

# End of life: a guide

A booklet for people in the final stages of life, and their carers



# About this booklet

This booklet explains what happens at the end of someone's life and how to plan for it.

Macmillan has produced this booklet with Marie Curie, a charity that provides care and support to people living with a terminal illness, and their families. It's about:

- coping with the news that you may be nearing the end of your life
- sorting out unfinished business
- getting financial help
- choosing where to be looked after
- who can help if you're being cared for at home
- what might happen in the last few weeks and days of life
- what happens after someone has died.

It also includes information for any relatives and close friends who may be involved in your care. So it may be helpful for them to read it too.

A lot of the information in this booklet is for people who are being cared for at home. But it will still be useful to you and your carers if you are being looked after somewhere else.

You may find some of the information in the booklet difficult and upsetting to read, particularly if you're reading it for the first time. But you don't have to read through the booklet in one go. You can use the contents list to help you decide which sections you want to read. Don't worry about skipping some of the sections if they aren't relevant for you.

Getting support from other people can be helpful. You may like to ask your partner, a close relative or a friend to read the booklet as well. You'll then be able to discuss the information together.

At the end of this booklet we've listed organisations that you may want to contact for help, information, or to talk about how you feel. You'll find helpful organisations on pages 121–126.

If your family or friends are helping to care for you, they may also want to read Macmillan's booklet **Caring for someone with advanced cancer** or visit **macmillan.org.uk/carers**

Marie Curie also has a booklet for carers called **Being there for someone with a terminal illness**, or visit **mariecurie.org.uk/being-there**

We've included some comments from people who have had experience in end of life care, which you might find helpful. Quotes are from the website **healthtalk.org**, the Macmillan online community (**macmillan.org.uk/community**) and from Marie Curie patients and carers. Some names have been changed.

# Contents

Coping with the news	5
Sorting things out	17
Financial help	35
Choosing where you would like to be looked after	41
Being looked after at home	51
The last few weeks of life	63
The last few days of life	91
Nearing death	101
National organisations that can help	113



# Chapter one

---

## Coping with the news

**This chapter includes  
information on:**

- Your feelings
- Facing an uncertain future
- People close to you
- Talking
- Talking to children
- If you live alone

Hearing that you may be nearing the end of your life can be very difficult and distressing. You might find it hard to believe what you're hearing, even if you know your illness is getting worse. You may experience 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 relative or a close friend to think about the future.

Some people find it easier to talk to someone outside their family. If you think this would be helpful, you can talk to your doctor, specialist nurse or social worker. Or you can call one of the support organisations listed on pages 121–126. They will be able to talk things through with you.

## Your feelings

You may experience many emotions when you hear you may be nearing the end of your life. You might feel angry because you feel more could have been done to prevent your illness, or diagnose it at an earlier stage. You may feel it's very unfair that this is happening to you. You may fear what the future will bring.

You may also feel tearful and depressed, and unsure of how to cope with your feelings and emotions. Some people find it difficult to see life going on as normal around them when their own world has changed so much.

Most people have some, or all, of these feelings. But, as time passes, people often find that the distress gets less frequent and intense.

'I can honestly say that my first feeling wasn't one of being upset for myself. My first thought was "what will happen to my girlfriend and my mum? How will I tell them?" It was strange. The people around me immediately became my focus and that actually strengthened me. Obviously it's completely life-shattering news, but you can't just process it straight away.'

Ross

## Facing an uncertain future

No one can be sure how long you will live and your doctors or nurses may be reluctant to give you a timescale. Even if one of your doctors has suggested you may have months or weeks to live, it's important to remember that this is an estimate. You may live longer or, unfortunately, you may live for less time than this.

You'll probably have times when you feel well and positive about life, and times when you feel less well and have less energy.



Although your future may be uncertain, you may still find it 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. There may also be important things you want to think about before you die. These include:

- where you want to be cared for (see pages 42–49)
- making a will (see page 21)
- writing an Advance Decision to Refuse Treatment (see pages 25–29).

## People close to you

When you're reaching the end of your life, partners, family and friends become even more important and provide support and reassurance.

However, terminal illness can sometimes make relationships 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 unrealistically cheerful, making it difficult for you to say how you feel.

Your partner, children or close friends may irritate you by being overprotective. Close family and lifelong friends may feel like strangers, just at the time when you need them most.

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

It's important to keep your relationship as normal as possible. If you've always been close and talked a lot, there's no reason not to continue to do this. When you don't know what to say, a hug or holding hands can be very comforting.

If you've always argued a lot, don't feel you must try to change this. There are bound to be times when you don't get on well. If you argue, having short breaks from each other can help you think more calmly.

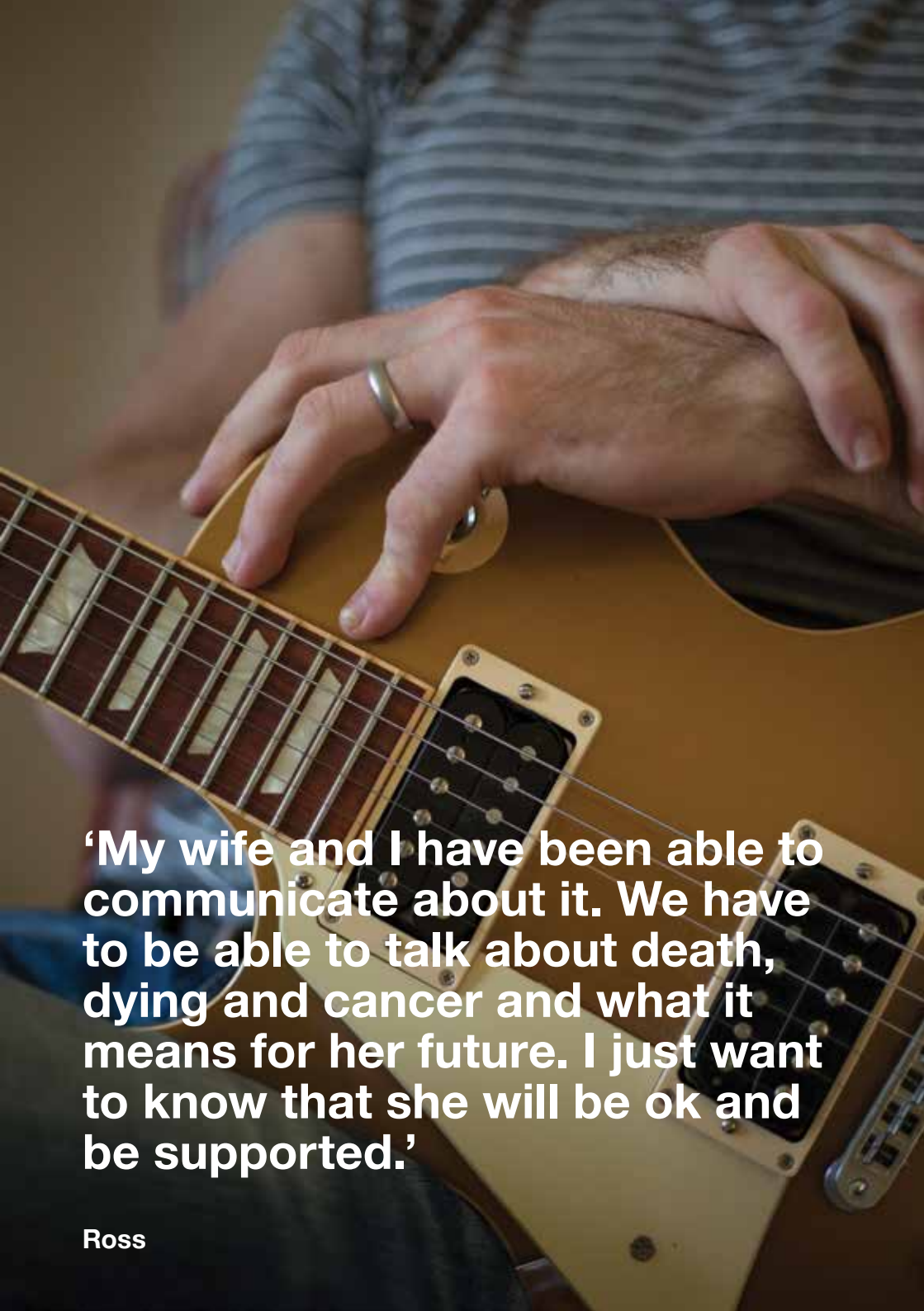
Remember that everyone will be shocked by the news. Your family and friends are also dealing with powerful emotions, and may need help and support to deal with them. Their feelings and emotions will also change over time.

Macmillan's cancer support specialists can provide advice and support for your family and friends. You can call them on **0808 808 00 00**. You can also call the Marie Curie Support Line on **0800 090 2309** for information and support on living with a terminal illness, or caring for someone who has a terminal illness.

Some people find their relationships improve as they, and the people close to them, realise what's really important. You may become much closer to some people. Your illness can also be an opportunity for you and others to get back in touch, or resolve past arguments or bad feelings.

'I felt that we actually drew closer to each other because we began to really talk about some things that we'd maybe not bothered to talk about before because it didn't seem to be important. But we began to talk much more about what we meant to each other, and the things that we'd experienced that we'd really enjoyed doing together. So that was a positive thing.'

Janet



**‘My wife and I have been able to communicate about it. We have to be able to talk about death, dying and cancer and what it means for her future. I just want to know that she will be ok and be supported.’**

**Ross**

## Talking

People who have a terminal illness sometimes feel they have to be the strong one. They have to start the difficult conversations and support other people, even though they are the one who is ill. If you're unwell or feeling low, it can be very difficult to do this.

But, if you can talk openly about how you feel, your family and friends will learn how they can help you and what you'd like from them. You can choose the people you want to talk to and who you feel will be able to help you. You can plan when you want to talk to them and what you want to say.

Sometimes it can help to talk to someone outside your own family and friends, such as a counsellor or one of the support organisations listed on pages 121–126.

Macmillan has a booklet called **Talking about your cancer**, which you may find helpful. You can also find information about having difficult conversations on the Marie Curie website at [mariecurie.org.uk/help](https://mariecurie.org.uk/help)

## Talking to children

There's no easy way to talk to children or grandchildren about the fact that you're very ill and nearing the end of your life. It's often best to be as open 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 don't say anything, they will usually sense that something is wrong and may become 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's important to tell them that it's not their fault.

How and what you choose to tell them depends on their age and how much they can understand. Macmillan and the Marie Curie Palliative Care Institute Liverpool produce information that you may find helpful. This includes:

- **Saying goodbye** – a series of leaflets for children and teenagers (Marie Curie Palliative Care Institute Liverpool)
- **Supporting toddlers and pre-school children when a parent or close relative is dying** (Marie Curie Palliative Care Institute Liverpool)
- **Talking to children and teenagers when an adult has cancer** (Macmillan)
- **Talking to children when someone is dying** (Marie Curie Palliative Care Institute Liverpool).

You can also find information about talking to children on the Marie Curie website at [mariecurie.org.uk/supporting-children](https://mariecurie.org.uk/supporting-children)

Publications developed by the Marie Curie Palliative Care Institute Liverpool are available at [sii-mcpcil.org.uk/resources-and-links.aspx](https://sii-mcpcil.org.uk/resources-and-links.aspx)

## If you live alone

It may be very hard to keep positive and be optimistic if you live alone. Even though you may value your independence, being ill can make you feel very lonely and frightened.

It's all right to ask for help. People who care about you will want to help in any way they can. Some people will find it difficult to talk, but may be happy to help in more practical ways, such as doing your shopping or helping with your 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 it to them. They can then choose to do something that will help you.

Other people may be able to listen to you and share your worries and fears.

Marie Curie has a free helper service available in parts of the UK. Someone can come over for a cup of tea, help you get to an appointment, run an errand, or just be there to listen when you need a friendly ear. For more information, visit [mariecurie.org.uk/helper](https://mariecurie.org.uk/helper) or call **0800 090 2309**.

Your GP, social worker, or district or community nurse will also be able to tell you what help and support is available from health, social care and voluntary organisations (see pages 121–126).





# Chapter two

---

## Sorting things out

**This chapter includes information on:**

- Unfinished business
- Spiritual and religious issues
- Making a will
- Making choices
- Your wishes for your care
- Advance Directives and Advance Decisions to Refuse Treatment
- Power of Attorney
- Tissue, organ and body donations
- Planning your funeral

Many people find that when they're told they may be nearing the end of their life, there are things they need to sort out.

## Unfinished business

You may find yourself thinking a lot about the past, and talking about good times you have had and maybe less good times. You may want to see old friends, think about places you have visited or look through photo albums. If you're well enough, you may want to visit some places again. You may also find yourself thinking about the future, and grieving for a time when you will no longer be here.

You may have difficult relationships with some people and want to talk to them about certain things. You could try writing to or ringing the person, explaining your illness and asking them to visit or get in touch.

You may also like to:

- write letters to people who are important to you
- record a CD, video or DVD to be given to them after you have died
- write down your family history for the next generation
- put together a scrapbook for your children or grandchildren.

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 with making it and filling it with special items.

Macmillan has more information on creating memory boxes, which we can send you.

These can be sad and perhaps difficult things to do. But they can also give you a chance to reflect on things that have happened in your life, both good and bad. They may even make you laugh as you remember happy events. The important thing is to do what feels right for you, when it feels right.



## Spiritual and religious issues

Towards the end of life, some people become more aware of 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, such as through music, arts, nature, or how you relate to your family or community.

Some people find comfort in prayer or meditation. And many gain support from knowing that other people are praying for them. But a person may start to question their faith, especially when they are suffering.

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, and 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, or a chaplain or religious leader. Don't be put off talking to a chaplain or religious leader if you are not religious. They are used to dealing with uncertainty and being with people who are distressed. They are also usually very good listeners and may be able to help you work out your thoughts and feelings.

You can find information about spiritual issues on the Marie Curie website at [mariecurie.org.uk/spiritualpain](https://mariecurie.org.uk/spiritualpain)

## Making a will

Whatever your age, having an up-to-date and valid will is important. Dying without a will means that your wishes for who you would like to leave your estate (property, personal possessions and money) to can't be guaranteed.

Making a will isn't as expensive or difficult as you might think, but it is a legal document and must be prepared properly. It's usually best to use a solicitor who will be able to help with the wording. They will make sure your wishes are clear and that they are carried out exactly as you want.

Macmillan has information called **Your step-by-step guide to making a will**. You can call Macmillan on **0808 808 00 00** to order a copy. You can also find information about making a will on the Marie Curie website at **[mariecurie.org.uk/wills](https://mariecurie.org.uk/wills)**

## 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 can't 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.

We give you some information about these over the next few pages. But you may find it helpful to read **Your life and your choices: plan ahead** (Macmillan), which has more information. There are separate booklets for England and Wales, Scotland and Northern Ireland because the way people can plan ahead varies across the four nations. Other booklets you may find helpful include **Planning ahead** (Marie Curie) or **Planning for your future care: a guide** (Dying Matters Coalition/National End of Life Care Programme/Nottingham University).

## Your wishes for your care

It's important to think about how and where you would like to be cared for if your health were to change and you were unable to tell others what you want to happen.

It's best to write down your wishes and preferences so your family and health or social care professionals know how you'd like to be cared for.

These advance statements of your wishes aren't legally binding. But they must be taken into consideration when healthcare professionals make decisions about your care.

There are a number of documents that can be used to record your wishes. You can ask your healthcare professional which documents are used in your area.

'I just want it to be natural. I want all the stuff taken away. If I need a breathing machine that's fine, but apart from that I don't want drips, I don't want lines, I don't want tubes. I just want it to be as natural and as quiet and as peaceful as possible.'

Patrick





## Advance Directives and Advance Decisions to Refuse Treatment

An Advance Decision to Refuse Treatment or Advance Directive is sometimes known as an Advance Decision, or Living Will. It's a decision about specific treatments you don't want to have. For example, you may decide that if your condition suddenly worsens and your breathing stops, you don't want people to try to bring you back to life (resuscitate you). Or, that if you're very ill and have an infection, you don't want to be given antibiotics to try to prolong your life.

If you refuse a particular treatment you will still receive good care and have medicines to help manage any symptoms you may have.

An Advance Decision to Refuse Treatment can only be made by someone aged 18 or over (16 in Scotland) who is able to understand the decision they are making. This is called having mental capacity. It must state exactly what treatment you want to refuse and may also state when the refusal should apply. It is helpful to include as much detail as possible.

An Advance Decision to Refuse Treatment or Advance Directive can't include a request to be given specific treatments or to have your life ended.

Before making an Advance Decision to Refuse Treatment, it's important to discuss the decisions you'd like to make with one of your healthcare professionals. It's also important to share your decision with your family so they understand your wishes.

Once you've made your Advance Decision to Refuse Treatment, it's best to write it down so that it can be kept in your medical and nursing notes. It's helpful to give a copy to your GP. You may also be asked for permission to give copies to the ambulance service, out-of-hours doctor, and district nursing and palliative care services (see page 45). This makes sure that your wishes and preferences are known to the teams that you may need to contact, day or night.

There are certain situations where the law says an Advance Decision to Refuse Treatment must be in writing, for example, if it refuses treatment to keep you alive.

## Advance Decisions to Refuse Treatment and the law

In England and Wales, an Advance Decision to Refuse Treatment is legally binding. This means it must be followed by your healthcare team, if they know about it. It must also meet certain criteria set out in the Mental Capacity Act (2005). Your healthcare team will be able to tell you more about this.

In Northern Ireland and Scotland, an Advance Decision to Refuse Treatment or Advance Directive is also legally binding. It's governed by common law instead of an Act and similar criteria apply.

You can change your mind and rewrite your Advance Decision to Refuse Treatment at any time, but this must be clearly recorded.

Macmillan and Marie Curie have more detailed information about Advance Decisions to Refuse Treatment and Advance Directives.

## Power of Attorney

This is when you appoint someone to make decisions on your behalf. These decisions may be about your property or finances, or your health and welfare.

Although you can create your own Power of Attorney (PoA), you may wish to get help from a solicitor. They will make sure that your PoA meets all the requirements of the law. If you don't have a solicitor you can find one by contacting The Law Society (see page 121).

## England and Wales

In England and Wales, a Lasting Power of Attorney (LPA) is a legal document. It allows you to put in writing the name of someone you trust to make decisions or manage your financial, legal or health affairs on your behalf if you're no longer able to do so in the future. The people you choose to make decisions on your behalf are known as attorneys.

There are two types of LPA that are valid in England and Wales:

- **Health and Welfare LPA** This allows your attorney(s) to make decisions about things such as treatment, care, medication and where you live.
- **Property and Financial Affairs LPA** This allows your attorney(s) to make decisions about things such as paying bills, dealing with the bank and selling your house.

You can get more information about making an LPA from a social worker, The Office of the Public Guardian (see page 122) or organisations such as Age UK (see page 121).

You may be unable to make a decision about your medical treatment and have no family or friends to represent your views. If so, the medical staff should appoint an Independent Mental Capacity Advocate to represent your interests.

Marie Curie has more information about mental capacity and making decisions in its booklet **Planning ahead** and on its website at [mariecurie.org.uk/help](https://mariecurie.org.uk/help)

## Scotland

In Scotland a PoA is a legal document. Three types of PoA are valid in Scotland:

- **Continuing PoA** This allows your attorney(s) to make decisions about things such as paying bills, dealing with the bank and selling your house.
- **Welfare PoA** This allows your attorney(s) to make decisions about things such as your treatment, care, medication and where you live.
- **Combined PoA** This combines continuing PoA and welfare PoA.

You can get more information about Welfare PoAs from a social worker, The Office of the Public Guardian Scotland (see page 122) and organisations such as Age Scotland (see page 121).

## Northern Ireland

In Northern Ireland you can appoint an Enduring Power of Attorney (EPA). This allows your attorney(s) to make decisions on your behalf about your property and financial affairs. It's not yet possible to appoint other people to make decisions about your care and treatment.

You can get more information about EPAs from your solicitor or from the Office of Care and Protection (see page 121).

## Tissue, organ and body donations

Many people think that if they have a medical condition, such as cancer, they won't be able to donate their organs or tissue (such as the corneas of the eye) to another person when they die.

Having a medical condition, such as cancer, doesn't mean that you are excluded from organ or tissue donation. But it may affect what you can donate.

The NHS Blood and Transplant website has information about donations and keeps a register of people who wish to donate their organs and body tissues (see page 126).

From the 1 December 2015 the way people in Wales choose to donate their organs will change. From that date, people living in Wales will be expected to opt out if they have an objection to being an organ donor. If you are from Wales and want to be a donor you can:

- choose to be a donor by registering a decision to be one, as you can now do (this is known as opting in)
- do nothing, which means you have no objection to being a donor (this is known as deemed consent).

If you **do not** want to be a donor then you must register a wish to not be a donor (this is known as opting out).

You can find more information about this at **[organdonationwales.org](http://organdonationwales.org)**

Some people may want to donate their body for medical research or teaching. If you're thinking about doing this, it's important to discuss it with your GP, hospital or palliative care team and your family or friends closest to you.

You can find out more about donating your body by contacting the Human Tissue Authority (see page 126). You should bear in mind that not everyone who wishes to donate their body will be able to do so.





## Planning your funeral

Funerals allow families and others to pay their respects to the person who has died. For family or close friends, arranging a funeral can be stressful if they don't know exactly what type of funeral service you would like. If you tell your family and friends what you want, your funeral is much more likely to reflect your wishes. It may also be one less thing for your family or friends to worry about.

You may find it helpful to discuss your funeral plans with your family and friends. They may have ideas and suggestions that will help them celebrate your life, say goodbye and remember you. Here are some suggestions of what you may want to include in your funeral plan:

- whether you want a burial or cremation
- whether you want to have a religious service or not
- whether you want specific songs played or things read out
- whether you want flowers
- whether you want donations given to specific charities
- what clothes you want to wear.

Funerals can be expensive so you may want to pay for your funeral in advance by taking out a funeral pre-payment plan. You can find out more about this from your local funeral directors or the National Association of Funeral Directors (see page 126). It's important to look into prices first. Make sure that you know what services are included in the price as they can vary.

## Important documents

You may find it helpful to make a list of your documents. This includes your will, Advance Decision to Refuse Treatment and your funeral plan. Include your bank and building society details, any insurance policies you have and the details of your accountant, solicitor and tax inspector. Write on the list where to find this information and make sure that your partner or the executor of your will knows where it's kept.

Marie Curie has information about planning a funeral and coping with bereavement in its booklet **When someone dies** and on its website at **[mariecurie.org.uk/bereavement](http://mariecurie.org.uk/bereavement)**



# Chapter three

---

## Financial help



**This chapter includes information on:**

- Benefits
- Other financial help
- Other things to think about

Having an illness, such as cancer, nearly always involves unexpected expenses. This can cause extra worry at a time when you least need it. Financial help is available from a number of sources and can sometimes be accessed at short notice.

## Benefits

Most people who need care towards the end of their lives qualify for either:

- **Personal Independence Payment (PIP)** or **Disability Living Allowance (DLA)**, if under the age of 65
- **Attendance Allowance (AA)**, if aged 65 or over.

In England, Scotland and Wales, PIP has replaced DLA for new claimants of working age.

If you live in Northern Ireland, you'll need to check with a benefits adviser or social worker whether you should claim DLA or PIP.

These benefits aren't means-tested.

If you're terminally ill and not expected to live for longer than six months, you can apply for these benefits under the 'special rules'. Your claim will be dealt with quickly and you'll receive the benefit at the highest rate. All special rules claims for AA, PIP and DLA are reviewed after three years. If you are claiming under these special rules you need to ask your doctor to complete a form.

Your district nurse, specialist nurse or social worker can tell you more about these benefits and whether you can apply for them.

Marie Curie has more information about the special rules and benefits in its booklet **Boosting your income** and on its website at [mariecurie.org.uk/benefits](https://mariecurie.org.uk/benefits)

You can also call Macmillan on **0808 808 00 00** to speak with one of our welfare rights advisers. They can give you advice about claiming benefits and help you with filling in claim forms. Depending on where you live, you may be able to visit a local Macmillan welfare rights adviser – visit [macmillan.org.uk/in-your-area](https://macmillan.org.uk/in-your-area) to check.

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.

If you live in Northern Ireland, you can contact your nearest Social Security Agency Office or Jobs and Benefits office for advice on benefits.

‘I applied for and got Disability Living Allowance, which is not means-tested. It’s an enormous help in paying for the extra help that you need in the house or for this and that.’

Liam

## Other financial help

### Grants

There are grants available from a variety of sources, including occupational funds, utility companies (gas, electricity and water companies) and charities.

Macmillan gives small one-off grants to help people meet expenses that have arisen from, or are associated with, their cancer. You have to apply for a Macmillan grant through a health or social care professional.

For more information, contact Macmillan and speak to a welfare rights adviser or a cancer support specialist on **0808 808 00 00**.

The **Guide to grants for individuals in need**, gives details of all the trusts and organisations that provide financial support to people in the UK. It's available from bookshops or public libraries.

### Prescriptions

These 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 things to think about

### Bank accounts

These are frozen at the time of death and can't be used, so you may want to consider putting bank accounts into joint names.

Marie Curie has more information about protecting or sharing any online accounts you have. Visit **mariecurie.org.uk/online-accounts** or see their booklet **Planning ahead**.

### Pension schemes

Some private or occupational pension schemes won't pay out any benefits to partners if the owner of the pension scheme wasn't married. This means that the pension fund is lost.

An **independent financial adviser** may be able to give you advice in these situations. You can contact a financial adviser through the Personal Finance Society or visit **unbiased.co.uk** (see page 125).

Marie Curie has more information about making the most of any pension schemes you may have. Visit **mariecurie.org.uk/pensions**

Macmillan also has a booklet called **Pensions**. We can send you a copy.





# Chapter four

---

# Choosing where you would like to be looked after

**This chapter includes  
information on:**

- Staying at home
- Hospices
- Care homes – residential or nursing
- Hospitals

Often the choice of where you'll die depends on what you want, what help you have from family and friends, what services are available in the area you live and your medical condition. Most people prefer to die at home, as long as they know they will have good quality care.

Wherever you're cared for, the most important thing is that your symptoms are well controlled and you get the care you need. This can happen in a variety of places. Even if you choose not to die at home, you can still be surrounded by people and things that are important to you.

We have included some information for relatives and friends on page 49.

## Staying at home

Staying at home allows you to be in familiar surroundings with close family or friends to care for you. It may help you feel more in control and may make it easier for you to say your goodbyes.

It's important that you and your carers have as much support as possible. Different healthcare professionals and voluntary organisations can help manage any symptoms you may have and support you and your family at home. If you'd like to be at home, let your nurse or doctor know.

There is more information about being looked after at home on pages 52–61.



## Hospices

Hospices specialise in caring for people who have a life-limiting illness and may be approaching the end of their life.

The staff are experts in controlling symptoms, such as pain, and providing emotional support. You can go into a hospice for different reasons. This may be for a short time to have your symptoms controlled or for a period of respite care to give your carer a break. You may decide that you'd like to die in a hospice. If so, you'll need to discuss your wishes with your GP and the hospice team involved with your care.

'The people were very kind. I was absolutely amazed at the organisation. The number of staff, the number of patients, all with different ailments, and everything worked like clockwork. I was very impressed.'

Jai

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

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

Many hospices have specialist **palliative care nurses** (nurses who are experts in symptom control and emotional support). They also have staff nurses or healthcare assistants who can visit and help care for people at home. Some have day centres for people living at home.

Accommodation and care in a hospice is always free of charge. Sometimes there's a waiting list but urgent admissions can usually be organised within a couple of days.

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 located across the UK (see page 126). If you're not sure about the idea of hospice care, you can ask to visit the hospice before making a decision. The staff will be able to show you around and chat through any questions or concerns you have.





## Care in residential homes or care homes with nursing

If you're likely to need care for several months, a residential care home or care home with nursing may be more appropriate than a hospice. 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 nursing home.

Your GP or healthcare team can explain the different types of care homes that are available.

Care homes may be:

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

A fee is charged for care in private care homes, although you can sometimes get help in paying for this if you have little or no savings.

You may be eligible for the NHS to fully fund your care in a care home with nursing. For example, if you're reaching the end stages of your illness or if you have a complex medical condition that means you need a lot of care and support.

A ward nurse, district nurse, hospice nurse or social worker can tell you more about fully funded care.



Marie Curie also has information about fully funded care on its website at [mariecurie.org.uk/continuinghealthcare](https://mariecurie.org.uk/continuinghealthcare)

If you live in Northern Ireland, funding for care homes is means-tested.

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](https://carehome.co.uk)

## Hospitals

If you've 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 may be possible, although it may be easier to organise if you've been in a small local hospital (for example, a cottage hospital) rather than in a busy 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'll need to fit into the ward routine, rather than being looked after in the way that you'd 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're in hospital. They can help manage your symptoms and can offer you and your family emotional support.

## Information for relatives and friends

You may find it difficult to look after someone at home for a variety of reasons. As time goes on, you may feel that the person you are caring for would be better looked after by healthcare professionals in a hospice or care home. This may be because their situation has changed and you don't have the emotional strength, or the nursing or medical skills to look after them.

Talk to the district nurse or GP if you feel 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 advise you on the best place for your relative to be cared for.

It's important to not feel guilty if the person you are caring for needs to be moved from home at some point near the end of their life. You shouldn't see this as a failure. Instead, you should see it as you wanting to make sure that they get the best possible care.

It's also important to look after yourself. Try and make some time for yourself, eat well and get some exercise. Let your GP know that you're caring for someone and tell them if you have any concerns about your own health.

Macmillan has more information in the booklet **Caring for someone with advanced cancer**, which we can send you.



# Chapter five

---

## Being looked after at home

This chapter includes information on:

- Who can help if you're looked after at home
- Where to get the equipment you need

Although dying is a natural process, few people have experience of looking after someone who is dying. If you're a carer, the thought of looking after someone you are close to at home can be frightening. However, with the right help it can also be rewarding and a time of great closeness.

## Who can help if you're looked after at home

Caring can be hard work, both physically and emotionally, so it's important that you and your carers have as much support as possible. It's not always easy to ask for help, as we often feel we should be able to cope alone. However, there are many health and social care professionals who can help.

'There were many times looking after my husband at home when I wished there was a place to go to access help and I wasn't sure what to do – it's that ghastly middle of the night feeling that you need help but you're not sure who to ask. It's very disconcerting when you're caring for someone who is dying and you just don't know when he might go.'

Hilary

## Your GP

While you're at home, your GP has overall responsibility for your care. They can help if you:

- are worried about any changes in your symptoms. They can arrange to see you either in the surgery or at home. They'll discuss what treatments might help control any symptoms you may have
- want to talk through what may happen as you become less well
- want to make an advance statement of your wishes (see page 23) or Advance Decision to Refuse Treatment (see pages 25–29) or a plan for dealing with emergencies (although this isn't often needed) so that you get the care you want
- need nursing care. They can arrange for you to be seen by a district nurse who will help to organise this for you at home
- need specialist care from a palliative care team (see pages 56–57). They can arrange for you to be seen at home by a palliative care nurse.

## District nurses

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

- 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 the supply of appropriate equipment to help with pressure care or incontinence
- showing your relatives or carers how to move you and take care of you.

District nurses often work with palliative care nurses to help support you and your carers so that 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.

‘We were supported by the local GP with whose support – and that of district nurses – we were able to continue to care for her at home. Although Fiona didn’t talk about where she wanted to be, I knew she wanted to be with us and not in a hospice.’

Susan

## Nurses who specialise in a specific disease

Some nurses specialise in caring for people with specific diseases or conditions such as:

- cancer
- heart failure
- renal disease
- motor neurone disease.

They are often called a clinical nurse specialist (CNS). They work in partnership with your GP, district nurses, hospital or community team.

## Marie Curie Nurses

Marie Curie provides free nursing care to people with all terminal illnesses across the UK, as well as support for family and friends. Marie Curie Nurses generally provide one-to-one nursing care and support overnight in your home, usually for eight or nine hours. In some areas, they also offer care for a shorter period of time, or during the evening or daytime, as well as care at very short notice in a crisis.

If you would like care and support in your home from a Marie Curie Nurse, contact your GP, district nurse or specialist nurse.



## Hospital or community specialist palliative care teams

Specialist palliative care teams provide care to help improve the quality of life of people and their carers who are coping with life-limiting progressive illnesses, including cancer. You may be referred to a palliative care team if you need specialist support or care. For example, if you have troublesome symptoms that need controlling.

Hospital palliative care teams are usually based in a hospital. They can visit you if you're an inpatient or if you're 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.

Palliative care teams can give you advice on pain control, coping with other symptoms, emotional support and practical problems.

Palliative care teams include specialist palliative care nurses and doctors. Many teams also have, or work closely with, a social worker, a counsellor, an occupational therapist, a physiotherapist and a spiritual care coordinator or chaplain.

**Specialist 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. Most specialist palliative care nurses work closely with a wider hospital or community palliative care team, including doctors and other healthcare professionals.

Some specialist palliative care nurses are called Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may see them when you're at clinic or in hospital.

Doctors specialising in palliative medicine 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, such as washing, dressing and giving drugs. A specialist palliative care nurse will tell you more about the care provided by their team and arrange it for you.

## Social workers/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 additional help for housework, shopping and cooking.

You or your doctor or district nurse can contact them to ask for an assessment of your needs and your carer's needs. You may be asked to pay towards the cost of this help, but it may be funded for you in some circumstances.

Social workers or care managers can also tell you about any benefits you may be able to claim (see pages 36–37). They may also be able to provide more advanced counselling and emotional support for you and your carers.

## Physiotherapists

Physiotherapists can help you to move around. They can also give you information and support about pain relief and breathing problems.

## Occupational therapists

Occupational therapists can help you maintain your independence. They can visit your home to see if specialist equipment would help you move around and do things for yourself for as long as possible. After their assessment, they will arrange to get the equipment you need.

Occupational therapists can also help you manage symptoms, such as fatigue and anxiety.

## Counsellors

Counsellors are trained to help people in all types of situations. Seeing a counsellor can help you understand and express your feelings, and cope better with your situation.

## Spiritual care coordinators or chaplains

Spiritual care coordinators or chaplains offer spiritual care and support. Even if you don't have a spiritual or religious faith, you may still find it helpful to talk to a chaplain about how you are feeling.

## Voluntary organisations and charities

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

Some organisations have volunteers who can provide short periods of respite care to give 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.

Your district nurse, specialist nurse or GP can tell you how to access these health and social care professionals and voluntary organisations. They will also be able to tell you about the specific types of help and support available in your area.

## Where to get the equipment you need

Your district nurse or occupational therapist can assess your needs and organise equipment to help you manage at home.

For example, your district nurse can arrange for you to have:

- a commode, urinal, bedpan or incontinence sheets
- a special mattress or chair cushion
- a hoist or sling
- a special bed – like a hospital bed with adjustable head and foot sections.

Your occupational therapist can assess you and possibly supply you with:

- a wheelchair or ramp
- stair rails
- specialist equipment to help you move or to help others to move you
- grab rails, a raised toilet seat and other equipment for your shower or bath.

Your occupational therapist can also give advice on small gadgets and where you can buy them. For example, two-handled mugs and special cutlery.

If you haven't seen an occupational therapist, but need some equipment that they usually supply, ask your district nurse, GP or community palliative care team to arrange for one to visit your home.

Many shops and organisations also sell or hire aids and equipment. The British Red Cross (see page 125) hires out equipment such as commodes and wheelchairs. You can also buy items, such as incontinence pads and urinals, from most large chemists or on the internet. You may be able to get financial help for equipment and adaptations through your local council.

Marie Curie has a booklet **Being cared for at home**, which has practical information for carers and people who are ill.

If you don't feel you're getting the practical or emotional help and support you need, it's important to let someone know. You can talk to your GP, district nurse or palliative care team. Tell them how you are feeling and what you think you need.



# Chapter six

---

## The last few weeks of life

This chapter includes information on:

- Emotional changes
- Coping with physical changes and symptoms
- Complementary therapies



During the last few weeks of life, you may experience different emotional and physical changes and symptoms. Even though this is normal, it 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 and depression. It's natural to have these feelings in the last few weeks of your life. You may also feel concerned that you're less able to do things and worry about the loss of your role in your family or with friends.

Talking to your family and friends about how you're feeling can help. If you're at home and have a nurse, you can talk to them about any concerns you have. You may find you feel much better once you've talked about your concerns.

Some people prefer to talk to a person they don't know, such as a trained counsellor. If you'd like to see a trained counsellor, your GP may be able to refer you.

Many support organisations (see pages 121–126) can help and some have helplines. Talking to a religious or spiritual adviser can also be helpful even if you've not attended religious services or had contact with spiritual leaders before.

It's not uncommon for people to become withdrawn. For some this may be due to depression. If you think you are depressed let your doctor or nurse know because they can give you help and support. For others, it's a natural part of gradually withdrawing from the world. You may find yourself losing interest in the things and the people around you, even close family.

### If you're a carer

It may be upsetting if your relative or friend seems to be losing interest in you and the things that are going on around them. And you may already be missing the way your relationship used to be and all the things you used to do together. This is quite natural and understandable.

It may feel as though they are giving up. But remember, it's often a natural part of dying. They may seem angry or very anxious and it's important to listen to what they're saying and acknowledge their feelings.

Although you may not feel as though you're doing much, just being there and listening can be more helpful than you think.

You may find it helpful to read Marie Curie's booklet **What to expect at the end of someone's life.**

## Coping with physical changes and symptoms

The physical changes and symptoms that occur vary with the type of illness a person has. Here, we describe physical changes that generally happen in the last few weeks of life, regardless of the condition. We also discuss specific changes that may occur with some types of cancer.

As you become less well, your doctor or nurse will review your medicines. Some medicines may be stopped if they're no longer needed. If you have new symptoms your doctor or nurse may prescribe new medicines to control them. Medicines can be changed as often as you need. Complementary therapies may improve quality of life and well-being. They may also sometimes help to reduce symptoms (see page 88).

### Tiredness and lack of energy

It's normal to have less energy and not be able to do things for yourself. Tiredness and weakness can make it harder for you to concentrate or take part in what's going on around you.

You may find you need to rest a lot during the day. If you're not moving around very much, you may get sore areas, for example on your bottom or heels. Your district nurse can organise equipment, such as a pressure-relieving cushion for your chair or a mattress for your bed, to help prevent this. It can also help to change your position regularly if you can.

### Helpful hints for managing tiredness

- Try to pace yourself and save your energy for the things that matter to you and that you enjoy.
- Cut down on any tasks, such as cooking, cleaning or making the bed. You could ask your friends and family to help you with these.
- Ask a carer to help you wash and dress if this tires you out.
- Accept and use equipment that helps you with daily tasks and avoids you getting so tired, such as a raised toilet seat, bath board or walking frame.
- 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're struggling with eating, you may find it easier to eat little and often.

Macmillan's booklet, **Coping with fatigue**, has further information on tiredness and lack of energy.

## Difficulty sleeping

Some people find they can't sleep well at night. There may be many reasons for this, including:

- taking some medicines which can keep you awake, for example, steroids
- feeling anxious or depressed, or perhaps fearful of dying in the night
- having symptoms that aren't controlled, such as pain, breathlessness or incontinence
- other factors, such as light, noise and sleeping during the day.

It's important to tell your doctor or nurse if you're not sleeping well. Once the causes of your sleeplessness are known, your sleep can often be improved.

Let your doctor or nurse know if you have any specific anxieties or symptoms, such as pain, breathlessness or incontinence, that are affecting your sleep. For example, if pain is causing sleeplessness, this may be helped by adjusting your dose of painkillers at night.

Your nurse can advise you about this.

### Helpful hints for helping you sleep

- If your mattress is uncomfortable, ask your nurse for advice on a more comfortable one.
- Try to reduce light and noise at night.
- Have a warm drink before going to bed, but avoid caffeine and alcohol at night time.
- Keep your bedroom for sleeping. If you wake up during the night, go to another room in the house if you can. If you need to sleep during the day, go to your bed and sleep.
- If you wake at night, try not to toss and turn. Get up and go to another room if you can. Having a warm drink may help. When you feel sleepy, go back to bed again.
- Avoid using any screen, such as a TV, computer screen, or smartphone for at least an hour before going to bed.
- Keep a 'worry book' so that if you wake up during the night you can write down the things you're worried about. You can work through your list of worries 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 to listen to some soothing music.
- If you find touch and massage helpful, you could ask your carer to give your hands or feet a gentle massage.

If, despite following these hints, you aren't sleeping enough, talk to your doctor or nurse. They may advise you to try taking sleeping tablets.

## Pain

Not everyone gets pain in the last few weeks of life. But if you do, there are usually effective ways of controlling it. If you have pain, it's important to tell your doctor or nurse exactly where your pain is, how it feels, and how it affects you so they can treat it effectively.

## Painkillers

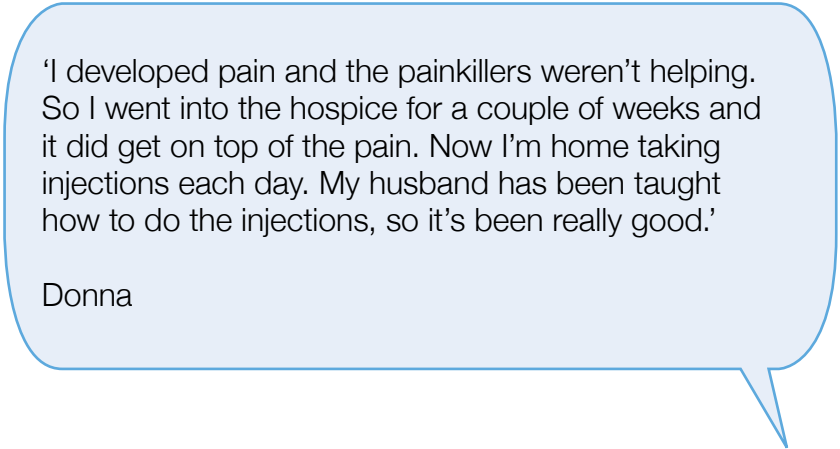
Everyone feels pain differently and there are different types of painkillers for different types of pain. You may need more than one type of painkiller to get the best effect. They include:

- simple painkillers, such as paracetamol
- moderately strong painkillers, such as codeine and tramadol
- strong painkillers, such as 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 usually given as:

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

If you're finding it difficult to swallow or are being sick, your nurse or doctor can give you painkillers, such as morphine, diamorphine and oxycodone, as an injection or by using a syringe driver.



'I developed pain and the painkillers weren't helping. So I went into the hospice for a couple of weeks and it did get on top of the pain. Now I'm home taking injections each day. My husband has been taught how to do the injections, so it's been really good.'

Donna



## Syringe drivers

A syringe driver is a small portable pump (see picture on the next page).

A syringe, usually containing enough drug(s) for 24 hours, is attached to the pump. The pump delivers a continuous dose of the drug(s) from the syringe through a small needle or tube that is inserted just under the skin of your tummy (abdomen) or arm.

Your nurse or doctor will set it up for you and your nurses will change the syringe each day or when needed. Painkillers, anti-sickness, anti-anxiety and several other medicines can be given by a syringe driver.

Many people worry that their pain will get worse as they near the end of their life and they'll need to take increasing doses of strong painkillers, such as morphine. It's important to remember that there's no such thing as a 'right' dose of morphine. The 'right' dose is the dose that helps your pain.

You may find it helpful to watch Marie Curie's film guide for carers about the use of syringe drivers at home. Visit [mariecurie.org.uk/syringedrivers](https://www.mariecurie.org.uk/syringedrivers) for more information.



## Side effects of painkillers

Strong painkillers have three common side effects.

- **Drowsiness** – This usually wears off after a few days. You should be pain-free and still alert enough to do all that you want to do. You shouldn't drive if your painkillers make you drowsy.
- **Sickness** – If you feel sick, your doctor can prescribe anti-sickness medicines (anti-emetics). Sickness usually settles over a few days.
- **Constipation** – This is a common side effect and most people taking strong painkillers need to take a laxative regularly. Your doctor, nurse or pharmacist can advise you about this.

### Helpful hints for controlling your pain with painkillers

- Always take your painkillers regularly as prescribed by your doctor or nurse.
- Let your doctor or nurse know as soon as possible if your pain isn't controlled.
- Keep a pain diary if you can. Ask your district nurse or specialist nurse if they can give you one.
- Be aware of the side effects of your painkillers and take medicines if needed to keep them controlled.
- If you get side effects that aren't being treated or responding to treatment, let your doctor or nurse know.

## Other ways of controlling pain

There are a number of other things which may help to control pain. They can be used alongside painkillers.

### Helpful hints for other ways to help control your pain

- Find a comfortable position to sit or lie in.
- Use any special equipment you have been given. For example, pressure relieving cushions on chairs.
- Use warmth or cold on the area of pain.
- Use relaxation techniques, such as deep breathing or meditation.
- Try to distract your attention away from the pain. For example, listen to music or watch a film you enjoy.
- Talk to your doctor or nurse about transcutaneous electrical nerve stimulation (TENS) and acupuncture, which are more specialised ways of controlling pain. They will let you know if these are suitable for you.
- If you know of methods that have helped control your pain in the past, try them to see if they help now.

You may find Macmillan's booklet **Controlling cancer pain** or Marie Curie's booklet **Controlling pain** useful.

## 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 control sickness. These may be taken as tablets or liquid medicines. If you find it difficult to swallow tablets or liquids, they can also be given as suppositories that are inserted into your back passage, as injections or by a syringe driver (see page 72).

### Helpful hints for reducing sickness

- If you've been given anti-sickness medicines, take them regularly to prevent the sickness returning.
- Have warm or cold food, as this doesn't 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.

## Weight loss and loss of appetite

You may lose weight, even if you're eating well, and this can be upsetting. You may also find that your appetite gradually reduces due to your illness or the medicines you're taking. You may be put off eating by the sight and smell of food.

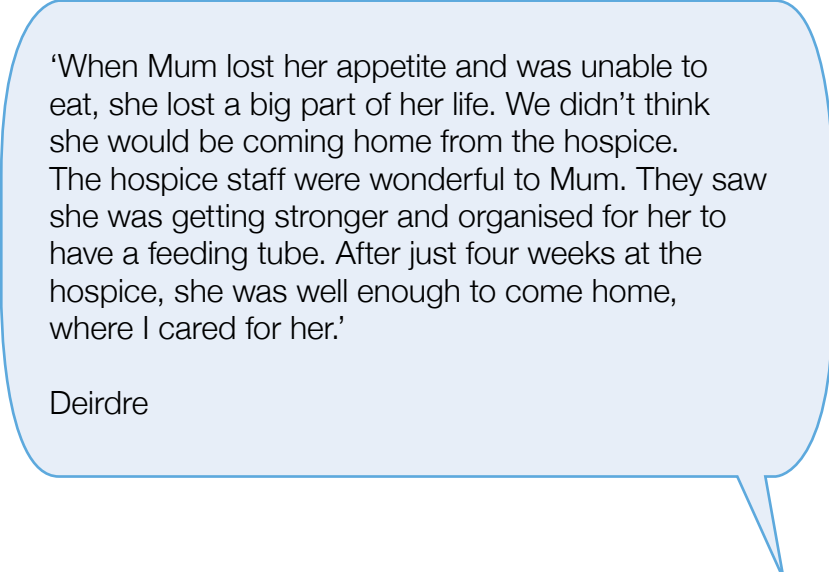
Medicines, such as steroids, can sometimes help to boost your appetite. Your doctor can prescribe these if they are suitable for you.

### Helpful hints for boosting your appetite

- Eat small frequent meals.
- Make your food look more appealing.
- If you find you are put off eating by the smell of cooking, ask someone else to cook your food and avoid foods with a strong smell.
- Have a glass of sherry, brandy or your favourite alcoholic drink about 30 minutes before eating. But remember that the effects of alcohol may increase if you're ill or taking particular medicines, so it's best to check this with your doctor or nurse.
- Have snacks handy to nibble.
- Have nourishing drinks.
- Avoid filling your stomach with fluid before meals as this may fill you up and cause you to eat less.
- Eat slowly.

As you near the end of your life, your body slows down. It doesn't need food as it can't digest it or absorb nutrients from it. Don't force yourself to eat as doing so may make you feel unwell.

As a carer, you might feel anxious or upset because your relative or friend no longer wants or enjoys food. Although this can be hard to accept, it's important not to try to force them to eat. You may want to offer them drinks they like instead.



'When Mum lost her appetite and was unable to eat, she lost a big part of her life. We didn't think she would be coming home from the hospice. The hospice staff were wonderful to Mum. They saw she was getting stronger and organised for her to have a feeding tube. After just four weeks at the hospice, she was well enough to come home, where I cared for her.'

Deirdre

## Constipation

Many people find that they get constipated more easily because they aren't moving around or eating and drinking as much. Medicines, such as strong painkillers, can also cause constipation.

### Helpful hints for managing constipation

- If you've been prescribed laxatives to help with constipation, it's important to take them as prescribed.
- If you are constipated, let your GP or nurse know as soon as possible. You should also let them know if your laxatives aren't working or if your bowels become too loose.
- Drink as much fluid as possible.
- Add high-fibre foods to your diet, such as fruit and vegetables, brown rice, brown bread or brown pasta if you're able to eat them.



## Breathlessness

Some people may feel breathless. This can be for a number of different reasons including:

- cancer in the lung
- chronic lung problems
- general weakness
- fluid inside the lung (pulmonary oedema)
- fluid around the lungs (pleural effusion)
- chest infections
- anaemia (low red blood cell count).

Breathlessness can be very frightening. But there are various ways of treating it, depending on what is causing it.

There are several medicines that can be used to help breathlessness, such as a very low dose of morphine.

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 breathlessness is caused by a build-up of fluid around your lungs (pleural effusion), the fluid can be drained off. If it's caused by anaemia (a low red blood cell count), then your doctor may arrange for you to have a blood transfusion (see page 86).

It's important to let your doctors and nurses know if you're breathless or suddenly become more breathless than usual. They can then help you as soon as possible.

Nurses can show you and your carers the best positions for you to sit or stand to help with your breathing. You can also be taught how to breathe more effectively, pace your activity and save your energy.

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

### Helpful hints for managing breathlessness

- Think about ways to arrange your home to make tasks easier. For example, a chair in the hallway or a chair at the top and bottom of the stairs could be used to take a rest when walking between rooms or climbing up and down the stairs.
- Sit down to carry out everyday tasks like washing and dressing.
- If you feel breathless, try sitting by an open window, or using 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, try using a baby monitor or alarm.
- If you're breathless in bed, try using a V-shaped pillow to help you sit in an upright position.
- If you have difficulty getting to the toilet, use a commode or urine bottle.

Macmillan's booklet **Managing breathlessness** has information about living with breathlessness and learning how to cope with it.

### Cough and wheezing

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

### Mouth problems

You may develop problems with your mouth, such as dryness, ulcers or an infection. These problems can sometimes be made worse by the medication you're taking. You will be more at risk of mouth problems if you find it difficult to take care of your mouth. It's important to let your nurse or doctor know if you develop any mouth problems so they can help.

### Helpful hints for preventing mouth problems

- 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 three or four times a day to remove debris and keep it clean. You can use water or a salt-water rinse (one teaspoon of salt to one 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.
- You may also find it helpful to watch Marie Curie's video called **Helping a person with mouthcare**.



## 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.

You may have swollen legs and ankles. Your doctor may prescribe special pressure stockings to help control this. Using a footstool to keep your feet up when you're 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. It may help to talk to your carers about how you feel. Your nurses can help you find ways of moving around.

## Changes in appearance

You may find it upsetting if your appearance has changed, for example if you've lost weight or put weight on. It can help to talk through your feelings with your carers or your nurses. They may be able to help you find ways to look and feel better.

## Infection

If you're not moving around much and aren't eating or drinking well, you may be more at risk of an infection, such as a chest or urine infection. Let your doctor know immediately 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're anaemic, your doctor or nurse may suggest you have a blood transfusion. You'll usually have this as a day patient in a hospital or hospice. In some areas it may be possible to have it at home.

A blood transfusion may help you feel better very quickly and can be repeated if it's needed and has helped you before.

### **Bladder problems**

If you have problems emptying or controlling your bladder, a thin, flexible tube (catheter) can be put into your bladder to drain the urine. This can also save you from the discomfort of trying to use a bedpan or bottle if you can't get out of bed.

### **Swollen tummy (ascites)**

With some types of cancer, fluid may sometimes build up in the tummy (abdomen) and make it swollen, 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 under local anaesthetic and can be repeated if needed. Ascites can sometimes be helped by taking water tablets (diuretics). Your GP or specialist palliative care nurse will discuss this with you.

Macmillan can send you information on ascites.

## High calcium levels (hypercalcaemia)

Some types of cancer can cause high calcium levels in the blood. This can make you feel drowsy or sick and can cause confusion or constipation. It may also make pain more difficult to cope with. If you develop these symptoms, let your nurse or doctor know so they can take a blood test to check your calcium levels.

If your calcium level is high, medicines called bisphosphonates may be needed to help bring your calcium levels down. You have this medicine through a drip and you will need to be in hospital or a hospice for a few days.

## Managing difficult symptoms

Usually, it's possible to manage your symptoms at home, but sometimes it can help to spend a few days or weeks in a hospital or hospice having them treated. Your community palliative care team, district nurse or GP will discuss this with you if they think it would be helpful. In the hospital or hospice, the doctors and nurses will be able to assess your symptoms. They can adjust the dose of your medicines or add in new ones to control your symptoms more quickly than if you were at home.

Once your symptoms are controlled, you can often go home again to the care of your GP, with the support of your community palliative care team and district nurses.



## Complementary therapies

Although complementary therapies can't cure illnesses, many people find they can help them feel stronger and more confident about coping with dying. They may also improve their quality of life and reduce symptoms.

Many hospices and hospitals offer complementary therapies alongside conventional care. These may include:

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

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

Many hospices and hospitals also offer free complementary therapies to carers. You can ask your nurse about which therapies are available in your local area.

Macmillan has a booklet, **Cancer and complementary therapies**, with more information.

## Information for relatives and friends

Caring can be physically and emotionally hard work. If you've been looking after your partner, relative or friend for some time, you may start to feel drained. It's also common to have a lot of intense emotions, including anger or resentment, towards the person you're looking after. If you feel like this, it's important to tell your GP or one of the nurses so they can help you cope.

You may find that you have very little time for yourself. This can be frustrating and may make you feel trapped or claustrophobic.

It's important to look after yourself too. Think about making arrangements for someone to come in regularly so you can have some time to yourself, even if it's only for a few hours a week. If there isn't a relative or friend who can help, you can contact the carers' organisations on pages 123–124. Having some support and help can allow you to regain your previous role as a partner, friend, or family member.

When you get time off from caring, try to relax. It's tempting to spend the break clearing up the house or doing the washing, but doing something you enjoy can help to revive your energy. You can also spend time just sitting with and talking to the person you're caring for, as this can be very rewarding.

Macmillan has information on looking after someone with cancer and Marie Curie has information on caring for someone with a terminal illness.




# Chapter seven

---

## The last few days of life

This chapter includes information on:

- Physical care
  - Symptoms
  - 'Just-in-case' medicines
- 

Information for relatives and friends is also included on pages 96–99.

Each person's experience of the last few days of life will be different. It can be difficult to predict exactly what will happen or how quickly changes will occur. Usually, you'll gradually become very weak and have very little energy, but sometimes changes will 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
- sleep a lot and feel drowsy when you're awake
- feel disorientated and unsure whether you're dreaming
- dream about people who aren't there or that you knew in the past – your mind may bring up old memories
- lose interest in your surroundings and even your close family.

## Physical care

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

Your mouth may become dry and need to be moistened regularly. Your district nurse can get mouth care sticks (like big cotton buds) and show your carers how to use them. They can also put lip balm on to your lips to stop them getting dry and cracked.

It's important that your carers moisturise your skin and help you change your position regularly. This is to stop your skin from getting sore. Your nurses can advise your carers on how to make sure you're in a comfortable position when you're unable to move yourself. You can use various pressure care aids to help keep you comfortable. These include:

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

Your district nurse can assess what you need and arrange these for you.

There may be a lot of time when you don't need to have anything done and you can just sit or lie quietly with your relatives and friends sitting with you. This can be a very intimate and special time. You can let them know whether you'd like to talk, have a quiet time or listen to music that you like. You can also let them know if you need some time on your own.

## Symptoms

If your symptoms change, your medicines may also need to be changed. Some medicines may no longer be needed and may be stopped. If you develop new symptoms, new medicines can be started.

If you find it difficult to swallow, it's possible to have your medicines either by injection, by patches stuck on to the skin or by using a syringe driver (see page 72).

## 'Just-in-case' medicines

You may hear your doctor, district nurse or palliative care nurse talk about leaving a small case or box of medicines in your home 'just in case' you need them. This is because it can be difficult to get drugs quickly at night or at weekends. This might be a problem if you get more pain or start to feel or be sick. If you have just-in-case medicines in your home, it means that a nurse or doctor can give them to you without delay if you need them.

Just-in-case medicines usually include injections to help with pain, sickness, restlessness and fluid on your chest (see page 96).





## Information for relatives and friends

This information is written for relatives and friends, but you may find it helpful to read it together.

As your relative or friend nears the end of their life, you may find that you need more support and help from professionals to care for them. You can contact their district nurse, specialist nurse or social worker. They will reassess their needs and arrange extra care services, if necessary.

### Pain

Your relative or friend may seem to be in pain. They may be restless, grimacing (screwing up their face) or moving as if they're in distress. They may sweat and have a fast heartbeat and breathing rate. If this happens, the dose of their painkillers may need to be increased. Let their doctor or specialist nurse know so they can advise you about this. They can also check for other causes of these changes, such as an infection.

### Breathing changes

Your relative or friend's breathing may change. For example, their breathing may become noisy because of fluid collecting in the breathing passages. Although this can be distressing for relatives and friends, the person won't usually seem distressed themselves. Their doctor or specialist nurse will be able to give medicines which may help.

## Restless moving, agitation, confusion, shouting, twitching or jerking of the body

Sometimes people 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. In this situation, they may get comfort from a close friend, trusted health professional or a spiritual or religious leader.

Terminal restlessness can often be well controlled with medicines such as sedatives. These can be given by injection or a syringe driver.

## Incontinence

As someone gets closer to death, they may lose control of their bowel and bladder. You can talk to the district nurse about this, and 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. Sometimes it may be more comfortable for the person to have a tube (catheter) put into the bladder to drain away the urine.

## Urine retention

Sometimes urine can't 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, it's important to contact your doctor or nurse 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

Your relative or friend may want particular practices carried out, or prayers read, as they are dying. It's important to do whatever you both feel is right and most helpful. Keep a note of anyone you need to contact in this situation.



## Contacting support services

If you're worried that your relative or friend seems to be distressed or has new or uncomfortable symptoms, contact their GP, district nurse or specialist nurse for advice and support.

You should be given telephone contact numbers for these services and numbers for use out-of-hours, for example, at night and weekends. Keep them in a safe place and use them if you need to.

## End of life care plan

You may hear the doctors and nurses talk about your relative or friend's end of life care plan. This is the care that the doctors and nurses will plan for your relative to meet their specific needs as they approach the end of their life. It will help to make sure that your relative or friend's 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 relative or friend's treatment and end of life care plan. They will also give you support.

If you would like more information about your relative or friend's care plan speak to one of the doctors or nurses looking after them.




# Chapter eight

---

## Nearing death

**This chapter includes information on:**

- What usually happens
  - Physical changes
  - Other changes
  - Final moments of life
  - What happens following a death
  - Bereavement
- 

**Most of this chapter is written for your carers, to help them look after you. You may find it helpful to read it together.**

**The thought of death nearing can be very frightening. Although death is a normal process, it's natural to worry about what will happen.**

**You may want to have a religious or spiritual adviser with you and you may want to carry out particular religious practices. It's important to do whatever you feel is right.**

## **What usually happens**

For many people, dying is very peaceful. You'll usually slip slowly into a deep sleep and find that it's difficult to wake up.

Generally, people gradually become completely unconscious. They can't be woken at all, but may still be able to hear and be aware of the people around them. Some people have phases where they are awake and can talk, and then slip back into unconsciousness.

If you're at home and anything happens that worries your carers, for example, if you have pain or other symptoms that are difficult to control, your carers can contact your district nurse, specialist nurse or GP.

They can give you medicines to control your symptoms, either as an injection or through a syringe driver. They can also discuss any concerns that you or your carers have and reassure you.

## Information for relatives and friends

Even if your relative or friend is unable to respond, they may still be able to hear you and know you're there.

It can help to speak to them and let them know what you're doing, especially if you're giving them medicines or moving them. This may feel strange as they can't respond, but it can be comforting for both of you. You may need to move them regularly to keep them comfortable. There may be times where not much needs to be done and you can just sit with them and be close to them.

It's fine to call your relative or friend's GP or specialist nurse to let them know what's happening and to ask for help and advice if you need it.

## Physical changes

Your relative or friend won't usually feel thirsty at this stage but their mouth may be dry and need to be moistened. If they feel sick, anti-sickness medicines (anti-emetics) can be given by a syringe driver (see page 72).



## Skin and sensation changes

In the last few hours, your relative or friend'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're doing.

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

## Breathing

As your relative or friend gets closer to death, their breathing pattern will probably change. Their breathing may become irregular, with longer gaps between the breaths at times and perhaps quicker breathing at other times. It may also become very noisy, due to a build-up of fluid in their air passages as they are lying flat. This may be distressing for you and any other people around, but it isn't usually distressing for the person who is dying.

If fluid does build up in the air passages, drugs can be given by injection or through a syringe driver to reduce the build-up of these secretions.

You may find it helpful to watch Marie Curie's film guide for carers about changes in breathing towards the end of life. Visit [mariecurie.org.uk/breathingchanges](https://mariecurie.org.uk/breathingchanges) for more information.

## Other changes

If your relative or friend is drifting in and out of consciousness, there may be times when they don't seem to recognise you or other people around them. You may find this distressing. They may also talk to people who they knew in the past or who died long ago, probably because they are thinking of these people. If they seem restless or agitated, this can be eased by giving sedatives by injection or through a syringe driver.

## Final moments of life

For most people, the final moments of life are very peaceful. Their 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 pinpoint 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's a belief that the person's consciousness (mind or soul) 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

### What the GP will do

If your relative 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 relative or friend dies at home, you'll need to let their GP or district nurse know what's happened within the next few hours. The GP or a district nurse will come as soon as possible to confirm the death. This is known as verifying the death.

If the GP comes, they will verify the death and give you a medical certificate for the cause of death with a form called **Notice to informant**. This tells you how to register the death. If a district nurse comes, or you have to call an out-of-hours doctor, they can verify the death but you may need to get the medical death certificate from your GP the following day.

When you have the Medical Certificate of Cause of Death (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's a good idea to ask for additional copies of the death certificate as they may be needed for business matters such as insurance, pensions or banking.

## Post-mortem

The doctor who certifies the death has a legal responsibility to inform the coroner (procurator fiscal in Scotland) if a post-mortem is needed. Usually, if the death was expected and the person was seen by their GP in the 14 days (28 days in Northern Ireland) before their death, there doesn't need to be a post mortem. However, there are some exceptions. For example, a post-mortem may be needed when a person dies of an occupational disease, such as mesothelioma.

It usually takes a few days to arrange a post-mortem. You'll get a medical certificate afterwards. This can help to give exact information about the cause of death.

You'll need to wait until the doctor has decided whether a post-mortem is needed before you set a date for the funeral or alternative service.

## What the 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. 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 126). The funeral director will come as soon as you want them to. If you or your family and friends would like to spend some time alone with your relative's or friend's body let the funeral director know.

Some people wish to look after their relative 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 relative's or friend's body and will wash them. This process is different for different religions and cultures but usually involves carefully washing and drying the body, closing the eyelids, and making sure their mouth is supported while closed. The person's hair is tidied and sometimes washed. The funeral director will also ask if you'd like them to be dressed in any specific clothes, such as a favourite outfit.

If you'd like to help the funeral directors wash and dress your relative or friend, let them know as soon as possible so they can arrange this.

Some people want 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 doesn't necessarily start when your relative or friend dies. You may already be missing the way your relationship used to be and all the things you used to do together.

Immediately after the death of your relative or friend, and for some time afterwards, it is normal to feel different emotions including:

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

Talking to your family and friends about how you are feeling may be helpful. But some people prefer to talk to someone outside their immediate circle of family and friends.

There are many organisations that you can talk to, such as Cruse Bereavement Care (see page 122). Your GP can provide support and may be able put you in touch with a local bereavement counsellor. And many hospices provide bereavement support for the families of people who have used their services.



If you have young children or teenagers they will also have many different emotions and these may affect their behaviour. This can be difficult when you are coping with your own feelings. There are many organisations that can help you support your children. One of these is Winston's wish (see page 123).

Marie Curie has a free booklet called **When someone dies**. This booklet provides an overview of the practical and emotional issues that may come up when someone close to you dies.

'The interesting thing about the final turning point on her death was that, after the initial emotional impact, it brought a tremendous relief. It was something that made you feel slightly guilty, but you had to reconcile your feeling of guilt. You had to balance it with the fact that it was so much better for her. She'd stopped suffering, she'd gone peacefully, she'd gone without pain, you'd done your best, so really you didn't really need to feel all that guilty.'

Clive






# Chapter nine

---

## National organisations that can help

**This chapter includes information on:**

- How Macmillan Cancer Support can help you
  - How Marie Curie can help you
  - Other useful organisations
- 

## How Macmillan can help you

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 leaflets or booklets like this one. Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

There you'll also find videos featuring real-life 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'd 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**.

### Help us improve our information

We know that the people who use our information are the real experts. That's why we always involve them in our work. If you've been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk**

You can get involved from home whenever you like, and we don't ask for any special skills – just an interest in our cancer information.

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

### 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 Mon–Fri, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial advice
- 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](https://www.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](https://www.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.

### 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 advice

Our financial guidance team can give you advice 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**

## How Marie Curie can help you

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

Our nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. Our hospices offer specialist round-the-clock care.

And we support people throughout their illness by giving practical information, support from trained volunteers and being there when someone wants to talk.

### Marie Curie Support Line

Ask questions and find support.

**Tel** 0800 090 2309  
Mon–Fri, 9am–5pm  
(your call may be recorded for training and monitoring purposes).

### Marie Curie Community

For anyone affected by terminal illness to share experiences and support each other. Available 24 hours a day. Visit **community.mariecurie.org.uk**

### Information and support

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

### Publications

You can order any of our publications for free by calling **0800 090 2309** or download them at **mariecurie.org.uk/publications**



### Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable. Visit [mariecurie.org.uk/nurses](https://mariecurie.org.uk/nurses)

### Marie Curie Helper

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

### Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day. Visit [mariecurie.org.uk/hospices](https://mariecurie.org.uk/hospices)

## Other useful organisations

### General organisations

#### Age UK

Tavis House,  
1–6 Tavistock Square,  
London WC1H 9NA

#### Helpline (England and Wales)

0800 169 6565

#### Helpline (Scotland)

0800 470 8090

#### Helpline (Northern Ireland)

0808 808 7575

(Daily, 8am–7pm)

#### [www.ageuk.org.uk](http://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.

#### The Law Society

Tel 020 7320 5650  
(Mon–Fri, 9am–5.30pm)

Email [findasolicitor@lawsociety.org.uk](mailto:findasolicitor@lawsociety.org.uk)  
[www.lawsociety.org.uk](http://www.lawsociety.org.uk)

The Law Society offers advice and support for members of the legal profession and signposts information for consumers of legal services.

#### NHS Direct

Tel 111  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

NHS health information service for England, covering all aspects of health, illness and treatments.

#### NHS 24 in Scotland

Tel 111  
[www.nhs24.com](http://www.nhs24.com)

#### The Office of Care and Protection

Room 2.2A, Second Floor, Royal Courts of Justice, Chichester Street, Belfast BT1 3JF  
Tel 028 9072 4733

**The Office of the  
Public Guardian (OPG)  
(England and Wales)**

PO Box 16185,  
Birmingham B2 2WH

**Tel** 0300 456 0300

(Mon, Tue, Thu, Fri,  
9am–5pm, Wed,  
10am to 5pm)

**Email** customerservices@  
publicguardian.gsi.gov.uk

The Office of the Public  
Guardian (OPG) 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 (OPG) (Scotland)**

Hadrian House,  
Callendar Business Park,  
Callendar Road,  
Falkirk FK1 1XR

**Tel** 01324 678300

(Mon–Fri, 9am–5pm)

**Bereavement**

**Cruse Bereavement Care**

Unit 0.1, One Victoria Villas,  
Richmond, TW9 2GW

**Helpline** 0844 477 9400

**www.cruse.org.uk**

Supports you after the  
death of someone close.

**Dying Matters**

**Tel** 08000 21 44 66

**www.dyingmatters.org**

Promotes public  
awareness of dying,  
death and bereavement.

**The Compassionate  
Friends (TCF)**

14 New King Street,  
London SE8 3HS

**Helpline** 0845 123 2304

**Email** helpline@tcf.org.uk

(Daily, 10am–4pm,  
7pm–10pm)

**www.tcf.org.uk**

A befriending service for  
parents, grandparents,  
or brothers and sisters of  
children who have died.  
The helpline is always  
answered by a bereaved  
parent who is there to listen  
when you need someone to  
talk to.

### **WAY Widowed and Young**

Suite 35, St. Loyes House,  
20 St. Loyes Street,  
Bedford MK40 1ZL

**Tel** 0300 012 4929

**Email** enquiries@

widowedandyoung.org.uk

**www.widowedandyoung.org.uk**

The only national charity in the UK for men and women of 51 or younger whose partner has died. It's a self-help group run by a network of volunteers who have been bereaved at a young age themselves, so they understand exactly what other members are going through.

### **Winston's Wish**

3<sup>rd</sup> Floor,  
Cheltenham House,  
Clarence Street,  
Cheltenham GL50 3PR

**Tel** 08452 03 04 05

**Email**

info@winstonswish.org.uk

**www.**

**winstonswish.org.uk**

Helps bereaved children and young people rebuild their lives after a family death.

They offer practical support and guidance to families, professionals and anyone concerned about a grieving child.

### **Support for carers**

#### **Carers Trust**

32–36 Loman Street,  
London SE1 0EH

**Tel** 0844 800 4361

**Email** info@carers.org

**www.carers.org**

Has a network of 116 independent carers' centres, 55 Crossroads Care schemes and 99 young carers' services. They provide access to desperately-needed breaks, information and advice and education, training and employment opportunities.

### **Carers UK**

**Tel (England, Scotland, Wales)** 0808 808 7777

**Tel (Northern Ireland)**  
028 9043 9843

(Wed–Thu, 10am–12pm  
and 2–4pm)

#### **Email**

[advice@carersuk.org](mailto:advice@carersuk.org)

**[www.carersuk.org](http://www.carersuk.org)**

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

### **Counselling and emotional support**

#### **British Association for Counselling and Psychotherapy (BACP)**

BACP House,  
15 St John's Business Park,  
Lutterworth,  
Leicestershire LE17 4HB

Tel 01455 883 300

**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services. Search for a qualified counsellor at **[itsgoodtotalk.org.uk](http://itsgoodtotalk.org.uk)**

### **Maggie's Centres**

20 St. James Street,  
London W6 9RW

**Tel** 0300 123 1801

**Email** [enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**[www.maggiescentres.org](http://www.maggiescentres.org)**

Provides information about cancer, benefits advice, and emotional or psychological support.

### **Samaritans**

Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**[www.samaritans.org](http://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.

### **UK Council for Psychotherapy (UKCP)**

2<sup>nd</sup> Floor, Edward House,  
2 Wakley Street,  
London EC1V 7LT

**Tel** 020 7014 9955

**Email** [info@ukcp.org.uk](mailto:info@ukcp.org.uk)

**www.**

**[psychotherapy.org.uk](http://psychotherapy.org.uk)**

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

## **Financial support**

### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of these websites:

#### **England and Wales**

[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

#### **Scotland**

[www.cas.org.uk](http://www.cas.org.uk)

#### **Northern Ireland**

[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

You can also find advice online in a range of languages at **[adviceguide.org.uk](http://adviceguide.org.uk)**

### **Personal Finance Society – ‘Find an Adviser’ service**

**[www.findanadviser.org](http://www.findanadviser.org)**

Use the website to find qualified financial advisers in your area.

### **Unbiased.co.uk**

#### **Email**

[contact@unbiased.co.uk](mailto:contact@unbiased.co.uk)

**[www.unbiased.co.uk](http://www.unbiased.co.uk)**

On the website you can search for qualified advisers who specialise in giving financial advice, mortgage, accounting or legal advice.

## **Practical support**

### **British Red Cross**

UK Office, 44 Moorfields,  
London EC2Y 9AL

**Tel** 0344 871 11 11

**Textphone** 020 7562 2050

**[www.redcross.org.uk](http://www.redcross.org.uk)**

Helps people in crisis, whoever and wherever they are.

### **Hospice UK**

34–44 Britannia Street,  
London WC1X 9JG

**Tel** 020 7520 8200

**Email** [info@hospiceuk.org](mailto:info@hospiceuk.org)

**www.hospiceuk.org**

Provides information about living with advanced illness. Has a directory of hospice services and practical booklets available free from the website.

### **Human Tissue Authority**

151 Buckingham  
Palace Road,  
London SW1W 9SZ

**Tel** 020 7269 1900

Controls the use of organs and human tissue from people in the UK, by licensing and inspecting research, education and medical organisations.

### **National Association of Funeral Directors**

618 Warwick Road,  
Solihull, B91 1AA

**Tel** 0845 230 1343

**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.

### **The Natural Death Centre**

The Hill House,  
Watley Lane, Twyford,  
Winchester, SO21 1QX

**Helpline** 01962 712 690

Provides help, support, advice or guidance when planning a funeral – either for yourself or for someone close to you.

### **NHS Blood and Transplant (NHSBT)**

Oak House,  
Reeds Crescent, Watford,  
Hertfordshire WD24 4QN

**Tel** 0300 123 23 23

**www.nhsbt.nhs.uk**

## **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 and Marie Curie do 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 photographs 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 our Senior Medical Editor, Dr Sara Booth, Macmillan Consultant in Palliative Medicine, and by our Chief Medical Editor, Dr Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Rosie Cotter, Content Manager, Information and Support, Marie Curie; Dr Jackie Dominey, Macmillan GP; Donal Gallagher, Bereavement Development Programme Manager, Macmillan Cancer Support; Dr Jo Hayes, Medical Director, Marie Curie Hospice Cardiff and The Vale; Anne McGee, End of Life Care Project Manager, Macmillan Cancer Support; Ethna Scallon, Acting Principal Social Worker, Marie Curie Hospice Belfast; and Jane Watson, Nurse Manager (Clinical Nurse Specialist), Marie Curie Hospice, Solihull.

Thanks also to the people affected by cancer and other terminal illnesses who reviewed this booklet, and those who shared their stories.



## Sources

We've listed a sample of the sources used in the publication below. If you'd like further information about the sources we use, please contact us at **[bookletfeedback@macmillan.org.uk](mailto:bookletfeedback@macmillan.org.uk)**

Department of Health. *End of life care strategy – promoting high quality care for adults at the end of life*. July 2008.

National Institute for Health and Care Excellence (NICE). *Quality standard for end of life care for adults. Quality standard 13*. Issued: August 2011, last modified: October 2013.

National Institute for Health and Care Excellence (NICE). *Guidelines CG140. Opioids in palliative care: safe and effective prescribing of strong opioids for pain in palliative care of adults*. May 2012.

NHS. *Advance Care Planning – A guide for health and social care staff*. 2008.

The Choice in End of Life Care Programme Board. *What's important to me: A Review of Choice in End of Life Care*. February 2015.

Questions about living with cancer?

Call the Macmillan Support Line free on 0808 808 00 00

(Monday–Friday 9am–8pm). Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)

Hard of hearing?

Use textphone 0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.



Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).

---

Marie Curie – what we're here for



Care and support  
through terminal illness

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

Marie Curie Support Line: 0800 090 2309

Ask questions and find support. Open 9am–5pm

Monday–Friday. (Your call may be recorded for training and monitoring purposes.) [mariecurie.org.uk/help](http://mariecurie.org.uk/help)

You can also visit [community.mariecurie.org.uk](http://community.mariecurie.org.uk) to share experiences and find support by talking to people in a similar situation.

Marie Curie, registered charity in England and Wales (207994) and Scotland (SC038731).



This organisation has been certified as a producer of reliable health and social care information.

[www.theinformationstandard.org](http://www.theinformationstandard.org)

Printed using sustainable material. Please recycle.

© Macmillan Cancer Support and Marie Curie, September 2015.

2<sup>nd</sup> edition. MAC14313. Next planned review in 2018.