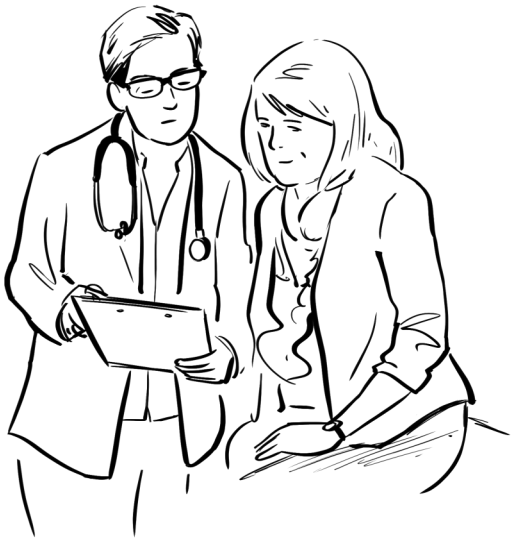
A guide for Clinicians

MEDICAL DECISION MAKING AND THE PERSON WHO LACKS CAPACITY

Includes information about

'Advance Care Directives & the form,

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



This Clinician Guide, together with: a Consumer Guide, *'Making Medical Decisions for another person'*; and a form, '*What I understand to be the person's preferences and values*' have been developed by a Working Group of the Department of Health and Human Services Victoria.

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This guide covers five areas that relate to making medical treatment decisions for a person who lacks medical decision making capacity to consent to their own treatment or to refuse that treatment:

1. **Medical decision making framework**
2. **The role of the Medical Treatment Decision Maker**
3. **Using Advance Care Directives**
4. **The form, 'What I understand to be the person's preferences and values'**
5. **Translating preferences & values into a medical treatment plan**

The focus of the guide is clinical aspects of decision making. This includes reference to relevant legislation but it is not intended to be a comprehensive description of this legislation, nor legal advice.

Supporting Resources

Reference is made throughout this document to resources that are 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

This website provides more detailed information about Advance Care Directives, Medical Treatment Decision Makers, and Consent. These resources should be consulted for further information. They include:

- Summary of the *Medical Treatment Planning and Decisions Act 2016*
- Guide to the *Medical Treatment Planning and Decisions Act 2016*
- Significant treatment clinical guidelines for *Medical Treatment Planning & Decisions Act 2016*
- A Guide for Consumers: Making medical decisions for another person.

Clinicians may find it helpful to read the ***AMA position statement on End of Life Care and Advance Care Planning***. https://ama.com.au/position-statement/end-life-care-and-advance-care-planning-2014

Advance Care Directive forms and information can be obtained from the **Office of the Public Advocate** website www.publicadvocate.vic.gov.au or Phone 1300 309 337

1. Medical decision making framework

Medical decisions require a partnership between patient and clinician. This partnership is reflected in the *Medical Treatment Planning and Decisions Act 2016.* The two sets of expertise that this partnership brings to the medical decision making are:

(i) the technical knowledge. This is where the clinicians will generally, though not always, have the greater expertise and experience; and

(ii) the knowledge of the patient, who they are, what they value, and their preferences regarding medical treatment. Not surprisingly, this is the area of expertise that belongs firstly to the patient, and 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. This requires learning about the patient, their **illness experience** and **what they value,** and explaining the treatment options, including possible benefits and possible adverse effects in a way that engages with what the patient values.

When the 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.

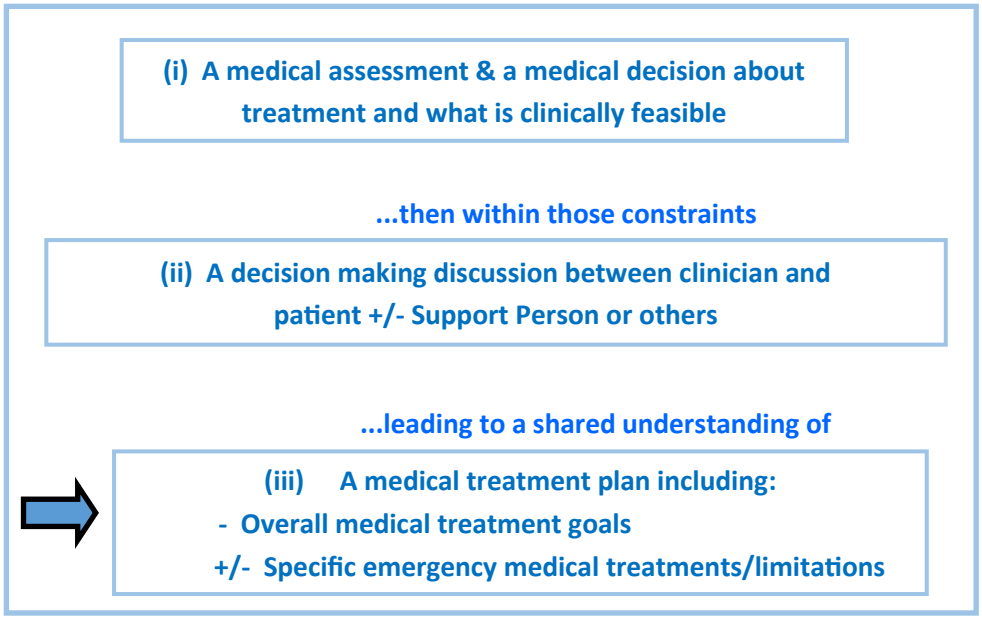
When the patient has capacity to make a medical decision, they can consent to treatment or refuse that treatment.

Treatment that could have no benefit for the patient's medical condition should not be offered. When a patient or family or Medical Treatment Decision Maker (MTDM) 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.

When the patient lacks capacity to make or communicate a medical decision it is important to check whether they have provided relevant consent or refusal in an **Instructional Directive** or in a **Refusal of Treatment Certificate that was completed prior to 12th March 2018**. This consent or refusal is applied without seeking medical treatment consent from the MTDM. Good ethical and medical practice would still require communication with the MTDM.

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 MTDM. The clinician explains and interprets the medical situation and possible treatment options to the MTDM. The MTDM needs to interpret the patient's **preferences and values** against those options to decide which of the treatments they will consent to, if any. This may include a plan for deterioration, including limits to treatment escalation. The following diagrams help illustrate this decision making process.

Patient *with* medical decision making capacity



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

ii. Patient provides consent or refuses offered treatments

iii. This may include a plan for deterioration

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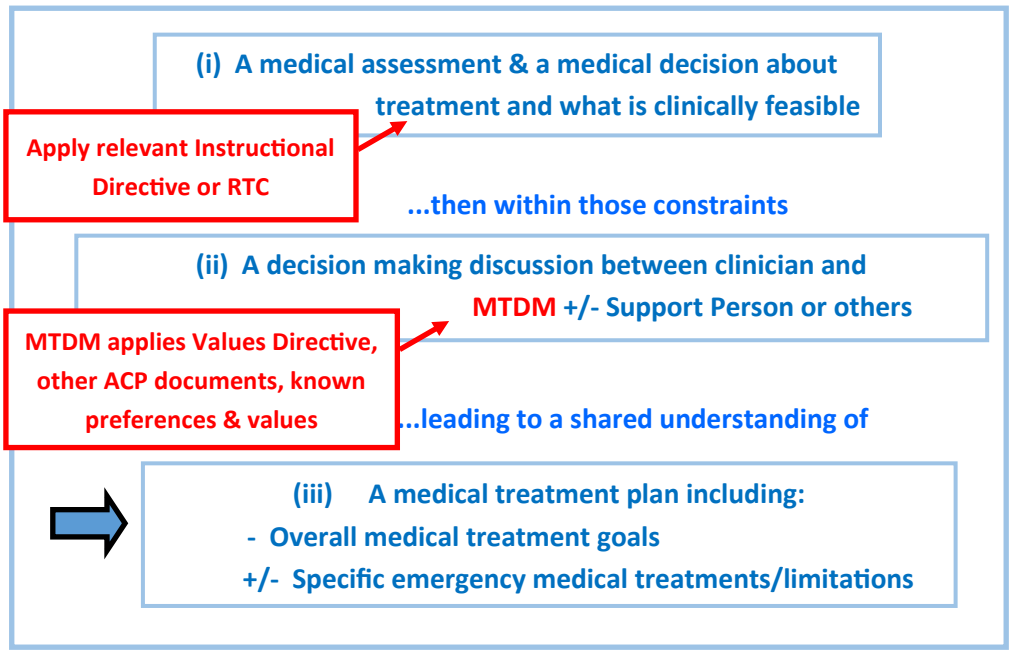
Patient *lacking* medical decision making capacity



i. Apply consent or refusal contained in an Instructional Directive or Refusal of Treatment Certificate (RTC)

ii. For other decisions, the MTDM consents to or refuses offered treatment/s, applying patient's preferences and values

iii. This may include a plan for deterioration

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2. 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 2016* provides a hierarchical list of who can be a person's Medical Treatment Decision Maker.

They can be appointed or non-appointed:

1. A person may have appointed someone to be their Medical Treatment Decision Maker. (includes appointments made prior to 12th March 2018 of Medical Enduring Power of Attorney, Guardian with health powers, or Enduring Power of Attorney with authority for personal matters)

2. VCAT may have appointed a Guardian to make medical treatment decisions.

If there is no-one appointed, as above, 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**:

3. The spouse or domestic partner
4. The primary carer of the person
5. An adult child of the person
6. A parent of the person
7. 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.

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.

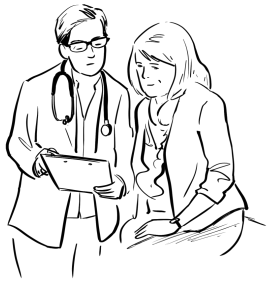
All Medical Treatment Decision Makers have authority to consent to medical treatment they believe the patient would want and to refuse medical treatment that they believe the patient would not want.

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 (see Significant Treatment Guidelines).

On occasions it may be necessary to apply to VCAT to appoint a Guardian for medical treatment decisions.

How should decisions be made?



The Medical Treatment Decision Maker (MTDM) 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 MTDM should make the same decision that the person would make for themself, 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 MTDM 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 that treatment.

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

If the health practitioner has any concerns about who should be the MTDM or the decision making process, the Office of the Public Advocate is available to help.

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 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, the Medical Treatment Decision Maker (MTDM) cannot 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 written information about the **preferences and values** that the person would want the MTDM to apply at a time of decision making. This information guides the decision and the MTDM 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 a formal **Advance Care Directive**. A person might choose to write this information down in another way, such as a letter or on 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 MTDM 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.

All this information will be useful for the Medical Treatment Decision Maker should they need to make a decision for someone else. The more they know about the person, the more likely they are to make a decision similar to what the person would have made for themself. A clinician may need to help a Medical Treatment Decision Maker to reflect on what they know about the person's preferences and values.

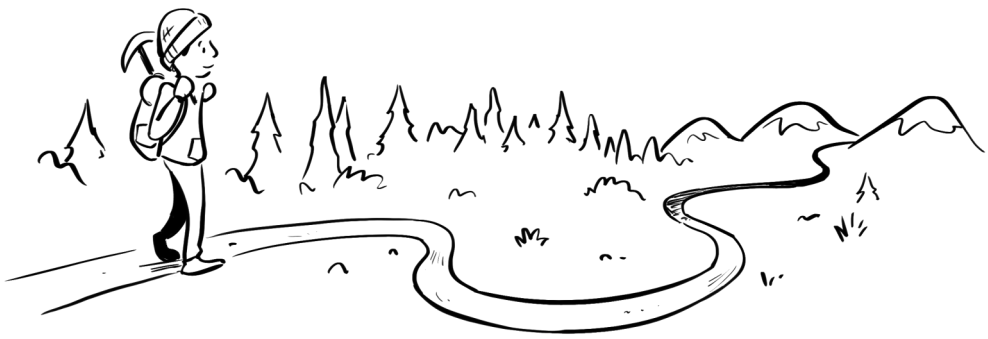
Patients and families tell stories. Speak with the Medical Treatment Decision Maker (MTDM) and others who know the patient well, such as family, friends and other clinicians to find out the patient's story; their illness trajectory or journey, and their experience of illness.

Many patients will have a history of chronic illness or poor health, rather than a single episode of decline. The questions in the following box may help. They will help you, the Clinician. They may also help the MTDM to reflect on what would be most important for the person they represent, and to separate this from their own response to the person's deterioration. Often the MTDM 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.

Don't forget that when a patient lacks 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.

- ⇒ **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?**



3. Using Advance Care Directives

Instructional and Values Directives

In Victoria, a person with 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 (MTDM) when making medical treatment decisions.

Health practitioners must act on the treatment consent or refusal contained within an **Instructional Directive.** The MTDM cannot have a role in these decisions that have already been made by the person for themself. Good professional and ethical practice would still require that the situation is discussed with the MTDM. 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 MTDM.

If there is a **Values Directive**, the MTDM must take this into consideration when making any decisions. As described on page 6, there may be other sources of knowledge about a person's preferences and values that are not in a written document. The MTDM 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 best.

Advance Care Directives must be witnessed by a 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 them-self from wanted treatment in situations they have not anticipated.

The challenges of making a medical decision for another

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
- when there are two options and the Medical Decision Maker doesn't want to choose either
- When decisions need to be made quickly. The Medical Treatment Decision Maker (MTDM) may be feeling tired and emotional, which makes it more difficult to think clearly. You may find it more useful to ask the MTDM how they **feel** about the situation, rather than what they **know**. The MTDM 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 MTDM 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.

4. 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 choose 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 MTDM and others who know the person well, to write this information down in a form called, **'What I understand to be the person's preferences and values'**. This process may help the MTDM to get their thoughts clearer prior to any crisis.

This 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 completed form may also help clinicians if a MTDM 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 the Office of the Public Advocate for consent to, or refusal of, significant medical treatment in the absence of a MTDM.

This form is available on the Victorian Department of Health and Human Services website and the Better Health Channel website. It is a form that 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.**

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?

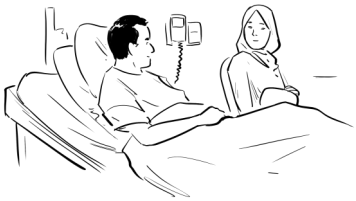
This form can be completed by one or more people who know the person. Those who may write information in this form include:

- 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.

5. Translating preferences and values into a medical treatment plan

Hospital



In hospitals it is common to record a Medical Treatment Plan, that is completed by a doctor in the form a Medical Treatment Order. This can be easily accessed by all clinical staff should the patient's condition suddenly deteriorate. It doesn't require in-the-moment interpretation of **Advance Care Directives, preferences and values** at a time of urgent decision making. This is particularly important for appropriate management of urgent deterioration such as cardiac arrest or respiratory distress. These Medical Treatment Orders take account of the patient's medical condition, as well as their preferences and values. Such a document can have many names, such as 'Goals of Patient Care' or a 'Resuscitation Plan'.

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. An **Instructional Directive** provides medical treatment consent and/or refusal in advance but the consent and refusal can only apply to the treatments being offered by the clinician. A **Values Directive** and information about a person's **preferences and values** are used to guide medical treatment decisions. As previously described, the person's **Advance Care Directive, preferences and values** are only part of the medical decision. There also needs to be medical input that 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, from the patient's perspective, applying their **preferences and values**.

A **Residential Aged Care Facility 'Goals of Care'** form is available for documenting Medical Treatment Orders for a resident. Examples are available from the **Department of Health & Human Services Victoria** website or local **Residential Aged Care In-Reach services**.

The form can be completed by a Residential In-Reach doctor or 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 wish to receive, or 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, they may need to call the ambulance. A decision may have been made that intubation, ventilation and CPR would not be appropriate, or would not be wanted by the person. If there is an Instructional Directive giving these instructions, ambulance paramedics will act on this.

If the **Advance Care Directive** does not cover the situation or if the person lacks capacity to complete an **Advance Care Directive**, their doctor can write a medical order to state that the person should not receive these treatments.

The carer or Medical Treatment Decision Maker should make ambulance paramedics or other clinicians aware of these orders.

Further information 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