# **Voluntary Assisted Dying Bill**

Discussion paper





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## Introduction from the Minister for Health

The Andrews Labor Government believes that all Victorians are entitled to high quality end of life care, consistent with their preferences and values.

This includes people having access to high quality palliative care, the right to consent and refuse medical treatments through advance care directives and, in limited circumstances, the option of voluntary assisted dying for those with a terminal illness who are dealing with unbearable suffering.

Over the past two years, our Government has undertaken significant reform in improving end of life choices for Victorians. We have released *Victoria's end of life and palliative care framework*, to guide improvements in end of life and palliative care services over the next decade. At the end of last year, the *Medical Treatment Planning and Decisions Act* was passed by the Parliament which provides statutory recognition of advance care directives.

The reality for some Victorians who are at the end of their lives is that even the best palliative care will not relieve pain. We must follow the lead of other countries and do more to give people with terminal illness genuine choice at the end of their lives.

Therefore, consistent with the proposed voluntary assisted dying framework recommended in the Parliamentary Committee Inquiry into end of life choices final report, the Government will introduce legislation into Parliament in 2017 to legalise voluntary assisted dying for terminally ill people in Victoria.

The Committee has provided a clear framework for assisted dying legislation, however, further work needs to be undertaken to design a workable scheme with strong safeguards and protections for the vulnerable.

To support this work, I have established an Expert Ministerial Advisory Panel (the Panel) made up of clinical, legal and consumer experts.

The role of the Panel is to build on the findings and recommendations of the Committee by seeking considered and expert advice on the details associated with developing and implementing a legislative framework for voluntary assisted dying.

The Panel is engaging key stakeholders with a range of perspectives about its development and implementation, harnessing their expertise and experience to provide perspectives on the best way to address issues relating to access, safeguards, and the practical considerations in creating a compassionate and safe assisted dying framework.

This Discussion Paper is part of the consultation process, identifying key issues and questions that will help guide decision making to create a compassionate legislative framework that is workable and includes strong safeguards.

The Panel will issue an interim report in April 2017 and a final report in July 2017. I am confident that with the work of the Committee, the expert Panel and through the contributions you make in response to this Discussion Paper, the model put forward will be one that protects every Victorian while providing the genuine choice a very small number of Victorians will seek at the end of their lives.

Legislation will be developed and considered by the Victorian Parliament in the second half of 2017.

Hon Jill Hennessy MP
Minister for Health

# Chair's message

I am very pleased to be chairing the Ministerial Advisory Panel and would like to confirm our commitment to ensuring the development of assisted dying legislation with proper safeguards for all Victorians, including doctors.

The panel will build on the consultation undertaken by the Parliamentary Committee and is made up of people with the skills and expertise to resolve the important questions about the practical implementation of voluntary assisted dying in Victoria. I am confident that we will deliver a safe and compassionate legislative framework.

The panel supports the core values for end-of-life care set out by the Parliamentary Committee. Core values that include recognition of the value of every life, the importance of high-quality end-of-life care and the importance of supports and protections for vulnerable people are fundamental to considerations about the place of voluntary assisted dying legislation in end-of-life care.

The consultation process will be guided by a set of principles that will respect the variety of views and expertise of the stakeholders and commits the panel to focusing on problem solving and resolution of the key considerations in developing the legislation. The principles are:

- The person, and the needs of the person, will be the central consideration in all discussions about voluntary assisted dying.
- Respect for the range of expertise and judgement of all people providers, family and carers supporting people at the end of their lives.
- Acknowledgement that providers will hold differing views about voluntary assisted dying and recognise that while individuals may seek to contribute to developing the legislation, they may choose not to participate in its implementation.
- A focus on problem solving and resolution of issues that will help create compassionate and safe voluntary assisted dying legislation.
- That the development of the legislation will be applied in a way that respects the diversity of culture and values of Victorians.

The panel is engaging key stakeholders with relevant expertise through forums and in-depth interviews to inform our advice to government on the development and implementation of voluntary assisted dying legislation.

The aim of this discussion paper is to seek feedback on key issues in developing a legislative framework, and each section asks respondents to address specific questions in their response.

Please note that the panel will not consider feedback that expresses an opinion for or against assisted dying. The panel is seeking feedback that is based on people's expertise and experience to provide perspectives on the access, safeguards and practical considerations in creating a compassionate and safe assisted dying framework.

The closing date for feedback on this discussion paper is Monday 10 April 2017. Responses should be submitted via <Assisteddying.frameworkresponses@dhhs.vic.gov.au>.

This public discussion paper is part of the panel's consultation process and I encourage you to provide feedback via the email address above.

**Professor Brian Owler** 

Chair

Ministerial Advisory Panel

## Introduction

On 9 June 2016 a cross-party Parliamentary Committee tabled its final report on its *Inquiry into end-of-life choices*. The inquiry was conducted over a year and included extensive consultations and research. The Parliamentary Committee received more than 1,000 submissions and held 17 days of public hearings, during which it heard from 154 witnesses. The Parliamentary Committee's final report includes 49 recommendations to improve end-of-life care in Victoria. The government has accepted 44 of these recommendations, and many are already being implemented. This includes recommendations about improving palliative care and advance care planning.

The Parliamentary Committee concluded that there was overwhelming evidence that the current legal and medical system in Victoria is not adequate to deal with the pain and suffering that some people may experience at the end of their life. The Parliamentary Committee recognised that how we are cared for at the end of life and how we are dying is changing with advances in medicine. It also found that people want genuine choice about how they die and would like to be able to plan for their death.

For the vast majority of people, palliative care and advance care planning will ensure they receive appropriate pain relief and have genuine choice. Victoria already has high-quality palliative care services, and the Victorian Government has committed to continuing to improve these services. The recently passed *Medical Treatment Planning and Decisions Act 2016* will allow people to make legally binding decisions about their future medical treatment through an advance care directive.

The Parliamentary Committee found that there were a small number of circumstances in which palliative care cannot provide the relief needed to address the pain and suffering at the end of life. To that end, it has recommended that in these very limited cases, medical practitioners should be allowed to assist people to die.

The focus of this discussion paper is recommendation 49 of the Parliamentary Committee – that the government introduces a legislative framework to allow voluntary assisted dying based on the framework recommended by the Parliamentary Committee. The government has committed to introducing legislation into parliament in 2017 but has recognised that further work is required to fill in the details of this framework. This discussion paper aims to progress this commitment.

This discussion paper does not repeat the moral and social arguments for and against voluntary assisted dying that were explored by the Parliamentary Committee. The purpose is to consider how the Parliamentary Committee's framework could be implemented in practice. The feedback will inform the development of the Voluntary Assisted Dying Bill.

When the bill is introduced into the parliament, the range of issues associated with voluntary assisted dying will be debated, along with the efficacy of the voluntary assisted dying framework. The purpose of this consultation is to ensure that parliament may debate the merits of voluntary assisted dying through well-informed and workable legislation.

The Parliamentary Committee's final report and details of the inquiry may be found on the Parliament of Victoria website at <www.parliament.vic.gov.au/lsic/inquiry/402>.

## What the Parliamentary Committee has recommended

The Parliamentary Committee has recommended a framework that would allow adults with decision-making capacity, who are suffering from a serious and incurable condition and at the end of their life, to be provided with assistance to die in certain circumstances. While the Parliamentary Committee's framework provides broad parameters, further considerations are required to determine the details of how this framework could work in practice.

## Responding to this discussion paper

You are invited to provide feedback on the key issues being considered by the Ministerial Advisory Panel. Please note that feedback that expresses an opinion for or against assisted dying will not be considered by the panel.

The key issues are provided below, along with a series of questions to consider and guide discussion. Your feedback will inform the development of the Voluntary Assisted Dying Bill.

The closing date for feedback on this discussion paper is Monday 10 April 2017. Responses should be submitted via <a href="mailto:Assisteddying.frameworkresponses@dhhs.vic.gov.au">Assisteddying.frameworkresponses@dhhs.vic.gov.au</a>.

## **Key issues**

The following sections of this discussion paper identify key issues being considered by the panel. Under each key issue is a series questions on which you are invited to provide feedback.

## The person

## **Parliamentary Committee recommendation:**

- An adult, 18 years and over, with decision-making capacity about their own medical treatment.
- People whose decision-making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.
- Ordinary resident in Victoria and an Australian citizen or permanent resident.

Requests for voluntary assisted dying must be voluntary and made by a person who fully understands their condition and the nature and consequences of the decision to request voluntary assisted dying.

Existing relevant legislation in Victoria includes a four-part test for assessing decision-making capacity:<sup>1</sup>

A person has decision-making capacity to make a decision if the person is able to do the following:

- a) understand the information relevant to the decision and the effect of the decision;
- b) retain that information to the extent necessary to make the decision;
- c) use or weigh that information as part of the process of making the decision;
- d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures, or other means.

This assessment is undertaken to ensure that an adult is able to understand the nature and effect of the decision and is applied in a wide range of circumstances, including financial and medical decision making.

This assessment is consistent with contemporary practice and is already widely administered by a range of professional groups. The purpose of the test is not to determine whether the decision is right or wrong but to determine whether the person is able to apply the relevant information to make a decision that is in line with their preferences and values. The information must be provided in a format that is accessible to the individual person.

In other relevant legislation there is a presumption that an adult has decision-making capacity. It is also recognised that capacity is decision-specific. Finding that an adult does not have decision-making capacity for one or more or all decisions deprives them of the ability to direct their own lives and, in one sense, removes their legal personhood

<sup>1</sup> Medical Treatment Planning and Decisions Act 2016, s. 4; Powers of Attorney Act 2014, s. 4; Mental Health Act 2014, s. 68

in relation to the decision or range of decisions being made. This is why undertaking a formal assessment is so important, in order to protect the right of those with decision-making capacity to make their own decisions and to ensure people will only make decisions when they understand the nature and effect of the decision.

A medical practitioner's assessment of capacity may, in some cases, involve referral to other disciplines when necessary in order to ensure potential influencing factors like coexisting physical symptoms, untreated mental conditions such as depression or anxiety, and family pressures or socioeconomic issues are appropriately assessed and managed.

The Parliamentary Committee recommended that any person whose decision-making capacity is in question due to mental illness must be referred to a psychiatrist for assessment.

- Is the existing decision-making capacity test in legislation such as the *Medical Treatment Planning and Decisions Act 2016* sufficient? (please see page 5)
- In what circumstances should a psychiatric assessment be required? Are there any other specialist referrals that would be appropriate for assessing decision-making capacity?

# The decision-making capacity test used in the Medical Treatment Planning and Decisions Act 2016 is:

- (1) A person has decision-making capacity to make a decision to which this Act applies if the person is able to do the following—
  - (a) understand the information relevant to the decision and the effect of the decision;
  - (b) retain that information to the extent necessary to make the decision;
  - (c) use or weigh that information as part of the process of making the decision;
  - (d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means.
- (2) An adult is presumed to have decision-making capacity unless there is evidence to the contrary.
- (3) A person is taken to understand information relevant to a decision if the person understands an explanation of the information given to the person in a way that is appropriate to the person's circumstances, whether by using modified language, visual aids or any other means.
- (4) In determining whether or not a person has decision-making capacity, regard must be had to the following—
  - (a) a person may have decision-making capacity to make some decisions and not others;
  - (b) if a person does not have decision-making capacity for a particular decision, it may be temporary and not permanent;
  - (c) it should not be assumed that a person does not have decision—making capacity to make a decision—
    - (i) on the basis of the person's appearance; or
    - (ii) because the person makes a decision that is, in the opinion of others, unwise;
  - (d) a person has decision-making capacity to make a decision if it is possible for the person to make a decision with practicable and appropriate support.

#### **Examples**

Practicable and appropriate support includes the following—

- (a) using information or formats tailored to the particular needs of a person;
- (b) communicating or assisting a person to communicate the person's decision;
- (c) giving a person additional time and discussing the matter with the person;
- (d) using technology that alleviates the effects of a person's disability.
- (5) A person who is assessing whether a person has decision-making capacity must take reasonable steps to conduct the assessment at a time and in an environment in which the person's decisionmaking capacity can be most accurately assessed.

## Access and eligibility

## **Parliamentary Committee recommendation:**

The person must be:

- at the end of life (final weeks or months of life); and
- suffering from a serious and incurable condition which is causing enduring and unbearable suffering that cannot be relieved in a manner the patient deems tolerable.

Suffering as a result of a mental illness only does not satisfy the eligibility criteria.

The Parliamentary Committee's framework sets out criteria that must be fulfilled in order to access voluntary assisted dying. While the Parliamentary Committee set broad limits, what these limits mean in practice requires further exploration.

The Parliamentary Committee recommended that a person must be 'at the end of life (final weeks or months of life)'. The Parliamentary Committee did not prescribe a set timeline and supports an approach that allows doctors to determine whether a patient is at the end of their life according to the nature of their condition and the likely trajectory. It was the opinion of the Parliamentary Committee that this is preferable to setting an arbitrary timeline. Some jurisdictions that have legislated for voluntary assisted dying have imposed a more precise requirement – for example, that the person has a prognosis of no more than six months to live.<sup>2</sup>

Making an accurate prognosis can be difficult, and the progression of some diseases is more difficult to predict than others. While it is difficult to identify an exact life expectancy, diagnosing a terminal illness and estimating life expectancy are part of standard medical practice. Some jurisdictions recognise this by including a more general requirement. For example, in Canada, among other things, death must be 'reasonably foreseeable' and a person must be suffering from a 'grievous and irremediable condition'.<sup>3</sup>

Imposing a prescribed time limit may clearly set out the expectations of an acceptable timeline for accessing voluntary assisted dying; however, it may also place unrealistic expectations on medical practitioners that they are able to precisely predict when a person is going to die.

The requirement that a person be suffering from a 'serious and incurable condition' may require further consideration. There is a range of conditions that may fall within this definition that some may feel should not qualify a person for voluntary assisted dying.

<sup>2</sup> Death with Dignity Act (Oregon), s. 127.800(12); Death with Dignity Act (Washington), s. 1(13)

<sup>3</sup> Criminal Code (Canada), s. 241.2(2)

While some jurisdictions use the term 'terminal disease', others similarly refer to a 'grievous and irremediable condition'.<sup>4</sup> The latter is the term used in Canada, along with the criterion that death is 'reasonably foreseeable'. Other jurisdictions do not elaborate on what these terms mean, and it may be inappropriate to include extensive definitions in legislation.

The Parliamentary Committee also recommended that the person be experiencing 'enduring and unbearable suffering'. It was the opinion of the Parliamentary Committee that this is fundamental to patient-centred care and should be a subjective measure judged by the patient themselves. This means that while a medical practitioner would determine that a person has a serious and incurable condition and is at the end of their life, it is the person who would determine whether or not their suffering is unbearable.

It should be noted that suffering as a result of a mental illness alone will not satisfy the eligibility criteria.

- Is greater specificity required to identify what constitutes a person being at the end of life and, if so, how should that specificity be worded?
- How should a 'serious and incurable condition' be defined?

<sup>4</sup> See, for example, Death with Dignity Act (Washington), s. 1(13) and Criminal Code (Canada), s. 241.2(2)

## Making a request

#### Parliamentary Committee recommendation:

- The request must come from the person themselves. The request must be voluntary and free of coercion. The request cannot be made in an advance care directive.
- The request must be enduring.
- The person must be able to withdraw the request at any time.

It is critical that a decision about voluntary assisted dying is made by the person themselves and that it is made voluntarily.

The Parliamentary Committee recommended that once the person has made a request that the request be enduring. This is demonstrated by the person making the request three times. There must be an initial verbal request, followed by a formal written request signed by two independent witnesses, and then a final verbal request. A potential safeguard may be to limit who may witness the formal written request; for example, it may be appropriate to exclude family members. This may need to be balanced with considerations about access, as the person may only have a small number of people they feel comfortable asking to witness the request.

The Parliamentary Committee did not specify a time period over which these requests should be made. In some jurisdictions a prescribed number of days need to pass between the first and last request – for example, 15 days. A prescribed period of time may help to ensure a request is enduring, but it may also be an arbitrary period that may unnecessarily prolong suffering in some cases. In Canada it is recognised that this delay may unfairly inhibit people's access to voluntary assisted dying because they may be about to lose capacity, and so a medical practitioner may recognise a request is enduring in a shorter period of time. While this reduces the risk that people may be prevented from accessing voluntary assisted dying, it also creates the potential for a rushed decision. It should, however, be noted that even once the final request is made, it is still up to the person to take the medication, and they may still opt to take the lethal dose of medication at any time or not at all.

<sup>5</sup> End of Life Option Act (California), 443.3(a)

<sup>6</sup> Criminal Code (Canada), s. 241.2(3)(g)

An additional safeguard to consider is the creation of new criminal offences related to voluntary assisted dying. This measure would ensure requests are voluntary by acting as a deterrent and sending a clear message that it would never be acceptable to push someone to access voluntary assisted dying. Appropriate offences may include inducing a person to request or access voluntary assisted dying through dishonesty or undue influence. It should be noted that existing offences, such as aiding or abetting suicide, may also still apply if people do not act in accordance with the new legislation. This may include prescribing a person a lethal dose of medication when they have not made a voluntary decision to access voluntary assisted dying in accordance with the framework in the legislation.

- What safeguards are necessary to ensure that a request is voluntary? How should this be assessed?
- Should there be a prescribed time period that must pass between the first and final request and, if so, what period?
- Should there be specific offences for those who fail to comply with the requirements in the Act or are the offences of homicide or aiding or abetting suicide appropriate and sufficient?

## **Properly informed**

## Parliamentary Committee recommendation:

A person must be properly informed. The primary and secondary doctor must each properly inform the person:

- 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; and
- of the probable result and potential risks of taking the lethal drug.

Seeking and gaining informed consent from the person is an important safeguard process because it ensures that the person requesting voluntary assisted dying has capacity, is acting voluntarily and that they understand the nature and effect of the decision they are making. Medical practitioners are already required by law to obtain informed consent before administrating medical treatment. There are well-established requirements for ensuring that patients are giving informed consent, and medical practitioners must provide information on:

- the diagnosis
- the recommended treatment
- the material risks associated with the recommended treatment, alternative treatment options, not providing treatment and significant risks to the particular individual.

A medical practitioner already has a duty of care to provide appropriate information to their patients. Consistent with existing medical practice, informed consent would be required for voluntary assisted dying. The Parliamentary Committee's recommendation about what constitutes being 'properly informed' applies the key elements of existing informed consent requirements specifically to voluntary assisted dying.

The more prescriptive requirements suggested by the Parliamentary Committee recognise that voluntary assisted dying is a new clinical intervention that requires new standards and practices to be introduced. It will be important to balance prescriptive requirements set out in legislation with the need to provide flexibility to respond to information requests from individual patients. Any details in legislation about the provision of information will also need to take into account any unintended outcomes that may limit existing informed consent requirements, such as limiting a medical practitioner's discretion to appropriately tailor information to the needs of their patient.

The provision of information to patients about voluntary assisted dying should take into account the evidence about what type of information patients want and how they want to receive it. Research regarding the provision of information to patients by health practitioners shows that patients generally want more, and better, information about their health, their healthcare and treatment options than they actually receive. Given the evolving understanding of how patients receive information and engage in discussions about their treatment options, it may be important to create resources that can be updated rather than set in legislation. Information should be provided in formats that meet the needs of all individuals, including plain English, Easy English and through appropriately accredited translators, including Auslan interpreters.

It is important that people be given the information they need to understand their diagnosis and prognosis and how voluntary assisted dying will work. For a person to have genuine choice, they must understand the alternative options available to voluntary assisted dying, such as the effectiveness of palliative care for their particular end-of-life care needs.

There are different approaches in other jurisdictions to the provision of information in relation to voluntary assisted dying. For example, in Vermont a patient has a 'right to information' and must be informed of all available options related to terminal care and must receive answers to any foreseeable risks and benefits of medication:<sup>7</sup>

The medical practitioner must also inform the patient both orally and in writing of:

- a) the patient's medical diagnosis;
- b) the patient's prognosis, including acknowledgment that the medical practitioner's prediction of the patient's life expectancy was an estimate based on the physician's best medical judgment and was not a guarantee of the actual time remaining in the patient's life, and that the patient could live longer than the time predicted;
- c) the range of treatment options appropriate for the patient and the patient's diagnosis;
- d) if the patient was not enrolled in hospice care, all feasible end-of-life services, including palliative care, comfort care, hospice care, and pain control;
- e) the range of possible results, including potential risks associated with taking the medication to be prescribed; and
- f) the probable result of taking the medication to be prescribed.<sup>8</sup>

<sup>7</sup> Patient Control at End of Life Act (Vermont), s. 5282

<sup>8</sup> Patient Control at End of Life Act (Vermont), s. 5283(6)

The framework proposed by the Parliamentary Committee recognises that in prescribing a person with a lethal dose of medication, a medical practitioner is empowering a person to make a decision to end their own life. It should be made clear to the person that just because they have chosen to obtain the medication, they are under no obligation to ingest it, and that if they do decide to ingest the medication they may do so when they choose to.

- Should the legislation include prescribed information that a medical practitioner must provide to a person requesting voluntary assisted dying and, if so, is the list recommended by the Parliamentary Committee in the box above sufficient?
- What resources should be developed to support legislative obligations to provide information that would be useful in practice?
- Who should undertake the assessments and provide information?

## Confirming a request

## **Parliamentary Committee recommendation:**

- The primary and secondary doctors must be independently satisfied that the patient's request is enduring and that a reasonable amount of time has passed between the patient's initial request and the provision of the lethal drug.
- In making this judgement the primary and secondary doctors must have regard to the patient's particular condition and its likely trajectory.
- The primary and secondary doctors must also assess the reasonableness of the
  request. This is to ensure that the patient truly understands and appreciates the
  nature and consequences of the decision to request assisted dying, as well as the
  alternatives to assisted dying, and that the patient's request is not ambivalent.
- Each doctor must be properly qualified to make a professional diagnosis and prognosis regarding the patient's specific condition. Each doctor must also assess the eligibility criteria.

In the Parliamentary Committee's framework the two medical practitioners perform the same tasks independently of each other. The second independent review is designed to ensure the primary medical practitioner's diagnosis and prognosis are accurate, that all the necessary information has been provided, and that the person understands the nature and effect of their decision.

It is important that medical practitioners have the appropriate skills and training to participate in voluntary assisted dying and to provide appropriate treatment advice to people. This will include an understanding of the person's disease and potential treatments, and the effectiveness of alternative treatments, including palliative care. Education and training will be vital in effectively enacting the legislation.

Medical practitioners will require appropriate qualifications to understand the person's disease and potential treatments, and the effectiveness of alternative treatments, including palliative care. Necessary qualifications to understand a person's condition and potential treatments will vary significantly depending on the person's condition.

While it is recognised that medical practitioners are required to practice within their field of expertise, the extent to which the legislation prescribes the required qualifications in the context of voluntary assisted dying needs to be determined. Other jurisdictions do not include prescriptive requirements about the qualifications of medical practitioners to participate in voluntary assisted dying in legislation.

The Parliamentary Committee has recommended that palliative care information be provided. Given this requirement it may be appropriate for legislation to prescribe the type of involvement expected for palliative care specialists – for example, prescribing a referral or a consultation with a palliative care specialist. Like the proposed review by a psychiatrist, this could be a separate consultation or referral requirement, rather than a prescribed specialty or responsibility of one of the two practitioners. This may be more appropriate as it recognises that the expertise of a palliative care specialist may be different from the specialist providing the diagnoses or treatment for the patient's condition.

- Should the legislation prescribe specialist expertise required for medical practitioners to participate in voluntary assisted dying?
- Should there be a requirement for a palliative care specialist referral or consultation?

## **Conscientious objections**

## **Parliamentary Committee recommendation:**

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

Some people and organisations have strong objections to voluntary assisted dying and should not be required to participate.

Currently, a health practitioner can conscientiously object to providing medical treatment but must take any steps necessary to ensure their patient's access to care is not impeded. In some circumstances, such as under the *Abortion Law Reform Act 2008*, there are more prescriptive requirements. The *Abortion Law Reform Act 2008* requires a health practitioner who conscientiously objects to abortion to inform a woman who requests an abortion of their objection and to refer the woman to another registered health practitioner in the same regulated health profession who the practitioner knows does not have a conscientious objection to abortion. This more prescriptive requirement ensures that a woman will still be able to access the treatment without having to recommence the process of finding an appropriate health practitioner.

People requesting voluntary assisted dying are likely to already have a relationship with a number of health practitioners, and forming new therapeutic relationships may be overly burdensome. If a person wishes to explore the possibility of voluntary assisted dying, they may prefer to initiate this conversation with a medical practitioner with whom they already have a therapeutic relationship. If the medical practitioner has a conscientious objection to voluntary assisted dying, they should be under no obligation to provide an eligible patient with a lethal dose of medication, but based on existing duty of care obligations they also should not hinder the person's access through another practitioner.

Other jurisdictions take different approaches to conscientious objection. In California it is recognised that participation is voluntary and that a person is not required to take any action in support of an individual's request for voluntary assisted dying, and a person will not face any criminal, civil, administrative or disciplinary action for refusing to participate. Health services may also prohibit their employees from participating while on the health service's premises or while they are acting within the scope of their employment. In Canada the legislation simply provides that nothing in the Act affects the guarantee of freedom of conscience and religion.

- How should conscientious objection to voluntary assisted dying operate?
- Should health practitioners who conscientiously object be required to refer patients to other health practitioners?
- Should health practitioners who conscientiously object be required to declare their objection? If yes, when should this occur?

<sup>9</sup> End of Life Option Act (California), 443.14(2)(e)

<sup>10</sup> End of Life Option Act (California), 443.15

<sup>11</sup> Bill C-14 (Canada), preamble

## Administering a lethal dose of medication

#### **Parliamentary Committee recommendation:**

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

The requirement that a person self-administer the lethal dose of medication provides an important safeguard for ensuring the decision to take the medication is voluntary. Being able to take the medication at a time the person chooses helps to ensure they do not feel pressured or obliged to take the medication. Despite this, just because someone is physically unable to self-administer medication, they should not be excluded from assisted dying. In these circumstances, it may be necessary to create additional safeguards to ensure the decision is voluntary. This may include, for example, an additional step or requirement at the time the medication is administered by the medical practitioner to ensure the person does not feel pressured to proceed because an appointment or time has been made. This consideration must, however, be weighed against the burden that additional administrative steps may create.

If a person is able to self-administer the lethal dose of medication, they may choose where they do this. While a person should also be able to choose where a medical practitioner administers the medication, there may be circumstance in which the medical practitioner may have practical concerns about a lack of access to support or assistance. There may be instances in which the most appropriate place to administer the lethal dose of medication is in a hospital. This may create practical issues for the hospital. Questions of location of treatment are normally made in consultation with patients and involve professional judgement about safety and efficacy. The needs of each person accessing assisted dying will be different, and it is not clear that prescriptive requirements in legislation would be appropriate.

- Are additional safeguards required when a medical practitioner administers the lethal dose of medication and, if so, what safeguards would be appropriate?
- Where should a medical practitioner administer the lethal dose of medication, and what practical and other challenges would this create?

## Monitoring the use of a lethal dose of medication

While the Parliamentary Committee recommended that an accountability system for tracking assisted dying be established, it does not specify how this should occur. A medical practitioner is responsible for the careful and proper prescription of medication. A person receiving the prescription should also take care to ensure it is securely stored.

While it is important to ensure that the lethal dose of medication is safely stored and properly monitored, it must also be recognised that there are already many prescription medications and other household items that may cause death if they are ingested. People are generally able to responsibly manage this risk, and it is expected that they will also be able to do so if they are prescribed a lethal dose of medication for assisted dying.

A person will be able to take the lethal dose of medication home and take it when they choose. This means they may store the medication at home for months, and so it may not be immediately clear to their medical practitioner when they have ingested the medication. It is anticipated that people suffering from a serious and incurable medical condition will have regular contact with medical practitioners or their care team, but it may not be appropriate to regularly enquire about their intentions to ingest the lethal dose of medication because the person may then feel pressured to take it. While appropriate oversight is important, overly burdensome administrative processes may cause unnecessary distress to people who are already suffering unbearable pain. With these considerations in mind, some key monitoring requirements may be necessary.

In California a range of steps must be taken to ensure the lethal dose of medication is appropriately monitored. The medical practitioner must record the request and prescription in the person's medical record and must file a copy of the dispensing record for the medication with their Department of Health within 30 days. The person must complete a form within 48 hours prior to self-administering the lethal dose of medication. Either this form or the medication must be returned when the person dies. The medical practitioner must submit a follow-up form with the Department of Health within 30 days of the person ingesting the medication. In Oregon a medical practitioner must place a record of the request and prescription on the medical record, and the healthcare provider must file a copy of the dispensing record of the medication with the Health Authority, but there are no further requirements.

#### Question to consider:

 How can a prescribed lethal dose of medication be effectively monitored without placing undue burdens or pressure on people accessing or using the medication?

<sup>13</sup> Death with Dignity Act (Oregon), 127.855 s 309

## **Attendance**

The Parliamentary Committee recommended that, in all cases except where a person is physically unable to, a person must self-administer the medication. The Parliamentary Committee did not specify whether a health practitioner may be present when the person self-administers the lethal dose of medication.

The framework recommended by the Parliamentary Committee recognises that voluntary assisted dying is a personal choice and that a person should make the choice to self-administer the medication when they are comfortable to do so. Many people would feel comforted if their health practitioner was present at the time they took the lethal dose of medication. While it may be beneficial to have a health practitioner present, it is not clear what their role and obligations would be. The health practitioner is not permitted to administer the medication, and they would only be required to take action if it was not effective.

Legislation in other jurisdictions recognises that a medical practitioner should not face criminal or civil liability for being present when a person ingests the lethal dose of medication in accordance with the Act.<sup>14</sup>

## **Questions to consider:**

• Should a health practitioner be allowed to be present at the time the person self-administers the lethal dose of medication? If so, what should their role and obligations be?

## Lethal dose of medication not effective

The Parliamentary Committee did not specify what should occur if the lethal dose of medication is not effective or an ambulance is called. As with any medical intervention, there are risks that need to be explained to the patient, and there may be errors or unforeseen side effects when a person ingests a lethal dose of medication. Experience in other jurisdictions suggests this will be rare. For example, in Oregon between 2010 and 2014, 386 people ingested the medication; of these, five people subsequently regained consciousness.<sup>15</sup> In 2013 and 2014, no-one who ingested the medication regained consciousness.<sup>16</sup>

Someone who is unaware that a person has taken the lethal dose of medication may call an ambulance. In such a case, the obligations of a health practitioner must be clear. Given the person's clear intention to end their life with the lethal dose of medication, it does not seem appropriate for health practitioners to provide life-sustaining treatment, and this will need to be clearly set out. Any obligations to provide palliative care to make the person as comfortable as possible also need to be made clear.

This will require ensuring that health practitioners are able to identify whether the person has taken the lethal dose of medication. After being prescribed the medication, the person may take it home and self-administer it at a time of their choosing. This may occur weeks or months later or not at all, and the person may still be accessing a range of medical treatments during this period. In California, to ensure it is clear that the person has chosen to take the medication, there is a requirement that, when the person is ready to take the medication, they complete a form stating that they will ingest the medication within the next 48 hours.<sup>17</sup> This approach would reduce any potential confusion about whether or not the person had ingested the medication or their intentions. If such a form has been completed a health practitioner's obligations will be clear. Other jurisdictions do not have a similar requirement, and completing a form does add an additional administrative step for the person.

- What should the obligations of a health practitioner be to treat a person who has chosen to ingest a lethal dose of medication?
- What is the best way to indicate that a person has chosen to take a lethal dose of medication?

<sup>15</sup> http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx

<sup>16</sup> ibid.

<sup>17</sup> End of Life Option Act (California), 443.11(c)

## After a person has died

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

It will be necessary to determine whether the person ingested the lethal dose of medication. If the lethal dose of medication has not been ingested, it will need to be destroyed. Some jurisdictions include specific requirements for destroying the medication, while others are silent on the issue and rely on ordinary procedures for disposing of medication.<sup>18</sup>

The Parliamentary Committee did not recommend how the death should be reported, and it is not clear what obligations a medical practitioner will have about how they record the cause of death. While the Parliamentary Committee recommended that the oversight body collects and publishes de-identified data on people accessing assisted dying, individuals accessing assisted dying will not necessarily want this listed as their cause of death. In many jurisdictions with assisted dying, the underlying disease is listed as the cause of death.

The role of the Coroner will also need to be established. The Coroner investigates reportable deaths, including deaths as a result of accident or injury, as well as suicides, poisonings, overdoses and homicides. While coronial investigations would add additional oversight, the purpose in a case of assisted dying is unclear. The cause of death would be clearly known, and if there were any suggestion of impropriety this would be a matter for Victoria Police. The Coroner could investigate if it was unclear whether or not the person ingested the lethal dose of medication.

- What safeguards are necessary to determine whether or not the person has ingested the lethal dose of medication and to destroy the medication if it has not been ingested?
- What should be recorded as the cause of death for a person who has ingested the lethal dose of medication?
- Should death as a result of voluntary assisted dying be a reportable death?

<sup>18</sup> See, for example, Patient Control at End of Life Act (Vermont), s. 5291.

<sup>19</sup> See, for example, End of Life Option Act (California), 443.13.

## **Oversight**

#### **Parliamentary Committee recommendation:**

That an Assisted Dying Review Board be established to review each approved request for assisted dying. Membership of the Assisted Dying Review Board should include:

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

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

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

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

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

The Parliamentary Committee recommended that the role of the Assisted Dying Review Board be to retrospectively review the actions of medical practitioners in each instance of voluntary assisted dying. To undertake this role, medical practitioners will be required to provide information to the board. There are numerous points at which this could occur – for example, each time a request is made, each time a prescription is written and each time a person ingests the lethal drug.

The board will be required to pass on information if it finds a breach of the legislation. This is generally considered a high threshold for passing on private information. It may also be appropriate to require the board to refer a matter to Victoria Police, the Coroner or the Australian Health Practitioner Regulation Agency where there is a reasonable suspicion that a person has breached the Act. While the board will have information provided by a medical practitioner, it may also require information from alternative sources in order to determine what has occurred.

There are numerous examples of similar bodies in other jurisdictions. In Oregon an authority receives records from medical practitioners regarding dispensing of a lethal dose of medication and reports annually on this.<sup>20</sup> In the Netherlands regional committees review the actions of medical practitioners following assisted death. The regional committee assesses whether the medical practitioner has acted in accordance with the statutory requirements and may call on the medical practitioner and others to give evidence.<sup>21</sup> The regional committees must also issue an annual report.<sup>22</sup>

- What information should a medical practitioner be required to report to an oversight body such as the Assisted Dying Review Board?
- At what stage should medical practitioners or pharmacists be required to report to the Assisted Dying Review Board?
- When should an oversight body be required to refer a matter to another agency?
- Should an oversight body have any investigatory powers, or should this be conducted by other agencies?
- Should a stand-alone review board be established? What are the alternatives? For example, would it fit within the investigative role of the Coroner's Court or the quality and safety mandate of a consultative council?

<sup>20</sup> Death with Dignity Act (Oregon), s 127.865, 3.11

<sup>21</sup> Termination of Life on Request and Assisted Suicide Act (Netherlands), art 8–9

<sup>22</sup> Termination of Life on Request and Assisted Suicide Act (Netherlands), art 17

## **Additional safeguards**

The process for accessing voluntary assisted dying recommended by the Parliamentary Committee is designed to include key requirements in order to protect vulnerable people and ensure that the request is voluntary. It does this by setting out requirements to ensure only those who fully understand their diagnosis and prognosis, and nature and consequences of accessing voluntary assisted dying, will be prescribed a lethal dose of medication. If there is any doubt about a person's ability to make the decision, they will need to be referred to a psychiatrist. The independent medical review and involvement of other independent witnesses will also ensure that any coercion or undue influence will be identified.

The requirement that a person make three requests and inclusion of multiple points of review also aims to ensure that a person is making a well-informed and considered decision and is not requesting access to voluntary assisted dying at a point in time when they may be feeling particularly vulnerable or despairing.

Disability advocacy groups in other jurisdictions have identified the need to protect vulnerable people with disabilities. It will be important to ensure that all vulnerable people are protected, but this should not occur through potentially discriminatory measures that identify particular groups.

- Does the Parliamentary Committee's framework provide sufficient protection to vulnerable people?
- What other additional safeguards could be considered?

## Liability and insurance

The Parliamentary Committee doesn't specify how liability and insurance issues should be managed under the voluntary assisted dying framework. Medical practitioners may face criminal or civil liability for failing to comply with the law or acting negligently. The new legislation will need to clearly state that a medical practitioner will face no criminal or civil liability for providing treatment that causes death if they have acted in accordance with the requirements in the legislation. A failure to comply with the requirements in the legislation or negligent behaviour would mean that the medical practitioner was open to criminal or civil liability.

Insurance issues may also arise for those who access or participate in voluntary assisted dying. Some jurisdictions explicitly recognise that for the purposes of insurance, the cause of death will be the underlying disease.<sup>23</sup> This recognises that people should not be discriminated against on the basis that they chose to access voluntary assisted dying.

- What protections would be necessary for health practitioners who act in accordance with the new legislation in good faith and without negligence?
- How should insurance and other annuities of people who access voluntary assisted dying be protected?

## Conclusion

#### Question to consider:

 Are there any further issues related to the Parliamentary Committee's recommended framework that require the Ministerial Advisory Panel's consideration?

The Parliamentary Committee has provided an excellent starting point for discussing the practical issues in creating a voluntary assisted dying framework in Victoria. Responses to this discussion paper will inform the considerations of the Ministerial Advisory Panel. The Ministerial Advisory Panel will issue an interim report in April 2017 and a final report in July 2017.

The closing date for feedback on this discussion paper is Monday 10 April 2017. Responses should be submitted via <Assisteddying.frameworkresponses@dhhs.vic.gov.au>.

To receive a hard copy of this discussion paper, please call 9096 8750 and leave your name and postal address.

