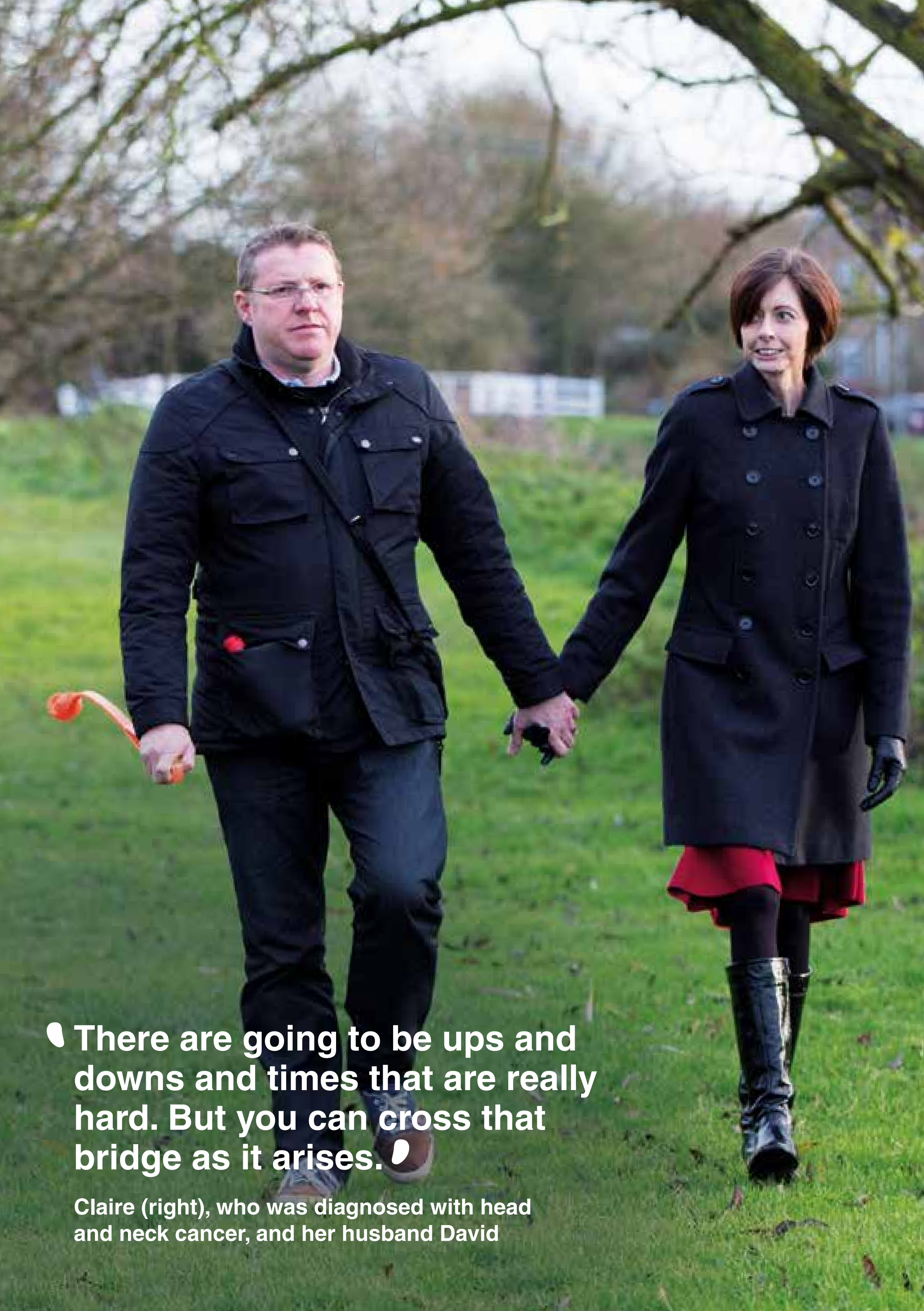
MACMILLAN
CANCER SUPPORT

A GUIDE FOR THE END OF LIFE



‘There are going to be ups and downs and times that are really hard. But you can cross that bridge as it arises.’

Claire (right), who was diagnosed with head and neck cancer, and her husband David

About this booklet

This booklet explains what happens at the end of someone’s life and how to plan for it. It is for anyone nearing the end of life. There is also information for people caring for someone nearing the end of life.

This booklet is about coping with the news that you may be nearing the end of your life, including sorting out your affairs, planning your care and understanding more about what might happen.

We hope it helps you deal with some of the questions or feelings you may have.

How to use this booklet

This booklet is split into sections to help you find what you need. You may find some of the information in the booklet difficult and upsetting to read, particularly if you are reading it for the first time. You do not have to read it from start to finish. You can use the contents list on page 5 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready. You may like to ask your partner, a close relative or a friend to read the booklet as well. You will then be able to discuss the information together.

On pages 138 to 144, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who are nearing the end of their life, and their family and friends. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. This includes Claire, who is on the cover of this booklet. Sadly, Claire died in February 2015. We'd like to thank her husband for allowing us to continue sharing her story, so others can benefit from Macmillan's support. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit macmillan.org.uk

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

Contents

COPING WITH THE NEWS

How you may cope with the news

Finding out that you may be nearing the end of your life can be very difficult and distressing. You might find it hard to believe, even if you know your illness is getting worse. You may have strong and often overwhelming emotions that make it difficult for you to think clearly. You may need some time on your own, or with your partner, a family member or a close friend, to think about your future.

Some people find it easier to talk about their fears and worries with someone outside their family or friends. If you would like to do this, you can talk to your GP, cancer doctor, specialist nurse or social worker. You may also find it helpful to call a support organisation (see pages 138 to 144).

Your feelings

You will probably have many emotions when you find out that you may be nearing the end of your life. You may feel tearful, upset and unsure of how to cope with your feelings and emotions. You might find it difficult to see normal life going on around you when your own world has changed so much.

You may be angry because you feel more could have been done to prevent your illness. Or you may think it could have been diagnosed at an earlier stage. It may feel unfair, and you may be unsure of what will happen in the future.

You might have some, or all, of these feelings. But as time passes you may find you feel less distressed, and that you feel distressed less often. With support from people around you, you may find you can think more clearly and cope better.

If you are finding your feelings difficult to cope with, there are people who can help (see pages 24 to 25).

> 'I'm not really one who likes to cry on people's shoulders. But there's been the odd occasion where I've found it quite hard to deal with. And Mandy's been there when I've been low. I feel very lucky to have had such support.'
>
> **Claire**

Facing an uncertain future

Many people with a serious illness want to know how long they might live for. This is a difficult question to answer. Your healthcare team may be able to give you some idea of how many weeks or months you might live for, but they cannot be sure. You may live longer than they say or, unfortunately, you may live for less time.

It is normal to have times when you feel well and positive, and other times when you feel less well and have less energy.

Although your future may be uncertain, it is often helpful to plan ahead and make the most of the days when you feel well. You may want to plan to do some nice things with your family and friends, or just spend time with them.

There are some important things you may want to think about before you die. These include:

- where you want to be cared for (see pages 58 to 64)
- making or updating a will (see pages 44 to 45)
- writing an advance decision or advance directive (see page 31 to 33).

It may be helpful to talk about these with your doctor or specialist nurse and family.

People close to you

When you are reaching the end of your life, your partner, family and friends become even more important. They can provide support and reassurance to help you cope with what is happening.

However, sometimes terminal illness can make relationships with others difficult. Many people find it hard to know what to say. You may find people react in unexpected ways. Some people may avoid talking about your illness completely. Others may be overly cheerful, and this can make it difficult for you to tell them how you feel.

Your partner, children or close friends may be overprotective. You might find this irritating at times. Sometimes, close family and friends may feel like strangers, at the time when you need them most.

Sometimes, partners try to protect each other from the truth by pretending it is not happening. But talking honestly with each other about your feelings can help you both cope with sadness, anxiety and uncertainty. You may find that your relationship becomes stronger as you deal with the challenge of your illness together.

It is important to keep your relationship as normal as possible. If you have always been close and talked a lot, there is no reason to stop doing this. When you do not know what to say, a hug or holding hands can be very comforting for both of you.

If you have always argued, do not feel you should change this. There will probably be times when you do not get on well. If you argue, having short breaks from each other can help you feel calmer and think more clearly.

Remember that people around you are likely to be shocked by the news. People close to you are also dealing with powerful emotions and may need support themselves. Their feelings and emotions will also change over time.

You may find your relationships get stronger as you, and the people close to you, value the things that are important. The illness can also be a chance for you to contact people you have not spoken to for a while, and for others to contact you. It may be an opportunity to resolve past arguments or bad feelings.

Macmillan's cancer support specialists can provide advice and support for your family and friends. You can call them on **0808 808 00 00**, 7 days a week, 8am to 8pm.

> 'One friend did distance herself from me. I think it must be hard for her and wondered if she didn't know what to say. I texted to assure her she was still my friend.'
>
> **Claire**

Talking

You might feel you have to be strong and be the one to start any difficult conversations. You may feel you need to support other people, even though you are the one who is ill. But if you are unwell or feeling low, it can be very difficult to do this.

If you can, talk openly with family members and friends about how you feel and what would help you. This will help them know how they can support you. You do not have to talk to everyone. You can choose who you want to talk to and who you feel will be able to help you. It may help to plan when you want to talk to them and what you want to say.

Sometimes it can help to talk to someone other than your family and friends. This could be a counsellor or a support organisation (see pages 138 to 144).

We have more information in our booklet **Talking about cancer** (see page 134).

Talking to children

It is never easy to tell children or grandchildren that you are very ill and nearing the end of your life. But it is often best to be as honest with them as you can, and give them information they can understand.

Children are often very aware of what is happening around them. Even if you do not say anything, they usually sense that something is wrong and may become worried or frightened. If they are told that everything is fine, it may be difficult for them to talk about how they are feeling.

Children can also feel that they are somehow to blame for your illness. So it is important to help them understand that it is not their fault.

How and what you choose to tell children depends on their age and how much they can understand. You can find more information in our booklets **Preparing a child for loss** and **Talking to children and teenagers when an adult has cancer** (see page 134).

If you live on your own

You may value your independence, especially if you live on your own. But being ill might make you feel lonely and frightened. It may be very hard to keep positive if you are on your own.

People who care about you will want to help in any way they can. It is ok to ask for and accept their help. You may have family members or friends who can spend time with you. It can be helpful to have someone to talk to who will listen to your worries and fears.

Others may be happy to help in more practical ways, such as helping with shopping, housework or the garden. You could make a list of practical things that would make your life easier. If people offer to help but are not sure what to do, you can show them the list. They can then choose to do something that will help you.

If you do not have anyone to help you, talk to your GP, social worker, or district or community nurse. They can tell you what help and support is available from health and social care professionals and voluntary organisations.

Emotional support

Approaching the end of your life can be a challenging and difficult time for you and your family and friends. You may find you get all the emotional support you need from your family and friends, and your healthcare team. But some people find it easier to get support from someone they do not know so well.

Some people may need more specialised help in dealing with their emotions. You might receive help from one of the following professionals.

Counsellor

Counsellors are trained to listen and help people talk through their problems. They will not give advice or answers, but can help you find your own ways to solve problems. Talking with a trained counsellor can help you express and understand your feelings. It can also help you find ways to deal with these feelings or the problems they relate to.

GP practices, hospitals and hospices often have counsellors. If they do not, they should be able to refer you to one. You can talk to one of our cancer support specialists to find out about counselling in your area. If you have more questions or would like to talk to someone, you can call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm or visit **macmillan.org.uk** The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (see page 141).

Your family might also find counselling helpful if they are finding it difficult to cope with their emotions.

Psychologist

Clinical psychologists are trained in understanding how people think, feel and behave. They are specialists in providing both psychological and emotional support to people with advanced cancer. For example, they can help if feelings of anxiety or depression become overwhelming, or if you are having relationship problems. They can sometimes offer support to carers and family members.

Clinical psychologists are often part of the hospital's cancer (oncology) services or the palliative care team.

Spiritual care coordinator or chaplain

Spiritual care coordinators or chaplains offer spiritual care and support. Even if you do not have a spiritual or religious faith, you may wish to talk to a chaplain about how you are feeling (see page 23).

SORTING THINGS OUT

Unfinished business

You may find yourself thinking a lot about the past. You may talk about good times and less good times you have had. You may want to:

- see old friends
- think about places you have visited
- visit some places again, if you are well enough
- look through photos or journals.

You may also think about the future and grieve for a time when you will no longer be here.

You may have difficult relationships with some people and want to talk to them. You could try writing to them or phoning them. You could explain your illness and why you are contacting them. You could ask them to contact you or visit.

You may also like to:

- write letters to people who are important to you
- record a voice message or video to be given to them after you have died
- write down your family history for the next generation
- make a scrapbook for your children or grandchildren
- think about what you would like to happen to any social media accounts you have
- think about giving a list of your passwords to someone you trust, so they can manage any personal accounts and social media accounts.

You may find it helpful to get support. This could be from a counsellor, a chaplain or family support services. They may be able to help resolve more difficult issues.

> ‘Writing a blog has let me put my thoughts down about a lot of important issues. I’ve found this a big help to me in reaching a broad acceptance of what’s happened.’
>
> **Michael**

Memory boxes

Memory boxes can be a helpful way of passing on memories to your family and friends. They can include messages and letters, a piece of jewellery, photographs, or a present to mark a special birthday. If the memory box is for a child, they may want to help you make it and fill it with special items.

Making a memory box can be a sad and difficult thing to do. But it can also give you a chance to reflect on your life, both good and bad. You may like to remember happy events, even if it also makes you feel sad. It is important to do what feels right for you, at a time when it feels right. Your local hospice family support team or chaplaincy services at your hospital can help you make a memory box. We have more information about making a memory box on our website. Visit **macmillan.org.uk** to find out more.

> ‘We put tickets or souvenirs of everything we’ve done together in little boxes so that our daughter Grace can go back years later and look through them. We’re remembering everything we do, rather than forgetting it.’
>
> **Ian, whose wife Kate was diagnosed with treatable but incurable cancer**

Spiritual and religious support

Towards the end of life, you might think more about religious beliefs or spiritual feelings. Thinking about the end of life can sometimes challenge what we believe. You may find you want to think and talk about what life means to you and explore your own experiences and beliefs.

Spirituality can be expressed in many ways. This could be through music, arts, nature, or how you relate to your family or community.

You might find comfort in prayer or meditation, or in knowing that other people are praying for you. But you may also start to question your faith, especially when you are suffering.

Talking to someone

You may find it helpful to talk through your thoughts and feelings with someone you trust. You only need to share as much as you want to, at a time when you feel ready. You can choose who you want to talk to and who you feel will be able to support you. This may be a close friend or family member.

You might feel calm about the fact that you are going to die. Or you might be scared and find it hard to talk to family or friends about it. You may prefer to speak with a spiritual or religious leader. This could be a chaplain, priest, rabbi or imam, depending on your faith or preference. They can offer emotional and spiritual comfort and help you feel more at peace with your situation.

It may still be helpful to talk to a religious leader even if you are not religious. Hospital and hospice chaplains offer spiritual support for anyone. It does not matter what your beliefs are. They are used to dealing with uncertainty and being with people who are distressed. They can also be very good listeners. Hospital and hospice chaplains may be able to help you cope with your thoughts and feelings.

If you prefer to talk to a non-religious person, Humanists UK have volunteers who can provide non-religious pastoral support. Visit **humanism.org.uk** to find out more.

Other support

Hospices or hospitals usually have local support groups. You may prefer to get support from an online group. Visit **macmillan.org.uk/community** to find out more

There are also meeting places called death cafés, where you can talk with other people about death. The meetings offer a safe place to express fears and concerns you might have about end of life care. They are led by someone who helps guide and support the conversation. They are usually held in places like libraries and shopping centres. Your local hospice may be able to tell you where and when death café meetings are being held in your area. You can find out more about death cafes at **deathcafe.com**

PLANNING AHEAD

Making choices

You may want to make important choices about your care and treatment in the later stages of your illness. Usually, you can talk about this with the doctors and nurses looking after you. However there may come a time when you cannot make decisions or communicate easily.

There are different ways you can plan ahead for a time when you may not be able to make decisions yourself.

This is sometimes known as advance care planning and includes:

- your wishes for your care
- advance decisions to refuse treatment
- power of attorney.

You can find more information in our booklets (see page 134):

- **Your life and your choices: plan ahead England and Wales**
- **Your life and your choices: plan ahead Scotland**
- **Your life and your choices: plan ahead Northern Ireland**

Your wishes for your care

It is important to think about how and where you would like to be cared for if your health changes. This is in case you become too unwell to tell other people what you would like to happen.

It is best to write down your wishes and what is important to you. This will help your family and health or social care professionals know how you would like to be cared for.

These advance statements of your wishes are not legally binding. But they must be considered when healthcare professionals make decisions about your care.

There are different documents that can be used to record your wishes. You can ask your healthcare team which documents are used in your area. It can be reassuring for family and friends to know that you have recorded your wishes. Make sure they know where you keep your documents.

> ‘Mum and I discussed her end of life wishes. I do wish we’d talked to medical professionals about options for end of life care though. It would have been good to know what the options are.’
>
> **Marlene, who cared for her mum until she died in 2018**

Important documents

You may find it helpful to make a list of important documents and where to find them. You can give a copy of the list to anyone who will be helping to manage your affairs.

The list could say where to find things like:

- your will (see pages 44 to 45)
- an advance decision to refuse treatment (see pages 31 to 33)
- your funeral plan
- your bank and building society details
- any insurance policies you have
- your birth certificate
- your marriage or civil partnership certificate, if you have one
- your national insurance number
- the details of your accountant, solicitor and tax inspector.

Advance directives and advance decisions to refuse treatment

An advance directive, or advance decision to refuse treatment (ADRT), is sometimes also called an advance decision, or living will. It is a decision about specific treatments you do not want to have.

To make an ADRT or advance directive, you must be able to understand the decision you are making. You must also be:

- aged 18 or over in England, Wales or Northern Ireland
- aged 16 or over in Scotland.

Being able to understand the decision you are making is called having mental capacity.

Before making an ADRT or advance directive, it is important to talk with a member of your healthcare team. This may be your GP, cancer doctor or specialist nurse. It is also important to discuss your decisions with your family, so they understand your wishes.

An advance directive or ADRT must state exactly what treatment you want to refuse. It can also state the situation when you want to refuse it. It is helpful to include as much detail as possible. An advance directive or ADRT cannot include a request to be given specific treatments, or to have your life ended.

Examples of advance directives or ADRTs

These are some examples of what you could state in your advance directive or ADRT:

- You may decide that if your condition suddenly gets worse and your breathing stops, you do not want people to try to bring you back to life (resuscitate you).
- You may decide that if you are very ill, you do not want to be given antibiotics to treat an infection, to prolong your life.

How an advance directive or ADRT is used

It is best to write down your ADRT or advance directive, so that it can be kept in your medical and nursing notes. It needs to be signed and witnessed.

It is helpful to give a copy to all the healthcare professionals involved in your care, including your GP. You may also be asked for permission to give copies to the ambulance service, out-of-hours doctors, district nursing and palliative care services. This is to make sure they know your wishes and preferences, if you need to contact them.

Your advance directive or ADRT will only be used if you cannot make or communicate a decision for yourself. If you refuse a certain treatment, you will still have the best possible care and support, and medicines to help manage any symptoms.

Advance decisions to refuse treatment and the law

In England and Wales, an advance decision to refuse treatment (ADRT) is legally binding if it meets the criteria set out in the Mental Capacity Act 2005. This means your healthcare team must follow it, if they know about it. There are certain situations where the law says an ADRT must be in writing. For example, it must be in writing if it states that you refuse treatment to keep you alive.

In Northern Ireland and Scotland, an ADRT or an advance directive is currently governed by common law instead of an Act. This means that it is likely to be treated as legally binding, if it meets certain criteria. This means your healthcare team will almost certainly take your wishes into account, if they know about them.

You can change your mind and rewrite your ADRT at any time. But this must be clearly recorded. Your healthcare team or solicitor can tell you more about this.

What is a power of attorney?

A power of attorney is a legal document. It lets you choose (appoint) someone to make decisions for you if you become unable to make decisions yourself. The person you appoint is called your attorney. The power you give them can be long or short term.

Your power of attorney usually has the authority to make legal and financial decisions. In England, Wales and Scotland, you can also give them the power to make healthcare decisions.

It is important to appoint someone you trust. They must be able to make these decisions for you. They must also agree to be your attorney. Here are some people you could appoint:

- your husband, wife, civil partner or partner
- a family member or a friend
- a professional, such as an accountant or lawyer.

If you make any type of power of attorney, it is a good idea to get help from a solicitor. But you do not have to use one.

England and Wales

In England and Wales, there are two types of lasting power of attorney (LPA). You can make one of them or both:

- An LPA for financial decisions. This includes things like paying bills or selling your home. It can be used when you are still able to make your own decisions. Or you can set it up to start once you become unable to make decisions for yourself.
- An LPA for health and welfare decisions. This includes things like giving consent for treatment, care, medication and where you live. This LPA can only be used if you become unable to make decisions for yourself. Some people also make an advance decision to refuse treatment (advance directive) – see pages 31 to 33.

You should talk to your solicitor about which is most suitable for you.

An LPA is a legal document. It needs to be registered with the Office of the Public Guardian before it can be used. This can take between 8 and 10 weeks.

You can cancel an LPA at any time before it is registered. After it has been registered, it can only be cancelled with the agreement of the Office of the Public Guardian.

You can find out more about making an LPA at
gov.uk/power-of-attorney/make-lasting-power

Lasting power of attorney replaced enduring power of attorney (EPA) in England and Wales in 2007. If you have an existing enduring power of attorney, it can still be used. However, this only applies to your financial affairs. Your attorney, or attorneys, cannot make decisions about your health and welfare using an EPA.

Scotland

In Scotland, there are three types of long-term power of attorney.

All of these types of power of attorney can only be used when they have been registered with the Office of the Public Guardian.

You can cancel a power of attorney at any time, as long as you have mental capacity. If you lose mental capacity, they can only be cancelled with the agreement of the Office of the Public Guardian.

Continuing power of attorney

A continuing power of attorney is for financial and legal decisions. It includes things like paying bills, managing your bank accounts or selling your home. It can be used when you are still able to make your own decisions, but would prefer your attorney to deal with these matters. Or you can set it up so that the powers cannot be used until you are unable to make decisions for yourself.

Welfare power of attorney

A welfare power of attorney is for health and care decisions. It includes things like treatment, care, medication and where you will live or be cared for. These powers can only start when you are not able to make these decisions for yourself. Some people also make an advance directive to make their wishes clear about treatment at the end of life (see pages 31 to 33). Talk to your solicitor about which is most suitable for you.

Combined power of attorney

A combined power of attorney is a combination of the first two types. It gives your attorney financial and welfare powers.

Northern Ireland

In Northern Ireland, an enduring power of attorney (EPA) can be used for financial decisions. This includes things like paying bills and selling your home. You can decide which powers to give your attorney.

You cannot give an attorney powers to make decisions about your care and treatment under an EPA. You can say how you would like to be cared for by using documents like the advance decision to refuse treatment (see pages 31 to 33).

While you are able to make decisions for yourself, an EPA can be used without being registered. But if you begin to lose or have lost mental capacity, your attorney must immediately register the EPA with the Office of Care and Protection.

You can set up your EPA so that the powers cannot be used until you become unable to make decisions for yourself.

Tissue, organ and body donations

You may think that having cancer means you cannot donate your organs or tissue to another person when you die. It is possible to donate if you have had cancer. But it may affect what organs and tissue you can donate.

England

In England, you choose to donate organs. However, the law on consent for organ donation is changing. No changes are expected before Spring 2020.

You can find out more about organ and tissue donation by visiting the NHS Blood and Transplant website (see page 140). They keep a register of people who wish to donate their organs or tissue after their death. You can join the register online, by phone or by text.

Scotland

In Scotland, the law on consent for organ donation is changing. But no changes are expected before 2020. You can read more information about these changes on the Scottish Government website. Visit **gov.scot/Topics/Health/Services/OrganDonation** to find out more.

You can find out more about organ and tissue donation on the Organ Donation Scotland website at **organdonationscotland.org** They keep a register of people who wish to donate their organs or tissue after their death. You can join the register online, by phone or by text.

Wales

In Wales, you are expected to opt out if you do not want to be an organ donor. This means you must register a wish to not be a donor.

If you want to be a donor, you can:

- register your decision to donate – this is called opting in
- do nothing, which means you have no objection to being a donor – this is called deemed consent.

You can find more information about this on the Organ Donation Wales website at **organdonationwales.org**

Donating your body for medical research

You may want to donate your body for medical teaching or research. Not everyone who wants to do this will be able to. If you are thinking about donating your body, you should discuss it with your GP, hospital team or palliative care team. You should also discuss it with your close family or friends. If it is something you want to do, it is a good idea to make other funeral plans. This is because the medical school may not be able to accept your donation.

You can find out more by contacting the Human Tissue Authority (see page 138).

Funeral planning

Funerals allow family, friends and others to pay their respects to the person who has died. If you tell your family or friends what you want, your funeral is much more likely to reflect your wishes. It may be one less thing for your family or friends to worry about. Although it can be hard to talk about, discussing your funeral plans with close family and friends can be helpful. They may have suggestions for ways to help them celebrate your life, say goodbye and remember you.

You could think about whether you want:

- a burial or cremation
- a religious or non-religious service
- specific songs or readings
- flowers
- donations to be given to specific charities
- to wear certain clothes that are significant to you, such as a military uniform.

Paying for a funeral and choosing a funeral director

Funerals can be expensive. You may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more from:

- your local funeral directors
- the National Association of Funeral Directors NAFD (see page 139)
- the National Society of Allied and Independent Funeral Directors SAIF (see page 139).

It is best to find out about prices first. Make sure you know what services are included in the price, as these can vary.

You do not need to use a funeral director. But it can be hard to arrange a funeral at such a distressing time. The Natural Death Centre has more information about this (see page 139).

> ‘I’ve planned my funeral. I’ve planned where I want it to be, who I want to be there and how I want it to be organised. There will be lots of prosecco and a jazz band.’
>
> **Alejanda**

Making a will

A will is a legal document. It gives instructions about who you want to give your money and belongings to when you die. People who get your money or possessions when you die are called your beneficiaries. Writing a will makes sure everything you leave goes to the people you want it to.

What you leave when you die is called your estate. This is made up of:

- everything you own, including money, property and belongings
- your share of anything you own jointly with someone else.

Anything you owe is taken off the value of your estate. For example, the value of a mortgage is taken off.

As well as instructions about money and belongings, your will can also include instructions about:

- who you want to look after your children – this person is called a legal guardian
- funeral plans
- who you want to sort out your estate – this person is called an executor.

Writing a will makes sure your wishes are followed after you die. It means that your loved ones will be provided for in the way that you want. It can also prevent them from having to make difficult decisions, or deal with financial problems. Such problems may happen if your wishes are not clear. You might find that writing you wishes in a will makes you less anxious about the future. A will can also be a way of remembering causes and organisations that are important to you.

If you die without making a will, it can take much longer to deal with your estate. It may also mean your money and belongings will not go to the people you would have chosen.

Making a will is not as expensive or difficult as you might think. But it is a legal document and must be prepared properly. So it is best to use a solicitor. They will make sure your wishes are clear and are carried out exactly as you want.

> ‘Writing a will is a chance to have your say. It’s about finding your voice. I made a will, because I didn’t want to leave any worries for my children. Writing it was about taking a little of the burden off them.’
>
> **Teresa**


Last will and testament

FINANCIAL HELP

Getting financial help

As you near the end of your life, you or your family may have concerns about:

- income
- additional costs
- managing your finances.

Financial help is available. You can sometimes access it at short notice.

It is likely that you will be able to get benefits in the last months of your life to help with your care. You may also be able to get free prescriptions. Some charities and other organisations provide grants to help with costs.

We have more information on benefits and other financial support at the end of life in our booklet **Help with the cost of cancer** (see page 134).

Benefits

Most people who need care towards the end of their lives qualify for disability benefits. These include:

- Personal Independence Payment (PIP)
- Attendance Allowance (AA), if they are aged 65 or over.

These benefits are not means-tested. This means the amount of money you have does not affect whether you can get the benefit.

You can apply for these benefits using a fast-track process if:

- you are terminally ill
- your doctor thinks you may reasonably be expected to live for less than 6 months.

This is called special rules. Your claim will be dealt with quickly and you will automatically be paid the higher rate. Special rules claims for AA and PIP apply for up to 3 years.

Under special rules, you can also apply for:

- Employment and Support Allowance, if you are unable to work because you are ill
- Universal Credit, if you are out of work or on a low income.

You will need to explain that you are claiming under special rules when you claim the benefit. We have information on how to do this in our booklet **Help with the cost of cancer** (see page 134).

Your cancer doctor or specialist nurse will also need to fill out a form called a DS1500 and send it to:

- the Department of Work and Pensions in England, Scotland or Wales
- the Disability and Carers Service in Northern Ireland.

You should get your payment within 2 weeks of sending the DS1500.

You can also call Macmillan on **0808 808 00 00** to speak to one of our welfare rights advisers. They can give you advice about claiming benefits and help you fill in claim forms. Depending on where you live, you may be able to visit a local Macmillan welfare rights adviser (see page 137).

You can also get more information and apply for certain benefits by visiting:

- **gov.uk** if you live in England, Scotland or Wales
- **nidirect.gov.uk** if you live in Northern Ireland.

Grants

You may be able to claim grants from many places.

Macmillan Grants are small payments to help people with the extra costs that cancer can cause. They are usually a one-off payment. They are for people who have a low level of income and savings.

You apply for the grant through a health or a social care professional. The Macmillan Grants team processes your application on the day they get it. If your application is approved, payments are usually sent out within 3 working days.

As well as Macmillan Grants, there may be other grants and loans available if you need financial help. These might include help from:

- government and local councils
- utility companies (gas, electricity and water companies)
- charities and other organisations (see pages 138 to 144).

We have more information about grants on page 137. You can also call us for free on **0808 808 00 00** to speak to a welfare rights adviser or a cancer support specialist. Your local library may have books about organisations that provide grants. One such book is **A guide to grants for individuals in need**, published by the Directory of Social Change.

Prescriptions

Prescriptions are free in Scotland, Wales and Northern Ireland.

In England, people with cancer and some long-term conditions can also get free prescriptions. You need to apply for an exemption certificate by collecting an FP92A form from your GP surgery or specialist.

Other financial things to think about

There may be other things to sort out, such as bank accounts and pensions.

Bank accounts

Your bank accounts will be frozen when you die. This means money can only be taken out if the person carrying out the instructions in your will transfers it. It is their job to tell the bank that you have died.

If you have a joint bank account with another person such as a partner, any money left in the account belongs to them. But in Scotland, any money you put into a joint account still belongs to you when you die. It then becomes part of your estate.

Pension schemes

You can nominate someone as your beneficiary using a legal nomination form provided by your pension scheme. This means that whatever is left in your pension when you die may pass directly to them. This depends on the terms and conditions of your pension scheme. Make sure your pension provider has up-to-date details of your beneficiary. If you have more than one pension, tell all your providers.

CHOOSING WHERE YOU WOULD LIKE TO BE LOOKED AFTER

Choosing where to die

The choice of where you will die often depends on:

- what you would like
- what help you have from family and friends
- the services available where you live
- your medical condition.

You might prefer to die at home, if you know you will have good quality care. Even if you choose not to, you can still be surrounded by people and things that are important to you.

Wherever you are cared for, it is important that your symptoms are well managed and you get the care you need. This can happen in different places.

At home

Staying at home allows you to be in a familiar place, with close family members or friends to look after you. It may help you feel more in control. It may also make it easier for you to say goodbye to people you love.

It is important that you and your carers have as much support as possible. There are people and organisations that can help you manage any symptoms and support you and your carers at home. If you would like to die at home, tell your GP, cancer doctor or nurse (see pages 66 to 73).

Hospice

Hospices specialise in caring for people who have a terminal illness and may be close to the end of their life.

They have doctors and specialist palliative care nurses who are experts in controlling symptoms such as pain. They also provide emotional support. Many hospices have nurses and healthcare assistants who can visit and help care for people at home.

You can go into a hospice for different reasons. For example, you may stay there for a short time to get your symptoms under control. Some hospices offer respite care. This means you can go in for a short time to give your carer a break. Your palliative care team can tell you what is available at your local hospice.

You may decide that you would like to die in a hospice. You will need to discuss your wishes with your family, your GP and the hospice team involved with your care.

Hospices are very different to hospitals. They are quieter and provide care to suit each person's situation. Visiting is usually less restricted than in a hospital. They may offer a wide range of services for patients and their families. These may include:

- counselling
- spiritual care
- complementary therapies
- psychological support
- bereavement support.

Accommodation and care in a hospice is always free of charge. Each hospice has a limited number of beds. There may be a waiting list, but urgent admissions can sometimes be arranged within a couple of days. It can help to talk to your GP and palliative care team to try and plan ahead.

Some hospices have outpatient services or day centres. If you are living at home, you can visit the day centre for a day or more each week. You can get care from the specialist team and support from other people who are living with similar illnesses.

You can find out more about your local hospice from your GP, district nurse or palliative care nurse. Hospice UK also has useful information about hospices and where they are across the UK. If you are not sure about hospice care, you can ask to visit the hospice. The staff will be able to show you around and talk through any questions or concerns you have. You can visit **hospiceuk.org** to find out more.

> ‘I always thought hospices were places where people just went to die, but they’re not. Mandy my Macmillan nurse reassured me. She explained that you can also just go there for a bit of respite.’
>
> **Claire**

Residential homes or care homes with nursing

If you might need care for several months, you may prefer to be looked after in a residential care home or care home with nursing (nursing home). A care home with nursing has qualified nurses on their staff to provide nursing care. They usually offer short-stay or long-stay care.

You may still be able to go to the hospice for day care. Or a specialist nurse from a hospice may be able to visit you in the care home.

Your GP or healthcare team can explain the different types of care homes. They may be:

- privately owned
- run by a charity
- run by the local council.

A private care home charges a fee for care. But you can sometimes get help with paying this if you have few or no savings.

You may be able to get NHS funding for your care in a care home with nursing. For example, this may be if you are reaching the end stages of your illness, or if you need a lot of nursing care and support. A hospital nurse, district nurse, hospice nurse or social worker can tell you more about fully-funded care. If you live in Northern Ireland, funding for care homes is based on your income (means-tested).

NHS UK has information about care homes and funding for care. (see page 140). You can get lists of local registered care homes and details of registered care homes with nursing from your local social services department and your area health authority. You can also search for a care home by visiting **carehome.co.uk**

Hospital

If you have been in and out of hospital over the last few months, you may want to go back to your usual hospital ward when you need full-time nursing care. This might be easier to arrange if you have been in a small local hospital (for example, a cottage hospital) rather than in a district general or teaching hospital.

Although many people die in hospital, it may not be the most peaceful place to be if the ward is busy. Often you will need to fit into the ward routine, rather than being looked after in the way that you would like.

Hospitals have palliative care teams that include specialist nurses and doctors. A specialist nurse or doctor from this team may be able to see you while you are in hospital. They can help manage your symptoms and offer you and your family emotional support.

Who can help if you are looked after at home

You may need extra help if you are being looked after at home. It is not always easy to ask for help, as you might feel you should be able to cope. But caring can be hard work for the people looking after you, both physically and emotionally. There are many health and social care professionals who can help you.

Your district nurse, specialist nurse or GP can tell you how to get help from health and social care professionals and voluntary organisations. They can also tell you about any specific help and support available in your area.

Your GP

When you are being looked after at home, your GP has overall responsibility for your care. Your GP is responsible for prescribing any drugs you need. If needed they can also arrange for you to go into hospital or a hospice. They can help with the following things:

- If you are worried about any changes in your symptoms, your GP can arrange to see you. This could be in the surgery or at home. They will discuss what treatments might help control any symptoms you may have. They can also refer you to the palliative care team if your symptoms are more troublesome.
- You can talk to them about what may happen as you become less well.
- They can help if you want to make plans for the future, so you get the care you want. This could include planning for emergencies, and making a statement of your wishes (see page 29) or an advance decision to refuse treatment (see pages 31 to 33).
- If you need nursing care, your GP can arrange for a district nurse to visit you. They will help to organise nursing care for you at home.

District nurses

District nurses work closely with GPs. They will visit you at home and assess your nursing needs. They can help with the following things:

- Coordinating your care. They can contact other health or social care professionals to help with your care, if needed.
- Monitoring and treating any symptoms you may have.
- Giving injections, changing dressings, giving advice and support on pressure area care and toilet problems, such as incontinence and constipation. They may organise equipment to help with pressure care or continence, such as a special mattress or a commode.
- Showing your family or carers how to move you and take care of your personal needs.

District nurses often work with palliative care nurses to help support you and your carers so you can stay at home. They may be able to arrange for a social carer or a healthcare assistant to help you with things such as washing and personal care.

Marie Curie Nurses

Marie Curie nurses are available in some parts of the UK (see page 140). You can get one-to-one, overnight care from a registered nurse or senior healthcare assistant in your home. The shifts are usually for eight or nine hours. In some parts of the UK, they also offer shorter shifts, evening shifts and day shifts. How much care they can provide may differ. They cannot usually offer complete, 24-hour care. The services of Marie Curie nurses are free. They are usually arranged through the district nurse, who will talk to you and your carers to decide what hours of care you need.

Social workers or care managers

If you need help with personal care, such as washing and dressing, a social worker or care manager can arrange a care package for you. They may also be able to arrange extra help with housework, shopping and cooking.

Your doctor or district nurse can refer you to social services. Or you can refer yourself. You are usually offered an assessment of your needs. You usually have to pay towards the cost of services, depending on your financial situation. But you may be able to get extra benefits to help you get care.

Social workers or care managers can tell you about any benefits you may be able to claim. They may also be able to provide more counselling and emotional support for you and your carers.

Physiotherapists

Physiotherapists can help keep you walking and moving around (mobile). They also offer treatment, massage and exercise programmes to help relieve pain. Your GP or community nurse can refer you to a physiotherapist.

Occupational therapists

Occupational therapists can help you keep your independence at home. After an assessment, they may be able to arrange for aids to be delivered to help your day-to-day living. These might include toilet frames, handrails or a wheelchair. They can also arrange for changes to be made to your home, such as fixing safety rails in bathrooms or making doors wider. If you have difficulty getting dressed, they may be able to suggest and arrange to have your clothes altered. Many occupational therapists can help you manage low moods, by changing daily routines and activities. Some therapists can also help with managing anxiety.

Voluntary organisations and charities

Voluntary organisations and charities offer different kinds of help, including information, loans of equipment, grants and transport.

Some organisations have volunteers who can provide short periods of respite care. This gives your carer a break during the day time. Others, including Marie Curie, provide befriending services for people who are on their own. They can introduce you to a trained volunteer who may be able to give one-to-one help and support.

Palliative care

Wherever you are being cared for, you can get help and support from a palliative care team.

Hospital or community specialist palliative care teams

Specialist palliative care teams provide care for people who are close to the end of their life. They can also provide support for the person's family and friends. Some people are referred to a palliative care team early on in their illness, for example if they have troublesome symptoms. The palliative care team may be involved in the person's care for some months.

Your cancer doctor, specialist nurse or GP can refer you to a palliative care team if you need specialist support or care. Hospital palliative care teams are usually based in a hospital. They can visit you if you are in hospital or attending a clinic appointment. Community palliative care teams are based in the community. They are often linked to a hospice and can visit you at home or in a care home.

What do palliative care teams do?

Palliative care teams might include or work closely with:

- specialist palliative care nurses
- specialist palliative care doctors
- a social worker
- a counsellor
- an occupational therapist
- a physiotherapist
- a spiritual care coordinator or chaplain.

Palliative care teams can give you advice on pain control, coping with other symptoms, emotional support and practical problems. They can also support you to make an advance care plan and help to coordinate your care.

Palliative care nurses are experienced in assessing and treating any symptoms you may have. They can also provide counselling and emotional support for you and your carers. Palliative care nurses are sometimes called Macmillan nurses. Many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may see them when you are at a clinic or in hospital.

Specialist palliative care doctors can give expert medical advice on the management of symptoms. They work closely with palliative care nurses and may visit people at home, if needed.

Some community palliative care teams have nurses or healthcare assistants who can visit you at home and provide practical care. This might include washing you, dressing you and giving you drugs. A palliative care nurse can tell you more about the care provided by their team.

THE LAST FEW WEEKS OF LIFE

The last few weeks

During the last few weeks of life, you may experience emotional and physical changes or symptoms. This is normal, but can be upsetting for you and the people around you. Being prepared for what may happen can make the situation a little easier to cope with.

Emotional changes

You may feel lots of different emotions, including:

- worry
- anxiety
- panic
- anger
- resentment
- sadness
- depression.

It is natural to have these feelings in the last few weeks of your life. You may also feel concerned that you are less able to do things. You may worry about losing your role in your family or with friends.

Talking to your family and friends about how you are feeling can help. You can find more information in our booklet **Talking about cancer** (see page 134). It may also help to talk to someone in your healthcare team. This could be a palliative care nurse or doctor. You may find you feel better once you have talked about your concerns. Some people prefer to talk to a person they do not know, such as a trained counsellor.

Many support organisations can help and some have helplines (see pages 138 to 144). You may also find it helpful to talk to a religious or spiritual adviser (see page 23) You can do this even if you have not attended religious services or had contact with spiritual leaders before.

You may not want to talk about what is happening. Everyone is different and it is important to do what is right for you. If other people want to talk about your situation and you do not, just tell them gently that you would prefer not to. They may find it helpful to call the Macmillan Support Line to talk about how they are feeling. Call **0808 808 00 00**, 7 days a week, 8am to 8pm.

You may become withdrawn and quiet. This may be caused by depression. If you think you might be depressed, tell your doctor or nurse. They can give you help and support. You can find more information in our booklet **How are you feeling? The emotional effects of cancer** (see page 134).

Becoming withdrawn can be a natural part of gradually retreating from the world. You may find yourself losing interest in the things and people around you, even close family.

Coping with physical changes and symptoms

The physical changes and symptoms that happen can vary. Here, we describe physical changes that generally happen in the last few weeks of life.

As you become less well, your doctor or nurse will review your medicines. They may stop some if you do not need them anymore. If you have new symptoms, your doctor or nurse may prescribe new medicines to manage them. Medicines can be changed as often as you need. Some people find complementary therapies improve their quality of life and well-being (see page 100). They may sometimes also help reduce symptoms.

Tiredness and lack of energy

It is normal to have less energy. You may need help to do things you usually do for yourself. Tiredness and weakness can make it harder for you to concentrate or take part in what is going on around you. You may find you need to rest a lot during the day.

Things that can help

- Try to pace yourself. Save your energy for the things that matter to you and that you enjoy.
- Try to do less cooking, cleaning or other household jobs. If you can, ask your friends and family to help you with these tasks.
- If washing and getting dressed tires you out, ask a carer to help you with this.
- Use equipment that helps you with daily tasks, such as a raised toilet seat, bath board or walking frame. These can help stop you getting so tired.
- If you have important things that you want to do, such as sorting out your financial affairs, do them at a time of day when you have more energy.
- If you find eating difficult, try eating little and often.

We have more information in our booklet **Coping with fatigue (tiredness)** – see page 134.

Difficulty sleeping

You might find you cannot sleep well at night. There may be many reasons for this, including:

- taking medicines which can keep you awake, such as steroids
- feeling anxious or depressed
- feeling afraid that you might die in the night
- having symptoms that are not well controlled, such as pain, breathlessness or incontinence
- other factors, such as light or noise, or sleeping too much during the day.

Tell your doctor or nurse if you are not sleeping well. There are things that can help you get a better night's sleep. Also tell them about any specific anxieties or symptoms that might be affecting your sleep. They may be able to suggest things to help, for example taking some medications at a different time. They may also suggest you try taking sleeping tablets.

Things that can help

- If your mattress is uncomfortable, ask your nurse for advice about a more comfortable one.
- Try to reduce light and noise at night. Wearing an eye mask might help if your room is too light.
- Have a warm drink before going to bed, but avoid caffeine and alcohol.
- Keep your bedroom for sleeping. If you wake up during the night, try not to toss and turn. Go to another room in the house, if you can. When you feel sleepy, go back to bed again. If you need to sleep during the day, go to your bed and sleep there.
- Avoid using any screen, such as a TV, computer, tablet or smartphone for at least an hour before going to bed.
- Keep a notebook by your bed. If you wake up during the night, you can write down anything you are worried about or need to do. You can work through your list during the day and get support and advice from your carers or your doctor or nurse.
- Try using relaxation techniques at night. You may find it helpful to use a relaxation CD or listen to some soothing music. An occupational therapist or physiotherapist may be able to show you some relaxation techniques.
- If you find touch and massage helpful, you could ask your carer to give your hands or feet a gentle massage.

Pain

Many people are worried about pain as their illness gets worse. Not everyone has pain in the last few weeks of life. But if you do, there are usually effective ways of controlling it. If you have pain, tell your doctor or nurse exactly where it is, how it feels, and how it affects you. This will help them treat it. We have more information in our booklet **Managing cancer pain** (see page 134).

Painkillers

Everyone feels pain differently. There are different painkillers for different types of pain. These include:

- simple painkillers, such as paracetamol
- moderately strong painkillers, such as codeine
- strong painkillers, such as tramadol, morphine, oxycodone, fentanyl and diamorphine
- anti-inflammatory drugs, such as ibuprofen and diclofenac
- painkillers for nerve pain, such as gabapentin, pregabalin, amitriptyline and duloxetine – some of these drugs are also used for other conditions.

Painkillers are often given as:

- tablets
- liquid medicines
- patches stuck on to the skin.

You may need more than one type of painkiller to get the best effect.

If you have trouble swallowing or are being sick, you can have painkillers as an injection or through a syringe pump. These drugs include morphine, diamorphine and oxycodone.

Syringe pumps

A syringe pump is a small portable pump that can be used to give medicines. It is sometimes called a syringe driver.

Syringe pumps are used for different reasons. They can be used if someone cannot absorb medicines properly through their stomach, or if they have difficulty in swallowing. In the last few weeks of life, you may find it more difficult to swallow medicines. Your doctor or nurse may suggest using a syringe pump to help you get the medicines you need. You can have, anti-sickness medicines, painkillers, anti-anxiety medicines and several other medicines through a syringe pump.

A syringe containing the medicines is attached to the pump. The pump delivers a continuous dose of the drug or drugs from the syringe through a small, thin needle. The needle is inserted just under your skin. It usually goes into your tummy (abdomen) or your arm and is held in place with a clear dressing. Usually each syringe contains enough medicine for 24 hours. The pump is usually put in a clear locked box to protect it.

Your nurse or doctor will set a syringe pump up for you.
Your nurses can change the syringe when needed.

How much painkiller you will need

You might worry you will need to take increasing doses of strong painkillers as you near the end of your life. It is important to remember that not everyone will have pain that gets worse. There is no right dose of morphine. The right dose is the dose that helps your pain.

Specialist palliative care doctors and nurses have lots of experience in managing pain. They can help make sure you have the right dose of painkillers to control your pain, without too many side effects. Your GP or cancer doctor can refer you to a specialist.

Side effects of painkillers

Strong painkillers have three common side effects:

- Drowsiness, which usually wears off after a few days. You should be pain-free and still awake enough to do everything you want to. You should not drive if your painkillers make you drowsy.
- Sickness, which usually gets better over a few days. Your doctor can prescribe anti-sickness medicines (anti-emetics) if you need them.
- Constipation, which means you will usually need to take a laxative regularly. Your doctor, nurse or pharmacist can advise you about this.

Things that can help

- Always take your painkillers regularly, as your doctor or nurse tells you to.
- Tell your doctor or nurse as soon as possible if your pain is not controlled.
- Be aware of the side effects of your painkillers and take medicines to keep them controlled, if needed.
- Make sure you do not run out of your prescribed medication. If you do not have much left, ask your doctor or nurse for another prescription.
- Keep a pain diary if you can. Ask your district nurse or specialist nurse if they can give you one. You can order a pain diary as part of our booklet **Managing cancer pain** (see page 134), or download a copy from our website. Visit **macmillan.org.uk**

Other ways of controlling pain

There are other things which may help to control pain – these can be used alongside painkillers:

- Find a comfortable position to sit or lie in.
- Use any special equipment you have been given. For example, you could use pressure relieving cushions on chairs.
- Use relaxation techniques, such as deep breathing or meditation.
- Try to distract yourself from the pain. For example, you could listen to music or watch a film you enjoy.

There are other, more specialised ways of controlling pain. These include transcutaneous electrical nerve stimulation (TENS) and acupuncture. Your doctor or nurse can tell you if these might be suitable for you. You may know of other things that have helped control your pain in the past. Talk to your doctor or nurse about trying them to see if they help now.

Feeling sick and vomiting

Your illness, or your medicines, may make you feel sick (nausea) or be sick (vomit). If this happens, your doctor or nurse can prescribe anti-sickness drugs (anti-emetics), which usually help. These may be taken as tablets or liquid medicines. If you find it difficult to swallow these, they can also be given:

- as suppositories that are inserted into your back passage
- as injections
- by a syringe pump (see page 83).

Things that can help

- Take anti-sickness medicines regularly to help stop the sickness returning.
- Have warm or cold food, as this does not smell as strong as hot food.
- Eat dry foods, such as crackers.
- Food or drink containing ginger can help. You could try crystallised ginger, ginger tea, ginger beer or ginger biscuits.
- Sip fizzy drinks.
- Eat little and often.
- If cooking smells make you feel sick, you could ask someone else to prepare food for you.

Weight loss and loss of appetite

You may lose weight, even if you are eating well. This can be upsetting. You may find that your appetite reduces over time because of your illness or the medicines you are taking. You may be put off eating by the sight and smell of food.

As you near the end of your life, your body slows down. It does not need food as it cannot digest it or absorb nutrients from it. Do not force yourself to eat. This could make you feel unwell.

Medicines, such as steroids, can sometimes boost your appetite. Your doctor can prescribe these if they are suitable for you.

Things that can help

- Eat small frequent meals. Try using a smaller plate and serve small portions.
- Do not feel you must eat – it is normal for your appetite to reduce as you near the end of your life.
- Eat if you feel like eating and eat the things you want to.
- If you want to eat but do not like the smell of cooking, ask someone else to cook your food.
- Have snacks nearby to eat.
- Eat slowly.
- Consider eating foods that are easy to chew and digest, such as soups, custard and ice cream.

Your family and friends might feel anxious or upset because you no longer feel hungry or enjoy food. Talk to them about what you would like to eat or drink. This way they know the best things to offer you.

Constipation

Many people find they get constipated more easily because they are not moving around or eating and drinking as much. Medicines such as strong painkillers can also cause constipation.

Things that can help

- Take your laxatives as your doctor or nurse tells you to.
- If you are constipated, tell your GP or nurse as soon as possible. Tell them if your laxatives are not working or if your stools (poo) become too loose.
- Drink as much fluid as possible.
- If you are able to eat, try things that are high in fibre. This includes fruit and vegetables, brown rice, brown bread or brown pasta.

Breathlessness

Some people may feel breathless. This can be for different reasons, including:

- cancer in the lung
- general weakness
- fluid around the lungs (pleural effusion)
- chest infections
- anaemia (low level of red blood cells).

Breathlessness can be very frightening. But there are things that can help, depending on what is causing it.

Some medicines, such as a very low dose of morphine, can be used to help breathlessness.

Oxygen may be helpful for some people. Your GP or nurse can arrange for you to have oxygen at home if you need it.

If you have a pleural effusion, your doctor at the hospital or hospice may be able to drain the fluid. If you are anaemic, your doctor may arrange for you to have a blood transfusion if they think it would help.

It is important to tell your doctors and nurses as soon as possible if:

- you are breathless
- you suddenly become more breathless than usual.

Then they can give you the best treatment to help.Nurses can show you and your carers the best positions for you to sit or stand to help with your breathing. They can also teach you how to breathe more effectively, plan your activities and save your energy.

Breathlessness may make you feel anxious. This can make your breathing feel even more difficult. Your nurse or a physiotherapist can teach you ways to relax, so that you feel less anxious and breathless. Sometimes medicines that treat anxiety can help with breathlessness.

Things that can help

- Think about ways to arrange your home to make tasks easier. For example, you could place a chair in the hallway or at the top of the stairs. This way, you can rest when walking between rooms or up and down stairs.
- Sit down to do everyday tasks like washing and dressing.
- If you feel breathless, try sitting by an open window. You can also use an electric fan or handheld fan to blow air on to your face.
- If you need to talk to someone in another room without getting up or shouting, use a mobile phone, a baby monitor or an alarm.
- If you are breathless in bed, try using a V-shaped pillow to help you sit in a more upright position.
- If you have difficulty getting to the toilet, use a commode or urine bottle.

Our booklet **Managing breathlessness** and our CD **Relax and breathe** may be helpful (see page 134).

Difficulty moving around

As your illness progresses, you may find it harder to move around. This may be because you are very tired, or have symptoms such as pain, swollen limbs or a swollen tummy.

If you are not moving around very much, you may get sore areas. For example, you may get sore on your bottom or heels. Your district nurse can arrange equipment, such as a pressure-relieving cushion for your chair or a mattress for your bed, to help prevent this. You can also help to ease soreness by changing your position regularly, if you can. we have more information about side effects and symptoms in our booklet **Managing the symptoms of cancer** (see pages 134).

Cough and wheezing

You may have a cough or feel wheezy. This can be tiring and upsetting. Your doctor can prescribe medicines to help with these symptoms. You may find it helpful to sit as upright as possible, supported on pillows. This may also help you breathe more easily.

Mouth problems

You may develop problems with your mouth, such as a dry mouth, ulcers or an infection. Some medicines can make these problems worse. Looking after your mouth is important and can help prevent mouth problems. Tell your nurse or doctor if you develop any mouth problems so they can help.

Things that can help

- If you can, brush your teeth twice a day using a fluoride toothpaste. Use a soft children's toothbrush if your mouth is sore.
- Rinse your mouth with fresh water after brushing.
- Rinse your mouth 3 or 4 times a day to remove debris and keep it clean. You can use plain water or a salt-water rinse (add 1 teaspoon of salt to 1 pint of cold or warm water). You should rinse your mouth with cold or warm water after using a salt-water rinse.
- If you have false teeth, clean these as usual and soak them overnight.
- Use any mouthwashes that have been prescribed for you, and follow the instructions.
- Cut down on smoking and substances that can dry or irritate the mouth, such as caffeine and alcohol.
- If you have a dry mouth, sip tonic water or lemonade, or try sucking ice lollies or ice cubes or chewing sugar-free gum.

We have more information about mouth problems on our website (see page 134).

Fluid build-up (oedema)

In some people, fluid collects in a part of their body. This is called oedema. Water tablets (diuretics) can sometimes help get rid of the fluid. Your doctor can tell you if they may be suitable for you.

The fluid may cause your legs and ankles to swell. Your doctor may prescribe pressure stockings to help control this. These are not suitable for everyone. Using a footstool to keep your feet up when you are sitting down, and gently exercising your legs may also help. A nurse or physiotherapist can show you some exercises to do.

You may find it harder to move around if your legs are swollen, and this can be frustrating. Your nurses can help you find ways of moving around.

Changes in appearance

Your appearance may change as your illness progresses. For example, you might put on or lose weight. This can be upsetting. You may find it helpful to talk about your feelings with your carers or your nurses. They may be able to help you find ways to look and feel better. Our booklets **Feel more like you** and **Body image and cancer** offer help and advice on changes in appearance (see page 134).

Infection

You may be more at risk of an infection, such as a chest or urine infection, if:

- you are not moving around much
- you are not eating or drinking well.

Tell your doctor straight away if you develop a high temperature or start to feel shivery, shaky or unwell. They may prescribe antibiotics to treat the infection.

Anaemia (low red blood cell levels)

Anaemia can make you very tired and breathless. If you are anaemic, your doctor or nurse may suggest you have a blood transfusion if they think it will help. You usually have this as a day patient in a hospital or hospice. You can find more information on our website at **macmillan.org.uk**

Swollen tummy (ascites)

With some types of cancer, fluid may sometimes build up in the tummy (abdomen). This can cause your tummy to swell and make it feel tight and uncomfortable. This is called ascites. Your doctor may suggest you have a tube put into your tummy to drain off the fluid. This is done using a local anaesthetic and can sometimes be repeated if needed. Taking water tablets (diuretics) can sometimes help with ascites. Your GP or specialist palliative care nurse can discuss this with you. We have more information on our website at **macmillan.org.uk** (see page 134).

High calcium levels (hypercalcaemia)

Some types of cancer can cause high calcium levels in the blood. This is called hypercalcaemia. It can make you feel drowsy or sick. It can also cause confusion or constipation. It may make pain more difficult to cope with. If you develop these symptoms, tell your nurse or doctor. They can do a blood test to check your calcium levels.

If your calcium level is high, your doctors may give you medicines to help reduce it. These are called bisphosphonates. You have them through a drip. You will need to be in hospital or a hospice for a few days.

Managing difficult symptoms

Usually, it is possible to manage your symptoms at home. But sometimes it can help to have them treated in a hospital or hospice for a few days or weeks. Your community palliative care team, district nurse or GP will talk to you about this if they think it would help. Being in the hospital or hospice means that the doctors and nurses can assess your symptoms better. They can adjust any medicines more quickly than if you were at home. This means they can control your symptoms more quickly. Once your symptoms are controlled, you can often go home again. You are then under the care of your GP, with the support of your community palliative care team and district nurses.

Bladder problems

You may have problems passing urine (peeing) or controlling your bladder. A nurse can put a thin, flexible tube (catheter) into your bladder to drain the urine. This can also save you the discomfort of using a bedpan or bottle if you cannot get out of bed.

Complementary therapies

Many people find complementary therapies can help them feel stronger and more able to cope with physical changes and their worries about dying. They may also improve their quality of life and reduce symptoms.

Some hospices and hospitals may offer complementary therapies alongside conventional care. Therapies may include:

- acupuncture
- homeopathy
- relaxation, visualisation, or guided imagery techniques
- aromatherapy
- reflexology
- reiki.

You might like to try some complementary therapies, such as relaxation and visualisation, to reduce anxiety. Hospital or hospice staff trained in complementary therapies may also be able to teach your carers how to give you a massage.

Some hospices and hospitals also offer free complementary therapies to carers. You can ask your nurse about which therapies are available in your local area. We have more information in our booklet **Cancer and complementary therapies** (see page 134)**.**

THE LAST FEW DAYS OF LIFE

The last few days

Each person's experience of the last few days of life will be different. It can be difficult to know exactly what will happen, or how quickly things will change. Usually, you slowly become a lot weaker and have very little energy. But sometimes changes happen more quickly. You may:

- find it difficult to move around and need help getting from your bed to a chair
- need to spend most, or all, of the day in bed
- lose interest in eating and drinking
- sleep a lot and feel sleepy when you are awake
- feel disorientated and unsure whether you are dreaming
- dream about people who are not there or that you knew in the past – your mind may think about old memories
- lose interest in your surroundings and the people around you, even your close family members.

Physical care

During your last few days, you will need a lot of help with things like washing and changing your clothes. It may feel strange to need so much help. But you may also become very close emotionally to the people who are caring for you at this time. If your carers need help to wash and bathe you, a district nurse or your specialist nurse can arrange this. They can also show your carers how to lift and move you safely and comfortably.

If you have a dry mouth, a district nurse can show your carers how to regularly moisten your mouth. They can also put lip balm on to your lips to stop them getting dry and cracked.

It is important that your carers moisturise your skin and help you change your position regularly. This helps to stop your skin getting sore. Your nurses can advise your carers on how to look after your skin. They can also help them make sure you are in a comfortable position if you cannot move yourself. There are pressure care aids to help keep you comfortable. These include:

- cushions for chairs
- mattresses for beds
- special beds with pressure-relieving mattresses.

A district nurse can assess what you need and arrange things for you.

There may be times when you do not need to have anything done. You can just sit or lie quietly with your family and friends. This can be a very intimate and special time. You can tell them if you would like to talk, be quiet or listen to music. You may want some time on your own. If you do, you could ask your carers to leave you alone for a while. But also tell them if you would like someone to be with you all the time. It will help your carers in planning your care.

Symptoms

If your symptoms change, your doctor or nurse may change your medicines so your symptoms are well-managed (see pages 78 to 99). They may also stop some medicines if you do not need them anymore. If you develop new symptoms, they can give you new medicines.

If you find it difficult to swallow, your doctor or nurse can give you your medicines:

- as an injection
- through patches stuck onto the skin
- through a syringe pump (see page 83).

‘Just-in-case’ medicines

Your GP, a district nurse or the palliative care team may suggest leaving a small case or box of medicines in your home in case you need them. These are sometimes called ‘just-in-case’ medicines. If you get more pain or start to feel or be sick, getting medicines quickly can be difficult, especially at night or weekends. If you have ‘just-in-case’ medicines at home, a nurse or doctor can give them to you straight away if you need them.

‘Just-in-case’ medicines usually include injections to help with pain, sickness, restlessness and fluid in your chest.

Nearing death

The thought of being close to death can be very frightening. Although death is a natural process, it is normal to worry about what will happen.

You may want to have a religious or spiritual adviser with you. There may be certain religious practices you want to follow. It is important to do whatever feels right for you.

It can be comforting to have someone with you as you die. Not everyone has family or friends who can do this. Some places have volunteers who can sit with you when you are nearing the end of your life. Soul midwives and doulas are people who can be with you when you are close to the end of your life. They are there to provide company and spiritual support during the dying process. You usually need to pay for their services. You can find more information on their website **soulmidwives.co.uk**

What usually happens

Dying is often very peaceful. You usually slip into a deep sleep, where it gets harder and harder to wake up.

Usually, you gradually become completely unconscious. You cannot be woken at all, but may still be able to hear and be aware of the people around you. There might be times when you are awake and can talk, and then you slip back into unconsciousness.

If you are at home, your carers can contact your district nurse, specialist nurse or GP 24 hours a day, 7 days a week. This could be if they are concerned you are in pain or have other symptoms that are difficult to control.

The GP or specialist nurse can give you medicines to control your symptoms, either as an injection or through a syringe pump. They can also discuss any concerns you or your carers have and reassure you.

We have information about what may happen when someone is dying (see pages 122 to 124).

IF YOU ARE A CARER

If the person you are caring for is near the end of life

Although dying is a natural process, few people have experience of looking after someone at the end of their life. If you are caring for a loved one, you may be anxious about looking after them at home. However, with the right help it can be rewarding and can also bring you closer to the person who is dying.

A lot of the information in other sections will be helpful for you as a carer. For example, there is information about who may be involved in the person's care and how they can help you. In this section, we explain more about:

- caring for someone in the last few weeks and days of life
- what happens after they have died.

> 'There was a 'pre-grieving' stage when mum was still alive. It's an emotional rollercoaster of feeling frustrated, sad, happy, angry and probably six other emotions.'
>
> **Max, whose mum died of cancer**

Emotional changes in the last few weeks of life

The person you are caring for may feel lots of different emotions during this time. These may include feeling worried, anxious, panicky, angry, resentful, sad and depressed. They may become quieter and want to communicate less (become withdrawn). They might also seem to lose interest in their surroundings. It is natural for them to have some or all of these feelings.

It can be upsetting if the person you are caring for becomes withdrawn and seems to lose interest in things around them. You may already miss the way your relationship used to be and the things you used to do together. This is understandable.

Sometimes, it may feel as though the person you are caring for is giving up. But remember, this is often part of the natural process of dying. If they seem upset, angry or afraid, try to listen to what they are saying and acknowledge their feelings.

You may not feel as though you are doing much, but just being there and listening will help your loved one feel supported. They can talk to you about important issues or worries if they want to. You do not need to have answers. Just listening is helpful and comforting.

Caring during the last few weeks of life

The person you are caring for may have different symptoms during this time (see pages 78 to 99). There are lots of things that can help make sure your loved one is as comfortable as possible. If you are worried about any symptoms, tell the healthcare professionals involved in the person's care. They may be able to change their medicines or arrange for some equipment that could help.

You may have been helping to prepare meals for your loved one. But as time goes on, they may not want to eat. This is quite natural, because the body does not need food towards the end of life. Although this can be hard to accept, it is important not to try to force them to eat. You may want to offer them drinks they like instead.

Caring can be physically and emotionally demanding. If you have been looking after your partner, family member or friend for some time, you may start to feel drained. You may also have a lot of strong emotions, including anger or resentment, towards the person you are looking after. If you feel like this, or are feeling trapped by your situation, it is important to tell your GP or a nurse. They can help you cope. You could also contact your local hospice to see what support they can offer.

Looking after yourself

It is important to look after yourself, as well as the person you are caring for. Try and make sure you eat well and do some exercise. Tell your GP that you are caring for someone. Also tell them if you have any concerns about your own health. Try to be honest with yourself, and your GP, if you need some emotional support at this difficult time. Often the hardest thing is admitting to someone that you need help.

You could arrange for someone to help regularly so you can have some time to yourself. This can help, even if it is only for a few hours a week. If there is not a family member or friend who can help, you could contact a carers' organisation, such as Carers Trust and Carers UK (see page 144). Having some help with caring may allow you to spend more time being a family member, partner or friend to your loved one.

When you get time off from caring, try to relax. It may be tempting to spend this time doing housework or the washing. But doing something you enjoy can help give you more energy and improve your mood. You could meet someone for coffee or do something that is for you, such as getting your hair done. You could also spend time just sitting with and talking to the person you are caring for. This can be very rewarding. Try not to feel guilty – looking after yourself will help you care for your loved one better.

If caring becomes difficult

You may find it difficult to look after someone at home for many reasons. As time goes on, you may feel they would be better looked after in a hospice or care home. This may be because their situation has changed and you do not have the nursing or medical skills to look after them. You may also feel that caring for them has become very difficult emotionally. Talk to the district nurse or GP if you need more help to care for the person at home. They may be able to provide the extra support you need. Or they can give you advice about where your loved one could be cared for.

It is important to not feel guilty if the person you are caring for needs to move from home near the end of their life. You should not see it as a failure. Instead, remember that you are making sure they get the best possible care.

> ‘Look after yourself. You cannot expect to look after and support your loved one if you don’t look after yourself.’
>
> **Max, whose mum died of cancer**

Caring for someone in the last few days of life

As your family member or friend gets close to the end of their life, you may need more support from health and social care professionals. You can contact the district nurse, palliative care nurse or social worker. They will review their needs, and arrange extra care services if necessary.

The person you are caring for will probably not want anything to eat or drink at this time. You can keep their mouth and lips moist to help them feel comfortable.

Pain

The person you are caring for may show signs of being in pain. They may be restless, screwing up their face (grimacing), or moving as if they are in pain. They may sweat and have a fast heartbeat and breathing rate. If this happens, tell the doctor or specialist nurse. They may need to increase the dose of their painkillers. There may be another cause for these symptoms, such as an infection. The doctor or specialist nurse can advise you about the best way to help and prescribe medicines if needed.

Breathing changes

The person's breathing may change. For example, their breathing may become irregular, or it may become noisy because of fluid in the breathing passages. This can be upsetting for you. But the person will not usually seem distressed. The doctor or specialist nurse can give medicines which may help.

Restlessness

The person you are caring for might have symptoms of restlessness, agitation, confusion, shouting or twitching. This is often called terminal restlessness. These symptoms can be caused by pain, constipation, difficulty passing urine, infection, side effects of medicines, or a build-up of waste chemicals (toxins) in the blood. Some people become restless because of emotional distress, a fear of dying or a fear of losing control. They may get comfort from a close friend or family member, a trusted health professional or a spiritual or religious leader.

The doctor or specialist nurse will try to treat the cause of the restlessness. But if this does not help or they do not know the cause, the symptoms can often be controlled with medicines such as sedatives. These can be given by injection or through a syringe pump.

Incontinence

As the person you are caring for gets closer to death, they may lose control of their bowel and bladder. This is natural. Talk to the district nurse about this, as they can get you aids to help, such as bed covers and pads. Men can have a sheath put over their penis to collect urine and drain it into a catheter bag. It may be more comfortable for the person to have a tube (catheter) put into the bladder to drain the urine.

Urine retention

Sometimes urine cannot drain out of the bladder, and so the person cannot pass urine. This causes severe abdominal pain, and their tummy (abdomen) will feel very hard and bloated. If this happens, contact your doctor or nurse straight away and ask them to come urgently. They can put a catheter into the bladder to drain the urine and relieve the pain.

Religious and spiritual needs

The person you are caring for may want particular practices carried out, or prayers read, as they are dying. It is important to do whatever you both feel is right and most helpful. It may be helpful to keep a note of anyone you need to contact in this situation.

Contacting support services

Make sure you have phone numbers for the:

- GP
- district nurse
- specialist nurse
- out-of-hours services (to use in the evening, at night and at weekends).

If you are worried that the person you are caring for seems distressed or has new or uncomfortable symptoms, contact one of them for advice and support.

Keep the numbers in a safe place. Make sure you know who to contact first. This will help you feel more confident if you need to contact anyone.

End of life care plan

You may hear the doctors and nurses talk about an end of life care plan for the person you are caring for. This explains the care your family member or friend will need as they approach the end of their life. It will help to make sure that their needs for food, drink, symptom control, and emotional, spiritual and social support, are met.

The doctors and nurses will involve you in decisions about your family member or friend's treatment and end of life care plan. They will also give you emotional and practical support.

If you would like more information about your family member or friend's end of life care plan, speak to one of their doctors or nurses.

Caring for someone nearing death

You can help keep your family member or friend comfortable as they near death. Even if they are unable to respond, they may still be able to hear you and know you are there.

You can still speak to them and tell them what you are doing, especially if you are giving them medicines or moving them. This may feel strange if they cannot respond, but it can be comforting for both of you. You may need to move them regularly to keep them comfortable. But there may be times when not much needs to be done for their care, and you can just sit with them and be close to them.

It is ok to contact your family member or friend’s GP or specialist nurse to tell them what is happening. Ask them for help and advice if you need it.

Physical changes

The person you are caring for will not usually feel thirsty at this stage. But their mouth may be dry and need to be moistened. The nurses can teach you how to help with mouth care. If your family member or friend feels sick, a nurse can give them anti-sickness medicines (anti-emetics) by a syringe pump or an injection.

Skin and sensation changes

In the last few hours, the person's hands, feet and skin may feel very cold and possibly moist. Sometimes the skin changes colour and becomes slightly more blue, grey or white. Their skin may also be very sensitive to touch. So if you move them, be very gentle and tell them what you are doing.

A few layers of light, warm clothing and bedding can help to keep them at a comfortable temperature.

Breathing

As the person gets closer to death, their breathing pattern will probably change. Their breathing may become irregular. At times there may be longer gaps between breaths and at other times their breathing might be quicker. It may also become very noisy. This is due to a build-up of fluid in their air passages when they are lying flat. This may be upsetting for you and any other people around. But it is not usually distressing for the person who is dying.

If fluid does build up in the air passages, changing the person's position may help. Or a nurse can give them drugs by injection or through a syringe pump to help reduce the build-up of fluid.

Other changes

The person you are caring for may drift in and out of consciousness. This means there may be times when they do not seem to recognise you or other people around them. You may find this distressing. They may also talk to people they knew in the past or who died long ago, probably because they are thinking of these people. If they seem restless or agitated, a nurse can give them sedatives by injection or through a syringe pump to help.

Final moments of life

For most people, the final moments of life are very peaceful. The person's breathing may become even slower and more irregular, with very long pauses between each breath. Their tummy (abdominal) muscles may take over control of the breathing from the chest muscles, so that their tummy rises and falls with each breath.

Finally, they will stop breathing altogether. This may seem to take a long time for some people. For others, it will only be a few minutes. Sometimes it can be difficult to know the exact moment of death. Often, the person's body will relax completely and they may look very peaceful. Some people feel they can sense when the person has died.

In some cultures, there is a belief that the person's mind or soul (consciousness) stays around the body for some time after death. Other people feel that their consciousness moves on quickly to another place. Some people believe that life just ends, and nothing is left of the person's mind or consciousness.

What happens after someone has died

If your family member or friend dies in a hospital or hospice, the nursing staff will be nearby. They will guide you through what needs to be done over the next few hours.

If your family member or friend dies at home, and this was expected, you will need to tell their GP or district nurse within a few hours. The GP or a district nurse will come as soon as possible to confirm the death. This is called verifying the death.

You do not need to rush to do this. It is fine to spend some time with your loved one before making any calls. If they died during the night or outside your GP's usual working hours, you do not need to contact the doctor until the following morning, unless you want to.

Medical Certificate of Cause of Death (MCCD) and death certificate

If the person's GP comes, they will verify the death and give you a MCCD with a form called Notice to Informant. This tells you how to register the death.

If a district nurse comes, or you have called an out-of-hours doctor, they can verify the death. But you may need to get the MCCD from the person's GP the next day.

Sometimes a police officer will need to come, even when a death at home is expected. You can usually avoid this by making sure your GP and district nurses know your family member or friend is dying.

You can tell them this in the days and weeks leading up to the person's death.

When you have the MCCD, you need to take this to the local registrar's office to register the death. You may need to make an appointment for this.

The registrar will then give you the death certificate. It is a good idea to ask for additional copies of the death certificate. This is because they may be needed for sorting things such as the person's insurance, pensions or banking.

Informing a coroner

In certain situations, the doctor who certifies the death has a legal responsibility to inform a coroner (or procurator fiscal in Scotland).

A coroner needs to be informed if a GP has not seen the person who has died in the 14 days before their death. They also need to be told if the person has died from an occupational disease, such as mesothelioma.

The coroner will decide whether a post mortem or further information is needed. If the person has died from a known illness, there is usually no need for a post mortem.

If a post-mortem is needed, it will take a few days to arrange. You will get a medical certificate afterwards. This can help to give exact information about the cause of death.

You will need to wait until the coroner has decided whether a post-mortem is needed before setting a date for the funeral or alternative service.

What your funeral director will do

Once the death has been verified by a nurse or doctor, you can contact a funeral director (undertaker).

They provide a 24-hour service and can advise you on what to do next. Details of funeral directors are in your local phone book or on the internet. You can also get information from the National Association of Funeral Directors (see page 139). The funeral director will come as soon as you want them to. Tell them if you or your family and friends would like to spend some time alone with your loved one’s body.

Some people wish to look after their family member or friend’s body at home until the funeral. The funeral director can help you with this. Or you may prefer for the body to be taken to the funeral director’s chapel of rest. You can visit the chapel of rest to be with the body if you wish.

Caring for the body

The funeral director will take care of your family member or friend’s body, and will prepare them for the funeral. This process is different for different religions and cultures. It usually involves carefully washing and drying the body, closing the eyelids and making sure the mouth is supported while closed. The person’s hair is tidied and sometimes washed. The funeral director will ask if you would like them to be dressed in any specific clothes, such as a favourite outfit.

If you would like to help the funeral directors wash and dress your family member or friend, let them know as soon as possible.

Embalming

Some people wish to be embalmed. This is when the body is disinfected and treated with chemicals to help preserve it. Blood is drained out of the body and replaced with embalming fluid. This is done at the funeral directors.

Bereavement

Grieving does not always start when your family member or friend dies. You may have already been missing the relationship you had with them and the things you shared with them.

Straight away after the death of your loved one, and for some time afterwards, it is normal to feel different emotions including:

- numbness and disbelief
- anger
- anxiety
- distress
- sadness
- loneliness.

Talking to your family and friends about how you are feeling may be helpful. But you might prefer to talk to someone you do not know. We have more information about coping with bereavement in our booklet **After someone dies: coping with bereavement** (see page 134). You can also find further information on our website at **macmillan.org.uk**

There are many organisations that you can talk to, such as Cruse Bereavement Care (see page 143). Your GP can provide support and may be able put you in contact with a local bereavement counsellor. Many hospices also provide bereavement support for the families of people who have used their services. Some may offer support even if your family member or friend did not use the hospice.

If you have young children or teenagers, they will also have many different emotions. These may affect their behaviour. This can be difficult to cope with when you are already dealing with your own feelings. There are many organisations that can help you support your children, including Winston's Wish (see page 143). Some hospices work with schools and also offer a wide range of support.

> 'After your loved one dies and you've had some time to process and had the funeral and a bit of time off work, before you know it, it'll be time to try to get back to some normality. My advice during this time is just to talk.'
>
> **Max, whose mum died of cancer**

FURTHER INFORMATION

About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more booklets or leaflets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

We have booklets about different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer treatment and information for carers, family and friends.

Online information

All our information is also available online at **macmillan.org.uk/information-and-support** You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**
If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you'd like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **macmillan.org.uk/informationcentres** or call us on **0808 808 00 00**.

Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That's why we help to bring people together in their communities and online.

Support groups

Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online Community

Thousands of people use our Online Community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people's posts at **macmillan.org.uk/community**

The Macmillan healthcare team

Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

Book reviews

Our volunteers review many books about cancer. These include people's stories of living with cancer, and books for children. Visit **publications.macmillan.org.uk** and search 'book reviews'.

> 'Everyone is so supportive on the Online Community, they know exactly what you're going through. It can be fun too. It's not all just chats about cancer.'
>
> **Mal**

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've been affected in this way, we can help.

Financial guidance

Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits

Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants

Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **macmillan.org.uk/financialsupport** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **macmillan.org.uk/work**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Macmillan Organiser

This includes a records book to write down information such as appointments, medications and contact details. You can also download the app on IOS or Android.

Other useful organisations

There are lots of other organisations that can give you information or support.

End of life support organisations

Dying Matters
Tel 0800 021 4466
Email info@dyingmatters.org
www.dyingmatters.org
Promotes public awareness of dying, death and bereavement.

Hospice UK
Tel 0207 520 8200
www.hospiceuk.org
Works to ensure adults and children living with terminal or life-shortening illnesses receive the care and support they need. Provides free booklets and online information.

Human Tissue Authority
Tel: 0207 269 1900
(Mon to Fri, 9am to 5pm)
www.hta.gov.uk
Provides information about tissue donation. Licenses and inspects organisations that store and use human tissue for research, patient treatment and teaching.

The Law Society for England and Wales
Tel 0207 242 1222
(Mon to Fri, 9am to 5pm)
www.lawsociety.org.uk
Provides details of regulated solicitors in England and Wales. Use their website to find details of local solicitors.

The Law Society of Scotland

Tel 0131 226 7411
(select option 1)
www.lawscot.org.uk/find-a-solicitor

Provides details of regulated solicitors in Scotland. Use their website to find details of local solicitors.

National Association of Funeral Directors (NAFD)

Tel 0121 711 1343
(Mon to Fri, 9am to 5pm)
www.nafd.org.uk

Monitors standards of funeral directors in the UK and gives help and advice on what to do in the event of a death. Also advises on arranging funerals and has information on what you should expect from a funeral director.

National Society of Allied and Independent Funeral Directors SAIF

Tel 0345 230 6777 (Monday to Friday 9am to 5pm)
Email info@saif.org.uk
Website **www.saif.org.uk**

SAIF is An organisation of independent funeral directors across the UK that offer different funeral options. Ensures a high standard of funerals is provided by its members and provides advice about funerals and what to do when someone dies.

The Natural Death Centre

Helpline 0196 271 2690
Email
rosie@naturaldeath.org.uk
www.naturaldeath.org.uk

Offers help, support, advice and guidance on planning a funeral for yourself or someone else. Aims to support those dying at home and their carers, and to help people arrange inexpensive, family-organised and environmentally-friendly funerals.

NHS Blood and Transplant Organ Donation
Tel 0300 123 2323
(24 hours a day, 7 days a week)
Text chat (SMS)
0786 003 4343
Text relay
18001 0300 1232323
Email enquiries@nhsbt.nhs.uk
www.organdonation.nhs.uk
Manages the UK transplant registry and national organ donor register. Also raises public awareness of the importance of organ donation.

Marie Curie
Helpline 0800 090 2309
(Mon to Fri, 9am to 5pm,
and Sat, 11am to 5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free end-of-life care to people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year. Call their helpline for support or to ask questions about care or symptoms.

General cancer support organisations

Maggie's Centres
Tel 0300 123 1801
Email
enquiries@maggiescentres.org
www.maggiescentres.org
Provides information about cancer, benefits advice, and emotional or psychological support.

General health information

NHS UK
Tel 111
www.nhs.uk
The UK's biggest health information website. 111 is the NHS non-emergency number. It is available 24 hours a day, 365 days a year.

NHS Inform

Helpline 0800 22 44 88
(Mon to Fri, 8am to 10pm,
and Sat and Sun, 9am to 5pm)
www.nhsinform.scot

Provides health information for Scotland. Has a service directory where you can search for health and wellbeing services in Scotland. Also has a webchat service.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

Provides health information for Scotland.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 0145 588 3300
(Mon to Fri, 9am to 5pm)
Email bacp@bacp.co.uk
www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

UK Council for Psychotherapy (UKCP)

Tel 0207 014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements. You can search for a therapist using their ‘Find a therapist’ form.

Emotional and mental health support

Samaritans

Helpline 116 123
Email jo@samaritans.org
www.samaritans.org

Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial or legal advice and information

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office by contacting:

England

Helpline 0344 411 1444
www.citizensadvice.org.uk

Wales

Helpline 0344 477 2020
www.citizensadvice.org.uk/wales

Scotland

Helpline 0808 800 9060
www.cas.org.uk

Northern Ireland

Helpline 0800 028 1881

The Office of Care and Protection (Northern Ireland)

Tel 0300 200 7812
www.justice-ni.gov.uk

The Office of the Public Guardian (England and Wales)

Tel 0300 456 0300
(Mon, Tue, Thu, Fri, 9am to 5pm, Wed, 10am to 5pm)
Email customerservices@publicguardian.gov.uk
www.gov.uk/government/organisations/office-of-the-public-guardian

Protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.

The Office of the Public Guardian (Scotland)

Tel 0132 467 8300
(Mon to Fri, 9am to 5pm)
Email opg@scotcourts.gov.uk
www.publicguardian-scotland.gov.uk

Has a range of functions under the Adults with Incapacity (Scotland) Act. It provides information, advice and guidance with regard to Powers of Attorney.

Bereavement support

Cruse Bereavement Care

Helpline 0808 808 1677
(Mon and Fri, 9.30am to 5pm, and Tue to Thu, 9.30am to 8pm)
Email info@cruse.org.uk
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Hope Again

Helpline 0808 808 1677
(Mon to Fri, 9.30am to 5pm)
Email
hopeagain@cruse.org.uk
www.hopeagain.org.uk
Designed for young people by young people, Hope Again is part of Cruse Bereavement Care. It supports young people across the UK after the death of someone close. Offers a private message service from the website.

Widowed and Young (WAY)

www.widowedandyoung.org.uk
A UK-wide support network to help young widows and widowers rebuild their lives after the death of a partner.

Winston's Wish

Helpline 0808 802 0021
(Mon to Fri, 9am to 5pm)
Email ask@winstonswish.org
www.winstonswish.org.uk
Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

Support for older people

Age UK

Helpline 0800 678 1602
(daily, 8am to 7pm)
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel 0345 330 3030
(Mon to Fri, 10am to 6pm)
Email helpline@lgbt.foundation
www.lgbt.foundation

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel 0300 772 9600
(Mon to Fri, 9am to 5pm)
Email info@carers.org
www.carers.org

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline
(England, Scotland, Wales)
0808 808 7777
(Mon and Tue, 10am to 4pm)
Helpline (Northern Ireland)
0289 043 9843
www.carersuk.org

Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Disclaimer

We make every effort to ensure that the information we provide is accurate and up to date but it should not be relied upon as a substitute for specialist professional advice tailored to your situation. So far as is permitted by law, Macmillan does not accept liability in relation to the use of any information contained in this publication, or third-party information or websites included or referred to in it. Some photos are of models.

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by Senior Medical Editors Dr Sara Booth Associate Lecturer, University of Cambridge and Emeritus Consultant in Palliative Medicine; and Dr Viv Lucas, Consultant in Palliative Care.

With thanks to: Karen Bird, Lead Nurse for End of Life Care Education; David Borrowman, Senior Partner, Caesar and Howie; Dr Kirsty Boyd, Honorary Clinical Senior Lecturer; Michelle Buono, Macmillan End of Life Education Nurse; Janet Dobie, District Nurse and Palliative Link Nurse; Julia Featherstone, Macmillan Financial Guide; Domino MacNaughton, Head of Legacy Promotions, Macmillan Cancer Support; Daniel McCracken, Trainee Solicitor, Wilson Nesbitt Solicitors; Ollie Minton, Macmillan Consultant in Palliative Medicine; Lucie Rudd, Macmillan Specialist Advisor, End of Life; Dr Louise Schofield, Consultant in Palliative Medicine; Fiona Wilson, Partner, Hempsons; and Joanne Wilson, Consultant Nurse.

Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

We have listed a sample of the sources used in the booklet below. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

BMJ Best Practice. Palliative care. 2018. Available from https://bestpractice.bmj.com/topics/en-us/1020/details (accessed June 2019).
GOV.UK. Department of health and social care guidance: Choice in end of life care: government progress. 2017. Available from www.gov.uk/government/publications/choice-in-end-of-life-care-government-progress (accessed June 2019).
NICE. Care of dying adults in the last days of life Available from www.nice.org.uk/guidance/QS144 (accessed June 2019).
NICE. End of life care for adults. Available from www.nice.org.uk/guidance/qs13 (accessed June 2019).
The National Gold Standards Framework. Available from www.goldstandardsframework.org.uk (accessed June 2019).

Can you do something to help?

We hope this booklet has been useful to you. It's just one of our many publications that are available free to anyone affected by cancer. They're produced by our cancer information specialists who, along with our nurses, benefits advisers, campaigners and volunteers, are part of the Macmillan team. When people are facing the toughest fight of their lives, we're there to support them every step of the way.

We want to make sure no one has to go through cancer alone, so we need more people to help us. When the time is right for you, here are some ways in which you can become a part of our team.

5 WAYS YOU CAN HELP
SOMEONE WITH CANCER

Share your cancer experience
Support people living with cancer by telling your story, online, in the media or face to face.

Campaign for change
We need your help to make sure everyone gets the right support. Take an action, big or small, for better cancer care.

Help someone in your community
A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money
Whatever you like doing you can raise money to help. Take part in one of our events or create your own.

Give money
Big or small, every penny helps. To make a one-off donation see over.

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Don’t let the taxman keep your money

Do you pay tax? If so, your gift will be worth 25% more to us – at no extra cost to you. All you have to do is tick the box below, and the tax office will give 25p for every pound you give.

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

Macmillan Cancer Support and our trading companies would like to hold your details in order to contact you about our fundraising, campaigning and services for people affected by cancer. If you would prefer us not to use your details in this way please tick this box. ☐

In order to carry out our work we may need to pass your details to agents or partners who act on our behalf.

Registered with FUNDRAISING REGULATOR

If you’d rather donate online go to macmillan.org.uk/donate

Please cut out this form and return it in an envelope (no stamp required) to:
Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851,
89 Albert Embankment, London SE1 7UQ

27530

This booklet explains what happens at the end of someone's life and how to plan for it. It is for anyone nearing the end of life. There is also information for people caring for someone nearing the end of life.

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these, visit **macmillan.org.uk/otherformats** or call our support line.

MACMILLAN
CANCER SUPPORT

Next planned review November 2022.
Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604). Also operating in Northern Ireland.
Printed on sustainable material. Please recycle.