



Advance Care Planning: Getting Started Guide

**Advance Care
Planning Australia**

BE OPEN | BE READY | BE HEARD

Why is advance care planning important?

Whatever our age may be, we all have values and preferences related to health and personal care. It's important to think about these values and preferences. Healthcare planning and conversations with loved ones are valuable and provide many benefits. You might also choose to write them down in an Advance Care Directive so that your preferences are understood and respected if you were in a situation where you were unable to communicate them yourself.

Advance care planning is particularly important for people who are older and are frail, or people who have a chronic illness, an early cognitive impairment such as dementia, or are approaching their end of life.

Advance care planning can involve the following:

- thinking and talking about your healthcare values and preferences
- appointing a substitute decision-maker
- completing an Advance Care Directive.

When should I start advance care planning?

You should start planning when you're healthy – before there's actually an urgent need for a plan. But having conversations and an Advance Care Directive in place becomes particularly significant towards the end of a person's life. About 85% of people die after chronic illness, not as the result of a sudden event – so it's important that your substitute decision-maker and Advance Care Directive is ready in case it's required someday.

How do I get started?

Here are some things to consider when starting advance care planning.

Be open – start thinking about your health, values and preferences

Be ready – have conversations with families, close friends and others

Be heard – document and communicate your decisions ready for the future

The following information will help you through these steps to develop your personal advance care plan and choose your substitute decision-maker. It will help your substitute decision-maker to better understand your healthcare preferences and to make the choices you want.

Be open about what matters most to you

To communicate your values and preferences to others, you must first know and understand these yourself. Take the time to consider the questions below. Consider your beliefs, values and preferences for your current and future health. Think about the medical treatment you may or may not want. There are no wrong answers to these questions.

Your current health

- Do you feel you have a good understanding of your current health?
- How does your current health affect your life?
- What makes life worth living? For example, spending time with your family.
- What do you enjoy doing? How does your health affect this?
- What would be unacceptable outcomes of medical treatment after illness or injury?
For example, loss of independence or not being able to communicate.

Your past experiences of health

Your past experiences can shape your views about medical treatment. You may have had an experience with a family member or friend who was faced with a decision about medical care. This may have been a difficult experience for you and led you to have certain views regarding what kinds of medical treatments you may or may not want in the future.

- Have you or anyone else you know had a positive or a difficult experience with healthcare?
- Are there things that you wish could have been done differently?
- Are there any medical treatments that you have experienced or seen others experience that influence your views?

Your future health

An important part of advance care planning is considering the kind of health issues that might arise in future. The questions below are a good place to start.

- Have you discussed with your doctor how your current health conditions might progress?
- How might this impact on the things you are hoping to do in the future?
- What short and long-term goals do you have? For example, attending a wedding, going on a holiday.

It's also useful to consider a scenario where your day-to-day living is severely impacted by a sudden event or worsening health. What abilities do you need to live well or maintain your dignity? For example, showering independently or recognising people you love.



Are there any medical treatments you would prefer to have or avoid?

- Would you accept treatment if it meant you were unable to recognise or talk to loved ones?
- Would you accept treatment that would mean you were unable to eat or drink?
- Would you accept treatment if it meant you could no longer live independently in your own home?
- How would your beliefs about religion and spirituality affect your choice of medical treatments?
- Would you accept treatment if you could no longer express your needs to those caring for you? For example, “I need to go to the toilet”, “I want to sit in the garden”, “I would like sugar in my tea”.



An Advance Care Directive may have a different title depending on the Australian state or territory you are in. Some of the other titles used are:

- Advance Health Directive
- Advance Personal Plan
- Health Direction

Be ready to engage others

Speak to your family

Speak to your family and others close to you about your views and preferences for your medical care from the questions listed previously. A close or loving relationship does not always mean someone knows or understands your preferences.

Speak to your doctor

Your doctor should provide you with information and advice regarding your current health situation and what may happen in the future.

Select a substitute decision-maker

It's a good idea to think about who you would want to make decisions about your health if you were unable to make those decisions for yourself. Choose a substitute decision-maker you can trust. This is someone you're confident can stand in your shoes and make the decisions you would make for yourself.

The person that you choose should be somebody:

- aged 18 or over, and does not need to be a family member
- who will listen and discuss your values and preferences
- you trust to follow the values and instructions you have discussed
- who is willing to accept this responsibility and available to take on the role if required
- who is comfortable to make decisions in stressful situations.



Substitute decision-makers may have different titles depending on the Australian state or territory you are in. Some of the other titles used are:

- Decision-Maker
- Enduring Guardian
- Enduring Power of Attorney
- Medical Enduring Power of Attorney
- Medical Treatment Decision-Maker

You may choose more than one substitute decision-maker.

To formalise your selection of substitute decision-maker, you'll need to complete the relevant form that's used in your state or territory. These forms are available from the Advance Care Planning Australia website: advancecareplanning.org.au.

Be heard and make your preferences known

To ensure your preferences are followed, you should write them down in an Advance Care Directive. We've listed some sample statements below to give you an idea of the kind of statements that are suitable for an Advance Care Directive.

- If I have a terminal condition and needed help to breathe, I would only wish to be put on a ventilator if it was for a short time, such as overnight.
- If I have dementia and I fall and hurt myself, I would agree to any treatment or surgery to manage pain and keep me comfortable.
- I am Italian and would prefer to be in an environment where people speak my language and I can eat Italian food.
- If I am dying, please try and keep me alive so my family members can see me to say goodbye before I die.
- If I have a serious condition with little chance of recovery, am incontinent, cannot eat and rely on others to move and wash me, I do not want life-prolonging treatment.

Will I need a lawyer to make an Advance Care Directive?

You are able to use a lawyer to make an Advance Care Directive, however you do not need to. You will find the relevant forms for your state or territory at advancecareplanning.org.au.

Your Advance Care Directive should include information about your values and preferences. All future circumstances cannot be predicted, however it will help your substitute decision-maker to understand what you would want. You should include the name and contact details of your substitute decision-maker.

Once it is written, it should be signed and dated by you and a witness. Copies of your Advance Care Directive and the form nominating your substitute decision-maker should be given to:

- your family
- your substitute decision-maker
- your hospital and local doctor
- the ambulance service
- anyone else who you feel is appropriate.

We also recommend you upload a copy to My Health Record: myhealthrecord.gov.au.

Changing your Advance Care Directive

You can change your Advance Care Directive at any time. Copies of your updated document should be given to everyone you have given a previous version to. You should also upload the document to My Health Record.

You should review your Advance Care Directive:

- when your preferences change
- if your substitute decision-maker changes
- when your medical condition changes.

Your advance care planning to-do list


Discuss your thoughts with those close to you – your family, substitute decision-maker, your GP and other involved healthcare providers.




- Ask your doctor any questions that you may have regarding your health and medical treatments.
- Seek advice from the National Advance Care Planning Advisory Service or access information on the Advance Care Planning Australia website.
- Legally appoint your substitute decision-maker and talk about your preferences with them.
- Complete an Advance Care Directive.
- Make sure your Advance Care Directive is accessible. Be sure to upload it to My Health Record and give copies to family members and those involved in your care.

Find out more

Advance Care Planning Australia

 advancecareplanning.org.au

 acpa@austin.org.au

 **1300 208 582**

For free advice call Monday to Friday, 9am–5pm (AEST)

Advance Care Planning Australia is funded by the Australian Government and administered by Austin Health.

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This publication is general in nature and people should seek appropriate professional advice about their specific circumstances, including advance care planning legislation in their state or territory.

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