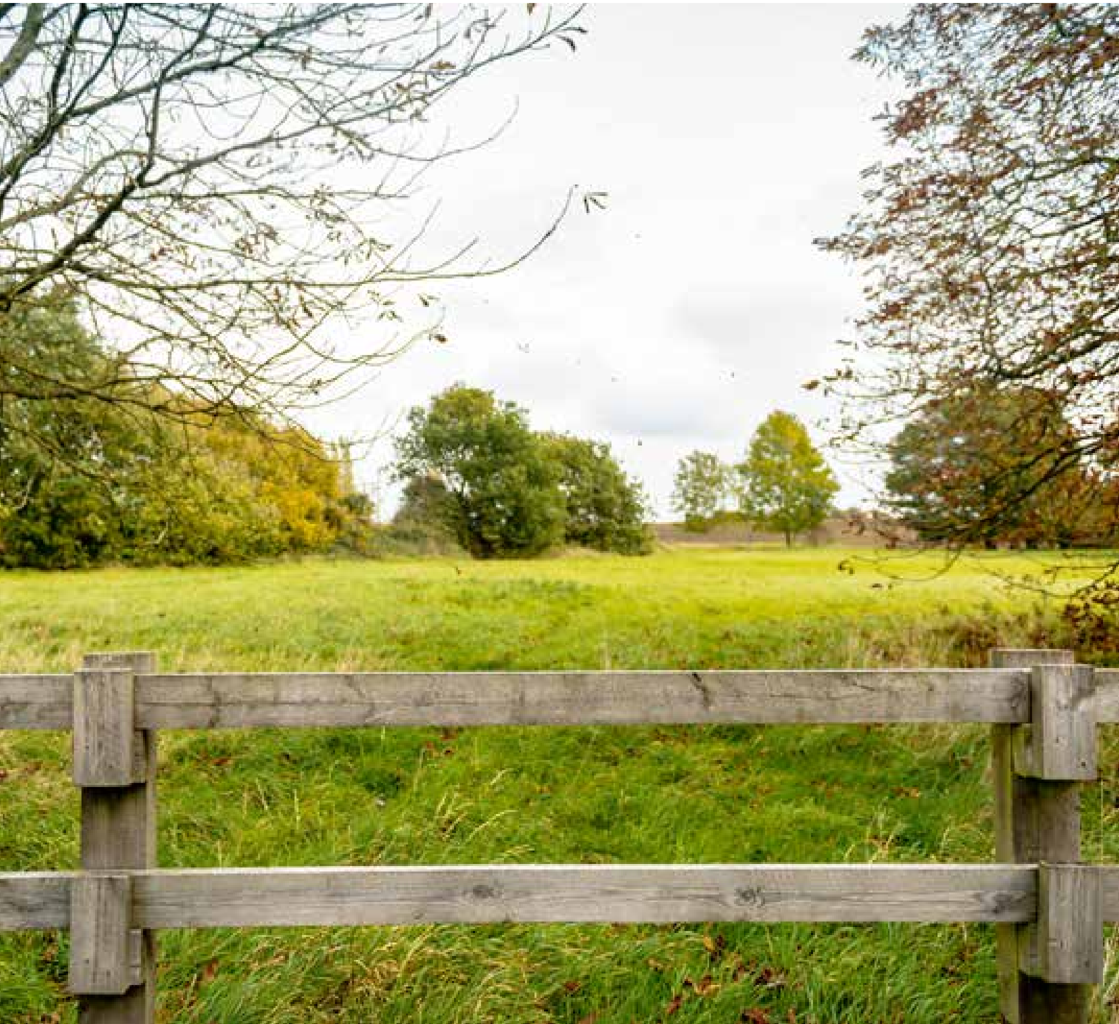
A guide for the end of life



About this booklet

This booklet is for anyone who may be approaching the end of their life. It includes information about coping with the news, sorting out your affairs and planning your care. It also tells you more about what might happen as your illness progresses. It may help you deal with some of the questions or feelings you may have.

There is also information for people caring for someone nearing the end of life.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 122 to 131, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse (page 132).

If you find this booklet helpful, you could pass it on to your family and friends. They may also want information to help them support you.

Quotes

In this booklet, we have included quotes from people who are nearing the end of their life, and their family and friends. Some are from our Online Community (**macmillan.org.uk/community**). The others are from people who have chosen to share their story with us. To share your experience, visit **macmillan.org.uk/shareyourstory**

For more information

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

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

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

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

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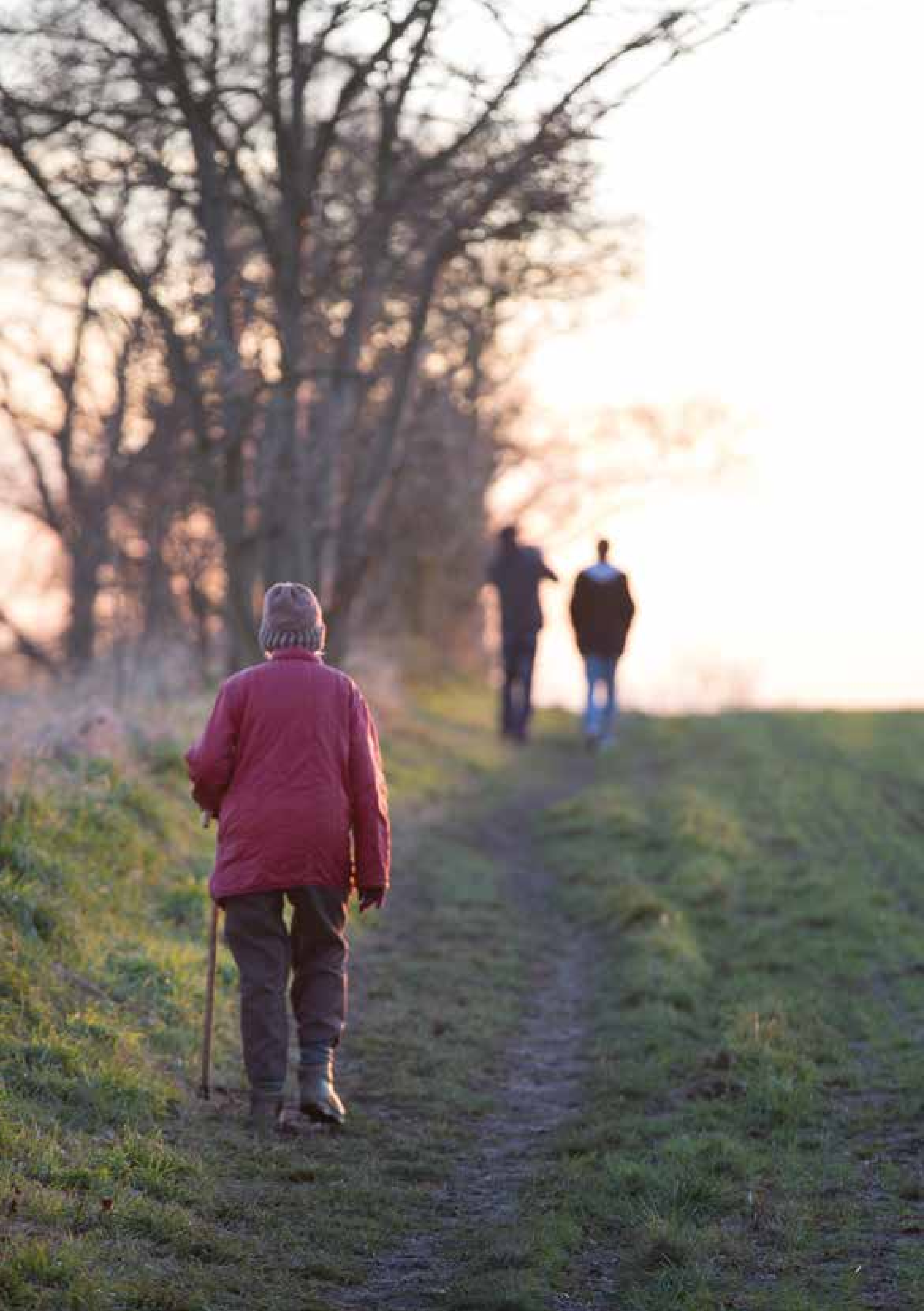


Coping with the news

Finding out you are near the end of life

Finding out that you are nearing the end of your life can be very difficult and distressing. You might find it hard to believe, even if you know your illness is getting worse. You may have strong and often overwhelming feelings that make it difficult to think clearly.

There is no right or wrong way to feel. Take your time to feel these emotions and ask any questions you need to ask. You may need some time on your own, or with people close to you, to cope with what is happening. You can also talk to your GP, cancer doctor, specialist nurse or social worker for advice and support.

Sometimes it is also useful to talk to someone you do not know. Your family or friends may find this helpful, too. Our cancer support specialists can give you information and emotional support. You can call them on **0808 808 00 00** or chat to them online. Or visit our Online Community to talk with other people in a similar situation, share your experience, and ask an expert your questions (see page 121).

Coping with uncertainty

Some people want to know how long they might live. This is known as a prognosis or life expectancy. Others do not want or need to know. Some people may never ask this question.

Your healthcare team may be able to give you an idea of how many weeks or months you might live for. But they cannot be sure. You may live longer than they say or, unfortunately, you may live for less time.

It is common for your mood to go up and down. Sometimes, you may feel well and positive, but at other times you may feel less well and have less energy.

Although your future may be uncertain, it can be helpful to plan ahead and make the most of the days when you feel well. You may want to focus on things you enjoy or want to achieve.

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

- where you want to be cared for at the end of life (page 23)
- making or updating a will (page 34)
- writing an advance decision or advance directive (pages 24 to 25).

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

Your feelings

You are likely to have many emotions when you find out you may be nearing the end of your life. You may feel tearful and upset, and unsure of how to cope with your feelings. You might feel numb. It may not feel like it is really happening to you.

You may be angry because you feel more could have been done to prevent or treat your illness. It may feel unfair, and you may be anxious about what will happen in the future.

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

If you find your feelings are difficult to cope with, there are people who can help.

Talking about your feelings

Talking about your situation and what is happening can help. But it can be hard, especially if you are feeling unwell. You might feel you have to be strong and support other people, even though you are the one who is ill. Or you may feel like you should be the one to start any difficult conversations.

You may find it helpful to talk through your thoughts and feelings with someone you trust. This may be a close friend, partner or family member. Talking openly about your feelings and what would help can also let them know how to support you. You should only share as much as you want to, and at a time when you feel ready. It may help to plan when you want to talk to someone and what you want to say.

You might find it easier to talk to a healthcare professional. Your GP, specialist nurse or healthcare team at the hospital can support you.

If you are finding it very difficult to cope with your feelings, you may need more specialised emotional support. This could be from a counsellor or psychologist (pages 10 and 11). If you think you may need this, ask your GP or specialist cancer doctor to refer you.

You can also get support from a support organisation or support group (pages 122 to 131).

Support with your feelings

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

You may need more specialised help in dealing with your emotions. This might be from one of the following professionals.

Counsellor

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

GP practices, hospitals and hospices often have their own counsellors. Or they should be able to refer you to one. You can talk to one of our cancer support specialists to find out about counselling in your area (page 118). The British Association for Counselling and Psychotherapy can also give you details of counsellors in your area (page 126).

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

Psychologist

Some people may find their emotions are too difficult to cope with. Anxiety and depression can cause problems sleeping and make other symptoms such as pain and breathlessness worse. If this happens to you, you may find it helpful to see a clinical psychologist.

Clinical psychologists are experts in understanding how people feel, think and behave. They may be part of the hospital cancer team or the palliative care team (pages 60 to 61). They specialise in providing psychological and emotional support to people. Some psychological services also offer support to carers and family members.

Spiritual and religious support

Spirituality can mean different things to different people. It may be religious, or it may be expressed in other ways. This can be through music, arts, nature, or how you relate to your family or community.

Towards the end of life, you might think more about religious beliefs, spiritual feelings or your sense of purpose in life. Many people find their faith offers them emotional support and strength during their illness. But thinking about the end of life may challenge what you believe.

You might feel calm about the fact that you are going to die. Or you might be scared about what is happening. You may find it helpful to talk through your thoughts and feelings with someone you trust. This may be a close friend, partner or family member, a health and social care professional or a chaplain or religious leader. You can speak to a chaplain or religious leader even if you are not religious. They are usually good listeners and may be able to help you work out your thoughts and feelings. They are also used to dealing with uncertainty and being with people who are distressed.

You may prefer to talk to someone who is not religious. Humanists UK (page 122) has volunteers who can offer non-religious pastoral support.

Your GP, specialist nurse or cancer doctor may also be able to help you find a non-religious counsellor or pastoral carer to talk to. You can search for counsellors on the British Association for Counselling and Psychotherapy website (page 126).

You may not want to talk about these issues. You may find it helpful to do an activity such as art therapy or meditation to help you process your feelings.

You can find information about spiritual issues on the Marie Curie website (page 123). This is a charity that provides care and support at the end of life.

Talking about death

Hospices or hospitals often have local support groups. Or you may prefer to get support from an online group such as the Macmillan Online Community (page 121).

Some people feel calm about the fact they are going to die. But others are frightened by the thought.

Dying is something that will happen to all of us. But it is not something that is easy to talk about. Most people do not talk about it very much. Your doctor or specialist nurse can talk to you about death and dying, and will do their best to answer your questions. They can also help you have difficult conversations with people close to you.

There are events called 'death cafés' which are safe places to meet with other people to talk about death. There are no agendas or objectives at a death café meeting. They are led by someone who helps guide and support the conversation.

Being with others who are having similar feelings and emotions can make it easier to talk about your own feelings. Death cafés are held in different places, such as a library or community hall. Some hospices help with these and have dates of when and where they are being held locally. Visit **deathcafe.com** to find out more and where and when death café meetings are happening.

If you live on your own

Living on your own can add extra stress. You may value your independence, but being ill may make you feel lonely and frightened.

People who care about you will want to help in any way they can. It is okay to ask for and accept their help.

Some people may be happy to help in practical ways, such as 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, they can choose to do something from your list.

Other people may be able to talk with and listen to you. This could help you to share your worries and fears.

Marie Curie (page 123) and Age UK (page 129) have free helper services available in parts of the UK. Some hospices may also offer this. Someone can visit you to have a chat over a cup of tea, help you get to an appointment or run an errand. There may be help and support available from health, social care and voluntary organisations. Your GP, social worker, local cancer information centre or district or community nurse can help you with this.

People close to you

When you are reaching the end of your life, the people close to you become even more important. But having a terminal illness can affect your relationships.

You may find people react in ways you did not expect. Some may find it hard to know what to say, or avoid talking about your illness completely. Others may be overly cheerful. This might be difficult for you, and it can be hard to tell them how you feel.

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

Partners

If you have a partner, you may try to protect each other from the truth by acting like it is not happening. If you can, talk to each other about your situation and your feelings. Being open and honest can help you both cope with sadness, anxiety and uncertainty. You may find that your relationship becomes stronger as you deal with the challenge together.

It is helpful to keep your relationship as normal as possible. If you have always been close and talked a lot, there is no reason to stop doing this. There may be times when you do not know what to say. A hug, holding hands or just being together quietly can sometimes mean as much as words. It can be very comforting for both of you.

If you have always argued, do not feel you should change this. It is a stressful situation and there will be times when you do not get on well. If you argue a lot, having short breaks from each other can help you feel calmer and think more clearly.

Talking to children and teenagers

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

Children are often aware of what is happening around them. Even if you do not say anything, they may sense that something is wrong and become worried or frightened. If they are told that everything is fine, they may imagine things that are not true. They may also find it difficult to talk about how they feel.

Children sometimes think they are somehow to blame for your illness. It is important to help them understand that it is not their fault.

How and what you choose to tell children depends on their age and how much they can understand. You may find our booklets **Talking to children and teenagers when an adult has cancer** and **Preparing a child for loss** helpful.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Teenagers

Teenagers may find it hard to talk about your situation or to show how they feel. It is important to encourage them to ask any questions they have and make sure they feel involved.

They may find it easier to talk to someone else, such as a close family member, friend, teacher or counsellor. It can help to tell teachers about your situation, so they know what is going on and can offer support. If the teenager is working, you could encourage them to tell their employer.

They may also find support online. If you are a parent, your children may find Riprap helpful (page 125). It is a website that offers information and support for teenagers who have a parent who is approaching the end of life.

Family and friends

Remember that people around you are likely to be shocked by the news. People close to you can provide support and comfort to help you cope with what is happening. But they are also dealing with strong emotions and may need support themselves. Their feelings and emotions will also change over time.

You may want to contact people you have not spoken to for a while. Other people may want to contact you when they learn about your situation. This could be a chance to reconnect, or resolve any past arguments or bad feelings.

Macmillan's cancer support specialists can provide advice and support for your family and friends. You can call them on **0808 808 00 00**.

Unfinished business

Nearing the end of life often makes people think about things that feel unfinished in their lives. There might be things you still want to do. Or there may be things you want to fix or make better from the past.

For example, you may want to:

- see old friends or visit some places again
- look through photos or journals
- finish a project
- make a difficult relationship better
- organise your affairs (pages 21 to 35).

Or you may want to do things for other people, such as:

- write letters to people who are important to you
- record a voice message or video to be given to someone after you have died
- write down your family history for others to read
- make a scrapbook for your loved ones.

Dealing with unfinished business can be very important. It can be a relief to complete a task or make something right. But thinking about these things and deciding what to do can also be hard work. It may be upsetting or cause strong feelings. And sometimes it is not possible to do exactly what you want to do.

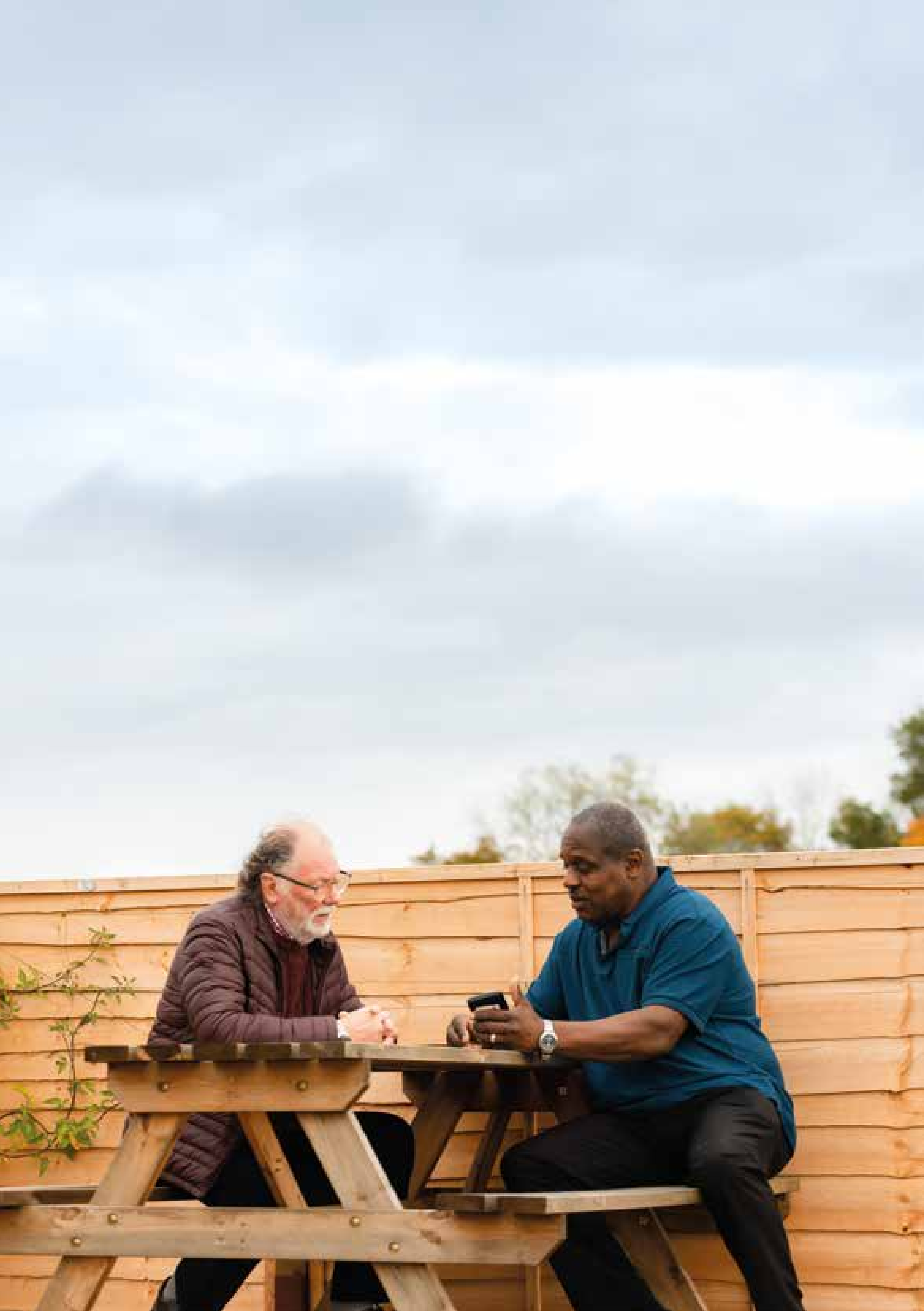
You may find it helpful to get support. Ask your GP or palliative care team for advice. They may be able to arrange for you to talk to a counsellor, a chaplain or family support services. They may be able to help resolve more difficult issues.

Memory boxes

A memory box is a container that holds special things belonging to you. It can be a helpful way of passing on memories to your family, partner or friends. It might include messages and letters, jewellery, photographs, or a present to mark a special birthday. If the memory box is for a child, they may want to help you make it and fill it with special items.

Making a memory box can be a sad and difficult thing to do. But it can also give you a chance to reflect on your life. You may like to remember happy events, even if it also makes you feel sad. It is important to do what feels right for you and at a time that feels right. Your local hospice family support team or chaplaincy services at your hospital can help you make a memory box.

We have more information about memory boxes on our website. Visit **macmillan.org.uk/memory-box**



Planning ahead

Making choices

You may want to decide on your care and treatment for the later stages of your illness. Usually, you can talk about this with the doctors and nurses looking after you. But there may come a time when you are not able to make decisions or communicate with other people.

You can plan ahead for a time when you may not be able to make decisions yourself. If other people know about your wishes, you are more likely to get the care you would like. Planning ahead is sometimes called advance care planning. It includes:

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

We have more detailed information about advance care planning in our booklets **Planning ahead for end of life (England and Wales)** and **Planning ahead for end of life (Scotland)**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Your wishes for your care

You may want to think about how and where you would like to be cared for in the future. It is best to write down your wishes and what is important to you. This will help your family, partner, friends, and health or social care professionals know how you want to be cared for.

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

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

> **"The Macmillan nurses came and planned my Dad's end of life care. He didn't want to go to a hospice and wished to die at home. The Macmillan nurses were supportive and sensitive to Dad's and Mum's wishes."**
>
> Grahame

Advance decision to refuse treatment or advance directive

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

An ADRT or advance directive must say the exact treatment you wish to refuse. It can also include the circumstances when you want to refuse it. If you refuse a certain treatment, you will still have the best possible care, support and medicines to help manage any symptoms.

You need to be aged over 18 (16 in Scotland) to make an ADRT or advance directive. You also need be able to understand the decision you are making. This is called having mental capacity.

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

It is best to write down your ADRT or advance directive. You should give a copy to all the healthcare professionals involved in your care. You may be asked for permission to give copies to the:

- ambulance service
- out-of-hours doctors
- district nursing and palliative care services.

Your ADRT or advance directive will only be used if you cannot make or communicate a decision yourself.

You can change your mind and rewrite your ADRT at any time. But this must be clearly recorded.

Advance decisions to refuse treatment and the law

In England and Wales, an ADRT is legally binding if it meets the legal requirements of the Mental Capacity Act 2005. This means your healthcare team must follow it if they know about it. If you are refusing a treatment that would keep you alive, your ADRT or advance directive must be in writing.

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

Power of attorney

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

Power of attorney laws are different across the nations of the UK.

England and Wales

In England and Wales, it is a called a lasting power of attorney (LPA). There are 2 types of LPA. You can make 1 of them, or both:

- An LPA for financial decisions – this includes paying bills or selling your home.
- An LPA for health and welfare decisions – this includes giving consent for treatment, care, medication and where you live.

You should talk to a solicitor about which is most suitable for you. An LPA is a legal document. It needs to be registered with the Office of the Public Guardian before it can be used. This can take between 8 and 10 weeks.

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

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

Scotland

In Scotland, there are 3 main types of power of attorney:

- A continuing power of attorney – this is for financial decisions, including paying bills and selling your home.
- A welfare power of attorney – this is for health and care decisions, including treatment, care, medication and where you live.
- A combined power of attorney – this is a combination of the first 2 types. It gives your attorney financial and welfare powers.

All 3 types can only be used when they have been registered with the Office of the Public Guardian.

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

You can find out more about power of attorney at **publicguardian-scotland.gov.uk/power-of-attorney**

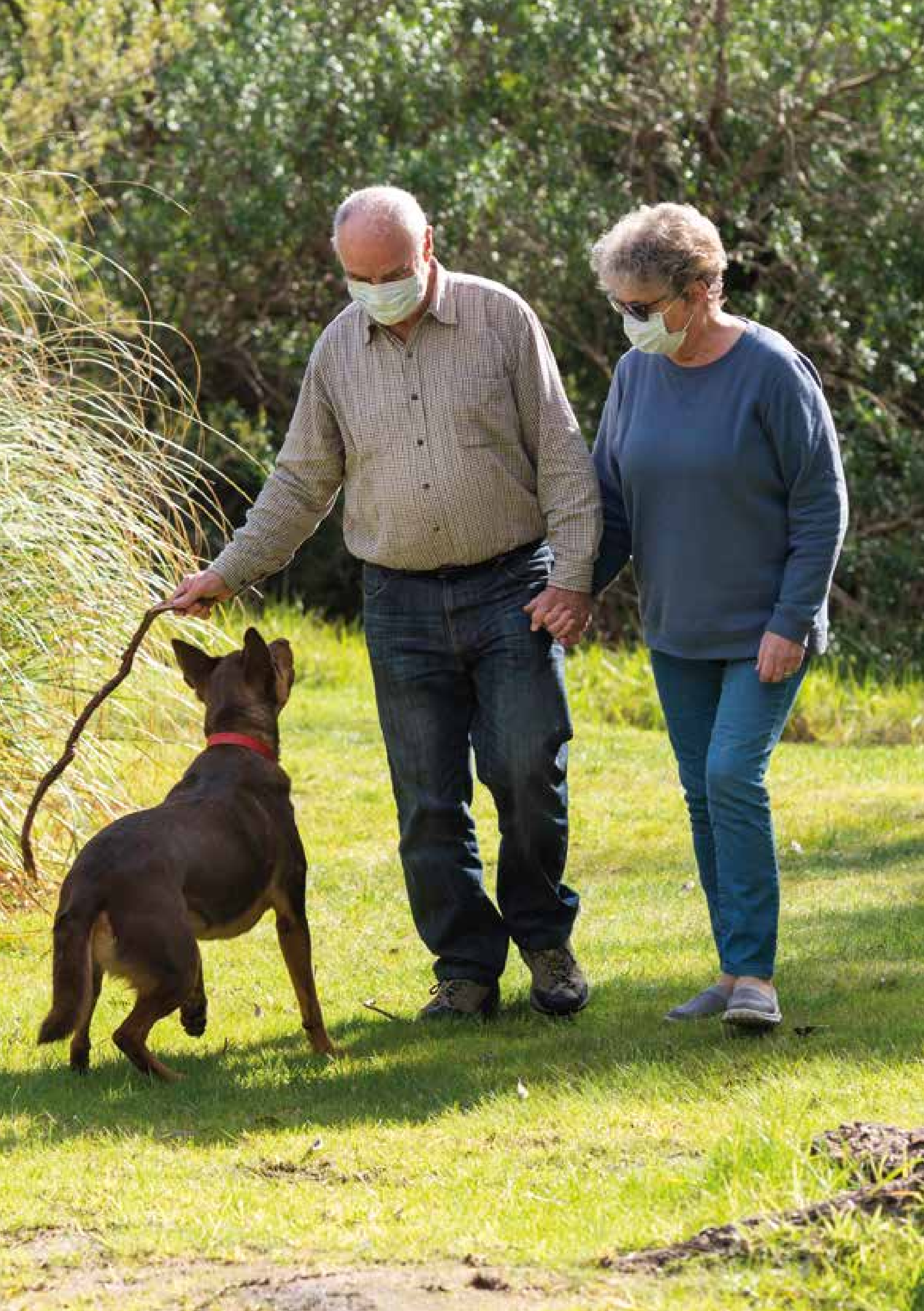
Northern Ireland

In Northern Ireland, you can appoint an enduring power of attorney (EPA) for financial decisions. This includes things like paying bills and selling your home. You can choose which powers you want to give your attorney. You may want to get legal advice to help with this.

You cannot give an attorney powers to make decisions about your care and treatment in Northern Ireland.

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

You can find out more about enduring power of attorney at **nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney**



Tissue, organ and body donations

Only a few people die in a situation where they can donate their organs. Having cancer does not mean you cannot donate your organs. But it may affect what you can donate. Medical specialists will decide if any of your organs are suitable at the time of donation.

The NHS Blood and Transplant website keeps a list of people who wish to donate their organs and tissue after their death. It is important to talk to your loved ones about your decision, so they know what you want. Your family will be asked about your views at the time of donation.

The laws for organ donation are different in each nation of the UK, and in the Crown dependencies of Jersey, Guernsey and the Isle of Man.

England, Scotland, Wales and Jersey have opt-out systems for organ and tissue donation. This means it is assumed that you are willing to donate your organs and tissue, unless you have registered that you do not want to donate. You can also register that you only want to donate some of your organs and tissue.

Northern Ireland, Guernsey and the Isle of Man currently have an opt-in system. This means you need to register that you want to donate your organs. The laws in these countries are being looked at and may change.

You can read more about organ and tissue donation and the laws in each part of the UK on the NHS Blood and Transplant website (page 124).

Donating your body for medical research

Some people want to donate their body to a medical school for medical teaching or research. If you are thinking about this, you should discuss it with your GP, hospital team or palliative care team. You should also discuss it with your close family or friends.

If you want to donate your body, it is a good idea to make other funeral plans as well. This is because the medical school may not be able to accept your donation.

You can find out more about donating your body by contacting the Human Tissue Authority (page 122).

Funeral or ceremony planning

Funerals or ceremonies give family, friends and others a way to pay their respects to the person who has died. Tell your loved ones your wishes for your funeral or ceremony. This can include any rituals or customs you would like to be included. This means it is more likely to be what you would want. They may also have suggestions for ways to help them celebrate your life, say goodbye and remember you.

You could think about whether you want:

- a burial or cremation
- specific songs, readings or prayers
- certain customs or rituals to be followed
- to be dressed or presented in a certain way
- donations to be given to specific charities.

Paying for a funeral and choosing a funeral director

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

- your local funeral directors
- the National Association of Funeral Directors (NAFD) – page 123
- the National Society of Allied and Independent Funeral Directors (SAIF) – page 124.

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

You do not need to use a funeral director. But it can be hard to arrange a funeral at such a distressing time. The Natural Death Centre has more information about this (page 124).

Not everyone wants to have a funeral. Some people choose to have a cremation without a service, so their loved ones can choose how they remember them. There are various organisations that offer this service.

Making a will

A will is a legal document. It gives instructions about who you want to give your money and belongings to when you die.

Writing a will makes sure your wishes are followed after you die. It means your loved ones and friends will be looked after in the way you want. A will can also be a way of remembering causes and organisations that are important to you. You might find that writing your wishes in a will makes you feel less anxious about the future.

If you die without making a will, your money and belongings may not go to the people you would choose. It can also take a lot longer to deal with your estate. Your estate is everything you own and your share of anything you jointly own.

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

We have more information in our booklet **Your step by step guide to making a will** (page 116).

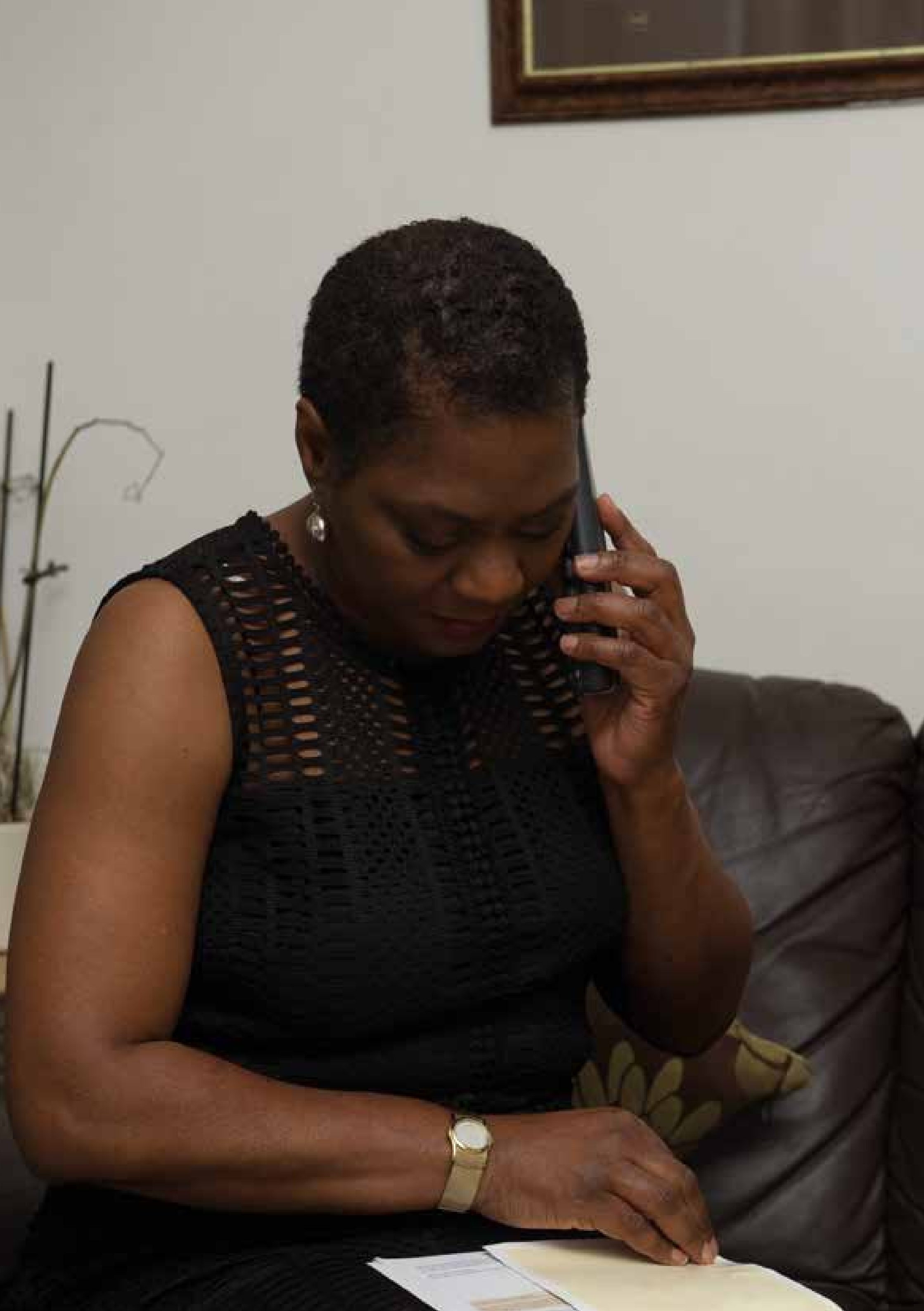
We have more information about making a will on our website. Visit **macmillan.org.uk/writing-a-will**

Important documents

You may find it helpful to make a list of important documents and where to find them. Make sure someone close to you knows where the list is.

The list could include details of where to find things like:

- your will
- an advance decision to refuse treatment
- your funeral plan
- your bank and building society details
- any insurance policies you have
- details of any pension scheme you have
- your birth certificate
- any marriage or civil partnership certificate
- any divorce certificates (decrees absolute) or civil partnership final orders
- your national insurance number
- the details of your accountant, solicitor and tax adviser.



Financial help

Help with money and benefits

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

- income
- additional costs
- managing your finances.

Our financial guides can help with money worries. They can give personalised support and guidance to help you:

- plan your budget
- manage your money
- understand your personal finance options.

To talk to a financial guide, call us on **0808 808 00 00** or chat online.

Financial help is often available. You can sometimes access it at short notice. Some types of financial help do not depend on your income or the money you have.

It is likely you will be able to get benefits in the last months of your life to help with your care. You may also be able to get free prescriptions. Some charities and other organisations offer grants to help with costs. We have more information on benefits and other financial support in our booklets **Help with the cost of cancer**, **Planning and managing your finances** and **Sorting out your affairs** (page 116).

Benefits

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

- Personal Independence Payment (PIP), if you are aged 16 to state pension age
- Attendance Allowance (AA), if you are at or above State Pension age.

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

You may also be able to apply for:

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

Our welfare rights advisers can give you advice about claiming benefits and help you fill in claim forms. To talk to a welfare rights adviser, call us on **0808 808 00 00** or chat online. Depending on where you live, you may be able to talk to a local Macmillan benefit advice service.

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

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

Terminal illness (special rules)

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. The rules are different depending on where you live in the UK and which benefit you are applying for. You can apply for special rules if your doctor or cancer nurse complete a form saying you have a terminal illness.

Special rules can be used for:

- Employment and Support Allowance (ESA)
- Personal Independence Payment (PIP)
- Disability Living Allowance (DLA)
- Attendance Allowance (AA)
- Universal Credit (UC).

If you apply for benefits under special rules, you can avoid extra assessments. You are automatically paid the higher rate, except for the mobility component of PIP and DLA. You must still apply for that, but the process may be quicker.

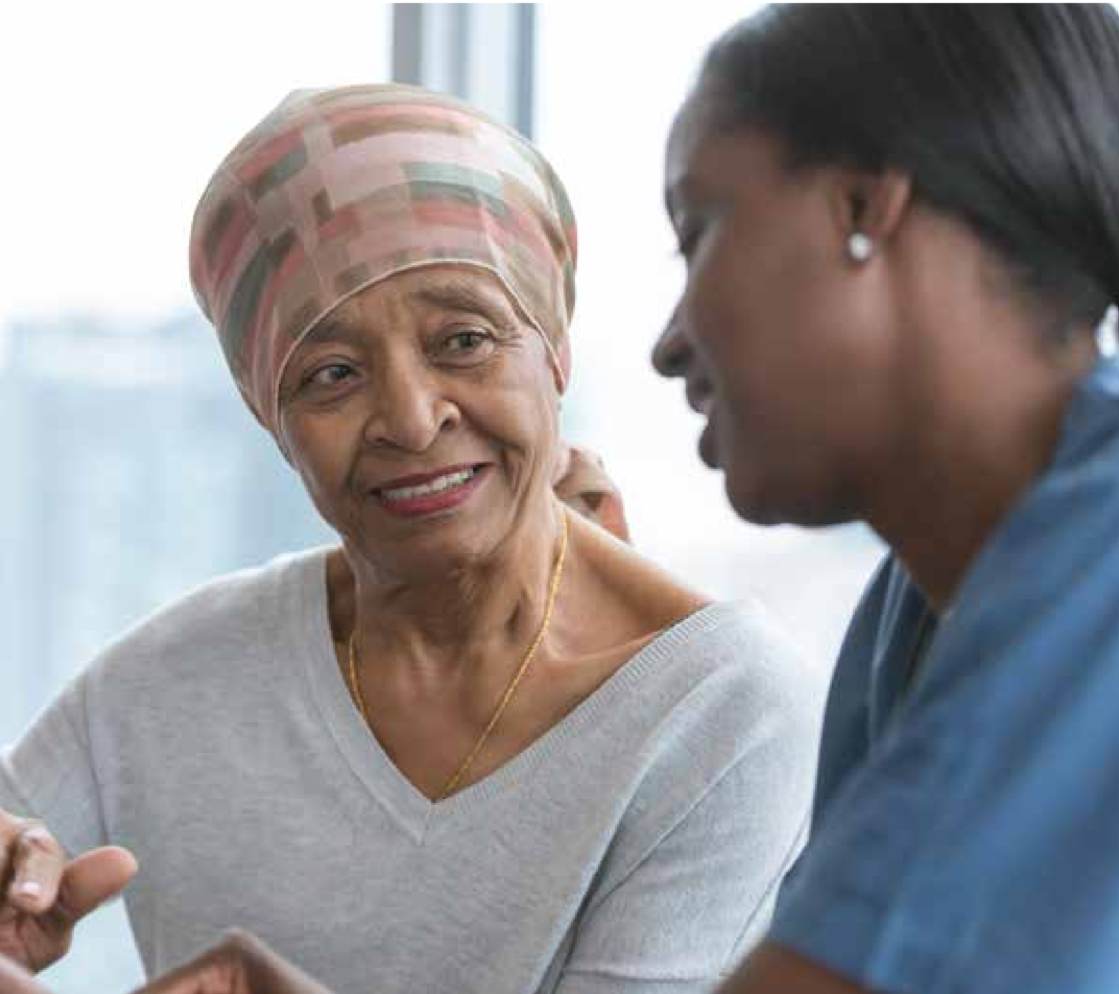
You must claim the benefit and explain that you are claiming under special rules. Your doctor or cancer nurse must also fill out:

- an SR1 form – if you are claiming UC or ESA
- a DS1500 form – if you are claiming PIP, DLA or AA
- a BASRiS form – if you live in Scotland and are claiming Adult Disability Payment or Child Disability Payment.

The form will then be sent to:

- the Department for Work and Pensions (DWP) in England and Wales
- Social Security Scotland in Scotland
- the Department for Communities (DfC) in Northern Ireland.

If you get benefits under special rules, you usually have them for a period of 3 years. They will be looked at again after this time if you live longer than originally expected. In Scotland, there is no time limit for getting Adult Disability Payment or Child Disability Payment under special rules.



Grants

Macmillan grants

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

You can find out more by calling our Welfare Rights team on **0808 808 00 00** (Monday to Friday, 8am to 8pm, and Saturday and Sunday, 9am to 5pm).

You can also apply through a health or social care professional. This may be a social worker, a district nurse, a benefits adviser, or a Macmillan nurse, if you have one.

Other grants

There may be other grants and loans available if you need financial help. These might include help from:

- government and local councils
- utility companies (gas, electricity and water companies)
- charities and other organisations.

Call our welfare rights advisers for more information about finding this type of financial help on **0808 808 00 00**.

Turn2us helps people find specific charities that may be able to offer financial help (page 129). It has a grants search tool on its website and offers some grants itself.

Your local library may have books about organisations that offer grants. This may include **A guide to grants for individuals in need**, published by the Directory of Social Change.

Prescriptions

The help you can get for prescriptions is different across the UK.

In Scotland, Wales and Northern Ireland, prescriptions are free for everyone.

In England, prescriptions are free for anything related to cancer or its effects. You need to collect an FP92A form from your GP surgery and apply for a medical exemption certificate.

An exemption certificate lasts for 5 years and can be renewed if you are still eligible. Once you have the exemption certificate, you do not need to pay for any prescriptions. This includes prescriptions for medicines that are not related to your cancer treatment. You will need to show the exemption certificate to the pharmacist when you collect your medicines.

In England, if you are a carer, or someone who is not having cancer-related treatment, you can get help to pay for prescriptions in some situations. To find out more, visit **www.nhs.uk/NHSEngland/healthcosts**

Other financial things to think about

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

Bank accounts

When you die, someone will need to tell your bank you have died. This will usually be the person you have named in your will as your executor (page 34). If you have not made a will, it will usually be your next of kin.

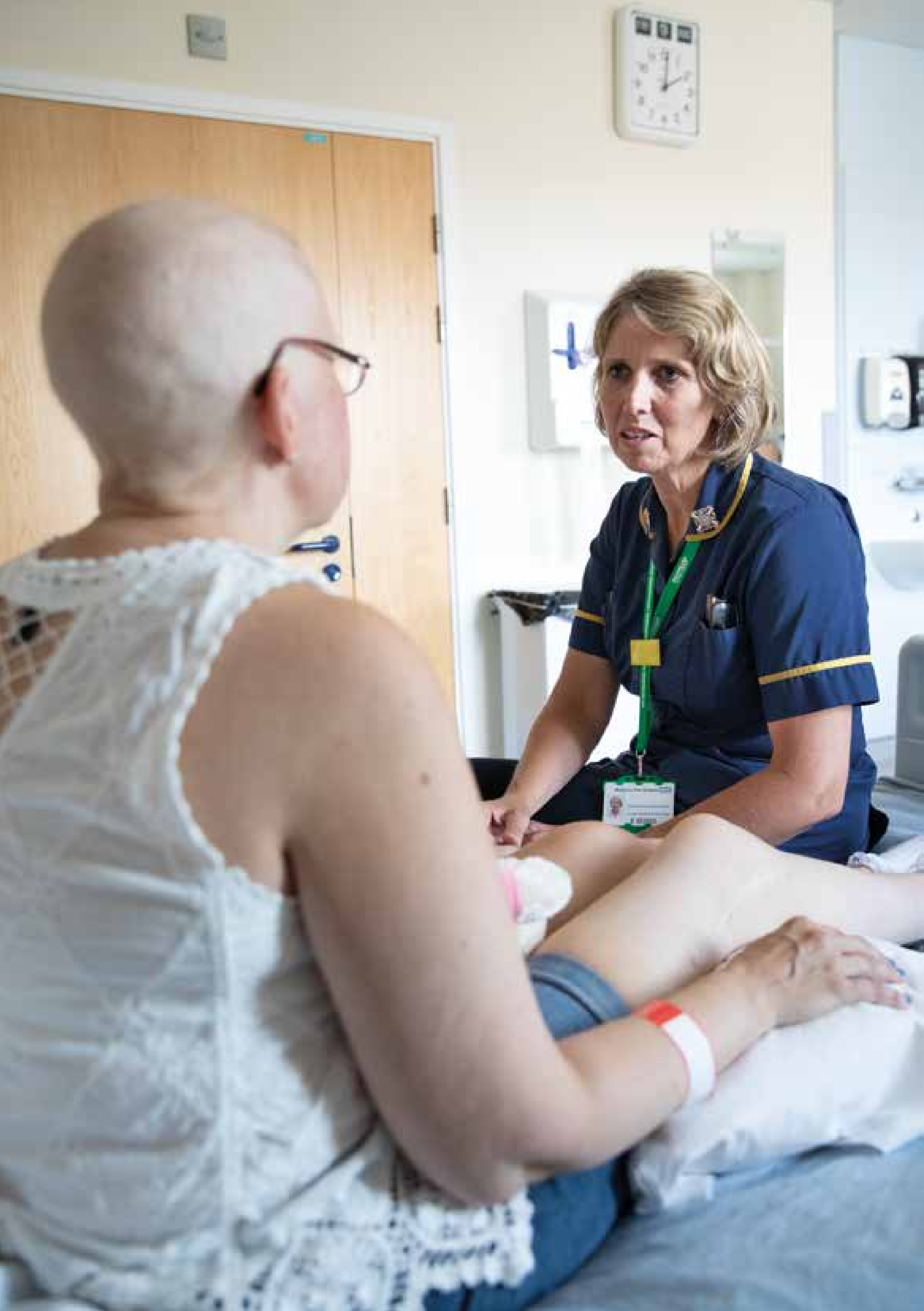
Your bank accounts will be frozen when you die. This means money can only be taken out if the executor transfers it.

If you have a joint bank account with another person, such as a partner, what happens depends on where you live in the UK:

- In England, Wales or Northern Ireland – any money left in the account belongs to the other person. It is not included as part of your estate.
- In Scotland – any money you put into the joint account still belongs to you when you die. It becomes part of your estate.

Pension schemes

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



Your care at the end of life

Choosing where to die

It can be hard to think about where you would prefer to die. The choice can depend on:

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

Some people prefer to die at home, surrounded by the people and things that are important to them. Others may prefer to be somewhere like a hospice. Wherever you are cared for, it is important that your symptoms are well managed and you get the care you need. This can happen in different places.

At home

Staying at home may help you feel more in control as it allows you to be in a familiar place. You may also have close family members, friends or a partner to look after you. You might find it easier to say goodbye to people you love when you are in your own home.

You may need extra help if you are being looked after at home. But caring can be hard work for the people looking after you, both physically and emotionally. There are many health and social care professionals who can help with your care.

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

GP

Your GP has overall responsibility for your care when you are at home. They can prescribe any drugs you need and arrange help from other professionals. They will also arrange for you to go into hospital or a hospice if needed (pages 54 to 59).

You can talk to your GP about what may happen as you become less well. They can discuss plans for the future with you. This might include:

- planning for emergencies
- making a statement of your wishes or an advance decision to refuse treatment (pages 24 to 25)
- deciding where you might prefer to be cared for as your illness progresses (page 23).

Your GP can also arrange for a district nurse to visit you if you need nursing care.

Nurses

There are different nurses who can visit you at home.

Community or district nurses

Community or district nurses can make regular home visits to help with:

- nursing care, such as changing dressings and giving medicines
- giving advice and support on pressure area care and toilet problems, such as incontinence and constipation
- showing your carers how to move you and look after your personal care needs, such as washing and toilet needs
- arranging for a social carer or healthcare assistant to help you with personal care
- arranging practical aids, such as pressure-relieving mattresses or commodes.

A community or district nurse will work with palliative care nurses to help support you and your carers so you can stay at home.

Palliative care nurses

Palliative care nurses specialise in caring for people who have an illness that cannot be cured. They can help with managing pain and other symptoms, and offer emotional support to you and your family, friends or partner. They can help you explore your fears and anxieties and listen to your concerns.

A palliative care nurse may speak to you on the phone or visit you at home regularly to see how you are and make sure any symptoms are being managed. They can also refer you to any other services provided at your local hospice. Palliative care nursing services are free. Your GP or your doctor or nurse at the hospital can refer you.

Marie Curie nurse or healthcare assistant

In some parts of the UK, you can get support from a Marie Curie nurse or healthcare assistant (page 123). A nurse can advise you about medication. A healthcare assistant can help with practical tasks such as washing and dressing. Marie Curie can sometimes provide nursing overnight from a registered nurse or healthcare assistant. Your GP or district nurse can tell you if Marie Curie nurses are in your area.

Other professionals

You may also get support from other professionals at home.

Occupational therapists

Occupational therapists working in the community can help you keep your independence. They can assess your situation and arrange for any aids or changes you need. Aids might include toilet frames, handrails or a wheelchair. A change might be something like fixing safety rails in your bathroom or making doors wider.

An occupational therapist may be able to help you change your daily routines and activities to help you manage low moods. Some can also help you manage anxiety, fatigue and breathlessness.

Physiotherapists

Physiotherapists can help keep you moving. They can advise you and your carers on the best and safest way for you to move around your home. They can also offer treatment and exercise programmes to help you manage symptoms such as pain, breathlessness and fatigue.

Social services

Social services can help if you find some parts of your daily life difficult. Social care can include getting help with:

- personal care, such as washing and dressing
- tasks like cleaning and cooking.

There are different ways to access social care. Your hospital team, GP or district nurse can refer you to social services. Or you can refer yourself. You will have a needs assessment before any care is arranged. A social worker will ask you about your daily routine and what you find difficult. Sometimes an occupational therapist or nurse may do this instead.

Each local authority has its own assessment procedure. Local authorities will have information on their website. They can also provide an up-to-date list of local providers and can signpost you to services. You can find your local authority by visiting **gov.uk/find-local-council**

You usually have to pay towards the cost of services. This depends on your financial situation. If you have a lot of care needs, you may be eligible for funding for your care. Your GP or a social worker can tell you more.

Charities and volunteers

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

Some organisations have volunteers who can spend time with you to give your carer a break during the daytime. Others can provide befriending services for people who are on their own.

Hospices

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

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

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

You may decide that you would prefer to die in a hospice. You will need to discuss your wishes with your GP and the hospice team involved with your care. You may also want to talk about your wishes with close family members, friends or a partner.

Hospices are very different to hospitals. They are smaller and quieter, and aim to provide care to suit each person's situation. Visiting is usually less restricted than in a hospital. As well as practical nursing care, they may offer other services for patients and their families. These may include counselling, spiritual care, and psychological support.

Accommodation and care in a hospice are free of charge. There is a limited number of beds in each hospice, so there may be a waiting list.

You can find out more about your local hospice from your GP, district nurse or palliative care nurse. Hospice UK also has useful information about hospices and where they are across the UK (page 122). If you are not sure about hospice care, you can ask to visit a hospice. The staff can show you around and talk through any questions or concerns you have.

> **"My late husband was diagnosed in 2018 with pancreatic cancer. We had a lot of support with pain management and end of life care from our local hospice."**
>
> Michelle

> "Mum decided to stay longer than the respite week because she could see it was better for her to have specialist care available whenever she needed it. „
>
> Anne

Residential homes or care homes with nursing

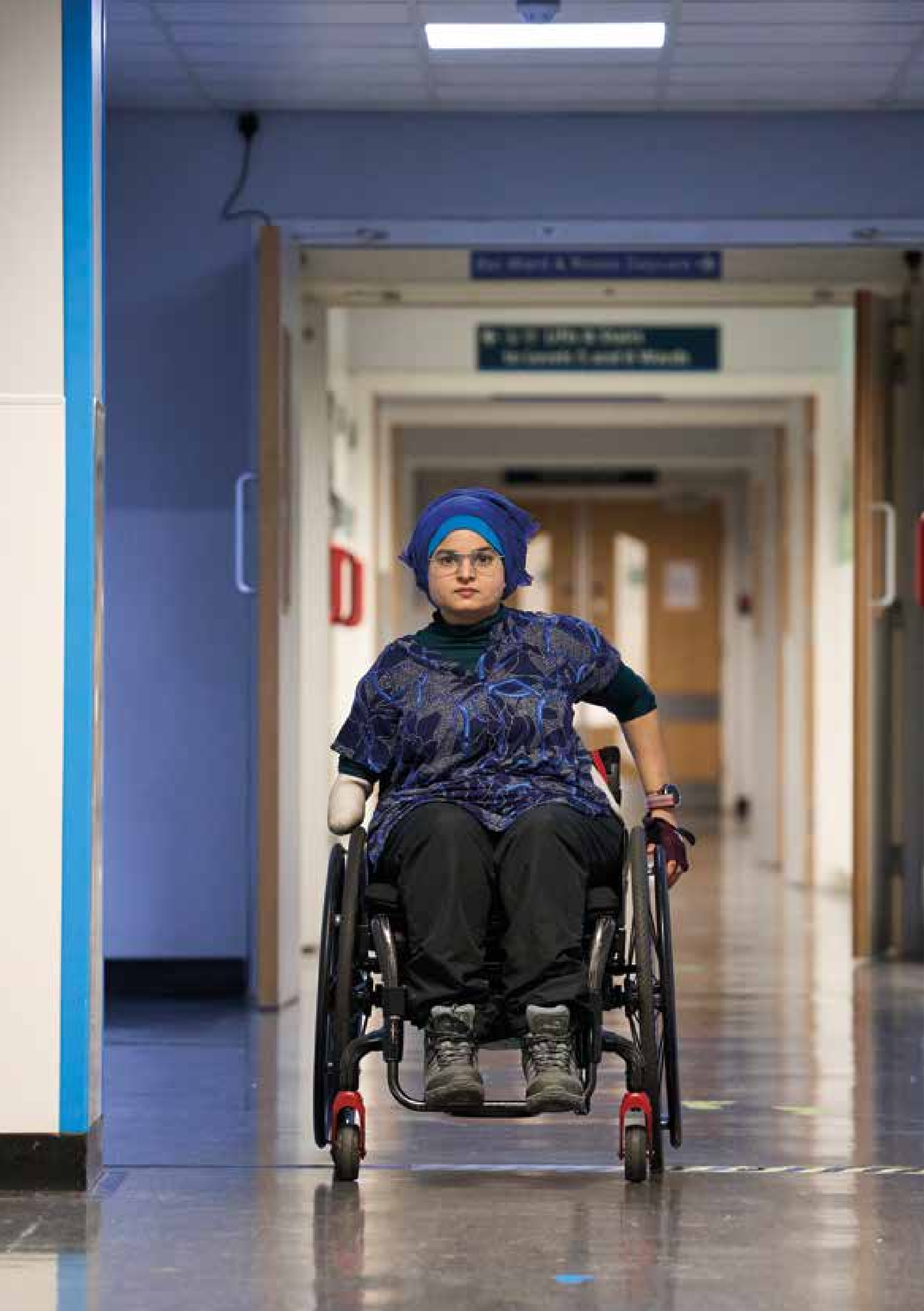
If you might need care for several months, you may prefer to be looked after in a residential care home, or care home with nursing (nursing home). A nursing home has qualified nurses on their staff to provide nursing care. They usually offer short-stay or long-stay care.

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

Your GP, district nurse or social worker can explain the different types of care homes to you. They can arrange for you to stay in a care home, either with or without nursing care.

Many care homes are privately owned. However, some are run by a charity or the local council. You usually need to contribute towards the costs of staying in a care home. This depends on your financial situation.

NHS UK has information about care homes and funding for care (page 125). You may be able to get a list of local care homes from your local county council. Carehome UK also has information about care homes and funding (page 131).



Hospital

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

Although many people die in hospital, it is not always a peaceful place to be. Often your care has to fit into the ward routine. This means you may not always be looked after in the way that you would like.

If you are in hospital, a palliative care team may be able to see you and be involved in your care. They can help manage your symptoms and offer you and your family emotional support.

Palliative care

Specialist palliative care teams provide advice and support for people who have a life-limiting illness. They also provide support for the person's family and friends. Some people are referred to a palliative care team early on in their illness. Others will only be referred as they approach the end of their life.

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

Palliative care teams can include:

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

What do palliative care teams do?

Palliative care teams can give you advice on managing pain and other symptoms. They also provide emotional support and can advise you about practical problems. They can help you make an advance care plan and help coordinate your care.

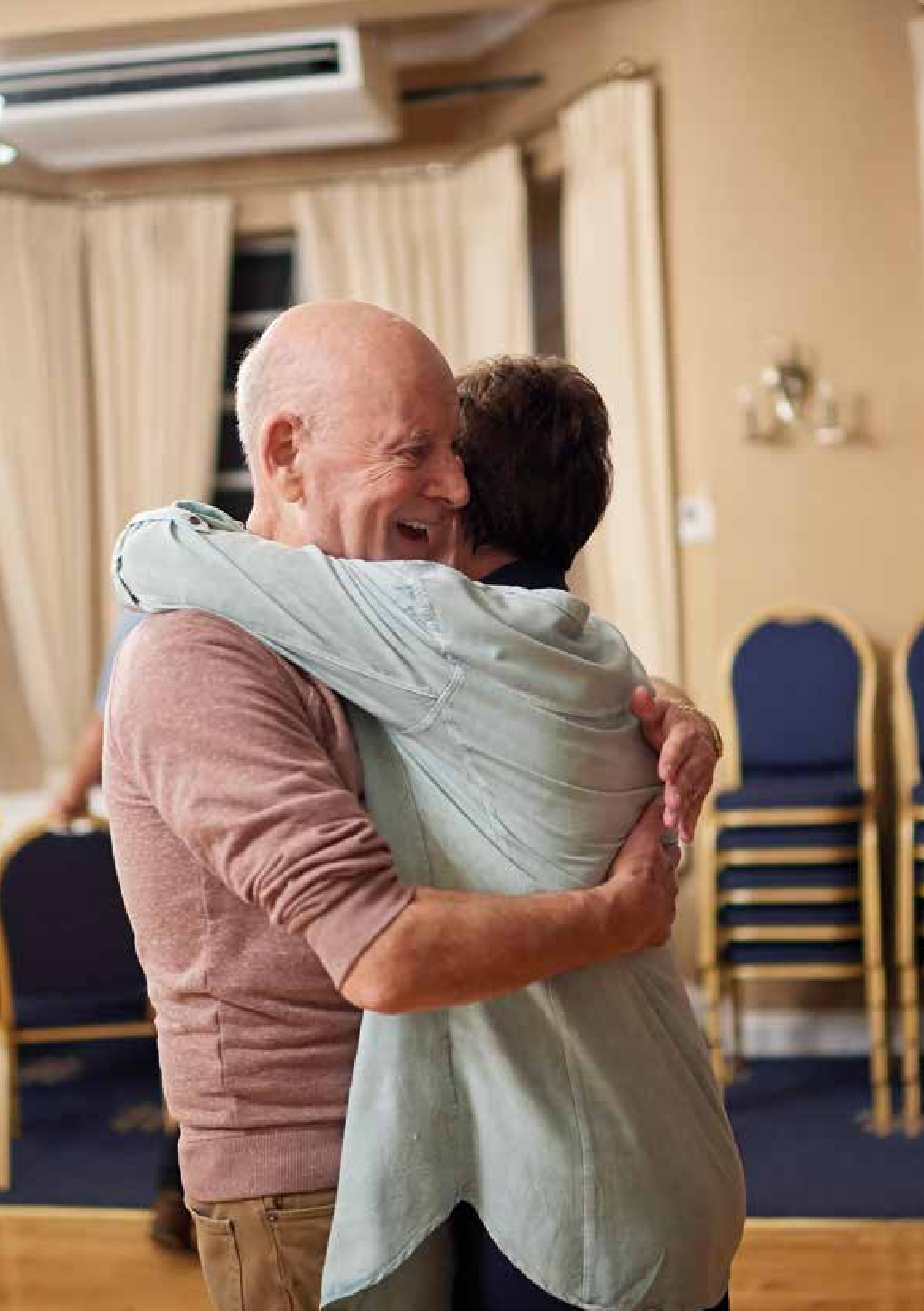
Palliative care nurses are experts in assessing and treating any symptoms you may have. They can also provide emotional support to you and your carers. Palliative care nurses are sometimes called Macmillan nurses. But not all Macmillan nurses specialise in palliative care.

Palliative care doctors specialise in the management of symptoms in people who are approaching the end of their life. 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 nursing and personal care. This might include washing you, dressing you and giving you drugs. A palliative care nurse can tell you more about the care provided by their team.

Palliative care nursing services are free. Your GP or your doctor or nurse at the hospital can refer you.

> **"The Macmillan nurses took away any worries we had about medication. Everything was there when he needed it – it was all fast tracked."**
>
> David



The last few weeks of life

The last weeks of life

During the last weeks of life, you may go through emotional and physical changes. You may also have new or different symptoms. This is normal. But 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
- depression.

It is natural to have any of these feelings in the last few weeks of your life. You may feel different things at different times. How you are feeling physically can often affect your emotions.

Talking to someone about your emotions and what is happening may help you feel better (pages 8 to 14). This could be a family member, friend or partner. Or it could be someone in your healthcare team, such as your GP or a palliative care nurse or doctor. You might prefer to talk to someone you do not know, such as a trained counsellor. You may also find it helpful to talk to a religious or spiritual adviser. You can do this even if you have not attended religious services or had contact with spiritual leaders before.

There are also support organisations that can help. For more information, visit **macmillan.org.uk/in-your-area**

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

You may become withdrawn and quiet. This is a natural part of gradually retreating from the world. You may find yourself losing interest in the things and people around you, even close family or friends.

Becoming withdrawn can sometimes be caused by depression. If you or people close to you think you might be depressed, tell your doctor or nurse. They can give you help and support (pages 10 to 14).

> **"The Macmillan nurses showed us simple ways to make Dad more comfortable in those final weeks. It was those simple things that made everything so much easier."**
>
> David

Coping with physical changes and symptoms

Physical changes and symptoms vary. Here, we describe some of the physical changes that can happen in the last few weeks of life. Some people may have symptoms we have not described here.

Your healthcare team will monitor you and review your symptoms and medicines. They may stop some medicines if you do not need them anymore. If you have new symptoms, your doctor or nurse may prescribe new medicines to help manage them.

Some people find complementary therapies can improve their quality of life and well-being (page 83). They may sometimes help reduce symptoms.

Tiredness and lack of energy

It is normal to have less energy as you approach the end of your life. You may find you need help to do things you usually do for yourself. You may also need to rest more. Tiredness and weakness can make it harder for you to focus or take part in what is going on around you.

Things that can help

- Try to pace yourself. Save your energy for the things that matter to you and that you enjoy.
- If you have important things that you need or want to do, do them at a time when you have more energy.
- Try to do less cooking, cleaning or other household jobs. If you can, ask family or friends to help.
- There are organisations and shops that can deliver ready-made meals. You can store these in a freezer until you want to use them.
- If you find eating tiring, try eating little and often.
- If you get tired when washing and getting dressed, ask someone to help you.
- Use equipment that helps you with daily tasks, such as a raised toilet seat, bath board or walking frame. Sit down to do tasks if you can.

We have more information in our booklet **Coping with fatigue (tiredness)**.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.

Difficulty sleeping

There are many reasons why you may find it difficult to sleep. These include:

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

Tell your doctor or nurse if you are not sleeping well. Also tell them about any specific worries or symptoms that might be affecting your sleep. They may be able to suggest things to help. For example, they may suggest taking some medications at a different time of the day. Sleeping tablets may help some people. Your doctor can prescribe these if they think they will help.

We have more information about difficulty sleeping and steroids at **macmillan.org.uk**

Things that can help

- If your mattress is uncomfortable, ask your nurse for advice about a more comfortable one.
- Try to reduce light and noise – wearing an eye mask might help if your room is too light.
- Try having a warm drink before going to bed. Avoid stimulants like caffeine and alcohol, as they will keep you awake.
- Keep your bedroom for sleeping. If you wake during the night, try not to toss and turn. Go to another room if you can. When you feel sleepy, go back to bed. If you need to sleep during the day, go to your bed and sleep there.
- Avoid using a screen, such as a TV, computer, tablet or smartphone, for at least 1 hour before going to bed.
- Keep a notebook by your bed. If you wake during the night, you can write down anything you are worried about or need to do. You can work through your list during the day and get support and advice from your loved ones, carers or healthcare team.
- Simple breathing and relaxation exercises may help to reduce anxiety and stress. You can learn them at home using a CD, DVD or podcasts.

Pain

Many people worry about pain as their illness gets worse. Not everyone has pain in the last few weeks of life. But if you do, it is important to let your healthcare team know so they can treat it. Tell them exactly where the pain is, how it feels, and how it affects you.

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

We have more information about pain in our booklet **Managing cancer pain** (page 116).

Painkillers

Your healthcare team can usually control pain well with painkillers. There are different painkillers for different types of pain. These include:

- mild painkillers, such as paracetamol
- moderately strong painkillers, such as codeine
- strong painkillers, such as tramadol, morphine and oxycodone
- anti-inflammatory drugs, such as ibuprofen and diclofenac
- painkillers for nerve pain, such as gabapentin, pregabalin and amitriptyline.

Different painkillers can be given in different ways including:

- tablets
- liquid medicines
- patches stuck onto the skin
- injections under the skin or through a syringe pump.

You may need more than 1 type of painkiller to get the best effect. Some people need to take larger doses of strong painkillers as they near the end of their life. This is quite normal and safe. Your healthcare team will tell you about your dose of painkillers

It is important to take your painkillers regularly as your doctors and nurses tell you. Tell them if your pain is not controlled. They can change the dose or may suggest a different painkiller.

Syringe pumps

A syringe pump is a small portable pump used to give medicines. It is also called a syringe driver.

A syringe pump may be used if you cannot take medicines by mouth. For example, if you have difficulty swallowing. A syringe pump may also be used if your body is not able to break down and use medicines taken by mouth. You can have painkillers, anti-sickness medicines, anti-anxiety medicines and several other medicines through a syringe pump.

A syringe holding the medicines is attached to the pump. The pump delivers a continuous dose of the drugs from the syringe through a small, thin needle. The needle is put in just under your skin and held in place with a clear dressing. It is usually placed in your arm, leg or tummy. Usually each syringe has enough medicine for 24 hours. The pump is usually put in a clear, locked box to protect it.

Your nurse will set up a syringe pump for you. Your nurses can change the syringe when needed, usually every 24 hours.

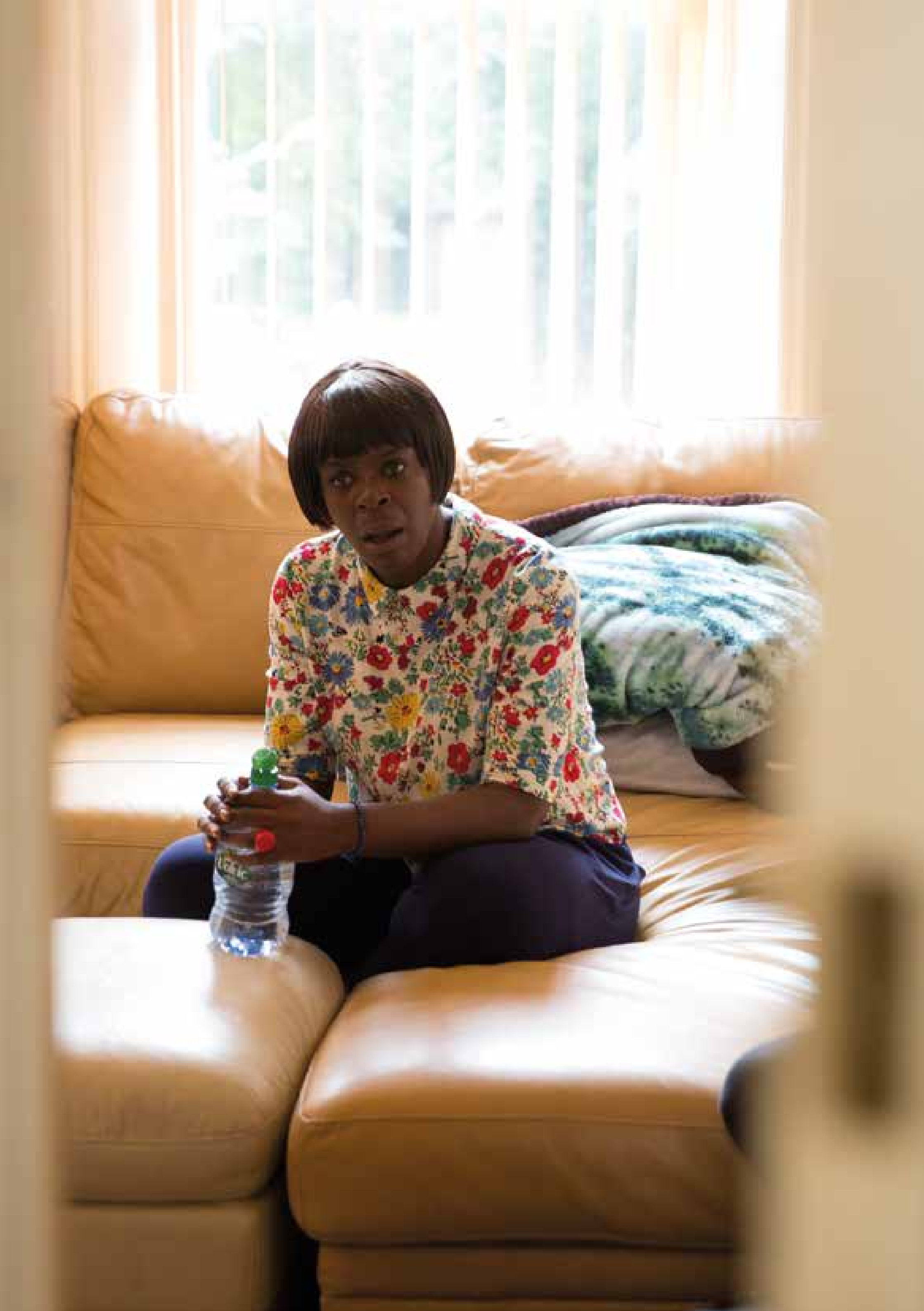
Side effects of painkillers

Painkillers such as codeine, tramadol, morphine and oxycodone have 3 common side effects:

- drowsiness – this usually goes away after a few days
- sickness – this usually gets better over a few days
- constipation – you often need to take a laxative regularly.

We have more information in our **Managing cancer pain** booklet.

You can order our booklets and leaflets for free.
Visit **be.macmillan.org.uk** or call us on **0808 808 00 00**.



Weight loss and loss of appetite

You may find that your appetite reduces over time because of your illness or medicines you are taking. You may find eating hard if you no longer like the sight, taste or smell of some foods. Even if you are eating well, you may lose weight, and this can be upsetting.

As you near the end of your life, your body slows down. It does not need as much food, as it cannot digest it or absorb nutrients from it. Do not feel you have to eat – it is normal for your appetite to reduce as you near the end of your life.

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

People close to you may be concerned if you are eating less. Talk to them about what you would like to eat or drink. This means they know the best things to offer you.

Things that can help

- Have frequent snacks or small meals rather than 3 meals a day. Only eat what you can manage. Do not force yourself to eat.
- Eat if you feel like eating, and eat the things you want to. Try keeping a flask or cool bag with drinks and snacks nearby. You can then eat or drink something whenever you feel hungry.
- If you want to eat but do not like the smell of cooking, ask someone else to cook your food.
- Try eating foods that are easy to chew and digest, such as soup, custard and ice cream.

Feeling sick and vomiting

If you feel sick (nausea) or are sick (vomit), your doctor or nurse can prescribe anti-sickness drugs (anti-emetics). These can usually help. There are different types of anti-sickness drugs. They can be given:

- as tablets or liquid medicines
- as injections
- through a syringe pump (page 71)
- as suppositories that are inserted into your back passage.

Things that can help

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

Constipation

You may get constipated because you are not moving around or eating and drinking as much. Medicines such as painkillers can also cause constipation. It is important to tell your doctor or nurse if you are constipated so they can prescribe medicines (laxatives) to help. There are different types of laxatives.

Things that can help

- Take your laxatives as your doctor or nurse tells you to.
- Tell your GP or nurse if your laxatives are not working, or if your stools (poo) become too loose.
- Drink as much fluid as you can.
- If you can eat, try to have some high-fibre foods, such as fruit and vegetables, brown rice, brown bread or brown pasta.
- If you can, do some gentle exercise like walking.

Breathlessness

There are different reasons why you might feel breathless. It is important to tell your doctors and nurses as soon as possible if:

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

Your doctor may suggest different ways to manage breathlessness, depending on the cause. For example, you may find:

- medicines, such as a low dose of morphine, can help
- oxygen may help some people – your GP or nurse can arrange for you to have oxygen at home
- if you have a build-up of fluid on the lungs (pleural effusion), your doctor at the hospital or hospice may be able to drain it
- if you have a low level of red blood cells (anaemia), your doctor may arrange for you to have a blood transfusion.

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

Things that can help

- Try sitting by an open window when you feel breathless. An electric or handheld fan blowing air on to your face may also help.
- How you sit or stand can affect your breathing. A nurse or physiotherapist can show you and your carers the best positions to help. They can also teach you how to breathe more effectively, plan your activities and save your energy.
- Think about ways to arrange your home to make tasks easier. For example, you could put a chair in the hallway or at the top of the stairs. Then you can rest when walking between rooms or up and down stairs.
- Sit down to do tasks like washing and dressing.
- Try using a mobile phone, baby monitor or a 2-way radio to talk to someone in another room, so you do not have to get up.
- If you have difficulty getting to the toilet, use a commode or urine bottle.
- Try using a V-shaped pillow to help you sit in a more upright position in bed.

Difficulty moving around

You may gradually find it harder to move around. This may be because you are tired or weak, or have symptoms such as pain, swollen limbs or a swollen tummy.

If you are not moving around very much, your skin may get sore. For example, you may get sore skin on your bottom or heels. Your district nurse can arrange equipment to help prevent this. This could be a pressure-relieving cushion for your chair or a mattress for your bed. It is important to change your position regularly if you can. If you need help, your nurse can show your carers how to move you safely so you are comfortable.

Mouth problems

Looking after your mouth is important and can help prevent problems such as a dry or sore mouth, ulcers or an infection. Tell your nurse or doctor if you develop any mouth problems so they can help.

Things that can help

- If you can, brush your teeth twice a day using a fluoride toothpaste. Use a soft children's toothbrush if your mouth is sore. Ask someone to help you if you cannot manage this yourself.
- Rinse your mouth 3 or 4 times a day to remove debris and keep it clean. You can use plain water or a salt-water rinse. To make the rinse, add 1 teaspoon of salt to 1 pint of cold or warm water. You should rinse your mouth with cold or warm water after using a salt-water rinse.
- If you have false teeth, clean them as usual and soak them overnight.
- Use any mouthwashes that you have been prescribed, and follow the instructions.
- If you have a dry mouth, try sipping water – some people find tonic water helpful. You could also try sucking ice lollies or ice chips, or chewing sugar-free gum.
- Use a water-based lip balm to keep your lips moist.

Swelling

In some people, fluid can build up in the body's tissues. This causes swelling called oedema.

You may get swelling in your legs and ankles. Your doctor may prescribe pressure stockings to help control this. These are not suitable for everyone. Keeping your feet up and gently exercising your legs may also help. A nurse or physiotherapist can show you some exercises to do.

Taking water tablets (diuretics) can sometimes help get rid of the fluid. Your doctor may prescribe these if they think they may help.

With some types of cancer, fluid can build up in the tummy (abdomen). This causes it to swell and feel tight and uncomfortable. This is called ascites. A doctor can put a tube into the lower part of your tummy to drain off the fluid. This is done using a local anaesthetic. It can be repeated if needed. Your GP or specialist palliative care nurse can discuss this with you. Taking water tablets can sometimes help with ascites.

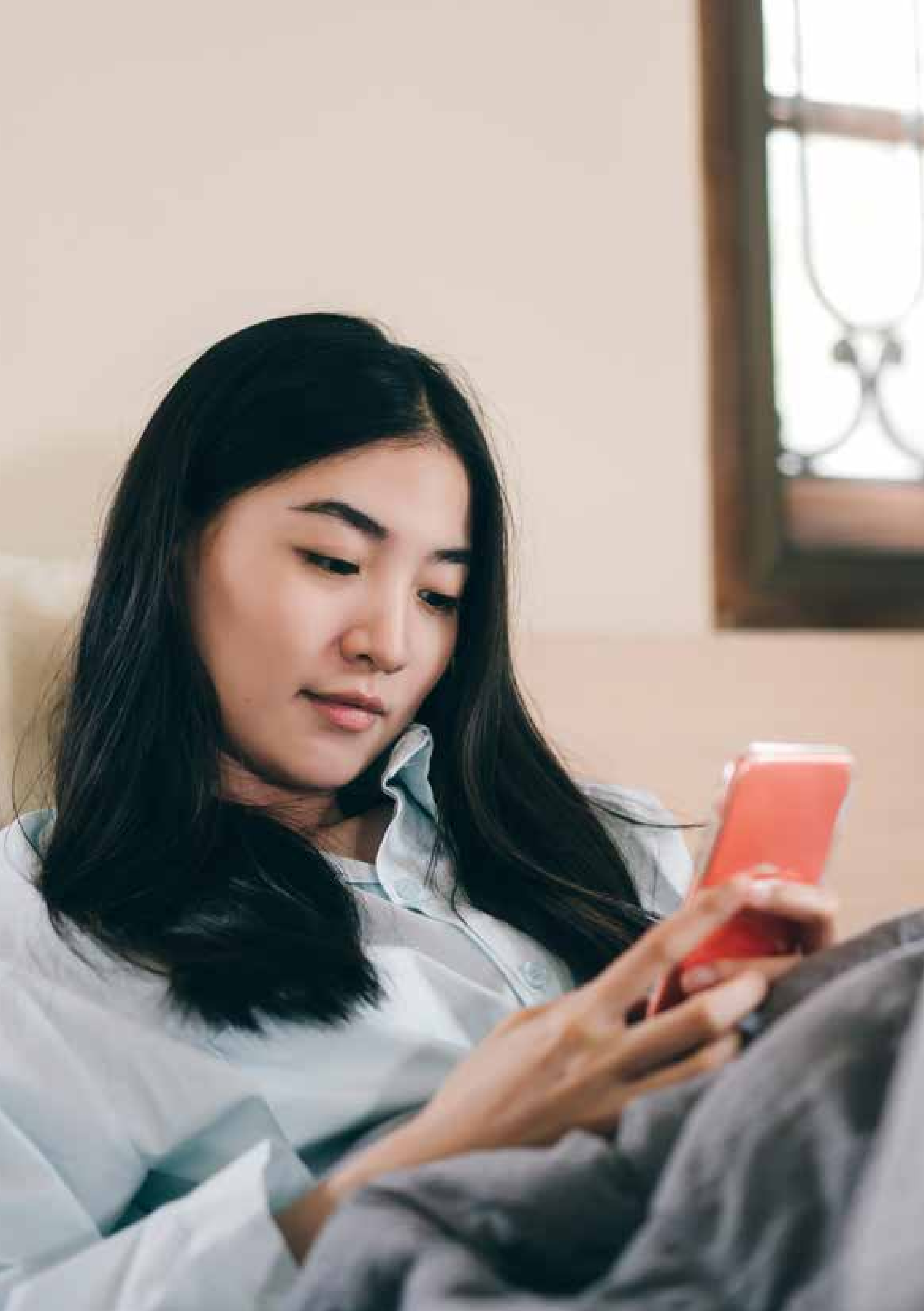
Bladder problems

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

Managing difficult symptoms

Usually, it is possible to manage your symptoms at home. But sometimes it can be helpful to go into a hospital or hospice to have them treated. Your community palliative care team, district nurse or GP will talk to you if they think this would help. Being in the hospital or hospice means that the doctors and nurses can assess your symptoms more regularly. They can adjust any medicines more quickly than if you were at home. This means they can also control your symptoms more quickly.

Once your symptoms are controlled better, you can often go home again. You will then be back under your GP's care, with support from your community palliative care team and district nurses.



Complementary therapies

Many people find complementary therapies can help them feel stronger. They can help you feel more able to cope with physical changes and your worries about dying. They may also improve your sense of well-being and reduce symptoms.

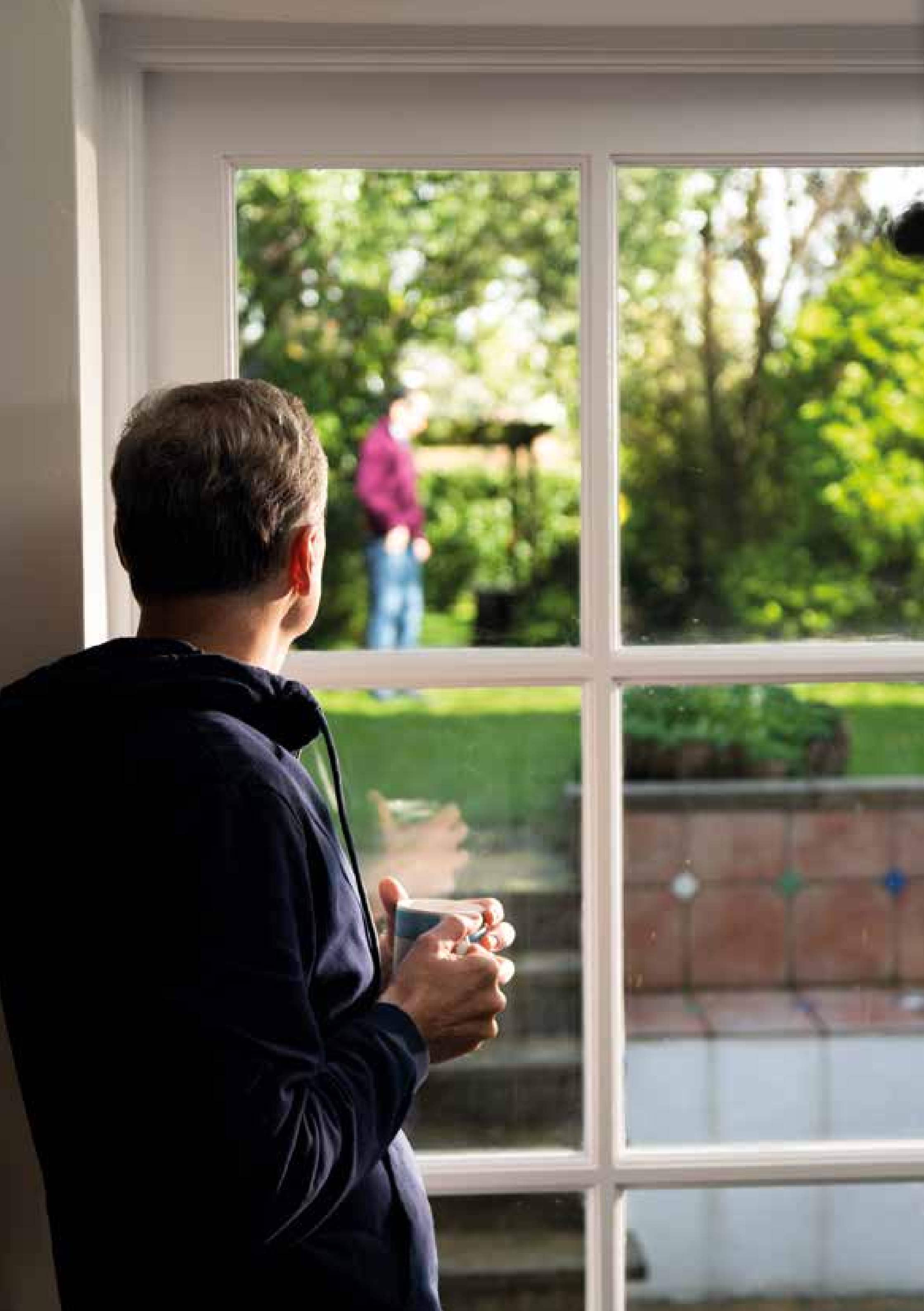
There are many different complementary therapies including:

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

Some hospices and hospitals may offer complementary therapies alongside conventional care. Ask at your local hospital or hospice to see what might be available. You may need to pay for complementary therapies at the hospital or hospice.

You can choose to pay privately for complementary therapies. If you wish to do this, it is important to choose a qualified therapist. It is important that a therapist knows about your medical condition and any treatments you are having.

We have more information in our booklet **Cancer and complementary therapies** (page 116).



The last few days of life

The last days of life

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

You may:

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

These are all natural things that can happen as you approach the end of your life.

Physical care

You will usually need help looking after yourself. Your family, friends or a partner may want and be able to look after you at this time. But you may need the help of professional carers as well, especially if you do not have people around you to help.

Your GP, district nurse or palliative care team can arrange professional care if needed. Carers can visit you at home. They can:

- support your family and friends in providing care for you
- show your family and friends how to provide some aspects of your care – this could include learning how to move you safely and helping keep your mouth and lips clean and comfortable
- provide some aspects of personal care, if you would prefer them to do this.

You will probably want to wear comfortable, loose-fitting clothing. Your family, friends or partner may be comfortable washing you and changing your clothes. But if not, the district nursing team or palliative care team can show them the best way to do this. You are not likely to want to eat or drink very much, so your mouth may get dry. Lip balm can help moisten your lips.

It is important that your carers moisturise your skin and help you change your position regularly. This helps to stop your skin getting sore. Your nurses can advise your carers on how to make sure you are in a comfortable position. They may be able to arrange pressure care aids to help keep you comfortable. These include:

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

Some people lose control of their bladder and bowel as they approach the end of life. This is normal but can be embarrassing for you and those around you. Your nurse can show you and your carers the best way to manage this so you are comfortable. You may need a tube (catheter) put into your bladder to drain urine (pee).

It may feel strange to need so much help. But you may get very close to the people who are looking after you at this time.

When you are not needing any care, you can sit or lie quietly. You may want to have your family, friends or a partner sitting with you. This can be a very intimate and special time. You may want to talk, or you may want to be quiet, watch the television or listen to music. You may want to have someone with you all the time. Or you may prefer to have some time on your own. Tell people around you what you would like, as it will help them in planning your care.

If you are at home, your carers can contact your district nurse, community palliative care nurse or GP at any time, day or night, if they are concerned. They can discuss your care and visit to give you medicines to control your symptoms if needed.

Medicines

Your doctor and nurse will monitor your symptoms to make sure they are managed as well as possible. They may change your medicines, or stop some medicines if you do not need them anymore.

There are different ways of having medicines. Sometimes, instead of tablets, it is better to have them:

- as an injection under the skin
- through skin patches
- as a continuous injection through a syringe pump (page 71).

Just-in-case medicines

Your GP, district nurse or the palliative care team may suggest leaving a small case or box of medicines in your home, in case you need them. These are sometimes called just-in-case medicines or anticipatory medicines. They usually include injections to help with pain, sickness, restlessness and fluid in your airways.

Getting medicines quickly can be difficult, especially at night or weekends. If you have 'just-in-case' medicines at home, a nurse or doctor can give them to you straight away if you need them.

Having someone with you

People often find it comforting to have someone with them. You may want to have family, friends or a partner with you. Or you may want to have a religious or spiritual adviser. There may be certain religious practices you want to be done, or prayers read. It is important to do whatever feels right for you.

Not everyone has family or friends who can be with them. In some parts of the UK, there may be volunteers who can sit with you when you are nearing the end of your life.

Soul midwife (doula)

A soul midwife is someone who can be with you as you are approaching the end of your life. A soul midwife is also called a doula or end-of-life doula. They are not medically trained, but can work with your medical team. They can provide company and spiritual support to you and your family. They might help with practical tasks to give your carers a break. Or they can sit with you, listen to you and support you with any difficult conversations about your feelings. You usually need to pay for their services.

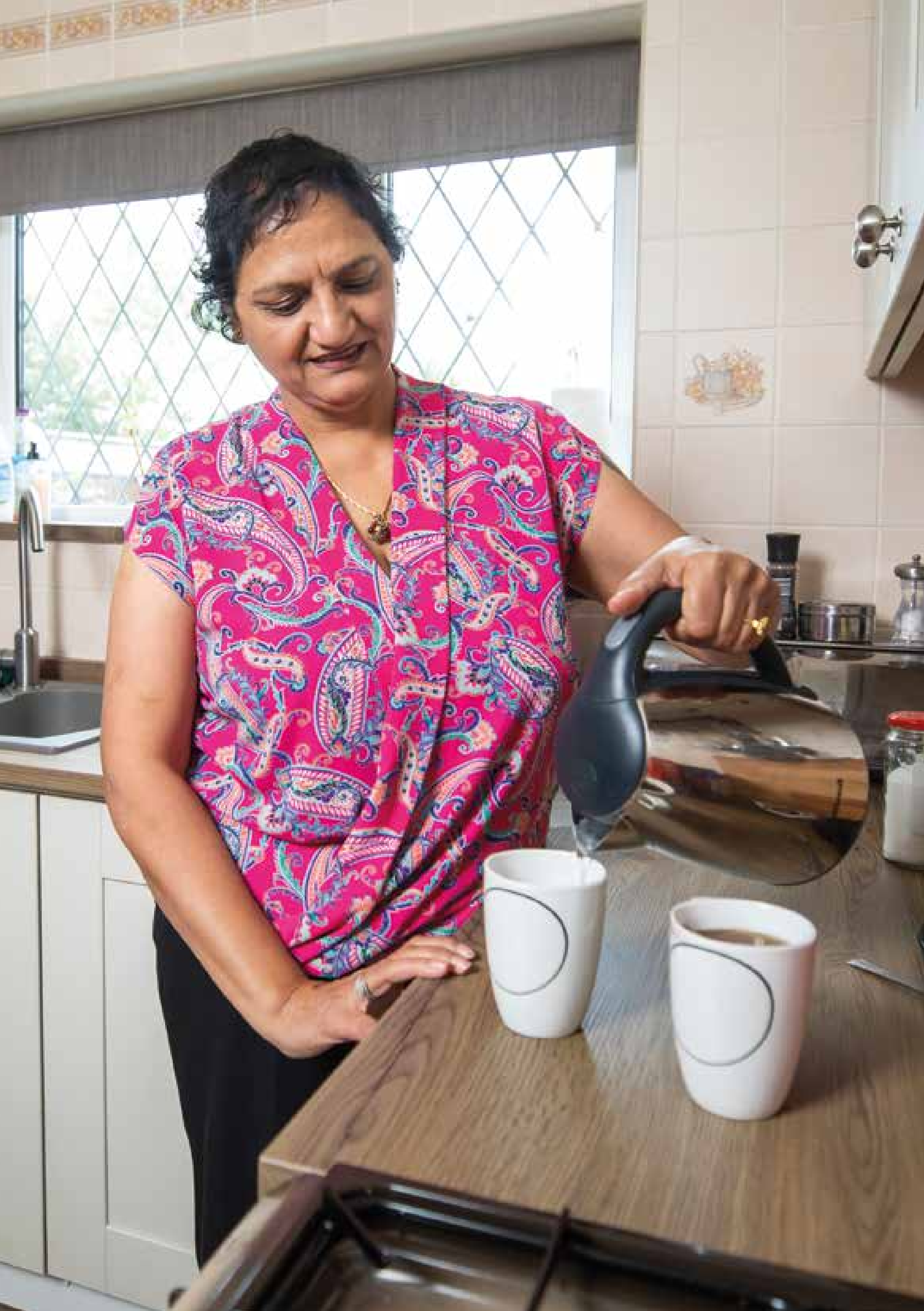
Nearing death

Although death is a natural process, it is normal to worry about what will happen. You may feel anxious or frightened. Or you may feel calm and peaceful.

Usually, you slip into a deep sleep where you are unconscious. You cannot be woken, but you may still be able to hear and be aware of the people around you. There might be times when you are awake and can talk, and then you slip back into unconsciousness.

The final moments

The final moments of life are usually very peaceful. Your breathing may gradually become even slower and more irregular, with very long pauses between each breath. Eventually, you will stop breathing altogether.



If you are a carer

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

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

A lot of the information in other sections will be helpful for you as a carer. In this section, we explain more about:

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

Emotional changes in the last few weeks of life

The person you are caring for may feel many different emotions during this time. They may feel anxious, panicky, angry, resentful, sad and depressed. They may become quieter and want to communicate less (become withdrawn). They might also seem to lose interest in their surroundings.

It is natural for them to have some or all of these feelings. But it can be upsetting for you to see these changes in them. You may already miss the way your relationship used to be and the things you used to do together. This is understandable.

Sometimes, it may feel as though the person is giving up. But this is often part of the natural process of dying. If they seem upset, angry or afraid, try to listen to what they are saying and acknowledge their feelings. Just being there and listening is helpful and comforting.

If you are concerned about how they are expressing their emotions, talk to their GP or another health professional.

Caring during the last few weeks of life

The person you are caring for may have different symptoms during this time (pages 66 to 81). There are lots of ways to help them feel as comfortable as possible. If you are worried about any symptoms, tell the healthcare professionals involved in the person's care. They can advise you about the best way to manage the symptoms.

As time goes on, the person may not want to eat much. This is quite natural, as the body does not need food towards the end of life. This can be hard for you, especially if you have worked hard to prepare food they might like. But it is important not to try to force them to eat. You may want to offer them drinks they like instead.

Looking after yourself

Caring can be physically and emotionally demanding. If you have been looking after your partner, family member or friend for some time, you may start to feel very tired.

As a carer, you may face extra challenges getting support when the person is at the end of life. For example, people who are LGBTQ+, or from a minority ethnic group, may worry that healthcare teams will not understand their needs. Whatever your background and identity, it is important to get support and look after yourself, as well as the person you are caring for.

Try and make sure you eat well and do some exercise. If you have any concerns about your own health, visit your GP. Tell them you are caring for someone.

You may also have some strong emotions. You may feel angry, or resent the person you are caring for. Talk to your GP about this too. They can discuss getting some support for you. It can be hard to admit that you might need help. But getting help can make caring a lot easier for you.

There are organisations that can provide information and support to you as a carer. There may be a local carers' organisation in your area. Or you could contact an organisation such as Carers Trust and Carers UK (page 130). The LGBT Foundation (page 130) and Carers UK have information for people who are LGBTQ+. You can also search for local carers' organisations at **carers.org**

It can also help to make sure you have some time to yourself. You could arrange for someone to help you regularly, even if it is only for a few hours a week.

When you get time off from caring, try to relax. Doing something you enjoy can help give you more energy and feel less stressed. You could meet someone for coffee or do something just for you, such as watching a film or getting your hair done. Try not to feel guilty – looking after yourself will help you care for your loved one better.

If caring becomes difficult

Caring for someone at home can become difficult for many reasons. As time goes on, you may feel they would be better looked after in a hospice or care home. This may be because you do not have the nursing or medical skills to look after them. Or you may feel that caring for them has become very difficult emotionally or physically.

Talk to the district nurse or GP if you are finding caring difficult. They may be able to provide extra support. Or they can give you advice about where your loved one could be cared for.

Sometimes the person you are caring for may need to move from home near the end of their life. It is important not to feel guilty, or feel that you have failed. Instead, remember that you are making sure they get the best possible care.

Caring for someone in the last few days of life

As your family member, partner or friend gets close to the end of their life, they will probably not want anything to eat or drink. You can keep their mouth and lips moist to help them feel comfortable.

You may need more support from health and social care professionals at this time. You can contact the GP, district nurse, palliative care nurse or social worker. They can review the person's needs and arrange extra care if needed.

If the person you are caring for seems distressed or has new or uncomfortable symptoms, tell a member of the healthcare team. Make sure you have phone numbers for the:

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

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

Pain

The person you are caring for may show signs of being in pain. They may:

- be restless
- screw up their face (grimace)
- move as if they are in pain
- sweat
- have a fast heartbeat and breathing rate.

If this happens, tell the doctor or specialist nurse. They may need to increase the dose or change painkillers.

There may be another cause for these symptoms, such as an infection. The doctor or specialist nurse can advise you about the best way to help. They can also prescribe medicines if needed.

Breathing changes

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

Restlessness

The person you are caring for might be restless. They may seem agitated or confused, and they might call out. Their body might twitch. This is called terminal restlessness or terminal agitation. These symptoms can be caused by different things. These include:

- pain
- constipation
- difficulty passing urine (peeing)
- infection
- side effects of medicines
- a build-up of waste chemicals in the blood.

Some people become restless because of emotional distress, a fear of dying or a fear of losing control. They may get comfort from a close friend or family member, a trusted health professional or a spiritual or religious leader.

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

Incontinence

As the person you are caring for gets closer to death, it is natural for them to lose control of their bowel and bladder. This can be distressing for both you and them. A district nurse can provide aids to help manage this, including:

- disposable bed pads
- pads to wear inside, or instead of, underwear
- a tube (catheter) that is put into the bladder and drains urine into a bag
- a urinary sheath that fits over the penis like a condom – it collects urine and drains it into a bag.

Urine retention

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

Religious and spiritual needs

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

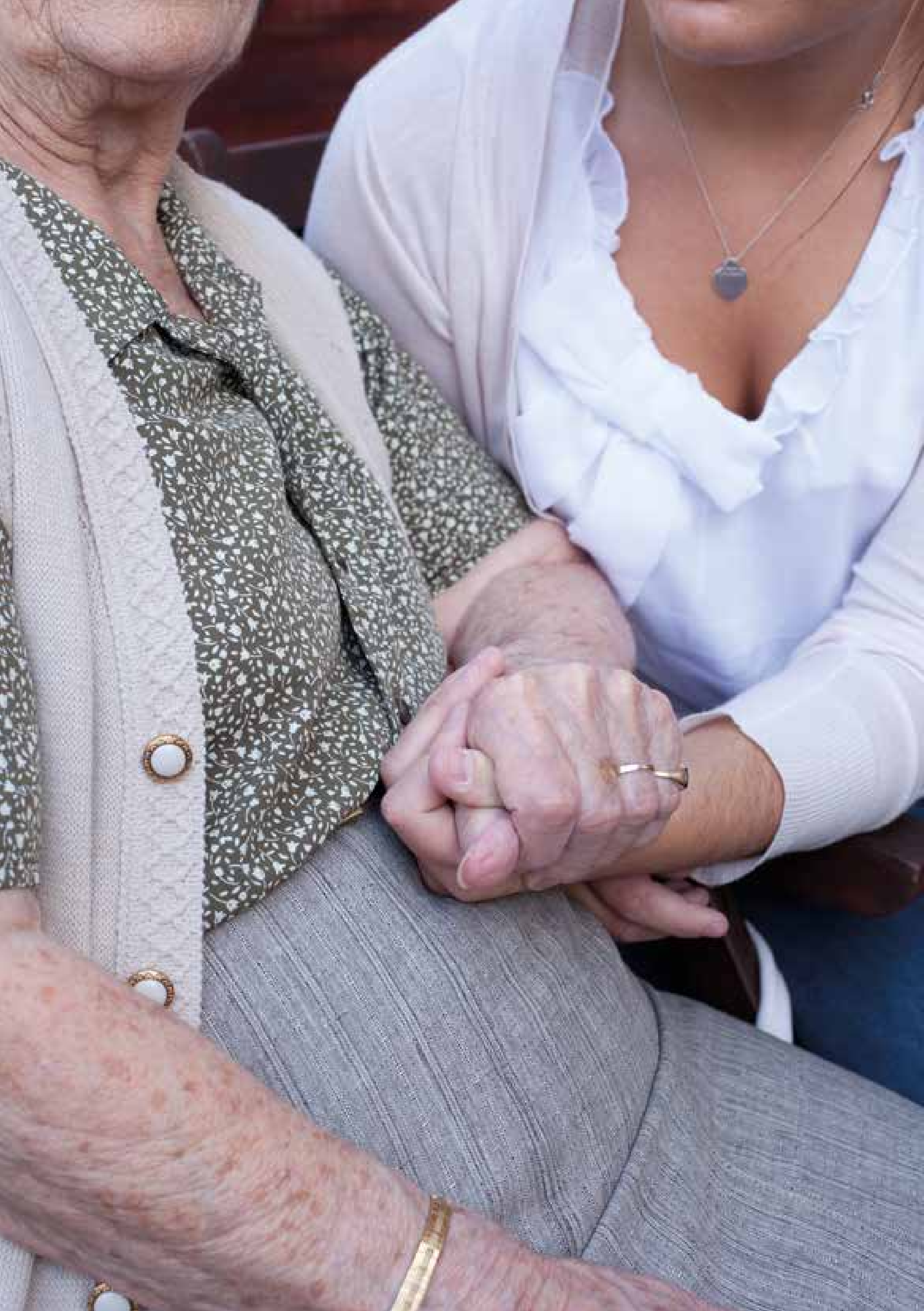
End of life care plan

You may hear the doctors and nurses talk about an end of life care plan. This explains the care your family member, partner or friend will need as they approach the end of their life. It will help make sure that their needs are met, including:

- food and drink
- symptom control
- emotional, spiritual and social support.

The doctors and nurses will involve you in any decisions and plans. They will also give you emotional and practical support.

If you would like more information about this, speak to one of the person's doctors or nurses.



Caring for someone nearing death

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

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

If you have any concerns, contact the person's GP or a member of their healthcare team for advice.

Physical changes

The person you are caring for will not usually feel thirsty at this stage. But their mouth may be dry and need to be moistened. The nurses can show you how to look after their mouth. If your family member or friend feels sick, a nurse can give them anti-sickness medicines (anti-emetics) by an injection or a syringe pump (page 71).

Skin and sensation changes

In the last few hours, the person's hands, feet and skin may feel very cold and sometimes moist. Their skin may change colour and become slightly more blue, grey or pale. Their skin may also be very sensitive to touch. If you move the person, be very gentle and tell them what you are doing.

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

Breathing

As the person gets closer to death, their breathing pattern will probably change. At times there may be longer gaps between breaths. At other times, their breathing might be quicker. It may also become very noisy. This is due to a build-up of fluid in the air passages. This can be upsetting for you, but it is not usually distressing for the person who is dying.

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

Other changes

The person you are caring for may drift in and out of consciousness. There may be times when they do not seem to recognise you or other people. They may also talk to people they knew in the past or who died long ago. This may be because they are thinking of these people.

Final moments of life

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

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

You may believe that the person's mind or soul (consciousness) stays around the body for some time after death. Or you might feel that their consciousness moves on quickly to another place. You may believe that life just ends, and nothing is left of the person's mind or consciousness. Everyone feels differently about what happens to someone when they die.

What happens after someone has died

If your family member, partner 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 the person dies at home, and this was expected, you need to tell their GP or district nurse. You do not need to rush to do this. It is fine to spend some time with your loved one before making any phone calls. If they died during the night or outside your GP's usual working hours, you do not need to contact the doctor until the following morning. But you can contact them during the night if you want to.

When you have contacted the GP or district nurse, they will come to verify the death.

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

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

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

When you have the MCCD, you need to take this to the local registrar's office to register the death. This needs to be done:

- within 5 days in England, Wales and Northern Ireland
- within 8 days in Scotland.

You may need to make an appointment to register the death.

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

Informing a coroner

In certain situations, the doctor who certifies the death needs to inform a coroner (or procurator fiscal in Scotland). This is a legal requirement.

The doctor will inform the coroner if they did not see the person who has died in the 14 days before their death. A coroner will also be told if the person has died from an occupational disease, such as mesothelioma.

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

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

The coroner must decide whether a post-mortem is needed before you set a date for the funeral or alternative service.

What the funeral director will do

When the death has been verified by a nurse or doctor, you can contact a funeral director (undertaker). They provide a 24-hour service and can advise you on what to do next.

You can get contact details of funeral directors from your local phone book or online. You can also find lists of funeral directors on the websites of:

- the National Association of Funeral Directors (NAFD) – page 123
- the National Society of Allied and Independent Funeral Directors (SAIF) – page 124.

The funeral director will come as soon as you want them to. Tell them if you or your family and friends would like to spend some time alone with your loved one's body.

Some people wish to look after their family member or friend's body at home until the funeral. Or you may want the funeral director to take the body to be looked after in their chapel of rest. You can visit your loved one's body in the chapel of rest if you wish.

Caring for the body

The funeral director can take care of your family member or friend's body, if you would like them to. They will carefully wash and dry the body and close the eyelids and mouth. They will tidy and sometimes wash their hair. You can help the funeral director wash and dress your loved one. If the funeral director dresses the person, they will also ask what you would like your loved one to be dressed in.

It may be important for you, or the person's family members, to wash and dress your loved one. Speak to the funeral director about your wishes.

Some people wish to be embalmed. This is when the body is disinfected and treated with chemicals to help preserve it. The funeral director can give you more information about this.

Bereavement

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

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

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

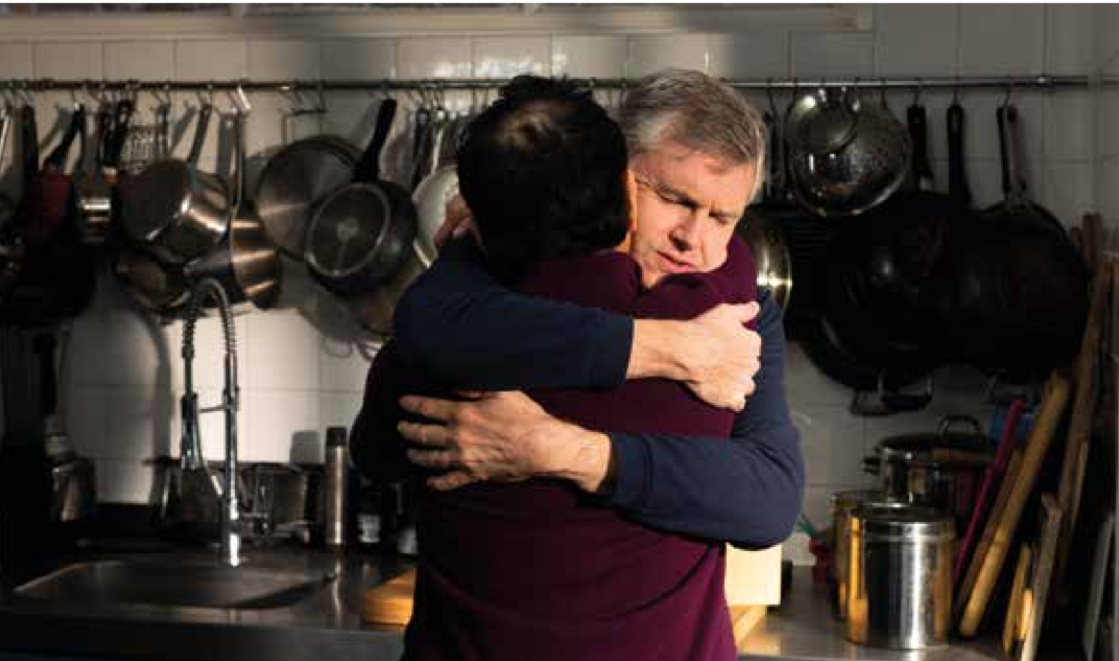
You may also have a sense of relief that your loved one is not suffering any more. The thoughts and feelings you have will vary. Sometimes they may be very intense and stop you doing things. At other times they may be in the background and you can still do your day-to-day activities.

Everyone experiences grief at some point in their lives. But sometimes your feelings can be very intense and difficult to deal with. We have more information in our booklet **After someone dies: coping with bereavement** (page 116).

You may want to talk to your family and friends about how you are feeling. Or you may prefer to talk to someone you do not know. Macmillan's Online Community also has forums for people who have been bereaved (page 121).

Some people need extra help to manage their emotions. There are organisations that can support you when you are bereaved, including Cruse Bereavement Care (page 131). Your GP can provide support and may be able put you in contact with a local bereavement counsellor. Many hospices also provide bereavement support.

Children or teenagers will have many different emotions and these may affect their behaviour. This can be difficult to cope with when you are already dealing with your own feelings. There are organisations that can help you support children, including Winston's Wish (page 131). Some hospices work with schools and also offer a wide range of support.



Further information

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

Find out more at **macmillan.org.uk/otherformats**

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

The language we use

We want everyone affected by cancer to feel our information is written for them.

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **macmillan.org.uk/ourinfo**

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

Our trained cancer information advisers can listen and signpost you to further support. Call us on **0808 808 00 00**. We are open 7 days a week, 8am to 8pm.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to **macmillan.org.uk/talktous**

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call **0808 808 00 00** and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

Our welfare rights advisers can help you find out what benefits you might be entitled to, and help you complete forms and apply for benefits. They can also tell you more about other financial help that may be available to you. 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 energy costs

Our energy advisers can help if you have difficulty paying your energy bills (gas, electricity and water). They can help you get access to schemes and charity grants to help with bills, advise you on boiler schemes and help you deal with water companies.

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 find out more about Macmillan Grants.

Help with work and cancer

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

Work support

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

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 is why we help bring people together in their communities and online.

Support groups

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

Online Community

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

You can also use our Ask an Expert service on the Online Community. You can ask a financial guide, cancer information nurse, work support advisor or an information and support advisor any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

Useful organisations at end of life

Hospice UK

Tel **0207 520 8200**
www.hospiceuk.org
Provides information about living with advanced illness. Also provides free booklets and a directory of hospice services in the UK.

Humanists UK

Tel **0207 324 3060**
www.humanists.uk
Provides information about humanism, humanist ceremonies and pastoral support.

Human Tissue Authority

Tel **0207 269 1900**
www.hta.gov.uk
Provides information about organ and body donation.

The Law Society for England and Wales

www.lawsociety.org.uk
Provides details of regulated solicitors in England and Wales. Use their website to find details of local solicitors.

The Law Society of Scotland

www.lawscot.org.uk/find-a-solicitor
Provides details of regulated solicitors in Scotland. Use their website to find details of local solicitors.

Marie Curie

Helpline **0800 090 2309**
www.mariecurie.org.uk
Marie Curie nurses provide free end of life care across the UK. They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

National Association of Funeral Directors (NAFD)

Tel **0121 711 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.

National Society of Allied and Independent Funeral Directors (SAIF)

Tel **0345 230 6777**
www.saif.org.uk
An organisation of independent funeral directors across the UK that offer different funeral options. Ensures a high standard of funerals is provided by its members and provides advice about funerals and what to do when someone dies.

The Natural Death Centre

Helpline **0196 271 2690**
www.naturaldeath.org.uk
Offers independent advice on aspects of dying, funeral planning and bereavement.

NHS Blood and Transplant Organ Donation

Tel **0300 123 2323**
Text chat (SMS) **0786 003 4343**
Text relay **18001 0300 123 2323**
www.organdonation.nhs.uk
Manages the UK transplant registry and national organ donor register. Also raises public awareness of the importance of organ donation.

General cancer support organisations

Cancer Black Care

Tel **0208 961 4151**
www.cancerblackcare.org.uk
Offers UK-wide information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

Riprap

www.riprap.org.uk
Developed especially for teenagers in the UK who have a parent with cancer. Has an online forum where teenagers going through similar experiences can talk to each other for support.

General health information

Health and Social Care in Northern Ireland

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Be Mindful

www.bemindfulonline.com
A digital course recommended by the NHS to improve mental well-being.

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email **jo@samaritans.org**
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

The Office of Care and Protection (Northern Ireland)

Tel **0300 200 7812**
www.justice-ni.gov.uk/articles/information-about-office-care-and-protection

The Office of the Public Guardian (England and Wales)

Tel **0300 456 0300**
Textphone **0115 934 2778**
www.gov.uk/government/organisations/office-of-the-public-guardian
Protects people in England and Wales who may not have the mental capacity to make certain decisions for themselves, such as about their health and finance.

The Office of the Public Guardian (Scotland)

Tel **0132 467 8300**
www.publicguardian-scotland.gov.uk
Has a range of functions under the Adults with Incapacity (Scotland) Act. It provides information, advice and guidance with regard to Powers of Attorney.

Turn2us

www.turn2us.org.uk
A website that helps people find specific charities that may be able to offer financial help.

Equipment and advice on living with a disability

British Red Cross

Tel **0344 871 11 11**
www.redcross.org.uk
Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

Support for older people

Age UK

Helpline **0800 055 6112**
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030**
www.lgbt.foundation
Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

Support for carers

Carers Trust

Tel **0300 772 9600**
www.carers.org
Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
Helpline (Northern Ireland) **0289 043 9843**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Care homes

Carehome.co.uk

Helpline **0800 808 5852**
www.carehome.co.uk
Provides advice about looking for and finding funding for a care home. Has reviews of over 100,000 care homes across the UK.

Bereavement support

Cruse Bereavement Care

Helpline **0808 808 1677**
www.cruse.org.uk
Provides bereavement support to anyone who needs it across the UK. You can find your local branch on the website.

Widowed and Young (WAY)

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

Winston's Wish

Helpline **0808 802 0021**
www.winstonswish.org
Helps bereaved children and young people throughout the UK re-adjust to life after the death of a parent or sibling.

Your notes and questions

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our Senior Medical Editor Dr Viv Lucas, Consultant in Palliative Care.

With thanks to: Kelly Wallace-Bates, Lead Nurse, End of Life and Palliative Care; Adrienne Betteley, Strategic Advisor for End of Life Care; Dr David Gray, Consultant in Palliative Medicine; Dr Marina Malthouse, Palliative Care Physician (retired); and Pauline McCulloch, Clinical Nurse Specialist.

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

Sources

Below is a sample of the sources used in our end of life information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Health Improvement Scotland/ NHS Scotland. Scottish Palliative Care Guidelines. Available from **www.palliativecareguidelines.scot.nhs.uk/** [accessed Nov 2021].

NICE. Care of dying adults in the last days of life. NICE guideline NG31 [Internet]. 2015. Available from **www.nice.org.uk/guidance/NG31** [accessed Nov 2021].

NICE. End of life care for adults: service delivery. NICE guideline NG142 [Internet]. 2019. Available from **www.nice.org.uk/guidance/ng142** [accessed Nov 2021].

NICE. Improving supportive and palliative care for adults with cancer. Cancer service guideline CSG4 [Internet]. 2004. Available from **www.nice.org.uk/guidance/csg4** [accessed Nov 2021].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

If you would rather donate online go to **macmillan.org.uk/donate**

Registered with FUNDRAISING REGULATOR

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

MACMILLAN
CANCER SUPPORT

A guide for the end of life

This booklet is for anyone who may be approaching the end of their life.

The booklet talks about coping with the news, sorting out your affairs and planning your care. It also tells you more about what might happen as your illness progresses.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** or visit **macmillan.org.uk**

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

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

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