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CANCER SUPPORT

A practical guide to tests and treatments

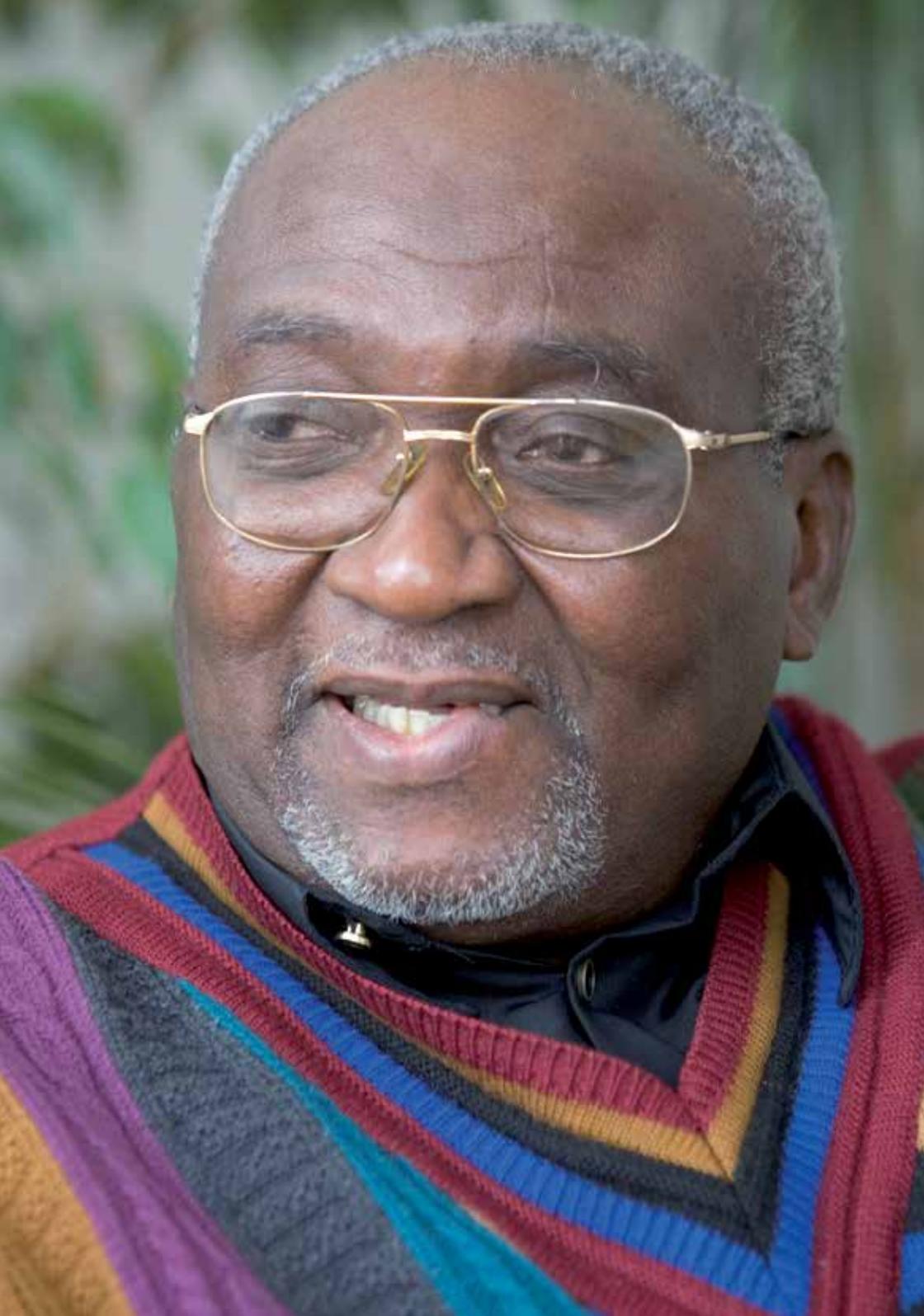
MANAGING THE LATE EFFECTS OF PELVIC RADIOTHERAPY IN MEN



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About this booklet

This booklet is for men who have had radiotherapy to the pelvic area and who are experiencing late effects. The pelvic area is the lower part of the abdomen (tummy), between the hip bones.

We have a separate booklet with information for women who have had pelvic radiotherapy.

Late effects are side effects that don't go away or that develop months or years after treatment has finished. If you are 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.

In this booklet, we explain how late effects can be managed or treated. There's also information about what you can do to help yourself and the support that's available to you. Not everyone gets late effects. You are unlikely to have all the late effects we've included, although some men 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 men get severe late effects.

Radiotherapy is an effective and successful treatment for many cancers that start in the pelvic area, including prostate cancer, bladder cancer, rectal cancer and anal cancer. The benefits of radiotherapy usually far outweigh the risks. Newer ways of giving radiotherapy are developed to reduce the chance of late effects as much as possible.

Throughout this booklet we've included quotes from people who are having late effects of pelvic radiotherapy. These are from people who have chosen to share their experiences with us by becoming a Cancer Voice. To find out more, visit **[macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices)**

At the end of this booklet are some useful addresses and websites (see pages 89–92).

We hope this booklet answers some of your questions and addresses the feelings you may have. We can't advise you about the best treatment for you. This information can only come from your own doctor, who knows your full medical history.

If you'd like to discuss the information in this booklet, 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](https://www.macmillan.org.uk)**

If you have found this booklet helpful, you could pass it on to your family and friends so that they can help and support you.

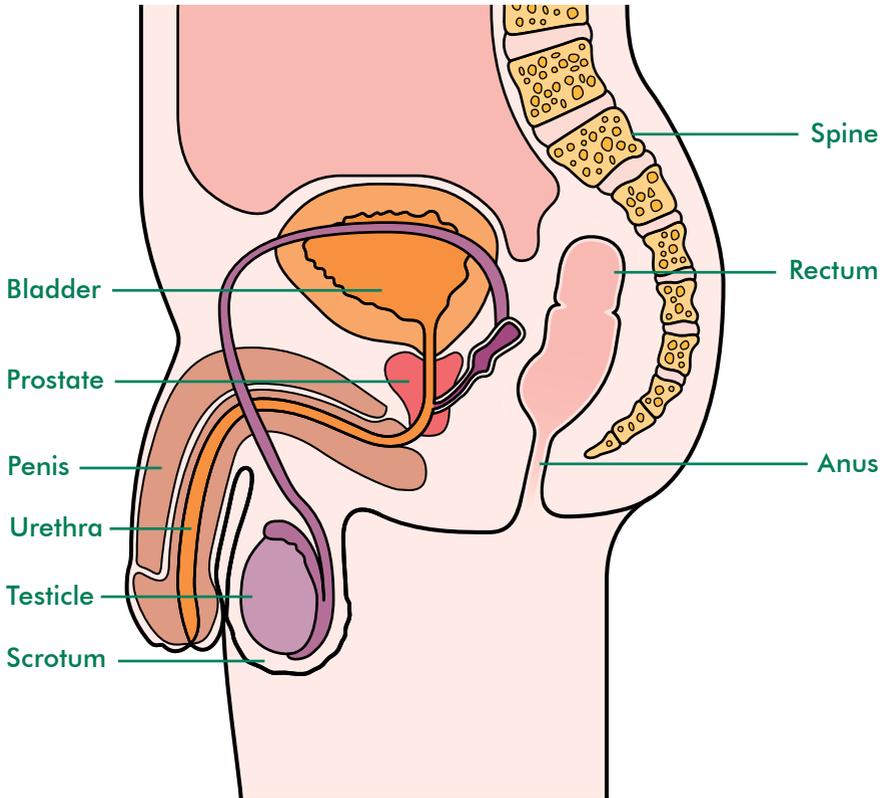
The pelvis

The pelvis is the area of the body between the hips in the lower part of the abdomen (tummy). In men it contains:

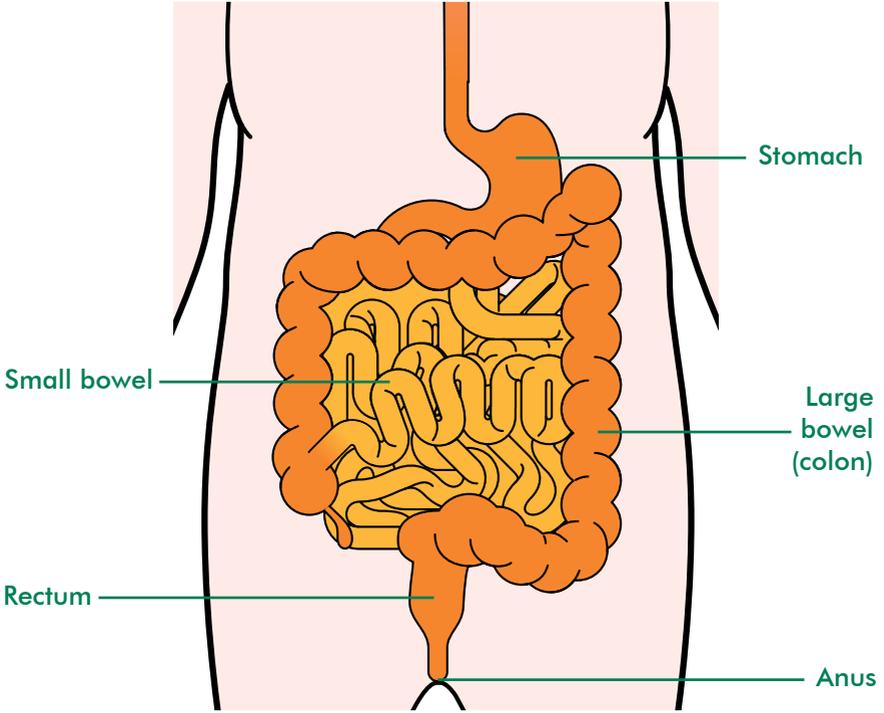
- the prostate gland
- the testicles
- the penis
- the bladder
- the lower end of the large bowel (the colon, rectum and anus)
- part of the small bowel
- lymph nodes (glands)
- the pelvic bones.

Pelvic radiotherapy is given to treat cancers of the prostate, bladder, rectum and anus.

Pelvic radiotherapy may affect the male sexual organs (the testicles, penis and prostate – see opposite), and the bladder (see page 14). It can also affect parts of the digestive system, including the small bowel, colon, rectum and anus (see page 8).



The male pelvic organs and surrounding structures



The digestive system

Pelvic radiotherapy

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

Radiotherapy to the pelvic area may be given externally (from outside the body) by a machine called a linear accelerator. It can also be given internally, by implanting radioactive material into the tissues. This way of giving radiotherapy is called **brachytherapy**.

Sometimes radiotherapy is given with chemotherapy. This is called **chemoradiation**.

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

Late effects of pelvic radiotherapy

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



Our booklet *Pelvic radiotherapy in men – managing side effects during treatment* explains the short-term side effects.

Late effects are side effects that either:

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

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 men may also have difficulty getting or keeping an erection, and they may notice changes in the physical and emotional feelings associated with sex.

The impact of late effects varies:

- They may be minor and not affect 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 have late effects, there are usually lots of things that can help you cope with them. This will help you live life as fully as possible. Some late effects improve over time and may eventually go away on their own. In the following sections, we explain ways you can manage and improve late effects.

Talking to your doctor

If the side effects of pelvic radiotherapy don't go away, always let your cancer doctor or specialist nurse know. If you have any new symptoms or problems after treatment, it is also important to tell them.

The more information you give your doctor, the more likely they are to be able to help you. You may feel embarrassed about 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.

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 (anus). It can be frightening to have symptoms after treatment ends, and you may worry that the cancer has come back.

Your cancer doctor will assess your symptoms and explain whether they could be caused by the radiotherapy. You may

need tests to rule out anything more serious, such as the cancer coming back or a new cancer. Sometimes symptoms are caused by other conditions not related to the cancer or its treatment.

Remember that you can arrange to see your cancer doctor or specialist nurse in between appointments, and you can 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 some expert doctors who specialise in treating late effects of radiotherapy. But this is a specialised area, so there aren't many of these doctors and you may need to travel to see one. A few hospitals have special clinics for people with late effects.

Your doctor or nurse can refer you to other specialists if needed. The organisations listed on pages 89–91 can also put you in touch with specialists.



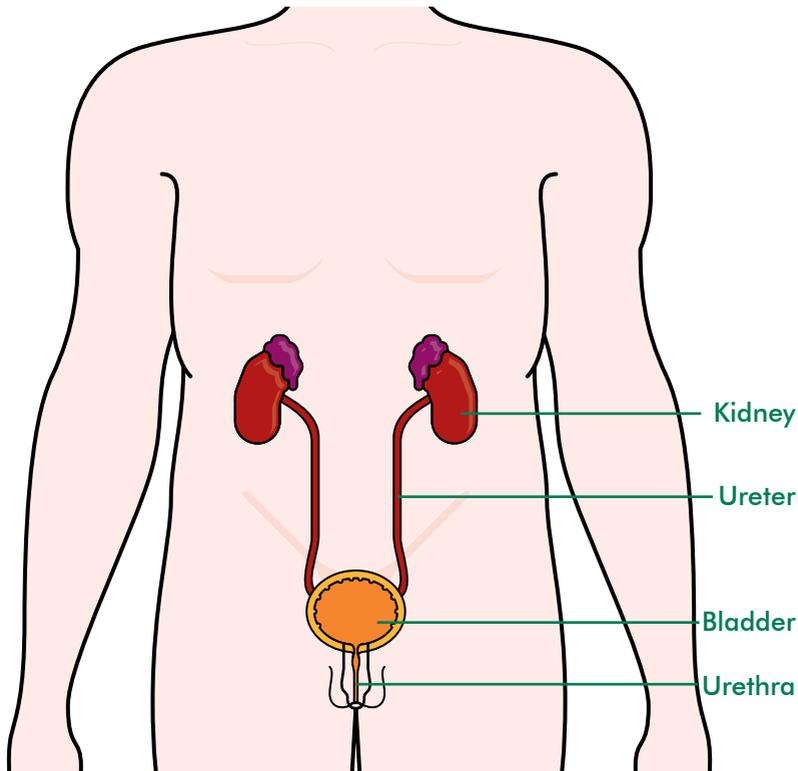
For more information on the help available,
contact the Macmillan Support Line free on
0808 808 00 00.



Bladder changes

Radiotherapy to treat bladder cancer and prostate cancer can cause changes to the bladder. Radiotherapy for rectal and anal cancer may also cause these changes, but this is less common. Changes also happen as the bladder muscles age, so the symptoms in this chapter are more common as men get older.

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



The male bladder and kidneys

The bladder is supported by the pelvic floor muscles. Some of these muscles wrap around the urethra. This is called the **urethral sphincter**, which keeps the bladder 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.

Possible late effects to the bladder

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

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

Sometimes radiotherapy makes the urethra narrow. This is called a urethral stricture (see page 27).

Symptoms

Many of the symptoms of late effects to the bladder 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.

There are ways to deal with many of these problems successfully (see pages 18–27).

Talking to your doctor

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

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

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

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

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

Managing bladder late effects

What you can do

There are things you can do to help reduce symptoms caused by the late effects of pelvic radiotherapy. These things will also help keep your bladder healthy.

Drink plenty of fluids

Try to drink at least two litres (four pints) of fluids a day. This is about eight glasses. And if it's hot or if you're exercising, it is important to drink even more. It's best to drink small amounts regularly throughout the day.

Drinking too little will make your symptoms worse. Urine that's concentrated irritates the bladder. Drinking more reduces bladder irritation and trains 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 or grapefruit juice)
- drinks with artificial sweeteners ('diet' or 'light' drinks).

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

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

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

Give up smoking

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

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



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

Avoid putting extra pressure on your pelvic floor muscles

The following will help avoid putting extra pressure on your pelvic floor muscles:

- Keep your weight within healthy limits (see page 57).
- Avoid constipation (see page 58).
- Avoid heavy lifting.

It is especially important to do this if you have stress incontinence (see page 22).

Find ways of reducing stress

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

There's more information on coping with bladder changes on pages 52–59.

Needing to pass urine often and at night

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

Bladder retraining

This means training yourself to ignore the feeling of needing to pass urine, 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 start by keeping a record of how often you go to the toilet and how much urine you pass each time. Your continence adviser may have a chart you can use.

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

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

Don't be tempted to cut down on fluids when you're retraining your bladder. Keep drinking fluids as normal.

You don't need to do the retraining exercises during the night. 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 gets easier and you will go to the toilet less often.

Drugs to relax the bladder

Some types of drug can help relax the bladder so it can hold more urine. These drugs may be used to treat an overactive bladder or stress incontinence (see page 22).

There are several drugs that can help. So if one doesn't work for you, talk to your doctor. They may be able to prescribe a different drug to try.

Treatment with botulinum toxin A (Botox®)

This involves having injections of Botox into the bladder muscles. It's done under a general anaesthetic.

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

This is still quite a new way of treating bladder symptoms, so doctors are still finding out how helpful it is and whether it has any drawbacks.

Leaking urine

Some people leak urine after pelvic radiotherapy. This can happen if the pelvic floor muscles and the valve that keeps the bladder closed are weakened.

You may leak small amounts of urine when you laugh, sneeze or cough, or when you'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 that incontinence can be treated and managed. If you have urge incontinence, some of the treatments listed in the section on an overactive bladder (see pages 20–21) can also help.



Urine can irritate the skin, so you will need to take extra care to look after your skin. There's more information about this on page 52.

Pelvic floor exercises

The most common way to improve urinary incontinence is to do exercises to strengthen the pelvic floor muscles.

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

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

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 89) can also give you details of your nearest adviser and can send you leaflets about pelvic floor exercises.

Biofeedback training

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

Other treatments

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

AUS (artificial urinary sphincter)

Men who are leaking a lot of urine most of the time can be assessed for this treatment. You need to have been incontinent for at least a year after radiotherapy to have this.

While you're under a general anaesthetic, a cuff is fitted around the urethra (see the illustration on page 14) and a small pump is placed under the skin in the scrotum. The cuff closes off the urethra to stop urine leaking. When you want to pass urine, you squeeze the pump under the skin by pressing it between your fingers. This deflates the cuff. It takes pressure off the urethra, allowing it to open so you can pass urine.

Blood in the urine (haematuria)

After radiotherapy, small blood vessels in the bladder lining may be more fragile and bleed easily. This can cause blood in your urine. If you have this, you'll need to have a cystoscopy (see page 17) to find out what's causing it.

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

Tablets

Tranexamic acid (Cyklokapron®) tablets can reduce bleeding. They help stop blood clots dissolving.

Your doctor may prescribe these tablets for you.

Giving drugs into the bladder

To stop the bleeding, some drugs can be given directly into the bladder as a fluid.

For this treatment, you lie down while a nurse gently passes a thin, flexible tube (a catheter) through the tip of your penis into the bladder. The nurse slowly passes fluid through the catheter into your bladder. Then they remove the catheter and the fluid stays in your bladder for about half an hour. This gives the treatment time to work. After this, you go to the toilet to empty your bladder. You may feel some discomfort when passing urine for a 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 they don't block your urethra. A nurse or doctor passes liquid through a catheter into your bladder. The liquid then drains back out of the catheter into a bag. This can be repeated until the clots have gone.

Cauterisation

If medicines don't stop the bleeding, your doctor may suggest using heat to seal the blood vessels that are bleeding. This is called cauterisation. It's done using a cystoscope (see page 17) while you're under a general anaesthetic.

Hyperbaric oxygen therapy

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



We have more information about hyperbaric oxygen therapy.

Treating anaemia

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



We have more information about blood transfusions.



Difficulty passing urine

Radiotherapy can make the urethra narrow (see the illustration on page 14). This is called a **urethral stricture**. You may have difficulty passing urine or find yourself straining to release it.

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

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

Another possible treatment for smaller strictures is an operation called a **urethrotomy**. This is done under a spinal anaesthetic (where you are awake but don't feel anything from the waist down) or general anaesthetic. A cystoscope is passed through the tip of the penis into the urethra. This lets the surgeon make small cuts to widen the urethra.

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

If bladder problems don't improve

If your bladder symptoms continue or don't improve after these treatments have been tried, your specialist may talk to you about other possibilities. When symptoms are severe, an operation to remove the bladder may be an option, but this is rare.

See pages 52–59 for practical ways to cope with bladder changes.

Bowel changes

Sometimes, men who have had pelvic radiotherapy have changes in the way their bowel works. For some men, 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 our digestive system (see page 8). It is made up of the small bowel and the large bowel. 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 opening to the outside of the body (anus).

Possible late effects to the bowel

Radiotherapy can affect the blood supply to the bowel. This makes the bowel tissue and the small blood vessels in it more fragile. It may cause bleeding from the back passage.

Radiotherapy can also 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 hold stool in the rectum can also be affected, which may cause problems with bowel control and leakage (incontinence).

Radiotherapy can also make the bowel narrow. When radiotherapy affects the small bowel, it can cause food intolerance (see page 39), or conditions such as bile acid malabsorption (see page 41) or small bowel bacterial overgrowth (see page 42).

Symptoms

The symptoms of late effects to the bowel can include:

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

Some men find their symptoms don't cause too many problems, and they can manage them fairly easily. The change in the way the bowel works may be small, for example having to go to the toilet twice a day instead of once. But sometimes bowel changes can have a much bigger impact and interfere with day-to-day life.

Talking to your doctor

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

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

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

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

These symptoms may not be due to anything serious, but you should always get them checked out. They can often be treated simply. Occasionally they can be a sign of a more serious problem, so it is important to find out the cause as soon as possible.

Tests

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

- blood and stool tests
- x-rays and scans
- an endoscopy – this is where a doctor or nurse passes a thin tube with a light on the end (an endoscope) into the bowel to look for any abnormal areas.

Some people may need to have a sample of tissue removed (a biopsy) from the bowel. This will 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 is usually mild and often doesn't need treatment. Bleeding sometimes improves gradually and can stop on its own after a few years.

Bleeding may not always be caused by the 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 nurse specialist if you have any bleeding from the back passage. It is important to find out the cause and to rule out serious problems. Your doctor will do an examination of your back passage and may refer you to have a test to look at the inside of your rectum (an endoscopy – see page 31).

Treatment

If there is only a small amount of blood and you are finding it manageable, you probably won't need any treatment. You will be given advice about your bowel habits to help minimise the bleeding and avoid constipation (see page 58). If you are taking blood-thinning drugs, your dose may be reduced and monitored.

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

The most commonly used treatment for bleeding from the back passage is a drug called sucralfate (Antepsin Suspension®). It is given as an **enema**. This is when a fluid (usually medicine)

is gently infused into your back passage through a short tube. Sucralfate works by coating the lining of the rectum. This reduces inflammation and encourages healing. It is important to avoid getting constipated (see page 58) when you are 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 using an endoscope (see page 31), which is passed into the bowel. You can have this done under a general anaesthetic.

If the bleeding is higher up in the large bowel (colon), or if enemas don't reduce the bleeding, other treatments may be helpful:

- **Argon plasma coagulation** directs heat at areas that are bleeding. The heat seals the blood vessels and destroys damaged tissue. It's given during a colonoscopy (where a doctor passes a thin, flexible tube with a light into your back passage). Doctors don't yet know how successfully this treats heavy bleeding. There is also a risk that it can cause complications, such as serious tissue damage. Your doctor will discuss this with you.
- **Hyperbaric oxygen therapy** works by increasing the amount of oxygen that gets to tissue that's been damaged by pelvic radiotherapy. This can encourage new blood vessels to grow and may help the tissue 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 more information about hyperbaric oxygen therapy.

Tenesmus

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

The spasms can often be controlled by:

- pelvic floor exercises (see pages 44–45)
- taking soluble fibre to bulk up the stool (see page 38)
- very low doses of certain anti-depressant drugs.

Sometimes tenesmus can be caused by constipation. It's also sometimes caused by a non-cancerous growth (a polyp) in the bowel, or it can be caused by a cancer.

If you have tenesmus, your doctor will examine your back passage and may arrange for you to have a test called a **flexible sigmoidoscopy**. This looks at the rectum and the lower part of the large bowel.

Fissure

After radiotherapy, some men develop a split in the skin of the anus. This is called a fissure. It can cause a sharp, intense pain when you pass a stool (bowel motion).

Your doctor can usually prescribe creams to apply to the area that will help. It's important to avoid getting constipated (see page 58), because this can make a fissure worse. Your doctor may also prescribe a laxative to make it easier for you to go to the toilet.

If the fissure doesn't get better, your doctor may advise treating it with injections of botulinum toxin A (Botox). These are given into the tissue lining the anus.

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



Bowel control problems

After radiotherapy, some men feel that they can't wait when they get the urge to open their bowels. This can be stressful, particularly when you're away from home. You may sometimes have leakage (incontinence). The amount of incontinence varies. You may just have a small amount that causes some staining on your underwear. But occasionally you 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 a lot of things can 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 bowel control problems depends on the symptoms you have and what's causing them, so it's important to be 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 ways of improving bowel control include:

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

Diet

What you eat affects your bowel. For example, fatty or spicy foods, or too much or too little fibre, can stimulate the bowel. This makes it harder to control. Caffeine, alcohol and artificial sweeteners can also cause problems.

Your doctor can refer you to a dietitian for expert advice on managing your diet. If you're losing weight because of bowel problems, it's especially important to see a dietitian.

'I have cut out nearly all caffeine. I eat root veggies, like carrots and potatoes, but no green veg. No spicy foods. No fizzy drinks and not much alcohol. It has made a huge difference to my quality of life. My comfort food – very important on bad days – is Haribo.'

David

Foods affect people differently, so you may need to try a few things 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 these foods without cutting them out altogether. See our food guide on pages 46–49 for information about foods that can cause or improve bowel problems.

Fibre

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

- **Insoluble fibre** helps with managing constipation, and it can also help with other bowel problems. You can get insoluble fibre from bran and seeds. It's also in multigrain, wholemeal and wholegrain foods, such as bread and cereals.
- **Soluble fibre** helps bulk up and slow down bowel movements, so it may help improve diarrhoea or soft stools. You can get soluble fibre from oats, porridge, bananas, and from apples and pears with their skins removed. It's important to remove the skins, because they contain insoluble fibre. Pulses, such as baked beans and lentils, are also high in soluble fibre. But pulses stimulate the bowel, so they aren't recommended for people with diarrhoea or soft stools.

Your specialist nurse, continence adviser or gastroenterologist 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 slowly. This gives your body time to adjust. Start with small amounts and slowly increase the amount when you're ready. Make sure you drink more water while you're having more fibre.

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 it may not be appropriate to follow the 'five a day' plan for fruit and vegetables. Some high-fibre foods make the bowel produce a lot of gas (wind). If wind is a problem for you, you may need to avoid these foods.

Fibre supplements

People who have frequent bowel motions or incontinence can often be prescribed soluble fibre supplements, such as Normacol® or Fybogel (soluble fibre). These supplements are also used to prevent constipation. They work by absorbing water and expanding to fill the bowel. This makes the stools bulkier and easier to push out.

Some people find that Fybogel can make the bowel produce a lot of gas (wind).

You can buy some fibre supplements at the chemist, or your doctor can prescribe them. When you're taking fibre supplements, always make sure you drink plenty of fluids – at least two litres every day.

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

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

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 (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 syrup, which allows you to take less and adjust the dose as needed.

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

Doctors can also prescribe low doses of anti-depressant drugs to help slow down the bowel.

Ongoing diarrhoea

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

Radiotherapy can cause other conditions that can lead to ongoing diarrhoea. These conditions include **bile acid malabsorption** and **small bowel bacterial overgrowth**. There is more information about these on the next pages.

Bile acid malabsorption

Bile acids are made in the liver and travel 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 reabsorb the bile acids. This is called malabsorption. It leads to diarrhoea.

A bowel specialist can diagnose bile acid malabsorption using a scan called a SeHCAT scan. Your specialist can tell you more about this. The scan will confirm whether you have bile acid malabsorption and also tell you how much will affect you. It is important to get the diagnosis right. This is because if you have bile acid malabsorption, you will need to take a drug for the rest of your life to treat it. You may also be advised to keep to a low-fat diet. 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.

If your bowel movements (stools) are sometimes pale, smelly and difficult to flush away, Questran may not work. Or it may make things worse. If this happens, your specialist may prescribe a newer medicine, called colesevelam (Cholestagel®). They may also refer you to a dietitian for advice on keeping to a low-fat diet.

Small bowel bacterial overgrowth

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

You will usually have a breath test to find out whether you have small bowel bacterial overgrowth. You can have the test as an outpatient and it takes around 2–4 hours. Your doctor or nurse can explain more about the test.

Small bowel bacterial overgrowth is usually treated with antibiotics.

Wind

After radiotherapy, some men have more wind because their pelvic floor muscles (see pages 44–45) 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 caused by the way the healthy bacteria and digestive enzymes in our bowel combine with the foods we eat. Some foods cause more wind than others. In particular high-fibre foods cause more wind, such as vegetables and pulses.

Too much wind can be caused by:

- eating certain types of foods (see page 46 of the food guide)
- constipation
- some medicines, such as Fybogel and Lactulose
- bowel conditions (such as diverticular disease)
- small bowel bacterial overgrowth.

If you have too much wind, these tips 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 doing pelvic floor exercises (see pages 44–45).
- Talk to your doctor or specialist nurse about trying laxatives other than Lactulose and Fybogel, which may cause less wind.
- Some people find peppermint oil, live yoghurts, probiotic drinks or charcoal tablets helpful in controlling wind.

Strengthening the muscles used for bowel control

You can do exercises to strengthen the muscles used in bowel control. These exercises can help you manage urgency, leakage and incontinence. Some men find they also help with wind (see pages 42–43), bowel cramps and tenesmus (see page 34).

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

Ask your doctor to refer you to a continence adviser to teach you how to do the exercises correctly. You can read more about pelvic floor exercises on pages 22–23. 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 its website (see page 89).

It is important to:

- do your pelvic floor exercises correctly, otherwise they won't work
- practise regularly to build up your muscles – aim for three times a day
- keep to a healthy weight, because 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. Because of this, you may find it hard to know whether 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 advise you on where you can get this training.

Other things you can do

As well as making changes to your diet, taking medicines to slow your bowel down 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. Many people need to go to the toilet after eating, so your regular time might 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 increase the amount of stool your bowel can hold.
- Find ways of reducing stress (see page 59).
- If you smoke, try to stop, because smoking stimulates the bowel.
- If you're taking other medicines, ask your doctor or nurse whether they could be making bowel problems worse. If so, they may be able to prescribe an alternative that affects you less.

We have advice on skincare, going out and lifestyle changes that may help you cope (see pages 52–59).

Food guide

In this section we list the foods that may cause or help bowel problems. This is only a guide, as foods can affect people in different ways.

Foods that may cause wind

If you have wind, the foods you should avoid 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, in some sugar-free foods and in apples, pears and peaches).

Foods that may help make your stools firmer

If you have problems with diarrhoea, loose stools or frequent bowel movements, these foods may be helpful.

These foods include:

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



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

If you have problems with diarrhoea, loose stools or frequent bowel movements, you should limit these foods. If you have constipation, these foods should help.

These foods include:

- some types of fresh, tinned or dried fruit – grapes, fruits with stones (such as apricots, plums, peaches and prunes), and most berries (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
- beans, especially baked beans, kidney beans and chickpeas
- bran and foods high in insoluble fibre
- greasy foods and fried foods
- spices such as chilli, curry and ginger
- caffeine in coffee, tea, chocolate drinks, cola drinks and energy drinks
- nuts, linseed and popcorn
- sugar-free foods containing sorbitol, mannitol or xylitol (such as sugar-free chewing gum, some mints, sweeteners and 'diet' drinks and foods)

- chocolate
- alcohol – especially beer and red wine
- some supplements, such as the mineral selenium, which the body only needs in small amounts.

Steatorrhoea

Some men notice that when their bowel motions (stools) are loose, they are also paler than usual and much more smelly. The stool may float in the toilet and be harder to flush away. There may also 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 these symptoms, you need to ask your GP to refer you to a gastroenterologist, who should be able to help you. Steatorrhoea can usually be treated effectively.

Uncommon and rare late effects

Very occasionally, men may have the following bowel problems because of pelvic radiotherapy.

Anal stricture

Radiotherapy may cause a tight band of scar tissue at the opening of the back passage (anus). This causes it to narrow. It is called an 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 take a stool-softening laxative or fibre supplement. This will make it easier to go to the toilet, which will help stretch the stricture. If the narrowing is more severe, your doctor may refer you to a bowel specialist. You may be able to have a procedure to stretch the opening. This is called dilatation. Or you may have an operation under general anaesthetic to cut through the scar tissue. Your doctor or specialist nurse can explain more about these treatments.

Ulcerated bowel

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

This can be treated with hyperbaric oxygen therapy (see page 25).

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. You may also be given treatment for constipation. Some people may need an operation to remove the blockage.

Hole in the bowel wall

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

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

Fistula

A fistula is an opening that forms between two parts of the body. After pelvic radiotherapy, an opening can develop between the rectum and urethra (see page 7), although this is rare. It is more likely to happen in men who've had brachytherapy (see page 9) for prostate cancer after a biopsy (removing a tissue sample) of the rectum.



We can send you more information about fistulas.

Coping with bowel or bladder changes

The day-to-day issues caused by bladder and bowel changes are often similar, so we cover them both in this chapter.

If you're having problems, you may feel worried about going out and social occasions. But there are lots of practical things you can do and lifestyle changes you can make. These will help you feel more confident and in control.

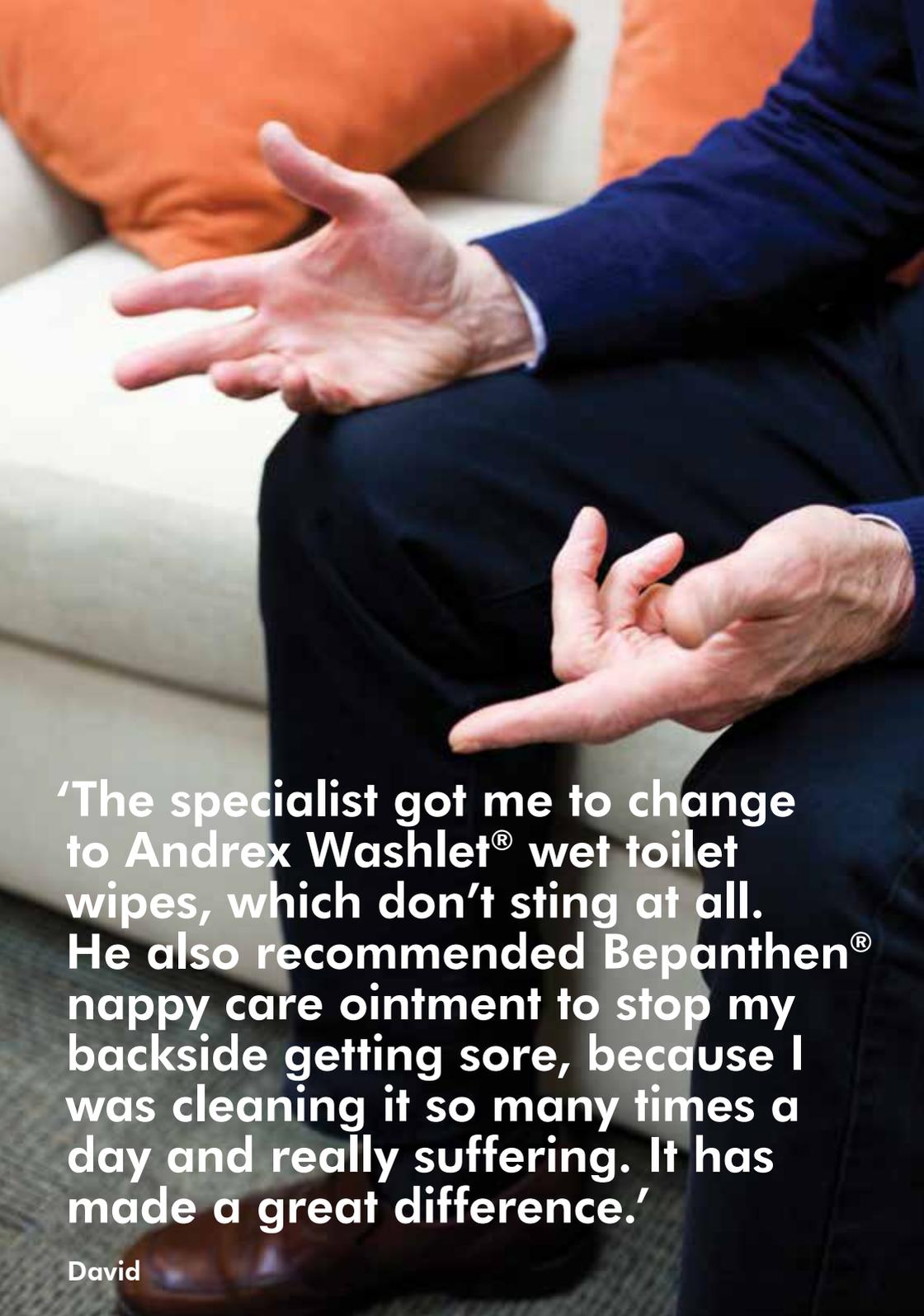
Protect your skin

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

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

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

- Unperfumed baby wipes are more gentle on your skin than toilet paper.
- Absorbent pads and barrier creams (such as Cavilon®) can help protect your skin.
- Cotton underwear allows your skin to breathe more than other materials.



'The specialist got me to change to Andrex Washlet® wet toilet wipes, which don't sting at all. He also recommended Bepanthen® nappy care ointment to stop my backside getting sore, because I was cleaning it so many times a day and really suffering. It has made a great difference.'

David

Going out

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

Access to toilets

If you'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 have lists or maps of the public toilets in their area. These are often 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 typing "public toilets" and the name of the place you're visiting into a search engine.

Carrying a Just Can't Wait card may help you access a toilet more quickly when you're out. The card states that the card-holder has a medical condition that means they need urgent access to a toilet. It can be used in places such as shops and pubs. You can get a Just Can't Wait card from the Bladder and Bowel Foundation or Disability Rights UK (see pages 89 and 90).

You can also use disabled toilets. These often have more privacy. They have a washbasin and more space if you need to change. The National Key Scheme for Toilets offers access to about 9,000 locked public toilets across the UK. You can buy a key for £20 from Disability Rights UK (see page 90). It can also send you details of where the toilets are.

Take a bag with supplies

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

- wet wipes or baby wipes
- barrier cream such as Cavilon® or Sudocrem®
- pads and pants
- a change of clothes
- a sealable bag
- loperamide (if you have problems with diarrhoea)
- your Just Can't Wait card.



Specialist products for leakage or soiling

If you have problems with leakage or soiling (incontinence), there's a wide range of products you can wear. These can help you feel more confident and protect your clothes if you have any leakage.

You can buy pads for mild to moderate incontinence in most supermarkets and pharmacies and online. If these aren't absorbent enough, you can get bigger pads from your continence adviser. They can also explain what's available to you on the NHS. This can vary from region to region. The Bladder and Bowel Foundation offers advice and support via its helpline and website (see page 89).

Products for bladder incontinence

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

Having a urine bottle near your bed may help you get a better night's sleep, because you won't have to walk to the toilet every time you need to go. And if you're worried about getting to the toilet in time during the day, keep the bottle nearby. You may want to keep one in your car.

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

Products for bowel incontinence

A continence adviser can help you choose products that suit your needs.

There are different types of pad you can wear during the day. There are also various types of pad you can use to cover your bed at night.

Anal plugs are made from soft foam and stop bowel leakage for up to 12 hours. There's a cord attached to the plug, which allows you to remove it when you're ready. Some people find anal plugs 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. Your GP can advise you about what the right weight is for your height.



Our booklets *Weight management after cancer treatment*, *Healthy eating and cancer* and *Recipes for people affected by 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 constipated. This is important to help look after your pelvic floor muscles. Exercise also encourages you to go to the toilet more regularly. And it helps you feel better and can reduce stress.

If you have stress incontinence, it's best to avoid anything that involves 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.



There's 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. Pages 48–49 of our food guide list foods that help improve constipation. Make sure you drink plenty of fluids and keep physically active.

Managing stress

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

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

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

Some people find that complementary therapies help them feel less stressed (see page 76–77). For details of what's available in your area, call our cancer support specialists on **0808 808 00 00**.

Getting support

Bladder or bowel problems can be embarrassing and difficult to talk about. This 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 are used to dealing with these issues and can refer you to a counsellor or specialist if you need more help.

Support groups, online community sites and specialist organisations (see pages 89–91) can also provide invaluable support. They're a good way of meeting people who've been through similar difficulties. You can share experiences and solutions with each other. Partners, family members and close friends can also help you cope with feelings.

Lymphoedema

The lymph nodes (sometimes called lymph glands) are part of our immune system and help us fight infection. Lymph fluid flows along fine channels between the nodes.

Sometimes lymph nodes in the pelvic area become damaged by pelvic radiotherapy or surgery. When this happens, lymph fluid can build up. One or occasionally both legs can become swollen. This is called lymphoedema and it can develop months or years after treatment. Some men get swelling in the genital area or in the lower tummy area, but this is rare.

Lymphoedema is not common after pelvic radiotherapy. But men who had surgery to remove the pelvic lymph nodes as well as pelvic radiotherapy are at a higher risk.

Reducing your lymphoedema risk

There are things you can do to reduce your risk of lymphoedema. In particular, it's important to protect the skin on your legs and feet. Infections can trigger lymphoedema, so it's important to avoid damaging your skin.

If you notice swelling in your foot or leg, always get it checked by your doctor or nurse. The earlier lymphoedema is treated, the more effective and straightforward the treatment is.

These are things you can do to reduce your risk of lymphoedema:

- Keep your skin clean and use moisturisers to keep it supple.
- Clean grazes or cuts straightaway, and see your GP if the area gets red, hot or swollen.

- Wear well-fitting shoes.
- Use nail clippers instead of scissors to cut your toenails.
- Cover your skin or use a high-factor sun cream (SPF 30 or above) on sunny days.
- Keep to a healthy weight.
- Keep physically active and avoid standing for too long in the same position.
- If you are travelling, wear compression garments such as flight socks (see next page).



Managing lymphoedema

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



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



Bone changes

Most men who have had pelvic radiotherapy won't have any bone problems. Damage to the bones in the pelvic area is a 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**). These can be painful. The pain is normally in the lower back when you're moving around, and it can make walking difficult. There isn't usually pain when you're resting or sleeping.

If you have pain or aching in the bones, always let your cancer doctor or nurse know. It can be caused by a number of conditions, but it is very important to get it checked. Because damage to the bones is a rare late effect of pelvic radiotherapy, 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 an 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. They will prescribe painkillers to control the pain, and they may give you drugs called bisphosphonates to strengthen the bones. They may also advise you to take calcium and vitamin D supplements for your bone health.

A physiotherapist will show you how to limit stress on the bones. They will also 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.

'I am now a good few months after treatment and have no pain at all in my bottom. But your hips can turn very stiff and I ended up with a bad back and pelvis. Everything is so tender now. I've been told that it is just tissue damage but I'm still having physio.'

Ashley

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. And men taking hormonal therapy drugs for prostate cancer are more at risk of bone thinning (osteoporosis). If you have any bone problems, it's important to follow your doctor's advice.

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

- Keep physically active to keep your bones strong. But if you have bone problems, ask your doctor for advice first. 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. Avoid having too much caffeine. We have more information about this 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. Our booklet *Giving up smoking* has more information that may help.
- If you drink alcohol, stay within the recommended guidelines. Alcohol can interfere with the balance of calcium in the body. Current guidelines recommend that men should drink no more than 21 units of alcohol a week.



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



'My hips and pelvis ached. I started gentle walking as soon as I could. Even now I do stiffen up, so keep mobilising as gently as you can.'

Rusty

Your sex life

Pelvic radiotherapy can affect your sex life and may cause problems with getting or keeping an erection. This may happen gradually. You are more likely to have problems if you've also had surgery to the pelvic area or chemotherapy treatment. Hormonal therapy for prostate cancer can also affect your sex life.

Sexual difficulties can also be caused by other medical conditions, and they're more common as men get older. There are things that can be done to help, so if you're having problems, it's important to talk to your doctor or nurse.

Erection problems

Pelvic radiotherapy can damage nerves in the pelvic area and blood vessels that supply blood to the penis. This can cause problems in getting or keeping an erection (impotence). Your risk of erection problems depends on the type of cancer you've had, the dose of radiotherapy you were given and any other treatments you've had. Your cancer specialist will discuss this with you.

Some treatments can help erection problems. These include:

- tablets that increase the blood supply to the penis, such as sildenafil (Viagra®), vardenafil (Levitra®) or tadalafil (Cialis®)
- pellets that are placed into the tip of the penis, called alprostadil (MUSE)
- injections into the base of the penis, such as alprostadil or papaverine
- vacuum pumps that are placed over the penis.

Your doctor or nurse should be able to advise you on the different treatments. They can also refer you to a specialist if necessary.

There's some evidence that starting tablets, such as Viagra, sooner rather than later is more likely to improve your ability to get and maintain an erection.



There's more information about these treatments in our booklet *Sexuality and cancer – information for men*. The Sexual Advice Association also produces leaflets (see page 91).

Changes in ejaculation

After pelvic radiotherapy, you produce less semen. This means that when you ejaculate, you may notice that only a small amount of fluid comes out. Some men don't produce any semen at all, and this is known as a dry ejaculation. Although you will still be able to orgasm (climax), some men find the sensation feels different from before.

It may take longer to reach orgasm and you may find the sensation is less intense after pelvic radiotherapy. This may be due to changes in the blood flow to, and nerves in, the pelvic and genital area. But it may also be caused by a change in the way you feel about yourself sexually.

Low sex drive (libido)

Some men may not have erection difficulties, but they may find they are less interested in sex after treatment.

There are different reasons for this:

- Coping with cancer and its treatment can cause anxiety, depression and low self-esteem.
- Tiredness (fatigue) may carry on for months after treatment.
- Late bladder or bowel effects may lower your sex drive because they affect the way you feel about yourself sexually.
- Occasionally, men who've had pelvic radiotherapy make less testosterone. This is important for sex drive.

You may find it helpful to get emotional support or talk to a counsellor or sex therapist (see opposite). As the late effects improve, you may start to feel better about yourself sexually.

If blood tests show you have low testosterone levels, your specialist may prescribe testosterone replacement therapy for you. Your specialist can tell you whether this is likely to be helpful for you. If you have had prostate cancer, it may not be suitable.

Getting help

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

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

Your GP may refer you to an erectile dysfunction (ED) service. This is a clinic for men who have problems getting and maintaining an erection. You may see doctors who specialise in the physical and psychological causes of ED, and ways to treat it. You will be asked about your general health and the problems you've been having. Some men may have blood tests and an examination of their genitals.

If you have a partner, talk to them about the effect treatment is having on your sex life. It's good to look at ways of overcoming any problems as a couple. The organisations listed at the end of this booklet may also be a source of help for you (see pages 89–91). For example, the College of Sexual and Relationship Therapists (see page 90) provides a list of qualified practitioners, and the Sexual Advice Association (see page 91) offers a confidential helpline.

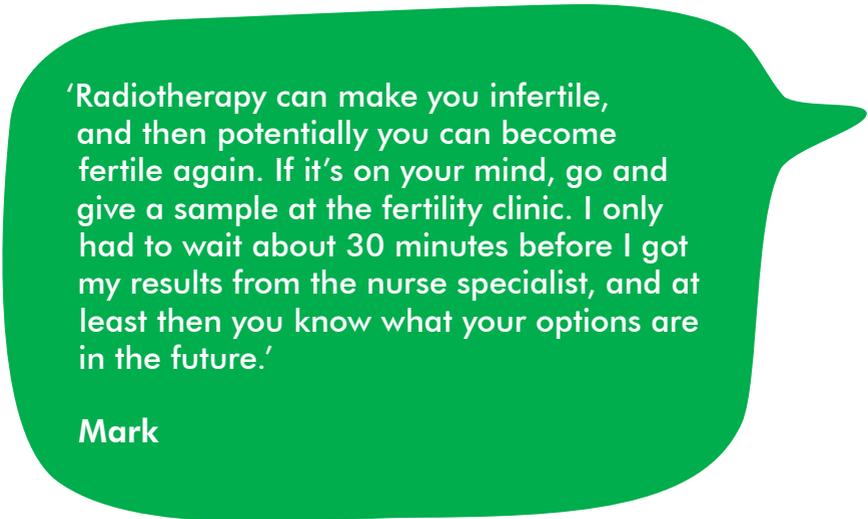


Our booklet *Sexuality and cancer – information for men* has more detailed information on dealing with the physical and emotional effects that cancer and its treatment may have on your sex life.

Fertility

Pelvic radiotherapy is likely to affect your fertility. You may not be able to father children after treatment. This is called infertility.

Sperm is produced in the testicles (see page 7). These are close to the bladder, prostate and rectum. The testicles are very sensitive to radiotherapy. Some men have sperm stored before starting radiotherapy. After treatment they can have fertility treatments to try to have a baby with a partner.



'Radiotherapy can make you infertile, and then potentially you can become fertile again. If it's on your mind, go and give a sample at the fertility clinic. I only had to wait about 30 minutes before I got my results from the nurse specialist, and at least then you know what your options are in the future.'

Mark

Infertility can be very distressing and difficult to live with. Some people find it helpful to talk things over with a partner, family member or friend. Others might prefer to talk to a trained counsellor. Your GP or cancer specialist can arrange this for you. Many hospitals also have specialist nurses who can offer support, and fertility clinics usually have a counsellor you can talk to.

Our cancer support specialists on **0808 808 00 00** can discuss problems you may have and they can also help you find a counsellor who can give you help and advice.



We have a leaflet called *Cancer and fertility – information for men* that has more information.

Contraception

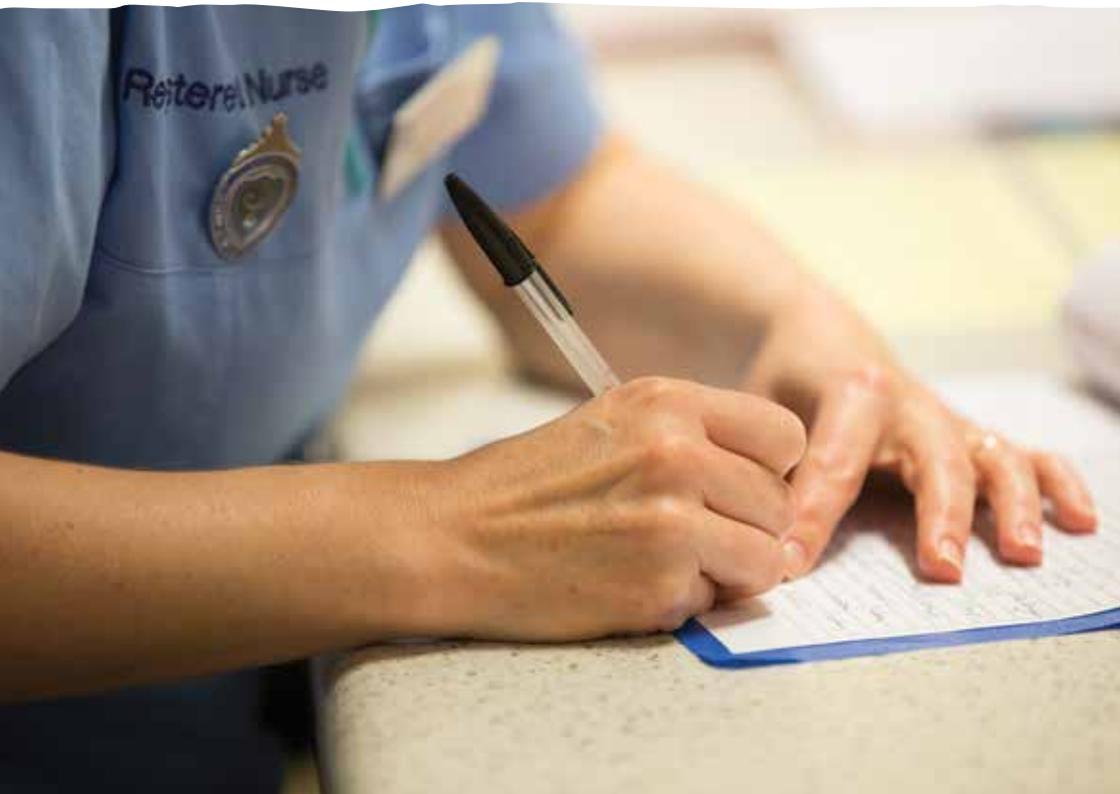
Although your fertility may be affected, it is still important to use effective contraception. This is because you may still be producing sperm for some time after treatment.

Some doctors recommend you use effective contraception for six months after treatment. Other doctors recommend you do it for up to two years after treatment. This is because sperm produced after treatment may still be fertile but could be damaged. This means that a child conceived soon after radiotherapy could have abnormalities. But at the moment, there isn't any evidence that children born to fathers who have had radiotherapy have an increased risk of abnormalities.

Second cancer

Having pelvic radiotherapy slightly increases the risk of developing a new cancer in the treatment area.

Some men may be advised by their specialist to have a test 5–10 years after radiotherapy to look for pre-cancerous changes in the bowel. Your doctor or nurse will discuss this with you.



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. This can make you feel isolated. You may also feel isolated as you begin to have less contact with the hospital or if you don't know anyone else with the same problems.

Uncertainty

You may worry that some of your late effects 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. It can help to know more about your late effects and where you can get support when you're worried.

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. It can be a relief to simply tell yourself and people you trust when you're feeling angry. Keeping strong feelings to yourself may make you feel depressed. You can talk to your doctor about seeing a counsellor.

Depression

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

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

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

Our booklet **How are you feeling? The emotional effects of cancer** has more detailed information that you may find helpful.

Complementary therapies

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

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

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

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

Getting help and support

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

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

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

After going through cancer, it's natural for your body to feel different, and for you to feel differently about your body.

Aches and pains that you might have ignored before may make you wonder whether the cancer has come back. This is a common reaction. If you are worried about symptoms or are struggling with your emotions, 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.

Our booklet **Life after cancer treatment** has more information about getting help and support after you've had treatment.

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 different ways to people returning to work. Occupational health departments may also offer counselling before and after your return to work. This is completely confidential.

Late effects such as tiredness, bowel changes or bladder changes may make work more difficult for you. There are laws protecting the rights of workers who are affected by illnesses such as cancer. Your employer has a duty to make 'reasonable adjustments' to your workplace and working practices to make sure you aren't at a disadvantage compared with others. Reasonable adjustments may include:

- help with a phased return to work
- giving you time off for medical appointments without taking it off your holiday allowance or sick pay
- creating more flexibility in your working hours
- changing your job description to take away tasks that might be physically challenging (either temporarily or permanently, depending on your preference)
- letting you do some or all of your work from home
- providing facilities that are appropriate for your disability
- giving you extra breaks to help you cope with tiredness.

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



Our booklets *Work and cancer* and *Self-employment and cancer* have more information that may be helpful. We also have a guide for employers who are supporting staff affected by cancer. This is called *Managing cancer in the workplace*.

Financial support

If you've had problems going back to work, you may have 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.

You can find out about state benefits and apply for them online at **gov.uk** (England, Scotland and Wales) and **nidirect.gov.uk** (Northern Ireland). These websites have information about financial support, your rights, employment and independent living.

You can also get information about these issues from the relevant Department for Work and Pensions helplines or Citizens Advice (see page 92). In Northern Ireland, you can call the Benefit Enquiry Line Northern Ireland on **0800 220 674**.



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

Insurance

It can be difficult to get travel insurance if you have cancer, or if you've had cancer before. You may find our booklet **Getting travel insurance** helpful.

An Independent Financial Adviser (IFA) can help you with life insurance. They can find the best deal for your situation. You can find a local IFA by:

- asking family or friends for a referral
- looking in your phone book
- contacting The Personal Finance Society or Unbiased (see page 92).



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

About our information

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

Order what you need

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

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

All of our information is also available online at **macmillan.org.uk/cancerinformation**

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

Other formats

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

- audiobooks
- Braille
- British Sign Language
- Easy Read booklets
- large print
- translations.

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

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

Help us improve our information

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

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

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



Other ways we can help you

At Macmillan, we know how a cancer diagnosis can affect everything, and we're here to support you. No one should face cancer alone.

Talk to us

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

Macmillan Support Line

Our free, confidential phone line is open Monday–Friday, 9am–8pm. Our cancer support specialists can:

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

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

Information centres

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

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

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

Talk to others

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

Support groups

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

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Macmillan Grants

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

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

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

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work.

Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

Other useful organisations

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

Bladder and Bowel Foundation

SATRA Innovation Park,
Rockingham Road,
Kettering NN16 9JH
Helpline 0845 345 0165

Email

info@bladderand
bowelfoundation.org

**www.bladderandbowel
foundation.org**

Provides information and support. Campaigns for people living with bladder and bowel disorders, including incontinence, constipation and diverticular disease. Also has Just Can't Wait cards.

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. Can refer people to a local counsellor, and has a searchable list on its website. Can also provide an information sheet for people looking for help.

College of Sexual and Relationship Therapists (COSRT)

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.

Crohn's and Colitis UK (NACC)

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

Information line
0845 130 2233

(Mon–Fri, 10am–1pm)

Support line 0845 130 3344

(Mon–Fri, 1–3.30pm and
6.30–9pm)

Email

info@crohnsandcolitis.org.uk

www.nacc.org.uk

Offers information and support to people with inflammatory bowel disease. Has its own Can't Wait Cards, which allow holders access to toilets in shops.

Disability Rights UK

Ground Floor, CAN Mezzanine,
49–51 East Road,
London N1 6AH

Tel 020 7250 8181

(Mon–Fri, 10am–12.30pm
and 1.30–4pm)

Email enquiries@disabilityrightsuk.org

www.disabilityrightsuk.org

Works to create a society where everyone with a disability or health condition can participate equally as full citizens. Has Just Can't Wait cards and keys for the National Key Scheme for Toilets.

The Institute of Psychosexual Medicine

Building 3, Chiswick Park,
566 Chiswick High Road,
London W4 5YA

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.

Pelvic Radiation Disease Association

PO Box 602,
Epsom KT17 9JB
Tel 01372 744338
www.prda.org.uk

A patient-led group whose aims are to provide support for people of all ages suffering from pelvic radiation damage, and to campaign for better recognition of pelvic radiation disease, as well as improved facilities for treatment within the NHS.

Relate

Premier House, Carolina Court,
Lakeside, Doncaster DN4 5RA
Tel 0300 100 1234
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
Helpline 0207 486 7262
Email info@sexualadvice
association.co.uk
www.sda.uk.net

A charity that was set up to help people with impotence (erectile dysfunction) and their partners. Provides up-to-date information on erectile dysfunction. Can help men with erectile dysfunction and their partners by putting them in touch with specialist practitioners.

Financial information

Benefit Enquiry Line

Northern Ireland

Tel 0800 220 674

(Mon–Wed and Fri, 9am–5pm,
Thu, 10am–5pm)

Textphone 0800 243 787

**www.nidirect.gov.uk/
money-tax-and-benefits**

Provides information
and advice about disability
benefits and carers' benefits.

Citizens Advice

Provides advice on financial,
legal, housing and employment
issues. Find details for your local
office in the phone book or on
one of the following websites:

England and Wales

www.citizensadvice.org.uk

Scotland

www.cas.org.uk

Northern Ireland

www.citizensadvice.co.uk

You can also find advice
online in a range of languages
at **adviceguide.org.uk**

Department for Work and Pensions (DWP)

Disability Benefits Helpline

08457 123 456

Textphone 0845 722 4433

Personal Independence Payment Helpline

0845 850 3322

Textphone 0845 601 6677

Carer's Allowance Unit

0845 608 4321

Textphone 0845 604 5312

**www.gov.uk/browse/
benefits**

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

Personal Finance Society – 'Find an Adviser' service

www.findanadviser.org

Use the website to find qualified
financial advisers in your area.

Unbiased.co.uk

Email contact@unbiased.co.uk

www.unbiased.co.uk

On the website you can
search for qualified advisers
who specialise in giving
financial advice, mortgage,
accounting or legal advice.

Disclaimer

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

Thanks

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

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Can you do something to help?

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

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



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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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 make or have made to Macmillan Cancer Support in the last 4 years as Gift Aid donations, until I notify you otherwise.

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

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

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



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

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

More than one in three of us will get cancer. For most of us it will be the toughest fight we ever face. And the feelings of isolation and loneliness that so many people experience make it even harder. But you don't have to go through it alone. The Macmillan team is with you every step of the way.

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 there for you online, any time. The supporters who make it all possible.

Together, we are all Macmillan Cancer Support.

For cancer support every step of the way, call Macmillan on 0808 808 00 00 (Mon–Fri, 9am–8pm) or visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.
Non-English speaker? Interpreters available.
Braille and large print versions on request.

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MACMILLAN.
CANCER SUPPORT**