

**A practical guide to living  
with and after cancer**

# **CONTROLLING THE SYMPTOMS OF CANCER**

**WE ARE  
MACMILLAN.  
CANCER SUPPORT**

# Contents

About <i>Controlling the symptoms of cancer</i>	3
Tiredness (fatigue)	5
Eating problems	10
Mouth problems	17
Emotional effects of cancer	24
Breathing difficulties	27
Bowel problems	33
Bladder problems	37
Skin problems	40
Symptom diary	inside centre pages
Medicines for symptom control	51
Cancer treatments for symptom control	54
Complementary therapies	56
What other people can do for you	60
Who can help	64
Financial help and benefits	69
How we can help you	71
Other useful organisations	75
Further resources	84
Questions you might like to ask your doctor or nurse	88



# About Controlling the symptoms of cancer

**This booklet is about some of the symptoms that may occur if you have cancer. We hope it answers some of your questions and helps you deal with some of the feelings you may have.**

It describes the wide variety of treatments available for controlling symptoms and discusses some of the support services that can help. Symptoms can usually be well controlled by you, your family and friends, and members of the medical and nursing team caring for you.

We can't advise you about the best treatment for yourself, because this information can only come from your own doctor who is familiar with your medical history.

You may have one or more of the symptoms described in this booklet, but you're unlikely to have more than a few of them. Some symptoms are only likely to occur with particular types of cancer, and some symptoms can be caused by cancer treatments. Sometimes one symptom can affect another one, for example pain may make it difficult to sleep. If you find a symptom is particularly troublesome, it's important to let your medical team know so they can arrange for appropriate help and treatment. You can read more about the support that may be available to you and your family on pages 64–67.

**If you would like information on controlling cancer pain, we have a separate booklet that we can send you.**

If you'd like to discuss the information in this booklet, call the Macmillan Support Line free on **0808 808 00 00**, Monday–Friday, 9am–8pm. If you're hard of hearing you can use textphone 0808 808 0121, or Text Relay. For non-English speakers, interpreters are available. Alternatively, visit **[macmillan.org.uk](http://macmillan.org.uk)**

Turn to pages 75–87 for some useful addresses and websites, and page 88 to write down questions for your doctor or nurse.

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

# Tiredness (fatigue)

Fatigue is feeling excessively tired or exhausted all or most of the time. It's one of the most common, and sometimes one of the most difficult, problems for people with cancer. Fatigue may be due to the cancer itself, or it may be a result of other symptoms like breathlessness, pain or anaemia (a low red blood cell count). It can also be a side effect of cancer treatment. For some people fatigue gradually improves after a course of cancer treatment has ended, while for others it remains a persistent problem.

The effects of fatigue can vary from person to person. Telling your doctors and nurses about how fatigue affects you can help them provide the best care for you. Note how your fatigue affects your ability to carry out daily activities and how much rest you need. This will help you identify the things that make your fatigue better or worse and can also help you plan activities for when you're feeling stronger. You may like to use the symptom diary in the centre of this booklet.

## What can help

Some causes of fatigue can be treated. For example, tiredness caused by anaemia can be helped by having a blood transfusion. Sometimes a course of steroids can help relieve fatigue.

Planning ahead and prioritising the most important tasks will help make sure you're able to do the things that are most important to you. Getting help with some tasks will mean that you may have more energy to do the things you enjoy. For example, many supermarkets now offer online shopping

with home delivery. You could also think about rearranging your home to make things easier, such as having your bedroom as close to the toilet as possible, and arranging your kitchen with frequently used items stored within easy reach. An occupational therapist (see page 66) can provide gadgets to make everyday chores easier to manage.

Try sitting down to do everyday tasks like washing, dressing and preparing food. Carry heavy items like laundry or shopping in a trolley. Having a mobile or cordless phone means you don't have to rush to answer the telephone. A baby monitor is a good way of talking to someone in another room without having to get up, especially at night.

Research has found that doing some exercise can help relieve the symptoms of fatigue. Going for a short walk can be a good start. Your doctor, nurse or physiotherapist (see page 66) can advise you about how much and which type of exercise would be helpful for you.

The Shopmobility, Motability and Blue Badge schemes may be able to help you get out and about. Ask your nurse or social worker (see page 66) for details.

You may find that your cancer treatment centre has a course on managing fatigue that your hospital doctor, nurse or physiotherapist can refer you to.

**We can send you our booklet *Coping with fatigue*, which has more information.**

## Sleep

Many people with cancer have sleeping difficulties at some point during their illness. There can be a number of reasons for this, including anxiety and symptoms such as pain and breathlessness. These symptoms can often be treated, so speak to your doctor about them. For example, if you have pain, ask your doctor about long-acting painkillers that will last through the night.

Some people may benefit from having a short nap during the day. However, too much sleep during the day can cause problems sleeping at night – try limiting yourself to one or two sleeps each day if you can't sleep at night. If possible, avoid sleeping in the late afternoon or evening.

If you do have difficulty sleeping at night, remember your body will still benefit from lying quietly in bed resting, even if you're not asleep.

### Tips for a better night's sleep

- Go to bed and get up at about the same time every day. Having a long lie-in after a sleepless night can lead to a disrupted sleep pattern.
- Gentle exercise like walking and keeping your mind occupied with activities like reading, games or puzzles will help you feel naturally tired and ready for sleep.
- Get into a relaxing routine before bed. Try having a warm bath or shower, reading or listening to soothing music. Listening to an audio book or a relaxation exercise on CD, tape or MP3 player can also be helpful.



- Make your bedroom a relaxing place to be in. Create an area that's dark, quiet and comfortable.
- Avoid large meals and stimulants like caffeine or cigarettes in the late evening. Try having a warm, milky drink before bed. Although a small alcoholic drink can help, too much alcohol can lead to disrupted sleep.
- Some medicines, for example steroids, can cause sleeplessness. Ask your doctor or nurse whether you could take them earlier in the day. They may suggest you take them before 2.00pm.
- If you find it difficult to fall asleep, or if you wake up during the night and can't get back to sleep again, get up and go to another room. Do something else, like read or watch TV, until you feel tired again.
- If you find that worries or concerns are keeping you awake, write them down. You can then speak to someone about them later.

Sleeplessness can sometimes be a sign of depression (see pages 25–26). Talking through your worries and concerns may be helpful. Some people benefit from counselling (see page 25) or relaxation therapy (see page 57).

Sometimes a short course of sleeping pills can help you get back to a regular sleeping pattern, or help you through a particularly difficult time. They usually work by helping you get to sleep, so they're best taken before bedtime rather than in the middle of the night.



# Eating problems

Cancer and some cancer treatments can cause problems with eating and digestion. These problems might include loss of appetite, feeling sick (nausea), heartburn, indigestion and hiccups. Other cancer symptoms such as constipation, pain and breathlessness can also lead to eating problems.

## Loss of appetite

If your appetite is poor, try having smaller, more frequent meals, rather than larger plates of food three times a day.

You can add high-protein powders to your normal food, or you can replace meals with nutritious, high-calorie drinks. These are available from most chemists and can be prescribed by your GP. You can also ask to be referred to a dietitian at the hospital. They can advise you on which foods are best for you and whether any food supplements would be helpful. If you're not in hospital your GP can arrange this for you.

If you need help with cooking or shopping, a district nurse or social worker can give you information about Meals on Wheels or a home help. You could also see if someone else could prepare your meals, so that you're not too tired to eat by the time they're ready.

If you've lost weight and are finding it difficult to put it back on, your doctor may prescribe a short course of steroids or a drug called megestrol acetate (Megace®) to boost your appetite. Your GP or palliative care team (see page 64) will discuss this with you to decide the most appropriate drug for you.

People who have very advanced cancer may find that they become weak and their body is not able to absorb food very well. In this case, it's best to eat what you want when you feel able to. In some cases steroids or other medication may help.

## **Nausea**

Cancer and cancer treatments can sometimes cause nausea (feeling sick) and vomiting (being sick). Treatment will be based on the most likely cause of your nausea. If something like pain, a raised calcium level or another chemical imbalance is causing your sickness, it's important that this is treated.

Your doctors may prescribe an anti-sickness (anti-emetic) drug. These often work better when they're taken regularly so that the sickness doesn't have a chance to come back. They're usually given as tablets, but if you can't keep tablets down there are other ways to have them. Some anti-sickness drugs can be dissolved in your mouth, others can be given by injection, or they can be given as a suppository into your back passage. Sometimes anti-sickness medicines are given by constant infusion under the skin (subcutaneously), using a small portable pump called a syringe driver (see page 52).

Complementary therapies such as relaxation and acupuncture can also be used to help reduce nausea and vomiting (see pages 56–60).

### **Tips for coping with nausea**

- Try to avoid eating or preparing food when you feel sick. If possible, let someone else do the cooking.
- Try to avoid fried foods and foods with a strong smell.

- Smaller meals on a small plate are easier to manage.
- Eat cold or warm food if the smell of hot food makes you feel sick.
- Eat several small snacks and meals each day, and chew the food well.
- Peppermints or peppermint tea help some people.
- Ginger can also be helpful – try ginger biscuits or ginger beer.
- Sip drinks slowly.
- Try not to have too much to drink just before you eat.

**We can send you a fact sheet about controlling nausea and vomiting, which has more information.**

## **Heartburn**

Heartburn is a burning sensation behind the breastbone that can be very painful. It's caused by the backflow of acid from the stomach into the gullet (oesophagus). Heartburn can be caused by certain foods and medicines. It can be made worse by lying flat or wearing tight clothing around the waist.

### **Tips to prevent heartburn**

- Avoid large meals, chocolate, alcohol, fatty foods, fizzy drinks, chewing gum, hard-boiled sweets, mint, aniseed and dill.
- Wear loose clothing around your waist.
- Try not to lie flat on your back, especially after meals.

Drug treatments can also help relieve troublesome heartburn. Your GP can prescribe these for you.

## Indigestion (dyspepsia)

This is discomfort in the upper part of the tummy (abdomen), occurring particularly after meals. It can be caused by:

- having a small stomach capacity
- irritation of the stomach or bowel lining caused by some drugs (such as steroids), or by some cancer treatments (such as radiotherapy or chemotherapy)
- overproduction of stomach acid
- not moving around much
- anxiety
- not eating or drinking much.

### Dealing with indigestion

The best way of dealing with indigestion depends on its cause.

If you have a small stomach, it can help to avoid drinking fluids at mealtimes. Try having small, frequent meals and snacks throughout the day, rather than two or three large meals.

Irritation of the stomach lining can be relieved by antacid medicines like Asilone<sup>®</sup>.

Drugs that reduce acid production, such as ranitidine (Zantac<sup>®</sup>) or omeprazole (Losec<sup>®</sup>), can relieve indigestion caused by the overproduction of stomach acid.

A drug called semeticone (Dentinol<sup>®</sup>, Infacol<sup>®</sup>) can reduce indigestion caused by wind.

An anti-sickness drug called metoclopramide can help with indigestion by causing the stomach to empty more quickly. This also helps to relieve nausea.

Your doctor will be able to prescribe the most suitable drug(s) for you, depending on the cause of your indigestion.

**Our booklet *Diet and cancer* has more information about eating problems.**

## Hiccups

Hiccups are a sudden contraction or spasm of the diaphragm (the breathing muscle under the lungs). They're a reflex action, so they aren't under your control.

Mild hiccups are common. They usually only last for a few minutes and don't need to be treated. However, if you have hiccups that keep coming back or that last for more than two days, you may need treatment. When hiccups last for a long time it can be distressing and uncomfortable. It can also make eating, drinking and sleeping difficult.

Hiccups can be caused by:

- a bloated stomach
- a change in the levels of certain chemicals in the blood
- certain medicines, such as steroids, painkillers and some chemotherapy drugs
- irritation to the diaphragm, caused by conditions such as an enlarged liver
- irritation to the brain caused by a tumour – although this is rare.

## Treatment for hiccups

Some people find that home remedies can help them get rid of hiccups more quickly. These include:

- sipping iced water or swallowing crushed ice
- holding your breath
- breathing into a paper bag
- pulling your knees up to your chest.

Other traditional remedies include drinking from the wrong (opposite) side of a cup, swallowing dry bread, quickly swallowing two teaspoons of granulated sugar or biting on a lemon.

If your hiccups don't go away after a couple of days or if they keep coming back, you should tell your doctor. There are medicines they can prescribe that may help. The best treatment for hiccups depends on the cause.

Treatments that may help if you have a bloated stomach include:

- drinking peppermint water, which relaxes the stomach and gullet, helping to release trapped air through burping
- anti-wind or antacid medicines (for example Asilone®)
- some anti-sickness medicines, for example metoclopramide and domperidone.

You shouldn't take peppermint water and metoclopramide at the same time, because they work against each other. Peppermint relaxes the stomach muscle, but metoclopramide stimulates it so that the stomach empties more quickly.



Other treatments that may help get rid of hiccups include:

- drugs that relax the muscles, such as baclofen or midazolam (in persistent hiccups, midazolam can be given by syringe driver)
- sedative drugs, for example haloperidol
- steroids, which are used to treat hiccups caused by an enlarged liver or pressure on a nerve
- drugs that act on the central nervous system (CNS), for example gabapentin.

If you're started on a drug treatment for hiccups, your doctor will usually check with you about three days later to see how well it's working. If the hiccups haven't gone away the dose may need to be increased, or you may need to try another drug.

Persistent hiccups may occasionally be treated by a **nerve block**. This is a procedure used by specialists who work in pain clinics (see page 65).

# Mouth problems

The effects of cancer or its treatment can lead to mouth problems. These can affect eating and drinking as well as your ability to talk comfortably.

Some of the common causes of mouth problems include:

- certain medicines that cause a dry mouth
- radiotherapy treatment to the head and neck area, which can cause a dry and sore mouth
- some chemotherapy drugs that can cause painful mouth ulcers
- infections of the mouth, lips and throat – particularly oral thrush (see page 22).

## Mouth care routine

Following a regular mouth care routine can help prevent or lessen mouth problems:

- Brush your teeth and gums every morning and evening using a small, soft-bristled toothbrush and fluoride toothpaste.
- Provided it isn't sore, gently brush your tongue when cleaning your teeth.
- Use water or an alcohol-free mouthwash to rinse your mouth after meals. You can do this more often if needed. You can make a mouthwash by dissolving one teaspoon of bicarbonate of soda in 600mls (1 pint) of boiled then cooled water.
- Rinse your dentures after meals.
- Remove your dentures at night. Clean them with a toothbrush and toothpaste or denture paste. Soak them overnight in a

denture solution containing sodium hypochlorite (for example 1tsp of Milton® in 400ml water), but if your dentures have metal parts use chlorhexidine solution instead. Rinse dentures well before use.

- If your doctor prescribes a mouthwash for you, use it regularly as prescribed.
- Gently use dental tape or floss daily.
- Keep your lips moist by using Vaseline® or a flavoured lip balm.
- A pen torch and mirror can be helpful for inspecting inside your mouth.

## Dry mouth

Some people with cancer have a dry mouth, because they produce less saliva or they breathe more through their mouth due to breathlessness. Oxygen treatment can also cause a dry mouth. Radiotherapy to the head and neck and certain drugs can be another cause. Speak to your doctor if it's likely that a drug is causing your dry mouth, as a replacement drug may be available. Feeling anxious can also make your mouth feel dry.

A dry mouth can be uncomfortable and change the way your food tastes.

### Tips for dealing with a dry mouth

- Regular mouthwashes can help keep your mouth clean and moist, but avoid any that contain alcohol or glycerine as these can dry the lining of your mouth. If your tongue is coated, try gently cleaning it with a soft toothbrush or cotton bud.
- Fizzy drinks such as fresh orange juice with soda water can be a refreshing way to keep your mouth moist. You could also try sucking flavoured ice cubes and ice lollies.

- Keep your lips moist by using Vaseline® or a flavoured lip balm. Smoothing a small amount of vegetable oil on the lining of your mouth can help to keep it moist, especially at night.
- Artificial saliva is available as gels, sprays, pastilles or lozenges. Your doctor can prescribe these for you.

### **Food hints that may help if you have a dry mouth**

- Have a drink with meals.
- Avoid dry foods and include plenty of sauces and gravy with meals.
- Sugar-free chewing gum can stimulate saliva production.
- Eat foods with a high fluid content, such as jelly, pureed fruits and soft puddings.
- Unsweetened pineapple chunks or melon can help keep your mouth fresh and moist.
- Avoid chocolate and pastry as they can stick to the roof of your mouth.

### **We can send you a fact sheet with more detailed information on coping with a dry mouth.**

If you have a dry mouth for a long time you have a higher risk of tooth decay, so it's important to take care of your teeth. Your dentist will be able to help you with this and will want you to have regular check-ups. Some dentists will visit you at home if you can't attend the surgery.



## Taste changes

You may find that your sense of taste changes, or that the texture of food seems different. This may be due to the cancer, or it can be a temporary change following cancer treatment. You may no longer enjoy certain foods, or find that all foods taste the same. Some people having chemotherapy notice a metallic taste in their mouth. Others find that food has no taste at all.

### Coping with taste changes

- Eat foods that you enjoy and ignore those that don't appeal to you, but try them again after a few weeks as your sense of taste may change again.
- Use seasonings, spices and herbs like rosemary, basil and mint to flavour your food.
- Try marinating meat in fruit juices or wine to improve its flavour, or eat it with strong sauces like sweet and sour or curry.
- Serve fish, chicken and egg dishes with sauces.
- Cold meats may taste better served with pickle or chutney.
- Sharp-tasting foods like fresh fruit, fruit juices and bitter boiled sweets can be refreshing and leave a pleasant taste in your mouth.
- If you go off the taste of tea or coffee, try lemon tea or green tea instead, or perhaps an ice-cold fizzy drink like lemonade or fresh orange juice with soda water.
- Some people find that cold foods taste more palatable than hot foods.

## Sore mouth and throat

If you have radiotherapy to your mouth and/or throat, the area can become sore and you may develop mouth ulcers. Many chemotherapy drugs cause the same problem. You may also develop a sore mouth if you:

- aren't able to eat a nutritious diet
- have a low immunity
- have an infection of the lining of your mouth or throat.

If your cancer treatment is likely to cause mouth ulcers, your doctor may prescribe an antiseptic and painkilling mouthwash for you to use during treatment. You may also be prescribed a protective gel that can help ease any pain and discomfort.

If you're taking antibiotics or steroids, you may develop a fungal infection in your mouth called thrush. This coats your tongue and can make eating unpleasant. Your doctor can prescribe an anti-fungal medicine to clear this. If your mouth or lips become sore after cancer treatment, see your doctor who can check for signs of infection or thrush. If you do have an infection, the doctor can prescribe treatment. If, after taking a course of anti-fungal medicine for thrush, your symptoms haven't improved, it's important to go back to your doctor to try a different type of anti-fungal medicine.

Always contact your doctor if mouth pain is making it difficult to eat or talk. They can prescribe painkillers if necessary.

## Helpful hints if you have a sore mouth

- Follow the mouth care routine on pages 17–18 as far as possible.
- If your toothpaste stings, use a mouthwash instead.
- If you wear dentures, you may find it easier to leave them out for a while to prevent them rubbing against your gums. Ask your doctor about this if you're having radiotherapy to the jaw area, as you may be advised to keep your dentures in as much as possible during the day to help maintain the shape of your gums.
- Avoid neat spirits, tobacco, hot spices, garlic, onion, vinegar and salty foods, as these may irritate your mouth.
- Keep your mouth and food moist. Add gravy and sauces to your food to make swallowing easier.
- Avoid rough-textured food, such as toast and crisps, as these can scrape sore areas.
- Try to drink at least one litre (about two pints) of fluid a day – this can include water, tea, weak coffee and soft drinks such as fruit juices.
- Try drinking through a straw to avoid irritating sore parts of your mouth.
- Cold foods and drinks can be soothing to a sore mouth. Try adding crushed ice to drinks and eating ice cream or ice lollies.
- Warm herbal teas may be more soothing than acidic drinks like orange and grapefruit juice.



# Emotional effects of cancer

## Anxiety

Anxiety is one of the most common emotional responses to cancer, and it's a natural reaction. Questions like 'How will I cope?', 'What's going to happen?', 'Will I get better?' and 'Will the treatment work?' may go through your mind.

Anxious feelings may be present all the time, or they may come and go. They can also vary in how severe and disruptive they are. Anxiety may show as physical symptoms such as:

- shaking
- breathlessness
- palpitations
- sweating
- a dry mouth.

It can be easy to confuse the symptoms of cancer, or cancer treatment, with the symptoms of anxiety. Being anxious on top of having cancer can also make your symptoms worse.

## Dealing with anxiety

When anxiety levels are high, the symptoms can be difficult to control and you may feel that you're having a 'panic attack'. Learning controlled breathing and relaxation techniques (see page 57) can help you manage these attacks.

Your doctor will be able to help you work out whether your symptoms are related to anxiety, and they may prescribe

medication to help. Anxiety can also be treated with a sedative drug such as diazepam.

Understanding the reason for your symptoms can be reassuring, but if you're still very anxious, try talking to your nurse or doctor. For some people, seeing a trained counsellor can help. Some of the organisations listed on pages 75–84 offer counselling and psychotherapy. These feelings are very common, so don't be embarrassed to discuss them or check whether your fears and concerns are justified.

## Depression

Some people become depressed as a result of having cancer or coping with symptoms. Everyone can feel down or anxious at times, but sometimes these feelings don't go away and can start to affect your everyday life. Common symptoms of depression include:

- not being able to enjoy anything
- sleeplessness
- a lack of energy
- difficulty concentrating
- feelings of hopelessness, guilt or worthlessness.

Depression often comes on gradually. The first step to feeling better is getting appropriate help. If you or your family think that you may be depressed, discuss this with your GP or nurse. They will be able to tell you about the different treatments that can help.

Counselling or talking therapies can help you express your emotions and clarify your feelings about what's happening

in your life. Trained counsellors, clinical psychologists and psychiatrists all deal with talking therapies. For some people they can be as effective as antidepressants or sedatives.

There are different types of talking therapy:

**Person-centred therapy** aims to help you sort out your feelings and find ways of coping with them through discussion with a trained counsellor. It's often used to help someone cope with recent events they have found difficult. This therapy is widely available.

**Cognitive behavioural therapy (CBT)** aims to help you change unhelpful thoughts and behaviours. CBT is available as one-to-one or group therapy. Self-help books and computer programmes are also available.

**Psychodynamic (psychoanalytic) psychotherapy** deals with immediate problems by encouraging you to look back at your past, to try to discover how your past affects how you are feeling, thinking and behaving now. This tends to be longer-term therapy.

### **Medicines for depression**

Your doctor may prescribe an antidepressant to help lift your mood. Antidepressants are thought to work by affecting certain chemicals within the brain. They work slowly, so you won't usually notice any improvement in your symptoms for a few weeks. Your doctor may have to try more than one drug to find the one that suits you best.

**We can send you our booklet *The emotional effects of cancer*, which has helpful tips on dealing with the feelings and emotions that cancer can cause.**

# Breathing difficulties

Some people with cancer have problems with breathlessness and coughing.

## Breathlessness

How breathlessness is treated depends on its cause. Sometimes there can be more than one cause, and each one may need different treatment.

These are some of the causes of breathlessness:

**Cancer involving the lung** – This can be a primary cancer, such as lung cancer, or a secondary cancer that has spread to the lung from another organ. Surgery, radiotherapy, chemotherapy or hormonal therapy may help to remove or shrink the cancer and relieve breathlessness.

**A chest infection** – Appropriate antibiotics can be used to treat this.

**Pleural effusion** – This is a build-up of fluid between the two layers of the pleura (the membranes that cover the lungs). It can cause pain and breathlessness. It's treated by placing a small tube between the two layers and draining off the fluid into a drainage bag or bottle. After the fluid has been drained, it may be possible to seal the two layers of the pleura and stop pleural effusions happening again. This is called a pleurodesis. We can send you a fact sheet about pleural effusions.

**Pulmonary oedema** – This is when fluid builds up in the lungs themselves. Treatment for pulmonary oedema will depend on the cause.

**Anaemia** – This is having a low level of red blood cells in your blood. It can make you very tired and breathless. Your doctors may recommend that you have a blood transfusion to treat it. We can send you a fact sheet about blood transfusions.

**Radiotherapy to the chest** – This can cause inflammation of the lung (pneumonitis), which can lead to a cough and breathlessness. This is usually a short-term side effect and can be treated with a course of steroids.

### **Medicines for breathlessness**

The painkiller morphine can be used to treat breathlessness. It can be given in tablet or liquid form, or by injection under the skin (subcutaneous injection). Drugs that help you relax can also help relieve the anxiety and panic that breathlessness can cause. If swallowing medicines is difficult, painkillers, sedatives and other drugs can be given by constant infusion under the skin (subcutaneously) using a syringe driver (see page 52).

Drugs called bronchodilators widen the air passages, increasing airflow. These can be given as tablets or as a fine spray that's breathed in (inhaler). They can also be given through a mask called a nebuliser.

### **Oxygen therapy**

This is where oxygen is given using a face mask, or through small tubes that sit under the nostrils (nasal cannula). Using a fan or sitting by an open window may give you the same benefit. Oxygen therapy is only suitable for some people who are breathless. Your doctor will let you know if oxygen therapy is



suitable for you, and if you need oxygen at home they can arrange this for you.

## **Managing breathlessness**

Tips for managing breathlessness at home:

- Sit down to carry out everyday tasks like washing, dressing and preparing food.
- Cool air blowing directly onto or across your face can help you breathe more easily. Try sitting by an open window or using a small handheld fan.
- Arrange your kitchen with frequently used items stored at waist-height, rather than having to bend or stretch to reach cupboards and shelves.
- Wear loose-fitting clothes, especially around your waist and chest. Sit down when dressing and bring your feet up to put on socks, tights and shoes, as bending can make you breathless. Slip-on shoes are easier to get on and off than shoes with laces.
- Using a telephone extension cord, or a cordless or mobile phone, will mean that you don't have to rush to answer the telephone.
- A baby monitor is a good way of talking to someone in another room without having to shout or get up, especially at night.

Breathlessness can cause you to breathe with your upper chest and shoulders in a rapid and shallow way. This can use up a lot of energy and tire you out. Learning a technique called controlled breathing can help you to relax and breathe gently and more effectively using your lower chest

and tummy muscles. A physiotherapist or specialist nurse can teach you these techniques.

**There's more information in our booklet *Managing breathlessness*, which we can send you.**

Being breathless can cause you to feel anxious, frustrated and panicky (see page 24). These emotions can cause rapid, shallow breathing, which can make you even more breathless. Understanding your emotional responses to breathlessness and learning to control them can help you manage your condition. Relaxation techniques can help you control anxiety and improve breathlessness (see page 57).

**We can send you our relaxation CD *Relax and breathe*.**

## **Coughing**

Coughing can be helpful because it helps to clear our airways, but it can also be uncomfortable, embarrassing and affect our ability to sleep, rest and eat.

If you're coughing up green or dark yellow phlegm (sputum), you may have an infection and need to take antibiotics. Some people need **physiotherapy** to help them clear their airways. Sometimes **steam inhalations** or **saline** given as a fine spray through a nebuliser are helpful.

If you have a dry irritable cough, your doctor may prescribe a **cough mixture** to help. If your cough is persistent then **painkillers** like codeine or morphine can be helpful.



Occasionally people cough up blood. It's important to let your doctor know if you begin to cough up blood or if this symptom gets worse. It can be caused by a chest infection, by a blood clot in the lung, by bleeding from small blood vessels in the lungs or from a tumour in the lungs. The treatment will depend on the cause, so you may need to have tests to find out what that is. **Antibiotics** can help treat a chest infection, or your doctor may prescribe a drug called **tranexamic acid**, which encourages blood to clot and reduces bleeding. **Radiotherapy** can often be helpful when the cause is a tumour in the lung.

# Bowel problems

## Constipation

Constipation can be a common problem, but many people find it embarrassing to discuss. Loss of appetite, poorly controlled pain and nausea can all lead to constipation. A lack of fibre (roughage) in your diet, low fluid intake and being less mobile can also contribute. Some medicines can cause constipation, particularly the painkillers morphine and codeine. If you're taking regular painkillers, you may need a laxative to help prevent constipation.

Everyone's normal bowel pattern is different, but as a general guide you should let your doctor or nurse know if you've not had a bowel movement for three days, unless this is usual for you.

Signs of constipation include:

- having less frequent bowel movements
- your stools becoming harder
- straining to pass motions
- a feeling of not having emptied your bowel but being unable to pass any more stool
- your tummy becoming bloated or uncomfortable.

### Tips for managing constipation

- Try to have plenty of fibre in your diet. Good sources of fibre include wholegrain breakfast cereals, porridge, muesli, wholemeal bread and flour, brown rice, wholemeal pasta, and fresh fruit and vegetables with their skins on.

- Drink plenty of fluids. Aim to drink at least two litres (3½ pints) of fluid a day.
- Gentle exercise will help keep your bowels moving.
- Natural remedies for constipation include apricots, prunes, prune juice and syrup of figs.
- Flaxseed (linseed) can help to ease constipation and soften stools. One teaspoon or dessertspoon of the seeds can be taken daily with a glass of water.

**If you have cancer of the gullet (oesophagus) or bowel, ask your doctor before taking fibre or linseed.**

## Laxatives

There are different types of laxative available. Your doctor or nurse will recommend a specific type of laxative, depending on the cause of the constipation.

**Softening laxatives**, for example lactulose, encourage more water to be taken up by the bowel, making stools softer and easier to pass along.

**Stimulant laxatives**, such as Senna®, increase the movement of the bowel wall to help push stools along.

Some laxatives **combine** a softening laxative with a stimulant laxative (for example Co-danthramer).

**Bulk-forming laxatives**, for example Fybogel®, increase the volume of stool. This is similar to the role of fibre in your diet. These laxatives can take a few days to work and need to be taken with plenty of fluid to be effective.

If you're very constipated, or if the laxatives aren't working, your doctor or nurse may recommend suppositories or an enema. These preparations are inserted into the bowel through the back passage.

**If you have cancer of the bowel, always ask your doctor for advice about dealing with constipation.**

## Diarrhoea

Diarrhoea may occur as a side effect of cancer treatments such as chemotherapy, or radiotherapy to the pelvis. It may also occur due to infection. Some medicines can cause diarrhoea, and some cancers may prevent food from being absorbed properly from the bowel, causing diarrhoea. Sometimes severe constipation can be mistaken for diarrhoea: when the bowel is blocked by constipation, liquid faeces pass around the solid faeces (sometimes called **overflow**), so it may seem as though you have diarrhoea.

### Tips for coping with diarrhoea

- Cut down on your fibre intake from cereals, fruit and vegetables. Eat peeled and cooked fruit and vegetables instead of raw ones.
- Avoid milk and dairy products, such as cheese, until the diarrhoea has stopped.
- Drink plenty of fluids to replace the water lost with the diarrhoea, but avoid alcohol and coffee. Also avoid fizzy drinks, which can cause wind and stomach cramps.
- Eat small, frequent meals made from light foods – white fish, chicken, eggs (well cooked), white bread, pasta and rice.

- Avoid highly spiced or fatty foods.
- Eat your meals slowly.
- If the diarrhoea continues for more than two days, tell your doctor. They can investigate the cause and prescribe some anti-diarrhoea medicines for you.
- Antibiotics can kill off the helpful bacteria normally found in the bowel, but eating live (probiotic) yoghurt can replace them. Live yoghurt can also help to replace the fluid lost by diarrhoea. If you're having chemotherapy, check with your doctor or nurse before using live yoghurt.
- If you have ongoing problems with diarrhoea, knowing you may need to get to a toilet quickly can make going out a source of worry and embarrassment. The **National Key Scheme (NKS)**, for people with continence problems, allows you to use around 9,000 locked public toilets in the UK. Radar or the Bladder and Bowel Foundation can tell you about the scheme (see pages 75–84).

**Our booklet *Diet and cancer* has tips on dealing with constipation and diarrhoea.**

### **Diarrhoea caused by radiotherapy**

Diarrhoea is a common temporary side effect of radiotherapy to the pelvis, and your doctor will prescribe medicine to help with it. If you have diarrhoea caused by radiotherapy, changing your diet is unlikely to help, and it's important that you take the anti-diarrhoea medicines prescribed by your doctor.

**We have information on coping with the side effects of pelvic radiotherapy.**

# Bladder problems

Bladder problems may be caused by a cancer pressing on or blocking the tube that urine passes through out of the bladder (urethra). This can lead to incontinence (loss of bladder control) or retention (when urine can't flow out of the bladder). Rarely, a tumour pressing on the nerves in the spine can cause nerve damage, leading to incontinence.

Urinary problems may also occur following some types of surgery to the bladder, prostate, bowel or womb. These problems may be caused by damage to the valve that controls the flow of urine from the bladder (urinary sphincter), or caused by nerve damage in the pelvis. These problems are often temporary and improve over weeks or months. If you have urinary problems after surgery, it may help to do exercises called pelvic floor or Kegel exercises. These help to retrain the muscles involved in bladder control. A continence nurse can tell you about these, or you can read more on the Bladder and Bowel Foundation website at [bladderandbowelfoundation.org](http://bladderandbowelfoundation.org)

After surgery to their prostate, some men have urinary problems due to an overactive bladder. Your doctor can prescribe drugs to help correct this. Most men find that their symptoms improve with time. Rarely however, if symptoms don't improve over several months, some men may be offered surgery to improve bladder control.

During and after radiotherapy to the pelvic area, you may need to pass urine more often than usual. You may also have some pain when you pass urine. These symptoms can also be caused by a bladder infection, or may become worse if one develops. Let your nurse or doctor know if you develop any pain when

passing urine or if your urine is cloudy or smelly. A urine sample can be tested, and any infection can be treated with antibiotics.

**We can send you a booklet about pelvic radiotherapy, which has more information about bladder problems and how to cope with them.**

If you're at increased risk of a urinary infection, perhaps because you're having radiotherapy to the pelvic area, you may want to try taking cranberry extracts. Cranberries contain a substance that can prevent bacteria from sticking to the walls of the bladder. Research has shown that taking daily cranberry extracts may help to prevent urinary infections for some people. However, it isn't clear what the best dose is or whether cranberry extract capsules are better than cranberry juice. Cranberry extracts aren't helpful for people who have a catheter, and if you take warfarin tablets it's important to avoid them, as they can affect how warfarin works.

If you have bladder problems, it can help to drink enough water to keep your urine a clear or pale yellow colour. It may also help to avoid drinking too much alcohol or drinks that contain caffeine, such as coffee, tea and cola.

Continence problems can occur if you find it difficult to get out of a chair or bed so can't get to a toilet quickly. Try to have your bed as close to a toilet as possible, or have a commode, bed pan or urine bottle close by.

## Dealing with incontinence

A wide range of continence aids is available. Your district nurse or a specialist continence nurse can arrange supplies for you. You may need to pay for these products, as what's available on the NHS varies in different parts of the country.

**Pads** use materials that draw urine away from the body. They are small and easily hidden, but secure enough to prevent leakage. For men, there are also **sheaths** for the penis and **dribble pouches**.

### Tips for dealing with urinary problems

- Some drinks, such as tea, coffee, cola and alcohol, cause bladder irritation and may make symptoms worse.
- After any operation that may affect your bladder, build up your physical activities gently. You should usually be able to do all your normal activities within 4–6 weeks.
- Constipation can make bladder problems worse. See pages 33–35 for tips on coping with constipation.
- Knowing you may need to get to a toilet quickly can make going out a source of worry and embarrassment. The **National Key Scheme** (NKS), for people with continence problems, allows you to use around 9,000 locked public toilets in the UK. Radar or the Bladder and Bowel Foundation can tell you about the scheme (see pages 75–84).

If you're restricted to bed, incontinence can be more difficult to cope with. In this situation, or if you have trouble emptying your bladder, a thin flexible plastic tube (catheter) can be inserted into your bladder so that urine is continuously drained away. This can prevent the discomfort that can occur with



severe incontinence. Catheters need to be changed regularly – about once a month or more often. During the day, if you're up and about, a catheter bag can be attached to your leg and hidden under clothes. Otherwise, bags and tubes can easily be covered by bedclothes or blankets.

Your doctor can refer you to a specialist continence adviser. The Bladder and Bowel Foundation (see page 75) can also give you advice about managing continence problems.

## Skin problems

### Itching (pruritus)

Itching is a common symptom of cancer and can affect any area of your body. It may affect all of your body or only one particular area.

Itching may be due to:

- dry skin
- chemicals released by the cancer (especially some cancers of the blood)
- medication (particularly the painkillers morphine and diamorphine)
- jaundice (see pages 48–51)
- kidney and liver problems.

## Dealing with itchy skin

- If your skin is dry use a simple moisturiser, such as aqueous cream, twice a day. A combination of aqueous cream and menthol can be helpful. If you store the cream in the fridge it will feel cool and soothing when applied.
- If hot or warm water makes the itching worse, take cool or lukewarm baths or showers. Try adding an emollient (moisturising solution) such as Oilatum® to bath water, and use aqueous cream instead of soap. A little baking soda added to plain bath water can also help. After bathing, apply emollients or aqueous cream while your skin is still damp.
- Protect your skin from the damage caused by scratching. Keep your nails clean and short, and rub rather than scratch the itchy area.
- Avoid things that may irritate the skin or make itching worse, such as biological washing powders, scented soaps, bubble baths and products containing lanolin.
- Keep cool by wearing light, natural fibres such as cotton, and by keeping the atmosphere around you cool but not too dry. Avoid alcohol and hot spicy foods and drinks.
- Use other activities to try to distract you from the itching. Counselling and relaxation techniques may help you cope (see page 57).
- Sometimes acupuncture (see page 56) or transcutaneous electrical nerve stimulation (TENS) can reduce itching. The aim of TENS is to stimulate the nerves reaching the brain, and so block out the sensation of itching. Acupuncture and TENS treatments are given at some NHS hospitals.



Itching can be difficult to control, but there are medicines that may help. Your doctor will try to find the cause of the itch. If a particular medicine is the cause, an alternative drug may be prescribed. For some cancers there are specific medicines that can control itching. Your doctor can discuss these with you.

Some drugs that may be helpful include:

- antihistamine tablets or lotion
- a short course of steroid cream or tablets
- anti-inflammatory drugs, cimetidine, aspirin and thalidomide
- drugs that affect blood pressure, such as propranolol
- drugs that act on the nervous system, including anaesthetics, antidepressants, anti-epileptic drugs, sedatives and some types of painkiller
- an anti-sickness drug called ondansetron.

## **Pressure sores**

A pressure sore (also called a bedsore or pressure ulcer) is damage that occurs to the skin and the tissue underneath. It can be caused by the weight of the body pressing down on the skin. Friction from clothing or skin being dragged when you're moved by others can also cause sores.

If your mobility has been restricted by your cancer or its treatment, you're at a higher risk of developing a pressure sore. You're also at a higher risk if you've lost a lot of weight or aren't managing to eat and drink well. Some drugs can also increase your risk, including chemotherapy drugs, steroids and anti-inflammatory drugs.

Inspect your skin, particularly bony areas like elbows and ankles. For areas that are difficult to see, like shoulder blades or the base of your spine, use a mirror or ask a friend to help. Look out for reddened or dark patches on these areas, or any blisters or breaks in the skin. Let your nurse know about them straight away.

### **Preventing pressure sores**

- If you spend a lot of time sitting or lying in bed, change your position regularly – preferably every half an hour. Wear loose, cotton bedclothes and use pillows to support yourself in comfortable positions.
- When possible, standing up for a short time or taking a short walk is the best way to relieve pressure. A physiotherapist can supply you with a walking aid to help with this, if needed.
- Your district nurse will be able to assess whether you need a pressure-relieving mattress or cushion and arrange these for you. It's still important to change position regularly when using these. A bed cradle can help keep the weight of bedclothes off your legs and feet.
- Tell your doctor or a district nurse if you think you have early signs of a pressure sore. They can give you help and advice to make sure that your skin heals properly and to prevent infection from developing. Organisations that can provide equipment to keep you comfortable are listed on pages 82–83.
- Treat dry skin using the tips on page 41.

# SYMPTOM DIARY

WE ARE  
MACMILLAN.  
CANCER SUPPORT

## How to use your symptom diary

1. Begin by noting down the date when you use a new diary. You can fill in the diary as often as you need to. If your symptoms aren't well-controlled, you may want to fill it in every 1–2 hours, but if they're better controlled, you could fill it in every 4–6 hours.
2. Note **where each symptom is on your body** – you can use the body outlines on the back page of the diary. It could be in one area (eg a leg) or in multiple areas (eg both legs and your ankles).
3. Describe **what each symptom feels like**, using words such as uncomfortable, comes and goes, constant, exhausting and unbearable. See the back page of the diary for more words you could use to describe your symptoms.
4. Rate the **level** of each symptom on a scale of 0 to 10, where 0 means 'no symptom' and 10 means 'severe' (see the back page of the diary).
5. Note down any **medicines** or **complementary therapies** you use, as well as anything that makes the symptom **better** or **worse**.

All this information will help you, your doctors and your nurses find the best symptom control methods for you. Remember to photocopy the back page of the symptom diary to go along with each diary you complete.



























# SYMPTOM DIARY

Keeping a record of your symptoms and nurses. If you photocopy this information about one or more symptoms

Time	Type of symptom	Area affected (if appropriate)	Level of symptom (where 0 = none and 10 = worst)
1am			0           5
2am			0           5
3am			0           5
4am			0           5
5am			0           5
6am			0           5
7am			0           5
8am			0           5
9am			0           5
10am			0           5
11am			0           5
12pm (noon)			0           5
1pm			0           5
2pm			0           5
3pm			0           5
4pm			0           5
5pm			0           5
6pm			0           5
7pm			0           5
8pm			0           5
9pm			0           5
10pm			0           5
11pm			0           5
12am (midnight)			0           5

ms will help you discuss them with your doctors  
diary before you fill it in, you can use it to record  
mptoms over a few days.

date     /     /    

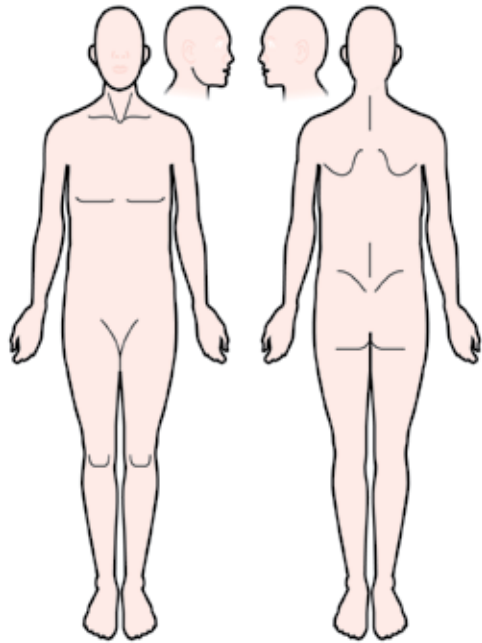
Symptom (= none severe)	Medicines/ therapies used	What makes it worse?	What makes it better?
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			
			



## Where is the symptom?

Is it in one part of your body or in more than one place? Does it start in one place and gradually spread during the day?

Use the diagrams to mark where your symptoms are.



front

back

## What is the symptom like?

You can use any of the following words, or your own words, to describe your symptom:

- aching
- bloated
- burning
- clammy
- comes and goes
- constant
- distended
- dry
- embarrassing
- excruciating
- exhausting
- frustrating
- hot
- inflamed
- intense
- irritating
- nauseating
- painful
- numb
- piercing
- pins and needles
- pricking
- red
- scratchy
- sharp
- sore
- spreading
- stinging
- sweaty
- swollen
- tender
- throbbing
- tickly
- tight
- tingling
- tiring
- unbearable
- uncomfortable

## How bad is the symptom?



If you measured it on a scale of 0 to 10, how would you rate it? (0 = no symptom and 10 = the symptom is severe.)

## Swollen ankles and legs

Sometimes fluid can build up in the ankles and legs, which can cause swelling.

There can be several reasons for this, including being unable to move about as much as usual. Using a footstool to keep your feet up when sitting down can help. It's also helpful to gently exercise your legs while you're sitting. A nurse or physiotherapist can show you some exercises to do. Water tablets (diuretics) may also be prescribed by your doctor to help reduce the swelling. In some situations, your doctor or nurse can supply pressure stockings to help the circulation in your legs.

**If the swelling is only in one leg or ankle and is painful, red and hot, this may be a sign of a blood clot (thrombosis). People with cancer have a higher risk of getting a blood clot. Some cancer treatments can also increase your risk. Let your doctor know if you develop any of these symptoms, as treatment needs to be given as soon as possible.**

## Lymphoedema

Lymphoedema is swelling caused by a build-up of a fluid called **lymph** in the body tissues. It usually affects an arm or a leg, but can affect other parts of the body. It can happen if lymph nodes (sometimes called glands) have been removed by surgery or damaged by radiotherapy, or if a cancer is blocking them. Lymph nodes are part of the lymphatic system, which is part of the body's immune system that helps us fight infections and other illnesses. If lymphoedema is diagnosed, you'll usually be referred to a lymphoedema specialist for a full assessment.

Lymphoedema specialists are usually based in hospitals, hospices or specialist lymphoedema centres. They can offer advice on self-care and treatments, including:

- skincare to prevent injury and infection
- positioning the limb and movement to help drain fluid
- compressing the limb or area using compression garments such as sleeves, stockings, special bras or compression bandages
- exercises and keeping active to improve the flow of lymph
- self-massage or specialised massage called manual lymphatic drainage (MLD) to help move fluid that's built up.

**We have a booklet called *Understanding lymphoedema*.**

## Ascites

Some types of cancer can cause a build-up of fluid in the tummy (abdomen). This is called ascites. The abdomen becomes swollen and distended, which can be uncomfortable or painful. Other symptoms include a tightness across the abdomen, unexplained weight gain, feeling breathless, feeling sick (nausea) and a reduced appetite.

Your doctors may treat ascites by inserting a small tube into your abdomen to drain off the fluid. This is usually done in hospital under a local anaesthetic. The fluid can be drained as often as necessary. Water tablets (diuretics) may be used to try to stop or slow down fluid build-up. Sometimes radiotherapy or chemotherapy treatment can prevent the fluid from coming back.

**We can send you detailed information about ascites.**

## Increased sweating

Sweating is one of the ways our body keeps our temperature normal, but some people with cancer can have episodes of increased sweating. When this is severe it can be very uncomfortable and affect activities like sleeping. There are different causes, including the cancer itself and certain medicines. Your doctor will be able to advise you on the best treatment, depending on the cause. There are also things you can do to help:

- Wear layers of light cotton clothing that can be taken off or put on easily.
- Keep rooms cool and well-aired – a fan can be helpful.
- Keep a sponge or flannel and some cool water by your bed for night sweats.
- Use light cotton bedding and put a large cotton towel on the bed underneath you. This will absorb any sweat and can be removed easily, rather than having to change all the bedclothes.
- Avoid things that may trigger sweats, for example some people find sweats are made worse by alcohol or spicy food.
- Your body loses fluid through sweating, so try to drink a bit more to prevent dehydration.

Some people will have night sweats caused by the menopause or as a side effect of hormonal treatment. We have fact sheets about these, which we can send you.

If your sweating is due to the cancer itself, there are drugs that can be used to treat it, such as steroids, amitriptyline, midazolam and cimetidine.

## High temperature (fever)

Fever is a common symptom of infection. If you've had chemotherapy within the last two weeks, the number of white cells in your blood may be temporarily reduced (neutropenia). White blood cells fight infection, so this could be the cause of your fever. If your temperature goes above 38°C (100.4°F), contact your doctor or hospital straight away. Fever caused by an infection should be treated using antibiotics.

High temperatures can be relieved with paracetamol, aspirin or an anti-inflammatory drug, for example ibuprofen. Your doctor or nurse will advise which is best for you. For tips on coping with sweating caused by fever, see page 47.

## Jaundice

Jaundice can occur if your bile duct becomes blocked by cancer. The bile duct drains bile from the liver and gall bladder into the bowel. You can also become jaundiced if there's an infection in your liver.

Symptoms of jaundice include:

- yellowing of the skin and the whites of the eyes
- itchy skin
- dark-coloured urine
- pale bowel motions
- feeling tired.

## Dealing with jaundice

If jaundice is caused by an infection, antibiotics may help. If it's caused by a tumour, treatment to remove or shrink the cancer may be recommended.

Your doctors may suggest putting in a **stent** – a small tube that holds the bile duct open. The stent can be put in using a procedure known as an **ERCP** (endoscopic retrograde cholangio-pancreatography). A thin, flexible tube called an endoscope is passed down your throat into your stomach and then into the first part of the small bowel – the duodenum. Once it's in position, the doctor can see through the endoscope into the opening of the bile duct. A stent is then put inside the duct to keep it open.

Sometimes another procedure called **PTC** (percutaneous transhepatic cholangiography) may be used to place a stent into the bile duct. It involves inserting a needle through the skin just below the ribcage. A fine guide wire is passed through the liver, into the blockage. The stent is passed along this wire.

Sometimes a stent can become dislodged or blocked. The first sign of this is often the jaundice returning. If this happens, the stent can be replaced.

An alternative treatment to relieve the blockage is **surgery** to bypass the bile duct. Surgery is only suitable for some people. The surgeon joins the gall bladder or bile duct to the bowel in an operation called a **cholecystoenterostomy**.

If it's possible to unblock the bile duct, your symptoms should begin to improve. Sometimes, however, it's not possible to do this and symptoms will continue.



Itchy skin can often be the most troublesome symptom of jaundice. You can find tips for dealing with itching on page 41. Medicines used to treat an itch caused by jaundice include prochlorperazine, colestyramine and antihistamine tablets.

## Medicines for symptom control

Medicines can often be used to reduce or get rid of unpleasant symptoms.

The patient information leaflet (PIL) is the leaflet supplied with a medicine that gives you more information about taking it. Always follow the leaflet instructions. Sometimes you'll be given a medicine to treat a symptom that isn't listed in the PIL. This is because the drug has been found to help relieve that symptom but it wasn't originally developed to treat it. It's important to follow the advice of the doctors and nurses looking after you.

If you're finding medicines difficult to take, speak to your doctor, nurse or pharmacist as an alternative may be available. Some medicines can be bought over the counter, for example medicines for sleeplessness, coughs and itchy skin. Always ask your doctor and pharmacist for advice before you buy over-the-counter remedies. It will help the pharmacist if you take a list of any other medicines you're taking.

Medicines to help control symptoms can be taken in different ways. Many are taken as **tablets** or **capsules**, and **liquid forms** of many drugs are available for people who find tablets



hard to swallow. Other ways of taking medications include **injections**, **suppositories** (which are inserted into the back passage) and **skin patches**.

Many pharmacies now offer free home delivery of prescription medicines.

### **Syringe drivers**

If medicines such as painkillers and anti-sickness medicines are difficult for you to swallow, your doctor or nurse may suggest that you have these or similar drugs **infused** (pumped slowly under the skin) using a small portable pump called a syringe driver. A syringe containing the medicines is put into the driver and attached via a tube to a fine needle placed under the skin (subcutaneously). A small dose of the drug is released at a constant rate for as long as you need it. A nurse will replace the syringe every 24 hours and care for the dressing that holds the needle in place.

### **Daily drug schedule**

If you're taking several different drugs, you may find it helpful to draw up a chart that lists:

- the names of the drugs
- what they do
- their doses
- what time of day to take them.

Your doctor, nurse or pharmacist can help you with this, or they may be able to give you a chart. Make sure the chart has space for you to tick off each dose as you take it. You may find it easier to have your drugs arranged by the pharmacist or

nurse in a container called a **pill reminder** or **dosette box**, labelled with the times to take them. Then, at any time during the day, you can check that you're up to date.

The aim is to make things as simple as possible. If you find that remembering to take medicines several times a day is difficult, talk to your doctor. There may be other forms of the same drug that have the same effect, but that don't need to be taken so often. You may also want to ask your doctor or nurse whether it's possible for you to take all your drugs at the same time each day.

## Keeping a symptom diary

You may find it useful to keep a diary of how well your pain and other symptoms are being controlled. There's a symptom diary in the centre of this booklet that you can use. This can also help your medical team. For example, they'll be able to see whether the doses of any of your drugs need changing. If you photocopy the diary before you fill it in, you can use it again as often as you need to. You can also use it to keep a record of all your different symptoms.

If you don't want to bother with a full diary, just make a note if your pain or other symptoms come back before your next dose of medicine is due, and record when you need to take extra doses.

If you find your symptoms are difficult to treat, your doctor may refer you to a specialist who deals with symptom control or to a palliative care clinic (see page 65).

# Cancer treatments for symptom control

If your symptoms are caused by a tumour, then cancer treatments such as radiotherapy, chemotherapy, surgery or hormonal therapy may help to relieve them.

**Radiotherapy** is sometimes used to reduce the size of a tumour and relieve symptoms. The treatment usually takes about 7–10 days to take effect. You may need to take other medicines to control your symptoms during this time.

The dose of radiotherapy used to treat symptoms is generally quite low and the treatment has few side effects other than some tiredness. However, it can increase symptoms slightly at first, before it starts to reduce them. The effect on your symptoms will depend on which part of the body is treated with radiotherapy. Your doctor can discuss with you the likely side effects and benefits of radiotherapy in your particular situation.

**Chemotherapy** can also sometimes reduce the size of tumours, which will help control and improve symptoms. It may help some people feel better, although it doesn't work for everyone and it may cause side effects that are difficult to deal with. Your doctor can discuss with you whether chemotherapy may be helpful. You may want to know how likely it is to work and what the possible side effects may be, so that you can decide whether chemotherapy would be right for you.

Making decisions about treatment can be difficult. You may need to discuss the benefits and side effects of treatment with your doctor or nurse more than once, before making a decision

about whether to have chemotherapy. You can discuss these issues with our cancer support specialists by calling us free on **0808 808 00 00**, or with one of the support organisations listed on pages 75–84.

**You may find our booklets *Understanding radiotherapy* and *Understanding chemotherapy* helpful.**

**Surgery** can be used to remove part of a tumour in particular areas of the body (such as an airway or the gullet), so that the part of the body can work normally again. Surgery using lasers may sometimes be used to destroy part of a tumour.

**Hormonal therapy** can be used to reduce symptoms for some types of cancer. It can reduce the size of some tumours by changing the levels of particular hormones in the body, or by preventing the hormones from attaching to the cancer cells. There are many different types of hormonal therapy and the side effects of each vary, but they aren't usually severe. You can ask your doctor how likely the treatment is to work for you and what the possible side effects are.

**We have fact sheets on all the commonly used hormonal therapy drugs.**

# Complementary therapies

Complementary methods of symptom control can be used on their own or in combination with medicines. They include:

- acupuncture
- homeopathy
- relaxation techniques
- hypnotherapy
- meditation
- visualisation.

Complementary therapies may be available at your hospital, hospice or through your GP practice. Some cancer support groups offer therapies. We can give you information about local groups in your area.

## Acupuncture

Acupuncture uses fine needles inserted just under the skin to stimulate energy flow in particular parts of the body. It can be helpful as a treatment for symptoms including pain, nausea, anxiety and the hot flushes caused by hormonal therapy. Your doctor can refer you to an NHS pain clinic that offers acupuncture. You can also contact the British Acupuncture Council for details of registered acupuncturists in your area (see page 75 for contact information).

## Homeopathy

Homeopathy is used for a number of illnesses and may be taken in addition to conventional treatment to try to improve the quality of life of people with cancer. There's no reliable scientific evidence for the effectiveness of homeopathy, however many people who use it say it has helped them.

It involves taking tiny amounts of a substance that can cause similar symptoms to the ones you're experiencing. It's based on the theory that this can help to treat these symptoms. Homeopathic remedies can be tablets, liquids or creams, and they contain very diluted forms of the active ingredients. Some GPs are trained in homeopathy. The Royal London Hospital for Integrated Medicine has a special programme for people with cancer, and the British Homeopathic Association can put you in touch with a local homeopath (details on page 76). Homeopathy is also available in some NHS hospitals.

## Relaxation

Simple breathing and relaxation exercises may be very useful for symptoms like anxiety and breathlessness. Relaxation can sometimes be used together with meditation and visualisation. Almost everyone can learn relaxation techniques. You can learn them at home using a CD, tape or DVD, or you may be able to join a local group. Relaxation resources may be available from your local library.

## Meditation

Meditation uses concentration or reflection to deeply relax and calm the mind, helping to reduce feelings of fear, pain, anxiety and depression. It can help to practise in a group until



you're familiar with the meditation technique. It's also good to talk regularly about your meditation to an experienced meditation practitioner.

People who have particular psychiatric conditions, such as psychosis, may find that some types of meditation make their psychiatric illness worse. It's best to talk to a meditation instructor from an established meditation organisation (and your psychological support team, if necessary) before trying meditation.

## **Visualisation**

Visualisation (creating mental images) is a technique that helps you bring happy, relaxed pictures into your mind and use them to overcome some of the discomfort caused by your symptoms. By 'seeing' and 'hearing' images and sounds that bring you pleasure, you may, to some extent, shut out symptoms of pain and discomfort.

## **Hypnotherapy**

Hypnotherapy can help some people deal with symptoms such as pain. It can also be useful in reducing some of the side effects associated with chemotherapy and radiotherapy, such as nausea and vomiting. A hypnotherapist leads you into a deeply relaxed state (hypnosis), during which you're still conscious of your surroundings. The hypnotherapist can then use suggestion to benefit you in different ways, such as feeling better or gaining some control over your symptoms.

If you're considering a complementary therapy, always use a qualified therapist. The British Complementary Medicine Association (see page 75) can give you the names of registered



therapists and advice on what to look for. Talk it over with your doctor or nurse and ask for their advice, especially if you're going to have a therapy that involves taking pills or medicines. Don't be misled by promises of cures. No reputable therapist would claim to be able to cure cancer.

**Our booklet *Cancer and complementary therapies* gives more detail about these therapies.**

## What other people can do for you

Medical treatments and complementary therapies are not the only way to control symptoms. They are only one part of treatment. Sometimes the simplest ways of making you feel more comfortable are overlooked. There are a lot of things that you and other people can do to help you feel better.

### **Are you comfortable?**

The way you sit or lie down can affect some symptoms (such as a cough or swollen legs), and what feels comfortable at first may be uncomfortable 15–20 minutes later. Family or friends can help you change position as often as necessary. This will also reduce the risk of your skin becoming sore and inflamed as a result of sitting or lying still in one position for long periods.

**It's important to change your position regularly.**

Sheets or bedding may need to be tidied or changed too. People feel a lot better when they get back into a cool bed with fresh bed linen. V-shaped pillows or supports can help to reduce back and neck ache, and a bed cradle can keep the weight of blankets off aching limbs.

Your district nurse may be able to get a pressure-relieving mattress and cushion for you. Other people from your care team, such as a physiotherapist or occupational therapist, can provide special equipment to help with movement and sitting. Organisations that supply equipment are listed on pages 82–83.

## **Occupying your mind**

Watching TV, listening to music or chatting to a friend will not make your symptoms go away, but it can help distract your attention from them, at least for a time. If you're feeling low, it's tempting to avoid people's company. But even short periods of entertainment and conversation can help raise your spirits and help you cope better with symptoms. Short, regular visits from relatives and friends are probably better than longer ones. They're less tiring, they help to break up the day and they're something to look forward to.

## **Talking things over**

Because anxiety and depression can make some symptoms (such as breathlessness) worse, it can help to talk about your worries and fears with people who are close to you. Acknowledge the emotions you're feeling and try not to bottle things up.

It's perfectly natural to feel a whole range of powerful emotions, including depression, when you have cancer. Talking through your feelings with your partner, a relative or a close friend can be very helpful. If you don't feel able to talk to them, perhaps because it upsets you both too much, you can ask your GP to put you in touch with a counsellor or you can contact one of the organisations on pages 75–78.

You might also find it helpful to talk to other people with cancer. Talking to people who are in a similar situation to you can help you feel less isolated. Call our cancer support specialists on **0808 808 00 00** to find out if there's a support group in your area. Or you can visit our online community at **[macmillan.org.uk/community](https://www.macmillan.org.uk/community)** where you can chat with other people who have cancer, or just read through the posts or blogs other people have written.

**We have a booklet called *The emotional effects of cancer that you may find helpful*.**

You may be anxious about your treatment or worried about coping at home. You may have financial problems. Often, relatives or friends can help by getting more information from doctors and nurses, or by finding out about services that can help. Sometimes there's little that they can say or do, but just being there to listen and understand can be enough. Emotional pain can make it harder to cope with any physical symptoms that occur.

It's often hard to accept or understand why an illness like cancer should happen in your life. People often have feelings of guilt, and worry about how the cancer will affect their family now and in the future. Sometimes the strength of these emotions may make you feel isolated and frightened, and make you

withdraw from family and friends. It can help to talk to someone about these feelings.

**You may find our booklets *Talking about your cancer (for people with cancer) and Lost for words (for relatives and friends)* helpful.**

## **Religion and spirituality**

Serious illness can force people to take stock of their life, and sometimes to question its meaning. Some people who have religious beliefs may find their faith severely shaken by their cancer diagnosis. People who don't see themselves as religious may begin to ask spiritual questions. People often ask questions like 'Is there life after death?' and 'Why should the people I love suffer?'

Some people find great comfort in religion at this time, and it may help them to talk to a local minister, hospital or hospice chaplain or other religious leader. If you don't feel that this is the right type of support for you, talking with family and friends or a counsellor may help. The British Humanist Association runs local groups and provides information for people who aren't religious (see page 76). A cancer support group may be another source of support. We can give you details of local support groups.

# Who can help

There are many people who can help you and your family cope with the symptoms of cancer. There are doctors and nurses throughout the country who specialise in this area, which is called **palliative care** or **supportive care**. They are based in hospitals, hospices, specialist palliative care units and pain clinics. There are also many home care teams of doctors and nurses who can visit you in your home. They can make sure that your symptoms are well controlled and that you have help and support.

## Care in your own home

When you're at home, your **GP** and **district nurse** will be responsible for your day-to-day care. In many areas of the country there are also specialist nurses called **palliative care nurses**. They can offer you support from when you're diagnosed with cancer. They can visit you at home and support you and your family. They're experienced in assessing and treating your symptoms. Many palliative care nurses are linked to the local hospice (see page 65). Your GP can usually arrange for you to be seen by a specialist nurse at home.

Palliative care nurses are sometimes referred to as Macmillan nurses. However, many Macmillan professionals are nurses who have specialist knowledge about a particular type of cancer. You may see them when you're at a clinic or in hospital.

**Marie Curie nurses** help to care for people who are no longer having active cancer treatment and want to stay in their own homes. They may be registered nurses or senior health assistants. Marie Curie nurses provide nursing care during the

day and, more usually, overnight. The district nurse usually decides whether to request a Marie Curie nurse.

## Care in hospital

Many hospitals have a **palliative care team** to support the staff caring for you. The team is usually made up of nurses and doctors who specialise in symptom control (palliative care specialists). If you're in hospital or visiting an outpatient clinic, your doctor or nurse can arrange for the palliative care team to visit you.

Some hospitals have **pain clinics** for the management of chronic pain. A specialist doctor can offer a range of treatments to help control pain. Other specialists such as psychologists, nurses, physiotherapists and occupational therapists can also help with the management of pain. Your GP or hospital doctor can refer you to a pain clinic.

## Care in hospices and specialist palliative care units

Hospices and specialist palliative care units specialise in the physical, emotional, spiritual and social needs of people with cancer and other life-limiting illnesses. They can help anyone with cancer, not just those who are dying or seriously ill. The care is free. Some are run by independent charities or by Marie Curie Cancer Care (known as Marie Curie Hospices). Others are run by local NHS trusts.

These units provide a variety of care:

- **Inpatient care**, where you can be admitted for a few days or weeks to have your symptoms controlled. Short stays can also be organised to give your carers a break from

care-giving (respite care). Some people may need inpatient care in a hospice when they are dying.

- **Day care** can provide specialist symptom control. It may also offer the opportunity for physiotherapy, complementary therapy and carer support, and the chance to meet with others who may be in a similar situation. Day care can also give your family or carers some time for themselves.
- **Outpatient clinics**, where people who are able to travel from home can get help from a palliative care specialist.

Your GP or hospital doctor can organise a referral for hospice support.

## Other professionals who can help

**Physiotherapists** can help you with breathing and mobility problems. They can offer expert advice about gentle exercise and relaxation techniques, and they can help you learn new ways of carrying out day-to-day activities that may be causing you difficulty.

**Occupational therapists** can help you find safe ways of completing tasks and activities at home, and prevent you from getting too tired or breathless. They may be able to supply you with simple but effective gadgets that can make everyday chores easier to manage.

A **social worker** can give you information about social services and other benefits you may be able to claim. For example, you may be entitled to Meals on Wheels, a home help or assistance with hospital fares.

## Practical support

If your symptoms are causing any kind of disability, there are organisations who provide equipment that can help you. Social services can often provide aids to daily living, such as handrails and ramps for your home. The Disabled Living Foundation (see page 83) runs an information service. It has specialist advisers on incontinence and clothing, and occupational therapists who can give personal advice on aids and equipment. It has showrooms with specialist equipment on display, from special cutlery to walking aids and wheelchairs.

The British Red Cross (see page 82) has branches across the UK. Their volunteers can provide transport to help you get out and about, or help with shopping and simple tasks around the home. They also lend equipment for nursing someone at home, such as wheelchairs and commodes.

In many areas there are volunteer schemes that can arrange for someone to visit your home to provide company for you and a break for your carer. You can contact your local Community Service Volunteers to find out what's available (see page 81). Local information may also be displayed on notice boards in your GP surgery, your local library, community centre or church.





# Financial help and benefits

There are a number of benefits you may be entitled to. You may qualify for Disability Living Allowance (DLA) if you're under 65 or for Attendance Allowance (AA) if you're over 65.

There is a fast-track claim for people who may not live longer than six months. People who claim under this 'special rule' need to get their doctor to complete a form for either benefit (called a DS1500). 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.

People who are unable to work due to illness or disability may consider applying for Employee Support Allowance (ESA). If you submit a DS1500 for Disability Living Allowance this can be used to fast-track your claim for ESA.

## Information about benefits and financial help

For more information about benefits and financial support, call us on **0808 808 00 00**. You may also find our booklet *Help with the cost of cancer* useful.

You can find out more about benefits from your local Citizens Advice or by calling the Benefit Enquiry Line on **0800 882 200**. You can also visit the Department for Work and Pensions website at **dwp.gov.uk**

## Direct payments

If your assessment shows that you need care from social services, you may be entitled to get direct payments from your local authority. This means that you're given payments to organise social services yourself, rather than the local social services paying for and organising them for you. You can get information about direct payments from the Department of Health website at [dh.gov.uk](https://www.dh.gov.uk) or from your local authority.

# How we can help you

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

## Get in touch

### Macmillan Cancer Support

89 Albert Embankment,  
London SE1 7UQ

### Questions about cancer?

Call free on **0808 808 00 00**

(Mon–Fri, 9am–8pm)

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

### Hard of hearing?

Use textphone

0808 808 0121 or Text Relay.

### Non-English speaker?

Interpreters are available.

## Clear, reliable information about cancer

We can help you by phone, email, via our website and publications or in person.

And our information is free to everyone affected by cancer.

## Macmillan Support Line

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

## Information centres

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

## Publications

We provide expert, up-to-date information about different types of cancer, tests and treatments, and information about living with and after cancer. We can send you free information in a variety of formats, including booklets, leaflets, fact sheets, and audiobooks. We can also provide our information in Braille and large print.

You can find all of our information, along with several videos, online at **macmillan.org.uk/cancerinformation**

## Review our information

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

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

## Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk** For medical attention out of hours, please contact your GP for their out-of-hours service.

## Someone to talk to

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

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

## Professional help

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

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

## Support for each other

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

### Support groups

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

### Online community

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

## Financial and work-related support

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

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

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

### Macmillan Grants

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

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

## Learning about cancer

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

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

# Other useful organisations

## **Bladder and Bowel Foundation**

SATRA Innovation Park,  
Rockingham Road,  
Kettering NN16 9JH

**Helpline** 0845 345 0165

### **General enquiries**

01536 533255

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

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

UK-wide charity that provides information and advice on a range of symptoms and conditions related to the bladder and bowel. Has information about the National Key Scheme.

## **British Acupuncture Council**

63 Jeddo Road,  
London W12 9HQ

**Tel** 020 8735 0400

**Email** from the website

**[www.acupuncture.org.uk](http://www.acupuncture.org.uk)**

Governs the work of acupuncturists. Search for a local acupuncturist on the website.

## **British Association for Counselling and Psychotherapy**

BACP House,  
15 St John's Business Park,  
Lutterworth LE17 4HB

### **Client Information Helpdesk**

01455 883316

### **General enquiries**

01455 883300

**Email** [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)

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

Aims to promote awareness of counselling and increase availability, and to signpost people to appropriate counselling services.

A searchable database of qualified counsellors can be accessed on their website.

## **British Complementary Medicine Association**

PO Box 5122,  
Bournemouth BH8 0WG

**Tel** 0845 345 5977

**Email** [office@bcma.co.uk](mailto:office@bcma.co.uk)

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

Umbrella body for a range of complementary medicine organisations. Keeps a register



of practitioners in various complementary therapies.

**British Homeopathic Association**

Hahnemann House,  
29 Park Street West,  
Luton LU1 3BE

**Tel** 01582 408675

**Email**

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

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

Has information on homeopathy and how to access homeopathic treatment.

**British Humanist Association**

1 Gower Street,  
London WC1E 6HD

**Tel** 020 7079 3580

**Email** from the website

[www.humanism.org.uk](http://www.humanism.org.uk)

Umbrella organisation for humanist groups in the UK. Provides information and services for humanists.

**British Wheel of Yoga**

25 Jermyn Street, Sleaford,  
Lincolnshire NG34 7RU

**Tel** 01529 306 851

**Email** [office@bwy.org.uk](mailto:office@bwy.org.uk)

**[www.bwy.org.uk](http://www.bwy.org.uk)**

The largest yoga organisation in the UK. Search for a local teacher on the website.

**Institute for**

**Complementary Medicine**

Can-Mezzanine,  
32–36 Loman Street,  
London SE1 0EH

**Tel** 0207 922 7980

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

**[www.i-c-m.co.uk](http://www.i-c-m.co.uk)**

Keeps a register of professional practitioners who work to a code of ethics and practice, and have full practitioner insurance. Search for information about local complementary practitioners on the website.

## **National Register of Hypnotherapists and Psychotherapists**

18 Carr Road, Nelson,  
Lancashire BB9 7JS

**Tel** 01282 716839

**Email** [admin@nrhp.co.uk](mailto:admin@nrhp.co.uk)

**www.nrhp.co.uk**

Keeps a database of hypnotherapists throughout the UK and provides a free referral service for those seeking a reputable practitioner. You can also search the register via the website.

## **Samaritans**

Chris, Freepost RSRB-KKBY-CYJK, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** [jo@samaritans.org](mailto:jo@samaritans.org)

**www.samaritans.org.uk**

Provides confidential non-judgemental emotional support, 24 hours a day, for people who are experiencing feelings of distress or despair, including those that could lead to suicide. Provides service by phone, email and letter.

## **General cancer support organisations**

### **Cancer Black Care**

79 Acton Lane,  
London NW10 8UT

**Tel** 020 8961 4151

(Mon–Fri, 9.30am–4.30pm)

**Email**

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

**www.cancerblackcare.org**

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

### **Irish Cancer Society**

43–45 Northumberland Road,  
Dublin 4, Ireland

**Cancer helpline**

1 800 200 700 (Mon–Thurs  
9am–7pm, Fri 9am–5pm)

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

**www.cancer.ie**

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

## **Maggie's Cancer Caring Centres**

8 Newton Place,  
Glasgow G3 7PR

**Tel** 0131 537 2456

**Email** enquiries@  
maggiescentres.org

**www.maggiescentres.org**

Located throughout the country, Maggie's Centres offer free, comprehensive support. You can access information, benefits advice, and emotional or psychological support.

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

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

**Tel** 0141 211 0122

**Email** taktent4u@gmail.com

**www.taktent.org**

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

## **Tenovus**

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

**Freephone helpline**

0808 808 1010

**Tel** 029 2076 8850

**Email** post@tenovus.com

**www.tenovus.org.uk**

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

## **Ulster Cancer Foundation**

40–44 Eglantine Avenue,  
Belfast BT9 6DX

**Freephone helpline**

0800 783 3339

**Tel** 028 9066 3281

**Helpline email**

infocis@ulstercancer.org

**Email** info@ulstercancer.org

**www.ulstercancer.org**

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

## Financial or legal advice and information

### Benefit Enquiry Line

Warbreck House, Warbreck Hill Road, Blackpool FY2 0YE

**Freephone** 0800 882 200

**Textphone** 0800 243 355

**Email** BEL-Customer-Services@dwp.gsi.gov.uk

**www.gov.uk/benefit-enquiry-line**

Provides advice about benefits, and can also provide help with the completion of some disability-related claim packs.

### Citizens Advice

Provides free, confidential, independent advice on a variety of issues including financial, legal, housing and employment. Find contact details for your local office in the phone book or at

**citizensadvice.org.uk**

Find advice online, in a range of languages, at **adviceguide.org.uk**

### Citizens Advice Scotland

**www.cas.org.uk**

## Support for carers

### Carers Direct

PO Box 4338,  
Manchester M61 0BY

**Helpline** 0808 802 0202

(Mon–Fri, 8am–9pm,  
weekends, 11am–4pm)

**Email** from the website

**www.nhs.uk/carersdirect/Pages/CarersDirectHome.aspx**

Aims to offer all the information you should need as a carer to access the financial help you're entitled to, as well as advice on getting a break from caring, going to work and much more.

### Carers UK

20 Great Dover Street,  
London SE1 4LX

**Tel** 020 7378 4999

### Carers' line

0808 808 7777 (Weds–Thurs,  
10am–12pm and 2–4pm)

**Email** info@carersuk.org

### Advice line email

adviceline@carersuk.org

**www.carersuk.org**

Offers information and support to carers. Can put you in contact with support groups for carers in your area. Has

national offices for Scotland, Wales and Northern Ireland:

### **Carers Scotland**

The Cottage, 21 Pearce Street, Glasgow G51 3UT

**Tel** 0141 445 3070

#### **Email**

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

**[www.carersuk.org/scotland](http://www.carersuk.org/scotland)**

### **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.carersuk.org/wales](http://www.carersuk.org/wales)**

### **Carers Northern Ireland**

58 Howard Street, Belfast BT1 6PJ

**Tel** 028 9043 9843

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

**[www.carersuk.org/northernireland](http://www.carersuk.org/northernireland)**

### **Crossroads Care**

10 Regent Place, Rugby, Warwickshire CV21 2PN

**Tel** 0845 450 0350

**Email** from the website

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

Provides services through a network of local providers across England and Wales, each offering Crossroads' core service where a trained carer support worker comes into the home to take over the caring responsibilities.

### **Crossroads**

#### **Caring Scotland**

24 George Square, Glasgow G2 1EG

#### **Carers' information and support line**

0141 353 6504

**Email** [info@crossroads-scotland.co.uk](mailto:info@crossroads-scotland.co.uk)

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

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

### **Crossroads Caring for Carers (Northern Ireland)**

7 Regent Street, Newtownards, Co Down, Northern Ireland BT23 4AB

**Tel** 028 9181 4455

#### **Email**

[mail@crossroadscare.co.uk](mailto:mail@crossroadscare.co.uk)

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

Provides respite for carers by providing them with a break.

**Community  
Service Volunteers**

237 Pentonville Road,  
London N1 9NJ

**Tel** 020 7278 6601

**Email** [information@csv.org.uk](mailto:information@csv.org.uk)

**[www.csv.org.uk](http://www.csv.org.uk)**

The UK's leading volunteering and training charity. Arranges for volunteers to assist people in their own homes.

**The Princess Royal Trust  
for Carers**

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

**Tel** 0844 800 4361

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

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

Largest provider of carers' support services in the UK. Through its network of 144 independently managed carers' centres and interactive websites, the trust provides information, advice and support.

**Young Carers Initiative**

The Children's Society,  
Edward Rudolf House,  
Margery Street,  
London WC1X 0JL

**Tel** 0845 300 1128

**Email** [supportercare@childrenssociety.org.uk](mailto:supportercare@childrenssociety.org.uk)

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

Works nationally to promote good practice for young carers and their families. From the website you can search for local young carers' projects in the UK, and also access information for young carers about health, school, the internet, being heard, who's who and the *Purple News* young carers' newsletter.

**Young Carers Net (YCNNet)**

Princess Royal Trust for Carers,  
Unit 14, Bourne Court,  
Southend Road, Woodford  
Green, Essex IG8 8HD

**Tel** 0844 800 4361

**Email**

[youngcarers@carers.org](mailto:youngcarers@carers.org)

**[www.youngcarers.net](http://www.youngcarers.net)**

Provides information and support to young carers through its 85 young carers' services. Provides online discussion

forums and advice for young people aged 18 and under in the UK who help to look after someone in their family.

## **Equipment and advice on living with disability**

### **Assist UK**

Redbank House, 1 Portland Street, Manchester M1 3BE

**Tel** 0161 238 8776

#### **Email**

[general.info@assist-uk.org](mailto:general.info@assist-uk.org)

**[www.assist-uk.org](http://www.assist-uk.org)**

An independent voluntary organisation with a network of Disabled Living Centres throughout the UK. Centres offer advice and a range of products and equipment designed to make life easier for people who have difficulty with daily activities.

### **The Blue Badge Scheme**

(Department for Transport)

**[www.dft.gov.uk/transportforyou/access/bluebadge](http://www.dft.gov.uk/transportforyou/access/bluebadge)**

Provides a national arrangement of parking concessions for people with severe walking difficulties who travel either as drivers or passengers. It allows badge holders parking concessions so they can park close to their destination. The scheme operates throughout the UK, and is administered by local authorities who deal with applications and issue badges.

### **British Red Cross**

44 Moorfields,  
London EC2Y 9AL

**Tel** 0844 871 11 11

#### **Email**

[information@redcross.org.uk](mailto:information@redcross.org.uk)

**[www.redcross.org.uk](http://www.redcross.org.uk)**

Offers a number of services for people with a disability, including a medical equipment loan service and a transport service. See the website for details of local offices.

## **DIAL UK**

St Catherine's, Tickhill Road,  
Balby, Doncaster DN4 8QN

**Tel** 01302 310 123

**Email** informationenquiries@  
dialuk.org.uk

**www.dialuk.info**

A national network of approximately 120 local Disability Information and Advice Line services (DIALs) run by and for disabled people. Based throughout the UK, the services provide information and advice to disabled people and others on all aspects of living with a disability. You can search for your local DIAL on the website.

## **Disability Alliance**

Universal House,  
88–94 Wentworth Street,  
London E1 7SA

**Tel (voice and minicom)**  
020 7247 8776

**Email**

office@disabilityalliance.org

**www.disabilityalliance.org**

A national charity that works to improve the living standards of disabled people. Provides information on social security benefits and disability rights.

## **Disabled Living Foundation (DLF)**

380–384 Harrow Road,  
London W9 2HU

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

**Tel** 020 7289 6111

**Email** helpline@dlf.org.uk

**www.dlf.org.uk**

A national charity that provides free, impartial advice about all types of disability equipment and mobility products through its helpline, website and demonstration centre.

## **Radar**

12 City Forum, 250 City Road,  
London EC1V 8AF

**Tel** 020 7250 3222

**Textphone** 020 7250 4119

**Email** radar@radar.org.uk

**www.radar.org.uk**

The UK's largest disability rights campaigning network. Has information about the National Key Scheme.



## Advanced cancer/ end-of-life care

### Help the Hospices

Hospice House,  
34–44 Britannia Street,  
London WC1X 9JG

**Tel** 020 7520 8200

#### Email

[info@helpthehospices.org.uk](mailto:info@helpthehospices.org.uk)  
[www.helpthehospices.org.uk](http://www.helpthehospices.org.uk)

Provides a wide range of information relevant to living with advanced illness. Compiles a comprehensive directory of Hospice Services, and free practical booklets.

### Marie Curie Cancer Care

89 Albert Embankment,  
London SE1 7TP

**Freephone** 0800 716 146

**Tel** 020 7599 7777 (England)  
0131 561 3900 (Scotland)  
01495 740 888 (Wales)  
028 9088 2060 (NI)

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

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

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

# Further resources

## Related Macmillan information

You may want to order some of the booklets mentioned in this booklet. These include:

- *Cancer and complementary therapies*
- *Controlling cancer pain*
- *Coping with fatigue*
- *Diet and cancer*
- *Help with the cost of cancer*
- *Lost for words: how to talk to someone with cancer*
- *Managing breathlessness*
- *Pelvic radiotherapy in men: possible late effects*
- *Pelvic radiotherapy in women: possible late effects*
- *Talking about your cancer*
- *The emotional effects of cancer*

- *Understanding chemotherapy*
- *Understanding lymphoedema*
- *Understanding radiotherapy*

To order, visit **be.macmillan.org.uk** To order the fact sheets mentioned in this booklet, call **0808 808 00 00**. This information is also available online.

## Macmillan audiobooks

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

We also have a relaxation CD called *Relax and breathe* that you may find useful.

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

## Videos

We have a video on our website about controlling advanced cancer symptoms, at **macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Advancedcancer/Symptomcontrol.aspx**

## Useful websites

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

## Macmillan Cancer Support **www.macmillan.org.uk**

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

- our 100+ booklets, 350+ fact sheets, videos featuring

real-life stories from people affected by cancer, and information from medical professionals

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

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

**(American Cancer Society)**

Nationwide community-based voluntary health organisation dedicated to eliminating cancer as a major health problem. It aims to do this through research, education, advocacy and service.

**[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)**

**(Cancer Research UK)**

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

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

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

(site for teens and young adults)

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

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

**Cancervoices  
(Macmillan Cancer Voices)**

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

**[www.cancer.gov](http://www.cancer.gov)**

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

Gives comprehensive information on cancer and its treatments.

**[www.nhs.uk](http://www.nhs.uk)**

**(NHS Choices)**

NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make decisions about your health.

**[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.nhs24.com](http://www.nhs24.com)**

**(NHS 24 in Scotland)**

Health information site for Scotland.

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

**nhs.uk**

**(NHS Direct Wales)**

Provides health information for Wales.

**[www.n-i.nhs.uk](http://www.n-i.nhs.uk)**

**(Health and Social Care in  
Northern Ireland)**

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

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

**(Patient UK)**

Provides good-quality information about health and disease. Includes evidence-based information leaflets on a wide variety of medical and health topics. Also reviews and links to many health- and illness-related websites.

**[www.riprap.org.uk](http://www.riprap.org.uk)**

**(Riprap)**

Developed especially for teenagers who have a parent with cancer.

# Questions you might like to ask your doctor or nurse

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

1.

---

Answer

2.

---

Answer

3.

---

Answer

4.

---

Answer

5.

---

Answer

6.

---

Answer

# Notes

## 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's Cancer Information Development team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Dr Sara Booth, Macmillan Consultant in Palliative Medicine; Audrey Cuthel, counsellor; Dr Charles Daniels, Consultant in Palliative Medicine; Theresa Mann, Palliative Care Clinical Nurse Specialist; Pauline McCulloch, Palliative Care Clinical Nurse Specialist; and the people affected by cancer who reviewed this edition.

## Sources

Hanks G, et al. *The Oxford textbook of palliative medicine*. 4<sup>th</sup> Edition. 2009. Oxford University Press, Oxford.

NHS Scotland. *The Lothian palliative care guidelines*. [www.palliativecareguidelines.scot.nhs.uk](http://www.palliativecareguidelines.scot.nhs.uk) (accessed July 2010).

*Improving supportive and palliative care for adults with cancer: the manual*. 2004. National Institute for Health and Care Excellence (NICE).

Dougherty L, Lister S. *The Royal Marsden Hospital manual of clinical nursing procedures*. 7<sup>th</sup> edition. 2008. Wiley-Blackwell.

# Can you do something to help?

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

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



## **Share your cancer experience**

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

## **Campaign for change**

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

## **Help someone in your community**

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

## **Raise money**

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

## **Give money**

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

**Call us to find out more**

**0300 1000 200**

**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**



## Please fill in your personal details

Mr/Mrs/Miss/Other \_\_\_\_\_

Name \_\_\_\_\_

Surname \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

I enclose a cheque / postal order /  
Charity Voucher made payable to  
Macmillan Cancer Support

OR debit my:

Visa / MasterCard / CAF Charity  
Card / Switch / Maestro

Card number

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Valid from

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------	----------------------

Expiry date

<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------	----------------------

Issue no

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Security number

<input type="text"/>	<input type="text"/>	<input type="text"/>
----------------------	----------------------	----------------------

Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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

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

I understand that I must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6 April one year to 5 April the next) that is at least equal to the amount of tax that Macmillan will reclaim on my gifts for that tax year.

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

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



If you'd rather donate online, go to [macmillan.org.uk/donate](http://macmillan.org.uk/donate)

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

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

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

Together, we are all Macmillan Cancer Support.

**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.**

© Macmillan Cancer Support, 2011. 7<sup>th</sup> edition. MAC11671.

Next planned review 2013. Macmillan Cancer Support, registered charity in England and Wales (261017), Scotland (SC039907) and the Isle of Man (604).



**WE ARE  
MACMILLAN.  
CANCER SUPPORT**