

Planning for...

A guide to help you prepare for an advance care planning conversation about your family member or friend's future health and personal care



What is advance care planning?

There may come a time when the person you care about is unable to make decisions for themselves. Advance care planning involves having conversations and planning for a person's future health and personal care. It helps family, close friends and health and care professionals to consider what would be important to the person about how they are cared for.

Advance care planning helps to ensure that a person is cared for in a way that respects their values and preferences. It also enables family members to be informed and supported to make health care decisions for the person when they can no longer decide for themselves.

Who is this guide for?

This guide is for family, carers and close friends of a person who is no longer able to make their own health decisions or who needs a lot of support to make these decisions. It can be challenging to make decisions for a person you love or know well who can no longer make health care decisions for themselves. This guide will help you reflect on your family member or friend's values, preferences and beliefs that could influence decisions about their health and personal care.

It might be particularly helpful to complete this guide if your family member or friend is being assessed for or is receiving services in the home or supported accommodation, such as a residential aged care home. Discussions about advance care planning are a routine part of care when a person needs such services. This ensures that the care provided is what the person would have wanted when they can no longer speak for themselves.

The health care team may also suggest that you complete this guide in preparation for an advance care planning discussion about your family member.

Understanding a person's capacity to make their own health care decisions

Knowing whether a person has capacity to make decisions is not always clear.

Generally, when a person does not have capacity to make a particular decision they cannot:

- Understand and appreciate the facts and choices involved
- Weigh up the consequences
- Communicate the decision

Making decisions about our own life is a human right and a part of a person's identity.

Where possible, advance care planning when the person is still able to communicate their wishes is valuable. Often, a person may have capacity to make some decisions (e.g., what clothes to wear or what they want to eat) but not more complex ones. A person's ability to make decisions may also change over time depending on their health or stress levels. People should be supported to make their own decisions as much as possible. Where this is not possible a family member or close friend of the person may be asked to be a substitute decision maker for them as part of advance care planning.

Who makes the decision when a person cannot decide for themselves?

If there is a legally appointed substitute decision maker, then this person should make the decision. This is called different things in different States and Territories, for example an enduring guardian or health attorney. A person may have nominated who they want their decision maker to be in an Advance Care Plan or Advance Care Directive.

If there have been no previous arrangements, then each State/Territory has a hierarchy of who should make health and lifestyle decisions. This is not necessarily the person's 'next of kin'. Specific information for each State or Territory can be found at advancecareplanning.org.au

Who should participate in the advance care planning discussion?

While there may be one or more legal substitute decision maker(s), there may also be other members of the family or a close friend who the person would have wanted to be involved in discussions about their care when they can no longer make decisions themselves.

Including these people in the advance care planning discussions may help them be prepared and be involved in the person's care.

Why complete this guide?

- This guide is a useful tool to help you start or continue thinking about advance care planning for your family member or friend and preparing for conversations with their health care professionals.
- It may also help you to have conversations with other people in the person's family who you think should be involved in the advance care planning discussion.
- It helps to think through these things when it is not a crisis situation, in case your family member or friend ever suddenly became more unwell.
- Completing this guide may help you to advocate for your family member or friend in discussions about their future care and think about what they would have wanted for themselves and what is important to them.

When completing this guide, it is important to know that:

- **This guide is not a formal legal document.** It is a communication aid to help you share what is important to your family or friend about their future care.
- This guide includes several questions to help you reflect on your family member or friend's values, preferences and beliefs. There are no right or wrong answers to these questions.
- In answering the questions in this guide, it is important to reflect your responses based on what you know about the values, beliefs and preferences of the person you are caring or advocating for.
- **You do not have to answer all the questions.** You can skip questions altogether or return to them later if you do not want to answer them now.
- There are spaces to write down your thoughts in this guide if you want to. You can change your answers at any time.
- Thinking about the future health of the person you care for might make you upset or angry. It is okay to feel these emotions. It is challenging to make these decisions for someone. It may help you to talk to someone you trust about how you feel.
- You may like to have someone you trust help you to complete this guide. Working through this guide with someone else may help you reflect better about what is important to the person you are planning ahead for.

On page **18** there are suggestions for the next steps in the advance care planning process after you have thought about the questions in this guide.

The name of your family member or friend (the person that this guide is about):

Your name (the main person completing this guide):

Your relationship with your family member or friend (tick all that apply):

- Legal guardian
- Spouse
- Adult child
- Other relative – specify _____
- Other – specify _____

Names of any other people who had input into completing this guide and their relationship to the person:

Date you initially completed this guide:

Below you may like to record any date(s) you updated this guide:

1. What your family member or friend would want their health and care team to know about them as a person and what matters most to them
 - a) Who are the most important people in their life?

b) What brings them the greatest joy in life?

c) How do they like to spend their time? Are there any routines that are important to them?

d) How would they like to be remembered?

e) Are there any cultural, religious, spiritual or family traditions that are important to them?

2. How your family member or friend would want information shared and decisions made about their care

a) Who in the person's family or network would they want to be informed or involved in decisions about their care?

b) Which health professionals would be important to involve in decisions about your family member or friend's care?

c) Is there anyone your family member or friend has said they would **not** want to be informed or involved in decisions about their care?

3. The information you want to know about your family member or friend's current or future health

a) What is your understanding about your family member or friend's current health conditions and what might be expected with their health in the future?

b) What further information do you want or need to know about their current or future health to help you plan for their future care? Do you have any questions, fears, or concerns about their current or future health? You might like to write down any questions or concerns here and discuss them with your family member or friend's doctor.

4. What you know about your family member or friend's preferences for their current or future personal and medical care

a) Has your family member or friend ever said what would be important to them about their current or future personal or medical care? If so, you may like to write down what they have told you here.

b) Have they ever expressed anything they would or would not want if they became seriously ill? If so, you may like to write down what they have told you here.

If your family member or friend ever wrote down their preferences for future care while they still had capacity to make decisions for themselves, then it would be important to ensure the health care team has a copy of that document (see page 18).

5. Your family member or friend's goals

a) 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 think your family member or friend would wish for?

6. Your family member or friend's preferences for care at the end of life

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.

a) What do you think your family member or friend would want *if they were very sick?*

Tick the box along this line to show what you think they would feel or you can tick 'I am not sure'.

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
				
Quality of life		Equally important		Length of life
They would want treatments that focus on comfort and quality of life				They would want treatments to prolong their life as long as possible
<input type="checkbox"/> I am not sure				

If you have any other thoughts about your family member or friend's preferences for medical treatments if they were very sick, you could write them here:

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.

b) Are there any circumstances where you think your family member or friend would want their doctors to stop (or not start) treatments that may prolong their life, and instead focus purely on their comfort and allow them to die naturally? If so, what are these circumstances?

c) Are there any treatments that your family member or friend would definitely *not* want at any time in the future? If so, what treatments would they definitely *not* want?

d) If your family member or friend were dying, where do you think they would prefer to be cared for (if possible)?

- At home
- In a residential care home
- In hospital
- In a palliative care hospital
- Other

e) Is there anything else that you think your family member or friend would want the health care team to know about **where** they are cared for, if they were very sick or dying? If so, you can write this here.

f) Are there any religious, spiritual or cultural beliefs that your family member or friend would want the health care team to know and consider if they were very sick or dying?

g) Is there anything else you think your family member or friend would want their health or care professionals to know about how they would like to be cared for if they 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) Has your family member or friend made any arrangements to donate their organs or discussed their preferences with you?

- They would want to donate their organs or body parts (if it were an option for them)
- They would not want to donate their organs or body parts
- I am not sure

Donation of organs or body parts may require a person to arrange this while they still had capacity to make their own decisions. If you would like more information about organ and tissue donation, ask your family member or friend's doctor or visit donatelife.gov.au

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

7. How your family member or friend would want to be cared for after they die

What would your family member or friend want their health care team to know about how they want to be cared for after they die? Things to consider:

- Are there any rituals they would want?
- Would they prefer to be buried or cremated?
- Would they have any special requests or plans for their funeral?
You may also like to include your family member or friend's preferred funeral director and contact details here (if known)

8. Other questions or things you would like to discuss with your family member or friend's health or care team about their care

Next steps

- Start or continue speaking to your family member or friend's health or care professionals about your answers to the questions in this guide. Speak to them about any other thoughts or preferences you think your family member or friend may have about their future care. You might like to provide a copy of this booklet to your family member or friend's health or care professionals when you have completed it.
- Make sure your family member or friend's health and care professionals have a copy of any formal legal documents signed by your family member or friend. For example, a legal appointment of a substitute decision maker or an Advance Care Directive. An Advance Care Directive is a legal document that formally records a person's preferences for their own care. It comes into effect once the person is no longer able to make decisions for themselves.

An Advance Care Directive cannot be completed on behalf of another person.

- Ask your family member or friend's doctor or nurse any questions you have about their future health care, so you can be prepared to make decisions on their behalf when required.
- Consider writing down your family member or friend's preferences in an Advance Care Plan with the assistance of your family member or friend's health care team.
 - An Advance Care Plan may be completed on behalf of a person when they no longer have capacity to make decisions about their own care.** It is only necessary when a person did not already complete their own Advance Care Directive. It should say what the person themselves would have wanted, to guide decisions about their care. Unlike an Advance Care Directive, an Advance Care Plan is not legally enforceable and the treating team is still required to seek appropriate consent for treatments and lifestyle decisions from the substitute decision maker. An Advance Care Plan can still be very helpful to enable the substitute decision maker, other family members and the health and care team to develop a shared understanding of what is known about the person's preferences and the goals of care, and any treatments that should be avoided. An example Advance Care Plan for a person who can no longer take part in their own decisions is available from metrosouth.health.qld.gov.au/sites/default/files/soc-qldhealth-form-b.pdf Your family member's health or aged care team may have an Advance Care Plan form that they prefer to use.
- Talking about the future health and death of someone you love can cause you to feel strong emotions. It is important that you take care of yourself too. Talking to other family members or friends and your own doctor or health care team about your feelings and concerns can help.

For more information and support

About advance care planning

- **Advance Care Planning Australia** provides further advice and information about advance care planning and being a substitute decision maker from advancecareplanning.org.au. There is a National Advance Care Planning advisory service available from Monday to Friday, 9.00 am to 5.00 pm. You can call them on **1300 208 582**.

Care and support options

- **My Aged Care** is the Australian Government service that provides information about, and access to, care services. My Aged Care has a helpline that you can call to talk about your family or friend's care needs. The helpline operates from Monday to Friday, 8.00 am to 8.00 pm, and Saturday from 10.00 am to 2.00 pm. You can call them on **1800 200 422**. More information is available at myagedcare.gov.au
- **Carer Gateway** is the Australian Government service that provides information about, and access to, services and supports for carers. Carer Gateway has a helpline where you can call to talk about your needs as a carer. The helpline operates 8.00 am to 5.00 pm Monday to Friday. You can call them on **1800 422 737**. More information is available at: carergateway.gov.au

About dementia (if your family member or friend has dementia)

- **Dementia Australia** has a wealth of information and resources about dementia, including factsheets and videos. Dementia Australia operates The National Dementia Helpline for people living with dementia, their carers, families and friends. The helpline operates from Monday to Friday, 9.00 am to 5.00 pm. You can call them on **1800 100 500**. More information is available at dementia.org.au
- **Dementia Support Australia** is a partnership led by HammondCare. Dementia Support Australia has a helpline for people living with dementia, their carers, families and friends. The helpline operates 24 hours a day, 365 days of the year. You can call them on **1800 699 799**. More information is available at www.dementia.com.au

Emotional support

- **Lifeline** is a national charity providing all Australians experiencing a personal crisis with access to 24-hour crisis support. You can call them on **13 11 14**. More information is available at lifeline.org.au
- You can also contact your doctor or nurse.

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In collaboration with



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