



# PARLIAMENT OF VICTORIA

Legislative Council

Legal and Social Issues Committee

# Inquiry into end of life choices

Final Report:  
Summary Booklet

Parliament of Victoria  
**Legal and Social Issues Committee**

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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.

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- Department of Justice and Regulation
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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:

- have chronic or non-terminal illnesses
- are currently underrepresented in palliative care
- would benefit from palliative care.....68

**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.....76

**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

**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. .... 81

**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.....87

**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

**RECOMMENDATION 22:** That the Victorian Government develop an education package for residential aged care workers on end of life care. . . . . 96

**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. . . . . 96

**RECOMMENDATION 24:** That the Victorian Government require that health services adopt palliative care training modules in orientation programs and annual competencies for clinical staff. . . . . 96

**RECOMMENDATION 25:** That the Victorian Government introduce a coordinated approach to disseminating information on palliative care and associated health services. . . . . 100

**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. . . . . 107

**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. . . . . 107

**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. . . . . 120

**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. . . . . 120

## 5 Improving advance care planning

**RECOMMENDATION 30:** That the Victorian Government undertake a community awareness campaign to improve understanding of end of life choices, particularly advance care planning. . . . . 146

**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. . . . . 146



**RECOMMENDATION 32:** That the Victorian Government support the recognition of Annual Dying to Know Day on 8 August. . . . . 146

**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. . . . . 148

**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. . . . . 148

**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. . . . . 149

**RECOMMENDATION 36:** That the Victorian Government establish a voluntary target to measure and encourage improvements in the level of advance care planning across Victoria. . . . . 150

**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. . . . . 151

**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. . . . . 151

**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. . . . . 152

**RECOMMENDATION 40:** That the Postgraduate Medical Council of Victoria ensure that medical interns are adequately trained on the subject of substitute decision making. . . . . 152

**RECOMMENDATION 41:** That the Victorian Government require doctors and nurses to undertake continuous professional development on advance care planning. . . . . 152

**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. . . . . 155

**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. . . . . 155

**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

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### 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.

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<b>The person</b>	<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>
<b>The condition</b>	<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>
<b>The request</b>	<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"><li>• 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</li><li>• of palliative care and its likely results</li><li>• that they are under no obligation to continue with a request for assisted dying, and may rescind their request at any time</li><li>• of the probable result and potential risks of taking the lethal drug.</li></ul> <p>Must be repeated three times:</p> <ul style="list-style-type: none"><li>• an initial verbal request</li><li>• a formal written request, which must be signed by two independent witnesses</li><li>• a final verbal request.</li></ul> <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>

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## 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.



