

# Living with a terminal illness

Support for you and those close to you



**Marie  
Curie**

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Care and support  
through terminal illness

# Introduction

We know that things can change quickly when you're ill and you can find yourself with 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 emotions and feel better prepared. It also gives information about how to take care of yourself so you can live well. 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 look at it with someone like a nurse or family member, 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, contact the Marie Curie Support Line on **0800 090 2309\***, or by web chat at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

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Simon Rawles/Marie Curie

## Section 1:

# Coping with change and people who can help

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## Coping with change and uncertainty

Everyone responds in their own way when they're told they have a terminal illness. Many 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, you may experience powerful and overwhelming emotions. These could include:

- denial
- anger
- shock
- fear
- sadness
- helplessness
- loneliness
- frustration
- acceptance
- guilt or regret.

All of these feelings are normal and you may experience some or all of them. As time passes, some people find that any feelings of distress become less intense or they change.

### 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. They may be dealing with their own feelings about your illness. See section 3 (page 33) 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 you aren't as close to. You can speak with your doctor or nurse about how you're feeling. They can also help you find further support, such as counselling, 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](https://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, what will happen with work, and exactly how much time you have left (your 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 33) has more on coping with your feelings, including help on how to share them with those close to you.

## What happens now?

Being diagnosed with a terminal illness can come as a shock. Some people tell us they feel stranded in the time between the initial diagnosis and their next medical appointment.

Speaking to your doctor can help you to know what your options are. They will also be able to tell you what sources of support are available locally.

You might find it helpful to take someone with you to your doctor appointments, in case you don't understand something or find it difficult to remember everything that was said. You may also want to take in a prepared list of questions that you'd like to ask, so you can refer back to them while you're there.

For the time between appointments, there are things you can do to help you feel more informed. You can find information and support on the Marie Curie website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**. You could also contact the Marie Curie Support Line on **0800 090 2309\*** or look for local support groups in your area.

## People who may be involved in your care

### 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 traditionally includes your GP, practice nurses and district nurses.

GPs will work with other specialists (like 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
- liaise with your district nurse regarding your care at home
- tell you about local hospices.

See page 39 for more on getting support. For help with talking to your doctor and preparing for appointments, visit **[mariecurie.org.uk/support](http://mariecurie.org.uk/support)** or contact the Marie Curie Support Line on **0800 090 2309**.\*

## District nurses

If you can't leave the house for appointments or treatment and you need care at home, a district nurse can help to arrange your care. A district nurse will be involved with organising home care and arranging for services to be provided.

District nurses coordinate lots of services, but the availability of these may vary from area to area. These can include community nurses, healthcare assistants, care workers, Marie Curie Nurses, clinical nurse specialists like Macmillan nurses, or other care agencies. After discussing it with you, the district nurse will prepare a personal care plan and refer you to services which may be helpful, like social services.

## Marie Curie Nurses

If you're being cared for at home, you might get help from a Marie Curie Nurse. Marie Curie Nurses can give you advice on the medication you've been prescribed. They can also assess your needs and plan what kind of help you should receive.



You may also get help from a Marie Curie Healthcare Assistant. These are trained professionals who can help you with washing, dressing and moving around. They can also help you with taking your medication.

To get care or support from a Marie Curie Nurse or Healthcare Assistant, you should contact your district nurse or GP. This service isn't available in every area of the UK. Your GP or district nurse will consider whether a Marie Curie Nurse or Healthcare Assistant is right for you and may be able to refer you if you need their help.

## 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 or 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. The social worker will talk to you about your needs and any difficulties you're facing and may mean you get support from social services. This support could include having meals delivered, getting your home adapted to help you with daily tasks, and help with things like washing, dressing and eating.

If you have a family member or friend who looks after you (your carer), a social worker might be able to help them to get support as well. They can talk to the social worker about their needs and any help they need with looking after you. This might include putting them in touch with local support groups, help with taxi fares if they don't drive, and getting someone to take over caring for a while so they can take a break (this is sometimes called respite care).

## 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 support and treatment for people living with a terminal illness, which is an illness that can't

be cured and that the person is likely to die from . It aims to make sure you have a good quality of life and are as well and active as possible. Palliative care also includes support for family and friends.

If you're referred to a specialist palliative care team, they will assess your needs and those of your family, and they'll try to provide the best possible care and support.

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**

A palliative care team might involve a number of health professionals, including doctors, nurses, occupational therapists and physiotherapists. A palliative care team is there to help you manage pain and other distressing symptoms, and they will offer emotional, spiritual and psychological support to you, your family and friends. This kind of care could be offered in your home, in hospital, in a hospice or in a care home.

You can find out more about your care options at **[mariecurie.org.uk/help](http://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, but they may call or visit you 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'll need to be referred by your GP, your hospital consultant, a district nurse or a hospital ward sister.

### Hospice care

Hospices provide free nursing and medical care in a friendly and comfortable setting, as well as emotional and practical support. Some people stay in a hospice when they need specialist care, while others visit for treatment or support. Hospices are run by various charities, including Marie Curie.

For more information on where care is provided, visit **[mariecurie.org.uk/help](https://mariecurie.org.uk/help)** or call the Marie Curie Support Line on **0800 090 2309**.\*

## 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. 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.

### 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 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 chores
- childcare routines.

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 Marie Curie Support Line on **0800 090 2309**.\*

## If you still work

If you're employed or self-employed, it can be hard to know what to do next. For some people, an illness leads them to change their priorities in life, which sometimes results in them thinking 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, taking into consideration your current health, finances and treatment options.

## Talking to your employer

Talking to your employer about your illness can be daunting. They're likely to be supportive of you, but it might still help to know what your rights are.

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 make you redundant (sack you) or find an excuse to make you redundant because of your illness. They also can't 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 don't have to tell your employer about your condition. But you might want to, so that you can become fully protected by discrimination law if you're then unfairly treated because of something related to your illness. You might also find it helps to tell them as they could make you feel more supported.

You are protected against discrimination by the Equality Act 2010 in England, Scotland and Wales, and the Disability Discrimination Act 1995 if you're in Northern Ireland.

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 or another location, flexible working hours, changing the duties of your role, or time off work for treatment. It's a good idea to take some time to think about your options before making any decisions.

If you need help with negotiating adjustments or contacting a solicitor, see pages 90–93 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 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.



Layton Thompson/Marie Curie

Some people prefer not to tell colleagues that they're ill. 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 your feelings, such as a family member or friend. Or you might prefer to chat to someone who you're not as close to, like a counsellor or nurse.

Your employer may have arrangements in place for some form of independent and confidential counselling or an Employee Assistance Programme (EAP) service. You may wish to explore this. You can find out more about counselling on page 54.

## 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 Statutory Sick Pay or occupational sick pay, which is sometimes called contractual sick pay. 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/support](https://mariecurie.org.uk/support)** 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. This is known as an ill health policy. Your human resources (HR) or pensions department should be able to tell you if your workplace has an ill health policy.

If you have less than a year to live, you may be able to take out all of your pension in one go.

Before you take out your pension or resign, you should check if you have life cover through work. Many work pension schemes have life cover. It is a sum of money which is paid to a person you've chosen if you die before withdrawing your pension. This sum of money can be more valuable than your pension, sometimes several times your salary. In most schemes, this sum won't be paid out if you've already started taking out some of your pension. So check with your HR or pensions department before making any decisions.

The rules around pensions are complicated, and what you can receive depends on what kind of scheme you are on. The Pensions Advisory Service has information about pension options if you're ill or if you're caring for someone who's ill. You can also find out about your pension entitlements and benefits on our website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or by calling the Marie Curie Support Line on **0800 090 2309**.\*

## Planning ahead

When you've been diagnosed with a terminal illness, you may start thinking about what's going to happen in the future. You might begin to think about:

- 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.

Your doctor or nurses can help you understand your options and what kind of care you might need. It can also be helpful to talk through your wishes with family and friends.

Planning ahead could help make sure you get the kind of care you want. It can also help your family and friends to be aware of your wishes. If you find it difficult to think about these things just yet, don't worry. You can talk about the future when you're ready.

For more information on planning ahead, call the Marie Curie Support Line on **0800 090 2309\*** or visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

## Making memories

If you feel ready to do so, you may want to think about leaving some messages for your loved ones to read or look at after you've died.

You might like to create a memory box with your family and friends which features messages, photographs and special items. You could also create a video message or voice message of yourself for your loved ones to watch or listen to after you've died.

There are also websites which allow you to write a digital message for your family and friends to read.

For further support, you can contact the Marie Curie Support Line on **0800 090 2309\*** or visit **[mariecurie.org.uk/support](https://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 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
- 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 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 their personalities and the relationships you have with them. Some people may be more willing to talk about it, while others might not be able to express what they're feeling as easily.

Talking to your family and loved ones about your illness can have lots of benefits. It can give you the opportunity to share messages of love, talk about your fears or concerns, and it may bring you closer together.

## How they might react

Your family and friends might find it difficult to talk about your illness. They might not want to face up to the reality of losing you. They might also be worried about both of you getting upset. Loved ones 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.

If you are finding it difficult to cope with the reactions of your family and friends, here are some things you could try:

- Ask for what you want or need. This could be practical things, like help with your shopping, or emotional support, like a conversation you'd like to have. You might think your friends and family aren't ready to talk or are struggling to cope with the truth. But if you keep your feelings bottled up, you could end up feeling isolated from them.

- Talk to your nurse or GP if you're not ready to speak to your family. They can offer you support and point you in the direction of other professionals, such as a counsellor, who you might find it easier to talk to. Your family could speak to them as well.
- Don't think you 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 subject at a time.
- If talking about it is too overwhelming, or you don't want to talk about it, you should tell them. You can always discuss things at another time. You might find it easier to write what you want to say down in a letter, or you could make a memory box together to remember the times you've shared.

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/support](https://mariecurie.org.uk/support)** for more information and to order one online.

## 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

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.

For some couples, dealing with an illness brings them closer together. For others, they may become more withdrawn and might avoid the subject. If your relationship starts to change, 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 86-89.

## 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.

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.

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.

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 that it is okay 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 okay to say: "I don't know."



- Use clear and specific terms so that you don't confuse them.
- Use your judgement around how much detail to give, based on the child's age and level of understanding.

You can find more information, including a reading list on talking to children, on our website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

## 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. You can find more information on our website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or by contacting the Marie Curie Support Line on **0800 090 2309**.\*

## People caring for you

When you become ill, sometimes your partner, children, friends or other family members 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 caregivers 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, and they may be eligible for support from social services. There is more information



on this on page 74, but you can also visit [mariecurie.org.uk/support](https://mariecurie.org.uk/support) or contact the Marie Curie Support Line on **0800 090 2309**.\*

## Having difficult conversations

Not talking about your illness can lead to feelings of isolation and make problems worse. Some 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 different ways to speak to them about your illness. There is no right or wrong way, as health can be very personal and our relationships are individual to each of us.

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, while out for a walk or over a meal for instance.

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

## **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.

## **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, you could ask a family member or close friend to be a spokesperson who can pass 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.

This could have an impact on the family member or friend who is being your spokesperson – you may want to check that they feel comfortable doing this.

## **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.

## **Asking for help**

Some people don't want to talk about their illness. Everyone responds differently, and there's no right or wrong way to react. If you are finding it difficult to talk about your illness, it may be easier to ask for help with practical tasks instead.

When you're first diagnosed, asking your family or friends to help you with the shopping or household chores can help them to feel useful if they or you 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 to do the washing.



## Talk online

Another option you could explore is sharing your experiences with family and friends through social media, such as Facebook 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 can't read your posts. If you're not sure how to do this, ask a family member or friend for help.

You could also create your own private website at CaringBridge (see page 88), a charity that sets up free personalised websites for people with serious medical conditions. You can choose who can see your website so they can read updates and send you messages of support.

## Section 3: Your feelings

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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 54-55 to explore other ways of coping with your feelings.

### Denial

Denying you are ill is a common reaction to learning you have a terminal illness. It can be hard to confront the future, or to come face to face with the reality of your illness. For some, 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 future. Although it might be difficult, try not to ignore your feelings. Counselling or other professional emotional support can help you to come to terms with your illness and any fears you might have.

### Anger

At some point, you might feel anger and resentment. You may think: "Why me?", "Why this illness?" You might look for someone or something to blame for your illness.

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 or it's affecting those around you, there are people you can talk to. Speak to your doctor or nurse or contact the Marie Curie Support Line on **0800 090 2309\*** or by web chat at **[mariecurie.org.uk/web-chat](https://mariecurie.org.uk/web-chat)**

## 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 or postpone death.

If you're struggling to come to terms with your illness, it could help to speak to your GP or nurse. They will be able to provide support and can help you find further guidance.

## Guilt and regret

In the last few months of life, a person might regret things they could have done differently, or things they haven't done at all. Many people with a terminal illness also experience guilt. Some people feel that they're being a burden and feel guilty for being dependent on others to look after them. Sometimes people feel responsible for their carer's hardships.

Try to remember that worrying is unlikely to make you feel better. Often, people who think they're being a burden on their families aren't at all – and their families see it very differently. If you have feelings of guilt that don't go away, it may be helpful to seek support from someone you trust, like a family member, friend, healthcare professional, counsellor or faith leader.

## Fear

It's natural to feel frightened and anxious. You may 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. And you might be afraid because you simply don't know what will happen.

You can find more information about common feelings and what you may expect at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

Many people also become fearful about the effect their illness and death will have on those around them. Whatever you feel, know that you're not alone. 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 a long time and can affect your ability to cope with eating, sleeping, social activities and work. Depression can be triggered by lots of things, including stressful and upsetting life events, and it can make you lose interest in things you once enjoyed.

If you are feeling depressed, speak to your GP or nurse. They will be able to discuss treatment with you. You can also learn more about depression in detail on pages 51-55.

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

## Feeling alone

Being diagnosed with a terminal illness can bring feelings of loneliness. This might be because you and your family no longer talk about future plans together, or because you don't have the strength to socialise like you used to. You might feel like no one understands what you're going through, so you find it hard to share your feelings.

Often, telling family and friends how you're feeling can help. If you feel like your loved ones won't understand what you're going through, you may want 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](https://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. Focusing on positive aspects of your life and trying to carry on with some normal routines can help you cope with feelings of uncertainty.

## 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 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.

You may reflect on things that you thought were important and things you would like your children to know about. These might not be huge – they may be small things that have mattered to you and the people around you. Sharing your thoughts, experiences and wisdom is a gift your loved ones can treasure for years to come.

Thinking about 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.

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. You don't have to be religious to receive support.

## 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.



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## 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. Try to avoid a lot of alcohol or unprescribed drugs, as they can make feelings of depression 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, or you aren't achieving the things you would like to. Feeling better takes time and happens gradually. It can be easy to rush through life without stopping. Paying more attention to the present moment, like how you are feeling and what's going on around you, can help you feel better. See section 4 (page 43) for more information on looking after your wellbeing.

## Talk to your healthcare team

Don't hesitate to discuss your worries and feelings with your nurse, doctor, or Marie Curie Nurse if you have one. 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/help](https://mariecurie.org.uk/help)** to find out if there is a hospice near 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 to help you work through your feelings.

You can find details of counsellors in your area by visiting the NHS website or the British Association for Counselling and Psychotherapy website (see page 87). This site also offers lots of helpful information about what a counselling session involves.

## 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 or another member of your healthcare team may 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 83–86 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 and learn how they coped with their emotions. The Marie Curie Community at **[community.mariecurie.org.uk](https://community.mariecurie.org.uk)** can be

a good place to share your experiences or get support from people who understand what you're going through.

Some charities have helplines that run a web chat or email service. You can contact Marie Curie's Support Line by email or web chat – visit **[mariecurie.org.uk/web-chat](https://mariecurie.org.uk/web-chat)**

## 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.

## Support from Marie Curie

For practical information and emotional support, you can speak to trained staff at the Marie Curie Support Line on **0800 090 2309**.\*

If you would find it easier to chat online, you can use the Marie Curie web chat at **[mariecurie.org.uk/web-chat](https://mariecurie.org.uk/web-chat)**

For more information on getting support from Marie Curie, see page 82.

## Section 4:

# 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 anxiety, 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
- controlling your blood pressure.

And it can benefit your mind by:

- reducing stress
- helping you sleep better
- improving your overall sense of wellbeing
- making you less tired.

You can find out more about staying active by visiting **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or contacting the Marie Curie Support Line on **0800 090 2309**.\*



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# Eating and drinking

Illness, treatments and medication might have caused you to lose some, or all, of your appetite. Your tastes and preferences may also be affected. Being breathless, tired or feeling low might affect how much you want to eat.

## 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.

The following suggestions may help:

- Eat small portions regularly, as they might be more appealing than large meals.
- Nibble on healthy snacks.
- Eat your largest meal whenever you feel hungriest, whether it's at breakfast, lunchtime or dinner.
- Tastes can change, so eat foods that appeal to you most.
- Some people may be used to having a glass of alcohol with meals. If drinking alcohol is part of your normal routine and something you enjoy doing, you may be able to continue drinking a small amount. You should check with your doctor first to make sure it doesn't interfere with 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

- Keep your mouth clean, as this could help you enjoy food and drink more. You can learn more about good mouthcare at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**
- Seek advice from your doctor or nurse on ways to get more calories in your diet.

## Nausea (feeling sick)

Nausea (feeling sick) and vomiting (being sick) are common problems for people living with a terminal illness. If you feel sick, speak to a nurse or doctor who can look for a specific cause and decide on the best way to help you. There are medicines and treatments that may be able to help.

If the smell of hot food makes you feel sick, try eating cold meals instead. Avoid spicy, greasy or fatty foods, and try bland foods instead, like crackers or toast. Eating smaller meals or snacks more often can be less challenging than big meals.

Boiled sweets can relieve nausea, and cold, fizzy drinks, like sparkling water or lemonade, can also help. If you have difficulty swallowing, avoid boiled sweets as they could cause you to choke. Visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** 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
- milkshakes.

Or soft foods like:

- mashed potato
- jelly
- ice cream.

Your GP or clinical nurse specialist may also advise nutritional supplements. Ask your doctor or nurse about what might be suitable for you.

If you have difficulties with swallowing, some of the foods above may not be as easy to eat. Again, speak to your healthcare team for advice on what you should try.

## Difficulty swallowing

Having difficulty swallowing is a common problem for people living with a terminal illness. If you have difficulty swallowing, you might find it harder to eat, feel like food is stuck in your throat, or have more saliva in your mouth than usual.

If you have difficulty swallowing, your healthcare team might recommend certain kinds of food or drink to make it easier for you to eat and drink more safely. For example, soft foods chopped into small pieces may be easier to swallow than dry foods or hard foods in large pieces. Thicker liquids may be easier for you to swallow than thin liquids (eg water). Your healthcare team might also change the thickness (consistency) of your food and drink using liquids, gels or powders.

If you have difficulty swallowing you may need specialist advice, so talk to your GP. There is further information on issues with swallowing in our booklet, *Difficulty swallowing*, and at [mariecurie.org.uk/support](https://mariecurie.org.uk/support)



## Practical issues

You might need some assistance during mealtimes. The following ideas are good things to try if you're struggling:

- It can be easier to sit upright. 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.
- Eating soft foods may be easier to eat as they require less effort. Chewing meat can be quite tiring if you are tired or breathless.

## Getting advice

If you carry on having problems with your appetite, have problems eating or you find you're losing weight, contact your nurse or doctor. 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. Talk to them before making any major changes to your diet.

## Managing 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. Some people won't experience any pain. The main thing to know is that with the right treatment and support, most pain can be managed.

## What causes pain?

When the nerve endings in the body are damaged, for example by a disease, they send a message to the brain which makes you feel pain or discomfort. Pain can affect your body in different ways – it can be

dull and aching, or be more specific, like a sharp or throbbing feeling in one area. It can be caused by your illness, an operation or your treatment. It can also happen because of a long-term condition, like arthritis.

Pain doesn't just cause physical discomfort – it can also affect you emotionally and psychologically. It can have an impact on your mood, how well you sleep, or even begin to affect your relationships.

## Getting help

Your GP and palliative care team will work with you to find the best way to manage your pain. Your doctor or nurse will carry out an assessment of your pain, in which they might ask you where the pain is, how often you get it, and the effect it is having on your life.

It is important to think about how you are feeling regularly, because you will know best what your pain feels like and how it's affecting your quality of life. Try to describe any pain you're experiencing to your doctor or nurse. This can be difficult, but it helps them decide what's causing your pain and what treatment is best for you. Your local pharmacist can give you information about when and how to take any medication you've been prescribed.

There are other treatments you can have to relieve pain which don't involve drugs. You can find out more about these, and possible side effects, in our booklet, *Managing pain*, and on **[mariecurie.org.uk/support](http://mariecurie.org.uk/support)**. You can also call the Marie Curie Support Line on **0800 090 2309**.\*

## Spiritual and emotional pain

You might experience emotional and spiritual pain when you are diagnosed with a terminal illness. Emotional and spiritual pain can happen if you're struggling to find sources of meaning, hope, love, peace, comfort, strength and connection in their life. These kinds of pain can make you re-evaluate the meaning of life and think more deeply about your beliefs and relationships.

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

Spirituality means different things to different people. Religion and faith might be part of someone's spirituality, but spirituality isn't always religious.

Spiritual needs may include:

- the need for meaning and purpose in our lives
- the need to love and feel loved
- the need to feel a sense of belonging and connection in life
- the need to feel hope and peace.

At times of illness, faith can be important. To some people faith may become more important to them and they find it a great support. Some people may turn to a faith tradition to try and find answers. Others may struggle with their faith, and ask questions like: "where is God now?" and "why is God allowing me to suffer?"

There may be anger and frustration because people cannot practise their faith in the ways they are accustomed to.

All these feelings are normal and it may help to talk to someone from your own faith tradition for support.

You can also visit our website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** for more information or call our Support Line on **0800 090 2309**.\*

## Depression and anxiety

When you're ill, you may feel very low or anxious and find it difficult to cope. Most people feel low or sad some of the time. It's normal to have ups and downs. But when feelings like sadness and hopelessness last for months without changing, it may be depression.

Depression can make you lose interest in things you once enjoyed, make you feel tired or irritable, or cause you to have lots of negative thoughts.

## Causes of depression

Depression can be triggered by lots of things, including stressful and upsetting life events. Anyone can get depression, but you're more likely to experience it if you have had it before or have a family history of it.

## Symptoms of depression

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

- sadness
- irritability
- feeling indecisive
- crying a lot
- a sense of helplessness
- feelings of hopelessness
- not wanting to see people
- lack of interest in anything
- feeling persistently low in your mood
- tired and low in energy, moving more slowly
- feeling worthless or having low self esteem
- not being able to find pleasure or enjoyment in things you previously enjoyed.

## Managing depression

Lots of people wait before seeking help for depression, but it is better to find help as soon as possible, so you can start getting support right away. You can tell your GP or nurse, who will be able to discuss treatments.

You can contact our Support Line on **0800 090 2309\*** or visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** for more information about managing depression.

## About anxiety

Anxiety is a feeling of worry or fear. Most of us feel anxious from time to time, but some people feel anxious often and may 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 fears about your symptoms and illness.

## Symptoms of anxiety

Symptoms of anxiety 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

Symptoms of anxiety and the worries that often come with living with a terminal illness can be similar, which sometimes makes it difficult to tell whether you've got anxiety or not. 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 you may start to feel worse. It's important to get help as early as possible so you can start getting support right away.

Treatment could include:

- exercise
- self-help techniques
- support groups
- mental health apps
- medication, including anti-depressants
- talking therapy, for example, cognitive behavioural therapy (CBT) or counselling.

## Getting help

You, your family and your close friends can ask your doctor, district nurse or Marie Curie Nurse about the different types of help available and how to access it. If you think you might benefit from counselling, you can get it free through the NHS. You can sometimes access counselling at your local hospice, and it may be quicker than going through the NHS. Visit [mariecurie.org.uk/help](https://mariecurie.org.uk/help) or call our Support Line on **0800 090 2309\*** to find out more about counselling at a Marie Curie Hospice.

## Talking therapies

Talking therapy services include cognitive behavioural therapy (CBT), a therapy that can help you to manage things you're worried about by changing the way you think and behave. There are different types of talking therapies, but in all of them, you will work with a trained therapist.

If you're in England, you don't need a referral from your GP if you want to have free therapy on the NHS, although you can get one if you prefer. You can refer yourself directly to therapy services like CBT or counselling. Although you don't need a GP referral, you must be registered with a GP to access therapy on the NHS.

You can find a local psychological therapy service on the NHS website. Once you contact the service, someone will get in touch and ask for more details about the problems you're having. If they think they can help you, they'll recommend a therapy.

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

You can also have counselling privately, although this isn't free. Ask your doctor about private counselling or visit the British Association for Counselling and Psychotherapy website (see page 87) to find out more.

## Helping yourself

There are some things you can do to help yourself. You could try making more time for things that you enjoy like listening to music, reading a book, going out, or spending time with family or friends. You might also like to exercise (see page 54) or relax with complementary therapies like massage.

## Complementary therapies

Complementary therapies are given alongside conventional medical treatment. They focus on your wellbeing and 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, tai chi and other exercise
- drama therapy
- music therapy.

Lots of people living with a terminal illness find that complementary therapy helps them in different ways. There isn't a lot of scientific evidence to say how well complementary therapies work, so it's best to speak to your doctor or nurse about what might work for you.

It's also important to tell the complementary therapist about your medical condition and any treatments that you've had or are having. They can make sure the therapy is suitable for you.



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## Finding and paying for complementary therapy

In most cases, the NHS doesn't offer complementary therapies, so speak to your doctor or nurse about what's available in your area. However, your local hospice or support group may offer free or reduced cost therapies. Marie Curie has nine hospices throughout the UK. You can find out more about these at **[mariecurie.org.uk/help](https://mariecurie.org.uk/help)**. You can also search for a local hospice on the Hospices UK website at **[hospiceuk.org](https://hospiceuk.org)**

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 83). 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. Sometimes the same therapy can be used as an alternative and complementary therapy, like aromatherapy.

Some types of alternative therapy may not be completely safe or might only work for a few illnesses. This is because many alternative therapies are based on principles, rather than scientific evidence. It's important to speak to your doctor before trying an alternative therapy.

## Sexuality

Sexuality refers to how you feel about yourself and how you connect to your partner, if you have one. It can include physical intimacy and affection, but it can also mean how you communicate your feelings.

Your illness and treatment might affect how you feel about yourself sexually, including how you feel about your body. People react differently, and this might be true of both you and your partner. Some couples might feel more strongly towards each other and become closer. However, you might also be affected by tiredness, low mood, or changes in appearance, which could affect your feelings towards sex and having a physical relationship.

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 and surroundings can affect how you feel about yourself sexually 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 function
- 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

Talking about sexuality can help with the wellbeing of both you and your partner, and it could bring you both closer together. 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. If you feel you would like some help with talking about

sexuality, your nurse or other healthcare professional may be able to encourage discussion and sharing between you and your partner. Your healthcare professional can refer you to someone else if they do not have the right knowledge.

## Talking to your partner about sex

For some people, it can be unusual or difficult to talk about sexual relationships. But if you feel unable to have sex either physically or emotionally, talking to your partner can help them to understand how you're feeling. Try not to hide your feelings and worry about it alone. Talking openly can have a positive impact on your wellbeing.

## Physical changes

As your illness progresses, your level of sexual interaction may decrease, or the type of interaction you have might change. For some people, physical closeness, touching and sharing how they feel might become more important and sex become less important.

In the palliative or terminal stage of an illness, physical and emotional changes may have an effect. You might stop having sex completely or you could find yourself becoming more sexually active. There's no right or wrong way to be – it's different for everyone.

## 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 88 for contact details.

## Emotional changes

Every relationship is unique, but you might find some of the experiences other people have had sounds 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.
- Reconnecting emotionally as a couple.
- Having different reactions to changes in your sexual relationship.

## People caring for you

When you become ill, your partner might take on the role of a caregiver. They may have to physically care for you, 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 might affect the dynamic of your relationship. Performing a number of different roles – like being a partner as well as a carer – can be stressful for both of you.

If you or your partner are finding it difficult, try talking to your doctor or nurse. They can tell you about the help that is available for carers. Alternatively, you can find more information at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**, or you could contact our Support Line on **0800 090 2309**.\*

## Section 5: Getting care and support

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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 help you move around better, or staying in touch with those close to you. There are also benefits available to help with extra costs.

## Healthcare

Healthcare is the treatment and care you are given when you are ill. Healthcare covers a range of things, including any medication you may take, the people who look after you, like doctors and nurses, and places where you might be cared for, like a hospital.

In the UK, healthcare is provided by the NHS (National Health Service). NHS services are available to everyone, and you don't have to pay for most of them. In Northern Ireland, the NHS is called HSC, and also includes social care services.

You can also access private healthcare, which you have to pay for. For more information on healthcare and who will look after you, see Section 1 (page 10).

## 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 who, because of their disability, need support in doing everyday tasks like washing, dressing and cooking meals.

## How to apply

You can find out what help you can get by asking your local council's social services department for a needs assessment. You can also ask for a carer's assessment for your carer. In Scotland, your carer will be offered an adult carer support plan, to help them with their caring needs. If you live in Northern Ireland, contact your local health and

social care trust and ask for an assessment of need.

Social services can charge for care services. But generally, the council will help pay for care costs if you have less than £23,250 in savings. After your needs or carer's assessment, you will have a financial assessment, where you'll be asked about your savings, pension and benefits. The council will then tell you how much you'll have to pay for your care.

If you qualify for council help with costs, you'll be offered a personal budget. This is a sum of money to support your health and care needs. The council will either pay this directly to you, or they'll manage it for you. You can choose which way to receive it. You can also ask them to pay it to another organisation, like a care provider, or pay it directly to someone you choose.

The council must regularly assess your financial situation to see whether it changes. This usually happens once a year.

If you live in Scotland, you may be able to get free personal care. Personal care includes things like help with hygiene, moving around, and support at mealtimes. Help with housework or doing the shopping isn't covered. To receive personal care, you'll have an assessment to decide whether you need it. The kind of care you get will depend on what needs you have.

You may also be eligible for benefits, which aren't means-tested, and can help pay for the cost of your care.

## NHS continuing healthcare

NHS continuing healthcare is health and social care that you may be able to get free from the NHS if you aren't in hospital but have complex care needs.



NHS continuing healthcare is only available for adults in England, Northern Ireland and Wales.

To receive NHS continuing healthcare, you'll need to be assessed. Most people will have an initial assessment, sometimes called a screening tool or initial checklist assessment, which will decide whether you are eligible for a full assessment. The full assessment will then look at how complex your needs are and what kind of help you need. The person doing the assessment will consider things like your mobility, any issues you have with breathing and help you need with eating and drinking.

If your needs are urgent, you may be given continuing healthcare on a fast track. This means you don't have to do the usual assessment, but will be assessed using something called the Fast Track Pathway Tool. Your needs are considered urgent if your health is deteriorating quickly and you're nearing the end of your life. If a fast track assessment is accepted, a care package may be put in place within two days.

Continuing healthcare is given to people who need a lot of help with their care. It's not decided by what kind of illness you have. It's decided by how complicated your needs are. You can apply for continuing healthcare if you:

- have a complex illness
- need substantial and long-term care.

If it's decided you can have continuing healthcare, a care and support package will be made for you, which explains what kind of care you will need and how you will receive it. Continuing healthcare can pay for care home fees, or for carers to come into your home. You can get continuing healthcare whether you're in your own home or in a care home.

Ben Gold/Marie Curie



If you do receive continuing healthcare, the NHS will pay for all your care and support. However, you might lose access to some benefits.

To apply for continuing healthcare, you should ask your GP or social worker to arrange an assessment. If you're in Northern Ireland, you should arrange an assessment through your local health and social care trust.

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 91) is a good place to start.

We have more detailed information about continuing healthcare at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or call the Marie Curie Support Line on **0800 090 2309**.\*

# Getting equipment and adapting your home

Adapting your home or getting specialist living equipment can make life much easier. Small aids and equipment can often be provided and you may be able to get help with paying for them or receiving them on loan (see page 67).

## Adaptations

Adaptations range from getting devices installed, such as an intercom or keysafe, to having parts of your home modified, allowing you to be more independent and helping you if you want to stay at home. 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:

- raised toilet seat
- a rail to help you get out the bath or shower
- bathing aids
- reclining chairs
- adaptations to raise your bed
- dressing aids
- adaptive cutlery to make eating easier
- adaptive cups to make it easier for you to drink without any help
- outdoor ramp or step rail
- walking aids and wheelchairs.

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

## Getting help

If you struggle getting around your home or having a shower, you might benefit from home adaptations. If this is the case, contact your local council or trust, who will carry out an assessment.

During the assessment, an occupational therapist will visit your home to see how you cope with everyday tasks, like making a cup of tea or getting out of bed.

Based on the assessment, the occupational therapist will recommend equipment and adaptations to make your life easier. Equipment can often be loaned. You may also be able to get financial support to help with the costs of adaptations.

## Paying for home adaptations

In England, your council should pay for minor adaptations to your home which cost less than £1,000, like handrails and wheelchair ramps. In Scotland it's the same, except the amount is £1,500.

In Wales, getting minor adaptations is means-tested, meaning you might have to pay for the adaptations yourself, depending on your income and savings. In Northern Ireland the local health and personal social services trust will pay for some minor adaptations.

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.

How much you get depends on your income and how much you have in savings. In England, the maximum you can get is £30,000. In Wales it's £36,000, and in Northern Ireland, it's £25,000.

In Scotland, the amount you get depends on your local council.

You may be able to get VAT relief, meaning you don't have to pay tax on adaptations to your home. See the **GOV.UK** website for more information.

If you're unsure what kind of equipment you need or what financial help you might be able to get, your local Home Improvement Agency can give you advice. See page 90 for contact details.

## Getting work done privately

You don't have to go through the council for adaptations to your home. You can pay to have the work done yourself. An occupational therapist at a hospital or local hospice can give you advice on the right equipment for you.

If you rent your home, you need to ask for your landlord's permission before you adapt it. Your landlord should make reasonable adjustments, but there are exceptions to this if you rent privately.

## Trying equipment before you buy it

You might want to hire equipment if you only need it for a short while, or if you want to test it out before you buy it. Independent Living Centres can give you advice about equipment and have products on display you can try out. You can also hire equipment from specialist hire companies.

For more on finding equipment and making adaptations, see pages 89-90, visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or contact the Marie Curie Support Line on **0800 090 2309**.\*

## Occupational therapy

Occupational therapy aims to improve your ability to do everyday tasks. Occupational therapists will look at things you struggle to do and see if there's an easier way to do them.

You can get a referral from your GP or ask your local council or trust to see if you can get occupational therapy for free.

You can also access occupational therapy privately. The Royal College of Occupational Therapists has a searchable directory to find independent therapists in your area. See page 90 for contact details.

## Benefits and financial support

When you're ill, you or your family or friends may stop working. You may also have to manage extra costs. Help is available from many sources, including the government, your local council and charities.

Be aware that the different benefits which are available and who is eligible for them might change. The booklet was published in May 2019. For up-to-date information, visit [mariecurie.org.uk/support](https://mariecurie.org.uk/support) or call the Support Line on **0800 090 2309**.\*

## Benefits and entitlements

The benefits system can seem like a maze. There are many different types of benefit, and it can be hard to know what you're entitled to. It's worth checking if you can claim any benefits 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 85-94 for contact details).

We also have more information about benefits and entitlements on our website at **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** 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 means that you may have your application fast-tracked and get the benefit at the highest rate if you qualify. Visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or call the Marie Curie Support Line on **0800 090 2309**\* for more information.

### Attendance Allowance

Attendance Allowance can help with the extra costs of your illness or disability.

Attendance Allowance isn't means-tested, so the amount of savings or earnings you have won't affect how much you get.

You can receive Attendance Allowance if you've reached State Pension age or older. State Pension age differs depending on what year you were born. You can't usually get Attendance Allowance if you're in a care home and the care home costs are paid for by the council. But if you pay for the costs of a care home yourself, you can claim Attendance Allowance.

If you're living with a terminal illness and are expected to live less than six months, you can receive Attendance Allowance more quickly and will get the higher rate. You'll need to complete an Attendance Allowance form, and ask your doctor for a DS 1500 form. They will either fill this out and give it to you to send off, or fill it out and send it to the Department of Work and Pensions directly. If you're in Northern Ireland, you should phone the Disability and Carers Service or visit your nearest Jobs and Benefits Office to get a claim form.

### **Personal Independence Payment**

You can get Personal Independence Payment (PIP) if you're over 16, haven't yet reached State Pension age, and have a long-term illness or disability. You may also receive PIP if you have difficulty getting around.

The amount you receive depends on how your condition affects your daily life. It doesn't depend on what kind of illness you have. You'll be assessed by a health professional to decide how much help you should receive.

You can get PIP more quickly when you're living with a terminal illness and are expected to live less than six months. You won't have to complete a face-to-face assessment and you should start getting your payments quicker.

To claim PIP, you should call the Department of Work and Pensions, or the PIP Centre if you're in Northern Ireland. You can find their contact details on page 91 of this booklet.



## **Disability Living Allowance**

Disability Living Allowance (DLA) is being replaced by Personal Independence Payment for people aged between 16 and 64.

You can now only apply for Disability Living Allowance if you're under 16.

If you already get DLA, and you were born on or before 8 April 1948, you'll continue to receive it for as long as you're eligible. If you were born after then, your DLA will end, and you'll be invited to apply for Personal Independence Payment instead.

## **Employment and Support Allowance**

If you're ill or disabled, Employment and Support Allowance (ESA) gives you financial support if you can't work. It can also give you personalised help so that you can work if you're able to. You can apply if you're employed, self-employed or unemployed, and if you're under State Pension age.

If you claim ESA you'll have to do a Work Capability Assessment, to see how your illness affects your ability to work.

If you make a claim for ESA now, you'll be claiming for something called new style Employment and Support Allowance. You may be able to get new style Employment and Support Allowance if:

- you are ill and unable to work
- you have paid, or been credited, a certain amount of National Insurance tax in the last two tax years.

To claim new style ESA, you will also need to provide a note from your GP.

If you are currently claiming benefits and have a severe disability premium (or have had one within the last month), you won't claim new style ESA. You will claim one of the existing benefits, like Jobseekers Allowance, Income Support, Housing Benefit, Child Tax Credit, or just normal Employment and Support Allowance.

ESA is gradually being replaced by Universal Credit. If you are currently claiming ESA, you don't have to do anything. The Department for Work and Pensions (or the Department for Communities if you live in Northern Ireland) will contact you when it's time to switch to Universal Credit.

However, if you have a change of circumstances, such as starting to work or starting to rent a new property, you will need to make a new claim for Universal Credit.

You can get new style ESA on its own or at the same time as Universal Credit.

If you claim both new style ESA and Universal Credit, the new style ESA you are paid will reduce your Universal Credit by the same amount.

## Universal Credit

Universal Credit is a new benefit which is replacing six means-tested benefits, including Employment Support Allowance. If a benefit is means-tested, it means the amount of money you have in savings and income will affect whether you can get that benefit or not.

You may be able to claim both Universal Credit and ESA at the same time, but this depends on how much you earn and your National Insurance contributions.

If you're an adult and you receive Personal Independence Payment or Disability Living Allowance, you will still get these as well as Universal Credit.

Like with ESA, Universal Credit requires a Work Capability Assessment to see how your illness affects your ability to work. However, if you've already done an assessment while claiming ESA, you might not have to do it again when you switch.

Universal Credit can be confusing. If you're not sure what kind of benefit you should apply for, you may find it useful to speak to a benefits adviser. You can find a benefits adviser by contacting Citizens Advice, Macmillan Cancer Support or Carers UK (see pages 85-94 for contact details).

## Benefits for carers

If your partner, a member of your family, or a friend cares for you, they might also be entitled to benefits. If you're on one of the benefits listed below and your carer looks after you for 35 hours a week or more, they could receive Carer's Allowance. If they are working, there is a maximum amount they can earn per week to get the benefit.

Your carer may be able to claim Carer's Allowance if you receive any of the following benefits:

- Personal Independence Payment (the daily living rate)
- Disability Living Allowance (middle or higher care rate)
- Attendance Allowance
- Constant Attendance Allowance
- Armed Forces Independence Payment.

Carer's Allowance is paid weekly or every four weeks into your carer's bank account. If your carer lives in Scotland and gets Carer's Allowance, they might also get an extra payment, called the Carer's Allowance Supplement.

For every week that your carer receives Carer's Allowance, they will also get National Insurance credits. These help to protect your carer's State Pension if they aren't working.

## How to apply

Social security benefits are handled by the Department for Work and Pensions (England, Scotland and Wales) and the Social Security Office (Northern Ireland). There are different branches depending on the benefit you're applying for. See pages 90-92 for contact details.

We have more information about getting help with financial matters on our website at [mariecurie.org.uk/support](https://mariecurie.org.uk/support) or call the Marie Curie Support Line on **0800 090 2309**.\*

## Other financial help

Living with a terminal illness can be expensive. Fortunately, there is support available to help you with certain costs.

## Grants

If you're eligible, you may be able to receive a grant. A grant can be a sum of money which you don't have to pay back. It can also be a product or a service. Grants are offered from a number of places, including grant-giving charities and health charities. Charities like Macmillan Cancer Support and Turn2us offer financial help in the form of grants.

To find out what grants you may be able to receive, Turn2us has a helpful calculator which works out what you are eligible for. See page 93 for more information.

## Help with your energy bills

If you're struggling to pay for your energy bills, you may be able to get help from the government or energy suppliers.

You can get a one-off payment, called the Winter Fuel Payment, to help you pay for heating during the winter if you were born on or before 5 November 1953.

You can also get payments for when the weather drops below a certain temperature. You are only eligible for this if you're receiving certain benefits.

Visit the Citizens Advice website (see page 91) to find out more on what you could receive.

## Help with transport costs

You may be able to get help with transport costs if you're living with a terminal illness.

If you need to go to hospital, and it's not an emergency, you may be eligible for patient transport services (PTS). These services provide free transport to and from the hospital for those who have difficulty walking or might need medical support during the journey. PTS aren't available in all areas, so speak to your GP or nurse to find out if you can receive them.

You may also be able to receive discounts on public transport, Vehicle Tax, or even get a Blue Badge. These all depend on whether you're eligible. Visit **[mariecurie.org.uk/support](https://mariecurie.org.uk/support)** or call the Marie Curie Support Line on **0800 090 2309\*** for more information.

## Affording a day out or holiday

When you've been diagnosed with a terminal illness, you may feel encouraged to do something you really enjoy.

There are charities which can help you arrange a special day, or even provide a grant for you to enjoy a relaxing break. Macmillan Cancer Support and the Honey Rose Foundation are two charities which do this. Visit their websites (see page 85-88) to find out more.

## 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. If you're feeling isolated or struggling with daily tasks like cleaning the house or washing, don't hesitate to speak to your GP, Marie Curie Nurse or district nurse. They can 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](https://nidirect.gov.uk)** in Northern Ireland.



Layton Thompson/Marie Curie

## 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 ringing you on the phone.

Befriending schemes can help you feel more positive, as well as making you feel cared for and improving your feelings of self-worth.

There are several free befriending schemes in the UK.

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 on a shopping trip, out for coffee, or to appointments. If you're not able to go out, they can simply visit you for a chat.

Visit **[mariecurie.org.uk/helper](https://mariecurie.org.uk/helper)** or call the Marie Curie Support Line on **0800 090 2309\*** for more information.

Age UK (see page 86-87) runs a network of befriending services, which works 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 86-87). 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 try might not suit you, it could lead you to finding another group or organisation.



Lots of hospices run day therapies like art groups, gentle exercise and relaxation. You can go to these even if you're not an inpatient at the hospice. Marie Curie has nine hospices across the UK. To find out where your nearest Marie Curie Hospice is, and what kind of day therapies it runs, visit **[mariecurie.org.uk/help](https://mariecurie.org.uk/help)**. Hospice UK is a charity which has a list of hospices on its website. You can find these at **[hospiceuk.org](https://hospiceuk.org)**

## Home repairs

Care and Repair is an organisation that helps people in England, Scotland and Wales with DIY jobs around the home. See page 87–88 for contact details.

## Carers and isolation

Isolation can also be a problem for carers. Many carers feel alone and without support. The organisations on page 94 may be able to help further, or you can 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](https://community.mariecurie.org.uk)**

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## How Marie Curie can help

We help everyone affected by a terminal illness get the information and support they need, including people who have been bereaved.

### Marie Curie Support Line

**0800 090 2309\***

For confidential emotional support and practical information on all aspects of terminal illness. Open 8am to 6pm Monday to Friday and 11am to 5pm Saturday. Your call may be recorded for training and monitoring purposes.

### Marie Curie Online Chat

You can talk to our trained staff and get information and support via our online chat service.

**[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

### Marie Curie Community

Share experiences and find support by talking to people in a similar situation.

**[community.mariecurie.org.uk](https://community.mariecurie.org.uk)**

### Marie Curie Information

We have a range of free information available to view online or as printed booklets.

**[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

### 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. Our hospices also support people who have been bereaved, and some offer support for children.

**[mariecurie.org.uk/help/hospice-care](https://mariecurie.org.uk/help/hospice-care)**

### **Marie Curie Nursing Services**

Marie Curie Nurses and Healthcare Assistants work 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](http://mariecurie.org.uk/nurses)**

### **Marie Curie Helper Volunteers**

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 over a cup of tea, help you get to an appointment or just listen when you need a friendly ear.

**[mariecurie.org.uk/helper](http://mariecurie.org.uk/helper)**

## **Useful organisations**

### **Health information**

#### **Alzheimer's Society**

0300 222 11 22

[alzheimers.org.uk](http://alzheimers.org.uk)

Works to improve quality of life for people affected by dementia. Its website includes guidance on symptoms and care and information on local services and support groups.

#### **Complementary and Natural Healthcare Council**

020 3668 0406

[cnhc.org.uk](http://cnhc.org.uk)

Accredited voluntary regulator for complementary therapists in the UK. Find a private therapist near you.

## **Dementia UK**

0800 888 6678

[dementiauk.org](http://dementiauk.org)

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

## **Diabetes UK**

0345 123 2399

[diabetes.org.uk](http://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**

0300 500 6184

[hcpc-uk.org](http://hcpc-uk.org)

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

## **Healthtalk.org**

[healthtalk.org](http://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](http://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](http://macmillan.org.uk)

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

### **MIND**

0300 123 3393 (text 86463)

[mind.org.uk](http://mind.org.uk)

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

### **Multiple Sclerosis (MS) Society**

0808 800 8000

[mssociety.org.uk](http://mssociety.org.uk)

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

### **Motor Neurone Disease (MND) Association**

0808 802 6262

[mndassociation.org](http://mndassociation.org)

Care, research, campaigning and information about motor neurone disease in England, Wales and Northern Ireland.

### **Motor Neurone Disease (MND) Scotland**

0141 332 3903

[mndscotland.org.uk](http://mndscotland.org.uk)

Provides care and support to people affected by motor neurone disease in Scotland.

### **NHS Live Well**

[nhs.uk/live-well](http://nhs.uk/live-well)

NHS information about wellbeing, including nutrition and exercise advice.

## **Parkinson's UK**

0808 800 0303

[parkinsons.org.uk](http://parkinsons.org.uk)

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

## **Patient.info**

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](http://scope.org.uk)

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

## **Stroke Association**

0303 3033 100

[stroke.org.uk](http://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 678 1602

[ageuk.org.uk](http://ageuk.org.uk)

A charity 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 12 44 222

[ageuk.org.uk/scotland](http://ageuk.org.uk/scotland)

The national branch of Age UK for Scotland.

### **Age Cymru (Wales)**

08000 223 444

[ageuk.org.uk/cymru](http://ageuk.org.uk/cymru)

The national branch of Age UK for Wales.

### **Age NI**

0808 808 7575

[ageuk.org.uk/northern-ireland](http://ageuk.org.uk/northern-ireland)

The national branch of Age UK for Northern Ireland.

### **Befriending Networks**

0131 261 8799

[befriending.co.uk](http://befriending.co.uk)

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

### **British Association of Counselling and Psychotherapy**

01455 883 300

[bacp.co.uk/therapists](http://bacp.co.uk/therapists)

A directory of qualified therapists working across the UK.

### **Care and Repair England**

0115 950 6500

[careandrepair-england.org.uk](http://careandrepair-england.org.uk)

Help with DIY jobs around the home if you're based in England.



## **Care and Repair Scotland**

0141 221 9879

[careandrepairsotland.co.uk](http://careandrepairsotland.co.uk)

Help with DIY jobs around the home if you're based in Scotland.

## **Care and Repair Cymru (Wales)**

0300 111 3333

[careandrepair.org.uk/en](http://careandrepair.org.uk/en)

Help with DIY jobs around the home if you're based in Wales.

## **CaringBridge**

[caringbridge.org](http://caringbridge.org)

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

## **Contact**

[contactni.com](http://contactni.com)

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

## **Honey Rose Foundation**

01744 451 919

[honeyrosefoundation.org.uk](http://honeyrosefoundation.org.uk)

A charity which grants special wishes, like spa days or tickets to shows, to adults with terminal illnesses.

## **Relate**

0300 003 0396

[relate.org.uk](http://relate.org.uk)

Counselling, support and information for all relationships. The website features a search for counselling in your area.

## **Samaritans**

116 123

[samaritans.org](http://samaritans.org)

A confidential support line for people struggling to cope.

## **Equipment, adaptations and transport**

### **British Red Cross**

0344 871 11 11

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

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

### **Capability Scotland**

0131 337 9876

[capability-scotland.org.uk](http://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)

[cilni.org](http://cilni.org)

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

### **Disabled Living Foundation**

0300 999 0004

[dlf.org.uk](http://dlf.org.uk)

A charity in England and Wales providing impartial advice, information and training on independent living. Its website contains tips for buying equipment and a self-help guide called AskSARA.

## **Foundations**

0300 124 0315

[foundations.uk.com](http://foundations.uk.com)

Appointed by the Ministry of Housing, Communities and Local Government, Foundations oversees Home Improvement Agencies in England.

## **Home Improvement Agencies**

0300 124 0315

[findmyhia.org.uk](http://findmyhia.org.uk)

Website where you can find your local Home Improvement Agency.

## **Living Made Easy**

0300 999 0004

[livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)

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

## **Royal College of Occupational Therapists**

020 7357 6480

[rcot.co.uk](http://rcot.co.uk)

Visit the website or call the association to find an occupational therapist.

## **Shopmobility**

01933 229 644

[nfsuk.org](http://nfsuk.org)

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

## Financial and legal support

### **Benefits Enquiry Line (Northern Ireland)**

0800 022 4250 (textphone 028 9031 1092)

[nidirect.gov.uk](http://nidirect.gov.uk)

Contact the advice line for information about benefits in Northern Ireland. You can also download most application forms and guides from here.

### **Citizens Advice**

03444 111 444

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

Citizens Advice provides access to information on your rights, including benefits, housing and employment, and on debt, consumer and legal issues.

### **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:**

0800 731 0122 (textphone 0800 731 0317)

### **Disability Living Allowance:**

If you were born after 8 April 1948

0800 121 4600 (textphone 0800 121 4523)

If you were born on or before 8 April 1948

0800 731 0122 (textphone 0800 731 0317)

## **Employment and Support Allowance:**

New style ESA:

0800 328 5644 (textphone 0800 328 1344)

Contribution-based and income-based ESA:

0800 169 0350 (textphone 0800 023 4888)

## **Personal Independence Payment:**

0800 121 4433 (textphone 0800 121 4493)

## **Carer's Allowance Unit:**

0800 731 0297 (textphone: 0800 731 0317)

## **Equality Advisory & Support Service**

0808 800 0082 (textphone 0808 800 0084)

[equalityadvisoryservice.com](https://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](https://equalityni.org)

Supports people with equality and human rights issues in Northern Ireland.

## **GOV.UK**

A directory of government benefits and services in England, Wales and Scotland, including bereavement benefits and pensions.

## **gov.scot**

The Scottish government website. Find information about what to do after a death and local contact details.

### **Law Society (England and Wales)**

020 7242 1222

[lawsociety.org.uk](http://lawsociety.org.uk)

Find a solicitor in England and Wales.

### **Law Society Scotland**

0131 226 7411 (textphone: 0131 476 8359)

[lawscot.org.uk](http://lawscot.org.uk)

Find a solicitor in Scotland.

### **Law Society Northern Ireland**

028 9023 1614

[lawsoc-ni.org](http://lawsoc-ni.org)

Find a solicitor in Northern Ireland.

### **Office of Care and Protection (Northern Ireland)**

0300 200 7812

[courtsni.gov.uk](http://courtsni.gov.uk)

The Office of Care and Protection (Northern Ireland) supervises 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.

### **[nidirect.gov.uk](http://nidirect.gov.uk)**

The Northern Ireland government portal includes online information about all aspects of money, tax and benefits.

### **PIP Centre**

For queries about Personal Independence Payment if you live in Northern Ireland.

0800 012 1573 for new claims

0800 587 0932 for existing claims

0800 012 1574 textphone for new claims

0800 587 0937 textphone for existing claims

## **Society of Will writers**

01522 687 888

[willwriters.com](http://willwriters.com)

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.

## **Turn2us**

[turn2us.org.uk](http://turn2us.org.uk)

A charity which provides people with financial support and information on benefits and grants.

# **Support for carers**

## **Care Information Scotland**

0800 011 3200

[careinfoscotland.scot](http://careinfoscotland.scot)

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

## **Carers Trust**

0300 772 9600

[carers.org](http://carers.org)

Provides support and information for carers through its network of carers centres.

## **Carers Trust Northern Ireland**

07826 930 508

[carers.org/northern-ireland](http://carers.org/northern-ireland)

## **Carers Trust Scotland**

0300 772 7701

[carers.org/Scotland](http://carers.org/Scotland)

### **Carers Trust Wales**

0300 772 9702

[carers.org/wales](http://carers.org/wales)

### **Carers UK**

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland)

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

Provides expert advice, information and support to carers.

## **About this information**

Did you find this information useful?

If you have any feedback about the information in this booklet, please email us at **[review@mariecurie.org.uk](mailto:review@mariecurie.org.uk)** or call the Marie Curie Support Line on **0800 090 2309**.\*

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](mailto: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.

## Marie Curie – who we're here for

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

### Marie Curie Support Line

**0800 090 2309\***

Ask questions and find support. Open 8am to 6pm  
Monday to Friday, 11am to 5pm Saturday.

**[mariecurie.org.uk/support](https://mariecurie.org.uk/support)**

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

\*Calls are free from landlines and mobiles.

Your call may be recorded for training and monitoring purposes.



**Care and support  
through terminal illness**