

A practical guide to tests
and treatments

MANAGING THE LATE EFFECTS OF PELVIC RADIOTHERAPY IN WOMEN

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CANCER SUPPORT

This booklet is for you if you have long-term or late effects of pelvic radiotherapy, and has information to help you manage them. If you are not experiencing late effects of radiotherapy to the pelvic area, one of our other resources may be more useful for you.

Our other information on pelvic radiotherapy includes:

- *Pelvic radiotherapy in women – side effects during treatment*
- *Understanding radiotherapy*

We also have booklets with detailed information on specific cancer types, so our information on your type of cancer may also have helpful information.

It's important to check with your hospital consultant or nurse specialist that this is the right booklet for you, and whether you need any additional information.

If you would like more information, you can contact our cancer support specialists on **0808 808 00 00**. They will be able to send you the resources that contain the information you need.

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About this booklet

This booklet is for women who have had radiotherapy to the pelvic area and who are experiencing late effects. The pelvic area is the area of the lower tummy, in between the hips.

Late effects are side effects that are affecting you six months or longer after radiotherapy. They can also be side effects that start months or years after treatment has finished. We have a separate booklet with information for men who have had pelvic radiotherapy.

We explain how late effects can be managed or treated, what you can do to help yourself and the support that's available to you. You won't have all the late effects we've included, although some women have more than one. You can use the contents page to guide you to the information you need. It can be worrying to read about late effects, but most can be treated successfully. Very few women get severe late effects.

Radiotherapy is an effective and successful treatment for many cancers that start in the pelvic area (see page 5), and the benefits of treatment with radiotherapy usually far outweigh the risks. Newer ways of giving radiotherapy are designed to limit the chance of late effects as much as possible.

If you're deciding whether to have radiotherapy and are worried about the risk of late effects, it's important to talk to your cancer specialist (**clinical oncologist**) before treatment starts.

We hope this booklet answers some of your questions and helps you deal with some of the feelings you may have. We've also listed other sources of support and information, which we hope you'll find useful.

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

Turn to pages 93–100 for some useful addresses and websites.

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

Pelvic radiotherapy

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). This is done using a machine called a **linear accelerator**. It can also be given internally (called **brachytherapy**), using a radioactive source. Radiotherapy is often used in combination with surgery or chemotherapy, which can increase the risk of late effects developing.

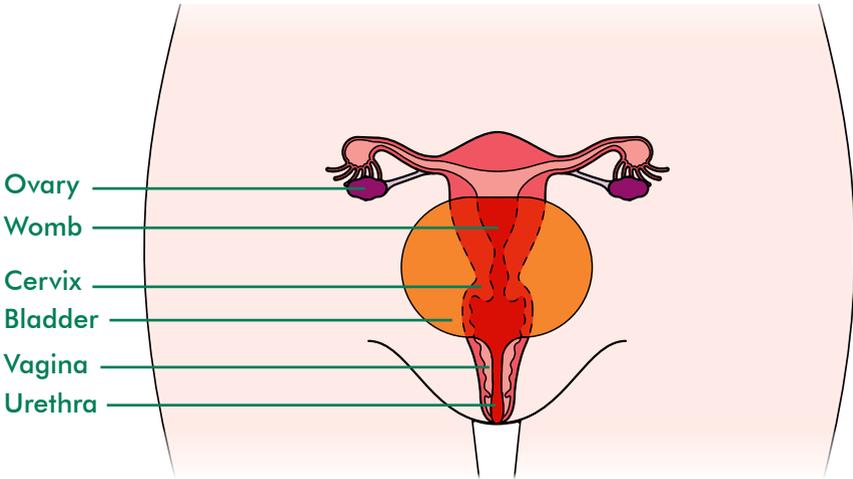
Cancers treated with pelvic radiotherapy

Pelvic radiotherapy is usually given to cure or control cervical cancer, womb (endometrial) cancer, vaginal cancer and vulval cancer. It's also used to treat cancers of the bladder, rectum and anus.

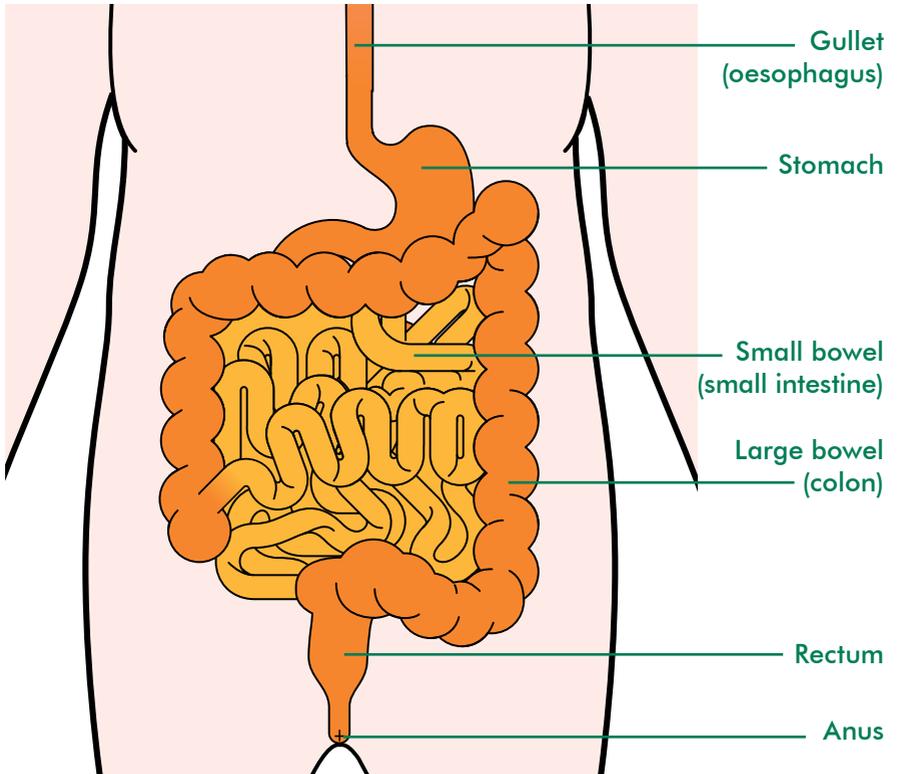
Pelvic radiotherapy may affect the female organs (the vagina, womb and ovaries – see page 6), and the bladder (see page 13). It can also affect parts of the digestive system, including the small bowel, colon, rectum and anus (see page 7).

Radiotherapy to the pelvic area can also affect:

- the lymph nodes (also known as lymph glands)
- the pelvic bones (made up of the two hip bones joined together by smaller bones).



The female pelvic organs



The digestive system

Late effects of pelvic radiotherapy

Most women have side effects during radiotherapy and for a few weeks afterwards. Usually these gradually improve over a few weeks or months after treatment has finished.

We have a fact sheet called *Pelvic radiotherapy in women – side effects during treatment*, which explains short-term side effects.

Late effects are:

- side effects that begin during or shortly after treatment and don't go away within six months (sometimes called long-term effects) – occasionally these effects become permanent
- side effects that don't affect you during treatment but begin months or even years later, as a delayed response to treatment.

Some late effects improve over time and may eventually go away on their own. The following sections introduce ways in which late effects can be managed and improved.

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

The most common late effects after pelvic radiotherapy are changes to the way the bladder and bowel work. Some women may also have changes to the vagina and changes in the physical and emotional feelings associated with sex.

The impact of late effects varies:

- They may be minor, not affecting your day-to-day life much.
- They can be more troublesome or difficult to live with, and can restrict or interfere with your day-to-day life.

If you do have late effects, there are usually lots of things that can help you cope with them, so that you can live life as fully as possible.

Pelvic radiotherapy slightly increases the risk of developing a new cancer in the treatment area, for example bowel cancer.

Talk to your doctor

Always let your cancer doctor or specialist nurse know if the side effects of radiotherapy don't go away, or if you develop new symptoms or problems after treatment is over. The more information you can give your doctor, the more likely it is they will be able to help you. You may feel embarrassed at the thought of talking about problems with your bowel, bladder or sex life. But doctors and nurses are very used to discussing intimate problems like this, so don't be put off.

It can be frightening to get symptoms after treatment and you may worry that the cancer has come back. Some of the symptoms of late effects are similar to symptoms you may have had when you were diagnosed with cancer (for example, blood in the urine or bleeding from the back passage).

Your cancer specialist will assess your symptoms and explain if they're likely to be a result of the radiotherapy. You may need to have tests to find out the cause and to rule out anything more serious, such as the cancer coming back or a new cancer.

Your symptoms may be due to another condition not related to the cancer or its treatment.

Remember you can always arrange to see your cancer specialist or specialist nurse in between appointments and contact your GP at any time.

Getting expert help

Depending on the late effects you have and how much they affect you, you may be referred to a doctor or nurse with expertise in that area. For example, if you're having bowel problems you may be referred to a doctor who specialises in bowel problems, called a **gastroenterologist**.

There are also doctors who specialise in treating late effects of radiotherapy. This is a specialist area, so there aren't many of these doctors – you may need to travel to see one. A few hospitals have special clinics for people with late effects.

Your doctor or nurse can also refer you to a specialist nurse or physiotherapist for continence advice, or to a relationship or sex therapist if needed. The Bladder and Bowel Foundation can also put you in touch with a specialist nurse or a physiotherapist (see page 93 for details) for continence advice.

Contact the Macmillan Support Line free on 0808 808 00 00 for more information on the help that's available.



Bladder changes

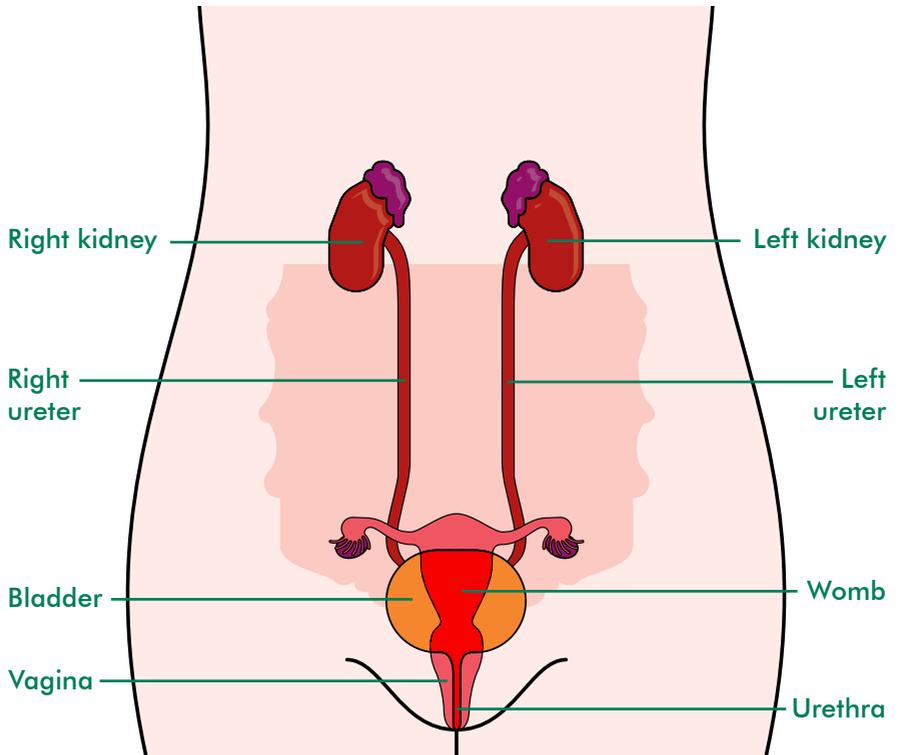
Sometimes, women who have had pelvic radiotherapy notice changes in the way their bladder works. For some women, these changes start during treatment and don't get better. But they may develop months or years after treatment has finished. Changes also happen as the bladder muscles age, so the symptoms here are more common in older women.

Women are also more likely to get urinary problems as a result of pregnancy, childbirth and the menopause, which can all weaken the pelvic floor muscles.

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

The bladder is supported by the pelvic floor muscles, which act a bit like a hammock. Some of these muscles wrap around the urethra (called the **urethral sphincter**), keeping it sealed like a valve until you need to pass urine.

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



The bladder and the kidneys

Possible late effects

Pelvic radiotherapy can cause scarring and hardening (**fibrosis**) of the bladder wall, which 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 (**incontinence**).

After radiotherapy, small blood vessels in the bladder lining may be more fragile and bleed easily. This can cause blood in your urine. Sometimes radiotherapy causes the **urethra** (the tube that carries urine from the bladder out of the body) to narrow. This is called a urethral stricture (see page 27).

Symptoms

Many of the symptoms of late effects are similar to the immediate side effects of radiotherapy.

The symptoms of late effects to the bladder can include:

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

Many of these problems can be dealt with successfully (see pages 17–27).

Talk to your doctor

There are lots of things that can be done to manage or treat your symptoms. Your doctor can advise you, or you may need to be referred to a specialist in bladder problems (a **urologist**). You can also be referred to a specialist nurse or physiotherapist for continence advice and treatment (we use the term **continence adviser** because it's shorter). The treatment that's right for you will depend on the symptoms or side effects you have and how much of a problem they are.

Tests

If you develop bladder problems after your treatment, your doctors will probably want you to have some tests to find out the cause. Your GP can test your urine to check if you have an infection, and take blood tests to find out how well your kidneys are working. Depending on your symptoms and how they respond to treatments, other tests may be arranged by a urologist or a continence adviser. These include:

- A **cystoscopy** to look at the inside of 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 under a local anaesthetic.
- **Urodynamic tests** to assess how well your bladder and urethra collect, hold and release urine. These are usually done to find out the causes of incontinence.



Managing bladder late effects

There are lots of things you can do to keep your bladder healthy and to help with symptoms caused by the late effects of pelvic radiotherapy.

What you can do

Drink plenty of fluids

Try to drink at least two litres (four pints) a day. That's about eight glasses. Drink even more if it's hot or if you're exercising. Try to drink small amounts regularly throughout the day and increase it gradually.

Not drinking enough will make your symptoms worse, not better. Urine that's concentrated irritates the bladder. Drinking more will reduce symptoms of bladder irritation and train your bladder to hold more urine. It also reduces your risk of getting urine infections.

Drink the right fluids

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

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

Try drinking water, diluted fruit juice and herbal teas (but avoid those that contain hibiscus).

If you're prone to urinary infections, drinking cranberry juice or taking cranberry capsules may help to prevent them. But don't have cranberry juice or take capsules if you're on medicine to thin your blood, such as warfarin. It can increase the effects of the medicine, which can be harmful. Cranberry juice is high in sugar, so it's not suitable for people with diabetes.

Try not to go to the toilet 'just in case'

If you go to the toilet as a precaution, the bladder won't fill completely and won't get used to holding more urine.

If you're a smoker, try to stop

The chemicals in cigarette smoke irritate and damage the lining of the bladder and can make your symptoms worse. Smoking is also a major risk factor for cancer and for other serious health conditions.

We have a leaflet called *Giving up smoking that you may find helpful.*

Avoid putting extra pressure on your pelvic floor muscles

Keep your weight within healthy limits (see page 58), and avoid constipation (see page 59) and heavy lifting. This is especially important if you have stress incontinence (see page 21).

Find ways of reducing your stress

Feeling anxious can make you feel as if you need to pass urine and can make your symptoms worse.

There's more information on coping with bladder changes on pages 55–61.

Needing to pass urine often and at night

You may have to pass urine more frequently than usual after having pelvic radiotherapy. Your bladder may be more sensitive and feel full even when there's not much urine in it. This is known as an **overactive bladder**. There are several 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, so your bladder gets used to feeling fuller. This can help the bladder hold more urine, so you won't need to go to the toilet as often. It can be difficult at first, but it gets easier with time. It's best to retrain your bladder with advice and support from a continence adviser or doctor.

You should begin by keeping a record of how often you go to the toilet and how much urine you pass each time. Your specialist nurse or physiotherapist may have a chart you can use.

Bladder retraining is done in stages. You start by 'holding on' for a few minutes and 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.

Don't be tempted to cut down on fluids when retraining your bladder. Keep drinking fluids as normal. Avoid retraining your bladder overnight – your daytime exercises will eventually mean you need to go to the toilet at night less often.

After some weeks, resisting the urge to pass urine straight away gets easier and you'll have longer spells between going to the toilet.

Drugs to relax the bladder

Some types of drugs, called antimuscarines or anticholinergics, can help relax the bladder so it can hold more urine. These drugs may be used to treat an overactive bladder or stress incontinence (see the next page).

There are several drugs that can help, so if one doesn't work you can try another.

Treatment with botulinum toxin A (Botox®)

This involves having injections of botulinum toxin A (Botox®) into the bladder muscles. It's done under a general anaesthetic. The drug paralyses part of the muscle to help relax the bladder. It should help you to hold on for longer and may also help reduce incontinence. This is still quite a new way of treating bladder symptoms, so doctors are still finding out how helpful it is and whether this treatment has any drawbacks.

Sacral nerve stimulation

This uses a mild electrical current that stimulates the sacral nerve that carries messages from the brain to your bladder muscles. This can help reduce the urge to pass urine. It involves having a small operation, and it's not suitable for everyone.

Leaking urine

Some women leak urine as a result of pelvic radiotherapy. Radiotherapy can weaken the valve that keeps the bladder closed and the pelvic floor muscles that help you control your bladder. You may leak small amounts of urine when you laugh, sneeze, cough or when you're exercising. This is called **stress incontinence**. If you have an overactive bladder, you may find that you can't always get to the toilet in time. This is called **urge incontinence**.

This section covers some of the ways in which incontinence can be treated and managed. Some of the treatments mentioned in the section on an overactive bladder (see page 19) can also help to improve urge incontinence.

Looking after your skin is very important as urine can irritate the skin. Our section on coping with bowel and bladder changes (see pages 55–61) has information on skin care, what to do when you're not at home, and getting support. There's also advice on special products, such as pads and pull-ups, you can use while you're waiting for treatment to work.

Pelvic floor exercises

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

It's best to ask your doctor to refer you to a continence adviser to teach you how to do the exercises correctly. The Bladder and Bowel Foundation (see page 93) can also provide details of your nearest adviser and can send you leaflets showing you how to do pelvic floor exercises.

Here's a brief description of how to do pelvic floor exercises, but we recommend you get more detailed information and professional advice.

- **This exercise involve squeezing your pelvic floor muscles by tightening the area around your back passage.** Pull the squeeze upwards and forwards around your vagina. Place your fingertips on the skin just behind the vagina and you should feel the skin lift up and away from your fingertips as you squeeze.
- **Sit comfortably and squeeze the muscles for up to 10 seconds. Release the muscles and relax for four seconds.** You should have a definite feeling of 'letting go'. Don't hold your breath or push down when you're doing the exercises – make sure you're squeezing and lifting up.
- **Try to repeat the squeeze 10 times, holding for up to 10 seconds each time.** To begin with, you may not be able to do as many as 10 or to hold for as long as 10 seconds. Just do as many as you can manage. With time you'll be able to do more.
- **After you've finished a set of 10, rest for a minute.** Then try to repeat 10 short squeezes, lifting up as quickly and strongly as you can and letting go straight away.

It can take at least 12 weeks of practising these exercises three times a day to get the muscles back into shape.

As your muscles improve, try doing them while you're doing everyday jobs. Squeeze them before standing up and when you're lifting or pulling anything, for example, when you're gardening. Try doing them before you cough, or squeeze to help prevent urine leaks (**stress incontinence**).

Biofeedback training

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

Other treatments

If incontinence problems don't improve with the treatments we've mentioned, there are other options. Your doctor may talk to you about these:

- **Acupuncture** This may help some people with mild incontinence. Your doctor may be able to refer you for acupuncture, or you can contact the British Medical Acupuncture Society (see page 96).
- **Duloxetine (Yentreve®)** This drug is sometimes prescribed to help reduce stress incontinence. As with most drugs, there may be side effects. So it's not usually prescribed until other treatments have been tried.

Surgery

Occasionally, some women may need treatment that involves having an operation to improve incontinence. Your doctor will discuss this with you. You'll be referred to a specialist surgeon for an assessment, and may need to have tests done before any treatment. Operations may include:

- **Tape to support the urethra** This is the most common type of operation, which involves inserting a tape through the vagina and placing it behind the urethra. This supports the urethra and helps prevent urine leaking when there's increased pressure on the bladder, such as when you cough or sneeze.
- **Bulking agents** These are materials that are injected into the tissue surrounding the urethra to help keep it closed and make 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. It may be suitable for some women who are leaking a lot of urine most of the time (severe incontinence) and who haven't been helped with other treatments. A small cuff is inserted around the urethra and attached to a pump placed under the skin of your tummy or leg. When the cuff is inflated, it stops urine leaking out. You can deflate it when you need to pass urine.

Blood in the urine (haematuria)

If you have blood in your urine, you'll need to have a cystoscopy (see page 15) to find out why. If the bleeding is a result of radiotherapy but is mild, you may not need any treatment. If it's regular, heavy or causing **anaemia** (when your body produces fewer red blood cells than usual), you're likely to need treatment. There are several possible treatments:

Tablets

Tranexamic acid (Cyklokapron®) tablets can stop clots dissolving and reduce bleeding. Your doctor may prescribe these for you.

Giving drugs into the bladder

Some drugs can be dissolved in fluid and given directly into the bladder to stop the bleeding.

For this treatment, you'll need to lie down while a nurse gently passes a thin, flexible tube (a catheter) into your urethra and through to the bladder. Fluid will slowly be passed through it. The catheter is then removed, and you hold the fluid in your bladder for about half an hour to give the treatment time to work. After this, you'll need to empty your bladder. You might feel some discomfort when passing urine for a couple of days afterwards.

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

Bladder wash out

If you're passing blood clots in your urine, these may need to be flushed out to make sure the clots don't block your urethra. A liquid is passed through a catheter into your bladder, and then drained into a bag attached to the catheter. A nurse or doctor will continue to flush out the bladder in this way until the clots have gone.

Using heat to seal off the bleeding points (cauterisation)

Sometimes, if medicines don't stop the bleeding, heat can be used to seal up the blood vessels causing the bleeding. This is done using a cystoscope (see page 15) while you're under a general anaesthetic.

Hyperbaric oxygen therapy

This treatment is normally only used after other treatments have been tried. It increases the amount of oxygen getting to tissue in the bladder that's been damaged by radiotherapy. This can encourage new blood vessels to grow and the tissues to heal.

We have a fact sheet about hyperbaric oxygen therapy.

Treating anaemia

If you have become anaemic because of bleeding from your bladder, you may feel breathless or tired. Your doctor may suggest you have a blood transfusion to replace the blood you've lost and make you feel better.

We have a fact sheet about blood transfusions.

Difficulty passing urine

Sometimes, radiotherapy can cause the urethra (the tube that drains urine from the bladder) to narrow. You may have difficulty passing urine or find yourself straining to release it.

Problems passing urine can be caused by many common conditions. So if you have these symptoms, it's important to get them checked out by your doctor. If urine builds up in the bladder and it isn't treated, it can cause infections and damage the kidneys. Your doctor or continence adviser will do tests to find out the cause so you can be offered the right treatment for your situation.

Sometimes, doctors treat a narrowed urethra (urethral stricture) by passing a thin plastic tube through to widen (dilate) it. This can be done under a general or local anaesthetic and repeated if necessary. Another possible treatment is an operation called a **urethrotomy**. This is done under general anaesthetic to allow the surgeon to make a cut along the stricture. A larger stricture may need to be treated with an operation that uses tissue from another part of the body to repair the urethra (a **reconstruction**).

If bladder problems don't improve

If symptoms continue or don't improve after the first treatments are tried, your specialist will be able to discuss other treatments that are available. Occasionally, surgery may be needed. If symptoms are very severe, an operation to remove the bladder may be needed. This is extremely rare, though.

See pages 55–61 for some practical ways of coping with bladder changes.



Bowel changes

Sometimes, women who have had pelvic radiotherapy notice changes in the way their bowel works. For some women, these changes start during treatment and don't get better. But for others, the changes may develop months or years after treatment.

The bowel is part of the digestive system. It's made up of the small bowel and large bowel (see the diagram on page 7). The small bowel absorbs nutrients from the food we eat. It then passes the liquid waste into the large bowel (**colon** and **rectum**). The colon absorbs water from the waste before passing the more solid waste (faeces or stool) into the rectum. The stool is held in the rectum until it's ready to be passed through the anus (the opening to the outside of the body).

Possible late effects

Radiotherapy can cause scarring (**fibrosis**) in the large bowel lining, making it thicker and less flexible. This causes solid waste to pass through more quickly than before, so nutrients may not be as well absorbed. The bowel will also be unable to hold as much solid waste (stool). The muscles that help to hold stool in the rectum can also be affected, which may cause problems with bowel control and leakage (**incontinence**).

The blood supply to the bowel can also be affected by radiotherapy, making the bowel tissue and the small blood vessels in it more fragile. Radiotherapy can cause the bowel to narrow. When radiotherapy affects the small bowel, it can cause food intolerances (see page 40), or conditions such as **bile acid malabsorption** (see page 41) or **small bowel bacterial overgrowth** (see page 42).

Symptoms

Some women find that their symptoms don't cause them too many problems, and that they can manage them fairly easily. Others may have more severe changes that interfere with how they live their day-to-day lives.

The symptoms of late effects to the bowel can include:

- bleeding from the back passage (bottom)
- passing mucus (a clear, sticky substance)
- cramps or spasms in the bowel and/or feeling that you haven't emptied your bowel completely (tenesmus)
- diarrhoea or severe constipation
- needing to rush to open your bowels (urgency)
- leaking or soiling (incontinence)
- passing a lot of wind.

The change in the way the bowel works may be slight, for example, having to go to the toilet twice a day instead of once. But sometimes bowel changes can have a much greater impact, interfering with day-to-day life.

Talk 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**) for tests. You may also be referred to a specialist nurse or physiotherapist for advice and treatment on incontinence (we use the term **continence adviser** because it's shorter).

There are three problems you must always talk to your doctor about:

1. Passing blood from your back passage.
2. Waking up from sleep to open your bowels.
3. Needing to rush to open your bowels, or having accidents.

These symptoms may not be due to anything serious, but should always be checked out. They often respond to simple treatments. Occasionally they can be a sign of a more serious problem, so it's important to find out the cause as soon as possible.

Tests

Tests can include blood and stool tests, x-rays and scans. You may have a test to look at the inside of your bowel. This involves a doctor or nurse passing a thin tube with a light on the end (an **endoscope**) into the bowel to look for any abnormal areas.

Occasionally, people need to have a sample of tissue removed (a **biopsy**) from the bowel, but this should only be done by an experienced bowel specialist.



Managing bowel late effects

Bleeding from the bowel

Bleeding from the back passage (rectum) after radiotherapy is common, but it's usually mild and often doesn't need treatment. Bleeding sometimes improves gradually and can stop on its own after a few years. Women who take blood-thinning medicines, such as aspirin or warfarin, may have heavier bleeding.

Bleeding may not always be a result of previous radiotherapy. It can be caused by piles (haemorrhoids) or straining on the toilet. But 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's important to find out the cause and to rule out serious problems. Your doctor will do an examination of your back passage and may refer you to have a test to look at the inside of your rectum (an **endoscopy**, see page 31).

Treatment

If bleeding is minor and manageable, you probably won't need any treatment. You'll be given advice about your bowel habits to help minimise the bleeding and avoid constipation (see page 59).

If the bleeding is interfering with your day-to-day life or if you have become **anaemic** (when your body produces fewer red blood cells than usual), you're likely to need treatment. If you're taking blood-thinning drugs, your dose may be reduced and monitored. Your doctor or specialist nurse will explain more about your treatment options and give you more detailed information.

The most commonly used treatment for bleeding from the rectum is a drug called **sucralfate** (Antepsin Suspension[®]), which is given as an **enema**. An enema is an injection of fluid into the rectum. Sucralfate works by coating the lining of the rectum, reducing inflammation and encouraging healing. It's important to avoid constipation (see page 59) when you're being treated with sucralfate.

A drug called **formalin** is also helpful for some people. It works by sealing the bleeding blood vessels. Your doctor can give it to you through a thin, flexible tube with a light on the end (endoscope), which is passed into the bowel. You can also have it done under a general anaesthetic.

If bleeding is higher up in the large bowel (colon), or isn't reduced with enemas, other treatments may be helpful:

- **Argon plasma coagulation** directs heat at areas that are bleeding and is given during an endoscopy. The heat seals the blood vessels and destroys damaged tissue. Doctors don't yet know how successfully this treats heavy bleeding. There's a risk of complications, such as serious tissue damage, with this treatment, which your doctor will discuss with you.
- **Hyperbaric oxygen therapy** works by increasing the amount of oxygen reaching tissue that's been damaged by pelvic radiotherapy. This can encourage new blood vessels to grow and may help tissues heal. Treatment takes up to eight weeks. This treatment isn't widely available, so you may need to travel some distance for it.

We have a fact sheet about hyperbaric oxygen therapy.

Tenesmus

Tenesmus is the feeling of needing to go to the toilet often, although your bowel is empty. It can involve straining, pain and cramping. It's probably due to cramp (spasms) in the muscles that stimulate the bowel, as radiotherapy can affect them.

The spasms can often be controlled by:

- doing pelvic floor exercises (see pages 21–22)
- taking extra soluble fibre to bulk up the stool (see page 38)
- taking very low doses of certain antidepressant drugs.

Sometimes tenesmus can be caused by constipation. It's also sometimes caused by a non-cancerous growth (a **polyp**) in the bowel, or can be caused by a cancer. Your doctor will examine your back passage and may arrange for you to have a test, called a **flexible sigmoidoscopy**, to look at the rectum and lower part of the large bowel.

Fissure

After radiotherapy, some women develop a split in the skin (a fissure) where the back passage opens to the outside of the body (anus). It can cause very sharp, intense pain when you pass a stool (bowel motion). Your doctor will usually prescribe creams that you can apply to the area. It's important to avoid constipation (see page 59), as this can make the fissure worse. Your doctor may prescribe a laxative to make it easier for you to use the toilet.

If the fissure doesn't improve, it can be treated with injections of botulinum toxin A (Botox®), which are given into the tissue lining the anus.

Bowel control problems

Feeling that you can't wait when you get the urge to open your bowels can be stressful, particularly when you're away from home. You may sometimes have leakage (**incontinence**). The degree of incontinence varies. You may just have a small amount that causes some staining on your underclothes. But occasionally, women may have an accident and leak a larger amount of stool. Although you might find this difficult to talk about, it's important to let your doctor know as there's a lot that can be done to help.

What can be done?

If you have bowel control problems, such as urgency, leakage, diarrhoea or constipation, there are several things that can help. The best way to manage any bowel control problems depends on the symptoms you have and what's causing them, so it's important you're properly assessed. If your symptoms don't improve, ask your GP to refer you to a gastroenterologist, a specialist nurse or continence adviser for advice.

The most common methods of improving bowel control include:

- making changes to your diet
- using medicines to slow the bowel down
- strengthening the muscles used for bowel control.

Diet

What you eat affects your bowel. For example, too much or too little fibre, or fatty or spicy foods can stimulate the bowel, making it more difficult to control. Ask your doctor to refer you to a dietitian for expert advice on managing your diet. If you're losing weight because of bowel problems, it's important to see a dietitian.

Foods affect people differently, so there may be some trial and error before you work out what's best for you. Try to find out which foods cause constipation or make your bowel motions loose. You may be able to eat less of them without cutting them out altogether. Caffeine, alcohol and artificial sweeteners can also cause problems.

See our food guide on pages 50–51 for information about foods that can cause or improve bowel problems.

Some supplements (such as the mineral selenium, which is only needed in small amounts), can cause diarrhoea.

Fibre

Fibre is important in regulating how your bowel works. There are two types of fibre:

- **Insoluble fibre** is found in bran, seeds, and multigrain, wholemeal or wholegrain foods, such as bread or cereals. It helps with managing constipation, but can also help with other bowel problems.
- **Soluble fibre** helps to bulk up and slow down bowel movements, so may help to reduce diarrhoea or soft stools. It's found in oats, porridge, bananas, and in apples and pears with their skins removed (the skins contain

insoluble fibre). Pulses, such as baked beans and lentils, are also high in soluble fibre, but they stimulate the bowel so aren't recommended for people with diarrhoea or soft stools.

Your specialist nurse, continence adviser or gastroenterologist (if you're seeing one) will advise you on the type of fibre you need and how much you should have.

If you're adding fibre to your diet, do it gradually to give your body time to adjust. Start with small amounts and slowly increase the amount when you're ready. Make sure you drink more water.

Adding more fibre won't be right for everyone. After pelvic radiotherapy, you may not be able to cope with as much fibre in your diet as before. So, 'five a day' may not always be appropriate. Some high-fibre foods make the bowel produce a lot of gas (wind). You may need to avoid these if wind is a problem for you.

Fibre supplements Soluble fibre supplements, such as Normacol[®] (an insoluble fibre), are often prescribed for people who have frequent bowel motions or incontinence. They're also used to prevent constipation. They work by absorbing water and expand to fill the bowel, making the stools bulkier and easier to push out. Fybogel[®] is another fibre supplement, but it makes the bowel produce a lot of gas (wind). Normacol is often a better option. You can buy some fibre supplements at the chemist, or your doctor can prescribe them. Always make sure you're drinking plenty of fluids each day (at least two litres) when you're taking fibre supplements.

Food intolerance

Sometimes, radiotherapy can affect how well your bowel copes with certain food types, such as:

- lactose, which is found in dairy products
- fructose, a fruit sugar sweetener often found in products labelled 'no added sugar'
- gluten, a wheat-based protein found in breads, cakes, biscuits and pasta.

Symptoms of food intolerance may include tummy cramps, feeling bloated, and increased wind after eating a particular food. If you think you may have a food intolerance, ask your GP to refer you to a gastroenterologist.

Anti-diarrhoea drugs

If changes to your diet aren't enough to control bowel problems, anti-diarrhoea drugs may help. It's important to speak to your doctor or specialist nurse before taking any medicines.

The most commonly used treatment is loperamide (also called Imodium® or Diareze®). It slows down your bowel, making the stools more solid and less frequent. Taking loperamide regularly, half an hour before meals, works very well for some people. It's safe to take it for as long as you need it, but discuss this with your doctor. The dose 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's right for you. Loperamide is also available as a syrup, so you can take less and adjust the dose as needed.

Other anti-diarrhoea tablets, such as codeine phosphate or diphenoxylate (Lomotil®), can also be prescribed. Your doctor or a continence adviser can advise you about the medicines that may be best for you.

Sometimes, low doses of anti-depressant drugs are prescribed to help slow down the bowel.

Ongoing diarrhoea

If you have diarrhoea and changes to your diet and anti-diarrhoea drugs don't help, ask your doctor to refer you to a bowel specialist (**gastroenterologist**). A number of things can cause diarrhoea, and a gastroenterologist will be able to assess the exact cause.

Radiotherapy can cause other conditions that can lead to ongoing diarrhoea, such as bile acid malabsorption and small bowel bacterial overgrowth.

Bile acid malabsorption Normally, bile acids are made in the liver and transported to the small bowel to help us digest fats. They are then absorbed back into our system. Sometimes radiotherapy damages the small bowel so it can't re-absorb the bile acids (malabsorption). This leads to diarrhoea.

Bile acid malabsorption can be diagnosed using a scan called a **SeHCAT scan**. Your doctor can tell you more about this. It's helpful to have the scan before treatment to confirm the diagnosis and the extent of its effect on you. If you have bile acid malabsorption, you'll need to take a drug for the rest of your life to treat it, and/or stick to a low fat diet. So it's important to get the diagnosis right.

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

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

Small bowel bacterial overgrowth A healthy small bowel contains almost no bacteria, although the large bowel contains lots of healthy or good bacteria, which help us digest food. After pelvic radiotherapy, bacteria sometimes grow in places in the small bowel where there shouldn't be any bacteria. These can cause a number of symptoms, but the most common is diarrhoea. Other symptoms include fatty stools, wind, bloating, constipation, feeling sick, vomiting or bad breath.

Small bowel bacterial overgrowth is usually treated with antibiotics.

Greasy and pale stools

Some women notice that, when their bowel motions are loose, they are also paler than usual and much more smelly. The stool may float and be more difficult to flush away, and there may be a film of oil on the toilet water. This is called **steatorrhoea**.

It can be caused by:

- small bowel bacterial overgrowth
- bile acid malabsorption
- too much fat in the diet
- a lack of proteins (enzymes) normally made by the pancreas to break down fat.

If you have symptoms of steatorrhoea, you should ask to be referred to a gastroenterologist, who will be able to help you. Steatorrhoea can usually be treated effectively.



Strengthening the muscles used for bowel control

Exercises to strengthen the muscles used in bowel control can help you manage urgency, leakage and incontinence. Some women find they also help with wind (see page 47–48), bowel cramps and tenesmus (see page 35).

The exercises work the muscles around the back passage and a deeper layer called the **anterior pelvic floor muscles**. These muscles also help with bladder control and are used during sex.

Ask your doctor to refer you to a continence adviser, who will teach you how to do the exercises correctly. You can read more about pelvic floor exercises on pages 21–22 in our section on bladder changes.

The Bladder and Bowel Foundation also produces a fact sheet with instructions on how to do these exercises. You can order the fact sheet or download the information from the website (see page 93).

It's important to:

- do your pelvic floor exercises correctly, otherwise they won't work
- practice regularly to build up your muscles (aim for three times a day)
- keep to a healthy weight, as being overweight puts extra stress on the pelvic floor muscles.

You need to do your exercises for at least three months to properly strengthen these muscles.

Biofeedback training

Normally our pelvic floor muscles work without us consciously controlling them. As a result, you may find it difficult to know if you're doing the exercises correctly.

Biofeedback training (see page 23) can help you with your pelvic floor exercises and bowel control. Your continence adviser can tell you where you can get this training.

Other things you can do

In addition to making changes to your diet, taking medicines to slow your bowel and doing bowel control exercises, there are other things you can do to improve bowel control. Your doctor, specialist nurse or continence adviser can advise you about these.

Some of the following may also help:

- Keep a diary of your bowel habits to help your specialist work out what might help you.
- Try to go to the toilet at regular times each day – eating triggers bowel movement for many people, so this may be after meals.
- If you feel you need to go to the toilet several times a day, practise holding the stool. Over time this will help to increase the amount of stool your bowel can hold.
- Find ways of reducing stress (see page 60).
- If you smoke, try to stop as smoking stimulates the bowel.
- If you're taking other medicines, ask your doctor or nurse if they could be making bowel problems worse. They may be able to prescribe an alternative that might affect you less.

Read our section on coping with bladder or bowel changes for advice on skin care, going out and lifestyle changes that may help you cope.

Wind

After radiotherapy, some women have more wind because their pelvic floor muscles are weaker. Although it can be an embarrassing problem, you may be more aware of it than the people around you.

The amount of wind we produce is the result of how healthy bacteria and digestive enzymes in our bowel combine with the foods we eat. Some foods, particularly high-fibre foods, such as vegetables and pulses, cause more wind than others.

Too much wind can be caused by:

- eating certain types of foods (see the food guide on pages 50–51)
- constipation
- some medicines, such as Fybogel and lactulose (another fibre product called Normacol® may work as well without causing a lot of wind – see page 39)
- bowel conditions (such as diverticular disease)
- small bowel bacterial overgrowth.

Here are some tips that may help:

- Cut down on foods and drinks that can cause wind.
- Try to have meals at the same times each day, eat more slowly and try not to swallow air.
- Avoid eating and drinking at the same time.
- Try pelvic floor exercises (see pages 21–22).

Some people find one or more of the following helpful in controlling wind:

- peppermint oil
- live yoghurts or probiotic drinks
- aloe vera capsules or juice
- charcoal tablets
- chewing cardamom seeds.



Food guide

This guide will help you choose foods that may help with some bowel problems. It can also help you identify foods that may make some bowel problems worse. This is only a guide, as foods can affect people differently.

Foods that may cause wind include:

- vegetables such as sprouts, broccoli, cabbage, cauliflower, cucumber, onions, radishes, spinach and sweetcorn
- baked beans, kidney beans, lentils, chickpeas and other pulses
- nuts
- dairy products
- drinks such as beer and fizzy drinks
- chewing gum
- sorbitol (a type of sugar found in some artificial sweeteners, some sugar-free foods and in apples, pears and peaches).

Foods that may help make your stools firmer include:

- apples and pears (with their skins removed), bananas and potatoes
- yoghurt, smooth peanut butter, pretzels and marshmallows
- white bread (not a high-fibre variety), white rice (boiled) and pasta (not a wholemeal variety)
- chicken and fish.

Foods that stimulate the bowel, make stools softer or more frequent include:

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

These foods should be limited if you have problems with diarrhoea, loose stools or frequent bowel movements. These foods may be helpful if you have constipation.

Uncommon and rare late effects

Very occasionally, women may experience other bowel problems as a result of pelvic radiotherapy:

Anal stricture

Radiotherapy may cause a tight band of scar tissue to develop at the opening of the back passage. This causes it to narrow (anal stricture). This can cause difficulty and pain when you try to open your bowels. If it's mild, your doctor will advise you to use a stool-softener laxative or fibre supplement to make it easier to go to the toilet, which will help stretch the stricture. If the narrowing is more severe, you may be referred to a bowel specialist to have the opening stretched (**dilatation**) or to have an operation under general anaesthetic to cut through the scar tissue.

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, and pain and cramping when you go to the toilet. It's often treated with **hyperbaric oxygen therapy** (see page 26).

Bowel blockage

A blockage (obstruction) in the bowel can cause sickness (vomiting), pain in the tummy and constipation. You may be given fluids through a drip to rest the bowel and treatment for constipation. Sometimes an operation to remove the blockage is necessary.

Fistulas

This is an opening that forms between two parts of the body. Rarely, an opening can develop between the back passage and vagina after pelvic radiotherapy.

We have a fact sheet about fistulas, which we can send you.

Hole in the bowel wall

Very rarely, a hole may develop in the bowel wall. This is called a **perforated bowel**. This can make you suddenly unwell and is usually treated straight away with an operation to remove the affected part of the bowel.

The next chapter suggests practical ways of coping with bowel changes.



Coping with bowel or bladder changes

The day-to-day issues caused by bladder and bowel changes are often similar, so we've covered them in this one chapter.

If you're having difficulties, you may feel worried about going out and social occasions. But there are many practical things you can do and lifestyle changes you can make to help you feel more confident and in control.

Protect your skin

If you have problems with leaking (incontinence) from your bladder or bowel, it can make the surrounding skin in that area sore. You can protect your skin by keeping it clean and dry. There are many products available, and your continence adviser will be able to give you more information.

Here are some suggestions:

- Keep your skin clean and dry.
- Try using unperfumed baby wipes rather than toilet paper, as they are gentler on your skin.
- Use absorbent pads and barrier creams (such as Cavilon®) to help protect your skin.
- Wear cotton underwear – it allows your skin to breathe more than other materials.

Going out

You may feel worried about going out if you have problems with bowel or bladder control. Planning ahead, so that you are prepared, can help you feel more confident.

Access to toilets

If you're going somewhere you're not familiar with, it's a good idea to find out where the toilets are in advance. Many towns and counties keep information about the public toilets in their area as lists or maps. Often these are on local authority websites. There are too many of these websites to list here, but you'll be able to find them on the internet. Try putting the term "public toilets" and the name of the place you plan to visit in a search engine to find out what's available.

Carrying a **Just Can't Wait** toilet card may help you to get access to a toilet more quickly when you're out. The card can be used in places such as shops and pubs, and states that the card-holder has a medical condition that requires urgent access to a toilet. You can get a Just Can't Wait card from the Bladder and Bowel Foundation (see page 93) or Disability Rights UK (see page 95).

You can use disabled toilets too. These often offer more privacy, have a wash basin and more space if you need to change. The **National Key Scheme for Toilets** offers disabled people access to about 9,000 locked public toilets across the UK. You can buy a key for £20 from the Royal Association for Disability and Rehabilitation (RADAR) – now part of Disability Rights UK (see page 95). They can also send you details of where the toilets are located.

Take a bag with supplies

Pack a bag of the things you may need when you go out. This will help you feel more confident.

You may want to include:

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

Always remember to take your Just Can't Wait toilet card with you when you're going out.

Specialist products for leakage or soiling

If you have problems with leakage or soiling (incontinence) there's a variety of products you can wear to help you feel more confident and to help if an accident does happen.

Pads for mild to moderate incontinence are available in most supermarkets, pharmacies and online. If these aren't absorbent enough, you can get bigger pads from your continence adviser. They'll also explain what's available to you on the NHS, which can vary from region to region. The Bladder and Bowel Foundation offers advice and support via its helpline and website (see page 93).

Bladder

Pads and pull-ups have a layer that draws urine away from the surface and absorbs it, so your skin stays dry. There's a variety available. Some can be worn inside your underwear, while others can be worn as a replacement for underwear. Some pads can be used to cover your bed.

Bowel

A continence adviser can help you choose a product that suits you for the daytime. There are also various types of pads you can use to cover your bed at night.

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

Keep to a healthy weight

Being overweight puts pressure on your pelvic floor muscles, so it's especially important to keep to a healthy diet if you have stress incontinence or problems with bowel control. Talk to your GP about the right weight for your height.

Our booklets on [Weight management after cancer treatment](#) and [Healthy eating and cancer](#) have more information. We can send you this information for free.

Keep physically active

Keeping active will help you manage your weight and avoid getting constipation. This is important to help look after your pelvic floor muscles. Exercise also encourages you to go to the toilet more regularly and avoid constipation. It helps you feel better and can reduce stress too.

If you have stress incontinence, it's best to avoid anything involving running or jumping. Walking or swimming are lower impact and are less likely to be a problem. When your symptoms are under control, you may want to gradually introduce other types of exercise.

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

Avoid constipation

This is important to help look after your pelvic floor muscles. Our food guide on pages 50–51 lists foods that help ease constipation. Make sure you drink plenty of fluids and keep physically active.

Managing stress

How you feel can affect both your bladder and bowel. Anxiety and stressful situations can make your symptoms worse and may make accidents more likely.

Learning to relax may help to improve some of your symptoms. Stress reduction is taught at some continence clinics. Your doctor or specialist nurse can tell you about relaxation classes in your area, and some support groups also offer this.

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

Some people find that complementary therapies (see page 85) help them feel less stressed.

Call our cancer support specialists on 0808 808 00 00 for details of what's available in your area.

Getting support

Bladder or bowel problems can be embarrassing and difficult to talk about, which can make you feel isolated. Health professionals can give you lots of support and advice if you let them know about any problems you're having. They're used to dealing with and discussing intimate problems and can refer you to a counsellor or specialist if you need more help (see page 83).

Support groups, online community sites and specialist organisations, such as the Pelvic Radiation Disease Association (see page 95), can also provide invaluable support. They're a good way of meeting people who've been through similar difficulties and you can share experiences and solutions with each other. Partners, family and close friends can also help you keep things in perspective and reassure you that you're valued for who you are.



Lymphoedema

If the lymph nodes (glands) in the pelvic area become damaged by pelvic radiotherapy or by surgery to remove them, fluid sometimes builds up in one or both legs. This is called lymphoedema. The lymph nodes are part of our immune system and help us fight infection. If they're damaged, lymph fluid, which flows along fine channels between the nodes, can build up.

Lymphoedema after pelvic radiotherapy is not common. The risk depends on the type of cancer you've had and on other treatments you've received. You're more at risk if you've had an operation to remove the pelvic lymph nodes as well as pelvic radiotherapy. Lymphoedema can develop months or even years after treatment, causing one or occasionally both legs to become swollen. Rarely, women get swelling in the trunk or genital area.

Reducing the risk of lymphoedema

There are things you can do to reduce your risk of lymphoedema, in particular protecting the skin on your legs and feet. Infections can trigger lymphoedema, so it's important to avoid damage to the skin. If you get swelling in your foot or leg, always get it checked by your doctor or nurse.

Our booklet *Understanding lymphoedema* has more detailed information. We also have several videos on our website about coping with lymphoedema. You can watch them at macmillan.org.uk/lymphoedema

What you can do:

- Keep the skin clean and use moisturisers to keep it supple.
- Clean grazes or cuts straight away and see your GP if the area gets red, hot or swollen.
- Use an electric razor if you want to shave your legs.
- Wear well-fitting shoes.
- Use nail clippers instead of scissors to cut your toenails.
- Cover up or use a high factor suncream (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.

Managing lymphoedema

The earlier treatment for lymphoedema begins, the more effective and straightforward it is. If you develop lymphoedema, you should be referred to a clinic for specialist advice. There are lots of things that can be done to reduce the swelling and prevent it getting worse.

At the lymphoedema clinic, you'll be given advice on caring for your skin. You'll also be shown positioning exercises and how to do self-massage. A specialist will measure you for a compression garment to wear on the affected leg to reduce the swelling. They may also recommend other treatments for you.

Bone changes

Most women who've had pelvic radiotherapy won't have any bone problems. Damage to the bones in the pelvic area is a very rare late effect of radiotherapy.

If radiotherapy damages the pelvic bones, it may increase the risk of fine, hair-line cracks (known as **pelvic insufficiency fractures**), which can be painful. The pain is normally in the lower back when you're moving around, and it can make walking difficult. The pain isn't usually there when you're resting or sleeping.

Pelvic radiotherapy causes early menopause (see pages 68–70) in younger women. This increases the risk of bone thinning (**osteoporosis**), but only if you can't take hormone replacement therapy (HRT).

Always let your cancer doctor or nurse know if you have pain or aching in the bones. This can be caused by a number of conditions, but it's very important to get it checked. Damage to the bones is a rare late effect of pelvic radiotherapy, so it's more likely to be caused by something else.

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 MRI scan. A special scan called a DEXA scan can also be done to check the strength of your bones.

Treatment

Pelvic insufficiency fractures don't usually need to be treated with an operation, but you'll be referred to a specialist bone (orthopaedic) doctor for advice. Your doctor will prescribe regular painkillers to control the pain.

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

If you have osteoporosis, you'll probably be prescribed drugs known as **bisphosphonates** to help strengthen the bones. Your doctor may also prescribe calcium and vitamin D supplements for your bone health.

Bone health

You may want to know more about keeping your bones healthy. Although radiotherapy damage to the bones is rare, other factors may contribute to bone changes. The bones naturally lose some strength with age, so this may be a factor. It's important to follow your doctor's advice if you have any bone problems.

What you can do:

- **Keep physically active** to keep bones strong, but if you have bone problems ask your doctor for advice. Our booklet *Physical activity and cancer treatment* has more information on keeping active.
- **Keep to a healthy weight** to avoid strain on your joints. You may find our booklet *Weight management after cancer treatment* helpful.
- **Eat healthily** to get plenty of calcium and vitamin D, and avoid too much caffeine. You can read more in our booklet *Healthy eating and cancer*.
- **Avoid smoking** – it's bad for the bones and it increases the risk of certain cancers and other illnesses. Read our leaflet *Giving up smoking* for more information that may help.
- **Drink alcohol within sensible guidelines**, as alcohol can interfere with the balance of calcium in the body. Current guidelines recommend that women should drink no more than 14 units of alcohol a week.

There's more information in our booklet *Bone health*.

Early menopause

Pelvic radiotherapy stops the ovaries from working and from producing the hormones oestrogen and progesterone. Your periods will stop and you'll start the menopause. Doctors often say early menopause is before 45.

Some symptoms of menopause are:

- hot flushes and sweats
- vaginal dryness
- passing urine more often
- lower sex drive
- sleep problems
- aches and pains
- mood swings and poor concentration.

Hormone replacement therapy (HRT)

You may be able to have HRT to replace the hormones your ovaries are no longer producing. It can improve some menopausal symptoms and protect your bones and heart. Early menopause can increase the risk of bone thinning (osteoporosis – see page 66).

If you've had cervical or rectal cancer, there's normally no reason why you shouldn't take HRT. But some cancers, for example womb cancer, are dependent on hormones to grow, so your specialist may not advise HRT for you. If you have had early menopause because of pelvic radiotherapy, ask your cancer specialist if HRT is suitable for you.

Managing menopausal symptoms

If HRT isn't advised or if you don't want to take it, there are different ways in which symptoms can be managed. If your symptoms are affecting your day-to-day life, ask your doctor about other medicines that may help with symptoms of the menopause.

Low doses of antidepressant drugs or a drug called clonidine (Catapres[®], Dixarit[®]) used to control blood pressure can reduce hot flushes and sweats. Some women find that using a slow, controlled breathing technique, yoga or acupuncture may help with flushes. Different lubricants or creams can be used to help reduce discomfort from vaginal dryness during sex (see page 75).

The Daisy Network is a support organisation for women who have early menopause (see page 94 for contact details).

What you can do

Making lifestyle changes may help reduce some of your symptoms and improve your general health.

- Eating healthily can make you feel better and give you more energy. Try to cut down on alcohol or caffeine, which can trigger a hot flush or affect sleep.
- If you smoke, try to stop as it can trigger hot flushes, weaken your bones and irritate your bladder. It's also a major risk factor for cancer and other health problems.
- Keeping physically active helps keep your weight healthy, makes you feel better and helps you sleep better. It also strengthens your bones and protects your heart. There's more information in our booklet *Physical activity and cancer treatment*.
- Yoga or meditation may help reduce stress and help with hot flushes.

Contact our cancer support specialists on freephone 0808 808 00 00 if you'd like more information.



Your sex life

Pelvic radiotherapy can affect your sex life and how you feel about yourself sexually. This can be more of a problem if you've had surgery to the pelvic area.

Physical changes can make having sex difficult, reduce your sex drive (**libido**) and affect how you feel about your body (body image). Tiredness, a low mood or feeling anxious can also affect your sex drive.

For some women, sexual difficulties are temporary and gradually improve over time. But even changes that are permanent can be improved. With support, you should still be able to enjoy a fulfilling sex life.

Low sex drive (**libido**)

If you have a partner, let them know how you feel. Explaining why you don't feel like having sex can reassure them that it isn't because you no longer find them attractive. You can show your partner how much you care in other sensual and physically affectionate ways. Being more relaxed and intimate with your partner may gradually lead to more sexual contact.

If sexual difficulties don't improve, it may be a good idea to ask for advice rather than letting things drift between you and your partner. Our section on getting help (see page 77) has more information on the help that's available.

Treating any late effects of pelvic radiotherapy that are causing you problems may improve things. For example, treatments for vaginal dryness will make sex more comfortable and improve your sex drive. If you don't have much energy, having sex in different, less energetic ways or quicker sexual contact can help.

Managing menopausal symptoms (see page 70) may help improve your sex drive. You may want to talk to your cancer doctor about taking hormone replacement therapy (HRT), especially if you've had the menopause early.

Occasionally, doctors may prescribe the hormone testosterone for women who are experiencing distress because of a low sex drive. This is generally only considered if other approaches haven't worked. Although testosterone is often thought of as a male hormone, women also produce it in smaller amounts.

If you have urinary or bowel problems, our booklet *Sexuality and cancer* has information about ways of adapting to having sex.

Changes to the vagina

Vaginal narrowing

Radiotherapy can make the vagina become narrower and less stretchy. The vaginal walls may also be dry and thin, and can stick together. This can make penetrative sex and internal examination uncomfortable, so it's important to try to prevent the vagina from narrowing.

Your hospital team may recommend you use vaginal dilators to help. Dilators are tampon-shaped plastic tubes of different sizes that you use with a lubricant. Although they're commonly used, there isn't strong evidence to say how effective they are. Rarely, they may cause damage to the vagina, especially if they aren't used correctly. Your specialist nurse or doctor will explain how best to use them in your situation.

Having regular penetrative sex, using a dildo or vibrator, or using lubricated fingers may also help prevent the vagina from narrowing. Even if you are having sex regularly, you may still be advised to use a dilator.

Bleeding

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 causing the vagina to narrow.

Always let your cancer doctor or nurse know if you have any bleeding. They will examine you and explain if it's likely to be caused by the radiotherapy. If the bleeding is minor, once you know the cause you may find that it doesn't trouble you much.

Using oestrogen creams (see next page) or trying to prevent vaginal narrowing (see above) may help reduce any bleeding. Make sure you use lubricants during sex. You may want to try different techniques and positions that may reduce the bleeding.

If the bleeding doesn't improve, a drug called silver nitrate may be applied to seal off the bleeding points. A drug called tranexamic acid may also be prescribed for you.

Occasionally, bleeding may be due to a sore (ulcer) in the vagina that's developed as a result of radiotherapy. You'll probably be advised to avoid penetrative sex until it has healed. Antibiotics are prescribed to treat any infection, and you may have the area rinsed regularly with antiseptic fluids (**irrigation**). Treatments can be applied directly to the ulcer to help it heal. Rarely, hyperbaric oxygen therapy may be used.

We have a fact sheet about hyperbaric oxygen therapy, which we can send you.

Always tell your cancer doctor or nurse if you have vaginal bleeding.

Vaginal dryness

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

If you've had the menopause early, hormone replacement therapy (HRT) will help with vaginal dryness. Your cancer specialist will let you know whether HRT is suitable for you, depending on the type of cancer you've had.

Oestrogen creams Your doctor may recommend using vaginal oestrogen creams or pessaries. They help with dryness and may prevent the vaginal wall from becoming thin. Although your body will absorb some oestrogen from the cream or pessaries, many doctors think it's too small an amount to be harmful. Your cancer doctor will let you know whether oestrogen creams or pessaries are suitable for you.

Moisturising creams and lubricants There are lots of products you can buy that help with vaginal dryness. Creams can be applied regularly to help draw more moisture into the vaginal tissue, and can be prescribed by your doctor. You use lubricants when you want to have sex to make it feel more comfortable and pleasurable.

Replens MD[®] is a cream that's available from most chemists. You apply it 2–3 times a week and it works for up to three days. Hyalofemme[®] is a newer cream that you can apply every day.

Water-based lubricants, including Senselle[®], Astroglide[®], Sylk[®], Vielle[®] or Durex[®] lube, can be bought at chemists or some supermarkets. Organic lubricant products, such as Yes[®] or V Gel[®], are available to buy online.

Vaginal dryness can make you more likely to get infections, such as thrush. Let your doctor know if you have symptoms such as vaginal itching or soreness.

Tablets, creams and pessaries to treat vaginal thrush are also available over the pharmacy counter under brand names such as Canesten[®]. But if you haven't had thrush before, see your GP first. Always see your GP if you're not sure whether it's thrush, if symptoms don't improve or if it keeps coming back.

Changes in sexual sensation

After radiotherapy, some women find it harder to get aroused or take longer to orgasm. This might be because of the effects of radiotherapy, and also of surgery (if you've had it) on the nerves in the pelvic area. But it may be due to a difference in the way you feel about yourself sexually. A sex therapist or counsellor may be able to help you if this is the case.

Getting help

It can be difficult to talk about your sex life and any problems you're having, but doctors and specialist nurses are used to dealing with intimate problems. They can often give you advice and support if things aren't going well. Your hospital doctor or GP can 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's good to look at ways of overcoming any problems as a couple. You can talk to sex therapists or counsellors in detail about the effects these changes are having on you and your partner. You can contact a sex therapist through your doctor or specialist nurse.

The organisations listed at the end of this booklet (see pages 93–97) may also be a source of help for you. For example, the College of Sexual and Relationship Therapists (see page 94) provides a list of qualified practitioners and The Sexual Advice Association (see page 95) offers a confidential helpline.

Our booklet *Sexuality and cancer* has more detailed information on dealing with the physical and emotional effects that cancer and its treatment may have on your sex life.

Fertility

After pelvic radiotherapy, you won't be able to have children due to the effect of radiotherapy on your womb and your ovaries. Infertility can be a distressing problem for women to cope with. Getting the right support can help you to find different 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. Your partner can also be included in any counselling you have.

Talking to other women in a similar position may help you feel less isolated. Some organisations (see pages 93–95) can provide this, as well as specialist advice and counselling. Or you can talk to people online. Our online community (see page 91) is a good place to talk to other women who may be in a similar situation. You can also talk things over with our cancer support specialists on **0808 808 00 00**.

Occasionally, women have their eggs removed and stored before having radiotherapy. This may happen if they want to consider trying to have a child through surrogacy (when another woman carries a baby for you) in the future.

Our leaflet *Cancer treatment and fertility – information for women* has more information.





Your feelings

It's 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. These feelings often become easier to cope with in time and with the right support.

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

Feeling alone

Some late effects can be embarrassing or difficult to talk about and can make you feel isolated. You may also feel this way as you begin to have less contact with the hospital or if you don't know anyone else experiencing the same problems. Our section on getting help and support (see page 83) has information that may help you.

Uncertainty

You may worry that some of your symptoms are a sign of the cancer coming back. After cancer treatment, it's also common to feel anxious about aches and pains that you wouldn't have worried about before. Knowing more about your late effects and where to get support can help.

Anger

It's natural to feel angry when you've had cancer, especially if you're coping with the late effects of treatment. Don't feel bad about feeling this way. Simply telling yourself and the people you trust when you're feeling angry can be a relief. Bottling up strong feelings may make you feel depressed. If there's no one you feel able to talk to, 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 cause people to feel depressed. Some signs of depression are: feeling low in mood; having no interest or enjoyment from the things you'd normally enjoy; and feeling helpless or hopeless. If you think you may be depressed, talk to your doctor. They can refer you to a counsellor or psychologist and prescribe a course of antidepressant drugs for you.

Our booklet *How are you feeling?* has more detailed information that you may find helpful.

Getting help and support

Talking about your feelings isn't always easy. But try to let your family and friends know how you're feeling so that they can support you.

Our booklet *Talking about your cancer* has some suggestions that may help you begin to talk about how you feel.

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 **0808 808 00 00** to speak to one of our cancer support specialists, who will also be able to give you details.

Remember, you don't have to wait until your next check-up to contact your doctor or any other health professional. If you have symptoms you're worried about or emotional problems, let your doctor or specialist nurse know as soon as possible. They can see you earlier than planned, assess your situation and arrange for you to have appropriate help.

At your hospital follow-up visits, your specialist will be assessing your late effects and how they're being managed, as well as checking that there are no signs of the cancer coming back.

You can read more in our booklet *Life after cancer treatment*, which has information about getting help and support.



Complementary therapies

Complementary therapies may help you feel better, reduce stress and anxiety, and improve some treatment side effects.

Our booklet *Cancer and complementary therapies* has information about different therapies and suggests ways of choosing a therapist.

Relaxation, counselling and psychological support are available at many cancer treatment hospitals. Some hospitals also offer visualisation, massage, reflexology, aromatherapy and hypnotherapy. Therapies are sometimes available through cancer support groups or your GP. Many complementary therapists have private practices.

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

Relationships

At any stage of a cancer experience, many people find that support from their family, friends or partner is invaluable. Sometimes, bonds are strengthened by the shared experience of overcoming cancer. But at the same time, both cancer and its treatment can put a strain on relationships.

The impact on your relationships is likely to depend on many factors, such as how the cancer and its treatment have affected your day-to-day life and how strong your relationships were before you were diagnosed. There's no 'normal' way that things go in a relationship after cancer treatment.

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

**There are useful tips on this in our booklet
*Talking about your cancer.***

Work

For most people, returning to work is a big step in their recovery. Many companies have an occupational health service for their employees, which can offer support in various ways for people returning to work. Some are able to rearrange their working days and times to avoid stressful periods such as rush hours. Sometimes, part-time work can be arranged at first, to ease you back into your job.

Occupational health departments may also offer you counselling, both before and after your return to work, which is completely confidential.

If you have a disability caused by cancer, your employer can get specialist help to enable you to work.

Our booklet *Work and cancer* has information about employment and disability rights and financial issues.

Financial support

If you've had problems getting back to work, you may be experiencing some financial difficulties. Our cancer support specialists on **0808 808 00 00** can help with checking the benefits you may be entitled to, filling in forms, accessing grants and giving general financial information. They may be able to put you in touch with a benefits adviser in your area.

We have a booklet called *Help with the cost of cancer*, which you may find useful.

You can find out more about benefits from your local Citizens Advice or by calling the Benefit Enquiry Line on **0800 882 200**. You can also find more information on **[direct.gov.uk](https://www.direct.gov.uk)**

Insurance

After having treatment for cancer, it can be more difficult to get life or travel insurance. An Independent Financial Adviser (IFA) can help you with life insurance and can find the best deal for your situation. You can find a local IFA by referral from family or friends, looking in your phone book, or by contacting The Personal Finance Society or Independent Financial Advisers Promotions Ltd (IFAP).

We can send you a booklet about travel and cancer and have a list of travel insurance companies who offer insurance to people with medical conditions including cancer.

How we can help you

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

Get in touch

Macmillan Cancer Support

89 Albert Embankment,
London SE1 7UQ

Questions about cancer?

Call free on **0808 808 00 00**

(Mon–Fri, 9am–8pm)

www.macmillan.org.uk

Hard of hearing?

Use textphone

0808 808 0121 or Text Relay.

Non-English speaker?

Interpreters are available.

Clear, reliable information about cancer

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

Macmillan Support Line

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

Information centres

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

Publications

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

You can find all of our information, along with several videos, online at **macmillan.org.uk/cancerinformation**

Need out-of-hours support?

You can find a lot of information on our website, **macmillan.org.uk**
For medical attention out of hours, please contact your GP for their out-of-hours service.

Review our information

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

If you'd like to hear more about becoming a reviewer, email **reviewing@macmillan.org.uk**

Someone to talk to

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

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

Professional help

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

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

Support for each other

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

Support groups

You can find out about support groups in your area by calling us or by visiting **macmillan.org.uk/selfhelpandsupport**

Online community

You can also share your experiences, ask questions, get and give support to others in our online community at **macmillan.org.uk/community**

Financial and work-related support

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

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

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

Macmillan Grants

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

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

Learning about cancer

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

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

Other useful organisations

Bladder and bowel support organisations

Bladder and Bowel Foundation

SATRA Innovation Park,
Rockingham Road,
Kettering NN16 9JH

Tel 0845 345 0165

Email info@bladderandbowelfoundation.org

www.bladderandbowelfoundation.org

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

Crohn's and Colitis UK (NACC)

4 Beaumont House,
Sutton Road, St Albans
AL1 5HH

Tel 0845 130 3344
(Mon–Fri, 1–3.30pm,
6.30–9pm)

Email

info@crohnsandcolitis.org.uk
www.nacc.org.uk

Offers information and support to people with inflammatory bowel disease. Also provides a Can't Wait Card, which provides access to toilets in public places.

Relationships, sex and fertility organisations

British Association for Counselling and Psychotherapy (BACP)

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

Tel 01455 883300

Email bacp@bacp.co.uk

www.bacp.co.uk

Aims to promote awareness of counselling and increase availability. BACP can refer people to a local counsellor, and has a searchable list on the website. It also provides an information sheet for those seeking help.

College of Sexual and Relationship Therapists (formally British Association of Sexual and Relationship Therapy)

The Administrator, PO Box 13686, London SW20 9HZ

Tel 020 8543 2707

Email info@cosrt.org.uk

www.cosrt.org.uk

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

The Daisy Network

PO Box 183,

Rossendale BB4 6WZ

Email

daisy@daisynetwork.org.uk

www.daisynetwork.org.uk

A premature menopause support group for women who have early ovarian failure.

The website gives information about premature menopause and related issues. Also has a live forum where members can talk to each other and share experiences.

The Institute of Psychosexual Medicine

12 Chandos Street, Cavendish Square, London W1G 9DR

Tel 020 7580 0631

Email admin@ipm.org.uk

www.ipm.org.uk

Has a comprehensive list of doctors throughout the country who are trained in psychosexual medicine.

Relate

Premier House,

Carolina Court, Lakeside, Doncaster DN4 5RA

Tel 0300 100 1234

Email from the website

www.relate.org.uk

Offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through the website.

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

Suite 301, Emblem
House, London Bridge
Hospital, 27 Tooley Street,
London SE1 2PR

Tel 0207 486 7262

Email info@sexualadviceassociation.co.uk

www.sda.uk.net

Provides up-to-date
information, and can help
sufferers and their partners
by putting them in touch
with specialist practitioners.

**Disability support
organisations**

Disability Rights UK

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

Tel 020 7250 3222

Email

office@disabilityalliance.org

www.disabilityalliance.org

Formed through a merger
of Disability Alliance, RADAR
and National Centre for
Independent Living. Aims to
be the largest national
pan-disability organisation
led by disabled people.

**Specialist pelvic
radiation organisations**

**Pelvic Radiation
Disease Association**

Pelvic Radiation Disease
Associaton, PO Box 602,
Epsom KT17 9JB

Tel 0845 434 5134

Email general@prda.org.uk

www.prda.org.uk

A patient-led group with the
aim of providing support for
people of all ages suffering
from pelvic radiation damage.
It also campaigns for better
recognition of pelvic radiation
disease, as well as improved
facilities for treatment within
the NHS.

Complementary therapy organisations

British Medical Acupuncture Society (BMAS)

Royal London Hospital
for Integrated Medicine,
60 Great Ormond Street,
London WC1N 3HR

Tel 020 7713 9437

Email bmaslondon@aol.com

www.medical-acupuncture.co.uk

Offers modern western acupuncture treatment and information by trained acupuncturists who are registered medical practitioners.

General cancer support organisations

Cancer Black Care

79 Acton Lane,
London NW10 8UT

Tel 020 8961 4151

(Mon–Fri, 9.30am–4.30pm)

Email

info@cancerblackcare.org.uk

www.cancerblackcare.org.uk

Offers a variety of information and support for people with cancer from ethnic communities, their families, carers and friends. Welcomes people from different ethnic groups including African, Asian, Turkish and African-Caribbean communities.

Cancer Support Scotland (Tak Tent)

Flat 5, 30 Shelley Court,
Gartnavel Complex,
Glasgow G12 0YN

Tel 0141 211 0122

Email [info@](mailto:info@cancersupportscotland.org)

cancersupportscotland.org

www.cancersupportscotland.org

Offers information and support to people with cancer, families, friends, and healthcare professionals. Runs a network of support groups across Scotland.

Irish Cancer Society

43–45 Northumberland Road,
Dublin 4, Ireland

Cancer Helpline

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

Email helpline@irishcancer.ie

www.cancer.ie

Operates Ireland’s only freephone cancer helpline, which is staffed by nurses trained in cancer care.

Maggie’s Cancer Caring Centres

8 Newton Place,
Glasgow G3 7PR

Tel 0300 123 1801

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

maggiescentres.org

www.maggiescentres.org

Maggie’s Centres offer free, comprehensive support for anyone affected by cancer. You can access information, benefits advice, and emotional or psychological support.

Tenovus

9th Floor, Gleider House,
Ty Glas Road, Llanishen,
Cardiff CF14 5BD

Freephone helpline

0808 808 1010

Tel 029 2076 8850

Email post@tenovus.com

www.tenovus.org.uk

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

The Ulster

Cancer Foundation

40–44 Eglantine Avenue,
Belfast BT9 6DX

Freephone helpline

0800 783 3339

Helpline email

infocis@ulstercancer.org

Tel 028 9066 3281

Email info@ulstercancer.org

www.ulstercancer.org

Provides a variety of services for people with cancer and their families, including a free telephone helpline, which is staffed by specially trained nurses with experience in cancer care.

Further resources

Related Macmillan information

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

- *Bone health*
- *Cancer and complementary therapies*
- *Cancer treatment and fertility – information for women*
- *Giving up smoking*
- *Healthy eating and cancer*
- *Help with the cost of cancer*
- *How are you feeling?*
- *Life after cancer treatment*
- *Physical activity and cancer*
- *Sexuality and cancer*
- *Talking about your cancer*

- *Understanding lymphoedema*
- *Weight management after cancer treatment*
- *Work and cancer*

To order, visit **be.macmillan.org.uk** or call **0808 808 00 00**. All of our information is also available online at **macmillan.org.uk/cancerinformation**

To order the fact sheets mentioned in this booklet, call **0808 808 00 00**.

Audio resources

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

To order your free CD, visit **be.macmillan.org.uk** or call **0808 808 00 00**.

Useful websites

A lot of information about cancer is available on the internet. Some websites are excellent; others have misleading or out-of-date information. The sites listed here are considered by nurses and doctors to contain accurate information and are regularly updated.

Macmillan Cancer Support **www.macmillan.org.uk**

Find out more about living with the practical, emotional and financial effects of cancer. Our website contains expert, accurate, up-to-date information about cancer and its treatments, including:

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

www.cancer.gov **(National Cancer Institute – National Institute of Health – USA)**

Gives comprehensive information on cancer and treatments.

www.cancer.org **(American Cancer Society)**

Nationwide community-based health organisation dedicated to eliminating cancer.

**www.cancerhelp.org.uk
(Cancer Research UK)**

Contains patient information on all types of cancer and has a clinical trials database.

**www.healthtalkonline.org
www.youthhealthtalk.org
(site for young people)**

Both websites contain information about some cancers and have video and audio clips of people talking about their experiences.

**[www.macmillan.org.uk/
cancervoices](http://www.macmillan.org.uk/cancervoices)
(Macmillan Cancer Voices)**

Enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

**www.nhs.uk
(NHS Choices)**

This is the country's biggest health website and gives all the information you need to make decisions about your health.

**www.nhsdirect.nhs.uk
(NHS Direct Online)**

NHS health information site for England – covers all aspects of health, illness and treatments.

**www.nhs24.com
(NHS 24 in Scotland)**

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

**www.n-i.nhs.uk
(Health and Social Care
in Northern Ireland)**

The official gateway to health and social care services in Northern Ireland.

**www.patient.co.uk
(Patient UK)**

Has evidence-based information leaflets on a variety of medical and health topics.

**www.riprap.org.uk
(Riprap)**

Developed especially for teenagers who have a parent with cancer.

Disclaimer

We make every effort to ensure that the information we provide is accurate, but it should not be relied upon to reflect the current state of medical research, which is constantly changing. If you are concerned about your health, you should consult a doctor. Macmillan cannot accept liability for any loss or damage resulting from any inaccuracy in this information or third-party information, such as information on websites to which we link. We feature real-life stories in all of our articles. Some photographs are of models.

Thanks

This booklet has been revised and edited by Macmillan Cancer Support's Cancer Information Development team. It has been approved by our medical editor, Dr Terry Priestman, Consultant Clinical Oncologist.

With thanks to: Dr Jervoise Andreyev, Consultant Gastroenterologist in Pelvic Radiation Disease; Dr Peter Blake, Consultant Clinical Oncologist; Julia Herbert, Clinic Specialist Continence Physiotherapist; Ann Muls, Macmillan Nurse Consultant (cancer late effects); Claire Parkinson, Macmillan Gynaecology Nurse Specialist; Dr Claire Taylor, Lecturer in Gastrointestinal Nursing; Dr Isabel White, Macmillan Clinical Research Fellow in Cancer Rehabilitation; and the people affected by cancer who reviewed this edition.

Sources

Andreyev J, et al. Defining pelvic-radiation disease for the survivorship era. *Lancet Oncology*. April 2010. 11(4):310–312.

Andreyev J. Gastrointestinal symptoms after pelvic radiotherapy: role for the gastroenterologist? *International Journal of Radiation Oncology*. August 2005. 62(5):1464–1471.

Andreyev J, et al. Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer. *Gut/BMJ*. November 2011.

- Denton, et al. Non-surgical interventions for late radiation proctitis in patients who have received radical radiotherapy to the pelvis. *Cochrane Database of Systematic Reviews*. 2001.
- Denton, et al. Non-surgical interventions for late radiation cystitis in patients who have received radical radiotherapy to the pelvis. *Cochrane Database of Systematic Reviews*. 2002.
- Ganz, Patricia A (ed). *Cancer Survivorship: today and tomorrow*. May 2007. Springer.
- Faithfull & Wells. *Supportive Care in Radiotherapy*. May 2003. Churchill Livingstone.
- Interventions for the physical aspects of sexual dysfunction in women following pelvic radiotherapy. *The Cochrane Library*. 2009
- Pelvic radiotherapy and its gastrointestinal side effects: Hobson's choice? *Gastrointestinal Nursing*. 2005. 3(7):18–24.
- Pelvic radiotherapy increases risk of pelvic bone fractures. *JAMA*. 2005. 294:2587–2593, 2635–2637.
- Urinary continence service for the conservative management of urinary incontinence in women. NICE (National Institute for Health and Clinical Excellence). 2008.
- Vaginal dilator therapy for women receiving pelvic radiotherapy. *The Cochrane Library*. 2010.
- Wilson Judy. *Living with bowel problems following radiotherapy: a scoping study*. The National Association for Colitis and Crohn's Disease. March 2006.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other _____

Name _____

Surname _____

Address _____

Postcode _____

Phone _____

Email _____

Please accept my gift of £ _____

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Valid from

□□	□□
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Expiry date

□□	□□
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Issue no

□□□

Security number

□□□□

Signature _____

Date / / _____

Don't let the taxman keep your money

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

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

I confirm I have paid or will pay an amount of Income Tax and/or Capital Gains Tax in each tax year, that is at least equal to the tax that Charities & CASCs I donate to will reclaim on my gifts. I understand that other taxes such as VAT and Council Tax do not qualify and that Macmillan Cancer Support will reclaim 25p of tax on every £1 that I give.

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

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



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

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

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

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

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

Questions about living with cancer?

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

Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone

0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available.

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CANCER SUPPORT**