

What is advance care planning?

If you knew someone who became very unwell and was not able to communicate their preferences to others, would you know what they wanted? Could you make healthcare decisions on their behalf?

If your loved one became more unwell or had a sudden emergency they may no longer be able to make their own decisions about health and personal care. This can happen to people of all ages, and especially towards end of life.

Writing an Advance Care Directive lets a person say what they would want, if they are ever unable to communicate for themselves.

Benefits for you and the people you care for

Advance care planning:

- Helps to ensure that a person's preferences, beliefs and values about health care are known and respected if they are too unwell to speak for themselves
- Research has shown that families of people who have done advance care planning have less anxiety and stress when asked to make important healthcare decisions for other people.



What does a substitute decision-maker do?

When a person prepares their Advance Care Directive, they may invite someone to be their substitute decision-maker. If the person loses their ability to make their own healthcare decisions, the substitute-decision maker can then make decisions on their behalf. The Advance Care Directive will provide direction and guidance.

Some state/territory laws may allow for more than one substitute decision-maker to be appointed.

How can a substitute decision-maker help with advance care planning?

Be open

- If someone asks you to be their substitute decision-maker, think about what it might mean for you before you agree.

Ideally, you need to be:

- Available (live in the same city or region) or readily contactable
- Over the age of 18
- Prepared to advocate and make decisions clearly and confidently on the person's behalf when talking to doctors, other health professionals and family members if needed
- Comfortable with encouraging the person to talk through their preferences with their family members and close friends.

Be ready

- Talk with the person about their values, beliefs and life goals. Make sure you understand and respect their approach to health care, living well and end-of-life decisions.
- If you and the person have conflicting beliefs, be honest with them. Remember that you may be called upon to advocate for them. If your beliefs are too different, it may be better for them to choose someone else.
- Talk about any potential issues that may arise with family members or partners who have different views. How will you cope with any disagreement that could arise? Do they know you are a substitute decision-maker?
- If you agree to being a substitute decision-maker, discuss whether they want you to be legally appointed.

Be heard

- Encourage the person to write an Advance Care Directive.
- Ask for a copy of the Advance Care Directive and keep it safe. Familiarise yourself with the person's preferences and ask them to explain anything that isn't clear.
- Encourage them to review their Advance Care Directive every year or if there is a change in their health or personal situation.
- Encourage them to load their Advance Care Directive onto 'My Health Record' at myhealthrecord.gov.au



What others say about being a substitute decision-maker

“I did what needed to be done to make her quality-of-life the best it could possibly be under the circumstances.”

“I’ve read Dad’s plan. It is so valuable to know because it’s not a plan I would have ever developed myself.”

“I was hoping that the decision I made was the same decision that the person I was acting on behalf of would have made.”

The law and advance care planning

When you are appointed as a substitute decision-maker, it will be helpful to understand the law in your state/territory. Different states and territories in Australia have different laws regarding advance care planning. There are also common law decisions in advance care planning.

Depending on the state/territory:

- A substitute decision-maker may be legally appointed as an Attorney, Enduring Guardian, Decision-Maker or Medical Treatment Decision-Maker.
- An Advance Care Directive may also be called an Advance Health Directive, Health Direction or Advance Personal Plan.

Conversation starters

To get started, choose a quiet setting where you have a lot of time, so you know that you won’t be interrupted. Be patient and take your time: you and your loved ones might need a few moments to think.

Sometimes you might get a bit sidetracked and that’s okay. Let the conversation happen naturally. You don’t need to talk about everything all at once. Remember that advance care planning is an ongoing conversation.

Here are some questions you may like to ask them:

- What do you currently value about your life?
- If your current health condition (e.g. cancer, dementia) got worse, what kind of medical treatment would you want and do not want?
- Describe a good day for you.
- If there was an emergency what kind of medical treatment would you want or not want?

At times, it can be challenging

Making medical decisions on behalf of someone else can be challenging.

When making decisions for someone else, you may:

- Feel uncertain about the outcomes of some decisions
- Feel that the preferences of the person for whom you are making decisions are unclear
- Question whether the decision you are making is the right one
- Have values and preferences that are in conflict with those of the person for whom you are making decisions
- Disagree with family members and/or treating health professionals over certain decisions.

Questions to ask your loved ones’s doctor:

- What are the risks and likely outcomes of this treatment or procedure?
- Are there other safer options available?
- What are the financial costs of this treatment or procedure?

Self-care is important

While being a substitute decision-maker is an important role, looking after yourself is also important. If you feel overwhelmed about being a substitute decision-maker we recommend that you seek counselling and support. You can also access your religious or spiritual communities and other social networks to help you through this process.

Knowing your rights

If you feel you are not the right person or you can no longer fulfil your duties, you can resign from your appointment. Be sure to inform the person who appointed you as their substitute decision-maker so they can appoint someone more suitable for the role.

We’re here to help

Free information is available from:

[Advance Care Planning Australia](#)

[i advancecareplanning.org.au](https://www.advancecareplanning.org.au)

[National Advisory Service: 1300 208 582](tel:1300208582)

[learning.advancecareplanning.org.au](https://www.learning.advancecareplanning.org.au)