

# Advance Care Planning

*A guide for people affected by cancer*

**This fact sheet has been developed to help you understand more about advance care planning – thinking about and discussing your future, and recording your preferences for care so your family and friends know what you want.**

## What is advance care planning?

Advance care planning involves thinking about the future and how you want to live and be cared for. You can talk about those plans with your family, friends and treatment team. This helps them understand your values and beliefs, and helps ensure that your wishes are respected.

## Who needs advance care planning?

Advance care planning is important for everyone. It can be done any time, whether you are sick or well. It is especially important for anyone with an illness that they will live with for the rest of their lives, such as:

- an advanced chronic illness
- a life-limiting illness, such as advanced cancer
- a risk of dementia or a related illness.

Like making a will, advance care planning helps you plan for the future. An advance care plan records your wishes for care while you are alive, while a will outlines your wishes for after you die.

## Starting the discussion

Thinking about the future can be difficult. However, some people find it a relief to talk about it and make plans with those around them.

Studies show that families can feel less stress and worry when a person reaching end of life has done advance care planning.<sup>1</sup>

## What does advance care planning involve?

Everyone has their own preferences for medical care and these can change over time. Advance care planning can involve:

### Asking for advice and help



- Talk with health professionals, family and friends, and making decisions about what is important to you.
- Discuss with family, friends and health professionals what treatments you want or do not want, including where you want to receive care (e.g. at home if possible).

### Details and documents



- Complete advance care documents.
- Appoint a substitute decision-maker.
- Share these documents and decisions with those close to you and those involved in your care.

Think about what matters most to you. You may want to find a balance between what medical care can achieve and the side effects of treatments.

How you feel may change as your circumstances change. It's okay to add to or make changes to your advance care plans. You and your family may find it useful to start thinking about these issues before they are raised by a health professional. Or you could ask a social worker for support.

### Some phrases to start the discussion

- “I know it’s uncomfortable to talk about what happens if I don’t get better, but it’s really important to me.”
  - “We’ve talked a bit about what happens after I die, but we need to talk about what happens if I become more unwell and not able to function.”
  - “My health care team say I should discuss a few things with you ...”
- For information on how to talk to your family and friends, see our booklets *Living with Advanced Cancer* and *Talking to Kids About Cancer* and listen to our “Living with Dying” episode of *The Thing About Advanced Cancer* podcast series.

### Advance care documents

As part of advance care planning, you can write down your wishes. This may be called an advance care directive, an advance personal plan or health direction depending on your state or territory. This legal document records your values and treatment preferences. You can find these documents for each state and territory at [advancecareplanning.org.au](http://advancecareplanning.org.au).

You may include:

- details of treatments that you want
- treatments you would refuse to have
- what is most important to you for end-of-life care.

Your health care team can help you write this, and you can change or cancel it at any time.

Doctors, family, carers and substitute decision-makers (see opposite) will consider this if you become unable to communicate or make decisions. You can ask your doctor or hospital to place the document on your medical record. You can also save it in your My Health Record at [digitalhealth.gov.au](http://digitalhealth.gov.au).

### Palliative care

Advance care planning sometimes forms part of palliative care. Palliative care is for people with a life-limiting illness. Sometimes called supportive care, it aims to maintain your quality of life by meeting physical, emotional, social, cultural and spiritual needs. Palliative care may be given at home, in a hospital, in a palliative care unit (which may also

### Advance care planning

Each state or territory has different laws that deal with advance care planning and substitute decision-makers.

### Legal advice



Talk to a lawyer for advice specific to your situation. In some cases, Cancer Council may be able to connect you with a lawyer for help in appointing a substitute decision-maker.

### Advisory service



For general advice, you can call Advance Care Planning Australia’s advisory service on 1300 208 582, or visit [advancecareplanning.org.au](http://advancecareplanning.org.au).

### Substitute decision-makers

Capacity means you are legally able to make your own decisions. In general, it means you can:

- understand and remember information about available choices
- understand the consequences of your decisions
- communicate your decisions.

A substitute decision-maker is someone you choose, by law, to make medical decisions for you if you cannot in the future. This should be someone you trust and who understands your values and preferences, and who will be able to make decisions you would want.

Talk with the person you want to choose as your substitute decision-maker first. They may not want the role, or they may not agree with your wishes.

be called a hospice), in a residential aged care facility or through community-based palliative care providers.

- For more information about palliative care, see our *Understanding Palliative Care* booklet or visit [palliativecare.org.au](http://palliativecare.org.au).

Depending on where you live, generally, an “enduring guardian” specifies a substitute decision-maker for your medical care and living arrangements once you have lost mental capacity, and an attorney appointed under an “enduring power of attorney” or a “financial manager” is a substitute decision maker for financial decisions once you have lost mental capacity.

## Default decision-maker

If you lose capacity to give consent for medical treatment and you don’t have an advance care document or a substitute decision-maker, the guardianship law in each state and territory outlines who may make medical treatment decisions for you. This is usually someone close to you.

## Questions for your doctor

You may find this checklist helpful when thinking about the questions you want to ask your doctor. Consider taking a support person with you – this could be a family member or a friend – to help you record and remember the answers

- What is advance care planning? Who can help me with this?
- What financial and practical assistance is available?
- Can you help me talk to my family about what is happening?
- Who can I talk to if I have concerns about my decisions?

## Where to get help and information

Call Cancer Connect on 13 11 20 or visit the website for more information about cancer and health care. Qualified professionals can listen to your concerns, put you in touch with local services and send you free copies of our booklets. You can also visit your local Cancer Council website.

Cancer Connect	<a href="http://cancerconnect.org.au">cancerconnect.org.au</a>
ACT	<a href="http://actcancer.org">actcancer.org</a>
NSW	<a href="http://cancercouncil.com.au">cancercouncil.com.au</a>
NT	<a href="http://cancer.org.au/nt">cancer.org.au/nt</a>
QLD	<a href="http://cancerqld.org.au">cancerqld.org.au</a>
SA	<a href="http://cancersa.org.au">cancersa.org.au</a>
TAS	<a href="http://cancer.org.au/tas">cancer.org.au/tas</a>
VIC	<a href="http://cancervic.org.au">cancervic.org.au</a>
WA	<a href="http://cancerwa.asn.au">cancerwa.asn.au</a>
Australia	<a href="http://cancer.org.au">cancer.org.au</a>

## Other useful websites

Advance Care Planning Australia	<a href="http://advancecareplanning.org.au">advancecareplanning.org.au</a>
Cancer Australia	<a href="http://canceraustralia.gov.au">canceraustralia.gov.au</a>
Services Australia	<a href="http://servicesaustralia.gov.au">servicesaustralia.gov.au</a>
Palliative Care Australia	<a href="http://palliativecare.org.au">palliativecare.org.au</a>
Queensland University of Technology’s End of Life Law in Australia	<a href="http://end-of-life.qut.edu.au">end-of-life.qut.edu.au</a>

### References

1. Zhang et al., Effects of advance care planning for patients with advanced cancer: A meta-analysis of randomized controlled studies, *International Journal of Nursing Studies*, Volume 168, 2025.

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### Note to reader

Always consult your doctor about matters that affect your health, a financial adviser or financial counsellor about matters affecting your finances, and a lawyer about legal matters. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. All care is taken to ensure that the information in this fact sheet is accurate at the time of publication. Please note that laws, regulations and entitlements that affect people with cancer may change. Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

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Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

