



Advance Care Planning Getting Started Guide



**Advance Care
Planning Australia**
An Australian Government initiative

Why is advance care planning important?

If you become very sick or injured, you might not be able to tell others what you would want for your care and medical treatment. Advance care planning can help you make some decisions now about the health care you would want in the future. This might include care at the end of your life.

Advance care planning gives you the chance to think and talk about your preferences for the care you would like to receive and the outcomes you would find acceptable or unacceptable. You might also choose to write down your preferences. This helps your loved ones and health providers know what matters most to you and respect your treatment preferences.

Advance care planning can involve the following:

- thinking and talking about your values and health care preferences
- appointing another person (a substitute decision-maker) to make decisions for you
- completing an advance care directive

When should I start advance care planning?

The best time to start advance care planning is right now, regardless of your age or health. If you haven't written your preferences or chosen a substitute decision-maker, doctors may need to make treatment decisions based on what they think is best for you. This may include treatments that you would not want.

How do I get started?

There are three things you need to do to start advance care planning.

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

Be ready – talk with family members or those closest to you

Be heard – share your preferences to be ready for the future

The following information will help you begin your advance care planning and choose your substitute decision-maker. It will also help your substitute decision-maker to better understand your health care preferences and to make the choices you want.

Be open about what matters most to you

Consider your beliefs, values and preferences for your future health. Consider what independence means to you such as your ability to look after yourself, verbally communicate or make simple decisions for yourself.

Reflect on the questions below, thinking about what matters most to you for your health and wellbeing.

Your current health

- How is your current health? Do you have any worries about your health?
- 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 sickness or injury? For example, no longer being able to feed yourself or speak to family.

Your past experiences of health

You may have seen a family member or friend make a challenging decision about their health care. This may have shaped your views about the kinds of medical treatments or care you may or may not want in the future.

- Have you, or anyone else you know, had a positive or a difficult experience with health care?
- Has this experience shaped your views about the sort of care you would or would not like to receive?
- Do you wish some things could have been done differently? What would they be and why?

Your future health

An important part of advance care planning is planning for health issues that might come up in the future. The questions below are a good place to start to think about this.

- Have you talked with your doctor about how your current medical 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, or going on a holiday. It is useful to consider a situation 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.



What medical treatments and outcomes would you accept?

- Would you accept treatment if it meant you could not recognise or talk to loved ones?
- Would you accept treatment that might 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 cultural, religious or spiritual beliefs or traditions shape your health care preferences and 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”, or “I have pain in my back”.



An Advance Care Directive documenting your preferences may have a different title depending on the Australian state or territory where you live. Some of the other titles are:

- Advance Health Directive
- Advance Personal Plan
- Health Direction

Be ready to share your thoughts

Speak to your family

Tell your family and others close to you about your views and preferences for your health care. It might be helpful to start with the questions on page 3. Being in a close relationship with someone does not mean they know or understand all your preferences.

Speak to your doctor

Your doctor can give you information and advice regarding your current health situation and what may happen in the future.

Choose a substitute decision-maker

It is a good idea to think about who you would want to make decisions about your health care and treatment options if you were unable to make those decisions for yourself. Choose a substitute decision-maker you can trust. This should be someone you feel confident will make the decisions you would make for yourself.

The person that you choose should be someone:

- aged 18 years or over – they do not need to be a family member
- who will listen and discuss your values and preferences
- you trust to follow your values and instructions
- who is willing to accept this responsibility and available to take on the role if needed
- who is able to make decisions in stressful situations.



- Substitute decision-makers may have different titles depending on the Australian state or territory where you live.
- A legal Substitute Decision-Maker may also be called an Attorney, Enduring Guardian, Enduring Power of Attorney, Decision-Maker or Medical Treatment Decision-Maker.
- Depending on your state/territory, you may be able to choose more than one substitute decision-maker.
- To appoint your substitute decision-maker, you will need to complete the form that is used in your state or territory. You can access these forms at advancecareplanning.org.au/create-your-plan or call the National Advance Care Planning Support Service™.

Be heard and share your preferences

Writing your personal preferences in an advance care directive means they are more likely to be followed. Be clear so others will understand what you want. The sample statements below might give you some ideas about what you might write in your advance care directive.

- 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, even if that meant I had to go to hospital.
- I would prefer to receive care from people who speak my language or understand my cultural background.
- If I have a serious condition with little chance of recovery, where I cannot eat or need to rely on others to take me to the toilet and wash me, I do not want any treatment that will prolong my life. I would prefer to receive care that focuses on my comfort.
- Having my family/pet/favourite music with me would help me to feel safe and loved.

You can't predict all future circumstances. Your advance care directive should include information about your values and preferences which will help your substitute decision-maker and health and care providers understand what you would want. You should include the name and phone contact details of your substitute decision-maker.

Do I need a lawyer to make an advance care directive?

You do not need to use a lawyer to make an advance care directive, however you may choose to do so. It is a good idea to speak with your doctor and in some states and territories, they will be required to sign your advance care directive. You will find information about the relevant laws and forms for your state or territory at advancecareplanning.org.au/create-your-plan

Storing your advance care planning documents

If you have completed your advance care directive or form used to choose a substitute decision-maker, they will need to be signed and dated by yourself and a witness. Copies of these forms should be given to:

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

It is also recommended you upload a copy of all advance care planning documents to My Health Record.

Changing your advance care planning documents

You can change your advance care directive or substitute decision-maker at any time. Copies of your updated documents should be given to everyone who had received a previous version. You should also upload the new documents to My Health Record.

You should review your advance care directive:

- if your preferences change
- if you want to change your substitute decision-maker
- if your medical condition or general health changes
- every one to two years.

Canceling or revoking your advance care planning documents

If you decide you no longer want to keep your advance care directive, you may cancel or revoke it. You can also revoke your substitute decision-maker appointment(s). Speak to your health care team or the National Advance Care Planning Support Service to learn how.



Steps for your advance care planning

- Discuss your thoughts with those close to you – your family, substitute decision-maker, your doctor and other healthcare providers.
- Ask your doctor any questions you may have regarding your health and medical treatments.
- Seek advice from the National Advance Care Planning Support Service or access information at advancecareplanning.org.au
- Legally appoint your substitute decision-maker by completing the relevant form and tell them your preferences.
- Complete an advance care directive.
- Make sure these documents are easily accessible. Be sure to give copies to family members and those involved in your care. Upload documents to My Health Record.



Find out more

Advance Care Planning Australia™

 advancecareplanning.org.au

 **National Advance Care Planning Support Service™**
For free support call 1300 208 582



Advance Care Planning Australia is an Australian Government initiative and administered by Brisbane South Palliative Care Collaborative, Metro South Health.

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.