

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?

Advanced illness or serious injury can sometimes mean that people cannot 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 (values and/or instructional) 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
- benefits those who are close to them. 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.

Making healthcare decisions for others can be difficult. An Advance Care Directive can give peace of mind and comfort as preferences are clear, understood and respected.



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?

It is important to consider the information below (and continued overleaf), when the person is making an Advance Care Directive.

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. More information is available from advancecareplanning.org.au.

Be heard

- Encourage the person to write an Advance Care Directive. See advancecareplanning.org.au for the relevant form, advance care planning legal factsheet, and/or substitute decision-maker documentation.
- Ask for a copy of the Advance Care Directive every year 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.

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. See advancecareplanning.org.au for information.

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.

Starting the conversation can be the hardest part, so here are a few ways to begin:

- What's on your bucket list? What are your goals?
- I'd like to know more about what decisions you would make for yourself, so if I need to I can make the decisions you would have made.
- What do you value most in life? What does it mean to 'live well'?

Where can I get more information?

Advance Care Planning Australia

- advancecareplanning.org.au
- National Advisory Service: 1300 208 582
- learning.advancecareplanning.org.au