

Planning ahead

Thinking about your care and wishes ahead of time



Care and support
through terminal illness

Introduction

You may not feel like planning ahead when you're ill, but it can help you to feel more in control if you do. It can also help those close to you handle your affairs if you aren't able to.

This booklet has information about some of the things you might want to think about, like deciding where and how you want to be cared for or making a Will. It doesn't have to be read from start to finish, and you can dip in and out or even skip some sections if you don't feel ready to read them.

You might like to read this alongside *Living with a terminal illness*, which has more information on coping with your feelings and help with day-to-day living.



You can learn more about planning ahead at mariecurie.org.uk/help or by calling the Marie Curie Support Line **0800 090 2309***.

Contents

Choosing where to be cared for	6
Care at home	6
Hospice care	6
Hospital care	8
Care homes	8
Nursing homes	8
Planning your care in advance	9
What is advance care planning?	9
What does advance care planning involve?	10
Does advance care planning guarantee my choices will happen?	10
Refusing treatment	12
Naming people who should be consulted about your care	13
Making your advance care plan	13
Setting up a Power of Attorney	15
Types of Power of Attorney	15
Choosing your attorney	17
Mental capacity and making decisions	18
Mental Capacity Act 2005 (England and Wales)	18
How it's decided whether someone has mental capacity	19
Making decisions on someone else's behalf	20
If you live in Northern Ireland or Scotland	22
Making a Will	23
How to make a Will	23
Who will inherit?	24

Protecting or sharing your online accounts	25
Managing your digital property	26
Planning your own funeral	30
Making your wishes known	30
Rehoming your pet	31
When to rehome	31
Information about your pet	31
How we can help	34
Useful organisations	36
Health information	36
Financial, legal and practical support	39
Pet rehoming	41
Further information	42

Choosing where to be cared for

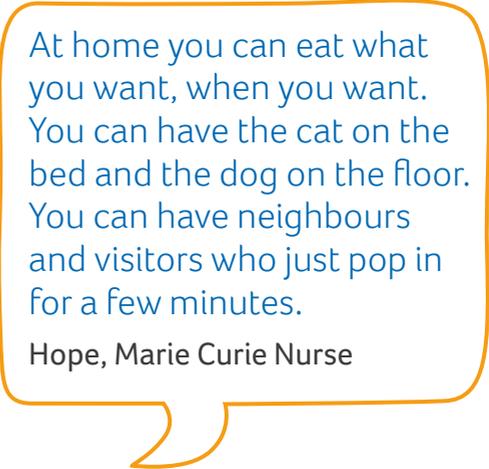
For many people, deciding where and how you would like to be cared for when you're ill is one of the most important decisions you can make.

Care at home

Many people prefer to be cared for at home surrounded by family and friends. If you wish to remain at home, speak to your GP about what can be arranged. It's likely that a district or community nurse will organise and coordinate your home care. Your GP may also arrange for specialist palliative care professionals to support you at home.

Hospice care

Hospices are smaller and have a different atmosphere to hospitals, making them feel more like someone's home. They provide free, tailored care that's suited to your needs. They are usually run by a team of doctors, nurses, social workers, counsellors and trained volunteers.



At home you can eat what you want, when you want. You can have the cat on the bed and the dog on the floor. You can have neighbours and visitors who just pop in for a few minutes.

Hope, Marie Curie Nurse

If you're unsure whether hospice care is right for you, or you want to find out more about what hospice services are available in your area, speak to your GP or district nurse.

There are nine Marie Curie Hospices around the UK. Visit mariecurie.org.uk/hospices to see our locations. Hospice UK (see page 37) can also help you to find a hospice near you.



Kieran Dodds/Marie Curie

Hospital care

If you have troublesome symptoms, your doctor or nurse may refer you to hospital. Decisions around your care could be made by staff in A&E (accident and emergency) at the point of admission, but many hospitals also have specialised palliative care units.

Care homes

You may choose to be cared for in a care home (sometimes called a residential home) if you can no longer manage in your own home. Care homes usually offer long-stay care, but they may also offer short-stay or respite care to support those caring for you.

Nursing homes

Some care homes provide skilled nursing care to residents when they need it. These are sometimes called nursing homes. If your condition means you need nursing care on a frequent basis, then this type of home may be more suitable.



To find out more about where you could be cared for, visit our website at mariecurie.org.uk/planningahead or call the Marie Curie Support Line on **0800 090 2309***.

Who can help?

Your GP, Marie Curie Nurse or district nurse will be able to help you with choosing where to be cared for. You can also contact a hospice for more about their services, although you'll need a referral to stay there.

Planning your care in advance

If you have specific wishes about your future care, it's a good idea to discuss these with your carer, family and doctor or nurse. You could also put them down in writing so people have a clear understanding of what you want. This discussion about your future care, including any resulting decisions, is called **advance care planning**.

There are a few differences in how advance care plans and decisions can be made and applied in the four different nations in the UK. These are highlighted below.

What is advance care planning?

Advance care planning is about thinking ahead and talking to the people involved in your care, such as your family, doctors or nurses. It's also referred to as an **advance directive** or **advance statement** or, in Scotland, **anticipatory care planning**. It's a process which allows you to express your preferences about the care you'd like to receive, including:

- what you want to happen
- what you don't want to happen
- who will speak on your behalf

Advance care planning is an entirely voluntary process and you shouldn't feel any pressure to include anything you're not comfortable with. You can change your mind about anything you put in your advance care plan at any time. This is fairly common; up to one third of people make changes to their advance care plan.

What does advance care planning involve?

Advance care planning includes anything to do with your future care.

For example:

- Where would you like to be looked after, such as at your home, in hospital, a nursing home or hospice?
- Where would you like to be at the end of your life and who you would like to be with you?
- Are there any spiritual or religious beliefs you would like taken into account in your care?
- Who should be consulted if you become unable to make decisions later in your care? (This isn't the same as appointing a legal Power of Attorney, see page 15 for more information).
- What are your views on particular treatments or types of care?
- How you would like practical matters dealt with, such as the care of a pet? (See page 31 for more on pets).

Advance care planning can happen at any time – talk to your carer or someone close to you. You may also find it helpful to get some advice from healthcare professionals to help you understand your options. It doesn't have to be in writing unless you're making an advance decision to refuse treatment (see page 12). However, you may find that writing your wishes down makes it easier for people to understand and stick to them.

Does advance care planning guarantee my choices will happen?

While every effort will be made to follow your advance care plan, it won't always be possible to have your choices guaranteed. However advance care planning ensures your wishes will always be taken into account. The only part of an advance care plan that is legally binding is an advance decision to refuse treatment, and even then some conditions still apply.



Layton Thompson/Marie Curie

Refusing treatment

As part of your advance care plan, you're entitled to say whether there are particular treatments you don't want to have. This is in case you become unable to make your own decisions in future. This is called making an **advance decision to refuse treatment** (also called a Living Will). It means your wishes about that particular treatment should be followed.

If you choose to make an advance decision to refuse treatment, you'll need to state which treatments you wish to refuse and in what circumstances your refusal will apply. This is important as there may be circumstances in which you'd like a particular treatment but not in others.

If you wish, you can refuse treatment that could potentially keep you alive (known as life sustaining treatment), such as a mechanical ventilator to help you breathe. If you want to refuse life sustaining treatment in future, you'll need to make sure the decision is:

- written down
- signed by you
- signed by a witness
- includes the statement "even if life is at risk as a result"

If you think you may want to refuse certain types of treatments in future, you may want to discuss the options with a doctor or nurse who knows your medical history.

An advance decision to refuse treatment is legally binding in England and Wales but only when the circumstances are appropriate, for example, if it's assessed that a patient has deteriorated and is in the last days of life. This isn't officially the case in Scotland or Northern Ireland, but is likely to be considered legally binding by a court (under common law).

Naming people who should be consulted about your care

Within your advance care plan you can name a person or people who you would like to be consulted if you become unable to make decisions about your care. These people can help express your wishes and feelings to enable healthcare professionals to act in your best interest. However, they cannot make decisions on your behalf.

If you do wish to nominate someone to make decisions for you, you will need to grant them legal authority to do so by making them your attorney. If you've granted someone a Power of Attorney, remember to mention this in your advance care plan. You can find out more about Power of Attorney on page 15.

Making your advance care plan

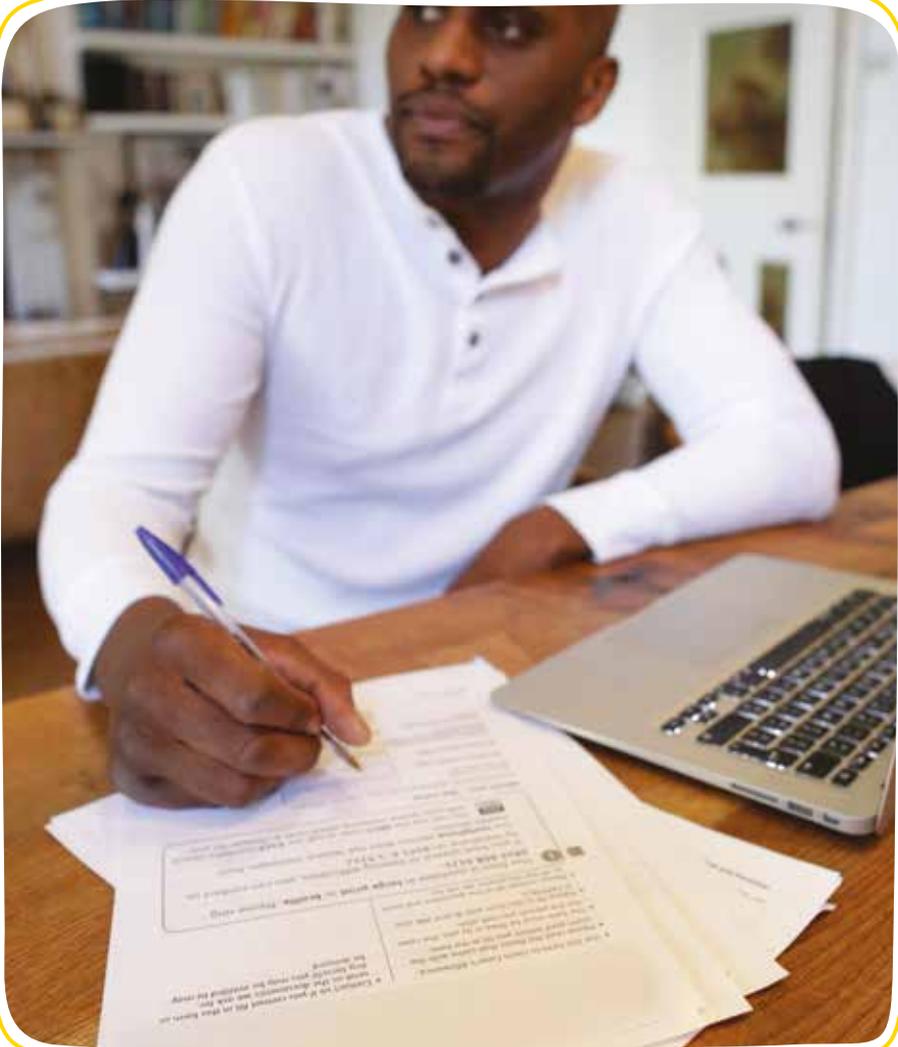
Your nurse or doctor may be able to give you forms that you can use to set out your advance care plan.

Once you've decided what to have in your plan, give a copy of any paperwork to the professionals involved in your care. Give a copy to your family members or friends as well – or tell them that you've recorded your wishes. This helps to ensure that people around you can act in your best interest.

If your health changes significantly you may find it useful to review your existing paperwork. It's also a good idea to do this on a regular basis even if there are no changes, just to make sure it still reflects your wishes. Remember, you can change your plan at any time.

Who can help?

You can speak to your GP or nurse about how you would like to be cared for. For legal matters, like Power of Attorney, you should consult a solicitor. You may also want to involve friends, family and carers so they're aware of your wishes.



Layton Thompson/Marie Curie

Setting up a Power of Attorney

Taking care of legal matters can be complex but help is available. It can help to plan ahead so you can get on with doing the things that you enjoy, like being with family and friends.

Types of Power of Attorney

There are three different types of Power of Attorney that can be used to manage your financial affairs and welfare.

An ordinary Power of Attorney (general Power of Attorney in Scotland and Northern Ireland)

This lets you transfer control of your affairs temporarily. It can cover all your financial affairs or just some aspects of them. You must have mental capacity (the ability to make this decision, see page 18 for more) to set one up. The power automatically stops if you lose capacity.

How to set up an ordinary Power of Attorney

The wording should be precise, so it's best to ask a solicitor or other legal expert, for example, at a local Citizens Advice Bureau (page 39), to draw up the document for you. The cost of a solicitor can vary, so it's worth contacting a few to compare prices. There are organisations that can help you find legal advice in your area on pages 39-40.

Lasting Power of Attorney for property and financial affairs (continuing Power of Attorney in Scotland and lasting Power of Attorney in Northern Ireland)

A lasting Power of Attorney allows you to give another person the right to make certain decisions about your affairs, your property and/or your welfare if you become unable to.

You must have mental capacity (see page 18) when you create it. You must register the Power of Attorney before the person acting for you (your attorney) can use it.

Lasting Power of Attorney for health and welfare (welfare Power of Attorney in Scotland)

In England, Wales and Scotland (but not Northern Ireland), there is a second type of lasting Power of Attorney. This gives someone else the right to take decisions about your healthcare and other aspects of your welfare, if you don't have the capacity to make these decisions yourself. It also allows them to access your health records.

There is currently no equivalent to a welfare Power of Attorney in Northern Ireland.

How to set up a lasting Power of Attorney

The government publishes the forms and guidance you need to set up a lasting Power of Attorney or its equivalent in Scotland and Northern Ireland. Letting someone else control your financial and legal affairs is an important decision, so you may want to get advice from a solicitor.

Choosing your attorney

Choose someone you trust completely and who understands you well. They'll have a duty to always act in your best interests.

Most people choose a family member – their husband, wife, partner, son or daughter (as long as they're 18 or older). Check that they're happy to take on this role. You'll also need to tell any other interested parties about what you're doing. Interested parties are family or friends who might be affected by your decision.

You can also appoint a firm – for example, a bank or solicitor – as your attorney, but it will charge a fee for this.



Visit our website for more information about planning ahead at mariecurie.org.uk/planningahead or contact the Marie Curie Support Line on **0800 090 2309***.

Who can help?

Citizens Advice can give you free information about Power of Attorney, including how to set one up. You may also want to consult a solicitor (see pages 39-40).

Mental capacity and making decisions

Mental capacity relates to a person's ability to understand and make decisions. Someone may lack mental capacity because of their health or a disability. People living with a terminal illness, and those close to them, may find they need to prepare for this possibility.

Mental Capacity Act 2005 (England and Wales)

The Mental Capacity Act 2005 is designed to protect people aged 16 and over who live in England and Wales. It applies in situations where someone is believed to lack mental capacity (the ability) to understand and make decisions. This could be because of a mental health condition (for example, dementia) or a severe learning disability, brain injury, stroke or being given end-of-life sedation.

The Mental Capacity Act doesn't apply to people living in Northern Ireland and Scotland, although some of the practical steps are similar.

The Mental Capacity Act protects people by enabling them to make as many decisions as they can for themselves, including decisions about their personal welfare, medical treatment or property. It also allows these decisions to be made on their behalf, and protects carers from being taken to court if something goes wrong while they've honestly and reasonably tried to act in the best interests of the person they look after. It also ensures that the person's local health body or council supports them to make decisions about serious medical treatment or moving to a care home when there are no family or friends available.

About mental capacity

Under the Mental Capacity Act a person should be supported to make their own decisions as much as possible. Many people with dementia, for example, are able to make decisions with the right support and encouragement.

Mental capacity can vary from day to day, and issue to issue. It can also vary according to the type and importance of the decision being taken. A person might be able to decide that they want to live at home (not a care home), but not be able to decide what to do about their Will.

Someone can only take decisions on another person's behalf if that person has been assessed as lacking capacity. Even then, someone can only make those decisions that the person assessed as lacking capacity can't make for themselves. For example, if they're able to decide that they want to live at home, their wishes should be followed, even if they lack capacity to make a Will.

All practical steps to help a person to make a decision must have been taken without success, before someone else can make a decision on their behalf. Practical steps might include involving an advocate or ensuring written information is made more accessible. Mental capacity is not based on the ability to make a wise or sensible decision.

How it's decided whether someone has mental capacity

Providers of services and their staff are required by law to assume that a person is capable. They must offer any support that may help the person to make a decision.

If a person is still unable to make a decision, a capacity assessment will be carried out by a healthcare professional. They will assess whether that person is able to make a specific decision, which includes:

- being able to understand the information relevant to the decision
- retain that information and use or weigh up that information to make a decision

If the person can't do any of these things, or they're unable to communicate their decision, they'll be treated as not having mental capacity to make that specific decision.

If it's felt that they don't have capacity for a particular decision, their health professionals will need to carefully consider what's in the person's best interests. They'll also need to consider anything that the person has said before and the views of relatives and friends. A person's wishes should be taken into account as much as possible.

Making decisions on someone else's behalf

If it's decided that a person lacks mental capacity, two possible ways for someone else to make decisions for them are:

- where they've previously been granted Power of Attorney (see page 15), which can now be put into effect
- where they apply to the Court of Protection for a decision to be made on a particular matter and, if there's a continuing need to make decisions on the person's behalf, they ask the Court of Protection to appoint them as the person's deputy

If there's nobody with Power of Attorney and no friend or relative who is suitable or willing to act, the possibilities include the following:

- If an NHS body has to decide whether someone needs medical treatment or a local council has to decide if someone should enter a care home, it can arrange for the person to have an independent mental capacity advocate.
- The Court of Protection can appoint a professional deputy.

Independent mental capacity advocate

If someone lacks mental capacity and an NHS body has to decide whether they need medical treatment, or a local council has to decide if they should enter a care home, it can arrange for the person who is lacking capacity to have an independent mental capacity advocate (IMCA). The NHS body or council has to arrange one if there's no one else, such as a family member or friend, available instead.

Being a deputy for someone who lacks mental capacity

It's possible to apply to become someone's deputy if they lack mental capacity. A deputy is usually a family member or someone who knows the person well. A deputy is appointed by and authorised by the Court of Protection to make decisions on the person's behalf in one or both of these areas:

- property and financial affairs, for example paying bills or organising a pension
- health and welfare, for example making decisions about medical treatment and how someone is looked after

Health and welfare deputyships are much rarer than property and financial deputyships, and the Court of Protection will usually only grant these in exceptional circumstances.

If there's no friend or family member who is suitable or willing to act, the Court of Protection can appoint a deputy from a panel of approved professionals.

If you live in Northern Ireland or Scotland

The Mental Capacity Act doesn't apply if you live in Northern Ireland or Scotland, but some of the processes are similar.

Northern Ireland

In Northern Ireland the test to decide if a person has mental capacity involves asking these questions:

- Can the person understand and retain information about their treatment?
- Does the person believe that information?
- Can the person assess the information, balancing risks and needs, to make a decision?

A draft Mental Capacity Bill for Northern Ireland is currently being reviewed by parliament, so the law may change.

Scotland

Scotland has its own mental capacity legislation called the Adults with Incapacity (Scotland) Act. It allows you to give someone else a Power of Attorney and to make an advance decision to refuse medical treatment (see page 12). For more information about mental capacity in Scotland, visit mariecurie.org.uk/help or call us on **0800 090 2309***.

For more details about the Adults with Incapacity (Scotland) Act visit the Compassion in Dying website (see page 36).

Who can help?

A GP, social worker or independent mental capacity advocate (IMCA) will be able to tell you more about mental capacity.



Layton Thompson/Marie Curie

Making a Will

Most people leave behind assets and possessions when they die and with a Will, you know that they'll be passed onto family, friends or charities that you choose. A Will can also help to prevent disagreements about who inherits what.

How to make a Will

It's a good idea to ask a legal professional to draw up the Will. They can ensure all the information and the correct clauses are included. This also helps you to avoid problems, such as someone you'd intended to inherit not getting anything because they were also a witness when you signed your Will. You can find out more by visiting mariecurie.org.uk/makingawill

Many charities offer a Will writing service. You should not be under any pressure to leave anything to the charity, but you might want to.

Who will inherit?

If you haven't made a Will, the law decides who will inherit your assets and possessions when you die.

The rules in Scotland and Northern Ireland are different from those in England and Wales, but in all four nations, the law aims to protect your husband, wife or civil partner and any children, including any adopted children. The law doesn't protect unmarried partners or step-children.



Marie Curie also has legacy advisers who can help you with making a Will. Visit mariecurie.org.uk/help or call the Marie Curie Support Line on **0800 090 2309*** for more details.

Who can help?

You can create a basic Will yourself but it's far better to get advice from a solicitor, independent financial adviser (IFA) or professional Will writer. Many charities, including Marie Curie and Citizens Advice, can help you with your Will.

Protecting or sharing your online accounts

Most people have dozens of passwords and accounts on various websites, especially on social media. But the idea of protecting these is still quite new in legal terms. You might decide that you don't want anyone looking at your social media pages after your death, and ask for them to be deleted. Or you might want to keep important emails or allow people to look at sentimental items like photos on Facebook.

If you don't plan for your online accounts in your Will, it could be difficult for your executors to follow your wishes. There aren't any



Layton Thompson/Marie Currie

Planning ahead

laws guaranteeing friends and family access to email accounts like Gmail or social media accounts like Facebook. Even with permission, it could take months to access your data without a password.

If you're not sure how to manage your online accounts, you might like to ask a friend or relative to help you.

Managing your digital property

Step one: create a document with all of your login and account details

The document could include details about:

- Music and other media subscriptions (Netflix, Spotify, newspaper subscriptions, online games).
- Social media (Facebook, Twitter, Pinterest).
- Professional sites (LinkedIn, Google Apps, Adobe).
- Email (Gmail, Hotmail).
- Cloud storage services (Dropbox, Apple cloud).
- Online shopping (Amazon, eBay).
- Smartphone or tablet applications.
- Accounts on the websites of utility or mobile network providers.

Online banking

Bank accounts are covered by probate so they will be managed in due course. It's up to you whether you include your online banking login on the file. If you write the details down and the account is accessed without your permission, the bank may refuse to compensate you for any damage. However, you may want to share Paypal account details (if you have one) so that people can transfer any remaining funds held in it to your bank account.

Remembering your passwords

It's quite common to forget your passwords. You may want to go through each of your online accounts and make a note of any passwords you need to reset in your document. You can then protect this document with a password (this is also known as encrypting) so you only have one password to remember to access all your online details. Most word processing and spreadsheet software, like Microsoft Word, Excel or Open Office, can encrypt documents.

Write this password down somewhere safe and give it to someone you trust. You may want to appoint a **social media executor** to look after all your online accounts after your death. You can name this person in your Will. They may be a different person to your normal executor, for example, someone who is more comfortable doing things online.

If you're worried about being able to manage these accounts while you're alive, you might consider naming the social media executor in your Power of Attorney (see page 15) if you have one.

Step two: decide what to do with each account

Memorialise

Facebook allows accounts to be memorialised. This means your timeline and any pictures will continue to be visible to existing friends and family. You can also appoint a legacy contact to look after your account after its memorialised. They will be able to update your profile, pin notices on your timeline and respond to new friend requests. You can add a legacy contact by following the instructions under the security settings tab.

If you don't have a legacy contact

If you haven't selected a legacy contact in advance, a friend or family

Planning ahead

member (or executor) will need to submit a request online, providing a link to proof of death online, if possible. This could be an online obituary, or a scan of the death certificate you've saved in an online folder like Dropbox.

Facebook will make sure no one can change any of the account details such as adding or deleting friends, but people will still be able to post dedications on the timeline. Facebook won't provide anyone with login information for a memorialised account. In some rare circumstances, however, it might be able to provide some data, like photographs, as long as the person applying can prove that they have permission to access it. This could be with a copy of the Will, naming them as executor.

Memorialising an account also means that there'll be no status updates or birthday reminders appearing in other people's timelines, which could be upsetting for friends and family once you're gone.

It can take Facebook several months to review memorialisation requests.

Deactivate

This keeps all the account information stored with the company in case anyone needs to access it in future, but removes it from the public domain. Your executor will need to provide a copy of the death certificate as well as proof that they have permission to access your accounts if they want to access any information after your death.

Email accounts like Gmail or Hotmail may come under this category as old emails might contain information that becomes important at a later date. Similarly, some online game accounts can be deactivated, but never permanently deleted.

Delete

If you want to ensure that no traces of the account are left online, you can delete your accounts. Be aware that if you do this with Facebook, all your pictures will be deleted as well.

It may be a good idea to delete any shopping accounts, such as Amazon, as they will often store payment details, such as credit and debit card numbers.

Step three: leave clear instructions about your wishes

It can take many months to access online accounts when someone has died, even if the person applying is an executor, so it's best to plan ahead.

Even if you give someone your passwords they might still be prevented from legally accessing your accounts according to the terms and conditions of a site.

Leaving clear instructions about your online accounts should make your intentions about your digital property clear. Ask a legal professional for advice on how to do this. You may want to leave instructions in a side letter rather than in the formal Will. This is because after your death the Will becomes public information so any login details could be seen by others.

Find a solicitor

If you'd like advice about creating a social media Will see pages 39-40 for a list of solicitors. You might like to ask whether they're accredited under the Law Society's Wills and Inheritance Quality Scheme Protocol (WIQS). This is an accreditation open to solicitors with three or more years' experience which includes digital assets in its guidelines.

Planning your own funeral

Although it may be uncomfortable, planning your own funeral is becoming more common and can relieve family and friends of difficult decisions at a stressful time. It can also help you come to terms with your own mortality as well as helping family and friends celebrate your life in the way you would prefer.

Making your wishes known

An easy way to make your wishes known is simply to write them in your Will, although this is the only part of a Will that is not binding. You should also make a separate copy of your wishes in case the Will is discovered too late to organise your funeral.

You might also want to speak to an independent financial adviser to ensure there is enough money to pay for the funeral.



For more information on planning and paying for a funeral, see mariecurie.org.uk/funeralplanning or contact the Marie Curie Support Line on **0800 090 2309*** for more information.

Who can help?

A funeral director will be able to give you information on planning your own funeral. A solicitor can help with expressing your wishes in a Will.

Rehoming your pet

Planning for your pet's future without you may make you feel sad, but it can also be reassuring to know that you've made the best arrangements for them.

When to rehome

If you're no longer able to look after your pet on your own, your family and friends might be able to help. If you're staying in a hospice, your pet might still be allowed to visit. You could also try a dog-walking service if you can't go out.

Rehoming your pet can be extremely upsetting but you're making a brave decision. You're only doing it because you care about your pet and want what's best for them.

Information about your pet

It can help to start gathering information about your pet and keeping it in a safe place so that you, or a friend or relative have everything to hand when it's needed. This could include your pet's vet records, details of when they were neutered, the date of their last vaccinations and any medicine they've been prescribed.

If they've been microchipped, write down their microchip number and instructions on how to update the details. Also include details of any pet insurance you've taken out. You could also write down some notes about your pet's preferred food and what they like doing, like fetching a ball or chasing string.



Layton Thompson/Marie Curie

Who can help?

If family and friends are unable to look after your pet, organisations like Blue Cross and the Cinnamon Trust can give you advice and rehome animals with loving and responsible new owners. Your vet can also give you advice. See page 41 for more organisations and their contact details.

How we can help

We help everyone affected by a terminal illness get the information and support they need, whether you have an illness yourself or you're a family member or friend.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Open 8am to 6pm Monday to Friday, 11am to 5pm Saturday. * Your call may be recorded for training and monitoring purposes.

Marie Curie Community

community.mariecurie.org.uk

For anyone affected by terminal illness to share experiences and support each other. Available 24 hours a day.

More information and further support

We also have an extensive range of information materials available to view online or in print. Visit **mariecurie.org.uk/help** where you can also find film guides, information about our services, and links to further support.

Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.

mariecurie.org.uk/nurses

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day.

mariecurie.org.uk/hospices

Marie Curie Helper

We know the little things can make a big difference when you're living with a terminal illness. That's where our trained Helper volunteers come in. They can visit you regularly to have a chat to over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

mariecurie.org.uk/helper

Useful organisations

Health information

Alzheimer's Society

0300 222 11 22

alzheimers.org.uk

Works to improve quality of life for people affected by dementia. Its website includes guidance on diagnosis, symptoms and care for people living with Alzheimer's, information on local services and support groups.

Compassion in Dying

0800 999 2434

compassionindying.org.uk

Help with making decisions about your healthcare, understanding your rights and advance planning.

Dementia UK

0845 257 9406

dementiauk.org

Committed to improving quality of life for all people affected by dementia. Its website includes information about the condition and where carers can get support.

Health and Care Professions Council

0845 300 6184

hcpc-uk.org/check

Check whether a healthcare professional is registered to practice across the UK. This doesn't apply for social workers.

Healthtalk.org

healthtalk.org

A website with information on a range of illnesses, with a focus on people's real-life experiences. Includes a forum where you can talk to other people in similar situations.

Hospice UK

020 7520 8200

hospiceuk.org

A UK and international directory of hospice and palliative care, plus other information for people with a terminal illness.

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

Provides practical, medical and financial support for people affected by cancer.

Multiple Sclerosis (MS) Society

0808 800 8000

mssociety.org.uk

Gives grants and provides information and support to people affected by multiple sclerosis.

Motor Neurone Disease (MND) Association

08457 626 262

mindassociation.org

Care, research, campaigning and information about motor neurone disease in England, Wales and Northern Ireland. Its website includes the latest research, as well as guidance on getting support.

Motor Neurone Disease (MND) Scotland

0141 945 1077

mndscotland.org.uk

Provides care and support to people affected by motor neurone disease in Scotland. It also provides information and education services to healthcare professionals and funds research.

MIND

0300 123 3393 (text 86463)

mind.org.uk

Provides information and support for a range of mental health problems.

Parkinson's UK

0808 800 0303 (textphone 18001 0808 800 0303)

parkinsons.org.uk

Gives information and support to people living with Parkinson's disease through its website and helpline.

Social Care Institute for Excellence

020 7535 0900

scie.org.uk

Works to improve the lives of people using care services in the UK. It can also help you with finding an independent mental capacity advocate (IMCA) in Wales and England.

Scope

0808 800 3333

scope.org.uk

Information and support for anyone with a learning disability or physical impairment.

Stroke Association

0303 3033 100

stroke.org.uk

Up-to-date information in audio format for people who have had a stroke, and their families and carers. It also offers has a directory of local services on its website.

Financial, legal and practical support

Citizens Advice

03454 04 05 06 / 03454 04 05 05 (Welsh)

adviceguide.org.uk

The Adviceguide website is the main public information service of Citizens Advice Bureau, providing 24/7 access to information on your rights, including benefits, housing and employment, and on debt, consumer and legal issues. Search the site for your nearest bureau in England, Wales, Scotland and Northern Ireland.

Court of Protection (England and Wales)

0300 456 4600

gov.uk/court-of-protection

The Court of Protection makes decisions on issues affecting people who lack mental capacity.

Law Society (England and Wales)

020 7320 5650

lawsociety.org.uk

Find a solicitor in England and Wales.

Law Society Scotland

0131 226 7411

lawscot.org.uk

Find a solicitor in Scotland.

Law Society Northern Ireland

028 9023 1614

lawsoc-ni.org

Find a solicitor in Northern Ireland.

Office of Care and Protection (Northern Ireland)

courtsni.gov.uk

The Office of Care and Protection (Northern Ireland) supervises people who have been appointed to manage the finances or property of adults who can no longer do so for themselves. It can help if you need to make a lasting Power of Attorney and can't find what you need online.

Office of the Public Guardian (Scotland)

01324 678 301

publicguardian-scotland.gov.uk

It has a responsibility in Scotland to supervise people appointed to make financial or property decisions on behalf of an incapable adult. It also registers continuing or welfare powers of attorney under the terms of the Adults with Incapacity (Scotland) Act 2000.

Society of Will writers

01522 687 888

thesocietyofwillwriters.co.uk

Information and advice about legislation for Wills and Power of Attorney in the UK from a self-regulatory, not-for-profit body. It can help you find a Will-writer in the UK.

Pet rehoming

7th Heaven Animal Rescue Trust

02894 432229

7thheaven.org.uk

Information about pet rehoming in Northern Ireland.

Blue Cross

0300 777 1897

bluecross.org.uk

Offers advice on rehoming your pet, with rehoming centres in England and Wales.

The Cinnamon Trust

01736 757 900

cinnamon.org.uk

UK-wide charity for people in their last years and their pets.

A network of volunteers provides practical pet care services and fostering is also available for long hospital stays.

Scottish SPCA

03000 999 999

scottishspca.org/rehoming/centres

Information about rehoming pets in Scotland, including rehoming centre contact details.

Further information

This booklet was produced by Marie Curie's Information and Support team. It has been reviewed by health and social care professionals and people affected by terminal illness.

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the Marie Curie Support Line on **0800 090 2309***.

Notice

The information in this publication is provided for the benefit and personal use of people with a terminal illness, their families and carers.

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Feedback form

If you have comments about this booklet, we'd love to hear from you. This will help us make sure we are providing the right information. Anything you tell us will only be used by the Information & Support Content team and will not be shared publicly. All information will be kept securely according to data protection standards.

We'd be very grateful if you could complete this form and return it to:

Information and Support Content team, Marie Curie,
89 Albert Embankment, London, SE1 7TP

Or you can email us at review@mariecurie.org.uk. Thank you.

Please tick

- I have a terminal illness
- I am a carer/ family member/ friend of someone with a terminal illness
- I am a health/social care professional using this resource to support someone affected by a terminal illness
- Other (please specify)

Where did you get this booklet from?

- Downloaded from the Marie Curie website
- Marie Curie Support Line
- Marie Curie Nurse, volunteer or hospice staff
- Healthcare professional (eg GP, district nurse)
- Other (please specify)

Did you find the information useful and did it meet your needs? eg, has this booklet given you a better understanding of the topic or helped you make a decision about next steps?

.....

Was there any information that you couldn't find that would have been helpful for you?

.....

Did you find the information in this booklet easy to understand?
Please tell us if anything was unclear.

.....

Did you think the tone was appropriate for the subject matter?

.....

Did you feel you had the right amount of information?

.....



Planning ahead

Would you have preferred to access this information in another format (eg large print, braille, audio)

.....

Do you have any other comments?

.....

About you

Finding out a little bit about you will help us to understand the needs of our audience and make sure our information reaches everyone.

What is your gender or gender identity?

- Female Male Prefer to self identify Prefer not to say
-

Age

- Under 16 16-24 25-34 35-44 45-54
 55-64 65-74 75-84 85 or over
-

Ethnicity

- White British Black or Black British Mixed
 White other Asian or Asian British
-

What is your religion or belief?

.....

What is your sexual orientation?

- Bisexual Gay woman/lesbian Other
 Gay man Heterosexual/straight Prefer not to say
-

Where do you live? (Please provide the first part of your postcode in the space below eg 'CB1' or SE11)

.....

We are always looking for volunteers to help us review our content for people affected by terminal illness. If you would like to help, please complete the details below and we'll be in touch with more details.

Name

Address

Telephone Email

How would you like to be contacted? Post Telephone Email



Marie Curie – why we're here

We're here for people living with any terminal illness, and their families. We offer expert care, guidance and support to help them get the most from the time they have left.

Support Line

We offer a free, confidential service to provide information on everything from day-to-day care, to sorting out money matters or coping with your feelings. And we're here when you just need someone to talk to.

0800 090 2309

Open Monday to Friday 8am to 6pm, Saturdays 11am to 5pm.
Your call may be recorded for training and monitoring purposes.

You can also connect with someone from our Support Line team using our online chat service. Visit **mariecurie.org.uk/help**

Online community

Share experiences and speak to people in a similar situation.
Visit **community.mariecurie.org.uk**

Information

We have a wide range of health and social care information that can help you live well, plan ahead and make informed decisions. This has been certified by The Information Standard as being reliable, up to date and evidence-based.

All our information is available online at **mariecurie.org.uk/help**
For printed copies call **0800 090 2309**
or email **review@mariecurie.org.uk**



Care and support
through terminal illness