

Living with a terminal illness

Support for you and those close to you



**Marie
Curie**

Care and support
through terminal illness

Introduction

We know that things can change quickly when you're ill and you can find yourself with a lot 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 gives information about how to live well and get the most from your time. It's divided into short chapters so you can read through it at your own pace.

If you don't feel ready to read this information yet, you might decide to come back to it another time. You can also ask someone to look at it with you, like a nurse, so you have their support.

The information here may also help your family, friends and carers to understand how things may change and how they can help. For further information and support, call the Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk/help**

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Layton Thompson/Marie Curie

Section 1: Coping with change and getting support

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Coping with change and uncertainty

Everyone responds in their own way when they're told they have a terminal illness. Most people tell us they initially feel shock and disbelief, even if they thought they might hear this news.

After the initial shock

Over the next few hours and days, this initial shock and disbelief may be replaced by powerful and overwhelming emotions. These may include:

- denial
- anger
- numbness
- fear
- sadness
- loss of control
- frustration
- guilt
- acceptance

All of these feelings are normal and most people will experience some or all of them. As time passes, people generally find that feelings of distress becomes less intense and frequent.

Coping with your feelings

Many people find it helpful to talk to those they love and trust. It may also help your family and friends to understand more about your situation and how they can support you. See section 3 on page 27 for more on coping with your feelings.

If talking to family and friends is too difficult, or you don't have people you can turn to, you might want to talk to someone who is

removed from your situation. Your doctor or nurse can help you find a counsellor or support service in your area.

Many specialist charities offer support through helplines, local groups and online communities. You can call the Marie Curie Support Line on **0800 090 2309***, or visit our online community at **community.mariecurie.org.uk**

Coping with uncertainty

Having a terminal illness is likely to make the future seem uncertain. You may have questions that currently have no definite answers. You might be wondering how your health will change, the effect your illness will have on your independence, relationships and working life, and exactly how much time you have left (the prognosis).

Not knowing what is going to happen can feel overwhelming and upsetting. Again, it may help to talk to family and friends about how you're feeling. Or you may prefer to speak to someone who is going through a similar experience about how they're coping with uncertainty.

Section 3 of this booklet (page 27) has more on coping with your feelings, including help on how to share them with those close to you.

People who may be involved in your care

GP and primary healthcare team

When you're ill and living at home, your medical care is the responsibility of the primary care team. This traditionally includes your GP, practice nurses, district nurses and health visitors. They are usually based in a health centre or surgery.

GPs will work with other specialists (oncologists, neurologists, palliative care consultants) 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
- liaise with your district nurse regarding your care at home
- tell you about local hospices and help you arrange a visit



See page 31 for more on getting support. For help with talking to your doctor and preparing for appointments, visit **mariecurie.org.uk/talkingtoyourdoctor** or contact the Marie Curie Support Line on **0800 090 2309***.

District nurses

A district nurse organises and coordinates home care and can arrange for services to be provided if you're being cared for at home. These vary from area to area but can include Marie Curie Nurses, Macmillan nurses, social services, and sitters who can visit regularly and deliver prepared meals.



Kieran Dodds/Marie Curie

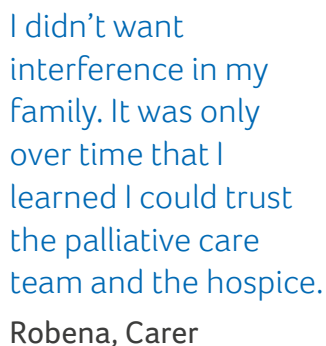
Social workers

If you have a social worker, they are likely to be part of your local social services department (social work department in Scotland, health and social care trust in Northern Ireland), which is responsible for providing non-medical support in your area.

If you want to remain at home, you, a member of your healthcare team, or a family member can request for a social worker to assess your needs and the needs of your carer. This will involve the social worker discussing your needs and any difficulties you're facing and may mean you get support from social services.

Specialist palliative care team

If you've been told you may not get better, you might also have heard about palliative care. Palliative care is for people living with a terminal illness where a cure is no longer possible. It's also for people who have a complex illness and need their symptoms controlled.



I didn't want interference in my family. It was only over time that I learned I could trust the palliative care team and the hospice.
Robena, Carer

If you're referred to a specialist palliative care team, they will assess your needs and those of your family. They will then provide the best possible care and support in your home, hospital or care home – wherever you've chosen to be cared for. You can find out more about your care options at mariecurie.org.uk/help

Macmillan nurses and other cancer specialists

Macmillan Cancer Support funds a wide range of professionals to support people affected by cancer. A Macmillan nurse can help with pain and symptom control and give you information about your treatment. They don't carry out routine nursing tasks such as personal hygiene, changing dressings and giving medicines. To get support from a Macmillan nurse, you'll need to be referred by your GP, your hospital consultant, a district nurse or a hospital ward sister.

If you still work

If you're employed or self-employed, it can be hard to know what to do next. For many people, an illness leads them to change their priorities in life, which often results in them leaving their job. You should do what feels right for you, taking into consideration your current health, condition and treatment options.

Talking to your employer

Although you may not think of yourself this way, the law states that people who are terminally ill are likely to be considered disabled. This means your employer can't sack you or find an excuse to make you redundant because of your illness. However your employer may be able to end your employment on grounds of capability because of health issues.

By law you don't have to tell your employer about your condition, but it usually makes sense to. This is so you can get the support you need and become fully protected by discrimination law if you're then unfairly treated as a result of something related to your disability. This protection is covered by the Equality Act 2010 in England, Scotland and Wales. In Northern Ireland, you're protected if you're directly discriminated against as a result of your illness as part of the Disability Discrimination Act 1995.

The law also means your employer must make reasonable adjustments to accommodate your ongoing needs at work, in consultation with you. These could include working from home or another location, flexible working hours, changing the duties of your role, or time off work for treatment. It's important that you think about your options at work and don't just resign.

If you need help with negotiating adjustments or contacting a solicitor, see pages 64–76 for the contact details of some helpful organisations.

Talking to your colleagues

Your employer shouldn't tell your colleagues about your illness without your permission. But if you decide your colleagues should be told, or choose to tell them yourself, you may find this helps. They'll be in a better position to offer you support and understand any changes to your role.

Some people prefer not to tell colleagues that they're ill. You may want to keep one area of your life as normal as possible to help you cope with your situation.

However, the effects of treatment, or the need to take time off, may mean you need to tell your colleagues eventually.

Stopping work for good

At some point, most people with a terminal illness will have to tell their employer they need to leave their job. 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're affected in this way, it may help to talk to someone about your feelings, such as a family member or friend. Or you might prefer to chat to someone removed from your situation, such as a counsellor. You can find out more about counselling on page 32.

Sick pay

If you work for an employer and you're too ill to work, you may be able to get sick pay. This could be either occupational sick pay, Statutory Sick Pay, or both. If your employer doesn't provide occupational sick pay, they must as a minimum pay you Statutory Sick Pay if you qualify.

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

Your pension

If you pay into a work pension scheme, or have in the past, you may be able to draw your pension early. Ask your human resources department if it has an ill-health retirement policy.



You can find out more about your pension entitlements and benefits on our website at **mariecurie.org.uk/help** or by calling the Marie Curie Support Line on **0800 090 2309***.

Enjoying yourself

You may start to think about what matters in your life and how you want to live in the future. Whether you choose to carry on as normal or break from your routine, it can help to talk through your wishes with family and health professionals.

Enjoying routines

You may want to maintain normality for as long as possible. You could continue to work, keep up with hobbies, or carry on with a daily or weekly routine.

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

Beginning a new chapter

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

This may 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
- creating memory boxes for family and friends that feature messages, photographs and special items
- writing letters or recording CDs or DVDs for family and friends to remember you by
- settling old disagreements so you feel more at peace

Again, whatever you decide is right for you, it can help to discuss what you want with family and friends, or your nurse or doctor. This can help them to understand your choices and provide the support you need to achieve the quality of life you want.

Julia said she'd love to see the sea again. We went along the seafront, visited an arcade, had some delicious fish and chips, and didn't stop laughing.

Lesley, Marie Curie Helper

Section 2:

Your family and friends

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Coping with the reactions of family and friends

You may find that family members and friends react to your illness differently. This may depend on the relationships you have with them. Some people may find it easy to talk about it because they've been through a lot with you already. Others may, at first, prefer to work through issues and problems alone.

If they become distant

Another reason why family or friends may not want to talk about your illness is because they don't want to face up to the reality of losing you. They might even change the subject, or be frightened about both of you getting upset.

If they become overbearing

In contrast, you may find that some people are ready to talk about your illness before you are. If this happens, don't be rushed into opening up before you're ready. Tell them you'll speak to them when you feel up to it, or ask someone you trust to do this for you.

Even when you're ready to talk, you might find the other person asks so many questions that it becomes overwhelming. People may also try to be too helpful, wanting to do every little thing for you. This is something you or someone you trust may need to manage in a polite but firm way.

Accept help if you need it

After hearing about your illness, family and friends may offer you lots of help with tasks like shopping, cleaning, cooking and childcare. If you'd like some help, try to make clear what support you need.

Over time, reactions of family and friends to your illness may become less intense. Letting others know when you're happy to talk and how you're feeling will help to make a potentially bumpy ride a lot smoother.

Support for family and friends

It can help to know that there's also support available for the people close to 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/help** for more information.

Changes in family dynamics

Your illness may change the relationships you have with your family members. Some will become stronger, while others may become strained. In most cases, the best way to solve any difficult changes is to talk about them.

Your partner

The stress of an uncertain future and the difficulties of your illness may put a strain on your relationship with your partner. This can happen when a partner starts to care for a loved one without having time to deal with the impact of the diagnosis. At first, they may find it difficult to face up to the reality of your illness.

If your relationship starts to change for the worse, try to talk about what you're feeling. If this proves too difficult, you may want to speak to family or friends separately. Sometimes talking to a counsellor can help, either separately or as a couple. You can also ask your doctor to refer you to a counsellor, or contact one of the organisations on pages 64–76.

It's important to acknowledge that the change in your relationship can also be positive. Your illness, and the difficulties you face, may draw you and your partner closer together. Some couples simply continue as they were before the illness.

Your children or grandchildren

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

They 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 what you're comfortable with them doing for you.

Younger children and teenagers can react in many different ways. They may become clingy or distant 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.



You can find more information, including a reading list, on talking to children on our website at **mariecurie.org.uk/supporting-children** or contact the Marie Curie Support Line on **0800 090 2309***.



Frank Harkin/Marie Curie

Your parents or siblings

The relationships that 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 is usually the best way to handle any changes to family dynamics.

Having difficult conversations

Not talking about your illness can lead to feelings of isolation and make problems worse. Many people also find that having difficult conversations with family and friends brings a sense of relief.



Layton Thompson/Marie Curie

Speak to family and friends individually

You'll have different relationships with your family and friends, so you may need to speak to each of them about your illness in different ways. Some may prefer to sit down with you for an in-depth, serious talk. Others may prefer it if you open up a conversation when they're more relaxed, perhaps when you're watching TV or cooking together.

With most difficult conversations, honesty is usually best. Don't be worried about showing your emotions. You may find the act of opening up liberating and soothing.

Speak to family and friends as a group

You may find it easier to talk to your family and friends in one large group or a number of smaller ones. This will save you repeating the same information, which can be emotionally draining.

It may also encourage family and friends to be more open about how they are feeling, because if one person speaks or asks you a question, more people are likely to follow.

Tell a trusted family member or friend to spread your news

You may want to talk to people about your illness but don't feel able to do this directly. In this case, ask a family member or close friend to be your 'spokesperson' who passes messages back and forth.

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

Ask a professional to be present

You may decide that the easiest way to speak with family and friends is to ask a professional involved in your care to talk for you. Otherwise you may decide that just having them there will give you more confidence to talk about your illness. You could also rehearse what to say with them beforehand.

Talk online

Another option you might want to explore is communication through social media, such as Facebook and Twitter. This can be an excellent way to send out short updates and talk about your situation from the comfort of your own home.

You may want to select who can and who can't read what you post to avoid a lot of people asking you questions or commenting. If you're not sure how to change the privacy settings on your social media accounts, ask a family member or friend for help.

You could create your own private website at CaringBridge (see page 70), a charity that sets up free personalised websites for people with serious medical conditions. You can then choose who gets your personal website address and password so they can read updates and send you messages of support.

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Feelings you may have

You're likely to feel many different emotions throughout your illness. These may change quickly, and at some points you may experience several feelings at once. However hard it might be, try not to push these emotions aside. If possible, speak to someone you trust about them or see pages 31–34 to explore other ways of coping with your feelings.

Denial

You may decide that the best way to cope with your situation is to deny it's happening. This won't necessarily be a conscious decision. It could just be that knowing and talking about your condition as little as possible is what works best for you right now.

If you feel like this, it's OK to be firm with the people around you who want to talk. However, if denial starts to get in the way of your treatment or makes your situation worse, you may need to seek help from a psychologist or counsellor.

Anger

At some point, you're likely to feel anger and resentment. This is a normal and natural reaction. You may want to shout, "Why me?", "Why this illness?". This could happen if your symptoms weren't taken seriously, or you feel the most appropriate investigations or treatments weren't carried out.

You might feel annoyed about how your condition has affected your life and relationships or caused you to cancel long-term plans. If you're distressed by the anger you're feeling, there are people you can talk to, including trained advisers on the Marie Curie Support Line on **0800 090 2309***.

Guilt

Many people with a terminal illness experience guilt. Sometimes this is because they blame their own lifestyle choices for their illness, or worry they could have noticed their symptoms sooner. Some people feel that they're being a burden, or are in some way responsible for their treatment not working.

Try to remember that worrying is unlikely to make you feel better. If possible, look ahead and live your life the best you can.

Fear

It's natural to feel frightened and anxious. Most of all, you're likely to be scared of dying or being in pain. You might be fearful of how your illness will affect you physically and emotionally. You may also be concerned about your treatment and any side effects.

Many people also become fearful about the effect their illness and death will have on those around them. However you feel, know that you're not alone. It's also worth knowing that people's fears are often different from the reality. As well as your family and friends, there are professionals, including your doctor and nurses, who can reassure you and help you manage your fear.

Depression

Depression is more than just feeling sad. It's an illness that can last for weeks and affect your ability to cope with eating, sleeping, hygiene, social activities and work. You can learn more about depression on pages 41–45.



If you're affected by any of these feelings or someone close to you is, you can find more information at **mariecurie.org.uk/feelings** or by calling the Marie Curie Support Line on **0800 090 2309***.

Feeling alone

Loneliness is a common feeling for people who are ill. This may be down to feeling different, not having as much social contact with people or because of changes in appearance due to illness or treatment.

Often, telling family and friends how you're feeling will help. Sometimes, however, you can feel that even loved ones won't understand what you're going through. This may be the time to speak to someone in your healthcare team or a counsellor. You could also join a support group or online community like the Marie Curie Community at **community.mariecurie.org.uk** to speak with people who have been through a similar experience.

Frustration

Accepting that your life and capabilities have changed can be difficult and frustrating. This feeling may be increased by uncertainty around what will happen, which makes 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. For many people, it can help to take small steps to regain some control over your life.

Acceptance

Not all people are able to accept the idea of dying. Reaching this stage takes time and can involve long discussions with family, friends or 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, more active life.

Looking for meaning

During your illness, you may start to think about life and its purpose. This could involve remembering experiences you've had and important events and relationships.

A review of your life so far may also remind you of conversations and activities that need to take place before death, and conflicts you'd like to resolve.

Thinking about your life can lead to feelings of guilt, anxiety and depression, but it can also be a positive experience which gives you a sense of accomplishment.

Getting support

You may feel like there's nothing that can be done to stop you feeling the way you do but there are many ways of helping you overcome difficult emotions. If you don't feel ready for any of these things now, it's worth trying them when you feel up to it.

Talk to family and friends

Speaking to someone you trust and feel comfortable with, such as a family member or friend, may be the best way to cope with your feelings. However, it's good to be aware that people close to you may have different reactions to your illness.

Take care of yourself

Eating a healthy, well-balanced diet may help you cope with depression and boost your energy levels. Avoid a lot of alcohol and recreational drugs, as they can make depressed feelings worse. Doing activities you enjoy may also help to lift your mood.

Try not to be frustrated with yourself if you find it difficult to do things. Feeling better takes time and happens gradually. Set small goals and build up to them. Some days, just getting out of the house can be an achievement. See section 4 of this booklet (page 35) for more information on looking after your wellbeing.

Talk to your healthcare team

If a Marie Curie Nurse is caring for you, don't hesitate to discuss your worries and feelings with them. You might also be able to get support from a local Marie Curie Hospice. Contact the Marie Curie Support Line on **0800 090 2309*** or visit **mariecurie.org.uk** to find out what we can offer you.

Clinical nurse specialists will also be able to help, and your doctor should be able to direct you to other sources of support. They may also prescribe you medication if you're feeling depressed.

Talk to a counsellor

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

You can find details of counsellors in your area by visiting the It's good to talk website (see page 70). This site also offers lots of helpful information about what a counselling session involves.

Layton Thompson/Marie Curie



Join a support group

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

Your district nurse, Marie Curie Nurse, or another member of your healthcare team should be able to tell about support groups in your area. Many organisations linked to a specific condition, like cancer charities, have details of support groups on their websites. See pages 64-76 for their contact details. If you're in England or Wales, you can also visit the **GOV.uk** website and search for community groups.

Chat online

Many organisations linked to a specific condition run online communities. These are websites where you can message and chat to other people. People with a serious or terminal illness often form strong relationships online in this way. It can help them cope with their emotions. The Marie Curie Community at **community.mariecurie.org.uk** can be a good place to share your experiences or get support from people who understand your feelings.

Learn about other people's experiences

Simply reading 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.

Many people have also written books and online diaries about terminal illness. Be aware that the way someone else copes may not necessarily work for you.

Think about keeping a journal of your thoughts and feelings. You might also want to share it online.

Religious and spiritual support

Some people find that having a belief system or philosophy makes it easier for them to cope with their emotions. Other people start to question their beliefs when they're ill, wondering what the meaning of life is.

Whatever you're feeling at the moment, you may find it helpful to speak to a hospital or hospice chaplain or religious leader to discuss your thoughts. Your nurse should also be able to help you get the right support so your religious or spiritual needs are met.

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Looking after your wellbeing

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Keeping active

Keeping active can help to reduce some of the effects of being ill, such as stress, pain and fatigue. Even gentle movement can improve your mood and quality of life, and make you feel more in control.

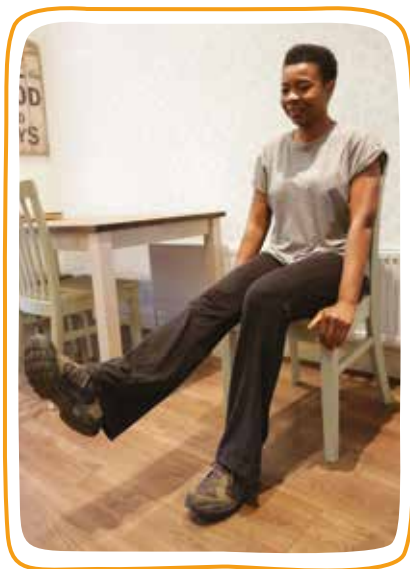
Why we need exercise

We all need exercise for our bodies to function well. It helps us feel well physically and mentally. It can help you physically by:

- giving you energy
- relieving breathlessness
- strengthening your body, by improving muscle tone and joint suppleness
- improving your circulation and blood pressure

And it can benefit your mind by:

- helping you to relax
- helping you sleep better
- improving your overall sense of wellbeing
- improving your concentration and making you more alert



Layton Thompson/Marie Curie



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

Eating well

Illness, treatments and medication might have caused you to lose some or all of your appetite. Your tastes and preferences may also be affected. Don't worry, this is common.

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.

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

The following suggestions may help:

- Eating small portions regularly is fine, and might be more appealing.
- Nibble on snacks, like almonds or pieces of fruit.
- Eat something for breakfast when you wake up in the morning – it's the time of day when appetite is at its best.
- It might be easier for you to eat sitting upright.
- A small glass of sherry or brandy half an hour before a meal or a glass of wine may help with appetite and digestion, but ask your doctor first.

More ideas

- Tastes can change, so choose the foods that appeal to you most.
- Try not to add salt or sugar, as many foods contain them anyway.
- Try to drink plenty of water.

Nausea

If the smell of hot food makes you feel sick, try eating cold meals, consisting of food that doesn't need to be cooked. Cold meats could be a good option and raw food, like fruits, vegetables, nuts, seeds and some dairy products, provide a lot of nutrition.

Boiled sweets can soothe a dry mouth and relieve nausea.

Fizzy drinks, like sparkling mineral water or lemonade, can also help.

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

Liquid and soft food

You may find it easier to manage liquid foods like:

- soup
- vegetable and fruit smoothies
- food supplements like Ensure, Fortisip or Complan
- flavoured milkshakes

Or soft foods like:

- mashed potato
- risotto
- jelly
- ice-cream

Often these foods can be eaten when other types of food aren't as easy or appealing to eat. Jelly beans can also be good if you're missing certain flavours, although they're not very nutritious.

Practical issues

You might need some assistance during mealtimes:

- If sitting up is difficult try using a few extra pillows to get you in the right position for eating.
- A table across the bed can also be helpful.
- Get someone to help you if you're finding it hard or tiring to eat your food.
- Meals can take a long time to eat, so allow for this.

Getting advice

If you carry on having problems with your appetite or you find you're losing weight, contact your nurse or doctor. They can also advise and treat you if nausea is stopping you from eating. Talk to your doctor before making any major changes to your diet.

Controlling pain

You and your carer may be worried about pain. Everyone's experience of pain is different, and pain can vary according to the illness, the individual and the treatment. The main thing to know is that most pain can be controlled, and sometimes people experience none at all.

What causes pain?

Pain can affect the muscles, bones, organs, skin, joints and tissues of the body. It can be caused by an illness, an operation or treatment. It can also occur because of a condition, like arthritis. When the nerve endings in the body are damaged, for example by a disease, they send a message to the brain, which makes someone feel pain or discomfort.

Pain management

Pain management is about controlling pain so that the person isn't suffering unnecessarily. However, managing pain doesn't always mean that someone will be completely free from pain. And some people find they prefer to have some discomfort rather than have high doses of painkillers, in case they become sleepy and unable to communicate. There is a range of different medicines that may help control someone's pain. These may be aimed at relieving pain or to help ease other symptoms.

Getting help

Good pain management will involve health professionals, such as doctors, nurses and physiotherapists, working with you to find the best way to help you.

This may involve you checking your own pain regularly, because you will know best what your pain feels like, how it's affecting your quality of life, and how much pain relief you need. You can talk to your doctor or nurse about the options for pain relief.

You should be able to decide on the level and type of pain management you need or want. Sometimes people prefer not to take too many drugs, and may want to try other methods of pain relief.

Your local pharmacist can give you information about when and how to take any medication you've been prescribed. They may also deliver medication to your home.



We have more information about pain relief and side effects in our booklet *Controlling pain* and on our website at **mariecurie.org.uk/pain** You can also call the Marie Curie Support Line on **0800 090 2309***.

Spiritual and emotional pain

Emotional and spiritual pain can happen when you lose a sense of meaning or purpose in life and have unmet emotional or spiritual needs. These can include the need to address the loss of meaning or purpose, and deal with regrets or unresolved issues. This pain is usually caused by a major event which challenges your core values and beliefs about how things are supposed to be. Those values and beliefs don't have to be religious, although they can be.

Emotional and spiritual pain is not the same as depression, although the two can happen together. Doctors recognise that it can also make physical pain worse. This means that reducing spiritual and emotional pain may also help to reduce physical pain.



Visit our website at **mariecurie.org.uk/spiritualpain** for more information.

Depression and anxiety

When you're ill, you may try to appear cheerful in front of family members or friends, but you may feel very low or anxious.

How you cope with your illness may depend on the type of person you are. You may be told regularly to be positive, but this is often hard to do. If you're in denial about your illness, you may also be covering up feelings of depression, without realising it.

About depression

Most people feel low or sad some of the time. It's normal to have ups and downs. But when feelings like sadness and anxiety last for months without changing, it may be depression.

Causes of depression

Causes of depression can include living with uncertainty and fear about what the future holds. Anyone can get depression, but you're more likely to experience it if you have a previous history, or a family history, of it.

Symptoms of depression

Symptoms vary between people and may affect you emotionally and physically. These can include:

- sadness
- irritability
- feeling indecisive
- crying all the time
- a sense of helplessness
- feelings of hopelessness
- not wanting to see people
- lack of interest in anything
- not being able to concentrate
- feeling persistently low in your mood
- an inability to see the future positively
- tired and low in energy, moving more slowly
- feeling worthless or having low self esteem
- not being able to find pleasure or enjoyment in anything

Common symptoms of terminal illness, like loss of appetite, weight changes and not sleeping properly, can also be symptoms of depression.

Managing depression

Depression can get worse if you don't or can't acknowledge your feelings or talk about them. Try to tell your nurse or doctor. They can assess you and decide how to help.

Tackling other symptoms like pain may help reduce symptoms of depression. Getting enough support and adjusting your other treatments might also help, but always speak to your doctor before you make any changes to your medication.



Contact us on **0800 090 2309*** to order our *Controlling pain* leaflet or visit **mariecurie.org.uk/help** for more information.

About anxiety

Most of us feel anxious from time to time, but some people may often feel anxious and have difficulty managing these feelings. This can really affect quality of life and, for people with a terminal illness, anxiety can make other symptoms worse. If you're depressed it may be linked with anxiety.

Anxiety can be caused by several things, including uncertainty about the future, money worries or your medication.

Symptoms of anxiety

These may include:

- feeling on edge or apprehensive
- feeling restless or agitated
- finding it difficult to concentrate or sleep
- sweating
- a racing heart
- being unable to get rid of your worries
- feeling breathless
- loss of appetite

Managing anxiety

If you're finding it difficult to control your anxiety or worries, it's good to let your nurse or doctor know so they can find out more about your symptoms and how they can help you.

Treatment for depression and anxiety

If your depression or anxiety is left untreated symptoms can become worse and more difficult to treat. It's important to get help as early as possible. Treatment can really improve your quality of life.

It could include:

- exercise
- self-help techniques
- support groups
- medication, including anti-depressants
- complementary therapy, like acupuncture
- talking therapy, for example, cognitive behavioural therapy (CBT) or counselling
- non-drug therapies, like relaxation techniques and advice on how to manage sleep and anxiety

Getting help

You, and your family and close friends, can ask your doctor, district nurse or Marie Curie Nurse about the different types of counselling available and how to access it. Counselling is often free at hospices, hospitals or GP surgeries.

Free counselling services usually focus on cognitive behavioural therapy (CBT), a talking therapy that could help you to deal with any issues you're worried about. You may be referred to a mental health professional, like a psychologist or psychiatrist, for specialist help. Alternatively, ask your doctor about private counselling, or visit the It's good to talk website (see page 70) to find out more.

Helping yourself

There are some things you can do to help yourself. You could try things that you enjoy like listening to music, reading a book or starting a new hobby. You might also like to exercise (see page 36) or relax with complementary therapies like massage.

Complementary therapies

Complementary therapies are given alongside conventional medical treatment. These may help you to feel more relaxed or to sleep better. They can also be used to relieve pain and tension in the body.

Complementary therapies include:

- acupressure
- acupuncture
- aromatherapy
- art therapy
- hypnotherapy
- massage
- reflexology
- reiki
- relaxation
- shiatsu massage
- meditation
- yoga, t'ai chi and other exercise
- drama therapy
- music therapy

I've had massages at the hospice too. I've [also] got arthritis which makes it difficult to put my arms into my shirt sleeves and get dressed. But the massage has really helped.

Willie, who is living with terminal illness

Complementary therapies aren't designed to take the place of traditional care, but some of their benefits are now widely recognised.

Finding and paying for complementary therapy

Some complementary therapies are provided free of charge by the NHS, so speak to your doctor or nurse about what's available in your area. Your local hospice or a local support group may also offer free or reduced cost therapies. Marie Curie has nine hospices throughout the UK or you can search for a local hospice on the Hospices UK website at **hospiceuk.org**



Layton Thompson/Marie Curie

If you'd like to find a private therapist, the Complementary and Natural Healthcare Council has a directory of qualified therapists listed by area on its website (see page 65). Private therapists can be expensive, so it's worth checking the cost first.

Alternative therapies

Alternative therapies are different from complementary therapies. They are given instead of conventional treatment, not alongside it. Be very cautious of alternative therapists who claim that they can cure cancer and other illnesses. Genuine therapists are unlikely to make inappropriate claims about the benefits of their therapies.

Sexuality

When physical and emotional changes happen because of your illness, your sense of sexuality may also change. Many people feel a sense of contentment and wellbeing when they continue or restart a loving and close relationship.

When you're ill there are many factors that can prevent you from continuing your relationship as usual or change how you feel about your sexuality. You may feel differently about having a physical relationship with your partner.

If you're single or not in a long-term relationship, your illness or treatments might put you off starting a new relationship.

Health and treatments

Your illness, medical treatments for it and surroundings can affect your expression of your sexuality, or may make it difficult for you to continue a physical relationship with a partner. Some factors could include:

- tiredness and nausea
- body image and body confidence
- sexual performance
- treatments and side effects
- control of bodily functions
- being cared for in a hospital, hospice or care home where there may be less privacy

Getting information

Not talking about sexuality can lead to distress, feelings of isolation and a sense that your needs aren't valid. Intimacy concerns are relevant at every age, for any sexual orientation and at any stage in life.

Bring up the topic with healthcare professionals if you would like to talk about it and be given advice. Nurses may be able to encourage discussion and information sharing between you and your partner. Or you could ask to be referred to someone else if the professional you speak to doesn't have the right knowledge.

Talking to your partner about sex

For some people, it's unusual or difficult to talk about sexual relationships. Others may try to avoid bringing up the subject if they think it may cause an argument. But if you feel unable to have sex either physically or psychologically, it's better to talk to your partner so that they can understand how you're feeling. Try not to hide your feelings and worry about it alone.

Physical changes

As your illness progresses from early stages to treatment and post-treatment, your level of sexual interaction is likely to decrease and then may return to normal.

In the palliative or terminal stage of an illness, physical changes may have an effect. Psychological changes may too. You may stop having sex completely or you may find yourself becoming more sexually active. It depends on you and it's different for everyone.

Towards the end of life, a range of different needs may be experienced, including:

- pleasure
- grief
- love
- relaxation
- distraction
- painkilling
- affirmation
- anger

These needs can change the meaning and purpose of your physical and sexual relationship with your partner.

Your need for physical closeness, to touch and be touched, may become more important to you towards the end of life.

Emotional changes

Every relationship is unique, but you might find some of the experiences other people have had familiar. These include:

- Growing closer and stronger in your relationship, despite the emotional and physical impact of illness and treatments.
- Moving apart as a couple.
- Feeling closer and further apart in waves.
- Re-connecting emotionally as a couple.
- Having different reactions to changes in your sexual relationship.
- Enjoying a new level of intimacy through the intensity of the caring experience.

Relationship advice

Talking about sexual and intimate matters doesn't come easily to everyone so you might find it easier to speak to someone who you don't know.

You could try talking to your doctor or nurse, or ask them to recommend a counsellor, support group or workshop. Relate, a charity offering relationship support, may also be able to help. See page 71 for contact details.

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You may need more emotional and practical support when you're unwell. This could involve making changes to your home to get around better or staying in touch with those close to you. There are also benefits available to help with extra costs.

Getting equipment and adapting your home

Adapting your home or getting specialist living equipment can make life much easier. These can usually be provided fairly quickly and you may be able to get help with paying for them or get them on loan (see page 54).

Adaptations

Adaptations range from getting devices installed or fitted, such as an intercom, to having parts of your home modified to make you more comfortable. For example, if you're using a wheelchair, you may need to get doors widened or the bath adjusted. You may not always need to get adaptations made – certain pieces of equipment could make all the difference.

Equipment

Common pieces of equipment include:

- hot water bottle or wheat bag
- bath lift
- foam cushion (pressure relieving cushion)
- raised toilet seat
- alternating pressure mattress
- overbed table
- wheelchair
- crutches
- hospital style bed

Many of these can be bought from a household shop rather than through a specialist supplier. Some bigger pieces of equipment can be supplied through your GP or occupational therapist.

Getting help from an occupational therapist

Before you get any equipment or make adaptations to your home, you should be assessed by an occupational therapist to find out what you need. Some adaptations can be made without a referral or assessment from an occupational therapist. In some cases, a district nurse can also carry out an assessment.

Occupational therapists can visit you at home, at work or in hospital. During their visit, it's likely they'll want to see you doing the thing you're having difficulty with, so try to arrange this for a time of day when you have more energy.

The occupational therapist's involvement can form part of a **care and support needs assessment**. This is carried out by your local social services department and includes a discussion about the kinds of care tasks that you're able to carry out unassisted. You may then be eligible for financial assistance. See page 54 for more information.

You can find an occupational therapist through the NHS or your local social services department. In Northern Ireland, contact your local health and social care trust.

You can also access them privately. The British Association of Occupational Therapists has a searchable directory to find independent therapists in your area. See page 71 for contact details.

Trying out equipment before you buy

It's a good idea to try out all equipment before you buy it. If you're considering buying an expensive item, ask to use the equipment for a trial period in your own home or check if you can try the equipment in-store. If you would then like to buy it, you may want to get a care and support needs assessment (see page 56) to see if you're eligible for any financial help. Some suppliers also offer second-hand equipment at a cheaper price. Ask the installation team to show you how any equipment works.

If you're a tenant

You'll need to get your landlord's permission to make adaptations if you're a tenant, otherwise you may be breaking your tenancy agreement, which could lead to eviction.

Financial help

You may be able to get free equipment from your local social services department or on a long-term loan from the NHS. Social services may also give financial support for equipment and minor adaptations under £1,000 (£1,500 in Scotland), but what you get often depends on where you live.

You could also be entitled to financial help for larger and more expensive items, known as major adaptations. This is called a Disabled Facilities Grant.

The occupational therapist at the hospice adapted my house so I could go home. They put handrails in my home and lent me an electric chair with a reclining back that raises up and down, which helps me with my disability. This means I can be comfortable in my own home.

Willie, who is living with terminal illness

Contact your local social services department, which will arrange an assessment. A social worker, sometimes accompanied by an occupational therapist, will visit your home and assess your requirements. If you qualify for assistance then the social services department will help organise the adaptations to your home.



For more on finding equipment and making adaptations, see pages 71–73, visit **mariecurie.org.uk/help** or contact the Marie Curie Support Line on **0800 090 2309***.

Benefits and financial support

When you're ill, you may choose to stop working or become too unwell to work. You may also have to manage extra costs. Help is available from many sources, including the government, your local council, charities and grant giving trusts.

Benefits and entitlements

The benefits system can seem like a maze. There are many different types of benefit, paid for all sorts of reasons. It's worth checking if you can claim any benefits, tax credits or other financial help. It's also a good idea to regularly review your entitlements because you may be able to get more benefits if your circumstances change or if the rules change.

We've outlined some of the main benefits on the next few pages, but it's a good idea to speak to a benefits adviser who will be able to help you understand your options. The rules are complex and may differ depending on where you live. You can find a benefits adviser by contacting Citizens Advice, Macmillan Cancer Support or Carers UK (see pages 64–76 for contact details).

We also have more information about benefits and entitlements on our website at **maricurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309***.

Help from social services

If you need practical support, you may qualify for help from social services. Social care and support is available for people aged 18 or over who, because of their disability, have substantial need for support in doing everyday tasks like getting out of bed, getting dressed, cooking and eating a meal, help with seeing friends and family or help caring for others.

How to apply

You can start finding out what help you can get by asking your local council's social services department for a **care and support needs assessment** or a **carer's assessment** for your carer. If you live in Northern Ireland, contact your local health and social care trust and ask for an **assessment of need**. You and your carer are entitled to have an assessment and social services have a duty to carry these out.

Generally, social services can charge for care services. Some local authorities only charge for some services, for example, meals on wheels or home helps. If you live in Scotland, are aged 65 or over, and get personal care or personal support care at home, you should get this free of charge.

NHS continuing healthcare

NHS continuing healthcare is health and social care that you may be able to get free of charge from the NHS if you aren't in hospital but have complex ongoing care needs. It's sometimes called fully-funded care.

If your needs are urgent, you may be given continuing healthcare on a fast track. This means you don't have to do any of the assessments. Your needs are considered urgent if your life could be in danger if you don't get help quickly.

Continuing healthcare is for anyone in the UK who mainly has a healthcare need. This means that the care needed is more about medical care than social care. These needs can either be at home, in a hospice or in a care home. You can apply for continuing healthcare if you:

- have a complex medical condition
- need substantial and ongoing care

Continuing healthcare covers care home fees including: accommodation costs, healthcare costs and personal care costs. If you need care at home, it covers personal costs and healthcare costs. It might also cover the cost of healthcare assistants.

Personal care means anything relating to hygiene, food, emotional wellbeing, mobility or simple treatments like applying lotions or eye drops. Healthcare is any care that needs to be provided by a healthcare professional like a nurse or doctor.

How to apply

You'll need to arrange an initial assessment through:

- your district nurse, doctor or another healthcare professional
- your local council or health and social care trust in Northern Ireland
- a hospital social worker
- your Marie Curie Nurse or hospice staff

When you apply, it's a good idea to get support from someone who understands how the system currently works, as the rules change quite often. Citizens Advice (page 73) is a good place to start.



We have more detailed information about continuing healthcare at **mariecurie.org.uk/continuinghealthcare** or call the Marie Curie Support Line on **0800 090 2309***.

Benefits for people who are ill or disabled

Below are some of the main benefits for people who are ill or disabled. There are special rules for people who have a terminal illness, which mean that you may have your application fast-tracked and get the benefit at the highest rate if you qualify. Visit **mariecurie.org.uk/specialrules** or call the Marie Curie Support Line on **0800 090 2309*** for more information.

Attendance Allowance

This is a tax-free benefit for people aged 65 or over. It can help with the extra costs of a disability or health condition.

Personal Independence Payment

This is a tax-free benefit that helps with the extra costs of having a disability or health condition. It's for people aged 16–64. You may also qualify if you need help with personal care or getting around. It's a new benefit that's gradually replacing Disability Living Allowance for people of working age.

Disability Living Allowance

This is a tax-free benefit for people who have a physical or mental disability and need help with personal care or supervision to remain safe, or need help with getting around. It's similar to Personal Independence Payment and Attendance Allowance. You can no longer make a new claim for Disability Living Allowance unless you are under 16 years old, or you live in Northern Ireland.

Employment and Support Allowance

This is the main benefit for people whose ability to work is limited by ill health or disability. Employment and Support Allowance (ESA) is a complicated benefit, so it's a good idea to get help from a benefits adviser before you apply.

How to apply

Social security benefits are handled by the Department for Work and Pensions (England, Scotland and Wales) and the Social Security Agency (Northern Ireland). There are different branches depending on the benefit you're applying for. See pages 73–74 for contact details.



We have more information about getting help with financial matters on our website at **mariecurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309***.

Benefits for carers

If someone is caring for you, they may be able to claim Carer's Allowance, which is a weekly benefit for people who care for someone who has a health condition or disability. Carer's Credit may also be available to protect their State Pension if they're not working.

If you live alone

If you live alone, you may feel that it's more difficult for you to get the help and support that you need. Not having visits from friends or family could also make it harder for you to cope with your illness.

Isolation can cause stress, anxiety, and depression. It can also create practical problems like missing out on meals, not being able to wash regularly or do household jobs like cleaning. If you're feeling isolated, don't hesitate to speak to a healthcare professional, like your GP, district nurse or Marie Curie Nurse, who'll let you know what support is available in your area.

Keeping busy

Activities and befriending schemes can help you to feel less lonely and isolated. There are lots of things you can do, like reading, painting or gardening (if you're able to do some physical activity).

You can find out about activities in your area from your local council or **nidirect.gov.uk** in Northern Ireland.

Befriending schemes

A befriending scheme is a network of people, usually volunteers, who can provide regular companionship and conversation. Befriending schemes can help to restore an important sense of belonging and confidence, as well as easing loneliness and anxiety.

There are several free befriending schemes in the UK. Some involve personal visits, others a phone call. There are also e-befriending services – for communicating by email.

Marie Curie runs a free scheme, called Marie Curie Helper, where a trained volunteer can visit you at home for up to three hours each week. Volunteers can take you out on a shopping trip or for coffee, or take you to appointments. If you're not able to go out, they can simply visit you for a chat.

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

Layton Thompson/Marie Curie



Age UK (see page 69) runs a network of long-term befriending services, which work by matching up an older person with a befriender. It also runs a telephone befriending service if you have difficulty leaving the house.

Getting out of the house

Another way to feel less isolated is by joining a special interest group. There are plenty around, including walking, golf, or art and writing groups. They can also help you to meet people.

You can find local groups by contacting your local branch of Age UK (see page 69). Community centres often organise outings and events – search for your local community centre online and see what it has on.

Don't hesitate to ask for help finding a group to join. Your doctor or nurse may be able to make some suggestions. Remember that although the first group you go to might not suit you it could lead you to finding another group or organisation to try.

Home repairs

Care and Repair is an organisation that helps people in England, Scotland and Wales with DIY jobs around the home, and offers one-to-one befriending opportunities as part of its free service. See page 70 for contact details.

Carers and isolation

Isolation is also a problem for carers. Many carers feel alone and without support. The organisations on page 76 may be able to help further, or call the Marie Curie Support Line on **0800 090 2309***.

The Marie Curie Community is also a good place to talk to people who understand how you're feeling. You can find it at **community.mariecurie.org.uk**

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How we can help

We help everyone affected by a terminal illness get the information and support they need, whether you have an illness yourself or you're a family member or friend.

Marie Curie Support Line

0800 090 2309*

Ask questions and find support. Open 8am to 6pm Monday to Friday, 11am to 5pm Saturday. (Your call may be recorded for training and monitoring purposes.)

*Calls from landlines and mobile phones are free.

Marie Curie Community

community.mariecurie.org.uk

For anyone affected by terminal illness to share experiences and support each other. Available 24 hours a day.

More information and further support

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

Marie Curie Nurses

Marie Curie Nurses work night and day, in people's homes across the UK, providing hands-on care and vital emotional support. If you're living with a terminal illness, they can help you stay surrounded by the people you care about most, in the place where you're most comfortable.

mariecurie.org.uk/nurses

Marie Curie Hospices

Our hospices offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether you're staying in the hospice, or just coming in for the day.

mariecurie.org.uk/hospices

Marie Curie Helper

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

mariecurie.org.uk/helper

Useful organisations

Health information

Alzheimer's Society

0300 222 11 22

alzheimers.org.uk

Works to improve quality of life for people affected by dementia. Its website includes guidance on diagnosis, symptoms and care for people living with Alzheimer's, information on local services and support groups.

Complementary and Natural Healthcare Council

020 7653 1971

cnhc.org.uk

Accredited voluntary regulator for complementary therapists in the UK. Find a private (paid for) therapist near you or read about the different therapies available.

Dementia UK

0845 257 9406

dementiauk.org

Committed to improving quality of life for all people affected by dementia. Its website includes information about the condition and where carers can get support.

Diabetes UK

0345 123 2399

diabetes.org.uk

Has a dedicated helpline for people with diabetes, their friends, family, carers and healthcare professionals. You can also find a local support group online.

Health and Care Professions Council

0845 300 6184

hcpc-uk.org/check

Check whether a healthcare professional is registered to practice across the UK. This doesn't apply for social workers.

Healthtalk.org

healthtalk.org

A website with information on a range of illnesses, with a focus on people's real-life experiences. Includes a forum where you can talk to other people in similar situations.

Hospice UK

020 7520 8200

hospiceuk.org

A UK and international directory of hospice and palliative care, plus other information for people with a terminal illness.

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

Provides practical, medical and financial support for people affected by cancer.

Multiple Sclerosis (MS) Society

0808 800 8000

mssociety.org.uk

Gives grants and provides information and support to people affected by multiple sclerosis.

Motor Neurone Disease (MND) Association

08457 626 262

mndassociation.org

Care, research, campaigning and information about motor neurone disease in England, Wales and Northern Ireland. Its website includes the latest research, as well as guidance on getting support.

Motor Neurone Disease (MND) Scotland

0141 945 1077

mndscotland.org.uk

Provides care and support to people affected by motor neurone disease in Scotland. It also provides information and education services to healthcare professionals and funds research.

MIND

0300 123 3393 (text 86463)

mind.org.uk

Provides information and support for a range of mental health problems.

NHS Live Well

nhs.uk/livewell

NHS information about wellbeing, including nutrition and exercise advice.

Parkinson's UK

0808 800 0303 (textphone 18001 0808 800 0303)

parkinsons.org.uk

Gives information and support to people living with Parkinson's disease through its website and helpline.

Patient.co.uk

A free health site which contains over 4,000 health information leaflets, a wellbeing centre, a free health check, and forums where you can discuss your experiences with others.

Scope

0808 800 3333

scope.org.uk

Information and support for anyone with a learning disability or physical impairment.

Stroke Association

0303 3033 100

stroke.org.uk

Up-to-date information in audio format for people who have had a stroke, and their families and carers. It also has a directory of local services on its website.

Emotional support

Age UK

0800 169 6565

ageuk.org.uk

A charity with a network of local branches that aims to help older people make the most out of life. It has a befriending service and sometimes loans out wheelchairs. It also has national branches:

Age Scotland

0800 4 70 80 90

ageuk.org.uk/scotland

Age Cymru (Wales)

08000 223 444

ageuk.org.uk/cymru

Age NI

0808 808 7575

ageuk.org.uk/northern-ireland

Befriending Networks

0131 261 8799

befriending.co.uk

Offers supportive, reliable relationships through volunteer befrienders to people who would otherwise be socially isolated.

Care and Repair

Help with DIY jobs around the home including befriending opportunities.

Care and Repair England

0115 950 6500

careandrepair-england.org.uk

Care and Repair Scotland

0141 221 9879

careandrepairsotland.co.uk

Care and Repair Cymru (Wales)

0300 111 3333

careandrepair.org.uk

CaringBridge

caringbridge.org

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

Contact

0808 808 8000

contactni.com

A counselling helpline for people of all ages in Northern Ireland.

It's good to talk

itsgoodtotalk.org.uk/therapists

Find a therapist across the UK. Part of the British Association of Counselling and Psychotherapy (BACP).

Relate

0300 100 1234

relate.org.uk

Counselling, support and information for all relationships.

The website features a search for counselling in your area.

Samaritans

08457 90 90 90

samaritans.org

A confidential support line for people struggling to cope.

Equipment, adaptations and occupational therapy

British Association of Occupational Therapists and College of Occupational Therapists

020 7357 6480

cot.co.uk

Visit the website or call the association to find an occupational therapist. It also has a range of leaflets about how an occupational therapist can help.

British Red Cross

0844 871 11 11

redcross.org.uk

Loans wheelchairs and other types of equipment to people around the UK.

Capability Scotland

0131 337 9876 (textphone 0131 346 2529)

capability-scotland.org.uk

Works with disabled people and their carers. It can give you advice on where to find equipment.

Centre for Independent Living NI

028 9064 8546 (textphone 028 9064 0598)

cilbelfast.org

The website has lots of useful fact sheets to help people live independently.

College of Occupational Therapists

0207 989 0681

cotss-ip.org.uk

Search the online directory to find a private (paid for) occupational therapist in the UK. The organisation can help advise you on equipment, adaptations and general mobility issues. You should also be able to get an occupational therapist through your local health service.

Disability Equipment Register

disabreg.pwp.blueyonder.co.uk

A website that lists second-hand mobility equipment available to buy throughout the UK.

Disabled Living Foundation

0300 999 0004

dlf.org.uk

A charity in England and Wales providing impartial advice, information and training on independent living. Its website contains a lot of useful tips for buying equipment and products and it has a self-help guide called AskSARA at **asksara.dlf.org.uk**

Living Made Easy

0300 999 0004

livingmadeeasy.org.uk

Find and compare a range of home adaptations, mobility aids and other equipment.

Shopmobility

0844 41 41 850

shopmobilityuk.org

A scheme that lends or hires out manual and powered wheelchairs and powered scooters.

Financial and legal support

Benefits Adviser Line (Northern Ireland)

0800 232 1271

Contact the advice line for information about benefits in Northern Ireland or visit **nidirect.gov.uk** for online information about all aspects of money, tax and benefits. You can also download most application forms and guides from here.

Citizens Advice

03454 04 05 06 / 03454 04 05 05 (Welsh)

adviceguide.org.uk

The Adviceguide website is the main public information service of Citizens Advice Bureau, providing 24/7 access to information on your rights, including benefits, housing and employment, and on debt, consumer and legal issues. Search the site for your nearest bureau in England, Wales, Scotland and Northern Ireland.

Department for Work and Pensions (England, Wales and Scotland)

The DWP deals with most benefits through a number of different centres and services. For help and to apply for specific benefits, use the contact numbers below or visit **GOV.uk**

Attendance Allowance: 0345 605 6055
(textphone 0345 604 5312)

Disability Living Allowance: 0345 712 3456
(textphone 0345 722 4433)

Personal Independence Payment: 0345 850 3322
(textphone 0345 601 6677)

Carer's Allowance Unit: 0345 608 4321
(textphone 0345 604 5312)

Employment and Support Allowance:
0800 055 6688 (textphone 0800 023 4888)
or Welsh language line 0800 012 1888

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 (England and Wales)

020 7320 5650

lawsociety.org.uk

Find a solicitor in England and Wales.

Law Society Scotland

0131 226 7411

lawscot.org.uk

Find a solicitor in Scotland.

Law Society Northern Ireland

028 9023 1614

lawsoc-ni.org

Find a solicitor in Northern Ireland.

Office of Care and Protection (Northern Ireland)

courtsni.gov.uk

The Office of Care and Protection (Northern Ireland) supervises those individuals who have been appointed to manage the finances or property of adults who can no longer do so for themselves. It can help if you need to make a lasting Power of Attorney and can't find what you need online.

Society of Will writers

01522 687 888

thesocietyofwillwriters.co.uk

Information and advice about legislation for Wills and Power of Attorney in the UK from a self-regulatory, not-for-profit body. It can help you find a Will writer in the UK.

Support for carers

Care Information Scotland

08456 001 001

careinfoscotland.co.uk

A telephone and website service providing information about care services for older people living in Scotland.

Carers Trust

0844 800 4361

carers.org

Provides support and information for carers through its network of carers centres. It also has an online community for young carers at

babble.carers.org

Carers Trust Northern Ireland

0779 431 8403

carers.org/northern-ireland

Carers Trust Scotland

0300 123 2008

carers.org/scotland

Carers Trust Wales / Cymru

029 20 090087

carers.org/wales

Carers UK

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland)

carersuk.org

Provides expert advice, information and support to carers. There are links to its national services from the website homepage.

Further information

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

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

Notice

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

This information is provided as general guidance for information purposes only. It should not be considered as medical or clinical advice, or used as a substitute for personalised or specific advice from a qualified medical practitioner. In respect of legal, financial or other matters covered by this information, you should also consider seeking specific professional advice about your personal circumstances.

While we try to ensure that this information is accurate, we do not accept any liability arising from its use. Please refer to our website for our full terms and conditions.

Feedback form

If you have comments about this booklet, we'd love to hear from you. This will help us make sure we are providing the right information. Anything you tell us will only be used by the Information & Support Content team and will not be shared publicly. All information will be kept securely according to data protection standards.

We'd be very grateful if you could complete this form and return it to:

Information and Support Content team, Marie Curie,

89 Albert Embankment, London, SE1 7TP

Or you can email us at **review@mariecurie.org.uk**. Thank you.

Please tick

- ☐ I have a terminal illness
- ☐ I am a carer/ family member/ friend of someone with a terminal illness
- ☐ I am a health/social care professional using this resource to support someone affected by a terminal illness
- ☐ Other (please specify)

Where did you get this booklet from?

- ☐ Downloaded from the Marie Curie website
- ☐ Marie Curie Support Line
- ☐ Marie Curie Nurse, volunteer or hospice staff
- ☐ Healthcare professional (eg GP, district nurse)
- ☐ Other (please specify)

Did you find the information useful and did it meet your needs? eg, has this booklet given you a better understanding of the topic or helped you make a decision about next steps?

.....
Was there any information that you couldn't find that would have been helpful for you?

.....
Did you find the information in this booklet easy to understand?
Please tell us if anything was unclear.

.....
Did you think the tone was appropriate for the subject matter?

.....
Did you feel you had the right amount of information?



Would you have preferred to access this information in another format (eg large print, braille, audio)

Do you have any other comments?

About you

Finding out a little bit about you will help us to understand the needs of our audience and make sure our information reaches everyone.

What is your gender or gender identity?

☐ Female ☐ Male ☐ Prefer to self identify ☐ Prefer not to say

Age

☐ Under 16 ☐ 16-24 ☐ 25-34 ☐ 35-44 ☐ 45-54
☐ 55-64 ☐ 65-74 ☐ 75-84 ☐ 85 or over

Ethnicity

☐ White British ☐ Black or Black British ☐ Mixed
☐ White other ☐ Asian or Asian British

What is your religion or belief?

What is your sexual orientation?

☐ Bisexual ☐ Gay woman/lesbian ☐ Other
☐ Gay man ☐ Heterosexual/straight ☐ Prefer not to say

Where do you live? (Please provide the first part of your postcode in the space below eg 'CB1' or SE11)

We are always looking for volunteers to help us review our content for people affected by terminal illness. If you would like to help, please complete the details below and we'll be in touch with more details.

Name

Address

Telephone Email

How would you like to be contacted? ☐ Post ☐ Telephone ☐ Email



Marie Curie – why we're here

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

Support Line

We offer a free, confidential service to provide information on everything from day-to-day care, to sorting out money matters or coping with your feelings. And we're here when you just need someone to talk to.

0800 090 2309

Open Monday to Friday 8am to 6pm, Saturdays 11am to 5pm.
Your call may be recorded for training and monitoring purposes.

You can also connect with someone from our Support Line team using our online chat service. Visit **mariecurie.org.uk/help**

Online community

Share experiences and speak to people in a similar situation.

Visit **community.mariecurie.org.uk**

Information

We have a wide range of health and social care information that can help you live well, plan ahead and make informed decisions. This has been certified by The Information Standard as being reliable, up to date and evidence-based.

All our information is available online at **mariecurie.org.uk/help**

For printed copies call **0800 090 2309**

or email **review@mariecurie.org.uk**



**Care and support
through terminal illness**