Advance Care Planning: Getting started
This booklet has been designed by Advance Care Planning Australia to support you in the process of developing an Advance Care Directive. We encourage you to refer to this booklet when using its companion publication, **Advance care planning: a personal guide**.


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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, discuss them and 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, multiple diseases, an early cognitive impairment, or are approaching their end of life.

Advance care planning involves:

- appointing a substitute decision-maker
- completing an Advance Care Directive.

When should I make an Advance Care Directive?

You should start planning when you’re healthy – before there’s actually an urgent need for a plan. But having 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 Advance Care Directive is ready in case it’s required someday.

How do I get started?

Advance care planning doesn’t need to be complicated, but it’s important to be open, be ready and be heard. It’s about starting sometimes difficult conversations with families and close friends.

Following this information will help you to communicate your decisions to the staff caring for you. It will help your substitute decision-maker to better understand your healthcare preferences and to make the choices you want.
To effectively communicate your values and preferences to others, you must first know and understand these yourself. Take the time to consider the prompts below.

Consider your beliefs, values and preferences for your current and future health. Think about the medical treatment you may or may not want. This is no different to arranging your life insurance or your Will. There are no wrong answers to these questions.

**Past experiences of health**
- Have any past experiences of healthcare influenced your views on your future care? These may be positive or negative experiences that have happened to yourself or others.

**Your current health**
- Do you feel you have a good understanding of your current health?
- How does your current health affect your life?

**Your future health**
- What makes life worth living? For example, talking to your family.
- What abilities do you need to maintain to preserve your dignity? For example, toileting independently.
- What if you cannot recognise or understand your family?
- What if you cannot eat or drink?
- What if you are not able to talk to your family and friends?
- What if you lost your independence and needed help to do everything?
- What short and long-term goals do you have? For example, attending a birthday, going on a holiday.
- What treatments will help you to live the way you want?
- What would be your minimum acceptable outcome? For example, feed yourself, think for yourself.
- How may your beliefs about religion and spirituality affect your choice of medical treatments?
- Are there any medical treatments that you feel strongly about, either having or not having?

**Who should make decisions?**
Think about who would you want to have making your medical decisions? Some people to consider are your:
- partner
- friend
- sibling
- adult child
- parent
- religious advisor
- legal representative.
Be ready to engage others

**Speak to your family**

Speak to your family and others close to you about your views and preference for your medical care.

A close or loving relationship does not always mean someone knows or understands your preferences.

The more a person understands your views and preferences, the easier it is for them to help guide your medical treatment.

The prompts from the ‘Be open’ section should help you decide the information to share with your family and substitute decision-maker.

**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**

Your substitute decision-maker will be asked to make medical treatment decisions on your behalf if you are not able to do so.

They should be somebody:

- you trust
- who is over 18 years
- who will listen carefully to your values and preferences for future care
- who will be comfortable making decisions in difficult situations.

When choosing your substitute decision-maker, you should ask yourself the question: ‘Am I confident this person will make decisions based on what I would want?’
You may also choose a second person (an alternate substitute decision-maker). They will be called on if your substitute decision-maker is unable to make decisions on your behalf.

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

- Medical Enduring Power of Attorney or Medical Treatment Decision-Maker (Victoria)
- Enduring Guardian (New South Wales, Tasmania, Western Australia)
- Enduring Power of Attorney (Queensland, ACT)
- Substitute Decision-maker (South Australia)
- Decision-maker (Northern Territory).

To formalise your selection of a substitute decision-maker, you’ll need to complete the relevant form that’s used in your state or territory. This form must be witnessed by someone who can authorise a statutory declaration, for example a:

- medical practitioner
- legal practitioner.

Links to these forms are available from the Advance Care Planning Australia website: advancecareplanning.org.au
To ensure your preferences are followed, you should write them down in an Advance Care Directive (instructional and/or values).

We recommend you discuss your document with your doctor. You do not require a lawyer to complete it.

Forms are available to guide the content of your Advance Care Directive.

It does not have to be written on one of these forms (except for South Australia).

Your Advance Care Directive should contain information about your values and preferences. As all future circumstances cannot be predicted, this information will help your substitute decision-maker to decide on what you would want. You should also include name and contact details of your substitute decision-maker(s).

Once it is written, it should be signed and dated by you. Your substitute decision-maker and a clinician (for example, your doctor) may also sign it.

Your Advance Care Directive cannot be followed if people do not have access to it. All emergency services will need to know your preferences and require access to your plan.

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.
Changing your Advance Care Plan

You can change your Advance Care Directive at any time. See ‘Advance care planning and the law’ factsheet for further details regarding revoking documents. Copies of your reviewed plan are distributed to all those listed above. The most recent version available is the one that will be followed.

Review your Advance Care Directive:
- when your preferences change
- if your substitute decision-maker changes
- when your medical condition changes.
Find out more

You can find more information including answers to frequently asked questions on the Advance Care Planning Australia website: advancecareplanning.org.au

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