Guide to advance care planning in NSW

What is advance care planning?

Advance care planning is a process by which you reflect upon and document your personal values and preferences to guide your future health care decisions in the event that you become unable to speak for yourself. It is about taking control of your health care wishes now and into the future.

Why have an advance care plan?

Should you become seriously ill and not able to make or communicate your own decisions then an advance care plan sets out your wishes into the future. Dying with Dignity NSW recommends that, if possible, you engage in advance care planning while you are well, or in the early stage of dementia.

Every competent adult has the legal right to accept or refuse any medical recommended treatment. If you are unable to make and communicate your own decisions at the time of treatment, doctors and other health professionals will refer to your plan to identify your wishes.

What is the advance care planning process?

The most important steps to follow in advance care planning are:

• Discussing your health care wishes with your family and close friends. You may also involve your general practitioner (GP) and/or your solicitor, but this is not compulsory.

• Thinking about which treatments you would want to have and which you would refuse.

• Writing down your wishes in a valid advance care directive (ACD), which will remain in force until it is replaced or revoked.

• Choosing a trusted person to make health decisions for you if you are unable to do so. This person is called your 'enduring guardian'. When deciding on whom to appoint, you should consider who would best understand your values and wishes and who would have the skills to make good decisions for you.

Remember that your end of life choices can only be respected if those involved know what you want and what you do not want.
What will my plan look like when it is complete?

At the end of the advance care planning process you should have one or two completed forms. These are:

- advance care directive (ACD); and
- ‘Appointment of enduring guardian’ (optional)

Where do I get these forms?

‘The Appointment of enduring guardian’ is a standard legal document produced by the NSW Trustee and Guardian. This form is provided to members of Dying with Dignity NSW upon joining. It includes helpful tips for filling it out within the body of the form.

In NSW there is no standard form for an advance care directive (ACD). It can actually be as simple as writing down your wishes in your own words on a piece of paper. However, your ACD must be specific enough to guide complex medical decisions. We encourage you to be as specific as possible in documenting your wishes, to ensure there is no ambiguity and all relevant treatment options have been contemplated.

Dying with Dignity NSW provides all new members with the comprehensive ACD form created by Professor Colleen Cartwright, which we have been providing to members since 2008 (updated regularly). It is widely endorsed by health professionals.

We also provide a shorter form recently developed by the NSW Ministry of Health, which is more values-based. The Ministry says that it is not possible for an ACD to cover all possible medical situations, so information about your values would be very helpful for the person responsible for making health decisions on your behalf.

You may like to look at other examples of publicly available ACD forms to find one that you prefer. We have compiled a list of resources for those people who want more examples of ACD forms or more information about the planning process - see page 7-8 of this guide. Please keep in mind that it is important to choose an ACD form that enables you to provide clear and specific details about treatments that you would accept or refuse. Some forms which appear short and simple actually use vague terms, which can be open to different interpretations at the time that the ACD needs to be relied upon.

Legislation and terminology differ across the states and territories of Australia, so it is preferable to use an ACD designed for the particular state or territory in which you are likely to have medical treatment. If you regularly travel between states, you are welcome to complete an ACD for each state or territory in which you expect to have treatment.
Can I complete an advance care directive if I have dementia?

Dementia covers a range of degenerative diseases that affect the brain. Dementia affects thinking, behaviour and the ability to perform everyday tasks. It can affect a person's capacity to make an informed decision.

In the first stage of dementia, the “recognition of onset stage”, the person should still have the mental competence to complete an advance care directive (ACD). As the disease progresses this competence may be lost.

As a person with dementia may be mentally incompetent at the time that their ACD needs to be acted upon, it is essential that they appoint a trustworthy enduring guardian to act for them. As you never know how your health will progress, Dying with Dignity NSW recommends that, where possible, you complete your ACD and nominate your enduring guardian while you are well, or in the early stage of dementia.

Dementia Australia (formerly known as Alzheimer’s Australia) has excellent resources for people diagnosed with dementia who want to plan ahead - https://www.dementia.org.au/about-dementia/i-am-a-carer-family-member-or-friend/advance-care-planning

Will my Advance Care Plan be legally binding?

Whilst the nomination of an enduring guardian is legally binding under The NSW Guardianship Act 1987, NSW does not have a specific statute governing ACDs. However, a 'valid' ACD is legally binding under common law (as confirmed by the NSW Supreme Court in 2009). This means that health professionals and the person responsible for making decisions on your behalf (including your enduring guardian if you have appointed one) have no authority to override a valid ACD.

Your ACD will be considered valid if:

- you had capacity when you wrote it
- you made it by choice, without coercion
- it is current
- it applies to the situation you are in at the time.
- it has clear and specific details about medical treatments that you would accept or refuse

The legally binding effect of an ACD is confined to refusals of treatment.

A demand or request in an ACD for a particular form of treatment does not mean the health care provider is legally obliged to provide it. However, listing treatments you would like to have may be considered as indicating your consent to the treatment and are likely to be taken into account by any health professional concerned with promoting your best interests at a time when you are unable to speak for yourself.
Things to discuss with family and friends before completing an advance care directive

To help you have a conversation with family and friends about your end of life wishes, Dying with Dignity NSW have prepared the following two pages of questions. The aim is to provide some ‘conversation starters’ that will help you reflect upon what is important to you. Thinking about these issues may also give you greater clarity regarding your own wishes and may be helpful when completing your advance care directive (ACD).

We recommend that you go through this section and answer these questions prior to completing your ACD. This section on pages 4 and 5 do not form part of your ACD, but you may like to file them with your completed ACD, to give some background information about your wishes and values.

Talking about end of life:

When thinking about the end of your life, which statement do you feel most closely represents your personal belief:

- [ ] I am frightened of dying and do not want to think about it happening to me or my loved ones. I do not discuss death or dying with others.
- [ ] Dying is a fact of life. You just have to deal with it when it happens. I hope that I can talk about it with loved ones and others before my time comes.
- [ ] Dying is a natural part of life. I am comfortable discussing death and dying with my loved ones and others. I want to be prepared for when my time comes.

When the time comes for me to die, I would like to be cared for:

- [ ] At home or in a home-like environment.
- [ ] In a hospital or in a hospital-like environment
- [ ] I do not know. I’m happy for my Enduring Guardian (or next of kin) to decide.

What matters most to you?

Write down some of the things in your life that matter most to you, such as being at home, doing gardening, engaging with your grandchildren, driving your car, visiting friends, reading, learning new things, going to church, playing cards, watching movies.

.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
.............................................................................................................................................
Personal Values

I would find life to be ‘acceptable’ OR ‘difficult but bearable’ OR ‘unbearable’, if for the rest of my life, I had the following condition:

<table>
<thead>
<tr>
<th>Condition - for the rest of my life</th>
<th>Acceptable</th>
<th>Difficult but bearable</th>
<th>Unbearable</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not recognise my family and loved ones</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not have control over my bladder and bowels</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot feed myself or wash myself or do my own personal grooming and dressing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot move myself around in or out of bed and rely on other people to reposition me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot eat or drink. I need food to be given to me through a tube in my stomach</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I cannot talk or read or write</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not understand what people are saying</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not get enjoyment from many of the things that I have always enjoyed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other........................................................................</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Acceptable levels of treatment

There are a number of life-prolonging treatments that may be used in your medical care. Now is a good time to think about the circumstances under which you would or would not want these interventions to prolong your life. Discuss this with friends and family. Feel free to talk to your GP if you have any questions or concerns about these treatments. These life-prolonging treatments include:

Artificial Feeding and Hydration - provision of food and fluid by artificial means when you are unable to eat or drink (by passing a feeding tube through the nose into the stomach or by inserting a tube into a vein or directly into your stomach).

Assisted Ventilation - use of a machine to help you breathe.

Cardiopulmonary Resuscitation (CPR) - emergency measures to keep the heart pumping (by massaging chest or using electrical stimulation) and artificial ventilation (mouth-to-mouth or using a ventilator).
Who should sign my forms?

‘The Appointment of enduring guardian’ is a statutory document that must be signed by you, your enduring guardian and an independent witness (a legislated signatory). A list of qualified people is on the appointment form. They include a Justice of the Peace, a solicitor or the Public Guardian.

Professor Colleen Cartwright recommends that you have your Advance Care Directive (ACD) signed by your GP, as well as an independent witness. Having your GP sign your ACD is not compulsory, but it provides a good opportunity to discuss your wishes and raise any questions that you might have about medical treatment options.

Unlike ‘The Appointment of enduring guardian’, it is not mandatory that your ACD is witnessed by anyone. However, having an independent witness is highly recommended, to verify that you are the person who signed the ACD and you were not under undue influence at the time of signing. You may ask a neighbour or a friend (who is not a beneficiary in your will) to be your independent witness.

If you plan to appoint an enduring guardian it would be wise and practical to use the same legislated signatory to witness both forms.

What do I do with my completed forms?

Once complete, we recommend that you keep your documents in a safe place at home that is known to close family, friends and/or neighbours.

Provide a copy of your advance care directive and your ‘Appointment of enduring guardian’ to your GP, any specialist medical practitioners that you consult regularly, your enduring guardian/s, and, if you wish, to your solicitor.

If you are admitted to a hospital or a residential aged care facility make sure staff know that you have an advance care directive and have appointed an enduring guardian/s.

Dying with Dignity NSW members are encouraged to keep their membership card in their wallet or purse. Use the back section of the card to indicate whether you have an ACD, where it can be found and whether you have appointed an enduring guardian.
Do I ever need to review my plan?

You should review your advance care directive (ACD) every couple of years, or sooner if there is a major change in your health. Remember to give updated copies of your ACD to all the people who had your original version. If you decide to make substantial changes to your ACD then it is best to complete a new ACD and destroy the old version.

Please ensure that you appoint a new enduring guardian if the person you have appointed dies, or no longer has the capacity to fulfil that role.

Where can I get more information?

• The NSW Government Planning Ahead Tools - Ph 1300 887 529 - provides information and advice for future legal, health and financial decisions 


• Professor Colleen Cartwright, now the Principal Director of Cartwright Consulting Australia, provides free downloadable resources, including various types of ACD forms, including one for people living in a residential aged care facility 
http://cartwrightconsultingaustralia.com.au

• NSW Trustee and Guardian Ph 1300 364 103 - Provides resources related to the appointment, revocation or resignation of enduring guardianship, the appointment of power of attorney (financial matters) and will making - http://www.tag.nsw.gov.au/

• Advance Care Planning Australia Ph 1300 208 582 - provides information and ACD forms by state in many languages - https://www.advancecareplanning.org.au/resources/advance-care-planning-in-my-state

• Dementia Australia (previously Alzheimer’s Australia) - phone the National Dementia Helpline on 1800 100 500 or see the advance care planning section of their website, which includes the ‘Planning for end of life publication and lecture series’ featuring Professor Colleen Cartwright and the Start2Talk initiative. 
https://www.dementia.org.au

• The Law Society of NSW - use their Solicitor Referral Service to find a local solicitor with experience in this area. Ph (02) 9926 0333 or 1800 422 713 
Where can I get more information? (continued)

- **NSW Ministry of Health publication** 'Dignity, Respect and Choice: Advance Care Planning for End of Life for People with Mental Illness' is designed to help support people with mental illness, their families and carers and health professionals – available in eleven languages - Ph (02) 9391 9000  

  plus Ambulance Authorised Palliative Care Plan (AAPCP) - This allows paramedics responding to a Triple Zero (000) phone call to treat palliative patients in their own home, on the instructions of their GP (as detailed in the AAPCP), rather than transfer them to hospital. It is a good idea to complete and lodge an AAPCP at the time that a decision is made that an individual will have not further treatment.  

For information about death and dying more generally:

- **End of life law in Australia** by Queensland University of Technology – information about Australian laws relating to death, dying and decision-making at the end of life.  
  email achlr@qut.edu.au to subscribe to updates -  https://end-of-life.qut.edu.au/

- **Life Circle Australia** - aims to connect people who are caring for a dying family member or friend to information and advice to help them make choices about end of life matters. Ph 9334 1719 - http://lifecircle.org.au/

- **The Groundswell Project** – their vision is that when someone is dying, caring or grieving, we all know what to do. They started 'Dying to Know You Day' on 8 August each year - http://www.thegroundswellproject.com/.