MACMILLAN CANCER SUPPORT

Managing the bowel late effects of pelvic radiotherapy

About this booklet

This booklet is about the late effects on the bowel after treatment with pelvic radiotherapy. It is for anyone treated with pelvic radiotherapy who has bowel side effects that continue after treatment or begin months or years later. There is also information for carers, family members and friends. The booklet explains how to manage the bowel late effects of pelvic radiotherapy.

This booklet does not have information about bladder late effects of pelvic radiotherapy. We have another booklet about this called Managing the bladder late effects of pelvic radiotherapy.

We hope it helps you deal with some of the questions or feelings you may have.

How to use this booklet

This booklet is split into sections to help you find what you need. You do not have to read it from start to finish. You can use the contents list to help you.

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

On pages 86 to 95, there are details of other organisations that can help.

There is also space to write down questions and notes for your doctor or nurse.

Quotes

In this booklet, we have included quotes from people who have had pelvic radiotherapy, which you may find helpful. These are from people who have chosen to share their story with us. To share your experience, visit macmillan.org.uk/shareyourstory

For more information

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

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 Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

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

Contents

The pelvis and late effects

The pelvis

The pelvis is the area of the body between the hip bones, in the lower part of the tummy (abdomen).

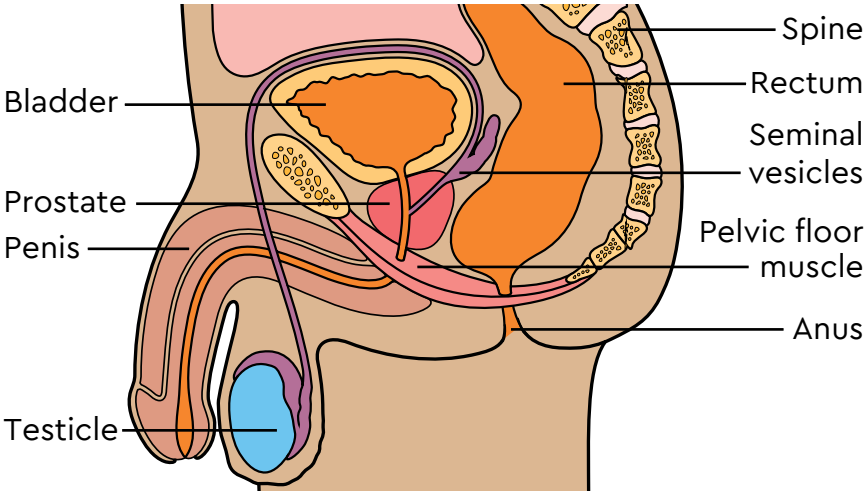
It contains:

- the sex organs
- the bladder
- a section of the small bowel
- the lower end of the large bowel (colon, rectum and anus).

The pelvis also contains bones, lymph nodes (glands), blood vessels and nerves.

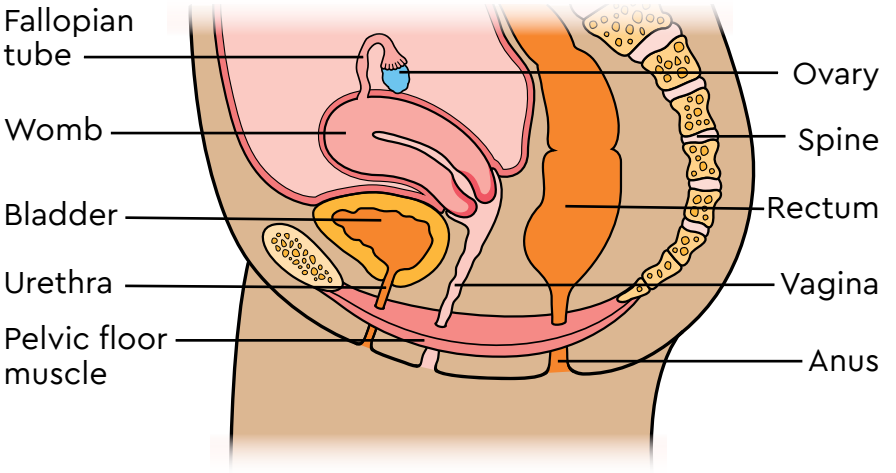
The male sex organs include the prostate gland, testicles and penis. People who have these sex organs can include men, trans women and people assigned male at birth.

The male pelvis



The female sex organs include the ovaries, fallopian tubes, uterus (womb), cervix and vagina. People who have these sex organs can include women, trans men and people assigned female at birth.

The female pelvis



If you are transgender

Not all transgender (trans) people have had genital gender affirming surgery. But if you have, you may not have all the sex organs you were born with. If you are not sure how this may affect your symptoms, talk to your doctor or nurse. They can give you more information.

The bowel

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

- the small bowel
- the large bowel.

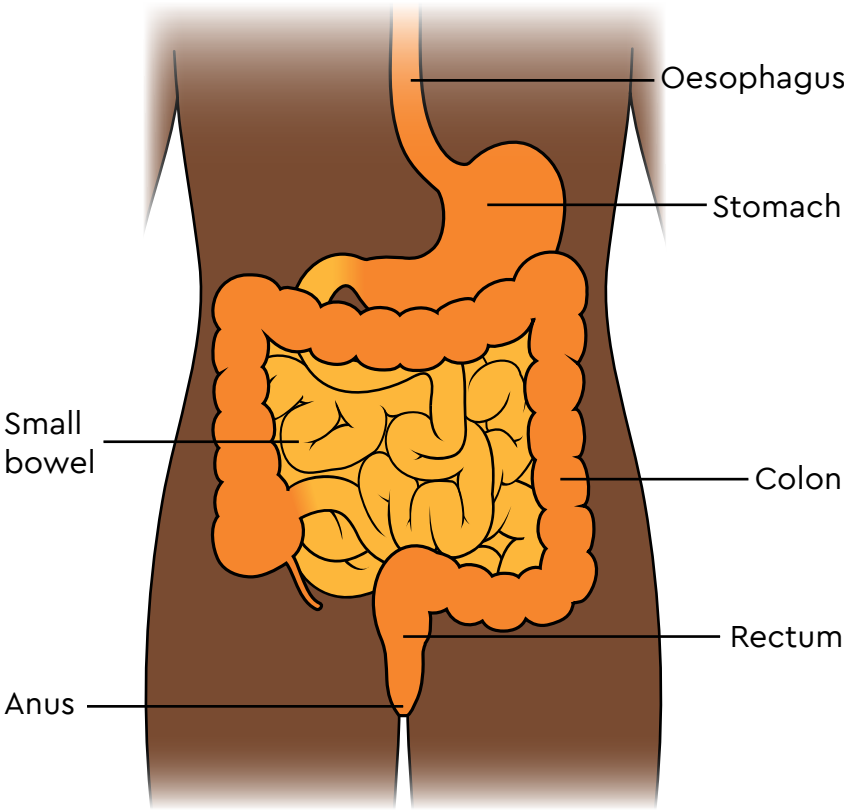
The large bowel is made up of the colon, rectum and anus.

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

The food then enters the small bowel, where nutrients and minerals are absorbed. The digested food then moves into the colon. This is where water is absorbed. The remaining waste matter is called stool (poo). It is held in the rectum (back passage).

Nerves and muscles in the rectum help to hold onto stool until it passes out of the body through the anus. The anus is the opening at the end of the large bowel. It contains a ring of muscle called the sphincter. This muscle helps to control when you empty your bowel (poo).

The bowel



What is pelvic radiotherapy?

Radiotherapy treats cancer by using high-energy x-rays to destroy cancer cells. It can also destroy normal cells in the treated area, but these can usually repair themselves. The pelvis is the lower part of the tummy (abdomen), between the hips. Using radiotherapy to treat cancer in the pelvis is called pelvic radiotherapy.

Pelvic radiotherapy can be given externally or internally.

External beam radiotherapy

This is when radiotherapy is given from a machine outside the body.

Internal radiotherapy

This uses a radioactive material that is put inside the body. It is called brachytherapy. Depending on your cancer, brachytherapy may be temporary or permanent. Temporary brachytherapy is when the radioactive material is taken out at the end of the treatment. Permanent brachytherapy is when the radioactive material stays in.

Some people may have a type of brachytherapy called Papillon treatment. This may be used for rectal cancer.

Chemoradiation

Sometimes radiotherapy is given with chemotherapy. This is called chemoradiation. Radiotherapy that is given in combination with surgery or chemotherapy can increase the risk of developing late effects.

What are late effects?

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

Sometimes side effects do not go away, or they start months or years after treatment has ended.

These side effects are called:

- long term effects – if they begin during treatment, or shortly after treatment has ended and last longer than 3 months
- late effects – if they begin months or even years later, as a delayed response to treatment.

In this information 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.

This information is about the bowel late effects of pelvic radiotherapy.

Other late effects of pelvic radiotherapy

As well as bowel changes, pelvic radiotherapy can cause other late effects. These include the following:

- Bladder problems – pelvic radiotherapy may affect the lining of the ureters, the bladder, the pelvic floor muscles and the urethra, which can cause symptoms.
- Lymphoedema – this is swelling caused by a build-up of fluid in the body tissues. It happens when the lymphatic system is not working properly. This can be after damage from cancer or cancer treatment.
- Bone changes – these can affect you long after treatment has ended.
- Changes to your sex life – these can be physical and emotional. There may be changes to the vagina or sexual problems such as erectile dysfunction.
- Fertility – there may be changes that can affect getting pregnant or making someone pregnant. Pelvic radiotherapy can cause an early menopause.
- Second cancer – pelvic radiotherapy may slightly increase the risk of a new and different cancer in the treated area. This is not the same as secondary cancer, when cancer spreads from where it started. The benefit of having pelvic radiotherapy outweighs the risk of second cancer. Your doctor or nurse can explain more about this.

We have more information on how to manage these other late effects. Call the Macmillan Support Line on 0808 808 00 00 or visit macmillan.org.uk

We have more information on how to manage these other late effects in our booklets:

- Managing the bladder late effects of pelvic radiotherapy
- Understanding lymphoedema
- Bone health and cancer treatment
- Cancer and your sex life
- Cancer and fertility.

Talking to your doctor

Some late effects may not affect your daily life very much. Others can be more difficult to live with. Help and support is available, and there are usually things that can help you cope.

Talk to your cancer doctor or specialist nurse if you have:

- side effects that do not go away
- new symptoms or problems after treatment has finished.

It can be frightening to have symptoms after treatment has finished. You may worry that the cancer has come back.

Your doctor or nurse can explain whether treatment may have caused your symptoms. You may need tests to check for other causes.

You may feel embarrassed talking about problems with your bowel, bladder or sex life. But doctors and nurses are used to speaking about these issues. They can try to answer your questions and help you.

Other types of expert help

Some people with late effects need help from other specialists. Your doctor or nurse can refer you to a specialist if needed. For example, you may meet with the following healthcare professionals:

- a gastroenterologist – a doctor who treats problems with the digestive system
- a colorectal surgeon – a doctor who does operations (surgery) on the large bowel
- a continence adviser – someone who gives advice and support to people with continence problems, this could be a specialist nurse or physiotherapist.

Some hospitals in the UK have special clinics for people with late effects from radiotherapy. Ask your healthcare team or GP whether there are any near you. Your doctor or nurse can refer you to other specialists if needed.

The Pelvic Radiation Disease Association also has information about support and late effects services.

You may find the organisations listed on pages 86 to 95 helpful. Or you can call the Macmillan Support Line free on 0808 808 00 00.

Bowel changes after treatment

Bowel changes

Pelvic radiotherapy often causes bowel symptoms. These usually get better within a few weeks after treatment has finished. But some people have late effects that start months or years after treatment.

Possible late effects to the bowel

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

Radiotherapy can also cause fibrosis (scarring) in the large bowel. This can make it narrower, thicker and less flexible. Waste will pass through it more quickly than before. Stool (poo) may be softer and looser, or liquid (diarrhoea). The rectum may not be able to hold as much stool. You may need go to the toilet more often and need to go more urgently.

Radiotherapy can also affect the muscles that help keep 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. You may become unable to digest some types of food. This is called food intolerance. Or you may have diarrhoea and other symptoms because:

- the small bowel is no longer able to re-absorb bile acids used in digestion – this is called bile acid malabsorption.
- bacteria that do not usually live in the small bowel are growing there – this is called small bowel bacterial overgrowth or small intestinal bacterial overgrowth.

Symptoms

Possible symptoms of late effects to the bowel include:

- bleeding from the rectum (back passage)
- passing mucus (a clear, sticky substance) from the rectum
- cramps or spasms in the bowel, which may be painful
- feeling that you need to pass stools (poo) even when your bowel is empty – this is called tenesmus
- not being able to empty your bowel completely
- diarrhoea
- constipation (not being able to pass stools as often as you normally do)
- needing to rush to empty your bowel (urgency)
- problems controlling your bowel, causing incontinence
- passing a lot of wind, or losing control of passing wind.

Some people have mild symptoms that do not cause too many problems. They may only notice small changes, such as having to go to the toilet twice a day instead of once. For other people, bowel changes have a much bigger impact and can affect daily life. Bowel symptoms can affect your appetite or weight. Talk to your doctor if you notice that you are losing weight.

Get symptoms checked

It is important that you get ongoing bowel symptoms checked by your doctor.

Bowel symptoms might not be caused your radiotherapy treatment. They can be a sign of a more serious problem. It is important to find out the cause as soon as possible.

There are 4 symptoms you must always talk to your doctor about:

- bleeding from your rectum
- waking up from sleep to empty your bowels
- needing to rush to empty your bowels
- bowel incontinence.

Bleeding from the rectum

Bleeding from the rectum (back passage) is common after pelvic radiotherapy. Treatment can damage the lining 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 you strain to pass stools (poo) or have hard stools.

Most people who have bleeding from the rectum only notice bleeding occasionally. For a few people, bleeding can be heavy. They will need treatment.

Changes in the bowel lining often get better over time. But this can take 5 to 10 years. You may have an assessment with a specialist in the meantime.

Tests

Bleeding can also be a sign of other problems such as haemorrhoids (piles) or straining on the toilet. Always tell your doctor or specialist nurse if you have any bleeding from the rectum, even if you think you know the cause. It is important to make sure there are not any serious problems.

Your doctor will examine your rectum. They may also refer you to have a sigmoidoscopy or colonoscopy. This is when a camera is used to look inside the bowel. A doctor or nurse passes a thin tube into the bowel. The tube is called a scope. It has a light and tiny camera on the end. It looks for any abnormal areas.

Treatment for bleeding caused by radiotherapy

If the bleeding is mild and not affecting your daily life, you will probably not need treatment. Your specialist will give you advice about your bowel habits and how to avoid constipation. This can help reduce bleeding.

You are likely to need treatment if:

- bleeding is affecting your daily life
- you become anaemic – this means you have a low number of red blood cells.

Your doctor or specialist nurse will explain more about your treatment options and give you more information.

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

A drug called sucralfate can sometimes reduce bleeding. This drug coats the lining of the bowel. It reduces inflammation and encourages healing. You have the drug as an enema. This means it is gently given as a liquid into the rectum, through a short tube. Your cancer team will show you how to do this yourself at home.

The following treatments may also reduce bleeding.

Thermal ablation

This treatment uses heat to seal areas that are bleeding. You have it during an endoscopy. This is when a doctor or nurse passes a thin, flexible tube with a light on the end into the rectum. Different types of thermal ablation include:

- radiofrequency ablation (RFA)
- argon plasma coagulation (APC).

Thermal ablation can cause complications, such as serious tissue damage. Your doctor will discuss this with you.

Formalin

This drug seals bleeding blood vessels. A doctor or nurse gives it to you during an endoscopy.

Formalin can cause complications, such as serious tissue damage. Your doctor will discuss this with you.

PuraStat®

This gel forms a coating over bleeding areas. A doctor or nurse gives it to you during an endoscopy. Your doctor can give you more information about this treatment.

Hyperbaric oxygen therapy (HBO)

During HBO you go into a special room or chamber and breathe in pure oxygen. The oxygen travels around the blood. The increased oxygen in your blood can help new blood vessels grow. This may help heal areas affected by radiotherapy. Treatment takes up to 8 weeks. HBO is not widely available and is not always available on the NHS.

Getting help with bowel control problems

If you have a bowel control problem, you may have:

- difficulty controlling when and how often you pass stools (poo) or wind
- leakage or soiling (bowel incontinence)
- cramps
- bloating
- diarrhoea
- constipation
- difficulty emptying your bowel completely.

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 they can do to help.

Tests

Your doctor or nurse will usually ask about your bowel problems and things that affect your symptoms. It is important that they properly assess your situation. The right treatments for bowel control problems depend on your symptoms and what is causing them.

You may have some of the following tests:

- blood tests
- stool tests
- x-rays and scans
- endoscopy (camera) tests, such as a colonoscopy or sigmoidoscopy
- breath tests – this is where doctors use samples of your breath to investigate symptoms such as diarrhoea or discomfort in your abdomen (tummy).

It may be helpful to write down your bowel habits and what you eat for 1 week before your appointment. You can use our food and symptom diary to do this. Your doctor or nurse will usually ask you about:

- how your bowel habits have changed
- what your stools look like
- your diet and lifestyle
- any medicines you take
- how the bowel problems are affecting your daily life.

They may suggest changes to your diet or using medicines to regulate your bowel. They may give you advice about strengthening the muscles used for bowel control.

Improving bowel control

Your doctor or specialist nurse will probably have helpful suggestions. The most common ways of improving bowel control include:

- changes to your diet
- drugs to regulate your bowel
- exercising and strengthening the muscles used for bowel control.

If your symptoms do not improve, you can ask your GP to refer you to a continence adviser or a doctor who treats problems with the digestive system (gastroenterologist).

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 stool (poo) loose or increase wind. 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 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 food and symptom diary. It lets them see the types of food you usually eat and what changes may help your symptoms.

Food and symptom diary

Date	Time	Food eaten and/or medication taken		Amount	Your symptoms and level (0 = no problem, 10 = severe)	Time and duration
6th August	Breakfast	Tea and toast		Small	No symptoms (0)	-
6th August	12.30pm	Cauliflower cheese		Medium	Wind (6)	1.30pm for half an hour

Fluids

Try to drink at least 1 to 2 litres (2 to 3½ pints) of fluids a day, unless your healthcare team tells you differently. Water is best. Drink small amounts throughout the day so you do not drink lots of fluids with meals.
Some types of drink can make bowel problems worse. You may want to limit drinking:

- fizzy drinks
- caffeinated drinks such as coffee, tea or cola
- alcohol
- sugar-free drinks that contain artificial sweeteners.

Fibre

Changing the amount of fibre in your diet may help with bowel problems. Your GP, cancer doctor, nurse or dietitian will give you advice about the type of fibre you need and how much you should have. This depends on the treatment you have had and the type of bowel problem.

There are 2 types of fibre:

- Insoluble fibre helps with managing constipation. It can also help with other bowel problems. You can get insoluble fibre from wholegrain bread and cereals, vegetables and fruit skins. It is also in bran and seeds.
- 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.

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. Fibre absorbs fluid, so make sure you also drink more water. This helps stools stay soft and move through the bowel easily.

Adding more fibre is not right for everyone. Following the 5-a-day plan for fruit and vegetables may not always be right for you. Your doctor, nurse or dietitian may give you advice about blending, slow cooking, and peeling fruit and vegetables to reduce the amount of fibre you have.

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 stool bulkier and easier to push out. But some people find Fybogel® makes the bowel produce more wind.

If you are taking fibre supplements, make sure you drink plenty of fluids. You should drink at least 2 litres (3½ pints) of fluids every day.

Food intolerance

Sometimes radiotherapy can affect how well your bowel copes with certain food types, such as lactose or fructose. Lactose is found in milk and some other dairy products. Fructose is found in sugar and fruit.

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

Anti-diarrhoea drugs may help if you have:

- urgency
- loose stools
- diarrhoea
- bowel incontinence.

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 stool 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. Always take medicines exactly as your cancer team, GP or pharmacist explains.

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 your symptoms are controlled. Loperamide is available as a syrup, which allows you to make small changes to the dose as needed.

Sometimes loperamide can cause cramps. If this happens, taking a lower dose may help.

Other types of anti-diarrhoea medicine include codeine phosphate and diphenoxylate (Lomotil®). Your GP, cancer team or a continence adviser can give you advice.

Drugs that can increase bowel symptoms

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

- Magnesium in antacids – this treatment for heartburn may cause diarrhoea.
- Proton pump inhibitors such as omeprazole (Losec®) may cause wind and diarrhoea.
- Laxatives such as Lactulose® and Fybogel® may cause wind and diarrhoea.
- Metoclopramide – this anti-sickness drug may cause diarrhoea.
- Metformin – this tablet to treat diabetes may cause diarrhoea, particularly when you have just started taking it.
- Beta-blockers – these tablets to treat high blood pressure and some heart problems may cause diarrhoea.

If you think a drug you are taking might be making your symptoms worse, tell your doctor. They may be able to prescribe a different drug that may affect you less.

Drugs to treat constipation

If you have problems with constipation or difficulty emptying your bowel completely, you may be given 1 of the following treatments:

- Soluble fibre supplements, such as Fybogel® or Normacol®.
- Suppositories – you put these into your rectum (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 when you are able to stay near a toilet for a while after inserting them. You may not need to use them every day. Ask your doctor or nurse if you want to try using them at night so they have longer to work.
- Enemas – these contain a small amount of gel or liquid that you squeeze into the lower bowel. This stimulates the bowel to empty.

Drugs that can cause constipation

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

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.

Smoking or vaping

If you have problems with urgency, loose stools or bowel incontinence, smoking or vaping may make things worse. This is because nicotine stimulates the bowel. Talk to your doctor about ways to stop smoking or smoke less. There are also Stop smoking services available.

Pelvic floor exercises

Pelvic floor exercises are exercises to strengthen the muscles used in bowel control. They may help with:

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

Pelvic floor exercises help strengthen the muscles that support your bladder, rectum and sex organs. These muscles help with bladder and bowel control.

You can do pelvic floor exercises while you are standing, sitting or lying down. It is easier to start doing them lying down with your knees bent up. When you get more confident at doing them, you can try sitting or standing. When done correctly, no one will know you are doing them.

You squeeze and relax the muscles around your anus, as if you are trying to stop yourself passing wind. Then squeeze the muscles as if you are trying to stop a flow of urine (pee) halfway through. Try not to squeeze your buttocks, thighs and tummy muscles or hold your breath. Now try to do both exercises at the same time and hold. When you can do it, start holding for longer.

You need to practise slow squeezes and short squeezes. For example, try to do:

- 10 slow squeezes lasting 10 seconds each with a 4 second rest between each one
- 10 fast squeezes at a speed of 1 per second.

Some people find it difficult to know which muscles to squeeze. If you are unsure or your symptoms are not getting better, ask your doctor to refer you to a specialist. They can check you are doing the exercises properly and give you advice.

It takes at least 3 months to strengthen these muscles. You need to do the exercises regularly and you need to keep doing them. Aim to do the sets of slow and quick squeezes 3 times every day. Try doing them at the same times each day to get into a routine. It can be helpful to set reminders on your phone or use a pelvic floor exercise app.

Bowel retraining

Some bowel control problems can make it difficult to know when you will need the toilet. This can be very stressful. You may worry that you will not be able to 'hold on'. Or you may be checking all the time for signs that you need to go.

A continence adviser may suggest a bowel retraining programme to help you feel more in control. This teaches you ways to:

- resist the urge to go straight away
- get your bowel habits into a regular, predictable pattern
- manage any anxiety you have about bowel control.

Bowel retraining may also involve taking anti-diarrhoea medicines and doing pelvic floor exercises.

Toilet habits

If you have ongoing problems with constipation or difficulty emptying your bowel, 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. It is important not to push hard to try to pass stools. This can weaken your pelvic floor muscles and may cause problems with bowel control in the future. If you have to wait for a long time on the toilet, you may be going to the toilet too soon. Or it may be a sign that you are constipated. Try not to go to the toilet until you have a strong urge to pass a stool. And try not to sit on the toilet for more than 20 minutes.

Toilet posture

Sitting in the right position on the toilet can help you to empty your bowel. 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 stools. You may find using a relaxed breathing technique helps.

The correct position for emptying the bowel

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

Diarrhoea

Many people find changing their diet and taking anti-diarrhoea drugs stops the diarrhoea. We have more information about managing diarrhoea by making changes to your diet or taking anti-diarrhoea drugs. But if this does not help, ask your doctor to refer you to a gastroenterologist. Diarrhoea can happen for a number of reasons. A gastroenterologist will be able to do a full assessment to find out the cause.

After pelvic radiotherapy, some people have diarrhoea caused by changes to the small bowel, such as:

- bile acid malabsorption (also called bile acid diarrhoea)
- small bowel bacterial overgrowth – also called small intestinal bacterial overgrowth (SIBO)
- exocrine pancreatic insufficiency (EPI).

Bile acid malabsorption

Bile acids are made in the liver. They go to the small bowel when you eat, where they help digest fats. When the bile acids reach the far end of the small bowel, they are absorbed back into the body.

Sometimes radiotherapy for bowel cancer damages the small bowel. Or part of the small bowel may be removed during surgery. If the small bowel cannot re-absorb the bile acids, this can cause watery diarrhoea, painful cramping and bloating. This is called bile acid malabsorption or bile acid diarrhoea.

Your doctor may advise you to start the following treatments, to see whether symptoms improve:

- Eat a low-fat diet – a dietitian will help you do this in a balanced way.
- Take anti-diarrhoea drugs
- Take drugs that reduce the effect of bile acids on the bowel. The drug most commonly used is colestyramine (Questran®, Questran Light®). It is a powder that you mix with water or fruit juice. If colestyramine does not work, your specialist may prescribe a tablet called colesevelam (Cholestagel®).

A SeHCAT scan can help diagnose bile acid malabsorption. Your doctor can explain more about this test. SeHCAT scans are not widely available and may not be needed.

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

Small bowel bacterial overgrowth

The large bowel contains lots of healthy or 'good' bacteria. These help digest food. But a healthy small bowel contains almost no bacteria. After pelvic radiotherapy, bacteria are sometimes found in the small bowel. This is called small bowel bacterial overgrowth or small intestinal bacterial overgrowth (SIBO). It can cause symptoms including:

- diarrhoea
- wind
- bloating
- constipation
- nausea (feeling sick)
- vomiting (being sick)
- bad breath.

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

Small bowel bacterial overgrowth is usually treated with antibiotics.

Exocrine pancreatic insufficiency (EPI)

This condition sometimes develops in people who have had pelvic radiotherapy to an area of the body that includes para-aortic lymph nodes. These are close to the pancreas. This type of radiotherapy is sometimes used to treat cervical cancer or womb cancer. We have more information in our booklets Understanding cervical cancer and Understanding womb (endometrial) cancer.

The pancreas makes proteins called enzymes. These help to digest food. EPI develops when the pancreas does not make enough enzymes to digest food properly. This can mean you are not getting enough nutrients. It can cause weight loss.

Symptoms of EPI include:

- diarrhoea
- painful cramps
- stools (poo) that are pale and difficult to flush.

If your doctor thinks you might have EPI, they can arrange for you to have a stool test (faecal elastase test). If you have EPI, you will need a supplement to replace the enzymes. Several different brands of supplement are available. They are made from pork. There are no vegetarian alternatives.

The most commonly used supplement is a tablet called Creon®. Previous rulings by Islamic scholars suggest that Muslims may use pork-based medicines if there is no alternative. It has been approved for use by Jewish patients by the Chief Rabbi. If you have concerns about this, speak to your religious leader.

You will need to take the supplement with everything you eat or drink. Most people with pancreatic insufficiency do not absorb enough vitamins and minerals. You may also need a multi-vitamin and mineral supplements. A dietitian will be able to help you use the tablets correctly, as it is important to take enough of the supplements.

Constipation

If you have problems with constipation after treatment, the following tips may help:

- include more fibre in your diet
- drink at least 1 to 2 litres (2 to 3½ pints) of fluid a day
- do daily exercise, such as walking
- get into a toilet routine
- use the correct toilet posture – this means sitting on the toilet in the right position
- check with your doctor whether you are taking medicines that can cause constipation
- take medicines to treat constipation.

If the constipation gets worse or you have severe tummy (abdominal) pain, get advice from your doctor or nurse.

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 cramps (spasms) in the muscles that stimulate the bowel.

Tell your doctor or nurse if you have these symptoms. Tenesmus can be caused by changes to the rectum (back passage) after radiotherapy or surgery. Sometimes it can be a symptom of another problem, including:

- constipation
- infection
- a non-cancerous growth called a polyp
- cancer in the bowel.

If you have tenesmus, your doctor will examine your rectum. They may arrange for you to have a test called a colonoscopy or flexible sigmoidoscopy. These use a camera to look at the bowel.

If your symptoms are a late effect of bowel cancer treatment, your doctor may suggest:

- pelvic floor exercises
- a toilet routine
- using the correct toilet posture – this means sitting on the toilet in the right position
- taking soluble fibre to bulk up stool (poo), or a fibre supplement such as Normacol®
- low doses of certain anti-depressant drugs to reduce the sensitivity of the rectum.

Wind

If you have problems with wind after bowel cancer treatment, the following tips may help:

- Cut down on foods and drinks that are causing wind.
- Eat your meals at the same times each day.
- Do not eat and drink at the same time.
- Use pelvic floor exercises to strengthen the muscles used for bowel control.
- Ask your doctor for advice if you take medicines that cause wind, such as Lactulose® or Fybogel®.
- Some people find taking peppermint oil or eating live yoghurt can help.

Tell your doctor if wind is a problem. Sometimes other things may be making wind worse – for example, constipation or bowel conditions such as diverticular disease. Wind can also be a symptom of a food intolerance or a condition called small bowel bacterial overgrowth after radiotherapy.

Sore or itchy skin

Ongoing diarrhoea or incontinence (leakage from the bowel) can make the skin around the anus sore. Sometimes radiotherapy for rectal or anal cancer can also make this area of skin sore or broken.

Tell your doctor or nurse if your skin is sore or passing stools (pooing) is painful. They can give you advice about looking after your skin. They may give you creams or ointments to use. They can also check your skin for signs of other problems such as haemorrhoids (piles) or fissures.

Anal fissure

After pelvic radiotherapy, the skin of the anus may become narrower and less stretchy. Sometimes a split develops in the skin of the anus. This is called an anal fissure. It can cause a sharp, intense pain when you pass stools (poo).

Your doctor can usually prescribe creams you apply to the area that help it heal. It is important to avoid getting constipated, because this can make a fissure worse. Your doctor may prescribe a laxative to make it easier for you to go to the toilet.

If the fissure does not get better, your doctor may advise injections of botulinum toxin A (Botox®). These are given into the tissue that lines the anus. Botox® causes the muscle to relax. This reduces the pain and increases the blood flow, which helps the fissure to heal.

Some people may need a minor operation to make a small cut in the muscle around the anus. This releases the tension in the muscle and allows the fissure to heal. You usually have this operation under a general anaesthetic, as a day patient.

Uncommon and rare late effects

Rarely, pelvic radiotherapy causes the following problems.

Anal stricture

Radiotherapy may cause a tight band of scar tissue around the anus (the opening of the back passage). This makes the anus narrower. It is called an anal stricture. It can cause difficulty and pain when you try to pass stools (poo).

If the stricture is mild, your doctor will advise you to take a stool-softening laxative or fibre supplement. This will make it easier to go to the toilet, which will help stretch the stricture.

If the stricture is more severe, your doctor can refer you to a specialist doctor to talk about treatments that might help. You may be able to have treatment to stretch the opening. This is called dilatation. This can be done by using a small, rounded device that can be placed into the anus regularly to help stretch the area. Your cancer team can talk to you about whether this is something that might help in your situation.

Or you may have surgery to cut through the scar tissue. You have this operation under a general anaesthetic.

Your specialist doctor or nurse can explain more about anal stricture treatments.

Bowel blockage

Signs of an obstruction (blockage) in the bowel may include:

- severe pain or cramping in your tummy (abdomen)
- vomiting (being sick)
- bloating
- loud gurgling sounds from the bowel
- tummy swelling
- inability to pass wind
- constipation.

If you have severe pain, you should contact a doctor straight away. You may need tests such as x-rays or a CT scan to check what is causing the pain. If your symptoms are caused by a blocked bowel, you may need urgent treatment.

Treating a blocked bowel

Usually, the bowel is only partly blocked and gets better 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 contains very low amounts of fibre. This means the digestive system can break food down more easily into smaller particles. Your nurse or doctor will explain this diet in more detail if you need to follow it for a short time.

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

Hole in the bowel wall

Very rarely, a hole may develop in the bowel wall. This is called a perforated bowel. It can make you feel suddenly unwell.

This is usually treated straight away with an operation to remove the affected part of the bowel.

Fistula

A fistula is an opening that forms between areas of the body that are not usually connected. Rarely after pelvic radiotherapy or surgery for rectal or anal cancer, an opening can develop between:

- the rectum (back passage) and vagina
- the rectum and bladder or urethra.

Sometimes a fistula closes on its own. It can then be managed with treatment to control symptoms. If this does not happen, it may be possible to have an operation to close it.

We have more information about fistulas on our website. Visit macmillan.org.uk/fistula.

Coping with bowel late effects

Coping with bowel changes

There are things you can do that will help bowel symptoms after treatment.

Keep to a healthy weight

Cancer treatment can sometimes cause weight gain. Being overweight puts pressure on your pelvic floor muscles and this can put pressure on the bladder and bowel. It is important to keep to a healthy weight if you have bladder or bowel late effects. Your GP can advise you on the weight range you should aim to keep within.

We have more information on our website. Visit macmillan.org.uk/changes-in-weight

Keep physically active

Try to keep physically active. This will help you manage your weight and avoid getting constipated. Exercise is important to help look after your pelvic floor muscles. It can also help you feel generally better and reduce stress. We have more information in our booklet Physical activity and cancer.

Your healthcare team may be able to suggest the most suitable exercise for you. Walking and swimming are low impact and less likely to cause problems. Your healthcare team may suggest building up the intensity of exercises gradually.

Certain exercises may cause accidental leakage from the bowel. During exercise, you may want to use a product such as a pad.

If you have been advised to do pelvic floor exercises, it is important to keep doing these regularly.

If you have a stoma, you should not play contact sports, but you can play other sports. Ask your stoma nurse if you are not sure what you can do.

Avoid constipation

Avoiding constipation can help protect your pelvic floor muscles.

To avoid constipation, you can try the following things:

- choose foods that reduce constipation
- make sure you are sitting in the correct position to empty your bowel, and have a good toilet routine
- drink plenty of fluids
- keep active.

Manage stress

Anxiety and stressful situations can make bowel symptoms worse.

Learning relaxation techniques 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 libraries, bookshops and some health shops. You can also download apps to your phone or tablet, listen to relaxation podcasts, or watch relaxation tutorials on YouTube.

Some people find that complementary therapies such as massage or yoga help them feel less stressed. We have more information in our booklet Cancer and complementary therapies.

For details of what is available in your area, call our cancer support specialists on 0808 808 00 00.

Get 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 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.

You can access the Macmillan Online Community at macmillan.org.uk/community

“I'm trying to get changes made to disabled toilets to make them inclusive for all disabilities, especially those that affect the bladder and bowel, which fall under the group of hidden disabilities and invisible illnesses. ”

Natalie, diagnosed with bowel cancer

Going out

If you have problems with bowel 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.

Access to toilets

If you are going somewhere new, it is a good idea to find out where the toilets are before you go.

Macmillan has a free toilet card you can use. This may help you access a toilet more quickly when you are out. You can use it in places such as shops and pubs. The card says you have a medical condition that means you need urgent access to a toilet.

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 it at orders.macmillan.org.uk

The Toilet Map website can help you to find public toilets by postcode or through the location on your mobile phone. There are toilet apps for mobile phones, which can find the nearest toilets to you. You can check the map at toiletmap.org.uk

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 for Toilets offers access to about 9,000 locked public toilets across the UK. You can buy a key online from places such as Disability Rights UK, which also has 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:

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

"I was feeling great in myself, working, playing golf again, slowly using less and less incontinence pads. I would go out most days without one with just a slight leakage. "

John, diagnosed with prostate cancer

Specialist products for leakage or soiling

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

For mild to moderate incontinence, you can buy pads in most supermarkets and pharmacies and online. If these are not absorbent enough, you can get different pads from your continence adviser.

Your continence adviser can also explain what is available to you on the NHS. This will depend on where you live. The Bladder and Bowel Community also has information about different products.

Disposable pads and underwear

There are different types of pads 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 pads you can use to cover your bed or chairs.

Anal plugs and inserts

Peristeen® anal plugs are inserted into the rectum to stop bowel leakage. They are made from soft foam covered with a film. When the plug is in place, the film dissolves and it swells up to fill the gap. They can stay in place for up to 12 hours. There is a cord attached to the plug, so you can remove it when you are ready to go to the toilet. 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. There are 2 discs at either end. The top disc is inserted using an applicator and the lower disc sits outside the anus to stop the insert from moving further in. They stop any leakage until you are ready to go to the toilet. The insert either gets pushed out when you have a bowel movement or you can remove it first.

Your continence adviser can help you choose products that suit your needs and show you how to use them.

Protecting your skin

If you have problems with incontinence (leakage) 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. Lots of products are 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.
- Use barrier creams to protect your skin – but only those recommended by specialist healthcare professionals or your GP.
- Try not to scratch if your skin is itchy. If you do sometimes scratch, it is best to keep your nails short. This will help prevent damage to your skin.
- Ask your GP, nurse or continence adviser about moisturisers and barrier creams or sprays to protect your skin.
- Use absorbent pads.
- Wear cotton underwear. This lets your skin breathe more than other materials.

Bowel and Bladder UK also has information on products that might help.

Your feelings and relationships

Your feelings

You may find it difficult to cope with some of your feelings. This can happen months or even years after treatment, especially if you have late effects. But the right support can make it easier to cope. Sharing your feelings with someone else may help you find that support. Try speaking to your GP, family or friends if you are struggling.

Feeling alone

Some late effects can feel 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. Tell your GP, family or friends if you are feeling this way. They may be able to suggest things that can help or know where you can get more support.

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 normal to feel angry at times, especially if you are coping with the late effects of treatment. It can help to tell people you trust when you feel angry. Keeping strong feelings to yourself may make you feel depressed. You can talk to your GP about seeing a counsellor and find a way to express your feelings.

Depression

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

- feeling low in mood
- having no interest in the things you 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

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 daily 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 feel that:

- the experience of cancer has improved and strengthened your relationships with people close to you
- you would not have coped as well without the support you had from family and friends
- your family and friends do not understand if you are not feeling positive about getting back to normal life
- your family and friends do not realise how much the effects of treatment continue to impact your life.

Talking openly about how you are feeling can help those close to you understand you better and give you the support you need.

We have more information about relationships online and in our booklets Talking about cancer and Cancer and relationships: Support for partners, families and friends.

You can order our booklets and leaflets for free.
Visit orders.macmillan.org.uk or call 0808 808 00 00.

Getting help and support

You may not have people close to you who you can talk to about the cancer and your 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 be able to help you find support, or they can just listen.

At your hospital follow-up appointments, 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. If you have any symptoms or problems in between appointments, you can contact your treatment team to let them know. After having cancer, it is normal 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, tell your doctor or specialist nurse 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 and improve your sense of wellbeing
- reduce stress and anxiety
- improve some side effects of treatment.

Relaxation techniques, 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. Choose a therapy that feels right for you and make sure you use a registered practitioner. Before using a complementary therapy, ask your healthcare team whether it could have any harmful effects after cancer treatment.

We have more information in our booklet Cancer and complementary therapies.

Work and finances

Work

If you have late effects after cancer treatment, you may find working more difficult. Some people may decide to change the type of work they do or the way they work. Others may not be able to work anymore because of the effects of cancer on their health.

Our booklets Work and cancer, Working while caring for someone with cancer and Self-employment and cancer have information that may be helpful if you are making decisions about this. There is also lots more information at macmillan.org.uk/work

Employment rights

If you have, or have ever had, cancer, the law considers this as a disability. This means you cannot be treated less favourably than people who do not have cancer because you have cancer, or for reasons connected to the cancer. That would be discrimination.

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work. For example, changes that might help with late effects such as tiredness, bowel changes or bladder changes could include:

- allowing some flexibility in working hours
- changing where you work – for example, moving you to a workstation nearer to a toilet
- allowing extra breaks to help you cope with tiredness
- changing your duties so you do not do physically challenging activities
- letting you work from home
- providing facilities that are appropriate for your disability.

If you live in England, Scotland or Wales, you are protected by the Equality Act 2010. If you live in Northern Ireland, you are protected by the Disability Discrimination Act 1995.

Our booklet Your rights at work when you are affected by cancer has more information.

Help with money and benefits

When you are affected by cancer, you may need help with extra costs. Or you may need support with money if you have to stop working. We have more information online about Statutory Sick Pay and benefits you may be entitled to. We also have information for carers.

Benefits are payments from the government to people who need help with money. You can find out more about benefits and apply for them online. Go to:

- gov.uk if you live in England or Wales
- socialsecurity.gov.scot if you live in Scotland
- nidirect.gov.uk if you live in Northern Ireland.

The benefits system and other types of financial support can be hard to understand. Macmillan has expert money advisers who can talk to you about your money worries, provide information about benefits and recommend other useful organisations that can help. You can speak to them by calling the Macmillan Support Line on 0808 808 00 00. Please note the opening times may vary by service.

You can also get information about benefits and other types of financial help from Citizens Advice if you live in England, Scotland or Wales, or Advice NI if you live in Northern Ireland.

Our booklet Help with the cost of cancer has lots more information.

Grants

You may be able to get some financial help from other charities, for example one-off grants. For further information, contact the Macmillan Support Line on 0808 808 00 00.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. We have information about insurance on our website. Visit macmillan.org.uk/insurance-cancer

We have more information about travel insurance in our booklet Travel and cancer. Our Online Community forum on Travel insurance may also be helpful. Visit macmillan.org.uk/community

Call the Macmillan Support Line free on 0808 808 00 00, 7 days a week, 8am to 8pm.

Further information

About our information

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

Our information has the PIF Tick quality mark for trusted health information. This means our information has been through a professional and strong production process.

Order what you need

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

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

Online information

All our information is also available online at macmillan.org.uk/information-and-support You can also find videos featuring stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

- audiobooks
- Braille
- British Sign Language
- easy read booklets
- interactive PDFs
- 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 at informationproductionteam@macmillan.org.uk or call us on 0808 808 00 00.

The language we use

We want everyone affected by cancer to feel our information is written for them.

We want our information to be as clear as possible. To do this, we try to:

- use plain English
- explain medical words
- use short sentences
- use illustrations to explain text
- structure the information clearly
- make sure important points are clear.

We use gender-inclusive language and talk to our readers as 'you' so that everyone feels included. Where clinically necessary we use the terms 'men' and 'women' or 'male' and 'female'. For example, we do so when talking about parts of the body or mentioning statistics or research about who is affected.

To find out more about how we produce our information, visit macmillan.org.uk/ourinfo

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 support line is made up of specialist teams who can help you with:

- emotional and practical support if you or someone you know has been diagnosed with cancer
- clinical information from our specialist nurses about things like diagnosis and treatments
- welfare rights advice, for information about benefits and general money worries.

To contact any of our teams, call the Macmillan Support Line for free on 0808 808 00 00. Or visit macmillan.org.uk/support-line to chat online and find the options and opening times.

Our trained cancer information advisers can listen and signpost you to further support.

Our cancer information nurse specialists can talk you through information about your diagnosis and treatment. They can help you understand what to expect from your diagnosis and provide information to help you manage symptoms and side effects.

If you are deaf or hard of hearing, call us using Relay UK on 18001 0808 808 00 00, or use the Relay UK app.

You can also email us, or use the Macmillan Chat Service via our website. You can use the chat service to ask our advisers about anything that is worrying you. Tell them what you would like to talk about so they can direct your chat to the right person. Click on the 'Chat to us' button, which appears on pages across the website. Or go to macmillan.org.uk/talktous

If you would like to talk to someone in a language other than English, we also offer an interpreter service for our Macmillan Support Line. Call 0808 808 00 00 and say, in English, the language you want to use. Or send us a web chat message saying you would like an interpreter. Let us know the language you need and we'll arrange for an interpreter to contact you.

Macmillan Information and Support Centres

Our Information and Support Centres are based in hospitals, libraries and mobile centres. Visit one to get the information you need and speak with someone face to face. If you would like a private chat, most centres have a room where you can speak with someone confidentially.

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

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. Please note the opening times may vary by service.

Financial advice

Our expert money advisers on the Macmillan Support Line can help you deal with money worries and recommend other useful organisations that can help.

Help accessing benefits

You can speak to our money advisers for more information. Call us free on 0808 808 00 00. Visit macmillan.org.uk/financialsupport for more information about benefits.

Help with work and cancer

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

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 bring people together in their communities and online.

Support groups

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

Online Community

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

You can also use our Ask an Expert service on the Online Community. You can ask a money adviser, cancer information nurse or an information and support adviser any questions you have.

Macmillan healthcare professionals

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.

Other useful organisations

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

Bowel organisations

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
www.bladderandbowel.org
Provides information and advice on a range of bladder and bowel symptoms and conditions.

Bowel and Bladder UK

Tel **0161 214 4591**
www.bbuk.org.uk
Provides confidential advice, information and products for people with bowel problems. You can order their Just Can't Wait Card, giving you access to toilets not available to the general public.

Bowel Cancer UK

www.bowelcanceruk.org.uk
Tel: **020 7940 1760**
Information and support for everyone affected by bowel cancer. Provides an online forum is a place for people to talk about their experiences, share their knowledge and support each other.

Colostomy UK

www.colostomyuk.org
Helpline: **0800 328 4257**
Support for people living with a stoma.

Daisy Network

www.daisynetwork.org
Email: info@daisynetwork.org.uk
A 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.

The Eve Appeal

www.eveappeal.org.uk
Tel **0808 802 0019**
Email: nurse@eveappeal.org.uk
Information and support for people affected by gynaecological cancers such as womb, cervical, vaginal and vulval cancer.

IA (Illeostomy and Internal Pouch Association)

www.iasupport.org
Tel: **0800 0184 724**
For anyone who has had or is about to have an ileostomy or internal pouch. Has a network of local groups throughout the UK. Hosts a number of forums for discussion of related issues. Membership fees apply.

National Key Scheme (NKS) for Toilets

www.nks.co.uk
Tel: **01395 265543** Mon to Fri: 9am – 5pm
The National Key Scheme (often called Radar Key) scheme also includes over 1000 changing places and accessible toilets, which have added specialist equipment. The NKS sells keys that open every lock on every toilet in the scheme. You can call them or order a key online.

Menopause matters

www.menopausematters.co.uk
Provides up-to-date, accurate information about the menopause, menopausal symptoms and treatment options.

Orchid

Helpline **0808 802 0010**
www.orchid-cancer.org.uk
Funds research into men's cancers and their prevention, diagnosis and treatment. Offers free information leaflets and fact sheets. Has an enquiry service supported by Orchid Male Cancer Information Nurses.

Pelvic Radiation Disease Association

www.prda.org.uk
Support and information for people affected by, or at risk of, pelvic radiation disease (PRD).

Prostate Cancer UK

Helpline **0800 074 8383**
www.prostatecanceruk.org
Provides information and support to men with prostate cancer and their families. Has offices in London, the Midlands, Scotland, Wales and Northern Ireland.

Sexual Advice Association

www.sexualadviceassociation.co.uk
Website has information on sexual problems as well as sexual health and wellbeing.

The Toilet Map

www.toiletmap.org.uk
Email: gbtoiletmap@gmail.com
The Toilet Map aims to map all publicly-accessible toilets – that means all toilets that the public can access without needing to be a customer.

General cancer support organisations

Black Women Rising

www.blackwomenrisinguk.org
Aims to educate, inspire and bring opportunities for women from the BAME community. Shares stories and supports Black cancer patients and survivors through treatment and remission.

Cancer Black Care

Tel **0734 047 1970**
www.cancerblackcare.org.uk
Provides support for all those living with and affected by cancer, with an emphasis on Black people and people of colour.

Cancer Focus Northern Ireland

Helpline **0800 783 3339**
www.cancerfocusni.org
Offers a variety of services to people affected by cancer in Northern Ireland.

Maggie's

Tel **0300 123 1801**
www.maggies.org
Has a network of centres in many locations throughout the UK. Provides free information about cancer and financial benefits. Also offers emotional and social support to people with cancer, their family, and friends.

General health information

Drinkaware

www.drinkaware.co.uk
Provides independent alcohol advice, information and tools to help people make better choices about their drinking. Also has a web chat, for anyone concerned about their own drinking, or someone else's.

Northern Health and Social Care Trust

www.northerntrust.hscni.net
Provides information about health and social care services in Northern Ireland.

NHS.UK

www.nhs.uk
The UK's biggest health information website. Has service information for England.

NHS 111 Wales

111.wales.nhs.uk
NHS health information site for Wales.

NHS Inform

Helpline **0800 22 44 88**
www.nhsinform.scot
NHS health information site for Scotland.

Stop smoking services

NHS Smokefree Helpline (England)

Tel **0300 123 1044**
www.nhs.uk/better-health/quit-smoking
Offers information, advice and support to people who want to stop smoking or have already stopped and do not want to start again.

Quit Your Way Scotland

Tel **0800 84 84 84**
www.nhsinform.scot/quit-your-way-scotland
Scotland's national stop smoking support service. Offers advice and information about how to stop smoking. You can also chat online to an adviser.

Help Me Quit (Wales)

Tel **0808 085 2219**
Text 'HMQ' to **80818**
www.helpmequit.wales
Offers information, advice and support on stopping smoking in English and Welsh.

Stop Smoking NI (Northern Ireland)

www.stopsmokingni.info
Has information and advice about stopping smoking. Also links to other support organisations for people in Northern Ireland who want to give up smoking.

Counselling

British Association for Behavioural and Cognitive Psychotherapies (BABCP)

Tel **0330 320 0851**
www.babcp.com/therapist/list
Promotes the practice, theory and development of cognitive behavioural therapy (CBT) in the UK and Ireland. You can search for therapists on the website.

UK Council for Psychotherapy (UKCP)

Tel **0207 014 9955**
www.psychotherapy.org.uk
Holds the national register of psychotherapists and psychotherapeutic counsellors, listing practitioners who meet exacting standards and training requirements.

Emotional and mental health support

Mind

Helpline **0300 123 3393**
www.mind.org.uk
Provides information, advice and support to anyone with a mental health problem through its helpline and website.

Samaritans

Helpline **116 123**
Email jo@samaritans.org
www.samaritans.org
Provides confidential and non-judgemental emotional support, 24 hours a day, 365 days a year, for people experiencing feelings of distress or despair.

Financial support or legal advice and information

Advice NI

Helpline **0800 915 4604**
www.adviceni.net
Provides advice on a variety of issues including financial, legal, housing and employment issues.

Citizens Advice

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

England

Helpline **0800 144 8848**
www.citizensadvice.org.uk

Scotland

Helpline **0800 028 1456**
www.cas.org.uk

Wales

Helpline **0800 702 2020**
www.citizensadvice.org.uk/wales

Equipment and advice on living with a disability

Disability Rights UK

www.disabilityrightsuk.org
Tel: **0330 995 0400**
Offers advice and information, and campaign for better rights, benefits, quality of life and economic opportunities for anyone with a disability.

LGBT-specific support

OUTpatients

www.outpatients.org.uk
A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produces resources about LGBT cancer experiences. OUTpatients runs a peer support group with Maggie's Barts.

Support for carers

Carers UK

Helpline **0808 808 7777**
www.carersuk.org
Offers information and support to carers across the UK. Has an online forum and can put people in contact with local support groups for carers.

Your notes and questions

Disclaimer

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

Thanks

This booklet has been written, revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by members of Macmillan's Centre of Clinical Expertise.

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

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

Sources

Below is a sample of the sources used in our late effects of bowel cancer information. If you would like more information about the sources we use, please contact us at informationproductionteam@macmillan.org.uk

National Institute for Health and Care Excellence (NICE). Clinical Knowledge Summary Faecal incontinence in adults: Faecal incontinence. Last revised in September 2022. Available from https://cks.nice.org.uk/topics/faecal-incontinence-in-adults/management/faecal-incontinence [Accessed Nov 2025]

Colorectal Disease. Management of treatment-related sequelae following colorectal cancer – S Haas et al – 2023. First published: 15 August 2022. https://doi.org/10.1111/codi.16299 Available from https://onlinelibrary.wiley.com/doi/10.1111/codi.16299 [Accessed Nov 2025]

Pelvic Radiation Disease Association. Best Practice Pathway for Pelvic Radiation Disease. September 2022. Available from https://www.prda.org.uk/wp-content/uploads/2022/09/PRDA_Best-Practice-Pathway_Toolkit.pdf [Accessed Nov 2025]

Guidance: The practical management of the gastrointestinal symptoms of pelvic radiation disease. Andreyev HJN, Muls AC, Norton C, et al. Frontline Gastroenterology, 2015; 6, 53–72. Available from https://fg.bmj.com/content/6/1/53 [Accessed Nov 2025]

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

2. **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.

3. **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?

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

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

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £
(Please delete as appropriate)

I enclose a cheque / postal order / Charity Voucher made payable to Macmillan Cancer Support
OR debit my:
Visa / MasterCard / CAF Charity Card / Switch / Maestro

Card number

Valid from

Expiry date

Issue no

Security number

Signature

Date / /

Do not let the taxman keep your money

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

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

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

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

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

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

Registered with FUNDRAISING REGULATOR

Please cut out this form and return it in an envelope (no stamp required) to: Supporter Donations, Freepost RUCY-XGCA-XTHU, Macmillan Cancer Support, PO Box 791, York House, York YO1 0NJ

MACMILLAN CANCER SUPPORT

This booklet is about the bowel late effects of pelvic radiotherapy. It is for anyone treated with pelvic radiotherapy who has bowel side effects that continue after treatment, or begin months or years later.

The booklet explains how to manage the bowel late effects of pelvic radiotherapy. It has information about emotional, practical and financial issues. It also has information for carers, family members and friends.

At Macmillan, we know cancer can disrupt your whole life. We'll do whatever it takes to help everyone living with cancer in the UK get the support they need right now, and transform cancer care for the future.

For information, support or just someone to talk to, call 0808 808 00 00 or visit macmillan.org.uk

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

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

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