

# MANAGING THE LATE EFFECTS OF BOWEL CANCER TREATMENT



“ I have disturbed sleep patterns and problems with mobility which can be difficult at times. I try to keep active and am always willing to help others with their cancer journeys. ”

Linda, who experienced late effects after bowel cancer treatment



# About this booklet

**This booklet is about managing the late effects of bowel cancer treatment. It is for anyone who has late effects after treatment for bowel cancer. There is also information for carers, family members and friends.**

Most people have side effects during and for a few weeks after treatment. Usually these gradually lessen and disappear. But some people may still have side effects months after treatment. Some may become permanent. Other people may develop delayed late effects of treatment months or years later. This booklet explains some of the possible side effects of bowel cancer treatment and how they can be improved and managed.

We hope this booklet helps you deal with some of the questions or feelings you may have. We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## For more information

If you have more questions or would like to talk to someone, call the Macmillan Support Line free on **0808 808 00 00**, 7 days a week, 8am to 8pm, or visit **macmillan.org.uk**

If you would prefer to speak to us in another language, interpreters are available. Please tell us, in English, the language you want to use.

If you are deaf or hard of hearing, call us using NGT (Text Relay) on **18001 0808 808 00 00**, or use the NGT Lite app.

We have some information in different languages and formats, including audio, eBooks, easy read, Braille, large print, and translations. To order these visit **macmillan.org.uk/otherformats** or call **0808 808 00 00**.

## How to use this booklet

This booklet is split into sections to help you find what you need. You don't have to read it from start to finish. You can use the contents list on page 3 to help you.

It is fine to skip parts of the booklet. You can always come back to them when you feel ready.

We have included quotes from people who have experienced late effects of bowel cancer treatment, which you may find helpful. They are from our Online Community (**community.macmillan.org.uk**).

To share your experience, visit **macmillan.org.uk/shareyourstory**

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# LATE EFFECTS AND THE BOWEL

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# Late effects

Most people have side effects during treatment. Usually, these gradually improve over a few weeks or months after treatment has ended.

Late effects may:

- affect you during or shortly after treatment and last for longer than 3 months – these are sometimes called long-term effects
- not affect you during treatment but begin months or even years later, as a delayed response to treatment.

We use the term **late effects** to include both long-term and late effects. Late effects after pelvic radiotherapy may also be called **pelvic radiation disease**.

Common late effects after bowel cancer treatment include:

- changes to the way the bladder and bowel work
- tiredness.

The impact of late effects may be:

- minor and not affect your day-to-day life very much
- more difficult to live with.

If you have late effects, there are usually things that can help you to cope and live life as fully as possible. It is important that you do not feel alone. Help and support is available.

In the following sections, we explain ways you can manage and improve late effects.

## Talking to your doctor

Always let your cancer doctor or specialist nurse know:

- if the side effects of treatment do not go away
- if you have any new symptoms or problems after treatment.

The more you tell your doctor, the more they may be able to help you. If you have problems with your bowel, bladder or sex life, you may feel embarrassed to talk about them. But doctors and nurses are used to speaking about these issues, so do not feel embarrassed.

Some late effects are similar to symptoms you may have had when you were diagnosed with cancer. It can be frightening to have symptoms after treatment ends. You may worry that the cancer has come back.

Your cancer team will assess your symptoms and explain whether they could be caused by the treatment. You may need tests to check for other causes, such as the cancer coming back or a new cancer. Sometimes, symptoms are caused by other conditions not related to the cancer or its treatment.

Remember that you can arrange to see your cancer doctor or specialist nurse in between appointments. You can also contact your GP at any time.

## Other types of expert help

Some people with late effects are referred to a doctor or nurse with expertise in that area. For example:

- a doctor who specialises in bowel problems, called a **gastroenterologist**
- a specialist nurse or physiotherapist who gives advice on treating incontinence (**continence adviser**).

A few hospitals have special clinics for people with late effects. Ask your healthcare team whether there are any near you. Some doctors and nurses specialise in treating late effects. You may need to travel to see one.

Your doctor or nurse can refer you to other specialists if needed. The useful organisations listed on pages 123 to 127 can also put you in touch with specialists.

For more information on the help available, call us on **0808 808 00 00**.



# Possible late effects of bowel cancer treatments

The most common late effect of bowel cancer treatment is a change in how the bowel works. Other possible late effects are changes to:

- the bladder
- your sex life
- your energy levels
- the feeling in your hands and feet.

The types of late effects you may have depend on the treatments you have had. The main treatments for bowel cancer are surgery, radiotherapy and chemotherapy.

We describe some of the late effects of these treatments over the next few pages.

## Surgery

Surgery for bowel cancer involves removing some of the colon or rectum, or both (see pages 14 to 15). These operations cause changes in how the bowel works (see pages 18 to 22).

Some people need to have a new opening (stoma) made in the tummy (abdomen). If the stoma is made from the small bowel, it is called an **ileostomy**. If the stoma is made from the large bowel, it is called a **colostomy**. A stoma may be temporary or permanent.

If you have a stoma, you will need to learn how to manage it. Specialist nurses, called **stoma care nurses**, will help and support you.

After rectal surgery, some people may have changes in how their bladder works (see pages 54 to 58) or changes to their sex life (see pages 84 to 89).

Surgery can cause changes in the tissues of the tummy (abdomen). The skin may be less stretchy and the abdominal muscles less strong. Weakness in the abdominal muscles can lead to a hernia developing months or years later (see pages 82 to 83). Sometimes, scar tissue inside the abdomen called **adhesions** may cause pain or discomfort, or may narrow the bowel (see pages 48 to 49).

## Radiotherapy

Pelvic radiotherapy often causes bowel symptoms. These usually get better within a few weeks of treatment ending. But some people have late (delayed) effects months or years after treatment. Possible late effects include changes in the way your bowel or bladder works and sexual difficulties.

Late effects caused by pelvic radiotherapy are sometimes called pelvic radiation disease (PRD). There is more information about pelvic radiotherapy on our website and in our booklets **Managing the late effects of pelvic radiotherapy in men** and **Managing the late effects of pelvic radiotherapy in women** – see page 118.



## Chemotherapy

Some chemotherapy drugs can damage nerves and cause pins and needles or numbness in your hands and feet (see pages 97 to 99). These changes may take several months to get better. For some people, they are permanent.

Chemotherapy and other cancer treatments for bowel cancer can also cause general changes in how you feel. You may be more tired than usual for several months after treatment (see pages 90 to 93). Some people may have difficulty concentrating or remembering things (see pages 94 to 96). These side effects usually improve gradually over time.

# The bowel

The bowel is part of the digestive system. It is divided into 2 parts:

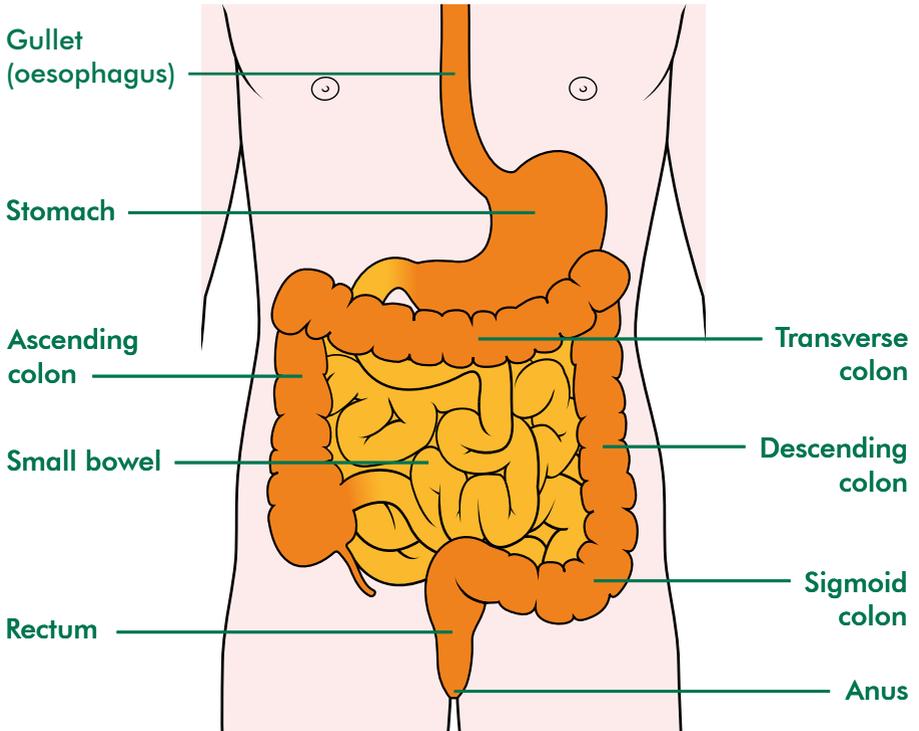
- the small bowel
- the large bowel.

The large bowel is made up of the colon, rectum and anus.

When you swallow food, it passes down the gullet (oesophagus) to the stomach, where digestion begins.

The food then enters the small bowel, where nutrients and minerals are absorbed. The digested food then moves into the colon, where water is absorbed. The remaining waste matter (poo) is held in the rectum (back passage). It stays there until it is ready to be passed out of the body through the anus.

## The digestive system





# BOWEL CHANGES AFTER TREATMENT

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# Changes to your bowel

Most people have changes to their bowel after surgery or radiotherapy for bowel cancer. After treatment ends, it may take at least a year for things to settle down. Over time, bowel symptoms usually become less troublesome. Your bowel habits may not go back to the way they were before treatment. But most people find they get into a new routine that becomes normal for them.

If you have ongoing bowel problems, there are many things that can help (see pages 23 to 43). Your doctor or specialist nurse can give you advice.

## Surgery

After bowel surgery, your large bowel is shorter than before. This means poo (stools) passes through more quickly. Stools may be softer and looser, or liquid. You may go to the toilet more often and need to go more urgently. These changes often improve as your body adjusts in the 3 to 6 months after your operation. But if part of the rectum was removed, there may be long-term changes in how your bowel works.

'Due to the shorter bowel, when I need to go, I have to go!'

**Luke**

After surgery for rectal cancer, the nerves and muscles that control bowel emptying may be affected. This may mean you cannot hold stools in your bowel as well as before. You may have less time to get to a toilet when you notice your bowel is ready to move. You may find it difficult to empty your bowel completely. Some people cannot tell the difference between wind or stool in their rectum.

If you had surgery on the right side of the colon, the surgeon may have removed a part of the bowel that re-absorbs bile acids. Bile acids help us digest food. When bile acids cannot be absorbed, it is called **bile acid malabsorption** or **bile acid diarrhoea** (see pages 36 to 37). It can cause sudden episodes of diarrhoea.

## Stoma

If you had a stoma made as part of your surgery, it can take some time to get used to it. You may have loose stools, or go between having loose stools and constipation. You may also be more aware of wind produced by your bowel. Some people find it difficult to tell when the stoma is going to be active.

Many of the suggestions we make for coping with bowel function problems are also suitable for people with a stoma (see pages 23 to 43). We have also included other information about coping with a stoma where we think this may be helpful.

## Stoma reversal

An operation to take away the stoma and re-join the bowel is called a stoma reversal. After this, it can take time for your bowel to get into a routine. It may take up to 2 years before your bowel is working normally again.



## Radiotherapy

Radiotherapy can weaken the lining of the bowel and the small blood vessels in it. This may cause bleeding from the bowel.

Radiotherapy can also cause scarring (fibrosis) in the large bowel. This can make the large bowel narrower, thicker and less flexible. This causes waste to pass through more quickly than before. It can also mean the rectum cannot hold as much stool.

Radiotherapy can also affect the muscles that help keep the stool inside the rectum. This can cause problems with bowel control and leakage of stool (bowel incontinence).

Sometimes radiotherapy can cause changes in the small bowel. This may make it difficult to:

- digest some types of food (see pages 26 to 29)
- re-absorb bile acids used in digestion (see pages 36 to 37)
- get rid of bacteria effectively (see page 37).

## Symptoms of bowel changes

Possible symptoms of late effects to the bowel include:

- bleeding from the back passage (after radiotherapy only)
- passing mucus (a clear, sticky substance)
- cramps or spasms in the bowel, which may be painful
- difficulty emptying your bowel completely and needing to return to the toilet quickly
- feeling that you need to pass stool even when your bowel is empty (tenesmus)
- diarrhoea
- constipation
- needing to rush to open your bowel (urgency)
- leakage or soiling (bowel incontinence)
- passing a lot of wind.

# Managing bowel control problems

After treatment, you may have changes in how your bowel works. This may make it difficult to control when and how often you pass stools or wind. You may sometimes have leakage (bowel incontinence).

Not feeling in control of your bowel can be stressful, particularly when you are away from home. Although you might find it difficult to talk about bowel control problems, it is important to tell your doctor or specialist nurse. There are many things that they can do to help.

## Assessment

The best treatments for bowel control problems depend on your symptoms and what is causing them. It is important that you see a doctor so they can properly assess your situation.

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

When you are being assessed, the doctor will usually ask about your bowel problems and things that might affect them. You may also have tests, such as blood tests, endoscopy tests (camera tests) or scans.

You might want to keep a record of your bowel habits and what you eat for a week before you go to your appointment. You can use our food and symptom diary to do this. You can find this on the opposite page. It could help give information about what might help you.

At your assessment, the doctor or nurse will usually ask you about:

- your bowel habits and how they have changed
- the appearance and consistency of your stools
- your diet and lifestyle
- what medicines you take
- how any change in bowel habit is affecting your day-to-day life.

## Treatment

The most common ways of improving bowel control include:

- changes to your diet (see pages 26 to 29)
- medicines to regulate your bowel (see pages 30 to 31)
- strengthening the muscles used for bowel control (see pages 32 to 35).



# FOOD DIARY

## FOOD DIARY

**Date**      **Time**      **Food eaten and/or medication taken**

1st August      Breakfast  
1st August      11:30 pm

Tea and toast  
Cough/fluver Genera

**Amount**

Small  
Medium

**Your symptoms and level**  
(0 = no problem, 10 = severe)

No symptoms (0)  
Wind (6)



## Diet

It is important to try to eat at regular times. This helps to encourage a regular bowel pattern. Skipping meals may make your symptoms worse.

You may notice certain foods make your stools loose or increase wind. If you experience this, you may want to try eating less of these foods without cutting them out altogether. It is best to do this with the support of a dietitian. This is because it is important to continue to eat a wide range of different food types.

Your doctor can refer you to a dietitian for expert advice on managing your diet. The dietitian may ask you to keep a note of all the food you eat for the 7 days before you see them. This is called a food diary or dietary diary. It lets them see the types of food you usually eat (see food diary on page 25).

**'My bowel does not function as it used to and I have had many accidents. But over time, I have worked out what foods I should avoid and what foods I should eat.'**

**Hina**

## Fluids

Aim to drink at least 1 to 2 litres (2 to 3.5 pints) of fluids a day. Water is best. Drink smaller amounts through the day rather than large amounts of fluids with meals. For some people, fizzy drinks, caffeinated drinks (like coffee, tea or cola) and alcohol can make bowel problems worse. You may want to limit how much of these you drink.



## Fibre

Changing how much fibre you take may help with bowel problems. This may mean increasing or decreasing the amount of fibre in your diet.

There are 2 types of fibre:

- **Insoluble fibre** helps with managing constipation, and it can also help with other bowel problems. You can get insoluble fibre from bran and seeds. It is also in multigrain, wholemeal and wholegrain foods, such as bread and cereals.
- **Soluble fibre** helps bulk up and slow down bowel movements, so it may help improve diarrhoea or soft stools. You can get soluble fibre from oats and bananas, and from apples and pears with their skins removed. It is important to remove the skins, because they contain insoluble fibre.

Your doctor, nurse or dietitian will give you advice on the type of fibre you need and how much you should have.

If you are adding fibre to your diet, do it slowly. This gives your body time to adjust. Start with small amounts and slowly increase the amount when you are ready. Make sure you drink more water while you are having more fibre.

Adding more fibre will not be right for everyone. Following the '5 a day' plan for fruit and vegetables may not always be appropriate.

## Soluble fibre supplements

People with bowel control problems are often prescribed soluble fibre supplements, such as Normacol® or Fybogel®. They work by absorbing water and expanding to fill the bowel. This makes the stools bulkier and easier to push out. But some people find Fybogel® makes their bowel produce more wind.

If you are taking fibre supplements, make sure you drink plenty of fluids. You should drink at least 2 litres (3.5 pints) every day.

## Food intolerance

Sometimes radiotherapy can affect how well your bowel copes with certain food types, such as lactose. Lactose is found in some dairy products, such as milk.

Symptoms of food intolerance may include:

- tummy cramps
- feeling bloated
- having more wind after eating a particular food.

If you think you may have a food intolerance, ask your GP to refer you to a gastroenterologist.

Food intolerance may improve over time, so it is worth trying foods again rather than avoiding them for long periods of time.

## Drugs

### Anti-diarrhoea drugs

If you have urgency, loose stools, diarrhoea or bowel incontinence, anti-diarrhoea drugs may help. It is important to speak to a doctor or specialist nurse before taking any medicines.

The most commonly used treatment is loperamide. It slows down your bowel, making the stools more solid and less frequent. Taking loperamide regularly can work very well for some people. It usually works best when taken about 20 to 30 minutes before eating a meal.

It is safe to take loperamide for as long as you need it. But you should discuss this with your doctor.

The dose of loperamide you take may need to be adjusted until you find what works best for you. Your doctor may recommend starting with a low dose and increasing this until it is right for you. Sometimes loperamide can cause cramps. If this happens, it is fine to continue taking it, but at a lower dose. Loperamide is available as a syrup, which allows you to adjust the dose as needed.

Sometimes doctors prescribe other types of anti-diarrhoea medicine, such as codeine phosphate or diphenoxylate (Lomotil®). Your doctor or a continence adviser can tell you about the medicines that may be best for you.

## Medicines that can increase bowel symptoms

You may be taking medicines that can make bowel symptoms worse.

Medicines that can increase bloating, wind, urgency or loose stools include:

- non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and diclofenac
- magnesium in antacids (for heartburn)
- proton pump inhibitors, such as omeprazole (Losec®)
- Lactulose® and Fybogel®
- metformin – a tablet used to treat diabetes
- beta-blockers – tablets to treat high blood pressure and some heart problems
- antibiotics
- some types of anti-depressants, such as venlafaxine and citalopram.

If you are taking any of these drugs, and think they may be making your symptoms worse, tell your doctor. They may be able to prescribe a different drug that may affect you less.

## Smoking or vaping

If you have problems with urgency, loose stools or bowel incontinence, smoking or vaping can make things worse. This is because nicotine stimulates the bowel. Talk to your doctor about ways to give up or cut back.

## Strengthening the muscles used for bowel control

Exercises to strengthen the muscles used in bowel control are called **pelvic floor exercises**. They may help with:

- urgency
- bowel incontinence
- difficulty emptying your bowel completely
- wind.

The exercises work the muscles around the anus and a deeper layer of muscles, called the **anterior pelvic floor muscles**. These muscles also help with bladder control and are used in sex.

You may want to ask your doctor to refer you to a continence adviser. They can teach you how to do the exercises.

To get the most benefit from doing these exercises, it is important to:

- do your pelvic floor exercises correctly
- practise regularly to build up your muscles – aim for 3 times a day
- continue to do the exercises
- keep to a healthy weight, as being overweight puts extra stress on the pelvic floor muscles.

It takes at least 3 months to strengthen these muscles. Try to do them at the same times each day to get into a routine. You can set reminders on your mobile phone.

## Biofeedback training

Biofeedback training helps you improve your bowel control. It helps you become more aware of signals from your own body and then learn how to use them. You may be offered it if you find it difficult to learn pelvic floor muscle exercises.

A probe with sensors is put into your rectum. As you squeeze your pelvic floor muscles, sensors in the probe measure the pressure. This helps you know when you are doing the exercises in the right way. Your continence adviser can tell you where you can get this training. Biofeedback training is often used with bowel retraining.

## Bowel retraining

Bowel retraining can help you to get your bowel habits back into a regular pattern. This means setting a regular time to open your bowel.

If you have loose stools or urgency, you may worry you will not be able to 'hold on'. Worrying you may not get to the toilet in time can make you anxious. You may try to monitor your bowel for signs that you need to go to the toilet. This can make you aware of any activity in your bowel, including wind.

Continence specialists can teach you to retrain your bowel. The aim is to help you build up the length of time you can 'hold on'. Bowel retraining is often used with other methods, such as anti-diarrhoea medicines and muscle-strengthening exercises.

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

## **Toilet habits**

If you have ongoing problems with constipation or difficulty emptying your bowel, developing good toilet habits can help.

### **Toilet routine**

Most people find the best time to empty their bowel is about 30 minutes after a meal. But this can vary. You may already know what time works best for you.

Straining to try to pass a stool can weaken your pelvic floor muscles. This can cause problems with bowel control in the future. If you have to wait for a long time after sitting on the toilet, you may be going to the toilet too soon. Or it may be a sign that you are constipated.

Try to not go to the toilet until you have a strong urge to pass a stool.

## Toilet posture

Sitting in the right position on the toilet can help you to empty your bowel better. Lean forward a little and rest your elbows on your knees. Use a small footstool to raise your feet off the floor by about 20cm (8 inches). This will make your knees higher than your hips.

Do not strain or hold your breath. Straining or holding your breath makes the muscles tighten instead of relaxing them so you can pass stool. You may find using a relaxed breathing technique helps.

## The correct position for emptying your bowel



**If you have had recent hip surgery, do not use this position. Always check with your doctor first.**

## Managing specific problems

### Ongoing diarrhoea

If changing your diet and taking anti-diarrhoea drugs does not stop the diarrhoea, ask your doctor to refer you to a gastroenterologist. Lots of different things can cause diarrhoea, and a gastroenterologist will be able to do a full assessment.

After bowel cancer treatment, particularly pelvic radiotherapy, some people have diarrhoea or pale, smelly stools that are difficult to flush away. This can be caused by one of the following conditions:

- **bile acid malabsorption**, also called bile acid diarrhoea (see below)
- **small bowel bacterial overgrowth** (see page 37).

### Bile acid malabsorption (bile acid diarrhoea)

Bile acids are made in the liver and go to the small bowel to help us digest fats. They are then absorbed into the small bowel. Sometimes radiotherapy damages the small bowel and it cannot re-absorb the bile acids. This is called bile acid malabsorption. It can cause bouts of watery diarrhoea, abdominal cramping and bloating. These can be related to the amount of fat eaten in the past 24 hours.

A bowel specialist can diagnose bile acid malabsorption using a SeHCAT scan. They will explain this test to you if you need it.

If you have bile acid malabsorption, they may advise you to follow a low-fat diet. A dietitian will be able to help you do this in a balanced way.

The drug most commonly used to treat bile acid malabsorption is colestyramine (Questran<sup>®</sup>, Questran Light<sup>®</sup>). It is a powder that you mix with water or fruit juice.

If colestyramine does not work, your specialist may prescribe a different medicine, called colesevelam (Cholestagel<sup>®</sup>). You take it as a tablet.

Most people with bile acid malabsorption do not absorb enough vitamins and need to take vitamin supplements. Your doctor can talk to you more about this.

### **Small bowel bacterial overgrowth**

A healthy small bowel contains almost no bacteria. But the large bowel contains lots of healthy or 'good' bacteria, which help us digest food. After pelvic radiotherapy, sometimes bacteria can be found in the small bowel. This can cause different symptoms, including:

- diarrhoea
- wind
- bloating
- constipation
- feeling sick
- vomiting
- bad breath.

A breath test can help to find out whether you have small bowel bacterial overgrowth. You can have the test as an outpatient. Samples of your breath are tested. This tells the doctors if there are bacteria in your small bowel.

Small bowel bacterial overgrowth is usually treated with antibiotics.

## Constipation

People sometimes have problems with constipation after treatment. The following tips may help improve constipation:

- include more fibre in your diet (see pages 28 to 29)
- drink 1 to 2 litres (2 to 3.5 pints) of fluid a day
- take regular daily exercise, such as walking
- get into a toilet routine (see pages 34 to 35)
- use a good toilet posture (sit on the toilet in the correct position)
- check with your doctor if you are taking medicines that can cause constipation
- take medicines for constipation.

### Medicines that can cause constipation

Your doctor can check whether you are taking any drugs that can cause constipation. They may be able to prescribe a different drug that may affect you less.

Medicines that may cause constipation include:

- opioid painkillers, such as codeine or morphine
- ondansetron, which is an anti-sickness drug
- iron tablets
- loperamide or other anti-diarrhoea drugs.

### Medicines to treat constipation

If you have problems with constipation or difficulty emptying your bowel completely, your doctor may give you treatments to help.

This may include one of the following treatments:

- Soluble fibre supplements, such as Fybogel® or Normacol® (see page 29).
- **Suppositories** – you put these into your back passage or stoma. As they dissolve, they release a lubricant. This encourages the bowel to empty. They usually take about 10 to 30 minutes to work. It may be easier to use them at a time when you are able to stay near a toilet for a while after inserting them. You may not need to use them every day.
- **Enemas** – these contain a small amount of gel or liquid that you squeeze into the lower bowel. This stimulates the bowel to empty.



## Tenesmus

Tenesmus is the feeling that you need to go to the toilet but your bowel is empty. It can involve straining, pain and cramping. It can be caused by cramp (spasms) in the muscles that stimulate the bowel.

The spasms may be helped with:

- pelvic floor exercises
- a toilet routine
- sitting on the toilet in the correct posture
- taking soluble fibre to bulk up the stool, or a fibre supplement such as Normacol®
- low doses of certain anti-depressant drugs.

Sometimes constipation or infection can cause tenesmus. It is also sometimes caused by a non-cancerous growth (a polyp) in the bowel, or by a cancer in the bowel.

If you have tenesmus, your doctor will examine your back passage and may arrange for you to have a test called a **colonoscopy** or **flexible sigmoidoscopy** to look at the bowel.

## Difficulty emptying the bowel

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 have passed a stool
- having smaller, pellet-like stools (fragmented)
- having leakage of stool after you go to the toilet
- needing to go back to the toilet several times after a bowel movement.

What can help will depend on the cause of your symptoms. Your doctor or continence specialist may suggest:

- a toilet routine
- using the correct toilet posture
- pelvic floor exercises
- changes to your diet
- medicines to regulate your bowel
- suppositories or enemas
- bowel or colostomy irrigation.

### **Medicines to regulate your bowel**

Some people may need to take laxatives to stimulate their bowel as well as making changes to their diet. Your doctor or a continence adviser can tell you about laxatives.

Bowel motions that are too soft can also cause problems with incomplete emptying. See our suggestions on diet and anti-diarrhoeal medicines for help in dealing with this on pages 26 to 30.

### **Suppositories or enemas**

If you still have difficulty emptying your bowel completely, your specialist may recommend using suppositories or enemas.

You put suppositories into your back passage or stoma. As they dissolve, they release a lubricant. This encourages the bowel to empty. They usually take about 10 to 30 minutes to work. It may be better to take them at night, so they have longer to work. You may not need to use them every day.

Enemas contain a small amount of gel or liquid that you squeeze into the lower bowel. This stimulates it to empty.

### **Bowel or colostomy irrigation**

This is a way of emptying the bowel by introducing warm water into it. You should only use bowel or colostomy irrigation if it is recommended by a health professional.

Bowel irrigation may help to control an irregular bowel habit. You can empty your bowel at a time that suits you. You will be less likely to have leakage or incontinence at other times.

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

Irrigation can also be used to regulate a stoma. This is called **colostomy irrigation**. It can mean fewer worries about a stoma becoming active at inconvenient times. Your continence specialist or stoma nurse can tell you more about bowel or colostomy irrigation. If it is suitable for you, they can teach you how to do it. They will also arrange for you to get the equipment you need on prescription.

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

## Wind

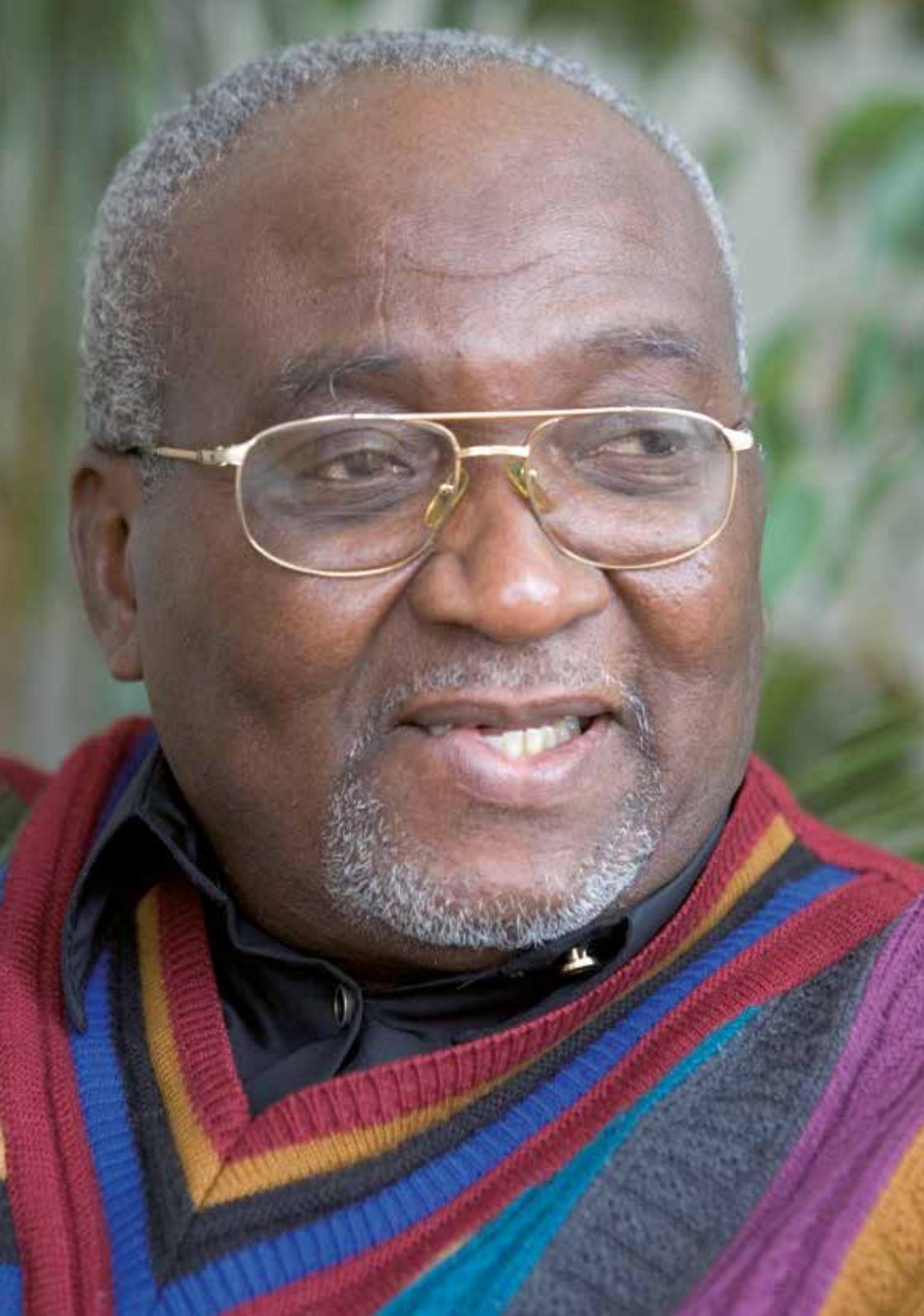
After treatment, some people have more wind than before. Tell your doctor if this is a problem.

Causes of wind include:

- certain types of food
- constipation
- some medicines, such as Fybogel® and Lactulose®
- bowel conditions (such as diverticular disease)
- small bowel bacterial overgrowth.

If you have too much wind, the following tips may help:

- cut down on foods and drinks that you notice can cause wind
- eat meals at the same times each day
- do not eat and drink at the same time
- use exercises to strengthen the muscles used for bowel control (pelvic floor exercises)
- change from Lactulose® or Fybogel® to laxatives that cause less wind
- eat peppermint oil, live yoghurts or charcoal tablets.



# Managing bleeding from the bowel

## Bleeding from the rectum

Bleeding from the back passage (rectum) after radiotherapy is common. Most people who have it will only notice bleeding occasionally, and this often does not need treatment. But for a few people, bleeding can be heavy and cause concern.

Bleeding may not always be caused by the radiotherapy. It can be caused by piles (haemorrhoids) or straining on the toilet. Even if you think you know the cause, always tell your cancer doctor or specialist nurse if you have any bleeding from the back passage. It is important to find out the cause and to rule out serious problems. Your doctor will do an examination of your back passage. They may also refer you to have a camera test to look at the inside of your rectum (a **sigmoidoscopy** or **colonoscopy**).

## Causes of bleeding after pelvic radiotherapy

Pelvic radiotherapy can damage the blood vessels in the wall of the bowel. As the bowel heals, it makes new, small blood vessels. These are on the surface of the bowel lining, rather than deep within the bowel wall. Because these small blood vessels are on the bowel surface, they sometimes break and bleed. This can happen when a person strains to pass a bowel motion, or has a slightly hard bowel motion.

These changes in the bowel lining will often get better over time. But this can take 5 to 10 years.

A camera test can show if the bleeding is due to radiotherapy changes. Sometimes other causes may be found. Depending on the cause of your bleeding, your doctor will discuss with you whether other treatment is necessary.

## Treatment

If bleeding is due to radiotherapy changes and is mild and not interfering with your daily life, you will probably not need treatment. You will be given advice about your bowel habits and how to avoid constipation. This will help reduce bleeding.

If bleeding is interfering with your day-to-day life or if you become **anaemic** (have a low number of red blood cells), you are likely to need treatment. Your doctor or specialist nurse will explain more about your treatment options and give you more detailed information.

If you are taking blood-thinning drugs, your dose may be reduced and monitored.

You may be offered treatment with a drug called sucralfate. If the blood is bright red, you have the drug as an enema. This is when a fluid (usually medicine) is gently passed into your back passage through a short tube. If the blood is darker and is coming from the colon, you take the drug as a tablet.

Sucralfate coats the lining of the bowel. This reduces inflammation and encourages healing. It is important to avoid getting constipated when you are being treated with sucralfate.

Other treatments that may help include the following:

- **Thermal ablation** – This treatment directs heat at areas that are bleeding. The heat seals the blood vessels and destroys damaged tissue. It is given during an endoscopy, where a doctor passes a thin, flexible tube with a light into your back passage. The most commonly used heat treatment is called **argon plasma coagulation (APC)**. There is a risk that thermal ablation can cause complications, such as serious tissue damage. Your doctor will discuss this with you.
- **Hyperbaric oxygen therapy** – This works by increasing the amount of oxygen that gets to tissue that has been damaged by pelvic radiotherapy. This can encourage new blood vessels to grow and may help the tissue heal. Treatment takes up to 8 weeks. This treatment is not widely available, so you may need to travel some distance for it.
- **Formalin** – This drug seals bleeding blood vessels. A doctor gives it to you during an endoscopy. There is a risk that formalin can cause complications, such as serious tissue damage. Your doctor will discuss this with you.

# Bowel adhesions after surgery

After 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 do not cause problems. But, sometimes they can cause pain in the abdomen. This may be more likely if you have also had radiotherapy to 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 pain or cramping in your tummy (abdomen)
- 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 what is causing the pain.**

## Treating a blocked bowel

Often the bowel is only partly blocked and gets better (unkinks) after being rested for a time. This may mean:

- a short stay in hospital
- not eating for a day or so and having fluids through a drip into a vein
- having a liquid or low-residue diet.

A low-residue diet is more easily broken down into smaller particles by the digestive system. Your nurse or doctor will explain more about this if you need to follow one for a short time.

If the bowel is completely blocked, you may need an urgent operation to relieve it.

## Treating adhesions

Most people do not need treatment for abdominal adhesions as they usually cause no problems. Surgery is the only way to break adhesions that cause pain or bowel blockage. However, surgery may cause more adhesions, so it is avoided where possible.



# BLADDER CHANGES AFTER TREATMENT

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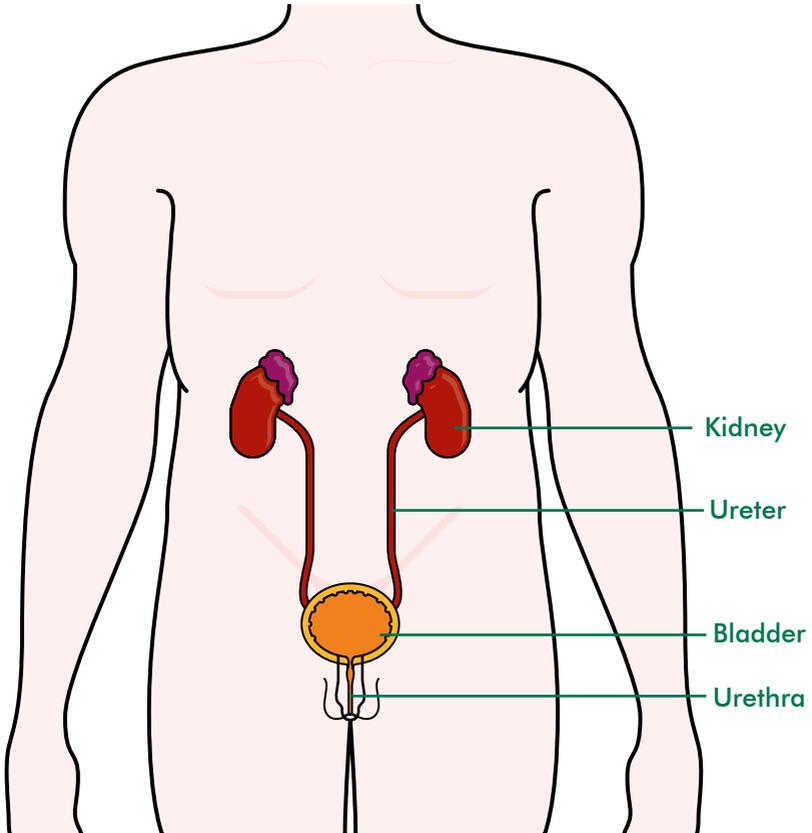
# The bladder

The bladder is a stretchy, muscular bag that collects and holds urine. It is in the lower part of the pelvis. It is connected to the kidneys, which produce urine, by tubes called the **ureters**. Urine drains from the bladder through a tube called the **urethra**.

The bladder is supported by the pelvic floor muscles (see page 32). Some of these muscles wrap around the urethra. This is called the **urethral sphincter**. It keeps the urethra sealed like a valve until you need to pass urine.

When the bladder is full, it tells the brain that you need to pass urine. When you are ready, the brain tells the pelvic floor muscles to relax and open the urethra. The bladder muscles tighten (contract) and push the urine out.

## The bladder and kidneys



# Bladder changes

Some people have problems with bladder control after treatment for rectal cancer.

Changes also happen as the bladder muscles age. This means symptoms may become more common as people get older.

Women who have given birth and gone through the menopause are also more likely to get urinary problems.

Bladder problems can be embarrassing and difficult to talk about. But if you are affected, it is important to talk to your doctor. There are many things that can be done to help.

We have information about coping with bowel and bladder changes (see pages 71 to 79).

## Possible late effects to the bladder

### Surgery

Sometimes, surgery to the rectum can affect the nerves to the bladder. These nerves control the muscles that hold urine in the bladder and empty the bladder. Nerve damage can cause loss of bladder control. This can lead to leakage of urine (urinary incontinence). Or it may cause difficulty in emptying the bladder (incomplete emptying).



## Radiotherapy

Radiotherapy to the bowel often causes bladder symptoms. These usually get better within a few weeks. Long-term changes to the bladder are not common. But a few people have changes to the way their bladder works several months after treatment.

There is more information about managing the effects of pelvic radiotherapy on our website and in our booklets **Managing the late effects of pelvic radiotherapy in men** and **Managing the late effects of pelvic radiotherapy in women** – see page 118.

## Possible symptoms

### After surgery

Sometimes, nerve damage means the bladder muscle cannot squeeze strongly enough. This means the bladder does not empty completely. The most common symptoms of this are:

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

If you have any of these symptoms, it is important to get them checked. They can lead to more serious problems if they are not treated.

## After radiotherapy

Many of the symptoms of late effects to the bladder are similar to what may happen during radiotherapy.

Possible symptoms of bladder changes include:

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

If you have any of these symptoms, it is important to have them checked by your doctor. Blood in the urine should always be checked by a doctor as soon as possible.

## Getting expert help

There are lots of things that can be done to manage or treat your symptoms. Your GP can advise you, or they may need to refer you to:

- a specialist doctor in bladder problems (a **urologist**)
- a specialist nurse or physiotherapist who gives continence advice and treatment (a **continence adviser**).

The right treatment for you will depend on the symptoms or side effects you have and how much of a problem they are.

## Tests

If you have bladder problems after your treatment, your doctors will usually arrange some tests to find out the cause. Your GP can test your urine to check for infection. They can also do blood tests to check how your kidneys are working.

Some people may need further tests arranged by a urologist or a continence adviser. These include the following:

- A **cystoscopy**, to look inside the bladder. A thin, flexible tube with a light on the end (a cystoscope) is passed through your urethra and into your bladder. This is usually done using a local anaesthetic.
- **Urodynamic tests**, to check how well your bladder and urethra collect, hold and release urine. These are usually done to find out the cause of incontinence.

# Managing bladder late effects

## What you can do

Here are some general things you can do to help reduce bladder symptoms:

### Drink plenty of fluids

Try to drink at least 2 litres (3.5 pints) of fluids a day. This is about 8 glasses. If it is hot or if you are exercising, you will need to drink more than this. It is best to drink regularly throughout the day.

Drinking too little will make your symptoms worse. Urine that is concentrated irritates the bladder. Drinking more fluids will:

- reduce bladder irritation
- train your bladder to hold more urine
- reduce your risk of getting urine infections.

### Drink the right fluids

Some drinks can irritate the bladder and make symptoms worse. Cut down or avoid:

- alcohol (especially spirits)
- fizzy drinks
- drinks that contain caffeine (such as tea, coffee, cola and cocoa)
- acidic drinks (such as fresh orange or grapefruit juice)
- drinks with artificial sweeteners ('diet' or 'light' drinks).

Try to drink water, diluted fruit juice and herbal teas.

## **Try not to go to the toilet ‘just in case’**

If you go to the toilet as a precaution, your bladder will not get used to holding more urine.

## **Give up smoking or vaping**

If you smoke or vape, ask your GP about getting help to give up.

The chemicals in smoke from cigarettes and e-cigarettes irritate and damage the lining of the bladder. This can make your symptoms worse. Smoking or vaping can also make you cough more. Coughing may make you more likely to leak urine. Smoking is also a major risk factor for cancer and other serious health conditions.

The NHS has a lot of information and support to help you give up smoking. Look on the NHS website for the country where you live.

## **Avoid putting extra pressure on your pelvic floor muscles**

To help avoid putting extra pressure on your pelvic floor muscles, try to:

- keep your weight within healthy limits
- avoid getting constipated
- avoid heavy lifting.

It is especially important to do this if you have stress incontinence.

## **Find ways of reducing stress**

Feeling anxious can make you feel like you need to pass urine. It can also make your symptoms worse.

## Needing to pass urine more often (overactive bladder)

After having pelvic radiotherapy, you may need to pass urine more often than usual. Your bladder may be more sensitive and feel full even when there is not much urine in it. This is known as an **overactive bladder**. There are lots of things that can help ease this. Your doctor or continence adviser may suggest one or a combination of the following treatments for you.

### Bladder retraining

This means training yourself to ignore the feeling of needing to pass urine. It will help your bladder get used to feeling fuller. This can help the bladder hold more urine, so you will not need to go to the toilet as often. It can be difficult at first, but it gets easier with time.

It is best to retrain your bladder with advice and support from a continence adviser or doctor.

Start by keeping a record of how often you go to the toilet and measure how much urine you pass each time. Your continence adviser may have a chart you can use.

Bladder retraining is done in stages. You start by 'holding on' for a few minutes when you need to pass urine. You gradually increase this by a few minutes each time. Here are some things you could try to take your mind off the urge to pass urine:

- Sit straight on a hard seat.
- Count backwards from 100 or recite the alphabet backwards.
- Read a book or a newspaper.

Do not be tempted to cut down on fluids when you are retraining your bladder. Keep drinking fluids as normal.

You do not need to do the retraining exercises during the night. Your daytime exercises will eventually mean that you need to go to the toilet at night less often.

After a few weeks, resisting the urge to pass urine gets easier. You will eventually find you need to go to the toilet less often.



## Drugs to relax the bladder

Some types of drug can help relax the bladder so it can hold more urine. These drugs may be used to treat an overactive bladder or stress incontinence.

There are several drugs that can help. Your doctor will check how well they are working for you. If one does not work for you, talk to your doctor. They may be able to prescribe a different drug.

### Treatment with botulinum toxin A (Botox®)

This involves having injections of Botox® into the bladder muscles. It is done under a general anaesthetic. It may be used if other treatments have not helped.

The drug paralyses part of the muscle, which helps relax the bladder. It should help you 'hold on' for longer. It may also help reduce incontinence.

You may find it becomes more difficult to pass urine after having Botox®. This is usually temporary. It may last for a few days or weeks. Before you have Botox®, a nurse will show you how to empty your bladder using a thin, plastic tube (catheter). Your doctor or nurse can tell you more about this.

## Nerve stimulation

Nerve stimulation uses electrical pulses to help bladder control. It may be used when other treatments have not helped. There are different types:

- **Sacral nerve stimulation (SNS)** has 2 stages. First, your doctor places electrodes under the skin in the lower back for a few weeks. This is to check if SNS works for you. If the test is successful, you can have a small, permanent implant fitted.
- **Percutaneous tibial nerve stimulation (PTNS)** may be used if you do not want sacral nerve stimulation or Botox® treatment. A nurse places a small needle through the skin near the ankle and connects this to an electrical stimulator. Most people have 12 weekly treatments. After this, you and your doctor can decide how much PTNS has helped and if more treatments are needed.

## Leaking urine (incontinence)

Urine leakage can happen if the pelvic floor muscles and the valve that keeps the bladder closed are weakened.

You may leak small amounts of urine when you laugh, sneeze or cough, or when you are exercising. This is called **stress incontinence**. If you have an overactive bladder, you may find that you cannot always get to the toilet in time. This is called **urge incontinence**.

The following information is about some of the ways that incontinence can be treated and managed. If you have urge incontinence, some of the treatments in the section on needing to pass urine more often can also help (see pages 61 to 64).

Urine can irritate the skin, so you will need to take extra care to look after the skin around your bottom (see page 72).

## **Pelvic floor exercises**

The most common treatment for urinary incontinence is to do exercises to strengthen the pelvic floor muscles.

You can do pelvic floor exercises while you are sitting or lying down. No one will know you are doing them. You squeeze and relax the muscles around your back passage (anus), as if you are trying to stop yourself passing wind.

Practising this exercise slowly then quickly several times a day for at least 3 months can strengthen the muscles. This will help you have more control over leaking urine.

It is best to ask your doctor to refer you to a continence adviser. They can teach you how to do the exercises correctly. The Bladder and Bowel Community can also give you details of your nearest adviser and can send you information about pelvic floor exercises (see page 123 for contact details).

## **Biofeedback training**

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

## Other treatments

If these treatments do not help, there are other options. You can ask your doctor about them.

### Drugs

Your doctor may suggest using drugs to help you control your bladder. Your doctor or continence adviser can tell you more about this.

### Surgery

Occasionally, some people need to have an operation to improve incontinence. If this could help you, your doctor will discuss it with you. You will be referred to a specialist surgeon for an assessment. You may need to have tests before any treatment.

Some types of operation may only be available as part of a clinical trial. Your specialist can tell you more about this. There is more information about clinical trials on our website and in our booklet **Understanding cancer research trials (clinical trials)** – see page 118.

It is important that you understand everything about your operation. You should be given an opportunity to discuss the operation with your surgeon. This might happen at the pre-assessment clinic. You will need to sign a consent form to say that you agree to the operation. No operation will be done without your consent.

Types of operation include:

- **Tape to support the urethra** – This is the most common type of operation to improve incontinence. The surgeon inserts a tape either:
  - through a cut in the vagina
  - behind the scrotum.

The surgeon then puts the tape under the urethra. This supports the urethra. It helps stop urine leaking when there is increased pressure on the bladder, for example when you cough or sneeze.

- **Bulking agents** – A doctor can inject these into the tissue surrounding the urethra. This helps keep it closed and makes it harder for urine to leak out. You may need several injections for them to work, and they lose their effectiveness over time.
- **AUS (artificial urinary sphincter)** – This treatment is used very occasionally when other treatments have not helped. It may be suitable for some people who are leaking a lot of urine most of the time. While you are under a general anaesthetic, a small cuff is inserted around the urethra. The cuff is attached to a pump that is placed either:
  - under the skin of the outer lips of the vulva (external female sex organs)
  - in the scrotum (sac containing the testicles).

When you want to pass urine, you deflate the cuff by squeezing the pump under the skin between your fingers. This takes pressure off the urethra, allowing it to open so you can pass urine.

## Difficulty passing urine (retention)

Sometimes, nerve damage means the bladder muscle cannot squeeze strongly enough. This means the bladder does not empty completely.

Some people may need to use a catheter to empty their bladder a few times a day. This is called **intermittent self-catheterisation**. Your doctor or continence adviser can tell you more about this.

If you have any difficulty passing urine, it is important to get this checked. It can lead to problems that are more serious if they are not treated.

## If bladder problems do not improve

If your bladder symptoms continue or do not improve after having these treatments, your specialist may talk to you about other possibilities. When symptoms are severe, an operation to remove the bladder may be an option, but this is rare.

We have information about coping with bladder changes (see pages 71 to 79).





# COPING WITH BOWEL AND BLADDER LATE EFFECTS

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Coping with bowel or bladder changes

72

# Coping with bowel or bladder changes

Changes to the bladder and bowel often cause the same day-to-day issues. So we have covered them together in this section.

## Protecting your skin

If you have problems with leaking (incontinence) from your bladder or bowel, it can make the skin in that area sore.

You can protect your skin by keeping it clean and dry. There are lots of products available to help you. Your continence adviser can give you more information.

Here are some suggestions to help keep your skin clean and dry:

- use a skin cleanser instead of soap and water
- unperfumed baby wipes are more gentle on your skin than toilet paper
- absorbent pads and a non-oil barrier cream or film can help protect your skin
- cotton underwear lets your skin breathe more than other materials.

## Going out

If you have problems with bowel or bladder control, you may feel worried about going out, especially to somewhere new. Planning ahead so that you are prepared can help you feel more confident.

'I must get to the toilet quickly. I have explained this to my friends, so that sudden departures from their company are not taken the wrong way.'

**Peter, Online Community member**

## Access to toilets

If you are going somewhere new, it is a good idea to find out where the toilets are before you go. Many towns and counties have lists or maps of the local public toilets. These are often on local authority websites. Try typing 'public toilets' and the name of the place you are visiting into a search engine such as Google.

Macmillan has a free toilet card you can use. It may help you access a toilet more quickly when you are out. You can use it in places such as shops and pubs. You can get one by calling the Macmillan Support Line on **0808 808 00 00** and speaking to a cancer support specialist. Or you can order one from **[be.macmillan.org.uk](http://be.macmillan.org.uk)**

The card says that the card-holder has a medical condition that means they need urgent access to a toilet.

You can also use disabled toilets. These often have more privacy. They have a wash basin and more space if you need to change. The National Key Scheme (NKS) offers access to about 9,000 locked public toilets across the UK. You can buy a key from Disability Rights UK (see page 125 for contact details). They also have a guide that explains where the toilets are.

## **Take a bag with supplies**

Pack a bag of the things you may need when you go out. This will help you feel more confident. You may want to include:

- wet wipes or baby wipes
- a non-oil barrier cream
- pads and pants
- a change of clothes
- a sealable bag
- anti-diarrhoea tablets – if you have problems with diarrhoea
- your Macmillan toilet card.

## **Specialist products for leakage or soiling**

If you have problems with leakage or soiling (incontinence), there are different products you can wear. These can help you feel more confident and protect your clothes. A continence adviser can help you choose products that suit your needs.

You can buy pads for mild to moderate incontinence in most supermarkets and pharmacies and online. If these are not absorbent enough, you can get different pads from your continence adviser. They can also explain what is available to you on the NHS. This can vary from region to region. The Bladder and Bowel Community also has information about different products (see page 123 for contact details).

Problems with leakage or soiling can mean you have extra expenses. Call us on **0808 808 00 00** to find out more about ways to help cover the cost.

## Products for bladder incontinence

Pads and pull-ups have a layer that draws urine away from the surface and absorbs it, so your skin stays dry. There are different types available. You can wear some inside your underwear and others as a replacement for underwear. You can also buy pads to cover your bed.

### For men

Having a urine bottle near your bed may help you get a better night's sleep. You will not have to walk to the toilet every time you need to go. If you are worried about getting to the toilet in time during the day, keep the bottle nearby. You may want to keep one in your car.

If you do not want to use pads, you may prefer to wear a sheath and leg bag. The sheath fits over your penis (like a condom), and urine is held in a bag that you strap to your leg. You can buy underwear with a built-in pocket to hold the bag.

## Products for bowel incontinence

There are different types of pad you can wear during the day and at night. Pads and pants with charcoal linings may help to reduce smell from leakage or wind. There are also different types of pad you can use to cover your bed or chairs.

### Anal plugs and inserts

Peristeen® Anal plugs are made from soft foam and stop bowel leakage for up to 12 hours. There is a cord attached to the plug, which allows you to remove it when you are ready. Some people find anal plugs uncomfortable to begin with. But most people get used to them after using them a few times.

Renew® Anal inserts are made from soft silicone and are placed in the anus. They stop any leakage until they are pushed out of the bowel when you have a bowel movement. You can also remove them before a bowel movement. Your continence adviser can help you choose products that suit your needs and show you how to use them.

## Keeping to a healthy weight

Being overweight puts pressure on your pelvic floor muscles. It is important to keep to a healthy weight if you have bladder or bowel late effects. Your GP can advise you on the ideal weight for your height.

## 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.

If you have stress incontinence, it is best to avoid anything that involves running or jumping. Walking or swimming are lower-impact and are less likely to cause problems. When your symptoms are under control, you may want to gradually try 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 are not sure what you can do. See page 118 to order our booklet on keeping physically active called **Move more**.



## Avoiding constipation

Avoiding constipation will help protect your pelvic floor muscles.

To avoid constipation, you can try the following things:

- choose foods that reduce constipation
- check you are sitting in the correct position to empty your bowel (see page 35)
- drink plenty of fluids
- keep active.

## Managing stress

Anxiety and stressful situations can make bladder and bowel symptoms worse.

Learning to relax may help improve some of your symptoms. Some continence clinics and support groups teach stress management. Your doctor or specialist nurse can tell you about relaxation classes in your area.

Relaxation CDs are available from bookshops and some health shops. You can also download relaxation podcasts from the internet.

Some people find that complementary therapies, such as massage or yoga, help them feel less stressed (see page 106). For details of what is available in your area, call our cancer support specialists on **0808 808 00 00**.

## Getting support

It is important to tell your doctor or nurse about any problems you have. They are used to dealing with these issues 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 are a good way of meeting people who have been through similar situations. You can share experiences and solutions with each other. Partners, family members and close friends can also help you cope with your feelings. Visit our Online Community at **[macmillan.org.uk/community](https://macmillan.org.uk/community)**



# OTHER LATE EFFECTS

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# Hernia after surgery

A hernia is a bulge caused by a part of the body, such as 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. Hernias are less common after keyhole surgery than after open surgery.

The main symptom of a hernia is often an ache or bulge in your tummy area (abdomen) or under the skin around a stoma (parastomal hernia). It may not be there all the time. You may notice it when you cough, sneeze or strain your tummy muscles. You may be able to push it back into place, or it may go away when you lie down.

Always see your doctor if you think you may have a hernia. Some people may worry that the swelling is linked to the cancer. Your doctor will examine you by feeling around the area. This will help them tell you what may be causing the bulge.

Sometimes, your doctor may arrange a CT (computerised tomography) scan or an ultrasound scan to give a picture of the hernia.

## Reducing your risk of getting a hernia

You can reduce your risk of developing a hernia by:

- keeping to a healthy weight for your height
- not smoking or vaping
- following a healthy, balanced diet
- strengthening your abdominal muscles with regular, moderate exercise such as walking, yoga or gentle aerobics and stretching exercises (ask your surgeon when it is okay to start exercising)
- 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.

## Treating a hernia

Most hernias will not need to be treated, especially if they are small and not causing any problems. Your doctor or nurse may advise you about lifestyle changes that could help, such as keeping to a healthy weight.

We have information about keeping to a healthy weight and physical activity and cancer treatment.

A hernia can also be treated with an operation to repair the tissue wall if necessary.

If an operation is not right for you, there are also specially designed hernia support garments you can wear. It is important that the size and fit are correct, so ask your doctor, specialist nurse or stoma care nurse for advice.

# Effects on your sex life

Bowel cancer and its treatment can affect your sex life. This can happen because 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 slowly improves, but sometimes it can last for months or even longer.

If you feel depressed or anxious, you are less likely to be aroused by thoughts of sex. This might also happen if you are worried about the cancer, the side effects of cancer treatment or your relationship.

Many people find it difficult to talk about sexual difficulties because they feel embarrassed or self-conscious. Your doctor or specialist nurse will be used to talking about these issues. They can advise you about where to go for specialist help and support. There are also organisations that offer information and treatment (see pages 123 to 125 for contact details).

There is more information about how cancer might affect your body image and sex life on our website and in our booklets **Cancer and your sex life for men**, **Cancer and your sex life for women**, and **Body image and cancer** – see page 118 for ways to order these.

## Reduced interest in sex

Some people find 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) can last for months after treatment.
- Changes to how you feel about yourself sexually may reduce your interest in or desire for sex.
- Treatment may reduce your levels of sex hormones.

If you have a partner, tell them how you feel. Explaining why you do not feel like having sex can reassure them that it is not 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 may be because of changes in the blood flow and nerves in the pelvic and genital area.

The vagina may be shortened or narrowed by surgery or radiotherapy. Sex may be uncomfortable in certain positions if the rectum has been removed. This is because it normally cushions the vagina.

Sometimes a different 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.

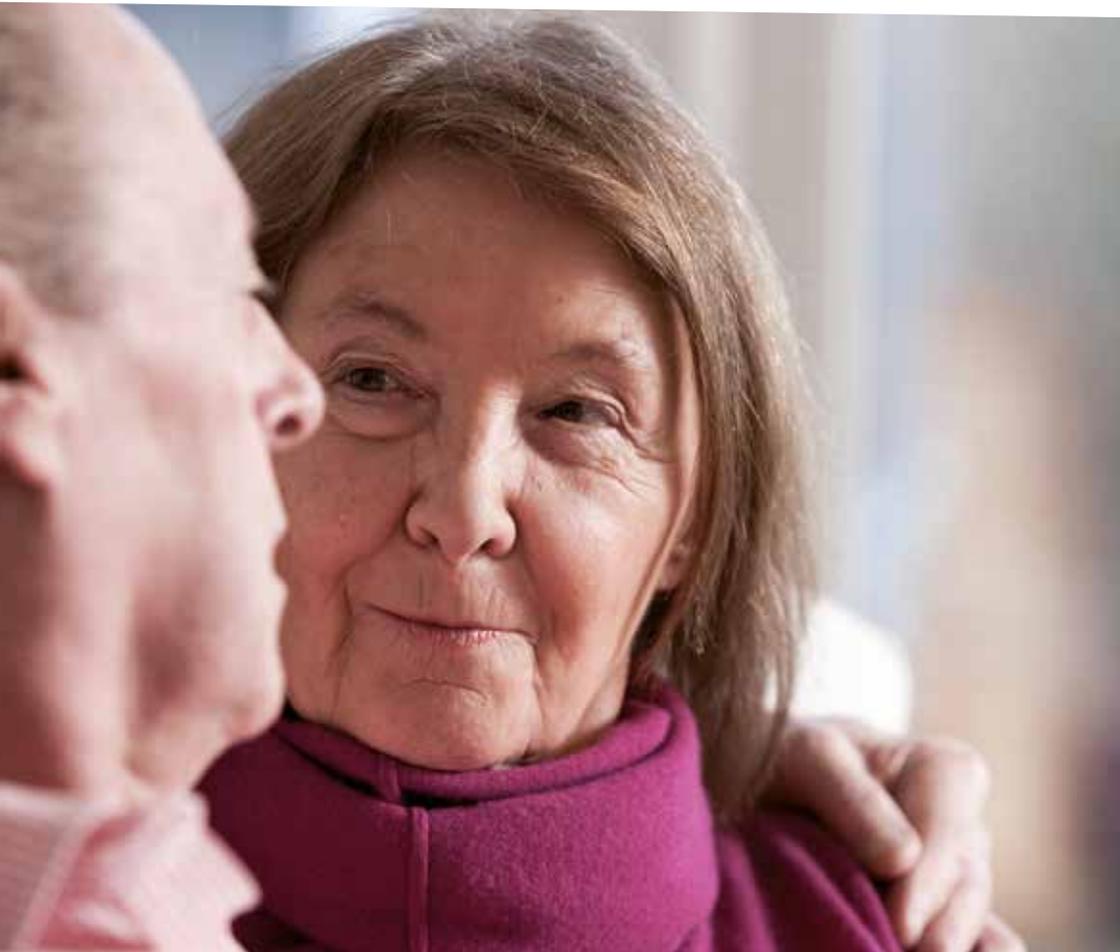
Radiotherapy to the pelvic area can cause changes to the vagina. It may become drier, narrower and less flexible. Your hospital team may recommend that you use vaginal dilators to help. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Your specialist nurse or 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. You can buy lubricants from most chemists. Your doctor can also prescribe hormonal creams.

## Menopausal symptoms

Treatments such as chemotherapy and pelvic radiotherapy can cause an earlier menopause. This can cause menopausal symptoms that make sex difficult, such as a dry vagina or lowered sex drive. Your doctor can usually prescribe hormone replacement therapy (HRT), which will improve these symptoms.

The Daisy Network offers information and support for women going through an early menopause (see page 124 for contact details).



## Possible sexual changes in men

Surgery or radiotherapy for rectal or anal 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 weaker 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 medicines, such as sildenafil (Viagra®), can help some men to get and maintain an erection after surgery or radiotherapy. If the tablets do not work, penile injections or vacuum devices can be tried. There is more information about erectile problems on our website and in our booklet **Cancer and your sex life – information for men** – see page 118.

### Low testosterone levels

After radiotherapy for rectal cancer, the levels of the male hormone testosterone are lower in some men. Your specialist can tell you if testosterone replacement therapy might be helpful for you.

## 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.

Sometimes, problems happen 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 talk openly with your partner about how you feel.

If you feel self-conscious about how you look, talking with your partner may help you regain 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 Ileostomy and Internal Pouch Support Group and the Sexual Advice Association (see pages 124 and 125 for contact details).

# Tiredness

Tiredness (fatigue) is probably the most common side effect of cancer treatment. Rest often does not help.

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

If you have fatigue, you may:

- have difficulty doing even very small chores, such as brushing your teeth, showering or cooking
- feel you have no energy, and that you could spend the whole day in bed
- have trouble thinking, making decisions or remembering things feel breathless after only light activity
- feel dizzy or light-headed
- have difficulty sleeping
- lose interest in sex
- feel more moody and emotional than usual
- avoid socialising because it is too much effort.

Getting help and support from your healthcare team may help to prevent or relieve some of these effects, and improve your quality of life.

## Possible causes

Sometimes fatigue can be caused by one or more of the following:

- depression
- difficulty sleeping
- pain
- anaemia (low number of red blood cells)
- thyroid problems
- low levels of vitamin B12
- eating problems.

It is important to find out what may be causing the fatigue, so that it can be treated. There is often more than one reason for it.

Always tell your doctor or nurse how you are feeling. Do not feel you have to hide how bad the fatigue is. Tell them how your fatigue is when it is at its worst.

**'It did take some time before I got my energy back, and having to learn to look after my stoma added to it. I am pleased to say things are going well.'**

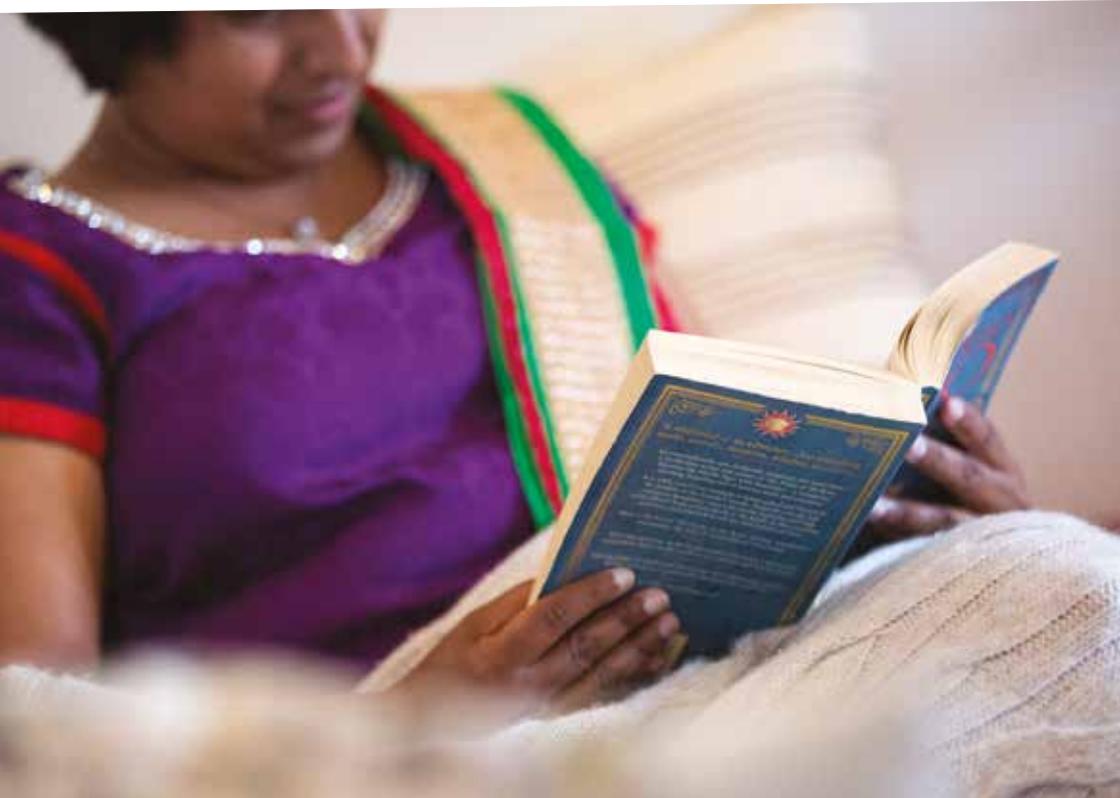
**Ann, Online Community member**

Your doctor can take blood samples to find out if you have anaemia, or if your thyroid gland is underactive. These conditions can be treated with medicines.

Fatigue is a common symptom of depression. It is not unusual to feel depressed, anxious or stressed after cancer treatment. If you think you may be depressed, talk to your doctor or nurse.

You and your doctor can work out if what you are feeling is depression or fatigue. Your doctor can refer you to a counsellor and may prescribe anti-depressants to treat depression.

If sleep problems or pain are making your fatigue worse, improving these will help you feel better.



## What you can do to help yourself

Taking care of yourself is important and can help you to feel better. Try to do the following:

- Take regular exercise to help build up your energy levels (see page 77). Start with short walks and gradually increase how much you do. Exercise also helps you sleep better and can reduce anxiety and depression.
- Keep to a routine. Going to bed and getting up at the same times each day can help. Try not to stay in bed after you wake up.
- Keep to as healthy a diet as possible. This can help you feel better and may help you to have more energy.

Allow people you trust, such as family, friends, neighbours and carers, to help you. Most people are glad to help, particularly if you can tell them what you need. Make a list of tasks you would like help with.

- If you use the internet, you can do your shopping and banking online.
- Complementary therapies may help to reduce stress and anxiety, and may improve fatigue (see page 106). Relaxation, counselling and psychological support are available at many cancer treatment hospitals.
- Problems with concentration and memory are common with fatigue and can be frustrating. We have more information about ways to cope with concentration and memory problems on pages 94 to 96.

There is more information on our website and in our booklets **Coping with fatigue** and **Cancer and complementary therapies** – see page 118.

# 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.

People sometimes call this 'chemo brain' or 'chemo fog'. But, these changes can also happen with other cancer treatments, not just chemotherapy.

Changes in memory or concentration are usually mild. They often get better within a year of finishing treatment. But they can sometimes last longer or have more of an impact on your day-to-day life.

People may:

- find it harder to concentrate
- feel mentally slower than before
- forget details of conversations or events
- mix up dates and appointments
- be unable to find things
- have difficulty doing more than one thing at a time (multi-tasking)
- struggle to remember everyday words or phrases.

Talk to your doctor or nurse if you have these problems. They will look for possible causes for your symptoms. They may arrange for you to have tests, such as blood tests or a scan.

If other things are affecting your concentration or memory, treating these could help. For example, feeling extremely tired (fatigue) is a common side effect of cancer treatment. It can cause problems with concentration and memory. Reducing the fatigue may help improve these problems. We have more information about coping with fatigue on pages 90 to 93.

Sometimes memory and concentration can be affected by other problems, such as:

- anxiety
- stress
- depression
- pain
- other late effects.

Treating these problems may also improve your memory and concentration.

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

Tell your family or friends about the difficulties you are having. They can often support you and help you find ways to make life easier.

Try to look after yourself. Get plenty of rest, but balance this with regular physical activity, such as walking.

Being more active improves:

- fatigue
- sleep problems
- concentration and memory.

Some people find activities such as yoga, exercise, meditation, reading and complementary therapies helpful. They can relax you and help with anxiety. There is more information about complementary therapies on our website and in our booklet **Cancer and complementary therapies** – see page 118.

Here are some other things you can try:

- Keep notes of anything important, such as conversations with your doctor or nurse and questions you want to ask them. Keep notes of anything important, such as conversations with your doctor or nurse and questions you want to ask them (see page 128).
- Have a daily routine. Try to continue with it and do one thing at a time. Remove things that distract you, such as background noise when you are trying to concentrate.
- Help your memory by using a pill box dispenser, planners, calendars, post-it notes and to-do lists.
- Keep things in the same place so you know where to find them, even if you do not remember putting them there.
- Try crosswords, word puzzles or sudoku to help your concentration.
- Keep a diary of your symptoms. They may seem worse first thing in the morning, or when you are tired or hungry. Noticing patterns can help you to plan your day so that you do more difficult tasks when you are feeling your best.

# Damage to nerves after chemotherapy

Damage to nerves that supply the hands, legs and feet is called **peripheral neuropathy**. The chemotherapy drug oxaliplatin is the most common cause of peripheral neuropathy in people who have had treatment for bowel cancer.

The nerves carry messages between the brain, the spinal cord and the rest of the body. Nerve damage affecting the hands and feet causes symptoms such as:

- pins and needles
- numbness
- weakness
- pain.

For a few people, this may lead to problems with balance and walking.

After chemotherapy, symptoms often improve as the nerves slowly recover. This usually takes several months. For some people, the nerves do not completely recover and some nerve damage never goes away.

The symptoms often become less troublesome over time as you find ways of coping with the changes.

We have more detailed information about peripheral neuropathy on our website, visit [macmillan.org.uk](https://www.macmillan.org.uk)

## Treating pain

There are different ways to treat nerve pain. Some drugs change nerve impulses and help to relieve nerve pain. They include:

- anti-convulsants (used to treat epilepsy)
- certain anti-depressant drugs.

Morphine can also sometimes be helpful in treating nerve pain.

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

Transcutaneous electrical nerve stimulation (TENS) blocks pain messages sent from the nerves to the brain. Pads put on the skin give off small electrical pulses to stimulate nerves close to the pain. A physiotherapist or a specialist at a pain clinic can give you more advice.

Acupuncture uses fine needles that are placed through the skin at particular points. It is not clear exactly how this works, but it may help to block pain messages being sent to the brain. Some hospitals and GP surgeries offer acupuncture on the NHS.

There is more information about complementary therapies on our website and in our booklet **Cancer and complementary therapies** – see page 118.

## Other support

If you have problems with balance, co-ordination or walking, a physiotherapist can give you treatment and advice.

If you have difficulty with daily tasks, 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 6 months and make it difficult to walk or do daily activities, there may be financial help available. You can call our cancer support specialists on **0808 808 00 00** for more information.

## What you can do to help yourself

Make sure you protect your hands and feet. Also try to reduce your risk of accidents and falls.

Here are some tips:

- Keep your hands and feet warm – wear gloves and warm socks in cold weather.
- Do not walk around barefoot, and check your feet regularly for any problems.
- Always wear well-fitting shoes.
- Wear gloves, for example when doing household chores, gardening or DIY.
- Use potholders and oven gloves to avoid burning your hands when cooking.
- Test the temperature of water with your elbow to make sure it is not too hot before baths or showers.
- Make sure rooms are well lit and there is nothing you could trip over. Turn a light on if you get up during the night.



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

It is not unusual to find it difficult to cope with some of your feelings months or even years after treatment, especially if you have late effects. But with the right support, coping can become easier. Sharing your feelings with someone else may help you find that support. Try to speak to your doctor, family or friends if you are struggling with how you are feeling.

Even with ongoing treatment effects, many people find that cancer has helped them focus on what is important in their lives.

## Feeling alone

Some late effects can be embarrassing or difficult to talk about. This can make you feel isolated, especially if you do not know anyone else with the same problems. You may also feel more alone as you begin to have less contact with the hospital when your treatment ends.

## Uncertainty

You may worry that some of your late effects are a sign of the cancer coming back. After cancer treatment, it is common to feel anxious about aches and pains that you would not have worried about before. It can help to know more about your late effects and where you can get support when you are worried.

## Anger

It is natural to feel angry at times, especially if you are coping with the late effects of treatment. Do not feel bad about feeling this way. It can be a relief to simply tell yourself and people you trust when you feel angry. Keeping strong feelings to yourself may make you feel depressed. You can talk to your doctor about seeing a counsellor.

## Depression

Coping with the late effects of treatment can be physically and emotionally demanding. This can sometimes make people feel depressed. Signs of depression include:

- feeling low in mood
- having no interest in, or enjoyment from, the things you would normally enjoy
- feeling helpless or hopeless.

If you think you may be depressed, talk to your doctor. They can refer you to a counsellor or psychologist, or prescribe a course of anti-depressant drugs for you.

# Relationships

Your experience of cancer may have improved and strengthened your relationships with people close to you. You may feel that you would not have coped as well without the support you had from family and friends.

However, cancer is stressful and this may change your relationships in different ways. The impact on your relationships is likely to depend on many factors. These include how the cancer and its treatment have affected your day-to-day life and how strong your relationships were before you were diagnosed. There is no 'normal' way for a relationship to be after cancer treatment.

You may sometimes feel that your family and friends do not understand if you are not feeling positive about getting back to normal life. Or you may feel they do not realise how much the effects of treatment interfere with your life. Talking openly about how you are feeling can help them to understand you better and give you the support you need.

There is more information on our website and in our booklets **Cancer, you and your partner** and **Talking about cancer** – see page 118.

# Getting help and support

Not everyone has people close to them who they can talk to about their cancer and its treatment. You can talk to other people facing similar challenges by joining a support group or by using social networking sites. Your specialist nurse will have details of cancer support groups and counselling services in your area. Or you can call us on **0808 808 00 00** to speak to one of our cancer support specialists. They will also be able to give you details.

At your hospital follow-up visits, your specialist will assess your late effects and how they are being managed. They will also check that there are no signs of the cancer coming back.

After going through cancer, it is natural for your body to feel different, and for you to feel differently about your body. If you are worried about symptoms or are struggling with your emotions, let your doctor or specialist nurse know as soon as possible. You do not have to wait until your next check-up to contact your doctor or any other health professional.

## Complementary therapies

Complementary therapies are usually used alongside conventional medical treatments. There are different types of complementary therapy, including acupuncture, aromatherapy and massage.

Complementary therapies may:

- help you feel better
- reduce stress and anxiety
- improve some side effects of treatment.

Relaxation, counselling and psychological support are available at many cancer hospitals. Complementary therapies are sometimes also available through cancer support groups or your GP. Many complementary therapists have private practices.

There are lots of different therapies. Some people find it helpful to use a combination of therapies. When you choose a therapy, choose one that feels right for you and choose a registered practitioner.

There is more information about complementary therapies on our website and in our booklet **Cancer and complementary therapies** – see page 118.





# WORK AND FINANCIAL SUPPORT

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# Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It is important to do what is right for you.

Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share.

On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It is important not to take on too much, too soon. Your consultant, GP or specialist nurse can help you decide when and if you should go back to work.

## Employment rights

The Equality Act 2010 protects anyone who has, or has had, cancer. Even if a person who had cancer in the past has been successfully treated and is now cured, they are still covered by the act. This means their employer must not discriminate against them for any reason, including their past cancer. The Disability Discrimination Act protects people in Northern Ireland.

There is more information about work and cancer on our website and in our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** – see page 118.

For most people, returning to work is a big step in their recovery. Many companies have an occupational health service. Occupational health departments can offer confidential support and counselling before and after your return to work.

Late effects such as tiredness, bowel changes or bladder changes may make work more difficult. Your employer has a duty to make 'reasonable adjustments' to your workplace and working practices. These may include:

- allowing some flexibility in working hours
- moving a work base – for example, transferring you to a work station nearer to a toilet
- allowing extra breaks to help you cope with tiredness
- taking away tasks from your job that might be physically challenging
- letting you work from home
- providing facilities that are appropriate for your disability.

For expensive adjustments, a government-funded scheme called **Access to Work** may help your employer with financial and practical support.

# Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available.

If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less.

Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled.

There are 2 different types of ESA:

- contribution-based (contributory) – you can get this if you have paid enough national insurance
- income-related (means tested) – you can get this if you don't qualify for contribution based ESA or if your income is low.

ESA is gradually being replaced by a new benefit called **Universal Credit**. This benefit is for people below retirement age who are out of work or on a low income. Personal Independence Payment (PIP) is a new benefit for people aged between 16 and 64. It is for people who have problems moving around and looking after themselves. You must have had these difficulties for at least 3 months and expect them to last for at least 9 months. PIP replaces an older benefit called Disability Living Allowance (DLA) for adults.

**Attendance Allowance (AA)** is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath or dressing yourself. You don't need to have a carer, but you must have had these problems for at least 6 months.

If you are terminally ill, and may be expected to live for less than 6 months, you can apply for PIP, DLA or AA under the special rules. It does not have to be certain and it does not matter if you live longer than 6 months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

## Help for carers

**Carer's Allowance** is a weekly benefit that helps people who look after someone with a lot of care needs. If you don't qualify for it, you can apply for Carer's Credit. This helps you to build up qualifying years for a State Pension.

## More information

The benefits system can be hard to understand, so it's a good idea to talk to an experienced welfare rights adviser. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

We have just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see pages 126 to 127 for contact details).

Our booklet **Help with the cost of cancer** has more detailed information. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

# Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 126 to 127.

Our booklet **Insurance** may also be helpful – see page 118 for ways to order this.



# FURTHER INFORMATION

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# About our information

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

## Order what you need

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

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

## Online information

All of our information is also available at **macmillan.org.uk/information-and-support**

There you will also find videos featuring real-life stories from people affected by cancer and information from health and social care professionals.

## Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- eBooks
- large print
- translations.

Find out more at **macmillan.org.uk/otherformats**

If you would like us to produce information in a different format for you, email us at **cancerinformationteam@macmillan.org.uk** or call us on **0808 808 00 00**.

## Help us improve our information

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

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

If you would like to hear more about becoming a reviewer, email [reviewing@macmillan.org.uk](mailto:reviewing@macmillan.org.uk) You can get involved from home whenever you like, and we do not ask for any special skills – just an interest in our cancer information.



# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

Our free, confidential phone line is open 7 days a week, 8am to 8pm. Our cancer support specialists can:

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

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

## Information centres

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

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

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

## Talk to others

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

## Support groups

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

## Online Community

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

## The Macmillan healthcare team

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

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

Mal

## Help with money worries

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

### Financial guidance

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

### Help accessing benefits

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

### Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area.

Visit **[macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport)** to find out more about how we can help you with your finances.

## Help with work and cancer

Whether you are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

### My Organiser app

Our free mobile app can help you manage your treatment, from appointment times and contact details, to reminders for when to take your medication. Search 'My Organiser' on the Apple App Store or Google Play on your phone.

# Other useful organisations

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

## **Beating Bowel Cancer Helpline** 020 8973 0011

**Email** nurse@

beatingbowelcancer.org

**www.beatingbowelcancer.org**

Works 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 Community Home Delivery Service**

0800 031 5406

**Medical Helpline**

0800 031 5412

**Legal Helpline** 01926 357 220

**Email**

help@bladderandbowel.org

**www.bladderandbowel.org**

Provides information and support. Campaigns for people living with bladder and bowel disorders.

## **Bowel Cancer UK**

**Tel** 020 7940 1760

**Email** admin@bowelcanceruk.org.uk

**www.bowelcanceruk.org.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 and leaflets.

## **Colostomy UK 24-hour helpline**

0800 328 4257

**Email** info@colostomyuk.org

**www.colostomyuk.org**

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.

### **Daisy Network**

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

**www.daisynetwork.org.uk**

A nationwide support group for women who have had a premature menopause. Membership fees apply. It offers information covering health, fertility and psychological topics, a forum to connect with other members and live chat sessions where you can ask medical experts questions.

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

**Freephone** 0800 0184 724

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

**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. Hosts a number of forums for discussion of related issues. Membership fees apply.

### **Counselling and emotional support**

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

**Tel** 01455 883 300

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

**www.itsgoodtotalk.org.uk**

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor.

#### **College of Sexual and Relationship Therapists**

**Tel** 020 8543 2707

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

**www.cosrt.org.uk**

Website has information about sexual wellbeing and what to expect from sex therapy. It also has a directory of therapists to help you find professional support in your local area.

#### **Relate**

**Tel** 0300 100 1234

**www.relate.org.uk**

Counselling, support and information for all relationships.

## LGBT-specific support

### **LGBT Foundation**

Tel 0345 330 3030

(Mon to Fri, 10am to 6pm)

Email [helpline@lgbt.foundation](mailto:helpline@lgbt.foundation)

**[www.lgbt.foundation](http://www.lgbt.foundation)**

Provides a range of services to the LGBT community, including a helpline, email advice and counselling. The website has information on various topics including sexual health, relationships, mental health, community groups and events.

### **Sexual Advice Association**

**[www.sexualadvice](http://www.sexualadvice)**

**[association.co.uk](http://association.co.uk)**

Website has information on sexual problems as well as sexual health and wellbeing.

## Equipment and advice on living with a disability

### **British Red Cross**

Tel 0344 871 11 11

Textphone 020 7562 2050

**Email**

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

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

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service. There is information on going back to work, direct payments, human rights issues and advice for disabled students. Information and Advice Line services (DIALs) run by and for disabled people.

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

**Helpline** 0300 999 0004

(Mon to Fri, 10am to 4pm)

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

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

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

## **Disability Rights UK**

**Tel** 0207 250 8181

(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)

**Email** enquiries@

disabilityrightsuk.org

**www.disabilityrightsuk.org**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues and advice for disabled students.

## **Financial or legal advice and information**

### **Citizens Advice**

Provides advice on a variety of issues including financial, legal, housing and employment issues. Use their online webchat or find details for your local office in the phone book or by contacting:

### **England**

**Helpline** 03444 111 444

**www.citizensadvice.org.uk**

### **Wales**

**Helpline** 03444 77 2020

**www.citizensadvice.org.uk/wales**

### **Scotland**

**Helpline** 0808 800 9060

**www.citizensadvice.org.uk/scotland**

### **Northern Ireland**

**Helpline** 0800 028 1181

**www.citizensadvice.org.uk**

### **Department for Work and Pensions (DWP)**

**Personal Independence**

**Payment (PIP) Helpline**

0345 850 3322

**Textphone** 0345 601 6677

(Mon to Fri, 8am to 6pm)

**Carer's Allowance Unit**

**Tel** 0800 731 0297

**Textphone** 0800 731 0317

(Mon to Fri, 8am to 6pm)

**www.gov.uk/carers-allowance**

Manages state benefits in England, Scotland and Wales. You can apply for benefits and find information online or through its helplines.

**GOV.UK****www.gov.uk**

Has information about social security benefits and public services in England, Scotland and Wales.

**Money Advice Service Helpline**

0800 138 7777 (English)

0800 138 0555 (Welsh)

(Mon to Fri, 8am to 8pm,  
Sat, 9am to 1pm)

**Typetalk**

18001 0300 500 5000

**Email** enquiries@

moneyadviceservice.org.uk

**www.moneyadviceservice.org.uk**

Runs a free financial health check service and gives advice about all types of financial matters across the UK. Has an online chat service for instant money advice.

**Money Advice Scotland**

**Tel** 0141 572 0237

**Email** info@moneyadvice  
scotland.org.uk

**www.moneyadvicescotland.org.uk**

Use the website to find qualified financial advisers in Scotland.

**National Debtline (England, Wales and Scotland)**

**Tel** 0808 808 4000

(Mon to Fri, 9am to 8pm,  
Sat, 9.30am to 1pm)

**www.nationaldebtline.org**

A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

**NiDirect**

**www.nidirect.gov.uk**

Has information about benefits and public services in Northern Ireland.

**Unbiased.co.uk**

**Helpline** 0800 023 6868

**Email** contact@unbiased.co.uk

**www.unbiased.co.uk**

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.



## Disclaimer

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

## Thanks

This booklet has been written, revised, and edited by Macmillan Cancer Support's Cancer Information Development team. With thanks to Dr Richard Adams, Consultant Clinical Oncologist; Mr Ian Botterill, Consultant Colorectal Surgeon; Dr Clare Donnellan, Consultant Gastroenterologist; Mr Mark George, Consultant Bowel Surgeon; John Green, Gastroenterologist; Helen Ludlow, Macmillan Senior Nurse for Late GI Effects of Treatment; Ann Muls, Macmillan Nurse Consultant (GI consequences of cancer treatments); Dr Claire Shaw, Consultant Dietitian; Dr Claire Taylor, Lecturer in Gastrointestinal Nursing and Rhiannon Williams, Specialist Oncology Dietitian. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

We welcome feedback on our information. If you have any, please contact [\*\*cancerinformationteam@macmillan.org.uk\*\*](mailto:cancerinformationteam@macmillan.org.uk)

## Sources

We have listed a sample of the sources used in the publication below. If you would like further information about the sources we use, please contact us at **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

J Andreyev. Guidance: The practical management of the gastrointestinal symptoms of pelvic radiation disease. *Frontline Gastroenterology*. 2014.

S Brown et al. Knowledge and awareness of long-term and late treatment consequences amongst colorectal cancer survivors: A qualitative study. *European Journal of Oncology Nursing* 20 191–198. 2016.

A Muls et al. The holistic management of consequences of cancer treatment by a gastrointestinal and nutrition team: a financially viable approach to an enormous problem? *Clinical Medicine* 2016 Vol 16 3.

National Institute for Health and Care Excellence. QS54 Faecal incontinence. February 2014.

I.D. White. Sexual Difficulties after Pelvic Radiotherapy: Improving Clinical Management. *Clinical Oncology* 27. 2015.

# 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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Signature \_\_\_\_\_

Date     /     / \_\_\_\_\_

## Don't let the taxman keep your money

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

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

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

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

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



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

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

**This booklet is about managing the late effects of bowel cancer treatment. It is for anyone who has late effects after treatment for bowel cancer. There is also information for carers, family members and friends.**

**The booklet explains how to manage the late effects of bowel cancer treatment. It also has information about emotional, practical and financial issues.**

We're here to help everyone with cancer live life as fully as they can, providing physical, financial and emotional support. So whatever cancer throws your way, we're right there with you. For information, support or just someone to talk to, call **0808 808 00 00** (7 days a week, 8am to 8pm) or visit **macmillan.org.uk**

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

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

**MACMILLAN  
CANCER SUPPORT**

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