



**Independent
Age**



Planning for the end of life

**Thinking ahead now
for peace of mind later**



Thank you

We would like to thank everyone who shared their experiences for this guide, and those who reviewed it. Our special thanks go to Marie Curie for their expert knowledge during the review.

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We spoke to older people about their experiences. Their quotes appear throughout. We have changed the names of some of the interviewees who wished to be anonymous. Some of the images seen throughout this guide are posed by friends of Independent Age.

The PIF TICK is the UK-wide Quality Mark for Health Information.

About this guide

Whether you're nearing the end of your life or simply planning for the future, this guide can help you think about your wishes, rights and needs. It can also help if you're supporting someone else to make decisions.

Thinking about your preferences in advance can make a stressful time easier for you and those around you. It's also important to know your rights to things like healthcare or benefits and to be aware of the support that is available.

You may find it uncomfortable to think about some things more than others, so don't feel you have to read the whole guide at once. Take your planning at a pace that suits you. You can decide what is important and when you're ready to consider it.



In this guide, you'll find references to our other free publications. You can order them by calling **0800 319 6789**, or by visiting **independentage.org/publications**.



1. Why plan ahead?

There are many reasons why you might start thinking about your death and making plans for how you would want it to be.

1. Why plan ahead?

Whatever your reasons, this can be an emotional subject to consider.

Thinking about the end of your life can be difficult. You may have lots of different feelings and putting it off is perfectly understandable. But there are many benefits to considering your views while you are able to do so.

Benefits of planning ahead

Planning ahead can:

- help you to feel in control of the situation and make informed decisions
- make sure your opinions and wishes are known – for example, whether you'd want to refuse certain medical treatments in particular circumstances, what care you would want and who you would want to inherit your property
- make things easier for your friends and family – they won't worry about what you wanted if you've made it clear to them.

“ It's like filling in a tax form – you know you've got to do it, but you leave it till the last minute.

Involving others in your plans

If you can, you may want to involve the people you're close to – such as your family and friends – in your planning.

Doing this can:

- provide you with emotional support
- prepare those close to you for the future
- make sure they're aware of your wishes.

Do they know your wishes?

You may think that people know what you'd want, but is there anything you've overlooked?

Often, family and friends are more willing to talk about end-of-life planning than you expect. But they may worry about upsetting you or think that you don't want to talk about it. See **chapter 2** for tips on starting the conversation.

1. Why plan ahead?

What would you want if you became ill?

Even if someone close to you knows your wishes, they won't automatically have the legal right to make decisions for you if you become too ill to make them yourself.

It's important to make sure your preferences for health and care treatment would be followed if you lost mental capacity (see **chapter 3**).

Finding someone to talk to

If you don't have anyone you feel you can discuss your wishes with, you can still plan for the future.

You could talk to your GP, nurse, or another health or care professional you trust. You may want to talk to a local faith leader. You do not need to be of their religion to talk to them.

You may also want to contact organisations that provide support and information about dying and planning for the end of your life – see **chapter 2**.



“ I’m someone who needs to know exactly what’s going to happen to me. I’m very meticulous and I do like to make plans.



2. Getting support to plan for the end of your life

When you begin to plan for the end of your life, you may feel overwhelmed by how many things you need to think about in advance.

It's important to remember that you can plan at your own pace. You can also talk to others and get support when you're ready.

Starting to talk about your plans

Talking to people you're close to may help, but you might not know how to start the conversation.

Your friends and family might not want to think about the idea of you dying, or they could think they don't know enough to help you plan. But they may also think you're not ready to talk about it or make plans, so it can be helpful to show them you're willing.

“ One important thing is getting your family to realise you're not going to be here that much longer. They think you're going to go on forever. And if they're prepared for it, it helps. If they know your attitude, it helps to ease it a bit.

2. Getting support to plan for the end of your life

How to start the conversation

Here are a few ways you could raise the subject.

- Think carefully about what you want to say and consider writing it down.
- Let people know that you'd like to talk about this beforehand. This gives them time to prepare, so they don't feel ambushed into discussing or planning.
- Pick the right time and place. You may like to do this while out walking or during a car journey for example. Don't introduce the subject when tensions are already running high or when you're pushed for time.
- Think about how you might introduce the topic – for example, 'Organising Dad's funeral made me think about what I would want'.

“ She used to say, I want you to do this; I want you to do that. I used to say, I'll be gone before you. I wasn't ready for that conversation. It was good to talk and I appreciate it now. We should have talked more.



For more tips, read our webpages called Talking about sensitive subjects (independentage.org/get-advice/family-friends-and-carers/sensitive-conversations).

You can also read Compassion in Dying's Starting the conversation guide (**0800 999 2434**, compassionindying.org.uk/starting-the-conversation) or Hospice UK's leaflet How to talk about death and dying (**020 7520 8200**, hospiceuk.org/our-campaigns/dying-matters/dying-matters-resources).

Support if you're living with a terminal illness

Being told you have an illness that will shorten your life can be very upsetting and overwhelming. Everyone will respond to this news in their own way.

You may need to spend some time on your own, or you may want to have family or others you trust around you for support. Give yourself time to take in what you have been told.

2. Getting support to plan for the end of your life

Terms you may encounter

Terminal illness

An illness or condition is terminal when:

- it cannot be cured and
- it is likely to lead to death, although you may still live a full and active life for many years.

It may also be called a life-limiting illness.

Prognosis

A prediction about the likely development and outcome of your medical condition.

Getting information and support

It's a good idea to talk to your doctor or another health professional about your illness and what to expect. You may find this hard, but they can answer your questions and talk about any worries you have.

Compassion in Dying has a useful guide to the questions you might want to ask (**0800 999 2434**, **compassionindying.org.uk/how-we-can-help/what-now-questions-terminal-diagnosis**).

Charities, hospices and other organisations helping people with certain illnesses can provide a range of help and advice, such as helplines, visits from volunteers, peer support groups, information and emotional support for you and those supporting you.

Marie Curie has a useful guide, *Living with a terminal illness*, which covers everything from diagnosis to emotional support and accessing care (mariecurie.org.uk/help/support/publications/all/living-terminal-illness).

Getting emotional support

You might find that your feelings are chaotic and it's hard to focus at first.

Feeling distressed, angry, hopeless and depressed are normal reactions. If you're struggling to cope, or these feelings have lasted a while, you might want to talk to your GP or healthcare team. You can also read our guide **Managing anxiety and depression**.

You might want to confide in those around you and talk about your fears and wishes. Some people find talking to a counsellor helpful too. Ask your GP, or the healthcare team where you're receiving care, what services are available.

2. Getting support to plan for the end of your life

You could also pay for a private counsellor. Make sure they're recognised by a professional body such as the British Association for Counselling and Psychotherapy. Ask your GP or healthcare team how to find one, or visit:

- BACP for England and Wales (**01455 883300**, bacp.co.uk/search/therapists)
- COSCA for Scotland (**01786 475140**, cosca.org.uk).

Marie Curie has more information about coping with a terminal diagnosis at mariecurie.org.uk/help/support/diagnosed/practical-emotional-support/coping.

Financial support

If you become unwell and need help to care for yourself, there may be financial help available. This may ease the strain on you and those around you at a stressful time.

Attendance Allowance

This is a benefit for people over State Pension age who need help with personal care, or need to be supervised, because of a physical or mental disability. It isn't means-tested, so your finances won't be considered.

Attendance Allowance is paid at two different rates, depending on how much care you need. If you're terminally ill and unlikely to live more than 12 months, you'll automatically qualify for the higher rate.

Pension Age Disability Payment is replacing Attendance Allowance in Scotland. Contact Social Security Scotland (**0800 182 2222**) for more information.



For more information, read our guide **Attendance Allowance**.



To do

You may also qualify for other benefits. Try our online benefits calculator (**independentage.org/benefits-calculator**) or call us on **0800 319 6789** to arrange a free benefits check.

Some charities offer grants for people with long-term health conditions and there may be other support available. Read our factsheet **Extra help with essential costs if you're living on a low income**.

2. Getting support to plan for the end of your life

NHS Continuing Healthcare

This is a free package of care arranged by the NHS in England and Wales. You may qualify if you have a high level of health and care needs. You can get this care in a variety of settings, such as a care home, hospice or your home.

If it seems you may need Continuing Healthcare, you'll be given an assessment to find out whether you qualify. If you do, the care you're assessed as needing will be paid for by the NHS.

If your health is getting worse very quickly and you're approaching the end of life, you may be able to get a fast-track assessment. If this finds that you qualify, your care should be in place within 48 hours. For more information, see our factsheet **Continuing Healthcare: Should the NHS be paying for your care?**

In Scotland, a system called Hospital Based Complex Clinical Care is used instead. For more information, visit Care Info Scotland (careinfoscotland.scot/topics/how-to-get-care-services/hospital-based-complex-clinical-care).

For information on the help available, visit our website (independentage.org/get-advice/money/benefits/help-health-costs).

Useful contacts

Hospice UK's Dying Matters campaign

Aims to raise awareness of, and encourage people to talk about, dying and bereavement. It also helps people to make plans for the end of their life and can help you to find local organisations that provide support at the end of life.

- **020 7520 8200**
- **hospiceuk.org/dying-matters**

Good Life, Good Death, Good Grief

Provides information and support on ill health, death and grief for people in Scotland.

- **0131 272 2735**
- **goodlifedeathgrief.org.uk**

Death Cafes

Death Cafes provide an open, accessible space to discuss death over tea and cake. The concept may seem off-putting, but they can give you a chance to talk about death, with other people who won't try to lead your views or actions.

- **deathcafe.com**

2. Getting support to plan for the end of your life

Marie Curie

Helps people living with a terminal illness – not just cancer – and those caring for them. They provide a free support line, information, an online community, and nursing and hospice care.

- **0800 090 2309**
- **mariecurie.org.uk**

Compassion in Dying

Provides free information to help people understand their options and make sure their wishes for their care and treatment are known and respected.

- **0800 999 2434**
- **compassionindying.org.uk**

The Anne Robson Trust

Runs a free national helpline for anyone who is terminally ill and those caring for them.

- **0808 801 0688**
- **annerobsontrust.org.uk**

Carers UK

Provides support for carers. They have a helpline, information and an online forum.

- **0808 808 7777**
- **carersuk.org**

Healthtalk.org

Interviews with people who are living with terminal illnesses.

- **healthtalk.org/introduction/living-dying**

Charities for specific conditions

- Alzheimer's Society (for England and Wales, **0333 150 3456, alzheimers.org.uk**; for Scotland, **0808 808 3000, alzscot.org**).
- Stroke Association (**0303 3033 100, stroke.org.uk**).
- Macmillan (**0808 808 0000, macmillan.org.uk**).
- Parkinson's UK (**0808 800 0303, parkinsons.org.uk**).
- The British Heart Foundation (**0808 802 1234, bhf.org.uk**).
- Asthma + Lung UK (**0300 222 5800, asthmaandlung.org.uk**)

You can also ask your GP or local charity branches about support available in your area.



3. Thinking about health and care

It can be difficult to think about what would happen if you became ill. However, this is just as important as considering your finances or funeral.

There might come a time when you're unable to tell people what you want – for example, following a stroke – so it's best to write it down in advance. Review your decisions regularly to make sure they still reflect your wishes or changes in your situation.

Terms you may encounter

Life-sustaining treatment

Treatment that could keep you alive, such as cardiopulmonary resuscitation (CPR) if your heart stops or using a ventilator if you're struggling to breathe.

Palliative care

Care that aims to improve your quality of life if you have a terminal illness. It includes healthcare, such as managing pain and symptoms, as well as help with emotional and spiritual needs. It might be given at home, or in a day centre, hospital, care home or hospice. You can have palliative care alongside care that aims to cure you.

Mental capacity

The ability to make and communicate your own decisions when they need to be made. You might lose this because of an illness such as dementia, or if you were unconscious, for example. You may have mental capacity at some times, but not at others.

3. Thinking about health and care

What you can decide on

If you have mental capacity, you have the right to make certain decisions about your treatment and care – for example:

- the right to refuse treatment, including life-sustaining treatment
- the right to be involved in planning and making decisions about your health and care.

If you were to lose mental capacity, then a medical professional would usually make decisions about your care and treatment.

Their decisions must be made in your best interests. There are rules about how they must go about this – for example, they must:

- take your past and present wishes, feelings, beliefs and values into account, and
- consult people close to you about what they think your wishes, beliefs and values are.

Even if someone close to you knows your wishes, they would not automatically have the legal right to make decisions for you. The medical professional would have the final say.



What the medical professionals decide may not reflect what you would have wanted. That is why it's important to plan for this situation. Read our factsheets **Future planning: Managing my affairs** and **Future planning: Mental capacity**.

Making decisions in advance

There are ways to make certain decisions ahead of time, so doctors and care staff know what your wishes are or what you'd have wanted. You could:

- talk to your GP, or another health or care professional, about your decisions and ask them to record this in your medical records
- record your preferences for future treatment and care using an advance statement
- refuse certain treatments using an advance decision or advance directive
- appoint someone you trust to make these decisions for you using a power of attorney.

These all need to be set up while you have mental capacity, and would only be used if you then lost mental capacity.

3. Thinking about health and care

Talking to a health or care professional

You can start planning ahead yourself. But if you're unsure where to begin, you could talk to your GP or other professionals involved in your care. They can help you plan your future treatment and care.

They should:

- help you explore and understand your options so you can decide what's right for you
- record any decisions you make
- make sure your decisions are shared with others involved in your care
- make sure your decisions are reviewed regularly.

“ We had a good experience. John's mother was dying in hospital, and we knew because we talked to her that she didn't want to be kept going. The doctor came and spoke to us and said, she has said she doesn't want us to keep giving her heavy medication – is that right? And we said yes, so they didn't and she just slipped away.

If you need palliative care

Many GP surgeries keep a register of patients who need palliative care. Being on the register can help health and care professionals to communicate and coordinate your palliative care.

If you have a terminal illness

You might want to talk about future treatment for your condition, including palliative care options. Your doctor should explain your options, and the pros and cons of each, in a way you can understand. This can be upsetting, so you could take a friend or relative with you for support or to help you ask questions.

Don't feel that you have to fit everything into one conversation. It can take a while to plan everything as you wish and you may not be able to take in all the information at once.

Ask questions over a few appointments if you need to. It can help to write down any questions you think of between appointments so you don't forget. Compassion in Dying's What now? guide has suggestions for questions to ask (**0800 999 2434**, **compassionindying.org.uk/how-we-can-help/what-now-questions-terminal-diagnosis**).

3. Thinking about health and care

Advance statement

This is a written statement of your wishes and preferences for your future care and treatment. You can write one while you have mental capacity.

Advance statements aren't legally binding anywhere in the UK, so may not always be followed, but they are taken into account. They can help your family, friends, carers and doctors know what your wishes are if they have to make a decision for you if you lose mental capacity.

Advance statements are not just about healthcare. You can include your preferences for lots of things – for example, what food you like and dislike, where you would prefer to live and how you like to spend your time.

Making your advance statement

You don't have to use a particular form or template but Compassion in Dying has a free advance statement form that can help you start (**0800 999 2434, [compassionindying.org.uk/how-we-can-help/advance-statement](https://www.compassionindying.org.uk/how-we-can-help/advance-statement)**).

Once you have written your statement, make sure you tell people it exists and where to find it. You could also give a copy to your GP to store with your medical records.



“ I think it is important to actually write things down, not just talk about it. Because they can forget or misinterpret you, so I think if you have particular wishes you should write them down and let people know where you've written it.

3. Thinking about health and care

Advance decisions and advance directives

These allow you to say which treatments you would want to refuse in certain situations if you didn't have mental capacity.

For example, you may state that if you were in a coma you wouldn't want:

- CPR if your heart stops
- ventilators to help you breathe
- food and fluids given artificially, such as through a drip.

They are known as an advance decision to refuse treatment (ADRT) in England and Wales, and an advance directive in Scotland. You may also hear them called a 'living will'.

“ My mum told all of us, ‘if I’m ill I don’t want to be resuscitated. I’m adamant on that’. She did it legally – she had to get it signed. And although you want to keep them for yourselves, you’ve got to respect their wishes.

You can use advance decisions or directives to state:

- which treatments you would want to refuse
- whether you would want to refuse treatments in all circumstances, or only in certain circumstances.

For example, you might state that if you had late-stage dementia, you would want to refuse antibiotics if you had a life-threatening condition, such as a lung infection.

However, you can also state that you wouldn't want to refuse antibiotics if you had a condition that would make you unwell but wasn't life threatening, such as a urinary tract infection.

You cannot use advance decisions or directives to:

- refuse basic comfort and care, such as food and water by mouth
- demand particular treatments
- choose someone to make decisions on your behalf
- ask for assistance to die.

3. Thinking about health and care

How to make an advance decision or directive

You can make one:

- in writing – if you want to refuse life-sustaining treatment, the advance decision or directive must be in writing. You and a witness must sign it. It must also state that it applies even if your life is at risk
- by telling someone about your wishes – for example, your GP or another health professional. They can talk through the decision with you and record it in your medical notes.

There's no set form if you make it in writing but, if you want to refuse any life-sustaining treatment, you do need to use specific wording. If you want some help to get started, Compassion in Dying has a free online service where you can make an advance decision (living will) at **advanceddecision.service.compassionindying.org.uk**. You can also download or order a paper copy of the form.

Before you make your advance decision or directive, it's a good idea to discuss it with a health or care professional. They can help you to understand any risks and make sure you have made your decision clear.

When they would be used

Your advance decision or directive would only be used if you lost the mental capacity to make a decision.

In England and Wales, advance decisions are legally binding so must be followed, as long as:

- you had mental capacity when you made it
- your advance decision applies to the specific situation you're in and treatments you're refusing
- there have been no changes since you made the advance decision that might have affected your original decision – for example, advances in medical treatment
- you haven't done anything that suggests you've changed your mind.

In Scotland, your advance directive isn't legally binding. But it should still be taken into account if a decision about your medical treatment needs to be made for you if you lose mental capacity.

If you choose to make an advance decision or directive, it's important to review it regularly so it still reflects what you would want.

3. Thinking about health and care

Do Not Attempt Resuscitation orders

CPR tries to restart your heart if it stops – its success varies. If your doctor thinks CPR would be unlikely to help you if your heart stopped, they might consider a Do Not Attempt Resuscitation (DNAR) order. These are called DNACPR forms in Scotland.

How DNAR orders are issued

DNAR orders are signed and issued by your doctor. When issuing one, your healthcare team must:

- involve you in discussions about CPR if they can
- make their decision based on your individual circumstances and not make blanket decisions.

DNAR orders are added to your medical records. They tell healthcare professionals not to try CPR if the situation came up. You cannot write your own DNAR order, but you can ask for your doctor to complete one. DNAR orders are not legally binding, so may not always be followed. If you wanted to make your preferences legally binding, you could set up an advance decision (in England or Wales) – advance directives in Scotland are not legally binding.

The difference between advance statements, advance decisions or directives, and DNAR orders can be confusing. You can call us on **0800 319 6789** to arrange to speak to an adviser.

Power of attorney for health and welfare

Power of attorney lets you appoint someone to help you make decisions, or to make them for you if you're unable to.

In England and Wales, it's known as a lasting power of attorney (LPA). There are two types: one for property and financial affairs (see **chapter 4**) and one for your health and welfare. You can set up either or both.

In Scotland, the two types are known as a welfare power of attorney (WPA) for your health and welfare, and a continuing power of attorney (CPA) for property and finances. If you want to set up both, it's called a combined power of attorney.



3. Thinking about health and care

What a health and welfare attorney can do

Your health and welfare attorney would be able to make decisions about things like:

- your medical treatment and care
- your daily routine – for example, how you dress and what you eat
- where you're cared for – for example, moving to a care home.

If you want to, you can specifically state if you want your attorneys to be able to give or refuse consent to life-sustaining treatment for you.

Choose your attorney carefully. Do you trust them to make these decisions and would they be happy to make them? You can appoint more than one person as attorney. If you do appoint more than one, you can decide if they need to make decisions together or separately.

When power of attorney could be used

A health and welfare power of attorney can only be used if you lose mental capacity. You can cancel or change it if you still have mental capacity.

For those living in England and Wales, if you have both an advance decision and an LPA for health and welfare, the most recent one would be used over the other if a decision about your health or care needed to be made. This would only apply to treatments or care that can be refused in an advance decision.

In Scotland, an advance directive isn't legally binding, so a WPA would always be able to override it. However, an advance directive could be useful to make sure that your attorney is aware of your wishes in particular situations.

“ Mum is in constant pain so I can understand why she says she's had enough. She has set up a power of attorney so that my sister and I are entitled to make decisions on her behalf: make payments, write cheques and access her bank and utility accounts.

3. Thinking about health and care

How to set up an LPA or WPA

To set up a power of attorney, you need to complete a form from the:

- Office of the Public Guardian (**0300 456 0300**, **gov.uk/government/organisations/office-of-the-public-guardian**) if you live in England or Wales
- Office of the Public Guardian Scotland (**0132 467 8300**, **publicguardian-scotland.gov.uk**) if you live in Scotland.

You'll then need to register it with them while you still have mental capacity. There is a charge for this. If you're on a low income or getting certain benefits, you may not have to pay the full fee.

Call us on **0800 319 6789** to arrange to speak to an adviser.



4. Thinking about finances and property

It's important to think about what would happen to any finances or property you may own, both after your death and if you became ill and were unable to manage them yourself.

4. Thinking about finances and property

Power of attorney for money and property

This type of power of attorney lets you appoint someone to make decisions about your money and property – for example, they could:

- manage your bank accounts
- collect your pension and benefits
- sell your home.

In England and Wales, it's known as a lasting power of attorney (LPA) for property and financial affairs. In Scotland, it's known as a continuing power of attorney (CPA).



Remember

Choose your attorney carefully. You can appoint more than one person as attorney if you want to.

See **page 36** for how to set up a power of attorney.

When it could be used

With the money and property power of attorney, you can state if you want it to be used while you still have mental capacity. It would also be used if you lost mental capacity.

You can cancel or change a power of attorney as long as you still have mental capacity.



For more information, read our factsheets **Future planning: Managing my affairs** and **Future planning: Mental capacity**.



4. Thinking about finances and property

Making a will

Make sure you have an up-to-date will. If you don't, the law decides what happens to your money and property when you die. This may not be the same as what you would have chosen.

Having a will can make it easier for your family or friends to sort everything out after your death.

You can use a will to specify what arrangements you want to make for any dependants. You might also want to make plans for any pets. The Cinnamon Trust may be able to help with this (**01736 757 900**, **cinnamon.org.uk**).

To make a will, you can:

- write one yourself – you can buy templates in stationery shops or online
- use a will-writing service
- use a solicitor.

Your will needs to be signed and witnessed to make it legally valid.

Getting support to make a will

Unless your will is completely straightforward, it's best to get advice rather than write it yourself.

For example, if your estate is likely to pay Inheritance Tax, it's a good idea to use a solicitor. Will-writing services can be cheaper than solicitors, but unlike solicitors, they aren't necessarily legally qualified.

Some charities offer free will-writing services from a solicitor – for example:

- Free Wills Month (**freewillsmoonth.org.uk**) runs twice a year in some parts of England and Wales. It allows people over 55 to get a simple will drawn up or updated free of charge by a solicitor. It usually runs in March and October. There may be a charge for complex wills, so check with the solicitor first
- Age Scotland (**0333 323 2400**, **agescotland.org.uk/information-advice/legal-support/free-will-writing-service**) provides free will-writing services through Solicitors for Older People Scotland if you're over 50 and living in Scotland.

In return, you might wish to make a donation or leave a gift in your will.

4. Thinking about finances and property

Make sure you let people know where they can find your will. If you wish, you can store your will with HM Courts and Tribunal Service for a fee. If you're on a low income or getting benefits, you can get help with costs. For more information, call the Probate helpline on **0300 303 0648** or visit **gov.uk/government/publications/store-a-will-with-the-probate-service/how-to-store-a-will-with-the-probate-service**.



Leaving a gift in your will

You may want to consider leaving a gift to charity in your will to help them continue their vital work. For example, by leaving a legacy to Independent Age, you'd be helping provide older people facing financial hardship with much-needed free information and advice, and practical support.

To request your free booklet on what to consider if you're leaving a legacy in your will, call our legacy team or visit our website (**0207 605 4223**, **independentage.org/support-us/legacies**).

Where to find a solicitor

You can find a solicitor through:

- the Law Society (**020 7320 5650, solicitors.lawsociety.org.uk**) if you live in England or Wales, or
- the Law Society of Scotland (**0131 226 7411, lawscot.org.uk/find-a-solicitor**) if you live in Scotland.

If you already support a charity, check if it's part of the National Free Wills Network (**nationalfreewills.net**). Some charities, including Independent Age, offer their supporters free will-writing services through this.

Visit the MoneyHelper website for advice on making a will (**moneyhelper.org.uk/en/family-and-care/death-and-bereavement/planning-what-to-leave-in-your-will**).

Your digital legacy

If you use the internet for things like social media, online banking and email, you may want to think about what happens to your accounts and profiles after you die. The Digital Legacy Association can help you plan – visit **digitallegacyassociation.org**.



5. Thinking about where to live

Choosing where to live at the end of your life and where to die may be very important to you. It's often a question of weighing up the benefits and drawbacks of each option.

Thinking about your options

Talk to your GP, or another health or care professional, and people you are close to about what you would want and what might be possible.

You may need to consider what type of care you need – for example, your home might feel more peaceful and familiar, but would it be the best choice if your condition is hard to manage there?

A combination of settings could be an option. For example, you might be able to live at home for as long as possible with support from care workers or district nurses, but move to a hospice or care home if you became unable to cope.

Your GP can record your preferences, so that everyone involved in your care is aware of your wishes. You could also record them in an advance statement (see **chapter 3**). Bear in mind that you may think or feel differently if your situation changes, so it's a good idea to regularly review your preferences.

If you need care in your own home or in a care home, make sure you check whether the council or NHS should be paying for any of it. Call us on **0800 319 6789** to arrange to speak to an adviser.

5. Thinking about where to live

At home

Spending the end of your life in your home can be very comforting – with the reassurance of your usual surroundings and belongings, and home life continuing around you. You may find it helps you to feel more in control.



If you're ill, you may be able to get services at home to support you. For example, you may receive visits from a district nurse, or a nurse specialising in palliative care or a particular illness. Speak to your GP about what services are available in your area.

You can also contact your local council to ask for a care needs assessment, which looks at what help you might need. Read our factsheet **First steps in getting help with your care needs in England and Wales** or **First steps in getting help with your care needs in Scotland**.

If a relative, friend or someone else is caring for you, you can check whether they could get support too, including carers' benefits. Read our guide **Caring for someone** for more information. It's a good idea to talk to them about whether they are able and willing to keep caring for you, because this might affect your decision of where to live.

Some people decide they want to spend the end of their life at home. But, if they're nearing death and very unwell, they may find this isn't possible.

5. Thinking about where to live

In hospital

Many people will die in hospital but, if you don't want this, talk to your doctor about other options.

Hospitals may provide less privacy and unknown surroundings, but staff will have the medical expertise to care for you and relieve pain where possible. Some hospitals will have a specialist palliative care team to provide advice on pain and symptom control.

If you want to donate your organs, this is only possible if you die in hospital. The law in England, Scotland and Wales now assumes you agree to donating your organs if you meet the criteria and haven't opted out. Find out more or register your decision by calling **0300 123 23 23** or visiting **organdonation.nhs.uk** or **organdonation.scot**.

In a hospice

Hospices provide specialist care for people with terminal illnesses. They are smaller, quieter and calmer than hospitals, with more focus on caring for people as individuals.

They provide a range of services, including medical care and emotional support, and services like bereavement support for those close to you.

Hospices also provide care for people in their own homes. You may also be able to stay in one for a few days to give your regular carer a break.

Hospice care is always free. However, if there isn't space, it might not be available when you need it. Ask your GP or a local hospice for more information, or contact Hospice UK (**020 7520 8200**, **hospiceuk.org**).

“ Hospices care for you in a way that is so supportive. If your life is going to end tomorrow, you want to be nurtured.

5. Thinking about where to live

In a care home

If you're already living in a care home, you might want your life to end in a place that you know.

Some care homes will have their own specialist end-of-life teams, while others may use visiting services – for example, from a hospice. Speak to the care home about what they can provide.

It may also be possible to move to a care home for a short period before you die, but bear in mind that some care homes have waiting lists and they can also be expensive. Check what is available in your local area.

Depending on your needs, you may qualify for NHS funding for your care home place (see **chapter 2**).



6. Thinking about your funeral

Funerals or memorial services give those around you a chance to say goodbye and celebrate your life.

6. Thinking about your funeral

You may have already considered what sort of funeral or memorial service you want, perhaps after attending one that was particularly good or bad.

If you have clear ideas about your funeral, make sure you let your friends or family know about them. This will help them to respect your wishes and also ease the planning process for them after your death.

Things to consider

- Do I want a religious or non-religious funeral?
- Would I want to be buried or cremated?
- Where would I want to be buried or to have my ashes scattered?
- Where would I want the funeral or wake to be held?
- What songs or hymns would I want at my funeral?
- Would I want guests to do anything in my memory – for example, bring flowers or make charitable donations?

You may want to write down your wishes so you can easily share them with your friends or family.

Marie Curie has useful information about planning a funeral at mariecurie.org.uk/help/support/terminal-illness/planning-ahead/planning-your-own-funeral.

Paying for your funeral

Funerals are expensive, so it can help to think about how yours will be paid for. There are a few options to consider – for example, you can:

- state in your will what money you're leaving to pay for your funeral. Bear in mind this money may not be released immediately, so your friends or relatives may have to pay the bill and reclaim the costs later
- use a pre-paid funeral plan. If you do this, check what it covers; it won't always cover every part of the funeral. And discuss it with those around you, because many people are left trying to trace pre-paid plans after a death
- pay for funeral insurance. Make sure you check how much the plan would pay out and whether you'd need to pay for anything extra.

MoneyHelper has more information about these options (**0800 138 7777**, moneyhelper.org.uk/en/family-and-care/death-and-bereavement/help-paying-for-a-funeral).

If you live in Scotland, the Scottish Government has an online guide to planning your own funeral, including information about paying for it (gov.scot/publications/planning-funeral-2).

6. Thinking about your funeral



If you or anyone you know is struggling with a death, our guide **Coping with bereavement** can help.

Checklist

In case of your death or an illness that left you unable to communicate, it's best to make sure people know about:

your will

your wishes for your funeral or other things you wish people to do in your memory

your wishes for your care and treatment

whether you have an advance decision or an advance statement if you live in England or Wales, or advance directive if you live in Scotland

where you would want to live and die

whether you have registered a decision on the Organ Donor Register

whether anyone has power of attorney for you and, if so, which type

what bank accounts, bills and insurance policies you have – make a list of these

whether you have a pre-paid funeral plan, and where it is

what you would want to happen to your pets if you have any.



Pauline's story

Me and my husband both have lasting powers of attorney for financial decisions. We are the attorneys for each other, along with our three children. We wanted to make sure that people could step in and pay our bills, and make decisions while we're still alive, if we can't do it ourselves.

We now need to update our wills – the executor has died and the wills were made when the children were young. But at this moment, any will is better than no will!

We're also considering getting pre-paid funeral plans. My sister recently didn't have the money to pay for her husband's funeral – she would have needed to get a loan to pay for it if someone in the family hadn't been able to lend her the money, and she ended up arranging a much more basic funeral than she wanted because of that. It was really stressful for her. She eventually got a grant from the armed forces charity SSAFA to help cover some of the cost as her husband had served in the navy.

We've been wary about scams and unregulated companies that offer funeral plans and people losing their money, so want to make sure we use a reputable company.

The recent funeral did prompt me to think about my wishes. I know I want to be cremated, and for my ashes to be scattered amongst nature. I don't want a lot of fuss. We all put it off until tomorrow and don't like to discuss these things until we have to, but it needs to be done.

“ The recent funeral did prompt me to think about my wishes.

About Independent Age

No one should face financial hardship in later life.

Independent Age is the national charity focused on improving the lives of older people facing financial hardship. We offer free impartial advice and information on what matters most: money, housing and care.

We financially support local community organisations across the UK through our grants programme. We campaign for change for older people struggling with their finances.

You can call us on freephone **0800 319 6789** (Monday to Friday, 8.30am to 5.30pm) or email **helpline@independentage.org** to arrange to speak to one of our advisers.

To donate or help support our work, please visit **independentage.org/support-us**.



Independent Age
18 Avonmore Road
London
W14 8RR

independentage.org

charity@independentage.org
Helpline 0800 319 6789



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