Thinking about end of life

Getting your affairs in order and thinking about your care needs

AgeUKIG51

Information written with you in mind.

This information guide has been produced with the help of older people, carers and expert peer reviewers.

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What this guide is about

Thinking about the end of your life can be difficult – so lots of us tend to avoid thinking about it until we have to. But giving it some thought now means you can consider all your options, plan ahead and start getting your affairs in order.

Taking steps now can make things easier for your loved ones further down the line. Not only does it give you confidence that your wishes are documented, it means that the people close to you know what you'd want to happen if there comes a time when you can't make your own decisions.

Making plans now doesn't mean you can't change them in the future – for example, you can update your will to reflect changes in your life whenever you'd like to.

"I've started getting my affairs in order so things are as simple as they can be for my family."

Joe, 78

This guide goes through things it's good to think about when you're planning ahead. It explains how to make your wishes and treatment preferences known, and helps you consider where you'd like to be looked after towards the end of your life. It also outlines options and services that could be available if you're diagnosed with a life-limiting illness.

Whether you have a life-limiting illness or you're just planning for the future more generally, this guide can help you think through your options.

This symbol indicates where information differs for Wales and Northern Ireland. As far as possible, the information in this guide is applicable across the UK.

Good to know

There may be some things in this guide that you don't feel ready to think about yet. And while planning for the end of your life is important, it's also very personal – so you might prefer to read the sections that feel most relevant to you now, and return to others later.

Practical considerations

When you're planning ahead, it's good to know what options you have and the practicalities you might need to think about. This section covers things you can do to get your affairs in order, which can help reassure you that you're prepared for the future and your wishes will be respected.

Making a will

The first thing to think about when you're getting your affairs in order is a will. Having an up-to-date will is important, as it means there are clear instructions about what you want to happen to your money, property, possessions (known as your 'estate') and your online accounts after you die.

If you've already made a will, it's sensible to review it every 5 years to check it still reflects your wishes – or sooner if there's a significant life event, such as the birth of a new grandchild.

If you die without making a will, it can take much longer to deal with your estate, and your money and possessions might not necessarily go to the people you'd have chosen.

It's best to use a lawyer when making a will. The Law Society (page 40) can provide you with a list of local solicitors.

Next steps

Our guide **Wills and estate planning** has more information about making a will.

Thinking about powers of attorney

Setting up a lasting power of attorney (LPA) is a way of giving someone you trust (known as your 'attorney') the legal authority to make decisions on your behalf. An LPA can be really helpful if a time comes when you lose **mental capacity**.

When we talk about having **mental capacity**, we mean that someone has the ability to make and understand the consequences of their decisions.

There are two types of LPA:

LPA for financial decisions

Under this type of LPA, the person you nominate can make decisions about your property and finances, including:

- buying or selling your property
- paying your mortgage
- investing your money
- paying your bills and managing your bank account
- arranging repairs to your property.

The person you nominate can make decisions like this if you lose mental capacity. When you're setting up this LPA, you can also choose to allow the person you nominate to make these kind of decisions for you even if you still have mental capacity.

"You never know what's around the corner, so I thought it was a good idea to arrange a power of attorney now – just in case."

Rose, 70

LPA for health and care decisions

This type of LPA gives someone the authority to make decisions about your health, care and personal welfare, including:

- your care arrangements
- your daily routine
- your medication and medical treatment
- your living arrangements.

You can also give special permission for your attorney to make decisions about life-saving treatment.

Under this type of LPA, the person you nominate can only make decisions on your behalf if a time comes that you lose mental capacity to make them yourself.

Good to know

Setting up a power of attorney can be particularly helpful if you're diagnosed with a condition such as dementia. That way, if there comes a time when you can no longer make decisions, someone you trust can make them for you.

Enduring powers of attorney

LPAs have replaced enduring powers of attorney (EPAs) in England and Wales. If you made an EPA before October 2007 then it remains valid – but it only covers decisions about property and financial affairs. You might want to think about setting up an LPA for health and care decisions too.

What if I don't set up an LPA and lose mental capacity?

If you lose mental capacity and you don't have an LPA (or an EPA), someone can apply to the Court of Protection to be appointed to make decisions on your behalf. This person is known as your 'deputy'. The court can appoint more than one deputy for the same person.

Deputies are normally close family members or friends who are trustworthy and have the necessary skills to make decisions for you – for example, being able to make financial decisions if they want to help look after your property and affairs. Sometimes, deputies are independent professionals such as solicitors.

Applying to be a deputy is an expensive process – so it's usually best to get an LPA in place.

If you receive benefits, the Department for Work and Pensions can appoint someone known as an 'appointee' to manage them for you if you've lost mental capacity. If your money is made up of benefits only, you may not need a deputy as well.

Next steps

The Office of the Public Guardian provides information and guidance on making an LPA or applying to the Court of Protection (page 41). Our guide **Power of attorney** has more information about setting up an LPA.

Managing your documents and accounts

It can be helpful to gather key documents in a safe place and tell someone you trust, such as a family member or the **executor** of your will, where they are. This can make things simpler for them later on.

Key documents include your:

- birth certificate
- passport
- driving licence
- recent bank statements (and details of all your bank accounts)
- pension plans
- insurance policies
- National Insurance number
- pre-paid funeral plan
- will.

Your **executor** is legally responsible for carrying out the instructions in your will and handling your estate (your money, property and possessions).

If you use the internet to pay bills, shop or keep in touch with friends, it's a good idea to think about what will happen to your digital legacy (your accounts and profiles) after you die.

The Law Society (page 40) recommends creating a personal assets log (an up-to-date list of all your online accounts) along with clear instructions about what you want to happen to each account after you die. For example, you might want social media accounts to be deactivated – or you might want close friends or family to be able to recover things like photographs that have been posted online.

If you have an online bank account, your executors can arrange for it to be closed and claim the money on behalf of your estate. But make sure you don't leave details of your passwords or PINs – someone using them after your death could be committing a criminal offence.

"I hadn't even thought about what might happen to my Facebook page when I'm no longer around."

Gary, 69

Next steps

Visit the Digital Legacy Association's website (page 39) for further information about dealing with online accounts for things like email, social media and banking.

Josephine made plans for the future when she noticed her health deteriorating.

After living with a lung condition for several years, Josephine started to notice there are things she can't manage as easily as she used to.

'I was diagnosed several years ago. I've been looking after myself well enough at home, taking my medication, doing a bit of exercise and eating well – but there are some things I can't manage like I used to.

'I had a couple of bad flare-ups that really took it out of me, so I went back to see my GP. He explained that my symptoms would gradually get worse. I think I knew that deep down – but I needed to hear it to start thinking ahead.

'I already had a will but I set up a lasting power of attorney for health and care so my close friend can make decisions about my treatment and care if a time comes I can't make them myself. We had a conversation about things like whether I'd want to go on life support and where I'd like to be looked after.

'It was hard for both of us – and there were some tears – but it was reassuring too. I made a lasting power of attorney for my finances too. It takes the pressure off and means I can focus on getting on with my life, knowing she'll do what's right for me.

'While I don't know what the future will bring, I'm glad I've done what I can to plan for it.'

Financial help

Whether you're living with a long-term health condition or you just want to be prepared in case there's a change to your health in the future, it's a good idea to think about your finances and how you might cover costs for things like care.

If you need care, you may qualify for Personal Independence Payment or Attendance Allowance, depending on whether you're under or over State Pension age.

Claiming these kinds of benefits shouldn't reduce any other income you receive, and might even mean you're entitled to further benefits. If you aren't expected to live longer than 12 months, you can claim them quickly and receive high rates. If you have a carer, make sure they check whether they're entitled to Carer's Allowance.

You may also be able to get a one-off grant from a charity that specialises in your health condition, or from unions or professional organisations that you belong to (or used to belong to). Turn2us can help you search and apply for grants (page 42). If you have cancer, Macmillan Cancer Support has a helpful booklet called **Help with the cost of cance**r (page 40).

Next steps

Find out what else you might be entitled to by contacting your local Age UK for a free benefits check, or using our online calculator at **www.ageuk.org.uk/benefitscheck**. In Wales, contact your local Age Cymru.

Our guide **More money in your pocket** has more information. Age Cymru and Age NI have their own versions of this guide.

Planning for your funeral

Thinking about your funeral can feel difficult – but giving it some thought can make things easier for everyone. Talking about what you would and wouldn't like, finding out how much things might cost, and putting some plans in place can reassure you as well as your family and friends. It also makes sure that your funeral reflects your wishes.

You might want to think about:

- where you'd like your funeral to be held
- whether you want a burial or cremation
- whether you want a religious service
- who you'd like to be invited
- what songs or readings you'd like
- whether you want flowers
- what clothes you want to wear
- what you'd like your guests to wear.

You might want a humanist or family-led funeral, or you might have a special request – such as a woodland burial or a coffin made from materials like wicker or cardboard. Whatever you want, it's important to let your loved ones know.

Paying for your funeral

Funerals can be very expensive – so you might want to consider setting up a funeral pre-payment plan. These let you pay for the type of funeral you want in advance at today's prices. You can find out more about these from a funeral director or the National Association of Funeral Directors (page 40). Make sure that you know which services are included in the price, as it can vary.

Alternatively, you can pay for your funeral with funeral insurance – also known as an 'over 50s plan'. This type of insurance pays out a fixed lump sum that covers the cost of your funeral, and can be used at any funeral director. It's important to check the terms and conditions, as you may be required to pay into the plan for the rest of your life.

Direct cremations are a less expensive option. The body is collected from a mortuary and taken to the crematorium where the cremation is carried out at a time that's convenient to the crematorium. There's no need for a hearse or ceremony. A commemorative ceremony can then be held at a time and place that suits friends and family.

Next steps

To find a funeral director, contact the National Association of Funeral Directors (page 40) or the National Society of Allied and Independent Funeral Directors (page 41). Visit the Moneyhelper website (page 40) to find out more about funeral payment options.

See our factsheet **Planning for your funeral** for more information on funeral planning.

Looking after your pets

If you have pets, you'll want to think about what will happen when you're no longer able to care for them. You might already know someone who's happy to help – but they may not be able to keep them permanently.

The Cinnamon Trust (page 38) is a charity for older people and their pets. Their volunteers can help you keep your pets at home for as long as possible – for example, by walking your dog or fostering your pet if you have a short stay in hospital. They also have a Pet Friendly Care Home Register you can search for care homes that are happy to accept your pets. You can also arrange for the Cinnamon Trust to take on lifetime care of your pet when you die.

Dogs Trust (page 39) offers a free Canine Care Card Scheme. When you die, Dogs Trust staff will arrange for your dog to be taken to its nearest rehoming centre, where they'll be looked after until a suitable new owner can be found.

Cats Protection (page 38) offers a free service called Cat Guardians. It will look after your cat until staff find a suitable new owner.

If you have specific wishes about what you want to happen to your pets, mention this in your will to give you peace of mind that your pets will be cared for after you die.

Talking about death

Even if you know what practical steps you'd like to take to plan for the future, having conversations about them can feel daunting. But talking to your loved ones about what you want to happen when you die can save a lot of stress further down the line. It can also be reassuring to know that your wishes are clear if a time comes when you're unable to make your own decisions.

Conversations with family and friends

It can be difficult to talk to loved ones about the end of your life – but whether you're simply thinking ahead or you've been diagnosed with a life-limiting illness, it can help to talk to your family and friends so they know your wishes and preferences.

Sharing your thoughts with those close to you can make it easier for them to make any necessary decisions in the future and help you all prepare for what may lie ahead. It can also give you the opportunity to tell people what they mean to you – and perhaps even help to bring some resolution to more complicated relationships.

These conversations can be hard, but there are some things you can try to make it a little bit easier:

- Choose a time and place where you won't be disturbed or rushed so that you can say everything you want to.
- It might be worth writing notes beforehand about what you want to discuss. This can help you stay focused and make sure you cover everything you want to.
- Give whoever you're speaking to advance notice so the conversation doesn't take them by surprise.
- Don't feel you need to try and cover everything in one conversation. It can take time to fully discuss all your wishes.
- Don't worry if you get emotional. Be honest and talk about all your feelings.

Sometimes, family and friends can be reluctant to have these conversations because they don't want to think about your death, or because they're worried about saying the wrong thing. It might reassure them if you say it would help you to talk, and that it could make things easier for them if they need to make decisions for you later on. If they're still reluctant, try telling them that while you don't have to talk about it now, it's something you would like to discuss at some point.

Next steps

For leaflets on how to start conversations about dying, death and bereavement, contact Hospice UK (page 39) or visit the end of life pages on the NHS website (page 41). In Wales, visit the NHS 111 Wales website (page 41).

There's no right or wrong way to have these conversations, but being open and frank can make them feel easier. Share as much information as you feel able to. If you don't feel ready to talk yet, that's OK too.

Talking to children and young adults

If you have children or young adults in the family, you might want to talk to them about what's going on if you become unwell. This can be difficult – but it can help them make sense of what's going to happen and allow you to answer their questions and address their fears and worries. Don't be afraid of getting upset. Showing your emotions lets them know that it's OK to feel emotional too.

"Mum asked us to talk to the kids about her condition first, so they'd feel more able to ask everything they needed."

Mike, 48

Next steps

Winston's Wish offers information and support for children and young adults affected by death (page 42).

Hospice UK produces a leaflet called **Talking about dying with children** (page 39).

Thinking about your loved ones

There might be things you'd like to share with people before you die – or you might want to create something to leave behind. Some people find it helpful to put together a memory box or scrapbook of their life.

The most important thing is to do what feels right for you, when it feels right.

It might be reassuring to know that there are a number of charities and organisations that can offer support and information to your loved ones after you die. For example, Cruse Bereavement Care (page 38) has a network of free confidential services across the UK that provide emotional support to those who have been bereaved.

There are more organisations that might be able to help listed on pages 38-42.

"My sons didn't want to talk about it at first. They always joked that I'd live forever."

June, 86

Next steps

Your loved ones might find it useful to read our guides **Bereavement** and **When someone dies**. Macmillan Cancer Support has more information about memory boxes (page 40).

Treatment and care

You might be living with a long-term health condition, or you might just want to plan for your future health and care needs. Whatever your situation, having arrangements in place can reassure you that you'll receive the treatment and care you want.

Advance decisions

If there are medical treatments you wouldn't want to receive in certain circumstances, you can write them down in an 'advance decision' in case there ever comes a time when you lose the capacity to make or communicate decisions. It'll only be used if and when this happens.

An advance decision:

- must be clear about the circumstances under which you don't want to receive specified treatments
- is legally binding if it's valid and applicable – those caring for you must follow your instructions
- allows you to refuse treatment, including life-sustaining treatment
- can't be used to request certain treatment
- can't be used to refuse basic care that would keep you comfortable
- can't be used to ask for your life to be ended.

"I thought I was asking silly questions, but the doctor really put me at ease."

Pauline, 72

To make sure your wishes are respected, people must know that you've made an advance decision. It's a good idea to speak to your GP before you draw it up – your GP and medical team must know about your advance decision so that they can include it in your medical notes. They can also help explain possible treatments you may be offered and what it might mean if you choose not to have them.

Once you've decided what to do, write down your advance decision and give a copy to your loved ones and all those involved in your care. You can change it at any time – but make sure that you clearly communicate and record any changes you make.

In Northern Ireland, an advance decision isn't legally binding but should still be taken into account in decisions made about treatment.

Good to know

If you want to refuse potentially life-sustaining treatment, your decision must be made in writing, signed, witnessed and include the statement 'even if life is at risk as a result'.

How does an advance decision interact with an LPA?

If an advance decision and an LPA for health and care deal with the same decision, whichever was made more recently takes priority. If you create an advance decision after creating an LPA for health and care, your attorney can't consent on your behalf to any treatment refused in the advance decision.

If you've made an advance decision and want to create an LPA for health and care decisions, you'll need to include a copy of your advance decision when you send off your LPA to be registered. You should also refer to the advance decision in the instructions section of the LPA form.

Advance statements of wishes

You might also want to write an advance statement of wishes and preferences – especially if you're starting to need help with personal care. Although not legally binding, it allows you to set out general wishes about how you'd like to be cared for. These should be taken into account by those involved in providing your care if you ever lose the ability to make or communicate your own decisions.

Advance statements can explain your likes and dislikes and what's important to you. For example, you might include:

- where you'd ideally like to be cared for – your home, a care home or a hospice (pages 29-34)
- your dietary requirements
- your beliefs and values
- who you want to be consulted about your care
- who you'd like to visit you
- foods you like and dislike.

It's a good idea to give a copy to all those involved in your care, especially your care staff, GP and medical team, so they know what your wishes are and can take them into account.

Next steps

See our factsheet **Advance decisions, advance statements and living wills** for more information. Alzheimer's Society has a draft form you might like to use to help set up your advance decision (page 38).

Conversations with your GP and medical team

If you're diagnosed with a life-limiting illness, your doctor should explain your condition and treatment options in a way that you understand. If your GP or medical team use phrases you're not familiar with, make sure you ask them to clarify what they mean. We've included an explanation of some terms you may hear on pages 27-28.

The doctor should answer any questions you have about your condition or life expectancy. You can also discuss any questions, fears or worries you or your loved ones might have.

You can decide how much or how little information you want – it's OK if you don't want all the information at once. Write down any questions as they come to mind – and you might like to discuss them with family or friends. It can help to ask questions over several appointments so you can talk through your options at your own pace.

It might be useful to discuss:

- what to expect as your illness progresses
- the different ways to manage any symptoms you may experience
- the pros and cons of your treatment options
- any treatment you don't want to receive
- your life expectancy
- where you'd like to die
- the practical and emotional support available
- the physical and emotional changes you could experience.

These aren't easy conversations to have – so don't worry if you get upset. It can be hard for GPs and medical teams to know how best to start a conversation about end-of-life care too, so don't be afraid or embarrassed to ask questions.

All of this can be hard to take in, so ask the staff to repeat any information you need them to. You might find it useful to take notes and ask if there's anything helpful you can read or websites you can visit. You could also consider inviting a family member or friend to attend appointments with you to help you remember the information and offer emotional support.

Your doctor and healthcare team should be able to tell you about national and local support groups where you can discuss your thoughts and feelings freely. There might be options online or in person.

"My daughter came with me to important appointments. She was a huge support."

Irene, 84

Good to know

Depending on your condition, there might be a helpline staffed by specialist nurses and advisers to offer you practical advice and emotional support. For example, Macmillan Cancer Support (page 40) has a cancer support helpline and Alzheimer's Society (page 38) and Dementia UK (page 39) have helplines for people affected by dementia.

Terms you may hear

You may hear your medical team using terms you're not familiar with. They can seem confusing – but the following definitions should help.

Terminal illness means an illness that can't be cured – but some people with terminal illnesses live for quite some time. These illnesses may also be referred to as life-limiting.

End of life refers to what is likely to be the last 12 months of a person's life.

End-of-life care is care that focuses on the quality of a person's life and death, rather than length of life. It includes support for family and carers.

End-of-life care planning involves looking at issues that are particularly significant as people reach the end of life. It can include:

- having conversations with your medical team, family and friends, and spiritual or religious community about your options and choices
- sorting out legal and financial issues, such as making sure you have an up-to-date will and you're getting all the financial support you're entitled to
- exploring options to decide where you'd like to die
- planning your funeral
- thinking about practicalities, such as what will happen to your pets.

Advance care planning is a specific form of end-of-life planning. It involves thinking about how you'd like to be cared for in the future if you lose the ability to make decisions for yourself. Advance care planning can include:

- talking to your medical team about your condition and how you'd like to be cared for if you have an illness that's likely to get worse
- setting up an LPA (page 7) in which you give someone you trust the legal authority to make decisions on your behalf
- making an advance decision (page 21) to refuse certain treatments in specific circumstances
- making an advance statement of wishes and preferences, which tells those involved in your care how you'd like to be cared for (page 24).

Palliative care is support for people to achieve the best quality of life they can following a diagnosis of a terminal illness. It can be offered at any stage of an illness, and is designed to manage physical and emotional needs – as well as making life more comfortable as a condition progresses. Palliative care should be available in all hospitals, hospices, care homes and in your own home.

Hospices focus on providing palliative care either within hospice premises or in your own home.

Thinking about where you'd like to be looked after

It can be helpful to think about where you'd like to be cared for if you become unwell. Your choice may not be feasible – but if doctors and loved ones know your wishes, they can do their best to follow them as closely as they can.

Your GP and medical team will be able to tell you what you can expect as your illness progresses, what options are available in your local area, and what support you can get, especially at the end of your life. You may want to involve your family or carers so you can make a decision together.

Wherever you're cared for, the most important thing is that you receive the support you need to spend your final days in the most peaceful and dignified way. Your medical team should develop a care plan tailored to your needs and preferences, and review it as necessary.

In some parts of England, there are local registers that hold key information about the preferences of people nearing the end of life. Your GP or medical team should tell you if there's a local register and ask you if you want to be placed on it. The register can be accessed by authorised staff – including your GP, specialist palliative care team staff, out-of-hours GP service staff and paramedics. If you live in Wales, contact your GP, medical team or NHS 111 Wales to see if there are equivalent services in your area.

Good to know

If you're a carer, see pages 35-36 to find out what advice and support you could receive.

Care homes

Choosing the right care home is a big decision. There are independent regulators that inspect and monitor care homes and can provide impartial information about them.

In England, you can read care home inspection reports on the Care Quality Commission website (page 38). In Wales, visit the Care Inspectorate Wales website (page 38). In Northern Ireland, visit the Regulation and Quality Improvement Authority (page 42).

If you're in the process of choosing the right one for you, talk to the manager about their experience of supporting residents at the end of their lives. Ask whether staff have had special training, and what GP and community nursing support is available to allow you to die in familiar surroundings and avoid unnecessary hospital admissions. You might also want to ask if the local hospice provides support to care homes.

If you already live in a care home, you might want to ask whether it can offer you the care and support your doctors say you'll need in the last few weeks and days of your life.

If you currently live in a residential care home, you may need to move to a nursing home where nursing staff are on duty 24 hours a day. If you need to move, ask your medical team if you qualify for free NHS care on account of your health needs.

If your needs mean you have to move to a different care home, think about the practical considerations of the move. Will you still be near your family and friends? Will your doctor and healthcare team stay the same? Involve your medical team as well as your family, friends and carers so you're all comfortable with your future care.

Good to know

Continuing Healthcare (CHC) is a free NHS care package for people whose needs are primarily healthcare needs. You should be considered for a CHC assessment in a variety of circumstances, such as being discharged from hospital. If you have a condition that's progressing quickly and might be entering a terminal phase, your assessment can be fast-tracked. To find out more, go to **www.nhs.uk** and search 'continuing healthcare'. In Wales, visit **www.gov.wales**.

Search for care homes that are recognised as providing high quality end-of-life care in England on the Gold Standard Framework website (page 39).

See our guide **Care homes** and factsheet **NHS Continuing Healthcare and NHS-funded nursing care** for more information. In Wales, see Age Cymru's version of this factsheet.

Hospice care

Hospices specialise in supporting people with terminal illnesses, often from the point of diagnosis. You might hear this support referred to as palliative care. The range of services offered by the medical, nursing and other specialist staff can include management of pain and other symptoms, rehabilitation to help you achieve personal goals and priorities for daily living, emotional support, and complementary therapies. They can also offer family bereavement support and might help arrange remembrance events.

Hospice beds are rarely a long-term option for care and most hospice care is provided through day care or in your own home.

Hospices are often involved in supporting people who wish to remain at home through a mix of specialist services such as:

- short-term inpatient care to control symptoms
- hands-on care
- advice on pain management and other symptoms
- emergency advice lines and information
- emotional support and respite services.

Hospices take care of people's physical needs as well as their emotional, spiritual and social needs. They provide support for carers, family members and friends, both during a person's illness and after their death. Hospice care is free for everyone and can be offered in a range of settings, including hospices, care homes, people's own homes and through day services run at a hospice.

Some hospices have day services, such as medical and complementary treatments, the chance to meet other people going through similar experiences, or social and emotional support while you live at home.

You can be admitted to a hospice for different reasons. It could be for a few days while your symptoms are controlled, or for a period of respite care to give your carer a break. Some people are admitted to a hospice for the final stages of their life.

Speak to your GP and medical team to find out more about local hospice services in your area. If you want to find out more about what support is available from a specific hospice, you can ask to visit or talk to staff there.

Next steps

Visit Hospice UK's website (page 39) for further information on hospices and the type of services they offer. In Northern Ireland, contact Northern Ireland Hospice (page 41).

Care at home

You might prefer to be cared for at home towards the end of your life. Some people feel most comfortable in their home and find it makes it easier to say goodbye.

If you'd like to be cared for at home, talk it over with your GP and the people you live with to see how they feel about it and whether it's feasible. Find out what support could be available to help you and your carers. If you live alone, speak to your healthcare team to see what support would be available.

If you have social care needs too, the council may have a duty to provide care and support. The first step is asking the council for a needs assessment. See our **Getting help at home** guide for more information about this.

Your GP has overall responsibility for your care at home. They should put you in touch with organisations that can support you, talk you through what might happen as your condition progresses, prescribe medication, liaise with your consultant, and refer you to other doctors if necessary.

Your GP can arrange for you to be supported by a district nurse who then organises your healthcare at home. The district nurse or an occupational therapist can advise on how your home could accommodate any equipment you need – for example, a hoist. You may also receive help from Marie Curie and other specialist nurses or hospice home care services if you need it.

Hospice staff and hospital-based palliative care teams can work closely with GPs, community nurses and Marie Curie nurses (page 40) to coordinate your care. They're often involved in supporting people who wish to remain at home.

Advice and support for carers

If you look after a partner, friend or relative who needs help because they're ill or disabled, then you're a carer – even if you've never thought about yourself in that way before.

Caring for a friend or relative can be rewarding, but it can also feel overwhelming at times. This can be especially true if the person you're caring for is coming to the end of their life.

If you spend at least 35 hours a week caring, you might also be entitled to financial assistance, such as Carer's Allowance and the carer element in Universal Credit.

Ask your local council for a carer's assessment. You might be able to get support with caring, equipment to help you in your caring duties, or respite care to give you a bit of a break. In Northern Ireland, contact Age NI (page 37) for information on what to do.

It's important to tell your GP that you're a carer and discuss the impact that this has on your own health. They'll be able to offer you advice and discuss the support that's available. As a carer, you might also be entitled to a free annual flu jab and coronavirus booster.

Try not to overlook your emotional health. The practical help is handy – but there are limits to the care you can provide, so it's just as important to make time for yourself and make sure you don't neglect your own needs. Family and friends, carers' groups, online forums offered by organisations such as Carers UK, your GP or a counsellor can all provide you with space to share your feelings.

"Sometimes I get so caught up in the day-to-day caring, I don't stop and think about myself. It's helpful to talk to someone about it all."

Thomas, 78

Next steps

See our guides **Advice for carers**, **Carer's Allowance** and **Caring for someone with dementia** for information about the practical and emotional help and support you can receive.

Useful organisations

Age UK

We provide information and advice for people in later life through our Age UK Advice Line, publications and website.

Age UK Advice: 0800 169 65 65
Lines are open seven days a week from 8am to 7pm.
www.ageuk.org.uk

In Wales, contact Age Cymru Advice: **0300 303 44 98**
www.agecymru.org.uk

In Northern Ireland, contact Age NI: **0808 808 7575**
www.ageni.org

In Scotland, contact Age Scotland: **0800 124 4222**
www.agescotland.org.uk

Alzheimer's Society
Offers advice, information and support in England and Wales to people with dementia, their families and carers through its helpline and local offices.
Tel: **0333 150 3456**
www.alzheimers.org.uk

Care Inspectorate Wales (CIW)
National regulatory body of care and social services in Wales.
Tel: **0300 7900 126**
E-mail: **CIW@gov.wales**
www.careinspectorate.wales

Care Quality Commission (CQC)
National independent regulator of all health and social care services in England.
Tel: **03000 616161**
www.cqc.org.uk

Cats Protection
Can arrange for your cat to be looked after until they can find a suitable new owner through their Cat Guardians service.
Tel: **03000 12 12 12**
www.cats.org.uk

Cinnamon Trust
Charity for older people and their pets.
Tel: **01736 757 900**
www.cinnamon.org.uk

Cruse Bereavement Care
Offers information and support to bereaved people, over the phone and face to face.
Tel: **0808 808 1677**
www.cruse.org.uk

Dementia UK

Provides information for those affected by dementia, their family, friends and carers. They have a helpline staffed by Admiral Nurses who can offer advice and support.
Tel: **020 8036 5400**
Admiral Nurse Helpline: **0800 888 6678**
www.dementiauk.org

Digital Legacy Association

Helps people manage their digital legacy, ensuring end-of-life wishes are met both online and offline.
Tel: **020 3286 6812**
www.digitallegacyassociation.org

Dogs Trust

Can arrange for your dog to be looked after until they can find a suitable owner through their free Canine Care Card Scheme.
Tel: **020 7837 0006**
www.dogstrust.org.uk

Gold Standard Framework

Provides training for organisations providing end-of-life care. You can visit their website for a list of accredited care homes.
www.goldstandardsframework.org.uk

Hospice UK

National charity for hospice care, supporting more than 200 member organisations. Runs the Dying Matters campaign.
Tel: **020 7520 8200**
www.hospiceuk.org
www.dyingmatters.org

Law Society of England and Wales

Helps people find a solicitor, advises on what to expect when they visit one, and produces guides to common legal problems.
Tel: **020 7242 1222**
www.lawsociety.org.uk

In Northern Ireland, contact the **Law Society of Northern Ireland**
Tel: **028 9023 1614**
www.lawsoc-ni.org

Macmillan Cancer Support

Provides practical, medical and financial support for people with cancer and their carers and loved ones.
Tel: **0808 808 00 00**
www.macmillan.org.uk

Marie Curie

Provides care and support to people with a terminal illness and their carers and families.
Tel: **0800 090 2309**
www.mariecurie.org.uk

MoneyHelper

Provides information and guidance on money management.
Tel: **0800 138 7777**
www.moneyhelper.org.uk

National Association of Funeral Directors

Offers support and information about funerals in the UK.
Tel: **0121 711 1343**
www.nafd.org.uk

National Society of Allied and Independent Funeral Directors

Trade association for independent funeral directors offering arbitration if you cannot resolve a complaint with a member.
Tel: **0345 230 6777** or **01279 726 777**
www.saif.org.uk

Natural Death Centre

Provides information on all types of funerals.
Tel: **01962 712 690**
www.naturaldeath.org.uk

NHS

Find out about local NHS services in England and get information on end-of-life care.
www.nhs.uk

In Wales, contact **NHS 111 Wales**
www.111.wales.nhs.uk

In Northern Ireland, contact **NI Direct**
www.nidirect.gov.uk

Northern Ireland Hospice

Provides specialist hospice care in Northern Ireland.
Tel: **028 9078 1836**
www.nihospice.org

Office of the Public Guardian

Provides information and guidance on appointing a power of attorney or applying to the Court of Protection.
Tel: **0300 456 0300**
www.gov.uk/government/organisations/office-of-the-public-guardian

Regulation and Quality Improvement Authority

Independent regulator of health and social care in Northern Ireland.
Tel: **028 9536 1111**
www.rqia.org.uk

Turn2us

Helps people access the money available to them through welfare benefits, grants and other help.
Tel: **0808 802 2000**
www.turn2us.org.uk

Winston's Wish

Offers support, information and guidance to bereaved children, young people and their families.
Tel: **08088 020 021**
www.winstonswish.org.uk

Help us be there for someone else

We hope you found this guide helpful. When times are tough, it's so important to get some support. Did you know you could help us reach someone else who needs a little help? Here's how:

Give your views on guides like this

Our Readers' Panel helps make sure the information we produce is right for older people and their families. We'd love you to join. Go to **www.ageuk.org.uk/readers-panel**.

Donate to us

Every donation we receive helps us be there for someone when they need us. To make a donation, call us on **0800 169 8787** or go to **www.ageuk.org/donate**.

Volunteer with us

Our volunteers make an incredible difference to people's lives. Get involved by contacting your local Age UK or at **www.ageuk.org.uk/volunteer**.

Campaign with us

We campaign to make life better for older people, and rely on the help of our strong network of campaigners. Add your voice to our latest campaigns at **www.ageuk.org.uk/campaigns**.

Remember us in your will

A gift to Age UK in your will is a very special way of helping older people get expert support in the years to come. Find out more by calling **020 3033 1421** or visit **www.ageuk.org.uk/legacy**.

What should I do now?

You may want to read some of our relevant information guides and factsheets, such as:

- **Wills and estate planning**
- **Power of attorney**
- **Living with dementia**

You can order any of our guides or factsheets by giving our Advice Line a ring for free on **0800 169 65 65** (8am-7pm, 365 days a year).

Our friendly advisers are there to help answer any questions.

All of our publications are available in large print and audio formats.

There's plenty of really useful information on our website, too. Visit **www.ageuk.org.uk/planningahead** to get started.

If contact details for your local Age UK are not in the below box, call Age UK Advice free on **0800 169 65 65.**

0800 169 65 65
www.ageuk.org.uk

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