



Information about advance care planning for patients, family members and the general community

What is advance care planning?

Advance care planning (ACP) is you thinking about and communicating to others how you would like to be treated in the future if you have a condition where you can no longer speak for yourself. This may happen, for example, because of a stroke, progressive dementia, or becoming unconscious from some form of accident or illness.

ACP is relevant for everyone, but particularly for people with progressive, life-limiting conditions such as cancer or late stage chronic disease. Other triggers to undertake ACP include diagnosis of early cognitive impairment and admission to a residential aged care facility.

An advance care directive (ACD) is a document that describes a person's acceptance or refusal of certain treatments in anticipation of a time when the person is unable to express those preferences because of illness or injury. Completion of an ACD is one component of the broader advance care planning process. Sometimes the terms advance care plan and advance care directive are used interchangeably.

Why is it important?

Undertaking ACP means that future decisions about your care are more likely to reflect your wishes. It helps you raise sensitive issues about the future with those close to you that they might otherwise avoid. It will mean that other people will not have to make decisions on your behalf without knowing what your real feelings and wishes would be. It reduces the chance of confusion and conflict when others are making decisions about your care. It means you and people close to you can feel comfortable and reassured that there will be a common and calm approach to your care toward the end-of-life.

Who will make decisions on your behalf?

Under normal circumstances, each of us has the right to make our own decisions about our lifestyle and whether or not we want specific healthcare treatments. When we lose capacity to make our own decisions (for example, in severe dementia, mental illness or unconsciousness) other people have to make such decisions for us.

While we normally see this role being taken by the 'next of kin', in New South Wales consent for medical or dental treatment must be gained by a substitute decision-maker defined under the Guardianship Act as the 'person responsible'. A treating doctor needs to go through a hierarchy of people to determine who the 'person responsible' for the particular patient is: an appointed guardian; the most recent spouse; an unpaid carer; or a close friend or relative. In most cases the 'person responsible' will be the same person as the 'next of kin', although this will not always be the case.

In most cases, decisions about your healthcare will be made fairly smoothly by the 'person responsible' and other people close to you after discussions with the treating doctor. However, problems can arise if:

- you do not have an obvious person in your life to make these decisions



- the person making the decisions does not know or really respect your wishes
- you have several people making decisions who may have conflicting views about your care.

If any of these situations apply to you, you could consider appointing one or more Enduring Guardians. This person or persons will have the clear legal responsibility to make lifestyle and healthcare decisions on your behalf. This will give you peace of mind that your wishes and interests will be most clearly represented at a time when you cannot speak for yourself.

There is a specific form that needs to be completed with a solicitor, barrister or Registrar of a Local Court. The Enduring Guardian needs to be appointed when the person appointing them still has capacity i.e. it is too late to appoint an Enduring Guardian once the person develops dementia. The Guardian only takes on the role of making decisions once the person clearly loses capacity themselves.

Discussing future health issues with your doctor

It is important to be well informed about your current health and ways that your current health may develop in the future. This will help you anticipate possible choices you may have to make in the future about treatments for your conditions and the impact of these treatments on your quality of life. You could discuss these issues with your GP or any Specialist doctors you are under.

Making a written ACP/ACD

You can commit your wishes about future healthcare to writing by completing an advance care plan or directive (ACP/ACD). You can make up your own document or else use one of a number of forms that have been developed for this purpose. Many of the forms allow you to document your beliefs and values as well as giving both general and specific instructions around treatment areas such as resuscitation, use of artificial feeding, artificial breathing support and palliative care.

The Local Health District has developed a form called *Statement of Wishes and Values* that can be used to document an ACP. Information about it and other programs can be found below.

NSW Health supports the use of ACPs/ACDs if they follow the four principles of being specific, current, completed by someone with capacity and witnessed. Not everyone feels the need to complete a written document. Some people will prefer to leave any decisions about their future care up to their loved ones. The least you could be doing is talking with those people about your values and wishes so they are clear about what you would want if they have to make decisions on your behalf.

What if the patient already lacks capacity?

If the patient is already at a stage where they cannot nominate a substitute decision-maker and they cannot write an ACP/ACD (such as in moderate-severe dementia), there are still benefits from the 'person responsible' undertaking advance care planning on behalf of the patient. In this case, the 'person responsible' can consider and document the values and wishes they believe the person would have expressed themselves if they were able to. Having these considered and documented will make it easier to make important decisions about the person's care at the end-of-life.

Legal and financial issues

Most people are familiar with Wills – which outline what you wish to happen to your assets after your death. It is also important to consider how your legal and financial affairs would be managed if you were still alive but unable to manage these yourself because of dementia or some other condition affecting your capacity to make decisions.



A Power of Attorney allows you to nominate another person to conduct your legal and financial affairs on your behalf. In terms of ACP, it is best in most cases to take out an Enduring Power of Attorney. In this case you specify in the form that it will continue to be active if the person loses capacity to make their own decisions. The form needs to be signed by the person you are giving the Enduring Power of Attorney to and witnessed by a solicitor or several other types of professional specified on the form.

It is very important to understand that both a normal Power of Attorney and an Enduring Power of Attorney can only make legal and financial decisions on behalf of another person – they CANNOT make decisions about their lifestyle or healthcare.

WHAT YOU COULD DO NOW ABOUT THESE ISSUES

- Consider – if you become unable to make your own decisions – who the healthcare system will use to make decisions on your behalf.
- If there is nobody clearly to take this role, or if you are unsure whether the person will strongly represent your interests, consider appointing someone as an Enduring Guardian.
- Talk to your GP or Specialist about your current health and some of the treatment choices you may have to make in the future as your health changes.
- Talk to the persons who may ultimately have to make decisions on your behalf about your values and wishes concerning the type of care and interventions you would want. The most important aspect of advance care planning is communication and developing a shared understanding of your wishes.
- To help your 'person responsible' advocate for you, and to have your views most clearly represented, consider completing an advance care plan/directive and leaving it with your doctor, 'person responsible' and other people close to you.
- To minimise complications with legal and financial matters if you do lose capacity in the future, consider appointing an Enduring Power of Attorney.
- If you are a resident within an aged care facility, you could let the Director of Nursing (DON) or Facility Manager know that you would like to discuss these issues further with them and complete any procedures and forms relevant to the specific facility.
- ***If you are the substitute decision maker/'person responsible' for a person who has already lost capacity to make their own decisions, you could work with their GP and/or DON/Facility Manager, if they are resident in an aged care facility, to develop an advance care plan for the person.***

Please see the next page for further information



FURTHER INFORMATION

The South Western Sydney Local Health District My Wishes Advance Care Planning Program

Further information about this program and copies of the ACP forms can be obtained from www.mywishes.org.au

Planning Ahead Tools website from NSW Government

A comprehensive site with practical information about a range of topics including Wills, Power of Attorney, Enduring Guardianship, advance care planning and elder abuse. It has a program that allows you to build your own plan. Available at: <http://www.planningaheadtools.com.au>

start2talk

A practical website for people in all parts of Australia who want to plan ahead for themselves or help somebody else plan ahead. The website has a number of worksheets that can be completed and stored online or else printed out and completed by hand. Available at: www.start2talk.org.au

'My Health, My Future, My Choice' and 'A Plan of Care'

Two booklets that help people either plan for themselves or plan for someone who has lost capacity. While some of the information is specific to New South Wales, much of it is relevant in any setting. Published by the Advance Care Directive Association. Available at: <http://www.advancecaredirectives.org.au>

Planning what I want

An Australian website that has information for the general public as well as healthcare professionals. It includes general information on a range of ACP-related topics, examples of forms and several video clips from experienced practitioners. Available at: <http://www.planningwhatiwant.com.au>

Respecting patient choices

A comprehensive Australian website with a range of information related to ACP. Available at: <http://www.respectingpatientchoices.org.au>

For further information go to:
www.mywishes.org.au