

Planning ahead

Thinking about your care
and wishes ahead of time



* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

Introduction

This booklet is written for people living with a terminal illness, but may also be useful if you're close to someone with a diagnosis.

It's up to you if you'd like to plan ahead, and what you'd like to plan. You may not feel like planning ahead when you're ill. Other people have told us that planning ahead can help you to feel more in control and support those close to you.

Some people choose to plan ahead while they still have the energy and ability to make big decisions. Some people might choose to include those important to them in their decisions too.

In this booklet, we've included information about some of the things you might want to think about. In the first chapters, we explain decisions that are directly linked to illness, such as advance care planning, deciding where to be cared for and refusing treatment. In the later chapters, we talk more generally about planning ahead, including leaving behind memories and making a Will.



You can learn more about planning ahead at [**mariecurie.org.uk/support**](https://mariecurie.org.uk/support) or by calling the free Marie Curie Support Line **0800 090 2309*** or emailing [**support@mariecurie.org.uk**](mailto:support@mariecurie.org.uk).

How to use this booklet

This booklet does not need to be read from start to finish. You can dip in and out, or even skip some sections if you do not feel ready to read them. It's not in any particular order. You can choose which sections you'd like to read or plan first.

Some people have told us that breaking down planning into small chunks can be helpful. Planning does not need to be done all at once. You might also like to discuss your plans with others in a similar situation.

This booklet has some prompts and blank space so you can make notes about your plans.

You might like to read this alongside our booklet **Living with a terminal illness**. It has more information about coping with your feelings and help with day-to-day living.

We also have specific information about planning ahead for LGBTQ+ people. You can download or order this booklet at: mariecurie.org.uk/publications, call the free Marie Curie Support Line on **0800 090 2309*** or email support@mariecurie.org.uk

Words we use

In this booklet, we use the term 'health and social care professionals' to talk about the people involved in your care. This might be your doctor, nurse, or healthcare assistant. It could also be your consultant, or any other professional involved in your care, such as a physiotherapist, psychologist, or social worker.

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Getting started

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Useful words and phrases

In this booklet, you might read some words or phrases that are unfamiliar to you. We've explained what some of these mean below:

Advance care plan: A written statement about what you'd like to happen to your care in the future, including any preferences, wishes or beliefs. This is not the same as an advance decision to refuse treatment. It is not legally binding, but it should be considered, should you become unable to communicate your wishes yourself.

Advance decision to refuse treatment (ADRT): Sometimes called a 'living will'. This is a written decision you can make now to refuse a specific type of treatment at some time in the future. It is used to let the people caring for you know your decision if you are unable to communicate. It is legally binding in England and Wales if it's written down and signed correctly.

Digital legacy: Your digital legacy is all of your online accounts and the digital assets they contain, like photos, videos and music. This could be social media accounts, email accounts, photos or videos stored digitally or anything else personal or important that you have stored online.

End of life care: End of life care involves treatment, care and support for people who are thought to be in the last year of life. This timeframe can be difficult to predict, so some people might have end of life care in their last weeks or days, and others might have it for longer.

Life-sustaining treatment: Treatment that supports or replaces bodily functions that potentially keep you alive.

Palliative care: Palliative care offers physical, emotional and practical support to people with a terminal illness. It can be offered at any point after a terminal diagnosis.

Power of Attorney: A person you appoint to make decisions on your behalf if you become unable to. There are different types of Power of Attorney. They include one for your finances, and one for your health and care. They have different names and processes depending on where in the UK you live.

Will: A legally binding document where you can say what you would like to happen to your money, property and possessions (including pets and children under 18) after you die.



Philip Hardman/Marie Curie

Emotions you might feel when planning ahead

Thinking about and planning for your future care is a unique experience for everyone. There's no right or wrong way to feel. And you might not know how you feel some of the time. Emotions such as grief, sadness, fear, or loneliness are all common while planning ahead.

Thinking about the future and making decisions can also feel overwhelming or tiring. Reach out for support when you need it. Support could come from people close to you. Or you might prefer to speak with healthcare professionals or the Marie Curie Support Line.

Planning ahead can bring up emotions that you might not be expecting. Talking about your plans with others can also be emotional, both for you and those important to you. We talk more about this on page 62.



The free Marie Curie Support Line is here to help you with any emotions you might feel when planning ahead. Call us on **0800 090 2309*** or email us at **support@mariecurie.org.uk**

Section 1: Planning your future care

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Choosing where to be cared for

It can be helpful to think about where you'd like to be cared for now, in the future, and also in your final days. These may be different places and you might change your mind over time.

You might like to think about if you'd prefer to be cared for:

- at home
- in a hospice (see page 71 for information about Marie Curie Hospices)
- in a care home or nursing home (residential care).

It's important to know that, even if you choose where you'd prefer to be cared for, this might not always be possible. This could be because you need emergency care in a hospital, your condition means you need specialist care in a specific place, or there are no beds available in your chosen place.

Who can help?

Wherever you are cared for, you should be well looked after and given the support you need. If you have any worries about where you might be cared for, it could help to speak with a healthcare professional, such as a GP, Marie Curie Nurse or district nurse. They will be able to help talk through options. You can also contact a hospice for more information about their services.

“It was a very different environment in the hospice, there were different activities going on that she could get involved with. She loved sitting out in the sun in the hospice gardens.”

Emma, whose Mum was cared for in the Marie Curie Bradford Hospice



To find out more about where you could be cared for, visit our website at [**mariecurie.org.uk/choosingwhere**](https://mariecurie.org.uk/choosingwhere), call the free Marie Curie Support Line on **0800 090 2309*** or email [**support@mariecurie.org.uk**](mailto:support@mariecurie.org.uk)



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Planning your care in advance

It can be helpful to think about what care you'd like to receive in the future. 'Care' can include day-to-day support, treatments and other things that are important to you.

It's a good idea to discuss your wishes and plans with your family, friends, and healthcare professionals. Talking about your plans may mean your wishes are more likely to be followed because the people close to you, or looking after you, will know what you want. Or you could write your plans down and let someone know where to find them, should they need them.



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“When it comes time to die, make sure dying is the only thing you have to do.”

Joan, who volunteers at the Marie Curie Belfast Hospice

What is advance care planning?

Advance care planning involves making decisions about your future care. It's usually done with the health and social care professionals looking after you, or people important to you.

In Scotland, you might hear it called **anticipatory care planning** or **future care planning**. In Wales, you might hear it called **advance** or **future care planning**.

Advance care planning means your wishes are more likely to be followed if you are not able to make decisions or tell people what you'd like in the future.

It should be your choice whether you make an advance care plan. Try not feel pressured to include anything you're not comfortable with. You can change your mind at any time.

You may hear this type of planning called making an advance care plan or an **advance statement**.

There are differences in how advance care plans and decisions can be made and applied in the four different nations in the UK. See pages 16–23 for more information.

How to make an advance care plan

There is no set template for an advance care plan. Advance care plans or statements can include anything about your future care. You might want to think about what is important to you, and what you want to happen or not to happen in your future care.

Advance care plans step-by-step

Advance care planning usually involves five steps.

Think about what you'd like to plan, including what you'd like to happen, or anything you would not like to happen. If you want to, talk about your wishes with your healthcare professionals, family and friends.

You can write your wishes down, but you do not have to. Writing your wishes down can make it easier for people to understand and follow them in the future. Your healthcare professional might have an advance care planning form to help you.

On page 17 we've shown how you might like to approach making an advance care plan. Follow the steps on this diagram to help create your plan, and share it with people who need to know.

On page 18 there's some space to write down any wishes about your future care. We've given some examples of questions you might like to think about.

Advance care plans step-by-step

THINK

Think about your future. What do you want or not want to happen?



TALK

Talk with people important to you.



RECORD

Record your thoughts and create your own advance care plan. Keep this somewhere safe.



DISCUSS

Discuss your plans with your healthcare professionals. They might need to advise you or sign some forms.



SHARE

Share information about your plans with people who need to know. Make sure it's recorded on your health records. You can review your advance care plan at any time.

Your wishes for your care

Writing your wishes down here will not be legally binding. But if you let people know about your wishes, these should be considered if you become unable to express your wishes or make decisions yourself.

How do you like to do things? For example, do you prefer a bath or a shower? Do you like an early morning or a lie in?

What are some of your favourite things? For example, this could be food, smells, being inside or outside, or anything else you enjoy.

continued on next page

Is there anything you do not like or would not like to happen?

Where would you like to be looked after in the future and in your final days? For example, at home, in a hospice, in a care home, or somewhere else.

Are there any spiritual or religious beliefs you would like to be considered?

continued on next page

Who would you like to spend time with?

If you become unable to express what you'd like, who should your doctors or nurses talk to about your wishes?

Do you have any children under 18 or pets that need to be taken care of? What should happen to them?

continued on next page

Is there anything you're especially worried about?

If you have questions for your healthcare professionals or the people supporting you, you can write them here.

Telling people about your advance care plan

It's up to you who sees your plans. You might like to keep a written record somewhere safe, and let people know where they can find it, if they need it.

You can ask your doctor or nurse about how to make sure that other health and social care professionals know about your advance care plan.

They might be able to do things like create an electronic record of your plan. This is called a:

- Summary Care Record in England
- Individual Care Record in Wales
- Key Information Summary in Scotland
- Northern Ireland Electronic Care Record (NIECR) or the Encompass system in Northern Ireland.

This record could be accessed by hospital staff or out-of-hours doctors. These services can vary depending on where you live.

Sharing your plan with other people important to you can help your wishes be followed and support you to feel in control. We have information about talking to those important to you on page 62.

Will my advance care plan be followed?

Advance care planning makes it more likely that your wishes will be understood and followed. But it is not legally binding. There could be circumstances when the doctors or nurses do not follow the wishes you've recorded. But your wishes should still be considered when making a decision in your best interests.

"I found it kind of liberating. Then you know, you have it down and think that's settled. And I don't have to bother about it."

Gaynor, who has made an advance care plan



Refusing treatment

If you live in England and Wales you can say whether there are particular treatments that you do not want to have, if you are over 18. This is called an **advance decision to refuse treatment (ADRT)**. It's sometimes called an **advance decision** or a **living will**.

Some people make an advance decision to refuse treatment if they do not want certain procedures to happen. For example, if your illness cannot get better and you do not want a feeding tube or a liquid drip to keep you alive.

An advance decision to refuse treatment will **only** be used if you lose the ability to make your own decisions about your treatment (see page 36).

How to make an advance decision to refuse treatment (ADRT)

Talk about your options

It's helpful to discuss your options with a healthcare professional who knows about your medical history and health conditions. You can ask them about treatments you're likely to need and what it might mean if you choose not to have them.

If you have a health and welfare Power of Attorney, or are thinking about making one (see page 32), it's important to think about how this will work with an ADRT. Whichever was made most recently could take priority over the other.

Decide on which treatments you wish to refuse

You'll need to state:

- the specific treatments you wish to refuse **and**
- in what circumstances your refusal will apply.

You can choose to refuse treatment that could potentially keep you alive. This is known as 'life-sustaining treatment' or 'life-prolonging treatment'. For example, a mechanical ventilator to help you breathe.

You cannot refuse care to make you comfortable or request help to end your life.

Write it down

You'll need to make sure your decision is:

- written down **and**
- signed by you **and**
- signed by a witness if you want to refuse life-sustaining treatment.

A witness can be any independent person who can witness you signing your decision.

If you choose to refuse life-sustaining treatment, you also need to make sure the phrase 'I refuse this treatment even if my life is at risk as a result' is included to make it legal.

Example of an advance decision to refuse treatment

Here's an example of some wording you might use when making an advance decision to refuse treatment:

I wish to refuse the following treatments	In these circumstances
I wish to refuse the use of invasive ventilation. I am refusing this treatment even if my life is at risk as a result.	I have a terminal illness and my heart and lungs stop functioning in a way that allows me to breathe on my own.
I wish to refuse artificial feeding or hydration. I am refusing this treatment even if my life is at risk as a result.	I have a terminal illness and I can no longer swallow food or liquids safely, even with the help of others.

Your healthcare professional may have a form or template you can use. Some organisations, such as Macmillan Cancer Support and Alzheimer's Society, also have forms you can download or order from their websites: [macmillan.org.uk](https://www.macmillan.org.uk) and [alzheimers.org.uk](https://www.alzheimers.org.uk).

You need to share your advance decision to refuse treatment with your health and social care professionals, so that they know which treatments you do not want. It might also be helpful to share it with people important to you.

Will my advance decision to refuse treatment be followed?

Your healthcare professionals must follow your advance decision to refuse treatment, as long as it is valid and applies to your situation at the time.

If you live in England or Wales

In England and Wales, an advance decision to refuse treatment is legally binding under the Mental Capacity Act 2005.

If you live in Scotland or Northern Ireland

In Scotland and Northern Ireland, an advance directive or advance decision do not follow an act. But they are likely to be considered legally binding by a court. This means your wishes should be respected unless there is clear clinical justification for going against the refusal of treatment documented. But, it is not protected by law.

Who can help?

You can speak to your healthcare professionals about how you would like to be cared for, and making advance care plans. You may also want to involve the people important to you, so they're aware of your wishes. A solicitor can help with making your documents legal.



Philip Hardman/Marie Curie

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Power of Attorney

When you have a terminal illness, organising and making decisions about financial matters and your healthcare can be hard. You can set up a Power of Attorney to let someone help you.

If you're worried about managing your affairs in the future, you may want to set up a **lasting Power of Attorney**.

Types of Power of Attorney

There are three different types of Power of Attorney. You can set up more than one type if you want.

Ordinary Power of Attorney

(called a general Power of Attorney in Scotland and Northern Ireland)

You might set up an ordinary Power of Attorney because:

- you'd like some help making decisions about your finances **or**
- you do not want to make decisions about your finances yourself.

It lets you transfer control of your financial affairs **temporarily** to the person you choose. It can cover all your financial affairs or just some aspects of them.

This type of Power of Attorney is for useful for people who have mental capacity, but would like help with making financial decisions.

An ordinary Power of Attorney automatically stops if:

- you lose the ability to make decisions for yourself (lack mental capacity) **or**
- you die **or**
- your attorney dies.

If you'd like a more permanent Power of Attorney, think about setting up a **lasting Power of Attorney**.

Lasting Power of Attorney for financial affairs

(called a continuing Power of Attorney in Scotland and enduring Power of Attorney in Northern Ireland)

This allows someone to make decisions about your financial affairs and property for you. For example, managing a bank account or selling your home.

This type of Power of Attorney comes into action if you lose mental capacity (see page 36). So, putting this in place now means the person you choose as your attorney automatically has the right to make decisions for you, should you become unable to make them yourself.

“Being able to deal with the various financial and medical authorities on Mum’s behalf, without having to jump through the hoops and obstacles which would have existed had there been no Power of Attorney in place, has been of infinite value to Dad.”

Steve, who helps care for his Mum after her dementia diagnosis

Planning ahead

You must have mental capacity when you create the Power of Attorney.

If you live in England, Wales or Scotland it needs to be registered with the Office of the Public Guardian before you can use it.

If you live in Northern Ireland, it can be used once the attorney(s) have signed it, if you still have capacity, and it does not need to be registered. But it must be registered with the Office of Care and Protection if you lose capacity.

Lasting Power of Attorney for health and welfare decisions

(called a welfare Power of Attorney in Scotland)

This gives someone else the right to make decisions about your healthcare and other aspects of your welfare. For example, medical care or moving into a care home. It also allows them to access your health records.

This type of Power of Attorney can continue if you lose mental capacity (see page 36). So, putting this in place now means that the person you choose as your attorney automatically has the right to make decisions for you, should you become unable to make them yourself.

You must have mental capacity when you create the Power of Attorney.

It can be used in England, Wales, and Scotland. There is currently no equivalent to a health and welfare Power of Attorney in Northern Ireland. Contact the Office of Care and Protection (OCP) for more information (page 75).

How to set up a Power of Attorney

To set up a Power of Attorney, you will need to:

- fill in some forms **and**
- send the forms to be registered.

Letting someone else control your financial and legal affairs is an important decision, so you may want to get advice from a solicitor.

You can set up a Power of Attorney without legal advice. The wording you must use does need to be specific, so read the guidance before registering your forms.

You can get general guidance from the Office of the Public Guardian in England, Wales, and Scotland, or the Office of Care and Protection in Northern Ireland. You can also use the Office of the Public Guardian's online service, which can help reduce any potential errors.

Registering a Power of Attorney can take many weeks. If you are concerned about losing capacity within that time, attach a letter to your forms or contact the Office of the Public Guardian (or the Office of Care and Protection if you live in Northern Ireland) to explain your situation.

Choosing your attorney

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

You can choose more than one attorney. If you do this, you'll need to decide if they will make decisions separately, together, or a mix of both.

Your attorney needs to be aged 18 or older in England, Wales and Northern Ireland, and aged 16 or older in Scotland. They need to have the ability to make their own decisions (mental capacity).

Many people choose a family member or friend to be their attorney. You can also appoint a firm – for example, a solicitor or an accountant – as your attorney, but they will charge a fee.

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, the Office of the Public Guardian in England, Scotland and Wales, or Office of Care and Protection in Northern Ireland (see pages 72–75).

Paying for a Power of Attorney

Making and registering a Power of Attorney costs money, and will cost more if you seek legal advice. You can register a Power of Attorney yourself, without legal advice. This can be a less expensive way to do it, if you feel confident doing so.

If you are receiving certain benefits, or are on a low income, you might be exempt from some fees, or can have some costs reduced. Visit mariecurie.org.uk/power-of-attorney for more information.



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Mental capacity and making decisions

Mental capacity is your ability to understand and make a decision. If you lack mental capacity, this means that you're unable to understand and make a particular decision at the time it needs to be made. In Scotland, people who lack capacity are sometimes called adults with incapacity.

You, and the people close to you, may need to prepare for this possibility and put plans in place.

People who may lack capacity include those with dementia, memory or thinking problems, or conditions that cause them to be confused, feel sleepy or faint.

Support with mental capacity

There are laws to protect and empower people aged 16 or over who may lack the mental capacity to make their own decisions.

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. For example, you might be able to decide where you want to live, but not be able to decide how you'd like to be cared for.

You should be supported to make your own decisions as much as possible. For example, many people with dementia can make decisions with the right support and encouragement.

All practical steps to help you make a decision must have been taken without success, before someone else can make a decision on your behalf. This includes things like involving an advocate or making sure written information is easy for you to use.

Mental capacity is not based on your ability to make a wise or sensible decision. But you should be able to make an informed decision. This means thinking about the benefits and risks of each option, and deciding which choice is best for you.

If you lose mental capacity

Someone can only make decisions on your behalf if you've been assessed as lacking capacity. Even then, someone can only make those decisions that you cannot make for yourself.

You can find out more about how mental capacity is assessed at mariecurie.org.uk/mentalcapacity, by calling our free Support Line on **0800 090 2309*** or by emailing support@mariecurie.org.uk

If you're not able to make a decision, the person making the decision for you should take into account what you would want and what is best for you. Any intervention should have the least restriction on your freedom. They should involve you as much as possible when decisions are being made.

If it's decided that you lack mental capacity, any **lasting Power of Attorney** (see page 31) will be put into effect.

Planning ahead

If there's no Power of Attorney in place, someone close to you can apply to make decisions on your behalf. This is called being a **deputy** in England and Wales, a **guardian** in Scotland and a **controller** in Northern Ireland.

The process for this is different depending on where you live. It can be a hard and expensive process.

You can find out more about your options for making decisions by contacting:

- The Court of Protection if you live in England and Wales (see page 72)
- The Office of the Public Guardian if you live in Scotland (see page 76)
- The Office of Care and Protection if you live Northern Ireland (see page 75).

If there is no lasting Power of Attorney in place, members of your healthcare team will make decisions on your behalf. Health and social care professionals might ask the people important to you to help build a picture of what you would like. But your family and friends will not be asked to make decisions on your behalf.



Find out more about making decisions on someone's behalf at mariecurie.org.uk/mentalcapacity. If you want to talk to one of our team members, call the free Marie Curie Support Line on **0800 090 2309*** or email support@mariecurie.org.uk

Section 3:

Getting your affairs in order

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Making a Will

Making a Will lets you decide what happens to your money, property and possessions when you die. These things are sometimes called your 'estate'. You can also use a Will to decide who should look after any children under 18 and any pets.

You might want to make a Will so that you can make these decisions yourself and to help people important to you feel less worried about the future.

If you have not made a Will or your Will is invalid, your money, property and possessions will be shared out according to the law. This could mean people you have not chosen could inherit your estate.

There are different reasons why a Will might be invalid. These include if:

- it is not signed correctly **or**
- it's been destroyed or altered **or**
- you did not know what you were doing when you made it.

Check the GOV.UK website (see page 73) or ask a legal professional if you are unsure.

Remember to review your Will every five years, or whenever circumstances change.

How to make a Will

On pages 41–42 there's some space to think about things that could make up your Will.

Thoughts about your Will

Writing your ideas down here will not be legally binding. But it could be helpful for you to discuss with a legal professional if you decide to make or update your Will.

What is the total value of any money, property and possessions you have (your 'estate')?

Who would you like to benefit from your Will? These are called beneficiaries.

What would you like each person to receive?

continued on next page

Who do you want to sort out your Will (the ‘executors’)? It could be your family, friends, or a professional, like a solicitor (lawyer) or an accountant.

What would you like to happen to children under 18 after you die? For example, is there someone close to you you’d like to look after them?

What would you like to happen to your pets after you die? For example, there may be someone close to you who can take them in, or a rehoming centre you’d like them to go to.

Once you’ve thought about some of the things you’d like to include in your Will, the next step is to write it down in a legal format. This includes signing it in front of two witnesses and getting them to sign it too.

It might be helpful to use a solicitor if your affairs are not straightforward.

For more information on making a valid Will, and who your witnesses can be, visit the GOV.UK website (see page 73).

Paying for a Will

You could use a solicitor or professional Will-writer to make your Will. These professionals will charge a fee, and this can be expensive. You can make a basic Will yourself, which can be a less expensive option. Consider getting advice from a solicitor, independent financial adviser (IFA) or a professional Will-writer.

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



Marie Curie offers a free Will-writing service for anyone aged 18 and over. Find out about the service and read more about how to make a Will at mariecurie.org.uk/makingawill



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Telling people about your Will

Give a copy of your Will, including a list of your money property and possessions, to:

- the person you've chosen to sort everything out (your executor) **or**
- your solicitor.

Or let them know where you keep your Will.

Executors will need to access the Will without requiring legal permission. You can leave your Will with a solicitor or store it with the government's probate service. Avoid putting your Will in places like a bank safety deposit box because legal permission will be required.

Who can help?

Many charities and organisations, including Marie Curie and Citizens Advice, can help you with your Will. Solicitors, Will-writers and financial advisers can also help you to make it legal and guide you through the process.

Rehoming your pet

Pets are counted as possessions after you die, so it's up to you what happens to them. You may be worried about who will look after your pet if your condition gets worse or after you've died. It may help to plan for your pet's future. This can be useful if someone needs to find a new home for your pet.

You might have a friend or family member who would like to look after your pet. You could ask them if they could help, either on a short-term or long-term basis.



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Planning ahead

There are organisations that can rehome pets with loving and responsible new owners. Some organisations have schemes where you can register your pet in advance to be looked after when you die.

Include any plans you have for your pets in your Will, if you have one. Or write your wishes down and let someone know where they can find it.

Information about your pet

It can help to write down information about your pet and keep it in a safe place so that you, or someone else, has everything to hand when it's needed.

This could include:

- what food your pet eats and how often
- any medical conditions your pet has
- any medication your pet needs (include dosages)
- your pet's vet records and dates of any operations or vaccinations
- details of your pet's vet (such as address and phone number)
- details of any pet insurance.

On the next page is some space for any notes you might like to make about your pets.

Your pet(s)

Who can help?

Organisations like Blue Cross, Battersea Dogs & Cats Home, National Animal Welfare Trust or The Dogs Trust can give you advice and rehome animals with loving and responsible new owners. Your vet can also give you advice.

Online accounts and social media

You may have online accounts or social media. The information they contain (such as contact details, photos or videos) are sometimes called digital assets.

It can be helpful to think about what you want to happen to these accounts and the assets they contain after you've died. You can put plans in place to make things easier for people important to you to carry out your wishes.

You could think about your accounts for:

- music, streaming and other media subscriptions (Netflix, Spotify, newspaper subscriptions)
- social media (Facebook, X (Twitter), TikTok, Instagram)
- professional sites (LinkedIn, Google Apps)
- email (Gmail, Hotmail)
- cloud storage services (Dropbox, Apple iCloud)
- accounts that hold money, currencies or assets of a financial value (gambling accounts, shopping accounts etc)
- smartphone or tablet apps
- online accounts for utility or mobile network providers.

Deciding what to do with each account

Decide what you want to do with each account and, if you can, put these plans in place with the company.

You might be able to do different things with your accounts:

- Memorialise a social media account, so that your timeline and pictures can be seen by friends, but no one can make changes to it.
- Download a copy of your data (photos, videos and messages) and keep in a secure place.
- Deactivate an account so that it's not publicly available, but the information is stored with the company in case someone needs to access it in the future.
- Delete an account so that it's not publicly available and all of the information is deleted.

Some companies have settings where you can choose to nominate someone to have access to some parts of your digital accounts:

- Apple has a 'legacy contact' option.
- Google has an 'inactive account manager' option.
- Facebook has a 'legacy contact' option.

Visit mariecurie.org.uk/social-media-online-accounts for more information.

“Everyone processes grief so differently, but talking about digital legacy, making a plan today, means you can save loved ones from heartache when you’re gone.”

Hayley, whose husband Matt was cared for at the Marie Curie Edinburgh hospice

Putting plans in place for your accounts

Once you have written down your account details, you might want to leave a copy with someone you trust.

Check with each company you have an account with before giving someone else your password. Someone else may not be able to access your account without breaking the terms and conditions of the company.



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There's space below for you to write down details of what you'd like to happen to your digital accounts after you die.

If you prefer, you can document your plans or wishes online at MyWishes or LifeLedger (see pages 74–75).

Your digital accounts

Social media accounts

Music and media accounts

Email accounts

Utility accounts

Details about your phone, laptop, PC or tablet

Who can help?

Each company may be able to tell you what your options are and how you can plan ahead. MyWishes and the Digital Legacy Association have guides on managing social media and other online accounts (see pages 72–75).

Bank and financial accounts

Bank, building society and other financial accounts are counted as part of your estate (your money, possessions and property). This means that your bank accounts will be managed by the executors of your Will, if you have one, when you die.

After you've died, your executors of your Will need to tell your bank.

If you do not have a Will or have not named an executor, the law decides who will deal with your bank accounts and finances.

Planning ahead for your bank accounts and finances

You may wish to make a list of all your bank and financial accounts so the people dealing with your affairs know which banks to contact after you've died.

Keep this list somewhere secure. This might be with your Will or your advance care plan. Let the people important to you, or a solicitor, know where they can find this.

Avoid giving out sensitive account details. Sharing PIN numbers or passwords is against the terms and conditions of bank accounts. If you feel like you need to share your PIN or password, contact your bank to see if they can help.

It can be difficult to remember all of your accounts. Think about if you have:

- debit accounts
- credit accounts
- savings accounts
- pension accounts
- premium bonds
- independent savings accounts (ISAs)
- investment bonds, portfolios or individual shareholdings
- other accounts with financial value, like cryptocurrency or gambling accounts.

Who can help?

Visit mariecurie.org.uk/bank-accounts for more information on planning ahead for your bank accounts and finances. For support over the phone, call the free Marie Curie Support Line on **0800 090 2309*** or email support@mariecurie.org.uk

Planning your own funeral

In this section, we talk about planning your own funeral. It mentions what might happen to your body after you die, and what a funeral ceremony might look like. If you do not want to read this section, or would prefer to come back to it at another time, skip to page 60.

Things to consider

Some people want to make decisions about what happens after they die, and other people do not. You could tell the people important to you about what you want for your funeral. It might help to write your wishes down.

You could also put plans in place for your funeral by organising it yourself or speaking to a funeral director.

There are lots of different funeral directors available. Look for one that is flexible and will respect your choices. Some people choose to visit a funeral site first, and then look for a funeral director who services that site.

Planning your funeral

You could consider things like:

What will happen to your body?

Do you want to be buried or cremated? If so, where?

If you're cremated, would you like your ashes to be kept or scattered?

What will the ceremony be like?

Would you like a religious ceremony, non-religious ceremony or no ceremony?

Where would you like the funeral to be held?

continued on next page

Are there any music, poems or readings you want included?

Would you like flowers, donations or something else to remember you? If you'd like donations, which charity or organisation would you like them to go to?

Would you like any photos or videos to be shown?

Do you want a wake, gathering, or something else - and, if so, where?

“I’ve planned my funeral, including the music and how I’d like my coffin to look. I’ve asked for a white coffin with cricket bats on it! It was straightforward and easy. I wanted to do it so my daughter doesn’t have to worry about what I might’ve liked.”

Jude, who volunteers for Marie Curie

Paying for your funeral

Some people choose to pay or put money aside for a funeral in advance. Here are some options you could consider when planning your funeral.

Pre-paid funeral plan

You might like to consider paying for your funeral in advance with a pre-paid funeral plan.

Pre-paid plans usually allow you to choose some options in advance. This can fix the cost of some things. You might:

- pay a small amount into the plan each month, over a number of years **or**
- pay it all at once (a lump sum).

Most pre-paid plans do not cover the whole cost of a funeral. It’s worth checking what’s included, and if there are restrictions, to avoid any surprises. Things like a wake, food and flowers are not usually covered.

Insurance

Insurance works in a similar way to a pre-paid funeral plan. The money that's paid out when you die can go towards different parts of your funeral, but you do not choose the options in advance. Life insurance does not fix the costs of your funeral.

Leaving money in your estate

You might choose to leave money in your estate to cover the funeral costs when you die.

Banks usually have some exceptions to allow for funeral expenses to be paid, even when an account is in the process of being closed or waiting for **probate**. Probate is a document that shows the person dealing with your finances has the right to do so.

The person organising your funeral might also be able to send a copy of the funeral invoice to the bank and ask them to pay directly.

If you plan to leave money in a bank account to pay for your funeral, think about writing instructions about where to find the money with your list of accounts. This could be helpful to the people sorting out your accounts after you die.

Help paying for a funeral

If you have a partner or close family member that receives certain state benefits, they might be entitled to receive a funeral expenses payment. Visit mariecurie.org.uk/help-with-funeral-costs for more information.

Planning your own funeral

If you do not have any money left in your estate, or there is no one close to you who can arrange and pay for the funeral, the local council or hospital can arrange a simple funeral for you. This is known as a Public Health Funeral.

Check the website of your local authority for more information about Public Health Funerals: [gov.uk/find-local-council](https://www.gov.uk/find-local-council)



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

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.



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Section 4: Sharing with the people important to you

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Talking about your plans

Talking about your plans with healthcare professionals, your family or your friends, is an important part of planning ahead. Letting other people know that you have made plans, or where to find your documents can be helpful to those important to you and help make sure your wishes are followed.

“Because we planned and knew what she wanted, the experience after Mum died didn’t feel stressful. It felt relatively easy, and that was because we had such a comprehensive plan and had discussed this as a family.”

Charlotte, who helped her mum to plan ahead

Deciding who to tell

It’s up to you who you tell. It’s helpful to let anyone who might be dealing with things like your Will or your funeral know if you have certain things you’d like to happen.

If you have a Power of Attorney, it’s a good idea to let them know about any plans and keep them updated if anything changes.

If you do not have a Power of Attorney, you might want to share your wishes with the person closest to you. This is the person who health and social care professionals would ask if you became unable to express your wishes yourself. It might be a partner, children, close family member or friend.

Starting the conversation

Starting the conversation about your plans for the end of life can be challenging for lots of different reasons. Even if you are very comfortable talking about your plans, other people might not be. You might be scared or anxious that the person will become upset, or that it will change the way they think or behave.

Here are some options for starting the conversation:

- You might like to tell the person you'd like to talk about your plans in advance. This will give them some time to prepare. It may mean they're not as shocked by the conversation. You might prefer to bring up the conversation more casually. For example, you could be prompted by something relevant on the TV or radio.
- If the conversation starts feeling too difficult, take a break and come back to it another day. Be patient and take the time you need. You could try having shorter discussions over a few days or weeks. Having long conversations about planning ahead can be tiring, so this might help.
- Find a suitable time and place. It's important that you feel comfortable and have time to discuss sensitive topics. Think about where you'd like to have the conversation. Some people find talking about planning ahead while walking or during car journeys helpful.

Other ways to share your plans

You might not feel comfortable talking to someone about your plans in person or on the phone. You could consider telling people about your plans in other ways, such as writing a letter or recording a message.

Talking to health and social care professionals

Health and social care professionals can support you:

- to understand what your future care might look like
- by explaining any treatment options
- to plan medical decisions and what they might mean for you.

It's important to tell health and social care professionals about any plans you'd like to make for your future care. Having this conversation means they can advise you about your care, treatment and medical options. And they can record any plans in your health records.



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Talking to health and social care professionals can feel challenging. You might not have a close relationship with them, or you could feel like there's not enough time during your appointment or when you see them.

Let them know you'd like to talk about your future care plans. If you can, write down any questions you have or plans you'd like to discuss with them. You might like to take this booklet with you to show them any topics you'd like to discuss.

Listening and understanding someone else's plans

Discussing plans for the end of life can be an emotional topic. If you are close to someone who is planning ahead, understanding their plans can be difficult, especially if you do not agree with them.

It's important to remember that having the conversation with you might have been challenging for them too. We've listed a few things below that might be helpful to remember when listening to someone else's plans:

- **Give them time to speak.** Allowing time for the person to share their thoughts can help them feel listened to and can give you time to think about your response.
- **Respect their views.** Everyone's idea of a good end of life is different. Be prepared to listen to their plans and have an open discussion about them. Respect their views, even if they are different to yours.
- **Be supportive.** It might have been challenging for the person to tell you about their plans. Or it might be an emotional conversation. Support each other and try again another time if it's too difficult at first.

Planning ahead

It could be helpful to think about your own future care plans and have an idea about what you'd like for yourself. This can be useful for starting conversations and for supporting each other to plan ahead.

 Want to talk to someone about how you're feeling? The free Marie Curie Support Line is available to anyone affected by terminal illness. Call the Support Line on **0800 090 2309** or email **support@mariecurie.org.uk**



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Leaving behind memories

Leaving behind messages and memories can bring comfort to those important to you after you've died. It can be emotional, and not everyone chooses to do this.

It's important to think about how the people you are leaving memories for might react to your messages or plans. It could be helpful to talk to them about your plans, so it does not surprise them.

“As we grieve Nikki and adjust to life without her, living her bucket list is helping to heal our sore hearts. The activities on her list have pushed us out of our comfort zones and reminded us it's important to try new things and see as much of the world as we can. It feels as if it's her final gift to us all.”

Carole, whose daughter Nikki died of cancer

Websites such as MyWishes (see page 74) have ideas and options for leaving behind memories. Organisations such as Stories for Life (see page 76) can also interview you, record your stories and share these with people important to you.



You might like to hear from other people in a similar situation and share thoughts about leaving behind memories. Our Online Community offers the chance to connect with others and share ideas. Visit community.mariecurie.org.uk to join Marie Curie's Online Community.



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Organisations that can help

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How Marie Curie can help

Marie Curie is here for anyone with an illness they're likely to die from, and those close to them. Whatever the illness, wherever you are, we're with you to the end.

Marie Curie Support Line

0800 090 2309*

Email: support@mariecurie.org.uk

Our free Support Line is for anyone with an illness they're likely to die from and those close to them. Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Our Support Line is available in over 200 languages, or via webchat at mariecurie.org.uk/support. Open between 8am to 6pm from Monday to Friday, and 11am to 5pm on Saturday.

Marie Curie Companions

Companion volunteers focus on what's important to you and those close to you. It might be accompanying you to appointments, being there to listen to how you're feeling without judgment, or stepping in so family or carers can take a break. Companions provide the emotional and practical support you want – at home, in hospital or over the phone.

mariecurie.org.uk/companions

Marie Curie Telephone Bereavement Service

Get ongoing bereavement support over the phone from the same volunteer. You can access up to six sessions of 45 minutes. We can help if your bereavement was expected, happened recently or was some time ago.

mariecurie.org.uk/bereavement

* Your call may be recorded for training and monitoring purposes.

Marie Curie Online Community

Our Online Community is a space for you to share thoughts, feelings and experiences. It's moderated by the Marie Curie Support Line team, who can also help answer your questions.

community.mariecurie.org.uk

Marie Curie Hospice care where it's needed

Our hospices

Our hospices help people with any illness they're likely to die from, and the people close to them, receive the support they need. From medical and physical support to psychological and emotional care, whatever your illness, at whatever stage of the journey, we help you to live the best life possible, right to the end.

mariecurie.org.uk/hospices

Hospice care at home

Our nurses, healthcare assistants and other healthcare professionals bring the clinical, practical and emotional help you need to you, in the comfort of your own home. And we offer support to the people close to you too – from reassurance and practical information to letting them take a break.

mariecurie.org.uk/nurses

Looking for more information?

If you found this booklet useful, we have free information available online at mariecurie.org.uk/support or to order at mariecurie.org.uk/publications

Useful organisations

Caring Bridge

caringbridge.org

Create your own website to share your experiences with family and friends.

Citizens Advice

England: **0800 144 8848**

Scotland: **0800 028 1456**

Wales: **0800 702 2020**

citizensadvice.org.uk

The Citizens Advice 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, Scotland and Wales, and independent advisers 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.

Digital Legacy Association

digitallegacyassociation.org

Provides resources for healthcare professionals and the public. Helps people make arrangements for their digital legacy.

End of Life Doula UK

eol-doula.uk

Find a local end of life doula to support you. End of life doulas provide non-medical support to help preserve quality of life. They can also help you to plan ahead.

GOV.UK

[GOV.UK](http://gov.uk)

Information on government services and information in England and Wales. Has a database to find your local council to find your local social care services.

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.

Health and Social Care in Northern Ireland

hscni.net

Has information about your local health and social care trust, including community and social care services.

Institute of Professional Will-writers

0345 257 2570

ipw.org.uk

Self-regulatory body safeguarding the public from unqualified practitioners and unethical business practices. Can help refer you to an accredited Will-writer in the UK.

The Law Society (England and Wales)

020 7320 5757

lawsociety.org.uk

Find a solicitor in England and Wales.

The Law Society of Northern Ireland

028 9023 1614

lawsoc-ni.org

Find a solicitor in Northern Ireland.

Law Society of Scotland

0131 226 7411

lawscot.org.uk

Find a solicitor in Scotland.

Life Ledger

lifeledger.com

A free online service where you can record all the companies that will need to be informed after your death.

Mental Welfare Commission for Scotland

0800 389 6809

mwcscot.org.uk

Information or advice on rights in relation to mental health care and treatment and incapacity law.

MyWishes

mywishes.co.uk

Information and resources for sorting out your digital legacy, including tutorials for people who want to put plans in place for their online accounts at the end of life.

nidirect

nidirect.gov.uk

The main hub of information from Northern Ireland government departments.

Office of Care and Protection (Northern Ireland)

028 9076 3000 (textphone **028 9052 7668**)

justice-ni.gov.uk/topics/courts-and-tribunals/office-care-and-protection-patients-section

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 Power of Attorney and cannot find what you need online.

Office of the Public Guardian

0300 456 0300

gov.uk/government/organisations/office-of-the-public-guardian

Helps people in England and Wales stay in control of decisions about their health and finance and make important decisions for others who cannot decide for themselves.

Office of the Public Guardian (Scotland)

01324 678 300

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.

Social Care Institute for Excellence

0203 840 40 40

[scie.org.uk](https://www.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.

Scottish Government

0300 244 4000

[gov.scot](https://www.gov.scot)

Responsible for the issues which concern the people of Scotland, including health, education, justice, rural affairs and transport. The website also has guidance, legislation and policy documents.

Society of Will Writers

01522 687 888

[willwriters.com](https://www.willwriters.com)

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.

STEP - Solicitors for Trusts, Estates and Planning in Scotland

[scotland.step.org](https://www.scotland.step.org)

Directory of solicitors in Scotland who can offer legal support for making Wills, Power of Attorney, and other future plans.

Stories for Life

storiesforlife.co.uk

A nationwide charity that records the life stories of people with life limiting conditions. They work across the UK and remotely to capture memories and record conversations.

Tell Us Once

0800 085 7308

gov.uk/tell-us-once

A service offered by most but not all local councils in England, Scotland and Wales. It allows you to report a death to most government organisations in one go.

About this information

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

If you'd like the list of sources used to create this information, please email review@mariecurie.org.uk or call the free 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.

Did you find this information useful?

If you have feedback about this booklet, please email us at review@mariecurie.org.uk or call the free Marie Curie Support Line on **0800 090 2309***.

Your notes

[illegible]

Your notes

[illegible]

Marie Curie

Marie Curie is the UK's leading end of life charity. Whatever the illness, wherever you are, we're with you to the end.



0800 090 2309*

Marie Curie provides free support over the phone in over 200 languages, and via webchat, to anyone with an illness they're likely to die from and those close to them.

Our team, including nurses and specialist Energy Support Officers, offers practical and emotional support on everything from symptom management and day-to-day care to financial information and bereavement support. Visit mariecurie.org.uk/support

We also have an Online Community where you can share thoughts, feelings and experiences at community.mariecurie.org.uk

We can't do it without you

Our free information and support services are entirely funded by your generous donations. Thanks to you, we can continue to offer people what they need, when they need it.

To donate, visit mariecurie.org.uk/donate

* Calls are free from landlines and mobiles. Your call may be recorded for training and monitoring purposes.

