



**DementiaUK**  
Helping families face dementia

# Advance care planning



### What is advance care planning?

Advance care planning is a process to help you plan and record your wishes and priorities for your future care with those close to you. This means there will be a record of your wishes should a time come when you can no longer make or communicate these decisions, including your wishes about the end of life. It is known as an advance care plan (ACP).

Advance care planning can initially seem daunting. Many people do not know where to start. You may also feel that you do not need to make an ACP yet, for example if you have only recently been diagnosed with dementia or if you are younger. However, it is impossible to predict how quickly dementia will progress, so it is important to consider your future plans at an early stage, while you are able to make your own decisions.

This leaflet will help you think about some of the things you may wish to talk about and consider writing down in a formal ACP, including:

- an advance statement of your future care wishes
- an advance decision to refuse treatment
- lasting power of attorney
- making a Will

Advance care planning is not a one-off procedure, but a process that may take time. Some of the decisions you need to make can be difficult to think about and need some consideration. You may wish to discuss them with people such as your family, close friends and your health and social care professionals.

It is advisable to review your ACP on a regular basis to ensure the contents are still valid and represent your wishes.



### Advance care plan template

You may wish to use our ACP template to record your wishes: please visit [▶ dementiauk.org/acp-template](https://dementiauk.org/acp-template)

It is designed to help you make a written record of your decisions and preferences. You can involve other people in deciding what to include, and complete as much or as little as you like.

There is space for you to make notes, and to record details of the people who may be involved in your care or in making decisions on your behalf.

Once you have completed your ACP, you can give copies to people who are close to you and/or involved in your care.

The following information covers the sections of our ACP template and what you may want to think about and include.

### Advance statement

An advance statement is a written record of your preferences, wishes, values and beliefs around your future care. It is not legally binding, but will help family, friends and professionals make decisions on your behalf, in your best interests, if you cannot make or communicate these decisions yourself.

These are some examples of information which you could consider when developing your advance statement:

- If you are no longer able to care for yourself, where would you prefer to be cared for if possible?
- What important things do the people who care for you or treat you need to know about you? For example, do you have any children or teenagers, other people or pets who are dependent on you?
- What are your thoughts and wishes about organ donation?
- What activities do you enjoy most in your life? Would you like help to continue these activities if you are able?

### Advance decision to refuse treatment

An advance decision to refuse treatment (ADRT) is different from the advance statement as it concerns medical treatments only. It is a legally binding document that allows you to state which treatments you do not want to receive if a situation occurs where you are unable to communicate your wishes.

In Scotland, ADRTs are known as advance directives. You may also hear them informally referred to as 'living Wills'.

An ADRT relates to life-sustaining medical treatments, eg:

- ventilation to support your breathing



- cardiopulmonary resuscitation (CPR) to attempt to restart your heart if it stops
- antibiotics to fight infection
- a feeding tube if you are unable to eat/swallow

When developing an ADRT, it is a good idea to speak to your GP or another healthcare professional who can explain what these treatments may involve and the pros and cons.

To be legally binding, an ADRT must be in writing and signed by you and a witness. It must also state clearly which treatments you do not want and include the words, ‘even if my life is at risk’. You can make an ADRT online at [▶ advanceddecision.service.compassionindying.org.uk](https://www.advanceddecision.service.compassionindying.org.uk) or print and complete a template such as [▶ cdn.compassionindying.org.uk/wp-content/uploads/advance-decision-pack-v2.3.pdf](https://cdn.compassionindying.org.uk/wp-content/uploads/advance-decision-pack-v2.3.pdf)

On our ACP template, there is a box to tick to indicate if you have made an ADRT; it is advisable to keep a copy with your ACP.

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You can change your mind or alter your ADRT at any time, provided you still have the mental capacity to do so. Mental capacity refers to the ability to make informed decisions – please see Sources of support on p11.

### Lasting power of attorney

Lasting power of attorney (LPA) is a legal process that nominates a trusted person/people to make decisions on your behalf, in your best interests, if you lack the mental capacity to do so yourself.

In Scotland, the equivalent of an LPA is called power of attorney; in Northern Ireland, it is called enduring power of attorney.

There are two types of LPA, and you can make one or both:

- health and welfare: this covers decisions about your daily wellbeing, care and medical treatment
- property and financial affairs: this covers decisions about your finances, benefits, pension, selling your home etc

The people you name in your LPA are known as ‘attorneys’. They may be your spouse/partner, child (if they are over 18), another family member, friend or a professional like a doctor or solicitor. You can have one attorney or more, and can have the same or different attorneys for both LPAs.

Because LPAs can only be drawn up if you have mental capacity, it is important to do this as soon as possible. There is space on the ACP template to record if you have made an LPA, and who your attorneys are.

For more information on LPA, please see Sources of support on p11.

### Making a Will

Making a Will is important for all adults and gives you control over





how your money, property and belongings are distributed after your death. If you die without making a Will, your money and belongings will be divided according to legal rules known as ‘intestacy’ – this can be a slow process and your assets may not go the people and causes you would have chosen.

### **How to make a Will**

While it is possible to make a Will yourself, it is advisable to draw it up with a professional Will writer or solicitor. This will ensure that you have thought properly about your wishes and that there are no errors that could cause problems after your death. Please see Sources of support on p11 for details of how to find a solicitor or Will writer.

Solicitors and Will writers will charge a fee, but Dementia UK also offers free Will writing services – there is no obligation to leave a gift to the charity, although of course we would be truly grateful for anything you could leave. Please see Sources of support on p10 for details.

You can only make a Will if you are deemed to have mental capacity, and it must be signed and witnessed by two people.

Before speaking to a solicitor or Will writer, it is helpful to:

- Calculate the value of your assets (your ‘estate’) – this includes larger assets including property, savings and investments, but also small items that you might wish to leave to a specific person, eg a meaningful piece of jewellery
- Choose the family and friends you would like to leave your assets to (the ‘beneficiaries’), and whether you would like to leave a gift to charity
- Decide who should have guardianship of any children under 18
- Decide who will sort out your Will and make sure your wishes are carried out (the ‘executor/s’)

### Changes to your Will

If you wish to change your Will – for example, if your assets have changed or if you wish to add or remove someone – you can do so by contacting the solicitor who originally helped you to make it, or a new solicitor. Simple changes or additions can be made with a supplement called a codicil. This needs to be signed and witnessed, but the witnesses need not be the same people who signed your original Will.

There is no limit to the number of codicils you can make, but if you wish to make any major changes, a new Will should be drawn up.

There is space on the ACP template to indicate if you have made a Will, and where it is stored.

### Funeral planning

While it can be very difficult to think about your funeral, giving some thought to what you would like may make the process easier for the people who will be involved in making the arrangements. It will also help ensure your wishes are respected.





You can make plans for your funeral yourself or ask a funeral director to help you. You might want to consider:

- whether you would like to be buried or cremated
- where you would like to be buried or have your ashes scattered
- your preferred funeral director
- any faith or belief you would like your funeral carried out in accordance with
- where you would like the funeral to take place
- who you would like to lead the funeral
- the music, hymns and readings you would like
- who you would like to do any readings/sing/play an instrument
- whether you would like flowers or donations

Some people set aside money to pay for their funeral. You could specify this in your Will or pay a funeral director in advance – many offer payment plans.

## Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, ‘Dementia: what next?’ at

➤ [dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to an Admiral Nurse on our free Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email ➤ [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit

➤ [dementiauk.org/book](https://dementiauk.org/book)

### Dementia UK resources

#### Advance care plan template

➤ [dementiauk.org/acp-template](https://dementiauk.org/acp-template)

#### End of life care

➤ [dementiauk.org/end-of-life-care](https://dementiauk.org/end-of-life-care)

#### Financial and legal sources of support

➤ [dementiauk.org/financial-and-legal-sources-of-support](https://dementiauk.org/financial-and-legal-sources-of-support)

#### Finance and young onset dementia

➤ [dementiauk.org/finance-and-young-onset-dementia](https://dementiauk.org/finance-and-young-onset-dementia)

#### Free Will offers

➤ [dementiauk.org/write-or-update-your-will-for-free](https://dementiauk.org/write-or-update-your-will-for-free)

### **Gifts in Wills guide**

- [dementiauk.org/request-free-gifts-in-wills-guide](https://dementiauk.org/request-free-gifts-in-wills-guide)

### **Lasting power of attorney**

- [dementiauk.org/lasting-power](https://dementiauk.org/lasting-power)

### **Mental capacity and decision making**

- [dementiauk.org/mental-capacity-and-decision-making](https://dementiauk.org/mental-capacity-and-decision-making)

### **Other resources**

#### **Advance decision to refuse treatment (ADRT)**

- [nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment](https://nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment)

#### **Advance statement**

- [nhs.uk/conditions/end-of-life-care/planning-ahead/advance-statement](https://nhs.uk/conditions/end-of-life-care/planning-ahead/advance-statement)

#### **Compassion in Dying**

- [compassionindying.org.uk](https://compassionindying.org.uk)

#### **Find a solicitor**

- [solicitors.lawsociety.org.uk](https://solicitors.lawsociety.org.uk) (England and Wales)
- [lawscot.org.uk/find-a-solicitor](https://lawscot.org.uk/find-a-solicitor) (Scotland)
- [lawsoc-ni.org/solicitors](https://lawsoc-ni.org/solicitors) (Northern Ireland)

#### **Institute of Professional Will Writers**

- [ipw.org.uk](https://ipw.org.uk)

#### **Mental Capacity Act (2005)**

- [nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act](https://nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act)

**To speak to a dementia specialist Admiral Nurse  
about any aspect of dementia:**

Contact our Helpline:  
**0800 888 6678** or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:  
[👉 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our  
life-changing work. If you would like to donate to help us  
support more families:**

- Call **0300 365 5500**
- Visit [👉 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

**Thank you.**



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**dementiauk.org • info@dementiauk.org**

Publication date: September 2024. Review date: September 2026. © Dementia UK 2024

Dementia UK, 7<sup>th</sup> Floor, One Aldgate, London EC3N 1RE  
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