

Thinking about end of life



Getting your affairs in order and
thinking about your care needs

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 life can be difficult and we tend to not think about it until we have to. But being well informed can help you consider all your options, plan ahead and start getting your affairs in order.

Taking steps now can give you confidence that your wishes are documented and that people close to you know what you would want, if a time comes when you can no longer make your own decisions. Making plans now can make things easier for those close to you down the line. And, if you want to, you can always change your plans in the future.

Whether you're just planning ahead or have been diagnosed with a life-limiting illness, this guide can help you prepare.

“I’ve started getting my affairs in order so things are as simple as they can be if anything happens to me.”

Joe, 78



This guide explains some of the things you should think about when planning ahead, as well as options and services could be available to you if you’re diagnosed with a life-limiting illness. It explains how to make your wishes and treatment preferences known, and helps you consider where you would like to be looked after towards the end of your life.



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



You may have already put some plans in place, and there may be some things that you don’t feel ready to plan for yet. Planning for the end of your life is a very sensitive and personal experience, so pick out the sections in this guide that are relevant to you now and those you’d like to return to later.



Talking about death

It can be tempting to avoid talking about death, but having these conversations about what you want to happen when you die or if you're unable to make decisions for yourself in the future can save a lot of stress down the line. You'll know there's a plan in place, and your wishes are clear.

Conversations with family and friends

Talking about death with loved ones is difficult, 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 as you reach the end of your life.

Sharing your thoughts with those close to you can make it easier for them to make decisions in the future and help you all prepare for what may lie ahead. It can even provide an opportunity to tell people what they mean to you and may bring resolutions to difficult relationships.

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

- It's a good idea to choose a time and place where you won't be disturbed or rushed so that you feel you can say everything you want to.
- Give your family advance notice so the conversation doesn't take them by surprise.
- Don't feel obliged to try and cover everything in one conversation. It can take time to fully discuss all your wishes and you shouldn't try to rush this process.
- It might be worth writing notes beforehand about what you want to discuss. This will help you stay focused and make sure you cover everything you want to.
- Don't be embarrassed if you get emotional. Be honest and talk about all your feelings, not just the positive ones.
- It's not easy, but try not to be put off by family members who say they don't want to discuss these things.

Next steps



For leaflets on how to start conversations about dying, death and bereavement, contact Dying Matters (page 40) or visit the end of life pages on the NHS website (page 41). In Wales, visit the NHS Wales website (page 41).

Sometimes family and friends are reluctant to have these conversations because they don't want to think about your death, or they might be worried about saying the wrong thing. It might reassure them if you say it would help you to talk. Talking now also might make their life easier if a time comes when they need to make decisions for you. If they're still reluctant, try telling them they don't have to talk about it now, but it's something you would like to discuss at some point.

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

Talking to children and young adults

If you have children or young adults in the family, you may 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. Being honest about your emotions is a good way to let them know that it's OK to show your feelings.

Good to know

The Childhood Bereavement Network and Winston's Wish offer information and support for children and young adults affected by death (pages 38 and 42).

Dying Matters produces a leaflet called **What should you tell children about death** (page 40).

Thinking about your loved ones

Perhaps there are things you would like to share with people before you die, or maybe you want to create something to leave behind. Some people find it helpful to put together a memory box or scrapbook of their life.

It may help you to know that there are a number of charities and organisations which can offer support and information to your loved ones after you die.

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

Cruse Bereavement Care has a network of free confidential services across the UK that provide emotional support to those who have been bereaved (page 39).

“My sons didn’t want to talk about it at first, joking that I’d live forever.”

June, 86



Next steps



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

Practical considerations

Thinking about end of life can be emotional and a difficult topic to talk about. But there are plenty of practical things you can do to get your affairs in order. Getting your affairs in order now means you can feel confident that the care and support you receive in the future will be right for you.

Making a will

The first thing to think about when sorting your affairs is making sure you have an up to date will. Having a 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 online accounts after you die. If you've already made a will, take time to review it to ensure it still reflects your wishes.

If you die having not made a will, it can take much longer to deal with your estate, and the people who inherit your money and possessions may not necessarily be the people you would have chosen.

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

Next steps



Our guide **Wills and estate planning** has more information on the importance of making a will and how to go about drawing one up.

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 help if you're no longer able to make or communicate your decisions – what's known as having lost '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 lasting powers of attorney:

LPA for financial decisions

This can be used when you no longer wish to make decisions regarding your property and finances, or if you lose the capacity to make and communicate your decisions. It gives the person you nominate control of your finances and they can make decisions about:

- buying or selling property
- paying the mortgage
- investing money
- paying bills
- arranging repairs to your property.

“You never know what might happen, so I thought it was a good idea to arrange a power of attorney just in case I ever need it.”

Thomas, 78





LPA for health and care decisions

This allows you to give someone the authority to make decisions about your healthcare and personal welfare if there comes a time when you can't make these decisions yourself.

The person you nominate can make decisions about:

- your care
- 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.

Good to know

Planning ahead and setting up a power of attorney can be particularly helpful if you are diagnosed with dementia or are currently living with dementia and still have mental capacity. That way, if there comes a time you can't make your own decisions, someone you trust can make them for you.

Enduring powers of attorney

LPA's have replaced Enduring Powers of Attorney (EPAs) in England and Wales.

If you've already set up an EPA then it remains valid but only covers decisions about property and financial affairs. If you have an EPA then it's a good idea to think about setting up an LPA for health and care.

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

If you lose the ability to make or communicate decisions and you don't have an LPA, your family, friends or carer can apply to the Court of Protection for permission to make decisions on your behalf.

The Court can appoint someone (called a deputy) who is trustworthy and has the necessary skills, such as a relative or an independent professional deputy such as a solicitor. However, this is an expensive and often lengthy process so it's best to plan ahead and get an LPA in place while you can.

Next steps



The Office of the Public Guardian provides information and guidance on making an LPA or applying to the Court of Protection (page 42). Our guide **Powers of attorney** has more information about setting one up.



Managing your documents and accounts

It can be helpful to gather key documents and keep everything in a safe place, telling a family member or the executor of your will where they are. This makes things simpler for them later on.

Some of the key documents to gather are:

- your birth certificate
- passport
- driving licence
- bank account details and recent bank statements (list all your accounts and account details)
- pension plans
- insurance policies
- National Insurance number
- your will.

If you rely on the internet to pay bills, shop online or keep in touch with friends, you should think about what will happen to your digital legacy (your accounts and profiles etc) 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 may want some social media accounts to be deactivated, or you may want close friends or family to be able to recover sentimental items you have stored online, such as photographs.

If you have an online bank account, your executors can arrange for it to be closed down and claim the money on behalf of your estate. Don't leave details of your passwords or PIN numbers as someone using them after your death could be committing a criminal offence.

“I hadn't even thought what might happen to my Facebook page when I'm not around.”

Gary, 69



Next steps

Visit the Digital Legacy Association's website for further information about dealing with your digital legacy – online accounts such as email, social media and banking (page 39).

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

'I was diagnosed with a lung condition 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 I'm starting to notice there are some things I can't do as well as I used to.

'I had a couple of bad flare-ups recently and they've really taken it out of me, so I went back to see my GP. He explained that my symptoms would gradually get worse. I knew that deep down but I needed to hear it to start thinking about the future.

'I already had a will but I set up a lasting power of attorney for health and care so my close friend can make medical decisions if necessary about my treatment and care in the future. 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 tears, but it was reassuring for us both. I made a lasting power of attorney for my finances too. It takes the pressure off my friend 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

If you're living with a long-term health condition, or just 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 meet certain costs, such as care costs.

If you need help with 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 may even mean you become entitled to other benefits. Anyone who isn't expected to live longer than six months can claim them quickly and receive the benefit at the highest rate available. If you have a carer, make sure they check whether they're entitled to Carer's Allowance.

You may also be able to get financial help in the form of a one-off grant from charities that specialise in certain health conditions, 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 have a helpful booklet called **Help with the cost of cancer** (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 use our online calculator at www.ageuk.org.uk/benefitscheck.

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



Thinking about your funeral

Thinking about your funeral can be difficult, but giving it some thought and talking about what you would like, finding out about likely costs and putting some plans in place can reassure and make things easier for your family and friends. It also makes sure that your funeral reflects your wishes.

Some of the things you might like to think about include:

- where you'd like your funeral to be
- whether you want a burial or cremation
- whether you want a religious service or not
- who you'd like to be invited
- what songs or readings you would 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 communicate these wishes to your loved ones.

Paying for your funeral

Funerals can be very expensive so you may want to consider setting up a funeral pre-payment plan. These allow you to decide the type of funeral you want and pay for it in advance at today's prices. You can find out more information about these from a funeral director or the National Association of Funeral Directors (page 41). Make sure that you know which services are included in the price as this can vary.

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 at the crematorium. A commemorative ceremony can then be held at a time and place that suits friends and family.

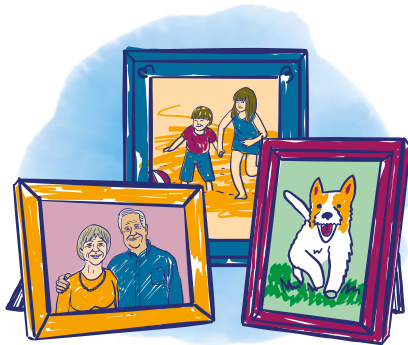
Next steps



To find a funeral director contact the National Association of Funeral Directors (page 41) or the National Society of Allied and Independent Funeral Directors (SAIF) (page 41).

If you would like to know more about 'green' funerals, contact the Natural Death Centre (page 41). Dying Matters produces **My funeral wishes**, where you can create your personal funeral plan (page 40).

See our factsheet **Planning for your funeral**.



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 may know someone who is happy to help but 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 where 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 it will be looked after until they can find a suitable new owner.

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

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

Treatment and care

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

Advance decisions to refuse treatment

If there are some 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 you can't communicate your wishes. This is legally binding and will only be used if you lose the capacity to make or communicate decisions.

To make sure your wishes are respected, people must know that you have 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 it down 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.

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

Pauline, 72



An advance decision:

- is legally binding – those caring for you must follow your instructions
- allows you to refuse treatment, including refusing life-sustaining treatment
- must be clear about the circumstances under which you don't want to receive specified 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.



In Northern Ireland an advance decision isn't legally binding but should 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 to any treatment refused in the advance decision.

If you have made an advance decision and want to create an LPA for health and care decisions, you'll need to send a copy of your advance decision with your LPA application form to identify any conflicts.



Next steps



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



Advance statement of wishes

You may also want to write an advance statement of wishes and preferences, especially if you're starting to need help with personal care. This allows you to make general statements about how you would 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 include anything that is important to you. For example, you might include information on:

- where you would 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 would like to visit you
- foods you do and don't like.

Although it's not legally binding, 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.

Conversations with your GP and medical team

If you are 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 maybe even discuss them with family or friends. It may help to ask questions over several appointments so that you can talk about your options at your own pace.

It might be useful to discuss the following topics:

- 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 would like to die.
- The practical and emotional support available.
- The physical and emotional changes you could experience.

These are not 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, 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, at any point. You may find it useful to take notes and ask if there is anything helpful you can read or websites you can visit. Also consider inviting a close 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 both national and local support groups, in person or online, where you can discuss your thoughts and feelings freely.

“My daughter came with me to important doctor’s appointments. She was a huge support.”

Irene, 84



Good to know



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

Terms you may hear

If you have a serious illness, you may hear your medical team using various terms. They can seem confusing but the following definitions should help.

Terminal refers to an illness that cannot be cured. They may also be referred to as life-limiting, but they're not necessarily imminently life-threatening.

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

End of life care focuses on the quality of a person's life and death, rather than the 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 and family and friends about your options and choices
- sorting out legal and financial issues, such as making sure you have an up-to-date will and are receiving all the financial support you're entitled to
- exploring the options to decide where you would like to die
- planning your funeral
- thinking of practicalities, such as what will happen to your pets.

Advance care planning is a specific form of end-of-life care 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 would like to be cared for if you have an illness that's likely to steadily get worse
- setting up a lasting power of attorney (page 11), in which you give someone you trust the legal authority to make decisions on your behalf
- making an advance decision to refuse certain treatment in specific circumstances, which is legally binding and must be followed by all those involved in your care
- making an advance statement of wishes and preferences, which tells those involved in your care how you would like to be cared for but isn't legally binding (page 24).

Palliative care support aims to help people achieve the best quality of life following a diagnosis of a life-limiting illness. It is designed to make life more comfortable as a condition progresses. A range of health professionals can be involved in palliative care and it should be available wherever someone is looked after. It may be appropriate at any stage of an illness, to support you and your family.

Hospices focus on providing palliative care, seeking to improve the quality of life of people with a terminal illness from diagnosis onwards, either within hospice premises or in your own home.

Considering where you would like to be looked after

It can be helpful to think about where you would like to be cared for if you become more unwell. Your choice may not be possible, but if doctors and loved ones know your wishes, they can do their best to follow them as best 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. It's important to involve your family or carers so you can make a decision together. Wherever you're cared for, the most important thing is 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 and update it as necessary.

In some areas 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 is 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 Direct Wales to see if there are equivalent services in your area.

Good to know



See the following pages for more information about where you may be looked after. If you are a carer, see page 35 to find out what advice and support you could receive.

Care at home

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

If you would 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. Find out what support could be available to help you and your carers during the day and at night. If you live alone, speak to your healthcare team to see what support would be available around the clock.

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 gets worse, prescribe medication, liaise with your consultant or refer you to other doctors if necessary.

Your GP can arrange for you to be supported by a district nurse who will organise and coordinate your healthcare at home. The district nurse or an occupational therapist can assess how easily your home can accommodate additional equipment that you might need. For example, you may need a hoist or a pressure-relieving mattress. They can advise on this and make necessary arrangements. You may also receive help from Marie Curie and other specialist nurses or hospice home care services if you need it (see page 41 for more information).

Many large hospitals have specialist palliative care teams, who work alongside and help hospital staff caring for people nearing the end of their life. They also work closely with local GPs, community palliative care services and hospices.

Hospice staff and hospital-based palliative care teams can work closely with GPs, community nurses and Marie Curie nurses to coordinate your care (page 41). They are often involved in supporting people who wish to remain at home. There's more information about hospice care on page 31.



Care from a hospice

Hospices specialise in supporting people with terminal illnesses, often from the point of diagnosis. You may hear this support referred to as palliative care. The range of services offered by their 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, and emotional support and services such as complementary therapies. They can also offer family bereavement support and may arrange remembrance events to celebrate the lives of people who have died.

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

Next steps

Visit Hospice UK's website (page 40) for further information on hospices and the type of services they offer. You can also read their booklet **What is hospice care?** In Northern Ireland, contact Northern Ireland Hospice (page 41).

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.

They 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 in bereavement. 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 and the chance to meet other people going through similar experiences, or provide social and emotional support while you live at home.

You can be admitted to a hospice for different reasons. It may 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 may be 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 local hospice, ask to visit the hospice or talk to staff before making a decision.



Care homes

If you live in a care home, you may wish 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.

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. Ask the manager if the local hospice provides support to care homes. You can also contact the hospice directly.

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 homes.



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

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 your needs mean the NHS should be responsible for funding your care.

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? Involving your medical team and family, friends and carers should mean that you are all comfortable with your future care.

Good to know



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



Advice and support for carers

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

Caring for a friend or relative can be rewarding, but at times it may also feel overwhelming and demanding. This can be especially true as the person you're caring for reaches the end of their life.

Next steps



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



Ask your local council for a carer's assessment. You may be able to get support with caring, equipment to help you in your caring duties or respite care to give you rest. In Northern Ireland, contact Age NI (page 37) to find out who to contact.

If you spend at least 35 hours a week caring, you may also be entitled to financial assistance, such as Carer's Allowance.

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

Don't 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 my emotions. It's helpful to talk to someone about it all.”

Rose, 70



Useful organisations

Age UK

We provide advice and information 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

Call Age UK Advice to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

In Wales, contact Age Cymru: **0800 022 3444**

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: **0300 222 1122**

www.alzheimers.org.uk

Care Inspectorate Wales (CIW)

National regulatory body of care and social services in Wales.

Tel: **0300 7900 126**

www.careinspectorate.wales

Care Quality Commission (CQC)

National, independent regulator of all health and social care services in England.

Tel: **03000 61 61 61**

www.cqc.org.uk

Cats Protection

Will 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

Childhood Bereavement Network

Offers support and advice for bereaved children, young people and their families.

Tel: **020 7843 6309**

www.childhoodbereavementnetwork.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, both over the phone and face to face.

Tel: **0808 808 1677**

www.cruse.org.uk

In Northern Ireland, contact **Cruse Bereavement Care Northern Ireland**

Tel: **0808 808 1677**

www.cruse.org.uk/northern-ireland

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 7697 4160** or **0800 888 6678** (Admiral Nurse helpline)

www.dementiauk.org

In Northern Ireland contact Dementia NI

Tel: **02896 931 555**

Digital Legacy Association

Helps people manage their digital legacy, ensuring end of life wishes are met in both the real world and digital realm.

Tel: **01525 630 349**

www.digitallegacyassociation.org

Dogs Trust

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

In Northern Ireland:

Tel: **028 2565 2977**

Dying Matters

Aims to help people talk more openly about dying, death and bereavement, and make plans for the end of life.

Tel: **08000 21 44 66**

www.dyingmatters.org

Includes an online directory of services at: **www.help.dyingmatters.org**

Gold Standard Framework

Provides a database of care homes that provide high quality end of life care.

www.goldstandardsframework.org.uk/accredited-care-homes

Hospice UK

The national charity for hospice care, supporting the work of more than 200 member organisations.

Tel: **020 7520 8200**

www.hospiceuk.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 7320 5650**

www.lawsociety.org.uk

Law Society of Northern Ireland

Tel: **028 9023 1614**

www.lawsoc-ni.org

Macmillan Cancer Support

Provides practical, medical and financial support for people facing cancer, their carers and loved ones.

Tel: **0808 808 0000**

www.macmillan.org.uk

Marie Curie

Provides care and support to people with a life-limiting illness, their carers and families.

Tel: **0800 090 2309**

www.mariecurie.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 Direct Wales**

Tel: **0845 4647**

www.nhsdirect.wales.nhs.uk

In Northern Ireland, contact **NI Direct**

www.nidirect.gov.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

This is a trade association for independent funeral directors and offers independent arbitration if you cannot resolve a complaint with a member.

Telephone **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

Northern Ireland Hospice

Tel: 028 90781836

www.nihospice.org

Office of the Public Guardian

Provides information and guidance on making 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 9051 7500

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:

1

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/publications/readers-panel.

2

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.

3

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.

4

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.

5

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 other relevant guides, such as:

- **Wills and estate planning**
- **Powers of attorney**
- **Living with early-stage 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 will also be able to help answer any questions you have about anything you've read.

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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