

# Planning & decision making

It is important that the person you are caring for conveys their preferences while they still have the legal capacity to make decisions.



## Advance care planning

A life-limiting illness may remove the capacity to make decisions about important matters in the final months and days of life. Advance care planning is the process of discussing and documenting future health care wishes, values and priorities. It enables doctors, friends, family and carers to understand what a person with a life-limiting illness wants, should they become so unwell that they are unable to speak for themselves.

It is recommended to begin these discussions and planning during the early stages of an illness. It is important that the person you are caring for conveys their preferences while they still have the legal capacity to make decisions.

## Advance Care Plan

Advance Care Planning means planning your care in advance of your condition worsening to the point where you are unable to make decisions for yourself. It is how you take control of your future health care decisions and help you live more positively.

The ability to decide what healthcare and health treatments we want is something we take for granted every day. However, there may come a

time when illness makes us unable to make clear what we want from our healthcare providers. If you are diagnosed with dementia for example – that time will certainly come and there are other illnesses and conditions that may also make your ability to communicate your wishes impossible.

An Advance Care Plan can be prepared by you or on your behalf by family or medical professionals who know what your wishes are.

## Aboriginal Communities

The NSW Trustee and Guardian booklet *Taking Care of Business* has helpful information for Aboriginal and Torres Strait Islander people to make culturally appropriate planning ahead documents.

The NSW Trustee & Guardian has information on planning ahead for Aboriginal people:

 [nsw.gov.au/family-and-relationships/planning-for-end-of-life/learn-about-wills](https://nsw.gov.au/family-and-relationships/planning-for-end-of-life/learn-about-wills)

Download the *Taking Care of Business* booklet here:

 [nsw.gov.au/sites/default/files/noindex/2024-04/nsw-trustee-guardian-taking-care-of-business-handbook.pdf](https://nsw.gov.au/sites/default/files/noindex/2024-04/nsw-trustee-guardian-taking-care-of-business-handbook.pdf)

## Advance Care Directives

In NSW an Advance Care Directive (or ACD) is a written statement completed by you that records your health and treatment goals of care. There is no set format but you can download a form from NSW Health.

Although there is no specific legislation for ACDs in NSW, an ACD has authority under common law and must be adhered to as long as it was made voluntarily by a competent adult. You cannot request Voluntary Assisted Dying (VAD) in an ACD because an ACD only comes into effect when you no longer have capacity, and you must have capacity to request VAD.

Advance Care Directive forms are available from **NSW Health**:

👉 [health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf](https://health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf)



## Enduring Guardianship

An enduring guardian is a person, over the age of 18 who agrees to be appointed by you to make personal and lifestyle decisions and/or medical treatment and healthcare decisions on your behalf only when you are no longer able to do so for yourself.

An enduring guardian legally appointed by you should consider your views both past and present. Your enduring guardian should also consider the views of professionals and other people important in your life at the time then make decisions on your behalf should the need arise.

Your enduring guardian's powers only come into effect and remain while you lack capacity to make decisions. The enduring nature of the power means that the guardian's authority continues while you are incapacitated.

**The NSW Trustee & Guardian** has information about appointing an Enduring Guardian. For more information, contact:

📞 1300 109 290

👉 [tag.nsw.gov.au](https://tag.nsw.gov.au)

## Enduring Power of Attorney

An enduring power of attorney is a legal document that you can use to appoint a person to make decisions about your property or financial affairs. It is only activated if you lose mental capacity, and ceases upon your death. They do not contribute to future healthcare decision-making.

More information about Power of Attorney and appointing a Power of Attorney can be found here:

 [nsw.gov.au/family-and-relationships/planning-for-end-of-life/make-power-of-attorney](https://nsw.gov.au/family-and-relationships/planning-for-end-of-life/make-power-of-attorney)

## Making a Will

Making a Will is the only way you can ensure that when you die, your estate will be distributed according to your wishes.

If you die without a Will, no one knows who you wanted as your beneficiaries. Your assets will be distributed according to a formula set by legislation. This means that certain relatives will receive a defined percentage of your assets, despite what you may have wished.

Dying without a Will is called dying intestate. Life circumstances change, so it's advisable to regularly review your Will to ensure that it accurately reflects your current wishes.

For more information, contact  
**NSW Trustee & Guardian:**

 1300 109 290

 [tag.nsw.gov.au](https://tag.nsw.gov.au)

You can choose your own executor or nominate **NSW Trustee & Guardian** for impartial and independent services.

## Organ and tissue donation

You must be 16 or older to register your donation decision for after your death.

You can list your decision to donate for transplants, including which organs and tissue you want to donate.

It's important to tell your family your decision about being an organ and tissue donor. This is because they'll have the final say.

Your family need to agree to donate your organs and tissue when you die. They may be more likely to follow your wishes if they already know about them.

For more information, contact  
**DonateLife:**

 (02) 8566 1700

 [donatelife.gov.au](https://donatelife.gov.au)

## Body donation

A number of universities throughout NSW offer a Body Donation Program through their Faculty of Medicine and Health Sciences. These Programs accept donations of human bodies to provide an invaluable contribution to the training of medical professionals and the advancement of scientific and medical knowledge.

If the person you are caring for intends to be a donor it is important for them to talk to their family. Not all donated bodies are accepted, which then leaves the family responsible for funeral arrangements and costs.

For more information or to register, contact the following universities:

University of NSW

University of Sydney

University of Western Sydney

University of Wollongong

University of New England Armidale

Macquarie University

University of Technology Sydney

## Choosing where to die

When asked where they would prefer to die, most people say they want to die at home. Home is what is familiar and comforting.

Encourage the person who is dying to discuss their views and preferences with you, family and friends.

Ideally, you and the person you're caring for will have the chance to discuss this with the GP or other healthcare professional, particularly if any decision depends on you and others to provide care at home. Your capacity to continue in the caring role, the preferences and care needs of the person you are caring for, access to Palliative Care and other practical considerations will help determine the best option. Also, it helps to be prepared if something unexpected happens such as a medical emergency. Other options for consideration include: a Residential Aged Care Facility, Palliative Care unit, hospice, or hospital.

It might be helpful to discuss a Plan A and a Plan B if things do not go as expected. It is important to have support and the capacity to look after yourself as well as your person if the decision is to stay at home.

## Voluntary Assisted Dying

Voluntary assisted dying (VAD) means an eligible person can ask for medical help to end their life. People can only access voluntary assisted dying in NSW if they meet all the eligibility criteria and follow the process outlined in the law. This includes getting approval from the NSW Voluntary Assisted Dying Board.

If you choose VAD you will still be able to access other care you might need, including palliative care.

For further information call the **NSW VAD Care Navigator service:**

 1300 802 133

## Planning the funeral

Whilst it may be a difficult conversation, it would be helpful to have conversations with the person you are caring for regarding their preferred funeral arrangements.

It may also be appropriate to have discussions with key members of the family and important friends to clarify their expectations and what role they may wish to take.

Issues for consideration include:

- The type and style of funeral service e.g. family led, private committal, church, cemetery chapel, graveside, memorial or other
- Burial, cremation or entombment
- Coffin or casket
- Death notices, mourning vehicles and flowers
- Audio/video recording
- Poetry, music, readings, photo presentations or memorabilia
- Preferences of deceased, family and friends
- Minister, celebrant or friend to officiate

- Ashes placement
- Cost implications.

There are several options for funerals including natural funerals, cardboard coffins and so on. Cost can be a burden on families so you may want to do some research on alternatives. Of course you can always talk to a traditional funeral director who can guide you through the planning process and explain your options.

## Making preferences known

Encourage the person you are caring for to:

- Let loved ones know what is important to them.
- Talk with their GP and other health care professionals caring for them about their health care treatment preferences.
- Give copies of their advance care planning documents to their health care providers, including their GP, medical specialists, Palliative Care team, hospital or aged care provider.
- Upload their advance care planning documentation to their electronic My Health Record.

For more information regarding **My Health Record**, contact:

 1800 723 471 (option 1)

 [digitalhealth.gov.au](https://digitalhealth.gov.au)

## Useful contacts

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### Australian Indigenous Health InfoNet

- ☎ (08) 9370 6336
- 👉 [healthinonet.ecu.edu.au/learn/health-system/palliative-care](http://healthinonet.ecu.edu.au/learn/health-system/palliative-care)

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### Cancer Council NSW

- ☎ 13 11 20
- 👉 [cancercouncil.com.au](http://cancercouncil.com.au)

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### Carer Gateway

- ☎ 1800 422 737
- 👉 [carergateway.gov.au](http://carergateway.gov.au)

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### Carers NSW

- ☎ (02) 9280 4744
- 👉 [carersnsw.org.au](http://carersnsw.org.au)

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### Caresearch

- ☎ (08) 7221 8233
- 👉 [caresearch.com.au](http://caresearch.com.au)

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### Centrelink

- ☎ 13 27 17
- 👉 [servicesaustralia.gov.au](http://servicesaustralia.gov.au)

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### Dementia Australia

- ☎ 1800 100 500
- 👉 [dementia.org.au](http://dementia.org.au)

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### GriefLine National

- ☎ 1300 845 745
- 👉 [griefline.org.au](http://griefline.org.au)

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### Leukaemia Foundation

- ☎ 1800 620 420
- ✉ [info@leukaemia.org.au](mailto:info@leukaemia.org.au)
- 👉 [leukaemia.org.au](http://leukaemia.org.au)

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### Lifeline

- ☎ 13 11 14
- 👉 [lifeline.org.au](http://lifeline.org.au)

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### My Aged Care

- ☎ 1800 200 422
- 👉 [myagedcare.gov.au](http://myagedcare.gov.au)

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### To access Palliative Care information in 35+ different languages

- 👉 [palliativecarensw.org.au/non-english-language-palliative-care-resources/](http://palliativecarensw.org.au/non-english-language-palliative-care-resources/)

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### My Health Record

- ☎ 1800 723 471
- 🖱 [myhealthrecord.gov.au](https://myhealthrecord.gov.au)

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### National Disability Insurance Service (NDIS)

- ☎ 1800 800 110
- 🖱 [ndis.gov.au](https://ndis.gov.au)

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### National Stroke Foundation

- ☎ StrokeLine: 1800 787 653
- 🖱 [strokefoundation.org.au](https://strokefoundation.org.au)

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### NSW Trustee & Guardian

- ☎ 1300 109 290
- 🖱 [tag.nsw.gov.au](https://tag.nsw.gov.au)

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### Palliative Care NSW

- ☎ (02) 8076 5600
- 🖱 [palliativecarensw.org.au](https://palliativecarensw.org.au)

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### Relationships Australia

- ☎ 1300 364 277
- 🖱 [relationships.org.au](https://relationships.org.au)

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### Services Australia

- ☎ [servicesaustralia.gov.au/individuals/contact-us/phone-us](https://servicesaustralia.gov.au/individuals/contact-us/phone-us)
- 🖱 [servicesaustralia.gov.au](https://servicesaustralia.gov.au)

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### The Department of Veteran's Affairs

- ☎ General enquiries: 1800 838 372
- ☎ Counselling Service: 1800 011 046
- 🖱 [dva.gov.au](https://dva.gov.au)

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### If you require an interpreter, contact the Translating and Interpreting Service (TIS National)

- ☎ 13 14 50
- 🖱 [tisnational.gov.au](https://tisnational.gov.au)

### If you have a hearing or speech impairment, contact the National Relay Service

- ☎ 24 hour relay call numbers  
TTY/voice calls: 133 677  
Speak and Listen: 1300 555 727  
SMS Relay: 0423 677 767
- 🖱 [relayservice.gov.au](https://relayservice.gov.au)

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### **Access our Palliative Care Guidance service**

The Palliative Care Guidance Manager provides non-clinical advice to carers, family members and health professionals on how to access appropriate services to meet end-of-life and palliative care needs.

☎ (02) 8076 5604

✉ [pcguide@palliativecarenewsw.org.au](mailto:pcguide@palliativecarenewsw.org.au)

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### **Register for our PalliLEARN online courses**

Easy-to-understand introductory online short courses designed to cultivate knowledge and compassion around palliative care and end-of-life-care, dying, death and grieving. You'll learn how to build the skills to support and care for those living with a life-limiting illness.

▶ [palliativecarenewsw.org.au/our-programs/pallilearn](http://palliativecarenewsw.org.au/our-programs/pallilearn)



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### **Attend or host a Community Conversation in your local area**

Community Conversations is a free, in-person 1.5-hour informal education session that brings together palliative care experts and local community members to have open, thoughtful discussions about palliative care, aging, dying, and grief.

▶ [palliativecarenewsw.org.au/community-conversations](http://palliativecarenewsw.org.au/community-conversations)



Palliative Care NSW  
recognises the joys and  
demands of your role. We  
provide resources and  
useful links to networks to  
help you do your best in  
your carer's role.

**[palliativecarenewsw.org.au](http://palliativecarenewsw.org.au)**



**Palliative Care**  
New South Wales

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