MACMILLAN
CANCER SUPPORT

MANAGING THE LATE EFFECTS OF BOWEL CANCER TREAMENT

> Being diagnosed with cancer is like becoming a member of a club you really don't want to belong to. But I realised that there was a lot of support out there and I didn't have to be so isolated.

Linda

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 colon, rectal or anal cancer. There is also information for carers, family members and friends.

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

But sometimes side effects do not go away, or they start months or years after treatment has ended. These are called late effects. This booklet explains some of the possible late effects of bowel cancer treatment and how they can be improved and managed.

We hope it 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.

How to use this booklet

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

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

On pages 135 to 140, there are details of other organisations that can help.

Quotes

In this booklet, we have included quotes from people who have had late effects of bowel cancer treatment, which you may find helpful. These are from people who have chosen to share their story with us. This includes Linda, who is on the cover of this booklet. 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 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**.

Help us improve our information. Scan the QR code below to tell us what you think.

Contents

LATE EFFECTS

What are late effects?

Most people have side effects during treatment for colon, rectal or anal cancer. These are all types of bowel cancer. Usually, these side effects gradually improve over a few weeks or months after treatment has ended.

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 of bowel cancer treatment

The most common late effect of bowel cancer treatment is a change in how the bowel works. Other common late effects include changes in how the bladder works or changes that may affect your sex life.

Sometimes late effects are more general, such as:

- tiredness
- pain
- concentration problems.

Some late effects are more likely depending on the type of treatment and the area of bowel treated.

Getting help with late effects

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 ended.

You can arrange to see your cancer doctor or specialist nurse in between appointments if needed. You can also contact your GP.

The more you tell your healthcare team, the more they may be able to help you. Some problems may feel embarrassing to talk about. But try not to let that stop you getting advice. Doctors and nurses are used to speaking about these issues and it is important that you get the right information and support.

Your doctor or nurse will check your symptoms. You may need tests to find out more and to check for other causes. They will give you advice and information about what may help.

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 see the following:

- 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 urologist – a doctor who treats problems with the kidneys, bladder and male reproductive system.
- A gynaecologist – a doctor who treats problems with the female reproductive system.
- A continence advisor – a specialist nurse or physiotherapist who gives advice and support to people with continence problems.
- A doctor or nurse who treats late effects.

A few hospitals have clinics for people with late effects. Ask your healthcare team whether there are any near you. The Pelvic Radiation Disease Association (see page 136) may also be able to help you contact specialists.

For more information about the help available, contact the Macmillan Support Line free on **0808 808 00 00**.

THE PELVIS, BOWEL AND BLADDER

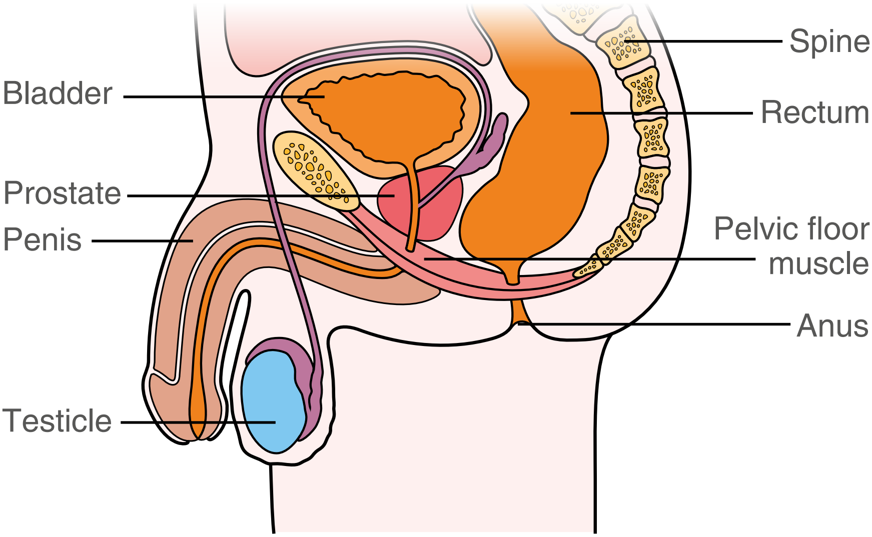
The pelvis

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 and the lower end of the large bowel (colon, rectum and anus). The pelvis also contains bones, lymph nodes (glands), blood vessels and nerves.

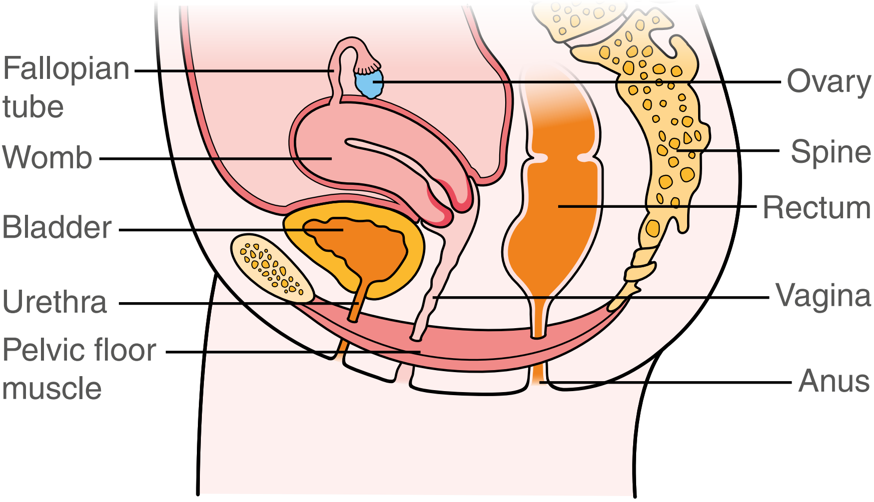
In men, and people assigned male at birth, the sex organs include the prostate gland, testicles and penis.

The pelvis



In women, and people assigned female at birth, the sex organs include the ovaries, fallopian tubes, uterus (womb), cervix and vagina.

The 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 affects 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.

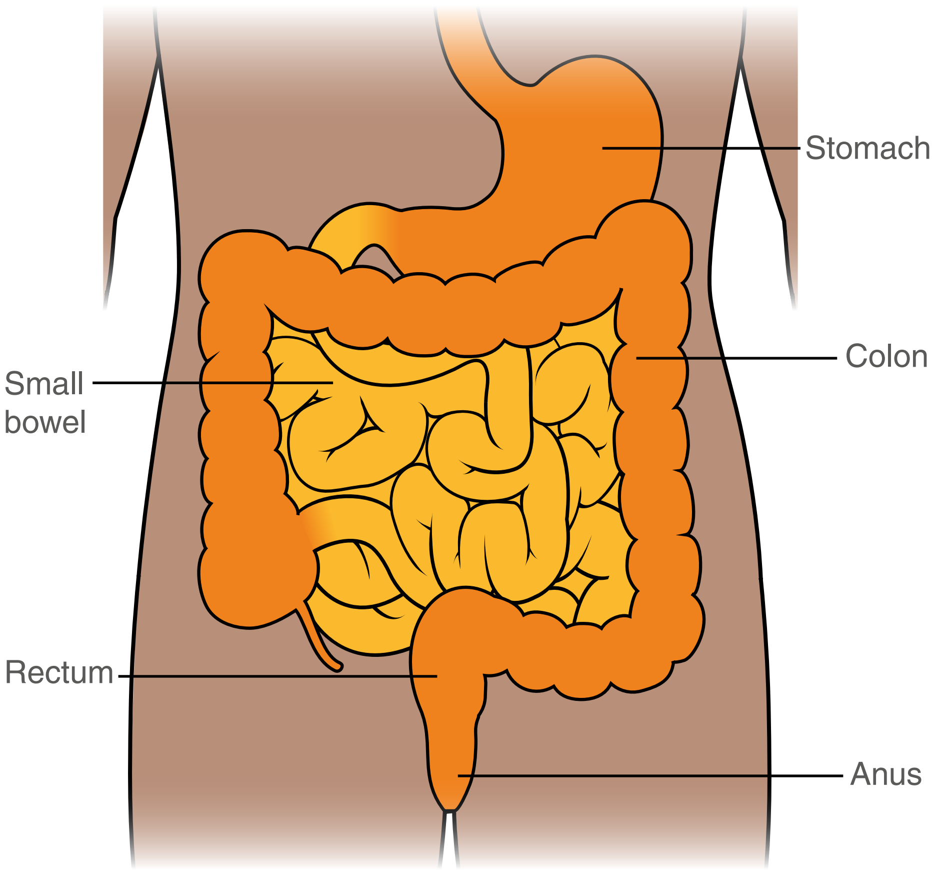
The large bowel is made up of the colon, rectum and anus.

When you swallow food, it passes down the gullet (oesophagus) 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 (stool, or poo) is held in the rectum (back passage).

Nerves and muscles in the rectum help to hold onto stools until they are passed 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 bowels.

Parts of the bowel



The bladder

The bladder is in your pelvis and its job is to collect, store and pass urine (pee).

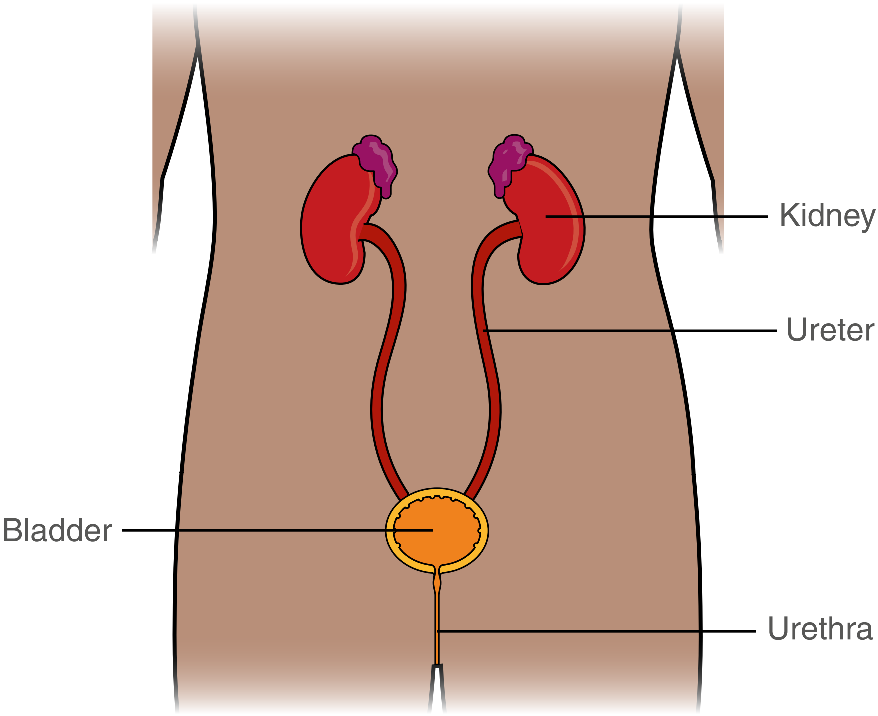
The kidneys produce urine. The kidneys are connected to the bladder by muscular tubes called ureters. The bladder is muscular and stretchy so that it can hold the urine until you feel the urge to go to the toilet.

When you need to pee, the urine exits your bladder through a tube called the urethra.

The bladder and urethra are supported by the pelvic floor muscles. The muscle that wraps around the urethra is called the urethral sphincter. It works like a valve to keep the opening at the bottom of the bladder closed until you want to pass urine.

When your bladder is full, it sends a signal to your brain that you need to go to the toilet. The pelvic floor muscles relax to open your urethral sphincter. At the same time, the bladder muscles tighten to push the urine out.

The bladder and kidneys



BOWEL LATE EFFECTS

Bowel changes after treatment

Most people have bowel changes after surgery or radiotherapy for colon, rectal or anal cancer (bowel cancer). Your bowel habits may not go back to the way they were before treatment. But over time, bowel symptoms usually become less troublesome. Most people find they get into a new routine that becomes normal for them. This can take a year or more.

If you have ongoing bowel problems, or any of the symptoms listed below, there are many things that can help. Your doctor or specialist nurse can give you advice.

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 the bowel completely and needing to return to the toilet quickly
- feeling that you need to pass stools (poo) even when your bowel is empty – this is called tenesmus
- diarrhoea or constipation
- needing to rush to empty your bowels (urgency)
- problems controlling your bowel, causing leakage or soiling (bowel incontinence)
- passing a lot of wind or losing control of passing wind.

Changes after surgery

Surgery for colon or rectal cancer often involves removing a section of bowel affected by cancer. This makes the large bowel shorter than before. Bowel movements (stools) pass 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.

If part of the rectum was removed, there may be long-term changes in how your bowel works. 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.

Surgery may also weaken the muscles where the operation was done and increase your risk of developing a hernia in the future. A hernia is a bulge caused by a part of the inside of the body, such as the bowel, pushing through a weakness in the muscle or tissue wall (see pages 108 to 110).

Stomas

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

Our advice about coping with bowel control problems is usually also suitable for people with a stoma. We have included other information specific to 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.

Changes after radiotherapy

Pelvic radiotherapy often causes bowel symptoms. These usually get better within a few weeks of treatment ending. But some people have late effects that start months or years after treatment. Late effects caused by pelvic radiotherapy are sometimes called pelvic radiation disease (PRD).

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

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

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. You may become unable to digest some types of food (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 (SIBO).

Diarrhoea

Many people find changing their diet and taking anti-diarrhoea drugs stops the diarrhoea. But if this does not help, 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 caused by changes to the small bowel, such as:

- bile acid malabsorption (also called bile acid diarrhoea)
- small bowel bacterial overgrowth.

We have more information about managing diarrhoea by making changes to your diet or taking anti-diarrhoea drugs (see pages 45 to 50).

Bile acid malabsorption

Bile acids are made in the liver and go to the small bowel when you eat to 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 if symptoms improve:

- Eating a low-fat diet – a dietitian will help you do this in a balanced way.
- Taking anti-diarrhoea drugs.
- Taking 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 scan called 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 more about this.

Small bowel bacterial overgrowth

The large bowel contains lots of healthy or ‘good’ bacteria, which help digest food. But a healthy small bowel contains almost no bacteria. After pelvic radiotherapy, sometimes this changes and bacteria are found in the small bowel. This is called small bowel bacterial overgrowth, or SIBO. It can cause 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 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.


LOVE

Constipation

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

- include more fibre in your diet (see pages 48 to 49)
- 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 (see page 56 to 57)
- use the correct toilet posture (sit on the toilet in the right position – see page 57)
- check with your doctor if you are taking medicines that can cause constipation (see page 54)
- take medicines to treat constipation (see page 54).

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 after radiotherapy or surgery. Sometimes it can be a symptom of another problem like constipation, infection or a non-cancerous growth (a polyp) or cancer in the bowel.

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

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

- pelvic floor exercises (see pages 84 to 85)
- a toilet routine (see pages 56 to 57)
- using the correct toilet posture (sitting on the toilet in the right position – see page 57)
- taking soluble fibre to bulk up the stool (poo), or a fibre supplement such as Normacol®
- low doses of certain anti-depressant drugs to reduce the sensitivity of the rectum.

Difficulty emptying the bowel

After rectal surgery, some people have problems emptying their bowel completely. Signs of this can include:

- feeling there is still something in your bowel after you have passed a stool (poo)
- having smaller, pellet-like stools (fragmented)
- 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 exact cause of your symptoms. Your doctor or continence specialist may suggest:

- a toilet routine (see page 56 to 57)
- using the correct toilet posture (sitting on the toilet in the right position – see page 57)
- pelvic floor exercise (see pages 84 to 85)
- changes to your diet (see pages 45 to 50)
- medicines to treat constipation (see page 54)
- anti-diarrhoea medicines if your stools are too soft (see pages 52 to 53)
- bowel or colostomy irrigation.

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 or colostomy irrigation means you can empty your bowel completely at a time that suits you. You will be less likely to have leakage or incontinence at other times. If you have a colostomy, it can mean less worry that your stoma will be active at inconvenient times.

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

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

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 (see pages 84 to 85).
- Ask your doctor for advice if you take medicines that cause wind, such as Lactulose® or Fybogel®.
- Try taking peppermint oil or charcoal tablets, or eating live yoghurts.

Tell your doctor if this symptom is a problem. Sometimes other things may be making wind worse. For example, constipation (see page 28) or bowel conditions, such as diverticular disease can make wind worse. Wind can also be a symptom of a food intolerance, or a condition called small bowel bacterial overgrowth (see page 26) after radiotherapy.

Bleeding from the rectum

Bleeding from the back passage (rectum) 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 a person strains to pass a bowel movement, or has slightly hard stools (poo).

Most people who have this side effect only notice bleeding occasionally. For a few people, bleeding can be heavy and needs treatment. These changes in the bowel lining often get better over time. But this can take 5 to 10 years, so you may see a specialist for assessment in the meantime.

Tests

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

Your doctor will examine 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). This is where a doctor or nurse passes a scope (a thin tube with a light and tiny camera on the end) into the bowel to look 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 (see page 28). This will help reduce bleeding.

If bleeding is affecting your daily 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 information.

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

Bleeding can sometimes be reduced with a drug called sucralfate. This drug coats the lining of the bowel. This reduces inflammation and encourages healing. If the blood is bright red, you have the drug as an enema. This means the drug is gently given as a liquid into your back passage through a short tube. If the blood is darker, you take the drug by mouth as a tablet. It is important to avoid getting constipated when you are being treated with sucralfate.

Other treatments that may reduce bleeding include the following.

Thermal ablation

This treatment uses heat to seal areas that are bleeding. It is given during an endoscopy, where a doctor or nurse passes a thin, flexible tube with a light on the end into your back passage. Different types of thermal ablation include radiofrequency ablation (RFA) and 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.

Formalin

This drug seals bleeding blood vessels. A doctor or nurse 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.

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 breath in pure oxygen. The oxygen travels in your blood. The increased oxygen level in your blood can help new blood vessels to grow. This may help areas affected by radiotherapy heal. Treatment takes up to 8 weeks. HBO is not widely available and is not always available on the NHS.

Sore or itchy skin

Ongoing diarrhoea or leaking (incontinence) 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, red or broken.

If your skin is sore or passing a bowel movement is painful, speak to your doctor or nurse. They can give you advice about looking after your skin and may give you creams or ointments to use. They can also check your skin for signs of other problems such as piles (haemorrhoids) or fissures.

Anal fissure

After 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 a stool (poo).

Your doctor can usually prescribe creams to apply to the area that help it heal. It is important to avoid getting constipated (see page 28), 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 treating it with injections of botulinum toxin A (Botox®). These are given into the tissue that lines the anus. Botox® causes the muscle to relax, reducing the pain and increasing 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.

> ‘I have been left with anal fissures, due to the permanent damage of the blood vessels in that area. In certain places my skin is very thin and I have to be very careful not to scratch it, as it can be very painful.’
>
> **Helena**

Adhesions

Normally, tissues and organs inside the tummy (abdomen) are slippery and move easily as the body moves. After surgery in the abdomen, bands of scar tissue (called adhesions) may form between abdominal tissues and organs, sticking them together.

Adhesions often do not cause any problems. But sometimes they can cause pain. This may be more likely if you have also had radiotherapy to the abdomen.

Rarely, adhesions can make part of the bowel 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
- sickness (vomiting)
- bloating
- loud gurgling sounds from the bowel
- tummy swelling
- not being able 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

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 contains very low amounts of fibre (see page 48 to 49). This means it is more easily broken down into smaller particles by the digestive system. 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.

Treating adhesions

Most people do not need treatment for 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.

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 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**

Managing 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
- problems controlling your bowel, leading to leakage or soiling, cramps, or bloating
- diarrhoea or 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 that 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 and stool tests
- x-rays and scans
- camera (endoscopy) tests such as a colonoscopy or sigmoidoscopy – this is where a doctor or nurse passes a scope (a thin tube with a light and tiny camera on the end) into the bowel to look for any abnormal areas
- breath tests – this is where a doctor uses samples of your breath to investigate symptoms such as diarrhoea or discomfort in your tummy (abdomen).

It may be helpful to record 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 (see pages 46 to 47). Your doctor or nurse will usually ask you about:

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

Improving bowel control

Your doctor or 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 advisor, 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 stools 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 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 food and symptom diary (see pages 46 to 47). It lets them see the types of food you usually eat and what changes may help your symptoms.

Food diary and symptom diary

Date	Time	Food eaten and/ or medication taken
6th August	8.00am	Tea and toast
6th August	12.30pm	Cauliflower cheese

Amount	Your symptoms and level (0 = no problem, 10 = severe)	Time and for how long
Small	No symptoms (0)	–
Medium	Wind (6)	1.30pm for 1 hour

Fluids

Try to drink at least 1 to 2 litres (2 to 3 1/2 pints) of fluids a day, unless your healthcare team tell you differently. Water is best. Drink smaller amounts through the day so that you do not drink lots of fluids with meals. Some types of drinks can make bowel problems worse. You may want to limit drinking:

- fizzy drinks
- caffeinated drinks (like 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 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 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 the stool 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 appropriate either. 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.

> **‘The normal advice for cancer patients is to eat a healthy diet with lots of fruit and fibre. But, fibre is a big problem. It has taken me over 2 years but I have sorted my diet, though I still have some difficult days.’**
>
> **Lynne**

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 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

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 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.

There are other types of anti-diarrhoea medicine, such as codeine phosphate or diphenoxylate (Lomotil®). Your doctor 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. For example:

- 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 one of the following treatments:

- Soluble fibre supplements, such as Fybogel® or Normacol®.
- 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. 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 can 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.

Exercises 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.

We have more about doing pelvic floor exercises (see pages 84 to 85). To avoid putting extra pressure on your pelvic floor muscles, try to keep your weight within healthy limits. You can also look after these muscles by avoiding getting constipated and not doing heavy lifting.

Bowel retraining

Some bowel control problems can make it difficult to predict when you will need a 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 advisor 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 other methods such as anti-diarrhoea medicines and 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 a stool. 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 (see page 28). 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 bowels. 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.

BLADDER LATE EFFECTS

Bladder changes after treatment

Treatment for bowel cancer may change the way the bladder works. It can also affect the muscles that support the bladder. Sometimes changes start during treatment and do not get better. Or they may develop months or years after treatment has finished.

Not all bladder symptoms are caused by cancer treatment. As you get older, the bladder and pelvic floor muscles naturally become weaker. Giving birth and going through the menopause can also affect these muscles.

If you have ongoing bladder problems or any of the symptoms listed here, there are many things that can help. Your doctor or specialist nurse can give you advice.

Symptoms after surgery

Sometimes, surgery to the rectum causes long-term changes to the nerves that control the bladder. This can affect your bladder control. It may cause leaking urine (urinary incontinence). Or it may mean the bladder does not empty completely. Symptoms of bladder late effects after surgery include:

- leaking urine (pee)
- 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 cause more serious problems if they are not treated.

Symptoms after radiotherapy

Radiotherapy to the rectum often causes bladder symptoms. These usually get better within a few weeks. But some people have late effects that start months or years after treatment. Late effects caused by pelvic radiotherapy are sometimes called pelvic radiation disease (PRD).

Symptoms may happen because radiotherapy can cause the bladder to shrink. This means it cannot hold as much urine as before. This happens when the bladder walls become scarred and the tissue becomes less stretchy.

Radiotherapy can also weaken the pelvic floor muscles and the urethral sphincter. This makes them less effective and can cause you to leak urine (incontinence).

Radiotherapy can damage the tissue and blood vessels in the lining of the bladder. This can cause pain or burning when you pass urine. It can also make you feel like you need to pass urine frequently (radiation cystitis). The small blood vessels in the bladder lining may become weaker and bleed more easily. This can cause blood in your urine (haematuria).

Rarely, radiotherapy damages the nerves near the bladder and affects how the bladder muscles work. This may mean the bladder does not empty completely. Treatment may also make the urethra narrow. This can make it more difficult to pass urine. The narrowing is called a urethral stricture.

Symptoms of bladder late effects after radiotherapy include:

- needing to pass urine more often than usual (frequency)
- being unable to wait to empty your bladder (urgency)
- leaking urine (incontinence)
- a burning feeling when you pass urine (cystitis)
- blood in your urine (haematuria)
- difficulty passing urine, or a feeling you still have urine left in your bladder after going to the toilet (retention)
- pain in the pelvic area.

The symptoms are similar if you have them during radiotherapy, or if they happen later on.

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.

Managing bladder problems

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

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 doctor or nurse may arrange some tests. Your GP or practice nurse can test your urine for infection. An infection can cause similar symptoms and make you feel unwell. They can also do blood tests to check how your kidneys are working. You may need some of the following further tests. These are arranged by a urologist or continence adviser:

- Scans, to look at your kidneys, ureters and bladder. These could be an ultrasound scan, an MRI scan, or a type of CT scan using dye (contrast).
- 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, but sometimes a general anaesthetic is used.
- Urodynamic tests, to check how well your bladder and urethra collect, hold and release urine. These are often done if you have symptoms of urgency or incontinence. Sometimes you have them after other tests, if more information is needed.

You may be asked to complete a diary of how much you drink and how much urine you pass, or complete questionnaires about your symptoms. These can find out the cause of your problems so you are given the correct advice and support from the right specialist.

There are also some things you can do to help reduce bladder symptoms.

Drink plenty of fluids

Try to drink at least 1 to 2 litres (2 to 3½ pints) of fluids a day. 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.

Not drinking enough could make your symptoms worse. Concentrated urine irritates the bladder. Drinking more fluids will help to:

- 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. Try to 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.

Stop smoking or vaping

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.

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

Exercise your pelvic floor muscles

Exercises to strengthen the muscles used in bladder control are called pelvic floor exercises (see pages 84 to 85). They may help with problems like incontinence.

To avoid putting extra pressure on your pelvic floor muscles, try to keep your weight within healthy limits. You can also look after these muscles by avoiding getting constipated and not doing heavy lifting.

Find ways of reducing stress

Feeling anxious can make you feel like you need to pass urine. It can also make your symptoms worse. Your healthcare team can help you find ways to cope with anxiety. There are also things you can do yourself that may help.

Needing to pass urine more often (overactive bladder)

An overactive bladder means you often suddenly feel you need to pass urine (pee). Your bladder feels full, even when there is not much in it.

There are things that can help and overactive bladder. Your specialist may suggest one or more of the following treatments.

Bladder retraining

Bladder retraining means learning ways to train your bladder to hold more urine. This means you do not have to pass urine as often. It is best to do bladder retraining with expert help from a specialist.

You may be asked to complete a chart to see:

- how much you drink
- how often you go to the toilet
- how much urine you pass.

It is important to keep drinking plenty of fluids, at least 1 to 2 litres (2 to 3½ pints) a day, so that your bladder learns to cope. It also helps to dilute your urine. This makes it less likely to irritate your bladder.

Bladder retraining should be done over a few weeks. 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. Sitting on a hard seat might help. You may find it easier to distract yourself by reading, listening to the radio, or watching television. Your specialist might have other suggestions to distract yourself, such as counting backwards.

You only do the bladder retraining in the day. By doing this, the aim is that you will eventually need to go to the toilet less often at night.

Because the bladder is a muscle, it becomes stronger with retraining exercises After a few weeks, you should find you need to go to the toilet less often.

Drugs to relax the bladder

If bladder retraining has not helped, you specialist might suggest other treatments.

There are drugs that can relax the bladder so it can hold more urine. These drugs can help an overactive bladder or if you leak urine (incontinence). You sometimes need to take them for a while to see if they are helpful. You may need to try different ones, to find one works for you. Your doctor can tell you more.

Botulinum toxin A (Botox®)

Botox® injections can help the symptoms of an overactive bladder. They may be used if other treatments have not helped.

The injections help to relax the bladder, meaning it can store more urine. They can also help you ‘hold on’ for longer.

The treatment can be done in the outpatient department with a local anaesthetic. Sometimes, a general anaesthetic is needed. The doctor passes a thin, flexible tube with a light on the end (a cystoscope) through your urethra and into your bladder. They then inject the Botox® injected into the wall of your bladder.

You may find it difficult to pass urine after having this treatment. This is usually temporary. It may last for a few days or weeks. Before you have Botox® injections, 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.

The effect of Botox® usually wears off over several months. But the injections can be repeated.

Nerve stimulation

Nerve stimulation uses electrical pulses to help with bladder and bowel problems. It may be used when other treatments have not helped. Your doctor or continence adviser can explain more about it. There are 2 types of nerve stimulation.

Sacral nerve stimulation (SNS)

This involves placing a wire under the skin of your lower back. This wire sends electrical pulses to your nerves that control your bladder. You need a small operation to place the wires. Before the operation, you may be given something to help you relax and feel more comfortable. Or you might have a general anaesthetic.

To start with, you wear a small box that sends the impulses. After a few weeks, if SNS is helping, you have a second operation to fit a small permanent implant under the skin instead. This is done under a general anaesthetic.

Percutaneous tibial nerve stimulation (PTNS)

This may be used if you do not want sacral nerve stimulation or Botox® treatment, or if other treatments have not worked for you. PTNS is done in an outpatient clinic.

You sit in a chair with your leg up. A nurse places a small, thin needle through the skin near the ankle and connects this to an electrical stimulator box. A sticky pad is put on the sole of our foot and is also attached to the box. The electrical pulses are turned up until you can feel a tingling in your foot. This is then left on for 30 minutes.

You might want to take a book or magazine to read, or have music to listen to. At the end, the needle is removed and you can go home. It can take several weeks to see if it is working for you. Most people have treatment once a week for 12 weeks. After this, you and your doctor can decide how much PTNS has helped and if more treatments are needed.

Leaking urine (incontinence)

Leaking urine (incontinence) 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. You can have one or both types (mixed 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 may also help (see pages 68 to 71).

If you have problems with leaking urine, it can make the skin in that area sore. You can protect your skin by keeping it clean and dry (see page 90). There are lots of products available to help you. Your specialist can give you more information.

We have more information about coping with bladder symptoms (see pages 79 to 91).

Pelvic floor exercises

The most common treatment for urinary incontinence is to do exercises to strengthen the pelvic floor muscles. We have more information about doing these exercises (see pages 84 to 85).

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 (see page 135) can also give you details of your nearest adviser and can send you information about pelvic floor exercises.

Drugs to control your bladder

If pelvic floor exercises do not help, 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, when other treatments have not helped, you may be offered an operation to improve incontinence. If this could help, 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.

It is important that you understand everything about your operation. You should be given the chance to discuss the operation with your surgeon and ask questions. 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.

Tape or sling to support the urethra

This operation may improve stress incontinence. The surgeon inserts a tape or sling inside the body under the urethra to support it. This helps stop urine leaking when there is increased pressure on the bladder, for example when you cough or sneeze.

Tape is made from a plastic mesh material. A sling is usually made from tissue. It is often the tissue that covers your abdominal (tummy) muscles.

Bulking agents

A doctor can inject these into the wall of your 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 become less effective over time.

Artificial urinary sphincter (AUS)

This treatment is not often done. It may be suitable for some people who are leaking a lot of urine most of the time. The surgeon inserts a small cuff around the urethra. The cuff is attached to a pump that the surgeon places in the skin next to the vagina or around 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. The cuff then automatically inflates again.

Difficulty passing urine

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 specialist can tell you more about this.

If you have any difficulty passing urine (pee), it is important to get this checked. It can cause 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 very rare.

We have information about coping with bladder changes (see pages 79 to 91).

COPING WITH BOWEL OR BLADDER CHANGES

Things you can do

Changes to the bladder and bowel often cause the same day-to-day issues. There are things you can do that may help your symptoms after treatment.

Keep 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. We have more information about in our booklet **Managing weight gain after cancer treatment** (see page 130).

Keep 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. We have more information in our booklet **Physical activity and cancer** (see page 130).

If you have stress incontinence, anything that involves running or jumping may cause leakage. Your specialist can advise on things that can help. For example, they may suggest building up the distance you run, or the intensity of exercises. You may want to use a product, such as a pad, during these exercises to begin with.

Walking or swimming are lower-impact and are less likely to cause problems. Your specialist may be able to suggest suitable exercise for you. 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.

Do not smoke

Smoking can make both bowel and bladder symptoms worse.

If you need advice about stopping smoking, talk to your GP.

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 (see pages 48 to 49)
- make sure you are sitting in the correct position to empty your bowels and have a good toilet routine (see pages 56 to 57)
- drink plenty of fluids
- keep active.

Manage 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 apps to your mobile phone or tablet, or relaxation podcasts from the internet.

Some people find that complementary therapies such as massage or yoga help them feel less stressed. For details of what is available in your area, call our cancer support specialists on **0808 808 00 00**. We have more information in our booklet **Cancer and complementary therapies** (see page 130).

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

Pelvic floor exercises

Pelvic floor exercises help strengthen the muscles that support your bladder, rectum (back passage) 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 then 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 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 both strong, long 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 if 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 mobile phone or use a pelvic floor exercise app.

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.

Access to toilets

If you are going somewhere new, it is a good idea to find out where the toilets are before you go. The Great British Toilet map can help you to find public toilets by postcode or through the location on your mobile phone. You can check the map at **toiletmap.org.uk** There are also toilet apps for mobile phones, that can find the toilets nearest to you.

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. The card says you have a medical condition that means you 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 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 (see page 139). 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 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)
- your Macmillan toilet card.

> **‘I always have to make a note of where the toilets are when I am out and about, as my muscles are damaged and I now don’t have particularly good control in the bowel department.’**
>
> **Helena**

Specialist products for leakage or soiling

If you have problems with leakage or soiling (incontinence), there are different products that can help. 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 will depend on where you live. The Bladder and Bowel Community also has information about different products (see page 135).

Problems with leakage or soiling can mean you have extra expenses. Call Macmillan 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 absorbs urine (pee), so your skin stays dry. Some are made to go inside your underwear and others are worn instead of underwear. You can also buy pads to cover your bed. It is best to avoid using sanitary pads, because they are made differently. Sanitary pads stay damp, which means the urine can make your skin sore.

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.

Urinary sheaths

A urinary sheath fits over the penis like a condom. It has a self-adhesive strip to keep it in place. The sheath has an outlet which you connect to a bag to collect urine. You strap the bag to your leg. You can buy underwear with a built-in pocket to hold the bag. Your continence adviser can help you choose products and show you how to use them.

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 inserted into the rectum to stop bowel leakage. They are made from soft foam covered with a film. When it 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. Then the insert either gets pushed out when you have a bowel movement, or you remove it first. 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.

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.
- Try not to scratch if your skin is itchy, but if you do sometimes scratch it is best to keep your nails short to 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, as it lets your skin breathe more than other materials.

OTHER LATE EFFECTS

Effects on your sex life

Bowel cancer and its treatment can affect your sex life. This can happen because of the physical, emotional and practical impacts of cancer and its treatment.

These effects may:

- affect your confidence
- change how you feel about your body
- reduce your sex drive (libido)
- make you less interested in sex.

Some treatments may change how your body and sex organs work during sex. Radiotherapy or surgery for rectal or anal cancer can affect tissues and nerves in this area. You may find sex feels different or that it is harder to get aroused or orgasm.

Many changes caused by cancer treatment are temporary and usually get better after treatment. But if your sexual well-being is affected after treatment, try not to let embarrassment stop you from asking for help. Your healthcare team are used to talking about sex.

There may be advice, support or treatments that can help. If needed, they may be able to refer you to a specialist such as the following:

- A gynaecologist – this is a doctor who treats problems with the female reproductive system.
- A urologist – this is a doctor who treats problems with the kidneys, bladder and male reproductive system.
- A sex therapist – this is someone who gives information and support to people with sexual problems.

We have more information about cancer, side effects and sex in aour booklet **Cancer and your sex life**. We also have information in our booklet **Body image and cancer**, which you may find helpful (see page 130).

> **I didn't know anything about impotence being a side effect of bowel cancer. 5 years on, I am still living with impotence. I realise I am lucky to be alive. But my self-confidence took a massive hit. I wasn't prepared for that.**
>
> **Ron**

Vaginal changes

Surgery or radiotherapy for rectal or anal cancer may make the vagina shorter or narrower. Pelvic radiotherapy can also make the vagina drier and less stretchy. The walls of the vagina may be more fragile and likely to bleed.

Ask your cancer team, GP or sexual health service for advice if you have pain or bleeding during vaginal sex. A doctor or nurse can examine you and give you advice.

The following tips may help:

- If you are with a partner, explain how you are feeling about vaginal sex.
- Experiment with different positions or other ways of giving and receiving pleasure.
- Ask your doctor or nurse for advice about lubricants or moisturisers to help with vaginal dryness. If you have had the menopause, hormone replacement therapy (HRT) may also help.
- Talk to your doctor or nurse about vaginal dilators. These are tampon-shaped plastic tubes of different sizes. You use them regularly inside the vagina with a lubricant, to gently push the walls of the vagina apart.

Menopausal changes

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

> **‘I am still challenged by the vaginal stenosis but I have a very supportive husband and thanks to the free squishy dilator, we are still able to enjoy a sex life.’**
>
> **Helena**

Erection problems

Surgery or radiotherapy for rectal or anal cancer can affect the nerves and blood vessels that supply the penis. This can make it difficult to get and keep an erection. If erection problems develop after radiotherapy, this usually happens slowly, a few months after treatment. It may continue getting worse for up to 3 years.

If you have problems getting or keeping an erection, there are treatments that may help. Ask your cancer team, GP or sexual health service for advice. It is often worth trying a few different treatments. Some may work better for you than others. Or you may find a combination of treatments gives you the best result.

You can find out more about treatments for erection problems in our information about cancer and sex. Visit **macmillan.org.uk**

Low testosterone levels

Radiotherapy for rectal or anal cancer may affect the testicles and cause low levels of the male hormone testosterone. This can cause a low sex drive and erection problems. Your doctor can tell you if testosterone replacement therapy might helpful for you.

Anal or rectal changes

Changes to the anus or rectum can be caused by surgery or radiotherapy for rectal or anal cancer. This may affect your sex life if you receive anal sex. It is important to ask your doctor or nurse for advice. They can explain what to expect and if it is safe for you to receive anal sex.

Sometimes changes can mean anal sex is no longer possible. A sex therapist may be able to help you cope and find different ways to enjoy sex.

If you have a stoma

Having a stoma can affect your confidence and the way you feel about your body. Sex will not harm the stoma, but it can make some positions uncomfortable. Choose positions that keep weight off it. You should not use the stoma opening for penetrative sex.

These tips might help:

- Make sure the stoma bag fits well and does not leak.
- Empty the bag before sex.
- You may want to wear clothing that covers or supports the bag to keep it secure.
- You may be able to plug the stoma or wash it out, so a bag is not needed for a short time. Ask your stoma nurse, cancer team or GP for advice.
- Your stoma is likely to be most active in the 2 hours after eating. Some foods can make the bag fill quickly. Avoid eating or drinking anything that usually causes you problems.

It can take time to get used to having a stoma. Your stoma nurses can give you advice and support. The Ileostomy and Internal Pouch Association (see page 136) also have more information about sex and stomas.

Tiredness (fatigue)

Tiredness (fatigue) is a very common side effect of cancer treatment. You may get tired more quickly after less activity and find that resting often does not help.

For most people, fatigue gets better after treatment finishes. But for some it may continue for months or sometimes years.

It is important to tell your doctors and nurses about your fatigue and how it makes you feel. Be honest and do not say you feel fine if you don't. There may be things they can do to help. For example, they can help treat the causes of fatigue, such as pain or difficulty sleeping

We have more information in our booklet **Coping with fatigue (tiredness)** – see page 130. You can also listen to this booklet as an audiobook. Visit **www.macmillan.org.uk**

> **The long-term disruptions that I feel have been caused by the treatment are disturbed sleep patterns and problems with mobility. It can certainly be very difficult at times.**
>
> **Linda**

What you can do

There are also things you can do for yourself that may help you cope:

- Try to keep active. Research has shown that being active and doing some gentle exercise can help with tiredness. Without regular activity, our muscles get weak and tiredness gets worse.
- Spread tasks out over the week. If you have a big task, break it down into smaller, easier ones.
- Try to plan your day so that you have energy to do the things you want to do most. For example, you may want to do tasks in the morning if this is when you feel less tired.
- Ask for help with childcare, housework, shopping and preparing meals.
- Try not to feel guilty about asking for help. Often friends and family members want to help and are pleased to be asked.
- Keep to as healthy a diet as possible. This can help you feel better and may help you to have more energy.

We have more information in the following booklets (see page 130):

- **Coping with fatigue (tiredness)**
- **Physical activity and cancer**
- **Work and cancer**

Concentration and memory problems

After cancer treatment, some people notice changes in memory or concentration and their ability to think clearly. This is often called cancer-related cognitive changes (CRCC) or chemo brain. But changes in memory and concentration can also affect people who have not had 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 daily life.

Common symptoms include:

- being unusually disorganised
- getting distracted more easily
- finding it hard to remember things
- feeling like you cannot think clearly.

Tell your doctor or nurse if you notice changes in your memory or ability to concentrate. They can give you more information and support.

What you can do

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. Here are some other tips:

- Keep things simple and have a daily routine.
- Do not try to do too much. Try to do one thing at a time and avoid distractions.
- Carry a notebook to write notes, lists and reminders in.
- Keep a calendar or diary to help you remember important dates and appointments.
- Keep your mind active by doing crosswords, word games or number puzzles like sudoku.

Relaxation can help reduce stress and may help to improve your memory and concentration. Some people find activities such as yoga, exercise, meditation, reading and complementary therapies helpful. They can relax you and help with anxiety. We have more information in our booklet **Cancer and complementary therapies** (see page 130).


ME
AND

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.

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 cause 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.

It is important to tell your doctor or nurse if you have any of these symptoms. The symptoms often become less troublesome over time as you find ways of coping with the changes. But some people may need drugs or other treatments.

We have more info about peripheral neuropathy on our website. Visit **macmillan.org.uk**

Treating nerve pain

Drugs that may help to relieve nerve pain include:

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

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)

This treatment blocks pain messages sent from the nerves to the brain. Pads are put onto the skin. These 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

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.

We have more information in our booklet **Cancer and complementary therapies** (see page 130).

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 3 months and make it difficult to walk or do daily activities, there may be financial help available. You can contact our cancer support specialists on **0800 808 00 00** for more information.

What you can do

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

Here are some tips:

- Wear gloves when working with your hands. For example, wear gloves if you are gardening or washing dishes.
- Take care to avoid burning your hands when cooking.
- Check the temperature of water with your elbow to make sure it is not too hot before washing.
- Wear clothes without buttons or zips.
- Wear gloves and warm socks in cold weather.
- Avoid walking around barefoot. Wear well-fitting shoes or boots.

Hernia after surgery

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

Usually, your muscles hold your bowel and other organs in place. But after surgery, 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 to find out what may be causing the bulge.

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

Sometimes a hernia can stop the blood supply to the tissue, or cause a blockage in the bowel. When this happens, the hernia needs to be treated as soon as possible. You should call a doctor straight away if you have severe pain, vomiting or difficulty passing wind or emptying your bowels.

Reducing your risk of getting a hernia

You can reduce your risk of developing a hernia by:

- keeping to a healthy weight
- giving up smoking or vaping
- eating healthily
- exercising to strengthen your abdominal muscles – this could be walking, yoga or gentle aerobics
- avoiding constipation
- learning how to lift heavy objects safely, so that your arm and leg muscles take the strain.

It is important to get advice before you start becoming more active. Always check with your doctor if you are recovering from cancer treatment or surgery.

Your cancer doctor, GP or specialist nurse can tell you what type of exercise is most appropriate for you. You can also get support from a physiotherapist or an occupational therapist.

Treating a hernia

Most hernias do 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.

A hernia can also be treated with surgery. The surgeon usually uses a piece of mesh to repair the tissue wall. Your doctor can tell you if this is suitable for you. It is important to understand the benefits and risks before you decide.

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.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

It is not unusual to 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 doctor, 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 doctor, 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 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 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 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

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:

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

Getting help and support

Not everyone has people close to them who they can talk to about the 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 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.

After having 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, 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
- 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. Choose a therapy that feels right for you and make sure you use a registered practitioner. Before using a complementary therapy, talk to your healthcare team and find out if it could have any harmful effects for you. We have more information in our booklet **Cancer and complementary therapies** (see page 130).

WORK AND FINANCES

Work

If you have late effects after cancer treatment, this may make 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 (see page 130). 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** (see page 130) has more information.

Financial help and benefits

When you are affected by cancer, you might need help with extra costs. Or you might need financial support if you have to stop working.

Statutory Sick Pay

If you work for an employer and take time off sick, you may be able to get Statutory Sick Pay. Your employer will pay this for up to 28 weeks.

Benefits

Benefits are payments from the government to people who need financial help. You can find out more about benefits and apply for them online. Go to gov.uk if you live in England, Wales or Scotland, or **nidirect.gov.uk** if you live in Northern Ireland.

Here are some benefits that you might be able to get if you are affected by cancer.

Employment and Support Allowance (ESA)

This benefit is for people under State Pension age who have an illness or disability that affects how much they can work. There are different types of ESA, so it is a good idea to speak to a welfare rights adviser to see if you can make a claim.

Universal Credit

Universal Credit (UC) is a benefit for people under State Pension age who are either:

- out of work – for example, because of an illness or because they are caring for someone
- on a low income.

UC can include money for basic living costs, looking after children and housing.

Personal Independence Payment

This benefit is for people aged 16 to State Pension age who have problems moving around or looking after themselves. You must have had these problems for 3 months and expect them to last for at least 9 months, unless you are terminally ill.

Attendance Allowance

This benefit is for people at or over State Pension age who have problems looking after themselves because of an illness or disability. This could mean problems getting out of bed, having a bath or getting dressed. You must have had these problems for at least 6 months, unless you are terminally ill.

Special rules

If you are terminally ill, you can apply for some benefits using a fast-track process called special rules. You can apply if your doctor thinks you may be reasonably expected to live for less than 6 months. Your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate. It does not matter if you live longer than 6 months. Your doctor or specialist nurse will need to fill out a form for you.

Help for carers

Carer’s Allowance is a weekly benefit to help people who look after someone with a lot of care needs. If you do not qualify for it, you may still be able to apply for Carer’s Credit.

Carer’s Credit helps prevent gaps in your National Insurance record if you have to stop working while you are caring for someone else. You do not get money, but it protects your right to a State Pension later in life.

Macmillan Grants

Macmillan Grants are small, mostly one-off payments to help people with the extra costs cancer can cause. They are for people who have a low level of income and savings.

If you need things like extra clothing, help paying heating bills or even a relaxing holiday, you may be able to get a Macmillan Grant.

How much you get will depend on your situation and needs. A grant from Macmillan does not normally affect the benefits you are entitled to. It is an extra bit of help, not a replacement for other support.

Insurance

If you have, or have had, cancer, you may find it hard to get certain types of insurance. This includes life and travel insurance.

A cancer diagnosis might also mean that you can get a payout from an insurance scheme that you already have.

If you are thinking about buying insurance or making a claim, one of our financial guides can help. You can call them on **0808 808 00 00**.

We have more information in our booklet **Travel and cancer** (see page 130). Our Online Community forum on Travel insurance may also be helpful.

More information

The benefits system and other types of financial support can be hard to understand. Macmillan has experienced welfare rights advisers and financial guides. You can speak to one by calling the Macmillan Support Line on **0808 808 00 00**.

You can also get information about benefits and other types of financial help from Citizens Advice (see page 137).

Our booklet **Help with the cost of cancer** has lots more information (see page 130).

FURTHER INFORMATION

About our information

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

Order what you need

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

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

Online information

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

Other formats

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

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

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

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

The language we use

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

We try to make sure our information is as clear as possible. We use plain English, avoid jargon, explain any medical words, use illustrations to explain text, and make sure important points are highlighted clearly.

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. Our aims are for our information to be as clear and relevant as possible for everyone.

You can read more about how we produce our information at **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 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**

Online Community

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

The Macmillan healthcare team

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

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** 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**

Work support

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

Other useful organisations

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

Bladder and Bowel Community

Home Delivery Service **0800 031 5406**
Email **help@bladderandbowel.org**
www.bladderandbowel.org
Information and support for anyone affected by bladder and bowel control problems as well as their families, carers and healthcare professionals.

Bowel Cancer UK

Email 'Ask the Nurse' **nurse@bowelcanceruk.org.uk**
Email **admin@bowelcanceruk.org.uk**
www.bowelcanceruk.org.uk
Information and support for everyone affected by bowel cancer. Provide an online forum is a place for people to talk about their experiences, share their knowledge and support each other.

Colostomy UK

Helpline: **0800 328 4257** (24 hours a day)
Email **info@colostomyuk.org**
www.colostomyuk.org
Support for people living with a stoma.

Daisy Network

Email **info@daisynetwork.org.uk**
www.daisynetwork.org
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.

IA (Illeostomy and Internal Pouch Association)

www.iasupport.org
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.

Pelvic Radiation Disease Association

Helpline **0113 278 5405**
Email **info@prda.org.uk**
www.prda.org.uk
Support and information for people affected by, or at risk of, pelvic radiation disease (PRD).

Sexual Advice Association

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

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)
Email **bacp@bacp.co.uk**
www.bacp.co.uk
Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their ‘How to find a therapist’ page.

College of Sexual and Relationship Therapists

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.

Financial support or legal advice and information

Advice NI

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

Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)
Textphone **028 9031 1092**
www.nidirect.gov.uk/money-tax-and-benefits
Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

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 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

GOV.UK

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

Local councils (England, Scotland and Wales)

Your local council may have a welfare rights unit that can help you with benefits. You can also contact your local council to claim Housing Benefit and Council Tax Reduction, education benefits, and for help from social services (the Social Work department in Scotland).

You should be able to find your local council's contact details in your phone book or visit:

England

www.gov.uk/find-local-council

Scotland

www.cosla.gov.uk/councils

Wales

www.wlga.wales/welsh-local-authority-links

Macmillan Benefits Advice Service (Northern Ireland)

Tel **0300 1233 233**

Money Advice Scotland

Tel **0141 572 0237**
Email **info@moneyadvicescotland.org.uk**
www.moneyadvicescotland.org.uk
Use the website to find qualified financial advisers in Scotland.

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.

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**
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.

Disability Rights UK

Tel **0330 995 0400** (this is not an advice line)
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.

Living Made Easy

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)
Email **info@dlf.org.uk**
www.livingmadeeasy.org.uk
Provides free, impartial advice about all types of disability equipment and mobility products.

Scope

Helpline **0808 800 3333** (Mon to Fri, 9am to 6pm,
and Sat to Sun, 10am to 6pm)
Textphone Use Type Talk by dialling **18001** from a textphone
followed by **0808 800 3333**
Email **helpline@scope.org.uk**
www.scope.org.uk

Offers advice and information on living with disability. Also supports an independent, UK-wide network of local Disability Information and Advice Line services (DIALs) run by and for disabled people.

LGBTQ+ support

LGBT Foundation

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)
Email **helpline@lgbt.foundation**
www.lgbt.foundation

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

Live Through This

livethroughthis.co.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 produce resources about LGBT cancer experiences. LTT run a peer support group with Maggie’s Barts.

Disclaimer

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

Thanks

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

With thanks to: Dr Katharine Aitken, Consultant Clinical Oncologist; Mr Ian Botterill, Consultant Colorectal Surgeon; Mr Mark George, Consultant Colorectal Surgeon; and Claire Taylor, Macmillan Nurse Consultant, Colorectal Cancer.

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

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

Sources

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

Andreyev HJN, Muls AC, Norton C, et al. Guidance: The practical management of the gastrointestinal symptoms of pelvic radiation disease. Frontline Gastroenterology, 2015; 6, 53-72.

NICE. Faecal incontinence in adults: management (CG49), 2007. Available from www.nice.org.uk/guidance/CG49 [accessed January 2021].

NICE. Lower urinary tract symptoms in men: management (CG97), 2015. Available from https://www.nice.org.uk/guidance/cg97 [accessed January 2021].

NICE. Urinary incontinence and pelvic organ prolapse in women: management (NG123), 2019. Available from https://www.nice.org.uk/guidance/ng123 [accessed January 2021].

Can you do something to help?

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

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

5 ways you can help someone with cancer

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

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

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

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

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

Call us to find out more 0300 1000 200
macmillan.org.uk/getinvolved

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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, 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 colon, rectal or anal 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.

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

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

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

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

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CANCER SUPPORT

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