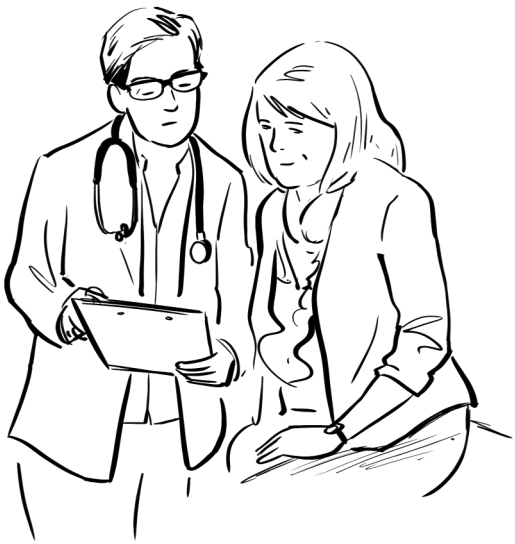
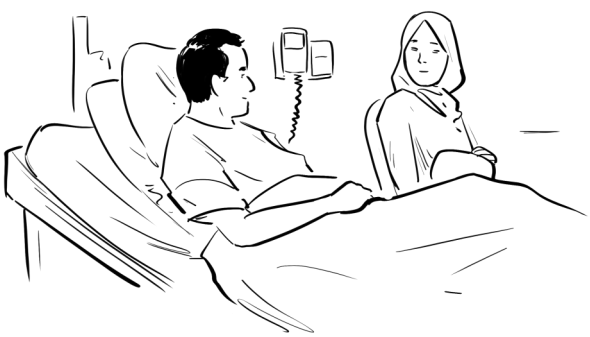
A guide for Consumers

MAKING MEDICAL DECISIONS FOR ANOTHER PERSON

Includes information about the form,

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





This guide covers the following topics:

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

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.

A person who has been appointed before 12th March 2018 as: a Medical Enduring Power of Attorney; a Guardian with health care powers; or an Enduring Power of Attorney with authority for personal matters, would also be called the MedicalTreatment Decision Maker.

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?

A person may have appointed someone to be their Medical Treatment Decision Maker.

If the person has not appointed someone to be their Medical Treatment Decision Maker, **Victorian law** tells us who should have this role. The Medical Treatment Decision Maker is the first available 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 child who will have this role.

What if someone doesn't want to be the Medical Treatment Decision Maker?

If a person does not want to be the Medical Treatment Decision Maker, they do not 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 Medical Treatment Decision Maker.

What if there is no-one who can act as Medical Treatment Decision Maker?

In an emergency, and for simple decisions that are not significant, the doctor will be able to go ahead with treatment. For decisions that are more significant, they will need to contact the Office of the Public Advocate for consent.

Sometimes VCAT (Victorian Civil and Administrative Tribunal) appoints a Guardian to make medical treatment decisions. This can occur when a person has no-one available from the above list or if there is disagreement about who would best represent the person.

How should medical decisions be made?

The Medical Treatment Decision Maker explains to the health practitioner, and any other relevant person, what is important for the person that they represent. As far as possible, they should make the same decision that the person would make for themself.

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.

The Medical Treatment Decision Maker can consent (agree) to treatment if they believe the person would want that treatment. They can refuse the treatment if they believe the person would not have wanted that treatment.

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, there can be a discussion with the Medical Treatment Decision Maker about which of these treatment options and potential outcomes would be most suitable.

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.

If you are a 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 don't understand or can't remember some things that were said. If you know you are going to talk to the doctor or health professional, 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.

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 the Medical Treatment Decision Maker does not need to make the decision – the person has already made that decision for themself.

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 the Medical Treatment Decision Maker to apply at a time of decision making. This information guides the decision but the Medical Treatment Decision Maker will be responsible for consenting to treatment that they believe the person would want and for refusing treatment that they 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 on some other form, 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.

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 the Medical Treatment Decision Maker to understand, without actual words, what the person thinks important.

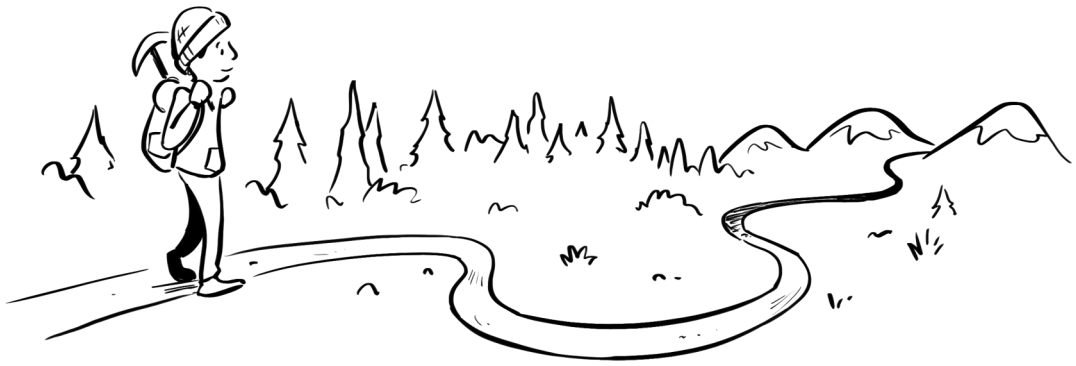
5. Sometimes, information comes from **observing** how the person responds to medical tests and treatments, going to hospital, being cared for by new people, or having a different routine.

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 themself.

If you are the Medical Treatment Decision Maker, thinking about the following questions 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.

- ⇒ **What matters most to them? 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 the Medical Treatment Decision Maker's own preferences and values differ from those of the person that they 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

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.

Making medical decisions for someone else can be hard:

- When there doesn't seem to be a clear choice; when there are two options and you don't want to choose either.
- When decisions need to be made quickly. If you are feeling tired and emotional 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 of a bad outcome would the person think worth taking for a chance of a good outcome.

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

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. **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 4); other **Advance Care Planning documents** such as a **Statement of Choices**; or conversations with those who might need to make future decisions.

⇒ You should speak to the person, if they are able. Talk about 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 participate in the own medical decisions. For example, if they are confused or unconscious, or they have a condition that affects their ability to 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.

A person can complete an **Instructional Directive**, in which they give **consent in advance** to specific medical treatments or **refuse in advance** specific medical treatments. The Medical Treatment Decision Maker will not need to make these decisions - the person has already made them.

A person can also complete a **Values Directive**. This describes the things that are most important to them and that they would want taken into account in any future medical treatment decisions. The **preferences and values** described in the **Values Directive** must be used by the 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 have not completed an **Advance Care Directive** or any other **Advance Care Planning documents**. Instead they choose to speak to those closest to them about the things that would be important. This knowledge is important if a decision needs to be made for the person. Writing this down in a form, like the **'What I understand to be the person's preferences and values'** can help the Medical Treatment Decision Maker remember what would be important, if a decision needs to be made in the future. It can also help guide health professionals if the Medical Treatment Decision Maker is not available and a decision needs to be made quickly. This form is discussed on the next page.

This form is available on the Victorian Department of Health and Human Services Advance Care Planning website. https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning

It is **completed on behalf of a person who is not able to express their own treatment preference**s. 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**.

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 involved.

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. What are they 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?

The original of the form, **'What I understand to be the person's values and preferences'** should remain with the person who has completed the 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 also completed other documents: (i) **appointment of a Medical Treatment Decision Make**r; (ii) an **Instructional and/or Values Directive**; or (iii) **other written information** about medical treatment preferences and values. Documents completed by the person themself would be given priority 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. Don't 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?

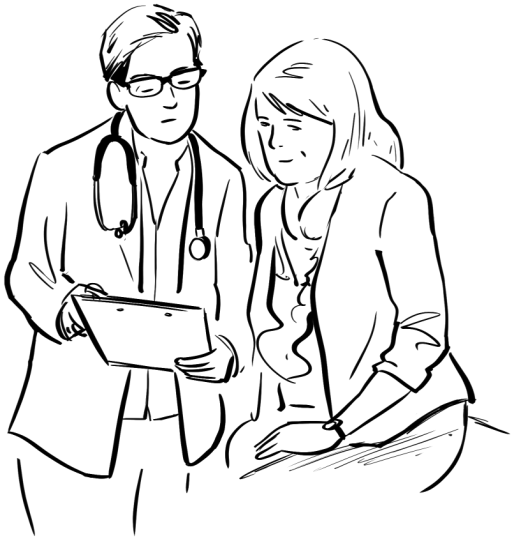
In hospitals or aged care facilities, information in the form, **'What I understand to be the person's preferences and values'** and any **Advance Care Directives** or **Advance Care Planning documents**, can be incorporated into a medical treatment plan.

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; and how likely it is that any episodes of future illness might be reversed. They can also explain what treatment options would be suitable.

The Medical Treatment Decision Maker can then decide what treatment options the person would want and that they would consent to. They can also refuse any treatments they know the person would not want.

This medical treatment plan is then written down so that all staff can follow it. There are different names for these medical treatment orders. For example, 'Goals of Care'.



If the person is at home, and there are some treatments that the Medical Treatment Decision Maker knows the person would not want to receive, or has been told would not work, this can be discussed with their General Practitioner. The GP can write medical treatment orders in a letter, to be shown to ambulance paramedics or other health professionals,

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

Discussions about whether to start cardiopulmonary resuscitation or 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. They will also be able to judge 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 doctors think CPR could be successful, they will want to have a discussion with the Medical Treatment Decision Maker about whether the person would want to have CPR.

Depending on a person's preferences and values, the Medical Treatment Decision Maker might agree to CPR. However, they may refuse future CPR if they believe the person would not want it because the chance of CPR working is too low and the risk of surviving, but not being able to do the things the person would want, is too high.

If the doctors know that CPR would not be successful then the Medical Treatment Decision Maker won't need to make a decision. The discussion would instead be about why the doctor would not start CPR, and about what other treatments could still be appropriate.

This 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 from 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 health care staff.

Where can I find more information?

Information about **Medical Treatment Decision Maker appointments, Advance Care Directives** and the form**, 'What I understand to be the person's preferences and values'** is available from:

Office of the Public Advocate Victoria

www.publicadvocate.vic.gov.au or Phone 1300 309 337

Department of Health and Human Services Victoria

Advance Care Planning Program

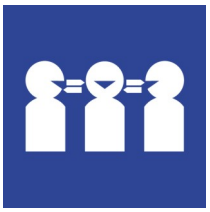
www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/advance-care-planning

Advance Care Planning Australia

www.advancecareplanning.org.au

Your local health service or doctor may also have this information

If you need an interpreter, please speak to your health care staff or call via TIS on 131 450



This Consumer Guide was prepared by a Working Group funded by the Department of Health and Human Services Victoria and Chaired by Dr Barbara Hayes (Northern Health). The Working Group membership included the Office of the Public Advocate Victoria, Advance Care Planning clinicians, Hospital and Residential In-Reach clinicians, General Practitioners and Residential Aged Care clinicians. The Consumer, Literacy, Evaluation & Review Group of Northern Health provided a consumer perspective.