

# WORK AND CANCER

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

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'As a self-employed person, all I could think about when I was told I had cancer, was how would I keep the business going?'

# About *Work and cancer*

**The booklet aims to help people with cancer find the information they need to understand how cancer and its treatment will affect their ability to work.**

It provides information to help you cope with any work issues you may face, and includes information about employment rights. There is advice about coping with the effects of treatment, such as tiredness, and tips on talking about cancer with your employer and colleagues. It may also help employers to support employees who have cancer.

Being diagnosed with cancer can be one of the most difficult situations that anyone has to face. It can cause great fear and worry, and can affect every aspect of your life, including your ability to work.

Many cancers can be cured. But the tests and treatments needed for cancer may mean spending some time in hospital. Treatments may include surgery, radiotherapy and chemotherapy, or other drugs that can cause unpleasant side effects.

**We have a separate booklet with information for people who are working while caring for someone with cancer, and further information to help employers support their employees who have been affected by cancer.**

The symptoms of cancer or the side effects of treatment may reduce your ability to work. For some people this will be temporary but for others it may be permanent. Some people may need to make changes to their work, such as changing patterns of work or working from home.

People have different views about work. For some, it is the centre of their lives and they would feel lost without it. For others, it's a means to an end: something they would give up if they could.

For some people, cancer and its treatment will be a challenge; something to get through so they can get back to their normal life, including work. For other people, it will be an opportunity to rethink their lives and consider retraining, retiring or taking early retirement.

Most of the information in this booklet is aimed at people who are employed in a company, but there is a section for people who are self-employed (see page 63). The section Financial issues applies to all people who are working.

## **Finances**

Many people find that they can't continue working while they are having treatment, which can sometimes lead to difficult financial situations. This booklet discusses sources of information and support for people in financial difficulty.

## **Further information**

At the end of this booklet are useful addresses, helpful books, CDs, audiotapes and websites (pages 73–83), and a page to write down your questions for your doctor, nurse or employer.

Our cancer support specialists on **0808 808 00 00** can give information about all aspects of cancer. Information can be interpreted into any language and is also on our website **macmillan.org.uk**

## What is cancer?

The organs and tissues of the body are made up of tiny building blocks called cells. Cancer is a disease of these cells. 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 kinds of cancer, each with its own name and treatment.

### Symptoms

Depending on the type of cancer and its position in the body, you may have symptoms such as tiredness, weight loss, breathlessness or pain. These may affect your ability to work.

### Information

It can help you to plan if you find out as much as possible about your cancer, including its likely effects and its treatment, and whether these may make it difficult for you to work.

Your GP will be able to give general advice and support, while your doctors and the healthcare staff at your hospital can give you more detailed information.

It often helps to have someone else with you, to help you remember what you want to ask, and to write things down.

You can also find information about your type of cancer from:

- our cancer support specialists, on freephone **0808 808 00 00**
- our website **macmillan.org.uk**
- your occupational health department at work
- some of the websites listed on pages 81–83.

## **Questions to ask your hospital doctor or specialist nurse**

These questions can help you find out how the cancer and its treatment may affect your ability to work.

- **What is the primary site of the cancer?** Where did it start in the body?
- **Can you explain the tests I will need?** How long will they take and will I need to take time off work?
- **What stage is it at?** The stage of a cancer describes its size and whether it has spread beyond the area of the body where it started. Knowing the extent of the cancer helps the doctors to decide on the most appropriate treatment.
- **How is the cancer likely to affect me?**
- **What are the options for treatment?**
- **How will the treatment affect me and the cancer?**

Many people find it helps to keep all their health information together. The NHS website has a secure place where you can store all your electronic health information. You can access it at **healthspace.nhs.uk**

You may find that doctors can't answer your questions fully, or that their answers sound vague. The cancer specialists (surgeons and oncologists) at the hospital know approximately how many people will benefit from particular treatments. They can often give some idea of whether your cancer is likely to be cured or whether it's very likely to come back after treatment.

However, it's usually impossible for them to say for certain whether the cancer can be cured or not in your particular case, as everyone is individual and responds to treatment differently.

Many people find this uncertainty hard to live with. It can also make it difficult to know whether, or how much, you will be able to work in the future.

It's a good idea to contact your line manager early on, if you feel comfortable doing this, to talk about the effect that your cancer may have on your ability to work (see page 18). If your manager is aware of the potential effects, they will be able to support you better.

If your workplace has an occupational health adviser, or a human resources (personnel) department, it can help to contact them as well. They will keep all information confidential if you ask them to.

## **Emotional effects**

It's natural to have a range of feelings and emotions when you have been diagnosed with cancer. Your emotions may make it difficult for you to concentrate or work effectively. You may need to take some time off to adjust to what is happening.



If you are off sick for more than seven days in a row (including the weekend), you'll need to get a doctor's certificate signing you off from work. Most employers will be sympathetic to this.

It can be difficult to talk to your manager, – or the occupational health or human resources staff – about your situation. But if you do, they will be able to support you better.

**We have a booklet, *The emotional effects of cancer*, which you might find helpful.**

## Cancer treatments

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.

Treatments that are most commonly used include surgery, radiotherapy and anti-cancer drugs (chemotherapy, hormonal therapy and targeted therapies). These may be given alone or in combination and are described below.

**We can give you detailed information about each treatment and its side effects.**

### Surgery

Surgery may aim to remove all, or part of a tumour. The effects of the surgery will depend on the part of the body being operated on and the extent of the surgery.



Some operations for cancer may be carried out as day surgery, which may mean that you only need to take a short time off work. Other operations are much larger and may mean spending a few weeks, or even months away from work. Some operations may mean that your ability to work is significantly affected – for example, if you have to have a limb amputated.

## **Radiotherapy**

Radiotherapy treats cancer by using high-energy x-rays to destroy the cancer cells while doing as little harm as possible to normal cells. Radiotherapy treatment that aims to cure the cancer will often mean that you need to go to the hospital every weekday for several weeks.

Each treatment only takes a few minutes, but travelling to and from the hospital and waiting for the treatment may take up a large part of the day.

Some people manage to continue to work during radiotherapy treatment, but may need to reduce their hours. Other people stop working completely while they're having radiotherapy and for a few weeks afterwards.

## **Side effects**

Radiotherapy may make you feel tired. Other side effects will depend on the area of the body being treated. The side effects tend to begin a couple of days after the treatment starts and may slowly worsen as treatment goes on.

The effects may continue for several weeks after the treatment has ended and then usually improve gradually. However, the tiredness can take longer to disappear and some people find it's many months before they regain their energy.

## Anti-cancer drugs

There are more than a hundred different drugs used in the treatment of cancer, and these fall into three main groups – cytotoxic drugs, hormonal treatments and targeted therapies:

### Cytotoxic drugs

Many of these drugs have been around for over 50 years and are what most of us think of as ‘chemotherapy’. The drugs interfere with the process of cell division, but affect normal cells as well as cancer cells. As a result, they often cause side effects.

The drugs are usually given as a liquid through a drip into a vein (intravenously), so that they can circulate in the bloodstream and reach the cancer cells wherever they are in the body. Some types are taken as tablets or capsules.

Chemotherapy is usually given in cycles of treatment. The drug (or drugs) is given and then followed by a few weeks of rest, so that the body can recover from the effects of the treatment. Intravenous chemotherapy may take minutes, hours or a few days. Usually 4–6 cycles of treatment are given, which takes from 4–8 months. Some treatments for particular types of cancer last much longer than this, others may be shorter.

Sometimes a drug is given continuously into the vein by a small portable pump over the course of a few months. This is known as a continuous infusion. Some chemotherapy treatments are given as tablets or capsules to take at home.

Cytotoxic chemotherapy affects people in different ways. Some people find that they can’t work at all. Others find they can keep working or that they just need to take a few days off after their treatment and can then work until their next treatment.

## **Side effects**

Cytotoxic chemotherapy can cause unpleasant side effects. It can temporarily stop the bone marrow from making new blood cells. This means your immunity is reduced and you're more prone to infections. You may also become anaemic (when the number of red blood cells in your blood is low) or have bleeding problems, such as nose bleeds or bruise easily.

If the bone marrow is not working properly you may need to take antibiotics to treat infection, or have a blood transfusion if you are anaemic. You will have regular blood tests between courses of treatment to monitor the effects.

Other common side effects include tiredness and weakness, feeling sick, a sore mouth, hair loss, diarrhoea or constipation, and numbness and tingling of the hands and feet. Medicines can be given to control some of these effects. The side effects will gradually disappear once the treatment has finished.

## **Hormonal therapies**

Hormonal therapies are drugs that can stop or slow the growth of cancer cells by either changing the level of particular hormones in the body, or preventing the hormones affecting the cancer cells. Most hormonal therapies are given as tablets, but some are given as injections every few weeks or months.

## **Side effects**

Hormonal therapies can cause side effects such as weight gain, hot flushes, sweats, tiredness, and lowered sex drive. These treatments are usually given for months or years and they usually have less of an effect on your ability to work than other cancer treatments.

## Targeted therapies

These are a newer group of treatments that work by targeting the growth of cancer cells. They generally have little effect on normal cell growth, so they usually have less troublesome side effects than cytotoxic drugs. Targeted therapies may be given as a drip (intravenous infusion) or as tablets.

## Side effects

Possible side effects include flu-like symptoms, chills, headaches, a temperature, low resistance to infection and tiredness (fatigue). Some treatments may also cause sickness and diarrhoea.

Many people are able to carry on working while taking these drugs, but tiredness and other side effects may sometimes make this difficult.

## Possible long-term effects of cancer treatments

Many people recover well and can return to a normal working life after their treatment has ended. However, others will have ongoing problems caused by their treatment. For example:

- tiredness for months or sometimes years
- soreness of an arm after breast surgery
- needing to eat little and often after stomach surgery
- needing to go to the toilet more often after bladder or bowel cancer treatment.

If you have long-term side effects from your treatment, you may need a lot of understanding and support from your employer. We discuss things they can do to help you on pages 30–31.



# Making decisions about treatment

Sometimes two different types of treatment may be equally effective in treating cancer, but have different side effects and so will have different effects on your day-to-day life and your ability to work.

Doctors and other healthcare professionals can give you information about the individual treatments and how each will affect your ability to work.

The final decision on which treatment to have or whether to have treatment at all, is yours.

It can help to find out as much as possible about the type of cancer you have and the treatments which are planned. You can then discuss your situation with your doctors and decide on the treatment that best suits your situation.

You can talk about the benefits and possible risks of each treatment with the health professionals looking after you. It's important to remember that it can be very difficult to predict how treatment will affect a person. This is because the same treatment can affect people differently.

For example, two people may be given the same dose of the same chemotherapy drug; one may have few side effects and be able to carry on working, while the other person may have severe side effects and be unable to work for a while.



## Questions you may want to ask your doctor:

- What treatments are available for my type of cancer?
- How effective is the treatment likely to be?
- What are the benefits and disadvantages of the treatment?
- How long will each treatment take and what does it involve?
- Will I be admitted to hospital, and if so, how long for?
- What are the possible side effects of treatment?
- What can be done about the side effects of the treatment?
- How much is the treatment likely to affect day-to-day life?
- How will the treatment affect my physical ability to do my job? (for example, can I drive? can I climb ladders? can I work shifts? can I travel by plane?)
- Will I still be able to work while I am having the treatment?
- Are there any treatment options that will make it easier for me to work?
- What will happen if I don't want to have any treatment?

Once you have the answers to these questions, you may need time to think through your choices and discuss them with your family or friends.

If you find it difficult to decide between the treatment options, it may help to talk to people who have already had those treatments. Your doctor may be able to put you in touch with other patients.

Many cancer organisations and support groups can also help you to find someone who has had a particular treatment. Details of support organisations are listed on pages 77–80. Some websites have video clips of patients talking about their experiences of treatment.

Many people use the internet to find information about cancer and its treatment. However, there's a lot of misleading or inaccurate information. So it's important to use high-quality and reputable sites. A list of sites with accurate and up-to-date information about cancer and work issues is on pages 81–83.

## **Second opinion**

You may want to get another medical opinion. Either your specialist or your GP should be willing to refer you to another specialist for a second opinion, if you feel it will be helpful.

Getting a second opinion may cause a delay in the start of your treatment, so you and your doctor need to be confident that it will give you useful information. If you do go for one, it may be a good idea to take someone with you so that you can make sure your concerns are covered during the discussion.

Some people prefer to leave treatment decisions completely to their doctors, as they find this easier and less stressful. However, even if you decide to do this, it is helpful to take the time to understand what your treatment will involve and how it will affect your ability to work.

## Working during treatment

Some people choose to carry on working, either full-time or part-time, during their treatment. Some people need to carry on working as much as possible for financial reasons.

Before treatment, it's often difficult to know exactly how the treatment may affect you and it will help to let your employer know this, so that they are aware you may need to change your work plans at short notice.

Some people choose to give up work completely during their treatment. If you're thinking about doing this, please see pages 27–28.

## Talking to your employer

Many people worry about telling their employer that they have been diagnosed with cancer and need to have treatment. You may worry that your employer might not support you and that they may be prejudiced or discriminate against you.

Some people worry that their employer will sack them or find an excuse to make them redundant if they say that they have cancer. However, employers should not do this and research has shown that it very rarely happens.

Anyone who has or has ever had cancer is protected by the Disability Discrimination Act, which prevents employers discriminating against people with a disability (see page 36).

The Act states that employers are expected to make reasonable adjustments to support employees in the workplace. You may be able to suggest adjustments that could help support you.

Although it helps to tell your employer that you have cancer, you don't have to do so by law. However, if you don't tell your employer that you have cancer, and the cancer and its treatment affect your ability to do your job, this could cause problems. In extreme cases, it may lead to disciplinary action being taken against you.

Also, if your employer doesn't know about your cancer and its effects, they are not required by law to make any necessary adjustments for you at work.

To consider any reasonable adjustments, your employer may ask for your permission to write to your doctor or a medical professional to get their advice on what might help. Your employer can't do this without your permission. You have the right to see any medical report before it is sent to them.

If your employer knows that you have cancer they can help you by providing support and giving you information about your rights. They can also make sure that you have time off if you need it and that you get all the financial help and benefits you are entitled to.

You can talk directly to your employer, your human resources manager or occupational health department, your trade union, or all four.

If carrying on as normal is important for you, you should say this to your employer so that they can support you in continuing with your work. However, if you can't go on working normally

because of the cancer or its treatment, then let your employer know. Arrangements can then be made to alter your work or give you time off if necessary.

**Our booklet, *Talking about cancer*, has useful tips on how to talk to others about your cancer.**

## Coping with symptoms and side effects

The cancer or its treatment may cause symptoms or side effects. Common side effects and ways of dealing with them are discussed on the following pages. We can send you detailed information about different cancers and the side effects of treatment.

### **Fatigue (tiredness and weakness)**

Cancer and its treatment often make people feel very tired and weak. Fatigue affects everyone differently and can have many different signs. Some people find that their tiredness is mild and doesn't interfere much with their work, however for others it is disruptive. Some of the more common effects of fatigue are:

- difficulty doing small tasks (everyday activities like brushing your hair or cooking can seem impossible)
- a feeling of having no strength or energy (you feel as if you could spend whole days in bed)
- having trouble remembering things, thinking, speaking, or making decisions

- breathlessness after only light activity
- dizziness or feeling light-headed
- feeling more emotional than usual.

Fatigue can affect the way you think and feel. You may find it impossible to concentrate on anything, which may greatly affect your work.

Fatigue may also affect your relationships with your manager or colleagues. It can make you become impatient with people, or make you want to avoid socialising as it's too much effort.

When you know a bit more about your treatment and what you may need, talking to your manager will help you plan so you're able to do the work that is most important to you when you feel least tired. It can help to keep a diary of your fatigue levels so that you can track how your treatment affects your energy.

You can then arrange to do important work activities at a time when your energy levels are higher. Keeping a note of your energy levels will help you to identify the days when you're best able to work, and you can then discuss this with your manager.

Don't feel that you have to work if you are too tired. Or if you do want to carry on working you may be able to find ways of making your work less tiring for a while.

**We can send you a booklet with tips about coping with fatigue.**

You can use the fatigue diary at the centre of this booklet to keep a record of your energy levels.



Energy levels can be described as:

- 1 No fatigue
- 2 Mild fatigue – but able to do normal activities
- 3 Some fatigue – but able to do some activities
- 4 Moderate fatigue – able to do some activities but need rest
- 5 Severe fatigue – difficulty walking or doing activities such as cooking or shopping
- 6 Extreme fatigue – needing to sleep or rest all day.

## **Work planning tips**

- Talk to your employer and colleagues about deadlines, which tasks are most important and what you can manage.
- Talk to your occupational health service if you have one. Their doctors and nurses have a responsibility to support you to be able to do your job and to help you with any health or medical problems that affect your work.
- Keep a diary of how you feel and see if patterns emerge – this will help you to judge peak performance hours.
- Talk to your manager about a change of duties if necessary.
- With your manager, plan a reduced or more flexible schedule if you can – look at the days you are needed at work and schedule your time around this.
- Delegate work when possible.
- If appropriate, name a person to assess which phone calls you need to take, and to forward important emails, etc.



- Work from home when possible. Your manager should tell you if there is a home-working policy and what is involved.
- Let colleagues know how you will manage things, how to contact you, and when you will check in with them.
- Talk to your doctors about the best times for appointments and treatments: for example, Friday afternoons to allow you to recover over the weekend.
- Try meditation/complementary therapies to reduce stress (see our booklet *Cancer and complementary therapies*).
- Eat as well as you can to keep your energy levels up (see our booklet *Diet and cancer*).
- Plan a period of rest after activity. Short naps and rest periods are useful – you may need a rest after meals.
- It can help to plan your days around your treatment. Try to avoid anything energetic or stressful for 24 hours before and after your treatments, or if you have a high temperature or low blood counts.

## How your manager can help

Your manager can help by:

- changing your hours so that you can travel to and from work at less busy times
- asking your colleagues to be supportive and to help with some of your work
- allowing you to take short breaks to rest or lie down
- finding you a parking space near to your place of work
- allowing you to work from home, if possible

- finding you lighter work if your job involves physical exertion or heavy lifting.

## Risk of infection

Some cancer treatments, particularly chemotherapy, can reduce the production of white blood cells, which fight infection in your body. If your level of white blood cells is very low, you're more likely to get an infection. Your doctor or nurse can tell you if your white blood cell count is low.

If it's very low, you may not be able to work so you may need to warn your employer about this. It's also a good idea to avoid people who have sore throats, colds, flu, diarrhoea and vomiting, or other kinds of infection, such as chickenpox.

If you come into contact with anyone who has an obvious infection, it's best to ask your hospital doctor or specialist nurse for advice as soon as possible. You may need to take medicines to prevent you from getting an infection.

During or after cancer treatment, it's important to get some gentle exercise and fresh air, but it's good to avoid crowds where possible. This includes avoiding using public transport, especially during the rush hour, and crowded workplaces where you may be mixing with people who may have an infection.

## Numbness or tingling of the hands and feet

Some chemotherapy drugs affect the nerves in the hands and feet. There may be increased sensitivity of the hands and feet, and pins and needles or numbness. This is called **peripheral neuropathy**. The sensations and numbness can make it difficult to hold things or to write or type. This can sometimes mean you take longer to carry out your normal tasks at work.

Some people may find it difficult to carry on working if they have this side effect. It will usually get better once you have finished your treatment but it can take weeks or months for you to fully recover.

## **Other symptoms or side effects**

Some people find that they have other effects such as soreness or pain, feeling sick or problems with eating. If you have any symptoms or side effects due to your treatment, your doctors can usually prescribe medicines to help reduce these.

If the effects are not helped by the medicines, let your doctor know so that more effective treatments can be prescribed. Sometimes, changing the time you take the medicines can make them more effective. You can discuss this with your doctor or nurse.

# Time off during treatment

You may need to take time off for appointments and follow-up. In most cases, your employer will give you a reasonable amount of time off work to attend necessary hospital appointments. If you have been diagnosed with cancer, you are protected by the Disability Discrimination Act (see page 36).

A reasonable adjustment your employer can make may be to allow you to attend hospital appointments. However, there is no absolute right to paid time off unless your contract of employment specifically states this.

Obviously it will help to give your employer as much warning as possible if you need time off, because if you give very short notice they may be unable to agree to the request.

You may also need to take time off during your treatment. This time off may be taken as sickness absence, or an agreed reduction in working hours or days per week. See pages 45–52 for information about taking time off sick, sick pay and other financial issues.

It will help to talk about your need for time off with your employer, so that they can support you in the best way possible.

## Emotional effects

Having to take time off can make you feel a range of emotions. You may feel angry that you can't be at work when you have a lot to do. You may also feel guilty if others have to take on some of your work when you're not there.

Taking a lot of time off can make you feel out of touch with what's going on at your workplace. You may lose confidence in your ability to do your job well, or you may think that your colleagues are annoyed with you or feel that you're not pulling your weight.


Some people can lose a sense of 'normality' when they're not working and some find that they lose confidence and self-esteem.

All of these emotions are natural and normal when you have to take time off for cancer treatment. It can help to talk honestly about these feelings to your manager and colleagues as well as family and friends.

## **Support**

Sometimes counselling can help people to cope with these feelings and to find ways of talking to colleagues. Counselling can also help to restore self-confidence. Some companies or GP surgeries provide counselling.

You can also have face-to-face or telephone counselling from the Cancer Counselling Trust (see page 77).



'I had no option but to stop work soon after I was diagnosed... I'd love to be working still as I'm bored at home.'

# How your employer can help and support you

## Information about your rights

Your employer or human resources manager will be able to give you information about your organisation's sickness policy and how much paid and unpaid time off you are entitled to.

## Flexible working

Most employers are willing to make changes to duties and working hours to enable employees with cancer to continue working if they want to. They usually understand that this is a very stressful time and do their best to be supportive. However, some employers who have not had experience of supporting an employee with cancer may find it difficult to understand what is needed.

## Privacy and confidentiality

If you tell your manager that you have cancer, but you don't want any of your colleagues to know, then your manager should respect your wish for privacy. They should only discuss this information with other people if you give them permission.

Union representatives and human resources managers should also respect your wish for privacy and should not tell other people about your cancer unless you want them to. Occupational health staff are bound by the confidentiality of all health professionals and won't tell anyone about your illness without your written permission.

If you want your colleagues to know about your cancer, but don't feel able to tell them yourself, then your employer or human resources manager may be able to do this for you in a sensitive way.

**We have information for employers, which gives advice about how to deal with cancer and cancer-related issues in the workplace.**

## **Buddy system**

Some people may find it hard to talk to their manager about cancer and the problems or concerns its causing for them at work. You may feel it would help to ask someone at your workplace to be your 'buddy' or mentor.

Choose someone you are comfortable with or perhaps someone who has had cancer themselves. This arrangement would need to be agreed between you and your mentor and both your managers.



# Talking to your colleagues

Talking about cancer can be very difficult. You may worry about how your colleagues will react – will they withdraw from you? Will they blame you? Or you may worry that talking about the cancer might make things awkward for yourself or your colleagues.

Some people may avoid you because they don't know what to say and are afraid of saying the wrong thing. You can help them by bringing up the subject and showing that you are willing to talk about the cancer.

Telling your colleagues can help as they then know what to expect. For example, if fatigue affects your moods or concentration, it gives them the opportunity to support you.

## If you don't want to tell colleagues

For some people it is the right thing not to tell colleagues. You may not want to tell your colleagues that you have cancer, so that you can keep one area of your life as normal as possible. This is a good way of coping for some people.

However, sometimes the effects of the cancer or cancer treatment (for example, if your hair falls out), and the need to take time off may make it impossible not to tell your colleagues.

Remember too, that your colleagues may be aware from your behaviour that something is wrong, and may feel uncomfortable if they do not know what it is.

## Risk to colleagues

There are many myths and misunderstandings about cancer. Some of your colleagues may worry that they can catch your cancer. But cancer can't be passed on like an infection and the people you work with have no risk of catching cancer.

Some people may also worry that they could be harmed if you are having treatments such as chemotherapy or radiotherapy. Again, there is no risk to your colleagues. Chemotherapy is broken down in the body and can't harm anyone you come into contact with. Radiotherapy treatment from an external machine doesn't make you radioactive.

Even if you've had internal radiotherapy, the radiation will only affect a small area of tissue in your body around the cancer and will not affect anyone that you come into contact with.

If you find it difficult to discuss these issues with your colleagues, you may find it helpful to talk in confidence to our cancer support specialists on **0808 808 00 00**.

# If you are a colleague of someone with cancer

When a colleague has been diagnosed with cancer, people can react in many different ways.

Some may have dealt with cancer before – perhaps they've had a family member who has had cancer. But others may not have dealt with cancer or any other serious illness before, and they may feel at a loss to know what to say or do. Some people may feel too embarrassed to say anything at all.

Your colleague may have told you themselves that they have cancer. Or you might have been told by someone else.

If your colleague tells you themselves, you could ask them how you can help and whether they'd like you to ask after their health, or would they rather not talk about it. You could ask who else knows of their situation, and if they want to keep it to only a few people or whether it's general knowledge. Take the lead from them about how they want to handle the situation.

There are some things that can generally help:

- Don't go quiet when your colleague walks into the room.
- Do respect your colleagues wish for privacy and confidentiality.
- Don't overdo the sympathy. Your colleague may be trying to keep life as normal as possible where they can – too much sympathy may just remind them of the cancer.

- Remember to invite your colleague to any social arrangements or other events. They will appreciate the invitation even if they're unable to come.
- Keeping in touch can be very helpful. If your co-worker may be off sick for a while, find out the best way to keep in touch. This might be a regular phone call or visit, or maybe regular emails or using a social networking website. You can ask your colleague what they'd like to know about and how often they'd like to hear from you.

A cancer diagnosis can often mean that we experience a range of emotions. These may include shock, sadness and anxiety. Some people find it difficult to talk about cancer or share their feelings.

You might think it's best to carry on as normal, as if nothing is wrong. But it's quite natural to feel upset or worried if your co-worker has been diagnosed with cancer. It's important to talk about your feelings, especially if it has a big impact on you at work.

You may find it helpful to talk to other colleagues or people outside of work. Some workplaces have an Employee Assistance Programme (EAP) or other support network to help employees affected by cancer or other illness. These are often available through the Human Resources department.

**You may find it helpful to read our booklet *Lost For Words*. It looks at some of the difficulties people may have when talking about cancer and suggests ways of overcoming them.**

# Discrimination at work

Research has shown that most employers do not discriminate against employees who are diagnosed with cancer and are having treatment. Your employer should provide help and support to enable you to do your job. There are laws protecting the rights of workers who suffer from illnesses like cancer.

## Disability Discrimination Act (DDA)

Under the Disability Discrimination Act (DDA), it is unlawful for an employer to discriminate against a person because of their disability. Everyone with cancer is classed as disabled under the DDA and so is protected by this Act.

The DDA covers workers who were disabled in the past, even if they are no longer disabled. So a person who had a cancer in the past that has been successfully treated and is now 'cured' will still be covered by the DDA. This means their employer must not discriminate against them for a reason relating to their past cancer.

The employer has a duty to make 'reasonable adjustments' to workplaces and working practices to ensure that people with a disability are not at a disadvantage compared to others.

What is considered a 'reasonable adjustment' depends on things such as:

- the cost of making the adjustment
- the amount the adjustment will benefit the employee

- the practicality of making the adjustment
- whether making the adjustment will affect the employer's business/service/financial situation.

Some examples of a reasonable adjustment include:

- allowing an employee time off to attend medical appointments
- modifying a job description to take away tasks that cause particular difficulty
- allowing some flexibility in working hours
- allowing extra breaks to help an employee cope with fatigue
- temporarily allowing the employee to be restricted to 'light duties'
- adjusting performance targets to take into account the effect of sick leave/fatigue etc on the employee
- moving the employee to a post with more suitable duties (with the employee's agreement)
- moving a work base – for example, transferring to a ground-floor office if breathlessness makes it difficult to climb stairs
- ensuring suitable access to premises for employees using wheelchairs/crutches etc
- providing toilet facilities appropriate for a disabled employee
- allowing working from home
- allowing 'phased (gradual) return' to work after extended sick leave

- providing appropriate software (such as voice-activated software for employees who can't type)
- changing a job interview date/time so as not to clash with an applicant's medical appointment.

The DDA covers the recruitment process; the terms and conditions of employment; opportunities for promotion, transfer, training and benefits; unfair dismissal; unfair treatment compared to other workers; and harassment and victimisation.

If you want to know how the DDA can help you, you can ask the information officers at the Equality and Human Rights Commission helpline (see page 79) or your local Citizens Advice Bureau (see page 78).

Despite these laws, discrimination may still occur if your employer doesn't take your situation into account. For example, this can include:

- an employer not making reasonable changes to enable you to do the job (eg to cope with fatigue)
- an employer suggesting that a person with cancer would be better off not continuing to work
- being dismissed for a reason relating to your cancer
- being demoted to a lower-paid or less demanding job
- being passed over for promotion in favour of someone with less experience or ability to do the job
- being chosen for redundancy for a reason related to the cancer (for example, if you've had a higher rate of sick time than your colleagues).

- not being given a job because of the cancer
- not being allowed time off for medical appointments
- having an unfavourable appraisal or performance review (for example, if you have had a lot of sick leave or tiredness and have not met targets or objectives as a result of this)
- an employer disrupting your entitlement to sick pay
- being harassed – an employer making an employee’s life very difficult so that the employee feels that they cannot stay in their job (eg being teased about hair loss, or being laughed at or whispered about by colleagues)
- being abused by employers or colleagues (for example, being given unfair workloads)
- victimisation (see below).

Some problems may happen because of misunderstandings about your cancer. Your employer may assume that you can no longer do the same job, or that the stress of having cancer makes you a poor candidate for promotion.

Your colleagues may also think that they will need to do extra work because you can’t do your job. Any of these attitudes towards people with cancer can lead to subtle or obvious discrimination in the workplace.

## **Victimisation**

Under disability rights law, victimisation is when a disabled employee is treated less favourably than other employees as a result of their attempt to assert their rights as a disabled person.



An example of this would be that an employee's manager is awkward about a request for time off for a chemotherapy appointment. The employee reports the problem to the human resources department. The human resources manager tells the manager that they must let the employee have the time off.

The manager is angry that the employee went 'over their head' to the human resources department. As a result the manager doesn't allow the employee to go on a training course and gives them a poor appraisal. So, victimisation occurs when an employer takes revenge on an employee for trying to assert their disability rights.

## **If you are being discriminated against or victimised**

If you feel that you are being discriminated against, you can work with your supervisor, manager or human resources department to resolve the problem informally.

Talking openly to your manager about your needs and their needs may help to resolve the situation.

If you feel unable to talk to your manager, you can ask someone in the human resources department or an occupational health adviser for help. If you belong to a trade union, you can get help and support from a union representative.

## **What you can do for yourself**

- Find out about relevant company policies from your employer or human resources department. Look at the Employee Handbook if you have one.

- Go to your employer with suggestions and solutions to demonstrate your commitment to your job.
- Suggest working from home, flexible hours, using holiday time, changing your role or job description, adjusting targets or objectives, or changing to lighter duties.
- If you go back to work after long-term sick leave, suggest a 'phased return' in which you increase your hours gradually over a period of time.
- Know your legal rights – ask your union representative or speak to one of the organisations on pages 78–80.
- If adjustments are needed at your workplace, ask about the 'Access to work scheme' at your local Jobcentre Plus office – see page 77.

## Unresolved problems

It's not possible in a short booklet to go into all the possible discrimination or victimisation problems that may occur. It's also not possible to explain your rights in each situation. However, the suggestions below may help you if you feel that you are being victimised or treated unfairly.

Think carefully about your goals and the possible outcomes before taking any action.

- Contact the organisations that give information about legal rights and employment issues. These are on pages 78–80.
- Find a colleague or union representative who would be willing to help you talk to the appropriate manager about your situation.



'It was awkward and sometimes difficult as my work colleagues didn't know how to treat me.'

- Always try to resolve any problems informally in the first instance. If this is unsuccessful, consider the consequences of raising a formal grievance or of going to an employment tribunal with a claim for disability discrimination, or unfair or constructive dismissal. Ask yourself whether the long and drawn-out process is worth it and how it will affect your life and family members. It may help to think about how you would feel if you lost the claim. It's important to examine these issues carefully, and to understand the possible impact of what you are getting into.
- Contact the Citizens Advice Bureau. It can provide free legal advice initially or put you in contact with a local solicitor who offers a free first interview, where they can assess your chances of success.
- Contact a lawyer if necessary. Law centres (listed in your local phone book) can give free legal advice and can assess your case. The Law Society (page 80) can give you details of lawyers specialising in employment rights.
- Be aware of your rights. The Disability Discrimination Act (DDA) covers any employee from the first day of their employment and even covers job applicants. You can use the Act to force an employer to make some adjustments to help you with your work or to compensate you for discrimination. The DDA does not cover members of the armed forces.
- Be aware of legal deadlines. If a dispute cannot be resolved and a worker covered by the DDA wishes to take legal action, an application must be submitted to an employment tribunal within three months of the discriminatory act/incident. The employer's grievance procedure must have been completed before the case is taken to an employment tribunal.

- If you are dismissed by your employer, usually you can only claim for unfair dismissal if you have 12 months or more continuous service with your employer. Unfair dismissal law only applies to people who are 'employees' in the strict sense of the word. It does not apply to casual workers, agency workers, self-employed contractors, apprentices, or people on work experience.
- If an employer treats you so unfairly that it causes a total breakdown of trust and confidence between you and your employer, and you feel that you cannot continue your work, you can resign and make a claim for constructive dismissal. However, this is extremely risky as you will have to resign and constructive dismissal claims are very hard to win. They should never be considered without taking legal advice. In order to claim constructive dismissal you must resign promptly in response to your employer's behaviour and must make your reason for leaving clear – for example, in your resignation letter.

## Help with legal costs

Be aware of the financial effects of legal action. Legal cases can be extremely expensive. Some solicitors take cases on a no-win–no-fee basis. This should mean that you only pay the solicitor if they win your case, but check with them to see if there are any hidden charges.

A small number of solicitors will take on disability discrimination claims under the government's Legal Help scheme, which is means tested. The scheme provides free legal assistance to prepare the case, but does not cover legal representation at a tribunal hearing. The Legal Services Commission has details of all solicitors who assist people under the Legal Help scheme (see page 78).

If you are a member of a union, the union may be prepared to take your case to tribunal on your behalf, with their own legal experts, solicitors etc.

Some specialist insurers can insure you against losing the case and having to pay both your own legal costs and your opponent's. The insurer will look at your case and assess your chances of success. The amount of your premium is then based upon your chances. The insurance only covers one specific case and is not general legal insurance.

## Financial issues

### Taking time off sick

During treatment some people may try to continue to work, but may need to take a few days or weeks off. This may be as one period of sick leave, or could be a few days every month for a period of time.

Some people choose or need to stop working throughout their treatment, which could be a period of weeks, months or even years. When deciding whether you want to carry on working or whether you would like to take the whole time off sick, you may like to think about the issues below and also the financial considerations on pages 54–55.

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 IFA Promotions or the Personal Finance Society (see page 79).

If you have any private insurance cover for income replacement, life insurance, loan or mortgage protection or critical illness cover, you should speak to your insurance company or financial adviser as soon as possible.

You can get advice from your insurer or financial adviser about any conditions which apply to your life insurance or pension plans, such as being able to take a break from payments or a waiver of premium. A waiver of premium benefit means that the insurance company will pay the premium for you for a set period of time (for example, until you are fit to work or until the end of the policy).

### **Sick pay**

All employees who earn enough money to pay national insurance contributions are eligible to receive Statutory Sick Pay (SSP) if they are off sick for more than four days (including the weekend), for a maximum period of 28 weeks.

To claim SSP, you must tell your employer that you are sick no later than seven days after you first become ill. The payment is made by the employer on behalf of the government. The employer claims a contribution towards the payment, which is deducted from the payment of national insurance contributions.

Some companies pay more than the basic rate of statutory sick pay and this is known as contractual or occupational sick pay. This will be detailed in your contract of employment/staff handbook or you could ask your human resources department for further information.

Occupational sick pay is usually paid as a top up to SSP (ie you don't get both: SSP is a part of your occupational sick pay).

### **Information for self-employed people is on page 63.**

SSP starts when you have been off work for four days and continues until you either return to or leave work, or until the end of the 28-week period. At the end of the 28-week period, your employer should then complete a form SSP1 (Statutory Sick Pay Leavers Statement) and give it to you. This will explain that your SSP is finishing and tell you where to get further help and advice about benefits.

Periods of SSP payment linked by less than eight weeks (56 days) are considered to be the same period of absence – in other words you need to be back at work for over eight weeks before you can claim again for the full 28 weeks of SSP.

### **Sick certificate**

If you are ill and not able to work for more than a few days, remember to ask your GP for a medical certificate to cover the period of your illness. If you are in hospital, ask your doctor or nurse for a certificate to cover the time that you are an inpatient. This will be necessary if you need to claim a benefit. You may need to take a medical test to assess if you are eligible to claim.

### **Benefits**

If you are still unable to work after receiving SSP for 28 weeks, or your contract ends before that time and you are still unable to work, you may be able to claim Employment and Support Allowance (ESA). This is a new benefit which replaces Incapacity Benefit.



There are two parts to ESA: a contributory part which is dependent on how much National Insurance you have paid, and a means tested part which is dependent on your income and savings. You may get either or both parts.

Usually, ESA is paid at a basic rate for the first 13 weeks. This is the assessment phase. During this time you may need to complete a questionnaire or attend a medical assessment. After the 13-week period you will be assessed and placed into one of two groups: the support group or the work-related activity group.

If you are found to have limited capability for work you will be placed in the support group. An additional payment will be paid to anyone in the support group.

If you are found not to have limited capability for work you will be placed in the work-related activity group. A small additional payment will be paid to anyone in this group. You will have to attend five more work- focused interviews. The interviews are to help you get back into work.

If you are self-employed you are entitled to claim ESA as long as you have paid the correct level of National Insurance contributions. People who have not paid the relevant National Insurance contributions may qualify for ESA under the means-tested route.

If you need help with personal care, you may qualify for Disability Living Allowance (DLA) if you are under 65 or for Attendance Allowance (AA) if you are over 65. People under 65 can also claim DLA if they have mobility problems. Ask your local Department for Work and Pensions office for claim forms or call the Benefit Enquiry Line on **0800 882200**.

There is a fast-track claim for people who may not live longer than six months. People who claim under these ‘special rules’ need to get their doctor to complete a form for either benefit.

It’s impossible to tell exactly how long someone may live and many people with advanced cancer may be entitled to this benefit. Special rules payments of AA and the DLA care component are reviewed after three years.

If you have a dispute over a benefit claim, a specialist welfare rights solicitor can advise you – the Legal Services Commission can give you details of specialist solicitors (see page 76). You could also contact your local Law Centre or Citizens Advice Bureau. Some of the organisations on pages 75–80 can also advise you about this.

## **Disability/life assurance and occupational pensions**

All life assurance, critical illness insurance and occupational pension schemes have different rules and operate in different ways. It’s important to get independent financial advice to find out about the policies you may have and the best thing to do in your situation. For example, you may want to use a payout from an insurance claim or from severance of your employment to pay a lump sum off your mortgage.

### **Life assurance policies**

If you have an existing life insurance policy and can’t continue to pay your premiums you can find out if a waiver of premium applies to the plan. This means the insurance company will pay the policy premium for you, for a time, if you are ill and unable to work. Different companies have different policies and the time they will pay the premiums may vary.

If you need money urgently, you could talk to an independent financial adviser about your options. For example, you may be able to take out a loan against your life insurance policy, sell the policy or surrender the policy.

However, you may find it impossible to take out a new life insurance policy for a few years after you have had cancer, so bear this in mind when planning your finances.

### **Occupational pensions**

If you are paying into an occupational pension scheme, or are considering paying into one, make sure you have full information about the scheme. Your human resources manager, trade union representative or pension scheme's trustees will be able to help.

You have the right to leave or decide not to join a scheme, but always consider the implications carefully and take advice from an independent financial adviser before you make a decision.

If you leave one job to go to another, there are several ways your pension rights may be dealt with. Find out what your options are from your new employer. You may want to discuss it with an independent financial adviser.

If you've had a temporary interruption of work due to sickness, find out how this affects your pension. There can be variations in the conditions which might affect your pension entitlement.

### **Information about financial issues**

For further detailed information on benefits and financial support please ring us on **0808 808 00 00**. Our booklet *Help with the cost of cancer* provides information about different



kinds of financial help available for people with cancer. Call us on **0808 808 00 00** for your free copy or order one at our website **[be.macmillan.org.uk](http://be.macmillan.org.uk)**.

You can also find out more about benefits from your local Citizens Advice Bureau or Social Security office. You will usually need to make an appointment. Their addresses and telephone numbers are in the phone book. You can also get information from the Benefit Enquiry Line on **0800 882200** or the Department for Work and Pensions website at **[dwp.gov.uk](http://dwp.gov.uk)**

The Benefit Enquiry Line has some advisers who speak other languages and can also arrange to give its information through interpreters. Benefit information in other languages is available on the Department for Work and Pensions website at **[dwp.gov.uk/otherlanguages](http://dwp.gov.uk/otherlanguages)**

The hospital social worker can give you advice on sources of financial help. *A Guide to Grants for Individuals in Need* (see page 81) is a book which gives details of all the trusts and organisations that provide financial support. It is available from bookshops or local libraries.

**We can send you a fact sheet about financial issues and sources of financial support.**

Remember that a change in your circumstances (such as a reduction or increase in your salary or in the number of hours you work) can mean you're entitled to more or less benefit. You need to find out in detail the regulations and conditions that apply to your benefits.

# Going back to work

Many people choose not to work during their treatment. Going back to work after a break of a few weeks or months can be difficult. You may feel that you're able to go back to your old job, but may feel nervous about it. It's common for people to feel awkward and to wonder if they'll still be able to do the job.

For some people, going back to work can help them to feel that the cancer is over and that they can return to normal life.

## Meeting with your employer

When you plan to go back, it will help to have a meeting with your employer, human resources department or occupational health staff. If you're still coping with some of the effects of cancer treatment, you can discuss any changes that can be made to your work to help you.

If your workplace has an occupational health adviser, your manager can arrange for you to see them and agree a 'return to work' plan. The adviser can see you from time to time until you are fully back at work.

If you feel that things have moved on while you were away, you may want to ask for time or training to catch up with the developments.

## Job flexibility

If you feel that you can't cope with your old job and would like to reduce your hours (go part-time) or need to change your job description, you should discuss this with your employer or the

HR manager as soon as possible. They should be willing to be flexible about your work arrangements to allow you to go on working as much as you can. They are required to consider this under the Disability Discrimination Act (see page 36).

## **Financial considerations when returning to work**

If you are considering going back to work after treatment, it's important to think about the following:

- The option of full-time or part-time work. Look at how much income you need to cover your monthly outgoings.
- You may have had your mortgage, bank loan or credit agreement paid by an insurance policy while you were ill. This will end when you go back to work, so remember to include it in your calculations.
- If you've been out of work for a long time you may have financial problems and possibly be in debt. The National Debtline can give you advice (see page 80).
- You can keep claiming some benefits even when you go back to work, but others will stop. For example, you might still be able to receive Disability Living Allowance while working, but Employment and Support Allowance could be affected.
- There are 'top-up benefits' for people on low income, especially for part-time workers, such as Working Tax Credit, Child Tax Credit, and Council Tax Benefit.
- Help is available for self-employed people or people who want to be self-employed – contact your nearest Citizens Advice Bureau or the Department for Work and Pensions.

- Do you have income from occupational pensions, private pensions, life assurance – can you freeze a pension, transfer a pension or cash-in a pension?
- It may help to contact an independent financial adviser (see organisations on page 79).

## If you have been claiming benefit

If you want to go back to work after some time away and you have been claiming benefits, there are options you will need to consider. Factors other than financial ones that may affect your decision are covered elsewhere in this booklet.

It's important to realise that there are many issues to take into account when assessing benefits and so it's only possible to give general information here. Each person's entitlement has conditions specific to their situation, taking into account age, savings, income, hours worked, number of people in the family, childcare costs, and housing costs.

Some benefits automatically entitle you to other benefits. It's possible to be eligible for more than one benefit (such as Income Support and Working Tax Credit) but not both at the same time.

It is essential that you take advice from an independent benefits adviser. You could call one of our cancer support specialists (**0808 808 00 00**), a Citizens Advice Bureau or welfare rights worker (see page 78). You can check if there's a benefits adviser in the social work department at your hospital.

You should check out your entitlement to benefits and tax credits to work out whether your income will be higher with these or if you go back to work. You will need to know:



- if you will be better off financially
- if savings affect your eligibility for certain benefits
- how much you would need to earn to compensate for the loss of benefits you may be receiving at present
- how the number of hours you work will affect your eligibility for certain benefits
- how claiming a different benefit would affect your situation
- who should make the claim for benefit if you're living with a partner. There could be occasions when it's beneficial for one partner rather than the other to claim.

### **Benefits not affected if you go back to work**

Disability Living Allowance (care and mobility components) and Attendance Allowance can both be paid whether or not you are working.

Eligibility for both allowances depends on your care needs (care component) and your inability to walk (mobility component). If your walking improves and/or you need less help with personal care, this could affect your entitlement to Disability Living Allowance and Attendance Allowance. The Department for Work and Pensions may re-assess the rate you are paid.

The higher rate of the mobility component of the allowance allows you an exemption from road tax and entitles you to a Blue Badge parking concession. You can also use the higher rate of the component to buy or lease a car under the Motability Scheme.

## Prescription charges

Prescription charges for people with cancer are changing.

**England** Since April 2009, cancer is one of the conditions that make you exempt from paying prescription charges. You can apply for an exemption certificate, which lasts for five years, by asking your doctor for the relevant form.

**Scotland** Prescription charges are being phased out in Scotland over the next three years (to be abolished by 2011). In line with this, the cost of a pre-payment certificate (see below) is going down.

**Northern Ireland** Prescription charges and pre-payment certificates reduced in price from January 2009 and are free from April 2010.

**Wales** Prescriptions are free to people who live in Wales.

If you need a lot of prescriptions but can't get them free, you may consider buying a pre-payment certificate for four months or for 12 months. You save money if you need more than five prescriptions items in four months or 14 items in 12 months.

## Council Tax reduction

You can claim a reduction of your council tax if you have special provisions for the disabled in your home.

Benefits that can top-up a low income

- Working Tax Credit
- Child Tax Credit

- Income Support
- Housing Benefit
- Council Tax Benefit
- Pension Credit
- Educational Maintenance Allowance
- free school meals
- help with NHS costs, prescriptions, hospital fares, dental or eye treatment.

### **Benefits affected if you go back to work**

If you receive Employment and Support Allowance (ESA) from the Department for Work and Pensions, this will stop if you go back to work. It's important to review your situation after a few weeks. If you are finding it difficult to continue to work, you may re-qualify for ESA at the same rate and on the same basis as before, if you make a fresh claim within 12 weeks.

### **Permitted Work**

Generally, ESA is paid on the basis that you are unable to work. But there are some types of work you may be able to do within certain limits. This is called 'Permitted Work' and allows you to see how you get on with some types of work and maybe learn some new skills.

You will need to check that what you want to do is covered by the Permitted Work rules. These say you can:

- work for less than 16 hours a week on average, with earnings up to £92.00 a week for 52 weeks



- work for less than 16 hours a week, on average, with earnings up to £92.00 a week if you are in the support group of the main phase of ESA
- work and earn up to £20 a week, at any time, for as long as you are receiving ESA
- do Supported Permitted Work and earn up to £92.00 a week for as long as you are receiving ESA, provided you continue to satisfy the Supported Permitted Work criteria.

If you do Permitted Work, you may be liable to pay tax on the extra income. You will need to tell HM Revenue and Customs (HMRC) when you start work. Other benefits such as Housing Benefit or Council Tax Benefit may also be affected.

It's best to discuss this with a personal adviser at your local Jobcentre Plus office. They can also tell you about local schemes to help people back into work.

# Looking for work

If you're looking for a new job, you may wonder whether you have to tell prospective employers that you have or have had cancer. An employer can ask you for information about a disability. However, this should only be asked for if it is needed to enable a recruitment decision or for a related purpose, such as equal opportunities monitoring.

Disability related questions must not be used to discriminate against a disabled person and an employer should only ask such questions if they are, or may be, relevant to the person's ability to do the job.

During the recruitment process, if you are asked directly whether you have a health condition, it's advisable to say that you have (or have had) cancer. Even if it won't affect your ability to do the job, it's sensible to make a potential employer aware so that they can support you if your cancer were to have an effect on your work at a later date.

It's important that you don't lie to an employer or potential employer. If you give false or incomplete information and it's found out at a later stage, your employer could reasonably assume you were hiding the information. This can lead to a breakdown in trust and confidence between you. On that basis the employer could potentially dismiss you and this would be considered a 'fair dismissal'.

Many people with cancer don't consider themselves to be disabled and if asked in general terms whether they consider themselves disabled will say no. However, if you are asked if you are disabled, you should say yes for the purposes of the

Disability Discrimination Act. This is because everyone with cancer is covered by the Act and the term disabled has a specific meaning under that Act.

If you are asked how much sick leave you have taken, it's best to give an honest answer, but you don't have to say it was due to the cancer, unless you are asked directly.

Understandably, many people worry that telling an employer about the cancer may put them at a disadvantage during the recruitment process. If the process allows you, you could choose to wait to tell them about your health.

It may be best to discuss it after a decision about the applicants has been made. This may reduce the risk that it could affect your chances of getting the job.

# If you are self-employed

If you are self-employed you are entitled to claim Employment and Support Allowance (ESA) as long as you have paid the correct level of National Insurance contributions. People who have not paid the relevant contributions may qualify for ESA under the means tested route.

There are specific rules for calculating the income of self-employed people, and entitlement to certain benefits differs from that of an employee, especially in the case of Jobseeker's Allowance and Income Support.

Depending on your particular circumstances, the benefits you may be eligible to claim include Housing/Council Tax Benefit, Working/Child Tax Credits, NHS Benefits, ESA, Disability Living Allowance, and Attendance Allowance.

The Department for Work and Pensions can give you information about benefits you may be entitled to claim. You can also contact our Benefits Helpline on **0808 808 00 00**.

You can discuss your situation with a benefits adviser at a Citizens Advice Bureau or Law Centre to find out about your entitlements. If you have a dispute over a benefit claim a specialist welfare rights solicitor can advise you. The Legal Services Commission (see page 78) can give you details of specialist solicitors.

Remember that a change in your circumstances (for example, a reduction or increase in your income/ number of hours you work) can change your entitlement to benefit. You need to find out the regulations and conditions that apply to your benefits.



# Help with disability caused by cancer

## Access to Work

Jobcentre Plus runs the Access to Work programme, which can help you if your cancer affects the way you do your job. It provides advice and support to people and their employers to help them overcome obstacles at work due to disability.

For example, you may get help to pay for equipment you need at work, adapting premises to meet your needs, or a support worker. It may also pay towards the cost of getting to work if you can't use public transport.

There may be a local Access to Work contact centre near you. Or you or your employer can contact them through your local Jobcentre Plus office.

You'll be sent an application form to complete. The Access to Work adviser will then talk to you and your employer to help you come to an arrangement about the best support for you. If necessary, the adviser will arrange for specialist advice.

Following this consultation, the adviser decides on a package of support, and gets approval of this from Jobcentre Plus. Both you and your employer will get a letter telling you about the support and grant available.

Your employer (or you, if you are self-employed) will need to arrange the support and buy any equipment needed. They can then claim reimbursement from Access to Work.

The amount of financial help you may get (the Access to Work Grant) varies, depending on how long you've been employed, whether you're self-employed and what support you need.

Access to Work can pay up to 100% of the approved costs if you are unemployed and starting a new job, self-employed or working for an employer and have been in the job for less than six weeks.

They pay a proportion of the costs of support if you're working for an employer, you've been in the job for six weeks or more and you need special equipment or adaptations to premises.

The exact financial arrangement and who pays for what is agreed between your employer and the Access to Work adviser. Access to Work will review your situation after one to three years.



# Giving up work for good

Some people choose to give up work completely when they are diagnosed with cancer. This allows them to focus on the cancer and its treatment and other aspects of their lives.

If work has been the major focus of your life it can be difficult to adjust to not working. It may help to talk to someone about your feelings, such as a counsellor at the Cancer Counselling Trust (see page 77).

You will need to think carefully about the effect on your finances of giving up work. It's important to get advice from an independent financial adviser. You need to consider the money you will receive from a state, occupational or private pension and from any other sources such as savings, shares or benefits.

If you give up work you also give up the rights which are associated with the employment, such as occupational sick pay, statutory sick pay, pension rights and occupation-linked private medical insurance.

## Early retirement

If you want to take early retirement on health grounds or for personal reasons, it's essential to take advice from your pension administrator. You may be able to take early payment of your pension on the grounds of ill health, but this will depend on the rules of your own particular pension scheme. You may have several options to consider.

Taking an occupational pension for health reasons can mean that you receive a higher amount of pension. However, if you

choose to retire early but are medically fit to work, the level of your pension may be lowered.

Your scheme may not allow you to retire early if you are fit to work. The provisions vary between schemes. Consider your own circumstances before deciding on a final settlement.

Getting advice from an independent financial adviser about the various options open to you may help you get a higher income from your pension.

You may need to decide between a large lump-sum payment plus small monthly income, or a small lump-sum payment plus large monthly income.

If you are claiming Employment and Support Allowance (ESA), this may be reduced if you receive payments of more than a certain amount per week from either a pension or health insurance scheme.

# After treatment

Even though cancer treatment may have lasting effects, people who have had cancer are still able to work hard and effectively. However, any cancer experience can be devastating and have a profound effect on someone's life.

People often expect to feel glad once treatment has ended, and think that they'll be able to put the cancer behind them and go back to their normal lives. Some people are able to do this. But many people find this can often be a difficult time as they adjust to all they have been through and the impact it has had.

It's normal to feel tired for several months after treatment and it takes time to recover your usual energy levels. Many people take time to make other adjustments in their life following cancer. This can include making changes to their diet, how they use their spare time, their sex life and their relationships.

## **We can send you information for people whose treatment is over apart from regular check-ups.**

People can experience many different emotions after cancer and its treatment. They may be afraid that the cancer will come back, and that they'll have to go through further treatment. They may wonder about whether the cancer has been cured. Some people may feel very depressed for a while.

Often, these feelings gradually become less frequent and after some time most people begin to enjoy life again. However, for some people they may need support and help in coping with their emotions. Some people find a support group helpful. Other people will find seeing a counsellor helpful.

You will usually continue to see your GP or go to hospital for check-up appointments for a few years after your treatment.

## Carers and family members

If you are a partner or family member of someone having cancer treatment and you need to take time off work to look after them, you may be entitled to take compassionate leave or unpaid leave.

If your relative does not need much care, but can't be left alone for long, your employer may be able to change your working arrangements to allow you to work from home. Carers UK (see page 77) has information about carers and work.

### Flexible working

An employee who is caring or expected to be caring for an adult (aged 18 or over) and has worked for their employer for more than 26 weeks, has the right to request flexible working. This might include flexible starting and finishing hours, job-sharing or home-working.

The employee must be married to (or the partner or civil partner of) the person, a relative or living at the same address. They can apply to make a permanent change to their terms and conditions.

The request must be made in writing and should include:

- confirmation that you are a carer
- an idea of the working pattern you would like

- your impression of how it might affect your job and how this could be managed
- the date you would like the flexible working to start.

You are able to make one request a year for flexible working. Your employer may refuse your request if they have good business reasons to do so. It's worth bearing this in mind when making your request. You might want to make suggestions about how any changes can be handled so that any impact on the business is kept to a minimum.

## Parents

A parent of a child under 18 with cancer may also be entitled to up to 18 weeks unpaid parental leave to look after the child. Some employers may allow paid leave to be taken, and some allow longer than the official entitlement. You can read more about parental leave on the **direct.gov** website.

## Discrimination against carers

Some carers of people with cancer may experience discrimination (see pages 36–45). Carers are not covered by the Disability Discrimination Act and there is less legal protection for family members or carers. However, if you are a relative or carer of a person with cancer and you experience discrimination at work you can get advice on your employment rights from the organisations on pages 78–80.

**We can send you our booklet *Working while caring for someone with cancer*.**





# 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 to 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/community](http://macmillan.org.uk/community)

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.

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 self-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.uk](https://www.be.macmillan.org.uk)**

## Other useful organisations

### **Access to Work Scheme**

**Tel** 0845 6060 234

**www.jobcentreplus.gov.uk**

Provides advice and practical support to disabled people and their employers to help overcome work-related obstacles resulting from a disability.

### **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 up-to-date information, independent advice, high-quality training, and works with employers and employees to solve problems and improve performance.

### **Benefit Enquiry Line**

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

**Tel** 0800 882200

### **Email** BEL-Customer-

Services@dwp.gsi.gov.uk

**www.direct.gov.uk/  
disability-money**

Provides advice about benefits. Helps people complete some disability-related claim packs.

### **Cancer Counselling Trust**

Edward House, 2 Wakley Street, London EC1V 7LT

**Tel** 020 7843 2292

**Email** support@cctrust.org.uk  
**www.cancercounselling.org.uk**

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

### **Carers UK**

20 Great Dover Street, London SE1 4LX

**Tel** 020 7378 4999

**Carers line** 0808 808 7777  
(Wed & Thurs, 10am–12pm & 2–4pm)

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

**www.carersuk.org**

Offers information and support to carers. Puts people in contact with support groups for carers in their area. Has national offices, listed below:

### **Carers Scotland**

91 Mitchell Street, Glasgow  
G1 3LN

**Tel** 0141 221 9141

**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**

### **Citizens Advice Bureau**

Contact details for your local office can be found in the phone book or at

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

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

**uk** Citizens Advice Bureaus provide free, confidential, independent advice on issues including financial, legal, housing and employment.

### **Community Legal Advice Legal Services Commission**

2 Harbour Exchange Square,  
London E14 9GE

**Helpline** 0845 345 4 345

**www.communitylegaladvice.org.uk**

Provides free initial advice on benefits and tax credits, debt, education, housing and employment in England and Wales.

### **The Disability Law Service**

39–45 Cavell Street,  
Whitechapel, London E1 2BP

**Tel** 020 7791 9801

**Typetalk**

18001 020 7791 9800

**Email** [advice@dls.org.uk](mailto:advice@dls.org.uk)

**www.dls.org.uk**

Offers free, confidential legal advice on disability discrimination in employment

to people with disabilities, their families and carers. Can take on certain cases on behalf of disabled employees or job applicants. Also offers advice about welfare benefits.

### **Disabled Living Foundation**

380-384 Harrow Road,  
London W9 2HU

**Helpline** 0845 130 9177  
(Mon–Fri, 10am–4pm)

**Email** [advice@dlf.org.uk](mailto:advice@dlf.org.uk)

**www.dlf.org.uk**

Provides free, impartial advice about all types of disability equipment and mobility products through their helpline, website and their equipment demonstration centre.

### **Department for Work and Pensions**

**www.dwp.gov.uk**

Department involved with a number of issues including work, benefits, retirement and disability. Has public information for people with a disability.

### **Equality and Human Rights Commission**

### **Helpline**

England 0845 6046610

Scotland 0845 6045510

Wales 0845 6048810

**Email** via website

**www.equalityhumanrights.com**

Promotes equality and provides information to people about their rights.

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

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

**Tel** 0800 085 3250

**Type talk** 0800 083 0196

**Email**

[ifacontact@unbiased.co.uk](mailto:ifacontact@unbiased.co.uk)

**www.unbiased.co.uk**

Helps people search for details of local member independent financial advisors. Also provides online searches at **unbiased.co.uk** and **moneymadeclear.fsa.gov.uk**

### **Law Centres Federation**

293–299 Kentish Town Road,  
London NW5 2TJ

**Tel** 020 7428 4400

**www.lawcentres.org.uk**

Provides details of local law centres that can give legal



advice and assistance with employment claims.

### **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**

Provides 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**

### **National Debtline**

Tricorn House, 51–53  
Hagley Road, Edgbaston,  
Birmingham B16 8TP

**Tel** 0808 808 4000

**www.nationaldebtline.  
co.uk**

Gives advice to anyone  
worried about debt.

### **Useful books and tapes**

#### ***Coping with Chemotherapy and Radiation***

Daniel Cukier et al.

McGraw-Hill Contemporary,  
2004

ISBN 13: 978-0-071444-72-9  
£8.99

This guide gives information  
on how radiotherapy and  
chemotherapy work, how the  
treatment may affect you and  
how to cope with and reduce  
side effects.

#### ***Coping with Chemotherapy***

Terry Priestman

Sheldon Press, 2005

ISBN 13: 978-0-859699-49-5  
£7.99

Written by Macmillan's medical  
editor (a senior consultant  
oncologist), this book explains  
what chemotherapy treatment  
is, how it works, and how to  
cope with any side effects.

### ***Coping with Radiotherapy***

Terry Priestman  
Sheldon Press, 2007  
ISBN 13: 978-0-859699-99-0  
£7.99

Written by Macmillan's medical editor (a senior consultant oncologist), this book explains what the treatment is, how it works, and how to cope with any side effects.

### ***The Cancer Survivor's Handbook***

Terry Priestman  
Sheldon Press, 2009  
ISBN 13: 978-1-84709-048-5  
£7.99

Written by Macmillan's medical editor (a senior consultant oncologist), this book is for people who have completed cancer treatment. It looks at some of the issues people might face after treatment, such as side effects, diet and exercise, sex and fertility, work and support.

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

Directory of Social Change,  
2009  
ISBN 13: 978-1-906294-30-4  
£50.00

A directory of charities and trusts that provide financial assistance to people in need. Quite expensive, but a copy is in most public libraries.

### ***Audiotapes and CDs***

Our high-quality audio materials (based on our range of booklets) include information about cancer types and different treatments. The booklets also give advice about living with cancer.

To order your free CD or tape visit **[be.macmillan.org.uk](http://be.macmillan.org.uk)** or call **0808 808 00 00**.

### ***Useful websites***

A lot of information about cancer is available on the internet. Some websites are excellent, but others have misleading or out-of-date information.

The sites listed here 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 all our 80+ booklets and 300+ fact sheets in full.
  - Recommends further reading.
- Has a search engine for cancer research clinical trials available to cancer patients in the UK and Europe.
  - Offers 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 and has a database of cancer research clinical trials.

**[www.compactlaw.co.uk/ivillage](http://www.compactlaw.co.uk/ivillage)  
(Compact Law)**

Discusses unfair dismissal, wrongful dismissal, redundancy, discrimination, maternity and paternity rights, flexible working and statutory sick pay.

**[www.disabilityalliance.org](http://www.disabilityalliance.org)  
(Disability Alliance)**

Has detailed information on all aspects of disability, including benefits.

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

Government information on all aspects of work and benefits.

**[www.healthtalkonline.org](http://www.healthtalkonline.org)  
(formerly [www.dipex.org](http://www.dipex.org))**

Contains information about some cancers and has video and audio clips of adults talking about their experiences of cancer and its treatments.

**[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)**

Has comprehensive information on cancer and treatments.

**[www.worksmart.org.uk](http://www.worksmart.org.uk)  
(Trades Union Congress)**

Has information about employment and disability rights.

## 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

This booklet has been written, revised and edited by Macmillan Cancer Support's information development nurses and editorial team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

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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

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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