

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 be used as a guide to your future health care 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. Your Advance Care Plan remains in force until it is required, if ever. We recommend that you make a plan while you are well, or in the early stage of dementia.

Every competent adult in NSW has the legal right to accept or refuse any 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 Advance Care Plan to identify your wishes.

What is the process for making an Advance Care Plan?

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 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 an Advance Care Directive.
- 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.

Your end of life choices can only be respected if those involved know what you want and what you do not want.



*To assist you to think about your wishes and to start a conversation with those close to you, we have included a section “**Things to discuss with my family and friends before completing an Advance Care Directive**” on pages 4 and 5 of this Guide.*

What will my plan look like when it is complete?

When your Advance Care Plan is complete you will have two completed forms.

These are:

- An ‘Appointment of Enduring Guardian’
- An Advance Care Directive



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. We suggest you add the relevant mobile phone numbers and email addresses to ensure that people can be contacted, if and when they are required in the future.

In NSW there is no standard form for an Advance Care Directive. It can actually be as simple as writing down your wishes in your own words on a piece of paper. However, your Advance Care Directive 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 recommends the Advance Care Directive form created by Professor Colleen Cartwright, which is widely endorsed by many health professionals.

You may like to look at other examples of publically-available Advance Care Directive forms, to find one that you prefer. However, keep in mind that it is important to find the right balance between a comprehensive (even if lengthy) form, that is very clear and specific in its statements, and those forms that are simple to complete, but possibly open to interpretation by others. We think that the Cartwright Advance Care Directive form strikes the correct balance, so this is the form we provide to our members upon joining.

Dying with Dignity NSW has compiled a list of resources to enable you to get more information about Advance Care Planning (if you wish) - see page 7 of this guide under ‘Where can I go for more information?’.

Legislation and terminology differ across the States and Territories of Australia, so it is wise to use a form designed for the particular State or Territory in which you expect to receive medical treatment. If you travel frequently, you can complete an Advance Care Directive for more than one State or Territory of Australia.

Can I complete an Advance Care Directive if I have Dementia?

Dementia covers a range of degenerative diseases that affect the mind. Dementia 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. As the disease progresses this competence may be lost.

As you may be mentally incompetent at the time your Advance Care Directive needs to be acted upon, it is essential that you have an Enduring Guardian to act for you. Dying with Dignity NSW recommends that you complete your Advance Care Directive and nominate your Enduring Guardian while you are well or in the early stage of dementia.



Alzheimer's Australia www.alzheimers.org.au has excellent resources for people diagnosed with dementia who want to plan ahead.

Another helpful website is www.advancedcaredirectives.org.au, which contains details about health care decision making for a person with dementia. Please see the "Where can I go for more information" list on Page 7 of this guide for more details.

Will my Advance Care Plan be legally binding?



The nomination of an Enduring Guardian is legally binding under *The NSW Guardianship Act 1987*.

Unlike much of Australia, NSW does not have a specific statute governing Advance Care Directives, but they are legally binding under common law (as confirmed by NSW Supreme Court in 2009), provided the person is mentally competent at the time of completing their directive and it has been made free from coercion.

The legally binding effect of an Advance Care Directive is confined to *refusals* of treatment. A demand or request in an Advance Care Directive for a particular form of treatment does not mean the health care provider is legally obliged to provide it, but it may be considered as indicating your consent to the treatment. In addition, the preferences you make in your Advance Care Directive are likely to be taken into account by anyone concerned with promoting your best interests at a time when you are unable to speak for yourself.

Please be aware that Advance Care Planning does not enable you to access treatments which are against the law at the time and place of your treatment. Voluntary Assisted Dying is currently against the law throughout Australia, but Dying with Dignity NSW hopes that this will not always be the case.

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 so, may be helpful when completing your Advance Care Directive.

We recommend that you go through this section and answer these questions prior to completing your Advance Care Directive. This section does not form part of your Advance Care Directive, but you may like to pull out the completed pages from the guide and file them with your completed Advance Care Directive, 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, playing with your grandchildren, driving your car, visiting friends, reading, learning new things, going to church, playing Bridge, 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:

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

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 General Practitioner, 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 yourself, your Enduring Guardian and an independent witness (a legislated signatory). Please see the left margin of the form for a list of people who would qualify as a legislated signatory. They include a Justice of the Peace, a Solicitor or the Public Guardian.




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

Unlike 'The Appointment of Enduring Guardian', it is not mandatory that your Advance Care Directive is witnessed by anyone. However, having an independent witness is a good idea, as they would sign to verify that you are the person who signed the directive 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. Alternatively, it might be easier to ask the person that is witnessing your 'Appointment of Enduring Guardian' to also witness your Advance Care Directive. *Please note that recently, the Registrar of the Court has not been permitted by their employer to witness Advance Care Directives.*

What do I do with my completed forms?

Once complete, we recommend that you photocopy both your Advance Care Directive and your 'Appointment of Enduring Guardian' and give a copy to the following people: your General Practitioner and other health care providers; your Enduring Guardian and family members, neighbours and/or other important people in your life.

You should also keep a copy at home in an easily accessible place known to your family, and especially to the person you have appointed as your Enduring Guardian.

 DWDnsw Membership Card	Emergency contact:
	Phones (H): (M):
	My Doctor is:
	Phones (W): (M):
	I have/have not (strike through whichever is not applicable) got an Advance Health Care Directive that sets out my medical treatment wishes if I cannot communicate my own decisions.
Name:	It is held by.....
Address:	
Phones (H): (M):	
Valid to: www.dwdnsw.org.au	

Dying with Dignity NSW members are encouraged to keep their Membership Card in their wallet or purse, with the section on the back indicating where their directive is located.

Do I ever need to review my Plan?

You should review your Advance Care Directive every couple of years, or sooner if there is a major change in your health. If you make changes, remember to give updated copy of your Advance Care Directive to all the people who had your original version. If you decide to make substantial changes to your current Advance Care Directive, then it is best to complete a new Advance Care Directive and destroy the old version.

Where can I go for more information?

The following organisations and websites provide more information about Advance Care Planning, if you would like to know more.

- The NSW Government **Planning Ahead Tools** <http://planningaheadtools.com.au/> provides information and advice for future legal, health and financial decisions - Ph 1300 887 529
- The NSW Government Health End of Life Decisions, the Law and Clinical Practical Information for Health Practitioners <http://healthlaw.planningaheadtools.com.au/>
- **NSW Trustee and Guardian** Ph 1300 364 103 www.tag.nsw.gov.au
Provides resources related to power of attorney, will making and financial mgt.
- **Guardianship Tribunal** at Level 3 / 2a Rowntree St Balmain NSW 2041
Ph 02 9556 7600 Toll free 1300 006 228
http://www.ncat.nsw.gov.au/Pages/guardianship/gd_forms.aspx
- **Alzheimer's Australia NSW**
Macquarie Hospital Building 21, Cnr 120 Coxs & Norton Roads North Ryde.
www.alzheimers.org.au see section Legal Planning & Dementia for "*Planning for the end of life for people with Dementia*" – By Professor Colleen Cartwright (2011) or request copies by calling the National Dementia Helpline on 1800 100 500.
They also have the Start2Talk website www.start2talk.org.au
- **The Capacity Toolkit**, produced by the Dept. of Attorney General and Justice, provides info about determining if a person has the capacity to make their own decisions.
http://www.publicguardian.lawlink.nsw.gov.au/agdbasev7wr/publicguardian/documents/pdf/capacity_toolkit0609.pdf
- ASLaRC Aged Services Unit Southern Cross University www.scu.edu.au/aslarc/
(NB: In 2014 **Prof. Colleen Cartwright** retired from SCU and became Principal Director of **Cartwright Consulting Australia P/L**, which has free downloadable resources at <http://cartwrightconsultingaustralia.com.au>).
- The NSW Dept of Health - ***Dignity, Respect and Choice: Advance Care Planning for End of Life for People with Mental Illness***. Their "Introductory Guide" is designed to help support people with mental illness, their families and carers and health professionals - available in eleven languages - published November 2015 - see <http://www.health.nsw.gov.au/patients/acp/Pages/introductory-guide.aspx>
- NSW Government Family & Community Services
219-241 Cleveland St, Redfern NSW 2016 Phone: (02) 9377 6000,
Ageing, Disability and Home Care – **Planning Ahead Kit in many languages**
http://www.adhc.nsw.gov.au/individuals/ageing_well/planning_for_the_future

(continued)

Where can I go for more information? (continued)

- Advance Care Planning by Dr Jerome Mellor at www.facebook.com/AdvanceCarePlanning - contains links to videos and documents aimed particularly at doctors wanting to help their patients.
- Advance Care Planning Australia www.advancecareplanning.org.au
NSW documents in many languages.
- **Ambulance NSW** State Headquarters Balmain Rd Rozelle
Ph 9320 7777 (weekdays 9am - 5pm) "Authorised Palliative Care Form"
http://www.slhd.nsw.gov.au/btf/pdfs/Amb/Adult_Palliative_Care_Plan.pdf
- Advance Care Directive Assoc Inc. website www.advancecaredirectives.org.au
at 18/113 Johnston St Annandale NSW 2038 or Phone 0423 157 003
- **The Council on the Ageing NSW** (COTA NSW) is for all people over 50 in NSW.
Level 6, 280 Pitt Street, Sydney Phone: (02) 9286 3860 or 1800 449 102
<http://cotansw.com.au/wp-content/uploads/2011/10/Wills-Advance-Health-Care-Directive.pdf>
- TARS www.tars.com.au is a community legal centre that protects the rights of older people providing telephone advice, advocacy, legal advice and educational services.
Level 4, 418A Elizabeth St, Surry Hills Ph 1800 424 079 Interpreter Service 13 14 50
- The Solicitor Referral Service of the Law Society of NSW can provide the names of private solicitors and legal services in your area. www.lawsociety.com.au
170 Phillip St, Sydney NSW 2000 Tel: (02) 9926 0333 or 1800 422 713
- Palliative Care NSW PO Box 487 Strawberry Hills NSW 2012 Ph 02 9206 2094
www.palliativecarensw.org.au
- LifeCircle Australia Limited website www.lifecircle.org.au
download helpsheets about planning, especially carers of the seriously ill.
LifeCircle NSW at 153 Dowling St Woolloomooloo NSW 2011 Ph 9334 1719



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