

Being there for someone with a terminal illness

Practical and emotional support for carers



Care and support
through terminal illness

When your partner, relative or friend is ill, you may find you're the best person to support and care for them. There are many reasons why you may become a carer for a relative or friend, for example because you live with them or are their next of kin. It could also be because other family members live far away or that you want to take on this role.

This booklet includes information about what support is available to you and ways to look after your own wellbeing. It's split into sections so you can easily find the information that you need at a time that's right for you. You may find it helpful to read it alongside *Being cared for at home*, which includes more information about practical caring tasks and planning ahead if you're caring for someone at home.

Many carers simply see themselves as a supportive husband, wife, partner, son, daughter or friend. However, it's worth being aware that there are support services and networks available to you that may describe you as a carer.



You can find more information about caring for someone with a terminal illness at **mariecurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309**.*

Contents

Becoming a carer	6
Things to think about	6
Getting help from the healthcare team	8
GP	8
District nurses	9
Social workers	10
Specialist palliative care team	11
Palliative and end of life care	12
Day to day caring	13
Care at home	13
Providing company	14
Controlling pain	15
Out-of-hours care	17
Creating an emergency plan	21
Accessing health records	22
Getting equipment and adapting the home	25
Adaptations	25
Equipment	25
Getting help from an occupational therapist	26
Trying out equipment before you buy it	27
If you're a tenant	27
Financial help	27
Benefits and financial support	28
Benefits and entitlements	28
Your rights as a carer	33
Flexible working	34
Taking time off in an emergency	35
Disability discrimination	36
Your feelings	37
Talking about your feelings	38

Coping with other people's feelings	39
The person you're caring for	39
Feelings of family members and friends	41
Talking to children	42
Who should tell children?	42
Picking a time and place	44
Getting started	44
What to tell them	45
Telling a child's teacher	46
Visiting if the person becomes very ill	46
Your own needs	47
Eating well	48
Keeping active	48
Getting enough sleep	49
Complementary therapies and relaxation	49
Respite breaks and taking time out	50
Preparing for the end of someone's life	52
Spiritual support	52
When your caring role ends	53
Feelings you may have	54
Looking back	54
Other changes in your life	56
Making time for yourself	56
Taking things at your own pace	57
Bereavement support	57
Volunteering	57
How we can help	58
Useful organisations	60

Becoming a carer

A carer is someone who looks after a friend or family member who's not able to manage all their needs by themselves.

Each caring role is different. It can happen gradually or very suddenly. It can last for a short time or for years. You might care for someone two or three hours a week or they might need you all the time.

If you have a choice, think about whether you can commit to becoming the person's main carer before offering. It's physically and emotionally demanding and may take up a lot of your time.

Caring for someone can be rewarding too. You may experience a much deeper relationship with your relative or friend. You may find it comforting to be able to make their final years, months or days as comfortable as possible.

Things to think about

Think carefully about whether you have the time and energy to care for someone in what may be a demanding situation. Even if you don't have a choice about caring for someone, or wouldn't consider any other option, these questions will help you prepare for what's involved.

- Are you physically fit enough to care for someone?
- How do you cope in stressful, unpredictable and emotional situations?
- Are you well organised?
- Can you give up some of your existing commitments and your social life while you're caring for the person?
- Are you able to change your daily routine, including your sleeping patterns?

- Can you function on less or interrupted sleep?
- Do you usually adapt well to new circumstances?
- Can you complete forms and make phone calls for the person?
- Will you need to reduce your working hours, and can you manage on a lower income?

Asking yourself these questions, and answering them honestly, is important. Agreeing to care for someone and finding yourself unable to cope later on could make things more difficult for your relative or friend.

Above all, try to take each day at a time and try to keep a positive attitude for you and the person you care for.

Online support

You might find it helpful to watch some videos about the experiences of other carers. Both **mariecurie.org.uk/help** and **healthtalk.org** have a selection of video clips about caring for someone with a terminal illness. These show people discussing their own experiences of caring and cover a range of topics.

You might also find it useful to meet other people who are in a similar situation to you, through local networks and online communities like the Marie Curie Community at **community.mariecurie.org.uk**

Getting help from the healthcare team

You may come into contact with a number of health and social care professionals in your role as a carer. In this section, we introduce some of the main ones and explain how they can support you and the person you care for.

GP

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

The GP will be able to:

- prescribe medications
- tell you how you can access information and support services
- work closely with the district nurse regarding care at home
- tell you about local hospices and help you arrange a visit

GPs will work closely with other specialists (oncologists, neurologists, palliative care consultants) to give the person you care for the best care possible.

The GP may also arrange for NHS services (HSC services in Northern Ireland), such as a district nurse, to visit if you're caring for someone at home. The nursing team can:

- give injections and change dressings
- help with wound care
- help with washing
- advise on nutrition and eating (including swallowing difficulties)
- advise on drinking and fluids

- provide bowel and bladder care
- help your relative or friend stay comfortable
- provide emotional support



Layton Thompson/Marie Curie

District nurses

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

Your district nurse can also give you and the person you care for information about local services such as:

- support groups
- local hospices
- information and support centres
- organisations that offer grants
- complementary therapy practitioners
- interpreting services
- other relevant services and organisations

If you're caring for your relative or friend at home, the district nurse may also carry out a formal assessment (called a continuing healthcare assessment – see page 30) of your relative or friend's nursing and related needs, in consultation with you and your family. This is to find out how much support will be needed to keep caring for them at home.

If you don't know who your district nurse is, speak to your GP surgery or health centre. It will tell you the name of your local district nurse and how to contact them. You may not always see the same nurse, and not everyone will have access to a district nurse.

Social workers

If you and the person you care for have a social worker, they are likely to be part of your local social services department (social work department in Scotland), which is responsible for providing non-medical support in your area. There are also hospital social workers, who can arrange care packages and liaise with community social workers.

If your relative or friend wants to remain at home, you, a member of your healthcare team, or a family member can ask for a social

worker to assess both your needs and the needs of the person you are caring for. This may mean you get some support from your local council. See page 29 for more information.

The social worker can also arrange for an occupational therapy assessment to see what equipment or adaptations might be needed in your home. See pages 25–28 for more information.

Specialist palliative care team

A specialist palliative care team provides multidisciplinary medical, nursing and psychological care and treatment to people who are living with, or affected by, serious or terminal illnesses. Their aim is to relieve pain and any other symptoms causing discomfort, and improve people's quality of life.

If your relative or friend is referred to a specialist palliative care team, they will assess their needs and those of the family. They will then provide the best possible care and support in your relative or friend's home, hospital or care home – wherever they've chosen to be cared for.

The main members of a specialist palliative care team usually include:

- palliative medicine consultants
- palliative care nurse specialists
- physiotherapists
- occupational therapists
- social workers

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

Palliative and end of life care

You may come across the terms palliative care or end of life care and feel you don't know much about them. People often find these terms confusing. Palliative care is for people living with a terminal illness where a cure is no longer possible. It's also for people who have a complex illness and need their symptoms controlled. Although these people usually have an advanced, progressive condition, this isn't always the case.

The goal of palliative care is to help the person who is ill, and everyone affected by their illness, to achieve the best quality of life. It aims to treat or manage pain and other physical symptoms. It will also help with any psychological, social or spiritual needs. Palliative care includes caring for people who are near the end of their life. This is called end of life care.

Palliative care teams are very aware that caring for someone who is ill can have a big impact on family members and friends. The team will do what it can to help people cope.

End of life care

End of life care is an important part of palliative care for people who are nearing the end of their life. It's for people who are considered to be in the last year of life, but this timeframe can be difficult to predict. End of life care aims to help people live as well as possible and to die with dignity. It also includes additional support, such as help with legal matters. End of life care continues for as long as someone needs it.



Chris Renton/Marie Curie

Day to day caring

Care at home

If you're caring for someone at home, it's likely that you'll be carrying out some basic medical and care tasks. These might include:

- reminding the person or helping them to take their medication
- helping the person to stand, walk or get out of the house
- washing, dressing, shaving, or brushing their hair
- managing their toilet needs
- getting the person in or out of bed and making them comfortable
- preparing food and drink

We really wanted to look after Mum at home but she initially wanted to go back into a hospice – I suppose she didn't want to burden us. I found that really hard because the only control we had as a family was Mum's care.

Natalie, Carer



Layton Thompson/Marie Curie



We have more information about this type of care in our booklet *Being cared for at home* and on our website at **mariecurie.org.uk/help** You can order the booklet for free by calling **0800 090 2309**.*

Providing company

Carrying out practical tasks often feels like the most important thing you can do for a relative or friend. But often what's most helpful is to find time to listen to them and keep them company. Don't worry if you can't think of anything to say. Encourage friends and family to visit too, but ask them to call first.

Your relative or friend might want to talk about the past, going over

good memories, and possibly some regrets too. Try to just listen and not pass judgements of your own, but be mindful of burdening yourself.

They'll probably want to do things by themselves if they're well enough. They're also likely to get tired more quickly than they used to and might need to nap during the day. They may also want and need help to do specific activities, like watching a film or going for a walk.

Controlling pain

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

What causes pain?

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

Pain management

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

Getting help

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

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

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

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

Helping someone communicate

If you're caring for someone who has trouble communicating, ask the nurse or doctor for other ways to tell if they're in pain. They might suggest a visual chart or picture cards if the person can't speak. If they can't communicate at all, there are several signs to look out for, including:

- high pulse
- changes in breathing
- changes in mood
- agitation or increased temper
- lack of concentration
- withdrawal or refusal to make eye contact

If you notice any of these things or are worried that your friend or relative is in pain, speak to a member of the healthcare team.



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



Layton Thompson/Marie Curie

Out-of-hours care

Many people prefer to be cared for at home in familiar surroundings with the people they're closest to. However, terminal illness can be unpredictable and there may be times when your friend or relative might need more care than you can provide. This can be especially difficult at night or in the early morning when their usual healthcare team might not be available.

If you're worried about what to do during these times, or just want some reassurance, you can get in touch with your local out-of-hours (OOH) service. It's a useful source of health advice and support and there doesn't have to be an emergency for you to contact it.

What is out-of-hours care?

Out-of-hours care is there to take care of your friend or relative's needs outside of the regular healthcare team's working hours. Normally this is from around 6:30pm to 8am on weekdays, and weekends and bank holidays when regular health services might not be available. Different types of care make up the service and your friend or relative might be treated by some or all of the following:

- a GP from another practice
- healthcare teams in primary care centres, accident and emergency, minor injury units or walk-in centres
- health workers (other than doctors) making a home visit
- ambulance services that will bring you to a doctor or nurse

Why might you need out-of-hours care?

You should consider contacting out-of-hours services if your friend or family member has symptoms that you can't manage, like extreme pain or agitation, and it's too late or early to contact their usual doctor or nurse. You can also get in touch if you're worried and want some reassurance. The service is there to help and you shouldn't feel as if you're bothering healthcare staff.

Accessing out-of-hours care

Getting access to out-of-hours care is straightforward and if you ring the GP surgery outside of its regular hours you should be directed to the service. Sometimes this may be a recorded message with more details on who to contact, so it might help to have a pen and paper handy.

If you don't have your surgery's contact details, you can find them by contacting one of the organisations on the next page.

HSC (Northern Ireland)

servicefinder.hscni.net or nidirect.gov.uk/out-of-hours-service

NHS 24 (Scotland)

www.nhs24.com/findlocal

Phone: 111

NHS Direct (England)

nhs.uk/service-search

Phone: 111

NHS Direct (Wales)

www.nhsdirect.wales.nhs.uk

Phone: 0845 46 47

In an emergency, you should ring 999.

What to expect

When calling an out-of-hours service, you may be asked some questions by an adviser so they can get you help. They then decide who you need to be put in touch with and can arrange a call back or house call from a doctor, nurse or other health worker. Services like NHS 111 can also send an ambulance if needed.

You may feel frustrated at being asked a lot of questions when someone close to you has difficulties. Try to stay calm and give the out-of-hours service all the detail that you can. If you'd rather not speak to them, you could ask a family member or carer to contact them instead, although you may want to stay nearby during the call to answer questions that they can't.

You can ask your GP to send a summary of your notes to the out-of-hours service so they can be prepared in an emergency.

Will my friend or relative have to go to hospital?

If your friend or relative prefers to stay at home while they're being cared for, a hospital admission may not be welcome. Depending on how their symptoms are managed they might have to go to hospital as a result of contacting out-of-hours care.

It's important that their wishes are made clear. Having a care plan in place will help with this. However, try not to feel guilty if plans change. Things don't always work out as expected. Your own wishes and practical limitations need to be considered too.



We have more information about care planning at **mariecurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309**.*

Managing symptoms at home

Being able to manage symptoms at home can help with avoiding an unwanted admission to hospital. In some cases a syringe driver can give a steady amount of medication to keep your friend or relative comfortable. A syringe driver helps reduce symptoms by delivering a steady flow of injected medication continuously under the skin.

It may also be possible to get a Just In Case box from the NHS in England, Scotland and Wales for home use. This can contain medication for breathlessness, agitation and breakthrough pain. It might have another name in your area, so ask your nurse or doctor for details. Your district nurse or doctor may be able to arrange something similar if you live in Northern Ireland.



We have more information about managing symptoms and syringe drivers on our website at **mariecurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309**.*

Overnight nursing care

Marie Curie specialises in overnight care and can arrange for an experienced nurse or healthcare assistant to be there for your friend or relative. They can help by administering medication for symptoms, giving emotional support and letting you have a chance to get some rest.

This kind of care is not an emergency service and is usually organised in advance, but a Marie Curie rapid response service is available at short notice in some areas. Your district nurse or GP will be able to help you with arranging care from a Marie Curie Nurse or call the Marie Curie Support Line on **0800 090 2309*** for more information.

Creating an emergency plan

Having an emergency plan can give you peace of mind in case something unexpected happens. If you fall ill or have to go into hospital, you need to know someone will step in to look after the person you care for.

What should I include?

Your emergency plan should include:

- the name, address and contact details of the person you care for
- details of any people you would like to be contacted in an emergency – for example, family, friends and health professionals
- a list of medication the person you care for is taking and details of their ongoing needs
- information on where essentials are located within the person's home

Who should I involve?

You may have family members or friends who are willing to look after the person you care for in an emergency. If so, make sure they are aware they are included in your plan.

If you don't have a personal network to fall back on, you can ask the local council, or local health and social care trust in Northern Ireland, for support. You can do this by asking for a **care and support needs assessment** for the person you're caring for and a **carer's assessment** for yourself. See page 29 for more information.

If you have a Marie Curie Nurse they may be able to help you with your emergency plan through the rapid response service that operates in some areas. They may also be able to provide out-of-hours support.

Emergency carer card schemes

Some parts of the UK have emergency carer card schemes set up by the local council or carers centre. These schemes provide a 24-hour response service, which you can call in an emergency.

Contact your local carers organisation to find out if there is a scheme in your area. You can search for this on the Carers UK website (see page 61) or call the Carers Direct helpline on **0300 123 1053**.

Accessing health records

You may need to access your relative or friend's health records for them. This could be to track their treatment or to get a better idea of their needs.

A health record is any record of information (electronic or paper-based copy) about the person's physical or mental health that has

been made by or on behalf of a health professional. Some examples are results of an MRI scan or x-rays and daily records of patient care.

Depending on what records you want to see, you'll need to submit a subject access request by email or in writing to where the records are held. This could be:

- the person's doctor
- the health records manager at the hospital where the person was treated
- any other place that holds personal information

You'll need the person's permission to make a request. You should send a copy of the person's written permission with your request if possible. If the person is unconscious or unable to give consent, their health professionals can decide about the use of information.

You can also access a person's health records if you have Power of Attorney for health and welfare, welfare Power of Attorney (in Scotland), or welfare guardianship.

If you're considering accessing a person's information where that person is unable to consent, you should be clear that it's in their best interests, and respects their wishes. You should also consider the feelings of other family members and carers.

Fees

An organisation may charge you a fee of up to £10 to access this information electronically. The fee can be up to £50 if you want a paper-based copy of the records, depending on the amount of administrative work needed. However, these fees are sometimes waived.



Getting equipment and adapting the home

Adapting your home or getting specialist living equipment can make life much easier for people having difficulty with daily activities. These can usually be provided fairly quickly and you may be able to get help with paying for them (see page 27) or get them on loan.

Adaptations

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

Equipment

Common pieces of equipment include:

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

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

Getting help from an occupational therapist

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

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

The occupational therapist's involvement can form part of a care and support needs assessment.

This is carried out by your local social services department and includes a discussion about the kinds of care tasks the person is able to carry out unassisted. They may then be eligible for financial assistance. See page 27 for more information.

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

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, which helps me with my disability. This means I can be comfortable in my own home.

Willie, living with a terminal illness

You can also access them privately. The British Association for Occupational Therapists and the College of Occupational Therapists has a searchable directory to find independent therapists in your area. See page 69 for contact details.

Trying out equipment before you buy it

It's a good idea to try out all equipment before you buy it. If you're considering buying an expensive item, ask to use the equipment for a trial period in your own home or check if you can try the equipment in-store. If you would then like to buy it, you may want to get a care and support needs assessment (see page 29) to see if you're eligible for any financial help. Some suppliers also offer second-hand equipment at a cheaper price. Ask the installation team to show you and your relative or friend how any equipment works.

If you're a tenant

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

Financial help

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

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

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



We have more information about financial help for equipment and adaptations at **mariecurie.org.uk/help** or call the Marie Curie Support Line on **0800 090 2309**.*

Benefits and financial support

Depending on whether you're a full or part-time carer, you could find yourself with less time to work or a smaller income. Whether you see yourself as a carer or not, help is available from many sources, including the government, your local council, charities and grant giving trusts.

Benefits and entitlements

The benefits system can seem like a maze. There are many different types of benefit, paid for all sorts of reasons. It's worth checking if you can claim any benefits, tax credits or other financial help. It's also worth regularly reviewing 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 over 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 60-70 for contact details).

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

Help from social services

If you or the person you're caring for need practical support, you may qualify for help from social services.

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

You may be able get help too. This help could include getting someone to be with the person you care for while you're out – sometimes called respite care (see page 50). Or it could be assistive technology that can help reassure you that they remain safe at home when you're not there. It might even include details of a local carers' support group.

How to apply

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

Generally, councils can charge for care services. Some local authorities only charge for some services, for example, meals on wheels or home

helps. If you live in Scotland, are aged 65 or over, and get personal care or personal support care at home, you should get this free of charge.

NHS continuing healthcare

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

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

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

- has a complex medical condition
- needs substantial and ongoing care

Continuing healthcare covers care home fees including: accommodation costs, healthcare costs and personal care costs. If the person needs care at home, it covers personal costs and healthcare costs.

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

How to apply

You'll need to arrange an initial assessment through:

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

When you apply, it's also a good idea to get support from someone who understands how the system currently works, as the rules change quite often. Citizens Advice (page 63) is a good place to start.



We have more detailed information about continuing healthcare at mariecurie.org.uk/continuinghealthcare or call us on **0800 090 2309**.*

Benefits for carers

Carer's Allowance

This is a weekly benefit for people who regularly spend at least 35 hours a week caring for someone who has a health condition or disability. If you're entitled to it, you may be able to get a **carer premium**, which is an additional payment that comes with certain benefits.

Carer's Credit

Some carers can't pay National Insurance (NI) contributions because they're not working or aren't earning enough. If you're in this situation, you may be able to protect your State Pension by gathering Carer's Credits in place of the NI contributions.

Benefits for people who are ill or disabled

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

Attendance Allowance

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

Personal Independence Payment

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

Disability Living Allowance

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

Employment and Support Allowance

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

How to apply

Social security benefits are handled by the Department for Work and Pensions (England, Scotland and Wales) and the Social Security Agency (Northern Ireland). There are different branches depending on the benefit you're applying for. See pages 60–70 for contact details.



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

Your rights as a carer

As a carer, you may be able to arrange flexible working or get time off in an emergency. You're also protected by law from unfair treatment and harassment.



Layton Thompson/Marie Curie

Flexible working

If you're employed and care for someone, you can ask for flexible working. This can help you to balance your work and caring responsibilities.

Flexible working usually means a permanent change to your employment contract to help you balance your work and caring responsibilities. It doesn't just mean working reduced hours. It could be a compressed working week (fewer but longer days), a job share with someone else, finishing earlier or more time working at home.

You don't have a legal right to flexible working, but you do have the right to request it if you've worked for your employer for at least 26 continuous weeks and you haven't made any other flexible working requests in the past 12 months. You also need to be one of the following:

- A parent of young or disabled children.
- A carer for your wife, husband, civil partner or partner, or considering becoming one.
- Caring for a near relative or someone you live with.

Your employer can only refuse a request for certain reasons and if it's reasonable to do so. For example, if they can show that flexible working would have a negative impact on their business.

How do you apply for flexible working?

You'll need to apply to your employer in writing. There is a helpful template application form on the **GOV.uk** website and the Working Families website (**workingfamilies.org.uk**) has a step-by-step guide.

Next, your employer should meet you to talk about your suggestions. These meetings don't have to be formal and they're a chance to negotiate. You can take a colleague or trade union representative with you if you wish.

Taking time off in an emergency

If you work for an employer you have the right to take unpaid time off work to deal with an unexpected event involving someone who depends on you. Your employer cannot penalise you for taking the time off as long as your reasons are genuine. However, they don't have to pay you for the time you take off.

Who counts as a dependant?

The definition is very broad. It could be your husband, wife or partner, child or parent, or someone living with you who isn't a tenant, lodger, boarder, or your employee. Others who rely on you for help in an emergency may also qualify, like an older neighbour.

How much time can you take off?

The amount of time you can take by law is only described as a **reasonable amount**. In some cases this is only a couple of days.

Other rights

You should also check if your employment contract allows for other help with taking time off, beyond what is set by law.

How do you apply?

There is no set way to do this. You must simply let your employer know the reason you need to take time off from work and for how long you expect to be away (unless it isn't possible for you to know how long you will be away until you return). You should also keep your employer updated on what is happening and make arrangements to come back to work as soon as you can.

Disability discrimination

People who experience unfair treatment (discrimination) because of their illness or other disability, and those associated with them, are protected under the Equality Act 2010. In Northern Ireland these rights are covered by the Disability Discrimination Act 1995.

The Equality Act makes it unlawful to discriminate against people because of a disability in connection with:

- employment
- education
- transport
- housing
- buying goods and services

This list covers some of the main areas under which people are protected by the Equality Act, but this protection isn't limited to these areas.

How is disability defined?

A disability is a **physical or mental impairment** which has a **substantial** and **long-term** adverse impact on someone's ability to carry out **daily activities**. Substantial means more than minor or trivial. An illness can count as substantial if someone has an illness that:

- will get worse over time, and as soon as it has any impact (as long as that impact is likely to become substantial)
- is likely to recur
- has effects that are being helped by treatment

Long term normally means 12 months or more. For people with a terminal illness, it means likely to last for the rest of their life (if that is less than 12 months). Some conditions like cancer and multiple sclerosis count as a disability from the date of diagnosis.

What is prohibited conduct?

There are four main types of behaviour in relation to disability that are unlawful under the Equality Act:

- **Direct discrimination** is where someone treats someone else less favourably specifically because of their disability (actual or perceived) or the disability of someone associated with them.
- **Indirect discrimination** is where a group of people are treated in the same way, but in a way that is more likely to negatively affect only particular people within that group, due to their disability.
- **Harassment** is where someone gives another person unwanted attention because of that person's disability with the intention or effect of violating that person's dignity or creating an intimidating, hostile, degrading, humiliating or offensive environment for that person.
- **Victimisation** is where someone is treated unfairly because they've made a complaint. For example, they have made a complaint about being discriminated against under the Equality Act.

Treatment of carers

While being a carer isn't in itself protected by the law from discrimination, there is protection if someone suffers from discrimination because of the disability of the person they are caring for. This means that a carer may bring a disability claim for **disability by association**, as long as they can show that the disability of the person they are caring for is the reason why they, the carer, are being unfavourably treated.

Your feelings

When you're taking care of someone who's ill, it's important to look after your own wellbeing too.

Being a carer can put pressure on relationships, make it difficult to keep up friendships and can often mean less time for socialising. All of this can make you more withdrawn from your usual relationships and make you feel alone.

You may feel resentment and guilt, and experience stress or feel low. It's better to face your feelings than ignore them, as they may be causing you discomfort, and may get worse.

It can make life feel more difficult and make it harder for you to function well if you're feeling strong emotions without expressing them. You may feel comfortable talking about your feelings, or prefer to express yourself through art, sport or relaxation techniques.

Talking about your feelings

Talking to others about your feelings, like a friend, counsellor or someone at a local support group, may help you to deal with your emotions and the impact that being a carer may have on your life.

It's important to have someone who will listen to you. If you'd rather not discuss your feelings with someone you know, you may want to get in touch with your local carer centre for support from people in a similar situation. Carers UK or Carers Trust can help you find a group near you (see page 61). The Marie Curie Helper service (see page 59) will also be able to offer support.

The hospice staff were very honest in what was happening to Mum, which I appreciated. Not everyone wants to know how long is left, but I did, I wanted to be prepared, or at least as much as I could be.

Rebecca, Carer

If you're finding your feelings overwhelming, try to discuss them with your GP. They may be able to organise free counselling for you,

depending on where you live. You can also find a paid-for counsellor through the *It's good to talk* directory (see page 69). It can help to speak to the counsellor before committing to pay for any sessions so you feel at ease with them.

Online communities

Online communities like the Marie Curie Community at **community.mariecurie.org.uk** can be useful when it comes to finding people in similar situations. They can often be a good place to get information or to share your experiences, especially if you feel unable to talk.

Coping with other people's feelings

Just as you have strong feelings and may struggle to cope at times, others might feel the same and look to you for support.

The person you're caring for

The person you're caring for is very likely to have good and bad days, or times of day. They may also try to hide their feelings or behave in ways that you don't expect. They could change from not wanting to upset you by talking about their illness to blaming you for it.

At other times they may act as if nothing is bothering them. This can be very distressing and may affect your relationship with the person.

It's likely that your relative or friend will experience a range of strong emotions. These can include:

- acceptance
- anger
- denial
- fear
- frustration
- helplessness
- sadness
- shock
- apathy
- relief

If they're struggling to cope with such strong and varying emotions, you could encourage them to talk to someone. This could be a doctor or nurse, members of a support group, or a counsellor.

Healthcare professionals can help, so don't hesitate to talk to them about how you or the person you care for are feeling. Marie Curie Nurses and Macmillan nurses can be a good place to start.

Aggression and loss of control

Your relative or friend may display emotions that you're not used to seeing. They could become aggressive and angry. Remember that they're losing a lot of control over their lives, as their illness may severely limit what they can do for themselves and the choices they have. They're likely to have a lot on their mind.

Try to encourage them to do as much as they can for themselves, and let them make their own choices or decisions whenever possible. This may help them feel more in control and give them a better sense of wellbeing.

Confusion and forgetfulness

You may find they become confused or forgetful. This may be related directly to their illness and general physical condition or there could be another cause. It's easy to lose a sense of time when you're ill, sleeping a lot or in the same place every day. This can also increase existing short-term memory loss or early dementia.

If your relative or friend had a very structured life, it may help them to keep to a routine, for example having set meal times and doing a particular activity on the same day each week. Similarly, if they used to have an irregular routine they might find a rigid schedule too restrictive.

Feelings of family members and friends

As your relative or friend's carer, you're likely to be the main person that other family members and friends contact to:

- find out how they're doing
- ask questions about their medical condition
- share their feelings

Family and friends might feel upset, frightened, angry, frustrated or confused. You'll often be the person telling them things, so you'll see their reactions and may find yourself feeling that you need to comfort or calm them.

A good way to avoid becoming an informal counsellor for friends and family is to remind people gently of your own reactions to any news. For example, "Yes, when I first heard I was very upset...". This reminds others that you have feelings too and often a close personal relationship with the person you're caring for.

It can also be helpful to make one or two other close family members or friends points of contact for updates on changes and outcomes of appointments for friends and family. Carers UK has a phone app called Jointly, to make communication easier.



We have more ideas about how friends and family can help on our website at mariecurie.org.uk/help

You could find that other people may be in denial or too optimistic about your relative or friend's condition. They may try to convince you to be more hopeful. This can be hard to cope with if you know their hope is likely to lead to disappointment.

It's helpful to remember that you're not responsible for other people's feelings and they need to take care of themselves. You could suggest

they join a local support network or visit a website that gives support to friends and relatives. There are also some support lines for friends and relatives that they may find helpful. See pages 58-70 for details.

Talking to children

You may need to speak to children about your relative or friend's illness. They could be your own children, grandchildren, great-grandchildren, nieces, nephews, or other children in your life. Whatever your situation, you may need some support.

Who should tell children?

If you're caring for your partner, it's usually best to do this together, but this may depend on how you normally talk as a family. Some people who are ill find this too difficult and ask their partner to talk for them. If this is the case, they may still want to be in the same room, depending on how they feel.

Another option is to ask a professional involved in your relative or friend's care to be there, so they can help to answer the children's questions. You may also find it helpful to speak to a professional for advice on what to say beforehand.

If the child you're speaking to is not your own child, you may find it best to talk about the person's illness with their parents present, or ask them to break the news. The child may then feel more able to ask questions and talk about their feelings with their parents.



Picking a time and place

It's usually best to let children know what is happening as soon as possible. It's also important not to underestimate how much children pick up, even very young ones. They're often sensitive to tensions and unease in the family.

Sometimes adults think that children will be unaffected if nothing is said. In fact, this can have a negative effect on a child because they may begin to blame themselves. It's usually much better to be honest.

Not talking about the person's illness may also make a child feel very lonely and afraid. Generally, children feel better if they're included and valued. This will also give them time to prepare for the future, minimising unnecessary anxiety and distress.

Choose a place where the child is likely to listen to what you're saying, feel comfortable asking questions and feel able to show their emotions, like their bedroom or somewhere else in the home. You may also want to find a place where you're unlikely to be interrupted.

Getting started

You may want to sit at the same level as them, for example if they're sitting on the floor. This will help you feel closer to them and get their attention.

There's no right or wrong way to begin such a difficult conversation. But you could start by talking about what the doctors have told you. For example, "The doctors have said that (the person) is ill and they will make sure they're not in pain, but they can't make them better."

It may also be helpful to view your first talk as the beginning of an ongoing process. You don't have to go into too much detail and it's best not to give the child too much information. You can gradually build up, giving them small chunks of information over time.

As your talk progresses, allow it to be directed by the child's reactions and questions. Also try to ask questions that encourage them to express what they're thinking and feeling. For example, you could begin questions with: "What do you feel about...?"

What to tell them

Children want adults to be honest, so give them an accurate picture of what is happening. If you're vague or hide things, they'll find it hard to believe you either now or later. Children who aren't told enough may also feel angry that they're being excluded.

Also remember there may not be any right words to express what is happening and how you and the person you're caring for are feeling. It's also fine to let the child know that you don't know the answer to a question. Tell them you'll try to find the answer and let them know as soon as you can.

What you tell a child will also depend on their age and understanding of serious illnesses. A teenager may understand more and want to talk in-depth about the person's illness. They could also appear to not care at all. Try not to be offended by this – it's just their way of coping.

Teenagers may also need more time to sort through their feelings. And they may want to discuss what the illness means for family life, especially if you or the person you're caring for is their parent and the family's financial situation is likely to change.

Telling a child's teacher

If the person who is ill is the child's parent, you may want to talk to their teacher or head teacher. You could ask them to let you know how the child is coping. Teachers can be very supportive if you keep them updated.

If you tell a child other than your own about the person's illness, for example, a grandchild, you may want to suggest to their parents that they do the same.

Visiting if the person becomes very ill

If your relative or friend's condition gets worse and they have to stay in a hospice or hospital, they may want children to visit. It's usually helpful to include children at this stage, although they may not wish to stay very long. They may also feel awkward or bored. Depending on the child's age, you could ask whoever is bringing them to pack a game or toy to keep them occupied.

The person who is ill may not want the child to visit, or the child themselves may not want to. In that case, you may want to ask them to make a picture or card, tape a message, or write a letter or poem.

Because some illnesses and treatments affect the way a person looks, you may be worried about how a child will react to any change in the person's appearance. If this is the case, it's a good idea to tell children in advance about what to expect and reassure them that they're still the same person.



We have more information about supporting children and family relationships at mariecurie.org.uk/help or call the Marie Curie Support Line on **0800 090 2309**.*

Your own needs

When you're caring for someone else, it can be easy to forget to take care of yourself. But taking time to look after your own health and wellbeing will benefit both yourself and the person you're caring for.

Being a carer can be both physically and emotionally draining. Carers are more likely to experience physical and mental health problems than people without caring responsibilities, like back pain, anxiety and depression. However, there are things that you can do to look after your own health, and support is available if you feel unable to cope.



Layton Thompson/Marie Curie

Eating well

A healthy diet is important no matter who you are. Eating well can help give you the energy to provide the best care you can.

A balanced diet includes:

- at least five portions of fruit or vegetables a day
- starchy foods such as bread, pasta, potatoes and cereals
- some protein, such as meat, fish, eggs and beans
- some dairy products, such as milk, cheese and yoghurt

It's healthy to limit the amount of salt, sugar and saturated fat in your diet. Choose low fat dairy options if you're trying to cut down on fat in your diet.

The NHS Live Well website ([nhs.uk/livewell](https://www.nhs.uk/livewell)) has more information on eating well, and Carers UK (see page 61) offers money and time-saving tips for healthy eating.

Keeping active

Exercise can help you feel physically fitter and stronger. It's also good for your mental health as it releases chemicals in your brain which can lift your mood. Exercising during the day can also help you sleep better.

It can be hard to find time to exercise when you're caring for someone, especially if you can't leave them alone. Don't be afraid to ask for, or accept help from friends or relatives who offer to sit with your relative or friend while you do some exercise.

Sometimes even a 10-minute walk can help relieve stress and you can also do certain kinds of exercise, such as gardening and yoga, without having to leave the house.

If you don't have a personal support network, there are organisations that provide respite care. This is when someone takes over your caring responsibilities for a short time to allow you to take a break. Respite care could be for a couple of hours a week or for a longer amount of time. See page 50 for more information.

Getting enough sleep

It can be difficult to get a good night's sleep when you're a carer. The person you're looking after may need help during the night or you may feel unable to leave them. Worrying about your family member or friend, money issues and other stresses can also keep you awake.

If you're having problems sleeping for more than a few nights, speak to your doctor. Marie Curie may also be able to help care for your relative or friend overnight. Call the Marie Curie Support Line on **0800 090 2309*** for more information.

Carers UK and NHS Live Well have further tips and advice on sleep. See page 58-70 for contact details.

Complementary therapies and relaxation

Try to include some relaxing activities in your day, even if it's just a short walk while someone else is visiting your relative or friend.

Complementary therapies may also help you to feel more relaxed or to sleep better. They can also be used to relieve pain and tension in the body. These therapies include:

- acupressure
- acupuncture
- aromatherapy

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

Finding and paying for complementary therapy

Some complementary therapies are provided free of charge to carers, so speak to your doctor or nurse about what's available in your area. Your local hospice or a local support group may also offer free or reduced cost therapies. Marie Curie has nine hospices throughout the UK (see page 59 for more information) or you can search for a local hospice on the Hospices UK website at **hospiceuk.org**

If you'd like to find a private therapist, the British Complementary Medicine Association has a directory of qualified therapists listed by area on its website (**bcma.co.uk**). Private therapists can be expensive, so it's worth checking the cost first.

Respite breaks and taking time out

Everyone needs time to themselves. When you're caring for someone who is ill, taking time out is important for your health and wellbeing. If you're unable to leave your relative or friend alone, alternative care is available.

What is a respite break?

A respite break simply means taking a break from caring. What sort of break, and for how long, is up to you. You may feel you need to have short regular breaks to enjoy a hobby, get some exercise, take care of your own needs or catch up on some sleep. Alternatively, you may need a longer break or holiday.

Respite care can either mean someone else looking after your friend or relative in their home, or the person who is ill spending time in residential care, a nursing home, or a hospice.

How do I get a respite break?

Sometimes family and friends may be able to help share your caring responsibilities. If you don't have a personal support network, there are other options.

If you're spending a lot of time caring for someone on a regular basis, you have the right to a carer's assessment. This covers your own needs, including your need for a break and time to yourself. Once you have had the assessment, the local council (local health and social care trust in Northern Ireland) must consider providing respite care (although they may charge you for this).

Carers UK and Carers Trust have more information about the different kinds of respite care that social services and local carers centres can offer. See page 61 for contact details.

Preparing for the end of someone's life

Everyone is different, so it's not easy to say exactly what will happen when the end of someone's life gets closer. But in the last weeks and days before death, it's common to experience certain changes in the body and mind.

Learning about these changes can make the future seem less frightening. It also helps with thinking ahead: what care will be needed, where is the best place to be, and how can family and friends be prepared?

This knowledge can be useful if you feel able to talk to your partner, relative or friend about their wishes. It can also help you to arrange their care so these wishes can be met. These decisions have to be guided by what the person really wants as they approach the end of their life, and their wishes must come first.



For more information about preparing for the end of life, visit mariecurie.org.uk/help or order our leaflet *What to expect at the end of someone's life* by calling **0800 090 2309**.*

Spiritual support

If you would like more support at this time, you may want to speak to a spiritual adviser or faith leader. Most faith leaders will have been through this experience with many others and they're happy to help people of any or no religious faith.

Ask your hospital or local hospice to put you in touch with someone nearby. Most hospitals and hospices offer religious, spiritual and pastoral care, with representatives from different faiths. It's difficult

to think about this now, but faith leaders may also help your partner, relative or friend have a calmer death and create a sense of deep respect when the time comes. They can also support you before and after the person you care about has died.

Caring for someone near the end of their life is hard, and having this kind of support can help you stay strong, so you can be there for the person you care about.



Getty Images

When your caring role ends

It can be hard to adjust to changes in your life when your caring role ends. Taking care of your relative or friend may have been your focus and it can often be a shock not to have those responsibilities any more. There will be many activities that have been a part of your daily routine that you no longer need to do.

Feelings you may have

You may suddenly feel a lack of purpose, now that you don't have someone to look after. Or you may feel relieved. Don't feel guilty if you do – it's a natural reaction to the pressure being taken away.

It's likely you'll have shared experiences with the person that no one else knows about. If they've died, it can seem as if part of your own life has disappeared too. Looking at old photos or writing down your memories can help bring those times to life again for you.

You might find that people who had always asked you about the person no longer know what to say. They may talk about everything except your relative or friend. This could be upsetting, or you may be grateful.

Looking back

Think about your experience of caring as a whole, the good parts and the bad. This may help you to understand it as a role with a clearly defined start and finish.

There may be some aspects of caring that you'll miss. Perhaps you liked having company every day and felt good about being able to comfort your relative or friend. You may have felt proud of being able to help them live the last part of their life in a place they wanted to be. Or you may have felt stressed that you weren't doing a good enough job. How you coped will have depended on your personality as much as events that took place. Now more than ever, don't be too hard on yourself.



Other changes in your life

As your relative or friend's carer, it's likely that you won't have had much time to spend with friends. But you'll have had regular contact with nurses, doctors and healthcare professionals involved in your relative or friend's care.

You'll probably have built up relationships of trust with many people who you won't necessarily see any more, for example hospital staff. This can be a shock, and you may feel quite lonely and isolated.

Some carers find that they want to continue these relationships, for example by returning to the hospice as a volunteer. It's a good idea to wait until a year after your relative or friend has died before volunteering at a hospice, as it may be too upsetting to return earlier.

You can also stay connected with Marie Curie by joining our Expert Voices Group. This is a group of people with experience of caring for someone with a terminal illness. They help us develop the support we offer to people with terminal illnesses and their family and friends. Contact us on **0800 090 2309*** to find out more.

Making time for yourself

Think about what you used to like doing before your caring role started. If you kept a diary it may surprise you to remember all the different things you used to do.

This is likely to be a painful time for you and you may not feel like taking up activities that you used to enjoy. But it's good to rediscover your own needs and interests after putting yourself second for such a long time. You may find the suggestions for looking after yourself on pages 47-50 useful too.

Taking things at your own pace

Try not to rush into lots of new activities and social groups. If you're grieving you might feel isolated, even within a group.

When you're ready, Carers UK (see page 61) has useful information about finding new activities to focus on. You can also call the Marie Curie Support Line on **0800 090 2309*** for information and support.

Bereavement support

It can be a very upsetting time when a relative or friend dies, so emotional and spiritual care for you and those around you is important.

Your nursing team, including your Marie Curie Nurse if you have one, can help. They can also arrange further bereavement support, so that family and friends don't have to cope with their feelings alone.

We have a free booklet about practical and emotional support during bereavement. Call the Marie Curie Support Line on **0800 090 2309*** to order it or to find bereavement services near you. We've also listed some organisations that offer free bereavement support on page 62.

Volunteering

When an appropriate period of time has passed, you may begin to feel like meeting new people again, as well as discovering new activities. One way of doing this is to volunteer. We have many volunteering opportunities and you might find one that suits you. Visit **mariecurie.org.uk/get-involved** or call the Marie Curie Support Line on **0800 090 2309***. The Do-it website (**do-it.org**) lists volunteering opportunities with other organisations.

Becoming a carer can feel overwhelming – you may need to take in a lot of information in a short space of time, or learn to do things you haven't done before. It's normal to feel this way and other carers have told Marie Curie that it can help to take each day at a time. Try to stay positive and don't worry about trying to be perfect.

How we can help

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

Marie Curie Support Line

0800 090 2309*

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

Marie Curie Community

community.mariecurie.org.uk

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

More information and further support

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

Marie Curie Nurses

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

mariecurie.org.uk/nurses

Marie Curie Hospices

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

mariecurie.org.uk/hospices

Marie Curie Helper

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

mariecurie.org.uk/helper

Useful organisations

General support

Age UK

0800 169 2081

ageuk.org.uk

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

Age Scotland

0800 4 70 80 90

ageuk.org.uk/scotland

Age Cymru (Wales)

08000 223 444

ageuk.org.uk/cymru

Age NI

0808 808 7575

ageuk.org.uk/northern-ireland

Care Information Scotland

08456 001 001

careinfoscotland.co.uk

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

Carers Trust

0844 800 4361

carers.org

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

babble.carers.org

Carers Trust Northern Ireland

0779 431 8403

carers.org/northern-ireland

Carers Trust Scotland

0300 123 2008

carers.org/scotland

Carers Trust Wales / Cymru

029 20 090087

carers.org/wales

Carers UK

0808 808 7777 (England, Wales and Scotland)

028 9043 9843 (Northern Ireland)

carersuk.org

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

Crossroads Caring for Carers (Northern Ireland)

028 9181 4455

crossroadscare.co.uk

Crossroads provides respite care for carers who care for an older, frail, ill or disabled friend or relative.

Crossroads Caring Scotland

0141 226 3793

www.crossroads-scotland.co.uk

Provides care at home to enable carers to take a break.

Carers Direct

0300 123 1053

nhs.uk/carersdirect

Has information for carers through its helpline and the website.

Bereavement support

Bereavement Advice Centre

0800 634 9494

bereavementadvice.org

Offers a free helpline for people who are bereaved and for professionals. It also has information on its website about practical matters and coping with grief.

Cruse Bereavement Care (England, Wales and Northern Ireland)

0844 477 9400

cruse.org.uk

Provides bereavement support, either face-to-face or over the phone, from trained volunteers around the UK.

Cruse Bereavement Care Scotland

0845 600 2227

crusescotland.org.uk

Provides bereavement support, either face-to-face or over the phone, from trained volunteers in Scotland.

Winston's Wish

08452 03 04 05

winstonswish.org.uk

A child bereavement charity which offers specialist practical support and guidance to bereaved children, their families and professionals.

Financial and legal support

Benefits Adviser Line (Northern Ireland)

0800 232 1271

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

Citizens Advice

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

adviceguide.org.uk

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

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

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

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

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

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

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

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

Equality Advisory & Support Service

0808 800 0082 (textphone 0808 800 0084)

equalityadvisoryservice.com

Supports people with equality and human rights issues in England,
Wales and Scotland.

Equality Commission for Northern Ireland

028 90 500 600

equalityni.org

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

Law Society (England and Wales)

020 7320 5650

lawsociety.org.uk

Find a solicitor in England and Wales.

Law Society Scotland

0131 226 7411 (textphone 0131 476 8359)

lawscot.org.uk

Find a solicitor in Scotland.

Law Society Northern Ireland

028 9023 1614

lawsoc-ni.org

Find a solicitor in Northern Ireland.

Stonewall

08000 50 20 20

stonewall.org.uk

A charity that supports gay, lesbian and bisexual people. It can't provide legal advice, but it can give information about civil partnerships, rights and discrimination. It also has details of solicitors and support groups.

Health information

Alzheimer's Society

alzheimers.org.uk

0300 222 11 22

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

Breast Cancer Care

0808 800 6000

breastcancercare.org.uk

A charity that helps anyone affected by breast cancer. It provides information and support, and campaign for improved standards of care.

British Heart Foundation

0300 330 3311

bhf.org.uk

The charity has a heart helpline, which is staffed by cardiac nurses and information support officers who can help you understand your heart condition, and how to keep your heart healthy.

Dementia UK

dementiauk.org

0845 257 9406

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

Diabetes UK

diabetes.org.uk

0345 123 2399

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

Macmillan Cancer Support

0808 808 00 00

macmillan.org.uk

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

Multiple Sclerosis (MS) Society

mssociety.org.uk

0808 800 8000

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

Motor Neurone Disease (MND) Association

mndassociation.org

01604 250 505

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

Motor Neurone Disease (MND) Scotland

0141 945 1077

mndscotland.org.uk

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

MIND

mind.org.uk

0300 123 3393 (text 86463)

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

NHS Live Well

nhs.uk/livewell

NHS information about wellbeing, including nutrition and exercise advice.

Parkinson's UK

parkinsons.org.uk

0808 800 0303 (textphone 18001 0808 800 0303)

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

Patient.co.uk

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

Scope

scope.org.uk

0808 800 3333

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

Stroke Association

stroke.org.uk

0303 3033 100

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

Emotional support

Befriending Networks

0131 261 8799

befriending.co.uk

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

Contact

0808 808 8000

contactni.com

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

It's good to talk

itsgoodtotalk.org.uk/therapists

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

Samaritans

08457 90 90 90

samaritans.org

A confidential support line for people struggling to cope.

Equipment, adaptations and occupational therapy

British Association of Occupational Therapists and College of Occupational Therapists

020 7357 6480

cot.co.uk

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

British Red Cross

redcross.org.uk

0844 871 11 11

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

Centre for Independent Living NI

cilbelfast.org

028 9064 8546 (textphone 028 9064 0598)

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

Capability Scotland

capability-scotland.org.uk

0131 337 9876 (textphone 0131 346 2529)

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

Disability Equipment Register

disabreg.pwp.blueyonder.co.uk

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

Disabled Living Foundation

0300 999 0004

dlf.org.uk

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

Shopmobility

0844 41 41 850

shopmobilityuk.org

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

Further information

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

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

Notice

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

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

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

Feedback form

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

We'd be very grateful if you could complete this form and return it to:
Information and Support Content team, Marie Curie,
89 Albert Embankment, London, SE1 7TP
Or you can email us at **review@mariecurie.org.uk**. Thank you.

Please tick

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

Where did you get this booklet from?

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

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

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

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

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

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



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

Do you have any other comments?

About you

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

What is your gender or gender identity?

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

Age

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

Ethnicity

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

What is your religion or belief?

What is your sexual orientation?

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

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

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

Name

Address

Telephone Email

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



Marie Curie – why we're here

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

Support Line

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

0800 090 2309

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

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

Online community

Share experiences and speak to people in a similar situation.

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

Information

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

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

For printed copies call **0800 090 2309**

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



Care and support
through terminal illness