

# Dementia & end of life

– the legal things you need to know

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**Dementia is an incredibly difficult diagnosis to come to terms with, and you will have many questions. One of the things you will need to consider, if you have not already done so, is what your (or your loved one's) wishes are for the end of life.**

While this is often a difficult subject to talk about, it is important that you put the right safeguards and plans in place. As dementia is progressive, it is likely that, by the time end of life approaches, a person with the condition is no longer able to make important decisions. It is therefore vital that their wishes are set down in advance, and that the right protections are put in place for them.

Although it is difficult emotionally, putting these legal safeguards in place now makes everything much easier and clearer later on, so you do not have to worry about such matters at the same time as dealing with the death of a loved one.

This guide is intended to help you and your relative make important decisions about care and financial matters now to ensure that, whatever happens, your/their wishes are respected as the end of life approaches – and beyond.

**When someone has dementia, particularly as the condition progresses, they become less able to make decisions, so someone else has to step in and make important decisions about their care, wellbeing and finances for them. But it is not always easy to judge when it is appropriate to make a decision on someone else's behalf.**

The Mental Capacity Act 2005 (and its Code of Practice) explains how to determine if someone can make their own decisions or not. It also tells you how to help them, and how to make decisions for them if they cannot do this for themselves.

Designed for professional carers, the Act provides a useful basis for making decisions for everyone, including family members who are not actually obliged to follow it, even though it is usually recommended that they do so.

## **What is mental capacity?**

Mental capacity is the ability to make or communicate decisions for yourself at the appropriate times. This means that to have mental capacity, you need to be able to understand the decision to be made, why you need to make it and what is likely to happen as a result.

Remember that some people will be able to make decisions about some things but not others. They may be able to decide what to wear that day, but not make important decisions about their future care.

Having difficulty in communicating or needing more time to understand things does not mean that you lack mental capacity. Someone with dementia may be able to understand but struggle to communicate their decision. If you (or your loved one) finds this hard, it is important to get help and allow plenty of time to overcome these difficulties.

For more information about the Act and how to approach making decisions for someone else, click here:

**[www.alzheimers.org.uk/get-support/daily-living/making-decisions-mental-capacity-act#content-start](http://www.alzheimers.org.uk/get-support/daily-living/making-decisions-mental-capacity-act#content-start)**

## Deprivation of Liberty Safeguards (DoLS)

DoLS is part of the Act, and aims to ensure that people in a care home or hospital setting are being looked after in a way that does not inappropriately restrict their freedom. Deprivation of liberty is when a person under continuous supervision and control is not free to leave, and lacks the capacity to consent to the arrangements.

The safeguards ensure that:

- the arrangements are in your best interest
- you have appointed someone to represent you
- you are given a legal right of appeal over the arrangements
- the arrangements are reviewed and continue for no longer than is necessary

For more information about DoLS, visit:

[www.alzheimers.org.uk/get-support/legal-financial/deprivation-liberty-safeguards-dols](http://www.alzheimers.org.uk/get-support/legal-financial/deprivation-liberty-safeguards-dols)

## Guardianship for people with dementia

DoLS only applies if someone is in hospital or a care home. If a person with dementia is still living at home, but some safeguards are needed, a guardian may be appointed to make decisions for them. A guardian has the power to:

- decide where you live
- decide that you need to go to specific places (for medical treatment, for example), though they cannot force you to do so
- demand that a doctor can visit you where you live

A guardian must always choose the least restrictive option for the person with dementia and make decisions that are in their best interests. They cannot force you to do anything you do not want to do, and they have no control over your money or property.

For more information, go to:

[www.alzheimers.org.uk/get-support/legal-and-financial/guardianship](http://www.alzheimers.org.uk/get-support/legal-and-financial/guardianship)



**In many cases, by the time someone with dementia needs to move into a care home they are no longer able to make the decision to do so on their own.**

## **Setting up a Power of Attorney (POA)**

If you have been diagnosed with dementia, it is a good idea to give someone Power of Attorney to make important decisions about your financial affairs, health and care (or both) for you as soon as possible. This can only be done while you still have the mental capacity to make the

decision yourself. If you become unable to do this, it becomes more complicated and the Court of Protection may have to get involved.

Remember also, that if you are married or in a civil partnership, your spouse does not automatically have the right to make decisions for you or have access to your bank account or pensions. If you want them to be able to do that, you need to set up a POA.

## Types of POA

There are two main types of POA, and you can choose to set up more than one.

### Ordinary power of attorney

This covers decisions about your financial affairs and is valid while you have mental capacity. It is suitable if you need help for a temporary period (hospital stay or holiday). This might be because you need someone to access your bank account for you, for example.

### Lasting power of attorney (LPA)

An LPA covers decisions about your financial affairs or your health and care. You can either let your attorney make all decisions for you or choose which types of decision you want them to make.

#### Finance LPA

You would set up an LPA if you want to make sure that someone you trust can make decisions for you about buying and selling property, managing investments and paying bills, for example. It comes into effect if you lose mental capacity or if you no longer want to make those decisions for yourself.

#### Health LPA

An LPA for health and care decisions is only used once you have lost the capacity to decide for yourself. It usually covers where you should live, your medical care, your diet, your social activities and

who has contact with you. You can also give permission for your attorney to make decisions about life-saving treatment.

## How to set up a Power of Attorney

Setting up POA is quite simple:

1. Choose your attorney – you can have more than one.
2. Fill in the relevant forms.
3. Register with the Office of the Public Guardian.

For more information and the forms you need, visit:

[www.gov.uk/power-of-attorney](http://www.gov.uk/power-of-attorney)

[www.gov.uk/courts-tribunals/court-of-protection](http://www.gov.uk/courts-tribunals/court-of-protection)





**It is important that everyone makes a will, as it is the only way to ensure that your estate (your property, money, investments and possessions) go to the people or causes that you choose.**

If you are married or in a civil partnership, your partner will have a right to inherit. But if you are not, they will have no rights without a will.

## How to write a will

### Value your estate

Drawing up a list of what you own (and any debts) will give you an idea of what your estate will be worth. An estate usually includes:

- your home and any other property that you own
- money and savings in bank and building society accounts, as well as National Savings (like premium bonds)
- life insurance policies
- pension funds that include a lump sum paid out on your death
- investments (e.g. stocks and shares, ISAs)
- cars or other vehicles
- jewellery, antiques and personal belongings
- furniture and household contents

Don't forget to take into account any debts (mortgage, credit card, overdraft, loans, equity release).

## Decide what you want to happen to your estate

Consider:

- who you want to benefit from your will – these people are called beneficiaries, and could be family, friends or a charity that you care about. If you want to give something to a charity, make sure you include the charity's full name, address and registered charity number.
- whether you want to give any particular gifts to someone (a sum of money or particular possessions).
- where the residue of your estate goes – this is anything that is left after paying funeral and administrative expenses, legacies and any taxes.
- what should happen if any of the people named as beneficiaries die before you do.

## Choose your executors

Executors are people who deal with making sure that your estate is distributed according to your will after you die. It is a responsible job and can involve a lot of work, so think carefully about who you choose to do this.



## Writing your will

There are a number of ways to write a will, and different people who can help you:

- **Lawyers** (a solicitor or chartered legal executive) – some solicitors specialise in will writing and probate (the legal process involved in dealing with someone's estate).
- **Professional will writers** – check that whoever you use is a member of the Institute of Professional Will Writers.
- **Charities** – some offer a free will-drafting service. If you want to leave money to a charity, check with them to see whether they can help you write your will.
- **Banks** – some offer will-writing services and advice about estate planning.
- **Make your own will** – you can write your own will, and there are some online services which allow you to download a template. If you choose to do this, be aware that a will is a legal document and must be written, signed and witnessed correctly. So it is better to seek advice first.

Once your will is made, for it to be valid it must be signed and witnessed by people other than beneficiaries, such as your spouse or civil partner, who could lose their right to inherit. Your witnesses must see you actually sign the will, so you have to be in the same room when you all sign.

## Making a will if you have dementia

If you are unable to sign your will yourself, someone can do it for you. But you must be in the room, and able to direct them to sign it for you. You must also have the mental capacity to make the will, otherwise it is not legal.

That is why it is a good idea to make a will as soon as possible, if you do not already have one.

For more information about wills:

[www.ageuk.org.uk/information-advice/money-legal/legal-issues/making-a-will](http://www.ageuk.org.uk/information-advice/money-legal/legal-issues/making-a-will)

[www.gov.uk/make-will](http://www.gov.uk/make-will)

The screenshot shows the Age UK website interface. At the top right, there are links for 'Find your local Age UK' and 'Contact us'. The Age UK logo is on the left, with the tagline 'Let's change how we age'. A search bar and a 'Please donate' button are also visible. A navigation menu includes 'Information and advice', 'Services', 'Get involved', and 'Our impact Buy products'. The breadcrumb trail reads 'Home / Information and advice / Money & legal / Legal issues / Making a will'. The main heading is 'Making a will', followed by a sub-heading: 'Making a will is the only way to make sure your money, property, possessions and investments (known as your estate) go to the people and causes you care about.' A 'Listen' button is present in the top right corner of the content area.

**If you have been diagnosed with dementia, you might want to think now about what will happen to you when your condition is more advanced, in case you are unable to make decisions or communicate your wishes.**

## An Advance Statement

This is a written statement that sets out your wishes and preferences for your future care. It can also include your values and beliefs, to ensure these are respected.

It can cover any area of your health or social care in the future and might include:

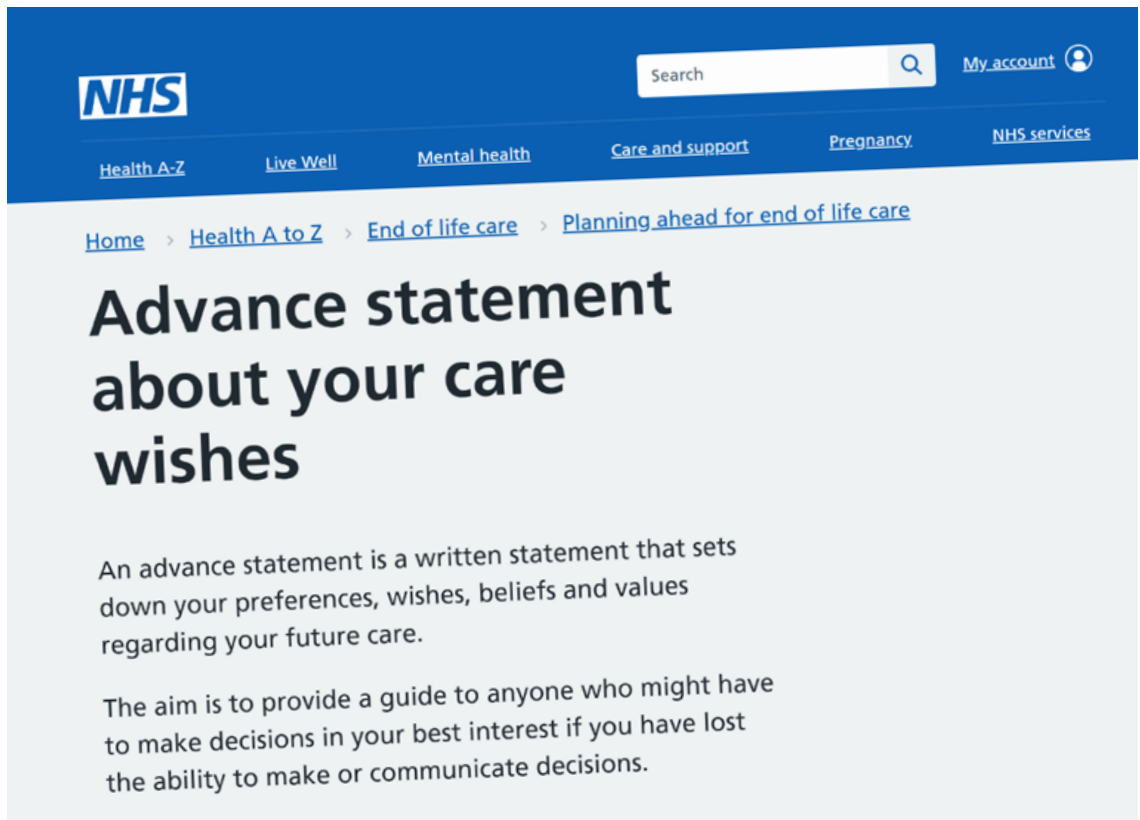
- where you want to be cared for – at home, in a nursing home, a hospital or a hospice
- how you prefer certain things to be done, and could include anything from whether you prefer a bath or a shower, to your favourite foods (whether you are a vegetarian, for example)
- whether you have any particular spiritual or religious beliefs that you would like to have reflected in your care
- any practical issues (if you are living at home, it could be arrangements for looking after a pet)

An Advance Statement is not legally binding, but it must be taken into account by anyone making decisions about your care. It does not have to be witnessed, but you should sign it so that it is clear that

these are your wishes. You can choose who sees it and where it is kept. Many people find it helpful to keep a copy in their medical notes.

For more information about Advance Statements, visit:

[www.nhs.uk/conditions/end-of-life-care/advance-statement](http://www.nhs.uk/conditions/end-of-life-care/advance-statement)



The screenshot shows the NHS website interface. At the top left is the NHS logo. To its right is a search bar with the text 'Search' and a magnifying glass icon. Further right is a 'My account' link with a user profile icon. Below these are navigation links: 'Health A-Z', 'Live Well', 'Mental health', 'Care and support', 'Pregnancy', and 'NHS services'. The main content area has a breadcrumb trail: 'Home > Health A to Z > End of life care > Planning ahead for end of life care'. The title 'Advance statement about your care wishes' is prominently displayed in large, bold, black text. Below the title, there is a paragraph: 'An advance statement is a written statement that sets down your preferences, wishes, beliefs and values regarding your future care.' Another paragraph follows: 'The aim is to provide a guide to anyone who might have to make decisions in your best interest if you have lost the ability to make or communicate decisions.'

**An Advance Decision (also known as a living will) is a different document that is legally binding – as long as it meets the criteria for it to be valid.**

This is a decision you can make now about whether you want to refuse certain treatments in the future, and lets people know your wishes if you are unable to communicate them yourself. It is important that you are clear about your intentions.

If you wish to refuse certain treatments, these must be named. You may decide that you wish to refuse certain treatments in some circumstances but not others. If so, you need to be clear about all these treatments and circumstances.

If you decide to refuse life-sustaining treatment in the future, you need to:

- write it down
- sign it in the presence of a witness
- have the witness sign it.

For information on Advance Decisions and life-sustaining treatments, visit:

**[www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment](http://www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment)**

This leaflet is part of a series designed to help people understand more about dementia – the different types, getting and living with a diagnosis, experiencing a full life with dementia and how to find the best dementia care for you or a loved one.

Visit our resource library for our other leaflets:  
[www.canfordhealthcare.co.uk/resource-library](http://www.canfordhealthcare.co.uk/resource-library)

We have used all reasonable care when compiling the information for this leaflet, however we cannot be held liable for any errors, omissions or advice/services provided by organisations mentioned in the leaflet.

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