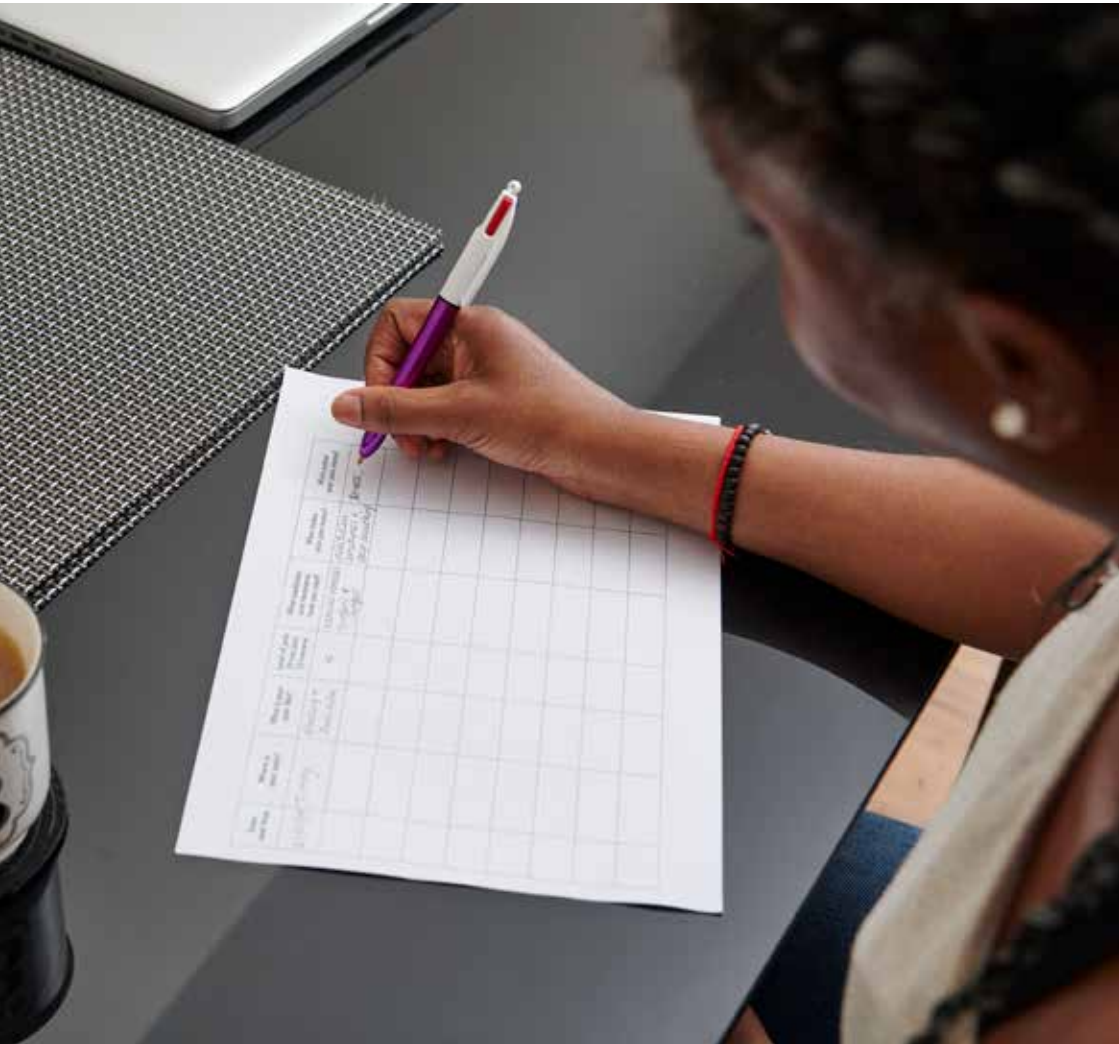


Managing the symptoms of cancer



About this booklet

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

The booklet describes some of the symptoms you may have, but you are unlikely to have more than a few of them. Talk to your doctor or nurse about your symptoms. They can arrange for any help and treatment you need. Most symptoms can be controlled with the help of your healthcare team, family and friends.

Some symptoms may only happen with certain cancers. You may want to read this booklet alongside our information about the type of cancer you have.

Some symptoms may be caused by treatments for cancer. We have separate information about side effects in our booklet **Side effects of cancer treatment** (see page 102).

We hope this booklet helps you deal with some of the questions or feelings you may have. If you find this booklet helpful, you may want to share it with family or friends.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list on page 3 to help you. It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

On pages 106 to 108, there are details of other organisations that can help. There is also space to write down questions and notes for your doctor or nurse (see page 109).

Quotes

In this booklet, we have included quotes from people who have been affected by cancer, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)) and the website [healthtalk.org](https://www.healthtalk.org). The others are from people who have chosen to share their story with us. The names may have been changed. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit [macmillan.org.uk](https://www.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](https://www.macmillan.org.uk/otherformats) or call **0808 808 00 00**.

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TIREDNESS AND SLEEP PROBLEMS

Tiredness (fatigue)

6

Sleep problems

10

Tiredness (fatigue)

Fatigue means feeling very tired or exhausted all or most of the time. It is a common symptom for people with cancer. You may feel tired due to the cancer or its treatment. But, there are symptoms that can also cause tiredness, including:

- pain
- being short of breath
- having a low red blood cell count (anaemia).

The effects of tiredness vary from person to person. Tell your cancer doctor or nurse if you are feeling very tired. Think about how fatigue is affecting you, and how much rest you need. This will help you work out what makes your tiredness better or worse.

Some causes of tiredness can be treated. For example, there are things that can help if you are not sleeping well are not eating enough or if you are anaemic.

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.

You might find our booklet **Coping with fatigue (tiredness)** helpful (see page 102). It is also available as an audiobook online, if you find listening easier than reading when you are tired. Visit macmillan.org.uk/fatigueaudio





What you can do

- Spread tasks out over the week. If you have a big task, break it down into smaller, easier ones.
- Try to plan your day so that you have energy to do the things you want to do most. For example, you may want to do tasks in the morning if this is when you feel less tired.
- Ask for help with childcare, housekeeping, shopping and preparing meals.
- 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 life easier. This might include having your bedroom as close to the toilet as possible. Or, you could arrange your kitchen to make preparing meals easier. An occupational therapist (OT) can help you plan this and provide gadgets to make things easier.
- Do your shopping online and have it delivered.
- Listen to audiobooks if you are too tired to read.
- If you work, talk to your employer or human resources (HR) department and tell them that you may need time off. Or ask your employer about ways of making adjustments so your work less tiring.
- Try to keep active. Research has shown that being active and doing some gentle exercise can help with tiredness. Without regular activity, our muscles get weak and tiredness gets worse.

We have more information in our booklets **Coping with fatigue (tiredness)**, **Physical activity and cancer** and **Work and cancer** (see page 102).

Physical activity

Do physical activity at your own pace. If you are very tired, start slowly. Start with activities such as going for a short walk or doing simple strengthening exercises like standing up and sitting down.

Your doctor, nurse, OT or physiotherapist can advise you about which type of exercise and how much would be helpful for you.

I find with fatigue that it's best not to battle it. So I might have one day of exercise and being busy, followed by one day of relaxation – doing hobbies, seeing a friend or snoozing!

Lorna

Sleep problems

Many people with cancer have problems with sleeping at some point. There can be for different reasons, including anxiety (see pages 72 to 73) or symptoms such as pain (see pages 14 to 17) or breathlessness (see pages 36 to 39). 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 feel better after a short nap during the day. But too much sleep during the day can cause problems sleeping later. Try to only have one or two short naps each day. If possible, avoid sleeping in the late afternoon or evening.

Some medicines, such as steroids, can affect your sleep. 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 70 to 77). Talking about your worries and concerns may be helpful. Some people find counselling or relaxation therapy helps. We have information about counselling services on page 107.

Sometimes a short course of sleeping pills can help you have a regular sleeping pattern, or help you through a difficult time. They are best taken before you go to bed, rather than in the middle of the night.

What you can do

- Go to bed and get up at about the same time every day. Staying in bed after a sleepless night can affect your sleep patterns.
- If you can, 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 affect your sleep.
- Have a relaxing routine before going to bed. For example, you could have a warm bath or shower, read or listen to soothing music before bed.
- Make your bedroom a relaxing place to be. Create an area that is dark, quiet and comfortable but not too warm.
- If you cannot sleep, it can help to get up and go to another room until you feel tired again. If you find that worries are keeping you awake, write them down. You can then speak to someone about them later.

PAIN

Pain management

14



Pain management

Cancer can cause pain for many reasons. The cancer may:

- press on body tissue, a bone or nerve
- stop parts of the body from working normally, such as a blockage in the bowel.

Sometimes treatment for the cancer can help reduce the pain.

Not all pain is due to the cancer. People with cancer can also have pain for other reasons. For example, you may have muscle weakness which can cause joint pain. It is important to talk to your doctor or nurse about any pain you have.

You may hear pain described in different ways, depending on how long you have had it and where it is in your body:

- Acute pain starts suddenly and is usually managed by treating the cause, such as removing a blockage or treating an infection.
- Chronic pain last longer and may be caused by the cancer itself or the longer-term effects of treatment.

Pain can affect your everyday life, but it can be managed.

Describing your pain will help your doctors and nurses find the best way of treating it. You might find using a pain diary helpful.

You can download and print a copy of a pain diary from our website at [macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/pain](https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/pain)

There are many people that can help with pain management.

Physiotherapists or occupational therapists can help with practical things such as providing equipment to help make you comfortable. A counsellor or psychologist can help you manage emotions that may be making your pain worse.

Specialist palliative care doctors and nurses are experts in helping people who are in pain. Specialist palliative care teams are found in hospitals, hospices and the community. Sometimes it can help to spend a short time in a hospice to have your pain treated.

Pain is usually treated with painkillers. You can have painkillers as:

- tablets or capsules
- liquids
- nasal sprays
- skin patches or gels
- suppositories into the back passage
- injections.

You may only need to take painkillers when you have pain. But some people need to have painkillers at regular times to keep their pain controlled.

Once your doctors and nurses have assessed your pain, they will prescribe the best painkillers to help control it. They may also prescribe other medicines to take with the painkillers. These can further reduce pain or help with the side effects of the painkillers.

We have more information you may find helpful in our booklet **Managing cancer pain** (see page 102).

What you can do

- Talking about the pain can make coping with it easier. You could talk to a partner, friend or family member. You can also talk to your healthcare team, GP or palliative care nurse
- Watching TV, reading, listening to music or short visits from friends and family can all help distract you for a while.
- It may also help to be as physically active as you can, with help if needed.

You may find our booklet **Physical activity and cancer** helpful for more ideas around getting active (see page 102).





MOUTH AND EATING PROBLEMS

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Poor appetite

Some types of cancer can cause you to have a poor appetite, or to feel full soon after starting a meal.

Talk to your doctor or nurse if you have problems with your diet or appetite. They can refer you to a dietitian. If you are not in hospital, your GP or district nurse can refer you to a community dietitian. They can visit you at home.

Dietitians can review your diet and your dietary requirements. They can advise you on which foods are best for you, and whether any food supplements would be helpful.

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.

If you can, ask your family and friends to help with cooking. This means that you are not too tired to eat by the time your meal is ready. A community or district nurse or a social worker can talk to you about getting meals delivered or getting help preparing food.

What you can do

- Eat small amounts often instead of three big meals a day.
- Keep snacks handy, such as bags of nuts or dried fruit, or a bowl of grated cheese. These are high-calorie (energy) foods. If these are hard for you to swallow, try yoghurt or ice cream.
- If you have lost weight, add extra calories to your food. You can add calories with butter, full-fat milk and cream.
- Try a nourishing drink, such as a fruit smoothie or milkshake. You can add ice cream to these for extra calories.
- Talk to a dietitian about food supplements. Your dietitian or GP can prescribe these.



Feeling sick (nausea)

Some cancers can make you feel sick (nausea) and be sick (vomit). Sickness can also be caused by:

- pain
- some stomach problems
- some cancer treatments
- raised calcium levels or other chemical imbalances.

It is important that the cause is treated.

Your doctor can prescribe anti-sickness drugs (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 you swallow, but they can also be given as:

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

What you can do

- Avoid eating or preparing food when you feel sick. If possible, ask someone else to cook.
- Avoid fried foods and foods with a strong smell.
- Eat cold or warm food if the smell of hot food makes you feel sick.
- Prepare small meals and eat little and often.
- Peppermints or peppermint tea may help some people.
- Try eating ginger biscuits or drinking ginger beer.
- Sip drinks slowly. Try not to drink a lot just before you eat.
- Complementary therapies, such as relaxation and acupuncture, may help some people (see page 93).

Indigestion and heartburn

Indigestion is discomfort in the upper part of the tummy (abdomen). It 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
- do not eat or drink much
- do not 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. Talk to your doctor about this.

What you can do

- Avoid things that irritate your stomach, such as smoking, chocolate, alcohol, fatty and spicy foods.
- Antacid medicines can help relieve irritation from the stomach acid. You can buy them at your local pharmacy.
- If you have a small stomach, it can help to avoid drinking at mealtimes.
- Eat small meals and snacks throughout the day, rather than three big meals. Try to relax for at least 45 to 60 minutes after eating.
- Avoid eating for three to four hours before bed.
- Sleep propped up on pillows.
- Talk to your doctor, as they may 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 that you cannot control.

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

Treatment for hiccups

Treatment for hiccups depends on the cause. Your doctor can prescribe drugs 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 taking drugs for hiccups, tell your doctor if they do not help within a few days. Your doctor may increase the dose, try another drug or refer you to a specialist.

What you can do

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

- sipping iced water
- swallowing crushed ice
- drinking from the wrong (opposite) side of a cup
- swallowing a teaspoon of granulated sugar
- breathing into a paper bag
- holding your breath.

Sore mouth and throat

You may have a sore mouth if you:

- have low immunity and are more prone to infection
- have an infection of the lining of your mouth or throat
- have not been able to eat a nutritious diet
- have had certain cancer treatments.

If you are taking antibiotics or steroids, you may have a fungal infection in your mouth called thrush. This usually looks like white patches or a white coating over the lining of the mouth, tongue or throat. It can also cause bad breath. Tell your doctor or nurse if you have these symptoms. They can give you anti-fungal treatment to help.



If your mouth or lips are sore, your doctor can check for signs of infection or thrush. They will prescribe treatment if needed. Tell your doctor if your symptoms don't get better with treatment.

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

What you can do

- Follow a good mouth care routine (see page 33).
- If your doctor prescribes a gel, spray or mouthwash or painkillers, use them as advised.
- If your toothpaste stings, talk to your cancer nurse or a 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. Ask your cancer nurse or doctor for advice.
- Avoid alcohol, tobacco and foods that irritate your mouth.
- Use gravy and mild sauces to make your food moist, softer and easier to swallow.
- If possible, drink at least 2 litres (about 3½ pints) of fluid a day.
- Drink 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 have a dry mouth because they produce less saliva, or they breathe more through their mouth. Lack of saliva can increase your risk of tooth decay or infections.

Dry mouth can be caused by:

- oxygen treatment
- radiotherapy to the head and neck area
- certain drugs
- feeling anxious.

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

Your doctor may suggest you use artificial saliva. These are available as gels, sprays, pastilles or lozenges. Your doctor can prescribe these for you. Or they may suggest a drug to stimulate your mouth to produce saliva.

If you have a dry mouth for a long time, you have a higher risk of dental problems. It is important to see your dentist regularly. Some dentists will visit you at home if you cannot go to the surgery.

What you can do

- Follow a good mouth care routine (see page 33).
- Regular mouthwashes can help keep your mouth clean and moist. Avoid any that contain alcohol or glycerine, as these can dry the lining of your mouth.
- 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. Take regular drinks to keep your mouth moist. Have a drink with meals.
- Use a lip salve to protect your lips.
- Eat soft, moist foods such as casseroles, soup, melon, grapes and ice cream. Add moisture and fat to make food easier to eat. For example, you could use gravies, sauces, extra oil, salad dressings, yoghurt, mayonnaise or butter to moisten foods.
- Chew sugar-free gum, as it can stimulate saliva production.
- Try to avoid foods that can irritate a dry mouth. This includes spicy, salty or hard and crunchy foods, or citrus fruits.
- Avoid toothpastes with foaming agents in them, as these can make your mouth dry. Foaming agents are usually an ingredient called sodium lauryl sulphate (SLS).



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peppermint or natural
flavors. For more information,
visit us online at www.oral-b.com
or call 1-800-452-7535.

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 your toothbrush 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.

BREATHING DIFFICULTIES

Breathlessness

36

Coughing

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Breathlessness

The treatment for being short of breath depends on what has caused it. 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
- anaemia – when the level of red blood cells in your blood is low
- pulmonary oedema – when fluid builds up in the lungs
- pleural effusion – when fluid builds up between the two membranes that cover the lungs (the pleura)
- ascites – when fluid builds up in the tummy area
- smoking tobacco – smoking makes breathlessness worse because the smoke causes irritation and inflammation of the airways.

Feeling breathless can make you feel anxious and panicky (see pages 72 to 73). This can cause rapid, shallow breathing, which can make you even more breathless.

We have more information about breathlessness in our booklet **Managing breathlessness**. You may also find our audiobook **Relax and breathe** helpful. You can order a free CD or listen online (see page 102).

If you want to give up smoking, ask your nurse or doctor for advice and support. You can also call our cancer support specialists on **0808 808 00 00** for more information.

Treatment for breathlessness

Your doctor may give you medicines to help ease your breathing, such as the following:

- Antibiotics, if you have a chest infection.
- Bronchodilators, which can widen the airways and increase air flow. You can breathe these drugs in through an inhaler, or a mask called a nebuliser. Sometimes they can be given as tablets.
- Salt water through a nebuliser, which can loosen sticky phlegm (mucus).
- Steroids, which can reduce inflammation in the lungs.
- Very small doses of painkillers, such as morphine, which can help with breathlessness even if there is no pain.
- Sedatives, which may relieve anxiety and help with breathlessness.
- Drugs to help you pass more urine (diuretics), which can help if you have too much fluid in or around your lungs.

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 helpful for people who are breathless because of low oxygen levels in the blood. If you need oxygen at home, your doctor can arrange this for you.

Breathing techniques

A physiotherapist and an occupational therapist can help you manage breathlessness. They may show you ways to make breathing easier. Or they may give you aids and advice to help make tasks easier.

If you have anaemia

Your doctors may recommend a blood transfusion. Your doctor may talk to you about other treatments or ways of managing your anaemia.

If you have a pleural effusion

Your doctor may place a small tube into your chest to drain the fluid into a drainage bottle. This is called a chest drain.

If you have ascites

Your doctor may place a small tube into your tummy (abdomen) to drain the fluid into a drainage bottle.

We have more information about these conditions on our website (see page 102).



What you can do

- Sit in a comfortable position that supports your upper chest muscles. This may be sitting in a chair with your back upright or sitting forward with your elbows leaning on your thighs.
- Wear loose-fitting clothes, especially around your waist and chest.
- Sleep with your head and chest raised supported by a few pillows. This will make it easier to breathe.
- Practice breathing and relaxation techniques when you are not breathless, so you find them easier when you are.
- Make a plan of things that help when you are breathless – this can help you feel more in control.
- Having cool air on your face may help ease breathlessness. Sit in front of an open window or hold a fan about 15cm (6 inches) away from your face. Most people feel this helps after a couple of minutes.
- Sit down to do everyday tasks like washing, dressing and preparing food. Think about rearranging your home to make things easier. An occupational therapist can help with planning this and provide gadgets to make everyday life easier.
- Try using a baby monitor or mobile phone to talk to people in other rooms. Then you will not have to shout or get up, especially at night.

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

Coughing

Coughing can help to clear our airways, but it can be uncomfortable or embarrassing.

Different things may cause a cough. A cough may be:

- a sign of a chest infection
- a symptom of a cancer in or close to the lungs
- a late effect of radiotherapy to the chest.

Always tell your doctor or nurse if you have a cough so they can find out the cause. Certain things, for example an infection, will need to be treated straight away with antibiotics.

If your coughing is caused by the cancer, then treating the cancer may improve the cough. Sometimes a short course of radiotherapy to the lung helps. Sometimes a cough and breathlessness can be caused by inflammation or scarring (fibrosis) in the lungs. This can be a late effect of radiotherapy to the chest. Drugs called steroids are sometimes used to treat this.

A cough that does not improve can be uncomfortable and upsetting. It may interrupt your sleep or interfere with eating. There are different things that may help.

Tell your doctor straight away if you cough up any blood.

You may have tests to find out what is causing the bleeding. The treatment you have will depend on the cause.

What you can do

- Always tell your doctor or nurse if your cough gets worse, or if you start coughing up mucous (phlegm). You may have an infection and need antibiotics.
- Ask your doctor if physiotherapy could improve your cough. A physiotherapist can show you the best way to clear your airways.
- Sometimes a steam inhalation or breathing in salt water (saline) through a small machine called a nebuliser can help. The machine turns the saline into a fine mist, so you can breathe it deeply into your lungs.
- If you have a dry, irritable cough, your doctor may prescribe a cough mixture to help. Codeine or morphine are drugs that are usually used to control pain. But your doctor may also prescribe them to relieve an ongoing cough, even if you do not have pain.



BLADDER AND BOWEL CHANGES

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Constipation

Everyone's normal bowel pattern is different. Constipation can be a common problem, but many people find it embarrassing to talk about. But as a general guide, you should let your doctor or nurse know if you have not had a bowel movement for 3 days, unless this is usual for you. They can give you advice and treatment.

Signs of constipation include:

- having less regular bowel movements
- your stools (poo) becoming harder
- straining to empty your bowels
- a feeling of not having emptied your bowel, but being unable to pass any more stool
- your tummy becoming bloated or uncomfortable.

Constipation can be caused by:

- a lack of fibre in your diet
- not drinking enough
- not being active
- some medicines – 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.

Don't let constipation get too bad. The oncology pharmacist suggested I start taking something the day before chemo to prevent it. She prescribed a laxative, which worked.

Claire

What you can do

- Try to have plenty of fibre in your diet. Fibre is in wholegrain cereals, porridge, muesli, wholemeal bread and pasta, brown rice, and fresh fruit and vegetables with their skins on.
- Drink at least 2 litres (3½ pints) of fluid a day.
- Try regular gentle exercise, such as walking. This will help keep your bowels moving.
- Try natural remedies for constipation. These include 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. Do not 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.

We have more information about cancer of the gullet and bowel in our booklets **Understanding oesophageal cancer** and **Understanding bowel cancer** (see page 102).

Diarrhoea

Some cancers can prevent food from being absorbed properly in the bowel, causing diarrhoea. Diarrhoea means passing more stools (poo) than is usual for you, or having watery or loose stools. If you have a stoma, it will be more active than usual.

Some 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.

Severe constipation can sometimes be mistaken for diarrhoea. If hard stools block the bowel, liquid stool sometimes passes around it. This is called overflow and can look like diarrhoea.

Tell your doctor if you have diarrhoea, or if it is getting worse. They can try to find out the cause and may prescribe anti-diarrhoea medicines for you.

What you can do

- 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 – such as white fish, chicken, eggs, white bread, pasta and rice. Avoid highly spiced or fatty foods.
- Eat your meals slowly.

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. They can also send you details of where the toilets are (see page 108).

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 (see page 102).

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.

What you can do

- Some foods may trigger incontinence, or it may happen 30 to 60 minutes after eating. Keep a diary to help you see if there is a pattern.
- If you are going out, use the toilet before you go. Take clean-up supplies and a change of underwear.
- Learn where the 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. This means you can get to the toilet more easily.
- Find out about toilet key and toilet card schemes to help you access toilets when you are out (see opposite page).

Bladder problems

Bladder problems include needing to pass urine (pee) more often than usual, or having 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
- your urine is cloudy
- your urine smells.

They can test a sample of your urine and treat any infection 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
- retention – when urine cannot flow out of the bladder.

Rarely, a tumour pressing on the nerves in the spine can cause nerve damage, leading to incontinence or retention.

If you find 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 a 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 or physiotherapist can tell you about these.

Your doctor may prescribe drugs to help with urinary problems. If the symptoms do not improve over several months, you may be offered surgery to improve your bladder control.

Urinary incontinence

If you have difficulty controlling when you pass urine, tell your doctor or nurse. They can do an assessment and arrange treatment or support. Sometimes your doctor may refer you to a specialist continence adviser. Different continence products can help, 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.

Incontinence can be more difficult to cope with if you have to stay in bed. If this happens, 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.

What you can do

- Drink at least 2 to 3 litres (3½ to 5½ pints) of fluids a day to keep your urine a clear or pale-yellow colour.
- Avoid drinks such as tea, coffee, cola and alcohol. These can irritate your bladder and may make symptoms worse.
- If you find it difficult to get to a toilet quickly, try to have your bedroom as close to a toilet as possible. Or you can have a commode, bed pan or urine bottle by your bed.
- Try to avoid constipation (see pages 44 to 46). This can make bladder problems worse.
- If you smoke, try to cut down or stop. Smoking can make the symptoms of bladder irritation worse.

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 48).



CHANGES TO SKIN

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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
- kidney and liver problems.

Your doctor will try to find the cause of the itch. For some cancers, medicines 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 different drugs or products that may help. Your doctor can discuss these with you.

What you can do

- 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 keep the cream in the fridge, it will feel cool and soothing when you are putting it on.
- If hot water makes the itching worse, have cool baths or showers. Try adding a moisturising solution such as Oilatum® to bath water. Use aqueous cream instead of soap. A little baking soda in your bath water can also help. After a bath or shower, apply moisturiser while your skin is still damp.
- Keep your nails clean and short. Rub, rather than scratch, the itchy area. Avoid things that may irritate your skin. This includes biological washing powders, scented soaps, bubble baths and products containing lanolin.
- Keep cool by wearing light, natural fibres such as cotton.
- Keep 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.
- 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.

Sitting or lying down for long periods of time may increase the risk of developing a pressure sore. The risk is also higher if you are not eating and drinking well, or 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.

What you can do

- If you spend a lot of time sitting or lying in bed, change your position regularly. Move every half an hour (30 minutes) 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 at least every hour. 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. We have a list of organisations that can provide equipment (see pages 107 to 108).
- Treat dry skin (see the first tip on page 57).

Increased sweating

Sweating helps to keep our temperature normal. Some people with cancer may have 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 have more information about menopausal symptoms and hormonal therapies on our website (see page 102).

If your sweating is due to the cancer itself, there are drugs that can be used to treat it. Your doctor can tell you more about this.

What you can do

- Wear natural fabrics, such as cotton.
- Wear layers, so you can remove clothes as needed.
- Keep the room cool or use a fan.
- Use cotton sheets and layers of bedding that you can take off during the night.
- Put a towel under you in bed to absorb sweat.
- Try a silk pillowcase or a special cooling pillow that contains a gel to absorb heat.
- Have cold drinks rather than hot ones.
- Have cool showers and baths rather than hot ones.
- Some people find sweats are made worse by drinking alcohol, tea or coffee or eating spicy foods.
- Try to drink plenty of fluid to replace what you lose through sweating.

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 cancer is blocking the bile duct or affecting the liver or 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 and smelly poo (stools) that is difficult to flush away.

If you have jaundice, you may have treatment to

- unblock the bile duct
- bypass the blockage
- improve your symptoms.

If jaundice is caused by cancer blocking the bile duct, your doctors may recommend treatment to remove or shrink the cancer. They may suggest putting in a stent. This is a small tube that holds the bile duct open. Your doctor or nurse will explain more about this.

Sometimes a stent is not successful or not possible. If this happens you 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.

If jaundice is caused by an infection, antibiotics may help.

Itchy skin can often be the most difficult symptom of jaundice. Your doctor can prescribe medicines to help with this. See pages 56 to 57 for advice on itching.

The stent provided great relief after over a week of being very uncomfortable with the jaundice. Then the jaundice started to fade over maybe 48 hours. I was able to be up and about, and get a break from the hospital and feeling unwell.

Steve



FLUID BUILD-UP

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Swollen legs and ankles (oedema)

Oedema is a build-up of fluid which causes swelling. It usually affects the legs and ankles, but can be in other parts of the body. The swelling can be uncomfortable, and the skin can become shiny and stretched. There are different reasons why fluid can build up. These include being unable to move about as much as usual. Treatment will depend on the cause of the oedema.

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. Speak to your doctor or nurse straight away if only one leg is swollen, as this can be due to a blood clot.

What you can do

- 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.
- Physical activity, like walking, can help your circulation.
- Take care of your skin and make sure your shoes are not too tight.

You might find our booklet **Physical activity and cancer** helpful (see page 102).

Lymphoedema

Lymphoedema 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, which helps us fight infections and other illnesses. You may find our **Understanding lymphoedema** booklet helpful (see page 102).

Lymphoedema is swelling caused by a build-up of fluid called lymph in the body tissues. You may notice your clothes, shoes or jewellery such as rings and watches getting tighter. You may notice aching in the affected area or change in sensation or appearance of the skin.

Lymphoedema can develop months or even years after cancer treatment. It can happen anywhere in the body, but the most common places for lymphoedema to develop are in the arm or leg.

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:

- taking care of your skin
- doing regular exercise and carefully positioning the limb
- using compression garments, bandages or pumps
- a type of massage called simple lymphatic drainage (SLD)
- a type of specialised massage from a trained therapist called manual lymphatic drainage (MLD).

Along with treatment, your lymphoedema specialist will also advise you to avoid pressure on the area. This is because it can affect the flow of lymph fluid. Tell your doctor or nurse if your skin on the affected area becomes red or hot. This may be a sign of an infection.



Ascites

Some types of cancer can cause a build-up of fluid in the tummy (abdomen). This is called ascites. The main symptom of ascites is a swollen tummy. Other symptoms include:

- pain and discomfort in the tummy
- feeling sick (nausea)
- reduced appetite
- indigestion
- feeling full
- tiredness
- breathlessness.

Ascites can make it difficult for you to get comfortable, sit up and walk.

The main treatment for ascites is to drain the fluid by putting a tube into the tummy. Draining the fluid will relieve the symptoms and help you feel more comfortable.

A doctor will usually put in the tube at the hospital. This is usually done under a local anaesthetic. The fluid can be drained as often as necessary. Some people may need a permanent drain put in.

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 have more information about ascites on our website (see page 102).

EMOTIONAL EFFECTS OF CANCER

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Anxiety

Feeling anxious is a natural reaction to an uncertain situation. You may be anxious about what will happen in the future. 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.

Symptoms of anxiety include:

- being irritable
- feeling restless
- having a constant feeling of dread.

If you are anxious you may also notice some physical symptoms such as:

- feeling short of breath
- feeling dizzy
- sweating
- having a dry mouth
- being unable to sleep.

It can be easy to confuse the symptoms of cancer 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. They may prescribe medication to help.

Understanding the reason for your symptoms can be reassuring. But if you are still anxious, try talking to your nurse or doctor. Some people find it helpful to see a counsellor. There are some organisations that can help you find a counsellor in your area (see page 107).

What you can do

- If you feel like talking, talk to someone who is a good listener. This may be a friend, partner or family member.
- Think about your breathing. Breathe in slowly and deeply through your nose and slowly out through your mouth.
- Do some physical activity. Even a short walk can help with anxiety.
- Activities such as yoga, meditation, or massage may help you relax and manage your anxiety.
- 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

You can order our booklet **How are you feeling?**
The emotional effects of cancer for more information
(see page 102).



Sadness and depression

You may feel sad if you have to change your plans because of the cancer, or if your future feels uncertain. Feeling sad is a natural reaction to changes or loss. This feeling may come and go.

When you have cancer, feeling sad at times is normal. For some people, the low mood may continue or get worse. This may mean they have depression. Depression is common and can be caused by different things. Sometimes other people may notice your symptoms.

Symptoms of depression can include:

- feeling low in mood or sad most of the time
- losing interest in things you used to enjoy, like your hobbies or social life
- changes in sleeping, eating or concentration
- feeling helpless or vulnerable
- problems starting or finishing tasks
- thinking about self-harm or suicide.

If you think you might have depression, speak to your GP or nurse. They will be able to tell you about different treatments that may help.

We have more information about coping with depression and the emotional impact of cancer in our booklet **How are you feeling? The emotional effects of cancer** (see page 102).

I quickly realised that all the worry in the world was not going to make any difference to what my team told me or what my treatment plan was. But stress and worry would actually make me ill and therefore less able to deal with my treatments.

Mike

What you can do

Some people find that talking about their feelings can help. If you can, talk to your family, friends or partner about how you feel so they can support you. You may find our booklet **Talking about cancer** helpful (see page 102).

Counselling or talking therapies can help you talk about your feelings about what is happening. Trained counsellors, clinical psychologists and psychiatrists all provide talking therapies. Your GP or nurse can tell you more. Some organisations like Mind can offer this type of support too (see page 107). We have more information about the different types of help available on our website (see page 102).

You can also try talking to someone who is going through similar experiences. This might be through a cancer support group or an online social networking site, such as our Online Community (see page 104).

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 will not 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.







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Medicines

Different medicines can be used to treat different symptoms. Medicines are often tablets or capsules. If you find tablets hard to swallow, you may be able to have the medicine as a syrup or soluble tablet. Other ways of taking medicines include injections, suppositories (into the back passage), nasal sprays and skin patches. If you find any medicines difficult to take, speak to your doctor, nurse or pharmacist.

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 your symptoms do not get better within 1 or 2 weeks of taking a medicine you have bought, see your GP or cancer specialist.

Taking your medicines

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

- the drug names
- what they do
- the doses
- when 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. Calendar blister packs are 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. They may be able to make some changes that will make it easier for you.





Keeping a symptom diary

You may find it useful to keep a diary of how well your symptoms are being managed. We have a symptom diary that you can use (see pages 84 to 87). Make copies of the diary before you fill it in, so you can keep using it for as long as it helps. You can also use it to keep a record of all your different symptoms.

You may want to keep notes of any symptoms you have between doses of medicine and whether you need to take extra doses to manage symptoms.

Keeping a diary can help your medical team. For example, they will be able to see if the doses of any of your drugs need changing.

If you find that your symptoms are difficult to treat, your doctor may refer you to a specialist team who deal with symptom control.

Symptom diary

How to use your symptom diary

You may want to photocopy the diary, 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. It could be in one area or different areas.
- 3.** Describe what each symptom **feels like**. You could use the words on the opposite page 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 opposite page).
- 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?

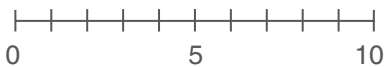
Is it in one part of your body or in more than one place? Does it start in one place and gradually spread during the day?

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.)

How would you describe it?	What helps with it?



Preparing for radiotherapy

Cancer treatments for symptom control

Cancer treatments may help to relieve some symptoms. You may be offered more than one type of treatment.

Radiotherapy

Radiotherapy uses high-energy rays to treat cancer. It can also help relieve symptoms. We have more information in our booklet **Understanding radiotherapy** (see page 102).

Your symptoms may get slightly worse before they start getting better. You can take 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.

Chemotherapy

Chemotherapy uses anti-cancer (cytotoxic) drugs to destroy cancer cells. It can reduce the size of tumours. This will help control and improve symptoms. Chemotherapy does not work for everyone and it may also cause side effects. 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.

We have more information in our booklet **Understanding chemotherapy** (see page 102).

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 doctors use lasers, electricity, freezing or heat to destroy part of a tumour.

Hormonal therapies

Some types of cancer depend on 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 each has different side effects. You can ask your doctor how likely the treatment is to work for you and what the possible side effects are.

Targeted therapies

Targeted therapy may sometimes be used to help control certain types of cancer. Targeted therapies work by targeting something in or around the cancer cell that is helping it grow and survive. Your doctor can give you more information.

Immunotherapies

Immunotherapies are treatments that use the immune system to find and attack cancer cells. There are different types of immunotherapy. Each one uses the immune system in a different way.

We have more information about these treatments on our website (see page 102).

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 also talk to our cancer support specialists by calling us free on **0808 808 00 00**.

We have more information in our booklet **Making treatment decisions** (see page 102).





Complementary therapies

People may use complementary therapies alongside conventional medical treatments. Complementary therapies do not claim that they can treat or cure cancer. People might use complementary therapies to improve their physical or emotional health. Or they may use them to reduce cancer symptoms or the side effects of cancer treatments.

There are many types of complementary therapy. Some are based on traditional medical systems outside of western medicine. These include traditional Chinese medicine and Indian Ayurvedic medicine.

Therapies can be grouped in different ways. Some may fit into more than one group. The main groups are:

- mind-body therapies
- massage and other touch-based therapies
- acupuncture
- therapies using herbs and plants
- therapies using supplements or diet.

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

Before making a decision, make sure you have the information you need about the complementary therapy you are interested in. Talk about it with your cancer doctor or specialist nurse.

We have more information about complementary therapies in our booklet **Cancer and complementary therapies** (see page 102).

Who can help?

Many people are available to help you and your family.

District nurses work closely with GPs and make regular visits to patients and their families at home if needed.

The hospital social worker can give you information about social services and benefits you may be able to claim. These may include meals on wheels, a home helper or money to help with hospital transport fares. The social worker may also be able to arrange childcare for you during and after treatment.

In many areas of the country, there are also specialist nurses called palliative care nurses. They are experienced in assessing and treating symptoms of advanced cancer. Palliative care nurses are sometimes known as Macmillan nurses. But many Macmillan professionals are nurses who have specialist knowledge in a particular type of cancer. You may meet them when you're at a clinic or in hospital.

Marie Curie nurses help care for people approaching the end of their lives in their own homes (see page 106). Your GP or hospital specialist nurse can usually arrange a visit by a palliative care or Marie Curie nurse.

There's also specialist help available to help you cope with the emotional impact of cancer and its treatment. You can ask your hospital doctor or GP to refer you to a doctor or counsellor who specialises in supporting people with cancer and their families. Our cancer support specialists on **0808 808 00 00** can tell you more about counselling and can let you know about services in your area.

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.

We have more information in our booklet **Managing cancer pain**, which you might find helpful (see page 102).

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. Some hospices and units are run by independent charities or by Marie Curie (see page 106). Others are run by local NHS and Health and Social Care Services. These units provide a variety of care, such as the following:

- Inpatient care – you may stay in the hospice or unit for a few days or weeks to have your symptoms controlled. Short stays can sometimes be organised to give your carers a break. This is called respite care.
- Day care – you visit the hospice for a day where the staff may provide specialist symptom control. You may also have physiotherapy or complementary therapy. It is a chance to meet with other people who may be in a similar situation. Day care can also give your family or your carers some time for themselves.
- Outpatient clinics – you can visit the hospice or unit as an outpatient to get help from a palliative care specialist.
- Outreach services – often, hospices have outreach services that can visit and support you at home when it is difficult for you to get to the hospice.

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 advice about gentle exercise and relaxation techniques. They can also help you think about different ways of doing day-to-day activities, to make life easier for you.

Occupational therapists (OTs)

OTs can help you find safe ways of managing at home and prevent you from getting too tired or breathless. They may be able to provide equipment 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 help at home, or help with hospital travel or parking costs.

Counsellors

Trained counsellors, clinical psychologists and psychiatrists can offer counselling or talking therapies to help you manage your feelings. Your GP or nurse can tell you more about this.

Practical support

If your symptoms are causing physical difficulties, there are organisations which can provide equipment to help you with managing practical tasks.

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

Living Made Easy runs an information service. It has specialist advisers who can help with incontinence and clothing (see page 107). Their occupational therapists can also give advice on aids and equipment. Living Made Easy has showrooms with specialist equipment on display. These include special cutlery, walking aids and wheelchairs.

The British Red Cross has branches across the UK (see page 107). Their volunteers can provide transport 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. The volunteer can give you some company and let your carer take 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.

Your data and the cancer registry

When you are diagnosed with cancer in the UK, some information about you, your cancer diagnosis and your treatment is collected in a cancer registry. This is used to plan and improve health and care services. Your hospital will usually give this information to the registry automatically. 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. If you do not want your information included in the registry, you can contact the cancer registry in your country to opt out.

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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 booklets or leaflets like this one.
Visit be.macmillan.org.uk or call us on **0808 808 00 00**.

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

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring 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 would 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**.

Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we are here to support you.

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 7 days a week, 8am to 8pm. Our cancer support specialists can:

- help with any medical questions you have about cancer or your 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 would 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 is 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](https://www.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](https://www.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.

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you have 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](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

Help with work and cancer

Whether you are 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](https://www.macmillan.org.uk/work)**

Work support

Our dedicated team of work support advisers can help you understand your rights at work. Call us on **0808 808 00 00** to speak to a work support adviser (Monday to Friday, 8am to 6pm).

Other useful organisations

There are lots of other organisations that can give you information or support. Details correct at time of printing.

General cancer support organisations

Cancer Black Care

Tel **020 8961 4151**

www.cancerblackcare.org.uk

Offers information and support for people from Black and ethnic minority communities who have cancer. Also supports their friends, carers and families.

Maggie's

Tel **0300 123 1801**

Email **enquiries@maggies.org**

www.maggies.org

Provides information about cancer and financial support.

Also offers emotional and social support to people with cancer, their family, and friends.

Marie Curie

Helpline **0800 090 2309**

(Mon to Fri, 8am to 6pm, and Sat, 11am to 5pm)

www.mariecurie.org.uk

Marie Curie nurses provide free end-of-life care across the UK.

They care for people in their own homes or in Marie Curie hospices, 24 hours a day, 365 days a year.

Penny Brohn UK

Helpline **0303 3000 118** (Mon to Fri, 10am to 2pm)

Email **helpline@pennybrohn.org.uk**

www.pennybrohn.org.uk

Offers physical, emotional and spiritual support across the UK, using complementary therapies and self-help techniques.

Counselling and support

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)

Email **bacp@bacp.co.uk**

www.bacp.co.uk

Signposts people to services across the UK.

Mind

Helpline **0300 123 3393** (Mon to Fri, 9am to 6pm)

Email **info@mind.org.uk**

www.mind.org.uk

Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Equipment and support

British Red Cross

Tel **0344 871 11 11**

Email **contactus@redcross.org.uk**

www.redcross.org.uk

Offers a range of services such as care in the home, and a medical equipment loan service.

Disability Rights UK

Tel **0330 995 0400** (not an advice line)

www.disabilityrightsuk.org/shop

Buy a radar key for toilet access and find toilet locations.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)

www.livingmadeeasy.org.uk

Provides advice about all types of disability equipment and mobility products.

Scope

Helpline **0808 800 3333** (Mon to Fri, 9am to 6pm,
and Sat to Sun, 10am to 6pm)

Textphone Use Type Talk by dialling **18001** from a textphone
followed by **0808 800 3333**

Email helpline@scope.org.uk

www.scope.org.uk

Offers advice and information on living with disability.

Also supports a network of local Disability Information and
Advice Line services (DIALs) run by and for disabled people.

Support for carers

Carers Trust

Tel **0300 772 9600** (Mon to Fri, 9am to 5pm)

Email info@carers.org

www.carers.org

Provides support, information, advice and services for people
caring at home.

Carers UK

Helpline (England, Scotland, Wales) **0808 808 7777**
(Mon to Fri, 9am to 6pm)

Helpline (Northern Ireland) **028 9043 9843**

www.carersuk.org

Offers information and support to carers across the UK, with an
online forum. Can put people in contact with local support groups

LGBT-specific support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)

Email helpline@lgbt.foundation

www.lgbt.foundation

Provides a range of services to the LGBT community,
including help, advice, information and events.

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 and Analysis Service

Tel 0207 654 8000

Email enquiries@phe.gov.uk

www.ndrs.nhs.uk

Tel (Ireland) 0214 318 014

www.ncri.ie (Ireland)

Scottish Cancer Registry

www.ndrs.nhs.uk/cancer-registration-your-rights-and-privacy

Welsh Cancer Intelligence and Surveillance Unit (WCISU)

Tel 02920 104 278

phw.nhs.wales/services-and-teams/welsh-cancer-intelligence-and-surveillance-unit-wcisu/

Northern Ireland Cancer Registry

Tel 0289 097 6028

Email nicr@qub.ac.uk

www.qub.ac.uk/nicr

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 Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

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Thanks also to the people affected by cancer who reviewed this edition, and those who shared their stories.

We welcome feedback on our information. If you have any, please contact **cancerinformationteam@macmillan.org.uk**

Sources

Below is a sample of the sources used in our managing symptoms information. If you would like more information about the sources we use, please contact us at **cancerinformationteam@macmillan.org.uk**

Kwekkeboom K.L. Cancer Symptom Cluster Management. *Seminars in Oncology Nursing*. 2016; Nov, 32(4): 373–382. Available from: www.sciencedirect.com [accessed Jan 2020]

United Kingdom Oncology Nursing Society. *Acute Oncology Initial Management Guidelines (Version 2)*. UKONS. 2018. Available from: www.nwscnsenate.nhs.uk [accessed March 2020]

Yarbro et al. *Cancer Symptom Management*. 4th edition. Jones and Bartlett Publishers. 2013.

Can you do something to help?

We hope this booklet has been useful to you. It is just one of our many publications that are available free to anyone affected by cancer. They are 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 are here 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 / /

Do not 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 would rather donate online
go to macmillan.org.uk/donate



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**FUNDRAISING
REGULATOR**



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.

The booklet describes some of the symptoms you may have, but you are unlikely to have more than a few of them. Most symptoms can be controlled with the help of your healthcare team, family and friends.

At Macmillan, we give people with cancer everything we've got. If you are diagnosed, your worries are our worries. We will help you live life as fully as you can.

For information, support or just someone to talk to, call **0808 808 00 00** 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.



Patient Information Forum