

Advance care planning and dementia

Frequently asked questions



Why should people living with dementia do advance care planning?

Everyone should consider advance care planning, regardless of their age or health. However, if you have recently been diagnosed with dementia it is especially important to discuss and record the treatment and care you would like to receive in the future.

There are many types of dementia and these impact people differently. Nevertheless, all types of dementia eventually cause a person to lose their legal capacity to consent to medical treatment.

In most cases, if a person has lost decision-making capacity and doesn't have an advance care directive, the doctor will make treatment decisions based on what they believe to be in the person's best interest. This might include treatments or treatment outcomes that the person would not want.

The doctor will ask a 'decision-maker' – usually a family member – to consent to specific medical treatments. These decisions can be stressful or difficult for families if they don't know what the person would have wanted.

Advance care planning is a voluntary process that allows you to:

- Talk to your family, friends, and doctors about how you would like to be cared for in the future
- Write those preferences down in an advance care directive
- Choose a person to make medical treatment and care decisions for you.

What's the difference between an advance care plan and an advance care directive?

There are distinct differences between an advance care plan and an advance care directive.

Advance care directives are completed by the person and involve documenting their own preferences for care and treatment. Most advance care directives are legally binding and provide direction for your health care team to follow. Forms and laws vary across the states and territories and require the person to have decision-making capacity.

Advance care plans are completed by someone else – usually a legally-appointed substitute decision-maker or family member – on behalf of a person who has already lost decision-making capacity.

When completing an advance care plan, the person who has reduced capacity should be present and supported to contribute as best as they can, such as making statements about their values and preferences.

Advance care plans help carers, substitute decision-makers and health practitioners make treatment decisions that align with the person's values and wishes. However, they are not legally binding.

Can I choose my substitute decision-maker?

Yes, your substitute decision-maker can be your spouse, a family member or even a friend. Nominating a legal substitute decision-maker is always a good idea, but especially if there is any chance of uncertainty or conflict between family members or friends.

Your substitute decision-maker should be someone you trust. They should be someone that is willing to support you to make decisions as your dementia progresses and then, if you lose decision-making capacity, make medical decisions on your behalf.

You can appoint (or change) your legal substitute decision-maker as long as you still have capacity. You can also appoint more than one substitute decision-maker.

Depending on where you live, your substitute decision-maker can also have responsibility for other aspects of your care, such as managing your money or where you live. For more information about substitute decision-making in your state or territory, call the [National Advance Care Planning Support Service™](#) on 1300 208 582.

Is it ever too late to do advance care planning?

It is never too late to talk about your health care choices. However, we do encourage people living with dementia to start advance care planning soon after they are diagnosed.

A diagnosis of dementia does not automatically remove your capacity to make an advance care directive. Decision-making capacity is situation specific – meaning it applies to that one decision, not every decision going forward.

With support and assistance from your substitute decision-maker, you can continue to make meaningful decisions, even as your dementia progresses.

If you are the substitute decision-maker or carer of a person whose legal capacity has been impacted by dementia, you should support the person to participate as much as they are able, and to assist them to make their own decisions when they can.

Most advance care directive forms contain safeguards that ensure you have decision-making capacity and are not subject to coercion. We encourage you to discuss advance care planning with your GP and have them sign your documents.

Further reading

- [Cognitive Decline Partnership Centre, Substitute decision-making handbook for people living with dementia and family members](#)
- [Dementia Australia, Understanding capacity and decision-making](#)

How do I talk to someone about advance care planning if they don't accept that they have dementia?

It can be challenging if a person displays cognitive impairment that they 'refuse' to acknowledge. Some people living with dementia experience a symptom called impaired metacognition, which can cause people to overestimate their cognitive ability or be unable to see changes in their behaviour. This is because their brain cannot recognise its own impairment.

People living with dementia may also be impacted by fear or grief. This is very normal when facing a life-limiting condition. You can encourage them to get support or counselling from a professional experienced with dementia. Family members and carers need support, too. Calling the [National Dementia Helpline](#) is a good place to start, to discuss your individual situation.

If the person is reluctant to talk about dementia, you could start the conversation by asking questions about what's important to them. Or, if someone they know experienced ill health, you could ask them if they would want the same types of treatment. Perhaps you can complete your advance care planning documents together.

Finally, it's okay if the person wants every treatment available to them or wants to follow the doctor's advice at the time. Advance care planning is not about just withholding treatment, it's about respecting the person's wishes, whatever they are.

Further reading

- [Dementia Australia, Talking about your diagnosis](#)
- [Alzheimer's Society UK, Understanding denial and lack of insight](#)

Are doctors required to provide treatment even if I have an advance care directive?

In most states and territories, advance care directives are legally binding and must be followed by your health care team.

However, doctors cannot provide treatment that has no benefit. So, if your advance care directive states that you want a treatment that would actually be harmful to you, they are not obliged to provide that treatment.

Everyone is legally allowed to choose to refuse treatment before or after it has commenced. In some Australian states, a nominated substitute decision-maker can also refuse treatment on behalf of the person who has lost capacity.

When making medical decisions, your doctor should be considering your health situation and your preferences, whether documented in an advance care directive or expressed verbally to your substitute decision-maker or family.

here are some situations where medical professionals, such as doctors or paramedics, are compelled to provide treatment. For example, if you are involved in an accident or emergency and your advance care directive is not available in that moment, life-prolonging treatments, like CPR, may be started until the treating doctors can talk to your substitute decision-maker or family about your preferences.

How do I help a person with dementia who is dying at home?

Your local doctor, hospital or palliative care service can provide various types of support for months before the person's death. This might include special equipment, medicine, social work, or emotional support.

Family, friends and neighbours can support carers with practical help, like cooking meals, doing shopping, or sitting with the dying person.

The [National Dementia Helpline](#) can also offer advice and support.

Resources

- [Care Search, free palliative care resources for patients and carers](#)
- [Dementia Australia, Palliative care and dementia - presented by Sarah Jamieson, Clinical Nurse Consultant](#)
- [Palliative Care Australia](#)

What about voluntary assisted dying?

Voluntary assisted dying is a process in which an individual is dispensed, and later takes, medication that will end their life at a time of their choosing. Voluntary assisted dying is legal in many parts of Australia, although laws vary from state to state. It is still illegal to access voluntary assisted dying in the NT and ACT; and does not come into effect in NSW until November 2023.

Legally, only individuals with decision-making capacity - from the first request to the final action of taking of the medication - can access voluntary assisted dying. A person cannot choose voluntary assisted dying in advance, such as in an advance care directive.

A substitute decision-maker cannot ask for voluntary assisted dying on a person's behalf.

People who die from dementia will not have decision-making capacity and are not eligible for voluntary assisted dying.

Advance care planning, however, empowers people with dementia, giving you choice and control over your end-of-life care. This includes where you would like to die; if you want treatments to prolong your life; or who or what you would like around you when you die.

Everyone - including a person with dementia - has the right to high quality aged and palliative care. This means that you should receive adequate pain relief, comfort, dignity, and person-centred care. This type of care cannot be withheld or refused.

Further reading

- [Advance Care Planning Australia, The role of advance care planning in the context of voluntary assisted dying](#)

Where can I get more information about advance care planning?

For more information about advance care planning, visit advancecareplanning.org.au.

If you would like personalised support regarding advance care planning, including:

- Starting or having a conversation
- Making sure your goals, values, and preferences are known
- Completing an advance care planning document in your state or territory
- Choosing, or being, a substitute decision-maker
- Storing your advance care planning documents.

Call the National Advance Care Planning Support Service™ on 1300 208 582. This service is available 9am - 5pm (AEST/AEDT) Monday to Friday. We also offer a call back service.

Where can I find out about dementia care and services?

As everyone's needs are unique, we suggest talking to a professional about your situation.

The National Dementia Helpline can answer questions about symptom management, dementia services, moving into an aged care home, and palliative care for people living with dementia. Call the [National Dementia Helpline](https://www.ndhelpline.org.au) on 1800 100 500. The National Dementia Helpline operates 24 hours a day, seven days a week.

If you are over the age of 65, you can call My Aged Care on 1800 200 422 for information about residential and home care services.

If you are under the age of 65, you can contact the National Disability Insurance Scheme (NDIS) on 1800 800 110.

Do you have resources to help culturally diverse communities with advance care planning?

Yes, Advance Care Planning Australia and Dementia Australia have a range of advance care planning resources in various languages.

- [Advance Care Planning Australia, Information in languages other than English](#)
- [Dementia Australia, Planning Ahead multilingual resources](#)

Where can I get more information?

Advance Care Planning Australia™

 advancecareplanning.org.au

 National Advance Care Planning Support Service™:
1300 208 582