

Interim report of the Ministerial Advisory Panel: Consultation overview

Voluntary Assisted Dying Bill



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Authorised and published by the Victorian Government, 1 Treasury Place, Melbourne.

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ISBN 978-0-7311-7197-2 (Print)

ISBN 978-0-7311-7198-9 (Pdf/online)

Available at <https://www2.health.vic.gov.au/about/health-strategies/voluntary-assisted-dying-bill>

Printed by Complete Colour, 84–86 Herald St, Cheltenham
(1701015)

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Letter from the Chair

28 April 2017

The Hon. Jill Hennessy MP
Minister for Health
50 Lonsdale Street
Melbourne VIC 3000

Dear Minister Hennessy

I am pleased to provide you with the Ministerial Advisory Panel's interim report covering the key issues raised in our Voluntary Assisted Dying Bill consultation process. We heard from more than 300 people through forums, roundtable discussions and written submissions in response to the Voluntary Assisted Dying Bill discussion paper.

It has been a privilege to be able to lead the consultations informing the development of the Voluntary Assisted Dying Bill, and the Panel would like to acknowledge those who have participated in the consultation process. All participants contributed in a considered and respectful way, generously sharing their personal and professional experiences and knowledge through written submissions or in person at the forums and roundtable discussions. The consultation has been an extremely valuable and constructive process that has strengthened our understanding and honed our thinking.

Stakeholders strongly endorsed the government's commitment to end-of-life care reform. This included promoting access to high-quality palliative care, as well as the right to consent and refuse medical treatments through advance care directives. It was acknowledged that it is important to develop voluntary assisted dying legislation within this context.

While the Panel has been specifically tasked with advising on voluntary assisted dying, we endorse the government's approach and uphold that voluntary assisted dying should not be viewed as a substitute for good palliative care and symptom management.

The task of the Panel has been to build on the findings and recommendations of the Legal and Social Issues Committee's 'Inquiry into end of life choices'. Members of the Panel are acutely aware of their responsibility to develop a voluntary assisted dying legislative framework with effective safeguards for all Victorians.

At the same time, the Panel is mindful of the need to balance safeguards with ensuring that those who are eligible are able to access voluntary assisted dying. Feedback about the proposed voluntary assisted dying legislation was that it should, wherever possible, maintain the therapeutic relationship between a person and their medical practitioner and not create an unnecessary burden for people who are already suffering.

The Panel is committed to using the information collected through the consultation process to ensure the development of the best possible compassionate and safe voluntary assisted dying legislative framework for all Victorians.



Professor Brian Owler

Chair
Ministerial Advisory Panel

The Ministerial Advisory Panel



Professor
Brian Owler
Chair

Clinical professor Brian Owler is an adult and paediatric neurosurgeon based in Sydney. He is a fellow of the Royal Australasian College of Surgeons and was federal president of the Australian Medical Association from 2014 to 2016. He has a broad knowledge of Australia's healthcare system through his AMA experience and roles with other healthcare organisations and committees.



Professor
Margaret O'Connor
AM
Deputy Chair

Professor Margaret O'Connor AM is Emeritus Professor of Nursing at Monash University. She has worked in numerous roles in palliative care, encompassing clinical care, management of services, education and research. Professor O'Connor served as president of Palliative Care Australia from 2006 to 2010 and was an inaugural trustee of the World Palliative Care Alliance. She has also served as a member of the Australian Health Ethics Committee of the National Health and Medical Research Council.

In 2005 Professor O'Connor was awarded a Member of the Order of Australia and in 2012 was awarded life membership of Palliative Care Victoria.



Ms Mary Draper
Member

Ms Mary Draper is a board director at Austin Health and immediate past CEO of the Health Issues Centre. She has expertise in academic and practical health administration in quality and safety, providing experience in analysing quality and safety of healthcare from a consumer's point of view. Ms Draper served as the chair of the Health Issues Centre prior to serving as CEO until November 2014.

Ms Draper has experience representing consumer perspectives on a range of quality-related national and state-level committees and for seven years was the director of clinical governance at the Royal Women's Hospital.



Mr Julian Gardner
AM
Member

Mr Julian Gardner AM is a lawyer and immediate past Victorian Public Advocate, providing experience in advocating for vulnerable people. Mr Gardner has previously served as president of the Mental Health Review Board, been the national convenor of the Social Security Appeals Tribunal, chair of the WorkCare Appeals Board and a director of the Victorian Legal Aid Commission.

Mr Gardner is currently the chair of Mind Australia Ltd, a non-government organisation providing community mental health services and the deputy chair of Alfred Health.



Dr
Roger Hunt
Member

Dr Roger Hunt is a palliative medicine consultant who has been a pioneer of palliative care in South Australia. Dr Hunt is a founding member of Daw House Hospice and founding fellow of the Chapter of Palliative Medicine, and was awarded a doctorate in medicine for published research: '*Epidemiology of terminal care in SA.*' Dr Hunt is also a senior lecturer at the University of Adelaide and has developed postgraduate courses at Flinders University.

Dr Hunt has been the director of a major metropolitan palliative care service for 10 years and is the former chair and honorary life member of the Palliative Care Council for services to palliative care.



Emeritus Professor
Ian Maddocks AM
Member

Emeritus Professor Ian Maddocks AM was appointed to the first chair of palliative care established at Flinders University. He was the first president of the Australian Association for Hospice and Palliative Care and the first president of the Australian and New Zealand Society for Palliative Medicine. He was a specialist physician in the Australian Administration of Papua New Guinea for 14 years.

Emeritus Professor Maddocks led concern for the prevention of war as president of Australia's Medical Association for Prevention of War and vice president of International Physicians for Prevention of Nuclear War in 1985, when it received the Nobel Prize for Peace.

Emeritus Professor Maddocks chaired the National Consultative Committee for Peace and Disarmament from 1990 to 2002 and in 2013 he was the National Recipient of the Senior Australian of the Year Award for his lifetime of achievements.



Ms Tricia Malowney
Member

Ms Tricia Malowney is a health advocate for women with disabilities and was the inaugural president of the Victorian Disability Services Board. She was also the deputy chair of the Victorian Disability Advisory Council.

Ms Malowney is currently the board chair of Independent Disability Services and a board director for Scope Disability Services and the Australian Orthotics and Prosthetics Association. She is a member of Women with Disabilities Victoria and the Disability Leadership Institute.

In 2008 Ms Malowney was awarded Rotary Australia's Shine On Award for services to Victorians with disabilities and in 2013 was inducted into the Victorian Honour Roll of Women for services to women with disabilities. In 2015 Ms Malowney travelled to Ireland on an Ethel Temby grant to research access to mainstream services for people with disabilities.

Terms of reference – The Ministerial Advisory Panel

Taking the assisted dying framework as outlined by the Legal and Social Issues Committee (the 'Parliamentary Committee') as the starting point, the Panel's task is to provide advice to government about how a compassionate and safe legislative framework for voluntary assisted dying could be implemented. This will include how it could be implemented in Victoria to provide access to eligible people while minimising risks to potentially vulnerable people.

The Panel will provide an interim report at three months and a final report at six months.

The Panel is asked to consider relevant policy and legal issues including:

- a) The terms used in the final report and the necessary definitions required for the drafting of appropriately clear legislation such as:
 - 'irreparable decline'
 - 'a serious and incurable condition'
 - when a person may be 'physically unable to administer medication'
 - any other key terms or concepts the Panel considers relevant.
- b) The eligibility criteria and how this can be clearly defined in a legislative framework.
- c) The risks to individuals and the community associated with voluntary assisted dying, and how these can be managed.
- d) Safeguards to address risks and procedures for assessing requests for voluntary assisted dying.
- e) The protection of medical practitioners' freedom of conscience.
- f) The appropriate oversight mechanisms.
- g) Integration with existing laws and agencies.
- h) Interaction with the existing healthcare system, including consideration of the necessary clinical and consumer tools and resources and appropriate community information and support.

While the Parliamentary Committee sets out a broad overview of an assisted dying framework in its final report, there is little practical detail about a number of important issues that need to be resolved in developing compassionate and safe voluntary assisted dying legislation. For example, further consideration needs to be given to:

- defining the phrases that would define the scope of voluntary assisted dying
- existing clinical and consumer tools or approaches that have been shown to support medical practitioners and consumers to engage in purposeful conversations for assessment proposes when someone requests voluntary assisted dying

continued...

- how the lethal medication would be monitored and prescribed, including the impact Commonwealth regulations may have on accessing and authorising whichever medication is chosen
- how qualification requirements for medical practitioners practising voluntary assisted dying in Victoria would be assessed or registered
- how the public safety challenges of prescribing lethal medication to be taken at a later date and in a non-regulated location (for example, in someone's home) would be managed
- how the administration of the lethal medication to a person physically unable to administer it themselves should be regulated
- how the process for consent and how the interaction with other health services would be managed, including protocols for information sharing to ensure a coordinated system response to an individual who takes the lethal medication
- how deaths as a result of voluntary assisted dying would be monitored or notified
- what type of regulations and powers would be required for a voluntary assisted dying review board to undertake its functions as outlined in the framework
- other terms and issues as identified.

Importantly, the Voluntary Assisted Dying Bill is being developed within the government's broader reform in end-of-life care, which is designed to improve access to end-of-life and palliative care services and give statutory recognition to advance care directives that provide genuine choice and treatment options for people approaching the end of their lives.

Introduction

Purpose of the interim report

The Voluntary Assisted Dying Ministerial Advisory Panel (the Panel) was tasked with providing the Minister for Health with an interim report within three months. This interim report sets out the key issues, concerns and potential solutions provided to the Panel by people who participated in the consultation process. While there was consensus on a number of issues, the Panel also heard a range of divergent views about the most appropriate way to develop and implement voluntary assisted dying legislation. The purpose of this interim report is to reflect the range of views that the Panel has noted and will be considering in the development of its recommendations for the introduction of voluntary assisted dying in Victoria.

Context

Over recent decades medical treatment has provided many cures for acute illnesses and has saved many people's lives. It has also prolonged people's lives by managing progressive and chronic conditions such as cancer, heart disease and neurological conditions. For many of these conditions there is no cure, and people will need to be supported and cared for along their illness trajectory that will, over time, include the need for end-of-life care. Of the approximately 39,000 people who die in Victoria each year¹, two thirds die from a chronic disease, including cancer.

We now have more medical interventions than ever before, and with this comes increased choice and more complex decision making about what medical treatment to accept or refuse. Just 'letting nature take its course' is no longer a simple proposition because medical interventions may have already changed the course of a person's illness or delayed what once would have been considered a 'natural death'. As a result, people have an extended period of time to contemplate their own death.

In Victoria, end-of-life care has recently become the focus of significant attention and reform. Over the past two years, a number of community and sector consultations have asked Victorians to consider the role and extent of end-of-life care and, as part of this, their own end-of-life choices.

Drawing on feedback from these consultations, two important reports, *Victoria's end of life and palliative care framework* and the Legal and Social Issues Committee's *Inquiry into end of life choices – final report* have set the foundations for the future of end-of-life care and end-of-life choices in Victoria.

The development of *Victoria's end of life and palliative care framework* was informed by the 2015 Improving End of Life Care consultation. This consultation included 28 forums across Victoria in which almost 700 people participated. The cross-party Legal and Social Issues Committee's 'Inquiry into end of life choices' followed an extensive consultation, also in 2015. Across these consultations clear and consistent themes have emerged about what matters to Victorians for their care at the end of life. These themes include support for the following:

¹ Australian Bureau of Statistics 2015, *Deaths* (Catalogue no. 3302, 28 September), ABS, Canberra.

- **Strengthened palliative care.** Victorians generally receive high-quality end-of-life and palliative care, and Victorians want increased government investment to improve access to and the high-quality of end-of-life care services. This includes greater integration of services and improved access to home-based palliative care.
- **Supporting conversations.** Many people have expressed difficulty in engaging in conversations about death and dying, about their personal medical conditions and their treatment options, and want more support to have these conversations with their family.
- **Placing people at the centre of decision making about their own medical treatments.** People want their preferences and values to direct the end-of-life treatment and care they receive. Feedback confirmed that people believe the person receiving treatment must be at the centre of clinical decision making and that the individual's decisions about treatment must be respected.
- **Supporting dying people and their families.** The end of a person's life is likely to be difficult for both the person and their family. It is therefore critical that appropriate support is available to anyone who needs it. This includes having access to treatment and care that relieves suffering, pain and other symptoms associated with end of life, as well as psychosocial and bereavement support before and after death.
- **Genuine choice that responds to people's needs.** People want genuine choice about their end-of-life care including access to the range of services needed, the place where care is offered and the place where death occurs. For some people this also includes the timing and manner of their death.

It is common in our society to avoid talking about death and dying, and often an individual's preferences for end-of-life care are unknown. When people are asked, the majority say they would prefer to die at home, supported by family and friends with good-quality care. Despite this, most people die in hospitals and nursing homes.

Victoria's end of life and palliative care framework

Victoria's end of life and palliative care framework (published in June 2016) emphasises that all Victorians are entitled to high-quality end-of-life care that relieves pain, distress and suffering, and that also provides support to their family, friends and carers.

The framework emphasises a person-centred approach to delivering care according to people's preferences and goals. It focuses on understanding what matters to people who are dying and to their families. It outlines plans to redesign Victoria's services to be more effective, with a focus on delivering care as everybody's responsibility in the healthcare system as part of an integrated service.

The framework includes five priority areas for improvement:

- person-centred services
- engaging communities, embracing diversity
- people receive services that are coordinated and integrated
- quality end of life and palliative care is everyone's responsibility
- specialist palliative care is strengthened.

Implementation plans address each of the five priority areas. Improvements will be progressively completed over the next decade, including extending hours of support, strengthening specialist services, providing more training, developing new models of referral and care and enhancing information services.

In support of end-of-life care, the Victorian Government has reformed the laws governing medical treatment decision making and advance care planning to strengthen people's ability to make decisions about future treatment and have those decisions respected.

Victoria's *Medical Treatment Planning and Decisions Act 2016* gives statutory recognition to advance care directives to ensure people's preferences and values regarding medical treatment are respected. In implementing the new Act, there will be community and professional education about advance care planning and the more general aspects of consent to medical treatment.

The Medical Treatment Planning and Decisions Act provides an enhanced focus that will support people to make decisions about their medical treatment and reassure people that they will receive treatment that is consistent with their preferences and values.


The Legal and Social Issues Committee's *Inquiry into end of life choices – final report*

The Legal and Social Issues Committee (the 'Parliamentary Committee') identified the need for community members to start conversations about how they envisage their own end of life and to communicate their preferences and values to their family, loved ones, general practitioners and other relevant health practitioners. It noted that people should be able to make decisions about the nature and extent of their treatment. This includes the opportunity to make a legally binding advance care directive for when they no longer have decision-making capacity.

Consistent with other reports, the Parliamentary Committee found that Victoria has good palliative care services available. However, people who could benefit from these services often receive them too late. A focus on ensuring access to quality palliative care services that provide person-centred care is a significant theme in the report. It also found that while palliative care has improved significantly in the past 20 years and can treat most pain and suffering to the satisfaction of the person, it cannot manage all pain and suffering.

Based on research and evidence that takes into account international experience, and drawing on feedback from the consultations and hearings, the Parliamentary Committee concluded that despite the best efforts of health practitioners, not all pain and suffering can be alleviated, or alleviated in a way that is satisfactory to the person. As a result, some people end their lives prematurely and in a manner that is harrowing for families, the community, healthcare workers and law enforcement.

The Parliamentary Committee therefore recommended that the Victorian Government introduce legislation to allow adults with decision-making capacity who are suffering from a serious and incurable condition, and who are at the end of life, to have access to assisted dying in certain circumstances.



Consistent with international experience, the Parliamentary Committee noted that if assisted dying were to be available in Victoria, the numbers of people accessing it would be small. For those people who do access assisted dying, many will not take the medication but would be comforted that, should they decide to use it, they will be able to do so. The Parliamentary Committee also noted that the availability of assisted dying may be of comfort to many other people by offering an additional choice about the timing and manner of their death should they face intolerable suffering.

The Parliamentary Committee's assisted dying framework

Following extensive consultations and an examination of the experience of overseas jurisdictions that have introduced assisted dying, the Parliamentary Committee recommended a framework for introducing assisted dying in Victoria. The Parliamentary Committee recognised that the framework should be implemented alongside other improvements in palliative care and advance care planning.

The Parliamentary Committee's framework allows a very limited number of people to access assisted dying. The framework is designed for those who are already at the end of their lives and who face intolerable suffering during their final weeks or months. The eligibility criteria proposed by the Parliamentary Committee combines the safeguards used in those jurisdictions in North America and Europe that currently allow assisted dying.

Jurisdictions in North America allow a person to access assisted dying only if that person is terminally ill, whereas in European jurisdictions, the focus is on the suffering the person is experiencing. The Parliamentary Committee recommended that both criteria must be fulfilled for a person to access assisted dying in Victoria. In this respect, the bar for Victorians to be eligible to access assisted dying would be higher than the North American and European jurisdictions.

The process for requesting assisted dying recommended by the Parliamentary Committee is similar to the approach taken in jurisdictions in North America. This approach prescribes a clear step-by-step process. A person seeking assisted dying must make three requests: a verbal request, followed by a written request, and then another verbal request, demonstrating that the request is enduring. This process is designed to ensure a person's decision to access assisted dying is well considered and that full access has been given to all relevant information. The requests must come from the person, who must have decision-making capacity regarding personal medical treatment at all stages. Requests cannot be made in an advance care directive.

The Parliamentary Committee recommended that a person's eligibility be assessed by both a primary doctor and an independent secondary doctor. The Parliamentary Committee recommended that both doctors must ensure that the person is properly informed.

If there was any doubt about the person's decision-making capacity as a result of a mental illness, the Parliamentary Committee recommended that the doctor must refer the person to a psychiatrist for assessment.

If the person fulfilled the eligibility criteria and completed the process, the Parliamentary Committee recommended that the doctor prescribe a lethal drug to the person, which they may then take without further assistance.

The Parliamentary Committee heard evidence that for many people just knowing that they had the option of ending their suffering by taking their life would provide significant comfort and reassurance, which may result in the drug not being taken.

The Parliamentary Committee recognised that it would be discriminatory to exclude people who are physically unable to self-administer the drug and recommended that in these very rare circumstances a doctor should be able to assist the person to die by administering the drug.

The Parliamentary Committee also recommended the establishment of a board called the Assisted Dying Review Board. This board would review the actions of the primary and secondary doctors in each case of assisted dying. The role of the board would not be to approve or reject requests; this would be the role of the primary doctor and independent secondary doctor in each case. The board would not hear appeals from those whose requests were rejected. The purpose of the board would be to ensure that doctors are complying with the requirements of the assisted dying framework.

The Parliamentary Committee's assisted dying framework

What did the Parliamentary Committee recommend?

- The Parliamentary Committee recommended an assisted dying framework to allow adults with decision-making capacity who are suffering from a serious and incurable condition and who are at the end of life to be given assistance to die in certain circumstances.
- The Parliamentary Committee is clear that the assisted dying framework is intended to provide an option that can limit suffering at the end of life and is not a way to end life for people who are not dying.
- No doctor, other health practitioner or health service will be forced to participate in assisted dying.

How would the Parliamentary Committee's recommendation work?

- The framework being proposed would involve a doctor prescribing a lethal drug that the person may then take without further assistance from the doctor.
 - The Parliamentary Committee recognised that doctors should assist people who are physically unable to take the drug themselves. In these cases the framework would allow a doctor to assist the person to die by administering the drug.
- The Parliamentary Committee did not detail where or how this should occur.

Who would be able to access assisted dying?

- The assisted dying framework outlines eligibility and assessment criteria for a person to be assisted to die. These are that the person:
 - is an adult with decision-making capacity
 - is ordinarily resident in Victoria and an Australian citizen or permanent resident
 - is at the end of their life (final weeks or months of life)

continued...

- is suffering from a serious and incurable condition that is causing enduring and unbearable suffering that cannot be relieved in a manner the person deems tolerable
- makes the request themselves
- shows an enduring request for assisted dying and requests it three times through an initial verbal request, a formal written request signed by two independent witnesses and a final verbal request
- is independently assessed by a primary and secondary doctor (it will be the role of the doctors to ensure the person is properly informed, they are satisfied that the person's request is enduring and to assess the reasonableness of the request)
- must not be suffering as a result of mental illness only.

How would assisted dying work in practice?

- A person who meets the above criteria would be able to make a request for assisted dying. This request would need to be enduring, which means the person would need to make three separate requests, one of which is in writing and witnessed.
- A primary and secondary doctor must independently assess the eligibility criteria. A primary and secondary doctor must each properly inform the person of their diagnosis and prognosis and treatment options and likely outcomes. They must also inform the person about palliative care and its likely results, that they are under no obligation to continue with their request and may rescind it at any time and of the probable result and potential risks of taking the lethal drug.
- Once the requests have been made and two doctors have found the person meets the eligibility criteria, the doctor may prescribe a lethal drug. The person may then self-administer the drug at a time of their choosing. If a person is physically unable to self-administer, the doctor may assist the person to die by administering the drug.

What oversight does the Parliamentary Committee propose?

- The assisted dying framework includes the establishment of a board called the Assisted Dying Review Board. The board would ensure doctors are complying with the requirements of the assisted dying framework by reviewing each approved request for assisted dying. The board would not approve or reject requests for assisted dying. The Parliamentary Committee recommends a five-year review of the assisted dying framework by a parliamentary committee.

Victorian Government response

On 8 December 2016 the government responded to the Parliamentary Committee's final report, supporting 44 of the 49 recommendations, and identifying three recommendations as requiring further work. As part of this response, the government announced that it will introduce legislation into parliament in the second half of 2017 to legalise voluntary assisted dying for Victorians who are at the end of their lives and have a serious and incurable condition that is causing intolerable suffering.

The Minister for Health established the Voluntary Assisted Dying Ministerial Advisory Panel (the Panel) and tasked it to conduct further consultation and to develop a legislative framework for the Voluntary Assisted Dying Bill. The Panel is made up of medical, nursing, legal, consumer and palliative care experts to advise on the detail of the legislation. The Panel released a discussion paper about the legislative reform for public comment on 30 January 2017 and has received written submissions. The Panel has also undertaken a series of consultation forums and roundtable discussions with key stakeholders to inform their deliberations on the detail of the legislation. This interim report provides a summary of the key issues raised in forums, roundtable discussions and written submissions. A final report will be released in July 2017 setting out the Panel's recommendations.

The Panel is using the framework recommended by the Parliamentary Committee as the starting point to develop a compassionate, safe and practical voluntary assisted dying legislative framework. The Panel used the Parliamentary Committee's framework as the basis for consultations with stakeholders and relevant experts to determine how voluntary assisted dying could work in practice in Victoria. This interim report summarises stakeholder feedback using the framework recommended by the Parliamentary Committee.

The Panel acknowledges that, for most people approaching the end of their life, the initiatives implemented as part of *Victoria's end of life and palliative care framework* to strengthen and improve end-of-life care, end-of-life decision making and palliative care across Victoria will provide the necessary treatment and care options. The introduction of voluntary assisted dying takes into account the expectations Victorians have about their end-of-life care decisions and options.

In this context, voluntary assisted dying will provide some people with another option at the end of their life, but in order to do so, the Panel needs to ensure the necessary safeguards are in place to provide protections for individuals and the community.

Charter of Human Rights and Responsibilities

The Victorian *Charter of Human Rights and Responsibilities Act 2006* provides important guidance for developing legislation for voluntary assisted dying. The Charter identifies 20 fundamental human rights, and legislation in Victoria must be consistent with the Charter.

Every human life has equal value, and human rights provide guidance for upholding and safeguarding this equal value. The Panel will use the Charter as a framework for promoting the rights of all Victorians in considering the implementation of voluntary assisted dying.

The human rights in the Charter are designed to protect people and allow them to flourish, and a balance needs to be struck between the aim of promoting autonomy and the need to provide appropriate safeguards. Providing for unfettered autonomy would leave many people at risk of abuse and would fail to redress social disadvantages that render some people less able to exercise their autonomy than others. Conversely, focusing solely on protecting people would result in a failure to respect people to make their own decisions about what is in their interests.

While both promoting autonomy and providing appropriate safeguards are critical, neither aim is paramount. Instead, these aims must be balanced. An appropriate balance between allowing for autonomy and providing safeguards should not only recognise the importance of these aims individually but also their necessity for promoting each other. Sometimes safeguards are necessary to ensure people are able to make informed and voluntary decisions to exercise their autonomy. Similarly, the ultimate aim of providing safeguards is to protect people so that they may flourish. This aim should not be lost in the immediate desire to prevent potential harm.

There are people in Victoria who may be vulnerable to abuse. Recent reports by the Victorian Parliament into abuse in disability services and the New South Wales Parliament on elder abuse illustrate this risk.

Giving effect to human rights that protect the sanctity of every human life, and applying safeguards that protect individuals who may be vulnerable to abuse, are part of a just and fair society. Within a just and fair society vulnerable people must also have the right to make decisions about their own lives. Under Victorian law there is a presumption of decision-making capacity for all adults.

In its considerations, the Panel seeks to balance a person's desire to make their own decisions about the timing and manner of their death with ensuring that this is provided for in a framework that gives all Victorians the appropriate protections to keep them safe from abuse.

The Charter recognises these competing ideals and provides a structure for balancing human rights. The Charter also recognises that some human rights may be limited, if this limitation is a proportionate response to legitimate concerns. That is to say, the limitation must not be an 'overboard response' to an issue and that the limitation actually targets the issue of concern. In order to determine this, factors such as the nature of the right, the purpose and degree of the limitation, and whether there are less restrictive ways to address the concern, must be considered.

There will invariably be circumstances in which one right must be limited to promote another. In order to create a compassionate, safe and practical voluntary assisted dying legislative framework, it may also be necessary to limit some rights in order to ensure protection from coercion or abuse. For example, the eligibility criteria for assisted dying proposed by the Parliamentary Committee excludes people who do not have decision-making capacity. This may mean that a person's 'right to equality' is limited in order to ensure their 'right to protection from torture and cruel, inhuman or degrading treatment'. This may be seen as a proportionate limitation on the right to equality because it provides protections against coercion and engages the right to certain protections for a group of people who may be considered at risk of abuse.

The Charter exhibits some of the tensions the Panel will need to weigh up in its deliberations. For example, the need to balance appropriate safeguards to protect the community with the need to make voluntary assisted dying practically accessible to people at the end of life who have made an autonomous decision. Voluntary assisted dying legislation will need to be consistent with the Charter, and the Panel will carefully consider how each of the human rights identified in the Charter can be promoted.

Charter of Human Rights and Responsibilities Act

Seven human rights in the Charter have particular relevance for developing voluntary assisted dying legislation:

- **The right to equality** (s. 8) is particularly relevant to questions of who should be able to access voluntary assisted dying. The right to equality suggests that no one should be excluded on the basis of a particular attribute; however, this right may be limited for reasons such as providing protection against coercion.
- **The right to life** (s. 9) is a right not to be arbitrarily deprived of life. The right to life does not appear to either require or prohibit voluntary assisted dying, but it suggests the right to make autonomous decisions about one's own life must be weighed against concerns about risk of misuse and the threat this poses to the lives of others in the community.
- **The right to protection from torture and cruel, inhuman or degrading treatment** (s. 10) requires that a person not be subjected to medical or scientific experimentation without full, free and informed consent.
- **The right to privacy and reputation** (s. 13(a)) requires that a person's privacy is not unlawfully or arbitrarily interfered with and is relevant to the question of data collection and reporting.
- **The right to freedom of thought, conscience, religion and belief** (s. 14(1)) ensures people are not required to do things that are contrary to their beliefs. This includes recognising that some health practitioners may conscientiously object to participating in voluntary assisted dying.
- **The right to protection of the best interests of the child** (s. 17(2)) offers limited guidance given the potential for different interpretations of what is in the best interests of a child.
- **The right to liberty and security of person** (s. 21(1)) recognises that the state should not arbitrarily limit individual freedom or interfere with a person's bodily integrity.

The consultation process

The Panel has consulted widely on the development of a compassionate, safe and practical voluntary assisted dying legislative framework for Victoria. The Panel has not repeated the consultations undertaken by the Parliamentary Committee's 'Inquiry into end of life choices', which received more than 1,000 submissions, held 17 days of public hearings and heard from 154 witnesses. Nor did the Panel replicate the work done by the Parliamentary Committee over the 10 months of the inquiry period in reviewing opinions on whether or not voluntary assisted dying should be legalised.

As the Panel has undertaken its work, it has respected the variety of views and expertise of stakeholders and been guided by the following principles:

- The person, and the needs of the person, is the central consideration in all discussions about voluntary assisted dying.
- Respect is maintained for the range of expertise and judgement of all people – providers, family and carers – who support people approaching the end of their life.
- Differing views among providers about voluntary assisted dying is acknowledged, with recognition that individuals may wish to contribute to developing the legislation but choose not to participate in its implementation.
- To help create a compassionate, safe and practical voluntary assisted dying legislative framework, the focus must be on problem solving and resolving contentious issues.
- Any legislative framework developed must allow application in a way that respects the diversity of culture and values among Victorians.

Using the terms of reference and these principles as a guide, the Panel has identified key issues for decision making. The consultation process has focused on resolving important questions about the practical implementation of voluntary assisted dying in Victoria.

Forums and roundtable discussions

The Panel conducted 14 consultation forums across Victoria, including five in regional Victoria. The forums were attended by approximately 300 people. Each forum provided participants with an opportunity to discuss, with members of the Panel, the key areas of the eligibility criteria, the voluntary assisted dying request process, and the oversight and safeguards required to implement a compassionate, safe and practical voluntary assisted dying legislative framework. The forums were very constructive and allowed participants to voice their concerns, ideas and diverse experiences as well as to hear responses directly from members of the Panel.

In addition, the Panel has undertaken a series of roundtable discussions with key stakeholders including medical bodies, consumer and carer groups, disability advocacy groups, legal organisations, mental health providers, commissioners, health administrators and a diverse range of other appropriate experts. The input provided in these roundtable discussions has been considered and practical, offering details and insights that have been of great value to the Panel's deliberations.

Written submissions to the discussion paper

The Panel released a discussion paper on the Voluntary Assisted Dying Bill on 30 January 2017. A summary of the paper was translated into easy English and 16 community languages. Written submissions on the discussion paper closed on 10 April 2017. The discussion paper set out and sought feedback on the key issues that the legislation will address. There were 176 written submissions received, and these contributions, together with the consultation forums and roundtable discussions, have added further to the feedback that is informing the development of the details of a potential legislative framework.

The discussion paper focused on the detail of voluntary assisted dying legislation and built on the work of the Parliamentary Committee. This is consistent with the role of the Panel, which is to create a compassionate and safe voluntary assisted dying legislative framework for parliament to consider. For this reason, the discussion paper clearly set out that feedback only expressing an opinion for or against voluntary assisted dying would not be considered. It is not the role of the Panel to determine whether or not voluntary assisted dying should be legalised.

Written submissions that only expressed a position supporting or opposing voluntary assisted dying and provided no substantive comment were not considered by the Panel.

Reflecting on the consultation process

The Panel received feedback from written submissions, consultation forums and roundtable discussions from people and organisations with a diverse range of views. In receiving feedback the Panel did not discriminate based on whether a person or organisation supported or opposed voluntary assisted dying, focusing instead on the practical concerns and potential solutions raised.

The Panel respects the way each participant in the forums and roundtable discussions engaged with the process to offer their considered input, reflecting their particular expertise and experience. Consulting with individuals and receiving feedback has been valuable and has strengthened the Panel's understanding and honed its thinking. The Panel is committed to using this information to develop the best possible voluntary assisted dying framework for Victorians.

It is fair to say that many Victorians have a clear opinion about whether or not voluntary assisted dying should be legalised. Many forum comments and written submissions expressed an opinion either in favour of or opposed to voluntary assisted dying. The Panel was impressed that all contributions were respectful.

Views were less clear when it came to determining some of the practical implementation issues of design for the legislative framework. The opportunity to discuss and work through the diverse views and complexities in the consultation forums and roundtable discussions was very informative and enabled the Panel to test its thinking.

The Panel would like to thank all who participated in the consultation process and who provided constructive feedback.

Chapter 1: Who could be eligible for voluntary assisted dying?

Introduction

The Parliamentary Committee recommended that to be eligible to access assisted dying a person:

- be an adult, aged 18 years and over
- be ordinarily resident in Victoria and an Australian citizen or permanent resident
- have decision-making capacity about their own medical treatment
- be suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner that the person deems tolerable
- be at the end of life (final weeks or months of life).

The person

An adult, aged 18 years and over

The Parliamentary Committee recommended that assisted dying be available to people aged 18 years and over. Age restrictions, combined with the requirement that people have decision-making capacity, are an important safeguard for access to voluntary assisted dying.

Internationally, Canada and the American states of Oregon, Washington, California, Colorado and Vermont only permit access to voluntary assisted dying for adults who are 18 years or older. In Belgium, Luxembourg and the Netherlands competent minors have access with the consent of their parents or guardian.

Participants in the forums strongly agreed that a person should be 18 years and over to access voluntary assisted dying.

The majority of participants thought this requirement was 'appropriate', 'reasonable' and 'good' and signalled a level of maturity that was reflected in other responsibilities expected of a person at the age of 18, such as voting and driving a car.

On the other hand, some forum participants thought that the age requirement was 'arbitrary'. For them, people aged 16 years and over are already able to make other decisions about their medical treatment. Specific reference was made to young people with life-threatening illnesses who can refuse life-sustaining treatments.

A small number of submissions considered that a person under the age of 18 should be able to access voluntary assisted dying provided they meet all the other eligibility criteria. It was submitted that, in some cases, older children are entirely capable of making a rational decision to request voluntary assisted dying but that it is more difficult with younger children. It was considered that allowing access to people under the age of 18 years 'would need very careful thought'.

Feedback from the forums and submissions was that if voluntary assisted dying was available to those under the age of 18, additional safeguards would be required to ensure the young person understood the implications of a decision to access voluntary assisted dying.

The majority of the feedback about age considerations came from the forums, with many submissions not providing detail on this issue. Despite some discussion about the existing rights of 'mature minors' to make medical treatment decisions, overall, the feedback was that voluntary assisted dying should be restricted to people aged 18 years and over, although one person said a person should be 21 years and over.

Ordinarily resident in Victoria and an Australia citizen or permanent resident

The Parliamentary Committee recommended that assisted dying be available to people who are ordinarily resident in Victoria and an Australian citizen or permanent resident.

Other jurisdictions, apart from Switzerland, prevent access to voluntary assisted dying for non-residents. In the Netherlands the residency requirement is enforced practically by requiring that voluntary assisted dying is part of the normal therapeutic relationship between patients and their healthcare practitioners.

There was strong support from forum participants for including a residency requirement.

Some forum participants and submissions suggested that 'ordinarily resident' should be defined according to the length of time a person must live in Victoria before being able to access voluntary assisted dying. Although forum participants did not express a view as to what this length of time should be, one submission suggested 'a minimum of one year'. There was also discussion across the forums that given a person would be suffering from a terminal illness it would be highly unlikely that they would be able to move interstate to access the Victorian legislation at the point when they would be eligible.

Cross-border issues between Victoria and New South Wales and Victoria and South Australia were also raised at forums, particularly those held in rural areas. At these forums participants noted that cross-border health service issues are resolved in a practical way through service agreements and memorandums of understanding and that this would need to be addressed as part of the implementation of voluntary assisted dying.

Decision-making capacity

The person has decision-making capacity about their own medical treatment

The Parliamentary Committee recommended that assisted dying be available to people who have decision-making capacity about their own medical treatment. This means that a request for voluntary assisted dying must be made by a person who fully understands: their condition and its consequences; the treatment options available to them; and the nature and consequences of their request, and who is able to retain and use that information to make a decision about voluntary assisted dying.

Internationally, both the North American and European legislative models emphasise that those who wish to access voluntary assisted dying must have the decision-making capacity to do so.

The Panel received substantial feedback from forum participants and submissions about this recommendation in relation to the legislative tests for decision-making capacity, issues around eligibility and access, and the making of referrals in relation to decision-making capacity.

The majority of forum participants agreed that requiring a person to have decision-making capacity about their own medical treatment at each stage in the request process was an important and necessary safeguard. This was specifically supported in a number of submissions from professional bodies.

Legislative tests for decision-making capacity

Feedback supported the use of a capacity test that recognises contemporary understanding of decision-making capacity. Feedback was that a best practice capacity test should recognise that capacity is presumed and that capacity is decision-specific.

Many forum participants commented that decision-making capacity can fluctuate and that a person may temporarily lose capacity and subsequently regain it – for example, in a person with acute delirium. It was thought that the assessment process for voluntary assisted dying should take into account these types of fluctuations.

The capacity assessment approaches set out in the *Medical Treatment Planning and Decisions Act 2016*, the *Mental Health Act 2014* and the *Powers of Attorney Act 2014* were all examples of capacity tests put forward by forum participants.

The test set out in the *Medical Treatment Planning and Decisions Act* received substantial support across the forums and in most of the submissions, including those received from medical, nursing and legal bodies. The test was described as ‘excellent’ and ‘very adequate’ in other submissions. It was also noted that tests for decision-making capacity need to occur in a therapeutic context where health practitioners are skilled in communication and assessment.

“ **The decision-making capacity test as outlined in the Medical Treatment Planning and Decisions Act 2016 is a reasonable starting point; however, it needs to be undertaken in the context of high quality communications with health professionals who are competent in communicating effectively and in having difficult conversations with people who are dealing with an incurable illness.**

Submission 74

Submissions and forum feedback also noted that having one test that applies across a range of medical interventions is simpler for health and legal professionals. One submission noted that introducing new or additional requirements may create confusion and add unnecessary complexity to decision making.

One submission argued that the test set out in the *Medical Treatment Planning and Decisions Act* is not a suitable decision-making capacity test given that it can be disputed that seeking assistance to take one’s own life is medical treatment.

Issues around eligibility and access

Concern was raised during forums and in submissions that the proposed assisted dying framework was too narrow and would deny access to people who may suffer in the future.

It was noted that some diseases cause a decline in a person's capacity early in their trajectory and would mean a person would be ineligible to access voluntary assisted dying under the framework because they did not meet one of the eligibility criteria despite meeting all other criteria. Forum participants thought this would impact most on people with non-cancer illnesses.

The forums and submissions focused on two groups of people to whom this would relate.

People whose illness means they may lose decision-making capacity early

People with conditions such as dementia, for example, can lose their decision-making capacity but live with the condition for many years. Forum participants noted that, for many people in the community, it is the end stage of these conditions that people most fear and want to avoid.

“A number of members expressed the view that eligibility to [voluntary assisted dying] should be broader than the recommendation made by the Parliamentary Committee as it excludes diseases and conditions where an individual loses decision making capacity.

Submission 158

Some disappointment was expressed in forums and submissions that people with these conditions would not be able to make a request for voluntary assisted dying in advance and access it at a time when they had lost decision-making capacity.


People whose illness means they will experience a long period of unbearable suffering

There was also concern about people who retain decision-making capacity but have a condition that causes them to suffer unbearably for a much longer period prior to their anticipated death. Motor neurone disease was the cited condition when this issue was raised.

Forum participants working with progressive neurological disorders, and the associated advocacy groups, were strongly of the view that people with motor neurone disease should not be disadvantaged because of the nature and trajectory of the disease. This view was also expressed in relation to some cerebrovascular (for example, strokes) and other non-cancer conditions.

Referrals in relation to decision-making capacity

There was broad agreement across the forums and in submissions that when decision-making capacity is in doubt, an appropriate referral should be made to a specialist able to provide expert opinion on decision-making capacity.



The majority of feedback suggested that referrals should be made to the appropriate specialists based on the reason that has given rise to the doubt about capacity, not as part of a mandatory capacity assessment requirement. Examples of factors that may interfere with decision-making capacity included cognitive impairment or significant decline, psychiatric illness or existing psychiatric treatment.

Where mental illness is suspected or present, forum participants and submissions generally agreed that referrals should be made to a psychiatrist to assess if the mental illness is impacting on the person's decision-making capacity. Some feedback suggested that a psychiatrist should not be prevented from offering treatments where they are clinically indicated.

Some forum participants and submissions commented that every person who requests voluntary assisted dying should undergo a psychiatric assessment. This position was informed by views that not all medical practitioners accurately identify when a person is suffering from a mental illness, particularly those with limited experience in the early stages of their medical careers. Mandatory referral to a psychiatrist was supported in some submissions, generally on the basis that it represented a good safeguard, at least initially. However, others considered that mandatory referrals would cause unnecessary delay and become burdensome because it would place increased demand on practitioners and resources in the area. Most forum participants considered that a referral to a psychiatrist should only occur when an assessing medical practitioner has concerns that warrant referral to a psychiatrist and that referrals should remain consistent with existing good medical practice and be based on the clinical needs of the person.

Feedback at roundtable discussions indicated that mental health specialists did not want to be seen as 'gatekeepers' to voluntary assisted dying, expressing concern that this would undermine their broader therapeutic role. It was also raised that mandatory referrals could potentially create an access barrier for some people living in rural areas. The roundtable discussions also confirmed confidence in the ability of experienced clinicians to identify issues that require referral to a psychiatrist.

Forum participants and submissions were largely supportive of the requirement for an assessing medical practitioner to refer a person to a psychiatrist where they thought an underlying mental illness may be present and affecting the person's decision-making capacity.

“ Psychiatric referrals for those seeking (and who meet the legally determined criteria) voluntary assisted dying should only be required if clinically necessary. A patient should be referred to a psychiatrist if the patient's treating medical practitioner believes that the patient may be depressed, suffering from another mental illness or may have impaired decision-making capacity. The role of the psychiatric referral would be to determine the patient's decision-making capacity.

Submission 47

It was noted that psychiatrists are not always the most appropriate specialist to deal with all issues relating to assessing capacity, and that referral should depend on the nature of the concern. This view was expressed consistently throughout the consultation process.

Forum participants and submissions noted that geriatricians, psychogeriatricians, neurologists, neuropsychologists, psycho-oncologists, psychologists, general practitioners and palliative care clinicians were all specialists who could make assessments in relation to a person's decision-making capacity. There was strong feedback that the legislation should not limit the types of referrals that can be made by an assessing medical practitioner.

One submission considered that other specialist referrals should not be needed because it would place an unnecessary burden on the person, while another submission commented that it would be rare for any other specialist assessment to be necessary or appropriate.

The condition

The Parliamentary Committee recommended that assisted dying be available to people who have a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner they deem tolerable, and who are at the end of life (final weeks or months of life).

Internationally, the American states of Oregon, Washington, California and Vermont all limit access to voluntary assisted dying to people who have a terminal disease that will result in death within six months. There is no requirement that people be experiencing unbearable suffering that cannot be relieved in a manner they deem tolerable. In some American states the six-month requirement aligns access to voluntary assisted dying with administrative requirements for access to hospice and palliative care benefits in the Medicare, Medicaid and other insurance programs.

Canada's legislation includes requirements that people have a grievous and irremediable condition resulting in an advance state of irreversible decline in capability, where death is reasonably foreseeable and they are experiencing enduring intolerable physical or psychological suffering that cannot be relieved under circumstances they consider acceptable.

The Netherlands requires that the person is experiencing lasting and unbearable suffering where they hold a conviction that there is no other reasonable solution for their situation apart from death. In Belgium, legislation requires that the person is in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated resulting from a serious and incurable disorder caused by illness or accident.

The person is suffering from a ‘serious and incurable’ condition

The Parliamentary Committee recommended that assisted dying be available to people suffering from a ‘serious and incurable’ condition.

There was considerable variation of views about the terms ‘serious’ and ‘incurable’. Many forum participants questioned what this terminology meant, suggesting that further clarity was required. Some thought that the criterion was too restrictive and were concerned about people who are in chronic pain and have ‘had enough’. Some submissions considered the terminology to be appropriate and not requiring further definition.

“ **Serious and incurable condition’ is clear and to the point.**

Submission 65

Some forum participants and submissions preferred that the criterion be linked to the requirement that the condition be terminal and that this should be determined by a medical practitioner who would make an assessment based on the likely trajectory of the person’s condition. Discussions at the forums raised the issue that a serious and incurable condition on its own did not necessarily mean that the condition was ‘terminal’. This was also reflected in some submissions.

“ **As some ‘serious and incurable’ conditions are compatible with a long and meaningful life, a link to an expectation of death within a short period of time as proposed is essential.**

Submission 40

One submission considered that the criterion should be determined by both the person and the medical practitioner, with the person assessing whether the condition is serious and the medical practitioner assessing whether the condition is incurable.

Many submissions, including those from medical organisations, supported a definition of a ‘serious and incurable condition’ as one that is also terminal.

“ **Use of the word terminal as opposed to ‘serious and incurable condition’ provides clarity that the person will indeed die from their disease.**

Submission 111

Submissions from legal bodies considered both ‘serious and incurable’ and ‘terminal’ to be unhelpful phrases. However, they noted that if the phrase ‘serious and incurable’ were properly defined in legislation, as in Canada, they would not hold any concerns about its use.

The definition of ‘serious’

The majority of forum participants and submissions suggested that the word ‘serious’ be interpreted according to the person’s own view rather than the view of medical practitioners. However, a number of participants also commented that if the word ‘serious’ were to be used, the legislation would need to provide guidance in relation to its meaning.

“ **Serious – ‘symptoms are of sufficient severity that a reasonable person would agree that a condition is serious’.**

Submission 16

There was consistent forum feedback that the word ‘advanced’ was a better reflection of the terms used in Australia – and certainly in Victoria. These forum participants considered ‘advanced’ to be better understood by practitioners and more specific than ‘serious’ if it was to relate to the end of life. A number of submissions made reference to terminology such as ‘suffering from an advanced incurable condition’. Some participants thought ‘progressive’ should be included in the criterion to indicate active deterioration of the person’s illness and that the person is not going to recover.

The definition of ‘incurable’

Forum participants and submissions generally considered the word ‘incurable’ did not need to be defined and denoted an illness for which there is no cure.


“ **Incurable – in the opinion of a qualified medical practitioner no new therapy or treatment is likely to be available during the remaining period of the person’s life which would cure the person’s condition.**

Submission 16

Some forum participants questioned whether ‘incurable’ meant all other treatment options had to be exhausted or proved futile before a person would meet this criterion.

Forum participants and submissions largely considered that, in defining ‘incurable’, the treatments that the person deems acceptable should be taken into account, noting that a person has an existing right to refuse or withdraw from medical treatment even if refusal will result in the person’s death. It was noted that people may refuse or withdraw treatment for a variety of reasons, and the most important consideration is that a person has capacity to make this decision.

The view across a number of the forums was that if someone had an advanced or a progressive condition, the treatment would not be focused on cure but more likely on managing the condition to promote quality of life and to manage symptoms to provide as much comfort as possible to the person.



Overall, forum participants considered that the criterion should be left broad. Many noted a risk in being too prescriptive (for example, using a predefined list of conditions), as some people may be deemed to be ineligible inappropriately. A predefined list of ‘incurable conditions’ was not supported at any of the forums. Participants said such a list would become outdated too quickly due to advances in diagnoses and treatments. This was also reflected in some submissions, with one proposing that it would be difficult to define these terms in the legislation in a way that would provide guidance to patients and practitioners. One submission suggested that specific conditions could perhaps be listed in the legislation.

“ [W]e recommend that ‘end of life’ and ‘serious and incurable condition’ be listed in the legislation as criteria for eligibility but that definitions of these phrases and how to determine whether a patient falls within them be dealt with in guidelines.

Submission 118

The person is experiencing ‘enduring and unbearable suffering’ that cannot be relieved in a manner the person deems tolerable

The Parliamentary Committee recommended that assisted dying be available to people experiencing enduring and unbearable suffering that cannot be relieved in a manner they deem tolerable.

There was general agreement among forum participants and in submissions that in order to access voluntary assisted dying, a person must be suffering as a result of their condition. However, there was also considerable discussion at the forums about not letting someone suffer ‘too much’ or unnecessarily in order to meet this criterion. Some participants were concerned that waiting for someone to be in ‘enduring and unbearable suffering’ was cruel and did not reflect the intent of the proposed legislation. Others thought that suffering was a necessary prerequisite to accessing voluntary assisted dying in order to limit access to people the legislation was intended for.

Despite these discussions, there was strong consensus that ‘enduring and unbearable suffering’ be determined according to the person’s own perception, not by anyone else (including medical practitioners). Almost all feedback recognised that the experience of suffering is individual and subjective. A number of submissions considered this to be ‘fundamental to patient-centred care’.

The majority of forum participants expressed strongly that enduring and unbearable suffering should not be limited to pain or physical suffering. They commented that there is a whole range of suffering, as well as pain, that impact on a person’s subjective assessment of what is unbearable, including symptoms such as breathlessness, difficulty swallowing, nausea and fatigue, as well as suffering due to lack of quality of life, loss of independence or loss of autonomy.

Some forum participants and submissions reflected that what is unbearable one day may be bearable on another day and, for this reason, a medical practitioner should be 'checking in' with the person throughout the assessment process, including at each request. It was thought that this practice would allow the medical practitioner to offer assistance and adjust treatment to relieve symptoms and help reduce the person's suffering as much as possible. Many participants commented that a person should still receive the best possible care after the voluntary assisted dying process has begun.

The person is at the end of life (final weeks or months of life)

The Parliamentary Committee recommended that assisted dying be available to people who are at the end of life (final weeks or months of life).

There was a strong view among forum participants and in submissions that this criterion would be difficult to apply. Some forum participants likened it to asking 'How long is a piece of string?' Many participants and submissions commented that accuracy in prognosis can be difficult for a number of conditions.

Use of a timeframe

There was no clear consensus in the feedback from the forums or submissions as to the definition of 'at the end of life (final weeks or months of life)' proposed by the Parliamentary Committee.

Some forum participants and submissions questioned whether it was appropriate to have a timeframe of 'final weeks or months' as the definition for end of life. The timeframe was described as 'arbitrary', 'too restrictive', 'too narrow' and 'not accurate'. Others commented that it was too narrow to capture progressive neurological conditions that cause slow decline. For this reason, it was thought the timeframe needed to be left more flexible to encompass the natural trajectory of these conditions and a person's own circumstances. This view was also put forward in a number of submissions including those from clinical and legal bodies.

“ [T]o impose an arbitrary time limit is not consistent with [the Panel's] first principle that 'The person, and the needs of the person, will be the central consideration in all discussions about voluntary assisted dying'.

Submission 18

Notwithstanding this, there was general agreement that some timeframe was required to give guidance to assessing medical practitioners and ensure consistency.

“ It is necessary to define what is meant by ‘end of life’ for the following reasons:

- To clarify the intent of the legislation as perceptions about when a person is close to ‘the end of life’ can vary significantly.
- To promote consistent interpretation and application of the legislation with reference to an objective criterion. This is important given that the assessment of the requirement that the person is experiencing ‘unbearable suffering that cannot be relieved in a manner the patient deems tolerable’ will be determined on the basis of the patient’s subjective experience.

Submission 74

Timeframes discussed by forum participants and raised in submissions included ‘foreseeable future’ (with no timeline) and six, 12, 18 and 24 months.

‘Foreseeable future’ was discussed on the basis that it may be more clinically relevant and based on the trajectory of a condition and specific to the person, or that it was consistent with the Parliamentary Committee’s belief that ‘the needs of the patient must be squarely at the centre of an effective framework’. There was also some support among forum participants and in submissions for the timeframe to describe death as ‘reasonably foreseeable’.

Several submissions considered that six months would be an appropriate upper end range to use as an objective criterion in specifying ‘end of life’. One submission stated that six months should be used because it would ‘be consistent with the person’s current health status and the likely trajectory of their medically diagnosed incurable disease’.

It was also noted in forums and submissions that a six month timeframe is currently used in American jurisdictions. However, people and organisations commented that this timeframe is connected to the time at which a person becomes eligible to receive hospice care payments and that its implementation would be arbitrary because there is no such limitation in Victoria.

The timeframe of 12 months was often proposed on the basis that it is consistent with existing policy documents. Reference was made to the *National Consensus Statement on essential elements for safe and high quality end of life care*, which defines end-of-life care as care for people “approaching the end of life” when they are likely to die within the next 12 months.² It was also noted that this definition of end-of-life care is consistent with *Victoria’s end of life and palliative care framework*, which will guide end-of-life care service delivery across Victoria for the next decade.³

² Australian Commission on Safety and Quality in Health Care 2015, *National Consensus Statement: Essential elements for safe and high quality end of life care*, Commonwealth of Australia, Canberra, p. 33.

³ Department of Health and Human Services 2016, *Victoria’s end of life and palliative care framework*, State of Victoria, Melbourne.

Some forum participants and submissions considered that a timeframe of 12 months would also better encompass both cancer and non-cancer conditions, in particular progressive neurological conditions such as motor neurone disease, but also degenerative diseases of the nervous system including Parkinson's disease and multiple sclerosis. A number of clinicians commented that they considered the 'surprise question' (Would I be surprised if my patient died in the next 12 months?) when planning for the treatment and care of people at the end of their life.⁴

One submission suggested an upper end range of 18 months, while another considered that 'end of life' should be worded to include years so as to capture lengthy, serious and incurable degenerative diseases such as multiple sclerosis and motor neurone disease. Another suggested 24 months.

Exclusions

The Parliamentary Committee recommended that suffering as a result of mental illness only, does not satisfy the eligibility criteria for assisted dying.

Overall, there was support for this recommendation in forums, roundtable discussions and submissions.

The potential for mental illness to impact on decision-making capacity was discussed at length by forum participants, in some roundtable discussions and noted in submissions. There was almost universal agreement that mental illness alone should not be a reason for accessing voluntary assisted dying. While some forum participants commented that the exclusion was discriminatory, they did not consider it to be wrong because it represented a good safeguard. All submissions from medical bodies indicated strong support for a framework that excludes suffering as a result of mental illness as a basis for accessing voluntary assisted dying. One submission noted that mental illness should be defined as being distinct from cognitive impairment.

It was also acknowledged in forums, roundtable discussions and submissions that depression and demoralisation may be a normal and expected response for many people with a terminal condition. Feedback was that a person with decision-making capacity who meets all the eligibility criteria should not be denied access to voluntary assisted dying because they have a mental illness. This position was supported by mental health groups, who considered that people with mental illness should have the same rights and protections as other members of the community under the legislation and that there should be a balance between providing safeguards and supporting access for people with mental illness if they met all the eligibility criteria.

4 Murray SA, Boyd K 2011, 'Using the "surprise question" can identify people with advanced heart failure and COPD who would benefit from a palliative care approach', *Palliative Medicine* 25(4): 382.

Consistent with mental illness, similar views were also expressed in the forums, roundtable discussions and submissions that the legislative framework should exclude people who are suffering as a result of disability alone. A number of disability advocacy groups and people with disabilities who participated in the forums and roundtable discussions did, however, note that people with disabilities who meet the eligibility criteria should not be excluded from accessing voluntary assisted dying. It was expressed that a person with decision-making capacity who meets all the eligibility criteria should not be denied access to voluntary assisted dying because they have a disability. One submission specifically submitted that people with disabilities should be provided with appropriate support to make decisions and that having a disability should not negate their right to voluntary assisted dying.

Protecting people who may access voluntary assisted dying

Elder abuse and coercion by family was of particular concern to many people and organisations. For some, the requirements of independent assessments by two medical practitioners and a request witnessed by two independent witnesses was sufficient for identifying coercion. It was noted that this was a much more rigorous process for identifying coercion than what generally occurs for major decisions in hospitals. Others expressed concern about subtle forms of coercion and even unintended pressure from family members, which they believed an ordinary medical practitioner would not identify.

“ I do not see a need for additional safeguards. The community – including vulnerable people in general and disabled people in particular – are well protected by the requirements of access and eligibility.

Submission 69

Many process safeguards were also discussed in the forums, roundtables and submissions. These included introducing a time period between the first and final request, and the presence of a witness if the medical practitioner administers the medication. While the need for a rigorous process was universally acknowledged, many argued that this needed to be balanced with recognising that adults with decision-making capacity can make decisions about their own lives. It was thought that the safeguards needed to be embedded in the process and not be additional hoops that people and medical practitioners had to jump through. It was noted that the safeguards should be aimed at ensuring people have sufficient information and are making a voluntary and informed decision to access voluntary assisted dying.

continued...

“ [I]t may be cruel and unnecessary if too many safeguards are created. Excessive safeguards will effectively become hurdles, that a dying patient will have to clear, at a time when they are presumably weak, unwell and already experiencing significant suffering.

I appreciate that safeguards, similar to those in the American laws, are necessary, however, the law needs to be workable and compassionate.

Submission 88

The fundamental safeguard is that the framework for assisted dying recommended by the Parliamentary Committee is voluntary and there is no obligation to proceed; a request may be rescinded at any time. In addition, the eligibility criteria set out by the Parliamentary Committee provide some strong safeguards for people who may be vulnerable to abuse:

- Access is limited to those with decision-making capacity, and is excluded for those whose suffering is solely as a result of mental illness.
- There is a three-request process, initiated by the individual person (no substitute decision-maker is allowed), which is witnessed and not included as part of an advance care plan or advance care directive.
- There is a requirement to properly inform the person of the diagnosis, prognosis and treatment options in relation to the condition(s) they suffer, as well as of palliative care and its benefits.
- There is a requirement to undergo a second independent assessment and referral to a psychiatrist if there is concern about impairment due to mental illness.

Chapter 2: The voluntary assisted dying process

Introduction

The Parliamentary Committee recommended that a request for assisted dying must come from the person themselves and be voluntary and free of coercion. The request must be repeated by the person three times – as an initial verbal request, a formal written request (signed by two independent witnesses) and a final verbal request.

The person making the request must also be properly informed by a primary and secondary doctor:

- 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.

The primary and secondary doctors must also be independently satisfied that the person's request is enduring and that a reasonable amount of time has passed between their initial request and the provision of the lethal drug. In making this judgement each doctor must have regard to the person's particular condition and its likely trajectory.

Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the person's specific condition and must independently judge whether the person's request satisfies the eligibility criteria. Each doctor must also assess the reasonableness of the request to ensure the person 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 person's request is not ambivalent.

Similar provisions apply in other jurisdictions that have introduced voluntary assisted dying. In order to access voluntary assisted dying in those jurisdictions, people must make repeated, voluntary, informed requests that are free of coercion. These requests must be assessed by two medical practitioners, who must be satisfied that all eligibility criteria have been met.

Initiating a request for voluntary assisted dying

The request must be made by the person

The Parliamentary Committee recommended that a request for assisted dying must come from the person themselves. Requests for assisted dying are not permitted in an advance care directive, nor can a substitute decision-maker make a request on behalf of a person, nor should medical practitioners initiate requests for a person.

Forum participants strongly indicated that legislation should support a person's right to autonomy regarding their choice about the timing and manner of their death. There was substantial support among forum participants and in submissions for the key elements proposed by the Parliamentary Committee. Feedback confirmed support for:

- the request being made by the person themselves, with many participants commenting that it would be inappropriate for voluntary assisted dying to be raised by a health practitioner or any other person

- ensuring that a substitute decision-maker of any kind should not be able to make a request for voluntary assisted dying for another person
- the ability of a person to s a request for voluntary assisted dying at any time.

A small number of submissions suggested that it would never be possible to ensure a person's request for voluntary assisted dying was completely voluntary. Others considered that assessment by two medical practitioners and two independent witnesses was sufficient to ensure a request was voluntary.

The request is free of coercion

The Parliamentary Committee recommended that a request for assisted dying must be completely voluntary and free of coercion.

There was discussion across a number of the forums about the impact of coercion on requests for voluntary assisted dying. Forum participants noted that coercion may influence a person's decision to access voluntary assisted dying and that it could take many forms. Examples of factors that could lead to coercion frequently raised by participants in the forums included where a person is made to feel like a burden on their family, or where family members stand to receive an inheritance after a person's death.

Forum participants also expressed divergent views as to whether family members should be involved in the voluntary assisted dying process.

“Some patients feel like a burden. Some family members want their inheritance earlier. These motives for ending life are not necessarily desirable.

Forum participant, 15 February 2017

“I don't think legislation needs to assume that everyone needs to be protected from their families. Just because there is some potential for exploitation doesn't mean voluntary assisted dying should not be available.

Forum participant, 15 February 2017

Some forum participants thought that family involvement should be encouraged where possible. A person who is suffering from an advanced illness or disease and being cared for at home will most likely be cared for by their family (or those who they consider to be their 'family' of choice). This view recognised that it is important to establish a dialogue about voluntary assisted dying early in the process so family members are able to understand that a decision to access voluntary assisted dying is the person's choice. Participants also commented on the importance of involving family members in the process to minimise anger, surprise, bewilderment and additional grief around a person's decision to request voluntary assisted dying.

Many health practitioners noted that most people who are dying are being cared for by loving and supportive families who, in turn, need support to be able to provide such care. It was considered that families generally provide both emotional and practical support for a person to be able to remain at home for as long as they wish. Health practitioners noted that if a person wants to die at home, having access to family and carers is a key determinant in achieving this goal.

Feedback also reflected that the potential for coercion could be linked to the role of family members in a person's life. As a result, there was a strong view that the voluntary assisted dying process should ensure an assessment of whether family members are placing pressure on a person to make a request for voluntary assisted dying.

“ **The identification of coercion seems to lie in a long consultation with an appropriately credentialed physician.**

Forum participant, 15 February 2017

On the other hand, some participants noted that the opposite may also be the case. That is, one or more family members may not support a person's decision to request voluntary assisted dying and place pressure on them to withdraw from the process. Some health practitioners noted that coercion often involves pressuring a person to accept more treatment rather than less, with family members wanting everything done for their loved one, even if the treatment is futile and not what the person themselves wants.

Feedback from the forums and the submissions also noted that the safeguards inherent in the proposed eligibility criteria – for example, that the person is dying from a serious and incurable disease – and the request process set out by the Parliamentary Committee would help to limit coercion. This included strong support for ensuring that people requesting voluntary assisted dying are 'properly informed' of all treatment and care options.

Some submissions raised concerns about elder abuse. Views about how accurately elder abuse could be identified in an assessment for voluntary assisted dying varied according to whether a person or organisation was opposed to or supported voluntary assisted dying. Some of those who opposed voluntary assisted dying thought that the risk of coercion and elder abuse could never be overcome, while many of those who supported voluntary assisted dying believed the proposed assessment process would identify cases of elder abuse.

Discussions in the forums also reflected that elder abuse occurs in a variety of circumstances, not only when older people are at the end of their life, and that in many circumstances, the person subjected to elder abuse would not meet the eligibility criteria. One participant suggested that a request by a person in these circumstances may actually 'flush out' elder abuse.

Many forum participants reflected that medical practitioners are already aware of the possibility of coercion and currently deal with it in practice, particularly in relation to family violence and elder abuse. Feedback was that medical practitioners have adopted approaches that are designed to 'hear a person's concerns and separate them from any coercive influences'.

Regardless of whether the feedback was concerned about family involvement or wanted it encouraged, there was strong support for promoting open communication between the person, their family and the medical practitioner about end of life generally as well as voluntary assisted dying. It was noted that families often find it difficult to talk about death and dying and this may lead to secrecy about voluntary assisted dying between those involved.

Good communication was described as essential to identify any concerns about coercion and abuse, and also encourage positive family involvement and understanding. Forum participants generally supported the idea of guidelines to help practitioners identify coercion and abuse and support family involvement.

Feedback also suggested that coercion may come from health practitioners. Even if unintended, a health practitioner's suggestion about a person's quality of life, for example, may encourage them to believe voluntary assisted dying is appropriate for them. Many stakeholders recognised that the views of a health practitioner may influence their patients. For this reason, there was strong support for the position that a health practitioner should be prohibited from raising the possibility of voluntary assisted dying and that a request should only ever come from the person themselves.

Form of request

The Parliamentary Committee recommended that a request for assisted dying must be repeated three times - as an initial verbal request, a formal written request and a final verbal request. This is consistent with the process adopted in Canada and jurisdictions in the United States that permit voluntary assisted dying.

There was strong support among forum participants and in submissions for a staged voluntary assisted dying request process. The majority of participants supported the three request process proposed by the Parliamentary Committee. This was on the basis that a staged process provides a number of opportunities for medical practitioners to assess and ensure that a person's request is voluntary, enduring and informed. It was also recognised that this would allow people time to consider all the information they are given.

There was a general view that all formal requests for voluntary assisted dying should be recorded on one standard prescribed form to ensure clear and consistent documentation. Some forum participants also thought that the form could set out the steps to be completed, along with any relevant timeframes, while other participants emphasised that a form containing a series of tick boxes would not be desirable. Some participants considered that all conversations about voluntary assisted dying should be documented in a person's medical record.

“ We didn't want a written request to be reduced to a form or tick boxes, but we also felt it was overly burdensome to force someone at the end of life to write a three page essay.

Forum participant, 1 March 2017

A number of forum participants described being unclear about what would constitute a formal request for voluntary assisted dying, describing conversations where people sought information, direction or support for aspects of their current clinical situation. These participants thought that further clarity regarding how to distinguish between a general request for information and a formal request for voluntary assisted dying was required. However, a view was put that a statement from a medical practitioner such as 'I am now taking this as your formal request' would be sufficient to make this distinction.

Many forum participants expressed that the first time a person raises voluntary assisted dying with a medical practitioner should not result in a formal request for voluntary assisted dying being made. Rather, participants considered that preliminary conversations should occur often between the person and their medical practitioner before a formal request is made.

It was thought that distinguishing between informal discussion and a formal request represented an important safeguard because it would address the issue of people requesting voluntary assisted dying when they are feeling depressed or vulnerable. Issues like these could then be dealt with outside the formal voluntary assisted dying process and, as a result, a person would not feel pressured to continue with a request.

Assessing a request for voluntary assisted dying

Assessment to be undertaken by two medical practitioners

The Parliamentary Committee recommended that both the primary and independent secondary doctor must independently judge whether the person's request satisfies all of the eligibility criteria. This is consistent with procedures adopted in both North American and European jurisdictions where voluntary assisted dying is permitted.

Overall, forum participants supported the use of two independent assessments. Many participants described this recommendation as a good safeguard. Some participants commented that it would be difficult to find two medical practitioners to assess a person's request for voluntary assisted dying in rural areas. Feedback suggested that a register of medical practitioners who are able to assess requests for voluntary assisted dying be developed, or that other ways of dealing with accessibility issues for rural areas be considered such as visiting specialist teams or the use of telehealth to connect people in rural areas with appropriate specialists.

“18,000 square kilometres with only three GPs, how do you get two independent expert assessments?”

Forum participant, 10 March 2017

Submissions generally supported the recommendation that two medical practitioners independently assess a person's request for voluntary assisted dying, although some noted that this may create access issues.

Some submissions suggested that voluntary assisted dying was not consistent with the goals and values of medical practice and that using medical practitioners and medical terminology is misleading. Some denominational submissions suggested it should not be called 'voluntary assisted dying' because it would obscure the role of medical practitioners in aiding suicide. An alternative view was expressed that the language of suicide should not be conflated with voluntary assisted dying because of the person's proximity to death due to illness.

The role of the primary doctor – the coordinating medical practitioner

Many forum participants and submissions considered it likely that requests for voluntary assisted dying would be made to a medical practitioner with whom the person had an existing therapeutic relationship. Participants and submissions emphasised the importance of this relationship and thought that legislation should facilitate and encourage existing doctor–patient relationships as much as possible. Submissions also noted the importance of an existing clinical relationship in undertaking an accurate assessment. As a result, it was thought that one of the assessing medical practitioners should take on a coordinating role because they would be familiar with, and have special knowledge about, the person as a result of a pre-existing relationship. It was noted by some participants that a person would not always have a pre-existing relationship with a medical practitioner, including if the person's medical practitioner conscientiously objected to participating in voluntary assisted dying.

“ It is important to have someone who knows the patient, but also it's important to have a specialist who understands the illness.

Forum participant, 1 March 2017

The role of the secondary doctor – the consulting medical practitioner

Many forum participants and submissions also considered that a pre-existing therapeutic relationship was not essential for both assessing medical practitioners. Given that the task of the second assessing medical practitioner is to provide an independent assessment against all of the eligibility criteria and repeat the assessment process, participants considered that it would be more important for the second assessing medical practitioner to be able to undertake a thorough assessment rather than necessarily have a relationship with the person. There was a general view that at least one of the medical practitioners undertaking the assessment should be a specialist in a field relevant to the person's condition.

The person must be properly informed

As noted in the introduction to this chapter, the Parliamentary Committee recommended that a person making a request for assisted dying must be properly informed by the primary and secondary doctors:

- 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.

The requirement that people who request access to voluntary assisted dying are properly informed is consistent with the criteria applied in North American and European jurisdictions.

Overall, forum participants and submissions were supportive of the factors identified by the Parliamentary Committee on which a person requesting voluntary assisted dying should be properly informed.

“Older people want clear, direct information about their state of health, treatment options and likely consequences – particularly the impact on quality of life.

Submission 158

It was recognised that health practitioners other than medical practitioners are likely to be involved in conversations about end-of-life care and voluntary assisted dying in particular.

Some forum participants and submissions commented that a medical practitioner already has a duty to properly inform a person in relation to other medical treatments and that voluntary assisted dying is no different. It was considered unnecessary to include an additional requirement in the legislation that a person be properly informed because the suggested factors are already required for proper informed consent.

Some submissions recommended that legislation mandate information that must be given to a person requesting voluntary assisted dying. These submissions varied significantly in the level of detail that should be mandated. Some suggested only general themes needed to be mandated, and medical practitioners could use their professional judgement to identify what each individual person needs to make decisions. Some submissions suggested the legislation should set out only general requirements and that the details should be provided in guidelines that supported the legislation. Others suggested that more detailed information must be provided to each person.

A number of forum participants acknowledged that, depending on their expertise, not all medical practitioners would be comfortable or skilled at providing all information required to properly inform a person about voluntary assisted dying and that in these instances a referral to an appropriate medical practitioner should be made. This is discussed further under the heading 'Appropriate referrals' below.

Some forum participants commented that having two medical practitioners independently assessing requests for voluntary assisted dying would ensure a person is properly informed. Others also considered that training for medical practitioners would assist in ensuring a person is properly informed. Participants often commented that engaging and informing a person about voluntary assisted dying cannot occur during one standard consultation and that this could only be achieved over the course of a few consultations. Normally, it would be expected that a request for voluntary assisted dying would come during the course of treatment for an illness and that one would expect that the person is being fully informed of their treatment options right from the start – that is, from the time the diagnosis was established. It was also noted that people often actively seek information about their illness from a range of sources.

Key issues identified in the consultation process to ensure quality assessments

The Parliamentary Committee did not recommend that the primary or secondary doctor have any additional qualifications, training or expertise. Internationally, while jurisdictions generally require assessment by medical practitioners, they vary in the extent to which practitioners are required to have additional expertise.


Qualifications

There was a strong view among forum participants that the two medical practitioners assessing requests for voluntary assisted dying should have particular qualifications and experience. Participants expressed views that both practitioners should have fellowship training or a minimum of five years' experience. They considered junior medical practitioners in the early stages of their career should not be involved in assessing requests for voluntary assisted dying. Some participants also thought that practitioners should be credentialed to assess requests.

The response to a requirement that medical practitioners have particular qualifications was mixed in submissions. Colleges and other professional organisations suggested a degree of experience and particular skills were necessary. Other submissions recognised that requiring medical practitioners to have specific qualifications may create access issues.

“**[M]edical practitioners choosing to be involved in assisted dying should have a minimum of 5 years post-fellowship level experience (or equivalent) in Australia.**

Submission 47



“ **Medical practitioners should only practise within their field of expertise, and we think this professional obligation is sufficient to ensure their ability to provide the required information to the person.**

Submission 104

Training

While there was a view that undergraduate medical training needs to include general education about voluntary assisted dying, there was strong consensus among forum participants and in submissions that there needed to be some form of additional training for medical practitioners who assess requests for voluntary assisted dying. Views varied in relation to what practitioners should be trained in and the form of training that would be appropriate. Suggestions put forward included that medical practitioners should be trained in:

- the voluntary assisted dying process and any requirements set out in legislation
- communication concerning dying and end-of-life care issues (including cultural considerations)
- working with and supporting the person and their family (including conflict management and identifying coercion)
- assessing decision-making capacity
- the lethal medication, dosages and complications.

Some forum participants commented that practitioners were already trained in some of these areas and that additional training may not be required. Others considered that the second medical practitioner should be specifically trained to carry out the voluntary assisted dying assessment.

Submissions varied on the question of whether additional training should be mandatory and, if so, what level of training should be required. Some submissions suggested that mandatory training would create access issues. Other submissions suggested mandatory training on new legal requirements was necessary, while some argued that more fulsome training about end-of-life care was required. It was noted in many submissions that medical practitioners already frequently provide end-of-life care on a daily basis and that the additional training required should be focused on voluntary assisted dying and the assessment process.

“ **Training should be mandated. People don't know what they don't know.**

Forum participant, 10 March 2017

Forum participants also considered that any training would need to be accessible, particularly to those living in rural areas. The majority of participants considered that training should involve a short course. However, there were divergent views as to whether this training should be conducted face to face or through an online training module. Some participants thought additional training should be government-funded.

It was also suggested that other health practitioners would require training in voluntary assisted dying because it will continue to be raised by people during conversations about end of life.

“ **Clinicians working in this space need to be credentialed. They need to have a clear understanding of what is in scope and what is out of scope.**


Forum participant, 3 February 2017

Appropriate referrals

Forum participants and submissions recognised that it may be necessary for a medical practitioner assessing a request for voluntary assisted dying to refer to a broad range of disciplines and that this would depend on the particular concern held by the referring practitioner.

As discussed in Chapter 1, referrals to appropriate specialists to provide expert advice and opinion about decision-making capacity is necessary as part of the assessment process. It was noted that this is already part of good medical practice. Feedback from the forums, roundtable discussions and submissions highlighted the importance of multidisciplinary care. While psychiatrists, neuro-psychiatrists, neuro-psychologists, psycho-oncologists, geriatricians, consultant clinicians, pain management specialists and palliative care clinicians were all identified as specialists who may receive a referral from an assessing medical practitioner there was also feedback that referrals should not be limited to medical practitioners, and should include other health practitioners with appropriate expertise.

Many forum participants commented that it was unlikely that a single medical practitioner would possess all the skills necessary to properly assess a request for voluntary assisted dying. Some were concerned about the potential for mental illness, or social factors such as stress and financial difficulties, to influence a person's decision to seek access to voluntary assisted dying. As a result, many of these participants considered that a multidisciplinary approach should be adopted in relation to assessing requests for voluntary assisted dying and that practice guidelines should outline how to work in a multidisciplinary setting. It was noted that a multidisciplinary approach would assist in ensuring that important information about the person is not lost in the assessment of their request for voluntary assisted dying.



The likelihood that many people who want to access voluntary assisted dying would be receiving palliative care was recognised. There was universal recognition in submissions that everyone must be offered access to high-quality palliative care. A number of submissions from palliative care services noted that while they may not necessarily be involved in the voluntary assisted dying process, their care of an individual requesting voluntary assisted dying would not be affected. There were divergent views in the forums and submissions as to whether a mandatory referral to a palliative care clinician should be required. Those in favour of this approach thought that a mandatory referral would ensure a person receives the appropriate information about the benefits of palliative care to make an informed decision, and this would ensure any misunderstandings about palliative care are dispelled. However, similar to the views of mental health specialists, others, particularly those working in palliative care, expressed concern that mandatory referrals would result in palliative care being seen as the ‘gatekeeper’ to voluntary assisted dying and that its services would be equated with voluntary assisted dying when this not the case.

“ **There is currently a high level of misunderstanding and misrepresentation around the positive health outcomes achieved by palliative medicine.**

Submission 150

“ **Sometimes people think that assisted dying is a good choice because they don’t know what other choices are available to them.**

Forum participant, 15 February 2017

Despite this, many forum participants and some submissions commented that palliative care clinicians possess a particular set of knowledge and skills that are relevant to voluntary assisted dying (such as providing information and clinical expertise in symptom management, treatment options and end-of-life issues) that an assessing medical practitioner may not have. As a result, it was thought that palliative care should be involved in the voluntary assisted dying process when necessary.

“ **Voluntary assisted dying should not be the end point of palliative care.**

Forum participant, 1 March 2017

“ [Our organisation] is gravely concerned that there is no requirement that part of any such assessment be meaningful and substantive contact with a palliative care provider in order to ensure that a fuller knowledge (and thus freer decision) can be provided to those requesting physician assisted suicide or euthanasia.

Submission 173

Responding to diversity

Many forum participants and submissions commented on the importance of having appropriate resources (such as interpreters and brochures in community languages) that could be used to properly inform people about voluntary assisted dying. People from culturally and linguistically diverse communities, people with communication or cognitive impairments, people with disabilities and the Deaf community were all identified as requiring additional resources. It was also noted that a person who does not speak English, or requires other types of communication assistance, should be able to seek assistance from an accredited interpreter, including an accredited Auslan interpreter, when accessing voluntary assisted dying. There was a strong view that under no circumstances should a family member act as an interpreter.

“ Good translating practices includes both information in-language and in English, subject expert assessment of the English text; culturally appropriate information; checking translations with community groups and native speakers.

Submission 55

Some forum participants and submissions suggested there was scope for supported decision making in the voluntary assisted dying process, and feedback highlighted that support with preparing a request may be necessary for people with communication impairments. It was noted that this assistance should be provided by a qualified and independent communication expert.

Confirming a request for voluntary assisted dying

The person's request is enduring

The Parliamentary Committee recommended that the primary and secondary doctors be independently satisfied that a person's request for assisted dying is enduring and that a reasonable amount of time has passed between their initial request and the provision of a lethal drug.

In American jurisdictions, there is a requirement that at least 15 days must pass between the first request and final request, or between the first request and prescription. In Canada 10 days must pass between signing the request and the provision of voluntary assisted dying. European jurisdictions do not specify time periods.

There was general support among forum participants and in submissions for a timeframe for the requests to be included in the legislation, and a range of timeframes were proposed. This support stemmed from the idea that a prescribed timeframe would provide guidance to medical practitioners assessing whether a request for voluntary assisted dying is enduring.

“ We believe that the critical issue is that the request is an enduring one; the timeframe and reconfirmation are merely ways in which to ensure this is the case.

Submission 104

Forum participants largely agreed that the request process should be greater than one day in order to ensure a person's request is enduring. Some participants considered that a request period of three days, with 24 hours between each request, would satisfy this requirement. However, these participants also acknowledged that it would be extremely difficult in practice to complete the request process within this timeframe, particularly in rural areas.

“ You need to make sure you have a process that may take some time and is not instant. There should be a period of conversation time before a formal request is made.

Forum participant, 3 February 2017

Other forum participants and some submissions thought the request period should not be shorter than seven days. Some suggested a timeframe of 10 days as being 'appropriate', while a number of participants and submissions considered a longer timeframe of 14–15 days to be 'satisfactory', 'reasonable' or 'about right' despite acknowledging that any timeframe is arbitrary. Those in favour of a longer request timeframe generally believed that the timeframe allowed time for information gathering, exploration and reflection and was likely to ensure a person's request was not impulsive.

“ **Two weeks is entirely arbitrary, but it does feel about right.**

Forum participant, 2 February 2017

Some considered a timeframe of 14 days and beyond to be too long for a person at the end of life. They believed a person would most likely die before the request timeframe had passed.

Forum participants and submissions also commented that imposing a longer request timeframe was cruel because it would require a person to experience enduring and unbearable suffering for longer than is necessary. It was also noted that a longer request timeframe increased the risk of a person losing capacity, resulting in them being unable to complete the voluntary assisted dying process. Many considered that there should be the ability to prescribe the lethal medication within a shorter period where the trajectory of the disease made this necessary.

“ **For a person who is terminally ill and experiencing enduring and unbearable suffering, even 24 hours is a very long time to wait to end that suffering.**

Submission 166

Some forum participants and submissions, consistent with the approach taken by the Parliamentary Committee, considered that no timeframe should be incorporated into the legislation. It was generally thought that whether a reasonable amount of time had passed to demonstrate that a person's request was enduring should be based on the trajectory of the person's disease and left to clinical judgement rather than legislative prescription.

“ **Building in a waiting period can be seen as artificial and prolonging intolerable suffering for the sake of process.**


Submission 128

“ **To be eligible you must be suffering. How much longer should the person be required to suffer for?**

Forum participant, 2 February 2017

Confirming that the eligibility criteria are met

The Parliamentary Committee recommended that the primary and secondary doctors must also assess the reasonableness of a person's request for assisted dying to ensure the person truly understands and appreciates the nature and consequences of the decision to request assisted dying and the treatment options available, including alternatives to assisted dying, as well as the alternatives to assisted dying, and that the person's request is not ambivalent.



While some forum participants and submissions commented that medical practitioners should determine the reasonableness of a person's request to access voluntary assisted dying, this did not resonate with the majority of participants or submissions. Instead, it was generally the view that a medical practitioner should be required to reconfirm that all eligibility criteria are met (for example, that the person was fully informed) before proceeding to prescribe the lethal medication, rather than being the arbiter of 'reasonableness'. Many questioned the basis upon which a medical practitioner could assess 'reasonableness', as there is no objective criteria for this.

Seeking another opinion

There was general support among forum participants for a person to seek other opinions if there was an unfavourable assessment in relation to a request for voluntary assisted dying. Some participants also considered there should be a limit to the number of opinions a person should be able to obtain. Other participants commented that a person could choose to see another medical practitioner for an assessment, but two independent medical practitioners would still need to assess that person's request, and this would reduce the risk of 'doctor shopping'. It was also noted that an oversight body that was reviewing cases would identify patterns of 'doctor shopping', particularly if one or two medical practitioners were consistently sought to provide opinions.

“ **If you are dying you are not going to be running around to doctors.**

Forum participant, 1 March 2017

“ **If two doctors have different opinions then there should be a third assessment, but if both agree then there is no need for reassessment.**

Forum participant, 1 March 2017

Forum participants questioned what recourse a person would have if they wished to appeal decisions. Suggestions were made that a tribunal (such as the Victorian Civil and Administrative Tribunal or the Mental Health Tribunal) may be able to hear and determine these disputes.

Voluntary assisted dying panels

Forum participants discussed the possibility of an expert panel undertaking one of the assessments. These discussions occurred in different contexts and were suggested as the solution to a range of problems.

Some participants suggested that a panel would help overcome access issues because it would be clear who would conduct assessments for voluntary assisted dying. This was raised in the rural forums where access to medical practitioners may be limited. One medical practitioner at a rural forum pointed out that he was the only medical practitioner for the town and was not clear how the second assessment would happen

if he agreed to be the first assessing medical practitioner. He was concerned about the stigma of being the 'doctor in town who killed people'. Other participants noted that having to wait for a panel to be available may only create further access issues.

Most people did not envisage a panel providing follow-up care or prescribing the medication. Participants thought that a panel may just add another administrative step in the assessment process and delay the person getting access to the care and support they needed.

Some participants suggested that panels could ensure that appropriate experts would always be available to conduct assessments and that this would enable practitioners to build expertise. Other participants recognised that this may be helpful but suggested that no medical practitioner would want to be known as a 'death doctor' and that it would be difficult to recruit members to such a panel.

The majority of forum participants strongly argued that an administrative process would undermine therapeutic relationships and would not necessarily result in a more accurate assessment. Many participants raised practical concerns about how the panel would conduct assessments and over what time period, noting that a medical practitioner who was already treating a person would have a far greater understanding of their condition.

“ **Panels would sacrifice the doctor–patient relationship and hand the power over to an anonymous panel.**

Forum participant, 1 March 2017


Many forum participants also raised concerns about how the requirement of approval by a panel would affect people requesting voluntary assisted dying. It was noted that this would create a further administrative burden, and it would be extremely stressful for a person in intolerable suffering to be required to appear before a panel. It was also suggested that appearing before a panel to have their eligibility determined would be disempowering for people requesting voluntary assisted dying.

Confirming a request for voluntary assisted dying

The Parliamentary Committee recommended that the formal written request for assisted dying must be signed by two independent witnesses.

Internationally, jurisdictions vary in the extent to which legislation specifies the form of written requests. North American legislation has the most detailed requirements. Generally, requests require two witnesses, at least one of whom cannot be a family member or beneficiary of the estate of the person making the request, nor is that person permitted to be involved in the care or treatment of the person making the request.

Many forum participants and submissions commented that not all people who request voluntary assisted dying will be able to sign formal documentation, and appropriate alternatives will need to be available.



There was general agreement among forum participants and in submissions that requiring two independent witnesses to sign a formal request for voluntary assisted dying was an important safeguard. Some said that what constituted ‘independent’ would need to be defined in legislation. There were divergent views on who could be an independent witness. Some commented that a family member should not be an independent witness and thought that a treating medical practitioner could witness a formal request. Others were of the view that a treating medical practitioner could be present while the formal request was witnessed but would not be an ‘independent’ witness. A view was put at forums that a solicitor may be involved in witnessing formal requests for voluntary assisted dying. However, participants raised concerns about imposing onerous witnessing requirements on people, particularly those who are socially isolated and at the end of their life.

Concerns about conflicts of interest were raised in a number of submissions. Some suggested that anyone who would benefit materially from the death of a person should be excluded from witnessing requests for voluntary assisted dying.

Completing the voluntary assisted dying process

The Parliamentary Committee recommended that assisted dying should in the vast majority of cases involve a doctor prescribing a lethal drug which the person may then take without further assistance. It recommended that where people are physically unable to take a lethal drug themselves a doctor should be able to assist a person to die by administering the drug.

Internationally, where voluntary assisted dying has been introduced, jurisdictions in the United States permit medical practitioners to prescribe a lethal dose, but individuals must administer it themselves. In Canada medical practitioners and nurse practitioners may both prescribe and administer the lethal dose. All European jurisdictions allow prescription and self-administration. Some also permit administration by a medical practitioner.

Prescription of the lethal medication

The majority of forum participants considered that the lethal medication should be prescribed by a medical practitioner who has conducted an assessment of the person’s request for voluntary assisted dying. This view was put on the basis that if a medical practitioner agrees to assess a person’s request, they should also be prepared to see the entire process through to prescription and, some also suggested, the certification of death. Participants said this was consistent with encouraging existing therapeutic relationships, would reduce the likelihood of coercion and address concerns about ‘doctor shopping’ because the practitioner would have a higher degree of knowledge about the person. Some participants also considered that the prescribing medical practitioner should assume responsibility for maintaining the therapeutic relationship after the prescription of the lethal medication.

Forum participants commented that prescription of the medication would most likely be confined to particular medical practitioners. These participants considered that a medical practitioner would need to obtain approval in order to prescribe the lethal medication. Some participants, including nurses, discussed whether nurse practitioners could potentially prescribe the lethal medication, which would require revision of their scope of practice.

Dispensing of the lethal medication

Forum participants commented that, as with other medications, dispensing of the lethal medication would be done by a pharmacist. Many participants considered that pharmacists would have an important role to play, particularly in terms of discussions around the safe storage of the medication. A view was put by some participants that the dispensing of lethal medication is different to other medications because of the lethal purpose or intention of the medication and, for this reason, some participants suggested that a central dispensing authority or a hospital pharmacy should dispense.

Some forum participants questioned what would occur if the medication from a filled prescription was misplaced or accidentally destroyed. They wondered if the person would need to complete the assessment process again or if they would obtain a repeat prescription.

Roundtable discussions with pharmacists emphasised that guidelines and protocols would need to be developed around the dispensing of the lethal medication. The important role of pharmacists in providing people with information about safe storage of medications was also noted.

Storing the lethal medication

Storage of a lethal dose of medication in people's homes was a significant concern for many forum participants and was frequently raised in submissions. While most of those concerned acknowledged that people already store many potentially lethal substances and medications in their homes seemingly without incident, many viewed this as different because the lethal medication was designed to cause death. It was recognised that adults could be trusted to be responsible for safely storing the medication and that interference may pressure the person to take the medication. Others thought that stronger protections were necessary, and requirements such as keeping the medication in a safe were suggested.

Some forum participants considered that pharmacists could store the prescribed lethal medication until a person was ready to self-administer. These participants generally said this would ensure safe storage or further guard against coercion. Others commented that it would be very difficult for a person who was at the end of their life to attend a pharmacy to collect the lethal medication. A number of participants considered that, like with other medications, an authorised agent should be able to collect the lethal medication on their behalf.

Administering the lethal medication

There was some discussion in the forums about the form of the lethal medication and the method of administration. Forum participants questioned whether the medication would be a tablet or liquid to be swallowed, a vial for injection, or if it could be administered in any one of these forms. A few participants commented that some methods of administration would be better than others. A number of participants and submissions expressed interest and concern as to the constitution of the lethal dose of medication, noting there is limited research to guide best practice use.

Self-administration

There was recognition by forum participants and in some submissions that the recommendations made by the Parliamentary Committee in relation to assisted dying largely focus on self-administration of the lethal medication. It was noted that self-administration acted as a strong safeguard in ensuring that a person's decision to access voluntary assisted dying is voluntary in nature.

Some forum participants were concerned about situations where a person self-administers the lethal medication in private and there are complications (for example, regurgitation of the medication or failure to swallow or absorb the medication) or the person is not found for some time. For these reasons, some considered it ideal for another person to be present at the time a person self-administers. Some participants considered that this person should be a medical or health practitioner and that this should be encouraged in conversations with the person. Others did not consider it necessary for the person to be a medical or health practitioner but that there be encouragement to have someone else with them.

Administration by a medical practitioner

“ To not have the option for assistance would discriminate against disabled people.

Forum participant, 17 February 2017

Forum participants generally thought there would be few instances where a person would be unable to administer the lethal medication themselves and that it would be 'unfair' or 'discriminatory' to exclude these people from accessing voluntary assisted dying. Some participants commented that physician-assisted administration should only occur when no other option for self-administration was available and the person continues to have capacity to request this. Reference was sometimes made to the use of specially designed devices that would enable a person to self-administer.

As with prescriptions, forum participants generally agreed that one of the assessing medical practitioners should be responsible for administering the lethal dose of medication in the rare cases where this is necessary because of the person's particular condition(s). Some participants and medical groups commented that a practitioner may be prepared to prescribe the lethal dose of medication to a person but be less comfortable administering it. This is discussed later in this chapter under the heading 'Conscientious objection'.

Forum participants and submissions commented on the need to protect medical practitioners who administer the lethal dose of medication, although feedback was mixed on the need for additional safeguards. Some submissions suggested that the three-request process was sufficient. There was recognition that requiring a person to have capacity represented a strong safeguard in protecting both the person and the medical practitioner. Some forum participants said that a final checklist should be completed before the administration, similar to what occurs prior to surgical procedures. It was also suggested that at least two medical practitioners should be present during physician-assisted administration so that there can be independent verification of the process and the person's state of mind and so that one medical practitioner would not have to bear the responsibility for the administration of the medication alone. Some participants and submissions expressed the view that a second person should be present as an independent check to protect both the medical practitioner and the person and to attest to the fact that the administration remained the voluntary decision of the person.

Administration by people other than medical practitioners

Some forum participants pointed out that medical practitioners rarely administer medication and that this role is generally undertaken by nurses. Some participants questioned why a medical practitioner had to administer the medication, and it was suggested that administration could perhaps be done by a family member with a medical practitioner present. Others expressed discomfort with this largely due to the risk of coercion and the risk of complicated bereavement issues after the death. These participants reasoned that administration of the medication should occur at arm's length from family members and be done by people who are trained and skilled in administering medication. One submission put the view that medical practitioners should never administer lethal medication, suggesting this could be done by a family member.

“ If a person is unable to administer the medication themselves, then they should be able to nominate someone else (e.g. next of kin or Medical Power of Attorney) to administer the medication. It is important that the nominated person is not forced to act against their conscience, and they should have the right to reject or accept the request to administer the lethal dose of medication.

Submission 47

Location

Forum participants, roundtable discussions and submissions reflected that people accessing voluntary assisted dying could be in a range of locations. Some commented that while many people would perhaps prefer to take the lethal medication in their own home, it is likely that many people at the end of life will be in a care setting, whether it be a hospital, hospice/palliative care unit or nursing home. Concern was expressed about both the lack of skill as well as lack of access to consistent medical practitioners and other professional support in nursing home settings.

Some forum participants and submissions considered there should be a facility where people can go to take the lethal medication or have it administered. Others were of the view that healthcare organisations would develop their own policies and procedures in relation to voluntary assisted dying, including where the medication is administered.

“ Will the person feel pressure to proceed if they organise a date and time to be administered voluntary assisted dying?

Forum participant, 1 March 2017

Retrieval of the medication (when not administered)

Many forum participants commented that once medication is dispensed to a person it becomes the property of that person. Despite this, there was a strong view among participants that it was important to retrieve unused medication. A number of participants expressed concern about the unused lethal medication being out in the community and were particularly concerned about surviving partners taking the medication, or the medication being inadvertently consumed by others. A number of participants did, however, acknowledge that there are a range of medications already out in the community that have the potential to be lethal when consumed. Many considered it reasonable for a person to be advised by their medical practitioner or a pharmacist that they should provide instructions to a trusted person to ensure the safe storage and return of the medication if it is not used. This is discussed further under the heading 'Retrieving unused medication' in Chapter 3.

Conscientious objection

The Parliamentary Committee recommended that no doctor, other health practitioner or health service can be forced to participate in assisted dying.

The provision for conscientious objection is generally incorporated into legislation for voluntary assisted dying in other jurisdictions. Victorian legislation provides for conscientious objection in certain circumstances such as the termination of pregnancy. There are existing legal and professional standards for managing conscientious objection. These include obligations not to interfere with or impede a person's access to treatment and services that are lawfully available to them.

Who

The majority of forum participants and submissions agreed with the Parliamentary Committee's recommendation that no doctor, health practitioner or health service be forced to participate in assisted dying. It was noted that a medical practitioner may be comfortable prescribing the medication to a person but conscientiously object to administering it. Others also noted that pharmacists may conscientiously object to dispensing the medication. Some participants and submissions suggested that the phrase 'conscientious objection' should not be used and instead a health practitioner could 'opt in', 'opt out' or 'choose not to participate' in voluntary assisted dying.

“ If a medical professional, or their employer, does not support the proposed assisted suicide regime, it would be a grave moral evil to require them, or their employing institution, to have any active participation in the assisted suicide procedures.

Submission 163

“ In a small rural town, a doctor may object to signing off on it due to social stigma.

Forum participant, 1 March 2017

Referral requirements

Forum participants and submissions generally considered that where a medical practitioner, health practitioner or health service conscientiously objects they should do so early in the process. Divergent views existed as to whether a medical practitioner should be required to refer a person to another medical practitioner when they conscientiously object. Some participants and submissions thought a medical practitioner who conscientiously objects should facilitate access for their patient through a referral consistent with requirements set out in the *Abortion Law Reform Act 2008*. However, others considered that a medical practitioner should not be required to refer but should not impede a person's decision to access voluntary assisted dying. Some participants and submissions suggested establishing a service (potentially based within the support organisation suggested by the Parliamentary Committee – End of Life Care Victoria) that people could contact for assistance when a conscientious objection is made. Participants generally thought that when a health service conscientiously objects, arrangements should be made to ensure that a person can still access voluntary assisted dying.

“ If the doctor is not willing to follow it through, they should conscientiously object at the beginning of the process.

Forum participant, 1 March 2017

“ If I agree to set a patient on a course, then I should have to follow through.

Forum participant, 1 March 2017

Access

Concern was expressed in forums and in submissions about the impact of conscientious objections by medical practitioners and other health practitioners on voluntary assisted dying in rural Victoria. Forum participants specifically referred to small towns where there are only a small number of medical practitioners available or part-time services. They noted that if all medical practitioners conscientiously object to voluntary assisted dying then a person is likely to be denied access to the process. The same concern was expressed in relation to pharmacists.

Safeguards supporting practitioners

The Parliamentary Committee recognised there are genuine concerns about protecting vulnerable people and ensuring safeguards are followed in an assisted dying framework. The Parliamentary Committee shared these concerns and looked to the international jurisdictions that allow assisted dying to discover what oversight, review and reporting mechanisms they use. The Parliamentary Committee recognised that doctors routinely assess medical treatment decisions and was clear that the best approach is to allow doctors to make clinical judgements about the person's condition. The Parliamentary Committee recommended that doctors, rather than a review body, are in the best position to assess whether a person is eligible for assisted dying. The safeguard for this judgement is the second independent assessment.

“ It shouldn't be a punitive or overly bureaucratic system or it will risk driving doctors away from the process.

Forum participant, 15 February 2017

Many of the medical practitioners consulted were concerned that their clinical practice would not be adequately protected and supported. Some examples of the other issues raised are:

- the availability of adequate training to support decision making and compliance with the legislative framework
- the ability to refer to other clinicians for specialist opinion – for example, about the mental health of the person
- the need to have comprehensive guidelines and parameters to provide for a clear scope of practice within the legislative framework
- concerns about clear legal protection from liability for participating medical practitioners, including protection for those medical practitioners who administer the medication on a person's behalf
- appropriate peer support for health practitioners dealing with voluntary assisted dying.

“ It should be good clinical practice, not set up by rogues on the fringe.

Forum participant, 2 February 2017

continued...

There was also a view that support should include emotional and psychological support for health practitioners involved in this process.

“ **Alongside a legal framework, additional safeguards should include those resources and community education strategies that inform patients, carers and health practitioners about emotional, psychological and existential issues that may be triggered.**

Submission 158

There were also suggestions of establishing a register of medical practitioners willing to participate in voluntary assisted dying; however, medical practitioners were of the view that this could leave them at risk of being adversely targeted by those who are opposed to assisted dying. Feedback from the forums and submissions supported the right of medical practitioners and other health professionals to elect not to participate in voluntary assisted dying.

The Panel recognises the importance of supporting and protecting health practitioners who participate in voluntary assisted dying. It notes that many of these matters will be addressed through comprehensive planning that will be necessary for implementation should the Voluntary Assisted Dying Bill pass. The consultation process has served to inform the Panel of what this work will require, including the development of clear clinical guidelines and other information.

“ **We consider that the Parliamentary Committee’s framework provides sufficient protection for vulnerable people.**

We consider that regular reviews, once the [Voluntary Assisted Dying] Act is in operation, would identify whether any additional safeguards need to be added.

Submission 109

Chapter 3: Oversight

Introduction

The Parliamentary 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. The Parliamentary Committee recommended the establishment of a board called the Assisted Dying Review Board to review each approved request for assisted dying. Most jurisdictions that allow voluntary assisted dying include an entity responsible for reviewing cases. Exactly how the entity is constituted differs between jurisdictions, as does its role.

The Parliamentary Committee recommended that the function of the board would not be to approve or reject requests from people who wish to access assisted dying as it considered that would be the role of the primary doctor and independent secondary doctor in each case. The purpose of the board as proposed by the Parliamentary Committee would be 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.

The Parliamentary Committee also recommended that the board should report to parliament on the operation of the assisted dying framework, including any trends it identifies and recommendations for improvement.

Establishing a voluntary assisted dying review board

There was almost universal agreement throughout the forums, roundtable discussions and submissions that a specific independent oversight body should be created to monitor the operation of the framework for voluntary assisted dying. There was a diverse range of views as to what its purpose should be and the particular roles such a body would play. The question of an oversight body initiated a wide range of conversations about what type of system needs to be in place to support voluntary assisted dying. In turn, this led to discussions about existing system supports and how these may operate together.

Membership

The Parliamentary Committee recommended that the 'Assisted Dying Review Board' should consist of a representative of the proposed End of Life Care Victoria, a doctor, a nurse, a legal professional and a community member. In forums it emerged that many considered the membership suggested was too broad or not sufficiently representative to provide the expertise required. Participants suggested that the membership needed to be more multidisciplinary to reflect mainstream models of care for people who are dying as well as to ensure consistent and robust decision making. Forum participants suggested, for example, the inclusion of ethicists, pharmacists and psychologists. It was suggested that there should be more specialised medical practitioners available to review particular matters and that disability representation and community representatives should also be included in the board's membership. The importance of making sure members were free from conflicts of interest that would bias their capacity to review cases of voluntary assisted dying effectively was also noted.

“ **The board is necessary to show people that the process works.**

Forum participant, 17 February 2017

Functions of the board

The Parliamentary Committee was clear that the role of the board would not be to approve requests, nor hear appeals, but to ensure compliance by reviewing cases of approved requests.

The Parliamentary Committee proposed that the board refer breaches of the framework to the appropriate authority. Depending on the nature of the breach, this may be Victoria Police, the Coroner, the Health Complaints Commissioner or the Australian Health Practitioner Regulation Agency.

As set out by the Parliamentary Committee, the board has functions relating to:

- reviewing compliance with requirements of the framework
- referring breaches to the appropriate authority
- providing transparency and accountability on the operation of the framework by identifying and reporting publicly on trends and then making recommendations for improvement.

All of these functions were discussed in forums and were reflected in some submissions. The discussions and comments are presented in more detail below. There was some variation in the views expressed about the specific details, and some additional functions were proposed. In forums some viewed the term ‘review board’ as not appropriate for the proposed functions of such a body, which would not have a role in reviewing the application of decisions of the assessing medical practitioners.

“ **A Review Body, if it is to be effective in protecting the public, needs to be a watchdog ... This is a very important issue. It is one thing to make a law stipulating that this or that should happen. But there needs also to be effective machinery for ensuring that it does happen.**

Submission 71

Ensuring compliance

Overall, there was general agreement that the board should ensure compliance and that it should not approve requests or hear appeals. The board was not seen as operating to veto requests or provide clinical oversight.

A number of discussions in the forums and comments in submissions advocated for the role of the board to be focused on quality assurance and quality improvement, rather than any punitive role regarding the compliance of individual medical practitioners. A view was expressed that it was not necessary to review every case; however, the majority agreed that, at least in the early stages of operation, the board should be reviewing every case of voluntary assisted dying to check that the process had been followed appropriately.

“ The focus of the oversight body should be on quality assurance and system improvement.

Submission 118

Discussions in the forums and feedback from submissions suggested that the board should also receive reports of anomalies and requests that have been denied, as well as first requests that may or may not be followed by subsequent requests. Many noted that this would provide more detailed information about the operation of the framework, and it was suggested that it could potentially facilitate follow-up of people who are not eligible to access voluntary assisted dying or who do not further pursue it. It was noted that if information about those whose request was denied was linked to other data such as suicides, it would provide a greater understanding of how the framework was operating.

Referring breaches

There was some discussion about providing the board with formal investigation and hearing powers, and a small number of submissions also recommended this, but many more noted that this would overlap with the functions and powers of existing authorities. One comment was that the board should have ‘teeth’ to better address the operation of ‘rogue’ medical practitioners. It was suggested that the board have a whistleblower arm that would enable other care providers to raise concerns about practitioners operating within or outside the framework.

“ The oversight body should have sufficient investigative powers to ask the medical practitioners to appear before it to respond to questions relating to any discrepancy in the documentation. If the discrepancy could not be resolved to the satisfaction of the Review Board then the matter would then be referred on to other agencies such as the Police or the Coroner.

Submission 54

Overall, there was agreement that certain existing functions should not be duplicated and should sit with existing bodies rather than the board. For example, the Australian Health Practitioner Regulation Agency already has powers to receive complaints about health practitioners, investigate complaints and refer matters to the relevant medical or other health practitioner boards. It was also noted that dispute resolution powers already sit with the Victorian Civil and Administrative Tribunal, and that the role of complaints investigation and resolution involving health services and practitioners lies with the Health Complaints Commissioner. However, one view was put that the board should be a one-stop shop that covers all of these functions.

Providing transparency and accountability

In discussions about the request process, forum participants considered the need for collecting broader information to support quality assurance and to allow for quality improvement. Suggestions were received about collecting data on those who were found to be ineligible and had their requests for voluntary assisted dying refused. It was also proposed that the board receive reports about the prescription and dispensing of medication, as well as copies of death certificates. Discussions balanced the desire to register all requests and collect detailed information with not making reporting requirements excessively onerous, creating administrative burden.

It was also considered an appropriate and desirable role of the board to monitor trends across all the data to inform system improvement and variations that may warrant further follow-up.

“ **The role of the review board should be what is making it easier, what is working better, and what is hindering – and if you do not see those altogether then you will not see the problems or the solutions.**

Forum participant, 4 April 2017

There was interest expressed in using the data collected to build an evidence base for what works well and what does not, as well as to develop best practice. Forum participants suggested that a quality improvement paradigm, taking into account any research that may need to be conducted as part of this process, be used to guide the scope of data collection necessary for robust analysis of the operation of the framework. Feedback also highlighted the importance of the board in using the information it collected to identify where guidelines and protocols may need to be developed. There was strong support for the board in playing a role in developing best practice guidance. It was also noted that the information collected by the board would be of great interest to researchers and policymakers and would better inform the community. Submissions also supported this view.

Other roles

Stakeholders expressed some confusion about the role of the board versus the role of the other bodies proposed by the Parliamentary Committee – particularly End of Life Care Victoria and the ‘Implementation Taskforce’ – as well as the role of the Department of Health and Human Services and the newly established healthcare safety agency Safer Care Victoria.

There were a number of suggestions about how the board could support quality improvements through developing guidelines for practitioners and advising on service delivery and models of care, and through encouraging relevant education for the community and medical practitioners. There were views expressed that a sole champion for all these functions may create a greater focus on end-of-life care; however, it could

also segregate end-of-life care from other medical treatment and risk a divergence from mainstream medical services. A number of health practitioners noted that the current policy and practice was to move away from setting up standalone 'end-of-life care' services with a focus on promoting the provision of good end-of-life care as 'everyone's business.'

“ **We propose the oversight body's functions should include independent review of assisted dying cases (retrospectively), systems-level monitoring of the assisted dying regime (including the ability to make recommendations for systemic reform), and appropriate data collection and reporting. The oversight body could also undertake research on the functioning of the regime.**

Submission 104

Across all stakeholder consultations there was a strong emphasis on the need to train medical practitioners, nurses, allied health professionals and pharmacists who wished to participate. Some pointed out that even those who wished to opt out needed education to ensure that they were able to refer people to appropriate support – for example, if a person wished to access voluntary assisted dying in a healthcare organisation that did not provide it. Community information (perhaps using a public health framework) and support for people who wished to access voluntary assisted dying, as well as family members and translators, was also considered fundamental. Many considered the board well suited to these roles.

Other suggestions for the functions of the board included auditing medication use such as authorising prescriptions and registering pharmacists who participate. Many participants proposed a register of participating practitioners and pharmacists, with the view that this would facilitate access for the public and referral by practitioners. Some medical bodies opposed this view, concerned that a register could facilitate negative targeting of practitioners.

Reporting and data collection

Stakeholders acknowledged the importance of reporting but also recognised the need to avoid onerous administrative burden posed by excessive requirements. On the whole, discussions about what should be reported by whom and at what stage tended to lean towards the side of wanting to obtain as much information as possible to enable appropriate monitoring and quality improvement, without placing unnecessary burdens on the person requesting voluntary assisted dying and not making the reporting requirements too burdensome for the health practitioners involved.

“ **All of the documentation relevant to assisted death should be reported to the Review Board.**

Submission 54

Most comments and discussions considered it important to register all requests for voluntary assisted dying (first, second and third), not just final approved requests. It was also thought valuable to receive reports regarding prescribing and dispensing of the medication. Facilitating reporting by enabling practitioners to report online through a secure portal was highlighted. Submissions provided a range of suggestions about the data that should be collected.

“ **Confirmation, in writing, that the patient was eligible (at the end of life, had an incurable condition, was suffering), that the process was carefully followed (witnesses, review/confirmation by two doctors), and circumstances at the end of life.**

Submission 174

Some submissions referred to the timing of reports in terms of duration – for example, within 48 hours or within seven days of death – whereas others referred to timing in terms of the stage of the process, such as when the written requests are received. A suggestion noted that reporting requirements should extend to all health practitioners involved, not just medical practitioners, so other practitioners such as pharmacists would also report to the board.

Organisations commented on the types of additional information that should be collected to support responsible research, evidence, quality assurance and standards in improving procedures and processes of voluntary assisted dying. Forum participants also suggested collecting demographic data in order to allay the fears of some community members in relation to groups who may be vulnerable.

Medication management

The Parliamentary Committee stated that an accountability system for tracking assisted dying medication that has been prescribed should be investigated as part of implementation.

Medical practitioners are responsible for prescribing medication and pharmacists are responsible for dispensing it. A person receiving the prescription is the owner of the medication and should also take care to ensure it is securely stored. In other jurisdictions where voluntary assisted dying is permitted, there are varying requirements for practitioners to record medication on the person's medical record, report on their actions and follow up once dispensing has occurred. In Victoria there is a well-established scheme for obtaining and managing high-risk (schedule 8) medications that may cause harm.

Experience from other jurisdictions suggests that approximately 30 per cent of people who are prescribed a lethal dose of medication do not take it. The comfort of having the option is believed to ease suffering and fear of a painful death to such an extent that the person chooses not to use it.⁵ However, it may not be apparent whether the medication has been taken, and once a person has died there is no clear responsibility for disposing of the medication if it has not been taken.

5 Legal and Social Issues Committee 2016, *Inquiry into end of life choices – final report*, Parliament of Victoria, Melbourne, p. 224.

“Oregon now has many years’ experience of this practice, and I am not aware of any cases in which the prescribed medicine has fallen into the wrong hands or been misused. I therefore believe that the Oregon requirements are adequate.

Submission 65

Stakeholders considered it important to balance the desire to monitor medication use with avoiding pressuring the person to administer the medication or imposing an undue administrative burden. Those consulted recognised that it would be a challenge to retrieve unused medication despite the desire to ensure it is not administered by someone else, intentionally or by accident, or acquired for other purposes.

“If you put a timeframe around it, it creates pressure. But on the other hand you need a mechanism to verify what is going on.

Forum participant, 17 February 2017

Discussions about the safe monitoring of medication focused on prescribing, dispensing, storing and retrieving unused medication. The matter sparked considerable interest, and as such there were extensive comments received during the forums as well as from submissions. However, there was significant variation about how prescriptive the legislation needed to be in terms of monitoring the medication once it had been dispensed to the person. On the one hand, there were views that noted there were already many lethal medications stored in people’s homes and that monitoring the medication for voluntary assisted dying should be just ‘business as usual’. On the other hand, there was a view that the medication was different because it was specifically formulated to end a person’s life and therefore should be tightly monitored. The feedback is described in further detail below.

Prescription and dispensing

There were comments that the lethal medication should be issued under an authority prescription scheme. As a further safeguard it was also suggested that the board could issue approvals to prescribe the medication once it had determined compliance with the process. Some participants and submissions proposed that the board receive a notification at the point of prescription and dispensing of the medication in order to provide additional monitoring.

Both the forums and submissions also proposed a range of safeguards that could be implemented by pharmacists at the point of dispensing, such as labelling and providing required information in writing. There were suggestions that only a limited number of registered pharmacies be involved in dispensing the medication, similar to the methadone program currently in operation in Victoria. Some thought the medication could remain with the pharmacist until the person was ready, but then acknowledged that this may place a time pressure on the person to use it. Others pointed out that it would be a considerable burden for someone who is near death to obtain the medication.

“ The lethal drug must be clearly labelled in secure, tamper-proof containers as a lethal drug, to prevent against accidental or unintended use.

Submission 124

It was suggested that an authorised agent would be able to collect a prescription on a person's behalf as per ordinary prescriptions. Many reasoned that the point at which the medication is dispensed would provide the ideal opportunity to communicate the importance of safely storing the medication including how it should be stored, as well as prompting people to arrange for the return of the medication if it is not used. Pharmacists advised that they would need additional training to support the sensitive conversations that would be required, and that they would need to have appropriate facilities so that these discussions could be held privately.

Safe storage

An important element of the proposed assisted dying framework is that a person will be able to take the medication home and administer it at a time of their choosing. However, enabling a lethal medication to be taken home and allowing freedom to choose the time of its use requires its safe storage. While many stakeholders expressed concern about lethal medication in the community, others also noted that this is already an issue that is not unique to this framework. Many examples of lethal substances routinely stored at home, including prescription medication, were offered. It was acknowledged that people were usually considered responsible enough to safely store these substances without it being a particular issue, and that voluntary assisted dying would involve very small numbers.

“ There are already so many drugs in people's homes that are dangerous. We might be being paternalistic.

Forum participant, 15 February 2017

“ Part of the education would be about how to store it. People have a lot of other medications in their house which are almost as dangerous if they have it in the right dose.

Forum participant, 15 February 2017

There was also a concern raised that a person may obtain the medication while in residential aged care or another health service where there could be a risk that another resident would inadvertently access the medication. It was noted that residential aged care services have legal obligations regarding the safe storage of medication.

Suggestions about tracking and storing the medication included real-time prescription monitoring and a range of storage measures such as the use of lock boxes, locked safes and tamper-proof containers. Ideas for technological solutions such as tracking devices, fingerprint scanners or applications for providing personalised access codes were also common. Many options were considered to be ineffective or impractical as soon as they were raised, particularly in light of the likely frailty and limited mobility of people at the end of life.

At the same time, it was pointed out that the person requesting voluntary assisted dying is taking full responsibility for this request and it is reasonable to expect them to take responsibility for the medication with advice from a pharmacist and their medical practitioner.

Retrieving unused medication

All participants in the forums summarily dismissed the Californian approach that requires a person to complete a form within 48 hours prior to self-administering the lethal dose of medication, although a couple of people who provided submissions thought it was not an unreasonable approach. It was noted that in Oregon there are no requirements beyond the prescription and dispensing record being submitted to the appropriate authority.

“ **When the person is prescribed the medication, they should not be required to fill out a form as their second last act.**

Forum participant, 3 February 2017

Participants in forums saw the merits of tracking whether the medication was actually used, but the majority accepted that sometimes this would be unknown and wished to avoid imposing an undue administrative burden or pressure on the person or their family. Nonetheless it was considered crucial information to inform the safe implementation of the legislative framework.

There was mostly agreement that intrusion on the family by way of a coronial investigation would not be appropriate, and the questions of whether and how the family should be imposed upon to return the medication remained a source of debate. It was acknowledged that it would be insensitive to follow up with the person or their family merely for that purpose but considered likely that the medical practitioner would have an ongoing therapeutic relationship with them and their family. Some suggested it could be the responsibility of health practitioners to retrieve the medication. Those with experience working in these settings noted that medication remains the property of the person and that it would not be appropriate for them to assume responsibility for any outstanding medication. Nurses, it was further noted, are not permitted to carry such medication. It was acknowledged that some people might be tempted to keep unused medication for personal use and it was unclear how this could be regulated. Many said it was reasonable that the person receiving the prescription be advised by their medical practitioner or pharmacist that they should instruct a trusted person to ensure the safe return of the medication to the pharmacist in the event it was unused.

“ If the person dies from natural causes, or has an assisted death, then all of that patient’s unused medication should be returned to the pharmacy where purchased to be destroyed.

Submission 54

After a person has died

The Parliamentary Committee did not make recommendations about what should occur after the death of a person who has been prescribed the lethal drug.

Determining cause of death

It was acknowledged that some people will die of an underlying condition without administering the medication. Some feedback suggested the Coroner should have a role in determining whether a person administered medication, and there was a suggestion that a condition of accessing the voluntary assisted dying process be agreement to a post-mortem blood test. Some thought this would be a less intrusive means of ascertaining if the medication was used, while others still viewed this option as insensitive and difficult to know when it would be required.

The majority of feedback did not support that voluntary assisted dying be considered a ‘reportable death’. The feedback generally confirmed that it would be unduly onerous and intrusive for the Coroner to review each case of voluntary assisted dying.

“ An assisted death should not be required to be reported to the Coroner, i.e. not a reportable death, but it should be required to be reported to the Assisted Dying Review Board for statistical and analytical purposes.

Submission 72

A number of forum participants argued that the involvement of the Coroner would go against the intention of the voluntary assisted dying framework, which is to allow a person to plan a death they view as peaceful. This is in keeping with the conclusion of the Parliamentary Committee that requiring the Coroner to examine each case would be unnecessary.⁶

The Coroners Court of Victoria suggested that deaths be reported, with a review after 12 months, and if experience over time suggested the court added no value then that may be an appropriate time to consider a legislative amendment to positively exclude voluntary assisted dying from the definition of reportable death.

⁶ This is because a death that occurs as a result of voluntary assisted dying would be reasonably expected and lawful and therefore should not qualify as a reportable death under the *Coroners Act 2008*.

“ It’s not terribly relevant whether or not they’ve used the medication – that’s up to them. The only thing that’s relevant is whether we need to dispose of excess.

Forum participant, 3 February 2017

Some forum participants assumed that the prescribing medical practitioner would know if the person took the medication, and some submissions suggested that the medical practitioner would be present. Others noted that the prescribing medical practitioner may not be present at the time of death, nor necessarily be the medical practitioner who signed the death certificate. For example, the death may be certified by a visiting medical officer, who may not be aware of the voluntary assisted dying prescription. It was thought that the next of kin could be asked, but this would presume that the person told family members of their intent.

“ A clear mechanism must be in place that clearly and promptly identifies patients who have accessed and ingested lethal medication, whether through a discrete identification bracelet/wristband or necklace that is issued to the patient immediately following confirmation of their assisted dying request.

Submission 125

Stakeholders also highlighted the potential issue of an ambulance officer or other healthcare worker being unaware that the person had ingested the medication and then seek to intervene. One suggestion to manage this was to ensure that those who accessed voluntary assisted dying lodged a refusal of treatment certificate as part of the process.

Certification of death

The Parliamentary Committee did not recommend how a death should be reported.

The majority of participants who discussed this matter were more comfortable with the underlying condition being listed as the cause of death because the person is dying from the condition anyway, rather than listing the means of death as voluntary assisted dying. This view was also supported by the majority of submissions that commented on this issue. This recognises the sensitivity of information provided on a death certificate, aspects of which some people may not want widely known. An opposite view was that there should be no shame in accessing voluntary assisted dying, so it should be stated on the death certificate. Nonetheless it was considered important that the privacy of the individual’s personal health information be respected.

“ [The cause of death] should be recorded on the death certificate as the underlying illness/disease – because this underscores the reality that this law is for people who are dying from a particular illness anyway.

Submission 130

Participants suggested the use of a signifier or code in place of ‘voluntary assisted death’ that would preserve the privacy of the person while recording the necessary data for monitoring. An alternative suggestion was that a separate form be used to notify the proposed review board of the death. It was noted that notification of a death can be submitted online, and that an option could be to include information about whether the person was known to have accessed voluntary assisted dying and whether they were known to have taken the lethal dose of medication. In this way the information could be submitted as part of an online notification of death without needing to be recorded on the final death certificate, the latter being used for closing electricity accounts and other purposes.

“ The death certificate should show that death was from the underlying illness. The report should be appended with a code to signify that voluntary assisted dying was involved, for statistical purposes.

Submission 72

There were suggestions that data about those who access voluntary assisted dying be linked with the Registry of Births, Deaths and Marriages to provide more complete information.

Information about the condition from which the person was dying and that they accessed voluntary assisted dying were both considered important sources of data for researchers – for example, in calculating survival curves for people with different conditions.

Liability and insurance

Professional liability issues

Some professional organisations and a range of individuals expressed concern about professional liability if they were to participate in voluntary assisted dying. Many commented that the legislation needed to specify that, provided the medical practitioner acts in accordance with the requirements of the legislation, they should not face criminal or civil liability. This included if a practitioner was present for self-administration of the lethal dose of medication. It was noted that acting outside the proposed legislation, such as aiding and abetting suicide, would still be a criminal offence.

“ The Bill must provide unambiguously clear protections to ensure that health professionals acting in accordance with the Voluntary assisted dying bill are protected from criminal or civil liability ... If these health professionals should require expensive insurance policies to provide them with confidence about liability, in order to enable them to assist an eligible person to die, this would be an impediment that will discourage and limit their involvement in any assisted death.

Submission 166

Life insurance

The impact of the listed cause of death on insurance eligibility was also highlighted in forums and submissions. It was noted that there should be no loss of insurance benefits as a result of exclusion clauses for suicide. This was one of the reasons many considered that voluntary assisted dying should not be listed on a death certificate. Others were of the view that it was clearly the underlying terminal illness or disease that was the cause of death so there should be no issues with insurance.

Annual reporting and review of the framework

The Parliamentary Committee recommended that the proposed 'Assisted Dying Review Board' 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 provided every six months. Following this initial period, the board should report annually. The Parliamentary Committee also recommended that the framework be the subject of a parliamentary review after five years of operation.

The need to evaluate the framework was consistently raised by forum participants. There was strong support for the implementation of voluntary assisted dying being evaluated, and participants were of the view that the suggested review process combining annual reporting and a five-year review was appropriate for a new framework. The submissions that provided feedback on this issue also supported this proposed approach.

“ Death brought about via medical assistance in dying must be reported in some form to enable audit of the scheme ... there is significant public interest in having this information available in a de-identified manner.

Submission 75

Safeguarding the community

The Parliamentary Committee's recommendations combined many of the safeguards used in other jurisdictions, and the Panel is resolved to use these as a base from which to deliver a compassionate and safe legislative framework. The proposed establishment of an assisted dying review board allows data to be collected and for broad monitoring to occur. This oversight body will enable access patterns to be identified, trends to be monitored and anomalies to be highlighted.

“ **The importance of effective safeguards is critical to any mooted regulatory framework being introduced.**

Submission 150

Feedback from the forums and submissions generally supported the need for an oversight board and that this board should review every case for compliance with the legislative framework. In addition, the Parliamentary Committee has recommended annual reporting to parliament and that the Act be reviewed after five years of operation. These approaches were also supported in the consultation process.

“ **The proposed approach in Victoria is rigorous and aligns with other jurisdictions overseas where reliable empirical evidence has concluded that safeguards have protected vulnerable groups from, for example, 'slippery slopes'. We do not propose additional safeguards but rather favour careful monitoring and research.**

Submission 104

There was also concern that the lethal dose of medication could pose a risk to the community if it was not safely stored and retrieved if unused. The risks associated with the lethal dose of medication were acknowledged in forums and submissions, but many noted that medications are already managed within the community. Nevertheless, there was a common view that a lethal dose of medication was different from a medication that could cause death and that additional safeguards were required. The forums and some submissions proposed a range of safeguards for storage and dispensing to support responsible management of the medication. It was also considered important to balance the desire to monitor medication use with the need to limit intrusion and the application of pressure on the person to administer the medication.

continued...

The important role played by Victoria Police, the Coroner and the Australian Health Practitioner Regulation Agency in protecting the community was acknowledged in forums, roundtable discussions and submissions. It was recognised that they would continue to perform this role if voluntary assisted dying is legalised. Many suggested these authorities were sufficiently empowered to identify illegal or inappropriate behaviour and it was appropriate to continue to rely on them to protect the community.

“ **Legislation exists in various parts of the world and the evidence exists as to what laws work – we don’t need to reinvent the wheel.**

Forum participant, 15 February 2017

In forums it was understood that, as part of the implementation of voluntary assisted dying, guidelines and procedures will be developed, and community education will be undertaken. Submissions also highlighted the need to undertake comprehensive planning and communication to support implementation.

The Panel notes that the oversight body and functions proposed by the Parliamentary Committee provide an independent, arm’s-length mechanism to ensure the function and purpose of voluntary assisted dying legislation are achieved. Parliament would continue to have oversight of the legislation through the regular reports provided by the proposed board. The Panel has been mindful throughout its deliberations of ensuring that robust safeguards are in place to address concerns associated with safe storage of medication.

Chapter 4: Implementation issues

Introduction

The Parliamentary Committee noted that evidence gathered during their inquiry indicated clinical and practical implementation issues in establishing an assisted dying framework that require further investigation. The Parliamentary Committee believed a taskforce of experts and medical practitioners would be well placed to advise on the best approach to these issues. To a large extent the Panel has undertaken this role and will consider and recommend solutions for the clinical and practical issues surrounding voluntary assisted dying to ensure the smooth transition of the voluntary assisted dying framework.

The Parliamentary Committee also proposed the establishment of a body called End of Life Care Victoria to support the operation of the framework. As part of its role, End of Life Care Victoria would provide policy and strategic direction on all aspects of end-of-life care and serve as an entry point for health practitioners and Victorians looking for information on end-of-life care issues, including assisted dying.

Furthermore, the Parliamentary Committee recommended that any assisted dying legislation should include an 18-month period between royal assent and operation, to allow appropriate time to prepare for the implementation of assisted dying on a practical and clinical level.

The Panel's consultation process has raised a range of practical considerations for both the development and implementation of voluntary assisted dying in Victoria. The feedback from forums, roundtable discussions and submissions has served to inform the Panel of what work will be required to plan for implementation, including the development of clear clinical guidelines and information. Some of the key considerations relating to professional support and information provision are highlighted in this chapter.

Professional support

Guidelines for voluntary assisted dying

A consistent theme across all the feedback was the need to develop guidelines to support the practical and clinical implementation of voluntary assisted dying legislation. Many stakeholders recommended that guidelines should be developed in consultation with health practitioners and that they should be developed using a multidisciplinary approach to support voluntary assisted dying delivery within mainstream healthcare systems. There was significant feedback that the proposed voluntary assisted dying review board could lead the development of guidelines.

Discussion about the guidelines varied depending on the stakeholder focus, but generally feedback noted that the development of guidelines would need to include:

- clinical guidelines for medical practitioners involved in the voluntary assisted dying assessment process
- medication and dispensing guidelines
- communication guidelines for health practitioners
- guidance to assist in complying with the legislative requirements.

“ There should be practice guidelines on what constitutes a timely and sensitive response to the initial request to access voluntary assisted dying. The individual needs of the person should be considered.

Submission 158

Organisational protocols

Forums, roundtable discussions and submissions also identified the need to develop organisational protocols for health practitioners who may receive a request for voluntary assisted dying as part of their day-to-day clinical practice with patients. It was noted that developing an agreed protocol about how organisations manage requests made to staff would go some way to alleviating any fears that a staff member would be left to ‘manage the request alone’. It was also thought that protocols that supported a consistent response to these requests would reduce variation in a person’s access to appropriate voluntary assisted dying information.

Providing education and training about communication skills

A consistent theme across all of the consultations was the need to provide and support health practitioners to develop and improve their communication skills. This view came from consumer and advocacy groups, academic centres, carer groups and health practitioners themselves. There was a strong view that communication training should focus on supporting health practitioners to be able to have difficult conversations about death, dying and end-of-life care.

“ [I]t appears critical that clinicians have evidence-based training opportunities to develop the skills that will be required if patients and families are to have these difficult conversations in a sensitive and supportive way. I am sure that many clinicians would feel ill prepared to have such conversations during their consultations.

Submission 37

Good listening skills were also identified as important, not only to ensure that the person’s preferences and values were respected but also as part of a skill set that supported assessing the existence of any pressures that the person might be feeling in requesting voluntary assisted dying.

“ What we want is to build the culture and train people in communication skills. You don’t want to create an illusion of information.

Forum participant, 1 March 2017

Information provision

Information about death and dying

The discussions and comments about communication also raised the broader issue of providing education and support materials that explained, in a practical and understandable way, the dying process. Feedback noted that this was important for everyone, including family and carers who would be supporting someone leading up to and during their dying. It was also noted that for some culturally and linguistically diverse communities, medical treatment decisions and caring for a dying person were seen in different ways.

“ [The provision of information] must be viewed from the perspective of the person seeking information.

Forum participant, 3 February 2017

Information about voluntary assisted dying

The need to ensure people, including health practitioners, are provided with clear, accurate and understandable information about voluntary assisted dying was a consistent theme across all of the consultations. This related to information about the process, treatments options and supports available for the person, their family and those health practitioners involved in voluntary assisted dying. There was significant feedback on the need to ensure people from diverse backgrounds had access to high-quality information and advice on voluntary assisted dying that they can understand.

It was also raised that general information needed to be provided to health practitioners who may be approached by people requesting information about voluntary assisted dying. While these health practitioners may not become directly involved in the voluntary assisted dying process, it was considered that the development of generic information that health practitioners could give people about voluntary assisted dying would be useful and important.

“ It would be helpful for a relevant government department, in consultation with civil society organizations representing the interests of patients, to develop a leaflet in plain language that briefly sets out the information that the patient should receive. This could be given both to physicians and to patients.

Submission 65

Submissions also noted that health practitioners needed to be informed about the type of information that should be provided to a person about the voluntary assisted dying process and end-of-life care.

“ Provision of a comprehensive printed booklet would ensure that patients are provided with all necessary information to enable them to make a properly informed decision about voluntary assisted dying (VAD). It would cover all aspects, including (but not limited to):

- consequences of taking VAD medication
- freedom from coercion
- ability to withdraw from VAD
- availability of palliative care
- advice to seek information on treatment options
- telephone hotlines.

Submission 72

Some forum participants also suggested that information should be held about medical practitioners willing to participate in voluntary assisted dying. Many forum participants rejected the idea of a publicly available list, but recognised that there needed to be some way for people to identify where they could access voluntary assisted dying.

Information and training formats

There were a number of suggestions at the forums, roundtable discussions and in submissions about the need to provide information and training in a range of formats that acknowledge Victoria's diverse population. Suggestions included:

- comprehensive, plain-language printed booklets in community languages and in accessible formats
- information on popular government websites
- creating resources covering palliative care options (online or hard copy) that medical practitioners can discuss in detail with patients
- face-to-face education and associated materials for health practitioners
- content in relevant undergraduate and postgraduate education
- frequently asked questions documents tailored for individuals and families
- consumer-directed pamphlets
- digital-based websites and information through specific government portals
- printed brochures describing information related to voluntary assisted dying available in general practice and health clinics, nursing homes and palliative care facilities.

“ Given that people access information in many different ways, the printed information to be provided on voluntary assisted dying should be also available in all other formats, e.g. websites, Facebook, podcasts and vodcasts (video podcasts). Information in languages other than English should also be provided.

Submission 72

“ Community education/campaigns/advertising ... should be provided in formats that meet the needs of all individuals, including plain English and through appropriately accredited translators, [and] available in a range of other languages relevant to the population, including Auslan interpreters.

Submission 152

Next steps

The issues presented in this interim report have been noted by the Panel and, if the Voluntary Assisted Dying Bill is passed by parliament, will contribute to an implementation plan.

The Panel is grateful for the considered and expert feedback it received during the consultation process. This feedback has substantially informed the Panel's thinking and it continues to consult with experts and health practitioners to fully consider the clinical and practical issues around establishing a voluntary assisted dying framework in Victoria.

The Panel's final report will be published at the end of July 2017. This report will contain the Panel's recommendations in relation to the assisted dying framework proposed in Recommendation 49 of the Parliamentary Committee's 'Inquiry into end of life choices'. The Panel's recommendations will relate to the eligibility criteria, the request process and the oversight and safeguards required to implement a compassionate, safe and practical voluntary assisted dying framework in Victoria.



