A practical guide to living with and after cancer

MANAGING THE SYMPTOMS OF CANCER
About this booklet

This booklet is about some of the symptoms you may have if you have cancer. It describes ways to help manage them.

You may have one or more of the symptoms we talk about in this booklet, but you are unlikely to have more than a few. Talk to your doctor or nurse about any symptoms you have. They can arrange for any help and treatment you need. Most symptoms can be well controlled with the help of your healthcare team, your family and your friends.

Some symptoms may only happen with certain cancers. You may want to read this booklet with our information about the type of cancer you have. Some symptoms may be caused by cancer treatments. We have separate information about the side effects of cancer treatments.

In this booklet, we have used this icon to show helpful tips about how to cope with each symptom. We hope you find the tips helpful.

We have also included quotes from people who have cancer. Some are from our online community (macmillan.org.uk/community) and some are from The Source, a collection of simple, practical tips from people affected by cancer (source.macmillan.org.uk). Others are from the website healthtalk.org Some names have been changed.

Turn to pages 97–102 for some contact details of other useful organisations. On pages 104–105 there is space to write down questions for your doctor or nurse.
If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, Monday to Friday, 9am to 8pm, or visit macmillan.org.uk If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use. If you are deaf or hard of hearing, call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app. We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print and translations. To order these visit macmillan.org.uk/otherformats or call 0808 808 00 00.

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.

**Your data and the cancer registry**

When you are diagnosed with cancer in the UK, some information about you is collected in a national database. This is called the cancer registry. It helps the NHS and other organisations plan and improve health and care services. Your hospital will give information about you, your cancer diagnosis and treatment to the registry automatically, unless you ask them not to. As with all medical records, there are strict rules to make sure the information is kept safely and securely. It will only be used for your direct care or for health and social care planning and research.

Talk to your doctor or nurse if you have any questions about the registry. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out. You can find more information at macmillan.org.uk/cancerregistry. To find details about the cancer registry in your area, see pages 100–101.
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Tiredness and sleep problems

Tiredness (fatigue) 6
Sleep problems 10
Fatigue is feeling very tired or exhausted all or most of the time. Tiredness is a common symptom for people with cancer. This may be due to the cancer itself. Sometimes it may be caused by other symptoms, such as pain, being short of breath, or having a low red blood cell count (anaemia).

Tiredness can also be a side effect of cancer treatment. It usually improves gradually after treatment ends, but sometimes it remains a problem.

The effects of tiredness vary from person to person. Think about how it is affecting your life and how much rest you need. This will help you work out what makes your tiredness better or worse.

Tell your doctors and nurses about your tiredness. This will help them give you the best care.

‘I did learn to plan to do things in small bursts of activity and just had to slow down in order to manage my breathing and fatigue.’

Helen
Tips to help you cope with tiredness

• Spread tasks out over the week.

• Plan to do the things you most want to do first. This could be in the morning, when you may feel less tired.

• Ask other people to help with things around the house. Try not to feel guilty. Often friends and relatives want to help and are pleased to be asked.

• Think about rearranging your home to make things easier. This could include having your bedroom as close to the toilet as possible, or arranging your kitchen to make cooking easier. An occupational therapist (OT) can help you plan this and provide gadgets to make things easier to do (see page 86).

• Do your shopping online and have it delivered.

• Listen to audiobooks if you are too tired to read.

• Talk to your employer or human resources (HR) department and let them know that you may need some time off. If you do want to carry on working, ask your employer about ways of making your work less tiring for a while. Your GP can give you something called a fit note to support this.

• Try to keep active. Research has shown that being active and doing some gentle exercise can help with tiredness. It may seem odd that exercise can help reduce tiredness, but without regular activity, our muscles get weak and tiredness gets worse.
Activity needs to be done at your own pace. If you are very tired, start slowly. Start with activities such as going for a short walk or simple strengthening exercises like standing up and sitting down. Your doctor, nurse, OT or physiotherapist (see page 86) can advise you about which type of exercise and how much would be helpful for you.

Some causes of tiredness can be treated. Your doctor may do blood tests to check if you are anaemic or if any other blood levels are too high or too low. Your doctor may also look at your medication to see if a change could help.

Your local hospital or hospice may run courses on managing tiredness. Your doctor, nurse, OT or physiotherapist can talk to you about this.

Our booklet **Coping with fatigue** has more information. A lot of our information is also available as audiobooks or MP3s. Call us on 0808 808 00 00 or visit be.macmillan.org.uk to order free copies.
Sleep problems

Many people with cancer have problems with sleeping at some point. There can be a number of reasons for this, including anxiety or symptoms such as pain and breathlessness. Ask your doctor or nurse about ways of managing these. For example, if you have pain, ask your doctor about painkillers that will last through the night.

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

Some medicines, such as steroids, can cause sleeplessness. Ask your doctor or nurse if you can take them earlier in the day. They may suggest you take them before 2pm.

Sleeplessness can sometimes be a sign of anxiety and depression (see pages 66–69). Talking about your worries and concerns may be helpful. Some people find counselling (see page 86) or relaxation therapy helpful (see page 79).

Sometimes a short course of sleeping pills can help you get back to a regular sleeping pattern or help you through a difficult time. They usually work by helping you get to sleep, so they are best taken before you go to bed rather than in the middle of the night.
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 affect your sleep patterns.

• Try to keep active during the day. This may help you feel tired and ready for sleep when you go to bed. Gentle exercise can also help.

• Avoid large meals and stimulants like caffeine or cigarettes late in the evening. Try having a warm, milky drink before going to bed. Although a small alcoholic drink may help you to relax, too much alcohol can lead to disrupted sleep.

• Have a relaxing routine before going to bed. Try having a warm bath or shower, reading a book or listening to soothing music. Make your bedroom a relaxing place to be. Create an area that is dark, quiet and comfortable but not too warm.

• Listen to an audiobook or do relaxation exercises to help you to relax.

• If you can’t sleep, get up and go to another room until you feel tired again.

If you find that worries or concerns are keeping you awake, write them down (you could use pages 104–105 for this). You can then speak to someone about them later. We have more information about coping with sleeping problems that we can send you.
# Eating and Mouth Problems

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Poor appetite

Some people find that they don’t feel hungry, or that they feel full soon after starting a meal.

Talk to your doctor if you have lost weight or are finding it difficult to put weight back on. They can refer you to a dietitian, who can advise you on which foods are best for you and whether food supplements would help. Your doctor may also prescribe drugs to boost your appetite, such as a short course of steroids.

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

Ask your family and friends to help with cooking so that you are not too tired to eat by the time your meal is ready. A community or district nurse or a social worker may talk to you about getting meals delivered (Meals on Wheels) or getting help to prepare food.
Tips to help you cope with a poor appetite

• Try having regular small meals, rather than large plates of food three times a day.

• Keep snacks handy to eat whenever you can, such as nuts, fruit, cheese or yoghurts.

• Add extra calories to your food with butter, full-fat milk and cream.

• If you can’t face a meal, you could have a sweet or savoury nourishing drink instead. Your dietitian can talk to you about these or your GP can prescribe them.

Our booklet *Eating problems and cancer* has more information.

‘When I was diagnosed, the thought of cooking made me want to cry. I was so tired and the smell made me want to be sick. A friend brought over some meals that she had made. She just made extras when making dinner for her family. She put them all in my freezer and then when I wanted something to eat, I just had to defrost and reheat. Amazingly thoughtful.’

Joanna
Feeling sick (nausea)

Cancer and some cancer treatments can make you feel sick (nausea) and be sick (vomit). Pain, some stomach problems, raised calcium levels or other chemical imbalances may cause sickness, so it is important that the cause is treated.

Your doctor can prescribe anti-sickness treatments (anti-emetics) to help. Sometimes a combination of different medications is needed. Anti-sickness drugs work better when they are taken regularly. They are usually given as tablets, but there are other ways to have them.

Some anti-sickness drugs can be given as:

- a tablet that dissolves in your mouth
- an injection
- a suppository into your back passage
- a continuous dose from a small, portable pump (syringe driver) into a fine needle just under the skin (subcutaneously).

Complementary therapies such as relaxation and acupuncture (see page 79) can also help with sickness.
Tips for coping with sickness

- Try to avoid eating or preparing food when you feel sick. If possible, let someone else do the cooking.
- Avoid fried foods and foods with a strong smell. Eat cold or warm food if the smell of hot food makes you feel sick.
- Eat several small snacks and meals each day.
- Try eating mints or drinking peppermint tea – these help some people.
- Try foods and drinks made with ginger, as these can also be helpful. You could try ginger biscuits or ginger beer.
- Sip drinks slowly. Try not to have too much to drink just before you eat.

‘When I was having my chemo, I had lots of ginger ale and always had mints in my bag. I think mints, ginger and lemon are really good if you’re feeling a bit queasy.’

Rahul
Weight gain

People don’t usually expect to gain weight during cancer treatment. But some treatments, side effects or even lifestyle changes can cause you to put on weight:

- Treatments – some chemotherapy drugs, steroids and hormonal therapies can cause weight gain.
- Fluid retention – this is caused by some cancers, and can cause weight gain. If fluid collects in your abdomen (called ascites), it may be possible to drain it (see page 63).
- Tiredness – this can be caused by cancer or its treatment and can make you less physically active than usual.
- Depression – feelings of sadness or worry about the cancer can develop into depression. Eating more and gaining weight may be symptoms of this.
- Stopping smoking – this is the healthiest decision anyone who smokes can make. But it can cause weight gain at first. You will be much healthier after quitting though, and you can gradually lose the extra weight.
- Comfort eating – some people turn to food for comfort when life is stressful, which can lead to weight gain.
- People offering food – this may be a way of showing that they care and want to be helpful. And it can be difficult to refuse such a kind offer.
Tips to help you manage weight gain

• Eating healthily and being more physically active will help you manage your weight.

• Stick to sensible drinking guidelines. Alcohol is high in calories and can lead to weight gain.

• Be realistic about how much weight you want to lose and over how much time. If you lose weight gradually, you are more likely to reach and stay at a healthy weight.

• To monitor your weight loss, weigh yourself weekly at the same time of day and using the same scales.

• If you think you have gained weight because you’re depressed, talk to your GP or nurse about treatments such as counselling and anti-depressants.

Don’t be too hard on yourself if you find you have put on weight. Knowing why it has happened can help you think of ways to manage it. Before trying to lose weight, it is important to speak to your GP, cancer doctor or nurse. They can talk to you about the right approach for you, based on the cancer you have and its treatment. They will also take into account your weight before diagnosis and any other medical conditions you may have.

Our booklets Managing weight gain after cancer treatment and Healthy eating and cancer have more information and advice. Our booklet Giving up smoking has tips on how to stop smoking. We also have information and advice on maintaining a healthy lifestyle on our website.
Indigestion and heartburn

Indigestion is discomfort in the upper part of the tummy (abdomen), which usually happens after meals. It happens when acid from the stomach irritates the lining of your stomach or the top part of your bowel.

You may get indigestion if you:

• have a small stomach
• don’t eat or drink much
• don’t move around very much.

Sometimes the stomach may produce too much acid. Some drugs, such as steroids or anti-inflammatory painkillers, can irritate the stomach lining. Some cancer treatments, such as chemotherapy, can also affect it. Anxiety can sometimes cause indigestion or make it worse.

Heartburn is a burning sensation behind the breastbone. This is caused by acid from the stomach irritating the lining of the gullet (oesophagus). Certain foods and medicines can cause heartburn. It may also happen if your tummy is very swollen. Lying flat or wearing tight clothing around the waist can make heartburn worse.

The best way of dealing with indigestion and heartburn depends on the cause.
Tips for coping with indigestion and heartburn

• Avoid things that irritate your stomach, such as smoking, chocolate, alcohol, and fatty and spicy foods.

• Antacid medicines can help relieve irritation from the stomach acid. You can buy them over the counter at your local pharmacy.

• If you have a small stomach, it can help to avoid drinking at mealtimes.

• Eat small, frequent meals and snacks throughout the day, rather than two or three large meals.

• Wear loose clothing around your waist.

• Try not to lie flat on your back, especially after meals. Avoid eating for three to four hours before you go to bed and sleep propped up on pillows.

• Talk to your doctor, as they can often prescribe medicines to help.
Hiccups

Hiccups are a sudden contraction or spasm of the diaphragm. This is the breathing muscle under the lungs. Hiccups are a reflex action, so you can’t control them.

Mild hiccups are common. They usually only last for a few minutes and don’t need treatment. But if you have hiccups that keep coming back or that last for more than two days, tell your doctor, as 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 full (bloated) stomach
• a change in the levels of certain chemicals in the blood
• an enlarged liver pressing against the stomach
• some medicines
• irritation to the diaphragm.
Treatment for hiccups

The best treatment for hiccups depends on the cause. Your doctor can prescribe medicines that may help, such as:

- anti-wind or antacid medicines
- some anti-sickness medicines
- drugs that relax the muscles
- steroids to treat hiccups caused by an enlarged liver or pressure on a nerve.

If you are started on a drug treatment for hiccups, tell your doctor if it has not helped after two to three days. If the hiccups haven’t gone away, your doctor may increase the dose or try another drug.

Tips to help you get rid of hiccups

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

- drinking peppermint water, which relaxes the stomach and gullet and helps to release trapped air through burping
- sipping iced water, swallowing crushed ice or drinking from the wrong (opposite) side of a cup
- eating dry bread, two teaspoons of granulated sugar or a spoonful of thick, chilled yoghurt
- holding your breath.
Sore mouth and throat

You may have a sore mouth if you:

- haven’t been able to eat a nutritious diet
- have low immunity and are more prone to infection
- have an infection of the lining of your mouth or throat.

If your cancer treatment is likely to cause mouth problems, your doctor may prescribe mouthwashes for you to use during treatment. They may also prescribe a protective gel that can help ease any pain and discomfort. You may need to take regular painkillers and keep to a diet of soft foods.

If you are taking antibiotics or steroids, you may develop a fungal infection in your mouth called thrush. This coats your tongue, the lining of your cheeks and the back of your throat. It can look red with spotty, pale patches. Thrush can make eating unpleasant and can change how things taste. Your doctor can prescribe an anti-fungal medicine to help.

If your mouth or lips become sore, your doctor can check for signs of infection or thrush. They can prescribe treatment if needed. If your symptoms don’t improve with treatment, it is important to go back to your doctor again.

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

- Follow a good mouth care routine (see page 29).
- If your toothpaste stings, talk to your cancer nurse or dentist. There may be a different one you can use.
- If you wear dentures, you may find it easier to leave them out for a while. This stops them rubbing against your gums. But if you are having radiotherapy to the jaw area, you may be advised to keep your dentures in as much as possible during the day. This helps maintain the shape of your gums during treatment.
- Avoid alcohol, tobacco and foods that irritate your mouth.
- Use gravy and mild sauces to make your food moist, softer and easier to swallow.
- Try to drink at least two litres (about three and a half pints) of fluid a day.
- Try drinking through a straw to avoid irritating sore parts of your mouth.
- Try adding crushed ice to drinks and eating ice cream or ice lollies. Cold foods and drinks can be soothing.
- Try drinking warm herbal teas – these may be more soothing than acidic drinks such as orange and grapefruit juice.
Dry mouth

Some people with cancer have a dry mouth because they produce less saliva or they breathe more through their mouth. Oxygen treatment, radiotherapy to the head and neck area, certain drugs and feeling anxious can also cause a dry mouth.

A dry mouth can be uncomfortable and change the way your food tastes. Your doctor can review your medicines with you to see if any of them are causing your dry mouth. An alternative drug may be available.

Your doctor may also talk to you about artificial saliva. These are available as gels, sprays, pastilles or lozenges. Your doctor can prescribe these for you.

If you have a dry mouth for a long time, you have a higher risk of tooth decay. This means it is 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 go to the surgery.

‘I think the dry mouth is the worst bit, especially when it stops you sleeping. I keep a little atomiser of water under my pillow and if I wake up in the night, I have a quick spray.’

Margaret
Tips for dealing with a dry mouth

• Follow a good mouth care routine (see page 29).

• 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. Take regular drinks to keep your mouth moist. Have a drink with meals.

• Carry a bottle of water with you when you go out. Keep a glass of water beside your bed at night so you can have a drink if you wake up.

• Try fizzy drinks such as fresh orange juice with soda water. You could also try sucking flavoured ice cubes and ice lollies. Unsweetened pineapple chunks or melon can also help keep your mouth moist.

• Eat foods with a high fluid content, such as jelly, puréed fruits and soft puddings. Include plenty of sauces and gravy with meals and avoid dry foods.

• Chew sugar-free gum, as it can stimulate saliva production.
Mouth care routine

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

- **Brush your teeth and gums every morning and evening.** Use a small, soft-bristled or children’s toothbrush and fluoride toothpaste. Replace the brush regularly.

- **Use a mouthwash to rinse your mouth at least four times a day after meals.** If your doctor prescribes a mouthwash for you, use it regularly as prescribed.

- **If you have dentures, rinse them after meals.** Clean your dentures with a toothbrush and toothpaste or denture paste. Take them out and soak them at night.

- **Keep your lips moist by using Vaseline® or a lip balm.**
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 side effect of cancer treatment. You may no longer enjoy certain foods, find that all foods taste the same, or find that foods have no taste at all.

Our booklet *Eating problems and cancer* has more information.
Tips to help you cope with taste changes

• Eat foods that you enjoy. Avoid those that you don’t like, but try them again after a few weeks as your sense of taste may change again.

• Use seasonings, spices, sauces and herbs to flavour your food. Marinate meat to improve its flavour, or eat it with strong sauces such as sweet and sour, or curry.

• Try sharp-tasting foods like fresh fruit, fruit juices and bitter boiled sweets. They can be refreshing and leave a pleasant taste in your mouth. Some people find that cold foods taste better than hot foods.

• If you no longer enjoy tea or coffee, try herbal, fruit or green teas. Or try an ice-cold fizzy drink like lemonade or fresh orange juice with soda water.

‘Eventually my saliva recovered a little, as did my taste buds. It’s just a matter of time and patience.’

Joycee
Breathing Difficulties

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Breathlessness

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

Some of the common causes of breathlessness are:

- **A chest infection** – Your doctors can prescribe antibiotics to treat this.

- **Anaemia** – This is when the level of red blood cells in your blood is low. Your doctors may recommend that you have a blood transfusion to treat it. We can send you more information about blood transfusions.

- **Pulmonary oedema** – This is when fluid builds up in the lungs. Treatment usually includes medication to get rid of the fluid. These are called diuretics or water tablets. You may also need oxygen therapy to help with your breathing (see next page).

- **Pleural effusion** – This is a build-up of fluid between the two membranes that cover the lungs (the pleura). Your doctor may place a small tube into your chest to drain the fluid into a drainage bottle. We can send you more information about pleural effusions.

- **Smoking tobacco** – Smoking makes breathlessness worse. The smoke causes irritation and inflammation of the airways. If you want to stop smoking, ask your nurse or doctor for advice. You can also call our cancer support specialists on 0808 808 00 00 for more information.

Breathlessness can make you feel anxious and panicky (see pages 66–67). This can cause rapid, shallow breathing, which can make you even more breathless.
Some people who are breathless lose their confidence to be active or go out. You can get advice and help from a physiotherapist or an occupational therapist (OT) to help you stay active (see page 86).

Your local hospital or hospice may run a breathlessness service where you can get further advice and support.

**Treatment for breathlessness**

Your doctor may give you medicines to help ease breathlessness, such as:

- bronchodilators, to widen the airways and increase air flow – you can breathe these drugs in through an inhaler, or a mask called a nebuliser (see page 37)
- steroids, to reduce inflammation in the lungs
- very small doses of painkillers, such as morphine, even if there is no pain
- drugs to relieve anxiety and panic
- drugs to help you pass more urine (diuretics).

**Oxygen therapy**

Your doctor may talk to you about oxygen therapy. This is when you have oxygen through a face mask, or through small tubes that sit under the nostrils (nasal cannula). It is only suitable for some people who are breathless. If you need oxygen at home, your doctor can arrange this for you.
Tips for managing breathlessness

• Try sitting by an open window or using a small fan. Cool air blowing directly on to or across your face can help you breathe more easily.

• 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.

• Sit down to do everyday tasks like washing, dressing and preparing food. Think about rearranging your home to make things easier. An OT can help with planning this and provide gadgets to make everyday life easier.

• Try using a baby monitor to talk to people in other rooms. This is helpful as you won’t have to shout or get up, especially at night.

• Try some relaxation techniques. These can help you control anxiety and improve breathlessness. A physiotherapist, OT or specialist nurse can teach you ways to relax and breathe gently and more effectively (see page 86).

There is more information in our booklet *Managing breathlessness*, which also includes a copy of our relaxation CD, *Relax and breathe*. 
Coughing

Coughing can help to clear our airways, but it can also be uncomfortable or embarrassing for some people. It can affect how you sleep, rest and eat.

If you are coughing up green or dark yellow phlegm (sputum), tell your doctor or nurse. You may have an infection and need antibiotics.

Some people need physiotherapy to help them clear their airways. Sometimes steam inhalations or saline through a nebuliser are helpful. A nebuliser is a small machine that turns the saline into a fine mist, so you can breathe it deep into your lungs.

If you have a dry, irritable cough, your doctor may prescribe a cough mixture to help. If your cough is persistent, painkillers such as codeine or morphine can help, even if you don’t have pain.

Sometimes people cough up blood. Tell your doctor straight away if this happens. The treatment you have will depend on the cause, so you may have tests to find out what is causing the bleeding.

‘I spend many hours standing at my bedroom window as fresh air seems to be the only thing to stop me coughing.’

Tony
BOWEL AND BLADDER PROBLEMS

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Constipation

Constipation can be a common problem, but many people find it embarrassing to talk about.

Signs of constipation include:

• moving your bowels less than you usually do
• your stools (poo) becoming harder
• straining to move your bowels
• a feeling of not having emptied your bowel but being unable to pass any more stool
• your tummy becoming bloated or uncomfortable.

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

Constipation can be caused by a lack of fibre (roughage) in your diet, not drinking enough and not being active. Some medicines can also cause it, such as the painkillers morphine and codeine.

If you are taking regular painkillers, you may need a laxative to help prevent constipation. Laxatives are medicines that can help you move your bowels. There are different types of laxative. Your doctor or nurse will recommend one depending on the cause of the constipation.
Tips for managing constipation

• Try to have plenty of fibre in your diet. This includes wholegrain cereals, porridge, muesli, wholemeal bread and pasta, brown rice, and fresh fruit and vegetables with their skins on.

• Try to drink at least two litres (three and a half pints) of fluid a day.

• Do gentle exercise regularly. This will help keep your bowels moving.

• Try natural remedies for constipation, including apricots, dried fruit, prunes, prune juice and syrup of figs.

• If you are prescribed a painkiller such as codeine or a stronger painkiller, you will nearly always need to take a laxative regularly too. Don’t wait until it becomes a problem.

If you have cancer of the gullet (oesophagus) or bowel, ask your doctor before taking fibre. They can give you advice about dealing with constipation.

‘When my partner had to change his diet in the first couple of months post-surgery, we changed our diet as a family. That way he didn’t feel different – we were all eating the same things.’

Nicola
Diarrhoea

Some cancers can prevent food from being absorbed properly in the bowel, causing diarrhoea. It may also be a side effect of some cancer treatments. Other medications or an infection can sometimes cause diarrhoea.

It may be a temporary, mild problem. But for some people, it can be severe and they will need to see a doctor to help manage it.

Sometimes severe constipation can be mistaken for diarrhoea. This happens when the bowel is blocked by constipation (hard stools) and loose liquid stool passes around the hard stool. This is called overflow and can look like diarrhoea.

Tell your doctor or nurse if you have diarrhoea. They can investigate the cause and may prescribe anti-diarrhoea medicines.

If your diarrhoea is caused by radiotherapy or chemotherapy, changing your diet is unlikely to help. So it is important to take the anti-diarrhoea medicines prescribed by your doctor. If you have diarrhoea after surgery for bowel cancer, discuss it with your doctor or specialist nurse before changing your diet.

‘I have been careful with my diet, and watching what foods make it worse. I now have a low-fibre diet.’

Lynne
**Tips for coping with diarrhoea**

- Cut down on fibre from cereals, fruit and vegetables.
- Avoid milk and dairy products.
- Drink plenty of fluids, but avoid alcohol and coffee. Also avoid fizzy drinks, which can cause wind and stomach cramps.
- Eat small, frequent meals of light foods. For example, white fish, chicken, eggs (well cooked), white bread, pasta and rice. Avoid highly spiced or fatty foods.
- Eat your meals slowly.
- Tell your doctor if the diarrhoea continues for more than two days. They can find out the cause and may prescribe anti-diarrhoea medicines for you.

**Access to public toilets**

If you have bowel problems, knowing you may need to get to a toilet quickly can make going out a worry.

The National Key Scheme (NKS) allows you to use around 9,000 locked public toilets in the UK. You can buy a key from Disability Rights UK (see page 102). They can also send you details of where the toilets are.

We can also send you a Macmillan Toilet Card, which you can show to people if you need to get to a toilet quickly while you are out. You can order it at be.macmillan.org.uk or call us on 0808 808 00 00.

Our booklet *Eating problems and cancer* also has tips on dealing with constipation and diarrhoea.
Faecal incontinence

Some people with cancer have difficulty controlling their bowels (faecal incontinence). You may have some leakage or be unable to get to the toilet in time. This may be a side effect of treatment or due to the cancer.

You may find this embarrassing and difficult to talk about. But your nurse or doctor will be used to talking to people about incontinence and will be able to support you. They can refer you to a continence specialist for advice, support, and supplies such as pads.

Tips for dealing with faecal incontinence

- Some foods may trigger incontinence, or it may happen 30 to 60 minutes after eating. Keep a diary to help you work out if there is a pattern.
- If you are going out, use the toilet before you go and take clean-up supplies and a change of underwear.
- Get to know where public toilets are when you go out.
- If you are going to the cinema or theatre, book a seat on the end of a row or at the back so you can get out more easily.
- Find out about toilet key and toilet card schemes to help you access toilets when you are out. See page 43 for more information.
**Bladder problems**

You may feel the need to pass urine more often than usual, or have some pain when you pass urine. These symptoms can be caused or made worse by a bladder infection. Let your nurse or doctor know if you have any pain when passing urine, or if your urine is cloudy or smells. A urine sample can be tested and any infection can be treated with antibiotics.

A cancer pressing on or blocking the tube that you pass urine through (urethra) can cause bladder problems. These may include incontinence (not being able to control when you pass urine) 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 or retention. Some types of surgery to the bladder, prostate, bowel or womb can also cause urinary problems.

If you are finding it difficult to pass urine, a nurse may pass a thin, flexible tube (catheter) into your bladder. This drains urine from the bladder. The catheter is connected to a bag which can be attached to your leg. This catheter can stay in place for as long as you need it.

Your nurse may teach you, or your carer if you have one, how to pass a catheter into your bladder to drain it. When your bladder is empty, the catheter is removed. This is called intermittent catheterisation.
Bladder problems are often temporary and improve over weeks or months. Pelvic floor exercises (Kegel exercises) can be helpful if you have urinary problems. These exercises help to retrain the muscles involved in bladder control. A continence nurse can tell you about these.

Your doctor may prescribe drugs to help with urinary problems. If the symptoms don’t improve over several months, sometimes you may be offered surgery to improve your bladder control.
Urinary incontinence

Your doctor can refer you to a specialist continence adviser. A wide range of continence aids is available, such as pads, sheaths and devices to collect urine. Your district nurse or a specialist continence nurse can arrange supplies for you. You may need to pay for these products.

Incontinence can be more difficult to cope with if you have to stay in bed. In this situation, a nurse can put in a catheter. This is a thin, flexible tube which goes into your bladder and drains the urine out into a bag. This can make you more comfortable and help to protect your skin. Your nurse can tell you more about this.

Tips for dealing with bladder problems

• Drink enough water to keep your urine a clear or pale yellow colour.

• Avoid drinks such as tea, coffee, cola and alcohol, as these can cause bladder irritation and may make symptoms worse.

• If you find it difficult to get to a toilet quickly, try to have your bed as close to a toilet as possible. Or you can have a commode, bed pan or urine bottle close by.

• Try to manage constipation, if you have it, as this can make bladder problems worse (see pages 40–41).

• You may feel worried and embarrassed knowing you may need to get to a toilet quickly. There are card and key schemes to help you access toilets when you are out. See page 43 for more information.
SKIN PROBLEMS

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Increased sweating 54
Jaundice 56
Itching

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

Itching may be due to:

- dry skin
- chemicals released by the cancer (especially some cancers of the blood)
- medication (such as the painkillers morphine and diamorphine)
- jaundice (see pages 56–57)
- kidney and liver problems.

Your doctor will try to find the cause of the itch. For some cancers, there are medicines that can help control itching. Or if a drug is causing the itching, your doctor may prescribe a different drug. Itching can be difficult to control, but there are medicines that may help. Your doctor can discuss these with you.

‘I dolloped aqueous cream onto my skin in handfuls, which seemed to keep my skin bearable.’

Bronwen
Tips for 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 water makes the itching worse, have 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.

• Keep your nails clean and short, and rub rather than scratch the itchy area. Avoid things that may irritate your skin, 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 rooms cool.

• Avoid alcoholic drinks and hot, spicy foods.

• Use other activities to try to distract you from the itching. Counselling and relaxation techniques may help (see pages 79 and 86).

Sometimes, transcutaneous electrical nerve stimulation (TENS) can reduce itching. It can stimulate the nerves reaching the brain, and block out the sensation of itching. TENS treatments are offered at some NHS hospitals.
Pressure sores

A pressure sore is damage to the skin and the tissue underneath it. They are also called bedsores or pressure ulcers. Pressure sores can be caused by the weight of your body pressing down on the skin, when you are lying or sitting. Friction from clothing, bedding or your skin being dragged when other people move you can also cause sores.

If you are sitting or lying down for long periods of time, you may have a higher risk of developing a pressure sore. The risk is also higher if you are not managing to eat and drink well, or if you have lost a lot of weight. Some drugs can also increase your risk. These include chemotherapy drugs, steroids and anti-inflammatory drugs.

Check your skin for any red areas or dark patches, or any blisters or breaks in the skin. Make sure you check areas like heels, ankles, elbows and the bottom of your spine. Use a mirror or ask a family member or friend to help check areas that are difficult to see.

Tell your doctor or community or district nurse if you think you have early signs of a pressure sore. They can help to make sure that your skin heals properly. They can also advise you on how to prevent an infection.
**Tips to prevent pressure sores**

- If you spend a lot of time sitting or lying in bed, change your position regularly. Move every half an hour if you can.
- In bed, wear loose, cotton clothes and use pillows to support yourself.
- If possible, stand up for a short time or take a short walk. This is the best way to relieve pressure. A physiotherapist can give you a walking aid to help, 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 is still important to change position regularly when using these. A bed cradle can help keep the weight of bedding off your legs and feet.Organisations that can provide equipment are listed on pages 101–102.
- Treat dry skin using the tips on page 51.
Increased sweating

Sweating helps to keep our temperature normal. Some people with cancer have episodes of increased sweating. When this is severe, it can be very uncomfortable. There are different causes, including the cancer itself and some medicines. The treatment will depend on the cause.

Sometimes you may sweat because you have a high temperature (fever). This is a common sign of infection. If you think you may have an infection, contact your doctor straight away. It is very important to do this if you have recently had chemotherapy. Follow the advice given by your chemotherapy team.

Some people have night sweats caused by the menopause or as a side effect of hormonal therapies. We can send you more information about menopausal symptoms and hormonal therapies.

If your sweating is due to the cancer itself, there are drugs that can be used to treat it. These include steroids, amitriptyline and cimetidine.
Tips to help you cope with increased sweating

• 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.
• If you have night sweats, keep a sponge or flannel and some cool water by your bed.
• Use light cotton bedding and put a large cotton towel on the bed under you. This will absorb any sweat and can be removed easily so you don’t have to change the bedding.
• Avoid things that may trigger sweats. For example, some people find sweats are made worse by drinking alcohol, tea or coffee or eating spicy food.
• Your body loses fluid through sweating, so try to drink a bit more.
Managing the symptoms of cancer

Jaundice

Jaundice can occur if your bile duct becomes blocked. The bile duct drains bile from the liver and gall bladder into the bowel. You can also become jaundiced if there is 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.
If jaundice is caused by an infection, antibiotics may help. If it is caused by a tumour, your doctors may recommend treatment to remove or shrink the cancer. They may suggest putting in a stent, which is a small tube that holds the bile duct open. Your doctor or nurse will explain more about this.

Some people may have surgery to relieve the blockage by bypassing the bile duct. Surgery is only suitable for some people. Your doctor can tell you more about this. If it is possible to unblock the bile duct, your symptoms should begin to improve. But sometimes, it is not possible and symptoms will continue.

Itchy skin can often be the most difficult symptom of jaundice. Your doctor can prescribe medicines to help with this. You can find tips for dealing with itching on page 51.

‘The stent provided great relief after over a week of being very uncomfortable with the jaundice. The jaundice starts to fade over maybe 48 hours. I was able to be up and about, and get a break from the hospital and feeling unwell. So yes, I would say a stent is a marvellous thing.’

Steve
FLUID BUILD-UP

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Ascites 63
Swollen legs and ankles

Sometimes fluid can build up in your legs and ankles, which causes swelling (oedema). There can be several reasons for this, including being unable to move about as much as usual.

If you develop swollen legs or ankles, your doctor may prescribe water tablets (diuretics) to help reduce the swelling. In some cases, your doctor, nurse or physiotherapist may give you pressure stockings to help the circulation in your legs.

If you have swelling in only one leg or ankle and it 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 straight away if you develop any of these symptoms. A blood clot is serious but can be treated. Your doctor or nurse can give you more information about this.

Tips if you have swollen legs and ankles

• Use a footstool to keep your feet up when sitting down.
• Gently exercise your legs while you are sitting. A nurse or physiotherapist can show you some exercises to do.
Lymphoedema

Lymphoedema is swelling caused by a build-up of fluid called lymph in the body tissues. It usually affects an arm or a leg, but can affect other parts of the body.

This can happen if lymph nodes are removed or damaged by cancer treatment, or if a cancer is blocking them. Lymph nodes are part of the lymphatic system. This is part of the body’s immune system that helps us fight infections and other illnesses.

If you are affected, you will usually be referred to a lymphoedema specialist. They can offer advice on treatments and things you can do, including:

• skincare to prevent injury and infection
• positioning the limb and movement to help drain fluid
• 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 has built up.

There is more information and advice in our booklet Understanding lymphoedema.
Ascites

Some types of cancer can cause a build-up of fluid in the tummy (abdomen). This is called ascites. Your tummy becomes swollen and distended, which can be uncomfortable or painful. Other symptoms include:

• tightness across your tummy
• unexplained weight gain
• feeling breathless
• feeling sick (nausea)
• a reduced appetite.

Your doctors may treat ascites by inserting a small tube into your tummy to drain off the fluid. This is usually done in hospital under a local anaesthetic. The fluid can be drained as often as necessary. Sometimes a permanent drain is needed.

Your doctors may prescribe water tablets (diuretics) to try to stop or slow down fluid build-up. Sometimes chemotherapy treatment can prevent the fluid coming back.

We can send you more detailed information about ascites. We also have information about ascites on our website (macmillan.org.uk).
EMOTIONAL EFFECTS OF CANCER

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Anxiety

Many people feel anxious after they have been diagnosed with cancer. This is natural. 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.

You may feel anxious all the time, or it may come and go. Your feelings can vary in how severe they are and how they are affecting you. Anxiety may cause physical symptoms, such as:

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

When anxiety levels are high, the symptoms can be difficult to control and you may feel that you are having a panic attack.

It can be easy to confuse the symptoms of cancer, or treatment side effects, with the symptoms of anxiety. Being anxious as well as having cancer can also make your symptoms worse. Your doctor can help you work out if anxiety is causing your symptoms, and they may prescribe medication to help.
Understanding the reason for your symptoms can be reassuring. But if you’re still very anxious, try talking to your nurse or doctor. Some people find it helpful to see a counsellor. Some of the organisations listed on page 97 offer counselling and psychotherapy.

These feelings are very common, so don’t be embarrassed to discuss them or check if your fears and concerns are justified.

**Tips for dealing with anxiety**

- Learn how to relax. Breathing exercises, relaxation techniques, yoga or Pilates can all help you manage anxiety.

- Alcohol and smoking can make anxiety worse. It is best to limit how much alcohol you drink and have one or two alcohol-free days each week. If you smoke, try to give up or cut down.

- You may find it helpful to join a support group or online community. You can visit Macmillan’s online community at [macmillan.org.uk/community](http://macmillan.org.uk/community)
Depression

Some people become depressed as a result of having cancer, coping with symptoms and worrying about the future. 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:

- having a very low mood most of the time
- getting little pleasure out of things you usually enjoy
- having problems sleeping
- a lack of energy
- difficulty concentrating.

The first step to feeling better is getting 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 sort out your feelings about what is happening in your life. Trained counsellors, clinical psychologists and psychiatrists all deal with talking therapies. For some people, they can be as effective as anti-depressants or sedatives. Your GP or nurse can tell you about these therapies.
Medicines for depression

Your doctor may prescribe an anti-depressant to help lift your mood. Anti-depressants are thought to work by affecting certain chemicals in 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 *How are you feeling? The emotional effects of cancer*. It has helpful tips on dealing with the feelings and emotions that cancer can cause. Call us on 0808 808 00 00 or visit be.macmillan.org.uk to order a free copy.

‘I think one of the biggest fears that we have to live with is the fear of the cancer returning. I had counselling after my first lot of treatment because I was feeling bewildered and abandoned.’

Edina
WAYS TO MANAGE SYMPTOMS

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Cancer treatments for symptom control 75
Complementary therapies 79
Other things you can do to help yourself 80
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Practical support 87
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**Medicines**

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

They can be taken in different ways. Many are taken as tablets or capsules. Liquid forms of many drugs are available for people who find tablets hard to swallow. Other ways of taking medicines include injections, suppositories (which are inserted into the back passage) and skin patches. If you are finding medicines difficult to take, speak to your doctor, nurse or pharmacist. There may be another way to take them.

You can buy some medicines over the counter, but always ask your doctor or pharmacist for advice first. It will help the pharmacist if you take a list of any other medicines you are taking. If a medicine you have bought hasn’t improved your symptoms within one to two weeks, you should see your GP or cancer specialist.

**Taking your medicines**

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

- the drug names
- what they do
- the 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 use a pill organiser or to have your medicines dispensed in a calendar blister pack. Your doctor, nurse and pharmacist can explain more about these.

Calendar blister packs come pre-prepared by the pharmacy and include the day and time when the medicine should be taken. Talk to your doctor or pharmacist if you think that a pill organiser or calendar blister pack will be helpful for you.

If you find it hard to remember to take your medicines several times a day, talk to your doctor. There may be other forms of the drug that have the same effect but don’t need to be taken so often.
Keeping a symptom diary

You may find it useful to keep a diary of how well your symptoms are being controlled. We have included a symptom diary on the opposite page that you can pull out and use. This can also help your medical team. For example, they will be able to see if 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 use the full diary, just note if your symptoms come back before your next dose of medicine is due. Also keep note if you need to take extra doses. You could use pages 104–105 for this.

If you find that your symptoms are difficult to treat, your doctor may refer you to a specialist who deals with symptom control.
Cancer treatments for symptom control

If your symptoms are caused by a tumour, then cancer treatments may help to relieve them.

You may be offered radiotherapy, chemotherapy, surgery, hormonal therapy or targeted (biological) therapy, or a combination of treatments.

We have more information we can send you about these treatments.

Radiotherapy

Radiotherapy is sometimes used to reduce the size of a tumour and relieve symptoms.

Radiotherapy can increase symptoms slightly at first, before it starts to reduce them. You should take other medicines to control your symptoms until they improve. The effect on your symptoms will depend on which part of the body is being treated. Your doctor will discuss the likely side effects and benefits of radiotherapy with you.
How to use your symptom diary

You may want to pull out this symptom diary and photocopy it, so you can use it more than once.

1. Write down the **date and time** when you have the symptom. You can do this as often as you need to.

2. Write down **where** each symptom is in your body. You can use the diagrams on the back page of the diary. It could be in one area or different areas.

3. Describe what each symptom **feels like**. You could use the words on the back page of the diary to help you. Or you can use your own words.

4. Rate each symptom from **0 to 10**, where 0 means no symptom and 10 means severe (see the back page of the diary).

5. Write down anything that makes the symptom **better**.

All this information will help you, your doctors and your nurses find the best way to manage your symptoms.

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.

How would you describe the symptom?

You can use these words, or your own words, to describe your symptom:

- aching
- throbbing
- pricking
- painful
- uncomfortable
- comes and goes
- constant
- tiring
- exhausting
- bloated
- sweaty
- dry
- hot
- burning
- tight
- tickly
- scratchy
- embarrassing
- frustrating
- irritating
- worrying

Rate the symptom

If you measured it on a scale of 0 to 10, how would you rate it? (Where 0 = no symptom and 10 = the symptom is severe.)
If you keep a record of your symptoms, this can help when you talk about them with your doctors and nurses. Photocopy this diary before you fill it in so that you can use it as often as you need to.

<table>
<thead>
<tr>
<th>Date and time</th>
<th>Where is the symptom?</th>
<th>What is the symptom?</th>
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<th>What helps with it?</th>
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Chemotherapy

Chemotherapy can reduce the size of tumours, which will help control and improve symptoms. But chemotherapy doesn’t work for everyone and it may cause side effects that are difficult to deal with. Your cancer 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. This can help you to decide if chemotherapy would be right for you.

Surgery

Surgery can remove all or part of a tumour to relieve symptoms. For example, a surgeon can remove part of a tumour in an airway to help make it easier to breathe. Sometimes surgeons use lasers to destroy part of a tumour.

Hormonal therapy

Some types of cancer need particular hormones to grow. Hormonal therapies can reduce the hormone levels or stop the hormones from attaching to the cancer cells. There are different types of hormonal therapy and the side effects of each vary. You can ask your doctor how likely the treatment is to work for you and what the possible side effects are.
Targeted (biological) therapy

Targeted (biological) therapy may sometimes be used to help control certain types of cancer. Targeted therapies work by changing the way that cells interact with or signal to each other. Your doctor can give you more information.

Making decisions

Making decisions about having treatment to control symptoms 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 what is best for you. You can discuss these issues with our cancer support specialists by calling us free on 0808 808 00 00. One of the support organisations listed on pages 98–100 may also be able to help.

Our booklet Making treatment decisions has helpful advice about how to make a decision about your treatment. Call us on 0808 808 00 00 or visit be.macmillan.org.uk to order a free copy.
Complementary therapies can be used on their own or in combination with medicines and cancer treatments. Complementary therapies can include:

- acupuncture
- homeopathy
- relaxation techniques
- massage
- aromatherapy
- reflexology
- meditation
- visualisation
- hypnotherapy.

Complementary therapies may be available at your hospital, hospice or through your GP practice. Some cancer support groups offer therapies.

Talk to your doctor or nurse and ask for their advice before starting any of these therapies. Don’t be misled by promises of cures. No reputable therapist would claim to be able to cure cancer. You should always tell your therapist that you have cancer.

Our booklet **Cancer and complementary therapies** has more information about these therapies.
Other things you can do to help yourself

There are a lot of things that you and other people can do to help you feel better.

Keeping busy

Watching TV, listening to music or chatting to a friend will not make your symptoms go away. But keeping busy can help distract you, at least for a time.

Try to keep your social life active by staying in touch with friends and family. If you are feeling low, you may feel like avoiding other people. Try to do things that you enjoy, such as going for a walk or meeting someone for a coffee. Going out or having visitors can raise your spirits and help you cope better with symptoms. Short, regular visits from family and friends are probably better than longer ones. They are less tiring, they help to break up the day and are something to look forward to. If people are not able to visit you in person, they can keep in touch with calls, texts or emails.
Talking about your feelings

Anxiety and depression can make some symptoms worse (see page 34). It can help to talk about your worries and fears with people you are close to.

It is natural to feel a range of powerful emotions when you have cancer. Talking about your feelings with your partner, a family member or a close friend can be very helpful. But sometimes it can be too upsetting. If you don’t feel able to talk to them, you could talk to someone from your local palliative care service (see pages 83–85) or your specialist nurse. You could also ask your GP or cancer specialist to put you in touch with a counsellor. One of the organisations at the back of this booklet may be able to help (see pages 97–100).

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 is a support group in your area. Or you can visit our online community at macmillan.org.uk/community Here you can chat with other people who have cancer, or just read through the posts or blogs other people have written.

We also have a booklet called How are you feeling? The emotional effects of cancer that you may find helpful.
Religion and spirituality

Serious illness leads some people to think carefully about 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. It may help them to talk to a local minister, a 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 ([humanism.org.uk](http://humanism.org.uk)) runs local groups and provides information for people who are not religious.
Who can help?

There are many people who can help you and your family cope with the symptoms of cancer. There are doctors, nurses and other healthcare professionals who specialise in palliative care or supportive care. They are based in hospitals, hospices and palliative care units. There are also home care teams who can visit you in your home. They can make sure that your symptoms are controlled and that you have help and support.

Care in your own home

When you are at home, your GP and district nurse will be responsible for your day-to-day care. In many areas of the country, there are specialist nurses called palliative care nurses. They can offer you support from when you are diagnosed with cancer. These nurses can visit you at home and support you and your family. They are experienced in assessing and treating your symptoms. Many palliative care nurses are linked to the local hospice (see page 85).

Palliative care nurses are sometimes referred to as Macmillan nurses. Some Macmillan professionals are nurses who have specialist knowledge about a particular type of cancer. You may see them at a clinic or in hospital.

Some Marie Curie nurses help to care for people who want to stay in their own homes (see page 99). They can 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 are in hospital or visiting an outpatient clinic, your doctor or nurse can arrange for someone from the palliative care team to talk to you.

You can also discuss your concerns with your clinical nurse specialist (CNS) or key worker. They offer ongoing support.

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 managing pain. Your GP or hospital doctor can refer you to a pain clinic.
Care in hospices and palliative care units

Hospices and palliative care units specialise in helping people with cancer and other life-limiting illnesses. They can help anyone with cancer, not just those who are dying or who are seriously ill.

The care is free. Hospices and units are run by independent charities or by Marie Curie. Others are run by local NHS and Health and Social Care Services. These units provide a variety of care:

- **Inpatient care** is when you stay in the hospice or unit for a few days or weeks to have your symptoms controlled. If you have carers, short stays can sometimes be organised to give them a break (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 the chance to meet with others who may be in a similar situation. Day care can also give your family, or your carers if you have them, some time for themselves.

- **Outpatient clinics** are for people who are able to travel from home to 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
Physiotherapists can help you with breathing and mobility problems. They can offer expert advice about gentle exercise and relaxation techniques. They can also help you think about new ways of doing day-to-day activities that may be causing you difficulty.

Occupational therapists (OTs)
OTs 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 give you gadgets that can make everyday life easier to manage.

Social workers
Social workers can give you information about social services and benefits you may be able to claim. For example, you may be entitled to Meals on Wheels, help at home, or help with hospital travel and parking costs.

Counsellors
Trained counsellors, clinical psychologists and psychiatrists can offer counselling or talking therapies to help you express your emotions and sort out your feelings about what is happening in your life. Your GP or nurse can tell you about these therapies.
Practical support

If your symptoms are causing any kind of disability, there are organisations which can provide equipment to help you.

Social services can often provide aids to help with your day-to-day life, such as handrails and ramps for your home.

The Disabled Living Foundation (see page 101) 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 also has showrooms with specialist equipment on display, including special cutlery, walking aids and wheelchairs.

The British Red Cross (see page 101) 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.

There are many volunteer schemes available in the UK. They can arrange for someone to visit your home to give you some company and give your carer a break. Ask your GP or nurse if there are any of these schemes in your area. Local information may be displayed on notice boards in your GP surgery, local library, community centre or church.
Holistic needs assessment

As part of your care, you should be given the opportunity to talk about any concerns you have about how the cancer has affected your life.

In some hospitals, this is called a holistic needs assessment (HNA). It asks about emotions, practical issues and relationships. This is a good time for you to think about all aspects of your life.

Your specialist nurse may write a care plan based on this assessment. This should give information about the support you are getting and other services that may be useful. Usually you get a copy of the care plan to take home.

There is more information about holistic needs assessments in our leaflet Planning your care and support: Having a holistic needs assessment.
About our information

We provide expert, up-to-date information about cancer. And all our information is free for everyone.

Order what you need

You may want to order more leaflets or booklets like this one. Visit be.macmillan.org.uk or call us on 0808 808 00 00.

We have booklets on different cancer types, treatments and side effects. We also have information about work, financial issues, diet, life after cancer and information for carers, family and friends.

All of our information is also available online at macmillan.org.uk/cancerinformation There you’ll also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

We also provide information in different languages and formats, including:

• audiobooks
• Braille
• British Sign Language
• Easy Read booklets
• ebooks
• large print
• translations.

Find out more at macmillan.org.uk/otherformats
If you’d like us to produce information in a different format for you, email us at cancerinformationteam@macmillan.org.uk or call us on 0808 808 00 00.
Help us improve our information

We know that the people who use our information are the real experts. That’s why we always involve them in our work. If you’ve been affected by cancer, you can help us improve our information.

We give you the chance to comment on a variety of information including booklets, leaflets and fact sheets.

If you’d like to hear more about becoming a reviewer, email reviewing@macmillan.org.uk You can get involved from home whenever you like, and we don’t ask for any special skills – just an interest in our cancer information.
Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we’re here to support you. No one should face cancer alone.

Talk to us

If you or someone you know is affected by cancer, talking about how you feel and sharing your concerns can really help.

Macmillan Support Line
Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

- help with any medical questions you have about your cancer or treatment
- help you access benefits and give you financial guidance
- be there to listen if you need someone to talk to
- tell you about services that can help you in your area.

Call us on 0808 808 00 00 or email us via our website, macmillan.org.uk/talktous

Information centres
Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face.

Visit one to get the information you need, or if you’d like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at macmillan.org.uk/informationcentres or call us on 0808 808 00 00.
Talk to others

No one knows more about the impact cancer can have on your life than those who have been through it themselves. That’s why we help to bring people together in their communities and online.

Support groups
Whether you are someone living with cancer or a carer, we can help you find support in your local area, so you can speak face to face with people who understand. Find out about support groups in your area by calling us or by visiting macmillan.org.uk/selfhelpandsupport

Online community
Thousands of people use our online community to make friends, blog about their experiences and join groups to meet other people going through the same things. You can access it any time of day or night. Share your experiences, ask questions, or just read through people’s posts at macmillan.org.uk/community

The Macmillan healthcare team
Our nurses, doctors and other health and social care professionals give expert care and support to individuals and their families. Call us or ask your GP, consultant, district nurse or hospital ward sister if there are any Macmillan professionals near you.

‘Everyone is so supportive on the online community, they know exactly what you’re going through. It can be fun too. It’s not all just chats about cancer.’

Mal
Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you’ve been affected in this way, we can help.

Financial guidance
Our financial team can give you guidance on mortgages, pensions, insurance, borrowing and savings.

Help accessing benefits
Our benefits advisers can offer advice and information on benefits, tax credits, grants and loans. They can help you work out what financial help you could be entitled to. They can also help you complete your forms and apply for benefits.

Macmillan Grants
Macmillan offers one-off payments to people with cancer. A grant can be for anything from heating bills or extra clothing to a much-needed break.

Call us on 0808 808 00 00 to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit macmillan.org.uk/financialsupport to find out more about how we can help you with your finances.

Help with work and cancer

Whether you’re an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit macmillan.org.uk/work

Macmillan’s My Organiser app
This free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search ‘My Organiser’ on the Apple App Store or Google Play on your phone.
Other useful organisations

There are lots of other organisations that can give you information or support.

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
BACP House,
15 St John’s Business Park,
Lutterworth,
Leicestershire LE17 4HB
Tel 01455 883 300
Email bacp@bacp.co.uk
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at itsgoodtotalk.org.uk

UK Council for Psychotherapy (UKCP)
2nd Floor,
Edward House,
2 Wakley Street,
London EC1V 7LT
Tel 020 7014 9955
Email info@ukcp.org.uk
www.psychotherapy.org.uk

Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Youth Access
1–2 Taylors Yard,
67 Alderbrook Road,
London SW12 8AD
Tel 020 8772 9900
(Mon–Fri, 9.30am–1pm and 2pm–5.30pm)
Email admin@youthaccess.org.uk
www.youthaccess.org.uk
A national organisation providing counselling and information for young people. Support is given through local young people’s services. Find your local service by visiting www.youthaccess.org.uk/find-your-local-service
Cancer information and support

Cancer Black Care
79 Acton Lane,
London NW10 8UT
Tel 020 8961 4151
Email info@cancerblackcare.org.uk
www.cancerblackcare.org.uk
Offers information and support for people with cancer from ethnic communities, their friends, carers and families.

Cancer Focus
Northern Ireland
40–44 Eglantine Avenue,
Belfast BT9 6DX
Helpline 0800 783 3339
(Mon–Fri, 9am–1pm)
Email helpline@cancerfocusni.org
www.cancerfocusni.org
Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK
Angel Building,
407 St John Street,
London EC1V 4AD
Helpline 0808 800 4040
(Mon–Fri, 9am–5pm)
www.cancerresearchuk.org
Has patient information on all types of cancer. Also has a clinical trials database.

Cancer Support Scotland
Cancer Support Scotland Centre,
75 Shelley Road,
Glasgow G12 0ZE
Tel 0800 652 4531
(Mon–Fri, 9am–5pm)
Email info@cancersupportscotland.org
www.cancersupportscotland.org
Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.
Irish Cancer Society
43–45 Northumberland Road,
Dublin 4, Ireland
Tel 1800 200 700
(Mon–Thu, 9am–7pm,
Fri, 9am–5pm)
Email helpline@irishcancer.ie
www.cancer.ie
National cancer charity offering
information, support and care
to people affected by cancer.
Has a helpline staffed by
specialist cancer nurses.

Maggie’s Centres
The Gatehouse,
10 Dumbarton Road,
Glasgow G11 6PA
Tel 0300 123 1801
Email enquiries@maggiescentres.org
www.maggiescentres.org
Has a network of centres in
various locations throughout
the UK. Provides free
information about cancer and
financial benefits. Also offers
emotional and social support to
people with cancer, their family,
and friends.

Marie Curie
89 Albert Embankment,
London SE1 7TP
Helpline 0800 090 2309
(Mon–Fri, 8am–6pm,
Sat, 11am–5pm)
www.mariecurie.org.uk
Marie Curie nurses provide free
end-of-life care to people in
their own homes, or in Marie
Curie hospices, 24 hours a day,
365 days a year.

Penny Brohn UK
Chapel Pill Lane, Pill,
Bristol BS20 0HH
Helpline 0303 3000 118
(Mon–Fri, 9.30am–5pm)
Email helpline@pennybrohn.org.uk
www.pennybrohn.org.uk
Offers a combination of
physical, emotional and
spiritual support, using
complementary therapies
and self-help techniques.
Tenovus
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD
Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)
Email info@tenovuscancercare.org.uk
www.tenovuscancercare.org.uk
Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an ‘Ask the nurse’ service on the website and benefits advice.

Cancer registries

The cancer registry
A national database that collects information on cancer diagnoses and treatment. This information helps the NHS and other organisations plan and improve health and care services. There is one in each country in the UK:

National Cancer Registration Service
Public Health England,
Wellington House,
London SWE1 8UG
Tel 020 7654 8000
Email enquiries@phe.gov.uk
www.ncr.nhs.uk

Northern Ireland Cancer Registry
Centre for Public Health,
School of Medicine,
Dentistry & Biomedical Sciences,
Queen’s University Belfast,
Mulhouse Building,
Grosvenor Road,
Belfast BT12 6DP
Tel 028 9097 6028
Email nicr@qub.ac.uk
www.qub.ac.uk/nicr

Scottish Cancer Registry
NHS Information Services,
Gyle Square,
1 South Gyle Crescent,
Edinburgh EH12 9EB
Tel 0131 275 7777
Email nss.csd@nhs.net
www.isdscotland.org/
Health-Topics/Cancer/
Scottish-Cancer-Registry
Welsh Cancer Intelligence and Surveillance Unit (WCISU)
Public Health Wales NHS Trust,
3rd Floor, 16 Cathedral Road,
Cardiff CF11 9LJ
Tel 02920 373500
Email general.enquiries@wales.nhs.uk
www.wcisu.wales.nhs.uk

Equipment and advice on living with a disability

The Blue Badge Scheme (Department for Transport)
www.gov.uk/browse/driving/blue-badge-parking
Contact your local authority for more details. The scheme allows drivers or passengers with severe mobility problems to park close to where they need to go. The scheme is managed by local authorities, which deal with applications and issue badges. Applications can be made through the website and are sent to your local authority to be assessed.

British Red Cross
UK Office,
44 Moorfields,
London EC2Y 9AL
Tel 0344 871 11 11
Email information@redcross.org.uk
www.redcross.org.uk
Offers a range of health and social care services such as care in the home, a medical equipment loan service and a transport service.

Disabled Living Foundation (DLF)
Unit 1,
34 Chatfield Road,
Wandsworth,
London SW11 3SE
Helpline 0300 999 0004
(Mon–Fri, 10am–4pm)
Email helpline@dlf.org.uk
www.dlf.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.
Managing the symptoms of cancer

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

Disability Rights UK
Ground Floor,
CAN Mezzanine,
49–51 East Road,
London N1 6AH
Tel 0207 250 8181
(Mon–Fri, 10am–12:30pm and 1.30pm–4pm)
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights. Has a number of helplines for specific support, including information on returning to work, direct payments, human rights issues, and advice for disabled students.

Scope
6 Market Road,
London N7 9PW
Helpline 0808 800 3333
(Mon–Fri, 9am–5pm)
Email helpline@scope.org.uk
www.scope.org.uk
Offers confidential advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

Support for older people

Age UK
Tavis House,
1–6 Tavistock Square,
London WC1H 9NA
Helpline (England and Wales) 0800 169 2081
Helpline (Scotland) 0800 470 8090
Helpline (Northern Ireland) 0808 808 7575
www.ageuk.org.uk
Provides information and advice for older people across the UK via the website and advice line. Also publishes impartial and informative fact sheets and advice guides.
Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support’s Cancer Information Development team. It has been approved by Dr Tim Iveson, Macmillan Chief Medical Editor.

With thanks to: Sandra Campbell, Macmillan Nurse Consultant for Cancer and Palliative Care; Dr Jackie Dominey, Macmillan GP Adviser; Anna-Marie Stevens, Macmillan Nurse Consultant – Palliative Care; Dr Jayne McAuley, Consultant in Palliative Care; and Dr Adrian Tookman, Consultant in Palliative Care. Thanks also to the people affected by cancer who reviewed this edition.

Sources

We’ve listed a sample of the sources used in this publication below. If you’d like further information about the sources we use, please contact us at bookletfeedback@macmillan.org.uk

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.

5 ways you can help someone with cancer

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

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

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

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

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

Call us to find out more
0300 1000 200
macmillan.org.uk/getinvolved
Please fill in your personal details

Mr/Mrs/Miss/Other
Name
Surname
Address

Postcode
Phone
Email

Please accept my gift of £

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

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

Card number

Valid from Expiry date

Issue no Security number

Signature

Date / /

Don’t let the taxman keep your money

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

☐ I am a UK tax payer and I would like Macmillan Cancer Support to treat all donations I make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

I understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. I understand Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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

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

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Macmillan Cancer Support, FREEPOST LON15851, 89 Albert Embankment, London SE1 7UQ
This booklet is about some of the symptoms you may have if you have cancer. It describes ways to help manage them.

You may have one or more of these symptoms, but you’re unlikely to have more than a few. Most symptoms can be well controlled with the help of your healthcare team, your family and your friends.

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on 0808 808 00 00, Monday to Friday, 9am to 8pm, or visit macmillan.org.uk

Would you prefer to speak to us in another language? Interpreters are available. Please tell us in English the language you would like to use. Are you deaf or hard of hearing? Call us using NGT (Text Relay) on 18001 0808 808 00 00, or use the NGT Lite app.

Need information in different languages or formats? We produce information in audio, eBooks, easy read, Braille, large print and translations. To order these visit macmillan.org.uk/otherformats or call our support line.