

# MANAGING THE BLADDER LATE EFFECTS OF PELVIC RADIOTHERAPY



# About this booklet

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

The booklet explains how to manage the bladder late effects of pelvic radiotherapy.

This booklet does not have information about bowel late effects of pelvic radiotherapy. We have another booklet about this called **Managing the bowel late effects of pelvic radiotherapy** (see page 74).

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

We cannot give advice about the best treatment for you. You should talk to your doctor, who knows your medical history.

## How to use this booklet

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

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

On pages 78 to 84, there are details of other organisations that can help.

## Quotes

In this booklet, we have included quotes from people who have had bladder late effects, which you may find helpful. Some are from our Online Community ([macmillan.org.uk/community](https://www.macmillan.org.uk/community)). The others are from people who have chosen to share their story with us. To share your experience, visit [macmillan.org.uk/shareyourstory](https://www.macmillan.org.uk/shareyourstory)

## For more information

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

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

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

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

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



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# THE PELVIS AND LATE EFFECTS

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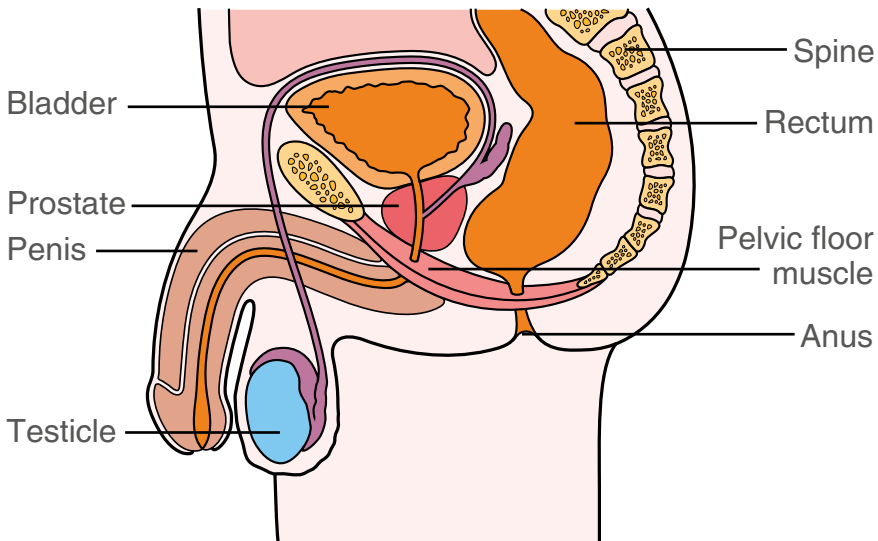
# The pelvis

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

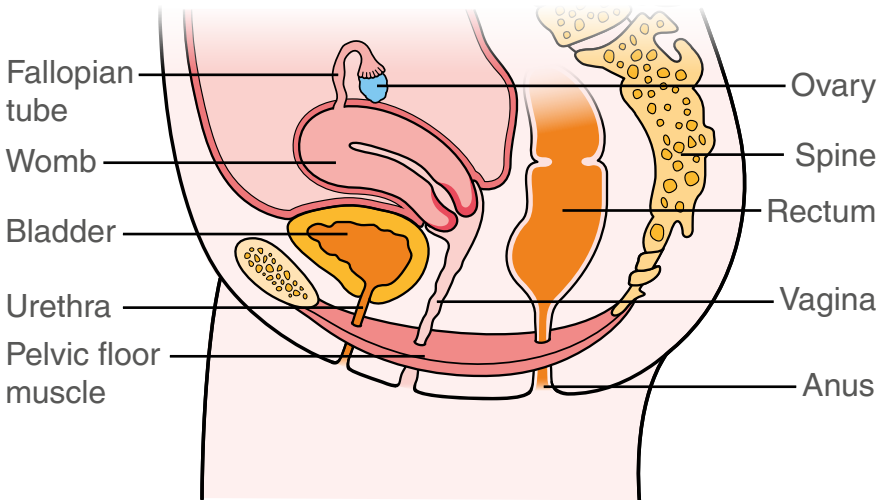
It contains the sex organs, the bladder, a section of the small bowel and the lower end of the large bowel (colon, rectum and anus). The pelvis also contains bones, lymph nodes (glands), blood vessels and nerves.

In men, and people assigned male at birth, the sex organs include the prostate gland, testicles and penis. In women, and people assigned female at birth, the sex organs include the ovaries, fallopian tubes, uterus (womb), cervix and vagina.

## The pelvis



## The pelvis



## If you are transgender

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

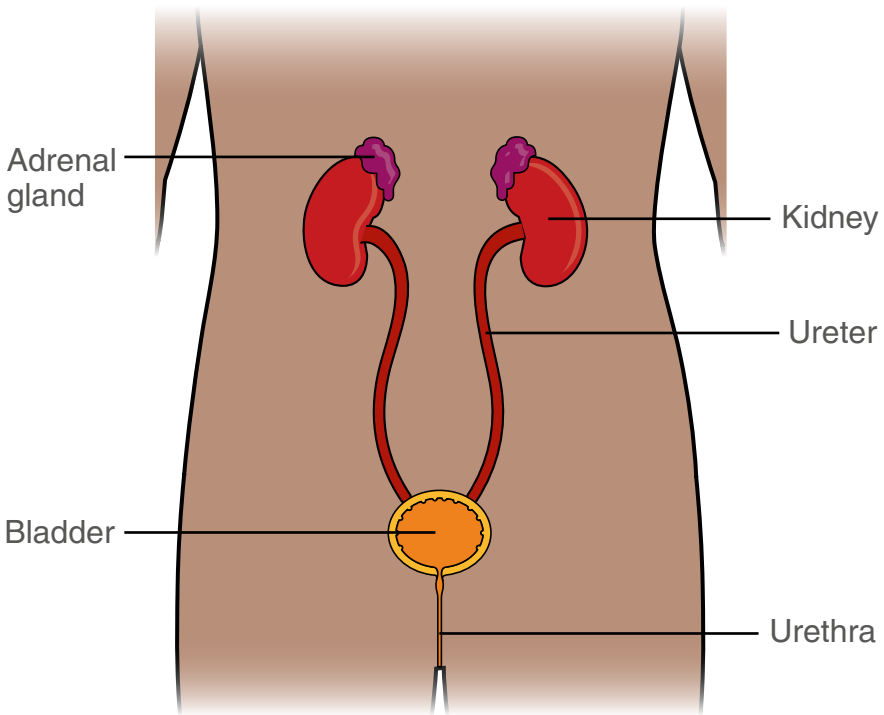


# The bladder

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

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

## The bladder and kidneys



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

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

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

# What is 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 can be given in 2 ways:

- Externally (from outside the body) by a machine called a linear accelerator.
- Internally, by putting radioactive material into the tissues – this is called brachytherapy. Some people with rectal cancer may have a type of brachytherapy called Papillon treatment.

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

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

# What are late effects?

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

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

These side effects are called:

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

In this information we use the term late effects to include both long-term and late effects. Late effects after pelvic radiotherapy may also be called pelvic radiation disease.

This information is about the bladder late effects of pelvic radiotherapy. We have other information about late effects in the following booklets (see page 74):

- **Managing the bowel late effects of pelvic radiotherapy**
- **Managing the late effects of bowel cancer treatment**
- **Managing the late effects of breast cancer treatment**
- **Managing the late effects of head and neck cancer treatment.**



## Other late effects of pelvic radiotherapy

As well as bladder changes, pelvic radiotherapy can cause other late effects, including the following:

- Bowel problems – there may be changes that affect how the body absorbs nutrients, digestion, the lining of the bowel, or the muscles that control going to the toilet.
- Lymphoedema – this is swelling caused by a build-up of lymph fluid in the body tissues. This can happen if the lymphatic system has been damaged by cancer or its treatment.
- Bone changes – these can affect you long after treatment has ended.
- Changes to your sex life – these can be physical and emotional. There may also be changes affecting the male pelvis and female pelvis.
- Fertility – there may be changes that can affect getting pregnant or making someone pregnant. Pelvic radiotherapy can cause an early menopause.
- Second cancer – you may be slightly more at risk of a new cancer in the treated area. But the benefit of having pelvic radiotherapy outweighs the risk. Your doctor or nurse can explain this.

We have more information on how to manage these other late effects, call the Macmillan Support Line on **0808 808 00 00** or visit **[macmillan.org.uk](http://macmillan.org.uk)**

## Talking to your doctor

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

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

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

If you have problems with your bowel, bladder or sex life, you may feel embarrassed to talk about them. But doctors and nurses are used to speaking about these issues. If they know you are having problems, they can answer your questions and help you.

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

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

## Other types of expert help

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

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

A few hospitals have special clinics for people with late effects. Ask your healthcare team whether there are any near you. Your doctor or nurse can refer you to other specialists if needed.

For more information about the help available, contact the Macmillan Support Line free on **0808 808 00 00**. You may also find the organisations listed on pages 78 to 84 helpful.



# BLADDER CHANGES AFTER TREATMENT

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# Bladder changes

Pelvic radiotherapy can cause changes in the way the bladder works. It can also affect the muscles that support the bladder. Sometimes, changes start during treatment and do not get better. Or they may develop months or years after treatment has finished.

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

Bladder problems can feel embarrassing and difficult to talk about. But the doctors, nurses, physiotherapists and other healthcare professionals are used to talking about them. There are many things that can be done to help.

**I noticed increased activity with my bowel and bladder, which is caused by the radiotherapy damaging the linings. But at least the sense of urgency improved slightly.**

Danielle

## Possible late effects to the bladder

Pelvic radiotherapy can cause the bladder to shrink. This means it cannot hold as much urine (pee) as before. This happens when the bladder walls become scarred and the tissue becomes less stretchy.

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

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

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

## Possible symptoms

Possible symptoms of bladder changes include:

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

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

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

## Getting expert help

There are lots of things that can be done to manage or treat your symptoms. Your GP can advise you, or they may need to refer you to a specialist healthcare professional. This might be a urologist, continence advisor or physiotherapist.

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

**I get a burning sensation when I urinate that can be painful, and that still exists today. I'm told it is due to the radiation treatment in the prostate area.**

**Lewis**

Preparing to have a CT scan



## Tests

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

- Scans, to look at your kidneys, ureters and bladder. These could be an ultrasound scan, an MRI scan, or a type of CT scan which using dye (contrast).
- A cystoscopy to look inside the bladder. A thin, flexible tube with a light on the end (a cystoscope) is passed through your urethra and into your bladder. This is usually done using a local anaesthetic, but sometimes a general anaesthetic is used.
- Urodynamic tests, to check how well your bladder and urethra collect, hold and release urine. These are often done if you have symptoms of urgency or incontinence. Sometimes you have them after other tests, if more information is needed.

We have more information about tests and scans on our website.

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



# Needing to pass urine more often (overactive bladder)

Pelvic radiotherapy can sometimes cause an overactive bladder. This can make you want to go to the toilet more often because your bladder feels full, even when there is not much in it.

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

## Bladder retraining

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

You may be asked to complete a chart to see:

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

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

Bladder retraining should be done over a few weeks. You start by 'holding on' for a few minutes when you need to pass urine. You gradually increase this by a few minutes each time. Sitting on a hard seat might help. You may find it easier to distract yourself by reading, listening to the radio, or watching television. Your specialist might have other suggestions to distract yourself, such as counting backwards.

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

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

## Drugs to relax the bladder

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

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

## Botulinum toxin A (Botox®)

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

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

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

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

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

## Nerve stimulation

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

### **Sacral nerve stimulation (SNS)**

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

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

## **Percutaneous tibial nerve stimulation (PTNS)**

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

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

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

# Leaking urine (incontinence)

Leaking urine (incontinence) can happen if the pelvic floor muscles and the valve that keeps the bladder closed are weakened.

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

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

If you have problems with leaking urine, it can make the skin in that area sore. You can protect your skin by keeping it clean and dry (see page 55). There are lots of products available to help you. Your specialist can give you more information.

We have more information about coping with bladder symptoms (see page 43).

## Pelvic floor exercises

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

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

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

You need to practise both strong, long squeezes and short squeezes. For example, try to do:

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

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

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





## Drugs to control your bladder

If pelvic floor exercises do not help, your doctor may suggest using drugs to help you control your bladder. Your doctor or continence adviser can tell you more about this.

## Surgery

Occasionally, when other treatments have not helped, you may be offered an operation to improve incontinence. If this could help, your doctor will discuss it with you. You will be referred to a specialist surgeon for an assessment. You may need to have tests before any treatment.

Some types of operation may only be available as part of a clinical trial. Your specialist can tell you more about this. We have more information about clinical trials on our website (see page 74).

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

## **Tape or sling to support the urethra**

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

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

## **Bulking agents**

A doctor can inject these into the wall of your urethra. This helps keep it closed and makes it harder for urine to leak out. You may need several injections for them to work, and they become less effective over time.

## **Artificial urinary sphincter (AUS)**

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

When you want to pass urine, you deflate the cuff by squeezing the pump under the skin between your fingers. This takes pressure off the urethra, allowing it to open so you can pass urine. The cuff then automatically inflates again.

# Changes to the lining of the bladder

Pelvic radiotherapy can cause damage to the tissue and blood vessels in the lining of the bladder. It can cause inflammation and scarring of the bladder lining (radiation cystitis) and blood in the urine (haematuria).

Symptoms are common during radiotherapy treatment. The symptoms often get better. But sometimes they can start, or come back, months or years later after treatment has ended. This is called chronic radiation cystitis.

## Radiation cystitis

Radiation cystitis can cause pain or burning when you pass urine (pee). It can also make you feel like you need to pass urine frequently. There are things you can do to help with symptoms, such as drinking plenty of fluids and the right types of fluids. But your specialist may also talk to you about treatments that can help.

## Giving drugs into the bladder

Cystistat® (sodium hyaluronate) or iAluRil® are drugs that can be given directly into the bladder as a fluid (bladder instillation). They can coat the surface of the bladder to build up a protective layer to help relieve symptoms of radiation cystitis.

Usually, you lie down while a nurse gently passes a thin, flexible tube (catheter) through the urethra and into the bladder. The catheter may be lubricated with a local anaesthetic to reduce any discomfort. Any urine in your bladder is drained out through the catheter.

Then the nurse slowly passes the drug through the catheter. The catheter is removed and the drug stays in your bladder for at least half an hour (30 minutes) to give it time to work. After this, you go to the toilet.

You may feel some discomfort when passing urine for a few days afterwards. You usually have this treatment weekly, or for a few weeks and then monthly until the symptoms improve.

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

## **Hyperbaric oxygen therapy (HBO)**

Hyperbaric oxygen therapy (HBO) can help bladder inflammation after pelvic radiotherapy. During HBO, you go into a special room or small chamber and breath in pure oxygen. The oxygen travels in your blood. The increased oxygen in your blood can help new blood vessels to grow and the tissue to heal in the area affected by radiotherapy.

It is usually only used for severe symptoms after other treatments have been tried. HBO is not available everywhere and it is not always available on the NHS.

We have more information about HBO on our website (see page 74).

## Blood in the urine

Pelvic radiotherapy can cause blood in the urine (haematuria). This is because radiotherapy can damage the tissue and blood vessels in the lining of the bladder. They can become weaker, and bleed more easily. If you have blood in the urine, it is likely you will need to have tests. This is because there are other reasons for blood in the urine, such as infection, and it is important to rule these out.

You may have a test called a cystoscopy, where a thin tube with a camera and light on the end is used to look inside your bladder. During the cystoscopy, the doctor may decide to treat the bleeding using heat to seal the blood vessels (called cauterisation or diathermy). This can be done with an electrical current or a laser.

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

## Tablets

Tranexamic acid (Cyklokapron®) tablets can reduce bleeding.

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

## Bladder wash-out

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

Sometimes a catheter with an extra opening can be used. This means a bag of fluid can be attached which goes through the catheter. The fluid washes clots out of your bladder and drains into a catheter bag. This is called bladder irrigation.

A bladder wash-out can also be done during a cystoscopy if the catheter methods have been tried before.

## Treating anaemia

Some people become anaemic because of bleeding from the bladder. Anaemia is when you do not have enough red blood cells to carry oxygen around the body. This can make you feel breathless or tired. Your doctor may suggest you take 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 on our website (see page 74).

# Difficulty passing urine (retention)

If you are having problems passing urine (pee), or feel that you are not emptying your bladder completely, 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.

Sometimes, difficulty passing urine can be caused by the pelvic floor muscles being unable to relax. This can be caused by pelvic radiotherapy. Less often, it can be caused by changes to the urethra or nerves that control the bladder.

## Urethral stricture

Pelvic radiotherapy can sometimes cause the urethra to become narrow. This can make it more difficult to pass urine. This narrowing is caused by scar tissue. It is called a urethral stricture.

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

Another possible treatment for smaller strictures is an operation called a urethrotomy. This is done under a spinal anaesthetic (where you are awake but do not feel anything from the waist down) or general anaesthetic. The surgeon passes a tube with a light on the end (cystoscope) into the urethra. This lets them make small cuts to widen the urethra. You may have a catheter for a couple of days to let the urethra heal.

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 urethroplasty.

## Nerve damage

Sometimes, pelvic radiotherapy can affect the nerves to the bladder. This nerve damage means the bladder muscle cannot squeeze strongly enough. This can mean the bladder does not empty completely.

Some people may need to use a catheter to empty their bladder a few times a day. This is called intermittent self-catheterisation. Your specialist can tell you more about this.



## If bladder problems do not improve

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

We have information about coping with bladder changes (see pages 44 to 55).





# **COPING WITH BLADDER LATE EFFECTS**

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# Coping with bladder changes

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

## Drink plenty of fluids

Try to drink at least 1 to 2 litres (2 to 3½ pints) of fluids a day. If it is hot or if you are exercising, you will need to drink more than this. It is best to drink regularly throughout the day.

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

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

## Drink the right fluids

Some drinks can irritate the bladder and make symptoms worse. Try to cut down or avoid:

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

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

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

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

## Stop smoking or vaping

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

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

## Keep to a healthy weight

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

We have more information in our booklet **Managing weight gain after cancer treatment** (see page 74).

## Keep physically active

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

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

Walking or swimming are lower-impact and are less likely to cause problems. Your specialist may be able to suggest suitable exercise for you. If you have been advised to do pelvic floor exercises, it is important to keep doing these regularly. You may find our booklet **Physical activity and cancer** helpful (see page 74).

## Avoid constipation

Avoiding constipation can help protect your pelvic floor muscles. This may help with bladder symptoms. To avoid constipation, you can try the following things:

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

Find out more in our booklet **Managing the bowel late effects of pelvic radiotherapy** (see page 74).





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

**Natalie**

## Manage stress

Anxiety and stressful situations can make bladder symptoms worse.

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

Relaxation CDs are available from bookshops and some health shops. You can also download apps to your mobile phone or tablet, or relaxation podcasts from the internet.

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

## Get support

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

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

Visit [macmillan.org.uk/inyourarea](https://www.macmillan.org.uk/inyourarea) to find support groups near you. Or access the Macmillan Online Community at [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

# Going out

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

## Access to toilets

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

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

You can also use disabled toilets. These often have more privacy. They have a wash basin and more space if you need to change. The National Key Scheme for Toilets offers access to about 9,000 locked public toilets across the UK. You can buy a key online from places such as Disability Rights UK (see page 83). They also have a guide that explains where the toilets are.

## Take a bag with supplies

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

- wet wipes or tissues
- a non-oil barrier cream
- pads and pants
- a change of clothes
- a sealable bag
- your Macmillan toilet card.

**Macmillan helped me to access a toilet card. Now I'm confident to go shopping as I know there'll be somewhere to go nearby.**

**Alistair**

# Specialist products for bladder incontinence

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

Having a urine bottle near your bed may help you get a better night's sleep. You will not have to walk to the toilet every time you need to go. If you are worried about getting to the toilet in time during the day, keep the bottle nearby. You may want to keep one in your car.

Problems with leakage can mean you have extra expenses. Call Macmillan on **0808 808 00 00** to find out more about ways to help cover the cost.

## Disposable pads and underwear

Pads and pull-ups have a layer that absorbs urine (pee), so your skin stays dry. Some are made to go inside your underwear and others are worn instead of underwear. You can also buy pads to cover your bed. It is best to avoid using sanitary pads, because they are made differently. Sanitary pads stay damp, which means the urine can make your skin sore.

You can buy pads for incontinence in most supermarkets and pharmacies and online. If these are not absorbent enough, you can get different pads from your continence adviser. They can also explain what is available to you on the NHS. This will depend on where you live. The Bladder and Bowel Community also has information about different products (see page 78).

## Urinary sheaths

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

# advice



# Protecting your skin

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

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

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

- Use a skin cleanser instead of soap and water.
- Try not to scratch if your skin is itchy, but if you do sometimes scratch it is best to keep your nails short to help prevent damage to your skin.
- Use absorbent pads.
- Wear cotton underwear, as it lets your skin breathe more than other materials.



# YOUR FEELINGS AND RELATIONSHIPS

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# Your feelings

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

## Feeling alone

Some late effects can feel embarrassing or difficult to talk about. This can make you feel isolated, especially if you do not know anyone else with the same problems. You may also feel more alone as you begin to have less contact with the hospital when your treatment ends. Tell your doctor, family or friends if you are feeling this way. They may be able to suggest things that can help, or know where you can get more support.

## Uncertainty

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

## Anger

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

## Depression

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

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

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

# Relationships

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

You may feel:

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

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



# Getting help and support

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

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

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

## Complementary therapies

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

Complementary therapies may:

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

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

There are lots of different therapies. Some people find it helpful to use a combination of therapies. Choose a therapy that feels right for you and make sure you use a registered practitioner. Before using a complementary therapy, talk to your healthcare team and find out if it could have any harmful effects for you.

We have more information in our booklet **Cancer and complementary therapies** (see page 74).





**YOUR  
WORK AND  
CANCER  
TOOLKIT**

**MACMILLAN  
AT WORK**

**MACMILLAN  
CANCER SUPPORT**

**MACMILLAN  
CANCER SUPPORT  
WORKING WITH  
SOMEONE**



# WORK AND FINANCES

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# Work

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

Our booklets **Work and cancer**, **Working while caring for someone with cancer** and **Self-employment and cancer** have information that may be helpful if you are making decisions about this (see page 74). There is also lots more information at [macmillan.org.uk/work](http://macmillan.org.uk/work)

## Employment rights

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

The law also says your employer must make reasonable adjustments (changes) to your workplace and their work practices to help you stay at work or return to work.

For example, changes that might help with late effects such as tiredness, bowel changes or bladder changes could include:

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

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

Our booklet **Your rights at work when you are affected by cancer** has more information (see page 74).

# Financial help and benefits

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

## Statutory Sick Pay

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

## Benefits

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

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

## Employment and Support Allowance (ESA)

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

## Universal Credit

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

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

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

## Personal Independence Payment

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

## Attendance Allowance

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

## Special rules

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

## Help for carers

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

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

## Macmillan Grants

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

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

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

## Insurance

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

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

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

We have more information in our booklet **Travel and cancer** (see page 74). Our Online Community forum on **Travel insurance** may also be helpful. Visit [macmillan.org.uk/travelinsurancegroup](https://www.macmillan.org.uk/travelinsurancegroup)

## More information

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

You can also get information about benefits and other types of financial help from Citizens Advice (see page 81).

Our booklet **Help with the cost of cancer** has lots more information (see page 74).



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MACMILLAN  
CANCER SUPPORT

# YOUR FEELINGS AFTER CANCER TREATMENT



MACMILLAN  
CANCER SUPPORT

# WHAT TO DO AFTER CANCER TREATMENT: 10 TOP TIPS



# About our information

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

## Order what you need

You may want to order more booklets or leaflets like this one.  
Visit [be.macmillan.org.uk](http://be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

## Online information

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

## Other formats

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

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

Find out more at [macmillan.org.uk/otherformats](http://macmillan.org.uk/otherformats)

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

# Other ways we can help you

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

## Talk to us

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

### Macmillan Support Line

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

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

Call us on **0808 808 00 00** or email us via our website, **[macmillan.org.uk/talktous](https://macmillan.org.uk/talktous)**

### Information centres

Our information and support centres are based in hospitals, libraries and mobile centres. There, you can speak with someone face to face. Visit one to get the information you need, or if you would like a private chat, most centres have a room where you can speak with someone alone and in confidence.

Find your nearest centre at **[macmillan.org.uk/informationcentres](https://macmillan.org.uk/informationcentres)** or call us on **0808 808 00 00**.

## Talk to others

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

### Support groups

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

## Help with money worries

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

## Financial guidance

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

## Help accessing benefits

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

## Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants.

We can also tell you about benefits advisers in your area. Visit **[macmillan.org.uk/financialsupport](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 are an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit **[macmillan.org.uk/work](https://www.macmillan.org.uk/work)**

## Work support

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

# Other useful organisations

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

## **Bladder and Bowel Community**

**[www.bladderandbowel.org](http://www.bladderandbowel.org)**

Information and support for anyone affected by bladder and bowel control problems as well as their families, carers and healthcare professionals.

## **Bladder Health UK**

Tel **0121 702 0820**

**[www.bladderhealthuk.org](http://www.bladderhealthuk.org)**

Support and information for people affected by bladder problems.

## **Bowel Cancer UK**

Email 'Ask the Nurse' **[nurse@bowelcanceruk.org](mailto:nurse@bowelcanceruk.org)**

**[www.bowelcanceruk.org.uk](http://www.bowelcanceruk.org.uk)**

Information and support for everyone affected by bowel cancer. Provide an online forum is a place for people to talk about their experiences, share their knowledge and support each other.

## **British Association of Urological Surgeons (BAUS)**

**[www.baus.org.uk](http://www.baus.org.uk)**

Provides information about urinary symptoms and treatments.

## **Daisy Network**

**[www.daisynetwork.org](http://www.daisynetwork.org)**

A support group for women who have had a premature menopause. Membership fees apply. It offers information covering health, fertility and psychological topics, a forum to connect with other members and live chat sessions where you can ask medical experts questions.

### **The Eve Appeal**

Tel **0808 802 0019**

Email **nurse@eveappeal.org.uk**

**www.eveappeal.org.uk**

Information and support for people affected by gynaecological cancers such as womb, cervical, vaginal and vulval cancer.

### **Jo's Trust**

Helpline **0808 802 8000** (hours vary)

**www.jostrust.org.uk**

Provides information, emotional and practical support to people affected by cancer of the cervix. There is support and information for people affected by, or at risk of, pelvic radiation disease (PRD).

### **Menopause matters**

**www.menopausematters.co.uk**

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

### **Orchid**

Helpline **0808 802 0010**

Email **helpline@orchid-cancer.org.uk** or

**nurse@orchid-cancer.org.uk**

**www.orchid-cancer.org.uk**

Works on behalf of anyone affected by prostate, testicular or penile cancer.

### **Pelvic Radiation Disease Association**

Helpline **0800 121 6811** (Tue, Wed, and Thu 10am to 2pm)

**info@prda.org.uk**

**www.prda.org.uk**

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



### **Prostate Cancer UK**

Helpline **0800 074 8383**

**[www.prostatecanceruk.org](http://www.prostatecanceruk.org)**

Information and support for anyone affected by prostate cancer.

### **Sexual Advice Association**

**[www.sexualadviceassociation.co.uk](http://www.sexualadviceassociation.co.uk)**

Has information on sexual problems as well as sexual health and wellbeing.

## **Counselling**

### **British Association for Counselling and Psychotherapy (BACP)**

Tel **0145 588 3300** (Mon to Fri, 10am to 4pm)

Email **[bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)**

**[www.bacp.co.uk](http://www.bacp.co.uk)**

Promotes awareness of counselling and signposts people to appropriate services across the UK. You can also search for a qualified counsellor on their 'How to find a therapist' page.

### **College of Sexual and Relationship Therapists**

**[www.cosrt.org.uk](http://www.cosrt.org.uk)**

Website has information about sexual wellbeing and what to expect from sex therapy. It also has a directory of therapists to help you find professional support in your local area.

### **Relate**

**[www.relate.org.uk](http://www.relate.org.uk)**

Counselling, support and information for all relationships.

## Financial support or legal advice and information

### Advice NI

Helpline **0800 915 4604**

Email **[advice@adviceni.net](mailto:advice@adviceni.net)**

Provides advice on a variety of issues including financial, legal, housing and employment issues.

### Benefit Enquiry Line Northern Ireland

Helpline **0800 232 1271** (Mon, Tue, Wed and Fri, 9am to 5pm, and Thu, 10am to 5pm)

Textphone **028 9031 1092**

**[www.nidirect.gov.uk/money-tax-and-benefits](http://www.nidirect.gov.uk/money-tax-and-benefits)**

Provides information and advice about disability benefits and carers' benefits in Northern Ireland.

### Citizens Advice

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

### England

Helpline **0800 144 8848**

**[www.citizensadvice.org.uk](http://www.citizensadvice.org.uk)**

### Scotland

Helpline **0800 028 1456**

**[www.cas.org.uk](http://www.cas.org.uk)**

### Wales

Helpline **0800 702 2020**

**[www.citizensadvice.org.uk/wales](http://www.citizensadvice.org.uk/wales)**

## **GOV.UK**

**[www.gov.uk](http://www.gov.uk)**

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

## **Local councils (England, Scotland and Wales)**

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

You should be able to find your local council's contact by visiting:

## **England**

**[www.gov.uk/find-local-council](http://www.gov.uk/find-local-council)**

## **Scotland**

**[www.cosla.gov.uk/councils](http://www.cosla.gov.uk/councils)**

## **Wales**

**[www.wlga.wales/welsh-local-authority-links](http://www.wlga.wales/welsh-local-authority-links)**

## **Macmillan Benefits Advice Service (Northern Ireland)**

Tel **0300 1233 233**

## **Money Advice Scotland**

Tel **0141 572 0237**

Email **[info@moneyadvicescotland.org.uk](mailto:info@moneyadvicescotland.org.uk)**

**[www.moneyadvicescotland.org.uk](http://www.moneyadvicescotland.org.uk)**

Use the website to find qualified financial advisers in Scotland.

### **Unbiased.co.uk**

Helpline **0800 023 6868**

Email **contact@unbiased.co.uk**

**www.unbiased.co.uk**

You can search the website for qualified advisers in the UK who can give expert advice about finances, mortgages, accounting or legal issues.

## **Equipment and advice on living with a disability**

### **British Red Cross**

Tel **0344 871 11 11**

Email **contactus@redcross.org.uk**

**www.redcross.org.uk**

Offers a range of health and social care services across the UK, such as care in the home, a medical equipment loan service and a transport service.

### **Disability Rights UK**

Tel **0330 995 0400** (not an advice line)

Email **enquiries@disabilityrightsuk.org**

**www.disabilityrightsuk.org**

Provides information on social security benefits and disability rights in the UK. Has a number of helplines for specific support, including information on going back to work, direct payments, human rights issues, and advice for disabled students.

They also sell Radar toilet keys that allow people to access the national key scheme's locked public toilets.

### **Living Made Easy**

Helpline **0300 999 0004** (Mon to Fri, 9am to 5pm)

Email **info@dlf.org.uk**

**www.dlf.org.uk**

Provides free, impartial advice about all types of disability equipment and mobility products.

### **Scope**

Helpline **0808 800 3333** (Mon to Sat, 8am to 8pm, and Sun, 10am to 6pm)

Textphone Type Talk by dialling **18001** from a textphone followed by **0808 800 3333**.

Email **helpline@scope.org.uk**

**www.scope.org.uk**

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

## **LGBTQ+ support**

### **LGBT Foundation**

Tel **0345 330 3030** (Mon to Fri, 9am to 9pm)

Email **helpline@lgbt.foundation**

**www.lgbt.foundation**

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

### **Live Through This**

**www.livethroughthis.co.uk**

A safe space for anybody who identifies as part of the queer spectrum and has had an experience with any kind of cancer at any stage. Also produce resources about LGBT cancer experiences. LTT run a peer support group with Maggie's Barts.

## Disclaimer

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

## Thanks

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

With thanks to: Emma Hallam, Advanced Practitioner in Radiotherapy Information and Support; Dr Rosie Harrand, Consultant Clinical Oncologist; Dr Anita Mitra, Consultant Clinical Oncologist; Mr Vinod Nargund, Consultant Urological Surgeon; and Alison Wyatt, Macmillan Specialist Physiotherapist.

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

We welcome feedback on our information. If you have any, please contact **[cancerinformationteam@macmillan.org.uk](mailto:cancerinformationteam@macmillan.org.uk)**

## Sources

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

Helissey C, Cavallero S, Brossard C et al. Chronic inflammation and radiation-induced cystitis: molecular background and therapeutic perspectives. *Cells*, 2020; 10, 1.

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

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

# Can you do something to help?

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

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

## 5 ways you can help someone with cancer

### **Share your cancer experience**

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

### **Campaign for change**

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

### **Help someone in your community**

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

### **Raise money**

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

### **Give money**

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

**Call us to find out more 0300 1000 200**  
**[macmillan.org.uk/getinvolved](http://macmillan.org.uk/getinvolved)**



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If you would rather donate online  
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**This booklet is about the bladder late effects of pelvic radiotherapy. It is for anyone treated with pelvic radiotherapy who has bladder side effects that continue after treatment, or begin months or years later. There is also information for carers, family members and friends.**

**The booklet explains how to manage the bladder late effects of pelvic radiotherapy. It also has information about emotional, practical and financial issues.**

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

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

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

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

**MACMILLAN  
CANCER SUPPORT**

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