported and unreported cases”, *BMJ*, 341 (2010), p. c5174.

The FCEC itself has stated that it is “not capable of assessing the proportion of declared cases of euthanasia compared with the number of real cases which have actually taken place.”¹¹⁸

There are numerous high-profile and well-documented cases of actions beyond the scope of the law in Belgium that are neither being reported nor referred to prosecutor. One recent example was a public interview given by Dr Mark Cosyns in which he concedes that he routinely fails to report and in which he details a recent case of euthanasia that was of questionable compliance.¹¹⁹ As noted above, Carine Brochier reports of a physician who stated that he routinely fails to declare instances of euthanasia.¹²⁰

In Oregon, low rates of reporting are a consequence of a regulatory regime that does not require sufficient scrutiny. According to Foley and Hendin, the Oregon Health Division has interpreted its mandate narrowly:

OHD limits its yearly reports to general epidemiological data and collects limited information from physicians who have prescribed lethal medication. Physicians who declined to prescribe the lethal medication, as well as nurses and social workers who cared for patients, are not interviewed. ... There is no provision for an independent evaluator or researcher to study whatever data are available. This OHD process has presented a full and open discussion.¹²¹

4.6.2 Confusion amongst physicians

A survey conducted among physicians in Belgium seven years after the legalisation of euthanasia demonstrated that there was little consensus among physicians as to how to label hypothetical end-of-life decisions or what reporting obligations attach to such decisions. The study was based on a survey of 3,006 physicians who had graduated in their area of specialty at least 12 months prior to the survey.

¹¹⁸ Federal Control and Evaluation Commission, *Annual Report*, 2002-2003.

¹¹⁹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p25 - See for example: an interview in *De Standaard* with Dr. Mark Cosyns, a palliative care specialist who has performed many PADs. When he is asked “Dr. Cosyns, you are still not reporting euthanasia to the Commission?” his answer is: “No, not when they are our own patients. I do everything on the basis of the Act on Patient's Rights [another piece of legislation]. We also don't have to justify each time we do an operation why this doesn't constitute assault.” [“Nee, niet als het om onze eigen patiënten gaat. Ik doe alles op basis van de wet op de patiëntenrechten. We moeten toch ook niet voor elke operatie verantwoorden dat we geen opzettelijke slagen en verwondingen toebrengen”] Veerle BEEL and Lieven SIOEN, “In de VS zat ik al lang achter de tralies. En jij samen met mij” [In de VS I'd already be in prison a long time ago. And you with me], *De Standaard*, 21 December 2013, online:

<http://www.standaard.be/cnt/dmf20131219_00896009>. In another interview, he admits, among other things, to have provided PAD to an elderly couple. “One of them” — to use his own words — “because of medical, terminal reasons and the other because of the psychological suffering of being old and having to continue living on her own after having lived nearly in symbiosis” [my translation of: “De ene om medische, terminale redenen en de ander omwille van het psychisch lijden van oud zijn en alleen verder te moeten na bijna in symbiose geleefd te hebben”] quoted in Fred VERBAKEL, “Niets is zo natuurlijk als sterven”, (2009) 2:4 *Relevant* 5, 6, available online: <https://www.nvve.nl/files/8513/8753/0895/Relevant_2009-2.pdf>.

¹²⁰ Cook, Michael, “Belgian Euthanasia: not such a big deal?”, BioEdge, 22 February 2013, http://www.bioedge.org/bioethics/bioethics_article/10401 (Accessed 30 May 2016)

See also Cohen-Almagor Raphael, “First do no harm: pressing concerns regarding euthanasia in Belgium”, *International Journal of Law and Psychiatry*, 2013, p5.

¹²¹ Foley K and Hendin H (Eds.), *The Case against Assisted Suicide, For the Right to End-of-Life Care*, Baltimore: Johns Hopkins University Press, 2002, pp144-145.

The report found considerable confusion in relation to classification of clear hypothetical situations:

... there is a lack of agreement among physicians in Belgium about the classification of euthanasia and other ELDs, and about which cases must be reported as euthanasia to the Federal Review Committee. Seven years after implementation of the euthanasia law in Belgium, 2 out of 10 physicians, likely to be involved in the care of dying patients, did not label a hypothetical case in which a physician ends the life a patient at that patient's explicit request using neuromuscular relaxants as 'euthanasia'. Three out of 10 physicians did not know that the case had to be reported to the Federal Review Committee.

Most physicians labelled the euthanasia case in which the physician ends the life of a patient at that patient's explicit request using morphine (case 3) as 'intensification of pain and symptom treatment' (39%) or as 'palliative/terminal sedation' (37%); only 21% of physicians labelled this case as 'euthanasia'.¹²²

Even among those physicians who labelled instances of euthanasia correctly, a considerable number did not know that they had an obligation to report such cases. This is likely to be a contributory factor to the low overall rates of reporting observed in Belgium.

4.6.3 The difficulty of deciding whether a case is terminal

Some euthanasia and assisted dying regimes limit eligibility to terminal cases. This might involve specifying a time-limit (e.g. a patient's prognosis is that they are likely to die within, say, 6 months) while others are more open-ended. In practice, deciding whether a patient is "terminal" is extremely difficult. Physicians find it difficult to put specific time estimates on many patients' conditions and, unsurprisingly, often disagree with each other.

In Oregon, a patient is only eligible for assisted suicide if they are terminally ill, with less than six months to live. When surveyed, over 50 per cent of Oregon physicians indicated that they were not confident that they could make such a prediction.¹²³ It is unclear at present how this uncertainty is communicated to patients seeking assisted suicide.

Compounding this difficulty in Oregon is the fact that the proportion of cases involving advanced cancer is trending down. There is an increasing tendency for patients seeking lethal prescriptions to have conditions with a less predictable future trajectory such as ALS (16% in 2014), chronic lower respiratory disease, Multiple Sclerosis, Parkinson's disease, diabetes and heart disease.¹²⁴ Of the 105 patients who took lethal drugs in 2014, 11 had been diagnosed as having less than six months to live in 2012 or 2013.¹²⁵

¹²² Smets, T., J. Cohen, J. Bilsen, Y. Van Wesemael, M. Rurup and L. Deliens, "The labelling and reporting of euthanasia by Belgian physicians: a study of hypothetical cases", *The European Journal of Public Health*, 2010, 1-8. See page 6 for the discussion of results.

¹²³ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, p154.

¹²⁴ Oregon Public Health Division, Annual Reports under the Death with Dignity Act: for the most recent report see <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

¹²⁵ Secretariat of Pro-Life Activities, "Assisted Suicide Laws in Oregon and Washington: What Safeguards", Washington D.C., 2015.

4.6.4 Doctor shopping

Foley and Hendin explore a case study in Oregon involving a woman in her mid-eighties with metastatic breast cancer who was in a hospice program. Given the lack of transparency surrounding assisted dying in Oregon, the information that they gathered included: reports from the staff of Compassion in Dying (the organisation that facilitated the assisted death); a news conference following the death; and information from anonymous interviews by the physician who prescribed the medication. According to these sources, the patient's *own* physician was not willing to assist in her suicide (for reasons not specified), a second physician refused on the basis that the patient was depressed and it was only when Compassion in Dying was contacted that a doctor was found who was willing to prescribe a lethal medication. The patient was seen by a psychiatrist – but only once.¹²⁶

While legally proscribed procedures appear to have been followed, the case raises a number of questions. First, the views of the patient's own doctor and the physician who believed that she was suffering from depression were essentially ignored. All that was required was for the patient to find another doctor willing to undertake the procedure. Any regime that permits such doctor shopping is prone to abuse. This kind of outcome is possible in a number of the euthanasia and assisted dying regimes currently in place.

This is similar to what occurred in the case of Godelieva De Troyer and is reflected in a study in Belgium which found that in 23 per cent of cases, euthanasia was preformed despite a divergence of opinions.¹²⁷

4.6.5 Nurses administering medicine

Recent studies provide evidence that in Belgium nurses commonly administer fatal doses in contravention of the law. One recent study surveyed 6,000 nurses in Flanders. Of 1,265 completed surveys, 128 nurses reported that the last patient in their care for whom a life-shortening end-of-life decision was made received euthanasia and 120 reported that the patient received life-ending drugs without his or her explicit request. Of the nurses involved in euthanasia, 64% were involved in the decision-making process. The drugs were administered by the nurse in 12% of cases, mostly without the physician co-administering (12/14 = 86%).¹²⁸ In using life-ending drugs without explicit request, 48% of nurses helped prepare drugs, 56% were present during administering and in 45 instances, the nurse administered the drugs, mostly without the physician co-administering (82%) but under physician orders (98%).¹²⁹

¹²⁶ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp146-148.

¹²⁷ Cohen-Almagor, "First do no harm: pressing concerns regarding euthanasia in Belgium", *International Journal of Law and Psychiatry*, 36 (2013): 515-521.

¹²⁸ E. Inghelbrecht, J. Bilsen, F. Mortier, L. Deliens, "The role of nurses in physician-assisted deaths in Belgium", *Canadian Medical Association Journal*, 182 (9) (2010, June 15), p 907.

¹²⁹ E. Inghelbrecht, J. Bilsen, F. Mortier, L. Deliens, "The role of nurses in physician-assisted deaths in Belgium", *Canadian Medical Association Journal*, 182 (9) (2010, June 15), pp 905-910.

Another study focused on situations in which patients were euthanised without having made an explicit request to die. This study found that, in almost half of the cases (6 of 13), the final drug was administered by a nurse.¹³⁰

The administration of drugs by nurses is not a major concern per se. Nurses are often the key caregivers at the end of life with the most intimate knowledge of a patient's preferences and needs. What is relevant in the current context is the fact that this practice is prevalent in a situation that is highly sensitive (the administration of fatal doses) and where the law clearly states that it should not occur. Clearly, in regimes where euthanasia and assisted suicide are legal, practices that breach the law occur and the extent to which they occur is not clear.

4.6.6 Potential conflicts of interest in supervisory body membership

Some of the physicians involved in recently high profile, controversial cases in Belgium sit on the Federal Control and Evaluation Commission, raising questions about the sufficiency of procedures to ensure the independence of the key regulatory body.¹³¹

4.6.7 Very few officially reported procedural failures

The number of reported procedural failures calls into question the effectiveness of current controls.

In Belgium, as of 2015, the Federal Control and Assessment Commission had only referred a single case of euthanasia to the Crown Prosecution Service out of more than 9,400 cases reported.¹³² In the Netherlands, out of 4,178 cases of euthanasia in 2012, 10 were found to be non-compliant and of 5,512 cases in 2015, 4 were found to be non-compliant.¹³³

A near zero non-compliance rate stretches credulity given the well documented cases above of:

- the existence of widespread practices in the grey area of what is legal, even in countries with legalised euthanasia/assisted suicide, including: publicly reported cases involving deaths that stretch the bounds of the law; and practices involving the use of life-ending drugs without explicit patient request;
- growing numbers of people undergoing euthanasia with mental illness and/or depression;
- regulatory agencies openly conceding their own limitations in monitoring the actual number of instances of euthanasia;
- doctors not reporting cases to the central authorities; and
- other procedural irregularities.

¹³⁰ K. Meeussen, L. Van den Block, N. Bossuyt *et al.*, "Physician reports of medication use with explicit intention of hastening the end of life in the absence of explicit patient request in general practice in Belgium", *BMC Public Health*, 10 (2010), p. 186.

¹³¹ Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), pp25-26.

¹³² Lemmens, Trudo, *The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium's Euthanasia Regime in the Post-Carter Era*, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p24.

¹³³ Dutch Regional Euthanasia Committees, see 2014 and 2015 reports.

4.6.8 Failure of drugs performing as designed

In Oregon, according to official statistics 24 patients are known to have regurgitated some of the legal dose and six regained consciousness after taking the drugs and died later.¹³⁴

In Washington State, according to official statistics, there have been at least 8 cases of regurgitation, 2 cases of “other” complications (2012 and 2015) and a seizure (2014).¹³⁵

A study of euthanasia and assisted suicide in the Netherlands found that complications arose in 7 per cent cases of assisted suicide and problems with completion (such as a longer-than-expected time to death, failure to induce coma or induction of coma following the awakening of the patient) occurred in 16 per cent of cases. The rate of complications and completion were lower in the case of euthanasia (3 per cent and 6 per cent respectively).¹³⁶

The proportion of complications is likely to be higher in assisted suicide schemes (such as that proposed in the Majority Report) than with euthanasia as it will generally be more difficult to ensure appropriate supervision of the administration of the lethal dosage in cases of assisted suicide.

Box 3: Failure of Safeguards

The following safeguards have proved to be difficult to enforce:

- **Reporting:** in Belgium, half or more cases of euthanasia are not reported to the FCEC. This is also a problem in the Netherlands.
- **Patients with depression:** suffering from depression does not mean that a person lacks competence to make important decisions, including whether to opt for euthanasia or assisted suicide. However, it is well documented that serious depression can impact on decision-making, which makes it an area of particular concern given the irreversibility of a decision to hasten one’s death. In addition, the categorisation of some forms of depression as treatment-resistant is problematic as numerous studies have indicated that, in at least some instances, such conditions can be managed.
- **Mentally ill patients:** the number of patients with mental illness being granted access to euthanasia and assisted suicide is increasing rapidly. There is considerable evidence of situations in which properly trained psychiatrists are not being adequately consulted.
- **Coercion:** it is well documented that people who are terminally ill often feel as though they are a burden on their family or carers. This can result in a subtle indirect coercion or, in some instances, a more overt coercion to actively consider a hastening of death.
- **Independent consultations:** in all jurisdictions, there is either a lack of transparency or at least some evidence that independent reviews are not occurring in some cases.

¹³⁴ For the number of regurgitations, see Table 1 of the 2015 report:

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year18.pdf>

For the number of instances of regained consciousness see Table 1 of the 2015 report but also, for more detailed breakdown, see Oregon Public Health Division Report for 2012, Table 1, note 13.

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

¹³⁵ Washington State Department of Health, *Washington State Department of Health 2015 Death with Dignity Act Report*, see reports for the years 2011-2015.

See <http://www.doh.wa.gov/portals/1/Documents/Pubs/422-109-DeathWithDignityAct2015.pdf> and reports for 2012-2014 (Accessed 30 May 2016)

¹³⁶ Groenewoud, Johanna, Agnes van der Heide, Bregje D. Onwuteaka-Philipsen, Dick Willems, Paul van der Maas and Gerrit van der Wal, “Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands”, *New England Journal of Medicine*, 2000, 342, 551-556.

4.7 Failure to monitor what occurs outside the law

It is true that many practices in Victoria at present operate outside the full view of the law. But to suggest that all activities undertaken at death are transparently monitored in regimes with legal euthanasia or assisted suicide is clearly not correct.

If anything, it is possible that a normalisation of the hastening of death might create an environment in which even more dubious activity occurs in the grey area that is known to exist but not actively monitored by law enforcement agencies or health regulators.

As noted above, in Belgium, the FCEC has conceded that it has little power to investigate what occurs beyond the reports that it receives from physicians. This is true to varying degrees in all jurisdictions.

Chin et al note that the Oregon Health Division is charged with collecting data under the Dying with Dignity Act and to report cases of noncompliance to the Oregon Board of Medical Examiners. However, they also note that:

Our responsibility to report noncompliance makes it difficult, if not impossible, to detect accurately and comment on underreporting. Furthermore, the reporting requirements can only ensure that the process for obtaining lethal medications complies with the law. We cannot determine whether physician-assisted suicide is being practiced outside the framework of the Death with Dignity Act.¹³⁷

These examples are corroborated by expert evidence to the Canadian Supreme Court. Professor Etienne Montero was retained by the Attorney-General of Canada to provide impartial, expert opinion to the Supreme Court of Canada in the case of *Carter v the Attorney-General of Canada et al.*¹³⁸ When commenting on the Belgian regime, his analysis led him to conclude that:

the provisions of the Act, as seemingly strict as they are, cannot be strictly enforced and controlled ...¹³⁹

¹³⁷ Chin, Arthur, Katrina Hedberg, Grant Higginson and David Fleming, "Legalized Physician-Assisted Suicide in Oregon – The First Year's Experience", *New England Journal of Medicine*, 1999, 340: 577-583.

¹³⁸ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, pp39-63.

¹³⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p41.

Box 4: Legalisation simply shifts where hidden activities occur

The argument that a legalized system creates transparency and ensures a clear understanding of what is happening in real life thus needs to be qualified: it gives us more data, but hidden practices remain and interpretation of the reported cases of compliance and non-compliance call for further refinement and interpretation. Although impossible to obtain reliable evidence, it could very well be that there is simply a data shift, with previously hidden practices now regulated, and an increase of other forms of euthanasia, including involuntary euthanasia and practices that do not respect the legal procedures. The *post-factum* reporting systems of Belgium and the Netherlands neither prevent this nor provide us more certainty about what is indeed happening. They could just as easily give us a false sense of security and control over the practice.¹⁴⁰

4.8 Noteworthy individual cases

This paper has largely focused on broader, peer-reviewed quantitative studies. This section will highlight some individual cases that relate to concerning trends in the current practice of euthanasia and assisted suicide in some jurisdictions. While focusing on individual cases can be criticised as resorting to anecdote, these cases usefully supplement the studies cited above.

Advocates of euthanasia often cite individual cases so as to stress the human consequences of the restrictions contained in current laws. That is appropriate. It is equally appropriate to stress the human side of the negative consequences of regimes that aim to help a certain group of people but inadvertently result in harm and abuse more broadly.

The following are a small number of the many problematic cases that have made it into the public sphere. It is likely that many more escape public attention:

- **Psychiatric patients:** the euthanasia of a psychiatric inmate in Belgium who was, at the time, incarcerated. Dr Marc Moens, President of the Association of Belge des Syndicats Medicaux (ABSyM) noted that: “Even if the request for euthanasia meets all the statutory conditions, the burning question in this social debate is whether the inmate would have made this decision under the appropriate psychiatric treatment.”¹⁴¹
- **Transgender:** the euthanasia of Nathan Verhelst (born Nancy) after at 44, after an unsuccessful sex change operation has raised questions about whether more support could have alleviated the distress experienced after the operation.¹⁴²

¹⁴⁰ Lemmens, Trudo, The Conflict Between Open-ended Access to Physician-Assisted Dying and The Protection of the Vulnerable: Lessons from Belgium’s Euthanasia Regime in the Post-Carter Era, (forthcoming), Catherine Regis, Lara Khoury & Robert Kouri, eds., *Key Conflicts in Health Law*, (Cowensville: Yvon Blais, 2016), p32.

¹⁴¹ Moens, Dr Marc, president of the ABSyM, press release [translation] Psychiatric inmates have the right to medical care (13 September 2012), and see referred to in Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p44.

¹⁴² La Libre Belgique (October 1, 2013) and also reference in Lemmens article, pp50-51.

- **Anticipation of future pain or suffering:** there are a number of instances of people being euthanised as a result of their anticipation of future pain, including Hugo Clause (renowned Flemish author); Christian de Duve (Nobel Prize in Medicine 1974); Emiel Pauwels and others.¹⁴³
- **Anticipation of blindness:** another high profile case was the euthanasia of twins Eddy and Marc Verbessen who were born deaf and were euthanised together at age 45 on the basis of a diagnosis of glaucoma which was gradually making them blind.¹⁴⁴
- **Tinnitus:** a 47-year old woman in the Netherlands was euthanised for tinnitus that was deemed to be incurable.¹⁴⁵
- **Depression:** there are many high profile cases where arguably treatable depression was the cause of the euthanasia, including the highly publicised case of Godelieva De Troyer as reported in *the New Yorker*.¹⁴⁶ In Oregon, the case of Michael Freeland received public attention as he consented to the release of his records. Over a year after receiving his prescription, Mr Freeland was admitted to a psychiatric facility with depression and suicidal intent. His treating psychiatrist wrote a letter to the court the day after his discharge saying he was not competent and needed a guardian. Mr Freeland accidentally called Physicians for Compassionate Care (he was trying to contact the suicide advocacy organisation Compassion in Dying) and was treated for his depression and assisted in reconciling with his estranged daughter. Several weeks later he died naturally and comfortably without taking lethal drugs - some two years after receiving his first lethal dose prescription.¹⁴⁷
- **Multiple disorders:** the case of Jeanne is illustrative. Jeanne was 88 years old and suffered from multiple conditions that cumulatively caused unbearable pain but that were not individually sufficient to justify euthanasia. For her former attending physician, it was “obvious that she did not have a serious incurable disease as required under the Act”.¹⁴⁸ The number of cases of “multiple disorders” increased from 3 in the FCEC’s first report to 57 in the fifth report.¹⁴⁹
- **Old age:** the case of Amelie Van Esbeen gained considerable publicity as it appeared that her old age was the principal reason for her being euthanised. Of note was that her attending physician refused to grant her request.
- **Doctor shopping:** The case of Kate Cheney in Oregon outlined above in detail is a good example of doctor shopping. The opinions of more than one doctor were essentially ignored.¹⁵⁰ Another instance of doctor shopping in Oregon involved a patient of Dr Charles Bentz, who would not prescribe a lethal dosage as the patient had documented depression for which he needed treatment. The patient’s oncologist found another physician required to provide the “second opinion” and did not refer the patient back to his primary physician at all. Dr Bentz obtained

¹⁴³ Montero op cit pp 45-45 and see also discussion in Lemmens, op cit, pp51-52 in relation to the elderly couple Anne and Francois, who were suffering from significant medical issues but were not at immediate risk of dying. They requested a desire to be euthanised together to avoid the prospect of being alone should one survive the other.

¹⁴⁴ Montero op cit pp 45-45 and also discussion in Lemmens, op cit, pp49-50.

¹⁴⁵ See this reported in the Guardian: <http://www.theguardian.com/lifeandstyle/2015/sep/11/assisted-dying-dutch-end-of-life-netherlands-unbearable-suffering>

¹⁴⁶ Avid, Rachel, “The Death Treatment”, *The New Yorker*, June 22 2015.

See: <http://www.newyorker.com/magazine/2015/06/22/the-death-treatment>

¹⁴⁷ See information provided by Vermont Alliance for Ethical Health Care, www.vaeh.org.

See also: <http://www.pccf.org/articles/art60.htm>

¹⁴⁸ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p46.

¹⁴⁹ Montero, Professor Etienne, Affidavit to Lee Carter v The Attorney General of Canada et al, Supreme Court of Canada, No. 35591, p49.

¹⁵⁰ Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp156-157. See also information provided by Vermont Alliance for Ethical Health Care at www.vaeh.org.

permission from the patient's family and obtained a copy of the death certificate which stated that death was from malignant melanoma.¹⁵¹

- **Feeling like a burden:** The case of Kate Cheney is an example of the potential impact of pressure due to feeling like a burden on one's family.¹⁵²
- **Difficulty in diagnosis:** In Oregon, Barbara Houck, aged 71, was diagnosed with Amyotrophic Lateral Sclerosis. She met with Dr Peter Rasmussen, an oncologist (but not a neurologist) and supporter of physician-assisted dying. Dr Rasmussen declined to give the prescription because he judged that she had more than 6 months to live. She saw him again in March and he gave the prescription. This case raises difficulties about the suitability of an oncologist giving an evaluation and prognosis for an uncommon neurologic disease.¹⁵³ Another case involved a cancer patient, Jeanette Hall. A doctor had given her a terminal diagnosis of six months to a year to live, based upon not being treated for the cancer. She was referred to Dr Kenneth Stevens. On her first visit with Dr Stevens she made it clear that she did not want to be treated. After suggesting that she discuss the idea with her son, she agreed to treatment and, at the time of Dr Stevens' affidavit, had been alive for 13 years. In his view, "the mere presence of legal assisted suicide had steered her to suicide."¹⁵⁴

4.9 Conclusion

This chapter has explored various reasons why it is likely that the number of instances of euthanasia and assisted dying continue to grow so strongly, even after a period of almost two decades following legalisation in some jurisdictions.

The most plausible explanations for the growth in overall numbers are:

- An increase in the scope of regimes, whether by legislative amendment or the reinterpretation of existing legislative provisions.
- A normalisation of the decision to opt for euthanasia or assisted suicide.
- An increase in the number of cases of euthanasia of people in a vulnerable position.
- A failure of safeguards to limit the operation of schemes within the boundaries originally intended.

The evidence of Professor Etienne Montero to the Canadian Supreme Court summarises the risks that legalisation would expose Victoria to:

legislative openness to euthanasia inevitably leads to certain abuses and excesses, to a violation of the letter and the spirit of the law, and to a broadening of the scope of the Act beyond the borders initially and firmly established.¹⁵⁵

¹⁵¹ Vermont Alliance for Ethical Health Care at www.vaeh.org.

¹⁵² Foley K and Hendin H (Eds.) *The Case against Assisted Suicide, For the Right to End-of-Life Care*. Pp192-209. Baltimore: Johns Hopkins University Press, 2002, pp156-157. See also information provided by Vermont Alliance for Ethical Health Care at www.vaeh.org.

¹⁵³ Vermont Alliance for Ethical Health Care, www.vaeh.org.

¹⁵⁴ Stevens, Dr Kenneth R., Affidavit in *Montanans Against Assisted Suicide & For Living With Dignity vs Board of Medical Examiners*, Montana Department of Labour and Industry, sworn at Craig D. Charlton Charlton Law Firm, 16 October 2013.

¹⁵⁵ Montero, Professor Etienne, Affidavit to *Lee Carter v The Attorney General of Canada et al*, Supreme Court of Canada, No. 35591, p41.

CHAPTER 5 – ISSUES WITH THE PROPOSED REGIME

The proposed regime for assisted dying contains a number of elements that have proved highly problematic in jurisdictions with legalised euthanasia or assisted suicide. While the scheme set out in the Majority Report claims that it contains a number of safeguards, there is serious doubt as to whether these will be effective in practice.

These include:

- **Scope creep.** Given what has occurred in other jurisdictions, the potential for any entity that is established to expand the scope an assisted suicide regime in Victoria through non-transparent reinterpretations of legislative provisions should not be discounted.
- **Independent review.** The proposed regime would do little to prevent doctor shopping, a practice that is widespread in other jurisdictions. This calls into doubt the effectiveness of the requirement for independent appraisals.
- **Post-factum reporting.** This approach to reviewing cases has proved to be ineffective in a number of jurisdictions, with low rates of reporting and transparency in Belgium and the Netherlands.
- **A requirement that patients have a terminal condition.** As is noted above, this is extremely difficult to enforce in practice, with doctors often disagreeing on whether a condition is terminal. This will be exacerbated by the fact that the requirement will not contain a specific time limit. Even in jurisdictions with a time limit, it has been difficult to enforce this condition.
- **That physicians will be able to administer drugs in certain circumstances.** This is a significant expansion from some assisted suicide regimes. Given that many aspects of regulatory environments have expanded in scope through interpretation, this could become a major loophole.
- **Psychiatric evaluations.** The proposed regime does little to deal with the growing problem of how to diagnose and treat depression and mental illness and, in addition, how to interpret and manage the impact of such conditions on consent.

CHAPTER 6 – ISSUES WITH POLLING RESULTS

It is often claimed that a strong majority in the community support euthanasia or assisted dying. It is true that a number of polls have been undertaken over the past two decades and that somewhere between 65 and 80 per cent of those polled have indicated support for euthanasia.

Given the limitations of some polls to date, it would be worthwhile examining public sentiment in a more detailed, rigorous manner.

6.1 Issues that warrant further examination

There are a number of methodological issues with of the polls that are cited by euthanasia advocates:

- The question is sometimes put in a confusing or ambiguous manner. For example, terms like “dying with dignity” and “assisted dying” could mean different things to different people. Some people consider the use of high doses of pain relief, even if it might have negative consequences, as “assisted dying” – yet this is clearly legal at present and considered part of standard practice by the medical profession.
- At least some of the polls suffer from “framing” issues. It is well established that the way a question is framed can affect the results. In the case of euthanasia and assisted dying, support for legalisation could potentially be affected by references to whether safeguards are seen as appropriate and whether the person being polled would be concerned if was established that safeguards are not working in at least some jurisdictions.

A more rigorous approach would be to undertake layered questioning that disentangles questions such as withdrawal of treatment, the application of pain relief (even if it might hasten death) and euthanasia/assisted suicide.

It would also be worthwhile undertaking polling with groups who have been informed about current best practice palliative care options. It is well established that providing balanced information to people prior to polling can have a material impact on results.

6.2 Specific wording of recent questions

It is worth focusing on some of the specific questions that have been asked in recent polls.

Ambiguous wording

In 2014, the ABC Vote Compass found 76 per cent support for the following proposition:

*Terminally ill patients should be able to legally end their own lives with medical assistance*¹⁵⁶

¹⁵⁶ <http://www.abc.net.au/news/2014-11-23/victorians-back-voluntary-euthanasia-vote-compass/5910668>

This is a good example of a question that is arguably ambiguous. The phrase “... with medical assistance” could mean the administration of high dosages of pain relief in the eyes of many – a practice that is currently permitted under the law. It is important to be clearer than this proposition.

Support for tightly defined entitlement

Where there is support for a clearly defined proposition, it is almost always confined to people who are terminally ill and experiencing unendurable suffering.

In 2015, there was 72 per cent support for assisted suicide in a poll commissioned by Essential Media Communications. The question was:

*Q. When a person has a disease that cannot be cured and is living in severe pain, do you think doctors should or should not be allowed by law to assist the patient to commit suicide if the patient requests it?*¹⁵⁷

This question includes the phrases “cannot be cured” and “living in severe pain”.

In a 2012 Newspann, over 80 per cent supported the following euthanasia in the following situation:

hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovering

As is discussed in detail above, many people currently opting for assisted suicide in North America and euthanasia and assisted suicide in Europe are not in severe pain at the time of the request. Moreover, in assisted dying regimes of the type supported by the Majority Report, there is little evidence that lethal doses are necessarily only given at such times.

It would be worth testing support for the proposition if it was in a broader context. In particular, it would be worthwhile testing community support for assisted suicide and euthanasia in situations not involving unendurable physical pain, such as anticipation of pain, loss of hope etc, which routinely give rise to assisted suicide in jurisdictions where it is legal.

6.3 The need for layered polling

It would be worthwhile testing framing effects. For example, is public support for assisted suicide or euthanasia contingent on the effectiveness of safeguards? Does the level of support change if people are aware of the rapid growth in the number of cases of assisted suicide and euthanasia in all jurisdictions where it is legal and the large body evidence calling into doubt the effectiveness of safeguards?

In polling undertaken by Environics Research Group, a majority of Canadians either strongly support (21%) or somewhat support (36%) legalising euthanasia. This is considerably higher than the proportion who strongly oppose (20%) or somewhat oppose (8%).¹⁵⁸

¹⁵⁷ <http://www.essentialvision.com.au/voluntary-euthanasia-3>

In the same survey:

- almost two thirds of those surveyed expressed concern that elderly Canadians could be pressured into accepting euthanasia (66% concerned vs 33% not concerned).¹⁵⁹
- almost eight in ten express concern that a significant number of sick, disabled or elderly could be euthanised without their consent (78% concerned vs 20% not concerned).¹⁶⁰

These are not mutually inconsistent positions. But it suggests that, at least to some degree, support for the legalisation of euthanasia and assisted suicide is contingent on the implementation and maintenance of effective safeguards. It is worth exploring how an informed, evidence-based discussion about these concerns could affect support levels.

Abingdon Research undertook a poll of attitudes to euthanasia in Quebec. 74% of respondents either strongly or moderately supported the legalisation of euthanasia.

The people surveyed were then asked to respond to six potential scenarios each dealing with risks associated with the reform. A significant proportion expressed concerns in relation to these risks. After being exposed to these concerns, 47% indicated that they felt the subject required further study, while 35% continued to advocate for legalisation.¹⁶¹

It would be worthwhile exploring the relationship between the risks associated with potential reform and the level of support for legalisation.

¹⁵⁸ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p5.

¹⁵⁹ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p11.

¹⁶⁰ Environics Research Group, *Canadians' Attitudes Towards Euthanasia*, Commissioned Research for Life Canada, October 2010, p14.

¹⁶¹ Abingdon Research, Quebec "Medical Aid in Dying Survey", 2013, p25.

RECOMMENDATIONS

RECOMMENDATION 1: That the Victorian government undertake rigorous analysis of trends in euthanasia and assisted suicide in foreign jurisdictions before deciding whether to develop a legal regime for consideration. This would include an understanding of:

- best practice palliative care in Victoria, Australia and internationally.
- the prevalence of failure in safeguards in euthanasia and assisted suicide regimes.
- the extent to which illegal activity continues to occur in jurisdictions with legal euthanasia or assisted suicide.
- the extent to which a rising number of instances of euthanasia or assisted suicide is impacting on the overall health care system.

RECOMMENDATION 2: That rigorous, layered polling be undertaken in Victoria and that this polling:

- clearly set out the scope of the reform being tested.
- adopt a range of different “frames” for the question, including frames that indicate the risks associated with containing the scope of euthanasia or assisted suicide in practice.
- explore the relationship between a person’s awareness of and attitude towards the various risks associated with legalisation and their level of support for legalisation.

CONCLUSION

The legalisation of either assisted suicide or euthanasia would represent a fundamental shift in the regulation of medical practice in Victoria. Overseas experience over almost two decades suggests that, while such a change may benefit a small minority of people toward the end of life, many more may be worse off as a result.

This Minority Report has argued that:

- It is possible to respect individual autonomy while not empowering health professionals to actively participate in acts of assisted suicide or euthanasia.
- Even if it can be argued that euthanasia or assisted suicide are justifiable in some instances, the negative consequences arising from legalisation far outweigh the benefits arising in that minority of cases.

In only a very small minority of end-of-life situations are the symptoms of pain unmanageable

Experts in palliative care, oncology and related fields provided the Committee with powerful evidence that almost all symptoms arising from physical pain at the end of life can now be managed. The palliative care and oncology experts who gave evidence also stated that, over long careers, the number of people expressing a desire to have their life shortened was very small. Moreover, pain relief techniques and palliative care are constantly improving.

Even where there is an expressed desire to die, it is critically important to understand the nuances of such requests. Where the person making the request is experiencing depression or a mental illness, which is relatively common, there are usually treatment options worth exploring. Holistic palliative care and other forms of assistance can often provide effective relief, even if not complete, and can often lead to a reversal in the expressed desire.

Consideration of assisted suicide and euthanasia requires a consideration of more than how best to give effect to individual autonomy

Proper consideration of assisted suicide and euthanasia requires an evaluation of the likely broader social impacts of the reform in addition to issues relating to individual autonomy. Individual autonomy is of great importance, but it is not the only consideration.

While there is arguably a gain from giving effect to some patients' wishes to hasten their death, this must be weighed against the potential for societal harm through a range of potential negative consequences, including: vulnerable people being pressured into euthanasia or assisted suicide; people having their death hastened without having given proper consent; and a gradual broadening of practices without transparent public consideration.

In practice, euthanasia and assisted suicide are a disproportionate response that cause far more social harm than good


The evidence is clear that the number of instances of euthanasia and assisted suicide is growing rapidly in all major jurisdictions where it is legal. This has been occurring for almost two decades in some jurisdictions, with no sign of abatement.

The usage of euthanasia and assisted suicide in practice is far out of proportion to the situations that were originally used to justify the practice in these jurisdictions: namely, that small minority of cases where the symptoms of pain are unmanageable. Moreover, the rapid growth in documented cases of euthanasia and assisted suicide probably materially understates the actual prevalence of the practice given low rates of reporting.

The effectiveness of safeguards in jurisdictions with legalised assisted suicide and euthanasia has been called into question by many academic studies and high profile media investigations. This, coupled with the growing prevalence of the practice, is a matter of great concern.

While legalisation was supposed to bring what was occurring in the shadows into the light, legalisation has simply pushed the boundary of what is legal out further and may have increased the amount of activity that occurs beyond the sight of regulators. Evidence suggests that it is doubtful that safeguards are working as intended, particularly for vulnerable people.

It is very unfortunate that some symptoms of pain cannot be totally managed – but the legalisation euthanasia or assisted suicide is not the appropriate response.



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