eastern community legal centre

# Planning Your Future Medical Care

*A guide for older people*

VICTORIA State Government

HUMAN RIGHTS
FAIRNESS
JUSTICE

# Planning Your Future Medical Care

To help make sure your wishes are followed if you can't make medical decisions for yourself in the future, you have the option of taking these three steps:

1

**Appoint a medical treatment decision maker.**

Choose someone you trust and who understands what is important to you in terms of medical care. Formalise this in writing in a way that complies with the law.

**To find out more, see PART 1 of this Guide.**

2

**Make an Advance Care Directive**

Write down what is important to you and what medical treatment you do and do not want in a document called an "Advance Care Directive".

**To find out more, see PART 2 of this Guide.**

3

**Talk to people you trust.**

Talk to people you trust about what you want in terms of your future medical care.

**To find out more, see PART 3 of this Guide.**

# Contents


**What this Guide is about** ..... 6

**Legal information in this Guide** ..... 6

**Part 1: Your medical treatment decision maker** ..... 10

Step 1 **Think about who you might choose**
Think about who you would want to make medical decisions for you if you couldn't. ..... 12

Step 2 **Decide if you want to appoint someone**
Decide if you want to formally make someone your 'medical treatment decision maker'. ..... 15

Step 3 **Decide what you don't want them to do**
Decide if there is anything you don't want them to do. ..... 16

Step 4 **Make careful choices**
Make careful choices to avoid problems. ..... 17

Step 5 **Make it official**
Formalise it in writing in a way that complies with the law. One way this can be done is with a form called an 'Appointment of Medical Treatment Decision Maker Form.' ..... 18


This Guide is general in nature and does not take into account your personal situation. You should seek legal advice if required. This Guide is specific to Victoria and may not be relevant or appropriate for people outside of Victoria.


**Part 2: Advance Care Directives** ..... 20

Step 1 **Plan ahead for your future medical care**
Think about what you want for your future medical care. ..... 22

Step 2 **Make careful choices**
Make careful choices to avoid problems. ..... 26

Step 3 **Make it official**
Formalise it in writing by doing an 'Advance Care Directive' document. ..... 28

**Part 3: Conversations about your future medical care** ..... 30

**Discussing your future medical care** ..... 30

**Wrapping up: Other important information** ..... 34

**After completing any medical planning document** ..... 34

**Complete the medical decisions checklist** ..... 36

**What to do if you change your mind** ..... 37

**Decision making capacity** ..... 38

**Further assistance** ..... 39

# What this Guide is about

Everybody wants their decisions about their own medical care to be heard, respected and followed, no matter what stage of life they are in.

This Guide is for older people who want to plan ahead and make informed decisions about their future medical care. While this Guide has a focus on older people, the law explained in this Guide applies to all Victorians and may be useful for people of any age, particularly those experiencing health challenges.

The Guide outlines the legal options available to you to help make sure your wishes and preferences for your medical care are respected, including:

1. **Choosing someone to make medical decisions for you, if you can't do it yourself, and**
2. **Recording what medical care you want (and don't want) in future.**

By planning your future medical care, you can have peace of mind knowing that, if you can't make your own decisions, others will know what you want and what is important to you. You can also reduce stress for your family and loved ones.

Legal language can be confusing to anyone. This can sometimes make it difficult to understand your rights and options. That's why this Guide explains legal terms in simple language that's easier to understand.

## Legal information in this Guide

This Guide is general in nature and does not take into account your personal situation. You should seek legal advice if required. This Guide is specific to Victoria and may not be relevant or appropriate for people outside of Victoria.

The three main topics covered in this Guide are:

**1**

### Appointing a medical treatment decision maker

- You can authorise someone to make medical decisions for you if you can't (such as if you are injured or very sick).
- In Victoria, this must be done in writing and cover specific things in order to be valid. It can be done via a form called an "Appointment of Medical Treatment Decision Maker" but doesn't have to be.
- This Guide explains how to go about appointing a medical treatment decision maker.

**2**

### Making an Advance Care Directive

- You can record what medical care and treatment you want in the future, and your doctor and anyone making medical decisions for you has to follow your wishes (with some limited exceptions).
- In Victoria, this is done via a document called an "Advance Care Directive".

**3**

### Having conversations about future medical care

- Talking to the people you love and trust about your future medical care is really important. But it can be a difficult thing to discuss. We discuss how you can best prepare for and have these conversations.

**We recommend that everyone considers these topics and thinks about what they should do next to plan for their future medical care.**

However, you don't have to make both types of documents that we discuss in this Guide or have the types of conversations that are suggested – you may choose to do just one or two of these things, or none of them at all – it's up to you. If there's anything in this Guide that you chose not to do, you should think about any problems that may come up if you don't take that step and keep it in the back of your mind as an option for later.

## What is capacity?

To make medical planning documents, you need to have what lawyers call ‘decision-making capacity’ or simply ‘capacity’.  Capacity is explained on page 38 of this Guide.

## JING’S STORY

**Jing wanted to plan her future medical care. Before her husband passed away, he had relied on Jing to make his medical decisions when he became unable to make them for himself. This experience made Jing think about what would happen if she couldn’t make decisions about her own medical care.**

**After doing some reading on the topic, she decided to:**

- appoint someone as her medical treatment decision maker; and
- make an Advance Care Directive, to explain what medical treatment she would or wouldn’t want.

Although Jing had avoided conversations about her future medical care with her family before, she also decided to speak to her family about it, to allow them to discuss it openly and help them understand what is important to her.

Jing downloaded the Appointment of Medical Treatment Decision Maker form from the Victorian Department of Health website. In the document, she made her son Stephen the first medical treatment decision maker and daughter Jane as the second. Jing decided not to appoint her eldest daughter Sarah, because Sarah had said to her that she would find it too difficult to make important decisions about Jing’s medical care. After carefully completing the form and following the instructions, Jing signed the form in front of a Justice of the Peace and another adult witness. Jing also spoke with her GP about making an Advance Care Directive.

After some advice from her GP, Jing downloaded an Advance Care Directive form from the Victorian Department of Health website. She completed the form herself, but also got advice from her GP about what to put in it. In her Advance Care Directive, she included:

- A values directive – including an explanation about what the most important things in her life were and health outcomes she wanted to avoid.
- An instructional directive explaining that she did not want to be given a particular medication that she had experienced negative side effects from in the past.

Jing knew that medical professionals would legally have to follow the instructional directive she had made. She made sure to get advice from her GP about the risks involved with what she had written. Her GP and another adult also witnessed her sign the document.

After her Appointment of Medical Treatment Decision Maker and Advance Care Directive forms were completed and signed, she made copies of the documents and had them certified by a Justice of the Peace. She then gave copies of the documents to Stephen and Jane, and put the original documents in a folder with her other important papers.

PART ONE

# Your medical treatment decision maker

If in future you can't make medical decisions for yourself, because of injury or illness, someone else might need to make those decisions for you. In Victoria, that person is known as a 'medical treatment decision maker'.

**You can choose who will be your medical treatment decision maker in writing, but it has to meet certain rules to be valid. One simple way to do that is by completing a form called an 'Appointment of Medical Treatment Decision Maker', which is available on the Victorian Department of Health website.**

**Steps 1-5 of this Part of the Guide explain the steps you should take to appoint a medical treatment decision maker.**

## What a medical treatment decision maker can do

A medical treatment decision maker's role is to make all necessary decisions about your medical treatment if you can't do that yourself. They have to make decisions that they believe you would have made, and those decisions need to be informed by your preferences and values.

Your medical treatment decision maker may make decisions for you (or be consulted about) medical decisions relating to:

- TREATMENT WITH PHYSICAL OR SURGICAL THERAPY
- TREATMENT FOR MENTAL ILLNESS
- TREATMENT WITH PRESCRIPTION PHARMACEUTICALS
- DENTAL TREATMENT
- PALLIATIVE CARE

Medical treatment decision makers are commonly involved with decision making at the end of someone's life. However your medical treatment decision maker cannot make decisions about voluntary assisted dying for you. If you require more information about voluntary assisted dying, please visit the Victorian Department of Health website.

1

## Already appointed someone?

You may have appointed someone to make medical decisions for you in an enduring power of attorney (medical treatment) or other legal document before 12 March 2018. If so, that document will still work if it was done correctly at the time and you haven't revoked (cancelled) it in a different document, for example by making a new document to appoint a medical treatment decision maker. If you are unsure whether you have appointed a medical treatment decision maker through a different document, consider getting legal advice or making a new one.

## Step 1 – Think about who you would want to make medical decisions for you if you couldn't.

**It is a good idea to appoint someone to be your medical treatment decision maker. That way, you know that someone you trust will be able to step in and make medical decisions for you if you can't.**

But it's your choice - you don't have to appoint a medical treatment decision maker.

To help you decide whether to appoint someone, it can be helpful to understand what happens if a medical decision needs to be made about you if you can't make that decision for yourself.

### What is a support person?

As well as, or instead of, appointing a medical treatment decision maker, you can also appoint a support person. A support person can help you make medical decisions and take steps to help medical professionals follow your wishes. But a support person cannot make medical decisions for you. If you appoint a support person, you should still consider appointing a medical treatment decision maker as well. More information on appointing a support person can be found on the Office of the Public Advocate website.

**What happens if you can't make a medical treatment decision – who steps in?**

If you can't make a medical treatment decision yourself - for example, if you are unconscious or can't communicate - the doctor will try and contact someone to make medical decisions for you.

The doctor has to try and find the right person to make these decisions and the law spells out who they need to contact.

The law says that your medical treatment decision maker (if you can't make your own decisions) is the first person who is reasonably available, willing and able to make the decision for you from this list:

- Someone you have appointed as your medical treatment decision maker
- A guardian appointed by VCAT
- The first person on the list below who has a close and continuing relationship with you:
  a) Your spouse or domestic partner
  b) Your primary carer (but not a paid carer)
  c) the first of the following (and, if more than one person fits the description, the oldest of those people):
     - Your adult child
     - Your parent
     - Your adult sibling

  Note: these rules are different for people who are receiving compulsory mental health treatment.



If you appoint a medical treatment decision maker, that means you get to choose who is first on the list if a doctor needs to contact someone to make a medical decision for you.

This is particularly important if:

a) You don't want or trust any of the people mentioned on the list on page 12 to make medical decisions for you.

b) The list on page 12 is not in the order you would prefer (for example, if you would rather one of your siblings be asked to make medical decisions for you rather than your adult children).

c) You want to make it clear who should make medical decisions for you to avoid any doubt or confusion amongst family members or loved ones.

If you aren't sure who would be the best person to make medical treatment decisions for you, consider the guidance in Step 2 about choosing the best person to appoint.

## ANDREW'S STORY

**Andrew needed to go under a general anaesthetic for surgery. When asked who would make medical decisions for him if something went wrong, Andrew wasn't sure and replied "probably my next-of-kin". However, he realised that this could become complicated. He wasn't sure who his next of kin would be and didn't have any documents in place formalising his wishes. Andrew decided to do an Appointment of Medical Treatment Decision Maker document and downloaded the form from the Victorian Department of Health website. Andrew felt like it was the right decision because he had peace of mind as to who would make medical decisions for him if he ever couldn't do that himself.**

## JANE'S STORY

Jane had a strained relationship with her son Michael and had not been close to him for years. When asked who she would like to make medical decisions for her if she couldn't, Jane initially thought of Michael.

But after thinking more about it, she realised that her friend Susan knew her better than Michael did and would make better decisions for her. Susan had supported Jane through difficult times, was there to help Jane when she needed it and always respected Jane's decisions.

Jane decided to appoint Susan as her first medical treatment decision maker. She also listed Michael as her second medical treatment decision maker in case Susan was unable to make decisions for her.

This means that, if they needed to, a doctor would first contact Susan to make medical decisions for Jane. But if Susan couldn't or didn't want to make the decision, the doctor would then contact Michael.



### Step 2 – Decide if you want to formally make someone your 'medical treatment decision maker'.

**If you decide to appoint a medical treatment decision maker, it can be challenging to choose the right person.**

It is important to carefully think about this before making up your mind.

When choosing the right person, you may want to consider:

- Trust: who you trust to make the best medical decisions for you that you would want.
- Relationship: who is close enough to you to know and understand what you would want, even things you haven't talked about before.
- Understanding: who would put their own beliefs and preferences aside, and put themselves in your shoes and make decisions that you would want.
- Communication: who you could imagine communicating well with medical professionals about your medical care.
- Respect: who would respect any wishes you have told them and would follow those.
- Pressure and stress: who would be able to make potentially difficult medical decisions for you, even if the situation was stressful.

You can appoint more than one medical treatment decision maker, but only one person can make medical decisions for you at any one time.

The first person on the list who is available, willing, and able to make a medical decision for you will be your medical treatment decision maker. That person will be able to make medical decisions on your behalf if you're ever unable to make those decisions yourself, so long as they have formally accepted their appointment by signing a statement of acceptance (see Step 5).

## What if there's no one you trust enough?

If you don't have someone in your life who you trust to make the right decisions for you, it may be best not to appoint anyone. In this case, consider getting advice from a lawyer about what to do.

## Step 3 – Decide if there is anything you don't want them to do.

**Your medical treatment decision maker may make almost any medical decisions for you unless you tell them they can't. There are some very limited exceptions, for example, your doctor can still provide palliative care to you regardless of what your medical treatment decision maker says.**

Your medical treatment decision maker can agree to or refuse medical care, including for an injury, an operation, dental treatment, or treatment for a mental illness (unless you are receiving mental health treatment under the Mental Health and Wellbeing Act 2022, in which case different rules apply.)

If there are specific things you don't want your medical treatment decision maker to do, you can put limitations or conditions on what they can do, if you want to.

**Most people don't do this and ordinarily it won't be needed** but you might choose to do it if you think it would be best for you.

### If you include conditions or limitations

Some examples of limitations or conditions that you could include are:

- Requiring your medical treatment decision maker to consult with other people before making decisions (or certain types of decisions) for you. Note: they already have to consult with anyone they think you would want them to in the circumstances.
- Requiring your medical treatment decision maker to tell the other person you have appointed as an alternative medical treatment decision maker (if this is applicable) before they can make a medical decision on your behalf. For example, if you appoint your two adult children, the person making a decision for you would need to notify their sibling before doing so.
- Stopping your medical treatment decision maker from making certain types of decisions for you. For example, you could say they could only (or could not) make decisions about treatment for certain health conditions.

These are just a few examples – there are many more conditions and limitations you could include – it is up to you.

If you want to include conditions or limitations, it's a good idea to get help from a lawyer to make sure the wording will work in practice in the way you intend.

Conditions or limitations may restrict what your medical treatment decision maker can do for you. This may mean that there will be a gap in the ways they could help you. If your appointed medical treatment decision makers can't make a decision for you because of a condition you have made preventing them from doing so, whoever else would be your medical treatment decision maker under Victorian law could then make that decision (see Step 1).



## Step 4 – Make careful choices to avoid problems

**Deciding who you want to make medical decisions for you is an important decision. It can give another person a lot of power – the power to make potentially life-changing (or even life-ending) decisions about your medical care.**

Before deciding to appoint someone, it's important to consider the possible problems that could come up – or the pros and cons – both with appointing someone and with not appointing someone.

The possible problems with appointing people include:

- They have the power to make very significant decisions, such as decisions about end-of-life care. It's important to choose someone you trust to make decisions that align with your wishes and values.
- Although it is unlawful, they could make unwanted decisions that go against your wishes or beliefs. For example, they may choose to pursue aggressive treatment when you would prefer a gentler approach.
- They might not know about your medical history or understand a health condition you have, so might not be able to make the most informed decision.
- It can be hard emotionally to be appointed as someone's medical treatment decision maker. If your decision maker is emotionally overwhelmed or stressed at a time you are unwell, they might not be able to make good decisions for you.

The possible problems with not appointing anyone:

- If you're injured or unwell and can't make your own medical decisions, you won't have a say over who makes those decisions for you if you haven't appointed someone. This is decided by the law – see Step 1 for who makes medical decisions for you if don't appoint someone.
- Conflict or tension might be more likely between your family or loved ones if you don't appoint someone, as they might have different opinions about what care you should receive if they aren't clear about what you would want.
- Someone who cares about you may need to apply to VCAT (a tribunal) to be appointed to make medical decisions for you. This can be a stressful process at what is likely to already be a stressful time if you are unwell or injured.
- There might be no one you currently know who is able to make decisions for you. In that case, any significant treatment medical decisions (non-urgent) may need to be made by the Public Advocate. It is the Public Advocate's role to make significant medical decisions for people in Victoria who don't have the capacity to make medical decisions and who don't have anyone else who can legally make medical decisions for them.

## Don't put it off

It's important to consider the risks involved carefully, but don't leave your decision for too long.

If you leave it too long, it might mean that you get sick or injured before you have a chance to appoint someone as your medical decision maker, or spell out your wishes in an Advance Care Directive.

### Step 5 – Formalise it all in a document

**After reading the information above, if you decide to appoint a medical treatment decision maker, it's time to put it in writing.**

Before appointing anyone, it's good to discuss it with them, to make sure they are comfortable accepting the role. You may also like to use the opportunity to discuss your values, beliefs, and preferences regarding medical treatment with them, so they can understand what you would want if you couldn't make medical decisions for yourself. **Part 3 of this Guide contains guidance about how you might have that conversation.**

## Do it right

If the medical treatment decision maker document is not done properly, it might not work. It can be helpful to have a lawyer do the document, if you can, to avoid this risk. You can also do it yourself but be very careful to make sure the document is completed and signed correctly.

The two most common ways to appoint a medical treatment decision maker are:

### Get help

The first option is to get a lawyer to prepare a document for you. Having a lawyer involved will reduce many of the risks involved, for example, the document being unclear, incomplete or signed incorrectly. A lawyer will give you advice and write the document for you, and organise the document to be signed correctly.

### Do it yourself

The second option is to do it yourself. One way of doing this is by:

a. Getting a copy of the Victorian Appointment of Medical Treatment Decision Maker form by:

   i) Downloading the form online for free from the Victorian Department of Health website, or

   ii) Asking your doctor if they can give you the document.

b. Carefully complete and sign the form, making sure to read and follow all instructions. After you have signed it, you should ensure that anyone you have appointed signs a statement of acceptance (which is part of the form), as they won't be able to make medical decisions for you unless they do so.

### After signing

After signing an Appointment of Medical Treatment Decision Maker, make sure you give certified copies of the documents to those who need them, store the originals carefully, and review the documents regularly. **Further information about those steps can be found on page 34.**

PART TWO

# Advance Care Directives

**Everyone wants their decisions respected – particularly when they relate to something as personal as medical care.**

But decisions about medical care are often tricky or complicated. This can make it difficult for those who need to make choices about someone else's medical care.

You can record your decisions about your future medical treatment in a document called an 'Advance Care Directive'. Then if in future you can't make your own medical decisions – for example, if you are very sick, injured or unable to communicate – other people have to consider your wishes and follow what you've directed in that document (with some limited exceptions),

An Advance Care Directive can include:

- **A values directive –** this is a record of your values and preferences about your medical treatment. For example, you may want to explain something that worries you about how your health might be in the future or write the types of outcomes you wouldn't want from medical treatment. Your medical treatment decision maker has to take this into account when making medical decisions on your behalf.
- **An instructional directive –** this is a record of what specific medical treatment you consent to or refuse. Your doctor is legally required to follow it (with some limited exceptions). For example, stating that you would or wouldn't want to receive cardiopulmonary resuscitation (CPR) if your heart stopped.

If you can't make a decision about your medical treatment, your doctor or other health professional has to try to find out whether you have an Advance Care Directive, so it can be followed when decisions are being made for you.

If an Advance Care Directive includes a statement that directs a health professional to do something that would break the law or is against their professional standards, they don't have to follow that part of the Advance Care Directive (but the rest of the document will still work).

It isn't possible for people to give directions about voluntary assisted dying in an Advance Care Directive and any statement included about it can't be followed. If you need further information about voluntary assisted dying, visit the Victorian Department of Health website.

2



PART 2

**Steps 1-3 of Part 2 of this Guide explain the steps you should take if you are considering making an Advance Care Directive.**

Those steps are:

**Step 1 -** Think about what you want for your future medical care.

**Step 2 -** Make careful choices to avoid problems.

**Step 3 -** Formalise it in a document.

## Step 1 – Think about what you want for your future medical care.

An Advance Care Directive can include:

| Type of directive | Purpose |
|---|---|
| **Values directives** | Values directives are statements about your values and preferences for future medical treatment.<br><br>If they need to make medical decisions for you, your medical treatment decision maker is legally required to first consider any values directive you have made.<br><br>Examples of what values directives can include are:<br><br>• Details of what matters most to you in life – for example, family and friends or being able to care for your pets.<br>• What living well means to you - for example, you could explain that being independent or being able to enjoy books or music is important to you.<br>• Things that worry you about the future - for example, you could explain that experiencing chronic pain without a chance of a full recovery is worrying to you.<br>• What you think is an unacceptable outcome for medical treatment or injury – for example loss of independence or not being able to recognise people close to you.<br>• Spiritual, religious or cultural requirements.<br>• A preferred place of care.<br>• Treatment with prescription medications and/or treatment for mental illness.<br><br>Your medical treatment decision maker would then consider these statements before making a medical treatment decision for you. |



| Type of directive | Purpose |
|---|---|
| **Instructional directives** | Instructional directives are legally binding statements that allow you to either consent to or refuse specific medical treatment. These directives are to health professionals caring for you, not your medical treatment decision maker.<br><br>If you make an instructional directive consenting to or refusing any treatment, medical professionals caring for you will need to follow those instructions (with some limited exceptions).<br><br>Examples of what can be included in instructional directives are:<br><br>• Consent to any medical treatment - for example, if you consent to a heart bypass operation in specified circumstances.<br>• Refusal of any medical treatment – for example if you have a terminal illness, refusing to be put on a respirator (a machine that breathes for you).<br><br>As instructional directives must legally be followed by any health professional caring for you, you should only make an instructional directive if you know exactly what type of medical treatment you do or do not want, and when you do or do not want that treatment.<br><br>**If you choose to make an instructional directive, you should always talk to your doctor about what you plan to include, and you should do this before you sign the document.**<br><br>If you are completing your instructional directive regarding a pre-existing condition, you should understand and talk to a doctor about your prognosis, the different treatment options available to you, and the risks and benefits of these options. If you include statements about treatment for mental illness or dental treatment, consider consulting your relevant health practitioners about these statements.<br><br>You should make sure that any statements or intentions you include are clear for the health professionals who may read the document one day. It can be useful to include the reasons for what you have included in any directive you make.<br><br>If any instructional directive you make is unclear or it is uncertain when it should be followed, the medical professionals caring for you may not have to follow it. |

If your Advance Care Directive doesn't include an instructional directive – or doesn't cover the exact situation that has come up (for example, if you are suffering from a health condition you hadn't thought of when you were preparing the document), the doctor has to consider any values directive that is relevant and get a decision from your medical treatment decision maker.

In some very limited situations, a doctor can refuse to follow an instructional directive but only if they think your circumstances have changed and the directive is no longer in line with your wishes and values, and the delay to apply to VCAT (a tribunal) and ask it to make the decision about what they should do would result in your condition becoming much worse.

## FATIMA'S STORY

Fatima had lung cancer and had been told by her doctors that she had less than a year to live. She did not have the quality of life she once had and was having problems with her memory and thinking.

Her doctor recommended that she make an Advance Care Directive, setting out her wishes for her future medical care.

Knowing that her condition would only get worse, Fatima included a statement in her Advance Care Directive saying that she didn't want to receive any treatment that would prolong her life.

Fatima's cognition went further downhill and she wasn't able to make her own decisions anymore. She was then diagnosed with bradycardia – a condition that made her heart beat too slowly. Her doctor advised her daughter (who was her medical treatment decision maker) that Fatima would need to have a permanent pacemaker inserted to treat the condition.

Fatima's daughter knew from Fatima's Advance Care Directive that she did not want any medical treatment that would prolong her life. Because of this, she felt able to tell Fatima's doctor that she did not want a pacemaker.



## ANIKA'S STORY

Anika had often thought about her future medical care. She had appointed her daughter Maya as her medical treatment decision maker, and wanted to make sure that Maya and her doctors understood what was important to her when it came to medical care.

Anika brought this up with Maya and her GP and her GP suggested she do an Advance Care Directive. Her GP advised her on how to word things and gave her advice about the types of issues that can come up in Advance Care Directives.

Anika went home and downloaded an Advance Care Directive form from the Department of Health website. She then completed the details on the form carefully. She completed:

- a values directive (statements about her values and preferences, that her medical treatment decision maker would have to take into account):
    - Explaining what was important to her, such as being independent and being able to spend time with friends and family.
    - Explaining what unacceptable outcomes were to her – such as being unable to communicate with or recognise family or friends, experiencing chronic pain, or completely losing her independence.
- An instructional directive (a statement that medical professionals caring for her would legally have to follow):
    - Recording that, if she ever develops a terminal illness, she does not want any life-prolonging treatment.

After writing the Advance Care Directive, she went back to her GP for advice about what she had written and to ask her GP to witness her sign the document. After it was signed, she then had the document certified, gave a certified copy to Maya and stored the original document in a safe place.

Anika was comforted knowing that her daughter and her doctors would know what was most important for her and care for her in the way she would want.

## Step 2 – Make careful choices to avoid problems

**Advance Care Directives let you record how you want to be cared for in the future. But of course, no one has a crystal ball and it's impossible to predict what will happen or what your health will be like in the future. Because of this, it's important to take great care when writing your Advance Care Directive.**

Before deciding whether or not to make an Advance Care Directive, it's important to consider the possible problems that could come up, both with making an Advance Care Directive and with not making one.

The possible problems with making an Advance Care Directive include:

- **Unplanned outcomes:** what you include may not work how you want it to, particularly if you include an instructional directive. Doctors must legally follow any instructional directive you make, even in situations you haven't thought about (regardless of what your medical treatment decision maker says) and they may need to be followed in situations you haven't considered. For example, someone may say that they 'do not ever want to be kept on a life support machine', preventing this from happening even in a situation where they were likely to make a full recovery.
- **Being unclear with a direction you make:** unclear directions can lead to issues if someone doesn't understand how to use a person's direction when making a medical decision for them. This could either lead to them being unable to follow the direction or doing something different than you would have wanted.
- **Unclear wording or errors:** these can make it difficult for people to follow what you want and increase the chance of mistakes and misunderstandings. Although it is possible to write an Advance Care Directive without professional help, it's always preferable to make it with the help of a professional if you can (for example, a doctor or lawyer). This can help you to make sure that the document is written correctly.

The possible problems of not making an Advance Care Directive include:

- **Loss of control:** you may lose control over what treatment you do or don't receive in the future.
- **Emotional strain on your loved ones:** it may be difficult and stressful on your loved ones to try and make the decisions they believe you would have wanted, without direction about what is most important to you.
- **Conflict between family or friends:** it may increase the chance that family or friends may disagree and argue about what treatment you do or don't receive. This can sometimes damage relationships between the people who you care about the most.
- **Unwanted decisions:** your medical treatment decision maker and medical professionals caring for you may not know the medical treatment you do (or do not) want to receive, leading them to make decisions that you would not have made yourself.
- **Unnecessary pain or suffering:** some medical interventions may lead to further suffering or a reduced quality of life. You may wish to avoid the possibility of such treatments being given to you.



### Involve your doctor

To avoid problems, it's best to involve a medical professional (for example your GP) when making an Advance Care Directive.

## MARGARET'S STORY

Margaret was planning her future medical care.

One worry she had was about the idea of being kept alive by a ventilator – a machine that helps someone breathe if they can't do it on their own. She had heard unpleasant stories about people needing this type of care and Margaret said she "wouldn't want to live if a machine had to keep me alive". She decided to make an Advance Care Directive to make this clear.

When preparing what to write in the Advance Care Directive, she planned to include an instructional directive stating that she didn't ever want to be kept on a ventilator.

When discussing her Advance Care Directive with a friend, her friend pointed out to Margaret that the statement could lead to problems. Her friend explained to Margaret that medical professionals treating her would have to follow her instructional directive and it would stop her ever being kept on a ventilator in any situation, even if it was likely that she would make a full recovery.

After talking about this, Margaret decided to use different wording and to use a values directive (instead of an instructional directive) to explain her wishes about the ventilator.

The values directive she made said that she didn't want to be kept on a ventilator if there was no prospect of her recovering to the point where she could live a happy life. She also explained in her values directive what living a happy life meant to her.

Using a values directive meant that her medical treatment decision maker would need to consider what she had written when making decisions for her but that medical professionals wouldn't legally have to follow the directive (it would be up to the medical treatment decision maker to decide the next step, using the directive to guide them).

Margaret trusts her medical treatment decision maker to use the information she put in her Advance Care Directive to make the best decision for her.

## Step 3 – Formalise it in a document (an Advance Care Directive)

The two most common ways to do this are:

**Get help**

The first option is to ask your doctor or lawyer for help with doing an Advance Care Directive. They can give you advice about the wording and having the document signed correctly. Because this document is so important, it is a good idea to get advice about its effect so you can make sure it will do what you intend it to.

**Do it yourself**

The second option is to do the Advance Care Directive yourself (and sign it later in front of a medical practitioner such as a doctor).

To do this, you can:

- Download the Victorian Advance Care Directive Form from the Victorian Department of Health website (for free) or ask your doctor or lawyer if they can provide you with the form.
- Carefully complete and sign the form, making sure to read and follow all instructions in the form. You should also ask your doctor to advise you about what you have included before you sign it (particularly if you include an instructional directive).

## After signing

After signing an Advance Care Directive, make sure you give certified copies of the documents to those who need them, store the originals carefully, and review the documents regularly. **Further information about those steps can be found on page 34 of this Guide.**

PART THREE

# Conversations

It's common to feel hesitant or uncomfortable about discussing your future medical care with loved ones, but it is a vital part of the process and can help your loved ones to understand what is important to you and help them to follow your wishes.

These discussions can give peace of mind to both you and your loved ones and make it easier for your loved ones to know what medical treatment you would or wouldn't want.

This part of the Guide explains how you can approach those conversations with your loved ones.

## Discussing your medical care

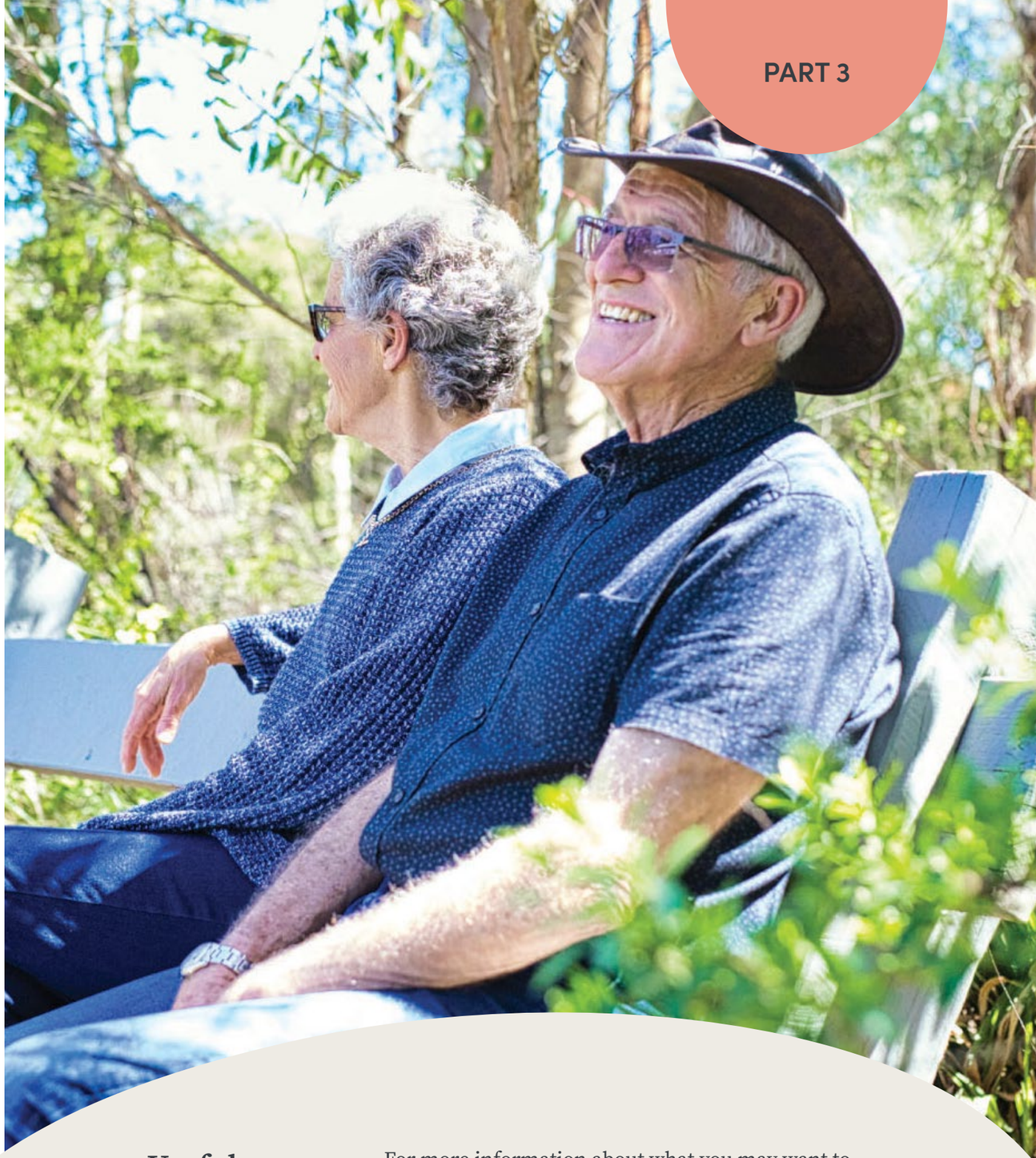
What you choose to discuss with your loved ones will depend on your personal preferences and priorities. Some examples of what you may wish to discuss include:

- What matters to you most from a medical perspective.
- What you expect of those appointed as your medical treatment decision makers.
- Any documents you have made regarding your medical care (for example, an Appointment of Medical Treatment Decision Maker and/or an Advance Care Directive).
- Any unique details in any document you have made, such as specific directives or conditions.
- Details about prior or existing medical conditions that you would like your loved ones to be aware of and to consider if making decisions for you.
- Your preferences beyond medical planning, such as what is important to you in your older age, what you want your life to be like, and any related legal documents you have made or intend to make (such as an enduring power of attorney).

3







**Useful resource**

For more information about what you may want to discuss and how to go about it, consider reading 'Preparing for your future: a Conversation Guide' available from justiceconnect.org.au.

If you expect to find these sorts of conversations difficult, you should consider trying the following:

| | |
|---|---|
| **Prepare yourself** | Before you meet, reflect on your own thoughts and feelings about your future medical care. Think about what you would like to say to your loved ones and how you would like to say it. |
| **Who you want to talk with** | Carefully consider who you want to talk with. You may feel comfortable talking to multiple people or perhaps you want to talk with just one. |
| **Find a good place to talk** | Find somewhere quiet, comfortable and private, where you and those you talk with can feel at ease. |
| **Choose the right time** | Choose a time when you and those you speak to are likely to be calm and not preoccupied with other commitments. Avoid starting the conversation during family gatherings or when people are likely to be focused on other things. |
| **Think about how to start the conversation** | Starting the conversation can be the hardest part, so you may want to plan how you would begin. For example, you may wish to explain that they are important in your life and/or why you want to have this conversation with them. |
| **Be kind and respectful** | Begin the conversation by showing that you care about your loved ones and that you think it's important for both you and them to have the conversation. |
| **Share your thoughts and feelings** | Tell them how you feel and what is important to you. Be open and honest about your wishes and preferences. |
| **Information** | You may wish to provide information and any documents you have already done. You could also give a copy of this booklet, for further information about the importance of planning for your future medical care. |
| **Take notes** | Consider writing things down as you discuss them. It's a good idea to keep a record of what you have discussed – it may be useful later or for you to reflect on. |
| **Be open to input from your loved ones** | Although the decisions about your future medical care are yours to make (and you should never feel pressured to make any decision about your medical care that you are uncomfortable with) it can be helpful to hear any concerns that your loved ones have about what you are planning. For example, a loved one may feel uncomfortable with a directive you have included in an Advance Care Directive. Having these discussions openly can be a good way to resolve any issues or help your loved ones understand why you have made a particular decision. |
| **Consider involving your doctor/GP** | If you want support to explain any medical terms, what is involved in different treatments or medical advice you have received, you may want to ask your doctor to be involved in the discussion. |
| **Keep the conversation going** | It's often best not to view these discussions as a one-off, but as a conversation that will continue over time. By becoming comfortable discussing these topics with your loved ones, you can update them about any changes to your wishes or medical planning. |

# Wrapping up: Other Important Information

## After completing any medical planning document

After you've made any medical planning documents, it's important to take some extra steps to make sure that they can be used as you have planned.

### Give copies of the documents to people who might need them.

So that people can abide by your wishes in terms of your medical care, it is important to give copies of the documents to the people who might need them. You should:

- Give a copy to any medical treatment decision maker/s you have appointed.
- Give a copy to any doctors, health or GP clinics, or hospitals that you expect might need the form one day.
- Consider uploading a copy of each or either document to your My Health Record **(https://www.myhealthrecord.gov.au)**, so that it can be found by your health professionals when they need it. You can ask your doctor for help with this step if you want to.

### Storing your documents carefully.

Once you have signed a medical planning document, it is important to look after the original.

It is best to store your document/s in one of the following ways:

- In a safe and private location, where your medical treatment decision maker would be able to find it. This may be with other important papers you have.
- With your medical treatment decision maker (if they have somewhere safe to store it).
- With your lawyer.
- In a safe deposit box (for example with a bank), making sure someone knows where to find it.

### Review your documents regularly

You should review any Appointment of Medical Treatment Decision Maker or Advance Care Directive that you make, ideally every 1-2 years, to make sure document/s still meet your needs and preferences.

Some people find it useful to do this at the same time each year, perhaps over summer or at the end of the financial year. You should also review the documents if your situation or preferences change – for example if you receive a new medical diagnosis or your relationship with someone close to you has changed.

If you decide you want to change or cancel your Appointment of Medical Treatment Decision Maker or Advance Care Directive, refer to Page 37 of this Guide about what to do next.

## JOHN'S STORY

John made an Appointment of Medical Treatment Decision Maker. Even though he had given certified copies to the people he appointed, John knew the importance of storing the document correctly, so that it could be found again if ever needed.

He decided to store the original document in a folder at home where all his important documents and paperwork were kept. He also told his family where he had stored the document, so they could find it if ever needed.

When the time came to use the Appointment of Medical Treatment Decision Maker, the person John had appointed had lost the certified copy that John had given to them. Thankfully, John had told them where to find the original document and they were able to make new copies to prove John had appointed them.

### Certified documents

It is best to get the copies of the document certified before you hand them out to people. A certified document is a document that has been verified and declared to be a true and accurate copy of the original. People who can certify documents include police officers, pharmacists, medical practitioners, and lawyers. A complete list of people who can certify documents can be found on the Department of Justice and Community Safety website (www.justice.vic.gov.au)

## Complete the medical decisions checklist

**Appointing a medical treatment decision maker**

- Consider if you should appoint a medical treatment decision maker and think about who would be your decision maker if you don't appoint anyone.
- Decide who you would want to appoint. Consider who you trust the most to make medical decisions for you.
- Decide if there is anything you don't want them to do. If there is, include a condition or limitation in the document.
- Make careful choices to avoid problems. Consider what will happpen if you do or don't appoint a medical treatment decision maker and how to avoid any concerns you might have.
- Appoint a medical treatment decision maker – follow the instructions in this Guide to make sure it is valid.

**Making an Advance Care Directive**

- Consider recording your preferences for future care by making an Advance Care Directive.
- Make careful choices to avoid problems. Consider what will happen if you do or don't make an Advance Care Directive and the potential problems that can happen with the different types of directives.
- Complete and sign an Advance Care Directive – follow the instructions in the Guide to make the document.

**After completing any medical planning document**

- Give copies of the documents to people who may need them.
- Store your original documents carefully.
- Review the documents regularly to make sure that they still meet your needs over time.



**Conversations**

Consider discussing these matters with your loved ones. Ideally, these conversations should begin with anyone you expect will need to make medical decisions for you before you make any medical planning documents.

### What to do if you change your mind

There may come a time where you change your mind about something you have included in an Advance Care Directive or who you have appointed to make medical decisions for you.

If that happens, it's best to cancel or replace the relevant document as soon as you can. If you do not do anything it's possible that you may become unwell or injured and unable to make your own decisions before you have a chance to fix the issue. If this happens, the document is likely to remain in place.

You can revoke (cancel) your Appointment of Medical Treatment Decision Maker if you do either or both of the following:

- Make a new Appointment of Medical Treatment Decision Maker; or
- Complete and sign a document that meets certain rules under the law. A simple way to do this is to complete a 'revocation of medical treatment decision maker' form or see a lawyer or a doctor for advice.

You can revoke (cancel) your Advance Care Directive if you do either or both of the following:

- Make a new Advance Care Directive; or
- Complete and sign a document that meets certain rules under the law. A simple way to do this is to complete and sign a 'revocation of Advance Care Directive' form or see a lawyer or a doctor for advice.

Relevant forms can be found on the Department of Health website.

Please remember that if you revoke (cancel) an Appointment of Medical Treatment Decision Maker or Advance Care Directive without making a new one, you won't have a working document in place.

If you revoke (cancel) any of your medical planning documents, make sure you tell your medical treatment decision maker and any other person or organisation you provided a copy of the document to. This is to make sure that any former document doesn't get used by someone who doesn't know you've cancelled it.

**Decision making capacity**

In order to make the medical planning documents discussed in the Guide, you need to have what lawyers refer to as 'decision-making capacity' or simply 'capacity'.

Capacity for health matters means the ability to understand information relevant to a medical decision, be able to remember that and weigh up that information, and to communicate the decision in some way.

If you don't have capacity to make medical decisions for yourself, you aren't able to make a valid Appointment of Medical Treatment Decision Maker or Advance Care Directive.

Someone might lack capacity if they have an acquired brain injury, cognitive (thinking) impairment, unconsciousness, inability to communicate (for example, after suffering a severe stroke), dementia, or issues with their memory.

But remember - having one of these conditions does not automatically mean you don't have capacity. Even if you lack the capacity to understand some things, you may still have the capacity to understand others.

It is also possible to lose capacity and then later regain it – so just because someone has lacked capacity at one point in their lives does not necessarily mean they will never have it again.

You should talk to a lawyer if:

- You have concerns about your own capacity to make medical decisions, and you want to make an Appointment of Medical Treatment Decision Maker or Advance Care Directive; or
- You are assisting another person to make these documents and you have concerns about their capacity to understand them.

## JANE'S STORY

**Jane was diagnosed with dementia.**

**She initially thought her diagnosis would prevent her from appointing a medical treatment decision maker and was concerned that one of her children would object and say she didn't understand what she was doing. She was worried about what might happen if she was no longer able to make medical decisions for herself.**

**Jane spoke with her lawyer about this. After some discussion, her lawyer informed her that she did still have the capacity to make an Appointment of Medical Treatment Decision Maker.**

**The lawyer took notes as evidence of what was discussed, to show that Jane had capacity. The lawyer explained that this could be relied upon if one of her children (or anyone) ever suggested she didn't have the capacity to make the document.**

**Jane was then able to sign a document appointing someone to make medical decisions for her.**

# Further Assistance

## Where to get further help and information

- Your local GP and/or lawyer – they will either be able to assist directly or let you know who could help.
- Law Institute of Victoria - provides a legal directory and referral service to search for private law firms. All firms listed provide an initial consultation free of charge. Website: www.liv.asn.au Tel: 03 9607 9311
- Federation of Community Legal Centres Victoria – assists to connect members of the public with community legal centres (CLCs) to help with their legal needs. Please note that CLCs generally do not directly assist with the preparation of Appointments of Medical Treatment Decisions Makers or Advance Care Directives. Website: www.fclc.org.au Tel: (03) 9652 1501
- The Victorian Department of Health – provides a range of forms and materials about future medical planning. The forms available include Appointment of Medical Treatment Decision Maker forms and Advance Care Directive forms. Resources can be found at the Department of Health website: www.health.vic.gov.au the Department of Health can be contacted on 1300 650 172
- The Victorian Office of the Public Advocate (OPA) - provides a number of useful resources relating to Appointments of Medical Treatment Decision Makers, Advance Care Directives, enduring powers of attorney, and other documents. Resources can be found at the advocate's website: www.publicadvocate.vic.gov.au and OPA can be contacted on 1300 309 337.
- Compass – provides guidance and information for people experiencing elder abuse or for people who want to assist others who are experiencing elder abuse. Website: www.compass.info Tel: 1800 353 374.
- Palliative Care Australia – provides information for patients, carers and professionals about palliative care, and the options and services for people in or in need of palliative care. Website: palliativecare.org.au Tel: (02) 6232 0700
- Advance Care Planning Australia - offers information and assistance to people wanting to complete an advance care plan. Website: www.advancecareplanning org.au Tel: 1300 208 582

eastern community legal centre

VICTORIA State Government

This guide was produced by Eastern Community Legal Centre and supported by the Victorian Government.

© Copyright Eastern Community Legal Centre 2024

**www.eclc.org.au/futuremedicalcare**

ECLC is an inclusive multidisciplinary legal service that works to prevent problems, progress fair outcomes and support the wellbeing and resilience of communities and community members in Melbourne's East.

ECLC acknowledges the Wurundjeri people of the Kulin Nation, the traditional custodians of the land across ECLC's region. We pay our deep respects to the elders, both past and present.

ECLC acknowledges all of the individuals and organisations that contributed to this guide, including Eastern Health and the many older adults who provided valuable input and helped shape its content.

**eclc.org.au**

**1300 32 52 00**
**eclc@eclc.org.au**