



Simplifying medical treatment decision making and advance care planning

Ensuring Victorians can make decisions
about their future medical treatment

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Summary

The Victorian Government is committed to giving statutory recognition to advance care directives so Victorians can document their treatment preferences for existing and/or future conditions.

The government believes all Victorians are entitled to quality medical treatment that is consistent with their preferences and values.

Currently, the legislative framework is complex and difficult for health practitioners and the public to navigate. Although there are a number of relevant Acts, there is little a person can do to ensure their preferences are followed in relation to future treatment when they no longer have capacity. This often leads to fear of invasive procedures that are not wanted, or are not reflective of a person's values and preferences.

To that end, the government is proposing to simplify the legislation regarding medical treatment decision making. The proposed Medical Treatment Planning and Decisions Act will provide a comprehensive legislative framework to ensure that people are empowered to make decisions about how they want to receive care, including through an advance care directive.

What the proposed Medical Treatment Planning and Decisions Act will do

The proposed Act aims to:

- provide Victorians with a new process for medical treatment decision making in line with contemporary views about how people participate in decisions about their own medical treatment
- simplify the existing legal framework for medical treatment decision making and ensure statutory recognition of advance care directives for current and future conditions
- support existing efforts in implementing advance care planning.

The purpose of this position paper

This position paper has been developed in order to:

- clearly communicate the government's intentions in relation to legislative changes to medical decision making and advance care directives
- seek feedback on the best ways to plan for and implement the proposed Act.

The proposed changes to the law will ensure Victorians can guide their medical treatment. These changes will not affect what constitutes unlawful medical treatment, including physician assisted dying.

Changing the legislation will allow Victorians to have confidence in the health system to respect their decisions about medical treatment. This *Simplifying medical decision making and advance care planning* position paper provides information about the government's proposed Medical Treatment Planning and Decisions Act and invites feedback via email at acp.responses@dhhs.vic.gov.au.

Please note that submissions about physician assisted dying in response to the position paper will not be considered relevant.

Developing a Medical Treatment Planning and Decisions Bill

In developing the proposed Medical Treatment Planning and Decisions Bill the government has considered evidence from a range of sources, including:

- national and international research on advance care planning and legal frameworks
- advance care planning legislative frameworks in other Australian jurisdictions
- the Victorian experience of implementing advance care planning in healthcare services
- preliminary discussions with a range of key stakeholders who may play a role in implementing important elements of the proposed law
- relevant feedback from broader Victorian consultation activities including the Greater Say for Victorians: Improving End of Life Care consultations and public submissions to the Parliamentary Standing Committee's Inquiry into End of Life Choices.

Inquiry into End of Life Choices

The Legislative Council's Legal and Social Issues Committee conducted an Inquiry into End of Life Choices. The Committee received more than 1,000 submissions and conducted 17 public hearings.

On 9 June 2016, the Committee tabled its report in Parliament. The government is considering each of the Committee's recommendations and will provide a full response in due course. This Position Paper and the proposed new legislation are focused on medical treatment decision making and advance care directives.

The proposed law does not deal with any legislative considerations related to physician assisted dying. This is a different issue and is not part of the proposed Medical Treatment Planning and Decisions Bill.

Greater Say for Victorians: Improving End of Life Care Consultation

The proposed legislation has also been developed considering the outcomes of a recent consultation with the community and key stakeholders involved in healthcare delivery.

As part of the government's Greater Say for Victorians: Improving End of Life Care consultations, almost 700 people participated in 28 forums across Victoria. A key focus of the consultation was how legislative changes to advance care planning could improve end of life care. The three most important issues for enabling genuine choice were identified as:

- community awareness and education
- open and documented discussions
- a legal framework that ensured advance care plans were respected.

This feedback has informed the government's approach to medical treatment decision making legislation.

Background

The current legislative framework is complex and difficult for health practitioners and the public to navigate. Studies have shown that even health practitioners working extensively in end of life care have critical gaps in their understanding of how decisions should be made for patients who no longer have decision making capacity.

There are four Acts that govern medical treatment decision making for people who do not have decision making capacity:

- the *Guardianship and Administration Act 1986*
- the *Medical Treatment Act 1988*
- the *Powers of Attorney Act 2014*
- the *Mental Health Act 2014*.

Each Act contains different definitions and tests for capacity, and creates different obligations.

Although there are a number of relevant Acts, there is little a person can do to ensure their preferences are followed in relation to future treatment when they no longer have capacity. Introducing a new Act to give statutory recognition to advance care directives within the existing framework is likely to create further complexity and confusion.

Creating a comprehensive legislative framework for advance care planning will help to ensure people are empowered to make decisions about how they want to receive care. This will provide comfort to people that their preferences and values will be respected and ensure that health practitioners can understand and comply with their legal obligations.

Establishing a legislative framework will support and strengthen the advance care planning that is already being undertaken by healthcare services across Victoria.

The strategy

Victorian health services have been undertaking advance care planning since the early 1990s, and in 2014 the *Advance care planning: Have the conversation – a strategy for Victorian health services 2014–2018* was released.

The strategy aims to ensure all Victorians accessing health services will have opportunities to express their preferences for future treatment and care through advance care planning. These preferences will guide treatment if they become unable to communicate or participate in decision making.

The government believes that statutory recognition of advance care directives will strengthen the existing implementation of advance care planning in Victoria.

A short history of relevant Victorian law

The common law gives all people with capacity the right to make decisions about what happens to their body. Any interference with a person's body by a health practitioner without consent is unlawful.

Victorian law on obtaining consent to medical treatment when a person does not have capacity has developed over the last 30 years and in response to particular policy concerns.

Guardianship and Administration Act 1986

The Guardianship and Administration Act was enacted to ensure that the 'best interests' of people with 'disabilities' are protected by a guardian. The Act established a scheme for appointing a decision-maker when an adult, because of disability, was incapable of giving consent. The Act enables guardians to be appointed to make decisions for people across a range of issues, including medical treatment.

Refusal of treatment

People have a common law right to demand the withdrawal of treatment, but if illness or injury impaired the capacity of a person, they could not make this demand. The *Medical Treatment Act 1988* established a system to allow people to refuse medical treatment for current conditions. By completing a refusal of treatment certificate, a person with decision making capacity can refuse treatment even if they subsequently become impaired and no longer have decision making capacity.

A person could refuse treatment for current conditions in a legally binding form; however, decision making more generally for patients who were not competent remained in the hands of a guardian appointed by a tribunal. The *Medical Treatment (Enduring Powers of Attorney) Act 1990* introduced the concept of an agent in to the Act to give people greater control. A person could now appoint an agent who would make decisions in accordance with their wishes if they lost the capacity to do so.

Amendment to the Guardianship and Administration Act 1986

The Guardianship and Administration Act was also amended by the *Guardianship and Administration (Amendment) Act 1999*. This acknowledged that there was often not a formally appointed substitute decision-maker, and instead family members or carers make decisions for patients. The Act introduced the concept of a 'person responsible' as a means of ensuring there would always be someone to make a decision.

Mental Health Act 2014

The Mental Health Act provides for the assessment, detention and compulsory treatment of people with severe mental illness. The Act allows a person to prepare an advance statement to guide treatment decisions in the event the person is made a compulsory patient. The Act also allows a person to nominate someone to support and advocate for them. The Mental Health Act will continue to operate alongside the proposed Act.

Powers of Attorney Act 2014

The Powers of Attorney Act introduced the role of an enduring attorney, who may make decisions on health matters. The Act established principles for enduring attorneys, including that they must exercise their power in a way that is least restrictive of the person's ability to decide, and is supportive of their inclusion in the process.

Figure 1: An overview of current approaches to advance care planning in Victoria



The government's proposal

The government believes a person should be able to determine which medical treatment they receive.

When a person has decision making capacity they can control their treatment, but currently a loss of capacity may also result in a loss of control. This can cause people to fear they will be provided with invasive procedures that they do not want, or that the treatment provided will not be consistent with their preferences and values.

The government's proposal will simplify the legal framework for medical treatment decision making when a person does not have capacity and ensure statutory recognition of advance care directives for current and future conditions.

To provide Victorians with a new process for medical treatment decision making, which is consistent with contemporary views about how people participate in decisions about their own healthcare, a new Act would:

- allow a person with decision making capacity to develop an advance care directive
- clarify the process for medical treatment decision making for people who do not have decision making capacity, including requirements to comply with advance care directives
- recognise supported decision making and that, when substitute decision making is required, decisions should be consistent with a person's preferences, values and rights.

The key changes proposed by government are listed in Table 1.



Table 1: Summary of key changes

Issue	Current position	Proposed position
Available legal instruments to make binding treatment decisions	Refusal of treatment certificate – with which a person may refuse treatment for current conditions.	Advance care directive – with which a person may refuse or consent to treatment for current and future conditions and outline their values.
Substitute decision-makers	A person may appoint an agent or an enduring attorney. The Victorian Civil and Administrative Tribunal may appoint a guardian. If no one has been appointed a 'person responsible' may be recognised. Each form of substitute decision-maker has different powers.	A person may appoint a medical treatment decision maker and the tribunal may appoint a guardian. If no one has been appointed, a medical treatment decision-maker may be recognised. Each form of medical treatment decision maker will have the same powers.
Considerations for making substitute decisions	Different legislation contains different considerations, including the person's 'best interests' and the person's wishes.	The proposed Act will contain a single test for all medical treatment decisions and medical research procedure decisions– that the decision is consistent with the person's preferences, values and rights.
Supported decision making	Different legislation contains different tests for capacity and some legislation does not recognise that capacity may vary over time and for different decisions.	The proposed Act will provide that a person should be presumed to have capacity and recognise that they should be supported to make their own decisions. The Act will also provide for the appointment of a support person.
The status of an expression of values	While a person may refuse a particular treatment, it is not clear what legal weight should be given to a written statement of values.	As part of their advance care directive, a person will be able to complete a values directive. Health practitioners and medical treatment decision makers will be required to give effect to a values directive.
Legal obligations of providers	The Medical Treatment Act only applies to registered medical practitioners under the Health Practitioner Regulation National Law and creates a criminal offence of medical trespass for noncompliance.	The proposed Act will apply to all practitioners registered under the Health Practitioner Regulation National Law and paramedics. Noncompliance may constitute unprofessional conduct.

Key elements of the proposed Medical Treatment Planning and Decisions Act

Broader application

The proposed Act would apply to all registered practitioners under the Health Practitioner Regulation National Law and paramedics. The Medical Treatment Act currently only applies to medical professionals. The proposed broader scope reflects changes in the way that medical treatment is delivered and recognises that health practitioners other than doctors have greater responsibilities.

'Medical treatment' is currently defined differently across different legislation. The definition of medical treatment is important because it will determine which treatments can be refused. It is proposed that:

- Palliative care continues to be excluded from the definition of medical treatment. This would preclude people refusing palliative care in an advance care directive and would prevent medical treatment decision makers refusing palliative care. However health practitioners will be required to consider the person's values, including any values expressed in an advance care directive in delivering palliative care.
- The provision and prescription of pharmaceuticals be included in the definition. Prescribed medications can be just as invasive as any other medical treatment and advances in pharmacological therapies mean that they are increasingly used in medical treatment.

An advance care directive for current and future conditions

The proposed Act will enable a person with decision making capacity to prepare an advance care directive. An advance care directive is a document that allows people to express their preferences and values for their future treatment. Ideally, the document is prepared over time, and in consultation with health practitioners, friends and family.

Many people already prepare advance care directives and are supported by health providers to do so; however, their legal status is unclear. A person may also prepare a refusal of treatment certificate for current conditions. In an advance care directive a person will be able to give directives in relation to both current and future conditions.

It is proposed that in an advance care directive a person will be able to:

- give an instructional directive (which will provide specific directives about treatment a person consents to or refuses and which health practitioners must comply with); and/or
- give a values directive (which will describe a person's views and values; a medical treatment decision maker and health practitioners will be required to give effect to a values directive as far as reasonably possible when making treatment decisions); and/or
- appoint a medical treatment decision maker (who will make decisions on behalf of a person when they no longer have decision making capacity); and/or
- appoint a support person (who will assist a person to make decisions for themselves by collecting and interpreting information or assisting the person to communicate their decisions).

Advance care directives encompassing preferences and values

How an advance care directive is used will vary depending on what a person's advance care directive contains. This includes the following circumstances:

- If there is a relevant instructional directive, this may constitute consent to treatment, and a health practitioner may proceed with clinically indicated treatment. The instructional directive may also constitute a refusal of treatment, which would require the health practitioner not to provide, or cease providing, a particular treatment or treatment generally.
- If there is a relevant values directive, the health practitioner must consider the values expressed but will need to turn to a medical treatment decision maker to consent to medical treatment.
- If a medical treatment decision maker is appointed, the health practitioner must turn to this person to receive consent to medical treatment if there is not a relevant instructional directive.

Examples of a values directive:

“If the time comes when I can no longer take part in decisions for my own future, I want to receive whatever quantity of drugs can keep me free from pain or distress, even if death is hastened. If there is no reasonable prospect of recovery I do not consent to be kept alive by artificial means. I do not wish to be transferred to hospital and should like to die in my own bed.”

“I do not want any cancer treatment if my disease progresses to the point where chemotherapy would only make me sicker or offer little benefit and drain any joy that I might otherwise experience in my last days.”

Simplifying decision making for someone without capacity

Rather than just introducing another legal document into an already complex space, it is proposed that a Act would create a consolidated framework for medical treatment decision making if a person does not have capacity to make a decision. The proposed Act would establish a simple process for health practitioners and members of the community to follow.

If a person has decision making capacity, they should always make treatment decisions for themselves.

Under the proposed Act, a health practitioner would need to determine whether a person has decision making capacity and there would be a presumption that a person had capacity. Consistent with contemporary practice, this would be determined by whether the person is able to:

- understand information relevant to the decision and the effect of the decision
- retain that information to the extent necessary to make the decision
- use or weigh that information as part of the process of making the decision
- communicate the decision, as well as their views and needs, in some way, including by speech, gestures or other means.

If a person does not have decision making capacity, a health practitioner will be required to make reasonable efforts to locate an advance care directive.

If an advance care directive is located, a health practitioner will be required to comply with the directive. A failure to comply with the directive may constitute unprofessional conduct.

Supporting people to make their own decisions

For some people with chronic diseases or dementia, for example, their illness trajectory may take them through stages of varying capacity. The proposed changes will make the law more consistent with contemporary practices around decision making, including creating a presumption that a person has decision making capacity and that decision making capacity should be assessed for each decision.

The Act would also recognise that just because a person needs support to make a decision, this does not mean that they do not have decision making capacity.

It is proposed that the role of a 'support person' be formally recognised. A formally appointed support person will assist the person to make their own decisions by having access to medical records (if relevant), communicating on behalf of the person and advocating for them.

“As a nurse with hospice experience I knew my friend could take on the role of advocate for me. I knew that she would help me stay informed, of being in charge of my own life/options. I was determined that I would have the information needed to decide how the last few months of my life would be lived.”

Preferences, values and rights

There are currently a range of tests through which medical treatment decision makers make medical treatment decisions, including 'best interests' tests and requirements that a decision be consistent with the person's wishes. 'Best interests' tests rely on subjective judgments about what the medical treatment decision maker believes would be best for a person. Relying on a person's wishes is equally unhelpful if a person has never expressed a view about the relevant decision.

The proposed Act will introduce a single test to guide medical treatment decision makers when there is not a relevant advance care directive. A medical treatment decision maker will first be required to consider any preferences expressed by the person. If there are no relevant preferences, the medical treatment decision maker will then consider the person's values they would likely consider if they were making the decision. If these also cannot be determined, the medical treatment decision maker will be required to make decisions that are consistent with the person's rights.

Simplifying the medical treatment decision-maker hierarchy

If a person has not given a relevant instructional directive or appointed a medical treatment decision maker, a health practitioner will be required to identify a medical treatment decision-maker to consent to or refuse medical treatment.

The Act would provide a hierarchy for determining who the medical treatment decision-maker is. This is likely to be the first of the following with a close and continuing relationship with the person:

- a spouse or domestic partner
- the primary provider of care and support (excluding paid care providers)
- a child
- a parent
- a sibling, or
- if none of the above can be located, the Public Advocate will be the decision-maker of last resort for medical treatment decisions for 'significant' treatments. If a medical treatment decision maker cannot be located, a health practitioner may proceed with a 'routine' treatment.

The Act would require the medical treatment decision maker to have a close and continuing relationship with the person they are making the decision for.

The Act would also allow the Victorian Civil and Administrative Tribunal (the Tribunal) to recognise a person as a medical treatment decision-maker, even if they do not have one of the listed relationships. For the Tribunal to recognise a medical treatment decision-maker, they would need to assess that the person has a close and continuing relationship and be able to show that, given their understanding of the preferences and values of the person, they would be the most appropriate medical treatment decision maker in the circumstances to make medical treatment decisions.

Removing the confusion about the powers of medical treatment decision makers

It is proposed that the current distinction between an appointed medical treatment decision maker being able to refuse treatment and a medical treatment decision maker recognised by statute being able to withhold consent, be removed. The distinction is confusing and not widely understood. Instead, it is proposed that all medical treatment decision-makers only be empowered to refuse treatment if:

- the medical treatment would cause unreasonable distress to that person, or
- there are reasonable grounds for believing that the person, if they had capacity, after giving serious consideration to their health and wellbeing, would have refused the treatment.

Better safeguards

The proposed Act will contain a number of safeguards to ensure that decisions are consistent with a person's preferences and values.

People will be encouraged to make advance care directives before they are actually required; this ensures they have time to reach considered positions and talk with family, friends and their health practitioners. While people will be advised to regularly review their advance care directive, it is recognised that there will inevitably be situations in which it would not be appropriate to apply an advance care directive.

The proposed Act will allow applications to the Tribunal for an order that an advance care directive should not be applied in the circumstances if circumstances have changed since the completion of the directive so that the practical effect of the directive would not be consistent with the person's preferences and values.

If treatment is required urgently, and there would not be sufficient time to apply to the Tribunal, a health practitioner may choose not to follow an advance care directive if the above circumstances apply. If it is unclear how an advance care directive applies in the circumstances, it will not be applicable.

It is also proposed that an additional safeguard be created to ensure that some decisions are reviewed. Where a medical treatment decision maker refuses significant medical treatment for a person in circumstances where a health practitioner reasonably believes that the medical treatment decision maker is unable to know or infer the person's values or preferences, the health practitioner must notify the Public Advocate. If the Public Advocate finds that the decision to refuse treatment is unreasonable in the circumstances, the Public Advocate must take the matter to the Tribunal. This safeguard will protect people who may never have been able to express their values and preferences or have had decision making capacity.

If there is a disagreement about how an advance care directive should be interpreted or applied in the circumstances, a health practitioner or any person that the Tribunal is satisfied has a special interest in the affairs of the person will be able to apply to the Tribunal to resolve the disagreement.

Young people

People under the age of 18 can consent to medical treatment if they have capacity to understand the nature and effect of the proposed treatment.

The level of maturity of some young people means that they are capable of understanding the nature and effect of a medical treatment. For other young people of the same age their level of maturity may mean they are not capable of understanding the nature and effect of a medical treatment. Advance care directives will allow people to make decisions about their future medical treatment. This may require young people to have a more developed understanding of themselves and an ability to think abstractly to identify how they may feel in the future. While some young people may be able to make decisions about medical treatment required immediately, they may not be able to make more abstract decisions.

The proposed Act will allow anyone with capacity to make an advance care directive. This recognises that, wherever possible, the person most affected by a medical treatment decision should be the person who makes that decision. This would mean that any person under 18 with the capacity to understand the nature and effect of the directive could make an advance care directive.

The parent of a person under 18 will automatically be their medical treatment decision maker.

Cory's story

“I've got a disease that makes me weaker all the time. It's painful and I basically live in hospital now. When they told me it couldn't be cured I was angry and a bit frightened - I'm only 17. My palliative care team is really good. I talk to them about controlling pain, about how I'm feeling, and what I want to do with my life. I can't go home, but I keep in touch with my friends and school. I talk to the carers about my treatment and getting into a hospice closer to home. I know what treatments I want and what I don't want, and they helped me write all that down so it's clear for everyone and they help my family as well.”

(Taken from *Living, dying, and grieving well: a guide to palliative care*)

Consolidating and clarifying laws

Currently the law in relation to medical treatment is spread across different legislation. The proposed Act will consolidate and clarify this law. This will include removing provisions governing medical research procedures from the Guardianship and Administration Act and placing them in the proposed Act.

The proposed Act will not significantly alter these laws, but there may be minor changes because the provisions will be in a proposed Act. For example, the proposed Act will introduce more contemporary concepts of capacity; supported decision making; and substitute decision making. It is anticipated that this will enable more people to make their own decisions. The proposed Act will not use a 'best interests' test, and instead decisions for people without capacity will be made by reference to their preferences, values and rights. This will also apply to decisions about medical research procedures.

The provisions relating to special procedures will remain in the Guardianship and Administration Act. The provisions relating to medical treatment for compulsory patients will remain in the Mental Health Act.



Conclusion

The Victorian Government is committed to giving Victorians a greater say in their healthcare by simplifying the legislation regarding medical treatment decision making.

The government recognises that these proposed changes will require a strong partnership between stakeholders and government to successfully implement the proposed Act and looks forward to working with the health sector and the community.

The government is interested to receive any feedback about the legislation outlined in this position paper. Comments can be provided to the Department of Health and Human Services by emailing [<acp.responses@dhhs.vic.gov.au>](mailto:acp.responses@dhhs.vic.gov.au)

The department reserves the right to publish stakeholders' views regarding the new legislation in subsequent reports or discussion papers. If you do not wish your submission to be quoted in other departmental publications, please indicate this in your submission.



