

WORKING WHILE CARING FOR SOMEONE WITH CANCER

A guide to coping with work when
you are caring for someone with cancer



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About this booklet

This booklet is for anyone who is working, either full-time or part-time, while caring for someone with cancer.

You may not think of yourself as a carer. But a carer is anyone who provides unpaid support to a partner, family member or friend who could not manage without this support.

This booklet aims to help you cope with any work issues you may face because of the impact of your caring role on your working life.

In this booklet, you'll find information about employment rights and how to get support at work, suggestions about flexible working, tips on talking about cancer with your employer and colleagues, and advice if you're self-employed.

Using this booklet

You don't have to read this booklet from start to finish. It is split into chapters to make it easier to dip into when you feel like it. We hope the information in this booklet will help you feel more in control, and help you get the best for you and those close to you.

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



Any information about benefits applies from April 2013–April 2014.

You may also find it helpful to read some of the information in our other booklets for carers:

- *Caring for someone with advanced cancer*
- *Hello, and how are you? A guide for carers, by carers*
- *When someone close to you has cancer* – a booklet about the emotional effects of cancer on partners, family members, carers and friends
- *Work it out for carers: essential questions to ask about work and cancer.*

You can order these for free by calling **0808 808 00 00** or by visiting **be.macmillan.org.uk**

Getting support

At the back of this booklet, you'll find a list of organisations that help carers in practical ways and with emotional support.

At Macmillan, we talk to carers every day. You can contact our cancer support specialists who are here to listen and provide the information you need. You can speak to them about anything that's on your mind or discuss the information in this booklet. Call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing, you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **macmillan.org.uk**

Being a carer

Around 300,000 people are diagnosed with cancer in the UK each year. As treatments for cancer improve, more and more people who have cancer are learning to live with it as a long-term illness. So are their families, friends and colleagues.

Many people affected by cancer depend on the practical and emotional support of a carer. We know there are currently more than a million people in the UK caring for someone with cancer, and this number is going to increase.

The rewards of caring

Becoming a carer can be stressful and unsettling, especially as it can happen at any time and may not have been planned. However, caring can also be a positive and rewarding experience. Many people say they feel closer to the person they are caring for and feel good about knowing that they are helping.

Working while caring

Very often, carers have to combine working and earning an income with their new – and often unplanned – role as a carer.

Macmillan estimates that in the UK there are 500,000 people working full-time or part-time who are caring for someone with cancer.

Carers UK estimates that:

- three million people in the UK juggle paid work with caring
- around one in six of these carers may give up work to take on a caring role, and many will reduce their hours.

If you're struggling to balance caring with work, Macmillan and the other organisations listed on pages 49–54 can help.

Different ways of caring

Caring means different things for every carer. What it involves will vary according to the needs of the person you're caring for and what you're able to do.

Caring can mean:

- being someone to talk to and a good listener – someone they can bounce ideas off, or a shoulder to cry on
- helping with shopping, collecting prescriptions and other errands
- providing transport or going with them on trips or to appointments
- helping with cooking, cleaning, laundry, gardening or other household jobs
- talking to others on their behalf, such as healthcare staff or social workers
- helping to get advice and information, for example about cancer, work or any support that is available

- helping with making phone calls, writing letters and emails or filling in forms
- giving medication, changing dressings and helping with other healthcare tasks
- babysitting or caring for children and other dependants
- sitting with or supervising them if they can't be left alone
- helping with washing, eating, dressing or using the toilet
- looking after pets
- helping with home or car maintenance, repairs and adaptations
- helping with managing finances
- being there and giving general support.

It's important to understand the needs of the person, and to find a good balance between what you think is right for them and what they want. You should also try to be aware of the limitations of what you can and can't do.

Remember that you don't have to do everything yourself. There's lots of help and support available (see pages 49–54).



Being there during diagnosis and treatment

This chapter discusses some of the practical and emotional issues you may face when the person you care for is having tests or being treated for cancer.

The person you're caring for may want you to be with them at different times during their diagnosis and treatment.

Some people like to have lots of independence for as long as possible. Others prefer to have someone with them for most of the time. The amount of support they need may vary from week to week, depending on what's happening to them and how they're coping.

One of the most helpful things you can do is to learn more about cancer and cancer treatments, so that you can understand what the person is going through. Our website [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation) has detailed information about different types of cancer and treatments. We also have this information as booklets, leaflets or audiobooks. You can order free copies at [be.macmillan.org.uk](https://www.be.macmillan.org.uk)

What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. Cancer is not a single disease with a single cause and a single type of treatment. There are more than 200 different types of cancer, each with its own name and treatment.

You can get information about cancer from:

- our cancer support specialists, on freephone **0808 808 00 00**
- our website at **[macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)**
- some of the websites listed on pages 58–59.

Tests and diagnosis

If the person you care for is going for investigations and tests, or waiting for results, this is probably an unpredictable and distressing time. There may be a number of visits to the hospital for different appointments before the doctors can confirm that your partner, relative or friend has cancer. This can take up a lot of time.

It can be a very difficult time when they are told they have cancer. You will both need time to come to terms with it and you may feel a range of emotions. This may affect your ability to work well.

During this time, you may want to think about:

- talking to your line manager or the human resources department at work to let them know your situation – see pages 18–23 for more information about talking to your employer
- preparing for more visits to the hospital so doctors can find out more about the cancer and decide how best to treat it – usually, appointments are booked in advance so that you can arrange time off work if you need to.

During treatment

Surgery

Some operations for cancer will mean the person you care for needs to stay in hospital for a short time. Sometimes, depending on the situation, the stay may be longer.

There may be a period of time after the surgery when they are recovering and need more support. You may want to:

- visit them in the hospital – this can be very tiring if you're working too
- take time off work to care for them in the days and weeks when they first come home.

During this time, it's important to give yourself time to rest. See pages 35–41 for more information about looking after yourself.

Radiotherapy

Radiotherapy treats cancer using high-energy x-rays. It's usually given in the following way:

- as an outpatient treatment (where the person does not need to stay in hospital overnight)
- at a specialist unit
- on a daily basis, from Monday–Friday, over a few weeks.

You may be planning to go with the person you are caring for when they have their treatment. Although each treatment takes only a few minutes, the travel time might add considerably to the amount of time you need away from work.

Anti-cancer drugs (including chemotherapy)

There are different types of anti-cancer drug. There are three main groups: chemotherapy drugs, targeted therapies and hormonal treatments.

- **Chemotherapy drugs** are usually given in a chemotherapy unit in the hospital over several months.
- **Targeted therapies** are a newer group of treatments that work by targeting the growth of cancer cells. They are also given in a chemotherapy unit in the hospital over several months.
- **Hormonal therapies** are drugs that can stop or slow the growth of cancer cells by either changing the level of particular hormones in the body, or preventing the hormones affecting the cancer cells.

Treatment with anti-cancer drugs is usually given every two or three weeks at scheduled times.

Each session will usually involve an afternoon or a full day in the chemotherapy unit at the hospital. But sometimes, it may involve a stay overnight or for a few days. This will depend on the type of cancer being treated and the anti-cancer drugs used.

Chemotherapy and targeted therapies are usually given regularly. But sometimes there are delays in treatment, for example if a person needs longer to recover from the side effects of treatment. It can help to explain this to your key contact at work and try to plan for the unexpected, wherever possible.

Most hormonal therapies are given as tablets, but some are given as injections every few weeks or months.

We can send you detailed information about these treatments, individual drugs and ways of coping with the side effects. Call us on **0808 808 00 00** or visit **[be.macmillan.org.uk](https://www.be.macmillan.org.uk)**

Helping the person you care for cope with treatment

Treatment can be stressful and exhausting. You may find that the person experiences mood swings that are out of character. It can help both of you to have some time alone.

Planning for visits to hospital

It's a good idea to plan ahead for each visit, especially if you will be there for a few hours. You may want to:

- find out how easy it is to park and whether there are free or reduced parking fees (some hospitals have special arrangements for people with cancer)
- check the ward visiting times – these can vary from hospital to hospital
- check whether you can get any food while you are there, or whether you can take a packed lunch
- take something to do or read
- find out whether the person you're caring for needs to stay overnight in hospital, and whether you need to stay somewhere nearby
- allow plenty of time if you are going with them to treatments or appointments – there can be delays and you may end up spending longer than you expected at the hospital.

Help with transport

Some people are able to travel to and from their treatments without any problems, but others may need some help with their transport.

It may be possible to arrange transport to take your relative or friend to their appointments. Some GP surgeries can arrange volunteer drivers and the hospital may also be able to help.

Some areas have local voluntary groups, which are sometimes called 'good neighbour' schemes. They provide practical help to people in need, and this often includes help with transport to hospital or your GP surgery. You could also ask family and friends about setting up a rota.

This is a time when working from home or flexible working may be useful. It may be worth discussing this with your employer.

Some people may need to stay in hospital while they have treatment. This may affect how much time off you might need if you want to be near them and the hospital is some distance away.

Follow-up treatment

Once the main treatments are finished, your relative or friend may have follow-up appointments and further treatment. This can include things such as ongoing medication and check-ups, scans and physiotherapy.

Many people who have been treated for cancer worry that it will come back. They might think that any new symptoms they have are caused by the cancer, when they may not be related to the cancer at all. This uncertainty can be difficult at a time when they feel they should be getting back to normal.



We have a booklet called *Life after cancer treatment*, which discusses the emotional and practical issues people often face at this time and what may help.

Making decisions about care

As a carer, it's important to find a balance between what support you want to give and what support you can actually give.

Each person with cancer is an individual with their own wishes and needs, and it's important to respect their preferences. However, they may not always ask for help. This might be because they don't want to burden you. Or it may be because they don't realise the demands that the illness and treatment may create. Their need for support may change over time.

The tips below may help when you're thinking about how involved you should be as a carer.

- At a time of uncertainty, your relative or friend may need to feel in control of their life. So wherever possible, they should be involved in making decisions about their care.
- Talking about what support you can provide will help you identify what's needed. This may include being someone to listen, someone to share thoughts and feelings with, or someone to provide practical help such as driving, shopping or housework.
- It may be that you don't feel able to provide the type of support they need. But you can help find that support from a range of organisations, such as those listed on pages 49–54.

- It's also important to look after your own health and well-being, and to recognise what you can and can't do yourself. You can read more about looking after yourself on pages 35–41.



We have a booklet called *Hello, and how are you?* It's a guide written by carers, for carers. We can send you a copy for free.



What to say at work

It's up to you whether you say anything at work about your caring responsibilities. You don't have to tell your employer or your colleagues. However, they're unlikely to be able to give you the support and understanding you need if they don't know what's happening. For example, if you want to make a flexible working request (see pages 25–27), your employer will need more details.

You're likely to need to plan some of your time around the needs of the person you're caring for, which can be difficult and unpredictable. It can be helpful to talk to your employer about your commitments and concerns.

It may be a good idea to find out more about your employer's policy for supporting carers before you talk to them about your situation. You can do this by checking your contract, reading your employee handbook or looking at your company's intranet. You may then wish to talk to your line manager, human resources department, or staff or union representative about what your statutory entitlements are and what other support is available to you from the organisation.

Talking to your employer – the initial discussion

If you decide to talk to your employer, the first step is to have a discussion with your manager to tell them about your caring responsibilities.

Your manager should be sensitive to the fact that you're coping with a cancer diagnosis. It can be a very difficult time and often turns lives upside down. They should allow you to explain the situation in your own way.

You can request that a colleague, friend, trade union or employee representative attends the meeting with you. Anyone attending the meeting should respect your privacy and the confidentiality of what is being discussed.

Your manager may choose to make notes at the meeting. If they do, and you would like a copy of them, ask your manager. They should not share the notes with anyone else without your permission. You may also want to make your own notes.

Typically, this first discussion may cover topics such as:

- your reaction to becoming a working carer and, in particular, any immediate work issues or concerns
- who knows about your situation, who you would like to know, and who needs to know
- whether, and how, you would like other managers and colleagues to be told, and what you would like to be said.

Your employer will want to get some idea of the likely impact of your caring responsibilities on your ability to attend work and fulfil your work duties. It will help to be prepared to talk about this in general terms. You may need to explain to the employer that cancer treatment doesn't always follow a smooth course and that last-minute changes may happen.

At this initial stage, you should begin to think about ways of doing your job that will suit both you and your employer.

The company will want to hear your thoughts about:

- the likely impact that being a carer will have on you personally – and your ability to do your job – in the short-, medium- and long-term
- how you think you will manage your work commitments while you are a carer.

If the company has a policy of no private internet use, you may want to discuss this at the meeting. For example, you might need to email the hospital or other people who care for the person with cancer during work hours. You may also want to talk about the possibility of accessing a private place to make and receive phone calls.

Your employer will be trying to balance the following things:

- Work and time off. Cancer treatment doesn't always go exactly to plan. Your plans will constantly change as you know more about the situation, and as treatment progresses.
- Company policies and procedures regarding carers (where they exist), and your specific needs as an employee. If your employer doesn't have procedures in place for carers, your manager may find the situation difficult as they may have to make decisions without guidance. They may benefit from ordering our *Work and cancer toolkit*, which contains information for both employers and employees. If there are already procedures in place at your place of work, your employer may need to apply them flexibly. The human resources department should also be aware of your legal rights as a carer, including flexible working, time off and emergency leave (see pages 25–28).

- How much you want your other managers and colleagues to know about the situation, and how your manager can work with you to tell them.
- The workload of your team. If you will need to have regular time off to carry out your carer responsibilities, this is likely to impact the rest of the team.

How your employer can support you

You may want to discuss things your employer can do to help you as a carer. Many employers support carers in a variety of ways. Take time to think about what you will need to change to help you in your roles as a carer and an employee.

Some employers may offer:

- a buddy or mentor
- access to a private telephone so that you can call the person you are caring for
- a reserved car parking space to make getting in and out of work quicker and easier.

As well as talking to your line manager or human resources department, you may:

- be able to talk to a welfare rights officer, occupational health adviser, union representative or employee assistance programme (EAP) counsellor – all of these people will offer understanding and support
- be put in touch with local support and networking groups.

Information from your employer

Your employer will probably take this opportunity to provide you with the company's information on:

- sick leave, sick pay, absence and leave policies (including emergency leave) and the associated remuneration and salary policies
- any relevant company benefits
- flexible working and work adjustment policies.

It's important to remember that not all companies will offer the same benefits. It may be that your employer will not be able to accommodate your requests for flexibility or changes to the way you carry out your role. The person you are caring for may also be given different information by their employer.

However, all companies should give their employees information about their statutory rights. They should also be able to signpost you to further sources of information about:

- relevant statutory benefits
- how to talk to your colleagues about cancer and the challenges of being a carer
- specialist organisations, such as Macmillan, and relevant charity helplines and websites, such as Carers UK (see page 52)
- counselling services that may be available to you as an employee.



We have guidelines for employers, which can be found on our website at [macmillan.org.uk/work](https://www.macmillan.org.uk/work)

After the initial meeting

Following this meeting, you can ask for a copy of any notes that have been taken, and make it clear whether you want anyone else in the company to see them. The company should respect your right to privacy, as should all those involved in the first meeting.

If, later on, you feel you need to discuss and agree on the points raised in the first meeting, you should ask for another meeting. Regular reviews are then helpful to check how arrangements are working, and to ensure you're receiving enough support. Any changes to the initial plan should be discussed and agreed as needed. It can also help to make the following clear:

- Who your main contact in the company will be in case your situation suddenly changes (and a secondary contact if the main contact isn't available).
- Whether you would prefer someone else to tell your work colleagues about your situation. Your employer can arrange for this to be carried out in a sensitive manner. Ideally, this will be by someone who has a good understanding of cancer and the effects of treatment on both the person with cancer and the carer. It should also be someone who is able to deal with the reactions of those being told.

Talking to colleagues

Colleagues can often be supportive, and sometimes just having someone to talk to can be a real help. You may discover that other employees in the organisation are also carers. It can be useful to share your experiences and the challenges of working while caring.



Your legal rights as a carer in paid work

Flexible working

The Work and Families Act 2006, the Employment Rights Act 1996 and the Employment Rights (Northern Ireland) Order 1996 give employed carers the right to request flexible working, such as changing hours or working from home. Where possible, flexible working can be arranged to maintain your normal income.

Requesting flexible working

To be eligible for flexible working, the person making the request must be caring for:

- their husband, wife, partner or civil partner
- a child under 17, or, if they receive Disability Living Allowance, a child under 18
- a near relative – this includes parents, parents-in-law, adult children, adopted adult children, siblings, brothers- and sisters-in-law, uncles, aunts, grandparents, step-relatives or someone who lives at the same address as the carer (excluding tenants, lodgers and employees).

Eligible carers who have worked for their employer for at least 26 weeks can apply to make a permanent or temporary change to their terms and conditions. Under this legislation, they can only make one request a year. However, more requests could be made outside of the legislation. An employer can refuse a request, but must give good reasons for doing so. If this happens, an employee can appeal the decision.

The right to request flexible working could make the difference between a carer leaving or staying at work.

Flexible working arrangements

Flexible working arrangements can make it easier for you to carry on working at the same time as caring for your relative or dependant. These arrangements could include:

- working from home
- flexible starting or finishing times
- compressed working hours (where you work your normal number of hours in a shorter time, for example fitting a five-day working week into four days)
- annualised working hours (this is where the amount of hours you are contracted for per month or year are worked in a flexible way)
- job-sharing or working part-time
- flexible holidays to fit in with alternative care arrangements.

If your employer refuses your request

Your employer can refuse a request for flexible working if it's not in the best interests of the business. This might be if:

- it would be too expensive
- it may affect the quality or performance of the business
- they cannot recruit additional required staff.

If your employer refuses your request, you can appeal their decision. Your appeal has to be made in writing within 14 days of their decision. There will be another meeting so that you can both discuss the request further. It can help to get advice and support from a union, work representative or the human resources department.

Your employer may not be able to accommodate your full request, but you may be able to compromise. For example, this might mean working from home for one or two days a week rather than full-time.

Time off in an emergency

If you're a carer in paid employment, you have the right to take a reasonable amount of unpaid time off to look after dependants in an emergency. In England, Scotland and Wales, this is covered by the Employment Rights Act 1996, as amended by the Employment Relations Act 1999. It is known as time off for dependants or dependants' leave.

In Northern Ireland, these laws are called the Employment Rights (Northern Ireland) Order 1996 and the Employment Relations (Northern Ireland) Order 1999.

A dependant could be:

- a mother, father, son, daughter, spouse or civil partner
- anyone who lives with you, other than a tenant, lodger, boarder or employee
- someone who would reasonably rely on you to help them if they become ill or need you to make care arrangements for them.

Possible emergencies can include:

- a breakdown in care arrangements
- the person you care for becoming ill or having an accident
- you needing to make longer-term care arrangements.

In each situation, this right applies from the start of a job. You don't need to have been in the job for a specific length of time before you can take time off in an emergency. However, the law doesn't define how much time you can take – it depends on the circumstances. To use this time off, you must inform your employer as soon as possible after the emergency has happened.

Emergency leave is usually unpaid unless your employer chooses to pay you.

Apart from this legal entitlement, your employer may have a policy or be open to discussing leave arrangements. Some options could be:

- carers' leave (paid or unpaid)
- compassionate leave
- borrowing holiday days from next year or buying additional days
- career breaks and sabbaticals (usually unpaid).

Protection from discrimination

The Equality Act 2010 and Disability Discrimination Act 1995

As a carer, you're protected from direct discrimination and harassment at work by the Equality Act in England, Scotland and Wales, and the Disability Discrimination Act in Northern Ireland. The Equality Act (England, Scotland and Wales only) also protects carers outside of work, such as when you shop for goods or services, and when you use public transport.

Direct discrimination occurs when you're treated less favourably than somebody else because of your caring responsibilities. For example, not being offered a job or being offered less favourable terms of employment because the person you are caring for has a disability. The act also protects people caring for someone with cancer outside of work when:

- you're discouraged from using a service
- it has been made impossible for you to use a facility
- you're given a worse service than you would have received if you weren't a carer.

Harassment is when you experience unwanted behaviour relating to disability, which makes you feel intimidated, degraded or offended. It's against the law for you to be harassed at work, and when you buy goods or services when caring for a disabled person.

Victimisation is when you're treated unfavourably because you've made a complaint about discrimination or harassment. This is covered under the Equality Act and the Disability Discrimination Act, as long as you genuinely believe your original complaint to be true.

The Equality Act also provides protection for employees from discrimination because of their association with an individual who has cancer. For example, if you are unfairly treated because your mother has cancer, there is protection against this.

What to do if you believe your employer isn't behaving in a reasonable or fair way

If you feel you can't resolve matters to your satisfaction, you may want to consider lodging a formal grievance.

Your employer should have a grievance policy that sets out the steps you will need to follow if you want to make a grievance. A staff or union representative can give you further advice.

If you feel that your grievance is not being dealt with fairly, and that your employer is being unreasonable, you can get advice from:

- a union representative if you have one
- ACAS (Advisory, Conciliation and Arbitration Service – see page 49)
- the Labour Relations Agency in Northern Ireland
- a solicitor specialising in employment law. You can find a solicitor by contacting one of the organisations on pages 50–51.

If you still feel unhappy about your grievance, you can complain to an employment tribunal. They can help resolve employment disputes between employees and employers. But you should be aware that going to an employment tribunal can be a long and expensive process. Most complaints need to be received by the tribunal within three months of the issue you are complaining about.



Making decisions about work

Giving up work completely

Some people will consider giving up work completely or taking early retirement to care for someone. This may have a big effect on your life in a number of ways. So it's something you need to think about carefully before making a decision.

It will affect your finances – not only your income, but also your pension and any employee benefits you're entitled to. Giving up work can also make you feel isolated, as you will lose the regular contact you had with your colleagues. It may also be difficult to keep your skills up to date and get back into the job market later on.



You may want to learn more about your rights as an employee and carer before making any decision. You may also find it helpful to talk to a financial adviser. You can call the Macmillan Support Line on 0808 808 00 00 to speak to one of our financial guides. Or you can contact the Carers UK advice line (see page 52).

Before giving up work, you may want to think about the following questions:

- Would requesting flexible working help you manage both working and caring?
- Could you take a paid or unpaid break from work to think about your options?
- Would taking a career break help?

If you are self-employed

If you're self-employed, you will have more control over your working life than someone who is employed. But you won't have the same rights and protection. You and your family may depend on the income from your business, too. This can put extra pressure on you as a carer.



If you plan to carry on working, there's a lot of support and help available. You may like to read our booklet, *Hello, and how are you?* It's written for carers, by carers and includes information about self-employment. We also have a booklet called *Self-employment and cancer*. It's written for people with cancer, but you may face some of the same problems.

Looking after yourself and getting support

Caring for someone can be physically and emotionally demanding. It's important to look after yourself, as well as the person you care for. Being aware of the first signs of stress, and planning how to deal with them, can help you.

You may want to:

- have a general health check with your doctor
- make a list of activities you like doing and schedule in some time each week to enjoy one or two of them
- spend time away from the house and/or person you're caring for (see pages 51–52 for organisations that offer help to carers).

To help look after yourself emotionally, you may wish to:

- talk to other carers in similar situations, perhaps at a support group – Carers UK can help you find a group in your area (see page 52 for contact details)
- ask the hospital or GP surgery for information that will help you manage the emotional challenges of caring
- talk to the nurses at the hospital where your partner, relative or friend is being treated
- look at some of the organisations and websites that offer practical and emotional support for carers (see pages 51–52).

Time for yourself

Remember that no one will expect you to do everything. You'll need space and time for yourself to help you cope with the demands of being a carer.

One of the most important times to schedule time off from work is when the person you're caring for is well so you can have some time to yourself. Try to make this a priority as it will be good for both of you.

You may find it helpful to read our booklet *How are you feeling? The emotional effects of cancer*. It has more information about looking after yourself while you're caring for someone with cancer. We can send you a copy for free. Or you may like to speak to one of our cancer support specialist on freephone **0808 808 00 00**.

Support from social services

The person you care for has a right to a community care assessment from their local social services, social work department or health and social care trust. This is to see whether they have a need for social care services.

If you're looking after someone on a regular and substantial basis, you also have a right to a carer's assessment. This can be an opportunity to speak with a social worker about any help you need with caring, as well as what help you might need to keep yourself healthy. You might also discuss how to balance caring with your life, work and family commitments.

You may want to talk about:

- any housing issues you may have
- your own health and the health of the person you care for
- the amount of time you spend caring and how you feel about it
- any equipment you may need to help you continue to support the person, such as a wheelchair, commode or hoist
- how caring is affecting your relationships
- how you would deal with emergencies
- your concerns for the future.

During a carer's assessment, the social worker will discuss your concerns about your paid work. You should mention any problems you have in balancing working with caring.

When available, support from social services can be very helpful. For example, you could ask for a paid care worker to visit the person you care for at different times of the day, or days of the week, to fit in with a flexible working arrangement you may have.

There are set criteria about who is eligible for social services. If your needs, and those of the person you care for, meet these criteria, these services must be provided.

A financial assessment will also be carried out to decide whether or not you would need to contribute to the cost of the service. As a carer, you should be assessed on your own resources and earnings, not those of the person you care for.



If you've been assessed as having a need for social services, you may be entitled to get direct payments from your local authority. These payments are also sometimes called individual budget/personal budget payments. This means that you are given payments to organise care services yourself, rather than the local social services organising and paying for them for you.

You can also have help with how you go about getting the care services if you are struggling with this. You should discuss this with social services when they agree to your payment.

If you live in England, Scotland or Wales, you can get information about direct payments and individual budgets from **gov.uk** (in the disabled people section), or from your local authority. If you live in Northern Ireland, visit **nidirect.gov.uk** (see the caring for someone section).

Help from social services for the person you're caring for can include:

- help at home – for example, to get them up in the morning, cook them a meal or help with their personal hygiene and care needs
- access to a meal or, in some circumstances, help to prepare them a meal
- day care services
- aids and equipment
- home adaptations
- respite care.

Carers' services can be anything that will help you in your caring role or maintain your own health and well-being while caring.

This can include:

- respite care to give you a break
- counselling to deal with emotional issues
- help from local voluntary organisations, for example support groups and benefit checks.

Financial support

Having cancer can be expensive for both you and the person you're caring for. There can be extra costs, such as travel to hospital, and your income may fall if you have to give up work or reduce your hours. However, there is help available, such as benefits, tax credits and grants. This includes help to meet NHS costs, such as travel for hospital treatment, prescriptions, wigs, dental treatment, and glasses and sight tests.

Carer's Allowance

Carer's Allowance is a weekly benefit that helps people who look after someone with substantial care needs.

You may be eligible if you're caring for someone who's receiving one of the following benefits:

- Attendance Allowance
- the care component of Disability Living Allowance at the middle or higher rate
- the daily living component of Personal Independence Payment at either rate.

You need to be aged 16 or over and be caring for someone for at least 35 hours a week to qualify for Carer's Allowance.

You don't need to be related to or living with the person you care for. You can be working, but there's a weekly earnings limit of £100 a week (after certain deductions). You can't claim Carer's Allowance if you're studying for 21 hours a week or more. Students and carers who don't qualify for Carer's Allowance may be able to protect their State Pension entitlement by applying for Carer's Credit (see below).

Carer Premium

If you're awarded Carer's Allowance, you may also be entitled to the Carer Premium. This is an extra payment that can be added to certain other benefits.

Carer's Credit

Carer's Credit can benefit carers who aren't entitled to claim Carer's Allowance.

Carer's Credit is a national insurance credit for carers of working age. It helps carers build up qualifying years for the basic State Pension and additional State Pension, so there are no gaps in your national insurance record if you're taking on caring responsibilities. It isn't a cash benefit. These credits can also count if you ever need to claim towards bereavement benefits.



For more information about benefits you may be entitled to, call the Macmillan Support Line free on 0808 808 00 00 or visit [macmillan.org.uk/financialissues](https://www.macmillan.org.uk/financialissues) We also have a booklet called *Help with the cost of cancer*, which has detailed information about benefits and financial help for people affected by cancer.



If the illness gets worse

If your partner, relative or friend's cancer gets worse, you may find that it's no longer realistic for you to continue to look after them at home.

Try not to feel guilty or that you have failed as a carer. Remember that as their illness develops, their needs may change. A different type of care may make them feel more secure and safe.

The demands of caring can have an effect on you, too. You may both feel that it's time to make other arrangements. It can help to talk about the situation and consider possible alternative arrangements that you would both feel happy about. The GP or community nursing or social service staff can give you advice. You should ask social services for a reassessment of your needs as a carer, as well as those of the person you are caring for.

This can be a difficult time and will continue to affect how you work. If you're no longer physically caring for your relative or friend, you may have more time to work, but feel emotionally less able. It's important to discuss the change in circumstances with your employer so that they can continue to support you.



Our booklet called *Caring for someone with advanced cancer* has useful information and advice that you may find helpful.

Bereavement

If someone close to you, and who you've cared for in the last stages of their life, dies, you'll probably experience a range of emotions. You may feel numb and shocked, however much you thought you had prepared for this moment. You may be deeply upset, and at the same time relieved that you can now make plans for your future.

You may also feel guilty that you are thinking of yourself at this time. These are all natural and normal emotions that you may feel long after the actual bereavement itself. Coping with bereavement is a long process. If you need help in coping with your feelings at this time, some organisations offer bereavement counselling. See page 51–54 for details or ask your GP surgery or local hospice.

Returning to work

Everyone copes with bereavement in their own way. The time to return to work will vary for each person. Some people feel able to carry on working and need to take very little time off, while others need longer.

Let your employer know how you're coping and discuss with them the best way for you to return to work. You may find it easier to work from home for a time, or to work part-time for a while. It can also be helpful to talk to your employer about telling your colleagues, and about whether you're happy for them to contact you while you're off.

There are many organisations that can support you at this time, including those listed on pages 49–54.

How we can help you

Cancer is the toughest fight most of us will ever face. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

Get in touch

Macmillan Cancer Support

89 Albert Embankment,
London SE1 7UQ

Questions about cancer?

Call free on **0808 808 00 00**

(Mon–Fri, 9am–8pm)

www.macmillan.org.uk

Hard of hearing?

Use textphone 0808 808 0121
or Text Relay.

Non-English speaker?

Interpreters are available.

Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists provide clinical, financial, emotional and practical information and support to anyone affected by cancer. Call us on **0808 808 00 00** or email us via our website, **macmillan.org.uk/talktous**

Information centres

Our information and support centres are based in hospitals, libraries and mobile centres, and offer you the opportunity to speak with someone face-to-face. Find your nearest one at **macmillan.org.uk/informationcentres**

Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free booklets, leaflets, and fact sheets.

Other formats

We have a small range of information in other languages and formats. Our translations are for people who don't speak English and our Easy Read booklets are useful for anyone who can't read our information. We also produce a range of audiobooks. Find out more at [macmillan.org.uk/otherformats](https://www.macmillan.org.uk/otherformats)

Please email us at cancerinformationteam@macmillan.org.uk if you'd like us to produce our information for you in Braille or large print.

You can find all of our information, along with several videos, online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

Review our information

Help us make our resources even better for people affected by cancer. Being one of our reviewers gives you the chance to comment on a variety of information including booklets, fact sheets, leaflets, videos, illustrations and website text.

If you'd like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk

Need out-of-hours support?

You can find a lot of information on our website, [macmillan.org.uk](https://www.macmillan.org.uk)

For medical attention out of hours, please contact your GP for their out-of-hours service.

Someone to talk to

When you or someone you know has cancer, it can be difficult to talk about how you're feeling. You can call our cancer support specialists to talk about how you feel and what's worrying you.

We can also help you find support in your local area, so you can speak face-to-face with people who understand what you're going through.

Professional help

Our Macmillan nurses, doctors and other health and social care professionals offer expert treatment and care. They help individuals and families deal with cancer from diagnosis onwards, until they no longer need this help.

You can ask your GP, hospital consultant, district nurse or hospital ward sister if there are any Macmillan professionals available in your area, or call us.

Support for each other

No one knows more about the impact cancer has on a person's life than those who have been affected by it themselves. That's why we help to bring people with cancer and carers together in their communities and online.

Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan.org.uk/community**

Financial and work-related support

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. Some people may have to stop working.

If you've been affected in this way, we can help. Call the Macmillan Support Line and one of our cancer support specialists will tell you about the benefits and other financial help you may be entitled to.

We can also give you information about your rights at work as an employee and help you find further support.

Macmillan Grants

Money worries are the last thing you need when you have cancer. A Macmillan Grant is a one-off payment for people with cancer, to cover a variety of practical needs including heating bills, extra clothing, or a much needed break.

Find out more about the financial and work-related support we can offer at [macmillan.org.uk](https://www.macmillan.org.uk)

Learning about cancer

You may find it useful to learn more about cancer and how to manage the impact it can have on your life.

You can do this online on our Learn Zone – [macmillan.org.uk/learnzone](https://www.macmillan.org.uk/learnzone) – which offers a variety of e-learning courses and workshops. There's also a section dedicated to supporting people with cancer – ideal for people who want to learn more about what their relative or friend is going through.

Other useful organisations

Work and employment

Access to Work

Tel (southeast and east England/London)

020 8426 3110

Tel (Scotland and northern England) 014 1950 5327

Tel (Wales and central England) 029 2042 3291

www.gov.uk/access-to-work

Provides advice and practical support to people with long-term health conditions and their employers to help pay for practical support so you can do your job.

Access to Work (NI)

www.nidirect.gov.uk/

[access-to-work-practicalhelp-at-work](http://www.nidirect.gov.uk/access-to-work-practicalhelp-at-work)

Gives support and advice to employees with disabilities and their employers. To apply for assistance through this programme, speak to an adviser at your local Jobs and Benefits Office.

Advisory, Conciliation and Arbitration Service (ACAS)

Euston Tower,
286 Euston Road,
London NW1 3JJ
Tel 08457 47 47 47

www.acas.org.uk

Gives advice to employees and employers to help improve working life and relations. Offers information, advice and training.

Labour Relations Agency

2–16 Gordon Street,
Belfast BT1 2LG

Tel 028 9032 1442

Email info@lra.org.uk

www.lra.org.uk

Responsible for promoting the improvement of employment relations in Northern Ireland. It can provide advice and support to both employees and employers, and help to resolve disputes.

Money or legal advice and information

Benefit Enquiry Line

Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

Textphone 0800 243 787

[www.nidirect.gov.uk/
money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Find details for your local office in the phone book or on one of the following websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice online in a range of languages at adviceguide.org.uk

Department for Work and Pensions

Disability Benefits Helpline

08457 123 456

Textphone 0845 722 4433

Personal Independence

Payment Helpline

0845 850 3322

Textphone 0845 601 6677

Carer's Allowance Unit

0845 608 4321

Textphone 0845 604 5312

[www.gov.uk/
browse/benefits](http://www.gov.uk/browse/benefits)

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

The Law Society

113 Chancery Lane,
London WC2A 1PL

Tel 0870 606 2555

www.lawsociety.org.uk

Represents solicitors in England and Wales and can provide details of local solicitors through its website.

The Law Society of Northern Ireland

96 Victoria Street,
Belfast BT1 3GN

Tel 028 9023 1614

www.lawsoc-ni.org

Can provide details of solicitors in Northern Ireland.

The Law Society of Scotland

26 Drumsheugh Gardens,
Edinburgh EH3 7YR

Tel 0131 226 7411

www.lawscot.org.uk

Can provide details of solicitors in Scotland.

Equipment and advice on living with disability

Blue Badge Scheme (Department of Transport)

www.dft.gov.uk/

apply-blue-badge

(England and Wales)

www.directscot.org/article/

blue-badge-scheme

(Scotland)

www.nidirect.gov.uk/the-

blue-badge-parking-scheme

(Northern Ireland)

The scheme allows people with severe walking difficulties, who travel either as drivers or passengers, to park close to their destination.

Support for carers

Carers Direct

Tel 0808 802 0202

www.nhs.uk/carersdirect

Provides information to help carers access the financial help they're entitled to, as well as advice on getting a break from caring and going to work.

Carers Trust (Princess Royal Trust for Carers in Scotland)

Tel (England) 0844 800 4361

Tel (Scotland) 0141 221 5066

Tel (Wales) 029 2009 0087

Email info@carers.org

www.carers.org and

www.youngcarers.net

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Carers UK

Tel (England, Scotland, Wales) 0808 808 7777

Tel (Northern Ireland)

028 9043 9843

(Wed–Thu, 10am–12pm and 2–4pm)

Email advice@carersuk.org

www.carersuk.org

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

Crossroads Caring for Carers (Northern Ireland)

7 Regent Street,

Newtownards,

Co. Down,

Northern Ireland

BT23 4AB

Tel 028 9181 4455

Email

mail@crossroadscare.co.uk

www.crossroadscare.co.uk

Charity providing respite care, so that carers can have a break.

Crossroads Caring Scotland

24 George Square,

Glasgow G2 1EG

Tel 0141 226 3793

Email

info@crossroadsscotland.co.uk

www.crossroads-scotland.

co.uk

Charity providing short breaks for carers within their own homes. Has services throughout Scotland that provide practical support for carers of all ages.

Cruse Bereavement Care

PO Box 800, Richmond,

Surrey TW9 1RG

Tel 0844 477 9400

Young person's helpline

0808 808 1677

(Mon–Fri, 9.30am–5pm)

Email helpline@cruse.org.uk

Young person's email

info@rd4u.org.uk

www.crusebereavementcare.

org.uk

Provides bereavement counselling, information and support to anyone who has been bereaved. Has a network of branches across the UK.

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151

Email

info@cancerblackcare.org
www.cancerblackcare.org.uk

Offers a range of information and support for people with cancer from ethnic communities, their friends, carers and families. Welcomes people from different ethnic groups including African, Asian, Turkish and West-Indian communities.

Cancer Focus Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX
Tel 0800 783 3339

Email hello@cancerfocusni.org
www.cancerfocusni.org

Provides a range of services for people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses.

Cancer Support Scotland

75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531

Email info@

cancersupportscotland.org
www.cancersupportscotland.org

Offers information and support for cancer patients, families, friends and health professionals. Runs a network of monthly support groups across Scotland. Also provides counselling and complementary therapies.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland
Tel 1800 200 700

Email helpline@irishcancer.ie
www.cancer.ie

Operates a freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

Maggie's Cancer Caring Centres

1st floor, 1 Waterloo Street,
Glasgow G3 7PR

Tel 0300 123 1801

Email enquiries@
maggiescentres.org

www.maggiescentres.org

Located throughout the country, Maggie's Centres are places to turn to for anyone affected by cancer. You can access information, benefits advice, and emotional or psychological support free of charge and under one roof. You don't have to make an appointment or be referred.

Tenovus

Gleider House, Ty Glas Road,
Cardiff CF14 5BD

Tel 0808 808 1010

Email post@tenovus.com

www.tenovus.org.uk

Provides a range of services to people with cancer and their families, including counselling and a freephone cancer helpline.



You can search for more organisations on our website at macmillan.org.uk/organisations or call us on 0808 808 00 00.



Further resources

Related Macmillan information

You may want to order some of the resources mentioned in this booklet. These include our other work and cancer booklets (see inside front cover), and:

- *Caring for someone with advanced cancer*
- *Hello, and how are you? A guide for carers, by carers*
- *Help with the cost of cancer*
- *How are you feeling? The emotional effects of cancer*
- *Life after cancer treatment*
- *When someone close to you has cancer*

To order a free resource, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

All of our information is also available online at **macmillan.org.uk/cancerinformation**

We have information about chemotherapy, radiotherapy and surgery in these languages: Bengali, Gujarati, Hindi, Polish, Punjabi, Russian, Traditional Chinese, Urdu and Welsh. We also have a range of Easy Read booklets. Visit **macmillan.org.uk/otherformats** to find out more.

Macmillan audiobooks

Our high-quality audiobooks, based on our variety of booklets, include information about cancer types, different treatments and about living with cancer.

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Helpful books

A Guide to Grants for Individuals in Need 2013/14 Directory of Social Change, 11th edition, 2013, £75.00.

A directory of charities and trusts that provide financial assistance to people in need. A copy is kept in most public libraries.

Carers UK publications

A full list of Carers UK publications can be found at **carersuk.org/professionals/order-publications** or contact Carers UK to order them (see page 52). The following two booklets can be downloaded free:

Carers and employment: a guide to the right to request flexible working

All you need to know about requesting flexible working including an application form and information on how to challenge a decision if your request for flexible working is refused.

Supporting working carers: a carer's guide

This booklet helps employees minimise the stresses of balancing work and caring. It also helps carers prepare to return to work and includes a four-page pull-out section to give to your employer.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support www.macmillan.org.uk

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate, up-to-date information on cancer and its treatments, including:

- all the information from our 150+ booklets and 360+ fact sheets

- videos featuring real-life stories from people affected by cancer and information from medical professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form for sending your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

American Cancer Society
www.cancer.org

Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

Cancer Research UK
www.cancerhelp.org.uk

Contains patient information on all types of cancer and has a clinical trials database.

Health and Social Care in Northern Ireland
www.n-i.nhs.uk

The official gateway to health and social care services in Northern Ireland.

Healthtalkonline and Youthhealthtalk
www.healthtalkonline.org
www.youthhealthtalk.org
(site for young people)

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

Macmillan Cancer Voices
www.macmillan.org.uk/cancervoices

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

**National Cancer Institute –
National Institute of
Health – USA**

www.cancer.gov

Gives information on cancer and treatments.

NHS Choices

www.nhs.uk

The country's biggest health website. Gives all the information you need to make decisions about your health.

NHS Direct Online

www.nhsdirect.nhs.uk

NHS health information site for England.

NHS 24 in Scotland

www.nhs24.com

NHS health information site for Scotland.

NHS Direct Wales

www.nhsdirect.wales.nhs.uk

NHS health information site for Wales.

Patient UK

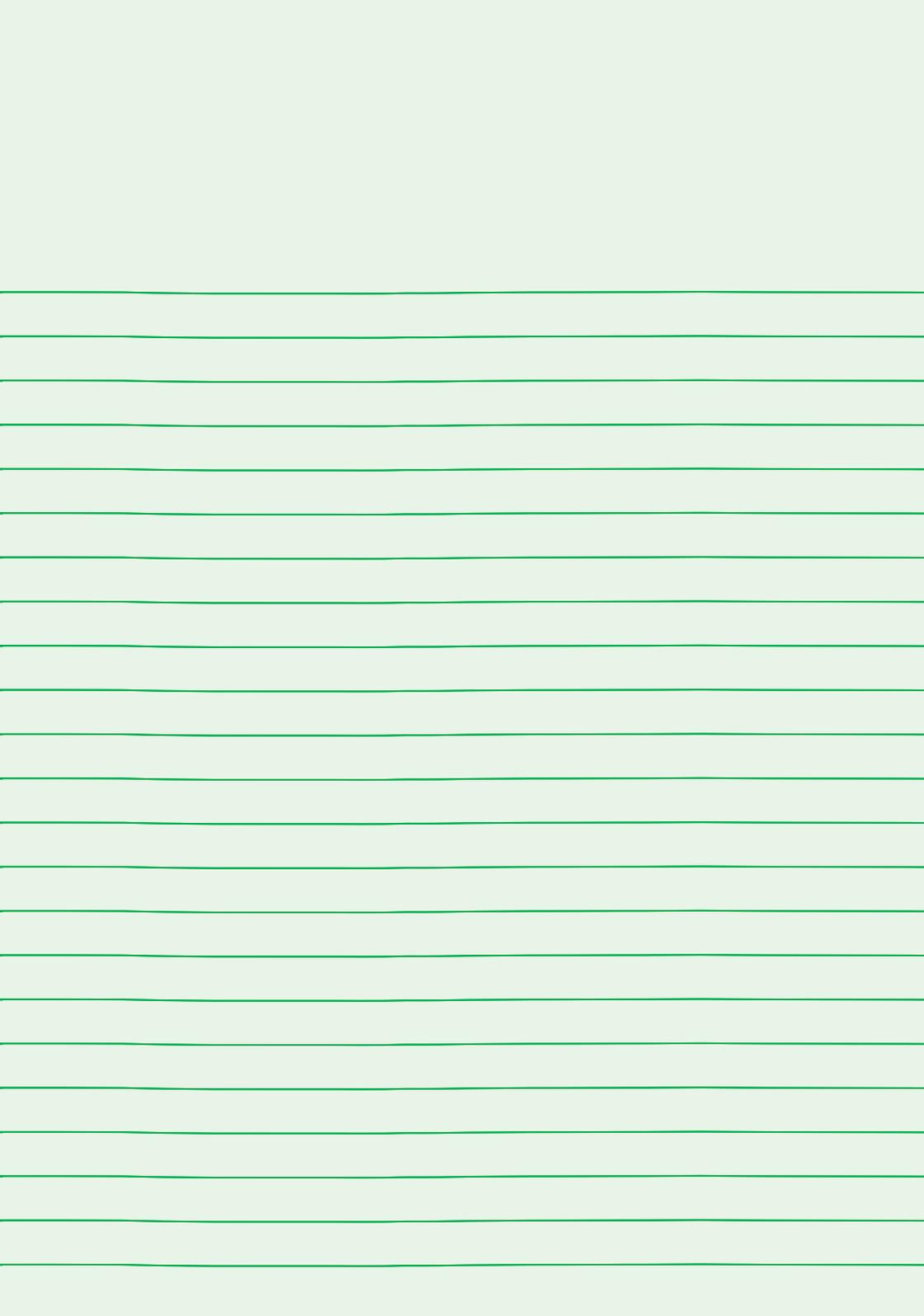
www.patient.co.uk

Provides information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics.

Riprap

www.riprap.org.uk

Developed especially for teenagers who have a parent with cancer.



Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Working Through Cancer team and Cancer Information Development team.

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Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

A lift to an appointment. Help with the shopping. Or just a cup of tea and a chat. Could you lend a hand?

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)
I enclose a cheque / postal order /
Charity Voucher made payable to
Macmillan Cancer Support

OR debit my:
Visa / MasterCard / CAF Charity
Card / Switch / Maestro

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Signature

Date / /

Don't let the taxman keep your money

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

- I am a UK taxpayer and I would like Macmillan Cancer Support to treat all donations I have made for the four years prior to this year, and all donations I make in the future, as Gift Aid donations, until I notify you otherwise.

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



If you'd rather donate online go to macmillan.org.uk/donate

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

We are the nurses and therapists helping you through treatment. The experts on the end of the phone. The advisers telling you which benefits you're entitled to. The volunteers giving you a hand with the everyday things. The campaigners improving cancer care. The community there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way,
call Macmillan on 0808 808 00 00
(Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone
0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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**WE ARE
MACMILLAN.
CANCER SUPPORT**