

Preparing for an advance care planning conversation

A guide to help you prepare for a conversation with your family or health care team about your wishes for future health and personal care



What is advance care planning?

Advance care planning is about having conversations and planning for your future health and personal care so that you, your family or close friends, and health care team know your values and preferences.

If you were very sick and could not make or communicate your own decisions, who would you want to speak for you? What would you want them to say on your behalf?

Advance care planning helps to ensure that your loved ones and your health care professionals know what your health and personal preferences are. This can bring comfort and peace of mind to you, your family and your health care team who may have to make health care decisions for you.

Who is this guide for?

If you would like to start thinking and talking about your future care, this guide is for you. It will prompt you to think about what is important to you now and what you might want in the future.

It includes thinking about the type of care you might want or not want if you were very sick or suddenly injured. It also includes thinking about things you would want people to know about the care you may want before and after you die.

Any adult might like to complete this guide. None of us can predict what might happen with our health. One is never too young or old to begin thinking and talking about what would be important to them if they became suddenly unwell.

This guide may be particularly relevant for people who are older or people who have a chronic or serious illness or multiple health problems.

Why complete this guide?

Talking about the future and your wishes for end-of-life care can be hard. It can also bring you closer to the people you love and help them feel more comfortable about any decisions they might have to make for you in the future. It provides a way for you to have a say about the care you receive in case you are ever in a situation where you are unable to make decisions for yourself.

People will only know what is important to you if you tell them. Thinking and talking about these things will help to ensure you receive the kind of care you would like, and it guides your loved ones with what may otherwise be stressful decisions.

The purpose of this guide

This guide includes a number of questions to help you explore your values and beliefs that could influence your future health care decisions. It's a useful tool to help you start thinking about advance care planning and preparing for conversations with your family and health care professionals.

Thinking about some of these questions might be hard but it will allow you to start processing your thoughts and preferences. You may change your mind about how you feel about these questions over time and that is okay, it is part of the process.

There are spaces to write down your thoughts in this guide if you want to. You can change your answers at any time.

There are no right or wrong answers to these questions. **You do not have to answer all of the questions and you can complete the questions in any order that you like.**

After thinking about the questions in this guide it is important to share your thoughts with the people who might be called upon to make decisions for you in the future, including your close family or friends and your doctor and nurse. You may like to show them your answers to the questions in this guide.

The conversations you have with your family and loved ones about advance care planning are important even if you never write down your preferences for future care. After having these conversations about advance care planning, you may choose to record your preferences in a legal document called an *Advance Care Directive*. Information about how to do this, if you want to, is on page 12 of this guide. On page 12, there are also suggestions for the next steps in the advance care planning process after you have thought about the questions in this guide.

Below you may like to record your name and the date(s) you reviewed or updated this guide.

My name:

Date I initially completed this guide:

Date(s) I reviewed this guide:

1. What I want my health care team and family to know about me and what matters to me

The sorts of questions you might want to consider are:

- What brings you the greatest joy?
- Who are the most important people in your life?
- How do you like to spend your time?
- Are there any routines that are important to you?
- How would you like to be remembered?
- Are there any cultural, religious or family traditions that are important to you?

2. The medical information I would want to know

Some people would want to know all the details about their illness if they became very sick, others would prefer as few details as possible. Please circle on a scale from 1 to 5, the number which best represents what you think your preference for information would be about your illness if you were very sick.

Prefer as few details as possible	1	2	3	4	5	Prefer as many details as possible
	←————→					

3. How I would want medical treatment decisions to be made

Some people like to be involved in medical treatment decisions, others would prefer to leave decisions about medical treatment up to their doctors. Others might want their family or friends to decide about the best treatments for them with their doctors, even if they were still able to decide for themselves.

a) How involved do you think you would want to be in decisions with your doctors about medical treatments if you became very unwell?

- I want to decide about medical treatment after hearing about the options
- I want to share decisions about medical treatment with my doctors
- I want my doctors to decide what medical treatments would be best for me

b) If you became very unwell and **could still make decisions for yourself**, how involved would you like your close family or friends to be in decisions about your medical treatments?

- I want to make decisions about medical treatments on my own or with my doctors
- I want my close family or friends to share decisions about my medical treatments with me
- I want my close family or friends to make decisions about my medical treatments for me or with input from my doctors

If there are other things you would want your loved ones or health care professionals to know about how you would want medical treatment decisions to be made if you were very unwell, you can write them here. For example, there may be a particular family member(s) or friend(s) that you would want to share medical decisions with.

4. Who could make medical decisions for me if I couldn't

Can you think of any family members or friends who might be able to make medical decisions for you in case you became **too unwell to make decisions for yourself?**

Yes or maybe. The name(s) of this person or people are:

No

Depending on your situation, it may be important to legally appoint one or more people to make medical decisions for you. More information about how to do this is available in the accompanying resource called *“Who will speak for you if you can't speak for yourself?”*. Information specific to your state or territory is available from www.advancecareplanning.org.au

5. My past experience with serious illness

You may remember someone close to you who was very sick or dying. Or you may have even experienced a serious illness yourself. Think about what went well and what did not go well. Is there anything you would or would not want for yourself based on these experiences?

6. My current and future health

You may be healthy now or you may have health problems. Do you have any questions, fears or concerns about your current or future health? If so, you might like to write them down here and discuss them with your doctor or nurse.

7. My personal goals

Some people have a list of things they would like to do or see, or people they would like to spend time with before they die. Is there anything you would wish for?

8. My preferences for care at the end of life

- a) People have different views about medical treatments if they became very sick. Some people would want all treatments that would be available to them to prolong their life as long as possible, even if there were significant side effects. Others would only want treatments to make them comfortable, even if this meant they may live for a shorter period. Others are somewhere in between.

If you had to decide now about the medical treatments you would want **if you were very sick**, where would you put yourself on this scale? (tick a box on the scale which best indicates how you feel)

←-----→

Quality of life I only want treatments to make me comfortable	Equally important	Length of life I want treatments to prolong my life as long as possible
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I am not sure

- b) Some people would want to stop receiving medical treatments to prolong their life if their circumstances changed. For example, if they were no longer able to live in their own home, use the toilet independently or have a conversation with their family. Are there any circumstances where you would want your doctors to stop (or not start) any treatments that may prolong your life and instead allow you to die naturally? If so, what are these circumstances?

c) Are there any treatments that you would definitely **not** want at any time in the future?
If so what treatments?

d) If you were dying, where would you prefer to be cared for (if possible)?

- At home
- In an aged care home
- In hospital
- In a palliative care hospital
- Other _____

e) How important is it to you that you die in the place that you selected above?

- Not important
- Somewhat important
- Very important

Is there anything else you would want your family or health care professionals to know about your preferences for where you are cared for, if you were very sick or dying? If so, you can write your thoughts here.

f) Are there any religious, spiritual or cultural beliefs that you would like your family and health care team to know and consider if you were sick or dying?

g) Is there anything else you would want your family and health care team to know about how you would like to be cared for if you were very sick or dying? For example, some people would want privacy, others would want to be surrounded by their family and friends. Some people would want music playing, others would want peace and quiet.

h) Some people decide to donate their organs or body parts (tissues) when they die. What are your views on this?

- I want to donate my organs or body parts (if it were an option for me)
- I do not want to donate my organs or body parts
- I am not sure

You can also make your wishes known about this on the Australian Organ Donor Register. If you would like more information about organ and tissue donation, ask your doctor or visit www.donatelife.gov.au

If there is any other information you would like your health care team or family to know about your views on organ or tissue donation you could write this here.

9. How I would want to be cared for after I die

What would you want your health care team and family to know about how you want to be cared for after you die? Things to consider:

- Are there any rituals you want?
- Would you prefer to be buried or cremated?
- Do you have any special requests or plans for your funeral?

10. Other questions or things I would like to discuss with my doctor, nurse or family about my future care

Next steps

- Speak to your close family or friends and health care professionals about your answers to the questions in this guide. Also speak to them about any other thoughts or preferences you may have about your future care.
- Ask your doctor or nurse any questions you have to help you think through your preferences.
- Think about appointing a substitute decision-maker for health care decisions.
 - See the accompanying resource, called “*Who will speak for you if you can’t speak for yourself?*”, for things to consider when choosing a substitute decision-maker for health care decisions and how to do this. Also think about how much flexibility you would want them to have when making decisions for you.
- Consider writing down your preferences in an *Advance Care Directive*.
 - An *Advance Care Directive* is a legal document that formally records your preferences. It only goes into effect if you are unable to make decisions for yourself. Your doctor can provide you with further information about this. If you do complete an *Advance Care Directive*, it needs to be shared with your health care team and preferred substitute decision-maker and any other family members you would want to have access to it. It is also important to review it from time to time if your preferences change and share any changes with the people who have a copy of your *Advance Care Directive*. You can also upload and update your Directive in My Health Record <https://www.myhealthrecord.gov.au/>

For more information and assistance

- Speak to your local doctor or nurse
- You can access further advice and documents for your state or territory from Advance Care Planning Australia www.advancecareplanning.org.au or the National Advance Care Planning advisory service on 1300 208 582

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