

A practical guide to living  
with and after cancer

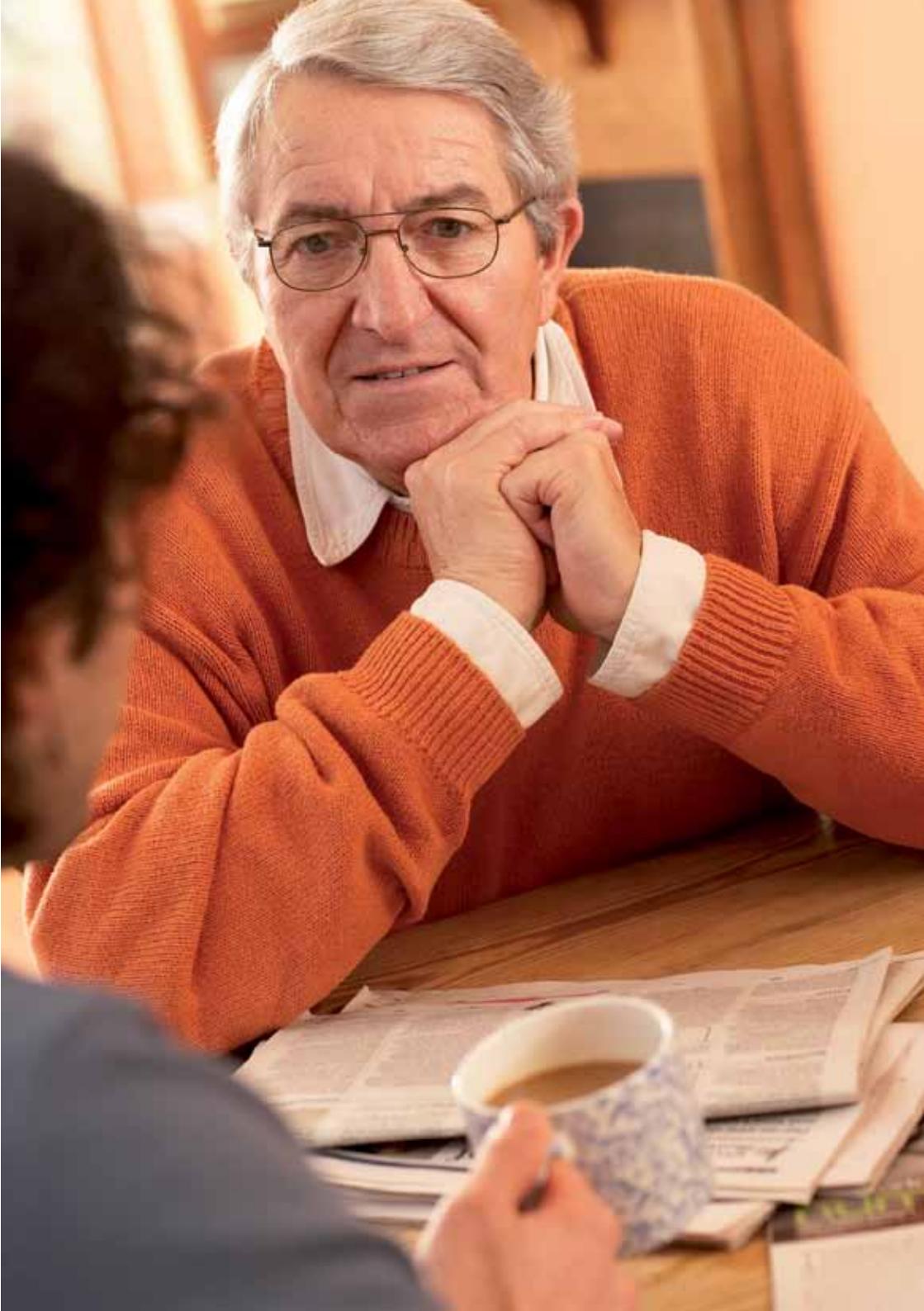
# MANAGING THE LATE EFFECTS OF BOWEL CANCER TREATMENT

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# About this booklet

**This information is for people who are still having side effects six months or more after treatment for bowel cancer. It aims to describe possible side effects, how they can be improved or managed, and who can help you.**

Most people have side effects during, and for a few weeks after, treatment for bowel cancer. Usually these effects gradually lessen and disappear. But some people may have side effects that continue months after treatment and sometimes become permanent. Other people may develop delayed late effects of treatment months or years later.

Not everyone has or gets long-term or late effects and many get better over time. How likely you are to have problems depends on different factors such as where in your bowel the cancer was (rectum or colon), the size of the cancer (stage) and the types of treatment you had.

Doctors and researchers are looking at ways of making sure people get the best treatment for bowel cancer with as few side effects as possible.

We hope that if you are experiencing long-term or late effects this booklet will help you know who can help and what can be done. It also suggests some positive ways in which you can help yourself.

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

Turn to pages 85–96 for some useful addresses, helpful books and websites, and page 97 to write down questions for your doctor or nurse.

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

# Long-term and late effects

You may come across different terms to describe side effects that happen or are still present after treatment is over.

There are two commonly used terms:

- long-term effects
- late effects.

**Long-term effects** begin during or shortly after treatment and don't go away within the following six months. They may go away eventually on their own, with symptoms gradually getting better for up to a year or two after treatment ends. Sometimes long-term effects are permanent.

**Late effects** are a delayed response to treatment. Late effects don't appear during treatment, but can happen months or even years later.

**In this booklet we use the term late effects to include both long-term and late effects.**

Some people think that side effects are a price they have to pay for being free of cancer. But, often this isn't the case. There are many things that can be done to manage or treat late effects. It's important that you don't feel you just have to put up with them.

**Always let your cancer doctor or nurse know if side effects you developed during treatment aren't going away, or if you develop new symptoms or problems after treatment is over.**

People sometimes worry that their symptoms are caused by the cancer coming back. Your doctor or nurse will be able to reassure you, or arrange to have your symptoms checked if necessary.

# Possible late effects of bowel cancer treatments

The main treatments for bowel cancer are surgery, radiotherapy and chemotherapy.

## Surgery

Surgery for bowel cancer involves removing some of the colon and/or rectum. Some people have surgery to create a new opening in the abdomen – a colostomy or ileostomy (also known as a stoma). This may be temporary or permanent. All of these operations cause changes in how the bowel works (see pages 15–17).

Surgery can cause changes in the tissues of the tummy (abdomen). The skin may be less stretchy and the abdominal wall less strong. Weakness in the muscle of the abdomen can lead to a hernia developing months or years later (see pages 10–11). Sometimes, scar tissue inside the abdomen (adhesions) may cause pain or discomfort, or may narrow the bowel (see pages 12–14).

If you have a stoma, as well as learning new skills to manage this, you'll also need time to adjust to the changes in your body. How long this takes varies from person to person. Specialist nurses, called stoma care nurses, are available to help and support you with this.

After rectal surgery, some people may have changes in how their bladder works (see pages 42–46) or sexual difficulties (see pages 53–58).

## **Radiotherapy**

Radiotherapy to the rectum and surrounding tissues (pelvic radiotherapy) often causes bowel symptoms that get better within a few weeks of treatment ending. But it can also cause late (delayed) effects months or years after treatment. Possible late effects include changes in bowel function (see pages 17–19), bladder function (see pages 42–46), or sexual difficulties (see page 53–58).

## **Chemotherapy**

Some chemotherapy drugs can cause changes in sensation (see pages 68–70), such as pins and needles or numbness in your hands and feet. These changes may take several months to get better and for some people are permanent.

Cancer treatment can also cause more general changes in how you feel. You may be more tired than usual (see pages 59–62) for many months after treatment or have difficulty concentrating or remembering things (see pages 63–67). These side effects usually improve gradually over time.

**You can read more about the main treatments for bowel cancer in our booklets *Understanding colon cancer* and *Understanding rectal cancer*.**

# Hernia

A hernia is a bulge caused by an internal part of the body, such as a part of the bowel, pushing through a weakness in the muscle or tissue wall.

Usually your muscles hold your intestines and organs in place. But after an operation, the area around the operation scar or stoma may become weaker and a hernia can develop.

The main symptom of a hernia is an ache or bulge in your tummy area (abdomen) or under the skin around your stoma. The bulge may not always be there but may appear when you cough, sneeze or strain your abdominal muscles. Your doctor will examine you by feeling around the area. They may also arrange a CT (computerised tomography) or ultrasound scan to give a picture of the hernia.

Smoking can increase the risk of a hernia developing. People who are overweight are also more likely to develop a hernia. Anything that increases the pressure inside your abdomen such as lifting heavy objects or straining can also increase your risk. You can reduce your risk of developing a hernia by:

- keeping to a healthy weight for your height or losing weight if you are overweight
- not smoking
- following a healthy, balanced diet

- strengthening your abdominal muscles with regular moderate exercise such as walking, yoga, or gentle aerobics and stretching exercises
- not straining on the toilet and avoiding constipation
- learning how to lift heavy objects safely, so that your arm and leg muscles take the strain.

Hernias are often treated with an operation to repair the tissue wall. The operation is usually done through one or more small cuts in the abdomen. This is called laparoscopic or keyhole surgery.

If an operation isn't right for you, there are specially designed hernia support garments available. It's important that the size and fit are correct; so ask your doctor, specialist nurse or stoma care nurse for advice.

If a hernia is very small and not causing any problems, you might not need treatment but may be advised about lifestyle changes that could help.

# Bowel adhesions

After any type of surgery in the abdomen, bands of tissue (called adhesions) may form between abdominal tissues and organs. Normally, tissues and organs are slippery and move easily as the body moves. But, if adhesions form they can make tissues and organs stick together.

Most adhesions don't cause problems. However, if you have also had radiotherapy to your bowel, you may be more likely to have symptoms.

Sometimes adhesions can cause pain in the abdomen. Rarely, they can cause a part of the bowel to twist or kink, pulling it out of place so that it becomes blocked. This can cause symptoms such as:

- severe abdominal pain or cramping
- sickness (vomiting)
- bloating
- loud gurgling sounds from the bowel
- tummy (abdominal) swelling
- inability to pass wind
- constipation.

**If you have severe pain you should contact a doctor straight away, as this could be a sign of a blocked bowel. You may need tests such as x-rays or scans to check.**



Often the bowel is only partly blocked and gets better (unkinks) after being rested for a time. This may mean not eating for a day or so and having fluids through a drip into a vein, or it may involve taking a liquid or low-residue diet.

A low-residue diet is high in protein, low in fibre, and more easily broken down into smaller particles by the digestive system. If the bowel is completely blocked, you may need an urgent operation to relieve it.

Most people don't need treatment for abdominal adhesions as they usually don't cause problems. Surgery is the only way to break adhesions that cause pain or bowel blockage. However, surgery may cause more adhesions to form, so it's avoided where possible.

# Changes in how your bowel works

Most people have changes in how their bowel works following surgery and/or radiotherapy for bowel cancer. Many people find that their bowel habits don't go back to being exactly as they were before treatment. It may take at least a year for things to settle down. With time, bowel symptoms usually become less troublesome and most people find they get into a new routine that's normal for them.

If bowel problems don't settle, help is available. There are many things that can be done to improve bowel symptoms. Ask your doctor for advice. They can discuss with you what may help. They may also refer you to a specialist in bowel control problems for further assessment and treatment.

## Changes in bowel function after surgery

After bowel surgery your large bowel is shorter than before, so bowel motions pass through more quickly. This often settles as your body adjusts. But if part of the rectum has been removed, there may be long-term changes to how your bowel works.

### Changes caused by a shorter bowel

You may find that stools pass through the bowel more quickly and are softer and looser, or liquid. You may go to the toilet more often (frequency).

Softer stools can be more difficult to pass out of the bowel completely. This can mean needing to go back to the toilet a few times after a bowel movement to finish passing the stool.

Stools may be stickier. You may need to wipe around your back passage more after passing a stool. This may cause sore skin.

Some people alternate between having loose stools and constipation, or feeling bloated at times and having problems with wind.

### **Additional changes after rectal surgery**

The rectum is the part of the large bowel that stores stool. It has nerves and muscles that help you to hold onto stools until you're ready to pass them. After surgery these nerves and muscles may be weakened. This means that you can't hold onto stools as well as before.

You may feel the need to rush to the toilet when the urge to pass a bowel movement comes on (urgency). There may be some leakage from your bowel or there may be occasions when you aren't able to get to the toilet in time. This is called faecal incontinence.

You may also have less control over when you pass wind or find it difficult to tell the difference between wind and stool in the back passage.

During surgery to remove the rectum, the surgeon may make an internal pouch from a piece of bowel to act as a store instead of the rectum. If you have an internal pouch you may not have problems with urgency, but you may find it more difficult to empty your bowel completely and this can sometimes lead to constipation.

## Problems for people who have a stoma

If you had a stoma formed as part of your bowel surgery, it can take some time to adjust. You may have loose stools, or alternate between loose stools and episodes of constipation. You may also be more aware of wind produced by your bowel.

Some people find it difficult to predict when the stoma is going to be active.

Many of the suggestions for treating bowel function problems in the following chapter are equally relevant to people with a stoma. We've also included additional information specific to coping with a stoma where we think this may be helpful for you.

## Changes after radiotherapy to the bowel (pelvic radiotherapy)

Pelvic radiotherapy can cause scarring (fibrosis) in the lining of the large bowel making it thicker and less flexible. This means that the bowel can't hold as much and stools pass through more quickly than before. The nerves and muscles that help to hold stool in the rectum can also be affected.

These changes cause similar symptoms to those mentioned for bowel surgery (see pages 15-16). These symptoms include loose stools, more frequent bowel movements, feeling the need to rush to the toilet to move your bowels (urgency), and sometimes incontinence.

Bleeding from your back passage is also quite common. This can happen after pelvic radiotherapy because the small blood vessels in the lining of the bowel become more fragile. Usually the bleeding is mild and doesn't need any treatment.

However, bleeding can be a sign of serious conditions (including cancer) so it's important to get it checked if you notice persistent bleeding from your back passage. You should always tell your doctor if you notice bleeding from your bowel.

## **Possible changes to the small bowel after radiotherapy**

As well as its effects on the colon and rectum, pelvic radiotherapy can also sometimes affect the small bowel. This may cause one or more of the following conditions:

### **Food intolerance**

Sometimes after radiotherapy for rectal cancer the bowel can't cope as well with certain types of food, such as:

- lactose, which is found in dairy products
- fructose – a sugar found in fruits (it may also be added to foods as a sweetener in products that are often labelled 'no artificial sweeteners')
- gluten – a wheat protein found in breads, cakes, biscuits and pasta.

Eating certain foods may cause symptoms such as tummy cramps, feeling bloated and increased wind. If you think you have a food intolerance, ask your doctor to refer you to a gastroenterologist (stomach and bowel specialist).

## Bile acid malabsorption

Bile acids help us to digest fats in our food. Pelvic radiotherapy may alter the balance of bile acids in the bowel. This can cause episodes of diarrhoea that come on suddenly.

You can read about how bile acid malabsorption is treated on page 40.

## Small bowel bacterial overgrowth

The large bowel contains lots of bacteria that help digest food. But, normally, there are almost no bacteria in the small bowel. After pelvic radiotherapy, bacteria may begin to grow in the small bowel. This is called small bowel bacterial overgrowth. It can cause a range of symptoms including: diarrhoea, stools that float, wind, bloating, constipation, feeling sick, vomiting and bad breath.

Small bowel bacterial overgrowth is treated with antibiotics.

**There is more information about the possible late effects of radiotherapy to the bowel in our booklets *Managing the late effects of pelvic radiotherapy in men* and *Managing the late effects of pelvic radiotherapy in women*.**

# Treating bowel function problems

There are a number of ways bowel problems can be treated. Which treatments are likely to work best for you will depend on your symptoms and what is causing them, so it's important that you see a doctor to be properly assessed.

Your cancer specialist and their team will probably have helpful suggestions. If your symptoms still don't improve, you can ask your GP to refer you to a continence specialist or a specialist in stomach and bowel problems (gastroenterologist).

**Treatments for bowel function problems are often based on one or more of the following:**

- slowing the time it takes for stools to pass through the large bowel (bowel transit time)
- emptying the bowel more effectively
- strengthening the muscles used for bowel control
- retraining the bowel.

The following chapters have information on these treatments and techniques.

# Slowing down bowel transit time

Slowing down the passage of stools through your bowel will help to reduce the frequency of bowel motions. It will also mean your stools are less liquid. If you have firmer bowel motions, they will be easier to control and it will be easier for you to completely empty your bowel.

Diet, anti-diarrhoeal medicines and stress management can all help slow bowel transit time. However, if these don't work, ask your GP for a referral to a gastroenterologist who might suggest other treatments which could be useful.

## Diet

It's important to try to continue to eat a wide range of different food types. If you're very limited in what you can eat because of how food affects your bowel, it's definitely worth getting advice from a doctor or dietitian. It may be that another treatment, such as anti-diarrhoeal medicine, would help you to manage your bowel symptoms better and allow you to eat a wider range of foods.

Your doctor or dietitian may recommend making changes to your diet to help with bowel symptoms. This may involve eating at regular times, adjusting the amount of fibre in your diet, or taking fibre supplements (see pages 24–25).

Skipping meals may make your symptoms worse by making your bowel habits unpredictable. Eating at regular times helps to encourage a regular bowel pattern.

It's important to drink at least 1–2 litres of liquid a day. Water is best. Drinking smaller amounts throughout the day is better than drinking large amounts of liquid with meals.

Some people notice that certain types of food increase their bowel symptoms. If you think certain foods are making your symptoms worse talk to your doctor about this. You may benefit from seeing a dietitian who can advise you on whether adjusting your diet may be helpful and how best to do this.

**Keeping a daily diary of what you eat and how this affects you can help you to work out if certain foods make your symptoms worse. You can use our food and symptom diary on pages 28–29.**

Foods affect people differently, so if you're making changes to your diet there may be some trial and error before you work out what is best for you.

If you think that you may have an intolerance (see page 18) to some types of food such as dairy products or wheat, it's best not to try to cope with this alone. Ask your doctor to refer you to a gastroenterologist.

There is information on how some foods may affect the bowel on page 26–27.



## Fibre

Fibre is important in regulating how your bowel works. There are two types of fibre; **insoluble fibre** and **soluble fibre**:

- Insoluble fibre speeds up bowel motions. It's useful for treating constipation but avoid it if you have soft, frequent bowel motions or leakage. Insoluble fibre is found in bran, seeds and foods such as bread or cereals labelled as multigrain, wholegrain or wholemeal.
- Soluble fibre can help to firm up and slow down bowel motions, so it may help to reduce diarrhoea or soft stools. It's found in oats, porridge, bananas, and in apples and pears with their skin removed (the skin contains insoluble fibre).

Pulses such as peas, beans and lentils are also high in soluble fibre, but pulses stimulate the bowel so are not recommended for people with diarrhoea or soft stools.

Your dietitian, specialist nurse, continence adviser or bowel specialist will advise you on the type of fibre you need and how much you should have.

**Fibre supplements** Soluble fibre supplements such as sterculia (Normacol®) and ispaghula (Fybogel®) are often prescribed for people who have frequent bowel motions, incontinence or incomplete bowel emptying (difficulty emptying the bowel). They're also used to prevent constipation.

Fibre supplements work by absorbing water and expanding to fill the bowel, making stools bulkier and easier to push out. Fybogel can make the bowel produce a lot of gas (wind).

If this is a problem for you, sterculia (Normacol®) works as well, but without causing excessive wind.

Always make sure you're drinking plenty of fluids each day (at least two litres) when you're taking fibre supplements.

If you're adding fibre to your diet, do so gradually to give your body time to adjust. Start with small amounts and slowly increase this when you're ready. Some high-fibre foods can make you produce more gas, so you may need to avoid these if you have problems with wind and bloating. You should also make sure you drink more water if you are adding more fibre to your diet.

**Eating more fibre won't be right for everyone. If you've had radiotherapy to your bowel, you may not be able to cope with as much fibre in your diet as before. So, eating the recommended five portions of fruit and/or vegetables every day may not always be appropriate.**

## Food Chart

The following foods may increase or reduce bowel symptoms. This is only a guide as foods can affect people differently.

**Foods that stimulate the bowel** Eating less of these foods may help if you have problems with diarrhoea, soft stools or frequent bowel movements. Eating more of them may be helpful if you have constipation:

- some types of fruit (fresh, tinned or dried), particularly: grapes, fruits with stones such as apricots, plums, peaches and prunes and most berry fruits except blueberries
- fruit juices – such as prune, orange, apple and grape juices
- vegetables and pulses – especially beans, broccoli, brussel sprouts, peas, cabbage, garlic, onions, peppers, spinach and sweetcorn
- bran and foods high in insoluble fibre – such as wholemeal bread and high fibre breakfast cereals including muesli and bran flakes
- spices such as chilli and curry
- caffeine in coffee, tea, hot chocolate, cola and in some energy drinks
- nuts, linseeds and popcorn
- sugar-free foods containing sorbitol, mannitol or xylitol: such as sugar-free chewing gum, some mints, sweeteners and diet drinks
- alcohol – especially beer and red wine.

### Foods that may cause wind

- vegetables and pulses – especially beans, broccoli, brussels sprouts, cabbage, cauliflower, cucumber, garlic, onions, peppers, spinach and sweetcorn
- beer and fizzy drinks
- chewing gum
- nuts
- sorbitol – a type of sugar found in some artificial sweeteners, some sugar-free foods and in apples, pears and peaches.

### Foods that may help wind or bloating

- peppermint oil (you can get capsules from the pharmacy or have it prescribed by your doctor)
- live yoghurts or probiotic drinks.

### Foods that may help make bowel motions firmer

Reducing the amount of fibre in your diet is likely to help make your bowel motions firmer. Including the following foods in your diet may help:

- bananas
- potatoes
- white bread (not high-fibre)
- white rice
- pasta (not wholemeal).

**The food and symptom diary on the following pages will help you to learn how different foods affect you.**

## Food and symptom diary



## Medicines

It's important to speak to your doctor or specialist nurse before taking medicines to treat bowel symptoms.

### Anti-diarrhoeal drugs

Anti-diarrhoeal drugs work by slowing bowel transit time and drying out the bowel motions.

The most commonly used anti-diarrhoeal drug is loperamide (also called Imodium® or Diareze®). It slows down your bowel; making the stools more solid and less frequent.

Taking loperamide regularly, half an hour before meals, works very well for some people. Loperamide is also available as a syrup, so you can adjust the dose as needed. It may take time to find what dose works best for you. Your doctor may recommend you start with a low dose and increase this until it's right for you.

It's safe to take loperamide for as long as you need it, but you should discuss this with your doctor. Other anti-diarrhoeal medicines, such as lomotil or codeine phosphate, are also sometimes used.

### Medicines that can increase bowel symptoms

Some medicines can make bowel symptoms such as wind or frequent bowel motions worse. These include:

- non-steroidal anti-inflammatory painkillers (NSAIDs), such as ibuprofen and diclofenac
- magnesium in antacids (for heartburn)
- lactulose and Fybogel

- metformin – a tablet used to treat diabetes
- beta-blockers – tablets to treat high blood pressure
- antibiotics
- some types of antidepressants such as venlafaxine and citalopram.

If you're taking any of these drugs and think they may be making your symptoms worse, talk to your doctor about whether there are any alternative drugs that might affect you less.

## Managing stress

Your emotions can also affect your bowel. Anxiety and stressful situations can make bowel movements looser and more frequent. If you don't feel in control of your bowel, this in itself can be stressful.

Learning how to relax may help to settle your bowel and will be good for your general health. Stress reduction is taught at some continence clinics. Your doctor or specialist nurse can tell you about relaxation classes in your area. Some support groups also offer relaxation classes.

Relaxation tapes and CDs are available from bookshops and some health shops, and you can download relaxation podcasts from the internet. See the back of this booklet for organisations that provide a mail order service.

Some people find that complementary therapies (see page 61) help them feel less stressed. Call our cancer support specialists on **0808 808 00 00** for details of what complementary therapies are available in your area.

# Emptying your bowel more effectively

After rectal surgery some people may find it difficult to completely empty their bowel. Signs that your lower bowel may not be emptying completely can include:

- feeling there is still something in your bowel after you've passed a stool
- having leakage of stool after you go to the toilet
- needing to return several times after having a bowel movement.

It's best to hold off going to the toilet until the urge to pass a stool is strong (see page 39 for some tips if this is difficult for you). For most people the best time to empty the bowel is around 30 minutes after eating a meal (breakfast or main meal).

Straining to try to complete a bowel movement can weaken your pelvic floor muscles and cause problems with bowel control in future. If you have to wait for a long time after sitting down this may mean that you're going to the toilet too soon or that you're constipated.

Sitting in the right position is very important in helping you to empty your bowels effectively. Lean forward a little and rest your elbows on your knees. Have your knees higher than your hips. It may help to place a small footstool or telephone book under your feet. Don't strain or hold your breath. You may find using a relaxed breathing technique helps.

The diagram below shows the correct position:



Caution; if you have had recent hip surgery don't use this position, and always check with your doctor first.

If you have constipation, include more fibre in your diet and eat more foods that encourage (stimulate) your bowel to empty (see page 26).

Our food and symptom diary (see page 28–29) will help you to learn how different foods affect you.

Some people may need to take laxatives to stimulate their bowel as well as making dietary changes. Your doctor or a continence adviser can assess your need for laxatives.

Bowel motions that are too soft can also cause problems with incomplete emptying. Look at our suggestions on diet and anti-diarrhoeal medicines on page 30 for help in dealing with this. If you still have difficulty emptying your bowel completely; suppositories, enemas or bowel irrigation may be recommended for you. Your doctor or a continence specialist can talk through these options with you and help you to decide which might suit you best.

## **Suppositories**

You put these into your back passage or stoma. As they dissolve they release a lubricant, such as glycerin, which encourages the bowel to empty. They usually take about 10–30 minutes to work.

## **Enemas**

These contain a small amount of gel or liquid that you squeeze into the lower bowel to stimulate it to empty.



## Bowel or colostomy irrigation

This is a way of emptying the bowel by introducing warm water into it. Some people use bowel irrigation to help control an irregular bowel habit.

It means you can empty your bowel at a time that suits you and that you are less likely to have leakage or incontinence at other times.

Irrigation can also be used to regulate a stoma (this is called colostomy irrigation). This can mean fewer worries about a stoma becoming active at inconvenient times.

You place a narrow, flexible tube (catheter) into your back passage or stoma and then introduce water into the bowel through this. You usually do this every day or every other day. It takes about half an hour.

Some people find bowel or colostomy irrigation too time-consuming, but others say they feel more in control of their bowel and more confident as a result.

If you want to know more about bowel or colostomy irrigation, ask your continence specialist or stoma nurse. If it's suitable for you, you'll be taught how to do it and given the equipment you need to carry it out.

**You should only use bowel or colostomy irrigation if recommended by a healthcare professional.**

# Exercises to strengthen the muscles used for bowel control

If you have leakage from your bowel, learning exercises to strengthen the muscles that are important for bowel control can help.

There are two main groups of muscles that are important for bowel control. These are the sphincter muscles in the back passage (anus) and the pelvic floor muscles, which are also important for bladder control and sexual function.

Pelvic floor exercises (sometimes called Kegel exercises) may help if you have problems with leakage of wind or stool from your back passage. A continence specialist can tell you if these exercises are likely to help you and can teach you how to do them.

The Bladder and Bowel Foundation also produces a fact sheet with instructions on how to do them which you can order or download from its website (see page 85).

It can take at least 12 weeks of practising pelvic floor exercises three times a day to get the muscles back into shape. As your muscles improve, try doing the exercises while you're doing everyday jobs.

## Biofeedback training

If you find it difficult to learn the exercises, you may be offered biofeedback training to help you. As you squeeze your pelvic floor muscles, the pressure is measured by sensors. This helps you to know when you're squeezing in the right way. Ask your continence adviser for more information about this.

# Bowel retraining

Having loose bowels or urgency can affect your confidence in your ability to ‘hold on’. Worrying that you may not get to the toilet in time can make you very anxious. You may be very aware of any activity in your bowel, including wind, as you try to monitor your bowel for signs that you need to ‘go’.

Continence specialists can help by teaching you to retrain your bowel. The aim is to help you build up the length of time you can ‘hold on’. Bowel retraining will most likely be used in combination with other approaches such as anti-diarrhoeal medicines (see page 30) and muscle strengthening exercises (see page 37).

With bowel retraining you learn to resist the urge to go right away. At first you start by getting to a toilet when you feel the urge. You then wait for a minute or so before actually sitting on the toilet to open your bowels. The aim is to gradually increase the time between feeling the urge to go and then emptying your bowel. This will build up your confidence and give you more control of your bowel.

# Other treatments

## Treating bile acid malabsorption

If you've had radiotherapy to the bowel, or surgery to the right side of the colon (a right hemicolectomy) and you have episodes of diarrhoea (that aren't helped by anti-diarrhoeal medicines) you may have bile acid malabsorption (see pages 18–19).

This can be treated by a drug called colestyramine (Questran®). It comes as a powder that you mix with water or fruit juice. Most specialists advise taking it at mealtimes rather than (as the instructions say) on an empty stomach, because they believe it works better and is easier to take this way.

If your stool is sometimes pale, smelly and difficult to flush away, colestyramine may not work or it may make things worse. If this happens, your specialist may prescribe a newer medicine called colesevelam (Cholestagel®). You may also be referred to a dietitian for advice on following a diet that's lower in fat.

## Sacral nerve stimulation

This is a new treatment that is sometimes used to treat bowel symptoms that are very troublesome and haven't been helped by other treatments.

Sacral nerve stimulation uses electrical pulses to stimulate the nerves to the bowel and regulate how it works. It involves placing electrodes under the skin in the lower back (sacral area) and connecting them to a pulse generator. This produces pulses of electricity that are thought to affect the nerves that control the lower part of the bowel and the anal sphincter.

The treatment is given in two parts. First you are tested with temporary electrodes to see if sacral nerve stimulation works for you. If the test is successful you'll be offered an operation to have a small permanent implant fitted.

## Specialist products

If you have problems with bowel leakage or incontinence, you may want to wear an absorbent pad in your underwear in case of accidents.

Pads and pants with charcoal linings, and stoma bags with filters can help to minimise odours from leakage or wind. There are a wide range of products available and a continence specialist or stoma nurse can help you select what type best suits your needs.

If you have a stoma, it can take some time to find the right equipment that works best for you. It's important that you get expert support and advice from your stoma nurse while you're doing this.

Anal plugs are used by some people who have leakage from their bowel. They are made from soft foam and stop leakage for up to 12 hours. A cord attached to the plug allows you to remove it when you're ready. Some people find anal plugs uncomfortable to begin with but most people get used to them after using them a few times. Your continence specialist can tell you more.

# Changes to bladder function

Some people have problems with bladder control after treatment for rectal cancer. Changes also happen as the bladder muscles age, so these symptoms can also be due to ageing, and are more common as people get older.

The bladder is a stretchy, muscular bag that collects and stores urine. It's in the lower part of the pelvis, connected to the kidneys (which produce urine) by tubes called the ureters. Urine drains from the bladder through a tube called the urethra, which connects the bladder to the outside of the body.

## Possible effects of surgery

Sometimes an operation to the rectum can affect the nerves to the bladder. These nerves control the muscles that hold urine in the bladder and also tell the muscles to squeeze to empty the bladder. Nerve damage can cause loss of bladder control leading to leakage of urine (urinary incontinence) or difficulty in emptying the bladder (incomplete emptying).

## Possible effects of radiotherapy

Radiotherapy to the rectum and surrounding tissues (pelvic radiotherapy) often causes bladder symptoms that get better within a few weeks of treatment ending. It's not common for radiotherapy to the bowel to cause long-term changes to the bladder, but a small proportion of people do notice changes to their bladder function several months after treatment.

Bladder symptoms due to the late effects of radiotherapy can include:

- needing to pass urine more often than usual
- a burning sensation when you pass urine (like cystitis)
- being unable to wait to empty your bladder (urgency)
- leaking urine (incontinence)
- blood in your urine (haematuria)
- difficulty passing urine.

**If you have any of these symptoms it's important to have them checked out by your doctor. Blood in the urine should always be checked by a doctor without delay.**

We have more detailed information about bladder changes due to pelvic radiotherapy, and what can help, in our booklets for men and women on managing the late effects of pelvic radiotherapy.

## Managing bladder changes

Bladder problems can be embarrassing and difficult to talk about. If you're having difficulties, you may feel worried about going out and taking part in social occasions. However, there are many things that can be done to manage symptoms.

We've included some information about these in the following pages. It's important to talk to your doctor if you're having problems. They can refer you to a specialist in bladder control problems, such as a urologist or continence nurse, for assessment and treatment.

You can also find helpful advice in the chapter Coping with bowel and bladder changes on pages 48–52.

### **Incomplete bladder emptying**

Sometimes nerve damage means the bladder muscle can't squeeze strongly enough to empty the bladder completely. The most common symptoms of this are:

- difficulty passing urine
- a delay in starting to pass urine
- a weak stream of urine
- straining to release urine.

If you have any of these symptoms, it's important to get them checked out as they can lead to more serious problems if left untreated. There are other common conditions that can cause problems with bladder emptying, such as an enlarged prostate gland in men, so this may not be related to your cancer treatment. Your doctor or continence specialist will do tests to find out the cause so you can be offered appropriate treatment.

### **Urinary incontinence**

Urinary incontinence can vary in its effects. For some people it means leaking just a few drops of urine when sneezing or coughing. For others it may mean a total loss of control over passing urine.



If you have symptoms, a continence specialist can assess the severity and type of incontinence you have and recommend treatment based on this.

One of the most common treatments for urinary incontinence is exercises to strengthen the muscles that are important for bladder control (pelvic floor muscles). These exercises can also help with bowel control. You can read more about these exercises on pages 37–38.

## Coping with urinary incontinence

There are specialist products and practical things that can help you to cope with urinary incontinence while you're waiting for a diagnosis or for a treatment to work. A continence specialist can give you more information about the different products available and can help you select which type best suits your needs. The Bladder and Bowel Foundation can also offer advice and support via its helpline and website – see page 85.

## Biofeedback training

If you find it difficult to learn pelvic floor exercises, you may be offered a procedure called biofeedback training to help you. As you squeeze your pelvic floor muscles, the pressure is measured by sensors. The results are either shown on a computer screen or they register as a sound. This helps you to know when you're squeezing the muscles in the right way. Your continence adviser or physiotherapist can advise you on where you can get this training.

## Specialist products

There is a wide range of pads and pull-ups that absorb urine leaks. They have a layer that draws urine away from the surface, so your skin stays dry. There are designs for both men and women and for different types of incontinence.

You can buy pads for mild to moderate incontinence in most supermarkets, pharmacies and online. If these pads aren't absorbent enough, you can get bigger pads from your continence nurse or district nurse.

Sheaths and leg bags may be useful for men who don't want to use pads. A sheath fits over the penis and urine is drained into a bag that is strapped to the leg.

There are also various types of pads that you can use on your bed at night. They soak up any urine leakage, keeping your skin dry and helping you sleep through the night.

What's available on the NHS varies from region to region. Your district nurse can advise you whether you're eligible for continence products through the NHS. The Bladder and Bowel Foundation also provides a list of suppliers of incontinence products – see page 85.

# Coping with bowel or bladder changes

If you have bowel or bladder changes, the most important thing to do is to ask for professional help. There are often things that can be done to improve symptoms or sometimes get rid of them entirely.

However, it may take time before your symptoms improve. In the meantime, there are things that can help you feel more confident and in control.

## Protecting your skin

If you have problems with leakage from your stoma, bowel or bladder, it can make the surrounding skin in the area sore. There are many products available that can help protect your skin. Your continence adviser or stoma nurse will be able to give you more information.

Here are some suggestions:

- Keep your skin clean and dry.
- Try using unperfumed wet wipes, rather than toilet paper, as they are kinder to your skin.
- Absorbent pads and barrier creams (such as Cavilon® or Sudocrem®) help to protect your skin.
- Wear cotton underwear – it allows your skin to breathe more than man-made materials.

## Going out

You may feel worried about going out, especially to somewhere new. Planning ahead so that you're prepared can help you feel more confident.

### Access to toilets

If you're going somewhere you're not familiar with, it's a good idea to find out where the toilets are in advance. Many towns and counties have lists, maps and information about the public toilets in their area as lists or maps. Often these are found on local authority websites.

There are too many of these websites to list here but you'll be able to find them on the internet. Try putting the terms 'public toilets' and the name of the place you plan to visit into a search engine to find out what's available.

Carrying a 'Just Can't Wait' card may help you to get access to a toilet more quickly when you're out. It states that the card holder has a medical condition that requires urgent access to a toilet. You can get a 'Just Can't Wait' card from the Bladder and Bowel Foundation or Disability Rights UK (see pages 85 and 86).

**You can use disabled toilets too. These often offer more privacy, have a wash basin and more space if you need to change. The National Key scheme for Toilets offers people with a disability access to about 9,000 locked public toilets across the UK.**

**You can buy a key from Disability Rights UK (see page 86). They can also send you details of where the toilets are located.**

### **Take a bag with supplies**

Pack a bag of the things you may need when you go out. This will make you feel more confident and help you to cope if an accident occurs.

You may want to include:

- wet wipes
- barrier cream such as Cavilon® or Sudocrem®
- loperamide (if you have bowel control problems)
- pads and pants (or stoma supplies if you have a stoma)
- a change of clothing
- a sealable bag.

### **Keep to a healthy weight**

Being overweight puts pressure on your pelvic floor muscles, so it's especially important to keep to a healthy weight if you have bowel or bladder control problems. Your GP can advise you on the healthy weight range for your height and build.

**Our booklets *Weight management* and *Healthy eating and cancer* have more information. We can send you this information for free.**

## Keeping physically active

Keeping active will help you manage your weight and avoid getting constipated. This is important to help look after your pelvic floor muscles. Exercise also helps you feel better and can reduce stress.

Some people find that more vigorous types of exercise make symptoms such as incontinence worse. If this is the case for you, try gentler (lower impact) exercise, such as walking or swimming. Once your symptoms are under control and you're feeling more confident, you may want to gradually introduce other types of exercise.

If you have a stoma, there is no restriction on the sports that you can play apart from contact sports. Ask your stoma nurse if you're in doubt about what you can do.

**There's more information in our booklet *Physical activity and cancer treatment*. We can send you a copy for free.**

## Getting support

Bowel or bladder problems can be embarrassing and difficult to talk about and can make you feel isolated. Everyone has their own ways of coping. Some people find it easier to talk about personal things than others do. Some use humour to help them keep positive, or some choose to see difficulties as challenges to be overcome. Do whatever feels right for you.

Health professionals can give you lots of support and advice, especially if you let them know about the problems you're having. They're used to dealing with and discussing intimate problems and can refer you to a counsellor or specialist if you need more help.

Support groups, online community sites and specialist organisations can also provide invaluable support. They're a good way of meeting other people who may have been through similar difficulties. You can then share experiences and solutions with each other. Partners, family and close friends can also help you keep things in perspective and reassure you that you're valued for who you are.

# Your sex life

Bowel cancer and its treatment can affect your sex life and how you see yourself (self image). Sexual difficulties can arise as a result of the physical and emotional effects of cancer and its treatment. You may feel too exhausted to have sex during treatment and for a while afterwards. Most people find that this gradually improves, but occasionally it can last for months or even longer.

Many people find it difficult to talk about sexual issues because they feel embarrassed or self-conscious. Your doctor or specialist nurse will be used to talking about these issues and can advise you where to go for specialist help and support. You can also find a list of organisations that offer information and treatment on pages 89–90.

**Our booklet *Sexuality and cancer*, has more detailed information about sexuality.**

## Low sex drive (libido)

Some people find that their interest in sex is reduced after treatment. There can be different reasons for this:

- Coping with cancer and its treatment can cause anxiety, depression and low self-esteem.
- Tiredness (fatigue) may carry on for months after treatment.
- Changes to how you feel about yourself sexually may lower your sex drive.

- Reduced levels of sex hormones due to treatment. There is more information about menopausal changes in women and reduced testosterone in men on the following pages.

If you have a partner, let them know how you feel. Explaining why you don't feel like sex can reassure them that it isn't because your feelings for them have changed.

## Possible sexual changes in women

After treatment for rectal cancer some women feel their orgasm is less intense than before. It may also take longer to reach orgasm. This is thought to be due to changes in the blood flow and nerves in the pelvic and genital area.

The vagina may be shortened or narrowed by surgery or radiotherapy. If the rectum, which normally cushions the vagina, has been removed, sex may be uncomfortable.

Sometimes a different sexual position can feel better. You may need to experiment to find out what works best for you. Some women feel more relaxed if they can take control over the depth and speed of penetration. You can also use pillows and cushions to give you support.

Radiotherapy to the pelvic area can cause changes to the vagina. It may become drier, narrower and less flexible. Your hospital team may recommend that you use vaginal dilators to help. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Your specialist nurse or doctor will explain how best to use them.



If you find sex uncomfortable because of vaginal dryness, your doctor can prescribe you a cream or gel to treat this. Simple lubricants such as Aquaglide®, Senselle® or Replens® can be bought from most chemists.

### **Menopausal symptoms**

Some treatments such as chemotherapy, radiotherapy or rectal surgery may affect the ovaries in women who haven't been through the menopause. This can cause menopausal symptoms that make sex difficult, such as a dry vagina or lowered sex drive. Your doctor may be able to give you hormone replacement therapy (HRT), which can make up for these changes.

A woman who has already had her menopause will have far fewer hormonal changes. The Daisy Network offers information and support for women going through an early menopause – see page 89 for details.

**You can find more information on managing possible sexual changes after radiotherapy in our booklet *Managing the late effects of pelvic radiotherapy in women*.**

### **Possible sexual changes in men**

Surgery or radiotherapy for rectal cancer can affect a man's ability to get and maintain an erection. During surgery to remove rectal cancer, nerves that supply the penis may be damaged. After radiotherapy some men notice that their erections are less strong than before and that this gradually gets worse over a year or two.

This may happen if radiotherapy has caused damage to nerves or scarring in blood vessels that supply the penis.

Treatment with drugs such as sildenafil (Viagra®) can help some men to get and maintain an erection after surgery or radiotherapy. When problems do occur after treatment, there's some evidence to suggest that by starting tablets (such as Viagra) sooner rather than later, your ability to get and maintain an erection will be improved.

For men who can't take these drugs or who aren't helped by them there are alternative methods that may help. You can find out more about these in our booklet *Sexuality and cancer*.

### **Low testosterone levels**

After radiotherapy for rectal cancer the levels of the male hormone testosterone are reduced in some men. If blood tests show you have low testosterone levels your specialist can tell you if testosterone replacement therapy is likely to be helpful for you.

**You can read more about the possible effects of radiotherapy in our booklet *Managing the late effects of pelvic radiotherapy in men*.**

## If you have a stoma

If you have a stoma, you may find some sexual positions uncomfortable. It can also affect your self-confidence and you may feel self-conscious about the change in your body. This may result in sexual difficulties with your partner or make you feel anxious about new relationships.

Occasionally problems may arise because partners are struggling with change. However, your partner may not have a problem with your changed appearance. It can be helpful to try to discuss it if you feel there's awkwardness between you.

If you're feeling self-conscious about how you look, talking with your partner about how you feel can help you regain some confidence. Focus on a part of your body that you like and use this as a foundation to build confidence in your body. If you feel very self-conscious, making love while partly dressed or keeping the lighting low may help.

Stoma nurses can give you advice and help with the effects a stoma can have on sexuality. Information is also available from the Sexual Advice Association (see page 90) or the Ileostomy and Internal Pouch Support Group (see page 86).

# Tiredness (fatigue)

Tiredness (fatigue) is probably the most common side effect of bowel cancer treatment. You may lack energy and find doing everyday tasks exhausting. Rest often doesn't make it better. It can affect the way you think and feel, and even things you usually enjoy, such as reading or watching TV, can be difficult. It can affect your relationships and make you impatient with people around you. You may avoid socialising because it's too much effort.

It's not unusual for fatigue to last for many months after treatment is over. Occasionally, in some people, it may last for a year or two.

If you're experiencing fatigue you may:

- feel that you've got no energy or strength and could spend whole days in bed
- have difficulty doing the smallest chores, and everyday activities like showering or cooking can seem impossible
- have difficulty concentrating or thinking clearly, or in making decisions and remembering things (page 63–67)
- feel breathless after very little exertion, or feel dizzy or light-headed
- have sleep problems
- lose interest in sex (page 53–54)
- feel more emotional than usual.

## Possible causes

Recovering from cancer treatments can take time and fatigue is often a part of this.

Sometimes fatigue is linked to problems such as depression, sleep problems, pain, anaemia or thyroid problems. So it's important to find out if there's a particular cause of your fatigue so that it can be treated.

**The most important thing is to tell your doctor or nurse how you're feeling. Don't play it down. Tell them how your fatigue is when it's at its worst.**

Your doctor can take blood samples to find out if you have anaemia (low number of red blood cells), or to find out if your thyroid gland is underactive. Both of these conditions can be treated with medicines.

Fatigue is a common symptom of depression. It's not unusual to feel depressed, anxious or stressed after treatment for cancer. If you think you're depressed, talk to your doctor or nurse. You and your doctor will be able to work out if what you're feeling is depression or fatigue. Talking about your feelings with a professional counsellor can often help depression, and antidepressants may help you feel better.

If sleep or pain problems are causing or contributing to your fatigue, then improving these will help you feel better.

**The quality of your sleep is important and you can read more about ways of getting a better night-time rest in our booklet *Coping with fatigue*.**

Coping with pain is tiring and also affects the quality of your sleep. If you have effective treatment for your pain, this may improve your energy levels.

## **What you can do to help yourself**

Taking care of yourself is very important and can help you to feel better.

- Regular exercise can help to reduce fatigue and build up your energy levels. It doesn't need to be strenuous – short walks are a good way to begin. Exercise also helps you to sleep better and can improve anxiety and depression. You can read more in our booklet *Physical activity and cancer treatment*.
- Complementary therapies may help to reduce stress and anxiety, and may improve fatigue. Relaxation, counselling and psychological support are available at many cancer treatment hospitals. You can read more in our booklet *Cancer and complementary therapies*.
- Keep to a routine. Going to bed at the same time and getting up at the same time each day can help. Try not to stay in bed in the morning after you've woken up.
- Eat well and keep to as healthy a diet as possible. This can help you feel better and may help you to have more energy.
- Allow people (family, friends, neighbours, social workers, carers) to help you. Generally people are glad to help, particularly if you can tell them what you need.

- Make a list of tasks you'd like help with such as taking out rubbish, paying bills or setting up direct debits to pay bills. If you have access to the internet, shopping can be done online and delivered to your home.

Problems with concentration and memory are common with fatigue and can be frustrating to deal with. You can read about ways to cope with concentration and memory problems on pages 66–67.

**Our booklet *Coping with fatigue* has more suggestions that you may find helpful.**

# Concentration and memory problems

After cancer treatment, some people have difficulties concentrating and remembering things. Doctors call this cognitive impairment. Cognitive means thinking or the way we process information. Impairment or dysfunction means that something isn't working.

At the moment it's not clear which treatments may cause these problems, or whether they may be caused by the cancer itself or by emotions such as anxiety and depression.

Because changes in memory and thinking were first noticed in people who'd had chemotherapy, the terms 'chemobrain', or 'chemofog', are sometimes used to describe these changes. However, these terms may be misleading as changes in memory and concentration can also happen in people who have had cancer, but have never had chemotherapy.

Changes in memory or in the ability to concentrate are usually mild and often get better within a year of finishing treatment.

Occasionally these changes can go on for longer or have more marked effects on daily activities.

Here are some examples of the difficulties people describe:

- difficulty in concentrating and focusing (feeling foggy)
- feeling mentally slower than before and finding it hard to take things in

- forgetting details of conversations or events that you'd usually have no problem remembering
- mixing up dates and appointments and not being able to find things easily
- difficulty doing more than one thing at a time (multitasking)
- struggling to find everyday words or phrases.

If you're having these problems it's a good idea to talk to your doctor about them. They will check if your symptoms are connected to any other causes. This can include the cancer itself, or the side effects of other treatments or medicines that you may be taking. Your doctors may decide to do some tests, such as blood tests or a scan, to investigate further. There may also be other factors contributing to your symptoms and having these treated could help.

Fatigue (extreme tiredness) is a common side effect of treatment and can cause problems with concentration and memory. Managing or treating fatigue may help improve these problems. You can read more about this on pages 61–62.

Anxiety, stress and depression can all cause difficulty with memory and concentration. These symptoms aren't unusual in people who've had treatment for cancer. They can also affect your sleep and make you feel very tired. Treating these symptoms may help to improve memory and concentration.

If you're in pain or have other symptoms, such as feeling sick, it can be difficult to focus on anything else. Having symptoms treated may help improve problems with concentration. If you think that the drugs you're taking to control your symptoms are affecting your concentration, let your doctor know.



## Treatments for concentration and memory problems

A number of drugs have been tried to help people with cognitive impairment but, as yet, none have definitely proved successful. Research is ongoing to find an effective treatment.

A type of talking therapy called Cognitive Behavioural Therapy (CBT), which focuses on memory and attention, may be helpful. Your GP can tell you more about this and can refer you for help.

## What you can do to help yourself

There are different things you can do to improve your symptoms and help you to cope:

- Use things to help your memory such as planners, calendars, post-it notes and to-do lists.
- Keep notes of anything important, such as conversations with your doctor or nurse.
- Try to do one thing at a time.
- Have a daily routine and try to stick with it. Whenever it's possible, cut out things that distract you (such as background noise) when you're trying to concentrate on a task.
- Keep things in the same place. You'll know where they are even if you don't remember putting them there.
- If you need to take something with you when you leave the house, put items near the front door beforehand.
- Use a pill box dispenser if you need to take medicines.
- Try brain exercises such as crosswords, word puzzles or sudoku to help improve your concentration.

- Try to do simple arithmetic in your head for things like calculating your change.
- Keep a diary or note of times when your concentration or memory problems are more noticeable or worse. You can then plan to do things that require more concentration when you're most likely to be at your best. You'll also be able to recognise if there are patterns or triggers that make things worse for you.
- Look after yourself. Get plenty of rest but try to balance this with regular exercise. Exercise can help with fatigue and sleep problems, so may in turn improve your concentration and memory.
- Tell your family and friends about the difficulties you're having. They can support you and help you find ways to make life easier.
- Find some quiet activities that help you to wind down and feel less anxious. Some examples are yoga, exercise, meditation, reading and complementary therapies.

# Peripheral neuropathy

Peripheral neuropathy (also called neuropathy) is a term used to describe damage to nerves that carry messages between the brain, the spinal cord and the rest of the body. Nerve damage can cause symptoms such as pins and needles, numbness, weakness, or pain in the hands and feet. For a few people this may lead to problems with balance and walking.

Treatment with the chemotherapy drug oxaliplatin is the most common cause of peripheral neuropathy in people who've had treatment for bowel cancer. After treatment is over, most people find their symptoms gradually improve as the nerves slowly recover. This usually takes several months. But for some people the nerves don't completely recover and some nerve damage is long-term.

Despite this, many people find that their symptoms become less troublesome over time as they adapt and find ways of coping with the changes.

**We have a fact sheet about peripheral neuropathy, which gives more detailed information.**

## Treating pain

Nerve pain can be treated in different ways. Some drugs alter nerve impulses and so help to relieve nerve pain. Drugs that can do this include: some antidepressants, anticonvulsants (drugs used to treat epilepsy) and some heart drugs. Drugs such as morphine can also sometimes be helpful.

If your pain is difficult to treat, you can ask for a referral to a pain clinic where you can get expert help from specialist doctors and nurses.

**Transcutaneous electrical nerve stimulation (TENS)** uses pads, put onto the skin, that give off small electrical pulses to stimulate nerves close to the pain. This may block pain messages sent from the nerves to the brain and is unlikely to cause side effects.

**Acupuncture** uses very fine needles that are placed through the skin at particular points. It isn't clear exactly how this works, but it may help to block pain messages from being sent to the brain. Some hospitals and GP surgeries offer acupuncture on the NHS. You can read more in our booklet *Cancer and complementary therapies*.

## Other support

A physiotherapist will be able to offer treatment and advice for problems with balance or walking.

If you're having difficulty carrying out daily tasks, you can ask to be referred to an occupational therapist. They can assess your needs and recommend aids and equipment to help you.

If your symptoms continue for more than six months and cause you difficulty in walking or carrying out daily activities, you may be entitled to financial help. You can contact our cancer support specialists on **0800 808 00 00** for more information.

## What you can do to help yourself

If your hands and/or feet are affected it's important to protect them as much as possible. If your balance, coordination or walking is affected, it's important to reduce your risk of accidents and falls.

Here are some general tips:

- Keep your hands/feet warm – wear gloves and warm socks in cold weather.
- Wear well-fitting shoes or boots.
- Wear gloves when working with your hands, for example when doing household chores, gardening or DIY.
- Use potholders and oven gloves to avoid burning your hands when cooking.
- Avoid walking around barefoot and check your feet regularly for any problems.
- Test the temperature of water with your elbow to make sure that it isn't too hot before baths or showers.
- Turn the temperature control to a lower setting for hot water or have a temperature control (thermostat) fitted.
- Make sure rooms are well lit, and always put on a light if you get up during the night.
- Keep areas that you walk through, such as halls, free of clutter and make sure there aren't things such as loose rugs that you could trip over.
- Get advice from a physiotherapist about walking aids if your balance is affected.

# Your feelings

It's not unusual to have difficult feelings to cope with months or even years after cancer treatment, especially if you have late effects from it. Some of the feelings you may have are explained below, along with what might help. Some people only experience a few of these and may be able to deal with them easily. For others they may be harder to cope with but most people find that they get better over time.

Even with ongoing treatment effects, many people find that cancer has helped them to focus on what's important in their lives. Some people feel that although they wouldn't have chosen to go through this experience, it's changed them in positive ways.

## Uncertainty

It's natural to worry about the cancer coming back. You might feel as if you can't plan for the future or enjoy day-to-day life. People often find that this feeling gets better over time as they focus on other things besides the cancer. Getting yourself organised each day and taking control of the things you can change in your life, such as your lifestyle, can help.

If your fears are becoming overwhelming, talk to your GP or cancer specialist. They can then refer you to a counsellor for expert help.

## Feeling alone (isolation)

After treatment, some people feel isolated or insecure. This may be because you have less contact with the hospital or because you don't know other people who are experiencing late effects.

You may find your follow-up appointments help with any sense of isolation. Follow-up involves checking for and treating any late effects and giving you advice on how to manage them.

Remember, you don't have to wait until your follow-up appointment if anything is worrying you. If you notice any new symptoms between appointments, let your doctor know.

You can also talk to your GP or our cancer support specialists on freephone **0808 808 00 00**. There are other ways in which you can build up your support, such as joining a support group or online social networking site.

## Negative feelings

You may worry that having negative feelings or feeling stressed may slow your recovery or increase the risk of the cancer coming back. But, there's no evidence that negative feelings or stress increases the risk of cancer coming back.

Most people who have had cancer – even the most optimistic – have times when they feel low or depressed. No one can be positive all of the time, so don't put pressure on yourself to stay on top of things when you're finding it tough. It's positive to acknowledge and talk about your feelings.

## Anger

It's natural to feel angry when you've had cancer, especially if you're still coping with late effects. Don't feel bad about feeling this way. Sometimes it can help to simply tell yourself, or people you trust, when you're angry. Even just saying the words 'I'm angry' can be a relief.

Bottling up feelings may make you feel depressed, tired and anxious. If you're bottling up your feelings because there's no one you feel able to talk to, counselling may be helpful.

## Depression

After treatment for bowel cancer, some people may feel physically and emotionally exhausted which can lower their mood. Usually, feelings of anxiety, sadness or anger lessen over time and your mood improves.

However, for some people these painful feelings don't get better and they may become depressed. Some of the emotional signs of depression can include:

- feeling low in mood most of the time
- having no interest in, or enjoyment from, things that you would normally enjoy
- feeling helpless or hopeless
- feeling numb, overwhelmed or out of control
- constantly focusing on worries.

You may have sleep problems, difficulty in concentrating or no interest in sex. Some people also have physical symptoms, such as a dry mouth and racing heart (palpitations).

If you think you may be depressed, talk to your doctor or nurse. These feelings are common and they can tell you what help is available. Your doctor can refer you to a counsellor or psychologist. Sometimes a short course of antidepressant drugs can be helpful.

Try to let your family and friends know how you're feeling so they can support you.

Talking about your feelings isn't always easy. You can read some helpful tips about this in our booklet *Talking about your cancer*.

**It's important to be kind to yourself and not feel bad about needing extra help to deal with your emotions.**

There are many other ways you can help yourself as well. Some people find using complementary therapies or taking regular exercise to be helpful. Talking to other people who are facing similar challenges by joining a support group or using social networking sites may also be helpful.

**You can join the Macmillan online community at [community.macmillan.org.uk](http://community.macmillan.org.uk) to talk to others and get support at any time.**

# Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you wouldn't have been able to cope so well without the support you've had from family and friends.

However, cancer is stressful and this sometimes has an effect on your relationships. Any problems usually improve over time, especially if you can talk openly with each other. On the following pages, we've listed some of the issues that sometimes arise in relationships and some ways of coping with these.

## Family and friends

You may sometimes feel that your family and friends don't understand if you aren't feeling positive about getting on with things. You may feel they don't realise how much the effects of treatment are interfering with your life. Talking openly about how you're feeling will help them to understand you better and give you the support you need.

**Our booklet *Talking about your cancer* has useful tips on how to talk to family and friends.**



## Children

How children have been affected by your illness often depends on their age. Younger children may feel that they're somehow to blame for your illness and could feel guilty.

Even if you've explained the situation when you were first diagnosed, you'll probably need to go over it again and reassure them that you're now recovering.

**Our booklet *Talking to children when an adult has cancer* has helpful tips.**

Try to talk openly and honestly with your children. Look for ways of getting them involved in your recovery, such as going for walks with you. Tell them what you can do and help them to understand that recovery takes time.

Teenagers may find it particularly difficult because they're going through a lot of emotional changes themselves. You may need them to take on more responsibilities around the home at a time when they're looking for more independence.

If they're finding it hard to talk to you, encourage them to talk to someone close who can support them, such as a relative or family friend. They may also find it useful to look at the website **riprap.org.uk**, which is for teenagers who have a parent with cancer.

## Your partner

Some couples become closer as a result of sharing the experience of cancer. However, cancer can put a lot of strain on a relationship.

Problems sometimes develop, even between close and loving couples who've been together for a long time. If a relationship was already difficult, the stress of a major illness may make problems worse.

Even couples that are close may assume that they know what the other is thinking, but they may not always be right.

Talking openly about your feelings and listening to each other can help you to understand each other's point of view.

If you and your partner feel that counselling would help you in your relationship, you can contact Relate (see page 90).

**Our leaflet called *Cancer, you and your partner* looks at the impact that cancer has on emotions, sexuality, practical issues and communication. It also gives you tips on how you can help your relationship.**

# Getting help and support

You don't necessarily have to wait until your next check-up to contact your doctor or any other health professional. If you have physical or emotional problems as a result of the cancer treatment, or if you think that your symptoms have come back, it's important to let your doctor or specialist nurse know as soon as possible.

Even if you're just feeling nervous or worried, it's fine to contact your doctor and let them know so you can get appropriate support. After going through cancer, it's natural for your body to feel different, and for you to feel differently about your body. Aches and pains that you would previously have shrugged off may make you wonder if the cancer has come back again. This is a very common reaction.

Your GP or cancer specialist can assess your situation and refer you to the appropriate services. Physical and emotional support services are generally available on the NHS, or from voluntary organisations. It's usually possible to arrange support services when you go for your outpatient appointment at the hospital.

## Work

Late effects of cancer treatment such as fatigue, changes in memory or concentration, or changes in your bladder or bowel function may make work more difficult for you. Many companies have an occupational health service for their employees, which can offer support in various ways.

There are laws protecting the rights of workers who are affected by illnesses such as cancer. Your employer has a duty to make 'reasonable adjustments' to your workplace and working practices to ensure that you aren't at a disadvantage compared with others. Examples of reasonable adjustments may include:

- allowing some flexibility in working hours
- moving a work base, for example, transferring to a work station nearer to a toilet
- providing toilet facilities appropriate for a disabled employee
- allowing extra breaks to help an employee cope with fatigue.

Where adjustments may be more costly, such as installing separate toilet facilities, a government funded scheme called 'Access to Work' may help your employer with financial and practical support.

**Our booklets *Work and cancer* and *Self-employment and cancer* have more information that may be helpful. We also have a guide for employers that are supporting staff affected by cancer called *Managing cancer in the workplace*.**

# How we can help you

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

## Get in touch

### **Macmillan Cancer Support**

89 Albert Embankment,  
London SE1 7UQ

### **Questions about cancer?**

Call free on **0808 808 00 00**  
(Mon–Fri, 9am–8pm)

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

### **Hard of hearing?**

Use textphone  
**0808 808 0121** or Text Relay.

### **Non-English speaker?**

Interpreters are available.

### **Clear, reliable information about cancer**

We can help you by phone, email, via our website and publications or in person. And our information is free to everyone affected by cancer.

### **Macmillan Support Line**

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

### **Information centres**

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

## Publications

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

You can find all of our information, along with several videos, online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

## Review our information

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

If you'd like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk)

## Need out-of-hours support?

You can find a lot of information on our website, [macmillan.org.uk](https://www.macmillan.org.uk)

For medical attention out of hours, please contact your GP for their out-of-hours service.

## Someone to talk to

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

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

## Professional help

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

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

## Support for each other

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

### Support groups

You can find out about support groups in your area by calling us or by visiting [macmillan.org.uk/selfhelpandsupport](https://www.macmillan.org.uk/selfhelpandsupport)

### Online community

You can also share your experiences, ask questions, get and give support to others in our online community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

## Financial and work-related support

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

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

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

## Macmillan Grants

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

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

## Learning about cancer

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

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

# Other useful organisations

## **Beating Bowel Cancer**

Harlequin House,  
7 High Street,  
Teddington TW11 8EE  
**Tel** 08450 719300  
(Mon–Thur, 9am–5.30pm,  
Fri, 9am–4pm)

### **Nurse Advisory Line**

0845 071 9301  
(Mon–Thurs, 9.30am–1.30pm)

### **Nurse Advisory Line email**

nurse@beating  
bowelcancer.org

### **www.beatingbowel cancer.org**

A charity that's working to raise awareness of symptoms, promote early diagnosis and encourage open access to treatment choice for those affected by bowel cancer.  
Provides information on bowel cancer through its website or Nurse Advisory Helpline.

## **Bladder and Bowel Foundation (formerly Incontact and the Continence Foundation)**

SATRA Innovation Park,  
Rockingham Road,  
Kettering NN16 9JH

### **Nurse helpline**

0845 345 0165

### **Counsellor helpline**

0870 770 3246

### **www.bladderandbowel foundation.org**

Provides information and support; campaigns for people living with bladder and bowel disorders, including incontinence, constipation and diverticular disease.

## **Bowel Cancer UK**

Raises awareness of bowel cancer and aims to improve the quality of life of those affected. Provides information about bowel cancer prevention, screening and symptoms through its website, leaflets and a helpline run by specialist colorectal nurses.  
[www.bowalcanceruk.org.uk](http://www.bowalcanceruk.org.uk)

**(London)** 7 Rickett Street,  
London SW6 1RU

**Tel (general enquiries)**  
0207 381 9711

**(Edinburgh)** 20 Queen  
Street Edinburgh EH2 1JX  
**Tel (general enquiries)**  
0131 225 5333

**Bowel Cancer Advisory  
Service Helpline**  
0870 850 6050  
(Mon–Fri, 10am–4pm)

**Colostomy Association**  
2 London Court, East Surrey,  
Reading RG1 4QL  
**Helpline** 0800 328 4257  
**www.colostomy  
association.org.uk**  
Offers support, reassurance  
and information to anyone  
who has had a colostomy or is  
facing one. Produces a range  
of free literature with useful  
and practical guidance. Offers  
home and hospital visits by  
experienced colostomates, and  
telephone advice and support.

## **Disability Rights UK**

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

**Tel** 020 7250 3222

**www.disabilityrightsuk.org**

A unification of Disability  
Alliance, Radar and National  
Centre for Independent Living.  
This is a national organisation  
run by and working for  
disabled people. With a  
membership of around 900  
disability organisations,  
they can provide information  
on any of these organisations  
or any aspect of disability.

## **IA (Ileostomy and Internal Pouch Support Group)**

Peverill House, 1–5 Mill Road,  
Ballyclare, Co. Antrim  
BT39 9DR

**Freephone** 0800 018 4724

**www.the-ia.org.uk**

For anyone who has had or is  
about to have an ileostomy or  
internal pouch. Has a network  
of branches throughout the UK  
providing advice, information  
leaflets, and home and  
hospital visiting. The website  
hosts a number of forums for  
discussion of related issues.  
Membership fees apply.

## General cancer support organisations

### 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 Support Scotland

Shelley Court, Gartnavel Complex, Glasgow G12 0YN

**Tel** 0141 211 0122

#### Email

info@cancersupportscotland.org  
**www.cancersupportscotland.org**

### Irish Cancer Society

43–45 Northumberland Road,  
Dublin 4, Ireland  
**Tel** 1800 200 700

## Cancer Focus Northern Ireland

40-44 Eglatine Avenue,  
Belfast BT9 6DX

**Tel** 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.

### Irish Cancer Society

43–45 Northumberland Road,  
Dublin 4, Ireland

**Tel** 1800 200 700  
(Mon–Thurs, 9am–7pm,  
Fri, 9am–5pm)

**Email** helpline@irishcancer.ie

### www.cancer.ie

Has a freephone cancer helpline staffed by nurses trained in cancer care.

You can also chat to a nurse online and use the site's message board.

## **Maggie's Centres**

1<sup>st</sup> Floor, One Waterloo Street,  
Glasgow G2 6AY

**Tel** 0300 123 1801

**Email** [enquiries@maggiescentres.org](mailto:enquiries@maggiescentres.org)

**www.maggiescentres.org**

Maggie's Centres provide information about cancer, benefits advice, and emotional or psychological support.

## **Marie Curie Cancer Care**

89 Albert Embankment,  
London SE1 7TP

**Tel** 0800 716 146

(Mon–Fri, 9am–5.30pm)

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

**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.

## **Tenovus**

Head Office, Gleider House,  
Ty Glas Road,  
Cardiff CF14 5BD

**Tel** 0808 808 1010

**www.tenovus.org.uk**

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

## **Counselling**

### **British Association for Counselling and Psychotherapy (BACP)**

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

**Tel** 01455 883 300

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

### **Samaritans**

Chris, PO Box 9090,  
Stirling FK8 2SA

**Tel** 08457 90 90 90

**Email** jo@samaritans.org

**www.samaritans.org**

Provides confidential and non-judgemental emotional support, 24 hours a day, for people who are experiencing feelings of distress or despair.

### **UK Council for Psychotherapy (UKCP)**

2<sup>nd</sup> 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.

### **Relationships and sexuality**

#### **College of Sexual and Relationship Therapists (formerly known as British Association of Sexual and Relationship Therapy)**

PO Box 13686, London,  
SW20 9ZH

**Tel** 020 8543 2707

**www.corst.org.uk**

Provides information on sexual problems. Lists of therapists are available on its website or from the information department.

#### **Daisy Network: Premature Menopause Support Group**

PO Box 183,  
Rossendale BB4 6WZ

**www.daisynetwork.org.uk**

A support group for women who have early ovarian failure. The website gives information about premature menopause and related issues. Also has a mailing list for subscribers and details of other helpful groups.

## **Relate**

Premier House,  
Carolina Court, Lakeside,  
Doncaster DN4 5RA

**Tel** 0300 100 1234

**www.relate.org.uk**

Centres throughout England,  
Wales and Northern Ireland  
offer counselling, psychosexual  
therapy and educational  
services to anyone wanting  
help with adult couple  
relationships. Some centres  
offer services to gay couples.

## **Sexual Advice Association (formerly The Sexual Dysfunction Association)**

Suite 301, Emblem House,  
London Bridge Hospital,  
27 Tooley Street,  
London SE1

**Helpline** 0207 486 7262

(Mon, Wed and Fri,  
9am–5pm)

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

**www.impotence.org.uk**

Has information and leaflets  
about male and female  
impotence. Has leaflets on  
all the medicines and pumps  
used for erectile dysfunction  
and impotence.

## **Money or legal advice and information**

### **Benefit Enquiry Line**

**(England, Wales, Scotland)**

Warbreck House, Warbreck  
Hill Road, Blackpool FY2 0YE

**Tel** 0800 882 200

(Mon–Fri, 8.30am–6.30pm)

**Email** [BEL-Customer-Services@dwp.gsi.gov.uk](mailto:BEL-Customer-Services@dwp.gsi.gov.uk)  
**www.gov.uk/benefit-enquiry-line**

Provides advice and  
information for disabled  
people and carers on the  
range of benefits available.

### **NI Direct**

**(Northern Ireland)**

**Tel** 0800 220 674

**www.nidirect.gov.uk/money-tax-and-benefits**

## Citizens Advice

Provides advice on a variety of issues including financial, legal, housing and employment issues. Details can be found for your local office in the phone book or on one of the following websites:

**England and Wales**  
[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)

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

**Northern Ireland**  
[www.citizensadvice.co.uk](http://www.citizensadvice.co.uk)

You can also find advice online in a range of language at [adviceguide.org.uk](http://adviceguide.org.uk)

## Support for carers

### **Carers Trust (Princess Royal Trust for Carers in Scotland)**

32–36 Loman Street,  
London SE1 0EH

**Tel** 0844 800 4361

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

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

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

Provides support, information, advice and services for everyone caring at home for a family member or friend. You can find details for UK offices on the website.

### **Carers UK**

20 Great Dover Street,  
London SE1 4LX

**Tel (England, Scotland, Wales)** 0808 808 7777

**Tel (Northern Ireland)**

028 9043 9843

(Wed–Thurs, 10am–12pm and 2–4pm)

**Email**

[adviceline@carersuk.org](mailto:adviceline@carersuk.org)

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

Offers information and support to carers across the UK. Can put people in contact with support groups for carers in their area.

## **Suppliers of relaxation products**

### **Talking Life**

36 Birkenhead Road, Hoylake,  
Wirral CH47 3BW

**Tel** 0151 632 0662

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

**www.talkinglife.co.uk**

Produces self-help and  
health audiotapes and CDs.

Has different versions of  
a 'stress and relaxation' kit,  
which includes books  
and tapes. Prices range  
from £14–£45.

### **Penny Brohn Cancer Care**

Chapel Pill Lane,  
Pill, Bristol BS20 0HH

**Tel** 0845 123 2310

(Mon–Fri, 9.30am–5pm)

**Email** [helpline@pennybrohn.org](mailto:helpline@pennybrohn.org)

**www.pennybrohn**

**cancercare.org**

Offers a combination of  
physical, emotional and  
spiritual support, using  
complementary therapies  
and self-help techniques.

# Further resources

## Related Macmillan information

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

- Cancer and complementary therapies
- Cancer, you and your partner
- Coping with fatigue
- Healthy eating and cancer
- Managing cancer in the workplace
- Managing the late effects of pelvic radiotherapy in men
- Managing the late effects of pelvic radiotherapy in women.
- Physical activity and cancer treatment
- Self-employment and cancer
- Sexuality and cancer

- Talking about your cancer
- Talking to children when an adult has cancer
- Understanding colon cancer
- Understanding rectal cancer
- Weight management after cancer treatment
- Work and cancer.

To order a booklet, visit [be.macmillan.org.uk](http://be.macmillan.org.uk).

To order a factsheet, call **0808 808 00 00**

All of our information is also available online at [macmillan.org.uk/cancerinformation](http://macmillan.org.uk/cancerinformation)

## Audio resources

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

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

## Useful websites

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

The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

### Macmillan Cancer Support [www.macmillan.org.uk](http://www.macmillan.org.uk)

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains

expert, accurate, up-to-date information about cancer and its treatments, including:

- all the information from our 100+ booklets and 350+ fact sheets
- videos featuring real-life stories from people affected by cancer and information from medical professionals
- how Macmillan can help, the services we offer and where to get support
- how to contact our cancer support specialists, including an email form to send your questions
- local support groups search, links to other cancer organisations and a directory of information materials
- a huge online community of people affected by cancer sharing their experiences, advice and support.

**[www.cancer.gov](http://www.cancer.gov) (National Cancer Institute – National Institute of Health – USA)**  
Gives comprehensive information on cancer and treatments.

**[www.cancer.org](http://www.cancer.org) (American Cancer Society)**  
Nationwide community-based health organisation dedicated to eliminating cancer. It aims to do this through research, education and advocacy.

**[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk) (Cancer Research UK)**  
Contains patient information on all types of cancer and has a clinical trials database.

**[www.healthtalkonline.org](http://www.healthtalkonline.org)  
[www.youthhealthtalk.org](http://www.youthhealthtalk.org) (sites for young people)**  
Both websites contain information about some cancers and have video and audio clips of people talking about their experiences of cancer and its treatments.

**[www.nhs.uk](http://www.nhs.uk) (NHS Choices)**  
NHS Choices is the online ‘front door’ to the NHS. It is the country’s biggest health website and gives all the information you need to make decisions about your health.

**[www.nhsdirect.nhs.uk](http://www.nhsdirect.nhs.uk) (NHS Direct Online)**  
NHS health information site for England – covers all aspects of health, illness and treatments.

**[www.nhs24.com](http://www.nhs24.com) (NHS 24 in Scotland)**

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

**[www.n-i.nhs.uk](http://www.n-i.nhs.uk) (Health and Social Care in Northern Ireland)**

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

**(Patient UK)**

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

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

**(Riprap)**

Developed especially for teenagers who have a parent with cancer.

# Your notes and questions

You could use these pages to write down any questions you want to ask your doctor or nurse, and then to write down the answers you receive.

## 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 photographs 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 our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Sue Airey, Head of Clinical and Care Services Bowel Cancer UK; Professor Alastair Munro, Consultant Clinical Oncologist; Christine Norton, Associate Dean (Research) and Burdett Professor of Gastrointestinal Nursing; Clare Shaw, Consultant Dietitian; Claire Taylor, Lecturer in Gastrointestinal Nursing; the Pelvic Radiation Disease Association; and the people affected by cancer who helped us review this booklet.

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# Can you do something to help?

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

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



## Share your cancer experience

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

## Campaign for change

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

## Help someone in your community

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

## Raise money

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

## Give money

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

## Call us to find out more

# 0300 1000 200

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

## Please fill in your personal details

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

Name \_\_\_\_\_

Surname \_\_\_\_\_

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

Postcode \_\_\_\_\_

Phone \_\_\_\_\_

Email \_\_\_\_\_

Please accept my gift of £ \_\_\_\_\_

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

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Valid from

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Expiry date

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Issue no

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Security number

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

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that 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](http://macmillan.org.uk/donate)

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

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**Cancer is the toughest fight most of us will ever face. If you or a loved one has been diagnosed, you need a team of people in your corner, supporting you every step of the way. That's who we are.**

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

You don't have to face cancer alone.  
We can give you the strength to get through it.  
We are Macmillan Cancer Support.

**Questions about living with cancer?**  
Call free on 0808 808 00 00 (Mon–Fri, 9am–8pm)  
Alternatively, visit [macmillan.org.uk](http://macmillan.org.uk)

**Hard of hearing? Use textphone  
0808 808 0121, or Text Relay.  
Non-English speaker? Interpreters available.**

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