

**WORKING  
WHILE  
CARING FOR  
SOMEONE  
WITH  
CANCER**

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MACMILLAN.  
CANCER SUPPORT**

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'After I was diagnosed, my husband had a very helpful employer. They allowed him to come and go when times suited him, such as when I was in hospital.'

# About *Working while caring for someone with cancer*

**This booklet is for anyone who is working, either full- or part-time, while also caring for an adult partner, relative or friend with cancer.**

It aims to help you cope with work issues you may face because of the impact of your caring role on your working life. You will find information on employment rights and how to get support at work, suggestions about flexible working and tips on talking about cancer with your employer and colleagues.

Approximately 289,000 adults 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 chronic illness. So are their families, friends and colleagues.

Many people affected by cancer depend on the physical and emotional support of a carer. Very often, that carer has to combine working and earning an income with their new – and often unplanned for – role as a carer.

There are approximately 3 million working carers in the UK, all having to combine the pressure of working while dealing with the physical and emotional pressures of caring for someone who is ill.

Continuing to work can be important for both the carer and the individual with cancer, as it can provide both income and social contact outside of the home.

There is a list of services offered by Carers UK on page 39 which you may find particularly helpful. There is also a list of useful addresses, helpful books, and websites (pages 39–46).

**You may find it helpful to read some of the information in our booklet, *Caring for someone with advanced cancer*.**

## Who is a carer?

Becoming a carer is likely to happen to almost everyone at some stage of their life. The Work and Families Act 2006 defines a carer as someone who cares for:

- their husband, wife, partner or civil partner
- a near relative – this includes parents, parents-in-law, adult children, adopted adult children, siblings, brothers and sisters in-law, uncles, aunts, grandparents and step-relatives
- someone who lives at the same address as the carer.

People who care for an elderly neighbour, for example, fall outside the remit of the act, although evidence shows that most employers are open to requests from those not eligible under the law.

The 2001 census revealed some interesting statistics about working carers:

- The vast majority of carers (80% or 8 in every 10 carers) are of working age.
- As many as 3 million carers already combine work and care.

- Carers make up over 12% (12 in 100) of the UK workforce.
- Every year, more than 2 million people become carers – so there are many new carers in the workforce every day.
- over 3 in 5 people (60%) will become carers at some point in their lives.

## Different ways of caring

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

Caring can mean:

- being a listening ear, someone they can bounce ideas off, or a shoulder to cry on
- giving physical nursing care, with or without support from professionals
- helping with personal care
- helping to find other sources of information or support
- providing transport
- offering a source of social contact, helping to prevent the person who is ill feeling isolated
- helping with everyday chores, or arranging things, like a child's birthday party or the car being serviced

- helping the person who is ill to take a break when treatment permits, to maintain some of the 'fun' things in life.

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 35–46).**

## 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. It's important to realise that 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. Throughout this booklet the word cancer is used to describe all forms of cancer including lymphoma, leukaemia and myeloma.

Some causes or risk factors of cancer are known, but in many instances no-one will know what has caused a particular cancer. It's important that individuals are not blamed for getting it either by themselves or by those who know them.

In some cancers that are slow-growing, or that have spread beyond their original area of the body, the aim may be to control the cancer and delay its progress, sometimes for many years.

For other people, cancer treatment is given to help relieve their symptoms.

**Our cancer support specialists on freephone  
0808 808 00 00 can give information about all  
aspects of cancer.**

**Information can be interpreted into any language  
and is also available at [macmillan.org.uk](https://www.macmillan.org.uk)**



# Cancer diagnosis and treatment

## The impact of cancer treatment on the working carer

It's likely that the person you're caring for may want you to be with them at different times during the diagnosis and treatment of their cancer.

Some people like to have a high level of independence for as long as possible, while 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.

## Initial investigation and diagnosis

Going for investigations and tests, and waiting for results, can be an unsettling time. There may be a number of visits to the hospital for different appointments before the doctors can confirm someone has cancer, which can take a lot of time.

There may be more visits after this 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 needed.

It can be a very difficult time when a relative or friend is told they have cancer. You will both need time to come to terms with the change in your circumstances and you may feel a range of emotions. This may affect your ability to work effectively.

During this time you may want to think about talking to your line manager or the human resources (HR) or personnel manager at work.

## **Treatment**

The following are brief explanations of the main treatments for cancer, and how they may affect your role as a carer. It's fairly common for a combination of treatments to be used. The doctors and nurses can give you further information about the treatments involved and their effects.

Cancer treatment is different for each person and depends on factors such as the stage and grade of the cancer (how far it has spread and how fast-growing it is), the person's age and their general health. The main treatments used are surgery, chemotherapy and radiotherapy.

## **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 quite often during their admission, and this can be very tiring if you are also working.

You may also want to take time off work to care for them in the days and weeks when they first come home. It's important to allow yourself plenty of time to rest. See page 27 for more information about looking after yourself.

## **Anti-cancer drugs (including chemotherapy)**

There are different types of anti-cancer drugs used in the treatment of cancer, and these fall into three main groups: cytotoxic drugs, targeted therapies and hormonal treatments.

Cytotoxic drugs and targeted therapies are usually given in a chemotherapy unit in the hospital over a period of several months. Most hormonal therapies are given as tablets. Cytotoxic drugs are what most of us think of as 'chemotherapy'.

Targeted therapies are a newer group of treatments that work by targeting the growth of cancer cells. Treatment is usually given every two or three weeks at scheduled times.

Each session will often involve an afternoon or a full day in the chemotherapy unit; sometimes, however, 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.

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 (some hospitals have special arrangements for people with cancer)
- check if you can get any food while you are there, or if you can take a packed lunch
- take something to do or read.

Cytotoxic and targeted therapies are usually given regularly, however delays in treatment can sometimes occur. It can help to explain this to your key contact at work and try to plan for the unexpected wherever possible.



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

## **Radiotherapy**

Radiotherapy treats cancer by using high-energy x-rays. It's typically given as an outpatient at a specialist unit on a daily basis, from Monday–Friday over a few weeks. Although each treatment takes only a few minutes, the travel time might add considerably to the amount of time you need away from work.

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 be able to help. You could also ask friends and family about setting up a rota. This is a time when working from home may be useful and it may be worth discussing this with your employer.

**We can send you detailed information about these treatments, including fact sheets about the individual drugs, and ways of coping with the side effects.**

## **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-up appointments, 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 in reality 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.

# Making decisions about care

Taking on the role of carer can be 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. As a carer, it's important to find a balance between what you think you can or should offer by way of support.

Each person with cancer is an individual with their own wishes and needs, and it's important to respect their preferences. However, you must also recognise that they may understate their need for help – so as not to be a burden to you, or simply because they don't realise the demands that the illness and treatment may create. Their need for support may change over time.

It's important to recognise that, at a time of uncertainty, they 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 be 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 to find that care from a range of organisations such as those listed on pages 39–44.

It's important, as a carer, to look after your own health and wellbeing and to recognise what you can and can't do yourself. You can read more on page 27.

# 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 you need if they don't know what's happening.

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

You might find it helpful to find out more about your employer's policy for supporting carers before you actually talk to them about your situation. You can do this by checking your contract, reading your employee handbook or intranet, or by talking to the company's occupational health adviser.

You may then wish to talk to your line manager, HR/personnel manager, or staff or union representative about what your statutory entitlements are and what other support might be available to you from within the company.

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

# Talking to your employer

## 1. 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 new role as a carer.

Your employer should be sensitive to the fact that coping with a cancer diagnosis in the family can be very difficult, and that it can often turn people's lives upside down. They will need to allow you to tell the news in your own way.

You may wish to have a colleague, friend, trade union or employee representative with you during the meeting, but they will need to respect your right to privacy. This applies to all further meetings and discussions with your employer.

The company representative may need to make notes of the meeting. They should offer you a copy of the notes, but can't share them with anyone else without your permission.

Typically, this first discussion will cover topics such as:

- your reaction to becoming a working carer
- who knows, who you would like to know and who needs to know
- whether, and how, you would like other managers and colleagues to be told about your situation
- what you would like to be said.



Your employer will also 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, explaining to the employer that treatment for cancer 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 on you personally – as well as on your ability to do your job – of caring for someone with cancer in the short-, medium- and long-term
- how you think you might manage your work commitments during the time you are a carer.

Your employer will be trying to balance:

- **Work and time off** – cancer treatment does not always go exactly to plan; plans will need constant fine-tuning, as more facts become known and as treatment progresses.
- **Company procedures** (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.

If procedures exist, but are too rigid, they may need some flexibility in their interpretation. HR should also be aware of your legal rights as a carer including flexible working, time off and emergency leave etc (see pages 21–23).

- **The level of communication required** and the level of communication you want about your situation with your manager as well as with other managers and colleagues in your team.
- **The workload of your team** – if you will need to have regular periods of absence in order to carry out your carer responsibilities, this can impact on the rest of the team.

### **Support at work**

You may want to discuss things your employer can do that will 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 dual role as carer and employee. Consider what support you would like from your employer, such as:

- 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 HR/personnel manager, you may:

- be able to talk to a welfare officer, occupational health adviser, or employee assistance programme counsellor, who understands the issues and challenges facing carers
- be put in touch with local support and networking groups.

### **Information from your employer**

It's likely that your employer will 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
- any employee assistance programme (EAP) or occupational health service available to you.

It's important to remember that not all companies will offer the same benefits. The person you are caring for may be given different information by their employer. However, all companies need to give their employees information on their statutory rights, and should 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. This support should come from a qualified health manager, or a reputable independent source such as Macmillan. There is more information about how we can help you on pages 35–38
- other specialist organisations, charity helplines and websites, such as Carers UK (see page 39)
- counselling services that may be available to you as an employee, perhaps from an EAP or your occupational health department.

Remember that each situation is different. You will need your own programme of support to meet your changing circumstances. The more open you are about your situation with your managers and your work colleagues, the more they will be able to support you.

Unfortunately, some managers or colleagues may not be as sympathetic as you hope or expect, but if you don't keep them informed then it makes it difficult for them to understand.

**We have guidelines for managers: *Working through cancer; a guide for employers.***

## **2. 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 will respect your right to privacy, as will all those involved in the first meeting.

If, after reflection, you feel you need to discuss and agree the points raised in the first meeting, you should ask for another meeting to do so.

Regular reviews are then helpful to check how arrangements are working, and to ensure you are receiving enough support. Any changes to the initial plan need to be discussed and agreed as and when necessary and/or appropriate.

It can also help to make clear:

- who your main contact in the company will be in case your situation suddenly changes
- 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, and who is able to deal with the reactions of those being told.

# Your legal rights as a carer in paid work

## Requesting flexible working

Since April 2007, the Work and Families Act 2006 has given certain carers the right to request flexible working, such as changing hours or working from home. See page 4 for the definition of a carer. Flexible working can be arranged to maintain your normal income.

Eligible carers who have worked for their employer for at least 26 weeks can apply to make a permanent change to their terms and conditions. They can only make one request a year. Their employer can refuse a request, but must give good reasons. In this case, an employee can appeal the decision.

The right to request flexible working could make the difference between a carer leaving or staying at work. Currently, 2.65 million carers could take advantage of this new right, but millions more will benefit in the future.

## Flexible working arrangements

Flexible working arrangements can make it easier for you to carry on working at the same time as caring for your friend or relative. These 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 employer can refuse a request for flexible working if they feel it's not in the best interests of the business. For example, they may feel that your request would:

- be too costly
- affect the quality or performance of the business
- mean they have to recruit new 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. A further meeting will be held so that both parties can discuss the request further. It can help to get advice and support from a union or work representative.

## **Time off in an emergency**

You have a right under the Employment Rights Act 1996, as amended by the Employment Relations Act 1999, to take time off to look after dependants in an emergency.

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, partner or anyone who lives with the employee and is solely dependent on 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.

This right applies right 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 off a person 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 negotiation about leave arrangements. These could include:

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



## **What to do if you believe your employer is not 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 to be followed when an employee wants to bring 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 complain to an employment tribunal. This can help resolve disputes between employees and employers about employment law.

There are very strict time limits on when you can make a complaint; most complaints need to be received by the tribunal within three months of the matter you are complaining about.

If you are considering taking a complaint to an employment tribunal it is a good idea to get advice from a union representative, ACAS (Advisory, Conciliation and Arbitration Service – see page 40), or a solicitor specialising in employment law.



# Giving up work completely

Some people will consider giving up work completely 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 employees' benefits you're entitled to. It can be isolating as you will lose the regular contact you had with your work colleagues. It may also be difficult to keep your skills up to date and get back into the job market later on.

Before giving up work you might want to consider:

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

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 expert (see page 31).

For some people early retirement may be possible and may be an advantage, but it may also leave you worse off so get advice to see if you would benefit.

# Looking after yourself, physically and emotionally

Caring for someone can place heavy physical and emotional demands on you as a carer. 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 might want to:

- have a general health check with your doctor
- make a list of activities that you like doing and schedule in some time each week to enjoy one or two of them
- spend time away from the house/person you are caring for.

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

- talk to other carers in similar situations to yours
- ask the hospital/doctors surgery for information that will help you manage the emotional challenges of caring
- talk to the nurses at the hospital where your relative or friend is being treated
- look at some of the websites that offer practical and emotional support for carers (see pages 45–46).

Remember that no-one will expect you to do everything. You will need space and time for yourself if you are to cope with the demands of being a carer. You may like to contact one of the organisations listed on pages 39–44.

## Time off when well

One of the most important times to schedule time off from work is when the person you are caring for is well. Try to make this a priority – it will be good for both of you.

**You may find it helpful to read our booklet, *The emotional effects of cancer*. We can send you a copy.**

# Social care

The person you care for has a right to a **community care assessment** from their local social services department. This is to see whether they have a need for services which the local authority should meet.

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 discuss with social services any help you need with caring, as well as what help you might need to keep yourself healthy, and 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 that of the person you care for
- the amount of time you spend caring and how you feel about it
- how caring is affecting your relationships
- how you would deal with emergencies
- your concerns for the future.

During a carer's assessment, social services will discuss your concerns about your paid work. You should mention any problems you have in balancing your work and the care that you give.

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.

Your local authority will have set criteria for who they provide social services to. If your needs, and those of the person you care for, meet these criteria they must provide the services.

You can learn more about the services your local authority provides by contacting them and asking for their *Better Care, Higher Standards* charter and the national guidance called *Fair Access to Care Services*.

Social services will also carry out a financial assessment 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, not those of the person you care for and any of their earnings can be disregarded.

If you've been assessed as having a need for social services, you may be entitled to get **direct payments** from your local authority. 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 get information about direct payments from the Directgov website at **direct.gov.uk** (in the disabled people section) or from your local authority.

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

- help at home, for example, to get them up in the morning or cook them a meal
- day-care services
- aids and equipment
- adaptations to the home
- respite care.

**Carers' services** can be anything that will help you in your caring role or maintain your own health and wellbeing while caring. This can include:

- respite care
- help with taxi fares so you can get to hospital appointments or get to work on time
- counselling to deal with emotional issues

# Financial support

Giving up paid employment, whether permanently or through a reduction in working hours, will often mean adjusting to a lower income. It's important to consider all the financial implications before making any decision to reduce your working hours.

It may help to contact an independent financial adviser (IFA) to get advice on your financial options. IFAs can assess your individual situation and recommend the best course of action.

You can find a local IFA by referral from family or friends, looking in your phone book, or by contacting the Personnel Financial Society or the Independent Financial Advisers Promotions Ltd (IFAP) – see pages 41–42.

As a carer you may be entitled to benefits or tax credits. This will depend upon your individual circumstances. The organisations listed on pages 40–42 can help with advice on entitlements to benefits, tax credits and other sources of income.

**We can send you more information about financial issues and cancer.**



## If the illness gets worse

If your relative or friend's cancer gets worse, you may find that it is no longer realistic for you to continue to look after them at home. Try not to feel guilty or that you have failed in your role. Remember that as their illness develops, your relative or friend's needs may change. A different type of care may make them feel more secure and safe.

The demands of caring may take their toll on you too. You may both feel that the time has come to make other arrangements. It can help to talk about the situation and consider possible alternative arrangements which you would both feel happy about. The GP or community nursing staff can give you advice.

This can be a difficult time and will continue to affect how you work. If you are 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, *Caring for someone with advanced cancer*, has useful information and advice that you might find helpful.**



# Bereavement

When someone close to you, and who you have cared for in the last stages of their life, dies you will 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 sad, and at the same time relieved that now you can make plans for your own future.

You may also feel guilty that you are thinking of yourself at this time. All these are natural and normal emotions that you may feel long after the actual bereavement itself. Coping with a bereavement is a long process. If you feel you need help in coping with your feelings at this time, many organisations offer bereavement counselling.

## Returning to work

Everyone copes with bereavement in their own way. When you are able 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; others need longer.

Let your employer know how you are 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 return part-time for a while. It can also be helpful to talk to your employer about telling your colleagues, and about whether you are happy for them to contact you.

**There are many organisations that can support you at this time, including those listed on page 42.**

# How we can help you

## **Macmillan Cancer Support**

89 Albert Embankment,  
London SE1 7UQ

### **General enquiries**

020 7840 7840

### **Questions about living with**

**cancer?** Call free on

**0808 808 00 00**

(Mon–Fri, 9am–8pm)

Alternatively, visit

**macmillan.org.uk**

### **Hard of hearing?** Use

textphone 0808 808 0121,  
or Text Relay.

### **Non English speaker?**

Interpreters available.

Macmillan Cancer Support improves the lives of people affected by cancer. We are a source of support: providing practical, medical, emotional and financial help. We are a force for change: listening to people affected by cancer and working together to improve cancer care locally and nationally.

We have a wide range of services and activities that might be of help and interest.

## **Clear, reliable information**

We provide expert, up-to-date information about cancer – the different types, tests and treatments, and living with the condition.

We can help you by phone, email, via our website and publications, or in person. And our information is free to all – people with cancer, families and friends, as well as professionals.

Just call and speak to one of our cancer support specialists. Or visit one of our information and support centres – based in hospitals, libraries and mobile centres – and speak with someone face-to-face.

## Need out-of-hours support?

Our helpline is open Monday –Friday, 9am–8pm. At any time of day, you can find a lot of information on our website, [macmillan.org.uk](http://macmillan.org.uk), or join our online community at [macmillan.org.uk/share](http://macmillan.org.uk/share). For medical attention out of hours, please contact your GP for their 'out-of-hours' service.

The following organisations can offer immediate information and support:

**NHS Direct** 0845 4647  
[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)

**NHS Scotland**  
0845 24 24 24  
[www.nhs24.com/content](http://www.nhs24.com/content)

**Samaritans** 0845 790 9090  
[www.samaritans.org.uk](http://www.samaritans.org.uk)

## Someone to talk to

When you, or someone close to you, has cancer, it can be difficult sometimes 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.

Alternatively, we can 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 people decide 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 the

disease themselves. That's why we help to bring people with cancer and carers together in their communities and online.

You can find out about people affected by cancer who meet in your area to support each other by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**.

You can also share your experiences, ask questions and get support from others by heading to 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. All you need to do is call our helpline and one of our 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 as an employee, and help you find further support.

## Helping you to help yourself

People affected by cancer want to take control of their lives again and regain their independence. We help you do this by providing opportunities to learn how to manage the impact cancer can have on your life.

You can do this online through our Learn Zone – **macmillan.org.uk/learnzone** – which offers a wide range of courses and information.

We produce booklets on specific cancers and treatments to help you manage the disease and side effects. And we provide a range of face-to-face training that offers practical advice to help you help yourself.

## **Get involved**

There are many ways to get involved with Macmillan and help other people affected by cancer.

## **Use your experience to speak out**

Share your experiences – online, in the media, with each other. Or use your experience to improve cancer care – join Macmillan Cancer Voices and get involved in opportunities that can make a real difference to people's lives.

## **Campaign with us**

Join one of our campaigns – help us fight discrimination, tackle inequalities and get a better deal for people affected by cancer.

## **Give your time**

Become a volunteer – give a bit of your time and energy to make a difference to others, and meet new friends at the same time.

## **Fundraise**

Raise some money – host a coffee morning, run a marathon, hold a street collection or organise your own sponsored event.

## **Donate**

Give some money – whether you give a one-off donation, set up a direct debit, donate through payroll giving or leave a legacy, we'll use every penny to help support people affected by cancer.

Find out more about all these opportunities on **[be.macmillan.org](https://www.be.macmillan.org)**.

# Other useful organisations

## **Carers UK**

20 Great Dover Street,  
London SE1 4LX

**Tel** 020 7378 4999

**Carers line** 0808 808 7777

(Weds and Thurs,  
10am–12pm and 2–4pm)

**Email** [info@carersuk.org](mailto:info@carersuk.org)

**www.carersuk.org**

Improves carers' lives by providing information and advice on carers' rights and campaigning for changes that make a real difference for them. Can put people in contact with support groups for carers in their area. Has national offices for Scotland, Wales and Northern Ireland:

## **Carers Scotland**

The Cottage, 21 Pearce Street,  
Glasgow G51 3UT

**Tel** 0141 445 3070

**Email** [info@carerscotland.org](mailto:info@carerscotland.org)

**www.carerscotland.org**

## **Carers Wales**

River House, Ynsbridge Court,  
Gwaelod-y-Garth, Cardiff  
CF15 9SS

**Tel** 029 2081 1370

**Email** [info@carerswales.org](mailto:info@carerswales.org)

**www.carerswales.org**

## **Carers Northern Ireland**

58 Howard Street, Belfast  
BT1 6PJ

**Tel** 028 9043 9843

**Email** [info@carersni.org](mailto:info@carersni.org)

**www.carersni.org**

## **Crossroads – Caring for Carers**

10 Regent Place, Rugby,  
Warwickshire CV21 2PN

**Tel** 0845 450 0350

**Email** from the website

**www.crossroads.org.uk**

Provides respite care for carers by providing practical support in the home. Has over 200 schemes across England and Wales.

## **Crossroads (Scotland)**

24 George Square, Glasgow  
G2 1EG

**Tel** 0141 353 6504

**Email** from the website

**www.crossroads-scotland.co.uk**



Has nearly 50 schemes running in Scotland that provide trained staff to take over the carer's role for an agreed period of time.

**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**

Offers practical support for carers by sending fully-trained care attendants into the home.

**The Princess Royal Trust for Carers**

142 Minories, London EC3N 1LB

**Tel** 020 7480 7788

**Email** help@carers.org

**www.carers.org**

Provides a range of information, support and advice to carers. Services include counselling and information on benefits.

**Financial and legal advice**

**Advisory, Conciliation and Arbitration Service (ACAS)**

Euston Tower, 286 Euston Road, London NW1 3JJ

**Helpline** 08457 47 47 47

**www.acas.org.uk**

Aims to improve organisations and working life through better employment relations. Provides information, independent advice and training. Also works with employers and employees to solve problems and improve performance.

**Association of Charity Officers**

**Tel** 01707 651 777

**www.aco.uk.net**

Helps individuals find specific charities that may be able to offer some financial assistance.

**Benefit Enquiry Line**

2<sup>nd</sup> Floor, Red Rose House, Lancaster Road, Preston, Lancashire PR1 1HB

**Tel** 0800 882200

**Textphone** 0800 243355

**Email** BEL-Customer-Services@dwp.gsi.gov.uk  
**www.direct.gov.uk/disability-money**

Provides advice about benefits and helps complete some disability related claim packs.

### **Citizens Advice Bureau**

Find contact details for your local office in the phone book or at **citizensadvice.org.uk**

Find advice for the UK online, in a range of languages, at **adviceguide.org.uk** Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

### **Community Legal Advice**

Legal Services Commission, 2 Harbour Exchange Square, London E14 9GE

**Helpline** 0845 345 4345  
**www.communitylegaladvice.org.uk**

Provides help and advice on a range of common legal issues in England and Wales. Free initial advice on benefits, tax credits, debt, education, housing and employment.

### **Independent Financial Advisers Promotion (IFAP)**

2<sup>nd</sup> Floor, 117 Farringdon Road, London EC1R 3BX

### **Consumer hotline**

0800 085 3250

**Email** ifacontact@unbiased.co.uk

### **Law Society England and Wales**

113 Chancery Lane, London WC2A 1PL

**Tel** 0870 606 2555

**Email** info.services@lawsociety.org.uk

**www.lawsociety.org.uk**

Has details of local solicitors.

### **Law Society of Scotland**

26 Drumsheugh Gardens, Edinburgh EH3 7YR

**Tel** 0131 226 7411

**Email** lawscot@lawscot.org.uk

**www.lawscot.org.uk**

### **Law Society of Northern Ireland**

40 Linenhall Street, Belfast BT2 8BA

**Tel** 028 9023 1614

**Email** info@lawsoc-ni.org

**www.lawsoc-ni.org**

**Personal Finance Society –  
‘Find an Adviser’ service**

42–48 High Road, South  
Woodford, London E18 2JP

**Tel** 020 8530 0852

**Email** [info@findanadviser.org](mailto:info@findanadviser.org)

**www.findanadviser.org**

The UK’s largest professional body for individual financial advisers. You can use the ‘Find an Adviser’ website to find qualified financial advisers in your area.

**Emotional support**

**Cancer Counselling Trust**

Edward House, 2 Wakley  
Street, London EC1V 7LT

**Tel** 020 7843 2292

**Email** [support@cctrust.org.uk](mailto:support@cctrust.org.uk)

**www.cancercounselling.org.uk**

Qualified counsellors and psychotherapists offer free, confidential counselling to anyone affected by cancer. Provides face-to-face counselling London and phone counselling for people unable to visit. Although the counselling is free, donations are welcomed.

**Cruse Bereavement Care**

PO Box 800, Richmond,  
Surrey TW9 1RG

**Helpline** 0844 477 9400

(Mon–Fri, 9.30am–5pm)

**Helpline email** [helpline@cruse.org.uk](mailto:helpline@cruse.org.uk)

**Young person’s freephone**

**helpline** 0808 808 1677

**Young person’s helpline**

**email** [info@rd4u.org.uk](mailto:info@rd4u.org.uk)

**www.crusebereavement.org.uk**

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

**General cancer organisations**

**Cancer Black Care**

79 Acton Lane, London  
NW10 8UT

**Tel** 020 8961 4151 (Mon–Fri,  
9.30am–4.30pm)

**Email**

[info@cancerblackcare.org](mailto:info@cancerblackcare.org)

**www.cancerblackcare.org**

Offers a range of information and support for people from ethnic communities who have

been affected by cancer. The centre welcomes people from different ethnic groups including African, Asian, Turkish and West Indian communities.

### **Irish Cancer Society**

43–45 Northumberland Road,  
Dublin 4, Ireland

### **Cancer Helpline**

1800 200 700 (Mon–Thurs,  
9am–7pm, Fri 9am–5pm)

**Email** [helpline@irishcancer.ie](mailto:helpline@irishcancer.ie)  
**www.cancer.ie**

Operates Ireland’s only freephone cancer helpline, which is staffed by qualified nurses trained in cancer care.

### **Maggie’s Centres**

The Stables, Western General Hospital, Crewe Road South,  
Edinburgh EH4 2XU

**Tel** 0131 537 2456

**Email** [enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

Aims to help people with cancer to be as healthy in mind and body as possible and enable them to make their own contribution to their medical treatment and

recovery. All services are free and work in partnership with local NHS trusts.

### **Marie Curie Cancer Care**

89 Albert Embankment,  
London SE1 7TP

**Tel** 020 7599 7777 (England)  
0131 456 3700 (Scotland)  
01495 740827 (Wales)  
028 9088 2060 (NI)

### **Email**

[info@mariecurie.org.uk](mailto:info@mariecurie.org.uk)

**www.mariecurie.org.uk**

Marie Curie nurses provide free, practical care to people with cancer in their own homes, 24-hours a day, 365 days a year. There are hospices across the UK.

### **Tak Tent Cancer Support – Scotland**

Flat 5, 30 Shelley Court,  
Gartnavel Complex, Glasgow  
G12 0YN

**Tel** 0141 211 0122

**Email** [tak.tent@care4free.net](mailto:tak.tent@care4free.net)

**www.taktent.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.

### **Tenovus**

9<sup>th</sup> Floor, Gleider House,  
Ty Glas Road, Llanishen,  
Cardiff CF14 5BD

**Tel** 0808 808 1010

**Email** [post@tenovus.com](mailto:post@tenovus.com)

**[www.tenovus.com](http://www.tenovus.com)**

Funds patient care, counselling and a freephone cancer helpline. Offers support, information and counselling to anyone affected by cancer.

### **The Ulster Cancer Foundation**

40–42 Eglantine Avenue,  
Belfast BT9 6DX

**Freephone helpline**

0800 783 3339

**Email**

[infocis@ulstercancer.org](mailto:infocis@ulstercancer.org)

**[www.ulstercancer.org](http://www.ulstercancer.org)**

Offers a free telephone and call-in service about all aspects of cancer. The service is provided by specially trained nurses with experience in cancer care.

## **Useful books and leaflets**

### **Carers UK publications**

The following two booklets are provided free to carers. Contact Carers UK to order them (see page 39):

#### ***Supporting working carers: a carer's guide***

This booklet helps employees to minimise the stresses of balancing work and caring. It also helps carers prepare to return to work and includes a 4-page pull-out section to give to your employer.

#### ***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.

A full list of Carers UK publications can be found at: **[carersuk.org/Professionals/Orderpublications](http://carersuk.org/Professionals/Orderpublications)**

## **A Guide to Grants for Individuals in Need 2009/10**

Directory of Social Change, 2009

ISBN: 978 1 906294 30 4

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

## **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 below are considered by doctors to contain accurate information and are regularly updated:

### **[www.macmillan.org.uk](http://www.macmillan.org.uk) Macmillan Cancer Support and Cancerbackup**

Macmillan has merged with Cancerbackup. Together we provide a wealth of high quality information about cancer. Our website:

- Contains over 6,500 pages of accurate, up-to-date information on all aspects of cancer and a searchable database of other organisations.
- Allows you to send questions to specialist cancer nurses by email and has a question-and-answer section.
- Contains our 80+ booklets and 300+ fact sheets.
- Recommends further reading.
- Has a search engine for cancer research clinical trials available to cancer patients in the UK and Europe
- Has links to recommended cancer websites.

### **[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) (Cancer Research UK)**

Contains patient information on all types of cancer. Has a database of cancer research clinical trials.

**[www.dwp.gov.uk](http://www.dwp.gov.uk)  
(Department for Work  
and Pensions)**

Government site with official information on all aspects of work and benefits.

**[www.facingbereavement.co.uk](http://www.facingbereavement.co.uk)**

**(Facing Bereavement)**  
Gives guidance and advice on how to get through the death of a loved one and look to the future.

**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk)  
(NHS Direct Online)**

NHS health information site for England – covers all aspects of health, illness and treatments.

**[www.nhsdirect.wales.nhs.uk](http://www.nhsdirect.wales.nhs.uk)  
(NHS Direct Wales)**

**[www.nhs24.com](http://www.nhs24.com)  
(NHS 24 in Scotland)**

**[www.cancer.gov](http://www.cancer.gov)  
(National Cancer Institute –  
National Institute of Health  
– USA)**

Gives comprehensive information on cancer and treatments.

**[www.unbiased.co.uk](http://www.unbiased.co.uk)  
(Unbiased)**

Helps people search for details of local member independent financial advisers. You can do online searches at **[unbiased.co.uk](http://unbiased.co.uk)** and **[moneymadeclear.fsa.gov.uk](http://moneymadeclear.fsa.gov.uk)**

## Disclaimer

We make every effort to ensure that the information we provide is accurate but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third party information such as information on websites to which we link.

We feature real life stories in all of our articles.  
Some photographs are of models.

## Thanks

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## Sources

Department of Work and Pensions website: [www.dwp.gov.uk](http://www.dwp.gov.uk) (accessed April 2009)

Carers UK website: [www.carersuk.org](http://www.carersuk.org) (accessed April 2009)

[www.direct.gov.uk](http://www.direct.gov.uk) (accessed April 2009)

Supporting working carers, a carers guide, Carers UK, January 2009



Macmillan Cancer Support improves the lives of people affected by cancer. We provide practical, medical, emotional and financial support and push for better cancer care.

One in three of us will get cancer. Two million of us are living with it. We are all affected by cancer. We can all help. We are Macmillan.



Working with  
Cancer

CARERS UK  
the voice of carers

General enquiries 020 7840 7840  
Questions about living with cancer?  
Call free on 0808 808 00 00  
(Mon–Fri 9am–8pm)

Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)  
Hard of hearing? Use textphone  
0808 808 0121, or Text Relay.  
Non English speaker? Interpreters available.

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