

We are the UK's leading cancer information and support charity. Our services are completely free to patients, carers, families and friends, but we depend on your contributions.

**You can contact us in many ways:**

- Call us to speak to one of our specialist cancer nurses on our Freephone helpline: 0808 800 1234 (Mon–Fri, 9am–8pm). If you have difficulty hearing on the telephone we are trained in using the **RNID typetalk** national telephone relay service.
- Visit our award-winning website: [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)
- Email our specialist nurses: [www.cancerbackup.org.uk/askanurse](http://www.cancerbackup.org.uk/askanurse)
- Visit one of our eight local centres staffed by cancer information specialists (see inside for details).
- Call 020 7696 9003 to order from our range of 72 booklets and leaflets and 300 factsheets. Our booklets are available in large print and over 50 are also on audiotape.
- Send your questions to: Cancer Information & Support Service, Cancerbackup, 3 Bath Place, Rivington Street, London, EC2A 3JR.

**Call us free to speak to a nurse in your language:**

Arabic	0808 800 0130	Bengali	0808 800 0131
Cantonese	0808 800 0132	French	0808 800 0133
Greek	0808 800 0134	Gujarati	0808 800 0135
Hindi	0808 800 0136	Polish	0808 800 0137
Punjabi	0808 800 0138	Turkish	0808 800 0139
Urdu	0808 800 0140	Vietnamese	0808 800 0141

Other languages – call 0808 800 1234 and we'll link to an interpreter.

## Working while caring for someone with cancer



**CARERS UK**  
the voice of carers

Working with  
**Cancer**



informing  
understanding  
supporting

 **cancerbackup**



**A message from Maurice Slevin MD FRCP,  
Chairman of Cancerbackup**

Every year we help many thousands of people with cancer, their carers and family get the information and support they need. We do this using specialist nurses who can answer any question on any type of cancer and in different ways: through our helpline, our website, answering emails, at any of our local centres and, of course, through producing information such as this booklet. We also represent patients' interests by speaking out for people affected by cancer, so that all patients are treated fairly and receive the information they need.

Cancerbackup is a registered charity, founded by Dr Vicky Clement-Jones, following her own experience with ovarian cancer. The helpline and all our information is free to people affected by cancer, carers and family members.

Thank you,

**PS If you would like to make a donation so that we can help more people, you can call 020 7696 9003, give online at [www.cancerbackup.org.uk/donations](http://www.cancerbackup.org.uk/donations), or use the card at the back of this booklet.**

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Cancerbackup has full independent editorial control of all its information content.

Please help Cancerbackup to help other people affected by cancer

**We hope that you found this booklet helpful**

Each year we send out over a quarter of a million booklets, and help more than 90,000 people directly through our Cancer Information and Support Service. But our services can be very busy, and some people have difficulty getting through to us by phone. This is why we need your help today. We depend on voluntary donations to provide our unique services, which are free to cancer patients, their families and friends.

**Will you please help us to help others?**

- £6 will pay for three booklets to be sent to help someone with cancer.
- £25 will allow one of our nurses to help two callers to our Freephone Cancer Information and Support Service.
- £220 will keep one of our phone lines open for a morning.

**You can make your donation by:**

- sending a cheque or CAF voucher to: Cancerbackup, Freepost KE7193, London, EC2B 2DW.
- making a credit or debit card donation by phoning 020 7696 9003.
- or give online at [www.cancerbackup.org.uk/donations](http://www.cancerbackup.org.uk/donations)

We can also send you information about how you can make a regular gift by standing order to Cancerbackup. Please call us on 020 7696 9003.

# Working while caring for someone with cancer:

A GUIDE FOR CARERS WHO WORK

*informing  
understanding  
supporting*

Cancerbackup is a registered charity  
Charity reg no 1019719



- Edited by and additional text written by Richard Elworthy, Expert Information Development Nurse
- Medical Reviewer: Dr Terry Priestman, Consultant Clinical Oncologist

**This booklet is produced by Cancerbackup in association with:**

**Carers UK** – a membership organisation of carers that provides information and campaigns for a better deal for carers.

**The Chartered Institute of Personnel and Development** – the professional body for those involved in the management and development of people.

**Working with Cancer** – an organisation formed by four women who have had cancer to provide information to employers about how they should treat employees affected by cancer as well as advice for employees.

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## Working while caring for someone with cancer: a guide for carers who work

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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, suggestions about flexible working, how to get support at work, and tips on talking about cancer with your employer and colleagues.

Each year approximately 280,000 adults are diagnosed with cancer in the UK. 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 at work.

Many of those 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, in terms of providing both income and social contact outside of the home.

**At the end of this booklet there is a list of services offered by Carers UK which you may find particularly helpful. There is also a list of useful addresses, helpful books, and websites (pages 29–41).**

**You may find it helpful to read some of the information in our booklet, *Caring for Someone with Advanced Cancer***

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## Who is a carer?

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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.
- It's thought that 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, over 2 million people become carers, some overnight, some more gradually – so there are many new carers in the workforce every day.
- 3 in 5 people (60%) will become carers at some point in their life.

## Different ways of caring

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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 an ear to listen or to bounce ideas off of, or a shoulder to cry on
- giving physical home nursing care, with or without professional support
- 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 or doing everyday chores, or those things that need to be arranged, 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 cannot do.

**Remember that you don't have to do everything yourself. There's lots of help and support available (see pages 29–41)**

## What is cancer?

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The organs and tissues of the body are made up of tiny building blocks called cells. Cancer\* is a disease of these cells. It is 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.

Some causes or risk factors of cancer are known, but in many instances we simply do not yet know what causes a particular cancer. However, it is important that individuals are not blamed for getting it – either by themselves or by those who know them.

The aim of cancer treatment for many people is to cure the cancer. In some cancers that are very 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.

**The nurses in our cancer support service (freephone 0808 800 1234) can give information about all aspects of cancer. Information can be interpreted into any language. Information is also available at [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)**

\* Throughout this booklet the word cancer is used to describe all forms of cancer including lymphoma, leukaemia, and myeloma.

## Cancer treatment

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### The impact of cancer treatment on the working carer

It's likely that the person you are 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 upon what is happening for them and how they are coping.

The following are brief explanations of the main treatments for cancer. It is fairly common for a combination of treatments to be used. The doctors and nurses can give you further information about the treatments involved and how they may affect your relative or friend.

The exact treatment will be different for each person and type of cancer.

**We can give you detailed information about the particular treatment the person you are caring for is having.**

### Initial investigation and diagnosis

Going for investigations and tests, and waiting for results, can be a very unsettling time. There may be a number of visits to the hospital for different appointments before the doctors can say it is cancer, which can take up 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 will be booked

in advance so that you can arrange time off work if you need to.

It can be a very difficult time when your relative or friend is told they have cancer. You will both need time to come to terms with the change in your circumstances. This may affect your ability to work effectively. During this time you might want to think about talking to your line manager or the human resources (HR) /personnel manager at work.

### Treatment

The treatment of cancer is individual 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 may be), the person's age and their general health. The main treatment options are surgery, chemotherapy and radiotherapy.

### Surgery

Some operations for cancer will require your relative or friend to stay in hospital for a short time. Sometimes, depending on the situation, the stay may be longer. There may be a period of convalescence after the surgery, when your relative or friend needs more support. You may want to visit the hospital fairly frequently 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 is important to allow yourself plenty of time to rest.

### Chemotherapy

Chemotherapy is the use of anti-cancer drugs. It is usually given in a chemotherapy unit in the hospital over a period of several months. The treatment is usually given regularly every two or three weeks at scheduled times. Often each session of

chemotherapy will 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 chemotherapy drugs used. Because you may be at the chemotherapy unit for a number of hours, it is a good idea to plan ahead for each visit.

You may want to:

- find out how easy it is to park
- check if you can get any food while you are there, or take a packed lunch
- take something to do or read.

Although chemotherapy is usually given regularly, delays can sometimes occur, depending on how well the person is. It can help to explain this to your key contact at work and try to plan for the unexpected wherever possible.

This period of treatment can be very stressful and exhausting for the person and you may find that they experience mood swings that are out of character. Space for both of you becomes very important.

## Radiotherapy

Radiotherapy treats cancer by using high-energy x-rays. It is typically given on a daily basis, at a specialist unit, over a period of weeks. It is usually given as an outpatient. Although each treatment itself takes only a couple of 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 radiotherapy appointments. Some GP surgeries can arrange volunteer drivers; the hospital may also 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 factsheets 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 get anxious that the cancer will come back. They might worry that new symptoms they have are caused by the cancer, when in reality they may not be cancer related. The uncertainty can be very difficult at a time when they feel they should be getting back to normal.

## Making decisions about care

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Taking on the role of carer can be very unsettling, especially as it can happen at any time and may not have been planned for. In your role as carer, it is important to find a balance between what you think you can or should offer by way of support.

As each person with cancer is an individual with their own wishes and needs, it is important to respect their preferences. However, you also need to recognise that they may understate their need for help so as not to be a burden to you, or simply because they don't recognise the demands that the illness and treatment may create. Their need for support may change over time. It is also 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 allowed to make decisions about their care.

Talking about what support you can provide will help you to identify the type(s) of support needed. This may be someone to listen, someone to share thoughts and feelings with, or someone to provide practical help such as driving, shopping, housework etc. It may be that you do not 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 30–41.

It is important, as a carer, to look after your own health and well-being and to recognise what you can and can't do yourself. You may also need to share your own thoughts and feelings with someone, and get support for yourself. You may like to contact one of the organisations listed on pages 30–41.

**You may find it helpful to read our booklet, *The Emotional Effects of Cancer*. We would be happy to send you a copy.**

## What to say at work

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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 are unlikely to be able to give you the support you need if they don't know what is happening.

You are 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 from time to time. It can be very 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 very 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

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## 1. First steps: initial discussion

If you decide to talk to your employer, the first step is to have a discussion with your line manager, HR manager or occupational health manager, so that you can tell them about your new role as a carer. Your employer needs to 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 with your employer will cover topics such as:

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

The company 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's helpful 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 be beginning 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 respond 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 carer, including flexible working, time-off/emergency leave etc.(see pages 19–21).
- **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 have an 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. Spend some time thinking about what you will need to change to fulfill 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/networking groups.

## Information from your employer

It is 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/work adjustment policies
- your rights under the Disability Discrimination Act
- any employee assistance programme or occupational health service available to you.

It is 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 Cancerbackup.
- Other specialist organisations and charity helplines, and websites such as Carers UK.
- Counselling services that may be available to you as an employee.

It is important to remember that each situation is different and that you will need an individualised programme of support to meet your often-changing circumstances. The more open you can be about your circumstances 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.

**Managers might be interested to know that *Cancer and Working: Guidelines for Employers, HR and Line Managers* can be downloaded from our website**

## **2. After the first steps 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.

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

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

It can also help to make it clear:

- Who will be your main contact in the company 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 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**

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### **Requesting flexible working**

From April 2007, the Work and Families Act 2006 gives certain carers the right to request flexible working, such as changing hours or working from home. Employees who have worked for their employer for at least 26 weeks can apply to make a permanent change to their terms and conditions. Only one request is allowed in a year. Employers can refuse a request, but must give good reasons. Employees can appeal.

The right to request flexible working could make the difference between a carer leaving or remaining 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 (the amount of hours you are contracted for per month or year are worked in a flexible way)
- job-sharing or part-time working
- 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 is not in the best interests of the business. For example, they may feel that your request:

- would be too costly
- would affect the quality or performance of the business
- would 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 Relations Act 1999 to take time off to look after dependants in an emergency. Possible emergencies can include:

- a breakdown in care arrangements
- the person you are caring for becomes ill or has an accident
- you need to make longer term care arrangements.

You don't need to have been in the job for any length of time before you can take time off in an emergency; it applies right from the start of the job. The law does not define what a 'reasonable' amount of time would be; it depends on the circumstances.

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 that should 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 your employer is being unreasonable then you may need to complain to an Employment Tribunal (see page 33). An Employment Tribunal 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. This time can be extended to six months if you have attempted to resolve the matter by following company grievance procedures.

If you are considering taking a complaint to an employment tribunal it is a good idea to get advice from a union representative, ACAS or a solicitor specialising in employment law.

## Looking after yourself, physically and emotionally

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Caring for someone can place heavy physical and emotional demands on the carer. It is important to be aware of the first signs of stress, and plan how to deal with them.

At a physical level, 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.

At an emotional level, you may wish to:

- talk to other carers in similar situations to yours
- ask the hospital/doctors surgery for information that will help you to 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.

Above all, remember that no-one is expecting you to be a 'superbeing', and that you will need space and time for yourself if you are to cope with the demands of being a carer.

### 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 and make this a priority – it will be good for both of you.

## Social care

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

If you are looking after someone on a regular and substantial basis you also have a right to a **carer's assessment**. Your assessment will be an opportunity to discuss with social services the help you need with caring, as well as any help you may want to maintain your own health 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
- the way you feel about your caring role
- how it affects your relationships with family and friends
- how you would go about dealing with emergencies
- your concerns for the future.

When carrying out a carer's assessment, social services should discuss any needs and wishes you have about your paid work. During the assessment you should raise any problems or concerns you have in juggling your work and the care that you give. Support from social services can be very helpful when you are trying to manage working and caring. You could, for example, ask for a paid care worker to visit the cared for person at home 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 eligibility criteria to help them decide who to provide services to. If your needs, and those of the person you care for, meet these criteria they must provide you with the services. You can obtain a copy of their eligibility criteria by phoning your local authority and asking for their Better Care, Higher Standards Charter.

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 have 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 [www.direct.gov.uk](http://www.direct.gov.uk) (in the disabled people section) or from your local authority.

Help from social services for the person you care for can include:

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

**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
- 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

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

It is helpful 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 Independent Financial Advisers Promotions Ltd (IFAP) (see page 34).

As a carer you may be entitled to benefits or tax credits. This will depend upon your individual circumstances. The organisations listed on pages 30–41 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

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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 them and yourself. As their illness develops, their needs may change and a different type of care may make them feel more secure and safe. The demands of caring full-time may be taking their toll on you too. You may both feel that the time has come to make other arrangements. It can help to discuss the situation and consider possible alternative arrangements which you would both feel happy about. Your GP or the community nursing staff can give you more 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 is 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*, gives useful information and advice that you might find helpful to read.**

## Bereavement

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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, and perhaps also 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.

### Returning to work

Everyone copes with bereavement in their own way. Knowing when you are able to return to work will be very individual. Some people will feel able to carry on working and will need to take very little time off, others need a little 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 discuss with your employer about telling your colleagues, and whether you are happy for them to contact you.

Above all, make sure that you are prepared by having the information you need to make informed decisions that will help you to cope with your situation.

**There are many organisations that can help support you at this time, including those listed on pages 30–41.**

## Further information

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### Information and support from Cancerbackup

Our cancer information specialist nurses give information on all aspects of cancer and its treatment, and on the practical and emotional aspects of living with cancer. To contact them:

- Call our Freephone helpline: **0808 800 1234**  
Lines are open Monday–Friday, 9am–8pm.  
A free interpreting service is available for people whose first language is not English. Calls to the helpline are confidential. Sometimes another member of our team may listen to a call for training purposes and to maintain quality.
- Ask a question online: [www.cancerbackup.org.uk/askanurse](http://www.cancerbackup.org.uk/askanurse)
- Fax: **020 7696 9002**
- Write to: 3 Bath Place, Rivington Street, London, EC2A 3JR  
Office tel: 020 7696 9003  
  
Suite 2, 3rd Floor, Cranston House,  
104–114 Argyle Street, Glasgow, G2 8BH  
Office tel: 0141 223 7676

### Cancerbackup information online

[www.cancerbackup.org.uk](http://www.cancerbackup.org.uk) – our award-winning website includes the full text of all our publications, 1300+ Q&As, and a database of support groups and other services.

[www.click4tic.org.uk](http://www.click4tic.org.uk) – site for teenagers affected by cancer.

[www.whatnow.org.uk](http://www.whatnow.org.uk) – share your experiences of cancer, find others in similar situations, read tips and watch videos.

### Local centres

Cancerbackup also has local drop-in centres staffed by specialist cancer nurses:

- **Coventry**  
Cancerbackup Information Centre, Ground floor, University Hospital, Clifford Bridge Road, Coventry, CV2 2DX  
Tel: 02476 966 052
- **Ipswich**  
Cancer Information Centre, Woolverstone Wing, Ipswich Hospital, Heath Rd, Ipswich, IP4 5PD  
Tel: 01473 715 748
- **Jersey**  
Cancerbackup Jersey, The Lido Medical Centre, St Saviour's Road, St Saviour, Jersey, JE2 7LA  
Tel: 01534 498 189  
Freephone: 0800 735 0275
- **London**  
The Vicky Clement-Jones Cancerbackup Information Centre, King George V Building, St Bartholomew's Hospital, London, EC1A  
Tel: 020 7601 7936
- **London**  
Cancerbackup Information Centre, The London Clinic 20 Devonshire Place, London W1G 6BW  
Tel: 020 7616 7628
- **London**  
Cancerbackup Walk-in Information Centre, Charing Cross Hospital, Fulham Palace Road London, W6 8RF  
Tel: 020 8383 0171
- **Manchester**  
Cancer Information Centre, The Christie Hospital, Wilmslow Road, Withington, Manchester, M20 4BX  
Tel: 0161 446 8100
- **Nottingham**  
Cancerbackup Information Centre, Oncology Block, Nottingham City Hospital, Hucknall Road, Nottingham, NG5 1PB  
Tel: 0115 840 2650

## Other useful organisations

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All contact details were correct at the time of going to press. Some may have changed. Current contact details can be checked on Cancerbackup's website at [www.cancerbackup.org.uk/ResourceSupport/Organisations/Searchall](http://www.cancerbackup.org.uk/ResourceSupport/Organisations/Searchall)

### **Carers UK**

32–36 Loman Street, London, SE1 OEE

*From July 1 2008 Carers UK will be located at:*

Longstone Court, 22 Great Dover Street, London.

Tel: 020 7922 8000

CarersLine: Freephone 0808 808 7777 (Wed & Thurs, 10am–12pm & 2pm–4pm)

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

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

Offers information and support to carers. Can put people in contact with support groups for carers in their area. Carers UK have National offices for Scotland, Wales and Northern Ireland - contact details are given below:

### **Carers Scotland**

91 Mitchell Street, Glasgow, G1 3LN

Tel: 0141 221 9141

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

Website: [www.carerscotland.org](http://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)

Website: [www.carerswales.org](http://www.carerswales.org)

### **Carers Northern Ireland**

58 Howard Street, Belfast, BT1 6PJ

Tel: 028 9043 9843

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

Website: [www.carersni.org](http://www.carersni.org)

### **Crossroads – Caring for Carers**

10 Regent Place, Rugby, Warwickshire CV21 2PN

Tel: 0845 450 0350

Fax: 01788 565498

Email: via the website

Website: [www.crossroads.org.uk](http://www.crossroads.org.uk)

Provides practical respite care for carers, with over 200 schemes across England and Wales and sister organisations in Scotland and Northern Ireland (see entries below). Crossroads is committed to providing practical support in the home. Trained carer support workers go into carers' homes to take over caring tasks, giving the carer a break.

### **Crossroads (Scotland)**

24 George Square, Glasgow, G2 1EG

Carers Information and Support Line: 0141 353 6504

Email: from the website

Website: [www.crossroads-scotland.co.uk](http://www.crossroads-scotland.co.uk)

### **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](mailto:mail@crossroadscare.co.uk)

Website: [www.crossroadscare.co.uk](http://www.crossroadscare.co.uk)

## **The Princess Royal Trust for Carers**

The largest provider of comprehensive carers support services in the UK. Provides quality information, advice and support through its network of 133 independently managed carers' centres and interactive websites.

Website: [www.carers.org](http://www.carers.org) and [www.youngcarers.net](http://www.youngcarers.net)

### **England**

Unit 14, Bourne Court, Southend Road, Woodford Green, IG8 8HD

Tel: 0844 800 4361

Fax: 0844 800 4362

Email: [info@carers.org](mailto:info@carers.org)

### **Scotland**

Charles Oakley House, 125 West Regent Street, Glasgow G2 2SD

Tel: 0141 221 5066

Fax: 0141 221 4623

Email: [infoscotland@carers.org](mailto:infoscotland@carers.org)

### **Wales**

Victoria House, 250 Cowbridge Road East, Canton, Cardiff, CF5 1GZ

Tel: 02920 221788

Email: [infowales@carers.org](mailto:infowales@carers.org)

## **Financial and legal advice**

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

Helpline: 08457 47 47 47 (Mon–Fri, 8am–6pm)

Website: [www.acas.org.uk](http://www.acas.org.uk)

Aims to improve organisations and working life through better employment relations. They provide up-to-date information, independent advice, high-quality training, and work with

employers and employees to solve problems and improve performance.

## **Association of Charity Officers**

Tel: 01707 651 777

Website: [www.aco.uk.net](http://www.aco.uk.net)

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

## **Benefits Enquiry Line (BEL)**

Tel: 0800 882200 (Free)

Textphone: 0800 243355 (Free)

Website: [www.dwp.gov.uk](http://www.dwp.gov.uk)

Provides advice about benefits for people with disabilities (including cancer patients) their carers, and representatives. Gives general information only. Large print or Braille copies can be provided on request. Can also provide help with the completion of some disability-related claim packs.

## **Citizens Advice Bureau**

Contact details for your local office can be found in the phone book or at [www.citizensadvice.org.uk](http://www.citizensadvice.org.uk).

Find advice online, in a range of languages and for each UK country, at [www.adviceguide.org.uk](http://www.adviceguide.org.uk).

Citizens Advice Bureaus provide free, confidential, independent advice on a variety of issues including financial, legal, housing and employment.

## **Employment Tribunals**

Enquiry line: 08457 959 775 (Mon–Fri, 9am–5pm)

Website: [www.employmenttribunals.gov.uk](http://www.employmenttribunals.gov.uk)

Employment Tribunals hears claims about matters to do with employment. They have offices throughout the UK.

### **Independent Financial Advisers Promotions Ltd (IFAP)**

2nd floor, 117 Farringdon Road, London, EC1R 3BX

Consumer hotline: 0800 085 3250

Type talk: 0800 083 0196

Email: [contact@ifap.org.uk](mailto:contact@ifap.org.uk)

Website: [www.ifap.org.uk](http://www.ifap.org.uk)

Helps people search for details of local member independent financial advisors via the consumer hotline and online searches at [www.unbiased.co.uk](http://www.unbiased.co.uk) and [www.fsa.gov.uk/consumer](http://www.fsa.gov.uk/consumer)

### **Law Society**

The Law Society can give details of local solicitors.

#### **England and Wales**

113 Chancery Lane, London, WC2A 1PL

Tel: 0870 606 2555

Email: [info.services@lawsociety.org.uk](mailto:info.services@lawsociety.org.uk)

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

#### **Law Society of Scotland**

26 Drumsheugh Gardens, Edinburgh, EH3 7YR

Tel: 0131 226 7411

Email: [lawscot@lawscot.org.uk](mailto:lawscot@lawscot.org.uk)

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

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

40 Linenhall Street, Belfast, BT2 8BA

Tel: 028 9023 1614

Email: [info@lawsoc-ni.org](mailto:info@lawsoc-ni.org)

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

### **Personal Finance Society**

20 Aldermanbury, London, EC2V 7HY

Tel: 020 8530 0852

Fax: 020 7796 3882

Email: [customer.serv@thepfs.org](mailto:customer.serv@thepfs.org)

Website: [www.thepfs.org](http://www.thepfs.org)

The UK's largest professional body for individual financial advisers (and people in related roles). It is part of the Chartered Insurance Institute.

### **Community Legal Advice**

Tel: 0800 0856 643 Mon–Fri 9–5

Email: on website

Website: [www.clsdirect.org.uk](http://www.clsdirect.org.uk)

Helps people to find their nearest advice centre/or solicitor disability law service. Can give telephone advice on community care and employment.

### **Emotional support**

#### **Cancer Counselling Trust**

1 Noel Road

London, N1 8HQ

Tel: 020 7704 1137

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

Website: [www.cancercounselling.org.uk](http://www.cancercounselling.org.uk)

Qualified counsellors and psychotherapists offer free, confidential counselling to cancer patients, as well as couples or families affected by cancer.

#### **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)

Website: [www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

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

### **Facing bereavement**

Daresbury Point, Green Wood Drive, Manor Park, Cheshire.WA7 1UP.

Tel: 01732 460000

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

Gives guidance and advice on how to get through the death of a loved one and look to the future.

## **General cancer organisations**

### **Cancer Black Care**

79 Acton Lane, London, NW10 8UT

Tel: 020 8961 4151 (Best time to telephone: 9.30am–4.30pm, Mon–Fri)

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

Website: [www.cancerblackcare.org](http://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 (Weekdays 9am–5pm, Tuesdays 9am–9pm)

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

Website: [www.cancer.ie](http://www.cancer.ie)

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

### **Marie Curie Cancer Care**

89 Albert Embankment, London, SE1 7TP

Tel: 020 7599 7777

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

Website: [www.mariecurie.org.uk](http://www.mariecurie.org.uk)

Marie Curie Nurses provide practical care, free of charge to people with cancer in their own homes, throughout the day or overnight, 365 days a year. There are Marie Curie hospices across the UK.

### **Macmillan Cancer Support**

89 Albert Embankment, London, SE1 7UQ

Macmillan CancerLine: 0808 808 2020 (Freephone) Mon– Fri 9am–10pm

Macmillan Benefit Helpline: 0808 801 0304

Email: [cancerline@macmillan.org.uk](mailto:cancerline@macmillan.org.uk)

Website: [www.macmillan.org.uk](http://www.macmillan.org.uk)

Provides specialist advice and support through Macmillan nurses and doctors, and financial advice and grants for people with cancer and their families.

### **Maggie's Centres**

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

Tel: 0131 537 3131

Website: [www.maggiescentres.org](http://www.maggiescentres.org)

Maggie's Centres are for anybody who has been affected by cancer. The aim of Maggie's Centres is 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.

### **Tak Tent Cancer Support**

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

Tel: 0141 211 0122

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

Website: [www.taktent.org](http://www.taktent.org)

Information and support for cancer patients, families, friends and health professionals. Runs a network of support groups across Scotland, meeting monthly in the evening. Also provides counselling and complementary therapies.

### **Tenovus**

43 The Parade, Cardiff, CF24 3AB

Freephone helpline: 0808 808 1010 (9am–4.30pm Mon–Fri, except Wed. pm)

Tel: 029 20 48 2000

Email: via the website

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

Funds patient care, counselling and a freephone cancer helpline. Has over a total of 30 oncology nurse specialists, social workers, welfare rights officers and counsellors located at several hospitals in England and Wales. Offers support and information to anyone affected by cancer.

### **The Ulster Cancer Foundation**

40–42 Eglantine Avenue, Belfast, BT9 6DX

Freephone helpline: 0800 783 3339

Tel: 028 9066 3281

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

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

Offers a free telephone and call in service, where information is available on all aspects of cancer. The service is provided by specially trained nurses with experience in cancer care.

## **Useful books and leaflets**

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### **Carers UK publications**

The following two booklets are provided free to carers:

#### **An Employees Guide to Work and Caring**

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

#### **Caring for Carers: The Business Case**

Information for employers in the private, public and voluntary sectors on the needs of employees who are carers, and ideas that will help you develop workplace policies and practices to support them.

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

## Useful websites

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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.cancerbackup.org.uk**

- Contains over 4500 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 all Cancerbackup's 70+ booklets and 270+ factsheets included in full.
- Recommends further reading.
- Provides guidance for health professionals and others on controversial cancer topics.
- Includes *Cancerbackup News*.
- Has a search engine for cancer research clinical trials available to cancer patients in the UK and Europe
- Offers links to recommended cancer websites around the world.

### **www.carersuk.org** (Carers UK)

Provides information and advice on carers rights. Useful information related to employers and caring can also be found at: [www.carersuk.org/Employersforcarers](http://www.carersuk.org/Employersforcarers)

**www.dwp.gov.uk** (Department of Work and Pensions)  
Government site that gives official information on all aspects of work and benefits.

### **www.cancerhelp.org.uk** (Cancer Research UK)

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

### **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** (NHS Direct Wales)

### **www.nhs24.com** (NHS 24 in Scotland)

### **www.cancer.gov** (National Cancer Institute – National Institute of Health – USA)

Gives comprehensive information on cancer and treatments.

### **www.intelihealth.com** (drug and medicines information)

Easy-to-use and free from medical jargon. Has patient information leaflets which can be printed off.

## Cancerbackup publications

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Cancerbackup has a wide range of booklets and factsheets about all types of cancer, cancer treatments and living with cancer.

- Understanding cancer research trials
- Understanding radiotherapy
- Cancerbackup recipes
- Cancer and complementary therapies
- Controlling cancer pain
- Controlling the symptoms of cancer
- Caring for someone with advanced cancer
- Coping with advanced cancer
- Coping with fatigue
- Coping with hair loss
- Diet and cancer
- Dying with cancer
- The emotional effects of cancer
- Cancer and older people
- Lost for words: how to talk to someone with cancer
- Sexuality and cancer
- Work and cancer
- Travel and cancer
- Talking to children about cancer
- Adjusting to life after cancer treatment
- Talking about your cancer

**People affected by cancer can order publications free from Cancerbackup's information service on 0808 800 1234**

**Health professionals or organisations wishing to place bulk orders can do so by ringing 020 7920 7240**

### Cancerbackup editorial policy

Cancerbackup's policy is to provide up-to-date and accurate information about cancer and its treatments, in line with accepted national and international guidelines. Where no such guidelines exist, our information is based on scientific evidence such as data from published clinical trials, or combined analyses of trials. Where such evidence is not available, our information is based on a consensus view of experts. Each Cancerbackup publication is regularly reviewed and updated by cancer doctors, specialist nurses, other relevant health professionals and patients. The medical information is approved by a member of Cancerbackup's Clinical Advisory Board and the Medical Editor.

All Cancerbackup's booklets that describe treatments are produced to meet the criteria of the Discern Index, a nationally recognised measure of health information quality. Where trusts have used Cancerbackup's booklets in evidence to support their good practice, it has helped them to achieve compliance with the standards of the Clinical Negligence Scheme for Trusts. The content of Cancerbackup publications is independent of sponsorship.

### Cancerbackup Clinical Advisory Board

Chair: Professor Tim Eisen

Ms Deborah Bernardes; Dr Peter Blake; Dr James Brennan; Ms Christine Clarke; Professor Hugh Coakham; Professor Karen Cox; Ms Stephanie Davies; Mr Mike Dixon; Mr Richard Elworthy; Mr John Fielding; Ms Sue Green; Ms Judy Gunn; Professor Rajnish Gupta; Ms Amelia Lee; Professor David Luesley; Dr James Mackay; Ms Pauline McCulloch; Ms Peggotty Moore; Professor Gareth Morgan; Professor Peter Mortimer; Dr Anne Naysmith; Dr Chris Parker; Dr Terry Priestman; Dr Karen Robb; Dr Clare Shaw; Dr Amen Sibtain; Dr Maurice Slevin; Mr Andrew Stanley; Ms Sandra Tang; Dr Andrew Webb; Dr Jeremy Whelan; Ms Tracy Williams; Professor Christopher Woodhouse; Ms Val Young

### **This booklet has been produced in accordance with the following sources and guidelines:**

- Department of Work and Pensions website: [www.dwp.gov.uk](http://www.dwp.gov.uk) (January 2008)
- Carers UK website: [www.carersuk.org](http://www.carersuk.org) (March 2008)
- *An Employees Guide to Working and Caring*, Carers UK, April 2007.
- *Looking after someone: A guide to carers' rights and benefits 2007/8*, Carers UK, October 2007.
- *How do I get help? Carers' Assessment Made Clear*. Carers UK, January 2007.

You can access up-to-date guidelines in the health professional section of Cancerbackup's website: [www.cancerbackup.org.uk](http://www.cancerbackup.org.uk)

# Questions you might like to ask your line manager or HR manager

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You can fill this in before you see your manager, and then use it to remind yourself of the questions you want to ask, and the answers you receive.

1. ....

Answer .....

2. ....

Answer .....

3. ....

Answer .....

4. ....

Answer .....

5. ....

Answer .....

6. ....

Answer .....