Office of the Public Advocate

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A medical treatment decision maker's guide

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 medical treatment decision makers 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.

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

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Public Advocate's message

This guide is to help those who might one day have to make a medical decision for someone else. This could be any one of us.

Making medical treatment decisions for someone else can be hard, especially when decisions need to be made quickly.

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

If you are the medical treatment decision maker for another person who lacks the ability to understand or make their own medical treatment decisions, it can be helpful to think ahead of time about what your role involves, and what the person would want.

This guide can help you understand that role and how to prepare for it.

The guide has been developed by a DHHS working group led by a palliative care consultant and Clinical Lead of Advance Care Planning at Northern Health, Dr Barbara Hayes.

The working group has drawn on the clinical experience of its members in preparing this resource for medical treatment decision makers.

I encourage you to take the time to carefully read through it.

You may be asked to make a decision for someone close to you who has not documented their wishes in any type of advance care planning documentation.

If this is the case, you may find it helpful to complete the form, 'What I understand to be the person's preferences and values' to help you think about what is important to the person. You will find information about this towards the end of this guide.

You may also find the Office of the Public Advocate (OPA) fact sheet, 'Information for medical treatment decision makers', helpful. It provides an overview of how medical treatment decision makers must make decisions under the *Medical Treatment Planning and Decisions Act 2016,* and is available on the OPA website.

I would like to acknowledge the Victorian Department of Health and Human Services that funded the development of this resource, and the working group that assisted Dr Hayes.

The working group membership included 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. The Consumer, Literacy, Evaluation and Review group of Northern Health provided a consumer perspective.

Colleen Pearce

Colleen Pearce
Public Advocate

What is a medical treatment decision maker?

When a person lacks the ability to understand or make their own medical decisions, they will need someone to speak for them and to make a medical treatment decision on their behalf.

This person is known as their **medical treatment decision maker**. Of course, there may be others who care about the person and who might also be part of that discussion. For example, family, carers and close friends.

Can the person still be involved in their own decisions?

Even when the person is not able to make their own medical treatment decisions, they should still be involved in any decisions as much as they are able, and as much as they want to be. If time is taken to provide information slowly and in a way that the person is able to understand, the person may be able to contribute to a decision, even if they are not able to fully make their own decision.

Who can be a medical treatment decision maker for an adult?

A person may have appointed someone to be their medical treatment decision maker.* (There are legal requirements for how this is done.)

In Victoria, if the person has not appointed anyone, the Medical Treatment Planning and Decisions Act tells us who has this role.

If the person has a guardian (appointed by VCAT) with authority to make medical treatment decisions, they will be the person's medical treatment decision maker.

Otherwise, the medical treatment decision maker is the first adult from the following list, who has a close and continuing relationship with the person, and who is reasonably available, and willing and able, to take on that role:

- the spouse or domestic partner
- the primary carer of the person
- an adult child of the person
- a parent of the person
- 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.

What if someone does not want to be the medical treatment decision maker?

If a person does not want to be the medical treatment decision maker, they don't have to. In that case, the next person on the list is the medical treatment decision maker. There are good reasons why a person may not want to accept this role. For example, a family member may feel they would be too emotional and upset to be the decision maker, or they may not want that responsibility. They may still wish to be involved in any discussions, although not as the decision-maker.

* Note: Valid appointments made before the Medical Treatment Planning and Decisions Act commenced on 12 March 2018 are recognised. For example, a person appointed under a medical enduring power of attorney, or enduring power of attorney for personal matters including healthcare, would be recognised as the person's 'appointed medical treatment decision maker'.

How should medical decisions be made?

If you are the medical treatment decision maker for a person, you explain to the health practitioner what is important for the person.

As far as possible, you should make the same decision that the person would make for themselves, if they were able to make the decision.

You should base this on what you know about the person's preferences for treatment and their values — what would matter most to them. Ideally, you will have had this discussion while the person was able to explain their own preferences and values, and what they would want taken into account.

As medical treatment decision maker, you can consent (agree) to treatment if you believe the person would want it. You can refuse the treatment if you believe the person would not want it.

The preferences and values of the person who is unwell is only part of a medical decision.

Firstly, the doctors or other health professionals have to assess the person's condition and the treatment options. Once this assessment has been made, they can discuss with you which of these treatment options and potential outcomes would be most suitable.

Key message

Remember that the medical treatment decision maker is not responsible for making the medical assessment and working out which treatments should be considered. This is the responsibility of the doctor or other health professionals.

As medical treatment decision maker, your responsibility is to make decisions on behalf of the person, and to consent to treatment that you believe the person would want.

Listen to what the doctor or health professional says. Ask questions if you do not understand or cannot remember some things that were said.

If you know you are going to talk to the doctor or health practitioner, it can help to write down your questions. It may help to speak to the person's General Practitioner, specialist, or a nurse who knows the person really well.

If there are family or friends who know the person well, it may help to share your thinking with them.

What if there is no one who can act as medical treatment decision maker?

In an emergency, and for simple treatment that is not significant, the doctor or other health practitioner will be able to go ahead with treatment.

For decisions that are more significant, the health practitioner will need to contact OPA to seek consent.

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

1. The person may have completed a written advance care directive. This could be 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, then you (as the medical treatment decision maker) do not need to make the decision — the person has already made that decision for themselves.
2. The person may have completed another type of advance care directive known as a 'values directive'. This provides information about the preferences and values that the person would want their medical treatment decision maker to apply at a time of decision-making.

   The values directive guides you, if you are the medical treatment decision maker who will be responsible for consenting to treatment that you believe the person would want, and for refusing treatment that you believe the person would not want.
3. Not everyone writes an advance care directive, either an instructional directive or a values directive. A person might choose to write this information down in another way, such as a letter or in some other way, such as a 'Statement of Choices' document. 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. This information guides you as the medical treatment decision maker.
4. Sometimes the person does not speak 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 you, as the medical treatment decision maker, to understand, without actual words, what the person thinks important.
5. Sometimes, information comes from observing how the person responds to medical tests and treatments, going to hospital, being cared for by new people, or having a different routine.

Key message

All this information will be useful if you need to make a decision for someone else. The more you know about the person, the more likely you are to make a decision that is similar to what the person would have made for themselves.

If you are the medical treatment decision maker, thinking about the questions on the following page may help you think through: the story of the person's illness or health problems; their illness or health journey; how it has affected their life; and what would be important when making medical decisions.

As you read through these questions and this guide, it may help to write down your thoughts as you go.

Question prompts

- What matters most to the person? 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?

What challenges can a medical treatment decision maker expect?

Making medical decisions for someone else can be hard, especially when your own preferences and values differ from those of the person that you make decisions for.

If you are the medical treatment decision maker, you may find it challenging to have to make decisions that are different from what you would choose in the same situation. Others, such as family, may also have different views about what they think is the best decision.

Key message

Remember, as the medical treatment decision maker, you are representing the person who is ill, rather than your own preferences or the wishes of others.

Advance care planning

Advance care planning is a process for people to plan ahead for a time when they might lose their ability to make or communicate their medical decisions.

It allows the person to still have a say in medical treatment decisions that need to be made by others, on their behalf. Advance care planning can lead to: a written advance care directive (discussed on page 7); other advance care planning documents such as a 'Statement of Choices'; or conversations with those who might need to make future decisions.

Making medical decisions for someone else can be hard when:

- there does not seem to be a clear choice
- there are two options and you do not want to choose either
- decisions need to be made quickly.

If you are feeling tired and upset, it can be difficult to think as clearly as you would want.

Most decisions will have potentially good outcomes and some unwanted outcomes. You are being asked to weigh up these potentially good and unwanted outcomes, and choose what you think the person would choose. How much risk would the person take for a chance of a good outcome?

You may find it helpful to have someone to support you when making decisions.

Key message

When a decision has to be made, you can only make the best decision possible with the information you have available at that time.

If you are the medical treatment decision maker, then considering in advance what the person would want can help you to get your thoughts a little clearer.

- Find out if the person has completed an advance care directive, or other advance care planning documents, and ensure you can access these if you need to.

- You should speak to the person, if they can talk with you. Discuss what they have written in their advance care directive or other advance care planning documents. You should also talk about anything else that would be important to the person when making medical decisions.
- If the person is not able to tell you what would be important, then consider what they have said in the past that would be helpful. What do you already know about the person's preferences and values that would be important for medical decisions?

If the person has an advance care directive, would the medical treatment decision maker still need to make decisions?

In Victoria, a person can complete an advance care directive. This comes into effect if the person loses their ability to make their own medical decisions. For example, if they are confused or unconscious, or they have a condition, such as a stroke, that means they cannot communicate. The advance care directive and other advance care planning documents guide medical decision-making at that time, allowing the person to still have a say in their treatment.

The person may have completed an instructional directive, in which they give consent in advance to specific medical treatments or refuse in advance specific medical treatments. If you are the medical treatment decision maker, you will not need to make these decisions — the person has already made them.

A person may have completed a values directive. This describes the things that are most important to them and that they would want you to take into account in any future medical treatment decisions. The preferences and values described in the values directive must be used by you, as medical treatment decision maker, to help make the decisions that the person would want, as far as this is possible.

What is the form ‘What I understand to be the person’s preferences and values’?

Some people choose not to complete an advance care directive or any other advance care planning documents.

Instead, they may choose to speak to those closest to them about the things that would be important.

If the person becomes unable to make their own medical treatment decisions, capturing this information can be very helpful for you, as their medical treatment decision maker.

Writing the information down can help you remember what would be important, if a decision needs to be made in the future. It can also help guide health professionals.

There is a form for this called ‘What I understand to be the person’s preferences and values’.

Find:

- the form on the ‘Resources for people who lack capacity to undertake Advance Care Planning’ page of the Northern Health website
- a link to the form on the ‘When a person cannot plan for their future’ webpage of the OPA website.

It is completed on behalf of a person who is not able to express their own treatment preferences. If a person is able to express their preferences regarding medical treatment, even if they need help to write these down, they should complete an advance care directive.

Key message

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.

What information should be included in the form?

Those completing this form should try to ‘stand in the shoes’ of the person and draw upon what they know about the person. If possible, the person to whom the form applies, should be involved as much as they are able or want to be.

Knowledge about the person, their preferences and values may come from:

- things they have said in the past about their healthcare or medical treatment, including their hopes and fears for their health

- things they have said about what they value in life; what gives their life the most meaning and pleasure and what they are most afraid of
- what can be known about them from observing how they live their life, how they make decisions, and what they give priority to in any decisions
- what is known about them from observing how they respond to medical tests and treatments, going to hospital, being cared for by new people, or a different routine.

The form can be added to over time by other people who know the person, or as new information becomes available or as the person's health changes.

What happens to the completed form?

Any updates should be made on the original form and only copies given to others, such as health services or doctors.

The person may have completed other documents:

- appointment of a medical treatment decision maker
- an instructional and/or values directive in an advance care directive
- other written information about medical treatment preferences and values.

Documents completed by the person, when they were able to, would be given priority by the medical treatment decision maker over the 'What I understand to be the person's values and preferences' form.

If you are the medical treatment decision maker, you should know where these documents are and provide a copy to the person's doctors, health services, or aged care services. Do not wait to be asked: tell health professionals or services that these documents exist. You may be asked to provide a copy of any documents.

How are a person's preferences and values turned into a medical treatment plan?

In hospitals or aged care facilities, information in the form 'What I understand to be the person's preferences and values' and any advance care directives or advance care planning documents, can be incorporated into a medical treatment plan.

The reason for this is that the preferences and values need to be brought together with the medical knowledge about the person's health issues and what problems might develop in the future.

The doctor can explain about:

- the person's condition
- how the illness is progressing
- what has caused any current change
- how likely it is that any episodes of future illness might be reversed.

They can also explain what treatment options would be suitable.

You, as the medical treatment decision maker, can then decide what options the person would want and that you consent to. You can also refuse any treatments you know the person would not want.

You will be asked to make medical treatment decisions at the point in time that the medical treatment is actually needed to treat the medical condition.

Sometimes, for example when a person is admitted to hospital, a doctor will anticipate that the person may need medical treatment in circumstances that may arise. They may be able to provide you with all the clinical information you need in order to make the medical treatment decision, if this treatment is required.

Keep in mind that the decisions about what type of medical treatment should be offered, and what treatment would not be beneficial, are ultimately clinical decisions of the doctor.

The medical treatment plan is written down by the doctor so that all staff can follow it. There are different names for this. For example, 'Goals of Care'.

If the person is at home, a General Practitioner can write a medical treatment plan in a letter which can be shown to ambulance paramedics or other health practitioners.

Why do doctors want to discuss CPR and resuscitation? A decision example

Discussions about whether to start cardiopulmonary resuscitation (CPR) are common in hospitals or aged care facilities.

CPR is the chest compressions and breathing help that is done when someone's heart stops beating (a cardiac arrest) or when someone stops breathing.

If someone's heart stops beating while they are out shopping or at a sporting event, bystanders are encouraged to attempt CPR. This is because it is often not clear at the time whether the person might benefit from CPR or not, and there is no time to think about it.

In hospitals or in aged care facilities the treating doctors will know more about the person's medical condition. They will, therefore, be able to judge:

- whether CPR would get the heart beating again or not
- how likely it is that the person would survive at their current level of health and function, or have some loss of function.

The doctors may want to have a plan in case the person's heart does stop beating.

If the patient lacks capacity to make their own medical treatment decisions, doctors will want to have a discussion with the medical treatment decision maker about this.

The medical treatment decision maker may also have information about the person's preferences and values that the doctor should know about.

Whether or not to start CPR is a clinical decision of the doctor.

If doctors know that CPR would not be successful then, despite any information that the medical treatment decision maker has about the values and preferences of the person, the doctor would not start CPR.

The discussion would instead be about why the doctor would not start CPR, and about what other treatments could still be appropriate.

A difficult discussion

The discussion with the doctor can be a really difficult discussion for the medical treatment decision maker.

Doctors know this is difficult but they also don't want to cause harm by providing treatment that the person would not want, or treatment that could not be successful.

This is why this difficult but important discussion is sometimes necessary, and why it is brought up by doctors or other healthcare staff.

Where to find the form and more information

Where to find the form

For the form:

> 'What I understand to be the person's preferences and values'

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

Alternatively, find a link to the form on the 'When a person cannot plan for their future' webpage of the OPA website.

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www.publicadvocate.vic.gov.au

Visit the OPA website for:

- a link to the form 'What I understand to be the person's preferences and values' (go to the 'When a person cannot plan for their future' webpage of the OPA website).
- information for medical treatment decision makers
- information about how to appoint a medical treatment decision maker and a link to the form
- information about advance care directives and a link to the advance care directive form.

If you need an interpreter to speak to the OPA Advice Service, let OPA know when you call, and OPA will arrange for a telephone interpreter.

Better Health website

www.betterhealth.vic.gov.au/havetheconversation

Visit the Better Health website for information about advance care planning.

There are also links to the appointment of medical treatment decision maker, and advance care directive forms.

Advance Care Planning Australia

Advance Care Planning Australia is a national program with resources for individuals and family, friends, and carers.

www.advancecareplanning.org.au

Other

Your local health service or doctor may also have information about advance care planning.

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