Office of the Public Advocate

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A clinician's guide to medical decision making

For when the person lacks capacity to undertake advance care planning

The Office of the Public Advocate acknowledges Victoria's Aboriginal communities and their rich culture.
OPA pays respect to their Ancestors, Elders and communities who are the custodians of the land on which we work.

About this guide

This guide for clinicians has been developed by a working group led by Clinical Lead of Advance Care Planning at Northern Health, Dr Barbara Hayes, and is published by the Office of the Public Advocate.

The information in this guide relates to Victoria. It includes reference to relevant legislation, but is not intended to be a comprehensive description of it.
For other supporting resources, see page 15.

For information about the law in other states, territories and countries, refer to resources from those jurisdictions.

Acknowledgements

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Members of a DHHS working group contributed to the development of this resource.

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Public Advocate's message

I welcome you to this resource for clinicians developed by clinicians.

As Victoria's Public Advocate, I have the role of making significant medical treatment decisions for people without capacity to make these decisions and who have no one else with legal authority to do so.

This guide has been developed for clinicians by a Department of Health and Human Services (DHHS) working group, led by Palliative Care Consultant and Clinical Lead of Advance Care Planning at Northern Health, Dr Barbara Hayes.

In preparing the guide, the group has drawn on a wide range of experience.

I would like to acknowledge Victoria's DHHS that funded the development of this resource.

I would also like to acknowledge the working group, which comprised advance care planning clinicians, hospital clinicians, clinicians providing in-reach support to people living in residential aged care services, General Practitioners, and residential aged care clinicians.

A consumer perspective was provided by the Consumer, Literacy, Evaluation and Review group of Northern Health.

I encourage you to read carefully through the guide and trust that you will find it useful in your important work with people who lack decision-making capacity to make their own medical treatment decisions.

Colleen Pearce

Colleen Pearce
Public Advocate

About this guide

This guide covers six areas that relate to making medical treatment decisions for a person who lacks decision-making capacity to consent to their own medical treatment or to refuse the treatment.

1. The medical decision-making framework
2. The role of the medical treatment decision maker
3. Using advance care directives
4. The challenges of making a medical decision for another person
5. The form 'What I understand to be the person's preferences and values'
6. Medical treatment plans.

The focus of the guide is clinical aspects of decision-making.

Find a list of useful supporting resources related to the *Medical Treatment Planning and Decisions Act 2016* on page 15.

Medical decision-making framework

Medical decisions require a partnership between the patient, the patient's medical treatment decision maker (if relevant), and the clinician. This partnership is reflected in the *Medical Treatment Planning and Decisions Act 2016*.

The two sets of expertise that this partnership brings to medical decision-making are:

- the technical knowledge
- the knowledge of the patient — who they are, what they value, and their preferences regarding medical treatment.

Clinicians will generally, though not always, have the greater technical knowledge.

Knowledge of the patient, not surprisingly, is the area of expertise that belongs:

- firstly to the patient
- secondly to those who know them best.

Both sets of expertise are essential to achieve a good decision because, whether the science and technology of medicine will be of benefit to the patient, will depend on how that individual patient values it and any potential risks.

This discussion requires a dialogue where the clinician explains the options in a way that is meaningful for that patient. It requires learning about the patient, their illness experience and what they value, and explaining the treatment options, including possible benefits and adverse effects in a way that engages with what the patient values.

Treatment that could have no benefit for the patient's medical condition should not be offered.

When a patient says 'I want everything done' (or their family or medical treatment decision maker says the patient would 'want everything done'), this can only mean everything that is suitable for the patient's condition.

This may range from admission to intensive care for very invasive life-prolonging treatment to the very best palliative care and symptom management, or somewhere in between.

The tables on the next two pages illustrate the decision-making process for a patient:

- *with* medical decision-making capacity
- *without* medical decision-making capacity.

Partnership to achieve the best possible outcomes

When the patient's medical treatment decision maker and the health professionals work in partnership, they bring together their different areas of knowledge and expertise, to achieve the best possible outcomes for the person. (See page 8 for information about who is a person's medical treatment decision maker.)

Patient *with* medical decision-making capacity

When the patient has capacity to make a medical decision, they can consent to treatment or refuse that treatment. See table below.

Patient *with* medical decision-making capacity	
Step 1 A medical assessment and a medical decision about treatment and what is clinically feasible.	Treatment that could have no benefit for the patient's medical condition should not be offered.
Then, within those constraints...	
Step 2 A discussion between clinician and patient, and their support person or others, if relevant.	Patient provides consent or refuses offered treatments.
Leading to a shared understanding of...	
Step 3 A medical treatment plan including: • overall medical treatment goals • specific emergency medical treatments/limitations, if relevant.	This may include a plan for deterioration.

Patient *without* medical decision-making capacity

When the patient lacks capacity to make a medical decision, it is important to check whether they have provided relevant consent or refusal in:

- an instructional directive in an advance care directive made on or after 12 March 2018 in accordance with the Medical Treatment Planning and Decisions Act
- a refusal of treatment certificate completed prior to 12 March 2018 under the *Medical Treatment Act 1988*.

This consent or refusal is applied without seeking a medical treatment decision by the medical treatment decision maker. Good ethical and medical practice would still require communication with the medical treatment decision maker.

If there are decisions that need to be made that are not covered by an instructional directive or refusal of treatment certificate, then a decision will need to be made by the medical treatment decision maker.

The clinician explains and interprets the medical situation and possible treatment options to the medical treatment decision maker.

The medical treatment decision maker needs to interpret the patient's preferences and values against those options to decide which of the treatments they will consent to, if any.

The clinician may discuss a plan for deterioration, including limits to treatment escalation.

The table below helps illustrate this decision-making process.

Patient *without* medical decision-making capacity	
Step 1 A medical assessment and a medical decision about treatment and what is clinically feasible.	Apply consent or refusal contained in an instructional directive or refusal of treatment certificate, if any.
Then, within those constraints...	
Step 2 A discussion between clinician and medical treatment decision maker, and support person or others, if relevant. (Note: Medical treatment decision maker applies values directive, other advance care planning documents, and known preferences and values.)	For these decisions, the medical treatment decision maker consents to or refuses offered treatment(s), applying patient's preferences and values.
Leading to a shared understanding of...	
Step 3 A medical treatment plan including overall medical treatment goals with specific emergency medical treatments/limitations, if appropriate.	This may include a plan for deterioration.

The role of the medical treatment decision maker

Who can make decisions for the patient who lacks capacity?

The Medical Treatment Planning and Decisions Act provides a hierarchical list of who can be a person's medical treatment decision maker. They can be appointed or non-appointed.

A person's medical treatment decision maker is the first person from the list below who is reasonably available and willing and able to make the medical treatment decision.

1. A medical treatment decision maker appointed by the person*
2. A guardian appointed by VCAT to make decisions about medical treatment.
3. The first adult from the following list who is in a close and continuing relationship with the person:
    a. The spouse or domestic partner
    b. The primary carer of the person
    c. An adult child of the person
    d. A parent of the person
    e. An adult brother or sister of the person.

Where there are two or more relatives in the first position, for example, two children, it is the oldest who will have this role.

There can only be one medical treatment decision maker for a decision. This does not mean that they will be the only person with an interest in the patient and the decision; commonly, discussions will be held with a number of family members or others who care about the patient. However, it is the medical treatment decision maker who has the authority to consent to medical treatment, or refuse that treatment.

Medical treatment decision makers have authority to consent to medical treatment they believe the patient would want, and to refuse medical treatment that they believe the patient would not want.

*** Medical treatment decision maker appointed by the person**

Note: Legal appointments made prior to the commencement of the Act are recognised.

This means that a person may have appointed their medical treatment decision maker in:

- an appointment of medical treatment decision maker under the Medical Treatment Planning and Decisions Act
- a medical enduring power of attorney made before 12 March 2018
- an enduring power of attorney appointing an attorney for personal matters, including healthcare matters, made between 1 September 2015 and 11 March 2018
- an enduring power of guardianship appointing an enduring guardian with healthcare powers made before 1 September 2015.

Also, valid appointments made in other Australian states and territories are recognised in Victoria.

What if there is no medical treatment decision maker?

Some patients will have no one available from the previous list, or no one who is willing to take on the role of medical treatment decision maker.

When the proposed treatment is routine, the health practitioner can proceed in the absence of consent, but is required to fully document their decision and the unavailability of a medical treatment decision maker.

If treatment is significant, medical treatment consent is required from the Office of the Public Advocate (OPA).

How should decisions be made?

The medical treatment decision maker should help the clinician understand the preferences and values of the person that they represent, and to advocate for these.

As far as possible, the medical treatment decision maker should make the same decision that the person would make, if the person had medical treatment decision-making capacity. They should base this on what they know about the person's preferences for treatment and their values — what would matter most to the person. Ideally, this discussion will have taken place while the person was able to explain their own preferences and values, and what they would want taken into account when decisions are made for them.

The medical treatment decision maker can consent to treatment if they believe the person would have consented to the treatment, or refuse the treatment if they believe the person would have refused it.

The preferences and values of the person who is unwell are only part of a medical decision. First, there must be an assessment by doctors or other health professionals about what the treatment options are. Once this medical assessment has been made, there can be a discussion with the medical treatment decision maker about which of these possible treatment options, including no treatment, would be most suitable for the person.

Keep in mind

The medical treatment decision maker is the substitute decision maker for the patient, not the substitute decision maker for the clinician.

How can the medical treatment decision maker know what the person would want?

1. The person may have completed an advance care directive. This could include an instructional directive, which provides consent and/or refusal to treatment in advance.

   If this instructional directive covers the decision that needs to be made, the medical treatment decision maker cannot make the decision, because the person has already made it.

2. The person may have completed another type of advance care directive — a values directive.

   This provides written information about the preferences and values that the person would want their medical treatment decision maker to apply at a time of decision-making. This information guides the decision of the medical treatment decision maker.

3. Not everyone writes a formal advance care directive. A person might choose to write this information down in another way, such as a letter or in some other form. Sometimes, the person talks

to their family about how they would like future medical decisions to be made and what would matter most to them at that time.

4. Sometimes the person does not speak openly to their family about how they would want future medical decisions to be made. However, the way they live their life, and the way they make other decisions, or talk about decisions that others have made, may help the medical treatment decision maker understand what the person thinks important.
5. Sometimes, important information about the person comes from observing how they respond to medical tests and treatments, having to go to hospital, being cared for by new people, or having a different routine.

Recap

All this information will be useful for a person's medical treatment decision maker should they need to make a decision.

The more the medical treatment decision maker knows about the person, the more likely they are to make a decision similar to what the person would have made.

A clinician may need to help a medical treatment decision maker to reflect on what they know about the person's preferences and values.

Patients' and families' stories

Speak with the medical treatment decision maker and others who know the patient well, such as family, friends and other clinicians to find out the patient's story, their illness trajectory or journey, and their experience of illness.

Many patients will have a history of chronic illness or poor health, rather than a single episode of decline. The question prompts below may help.

These questions will help you, the clinician.

They may also help the medical treatment decision maker to reflect on what would be most important for the person, and to separate this from their own response to the person's deterioration.

Often the medical treatment decision maker or family will offer up how they feel, or fear the person's story will end. The family can be quite accurate in their assessment.

Some people become suddenly unwell. If a patient has an acute event on a background of good health, the first two questions in this list will be helpful.

Do not forget that, when a patient does not have capacity to make their own medical treatment decisions, they should still be involved in discussions as much as they are able, or want to be involved.

Question prompts

What matters most to the patient?

What gives their life the most meaning?

Have they said anything about this sort of situation?

How has their illness or health been changing over time?

How did they feel at times when their health got worse?

How have they been coping with the illness?

What do they find is the worst part of the illness?

What do they fear most or worry about most?

What do they hope for?

Using advance care directives

Instructional and values directives

In Victoria, a person with decision-making capacity can complete an advance care directive, which only comes into effect should the person lose their ability to participate in their own medical decisions. This may be a permanent or temporary loss of capacity.

An **instructional directive** provides consent or refusal in advance to specific medical treatments.

A **values directive** describes the things that are most important to the person and that they would want considered by their medical treatment decision maker when making medical treatment decisions.

Health practitioners must act on the treatment consent or refusal contained within an **instructional directive**. The medical treatment decision maker cannot have a role in these decisions that have already been made by the person.

Good professional and ethical practice would still require that the situation is discussed with the medical treatment decision maker. It is also likely that there will be other decisions still to be made, that are not covered by the instructional directive, and which will require decisions by the medical treatment decision maker.

If there is a **values directive**, the medical treatment decision maker must take this into consideration when making any decisions.

As described on pages 9 and 10, there may be other sources of knowledge about a person's preferences and values that are not in a written document.

The medical treatment decision maker is responsible for consenting to medical treatment that they believe the person would want, or refusing treatment that they believe the person would not want. Medical treatment decisions must reflect what the person would want; not what others think is best.

Witnessing an advance care directive

Advance care directives must be witnessed by a medical doctor plus another person.

If you are a doctor, before witnessing an instructional directive, it is important to consider with the person whether they might be unintentionally excluding themselves from wanted treatment in situations they have not anticipated.

See also OPA's **Information for witnesses — Advance care directive** fact sheet.

The challenges of making a medical decision for another person

Making medical decisions for someone else can be hard when the medical treatment decision maker's own preferences and values differ from those of the patient. Others, such as family, may also have different views about what they think is the best decision for the patient.

(The clinician should also be aware of their own preferences and values and how these might differ from those of their patient.)

Making medical decisions for someone else can be hard when:

- there doesn't seem to be a clear choice
- there are two options and the medical treatment decision maker doesn't want to choose either
- decisions need to be made quickly.

The medical treatment decision maker may be feeling tired and emotional, which makes it more difficult to think clearly.

You may find it more useful to ask the medical treatment decision maker how they feel about the situation, rather than what they know. The medical treatment decision maker might also notice a 'head and heart' disconnect. Family members often report that their head knows what is happening but their heart is not yet ready.

Provide information using simple language and concepts. In some situations, diagrams may also help. Information may need to be repeated before it is fully understood and remembered.

Most decisions have potentially good outcomes and some unwanted outcomes.

The medical treatment decision maker is being asked to weigh up these potentially good and unwanted outcomes and choose what they think the person would choose. How much risk of a bad outcome would the person think worth taking, for a chance of a good outcome? This process applies to the most simple of medical decisions as well as the more complex and serious decisions.

When a decision has to be made, the medical treatment decision maker may need reassuring that they can only make the best decision possible with the information they have available at that time.

Sometimes, there is no 'right' or 'perfect' decision; just the best decision possible in the circumstances, taking account of what is known of the person's known preferences and values.

The form, ‘What I understand to be the person’s preferences and values’

Some people will not have completed an advance care directive or any advance care planning documents. Instead, they may have chosen to speak to those closest to them about the things that would be important. This knowledge is really important if a decision needs to be made for the person.

It can be helpful for the medical treatment decision maker and others who know the person well, to write this information down.

There is a form for this.

The process of writing the information down may help the medical treatment decision maker to get their thoughts clearer, prior to any crisis.

The information may also help clinicians if a medical treatment decision maker is not contactable. The information will be helpful if the clinician needs to make an urgent decision about treatment, or if the clinician needs to contact OPA for consent to, or refusal of, significant medical treatment in the absence of a medical treatment decision maker.

Find the ‘What I understand to be the person’s preferences and values’ form:

- on the ‘Resources for people who lack capacity to undertake Advance Care Planning’ page of the Northern Health website
- via a link on the ‘When a person cannot plan for their future’ page of the OPA website (under the ‘Plan for the future’ tab).

The form is completed on behalf of a person who is not able to express their own treatment preferences or values.

It is **not** an advance care directive, nor an advance care planning document. Remember that advance care directives are prepared by a person with capacity, for a time when they do not have capacity.

The aim of this form

The aim of this form is to capture in writing what is known about the person that would help when making future medical decisions for them.

Who can complete this form?

This form can be completed by one or more people who know the person. Those who may write information in this form include:

- the person’s medical treatment decision maker
- a family member, carer or close friend
- a professional care worker who the person has known for some time and who has knowledge of what is important to the person.

If there is conflicting information in the form, that has been provided by different people, this would be a prompt to discuss these different perspectives.

Medical treatment plans

Hospital

In hospitals, it is common to record a medical treatment plan that is completed by a doctor in the form of a Medical Treatment Order.

This can be easily accessed by all clinical staff should the patient's condition suddenly deteriorate. It does not require urgent in-the-moment interpretation of advance care directives.

This is particularly important for appropriate management of urgent deterioration such as cardiac arrest or respiratory distress. Treatment that could have no benefit for the patient's medical condition should not be offered.

Medical Treatment Orders can have many names, such as 'Goals of Patient Care' or a 'Resuscitation Plan'.

Before completing Medical Treatment Orders the doctor should have a discussion with the patient, or their medical treatment decision maker if the patient does not have decision-making capacity for the medical treatment decisions.

A patient with decision-making capacity can provide consent or refuse offered treatments.

Where the patient does not have decision-making capacity, the doctor applies consent or refusal contained in an instructional directive or refusal of treatment certificate, if any. For other decisions, the patient's medical treatment decision maker consents to, or refuses, offered treatment(s), applying the patient's preferences and values.

The patient or their medical treatment decision maker makes medical treatment decisions at the point in time that the medical treatment is actually needed to treat the medical condition. Sometimes a doctor will be able to anticipate that the person may need medical treatment in circumstances that may arise. They may be able to provide the patient, or their medical treatment decision maker, with all the clinical information they will need in order to make the medical treatment decision, if this is required.

Residential aged care facility

In residential aged care facilities, there is a similar need to have a clear medical treatment plan, and clear Medical Treatment Orders, to appropriately manage deterioration.

As previously described, the doctor is able to define the types of deterioration that might be expected, the potential to reverse this, and any limits to what might be possible if a person is already very frail or has multiple co-morbidities.

Transfer to hospital can cause its own harm by moving the person from a familiar environment and their routine. Like any other medical intervention, this requires weighing up the potential benefits against the potential harms.

A residential aged care facility 'Goals of Care' form is available for documenting Medical Treatment Orders for a resident. (See page 15 for where to find this form.) The form can be completed by a Residential In-Reach doctor, General Practitioner, or by a hospital doctor for a person transferring to a residential aged care facility.

Home

If the person lives at home and there are treatments that the clinician knows the person would not benefit from, Medical Treatment Orders can be recorded on letterhead by a doctor. This will be helpful for ambulance paramedics or other health practitioners who might be seeing the person at home.

For example, a person may have advanced respiratory disease and is at risk of deterioration. If they develop acute dyspnoea, an ambulance may need to be called. A decision may have been made that intubation, ventilation and CPR would not be appropriate. The person's doctor can write a Medical Treatment Order to state that the person should not receive these treatments.

There may also be an instructional directive completed by the person giving these instructions. If so, the ambulance paramedics will act on this.

The carer or medical treatment decision maker should make ambulance paramedics or other clinicians aware of these Medical Treatment Orders completed by a doctor, or instructional directive completed by the person.

Where to find the forms and more information

Where to find the forms referred to in this guide

Find the following forms on the 'Resources for people who lack capacity to undertake Advance Care Planning' page of the Northern Health website at **www.nh.org.au**

- 'What I understand to be the person's preferences and values' form
- Examples of 'Goals of Care' forms.

Find a link to the advance care directive form on the OPA website.

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See the 'Information for health practitioners' page of the OPA website (under the 'Medical decisions' tab) for a range of fact sheets and resources.

DHHS resources

See the **health.vic** website (or find a link on the OPA website) for:

- Significant treatment clinical guidelines for the *Medical Treatment Planning and Decisions Act 2016*
- Consent to pharmaceuticals by a medical treatment decision maker
- Summary of the *Medical Treatment Planning and Decisions Act 2016*
- Advance care directives and attempted suicides.

AMA position statement

Clinicians may find it helpful to read the AMA position statement on 'End of Life Care and Advance Care Planning'.
www.ama.com.au

Advance Care Planning Australia

www.advancecareplanning.org.au

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