

Advance care planning and dementia

Who will speak for you if you can't speak for yourself?

Advance care planning is about your future health and personal care. It gives you the opportunity to plan for what you would want, if you were unable to say it yourself. This factsheet is about advance care planning and dementia.

Your substitute decision-maker

If you lose the ability to make decisions – either because of an accident, sudden illness or a progressive illness like dementia, someone else will be asked to make decisions for you. This person is called a 'substitute decision-maker'.

There are laws in each state and territory setting out a priority order of decision-makers. These laws determine who would be your substitute decision-maker.

However, you can appoint a different person if you want to. This does not have to be a family member.

'Identifying and appointing someone who will make decisions on your behalf, is an important part of planning ahead.'

Persons identified in state or territory laws to be your substitute decision-maker

The laws that decide who will be your substitute decision-maker vary across the states of Australia. The first person on the list in all states and territories is someone you have legally appointed. After that, the list involves certain types of people.

For example:

- an appointed substitute decision-maker
- a spouse
- an unpaid person who provides care and assistance
- a close friend
- a family member.

Information for your state or territory can be found at advancecareplanning.org.au

Is this the person you would have chosen for yourself?

In many cases, the person automatically identified as your decision-maker is the same person that you would have chosen yourself. But this is not always the case. For example, you want your daughter or neighbour as your substitute decision-maker but the hospital may contact your brother or sister during an emergency.

Legally appointing your decisionmaker

If the person automatically selected to be your substitute decision-maker is different to the person you would choose, you can legally appoint your preferred person. They will have the authority to act on your behalf. It can also give you peace of mind. You will know decisions will be made by someone you trust and want to make your decisions for you.

Things to consider when choosing a substitute decision-maker

This is a very important role and something you should consider carefully. Ideally, the person (or people) you choose:

- would be willing to speak on your behalf
- would be able to act on your preferences
- can separate their own feelings from yours
- is available (preferably living nearby)
- knows you well and understands what's important to you
- will talk with you now about sensitive issues and will listen to your preferences
- will likely be around for some time into the future
- can confidently speak with health professionals and other family members about your preferences.

'The most important consideration is to have someone you trust.'

How to appoint your substitute decision-maker

You will need to complete documents from your Australian state or territory. It is best to complete these early as you need to be 'legally competent'. Being competent means you are able to understand the document you are signing, and the implications of this.

A person appointed by you as your substitute decision-maker only takes on this role if you lose capacity to make your own decisions. This person does not have the power to manage your financial affairs. If you want them to manage your financial affairs you need to appoint them separately to have that role.

In most states or territories you can appoint more than one person. You can give them the power to act alone or together in making decisions.

Explain to others who may expect to have a say in your care:

- who you have nominated and why, and
- ask these people to support the person you have appointed.

Supporting your substitute decision-maker

You can help your substitute decision-maker perform their role:

- Talk with them about your preferences for future care.
- Make sure they are happy to do it.
- Make sure they have copies of any relevant documents, such as your Advance Care Directive.

For more information and assistance

- Your local doctor/GP
- Access information and documents for your state or territory at advancecareplanning.org.au
- Alternatively, call the National Dementia Helpline on 1800 100 500

Where can I get more information?

Advance Care Planning Australia:

advancecareplanning.org.au

National Advisory Service: 1300 208 582