Living with a terminal illness

Marie Curie

A guide for people living with a terminal illness and the people important to them

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

Introduction

We know things can change quickly when you're ill, and you might find you have lots of questions. You might wonder where you can get support, how to cope with your feelings, or how to talk to those close to you.

This booklet aims to help you understand your feelings and feel better prepared. It also gives information about how to take care of yourself so you can live well.

We've divided this booklet into short chapters so you can read through it at your own pace. You could also look at it with someone else, like a nurse or someone important to you, so you have their support.

If you have family, friends or carers, this information could also help them to understand how things may change, and how they can help.

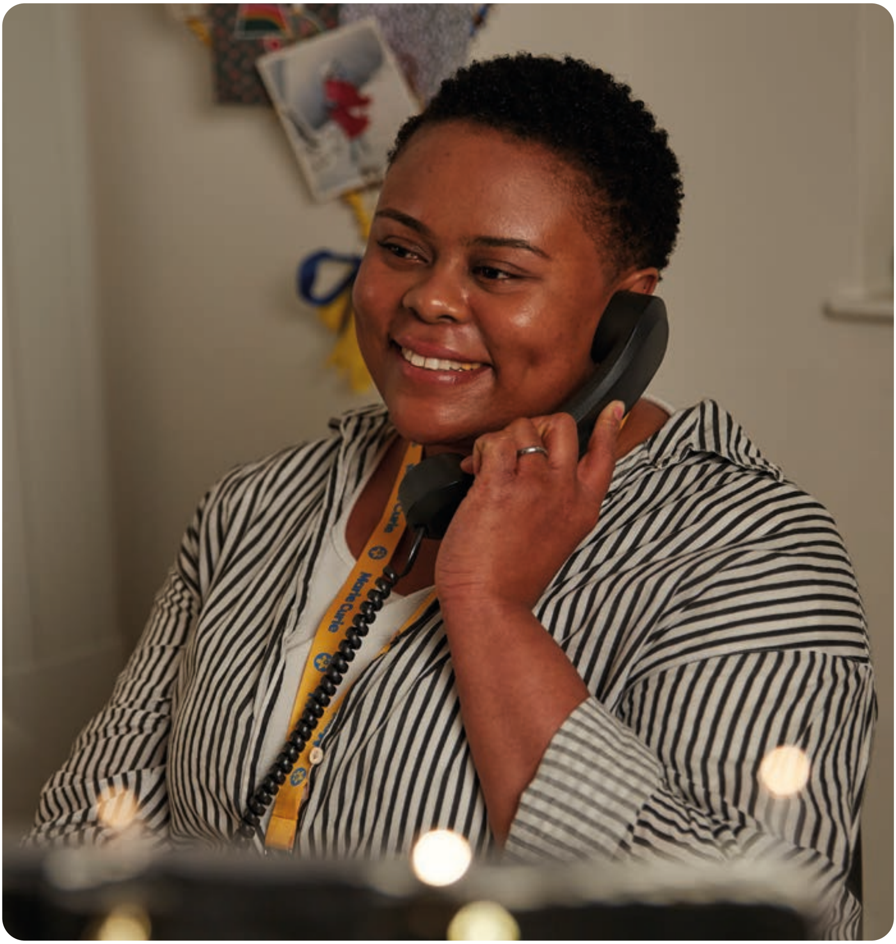
The words we use in this booklet

We use the word **carer** to speak about anyone who spends time helping to look after you, but is not a paid carer or a health or social care professional. For example, this might be a family member, friend, or partner.

When we talk about your **family or friends**, we mean anyone who is important to you. This might be a partner or partners, husband, wife, civil partner, birth family, family of choice, rainbow family, or your friends.

We're here to support you

We know not everyone has family and friends in their lives. Some people may get support from local community or support groups, places of worship, health and social care professionals, or charities that provide support services. We're here to support you – call the free Marie Curie Support Line on **0800 090 2309***, or see page 102 of this booklet for more ways Marie Curie can help.



Philip Hardman/Marie Curie

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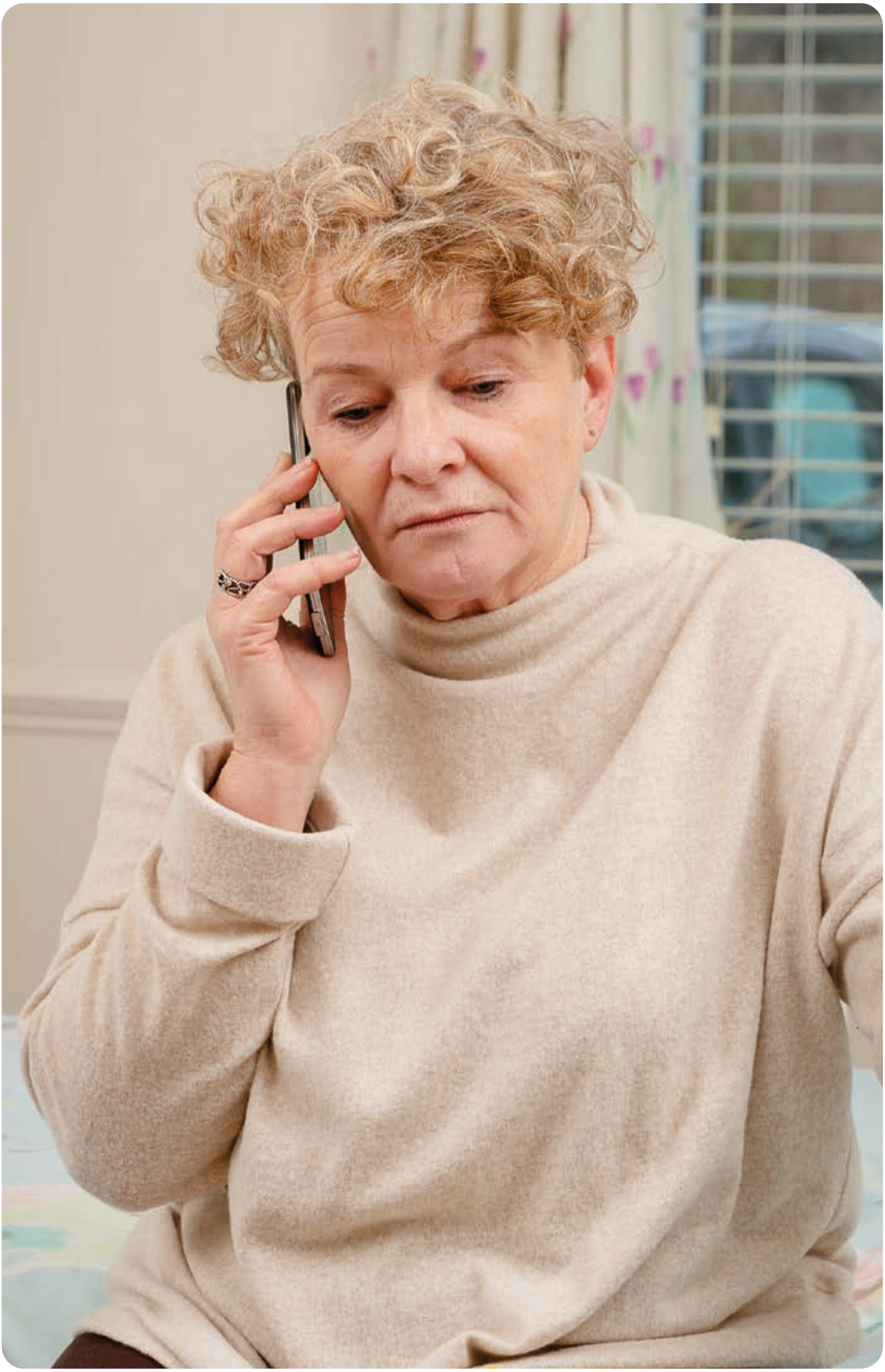

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Section 1:
After your diagnosis and what might change

Understanding terminal illness

If you've been told you have a terminal illness, you might be wondering exactly what this means. A terminal illness is an illness or condition which cannot be cured, and is likely to lead to someone's death.

It can be shocking or upsetting to get a terminal diagnosis, as people sometimes think the word 'terminal' means they will die soon. This might be a worry for you too. It may help to remember that no two experiences of a terminal illness are the same. Someone with a terminal illness may live for days, weeks, months or years. It often depends on your diagnosis and any treatment you are having.

At Marie Curie, we usually use the words terminal illness in our information. But some people prefer to use the words life-limiting illness or incurable illness. Please read this booklet using the language you feel most comfortable with.

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What happens now?

Some people tell us they feel stranded in the time between the initial diagnosis and their next medical appointment. For the time between appointments, there are things you can do to help you feel more informed.

▶ You can find information on the Marie Curie website at **mariecurie.org.uk/support**. You could also contact the free Marie Curie Support Line on **0800 090 2309*** for more information and emotional support.

Many people find it hard to take everything in during their medical appointments. You may find it helpful to take in a prepared list of questions you'd like to ask, so you can refer back to them while you're there. You could use the Notes section on page 114 of this booklet to write these down.

You might also want to take someone with you, like a family member or friend. They could help in case you do not understand something, or find it difficult to remember everything that was said. They could also take a notebook or their phone, to write down answers to your questions and any other information.

"My wife always comes to appointments with me. She asks questions and remembers things I often forget."

Mark, who is living with a terminal illness

Questions about your future

Knowing you have a terminal illness is likely to make the future seem uncertain. You may have questions that currently have no definite answers, and some questions may remain unanswered. For example, you might be wondering how your health will change, what will happen with work, or exactly how long you will live for.

Not knowing what is going to happen can feel overwhelming and upsetting. It's common to feel this way, and you might find it helpful to talk with other people. You could discuss your worries with your healthcare professionals. They'll know your situation and the details of your diagnosis, so can help with any questions you have. If you're not sure who to speak to, you could try your GP first.

You could also speak to people you're close to, or others in a similar situation. See page 27 for more ways to get support with how you're feeling.

How day-to-day life might change

You may start to think about what matters in your life and how you want to live in the future. You might choose to carry on as usual, or break from your routine. Whatever you decide, it can help to talk to the people important to you, and your healthcare professionals.

Routines

You might want to keep your normal routine for as long as possible. Depending on your situation, you may continue to work and keep up with hobbies.

If this is important to you, try to talk about your wishes with the people important to you and your healthcare team. This will give them a clearer understanding of the best type of care, support and treatment to provide.

You may also find that your daily or weekly routine changes. Some things that might be different include sleeping in a different room, who's in charge of household tasks, and childcare routines. If you work, your working life might also change. For example, you might stop work, or change how much you work.

If you are finding any changes to daily life difficult, speak to your GP or nurse. They may be able to help you find support. You can also call the free Marie Curie Support Line on **0800 090 2309***.

If you work

If you're working, it can be hard to know what to do next. For some people, an illness means their priorities in life change. This sometimes means they think about leaving their job.

You may choose to carry on working, change the type or amount of work you do, or stop working. You should do what feels right for you, while considering your current health, possible treatment options, finances and the things that are important to you.

Making these decisions can be difficult, and if you're worrying about finances too, you might be feeling overwhelmed. See Section 6 (page 87) for ways to get financial support and where to get more advice.

Talking to your employer

You may feel worried about talking to your employer about your illness. They're likely to be supportive of you, but it can still help to know your rights.

Although you may not think of yourself this way, the law states that people who are terminally ill are likely to be considered disabled. You are protected against discrimination by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 in Northern Ireland.

This means your employer cannot dismiss you (fire you) or find an excuse to make you redundant because of your illness. They also cannot force you to retire or resign. However, your employer may be able to end your employment on grounds of capability because of health issues.

By law, you do not have to tell your employer about your condition. But you might want to, so you can become fully protected by discrimination law if you're then treated unfairly, because of something related to your illness. You may also want to tell them as they could make you feel more supported. It's a good idea to take some time to think about your options before making any decisions. You could also discuss this with the people important to you.

The law also states that your employer must make reasonable adjustments to accommodate your needs at work. However, they only have to make these adjustments if they think they're reasonable – there are no set rules for this. Reasonable adjustments could include working from home, flexible working hours, changing the duties of your role, or time off work for treatment.

If you need help with negotiating adjustments or contacting a solicitor, see page 111 for the contact details of some helpful organisations.

Talking to your colleagues

Your employer should not tell your colleagues about your illness without your permission. But you might find telling your colleagues helps. They may be able to offer you support, and it could help them understand the reason behind any changes to your role.

Some people prefer not to tell colleagues they're ill, and this is OK too. It's your decision whether to tell them or not. But you might find because of the effects of your treatment, or because you may take time off, that you'd like to tell them eventually.

Stopping work for good

At some point, most people with a terminal illness will have to tell their employer they need to stop working. If work has been a major focus of your life, you may find it difficult to adjust to the idea of not working.

If you are affected in this way, it could help to talk to someone about how you're feeling. Your employer may have arrangements in place for some form of independent and confidential counselling, or an Employee Assistance Programme (EAP) service. See page 27 for more ways to get emotional support.

Sick pay

If you work for an employer and you're too ill to work, you may be able to get sick pay. Depending on your contract, you might get Statutory Sick Pay or occupational sick pay, which is sometimes called contractual sick pay. If your employer does not provide occupational sick pay, they must pay you Statutory Sick Pay as a minimum, if you're eligible.

▶ You can find out more about Statutory Sick Pay online at **mariecurie.org.uk/benefits** or by calling the free Marie Curie Support Line on **0800 090 2309***.

Your pension

If you have a workplace or private pension, you may be able to take your pension early because you're ill. This is known as ill health retirement. Each pension scheme has different rules for accessing your pension early, so it's best to contact your pension provider for information.

There might also be certain rules if you have a terminal illness. If you've been told your life expectancy is less than one year, you might be able to take all your pension as a tax-free lump sum.

Before you take out your pension, there are some important things to consider:

- If you have an income protection plan (also called permanent health insurance) income from your pension could reduce payments from the income protection plan. Check with your HR or pensions department before making any decisions.
- Check whether accessing your pension could affect your eligibility for any benefits.

You cannot take your State Pension before you reach State Pension age, but you might be able to get other benefits. See page 87 for information about benefits and financial support.

The rules around pensions are complicated. The Pension Wise service has information about pensions if you're ill, or if you're caring for someone who's ill. See page 110 for more information.

Planning ahead

You may start thinking about what's going to happen in the future, for example:

- what kind of care you'd like to receive as your illness progresses
- where you'd like to be cared for in your final days
- practical matters, such as rehoming a pet or writing a Will
- who you'd like to make decisions for you, if you become unable to.

There may be some things you feel comfortable thinking about now, and other things you'd rather leave to another time. You may not want to think about these things at all.

Planning ahead could help make sure you get the kind of care you want. This is called Advance Care Planning, or Anticipatory Care Planning in Scotland. Your doctors or nurses can help you understand your options and what kind of care you might need. It can also help make the people important to you, aware of your wishes.

Find more information on planning ahead

For online information, visit **mariecurie.org.uk/planningahead**, or **mariecurie.org.uk/planning-ahead-lgbtq** for information specific to LGBTQ+ communities.

We also have free booklets on planning ahead: **Planning ahead** and the LGBTQ+ booklet: **Getting care and planning for the future**.

You can order booklets by calling the free Marie Curie Support Line on **0800 090 2309***, or visit **mariecurie.org.uk/publications** to order online.

Making memories

If you feel ready to, you may want to leave some messages for the people important to you to look at or read, after you've died. Not everyone chooses to do this, but here are some ideas in case you want to think about it:

- Create a memory box with people important to you which contains messages, photographs, and special items.
- Make a video message or voice message of yourself, for people close to you to watch or listen to after you've died.
- Write letters or record messages for special future events for the people around you. For example, writing cards for special birthdays, or writing out family recipes.
- There are websites which allow you to write a digital message for the people important to you to read.

▶ For more ideas about making memories, contact the free Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/support**

Beginning a new chapter

Some people tell us that having a terminal illness encourages them to break out of routines, live life to the full and take care of unfinished business.

This could involve:

- going on holiday to places you've always wanted to visit
- revisiting places that have been important in your life
- trying new experiences or learning new skills
- contacting people important to you and sharing your feelings
- settling old disagreements so you feel more at peace.

Some people find it difficult to start trying new things, or may not want to. Whatever you decide is right for you, it can help to discuss what you want with the people important to you, or your healthcare professional. This can help them to understand your choices, and provide the support you need to help you achieve the things you want to do.

> **"It sounds strange but once I'd come to terms with my diagnosis, it was a bit of a turning point for me in my life. I've done all sorts of different things since, and I've changed as a person."**
>
> Mark, who is living with a terminal illness

Section 2: Your feelings

Feelings you may have

Everyone responds in their own way when they're told they have a terminal illness. There is no right or wrong way to react. Many people tell us they initially feel shock and disbelief, even if they thought they might hear this news.

It's normal to have many different feelings throughout your illness, and they will not necessarily come in a particular order. It's also common to experience what could feel like conflicting feelings at the same time. For example, feeling both love and loneliness, or relief and anger. In this section, we talk about some of the most common feelings, but there are many other feelings you may experience too.

Denial

Denying you are ill is a common reaction to learning you have a terminal illness. It can be hard to face the reality of your illness and what will happen in the future. For some people, denial is a way to cope.

But denying you are ill can be difficult emotionally, both for you and the people close to you. It may prevent you from talking about your feelings, or discussing how you would like to be cared for in the future.

Anger

At some point, you might feel anger and resentment. You may think, "Why me?" or "Why this illness?" You might look for someone or something to blame. You might feel annoyed about how your condition has affected your life and relationships, or caused you to cancel long-term plans.

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You may feel angry or frustrated at not feeling in control of some things, like what you can do, or how your body looks or feels. Not feeling in control over some parts of your life could lead to other feelings, like feeling powerless.

Some people may feel angry as a way to cope, and to hide that they're feeling scared, sad or anxious. Getting emotional and spiritual care can help with anger – see page 61 for more about this.

Bargaining

At some point, you might feel like you would give anything to make your symptoms go away, or to extend your life somehow. This is called bargaining. You might find yourself saying, "I'd give anything if…", because you hope you can delay death.

This is not something to be ashamed of – it is completely natural to feel this way.

Guilt and regret

Many people with a terminal illness experience guilt. Some people feel they're being a burden, and feel guilty about depending on others to look after them. Sometimes people feel responsible for any difficulties their carer experiences.

In the last few months of life, some people might also feel regret. They may regret things they could have done differently, or things they have not done at all.

Try to remember that worrying is unlikely to make you feel better. Often, people who think they're being a burden on those helping to look after them are not, and their carers see it very differently. If you find these feelings are affecting your relationships with those important to you, it can help to have open and honest conversations about how you're feeling.

Feeling worried or scared

It's natural to feel worried. You may be scared of dying or being in pain. You may be worried about your treatment and any side effects you could have. And you might be afraid because you do not know what will happen in the future. Many people also become worried about the effect their illness and death will have on those around them.

Whatever you feel, know that you're not alone – there are people you can talk to. Talking about the reality of what may happen can make it less frightening.

> **"When you're first given the news, it's a very scary time trying to come to terms with it. Talking to a loved one can help you deal with it – they can give you support."**
> Mark, who is living with a terminal illness

Feeling alone

Being diagnosed with a terminal illness can bring feelings of loneliness. This might be because your symptoms or medication stop you from socialising, and doing things you enjoy. It could be that you and the people close to you no longer talk about future plans together. Or it may be that you do not have people you feel close to in your life.

You might feel like no one understands what you're going through, so you find it hard to share your feelings. But telling someone how you're feeling can often help. See page 27 for ways to get emotional support.

If you live alone, or do not have family or friends in your life, you may feel you are not getting the care and support you need. See page 72 for ways you could get support.

Feeling uncertain

Feeling uncertain about what will happen can make it hard to plan for the future. Uncertainty is one of the hardest things to deal with, and can cause a lot of tension. But there are different ways of learning to live with these feelings. You may find it helps to try focusing on positive aspects of your life, and trying to carry on with some of your usual routines.

Acceptance

Not everyone is able to accept the idea of dying. Reaching this stage takes time, and might involve long discussions with family, friends or the professionals who are caring for you. You might also go through a difficult emotional journey.

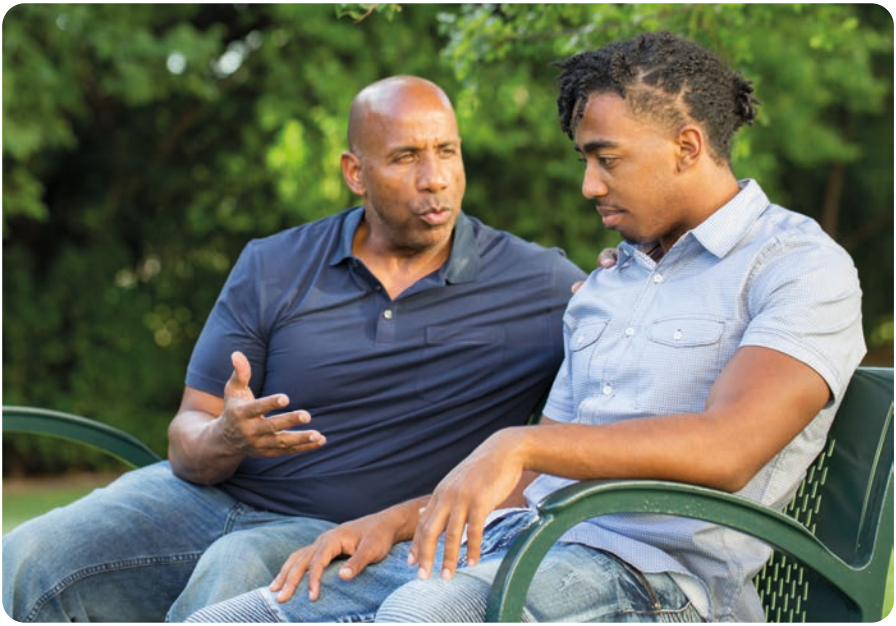
People who do accept their situation often feel a greater sense of calm, and start to have more positive thoughts. Acceptance may also make you feel more in control of your situation, and help you lead a fuller life.

Looking for meaning

During your illness, you might start to think about your values and beliefs, and the meaning and purpose of life. You might be experiencing what's sometimes called emotional or spiritual pain.

People do different things to help with emotional or spiritual pain, depending on what's important to them – see page 61 for more information.

Visit **mariecurie.org.uk/feelings** to find more information about feelings you may have, after being diagnosed with a terminal illness.



iStock/Marie Curie

Getting emotional support

You may feel like there's nothing that can be done to stop you feeling the way you do. As time passes, some people find that feelings of distress change or become less intense. But if you're struggling with how you're feeling, you do not have to cope alone – there are ways of helping you get through difficult emotions. If you're not ready to try any of these things now, it's worth trying them when you feel up to it.

Talk to someone you're close to

Speaking to someone you trust and feel comfortable with may be the best way to cope with your feelings. However, it's good to be aware that people close to you may be dealing with their own feelings about your illness, and may have different reactions. See page 76 for information on how people important to you might react.

Talk to your healthcare team or another professional

Discuss your worries and feelings with your nurse, doctor, or another healthcare professional involved with your care. They may also be able to direct you to other sources of support.

You might find it helpful to speak to a hospital or hospice chaplain, a spiritual adviser, or a religious leader. You do not have to be religious to get support. Ask your doctor or nurse if they can help with this.

Talk to a counsellor

Many people find it easier to talk to someone detached from their situation. Counsellors are trained to listen and to help you work through your feelings.

See page 33 for more information on counselling and other talking therapies.

Take care of yourself

There are things you can do to help look after yourself. These include eating a healthy diet, keeping active, and avoiding a lot of alcohol or unprescribed drugs. Speak to your GP if you need help with any of these things.

Try not to be frustrated with yourself if you find it difficult to do things, or if you're not achieving the things you would like to. Taking care of your mental wellbeing is important too. See section 4 of this booklet (page 51) for more information on looking after your wellbeing.

Join a support group

You may feel that only someone who also has a terminal illness or the same condition as you, can understand what you're going through. There are many local support groups throughout the UK where people meet to share their experiences, support each other and take part in activities.

Your healthcare team may be able to tell you about support groups in your area. Many health organisations have details of support groups on their websites. If you live in England or Wales, you can also visit the **GOV.UK** website and search for community support groups.

Chat online

Many health organisations run online communities. These are websites where you can chat to other people and learn how they coped with their emotions. The Marie Curie Community can be a good place to share your experiences, or get support from people who understand what you're going through. Visit **community.mariecurie.org.uk**

Some charities have helplines that run a web chat or email service. You can contact Marie Curie's free Support Line by web chat or email – visit **mariecurie.org.uk/web-chat** or email **support@mariecurie.org.uk**

Learn about other people's experiences

Simply reading, watching or hearing about how other people have coped with their illness may be helpful. You could do this by visiting an online community and reading other people's posts without contacting anyone directly.

You could also watch or listen to videos, such as the videos Marie Curie has produced with people with a terminal illness. You can watch these at **youtube.com/mariecurieuk**. Many people have also written books and online diaries about terminal illness.

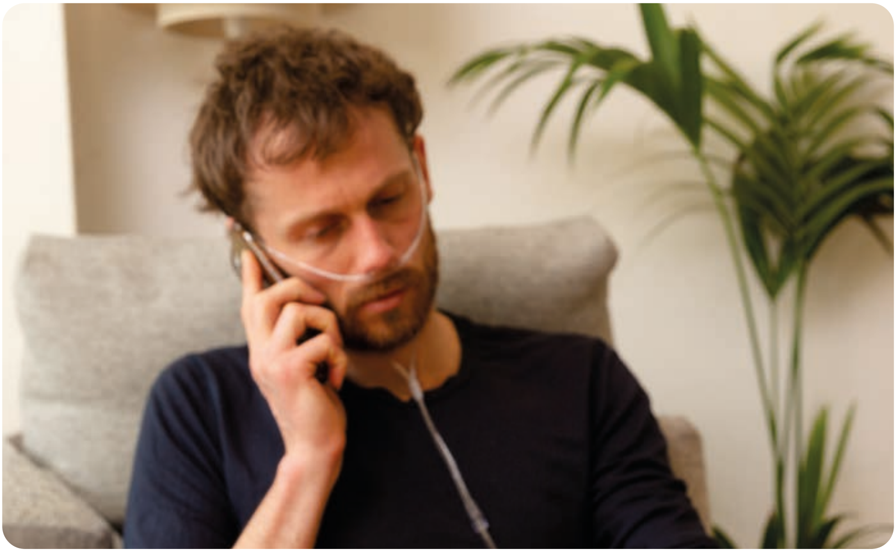
It's important to remember that, while there are often similarities in how people feel when dealing with similar experiences, everyone is different. You might experience different feelings to other people you talk to, and at different times, and that does not mean there is anything wrong.

Support from Marie Curie

You might find it easier to talk to someone you do not know. Marie Curie can offer different types of support, including a free Support Line on **0800 090 2309***, and nursing and hospice services. For more information on getting support from Marie Curie, see page 102.

> **"I find my volunteer very helpful and supportive. We talk about heavy stuff as well which is good. I prefer speaking to someone not in my family."**
>
> Someone living with a terminal illness who uses the Marie Curie Check in and Chat service

See page 102 for more information about the Marie Curie Check In and Chat service.



Philip Hardman/Marie Curie

Depression and anxiety

It's common to feel low or anxious when you're ill. But if these feelings last a long time without changing, it could be depression or anxiety, and you may need extra support or treatment.

If you need urgent support at any time, call the Samaritans for free on **116 123** – they're available 24 hours a day, every day.

Depression

Depression is more than simply feeling sad for a few days. It affects people in different ways, but can include feeling sad or hopeless for weeks or months.

Symptoms of depression

Depression affects everyone differently. People have different symptoms, and these can be emotional, physical, or social. Symptoms might include feeling constantly sad or low, having a lack of energy, and not finding your hobbies and interests enjoyable anymore.

Some physical symptoms of depression can be similar to the symptoms you might get with your illness or treatments.

There are many other symptoms of depression, and it's unlikely you will experience all of them.

Causes of depression

Depression can be caused by lots of things, including stressful and upsetting life events. Sometimes there's more than one cause, but depression can also have no obvious cause. There are some things that can make you more likely to have depression, including having a terminal illness.

For more information about depression, visit mind.org.uk or contact them for more information (see page 105 for contact details).

Anxiety

Anxiety is a feeling of worry or fear. Most of us have feelings of anxiety from time to time. But some people feel anxious often, and may find it hard to control these feelings.

This can really affect quality of life, and for people with a terminal illness, anxiety can make other symptoms worse.

Symptoms of anxiety

Symptoms are different for everyone, and they can be emotional and physical. These might include feeling worried, having a sense of dread, getting a churning feeling in your stomach, and feeling light-headed.

This is not a complete list of symptoms. How many you have or how bad they are is different for everyone.

Your symptoms might mean you stop seeing the people important to you, to avoid feeling worried or scared.

Causes of anxiety

There can be many reasons someone experiences anxiety. It's different for everyone, and sometimes there is more than one cause. People can also develop anxiety for no clear reason. People living with a terminal illness are more likely to experience anxiety. Other causes include fears about pain not being controlled, worrying about becoming a burden, and fears about dying.

For more information about anxiety, visit mind.org.uk or contact them for more information (see page 105 for contact details).

Treatment for depression and anxiety

Lots of people put off seeking help, but it's best to tell your GP or nurse how you're feeling as soon as you can. Your GP will then ask you questions about how this is affecting you, and will be able to suggest treatments. These could include self-help techniques, medication such as antidepressants, talking therapy such as counselling, or a combination of these.

Talking therapies

There are lots of types of talking therapy, and they all involve working with a trained therapist. Examples include cognitive behavioural therapy (CBT), counselling, and guided self-help.

Help through the NHS

Talking therapies are available for free on the NHS. You must be registered with a GP to access this support. If you live in England and are aged 18 or over, you can access NHS talking therapies services. You can refer yourself, or a GP can refer you. You can find out more about this at nhs.uk.

If you live in Scotland, Wales or Northern Ireland, you should contact your GP if you think talking therapies could help you. They will be able to refer you to a therapy service.

Your GP might also know of local services you could access, for example at local charities or hospices.

Help at hospices

You can sometimes access counselling at your local hospice – contact them directly to find out what services they offer. Visit **mariecurie.org.uk/help** for information about counselling services at Marie Curie Hospices.

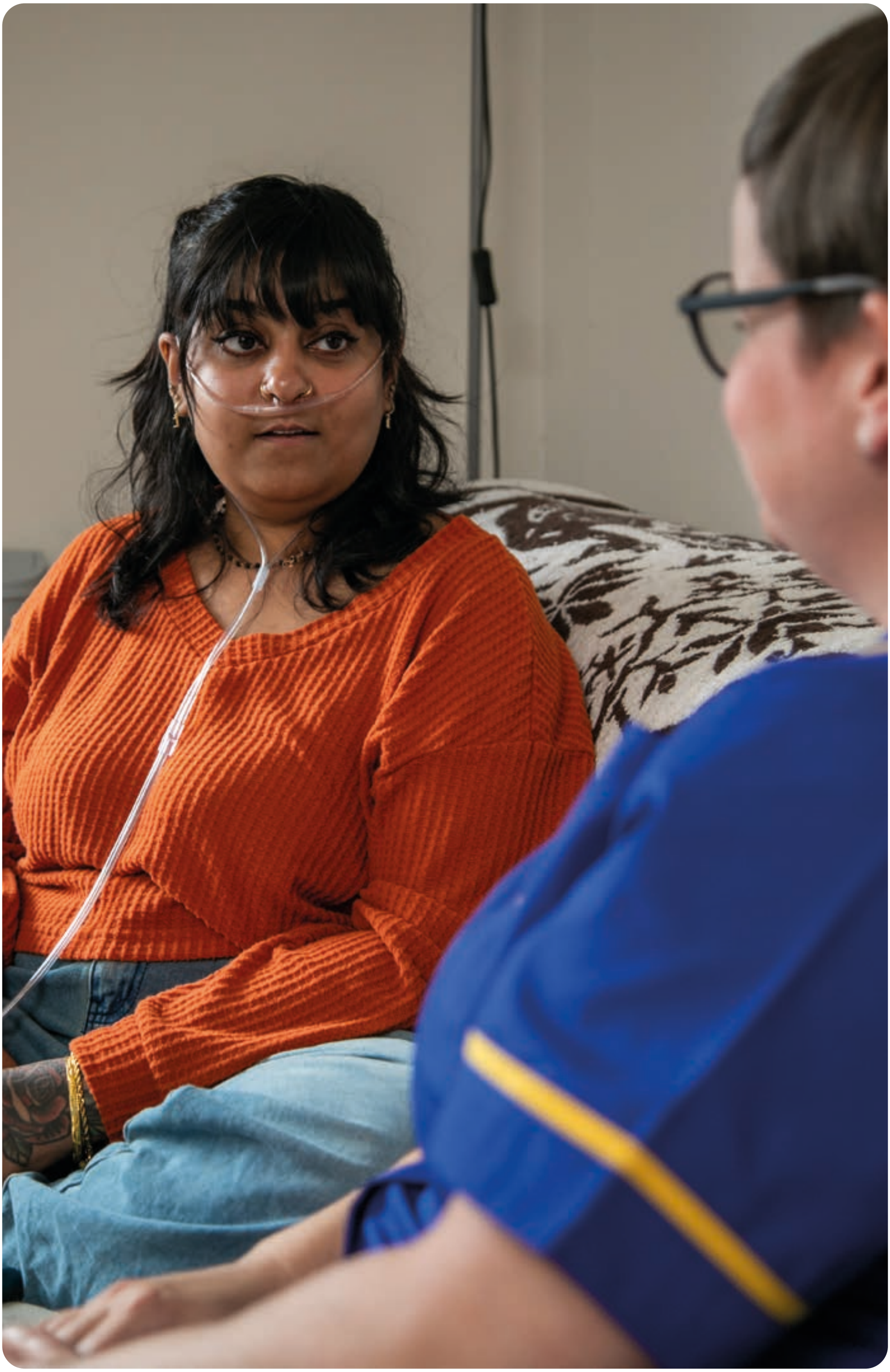
Getting help privately

You can also have counselling privately, but this is not free. Ask your doctor about private counselling or visit the British Association for Counselling and Psychotherapy website at **bacp.co.uk** to find out more.

Helping yourself

- Try the suggestions under **Getting emotional support** on page 27 – these may help with depression and anxiety too.
- Write about how you feel if you are not comfortable talking about it.
- Take your medicine – your doctor or pharmacist can help with questions about your medication.
- Try complementary therapies to help you relax – see page 65 for more information.
- Make time for mindfulness or meditation – visit **mariecurie.org.uk/support** for more information.

Section 3:
Getting care and support



Tegan James/Marie Curie

People who may be involved in your care

There may be several health and social care professionals involved in your care. But you might have one person who coordinates your care – you may hear them being called a key worker or named person. Your condition and your health and care needs will help decide who your key worker is. For example, they could be a GP, district nurse, clinical nurse specialist, or social worker. As your needs change throughout your illness, so will your key worker.

If you do not know who your key worker is, the best person to contact is your GP.

GP and primary healthcare team

When you're ill and living at home, the primary care team are in charge of looking after your medical care. This normally includes your GP, practice nurses, and community nurses. It can also include district nurses if you are unable to leave the house and have a specific nursing need.

A GP may be your key worker if you're living at home, and can leave the house. They will work with other specialists like cancer specialists (oncologists), physiotherapists, nutritional experts and clinical nurse specialists, to get you the best care possible.

Your GP will be able to:

- prescribe your medications
- tell you how you can get information on your condition and the support services available
- tell you about local hospices
- speak to a district nurse if you need to be cared for at home.

District nurses

A district nurse may be your key worker if you're unable to leave your home, and you have a specific nursing need. For example, if you need regular injections, or continence care. They will be involved in co-ordinating your care at home, and arranging for services to be provided. District nurses do not see people who can leave the house. And having a terminal illness does not mean you will automatically see a district nurse.

District nurses co-ordinate and refer to other services, but the availability of these may vary between areas. These services might include community nurses, healthcare assistants, care workers, Marie Curie Nurses and Marie Curie Healthcare Assistants, and other health and social care professionals. The district nurse will agree a personal care plan with you, and may refer you to services which could be helpful, like social services.

District nurses can support you to manage your illness and care for yourself. If you have a carer, the district nurse can also show them how to care for you.

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Marie Curie Nursing team

If you're being cared for at home, you might get help from a Marie Curie Registered Nurse, or a Marie Curie Healthcare Assistant. The Marie Curie Nursing team can help with different tasks. Registered Nurses can give you medications you've been prescribed. They can also assess your needs, and plan what kind of help you should receive.

Marie Curie Healthcare Assistants are trained professionals who can help you with washing, dressing and moving around. They may also be able to help you take your routine medication.

How to get support from the Marie Curie Nursing team

To get care or support from a Marie Curie Nursing team, you should contact your GP, or district nurse or specialist nurse if you have one. They will discuss with you whether a referral to Marie Curie is right for you. If you both agree you would benefit from Marie Curie care, they may be able to refer you. Marie Curie Nurses and Healthcare Assistants are not available in every area of the UK.

Macmillan nurses and other specialist nurses

A specialist nurse may be your key worker if you're having treatment in a hospital. If you have cancer, a Macmillan nurse can help with pain and symptom control, and give you information about your treatment. They do not carry out routine nursing tasks, but they may call or visit you at home or in hospital to check on your symptoms. Some specialise in palliative care and controlling your symptoms, while others specialise in cancer. To get support from a Macmillan nurse, you need to be referred by your cancer doctor (oncologist), nurse, or GP.

There are specialist nurses for many other conditions too, such as motor neurone disease (MND), multiple sclerosis (MS), kidney failure and heart failure. You can speak to your treatment team to see if you can have a specialist nurse.

Social workers

Social workers can be part of your local social services department, or they could be employed by a hospice, hospital or another organisation. They co-ordinate services to support people's wellbeing, in a wide range of situations. A social worker may be your key worker if you have social care needs rather than healthcare needs.

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If you want to stay at home, you, someone you're close to, or a healthcare professional, can request for a social worker to assess your needs. They'll look at what you need and any difficulties you're facing. You might then get support from social services. If you have a carer, they can also request an assessment to see if they can get any help.

See page 44 to find out more about getting social care.

Occupational therapists

Occupational therapists support people in hospices, hospitals, and at home. They can help if you have difficulties doing daily tasks and activities that are important to you, by sharing new ways of doing things. They may also recommend adaptations and equipment to help you (see page 48). Occupational therapists aim to help you adapt to your illness, and keep your independence and quality of life.

You could get occupational therapy for free. Contact your GP for a referral, or ask your local council or Health and Social Care Trust if you live in Northern Ireland.

Occupational therapists in hospices can help people in a variety of ways. They might be able to offer you help with rehabilitation, living with your symptoms, and support you with planning your care in advance. To find out what services your local hospice offers, visit their website or speak to your healthcare professional. Visit **mariecurie.org.uk/help** for information about Marie Curie Hospices.

You can also get occupational therapy privately. You can search for qualified therapists in your area on The Royal College of Occupational Therapists website at **rcot.co.uk** (see page 105).

Specialist palliative care team

Palliative care offers physical, emotional and practical support to people with a terminal illness. It also focuses on managing symptoms and supporting you to have a good quality of life.

If you're referred to a specialist palliative care team, they will assess your needs and the needs of those important to you. They will be able to provide care and support throughout your illness.

A specialist palliative care team will involve healthcare professionals who specialise in palliative care. This might include doctors, nurses, occupational therapists and physiotherapists. This team is there to help you manage pain and other symptoms of your illness. They will also offer emotional, spiritual and psychological support to you and the people important to you. This kind of care could be offered in your home, in hospital, in a hospice or in a care home.

Philip Hardman/Marie Curie

Hospice care

Hospices can support you at any stage of your terminal illness. They provide free nursing and medical care in a friendly and comfortable setting, as well as social, practical, emotional and spiritual support. Some people stay in a hospice when they need specialist care, while others visit for treatment or other services. This includes out-patient appointments, pain management groups, psychological support, physiotherapy, and much more. They can also support the people important to you.

Hospices are run by various charities, including Marie Curie. For more information on where care is provided, visit mariecurie.org.uk/support or call the free Marie Curie Support Line on **0800 090 2309***.

> **“We met another couple...they thought the hospice was about ‘the end’. I’ve heard a lot of people who have that perception and I would love to get that changed...yes you can go there to die, but they can also support you for respite, pain management and also just general advice on your finances and benefits. They’re a wealth of information.”**
>
> Wayne, who was cared for at the Marie Curie Hospice, West Midlands

Help from social services

You may be able to get help from social services if you need practical support to help you stay living at home. Social care can include getting equipment and changes to your home, and help with daily tasks like washing, dressing and eating.

If you live in Scotland, you can get help from a paid carer for free, as long as you're assessed as being eligible for this.

How to get social care

Request a needs assessment by contacting your local council in England, Scotland and Wales, or your Health and Social Care (HSC) trust in Northern Ireland. In Scotland, a needs assessment might be called an assessment of your care needs or a community care assessment. In Northern Ireland, it's called an assessment of need.

The council or HSC trust will work out if you need to pay towards the cost of your care and, if you do, how much you need to contribute.

Help for carers

If someone cares for you, they can get a carer's assessment by contacting their local council or HSC trust. In Scotland, it's called an adult carer support plan. Support for carers could include having someone take over caring so they can take a break, and connecting them with local support groups.

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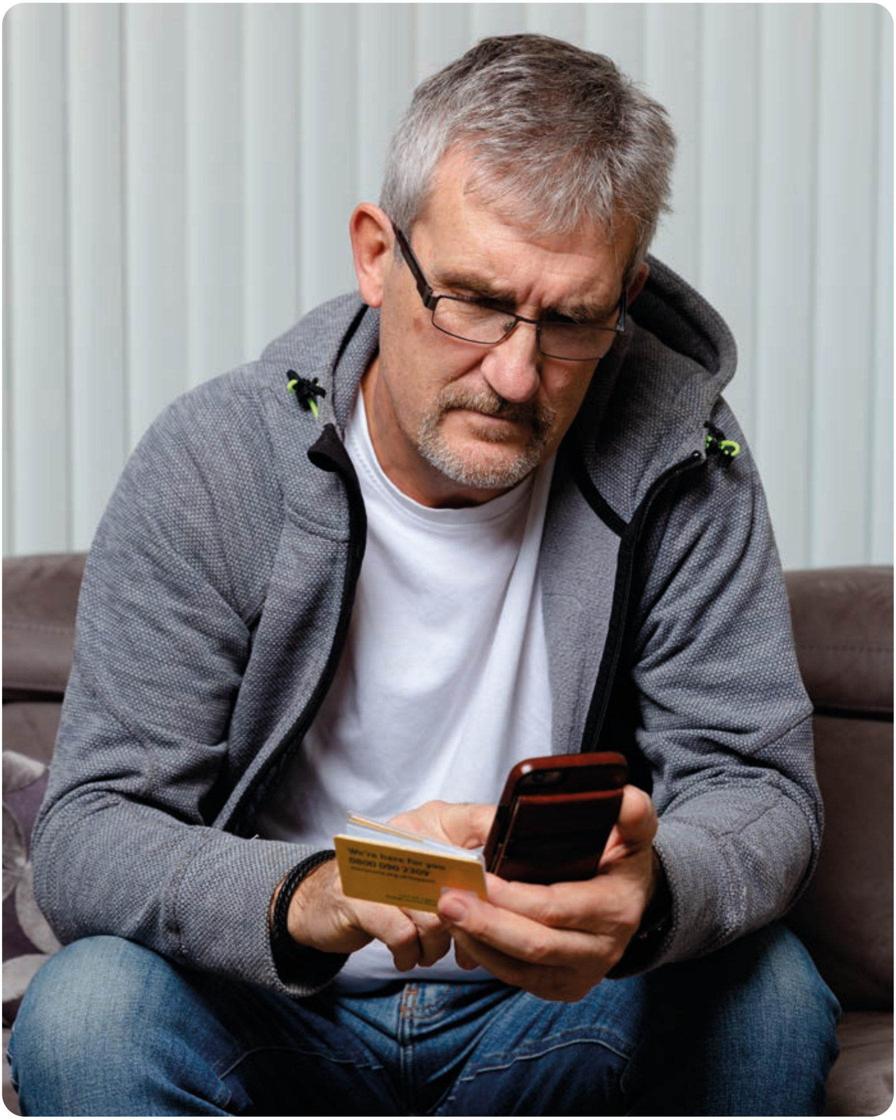
Find more information about getting social care at **mariecurie.org.uk/socialcare**, or call the free Marie Curie Support Line on **0800 090 2309***.



Phil Hardman/Marie Curie

NHS continuing healthcare

NHS continuing healthcare is free social care for adults, which could cover care in your own home or care home fees. Some people with long-term complicated health needs are eligible. You might see it written as NHS CHC. Check if it's available where you live:

UK country	Is NHS CHC available?	Is an alternative available?
England	Yes	No
Scotland	No	Yes – Hospital Based Complex Clinical Care
Wales	Yes	No
Northern Ireland	Yes, but it's not as easy to access and the assessment process is different.	No

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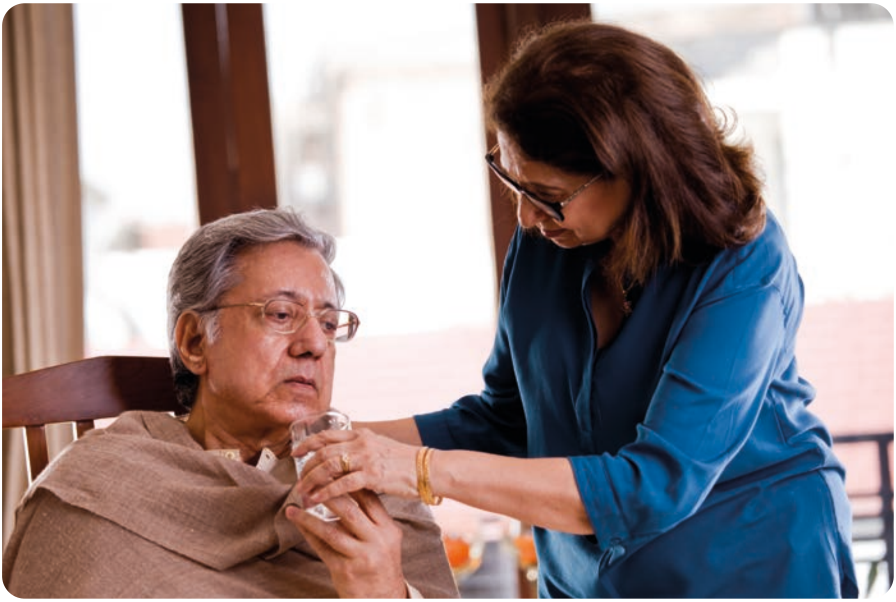
How to get NHS continuing healthcare

You need to be assessed to get NHS continuing healthcare. Speak to your GP, social worker, or district nurse if you have one – they can arrange an assessment.

Having a terminal illness does not mean you are automatically eligible, as eligibility depends on your assessed needs. It's not means-tested, so whether you can get it is not affected by how much money or savings you have. If you have a terminal illness and are approaching the end of your life, your assessment may be fast-tracked.

Getting NHS continuing healthcare could affect some benefits. Find out more about NHS continuing healthcare at [mariecurie.org.uk/continuing-healthcare]() or call the free Marie Curie Support Line on **0800 090 2309***.



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Adapting your home and getting equipment

If you're living with a terminal illness, it may get harder to move around your home or do everyday tasks. Making changes to your home or getting equipment might help make life easier.

Changes to your home can be big or small. For example, fitting a stairlift or a banister on the stairs, or installing a walk-in shower or grab rail.

There's also a wide range of equipment you could get, for example a raised toilet seat, a bath or shower seat, or a wheelchair or walking aid.

How to get home adaptations and equipment

In England and Wales, apply for a home assessment from your local council.

In Northern Ireland, home adaptations and equipment are covered in your assessment of need.

In Scotland, they should be discussed as part of the assessment of your care needs – if it's not, you can bring it up as part of your assessment. See page 44 for more about these assessments.

To get a wheelchair or walking aid, speak to someone from your healthcare team. They may be able to arrange for you to have or borrow what you need, or refer you to a specialist service for assessment.

Paying for home adaptations and equipment

If you have been assessed as needing adaptations, you could get some or all of these for free. This depends on where you live, your household income and savings, and how big the adaptations are.

In England, Scotland and Wales you will normally need to contact your local council about adaptations. In Northern Ireland you need to contact your local Health and Social Care (HSC) trust.

Adaptations are normally split into two categories: minor and major. Minor adaptations include things like handrails around the home. Contact your local council or HSC trust to see if they can provide any equipment and small adaptations for free.

Major adaptions include things like installing a downstairs shower room or widening doorways. In England, Wales and Northern Ireland you could get a Disabled Facilities Grant to help pay for these. Contact your local council or HSC trust to apply. In Scotland, what you could get and how to apply depends on if you own or rent your home. Contact your local authority or housing association for more information.

Other ways to get home adaptations and equipment

- Borrow equipment – the NHS, your local council and other organisations may be able to loan you some equipment.
- Look for other grants to help pay for adaptations or equipment – see page 95 for more information.
- Organise and pay for home adaptations and equipment yourself. It's best to get an assessment first (see page 48).

See page 107 for who else to contact for help with making adaptations and getting equipment.

If you rent your home, you will need your landlord's permission to make adaptations. Contact Citizens Advice to get information and advice about this (see page 109).

▶ For more on information on adaptations and equipment, visit **mariecurie.org.uk/support** or contact the free Marie Curie Support Line on **0800 090 2309***.

Section 4: Looking after your wellbeing

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Keeping active

Keeping active when you have a terminal illness can have lots of benefits, for both your body and mind. Exercise can make your muscles stronger and give you energy, and it can help to reduce symptoms like pain, fatigue, constipation and shortness of breath.

Exercise can benefit your mind by helping you to relax and sleep better, improving your concentration, and making you more alert. It can also help to improve your mood and reduce anxiety, stress and depression.

Speak to your doctor, nurse, occupational therapist or physiotherapist for advice about keeping active. They can help you plan an exercise programme that's right for you. There are lots of options, including walking, balance, flexibility and strength exercises, and group exercise classes.

▶ You can find out more about staying active by visiting **mariecurie.org.uk/exercise** or contacting the free Marie Curie Support Line on **0800 090 2309***.

Eating and drinking

Your illness, treatments and medication might change the way you eat and drink. For example, you might experience changes to your appetite and the foods you like. But there are ways to manage these changes, and to get support with any difficulties you might have.

Appetite loss

Sometimes you might not feel like eating, even if someone has made something especially for you. This could be because of difficulties with swallowing or digestion, a sore mouth, or because of your illness or treatments. Being breathless, tired or feeling low might also affect how much you want to eat.

If you have a low appetite, you could try the following tips:

- Eat small meals and healthy snacks regularly – these might be easier to manage and more enjoyable than large meals.
- Try eating bigger meals whenever you feel hungriest.
- Eat the foods you want to eat – these might change over time.

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- Take good care of your mouth, including cleaning your teeth or dentures twice a day. This can make eating and drinking easier and more enjoyable. You can learn more about good mouth care at **mariecurie.org.uk/support**.
- Ask your doctor or nurse about ways to get more calories in your diet if you cannot eat big portions.
- A glass of sherry or brandy half an hour before a meal may help to increase your appetite. Some people also find a glass of wine with their meals can help their digestion. You should check with your doctor first to make sure it does not affect your medication.

“After four months, Mum didn’t need the tube anymore. The first thing she ate was a small piece of fish – but then she got back on to proper food. She became very adventurous in her tastes, enjoying flavours she never would have eaten before she was ill.”

Deirdre, Carer

Feeling sick

Feeling sick (also called nausea) and being sick (also called vomiting) are common problems for people living with a terminal illness. They can be caused by things such as your illness, some medications, and anxiety. If you feel sick, speak to your nurse or doctor – they can look for a specific cause and decide on the best way to help you.

There are medicines and treatments that could help you. These include anti-sickness medicines, and some people find complementary therapies help, such as acupressure and acupuncture. See page 65 for more information on complementary therapies.

Things you could try if you feel sick

If you have difficulty with eating, drinking or swallowing, some of the following suggestions might not be suitable for you – speak to your doctor or nurse before trying these.

- If the smell of cooking makes you feel sick:
  - try eating cold meals instead, or
  - if possible, ask someone else to cook your meals.
- Avoid greasy, fatty or fried foods.
- Try eating dry food such as toast or crackers, first thing in the morning before you get up.
- Eat small meals and healthy snacks regularly – these might be easier to manage than large meals.

- Start with light foods like thin soups, then gradually start having small amounts of your favourite foods. Slowly build up to eating more.
- Have drinks between meals instead of drinking when you eat.
- Try food or drink containing ginger, like crystallised ginger, ginger tea or ginger biscuits.
- Try sipping on fizzy drinks through a straw, like sparkling water or lemonade.

▶ Visit **mariecurie.org.uk/feeling-sick** or contact the free Marie Curie Support Line on **0800 090 2309*** for more information.

Liquid and soft food

If you have difficulty swallowing, some of these suggestions might not be suitable to eat. Speak to your doctor or nurse before changing what you eat.

Eating soft or liquid foods may be easier to eat as they need less effort. Chewing some foods like meat, can be quite tiring if you are tired or breathless. Soft foods could include mashed potato, jelly, mousse, and ice cream. Liquid foods might include smooth soup, vegetable and fruit smoothies, and milkshakes.

Your GP or clinical nurse specialist may also advise nutritional supplements.

Difficulty swallowing

Having difficulty swallowing is a common problem for people living with a terminal illness. It can mean you find it harder to eat, feel like food is stuck in your throat, or have more saliva in your mouth than usual. The medical term for swallowing difficulties is dysphagia.

If you’re having any problems with swallowing, talk to your doctor or nurse. They will look at what could be causing this, and try different things to help you.
They might:

- recommend you stop or reduce medication
- involve other professionals such as a speech and language therapist or dietician
- recommend changes to your food and drink such as
  - soft foods chopped into small pieces, with extra gravy or sauce, instead of dry or hard foods in bigger pieces
  - thicker liquids instead of thin liquids like water
  - using liquids, gels or powders to change the thickness of your food and drink
  - high calorie drinks so you do not have to eat as much.

There are also things you could try yourself:

- Sit in an upright position when you eat or drink if possible. If sitting up is difficult, try using a few extra pillows to get you in the right position for eating.

- Ask if you can get a table across the bed, as this can make eating easier.
- Take your time when you're eating or drinking.
- Chew your food thoroughly before you swallow.
- Ask for help whenever you need support to eat, drink or take medication.

Some of the tips on pages 54–57 to help with appetite loss and feeling sick, might also help if you have difficulty swallowing.

You can order our free booklet, **Difficulty swallowing**, by calling the free Marie Curie Support Line on **0800 090 2309***, or visiting **mariecurie.org.uk/publications** to order online.

Getting help with eating and drinking

Contact your nurse or doctor if you continue having problems with your appetite, issues when eating, or you're losing weight. Towards the end of life, it is natural to want to eat less. But your nurse or doctor can advise you on what is normal, and help if symptoms such as nausea are stopping you from eating.

Always talk to a healthcare professional before making any major changes to your diet. You could also visit **nhs.uk/live-well** for information and advice about eating a healthy, balanced diet, and for guidelines on exercising.

Managing pain

Everyone's experience of pain is different, and some people may not experience any pain. The main thing to know is that with the right treatment and support, most pain can be managed.

What causes pain?

Pain can be caused by your illness, an operation, or your treatment. Long-term conditions such as arthritis can also cause pain. It can affect your body in different ways – pain can be dull and aching, or more specific, like a sharp or throbbing feeling in one area.

Pain can also affect you emotionally. It can affect your mood, how well you sleep, or even begin to affect your relationships. See page 61 for more information about emotional pain.

Getting help

Your GP and palliative care team will work with you to find the best way to manage your pain. You will have a pain assessment, where your doctor or nurse will ask you questions about your pain. If you cannot communicate, they will ask your family or carers. They might ask where the pain is, when it started, and the effect it's having on your life.

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You will know best what your pain feels like and how it's affecting your quality of life, but it can be difficult to describe this. You might find it helpful to keep a pain diary – Macmillan have a handy template which you can find at **macmillan.org.uk/pain**. This is somewhere you can write down things like: when you feel pain, what it feels like, and what you were doing at the time. Giving your doctor or nurse this information helps them figure out what's causing your pain, and what treatment is best for you.

There are lots of medicines for treating pain. Your local pharmacist can give you information about when and how to take any medication you've been prescribed. There are also other treatments to relieve pain which do not involve medication.

▶ Find out more about pain and treatments at **mariecurie.org.uk/pain**, or in our booklet, **Managing pain**. You can order this by calling the Marie Curie Support Line on **0800 090 2309***, or visit **mariecurie.org.uk/publications** to order online.

Emotional and spiritual pain

Emotional pain

Emotional pain is when someone feels like they cannot cope with their emotions. If you're experiencing this, you might feel a mix of emotions such as those listed in Section 2 of this booklet (page 21). Some people may also have depression or anxiety. Different things can cause emotional pain, including physical pain, isolation, loss of control or fear of dying.

There are things you could try yourself, to help you cope with how you're feeling:

- Write in a diary about what you're thinking or feeling.
- Make a memory box and fill it with mementos, photographs, or things which remind you of times in your life.
- Try a complementary therapy (see page 65 for more information).
- Try a talking therapy, like cognitive behavioural therapy.
- Make a list of things you enjoy doing – even if you do not feel up to them now, just writing them down and remembering happy times might help.

Spiritual pain

You might be experiencing spiritual pain if you cannot find hope, peace and comfort. You may be struggling to find meaning and purpose, or be questioning your beliefs. Spiritual pain happens when someone's spiritual needs are not met. Everyone's spiritual needs are different and can change over time. They might include the need to feel a sense of belonging, or the need for meaning, peace or love.

Spirituality means different things to different people. For some people it might involve religion, but it's not the same as religious beliefs. Spiritual issues can affect everyone – you do not need to be religious to have spiritual needs.

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Everyone does different things to meet their spiritual needs. Some people spend time with the people important to them, go out in nature, or spend time on their hobbies. Some people may follow religious customs, like prayer or going to religious services.

Philip Hardman/Marie Curie

Getting support

Talking to people could help with both emotional and spiritual pain. You could try talking about your feelings with the people close to you. Or you might want to speak to someone you're not as close to:

- Chaplains, spiritual co-ordinators and faith leaders – they can support you whether you're religious or not. They're often based in hospitals or hospices.
- Your own faith leader.
- Someone offering non-religious support. Humanist Care has a network of trained volunteers in hospitals and hospices who provide support to everyone, regardless of their religion or belief.
- Your doctor, nurse, social worker, or someone else from your healthcare team.

Healthcare professionals recognise that emotional and spiritual pain can make physical pain or other symptoms worse. This means reducing emotional and spiritual pain may also help to reduce physical pain.

Not everyone finds talking about their feelings helpful. You could also let those around you know that you do not want to talk. Ask them to respect your decision and let them know they're still important to you. Some things you could try instead include art therapy, meditation, or relaxation.

Visit **mariecurie.org.uk/spiritualpain** for more information or call the free Marie Curie Support Line on **0800 090 2309***.

Complementary therapies

Complementary therapies are treatments you can have alongside your regular medical care. There is research that shows some types may help treat pain, when used on top of conventional medical care. But there is not enough evidence to say for sure how well they work for all health issues and illnesses. Some people find complementary therapies help with other symptoms like anxiety and stress.

Speak to your doctor or nurse before you have complementary therapy. Some types might not be safe for you, depending on your condition and any treatment you're having. It's also important to tell the complementary therapist about your medical condition and any treatments you've had or are having. They can make sure the therapy is suitable for you.

Examples of complementary therapies include acupuncture, aromatherapy, and massage therapy.

Finding and paying for complementary therapy

In most cases, the NHS does not offer complementary therapies, so speak to your doctor or nurse about what's available in your area.

Your local hospice or support group may offer free or reduced cost therapies. Each Marie Curie Hospice offers a range of complementary therapies, with some sessions open to carers. You can find out more about Marie Curie Hospices at **mariecurie.org.uk/help**. You can also search for a local hospice on the Hospice UK website at **hospiceuk.org**.

You can also pay to get complementary therapy from a private therapist. The Complementary & Natural Healthcare Council has a directory of qualified therapists at cnhc.org.uk.

Alternative therapies

Alternative therapies are different from complementary therapies. They are given instead of conventional treatment, not alongside it. Sometimes the same therapy can be used as alternative therapy and complementary therapy, like aromatherapy.

Some types of alternative therapy may not be safe in certain situations and could cause harmful side effects. For example, if you're taking other medicines, are about to have surgery, or are pregnant. Most alternative therapies are not tested in the same way that conventional treatments are.

Remember to speak to your doctor or nurse before you have any complementary or alternative therapy, herbal medicines, or dietary supplements. And you should tell your therapist about your health condition and treatment.

▶ Visit **mariecurie.org.uk/complementarytherapies** for more information or call the free Marie Curie Support Line on **0800 090 2309***.

Sexuality, intimacy and relationships

Sexuality and intimacy mean different things to different people. And what they mean to you might change throughout your life.

Sexuality and intimacy are not just about having sex. They might give you a feeling of belonging, or of being accepted by another person. They can be a way for you to enjoy closeness with yourself or with someone else. And they might help you to find meaning and purpose in life.

There can be lots of benefits of sexuality and intimacy, including making you feel reassured, and providing a distraction and relief from your illness. They can also help to reduce stress, anxiety, and depression.

How your illness might affect sex, intimacy and relationships

Being diagnosed with a terminal illness can affect how you feel about yourself and your body image. It might also affect intimate relationships you may have with people. You might find your illness makes you want sex and intimacy more or less often.

Your illness or treatments might put you off starting a new relationship. Or you may feel like a new relationship would bring you comfort.

As your illness progresses, the way you feel about sex and intimacy might continue to change. There's no right or wrong way to be – it's different for everyone.

For many people, intimate relationships and sex are important aspects of their life. So a change in their sexuality and intimacy can affect their wellbeing, relationships and overall quality of life.

When you're ill, lots of things can affect how you feel about sex, your body, and being intimate. These might include things like:

- not having enough privacy, for example if paid carers are coming into your home often, or you're staying in a hospice or hospital
- extreme tiredness (fatigue)
- treatments and side effects
- symptoms such as nausea and pain
- low sex drive
- feeling depressed or anxious.

The people you're intimate with

If you have a partner, or more than one person you're intimate with, the way they feel about sex and intimacy might change too.

When you become ill, your partner might take on the role of a caregiver. They may start helping with eating, washing, and dressing. Or they make take on new responsibilities in the home. Some people find it difficult to go from being a partner or spouse, to acting as a carer. The change in roles can be difficult for both of you, and might affect the dynamic of your relationship.

Talking to your partner

You might find it harder to talk about sex with your partner since being diagnosed with a terminal illness. But if you can, talking about how you're both feeling can help you to better understand what you both want. It could also help with finding ways for you to both feel fulfilled and close to each other.

Talking to healthcare professionals

You may have questions for your healthcare professionals, or want their advice. It's OK if you feel embarrassed to bring it up with them, but remember they are there to help you. Palliative care involves looking after all aspects of your wellbeing – this includes sex and intimacy.

You might want to know things like:

- how your illness, treatment and symptoms will affect your sex life
- ways you can make it easier to have sex (for example, if symptoms like pain and fatigue make it more difficult, or if your illness is affecting your ability to have sex)
- if you are trans or non-binary, how your illness or treatments might affect hormone therapy or medical transitioning.

When it comes to talking about sex or relationships, your doctor or healthcare team might not always start these conversations with you. But they can put you in touch with the right person to help you. This might be a psychologist, counsellor, or therapist.

If you're worried about talking

You may worry about talking to healthcare professionals about sex, intimacy or relationships.

For example, sometimes other people may make assumptions about your sexual orientation or gender identity, which could make the conversation more difficult for you. Whether you tell people about your sexual orientation depends on what you're comfortable with, and it's different for everyone.

You should always receive high quality care, regardless of your sexual orientation or gender identity. Visit mariecurie.org.uk/support for information on what to do if you're not happy with your care, or call the free Marie Curie Support Line on **0800 090 2309***.

Philip Hardman/Marie Curie

Things to help with sex and intimacy

These are some things you could try if your sex and intimacy needs have changed:

- Asking for privacy – a private room, larger bed or setting time with no interruptions from healthcare staff could help with this. Tell the people involved in your care what you need.
- Managing your symptoms – speak to your doctor if you have symptoms from your illness or treatment that make it more difficult to be intimate.
- Try new ways to connect – this could include having sex in different ways, touching, and doing things you enjoy together.
- Having safe sex – speak to your GP if you're worried about contraception, safe sex, pregnancy, or having sex after having treatment.

You can find more things that could help with sex and intimacy at **mariecurie.org.uk/intimacy**.

If you live alone

If you live alone, you may feel it's more difficult for you to get the help and support you need. If you're feeling isolated or struggling with daily tasks like cleaning the house or doing laundry, speak to your GP, or another member of your healthcare team. They can let you know what support is available in your area. If you need help with personal care like washing or dressing, see page 44 for how to get help from social services.

Help from Marie Curie

Marie Curie has different services where trained volunteers can offer ongoing support in person or over the phone. Some services are not in all areas, while others are available across the UK. See page 102 for more ways Marie Curie can help.

Befriending schemes

A befriending scheme is a network of people, usually volunteers, who can provide regular companionship and conversation, by visiting you at home or by phone call. They may help you feel more positive and cared for, which can help improve your feelings of self-worth.

There are several free befriending schemes in the UK – see page 105 for details.

Getting out of the house

Trying an activity or joining a group could also help if you feel lonely or isolated. There are lots of things you can try, and these will vary depending on where you live. These might include art, writing, book clubs, quiz nights, walking, or gardening (if you're able to do some physical activity).

You can find out about activities and groups in your area by contacting your local council, community centre, or your local branch of Age UK. There may also be other local organisations that offer this support (see page 105).

Even if the first activity or group you try does not suit you, it could lead you to finding another group or organisation. And they're a good way to meet new people.

If you need help finding a group to join, you could ask a member of your healthcare team.

Help from a hospice

Lots of hospices run day therapies like art groups, gentle exercise and relaxation. You may be able to go to these even if you're not an inpatient at the hospice. Marie Curie Hospices offer these services. To find out where your nearest Marie Curie Hospice is, and what kind of day therapies it runs, visit **mariecurie.org.uk/help** or call the free Marie Curie Support Line on **0800 090 2309***.

You can also search for a local hospice on the Hospice UK website at **hospiceuk.org**.

Phil Hardman/Marie Curie

Section 5: People important to you

People important to you may include family, friends, and anyone else important in your life. We sometimes say family and friends instead, to talk about the same people. These important people might be a partner or partners, husband, wife, civil partner, birth family, family of choice, rainbow family, or your friends.

We know not everyone has family and friends in their lives. Some people may get support from local support or community groups, places of worship, their health and social care professionals, or charities that provide support services. We're here to support you – call the Marie Curie Support line on **0800 090 2309***, or see page 102 of this booklet for more ways Marie Curie can help.

How they might react to your illness

It can be difficult to know how the people important to you might react to your illness, and you might be worried about telling them. But talking to them about your illness can have lots of benefits. It can give you the opportunity to share messages of love, talk about your worries, and it may bring you closer together.

You may find that people react to your illness differently. This might depend on their personalities and the relationships you have with them. They may feel shocked and overwhelmed, and might go through a range of feelings. They may not experience the same feelings at the same time as you. This can mean that sometimes, they may react in ways you might not find helpful.

Some people may be more willing to talk about it, while others might not be able to express what they're feeling as easily. Some people might not want to talk about it at all – they might not be able to come to terms with the reality of your death. They might also be worried about getting upset in front of you, or making you upset.

People close to you may be worried about their finances, feeling run down or being overwhelmed. Or they might feel guilty for worrying about themselves. You might also be worried about how much you share with them, feeling pitied, or being a burden.

It can help to know there's also support available for the people around you.

▶ Our booklet, **Being there for someone with a terminal illness**, has information on practical and emotional issues for carers. Call the Marie Curie Support Line on **0800 090 2309*** for a copy, or visit **mariecurie.org.uk/publications** to order one online.

Changes in relationship dynamics

Your illness may change the relationships you have with the people important to you. Some relationships may become stronger, while others could become strained. In most cases, the best way to try to solve any difficult changes is to talk about them.

Your partner

If you have a partner, the stress of your illness might put a strain on your relationship. They might be worried about the future becoming uncertain, how to comfort you properly, and the effects of your treatment. In some relationships, dealing with an illness brings people closer together. In others, people may become more withdrawn and might avoid the subject.

If your sexual relationship is affected and you're struggling, there are ways to get help. See page 67 for more on sexuality, intimacy and relationships.

If your relationship starts to change, try to talk to each other about how you're feeling. If this is too difficult, you may each want to speak to other people on your own. Sometimes talking to a counsellor can help, either separately or together. See page 33 for the different ways to access counselling or other talking therapies.

“Jacky was a natural carer, so, the relationship is quite different now. It’s hard to put into words, but I love her dearly.”

Shelley talking about caring for her partner Jacky, who died in 2023

Your children or grandchildren

If you have children or grandchildren, you may be worried about telling them about your illness, and how it will affect your relationship.

Younger children and teenagers can react in many different ways. They may become clingy or distant. This could be because they feel angry or guilty that in some way they caused your illness. They may also want to take on a more adult role and responsibilities within the home.

Having an illness can disrupt the daily routine. Your children and grandchildren might also start to care for you, leading to a role reversal. This can be difficult, so try to talk openly about your worries and needs. Talk to them about the things you’re comfortable with them doing for you.

Talking to children or grandchildren

At some point, you may have to talk to your children or grandchildren about death. When having a conversation with them about your illness, here are some things that may help:

- Let them know it's OK for them to have many different feelings, and that you have many of the same feelings too.
- Reassure them that they can ask any questions and be honest when answering. It's OK to say "I don't know."
- Use clear and specific terms so they do not get confused.
- Use your judgement around how much detail to give, based on the child's age and level of understanding.

▶ You can find more information about talking to and supporting children on our website, at **mariecurie.org.uk/support**

Your parents or siblings

The relationships people have with their parents and siblings are unique. Some families are very close, while others are not. As always, communication is important. When you feel up to it, try to talk to them about your illness, any problems you've had, and how you're feeling. This can help them understand what you need, and why things might feel different in your relationship.

You might notice changes in the relationships between some family members, for example if they have different reactions to your illness. This can be difficult to deal with, and you or they might find it easier to talk to someone outside of your family. See page 102 to find out how Marie Curie can support you and your family, or contact the Marie Curie Support Line on **0800 090 2309***.

People caring for you

When you become ill, sometimes your partner, children, other family members or friends will start to care for you. For some people, it can be difficult to adjust to this caregiving role.

Changing the daily routine, working different hours, or having to physically care for someone can all be stressful. Some carers have to take on new responsibilities, and the dynamics of the relationship between you may change.

If you or your carer are struggling, talk to your nurse or doctor about what support is available. Carers may be able to access benefits which help with the additional costs of caring (see page 93), and they may be eligible for support from social services (see page 44). You can also visit **mariecurie.org.uk/support** or contact the Marie Curie Support Line on **0800 090 2309***.

Talking to people about your diagnosis

Although it can be hard, some people find that talking about their diagnosis can bring a sense of relief. If you decide to talk about it, you may be thinking of the best way to start the conversation. This section has some different approaches you could try.

Choosing who to tell first

It might be helpful to figure out if there's one person you want to tell first. While you probably cannot predict exactly how someone will react, there might be someone you feel most comfortable telling, who you think can give you the support you need.

Speak to people as a group

You may find it easiest to talk to the people important to you in one large group or a number of smaller ones. This will save you repeating the same information, which can be emotionally draining.

Speak to people individually

You'll have different relationships with the people important to you, so you may need different ways to speak to them about your illness. You might want to plan a time and place to have a discussion, so you can think about what you want to say in advance. Sometimes, it might be easier to have a conversation more casually, for example while out for a walk or over a meal.

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With most important conversations, honesty is usually best. Try not to be worried about showing your emotions – it's normal to find these conversations difficult.

Ask someone you trust to share your news

You may want to talk to people about your illness, but feel unable to do this directly. Instead, you could ask someone important to you to be a spokesperson, and pass messages back and forth.

By doing this, you can keep people up to date without wearing yourself out emotionally. You'll also be able to respond to people's questions in your own time.

Your chosen spokesperson could be impacted by doing this, so it's a good idea to check they feel comfortable doing this.

Take it one step at a time

You do not have to talk about everything at once. There may be lots of things you'd like to discuss, but you might find it easier to talk about one thing at a time.

Ask a professional to help

Some people find it too difficult to speak to people they're close to about their illness. If you're experiencing this, you could ask a professional involved in your care to help you, such as your doctor or nurse. They could have those conversations with the people important to you. Or, you may decide just having them there will give you more confidence to talk about your illness. You could also rehearse what to say with them beforehand.

Your doctor or nurse can also point you in the direction of other professionals, such as a counsellor, who you might find it easier to talk to. The people important to you could speak to a counsellor as well.

> **“Our Marie Curie Nurse acted as a translator of complex information and pieced bits of the health system jigsaw together. If your loved one has a diagnosis, ask them to give permission for someone like a nurse to liaise directly with you. It will help you understand all the bits of the care plan.”**
>
> Rachel, whose mum died in 2021

Ask for help with practical things

Some people do not want to talk about their illness. Everyone responds differently, and there’s no right or wrong way to react. If you’re finding it difficult to talk about your illness, it might be easier to get help with practical tasks instead. It can be a burden to figure out exactly what you want help with. It’s OK to say to the people around you that it’s helpful for them to offer, rather than waiting for you to ask.

When you’re first diagnosed, you could ask them to help you with the shopping or household chores. This can help them to feel useful if you, or they, are finding emotional conversations difficult. You might then find it easier to ask for help with bigger tasks or emotional support, as your illness progresses.

Some small things you could ask for help with include:

- taking you to do a food shop, or doing one for you
- looking after a pet or walking a dog
- helping you do the washing.

Talk online

Another option you could explore is sharing your experiences with people important to you through social media, such as Facebook, Instagram and Twitter. Sharing online can be a good way to connect with others, especially if you want to tell a wider circle about what you're going through.

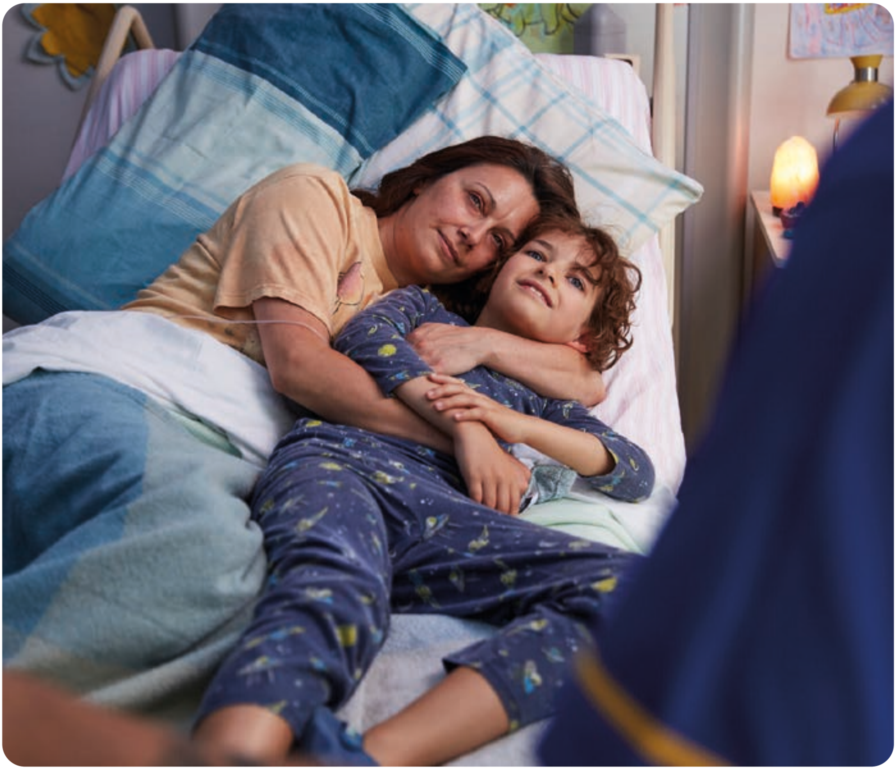
You may want to select who can and cannot read your posts. If you're not sure how to do this, you could ask someone around you for help.

You could also create your own private website for free at **caringbridge.org**. CaringBridge help people with medical conditions set up personalised websites, to share their health news with the people important to them. You might find this easier than sharing updates in different ways with different people. You can choose who can see your website so they can see updates and send you messages of support.

Other ways to communicate with people important to you

If talking about your illness is too overwhelming, or you do not want to talk about it, you should tell them. You can always discuss things at another time. Instead of talking:

- you might find it easier to write down what you want to say in a letter
- you could make a memory box together to remember the times you've shared. See page 19 for more information about making memories.



Philip Hardman/Marie Curie

Section 6: Benefits and financial support

Benefits

Benefits can change regularly, including what's available and who's eligible. This booklet was accurate at the time of publishing in March 2023. For up-to-date benefits information, visit **mariecurie.org.uk/benefits** or call the free Marie Curie Support Line on **0800 090 2309***.

When you're ill, you, and the people that care for you, may need extra help with finances. It's important to speak to a benefits adviser who will be able to help you understand your options. See pages 109–110 for where to get benefits advice.

▶ You can check which benefits you may be able to claim by using our free Benefits Calculator at **mariecurie.entitledto.co.uk**

Special Rules for people living with a terminal illness

If you're living with a terminal illness and looking into benefits, you might have heard of the Special Rules. The Special Rules might mean you do not need medical assessments, your claim could be fast-tracked, and it could be paid at a higher rate. What the Special Rules are, the criteria you need to meet, and the form you need, varies between benefits.

Visit **mariecurie.org.uk/specialrules** or call the free Marie Curie Support Line on **0800 090 2309*** for more information.

Benefits if you're living with a terminal illness

In this section, we give an overview of the main benefits you may be eligible for. Find out more about these benefits, including the exact criteria you need to meet and how to apply, by visiting **mariecurie.org.uk/benefits** or calling the free Marie Curie Support Line on **0800 090 2309***.

Employment and Support Allowance (ESA)

If you have a health condition or a disability, including a terminal illness, Employment and Support Allowance (ESA) can help you:

- get money if you cannot work or your ability to work is limited
- get personalised support to help you get back into work if you can.

In this booklet, we only talk about New Style ESA. For information about the old types of ESA, visit **mariecurie.org.uk/esa** or talk to a benefits adviser (see pages 109–110 for contact details).

New Style ESA is not means-tested. This means whether you can get it, and how much you get, is not affected by your income, savings, or investments. But it may be affected by certain pension payments.

You **may** be able to claim New Style ESA if all the following apply:

- You're aged 16 or over, and are under State Pension age.
- You have an illness or disability that affects how much you can work.
- You have worked as an employee or have been self-employed.
- You meet the National Insurance conditions.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) can help with extra costs if you have a long-term illness or disability. It is not means-tested. This means whether you can get it and how much you get, is not affected by your income, savings and investments.

If you live in Scotland, you will need to apply for Adult Disability Payment instead (see page 92).

You **may** be able to claim PIP if all the following apply:

- You're aged 16 or over, and you usually have to be under State Pension age.
- You have a terminal illness, disability, or a long-term physical or mental health condition.
- Your illness or disability has made daily living or getting around difficult.

You can only get PIP for needs that start before you reach State Pension age. The rules around this can be complicated. See pages 109–110 for who to contact for more information about this.

Attendance Allowance

Attendance Allowance can help with the extra costs of your illness or disability if you need looking after and you're State Pension age or older.

It is not means-tested. This means whether you can get it and how much you get, is not affected by your income, savings, or investments.

You **may** be able to claim Attendance Allowance if all the following apply:

- You're State Pension age or older.
- You have a terminal illness or a physical and/or mental disability (including learning difficulties).
- You need help caring for yourself, or need someone to supervise you.
- You do not have to currently be getting help, to be eligible for Attendance Allowance.

Universal Credit

Universal Credit can help with living costs if you're on a low income. You can claim if you're in work, looking for work, or unable to work. You could get extra amounts if you have a partner, children, or both. Universal Credit may also include extra amounts if you're unable to work because:

- you have a terminal illness
- you have a disability or long-term condition
- you're a carer.

Universal Credit is means-tested. This means how much you're entitled to depends on your circumstances, and the amount of income, savings and investments you have.

You **may** be able to claim Universal Credit if all the following apply:

- You live in the UK.
- You're aged 18 or over (there are some exceptions if you're 16 or 17).
- You are under State Pension age. If you have a partner, one of you must be under State Pension age.
- You (and your partner, if you have one) have £16,000 or less in money, savings and investments between you.

You cannot get Universal Credit if you and/or your partner have over £16,000 in money, savings and investments. Different rules may apply if you are transferring to Universal Credit from Tax Credits, under **managed migration**.

Managed migration is a process where people are moved from legacy benefits (for example Child Tax Credits and Working Tax Credits) to Universal Credit.

Adult Disability Payment (ADP)

Adult Disability Payment (ADP) is a benefit in Scotland for people with a terminal illness, health condition, or a disability. It has replaced PIP in Scotland.

ADP is not means-tested. This means whether you can get it and how much you get, is not affected by your income, savings, or investments.

You **may** be able to claim ADP if both the following apply:

- You're aged 16 or over, and are under State Pension age.
- You have a terminal illness, a physical or mental health condition, or a disability.

Disability Living Allowance (DLA)

You can no longer apply for Disability Living Allowance (DLA) if you're aged 16 or over. In England, Wales and Northern Ireland, DLA for adults has been replaced by Personal Independence Payment (PIP). In Scotland, DLA for adults has been replaced by Adult Disability Payment.

If you were born on or before 8 April 1948, you'll continue to get DLA as long as you're eligible for it.

Benefits for carers

Carer's Allowance

Carer's Allowance is a benefit for carers. It is not means-tested. This means how much someone gets is not affected by their income, savings, or investments. But they do have to be earning below a certain amount to get it.

▶ If your carer gets Carer's Allowance, it could affect some of your benefits. So it's a good idea to speak about this together, and get expert advice (see pages 109–110 for who to contact).

Someone **may** be able to claim Carer's Allowance if:

- they spend at least 35 hours a week caring for someone
- the person they care for gets certain benefits
- they're aged 16 or over
- they earn under a certain amount, if they work.

The Scottish Government plan to replace Carer's Allowance with a benefit called Carer Support Payment. For the latest information visit **mariecurie.org.uk/benefits** or call the free Marie Curie Support Line on **0800 090 2309***.

Other support for carers

- Carer's Allowance Supplement (Scotland only) – an extra payment on top of Carer's Allowance for people who live in Scotland. The Scottish Government plan to replace this with a benefit called Carer Support Payment.
- Carer Premium/Carer Addition – these are the same thing. The Carer Premium is an extra amount added to certain benefits if someone is a carer. It's called the Carer Addition when it's added to Pension Credit.
- Carer Element – an extra amount added to someone's Universal Credit if they're a carer. If your carer gets this, it could affect some of your benefits. Make sure you get expert advice (see pages 109–110).
- Carer's Credit – this is a National Insurance credit, not a payment. It helps protect someone's State Pension if they cannot work because they're caring for someone.

Certain conditions need to be met for someone to get any of these payments.

▶ For the latest information about financial support for carers, visit **mariecurie.org.uk/benefits** or call the free Marie Curie Support Line on **0800 090 2309***.

Other financial help

As well as benefits, there are different ways you may be able to get help with certain costs.

Grants

Grants are sums of money you do not have to pay back. There are grants available for specific conditions, holidays, unpaid carers, household items and more.

Some grants are counted as income and may affect your benefits, if you claim any. If you have any questions, it might help to speak to a benefits adviser (see pages 109–110).

Where to look for grants:

- Search online: try **turn2us.org.uk** and **disability-grants.org**.
- Ask your local council if they offer any grants or if there's any support available from the government.
- If you need to make changes to your home, see if you could get a Disabled Facilities Grant. See page 49 for more information.

For more information about grants, visit **mariecurie.org.uk/grants** or call the free Marie Curie Support Line on **0800 090 2309***.

Help with your energy bills

If you're living with a terminal illness, you might be able to get help with your energy bills. If someone cares for you, they might be able to get help too.

Help from the government

- Winter Fuel Payment – a tax-free amount paid once a year, and how much you get depends on your circumstances. You have to be over a certain age to get it.
- Cold Weather Payment – tax-free payments for when the weather drops below a certain temperature. You usually need to be claiming certain benefits to get it. This is not available in Scotland, where they have the Winter Heating Payment instead.
- Winter Heating Payment – for people who live in Scotland only. A tax-free amount paid once a year, and it does not depend on the temperature. You usually need to be claiming certain benefits to get it.
- Warm Home Discount – a government-backed scheme where some energy suppliers give you a one-off discount on your energy bill (the money is not paid to you). You usually need to be claiming certain benefits to get it.

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Other help with energy bills

There are other ways you might be able to get help with your energy bills, energy efficiency (using less energy) and your energy supply:

- Energy grants – check your government's website to see what is available in your area, such as financial support and energy saving grants.
- Fuel vouchers – these are normally for people who cannot afford to top up their prepayment meter. Contact your local council to see if they can help you get a fuel voucher.
- Ask your local council if they have a welfare assistance or Household Support Fund scheme – these could help with essential costs like energy bills.
- Electricity refund if you use an oxygen concentrator – contact the company that provides your oxygen concentrator for more information.
- The Priority Services Register – a free support service offered by energy and water suppliers. You could get extra help like priority support in an emergency. Contact your supplier directly for more information.

For more information about help with energy bills, visit **mariecurie.org.uk/energy-bills** or call the free Marie Curie Support Line on **0800 090 2309***.

Help with transport costs

You may be able to get help with the costs of getting around if you have a terminal illness. If there's someone caring for you, they might be able to get help too. Here are some of the ways you could get help:

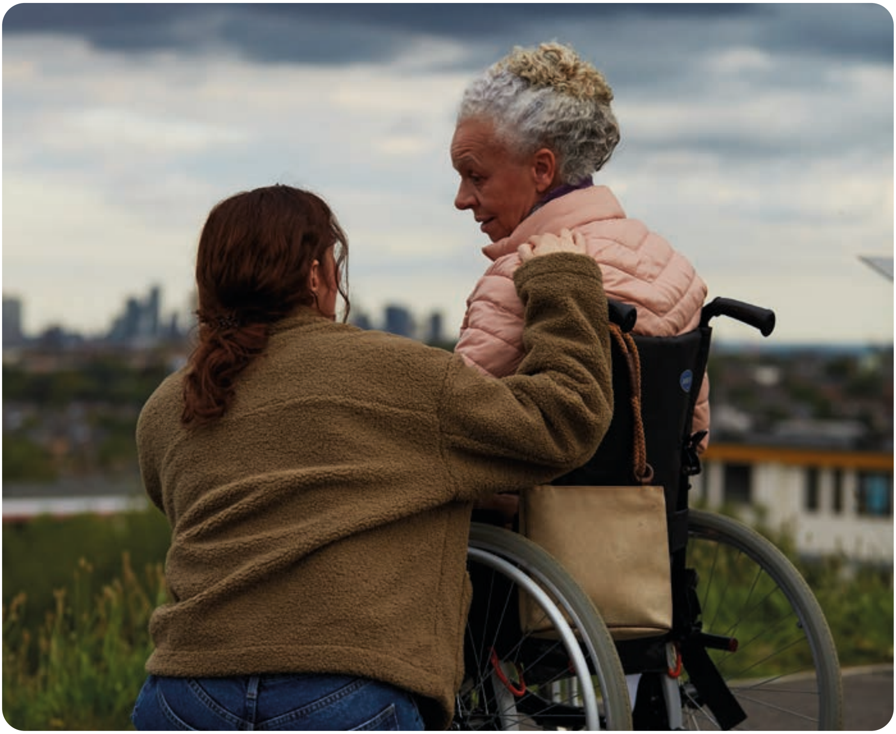
- Patient transport services (PTS) – free transport to and from hospital, for people with specific needs. Speak to your GP to see if you can use PTS.
- You may be able to claim a refund for all, or part of, the cost of travelling to hospital. Ask at the hospital about how to claim.
- Free or discounted NHS hospital parking – check your hospital's website to see who gets free or discounted parking.
- Free or discounted public transport – people with a disability and carers may be able to get travel passes.
- Blue Badge Scheme – having a Blue Badge means you can park your car nearer to where you're visiting. The cost depends on where you live.
- Motability Scheme – people with a disability that claim certain benefits can lease a car, adapted vehicle, powered wheelchair, or mobility scooter.
- Free or reduced vehicle tax.

What you can get depends on where you live, and if you're eligible. Visit **mariecurie.org.uk/benefits** or call the free Marie Curie Support Line on **0800 090 2309*** for more information.

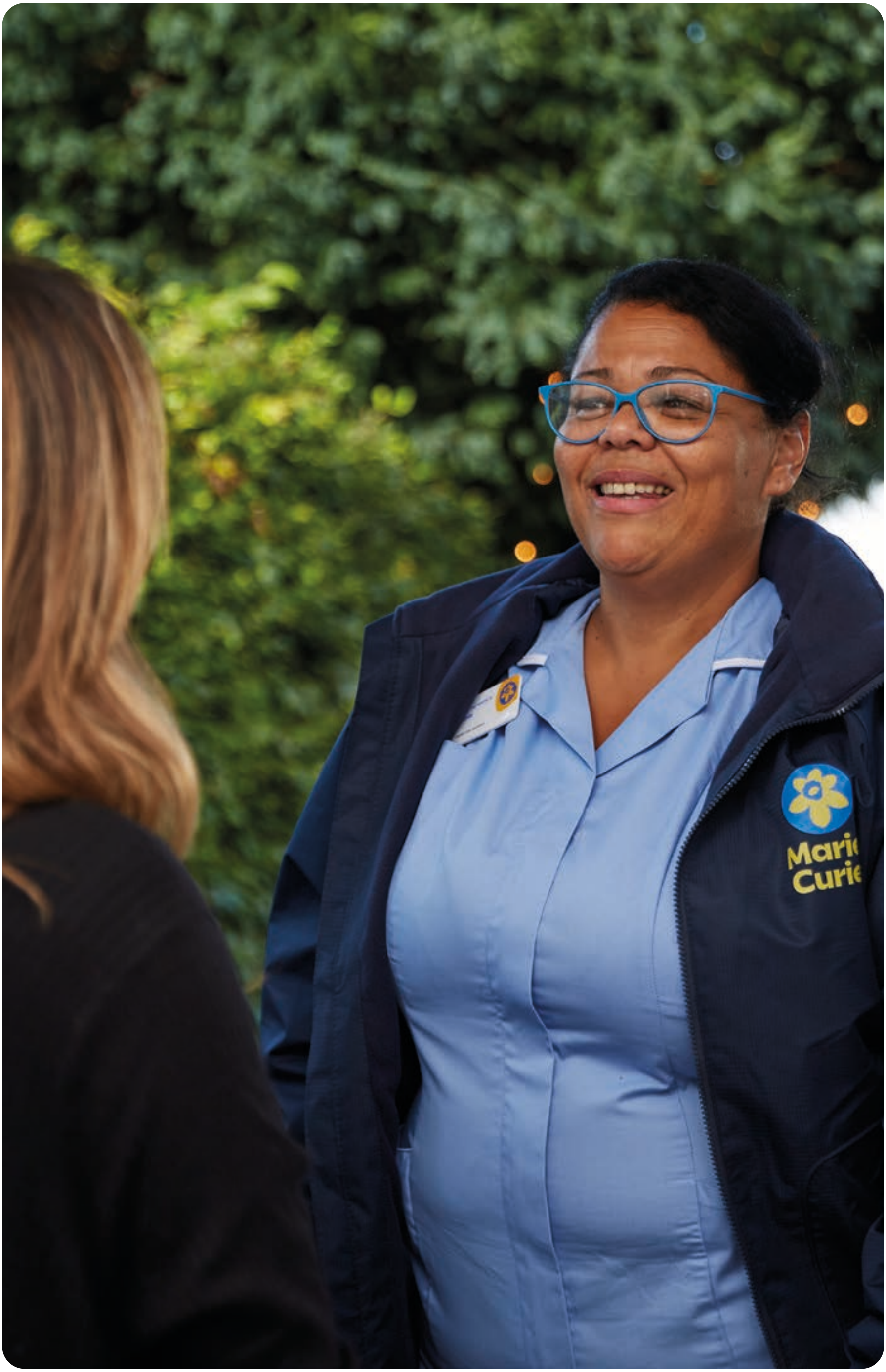
Help with the costs of prescriptions, wigs, dental and eye care

If you're living with a terminal illness, you might be able to get help with the costs of prescriptions, dental care, eye care, and wigs. You could also get some of these for free. What you can get normally depends on where you live, if you meet certain criteria, or both.

Visit **mariecurie.org.uk/benefits** or call the free Marie Curie Support Line on **0800 090 2309*** for more information.



Philip Hardman/Marie Curie



Philip Hardman/Marie Curie

Section 7: Organisations that can help

How Marie Curie can help

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

Marie Curie Support Line

0800 090 2309*

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

Marie Curie Companions

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

Marie Curie Telephone Bereavement Service

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

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Marie Curie Online Community

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

Marie Curie Hospice care where it's needed

Our hospices

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

Hospice care at home

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

Looking for more information?

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

Useful organisations

Health and care information

British Association of Counselling and Psychotherapy (BACP)

01455 883300
bacp.co.uk/therapists
Provides an online directory of qualified therapists working across the UK.

Care Information Scotland

0800 011 3200
careinfoscotland.scot
A phone, webchat and website service providing information about care services for people living in Scotland.

Hospice UK

020 7520 8200
hospiceuk.org
Their website has a Hospice Finder to show you hospices near you. They also have information for people at the end of life and their carers.

Macmillan Cancer Support

0808 808 00 00
macmillan.org.uk
Provides practical, medical and financial support for people affected by cancer.

Mind

0300 123 3393
mind.org.uk
Provides information and support for a range of mental health problems.

Royal College of Occupational Therapists

020 3141 4600
rcot.co.uk
Provides an online directory of professionally qualified occupational therapists in the UK.

Emotional support and befriending services

Age UK

England: **0800 678 1602**
Scotland: **0800 12 44 222**
Wales: **029 2043 1555**
Northern Ireland: **0808 808 7575**
ageuk.org.uk
The Age UK network includes Age Scotland, Age Cymru and Age NI, and more than 125 local Age UKs throughout England. It has a telephone friendship service, and many local Age UKs have face-to-face befriending services.

Befriending Networks

0131 261 8799
befriending.co.uk
Has a Befriending Directory for befriending services across the UK.

Breathing Space (Scotland)

0800 83 85 87
breathingspace.scot
A free, confidential, phone and web chat service for anyone in Scotland over the age of 16 experiencing low mood, depression or anxiety.

Re-engage

0800 716543
reengage.org.uk
Re-engage runs group and one-to-one social activities to help older people connect with others.

Lifeline (Northern Ireland)

0808 808 800
lifelinehelpline.info
Northern Ireland's free crisis response helpline for people experiencing distress or despair. Available 24 hours a day, 7 days a week, every day of the year.

Relate

0300 003 0396
relate.org.uk
Provides different types of counselling for people in England, Wales and Northern Ireland. The website features a search for counselling in your area.

Samaritans

116 123
samaritans.org
A safe place for you to talk, any time you like, in your own way – about whatever you're going through.

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The Silver Line

0800 470 8090
thesilverline.org.uk
A free, confidential telephone service just for older people. Provides friendship, conversation and support 24 hours a day, 7 days a week.

Home adaptations and equipment

British Red Cross

0344 871 11 11
redcross.org.uk
Loans wheelchairs and toilet aids to people around the UK.

Care and Repair Scotland

0141 221 9879
careandrepairscotland.co.uk
Offers independent advice and assistance to help people in Scotland repair, improve or adapt their homes.

Care & Repair Cymru (Wales)

0300 111 3333
careandrepair.org.uk
Helps people in Wales with home repairs, adaptations, disability support, building advice and more.

Fold Housing Trust (Staying Put Department)

028 9042 8314
E-mail: **stayingput@foldgroup.co.uk** or
info@foldgroup.co.uk
Offers elderly and disabled people practical assistance and support to repair, adapt or improve homes in all other areas of Northern Ireland that are not covered by Gable.

Foundations

0300 124 0315

foundations.uk.com

Provides a directory of local Home Improvement Agencies in England, and a website to check how well your home meets your needs.

GABLE (A Shelter Northern Ireland project)

028 7188 2147

shelterni.org/gable

Helps older and disabled people in certain areas of Northern Ireland to them maintain their independence and live more safely and securely in their own homes.

Living Made Easy

0300 999 0004

livingmadeeasy.org.uk

Provides free and impartial advice and information on solutions, gadgets, adaptations and aids to make life easier. It has an online guide called AskSARA which can help guide you to the right sort of products for your needs.

ShopMobility UK

shopmobilityuk.org

Hires out mobility equipment to the public – mainly manual wheelchairs, powerchairs and mobility scooters. These are low cost or sometimes free. Find the phone number for your local centre on the website.

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Benefits and financial support

Advice NI

0800 915 4604
adviceni.net
Delivers a range of advice services to the public including benefits, personal and business Debt, EU Settlement Scheme, Tax Credits and other HMRC services.

Citizens Advice

England: **0800 144 8848**
Wales: **0800 702 2020**
Scotland: **0800 028 1456**
citizensadvice.org.uk
Provides confidential advice online, over the phone, and in person, for free. Advisers can help with benefits, employment, debt, consumer and legal issues, family and housing.

Disability Grants

disability-grants.org
Provides information about lots of different types of grants. Search for grants in your area, for your condition, and more.

GOV.UK

GOV.UK
Provides a directory of government benefits in England, Wales and Scotland. Some local differences may apply.

Make the Call Service (Northern Ireland)

0800 232 1271

nidirect.gov.uk/contacts/make-call-service

Speak to a benefits adviser to make sure you're getting all the benefits, services and supports you're entitled to.

mygov.scot

mygov.scot

Provides information on benefits, funds and grants in Scotland.

nidirect.gov.uk

nidirect.gov.uk

Provides online information about benefits, financial support, taxes and debt in Northern Ireland.

Pension Wise

0800 011 3797

moneyhelper.org.uk

Pension Wise is a service from MoneyHelper, backed by government. They offer free, impartial guidance to over 50s. They can explain the options to take money from your pension pots.

Turn2us

turn2us.org.uk

Turn2us has a search function to find grants, and benefits advisers in your area. Also provides people with financial support and information on benefits and grants.

Legal support

Equality Advisory & Support Service

0808 800 0082 (Textphone: **0808 800 0084**)
equalityadvisoryservice.com
Supports people with equality and human rights issues in England, Wales and Scotland.

Equality Commission for Northern Ireland

028 90 500 600
equalityni.org
Supports people with equality and human rights issues in Northern Ireland.

Law Society of Scotland

0131 226 7411 (Textphone: **0131 476 8359**)
lawscot.org.uk
Provides an online search tool to find a solicitor in your area.

The Law Society (England and Wales)

020 7320 5650
lawsociety.org.uk
Provides an online search tool to find a solicitor in your area.

The Law Society of Northern Ireland

028 9023 1614
lawsoc-ni.org
Provides an online search tool to find a solicitor in your area.

Support for carers

Carers Trust

England: **0300 772 9600**
Wales: **0300 772 9702**
Scotland: **0300 772 7701**
carers.org
Provides help and information for carers on a range of issues including benefits, health and wellbeing. Has a network of partners throughout some areas of the UK.

Carers UK

0808 808 7777
carersuk.org
Provides information, advice and support to cares, and helps carers connect with each other.

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About this information

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

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

Notice

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

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Did you find this information useful?

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

Your notes

Your notes

Your notes

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Marie Curie

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

0800 090 2309*

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

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

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

We can't do it without you

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To donate, visit **mariecurie.org.uk/donate**

Trusted Information Creator
Patient Information Forum

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