MACMILLAN
CANCER SUPPORT

MANAGING THE LATE EFFECTS OF PELVIC RADIOTHERAPY IN WOMEN

About this booklet

This booklet is for women who have had radiotherapy to the pelvic area and are experiencing late effects. The pelvic area is the lower part of the tummy (abdomen) between the hip bones. There is also information for carers, family members and friends.

The booklet explains how women can manage the late effects of pelvic radiotherapy. These late effects are side effects that appear after pelvic radiotherapy. Not everyone gets late effects. And if you do, it is not common to have all of them. They can appear months or even years after treatment has finished. For some people, they may become permanent. They can also vary in severity. They affect each person differently, so use the contents list on page 3 to find the information you need.

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

There is a separate booklet with information to help men manage the late effects of pelvic radiotherapy. It is called **Managing the late effects of pelvic radiotherapy in men**. You can get a copy by calling the Macmillan Support Line free on **0808 808 00 00** or by visiting **be.macmillan.org.uk**

For more information

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

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

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

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

How to use this booklet

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

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

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

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

Contents

THE PELVIS AND LATE EFFECTS

The pelvis

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

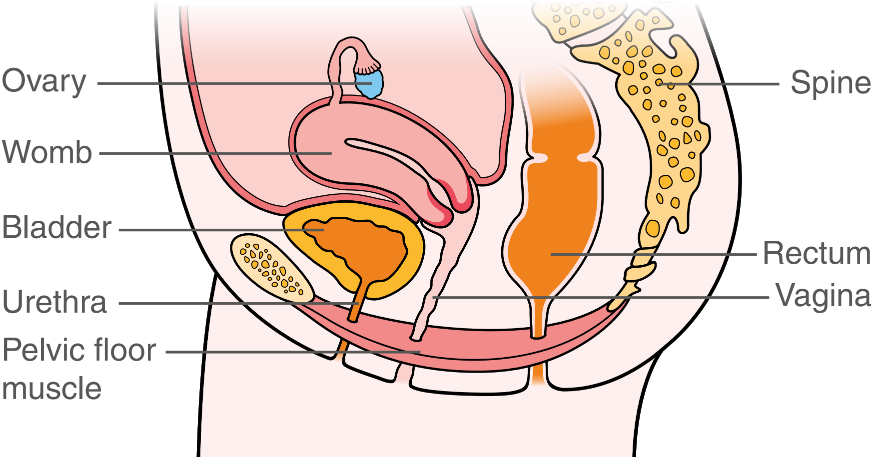
In women, it contains:

- the ovaries
- the fallopian tubes
- the womb (uterus)
- the cervix
- the vagina
- the bladder
- the lower end of the large bowel (the colon, rectum, and anus)
- part of the small bowel
- lymph nodes (glands)
- the pelvic bones
- blood vessels and nerves.

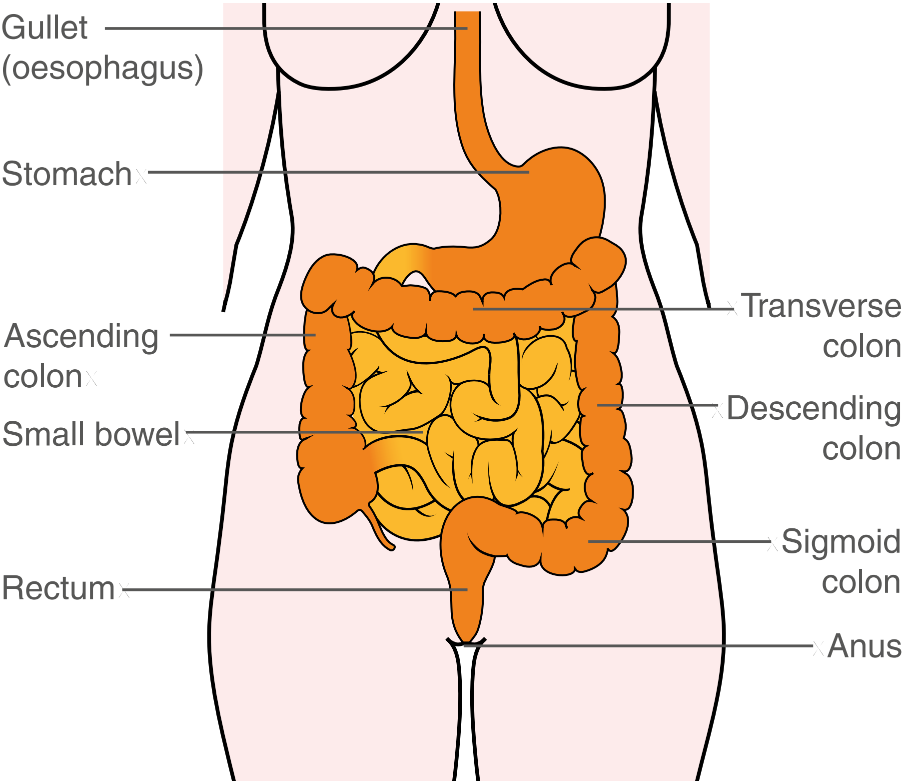
You may have pelvic radiotherapy to treat cervical cancer, womb (endometrial) cancer, vaginal cancer, and vulval cancer. It is also used to treat cancers of the bladder, rectum, and anus.

Pelvic radiotherapy may affect the female sexual organs (including the vagina, womb, and ovaries), and the bladder (see below). It can also affect parts of the digestive system, including the small bowel, colon, rectum, and anus (see page 8).

Organs in female pelvis and pelvic floor



The digestive system



Pelvic radiotherapy

Pelvic radiotherapy treats cancer by using high-energy x-rays to destroy cancer cells. Normal cells in the treatment area can also be damaged by radiotherapy, but usually they can repair themselves.

Radiotherapy to the pelvic area may be given:

- externally (from outside the body) by a machine called a **linear accelerator**
- internally, by putting radioactive material into the tissues – this is called **brachytherapy**.
- Sometimes radiotherapy is given with chemotherapy. This is called **chemoradiation**.

Radiotherapy that is given in combination with surgery or chemotherapy can increase the risk of developing late effects.

Late effects

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

Late effects may:

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

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

Common late effects after pelvic radiotherapy include:

- changes to the way the bladder and bowel work
- changes to your sex life
- tiredness.

The impact of late effects may be:

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

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

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

Talking to your doctor

Always let your cancer doctor or specialist nurse know:

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

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

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

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

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

Other types of expert help

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

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

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

Your doctor or nurse can refer you to other specialists if needed. The organisations listed on pages 121 to 123 can also help.

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

BLADDER CHANGES AFTER TREATMENT

The bladder

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

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

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

The illustration on page 7 shows the bladder and pelvic floor muscles in the pelvis.

Bladder changes

Sometimes, people who have had pelvic radiotherapy notice changes in the way their bladder works. For some people, these changes start during treatment and do not get better. But sometimes bladder changes may develop months or years after treatment has finished.

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

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

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

We have information about coping with bowel and bladder changes (see pages 68 to 75).

Possible late effects to the bladder

Pelvic radiotherapy can cause scarring and hardening (fibrosis) of the bladder wall. This shrinks the bladder so it holds less urine. It can also weaken the pelvic floor muscles and the valve that holds the bladder closed. This means that small amounts of urine can leak out. This is called **incontinence**.

After radiotherapy, small blood vessels in the bladder lining may be weaker and bleed easily. This can cause blood in your urine.

Sometimes, radiotherapy makes the urethra narrow. This is called a **urethral stricture** (see page 30).

Possible symptoms

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

Possible symptoms of bladder changes include:

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

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

Getting expert help

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

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

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

Tests

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

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

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

Managing bladder late effects

What you can do

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

Drink plenty of fluids

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

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

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

Drink the right fluids

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

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

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

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

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

Give up smoking or vaping

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

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

There is more information about giving up smoking on our website – see page 116.

Avoid putting extra pressure on your pelvic floor muscles

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

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

It is especially important to do this if you have stress incontinence (see page 24).

Find ways of reducing stress

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

Needing to pass urine more often (overactive bladder)

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

Bladder retraining

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

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

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

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

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

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

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

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

Drugs to relax the bladder

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

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

Treatment with botulinum toxin A (Botox®)

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

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

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

Nerve stimulation

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

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

Leaking urine (incontinence)

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

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

The following information is about some of the ways that incontinence can be treated and managed. If you have urge incontinence, some of the treatments in the section on needing to pass urine more often can also help (see pages 22 to 24).

Urine can irritate the skin, so you will need to take extra care to look after the skin around your bottom (see page 68).

Pelvic floor exercises

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

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

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

It is best to ask your doctor to refer you to a continence adviser. They can teach you how to do the exercises correctly. The Bladder and Bowel Community can also give you details of your nearest adviser and can send you information about pelvic floor exercises (see page 121).

Biofeedback training

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

Other treatments

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

Drugs

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

Surgery

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

Some types of operation may only be available as part of a clinical trial. Your specialist can tell you more about this. There is more information about clinical trials on our website and in our booklet **Understanding cancer research trials (clinical trials)** – see page 116.

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

Types of operation include:

- **Tape to support the urethra** – This is the most common type of operation to improve incontinence. The surgeon inserts a tape through a cut in the vagina. The surgeon then puts the tape under the urethra. This supports the urethra. It helps stop urine leaking when there is increased pressure on the bladder, for example when you cough or sneeze.
- **Bulking agents** – A doctor can inject these into the tissue surrounding the urethra. This helps keep it closed and makes it harder for urine to leak out. You may need several injections for them to work, and they lose their effectiveness over time.
- **AUS (artificial urinary sphincter)** – This treatment is used very occasionally when other treatments have not helped. It may be suitable for some people who are leaking a lot of urine most of the time. While you are under a general anaesthetic, a small cuff is inserted around the urethra. The cuff is attached to a pump that is placed under the skin of the outer lips of the vulva (external female sex organs). 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.

Blood in the urine (haematuria)

After radiotherapy, small blood vessels in the bladder lining may be weaker and bleed easily. This can cause blood in your urine. If you have this, you will need to have a cystoscopy to find out what is causing it (see page 19).

If there is only a small amount of bleeding that has been caused by radiotherapy, you may not need any treatment. But if the bleeding is regular or heavy, or you become anaemic (have a low number of red blood cells), you are likely to need treatment. There are several possible treatments.

Tablets

Tranexamic acid (Cyklokapron®) tablets can reduce bleeding.

Your doctor may prescribe these tablets for you for a short time There is a slightly increased risk of having a blood clot with tranexamic acid. You can discuss this with your doctor before taking the tablets.

Giving drugs into the bladder

To stop the bleeding, drugs such as Cystistat® (sodium hyaluronate) can be given directly into the bladder as a fluid.

For this treatment, you lie down while a nurse gently passes a thin, flexible tube (catheter) through the urethra and into the bladder. The nurse slowly passes fluid through the catheter into your bladder. Then they remove the catheter and the fluid stays in your bladder for about half an hour. This gives the treatment time to work. After this, you go to the toilet to empty your bladder. You may feel some discomfort when passing urine for a few days afterwards. You usually have this treatment weekly for 6 weeks and then monthly until the symptoms improve.

Your doctor will explain more about this treatment and its possible side effects.

Bladder wash-out

If you are passing blood clots in your urine, these may need to be flushed out to make sure they do not block your urethra. A nurse or doctor passes liquid through a catheter into your bladder. The liquid then drains back out of the catheter into a bag. This can be repeated until the clots have gone.

Cauterisation

If medicines do not stop the bleeding, your doctor may suggest using heat to seal the blood vessels that are bleeding. This is called cauterisation. It is done using a cystoscope while you are under a general anaesthetic (see page 19).

Hyperbaric oxygen therapy

This treatment increases the amount of oxygen that reaches the bladder tissues. It can encourage new blood vessels to grow and the tissue to heal. This may help areas damaged by radiotherapy. It is usually only used after other treatments have been tried. Hyperbaric oxygen therapy is not available everywhere and you may have to travel to get this treatment.

Treating anaemia

Some people become anaemic because of bleeding from the bladder. This can make you feel breathless or tired. Your doctor may suggest you have iron tablets, which will help you make red blood cells. This will improve your symptoms and make you feel better. Some people may need a blood transfusion.

To find out more about these topics, including blood transfusions and hyperbaric oxygen therapy, call the Macmillan Support Line on **0808 808 00 00** or visit **macmillan.org.uk**

Difficulty passing urine (retention)

Radiotherapy can make the urethra narrow. This is called a **urethral stricture**. This may make it more difficult to pass urine.

If you are having problems passing urine, it is important to see your doctor. If urine builds up in the bladder, it can cause infections and damage the kidneys. Your doctor or continence adviser will do tests to find out the cause so they can offer you the right treatment for your situation. A urethral stricture can be treated in several ways, depending on its size.

Small strictures can be treated by passing a thin, plastic tube through the urethra to widen (dilate) it. This can be done under a general or local anaesthetic. Sometimes it may need to be repeated.

Another possible treatment for smaller strictures is an operation called a **urethrotomy**. This is done under a spinal anaesthetic (where you are awake but do not feel anything from the waist down) or general anaesthetic. The surgeon passes a cystoscope into the urethra (see page 19). This lets them make small cuts to widen the urethra.

A larger stricture may need to be treated with an operation that uses tissue from another part of the body to repair the urethra. This is called a **reconstruction**.

If bladder problems do not improve

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

We have information about coping with bladder changes (see pages 68 to 75).

BOWEL CHANGES AFTER TREATMENT

Bowel changes

Sometimes pelvic radiotherapy can cause long-term changes to the way the bowel works. These changes may start during treatment and not get better. Or the changes may develop months or years after treatment.

How the bowel works

The bowel is part of our digestive system. It is made up of the small bowel and the large bowel. The small bowel absorbs nutrients from the food we eat, then it passes the liquid waste into the colon. The colon absorbs water from the waste before passing solid waste (stool) into the rectum. The rectum holds the stool until it can be passed out of the body through the anus.

Possible late effects to the bowel

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

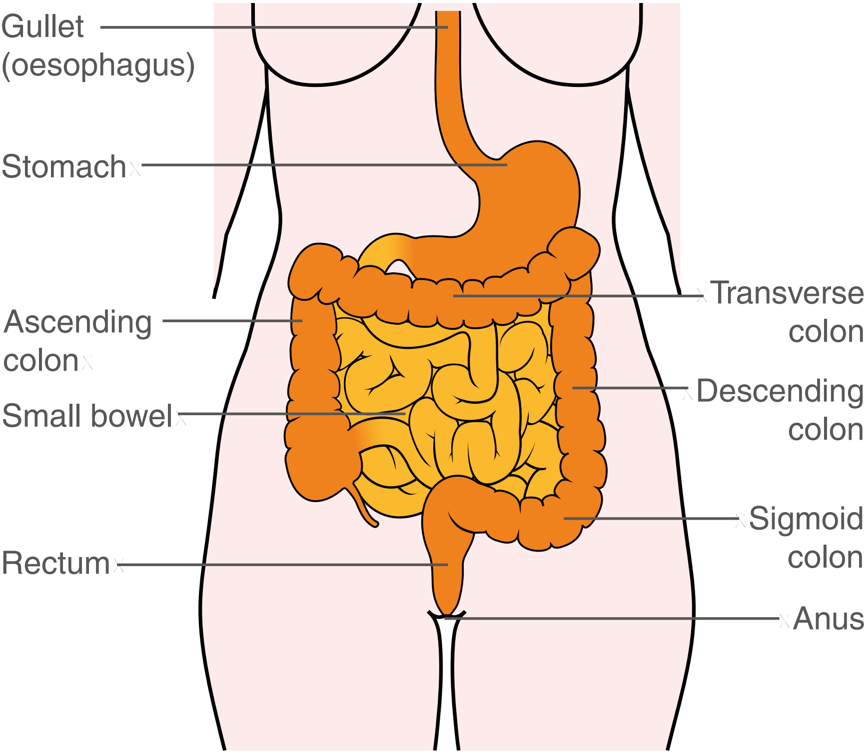
Radiotherapy can also cause scarring (fibrosis) in the large bowel. This can make the large bowel narrower, thicker, and less flexible. This causes waste to pass through more quickly than before. It can also mean the rectum cannot hold as much stool.

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

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

- digest some types of food (**food intolerance**)
- absorb bile acids used in digestion (**bile acid malabsorption**)
- get rid of bacteria effectively (**small bowel bacterial overgrowth** or SIBO).

The digestive system



Symptoms

Possible symptoms of late effects to the bowel include:

- bleeding from the back passage
- passing mucus (a clear, sticky substance)
- cramps or spasms in the bowel, which may be painful
- feeling that you need to pass stool even when your bowel is empty (tenesmus)
- not being able to empty the bowel completely
- diarrhoea
- constipation
- needing to rush to open your bowel (urgency)
- leakage or soiling (bowel incontinence)
- passing a lot of wind or losing control of passing wind.

Some people have mild symptoms that do not cause too many problems. They may only notice small changes, such as having to go to the toilet twice a day instead of once. For other people, bowel changes have a much bigger impact and can interfere with daily life.

Talking to your doctor

There are lots of ways of managing or treating your symptoms. Your doctor can advise you. Or they may refer you to:

- a specialist in bowel problems (a **gastroenterologist**)
- a specialist nurse or physiotherapist who gives advice on problems with bowel control (a **continence adviser**).

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

- passing blood from your back passage
- waking up from sleep to open your bowel
- needing to rush to open your bowel
- bowel incontinence.

These symptoms may not be due to anything serious and they can often be easily treated. But you should always get them checked by your doctor. Occasionally, they can be a sign of a more serious problem. It is important to find out the cause as soon as possible.

Tests

You may have tests to find out what is causing your symptoms. Tests can include:

- blood and stool tests
- x-rays and scans
- a **colonoscopy** or **sigmoidoscopy** – 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
- a **gastroscopy** – a doctor or nurse passes a scope into the mouth and down into the upper part of the small bowel to look for any abnormal areas
- breath tests – doctors use samples of your breath to investigate symptoms such as diarrhoea or discomfort in your tummy (abdomen).

Managing bleeding from the bowel

Bleeding from the rectum

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

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

Causes of bleeding after pelvic radiotherapy

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

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

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

Treatment

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

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

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

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

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

Other treatments that may help include:

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

Fissure

After radiotherapy, some people develop a split in the skin of the anus. This is called an anal fissure. It can cause a sharp, intense pain when you pass a stool.

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

If the fissure does not get better, your doctor may advise treating it with injections of botulinum toxin A (Botox®). These are given into the tissue that lines the anus.

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, and it can be done as a day patient.

Managing bowel control problems

After radiotherapy, you may have changes in how your bowel works. This may make it difficult to control when and how often you pass stools or wind. You may sometimes have leakage (bowel incontinence). Not feeling in control of your bowel can be stressful, particularly when you are away from home. Although you might find it difficult to talk about bowel control problems, it is important to tell your doctor or specialist nurse. There are many things that they can do to help.

Assessment

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

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

When you are being assessed, the doctor will usually ask about your bowel problems and things that might affect them. You may also have tests such as blood tests, endoscopy tests (camera tests – see page 37), or scans.

You might want to keep a record of your bowel habits and what you eat for a week before you go to your appointment. You can use our food and symptom diary to do this (see page 45).
It could help give information about what might help you. At your assessment, the doctor or nurse will usually ask you about:

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

Treatment

The most common ways of improving bowel control include:

- changes to your diet
- medicines to regulate your bowel
- strengthening the muscles used for bowel control.

Diet

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

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

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

Fluids

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

Fibre

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

There are 2 types of fibre:

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

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

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

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

Soluble fibre supplements

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

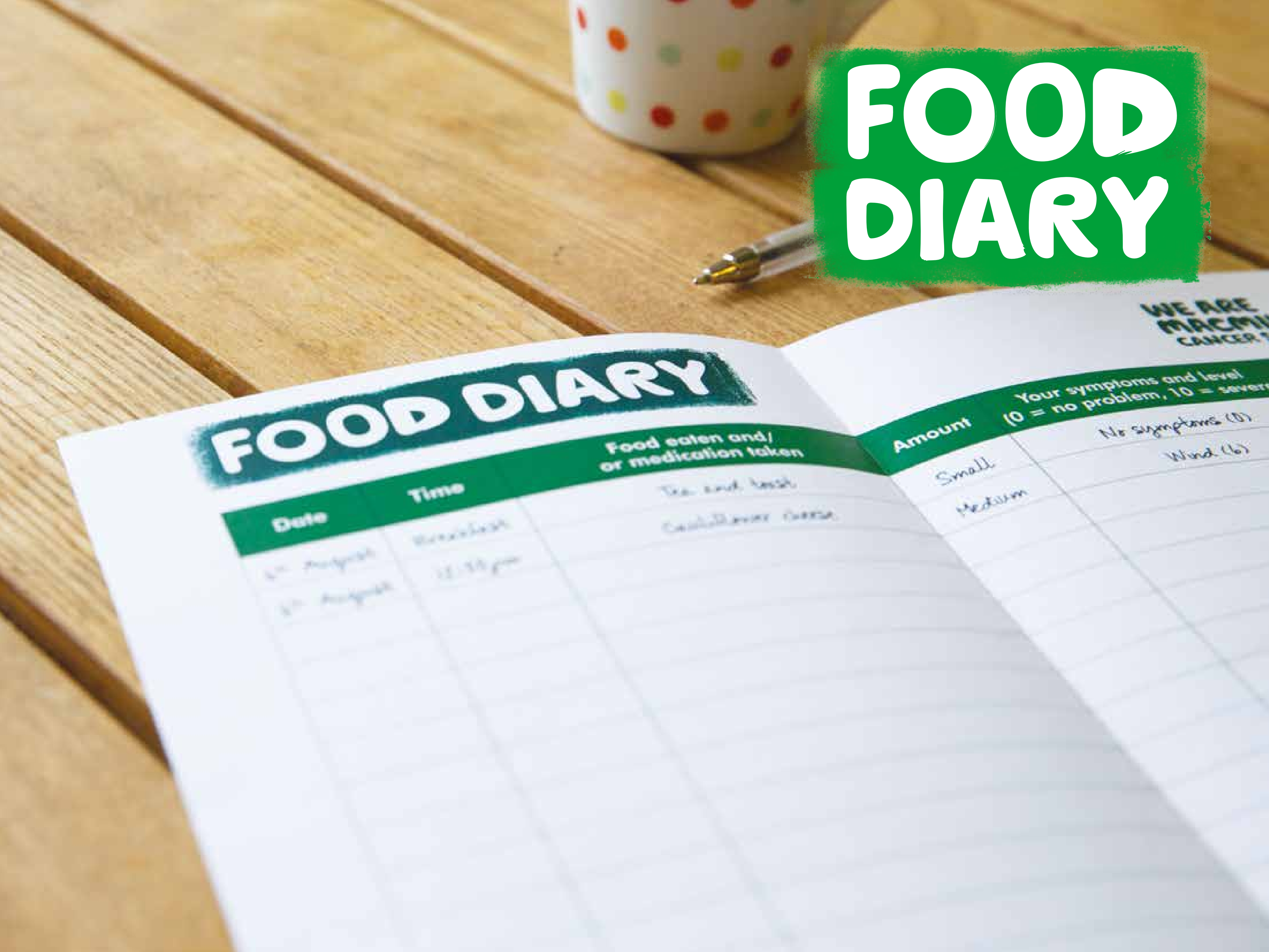
If you are taking fibre supplements, make sure you drink plenty of fluids. You should drink at least 2 litres (3.5 pints) every day.

Food intolerance

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

Symptoms of food intolerance may include tummy cramps, feeling bloated, and 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.


FOOD DIARY
Date
Time
Food eaten and/ or medication taken
Amount
Your symptoms and level (0 = no problem, 10 = sever
Tea and toast
Cauliflower cheese
Small
Medium
No symptoms (0)
Wind (6)
WE ARE MACMI
CANCER

FOOD DIARY

FOOD DIARY

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

Drugs

Anti-diarrhoea drugs

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

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

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

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

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

Medicines that can increase bowel symptoms

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

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

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

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

Smoking or vaping

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

Strengthening the muscles used for bowel control

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

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

The exercises work the muscles around the anus and a deeper layer of muscles, called the anterior pelvic floor muscles. These muscles also help with bladder control and are used in sex. Pelvic muscles support the bladder, womb, and rectum. The illustration on page 7 where the pelvic muscles are in the body.

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

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

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

It takes at least 3 months to strengthen these muscles. Try to do them at the same times each day to get into a routine (see page 25). You can set reminders on your mobile phone.

Biofeedback training

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

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

Bowel retraining

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

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

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

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

Toilet habits

Learning these toilet habits can help with problems, such as constipation or straining on the toilet.

Toilet routine

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

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

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

Toilet posture

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

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

The correct position for emptying your bowel

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

Managing specific problems

Ongoing diarrhoea

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

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

- **bile acid malabsorption** – also called bile acid diarrhoea (see below)
- **small bowel bacterial overgrowth** (see page 56)
- **exocrine pancreatic insufficiency** (EPI) (see page 57).

Bile acid malabsorption (bile acid diarrhoea)

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

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

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

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

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

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

Small bowel bacterial overgrowth

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

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

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

Small bowel bacterial overgrowth is usually treated with antibiotics.

Exocrine pancreatic insufficiency (EPI)

This condition sometimes develops in people who have had pelvic radiotherapy that includes para-aortic lymph nodes, which are close to the pancreas. This type of radiotherapy is sometimes used to treat women with cervical cancer or womb cancer.

The pancreas makes proteins called enzymes that help to digest food. Exocrine pancreatic insufficiency develops when the pancreas does not make enough enzymes to digest food properly.

If your doctor thinks you might have EPI, they can arrange for you to have a stool test (**faecal elastase test**) to find out. If you have EPI, you will need a supplement to replace the enzymes. There are several different brands available. Most supplements are made from pigs. It is also possible to get supplements made from beef. Vegetarian-based enzymes are not available.

The most commonly used supplement is a tablet called Creon, which is a pork-based enzyme replacement. There is no alternative that is not pork-based. It has been approved for use by Jewish patients by the Chief Rabbi. Previous rulings by Islamic scholars suggest that Muslims may use pork-based medicines if there is no alternative. If you have concerns about this, speak to your religious leader.

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

Constipation

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

- include more fibre in your diet (see pages 46 to 47)
- drink 1 to 2 litres (2 to 3.5 pints) of fluid a day
- take regular daily exercise, such as walking
- get into a toilet routine
- use a good toilet posture by sitting on the toilet in the correct position (see page 54)
- check with your doctor if you are taking medicines that can cause constipation
- take medicines for constipation.

Medicines that can cause constipation

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

Medicines that may cause constipation include:

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

Medicines to treat constipation

If you have problems with constipation or difficulty emptying your bowel completely, 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.
- **Enemas** – these contain a small amount of gel or liquid that you squeeze into the lower bowel. This stimulates the bowel to empty.

Tenesmus

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

The spasms may be helped with:

- pelvic floor exercises (see page 25)
- a toilet routine
- sitting on the toilet in the correct posture
- taking soluble fibre to bulk up the stool or a fibre supplement such as Normacol®
- low doses of certain anti-depressant drugs.

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

If you have tenesmus, your doctor will examine your back passage and may arrange for you to have a test called a **colonoscopy** or **flexible sigmoidoscopy** to look at the bowel (see page 37).

Wind

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

Causes of wind include:

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

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

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

Uncommon and rare late effects

Very occasionally, people may have the problems listed over the next few pages because of pelvic radiotherapy.

Anal stricture

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

If it is mild, your doctor will advise you to take a stool-softening laxative or fibre supplement. This will make it easier to go to the toilet, which will help stretch the stricture. If the narrowing is more severe, your doctor may refer you to a bowel specialist. You may be able to have a procedure to stretch the opening. This is called **dilatation**. Or you may have an operation under general anaesthetic to cut through the scar tissue. Your doctor or specialist nurse can explain more about these treatments.

Ulcerated bowel

An area of bowel tissue may break down (ulcerate) and not heal. This can cause watery diarrhoea with blood or mucus in it. It can also cause pain and cramps when you go to the toilet.

This may be treated with hyperbaric oxygen therapy. There is more information on hyperbaric oxygen therapy on **macmillan.org.uk**

Bowel blockage

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

- being unable to pass wind
- constipation
- tummy pain
- feeling sick or being sick (vomiting).

A bowel blockage is usually treated with fluids through a drip to let the bowel rest. Some people also have treatment for constipation. If the bowel continues to be blocked, some people may need an operation to remove the blockage.

Hole in the bowel wall

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

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

Fistula

A fistula is an abnormal opening that forms between 2 parts of the body. Rarely after pelvic radiotherapy, an opening can develop between:

- the rectum and vagina
- the rectum and urethra.

Sometimes a fistula will close 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.

Effects on nerves (lumbosacral plexopathy)

Very rarely, radiotherapy may affect the nerves in the pelvis. This may cause:

- leg weakness
- changes in sensation, including tingling and numbness
- changes in how the bladder or bowel work.

Tell your doctor if you notice this. They may do some tests to find out what is causing the changes. Physiotherapy may help to improve some symptoms.

COPING WITH BOWEL AND BLADDER LATE EFFECTS

Coping with bowel or bladder changes

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

Protecting your skin

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

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

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

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

Going out

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

Access to toilets

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

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

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

You can also use disabled toilets. These often have more privacy. They have a wash basin and more space if you need to change. The National Key Scheme for Toilets offers access to about 9,000 locked public toilets across the UK. You can buy a key from Disability Rights UK (see page 123). It also has a guide that explains where the toilets are.

Take a bag with supplies

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

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

Specialist products for leakage or soiling

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

You can buy pads for mild to moderate incontinence in most supermarkets and pharmacies and online. If these are not absorbent enough, you can get different pads from your continence adviser. They can also explain what is available to you on the NHS. This can vary from region to region. The Bladder and Bowel Community also has information about different products (see page 121).

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

Products for bowel incontinence

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

Anal plugs and inserts

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

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

Keeping to a healthy weight

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

Keeping physically active

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

If you have stress incontinence, it is best to avoid anything that involves running or jumping. Walking or swimming are lower-impact and are less likely to cause problems. When your symptoms are under control, you may want to gradually try other types of exercise. There is more information about staying active on our website and in our **Move more guide** – see page 116. If you have a stoma, there is no restriction on the sports that you can play apart from contact sports. Ask your stoma nurse if you are not sure what you can do.

Avoiding constipation

Avoiding constipation will help protect your pelvic floor muscles.

To avoid constipation, you can try the following things:

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

Managing stress

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

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

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

Some people find that complementary therapies, such as massage or yoga, help them feel less stressed (see page 105). For details of what is available in your area, call our cancer support specialists on **0808 808 00 00**.

Getting support

It is important to tell your doctor or nurse about any problems you have. They are used to dealing with these issues and can refer you to a counsellor or specialist if you need more help.

Support groups, online community sites, and specialist organisations can also provide invaluable support. They are a good way of meeting people who have been through similar situations. You can share experiences and solutions with each other. Partners, family members, and close friends can also help you cope with your feelings.

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

OTHER LATE EFFECTS

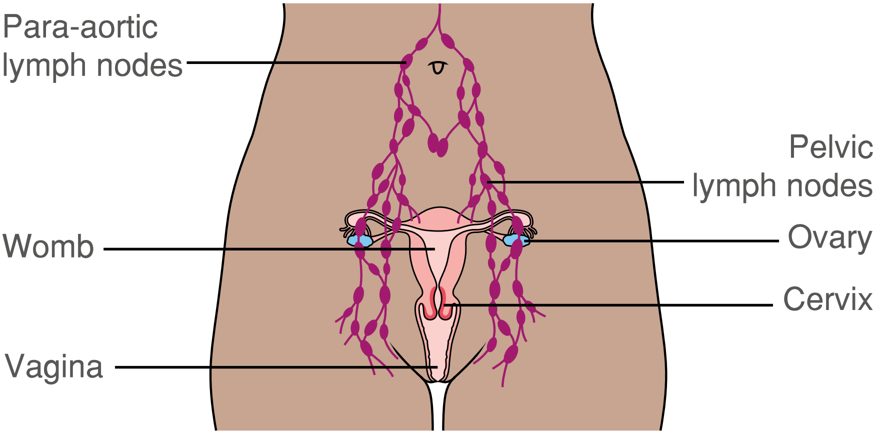
Lymphoedema

Lymphoedema is swelling that develops because of a build-up of fluid in the body's tissues. This happens when the lymphatic system, which normally drains the fluid away, is not working properly.

Lymphoedema is not common after pelvic radiotherapy. But, if you have had surgery to remove the pelvic lymph nodes as well as pelvic radiotherapy, the risk may be higher.

Lymphoedema is caused when lymph fluid cannot pass through the vessels or lymph nodes in the pelvic area and the fluid cannot drain away in the usual way. The fluid then builds up between the tissues and causes swelling in one or, occasionally, both legs. This can develop months or years after treatment. Some people get swelling in the genital area or in the lower tummy area, but this is rare.

Pelvic and abdominal lymph nodes



Reducing your lymphoedema risk

Infections can trigger lymphoedema, so it is important to avoid damaging your skin on your legs and feet. If you notice swelling in your foot or leg, always get it checked by your doctor or nurse.

The earlier lymphoedema is treated, the more effective and straightforward the treatment is.

To reduce your risk of lymphoedema:

- Keep your skin clean and use moisturisers to keep it supple.
- Clean grazes or cuts straight away. See your GP if the area gets red, hot, or swollen.
- Wear well-fitting shoes.
- Use nail clippers instead of scissors to cut your toenails.
- Cover your skin or use a high-factor sun cream (SPF 30 or above) on sunny days.
- Keep to a healthy weight.
- Keep physically active and avoid standing for too long in the same position.
- If you are travelling, wear flight socks that fit well. Your GP or specialist nurse can give you advice if you can not find a pair that fits.

Managing lymphoedema

If you develop lymphoedema, your GP should refer you to a clinic for specialist advice. There are lots of things that can reduce the swelling and stop it getting worse.

At the lymphoedema clinic, you will be shown how to:

- care for your skin
- position an affected leg
- do self-massage.

A specialist will measure you for a compression garment. You wear this on the affected leg to reduce the swelling. They may also recommend other treatments for you.

Bone changes

Radiotherapy to the pelvis may damage the bones in this area. But, most women will not develop bone problems because of their treatment.

If radiotherapy damages the pelvic bones, it may increase the risk of fine, hair-line cracks in the bones. These are known as **pelvic insufficiency fractures**. They often do not cause any symptoms but may be seen on a scan. Sometimes they can be painful. The pain is normally in the lower back or pelvis when you are moving around. It can make walking difficult. Pain is not usually a problem when you are resting or sleeping.

Pelvic radiotherapy also causes an early menopause in younger women (see pages 84 to 85). The menopause increases the risk of bone thinning (**osteoporosis**), but only if you cannot have hormone replacement therapy (HRT).

If you have pain or aching in the bones, always let your cancer doctor or nurse know. It can be caused by lots of conditions, but it is very important to get it checked.

If you have symptoms that last for more than a few weeks, your doctors will need to do tests, such as a bone scan or an MRI scan. You may also have a scan called a DEXA scan to check the strength of your bones.

There is more information on our website and in our booklet **Bone health** – see page 116.

Treatment

The main treatment is usually regular painkillers to control the pain. Your doctor may also refer you to a specialist bone (orthopaedic) doctor for advice.

A physiotherapist will show you how to limit stress on the bones. They will also give you exercises to do. If you are having problems with day-to-day tasks, an occupational therapist can assess you and advise you on equipment to make things easier.

If you are diagnosed with bone thinning, you will probably be prescribed drugs called **bisphosphonates**. These drugs help strengthen the bones. Your doctor may also prescribe vitamin D and possibly calcium supplements for your bone health.

Bone health

You may want to know more about keeping your bones healthy. Radiotherapy damage to the bones is not common, but other factors may contribute to bone changes. The bones naturally lose some strength with age. And people taking hormonal therapy drugs are more at risk of bone thinning (osteoporosis). If you have any bone problems, it is important to follow your doctor's advice.

These are things you can do to help keep your bones healthy:

- Keep physically active to keep your bones strong (see page 73). But if you have bone problems, ask your doctor for advice first.
- Eat healthily and make sure you eat foods that contain calcium and vitamin D.
- To help your body make vitamin D, your skin needs to be exposed to sunlight. In the UK, this means getting 10 minutes of sun (without sunscreen) between 11am and 3pm from May to September. Do this once or twice a day depending on your skin type. Take care not to burn especially during strong sunshine. On cloudy days, it will take longer than 10 minutes to make Vitamin D. From September to May, when the sun is weaker, it is recommended people take a daily supplement containing 10mcg (800 IU) of vitamin D.
- Avoid smoking. It is bad for the bones and it increases the risk of certain cancers and other illnesses. There is more information about giving up smoking on our website – see page 116.
- Binge drinking or drinking heavily can cause bone loss. If you drink alcohol, follow safe drinking guidelines. NHS guidelines say that you should drink no more than 14 units of alcohol a week.

Early menopause

If you have not had your natural menopause, pelvic radiotherapy will cause an early menopause. This is because it stops the ovaries working and they will no longer make the hormones oestrogen and progesterone. Your periods will gradually stop and you may get the symptoms of the menopause.

If you go through the menopause before the age of 45, doctors call this an early menopause.

The Daisy Network is a support organisation for women who have an early menopause (see page 121).

The symptoms of an early menopause can include:

- hot flushes and sweats
- vaginal dryness
- passing urine more often
- lower interest in sex
- sleep problems
- aches and pains
- mood swings and lower confidence
- poor concentration and effects on memory.

Hormone replacement therapy (HRT)

Your doctor may prescribe hormone replacement therapy (HRT) to replace the hormones that your ovaries are no longer producing. If you had cancer of the cervix or rectum, it is usually safe to take HRT. But some cancers depend on hormones to grow, for example, womb cancer. You can ask your cancer specialist whether HRT is suitable for you.

HRT can improve some menopausal symptoms. It can also protect your bones and heart. Early menopause increases the risk of bone thinning (osteoporosis).

Managing menopausal symptoms

If your specialist does not advise HRT, or if you decide not to take it, there are different ways to manage your symptoms. If your symptoms are affecting your day-to-day life, ask your doctor about other medicines that may help reduce them.

Drugs that can be used to reduce hot flushes and sweats include:

- some anti-depressant drugs, such as venlafaxine
- clonidine, which is usually used to control blood pressure
- gabapentin, which is usually used to treat epilepsy or nerve pain.

Some women find that slow, controlled breathing techniques or acupuncture help with hot flushes.

You can use lubricants or creams to help reduce vaginal dryness and make it easier to have sex (see pages 86 to 93).

Your sex life

Pelvic radiotherapy can cause changes that affect your sex life. Sexual problems are more likely if you have also had surgery to the pelvic area, or chemotherapy or hormonal therapy.

Sexual difficulties may be linked to:

- physical changes that make having sex difficult
- a reduced interest in or desire for sex
- a change in how you feel about your body and yourself as a woman (your body image)
- changes in your mood or energy levels.

These difficulties may be temporary and gradually improve over time. But even permanent changes that affect your sex life can often be improved.

Getting help

It can be difficult to talk about sexual difficulties. But doctors and specialist nurses are used to speaking to people about these issues. They can often give you advice and support if things are not going well. Your hospital doctor, specialist nurse, or GP can also refer you to a counsellor or sex therapist.

A sex therapist can help you adjust to physical changes and explore different ways of getting sexual satisfaction. If emotional problems are affecting your sex life, ask your doctor to refer you to a counsellor or doctor who specialises in emotional support.

If you have a partner, talk to them about the effect that treatment is having on your sex life. It is good to think about ways of improving any problems as a couple.

Organisations that may be helpful include:

- the College of Sexual and Relationship Therapists (see page 122)
- the Sexual Advice Association (see page 122).

> **‘I had a chat with the clinical radiographer, who gave me various leaflets about the late effects of pelvic radiotherapy. I was also given a dilator and instruction DVD so I was prepared.’**
>
> **Ann**

Reduced desire for sex

If you have lost interest in sex and you have a partner, let them know how you feel. Explaining why you do not feel like having sex can reassure them that your feelings for them have not changed. You can show your partner how much you care in other sensual and physically affectionate ways.

If sexual difficulties do not improve, it is usually best to ask for advice.

Treating any late effects of pelvic radiotherapy that are causing you problems may help. For example, treatments for vaginal dryness will make sex more comfortable (see page 91).

If you have menopausal symptoms, this can reduce your interest in sex (see pages 84 to 85). Treating these symptoms may improve this. If you have had an early menopause, ask your cancer doctor about hormone replacement therapy (HRT).

There is more information on our website and in our booklet **Cancer and your sex life – information for women** – see page 116.

Vaginal narrowing

After pelvic radiotherapy, the vagina can lose its natural stretchiness. It may also become shorter and narrower. The vaginal walls may be scarred. This can make them stick together. The blood supply to the vagina may also be reduced, which can cause vaginal dryness (see page 91). These changes to the vagina can make penetrative sex uncomfortable or difficult. It can also make it uncomfortable to have an internal examination.

Your radiographer, specialist nurse, or doctor may recommend treatments that can stop the walls of the vagina sticking together and help maintain its stretchiness. They may recommend that you use vaginal dilators. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Although they are commonly used, there is no strong evidence to show how effective they are. Rarely, they may cause damage to the vagina, especially if they are not used correctly. Your specialist nurse or doctor will explain the best way to use them in your situation.

Other ways to help stop the vagina narrowing include:

- having regular penetrative sex
- using a dildo or vibrator
- using lubricated fingers.

Vaginal bleeding

After pelvic radiotherapy, the blood vessels in the lining of the vagina can become fragile and bleed more easily, especially after sex. Bleeding may also be caused by the vaginal tissue sticking together, or scar tissue making the vagina narrower.

If you notice bleeding, tell your cancer doctor or nurse. They will examine you and explain whether it is caused by radiotherapy.

Using oestrogen creams or trying to prevent vaginal narrowing may help reduce bleeding. Make sure you use lubricants during sex.

If you do not have much bleeding, you may find that it does not trouble you very much. But if the bleeding is causing you problems, your doctor may use a drug called silver nitrate to seal the areas that bleed. Your doctor may also give you a drug called tranexamic acid. It stops blood clots dissolving, so it can help reduce unwanted bleeding.

Sometimes, bleeding may be caused by an ulcer in the vagina that can develop after radiotherapy. Your doctor will probably advise you to avoid penetrative sex until it heals.

Vaginal dryness

Radiotherapy reduces the natural lubrication in the vagina. This can make having sex uncomfortable. There are creams, gels, lubricants, and pessaries (small pellets you put inside the vagina) that can help with this.

If you have had an early menopause, hormone replacement therapy (HRT) will help with vaginal dryness. Ask your cancer specialist whether HRT is suitable for you.

Oestrogen creams and pessaries

Vaginal oestrogen creams or pessaries are prescribed by a doctor. They reduce dryness and may stop the vaginal wall from becoming thin. Some types of cancer are sensitive to oestrogen. Your cancer specialist can tell you whether treatment containing oestrogen is suitable for you.

Moisturising creams and lubricants

There are lots of products to relieve vaginal dryness. You can buy them in chemists or online, or your doctor can prescribe them. Moisturisers work by drawing moisture into the vaginal tissue. You apply them regularly.

You can also use lubricants when you have sex to make it feel more comfortable and pleasurable. Lubricants can be water-based or oil-based.

You can buy these from chemists, some supermarkets, or online. Your doctor, specialist nurse, or pharmacist can give you advice on the different types.

Vaginal infections

Vaginal dryness can make you more likely to get vaginal infections such as **thrush**. Symptoms of thrush include a creamy-white discharge and itchiness in the vaginal area that gets worse if you scratch it. You can buy tablets, creams, and pessaries to treat vaginal thrush. There are different brands, such as Canesten®. If you have had sexual contact, including oral sex, your partner may also need treatment.

If you have not had thrush before, you should see your GP first. Always see your GP if:

- you are not sure whether it is thrush
- symptoms do not improve
- it keeps coming back.

Changes in sexual sensation

After radiotherapy or surgery to the pelvic area, some women find it harder to get aroused, or take longer to orgasm. This might be because of the effects of radiotherapy or surgery on the nerves in the pelvic area. But it may be because of a change in the way you feel about yourself sexually. If you have a partner, explain to them that you may need more time to become aroused or reach orgasm. Try not to put too much pressure on yourself to expect the same levels of sensation that you had before your treatment. A sex therapist or counsellor may be able to help you with these issues.

Changes to the anus and rectum

After radiotherapy, you may need to be cautious with anal sex. The tissues in the area may be fragile and less able to heal. It may make anal sex uncomfortable or impossible. Your doctor can tell you more about this.

Fertility

After pelvic radiotherapy, usually you will not be able to have children. This is because of the effect of the radiotherapy on your womb and ovaries. Infertility can be distressing. Getting the right support can help you find ways of coping.

Some women find it helpful to talk things over with the people closest to them. Or you may want to talk to a specialist nurse or counsellor for more specialised support. Your GP or cancer specialist can usually arrange this for you. If you have a partner, they can also come to any counselling you have.

Talking to other women in a similar position may help you. Some organisations provide this, as well as specialist advice and counselling (see pages 121 to 122). Or you can talk to people online – our Online Community is a good place to talk to other women in a similar situation. You can access the Macmillan Online Community at **macmillan.org.uk/community**

You can also talk things over with our cancer support specialists on **0808 808 00 00**.

There is more information about cancer and fertility on our website and in our booklet **Cancer treatment and fertility – information for women** – see page 116.

Tiredness

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

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

If you have fatigue, you may:

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

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

There is more information on our website and in our booklet **Coping with fatigue** – see page 116.

What you can do to help yourself

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

- Take regular exercise to help build up your energy levels (see page 73). Start with short walks and gradually increase how much you do. Exercise also helps you sleep better and can reduce anxiety and depression.
- Keep to a routine. Going to bed and getting up at the same times each day can help. Try not to stay in bed after you wake up.
- Keep to as healthy a diet as possible. This can help you feel better and may help you to have more energy.

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

- If you use the internet, you can do your shopping and banking online.
- Complementary therapies may help to reduce stress and anxiety, and may improve fatigue (see page 105). Relaxation, counselling, and psychological support are available at many cancer treatment hospitals.
- Problems with concentration and memory are common with fatigue and can be frustrating. For more information on how to manage memory and concentration issues, call the Macmillan Support Line on **0808 808 00 00** or visit **macmillan.org.uk**

Developing a second cancer

Having pelvic radiotherapy may slightly increase the risk of developing a new cancer in the treatment area. But the benefits of pelvic radiotherapy outweigh the risk of developing a second cancer. Your doctor or nurse will discuss this with you.

YOUR FEELINGS AND RELATIONSHIPS

Your feelings

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

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

Feeling alone

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

Uncertainty

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

Anger

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

Depression

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

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

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

Relationships

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

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

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

There is more information on our website and in our booklets **Cancer, you and your partner** and **Talking about cancer** – see page 116.

Getting help and support

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

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

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

There is more information on our website and in our booklets **Life after cancer treatment** and **How are you feeling? The emotional effects of cancer** – see page 116.

Complementary therapies

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

Complementary therapies may:

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

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

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

There is more information on our website and in our booklet **Cancer and complementary therapies** – see page 116.

WORK AND FINANCIAL SUPPORT

Work

You may need to take time off work during your treatment and for a while afterwards. It can be hard to judge the best time to go back to work, and this will depend mainly on the type of work you do and how much your income is affected. It is important to do what is right for you. Getting back into your normal routine can be very helpful, and you may want to go back to work as soon as possible. It can be helpful to talk to your employer about the situation – it may be possible for you to work part-time or job share. On the other hand, it can take a long time to recover fully from cancer treatment, and it may be many months before you feel ready to return to work. It is important not to take on too much, too soon. Your consultant, GP, or specialist nurse can help you decide when and if you should go back to work.

Employment rights

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

There is more information about work and cancer on our website and in our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** – see page 116.

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

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

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

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

Financial help and benefits

If you are struggling to cope with the financial effects of cancer, help is available. If you cannot work because you are ill, you may be able to get **Statutory Sick Pay**. Your employer will pay this for up to 28 weeks of sickness. If you qualify for it, they cannot pay you less. Before your Statutory Sick Pay ends, or if you do not qualify for it, check whether you can get **Employment and Support Allowance (ESA)**. This benefit is for people who cannot work because they are ill or disabled. There are 2 different types of ESA:

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

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

Attendance Allowance (AA) is for people aged 65 or over who have problems looking after themselves. You may qualify if you have problems with personal care, for example getting out of bed, having a bath, or dressing yourself. You don't need to have a carer, but you must have had these problems for at least 6 months. If you are terminally ill, and may be expected to live for less than 6 months, you can apply for PIP, DLA, or AA under the special rules. It does not have to be certain and it does not matter if you live longer than 6 months. This means your claim will be dealt with quickly and you will get the benefit you applied for at the highest rate.

Help for carers

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

More information

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

We’ve just listed some benefits here, but there may be others you can get. You can find out about state benefits and apply for them online at **gov.uk** (England, Wales, and Scotland) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment, and independent living. You can also get information about these issues from the relevant Department for Work and Pensions helplines (see pages 122 to 123) or Citizens Advice (see pages 122 to 123).

Our booklet **Help with the cost of cancer** has more detailed information – see page 116. You might also find our video at **macmillan.org.uk/gettingfinancialhelp** useful.

Insurance

People who have, or have had, cancer may find it hard to get certain types of insurance, including life and travel insurance. A financial adviser can help you look at your needs and find the best deal for you. You can find a financial adviser by contacting one of the organisations on pages 122 to 123.

Our booklet **Insurance** may also be helpful – see page 116.


HELP WITH THE COST OF CANCER
A guide to benefits and financial help for people affected by cancer
WE ARE MACMILLAN.

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

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

Online information

All of our information is also available at **macmillan.org.uk/information-and-support** There you will also find videos featuring real-life stories from people affected by cancer, and information from health and social care professionals.

Other formats

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

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

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

Help us improve our information

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

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

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

Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

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.

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

Help with money worries

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

Financial guidance

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

Help accessing benefits

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

Macmillan Grants

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

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

Visit **macmillan.org.uk/financialsupport** 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**

My Organiser app

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

Other useful organisations

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

Bladder and Bowel Community

Helpline 0800 031 5412
Email help@bladderandbowel.org
www.bladderandbowel.org
Provides information and support. Campaigns for people living with bladder and bowel disorders.

The Daisy Network

Email info@daisynetwork.org.uk
www.daisynetwork.org.uk
A nationwide support group for women who have had a premature menopause. Membership fees apply. 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.

Pelvic Radiation Disease Association

Tel 01372 744338
Email info@prda.org.uk
www.prda.org.uk
A patient-led group whose aims are to provide support for people of all ages suffering from pelvic radiation damage, and to campaign for better recognition of pelvic radiation disease, as well as improved facilities for treatment within the NHS.

Counselling

British Association for Counselling and Psychotherapy (BACP)

Tel 01455 883 300
Email bacp@bacp.co.uk
www.itsgoodtotalk.org.uk/
Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor.

Relate

Tel 0300 100 1234
www.relate.org.uk
Counselling, support and information for all relationships.

The College of Sexual and Relationship Therapists

Tel 020 8543 2707
Email info@cosrt.org.uk
www.cosrt.org.uk
Website has information about sexual wellbeing and what to expect from sex therapy. It also has a directory of therapists to help you find professional support in your local area.

The Sexual Advice Association

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

Financial or legal advice and information

Citizens Advice

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

England

Helpline 03444 111 444
www.citizensadvice.org.uk

Scotland

Helpline 0808 800 9060
www.citizensadvice.org.uk/scotland

Wales

Helpline 03444 77 2020
www.citizensadvice.org.uk/wales

Northern Ireland

Helpline 0800 028 1881
www.citizensadvice.co.uk

Department for Work and Pensions (DWP)

Personal Independence Payment (PIP) Helpline
0345 850 3322
Textphone 0345 601 6677
(Mon to Fri, 8am to 6pm)

Carer's Allowance Unit
Tel 0800 731 0297
Textphone 0800 731 0317
(Mon to Fri, 8am to 6pm)
www.gov.uk/browse/benefits

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

GOV.UK

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

National Debtline (England, Scotland, and Wales)

Tel 0808 808 4000
(Mon to Fri, 9am to 8pm, Sat, 9.30am to 1pm)
www.nationaldebtline.org
A national helpline for people with debt problems. The service is free, confidential and independent. Has an online chat service with an expert debt advisor.

NiDirect

www.nidirect.gov.uk
Has information about benefits and public services in Northern Ireland.

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 0207 250 8181
(Mon to Fri, 10am to 12.30pm, then 1.30pm to 4pm)
Email enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org
Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

YOUR NOTES AND QUESTIONS

Disclaimer

Thanks

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

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

Sources

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

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Can you do something to help?

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

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

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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89 Albert Embankment, London SE1 7UQ

27530

This booklet is for women who have had radiotherapy to the pelvic area and are experiencing late effects. The pelvic area is the lower part of the tummy (abdomen) between the hip bones. There is also information for carers, family members and friends.

The booklet explains how women can manage the late effects of pelvic radiotherapy. It also has information on practical, emotional and financial issues.

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

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

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

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