MACMILLAN
CANCER SUPPORT

PELVIC RADIOTHERAPY IN MEN — MANAGING SIDE EFFECTS DURING TREATMENT



About this booklet

This booklet is for men who are having, or are going to have, radiotherapy to the pelvic area. The pelvic area is the lower part of the tummy (abdomen), between the hips.

The booklet explains:

- side effects that may happen during, or shortly after, pelvic radiotherapy
- how side effects can be controlled or reduced
- what you can do to help yourself.

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

This booklet also has some information about side effects that may happen months, or years, after pelvic radiotherapy. These are called late effects. We have more detailed information about late effects in our booklet Managing the late effects of pelvic radiotherapy in men (see page 56).

For more information

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

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

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

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

How to use this booklet

The booklet is split into sections to help you find what you need. You 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.

In this booklet, we have included guotes from people who have had pelvic radiotherapy, which you may find helpful. Some of these quotes are from people who have chosen to share their story with us. The others are from **healthtalk.org** Some names have been changed.

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THE PELVIS AND PELVIC RADIOTHERAPY

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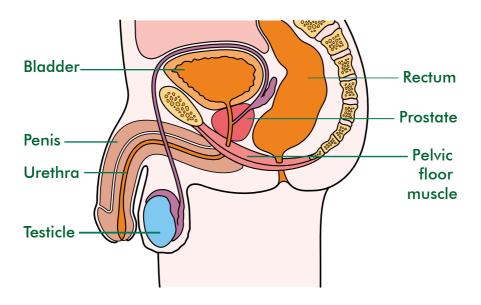
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The pelvis

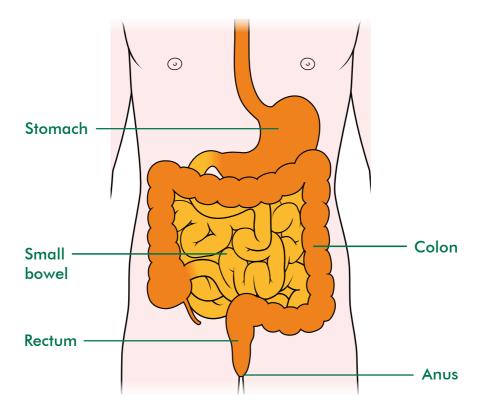
The pelvis is the lower part of the tummy (abdomen) between the hips. In men, it has the following:

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

The male pelvis



The bowel



Radiotherapy

Radiotherapy treats cancer by using high-energy rays to destroy the cancer cells. Using radiotherapy to treat cancer in the pelvis is called pelvic radiotherapy.

You may have pelvic radiotherapy to treat:

- prostate cancer
- bladder cancer
- rectal cancer
- anal cancer
- penile cancer
- lymphoma in the pelvic area.

We have more information about these different cancer types (see page 56).

You may have radiotherapy from outside the body, called external beam radiotherapy. Or you can have it from inside the body, called internal radiotherapy or brachytherapy. Some people have both types.

A team of specialists plan and give you radiotherapy. They also give you information, practical care and support throughout your treatment. Your team includes:

- a cancer doctor (clinical oncologist) or a consultant radiographer experts in treating cancer with radiotherapy
- therapeutic radiographers who help plan and give each radiotherapy treatment and offer advice and support
- a specialist nurse (usually) who can give advice and support.

You can discuss any worries you have about treatment or side effects with your team.



External beam radiotherapy

You normally have this as several short, daily treatments in a radiotherapy department. It is given using a machine that looks like a large x-ray machine or CT scanner.

You usually have external beam radiotherapy as an outpatient. Sometimes, you have it during a hospital stay. Your cancer doctor, radiographer or nurse will explain how many treatment sessions you need, and when you will have them.

Each treatment takes a few minutes and is painless. It does not make you radioactive. It is safe for you to be with other people throughout treatment. This includes children and pregnant women.

Internal radiotherapy (brachytherapy)

Internal radiotherapy uses a radioactive material that is put inside the body to treat the cancer. This is also called brachytherapy.

You may have it as an outpatient over a few separate treatments. Or you might have it as an inpatient over a few days. This depends on the type of cancer you have. Some people have a general anaesthetic or spinal anaesthetic (injection of painkillers into the spine).

Brachytherapy is given through hollow tubes that are placed inside the body. The tubes can feel uncomfortable while they are in place. The nurses will give you painkillers to help with this. You cannot feel the radiotherapy when you are having it. The tubes are removed when treatment is finished.

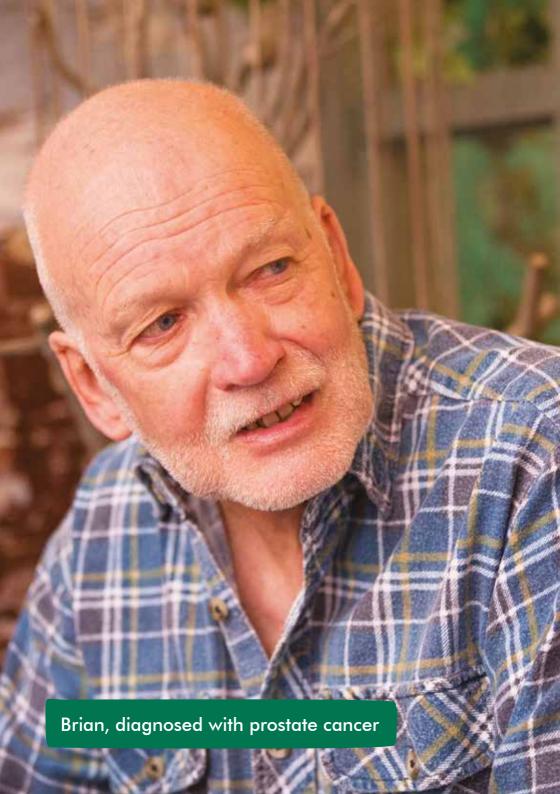
There may be some differences in how each hospital does brachytherapy. Your doctor or nurse will explain what to expect.

Radiation safety during brachytherapy

While the radioactive material is inside the body, your team are careful to protect people around you from radiation. For example, they may look after you in a single treatment room. As soon as the radioactive material is removed from your body, there is no risk to people around you. You are not radioactive.

For some types of brachytherapy, tiny radioactive seeds stay inside the body permanently. The seeds release radiation slowly. They become less radioactive over several months. As a precaution, you may be asked to avoid close contact with children or pregnant women for a time. Your team will explain this, and any other safety measures you need to know about.

We have more information about radiotherapy in our booklet Understanding radiotherapy (see page 56).



SIDE EFFECTS DURING TREATMENT

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How radiotherapy might affect you

Radiotherapy destroys cancer cells in the area where it is given. It can also damage some normal cells in the same area. This may cause side effects.

Side effects do not usually happen straight away. They may develop during your course of treatment, or in the days or weeks after treatment finishes. After you have finished radiotherapy, side effects may get worse for a time before they get better.

You may have a small risk of long-term side effects. Side effects can sometimes also start months or years after radiotherapy. These are called late effects.

Your team will explain what to expect from treatment. But it is difficult for them to know exactly what side effects you will have. Always tell them if you have side effects during, or after, radiotherapy. They can give advice and support to help you cope.

If you smoke, try to stop. Research shows that stopping smoking during and after radiotherapy may help it work better. It can also reduce the side effects of treatment. Your radiotherapy team, GP or a pharmacist can help.

Giving up smoking can be difficult, but there is lots of support available (see page 63).

You are unlikely to get all the different side effects of radiotherapy. The side effects you have may depend on:

- the area of your pelvis having treatment
- whether you have external or internal radiotherapy (see pages 10 to 11)
- other cancer treatments you are having, such as surgery, chemotherapy or hormonal therapy.

Having chemotherapy at the same time as radiotherapy is called chemoradiation. This may cause more severe side effects. You may also find it helpful to read our information about the type of cancer you are having treatment for (see page 56). This information has more detail about your treatment, and the other possible side effects.

We also have more information about chemotherapy in our booklet Understanding chemotherapy (see page 56).

Tiredness

Not everyone feels tired during radiotherapy treatment, but many people do. Tiredness (fatigue) can continue for weeks, or a few months after your treatment has finished.

You might be more tired if you have to travel to hospital every day, or if you are recovering from other treatments. These may include surgery, chemotherapy or hormone therapy. We have more information about these treatments (see page 56).

Some people are able to continue with their day-to-day activities. Others might need more rest.

'It didn't take long for me to get back to walking. Just a mile or two, but slowly building up.'

John

Coping with tiredness

There are things you can do that may help you cope with tiredness:

- Get plenty of rest, but balance this with some gentle exercise, such as short walks. This gives you more energy and keeps your muscles working.
- Eat a healthy diet and drink plenty of fluids.
- Save some energy for doing the things you enjoy.
- Ask others for help doing everyday tasks, if they are making you tired.
- If you feel very tired, it is best not to drive.

We have more information about coping with tiredness (fatigue) in our booklet **Coping with fatigue**. We also have more information about living a healthy lifestyle in our booklets Physical activity and cancer and Healthy eating and cancer. See page 56 for information on how to order these.



Effects on the skin

Sometimes, pelvic radiotherapy can cause a skin reaction in the area being treated. This can be uncomfortable, particularly in sensitive areas. These areas may include the anus, penis, scrotum, either side of the groin or between the buttocks.

If a skin reaction happens, it usually starts after about 10 to 14 days of treatment. You may find your skin becomes red, or darkens in the area having treatment. It may also feel warm, itchy or sore. Sometimes, the skin gets very sore and may blister, break or leak fluid.

Your radiographer or nurse will check your skin regularly. Tell them if your skin is sore, or if you notice any other changes during, or after, radiotherapy. They will give you advice about managing it. They may give you dressings, or a gel or other products to help. They can also give you painkillers to take, if you need them.

Skin reactions can take time to improve. They are usually worst in the first 2 weeks after treatment finishes. They then start to get better as the skin heals.

Pelvic radiotherapy may also make your pubic hair fall out. It should start to grow back again within a few weeks after radiotherapy finishes, but it may be thinner. Sometimes, hair loss is permanent.

Skin care

Your radiographer or nurse will explain how to look after your skin during pelvic radiotherapy. They will usually give you advice, including some of the following:

- Have showers rather than baths if you can. Soaking in a bath can make the skin too moist. When you shower, use a very gentle stream of lukewarm water. If you have a bath, do not use very hot water. Try not to soak in the water for longer than a few minutes.
- Follow your team's advice about using soaps, moisturisers, creams and deodorants.
- Wear loose underwear or shorts made from natural fibres. such as cotton or silk. This means they will not rub against the skin. Avoid wearing tight-fitting underpants and trousers.
- Do not shave, wax or use hair removal creams in the treatment area during radiotherapy. Wait until a few weeks after radiotherapy is over and any skin reaction has healed.
- Protect the skin of the treated area from the sun for the first year after radiotherapy. You should do this even after any skin reaction has settled. It is best to always wear sunscreen with a high sun protection factor (SPF) of at least 30.
- If you smoke, try to stop. Smoking can make skin reactions worse. Giving up smoking can be difficult, but there is lots of support available (see page 63).

Bladder side effects

Pelvic radiotherapy can irritate the lining of the bladder. This can cause side effects such as:

- passing urine (peeing) more often than usual
- passing urine during the night
- a burning feeling when you pass urine (similar to a urine infection)
- a feeling that you are not able to wait when you need to pass urine
- blood in your urine
- leaking small amounts of urine (incontinence).

Coping with bladder side effects

Always tell your radiotherapy team if you are having side effects during, or after your course of treatment. There are drugs that can improve bladder side effects and help you feel more comfortable. Your team may ask you for a urine sample to check if you have an infection. An infection is a common cause of symptoms and is easy to treat.

Contact the hospital straight away if:

- your symptoms get worse
- you have a high temperature
- you feel you cannot pass urine.

Your team can advise you about coping with any bladder problems. If the problems do not improve within a few weeks, they may arrange tests. Or they may get more advice for you from a continence specialist.

People often feel embarrassed talking about bladder problems. But if you tell your doctor, radiographer or nurse, they can help and it is usually possible to improve it.

There are some things you can do that may help with bladder side effects:

- Try to drink plenty. If your urine is dark and concentrated, it can irritate the bladder and make symptoms worse. Drinking more makes your urine paler and less concentrated. Aim to drink at least 2 to 3 litres ($3\frac{1}{2}$ to $5\frac{1}{2}$ pints) of fluids a day.
- Try to drink more water and less of drinks that may irritate the bladder. These include drinks containing caffeine, such as tea, coffee, drinking chocolate and cola. You should also try to drink less alcohol, fizzy drinks, acidic drinks (orange and grapefruit juice) and drinks with artificial sweeteners (diet or light drinks).
- Try drinking cranberry juice or taking cranberry capsules to help reduce symptoms. But you should not have cranberry products if you are taking a drug called warfarin.
- If you smoke, try to stop. Smoking can make bladder side effects worse. Giving up smoking can be difficult, but there is lots of support available (see page 63).
- · Look at our tips for finding a toilet when you are out in public (see pages 27 to 28).

Other urinary problems

Radiotherapy for prostate or penile cancer may also cause swelling around the urethra (see page 6). This is the tube that carries urine from the bladder, through the prostate, to the opening at the tip of the penis.

This can cause side effects such as:

- passing urine more often than usual
- a feeling that you cannot wait when you need to pass urine
- needing to wait for the flow of urine to begin
- having a weak flow of urine
- feeling that you have not fully emptied your bladder.

Tell your team if you have any of these side effects. They may give you drugs to help.

It is important to contact the hospital straight away if you cannot pass urine at all. This is a rare side effect caused by swelling that closes the urethra completely. This stops urine flowing out of the bladder. It may affect you after brachytherapy for prostate cancer. You may have drugs that reduce the swelling. Or you may have a tube (catheter) put into the bladder for a short time.



Bowel side effects

Pelvic radiotherapy can cause some of the following side effects:

- loose stools (poo) or diarrhoea
- hard stools or constipation
- needing to empty your bowel (poo) urgently
- cramping pains in your tummy (abdomen) or back passage (rectum)
- passing a lot of wind.

Some other, less common side effects are:

- feeling you need to go to the toilet although your bowels are empty (tenesmus)
- passing mucus or blood when you empty your bowels
- bleeding from piles (haemorrhoids)
- slight soiling of your underwear or some leakage (incontinence).

Bowel side effects usually start to improve about 2 weeks after radiotherapy finishes. Sometimes, they may take a few months to get better.

Coping with bowel side effects

Tell your doctor, radiographer or nurse about any bowel side effects you have. They can give you advice to help. They may advise you to make changes to your diet during radiotherapy. This will help prevent or improve bowel side effects. Or they may give you drugs to help. Follow their advice carefully, and tell them if your side effects get worse.

Diarrhoea is the most common side effect. It usually starts during, or after 2 weeks of radiotherapy. If you have diarrhoea, your team may give you tablets to help reduce it. Try to drink at least 2 to 3 litres of fluids a day.

If you have any soiling or incontinence, tell your team. They will give you advice about coping with this, and looking after vour skin.

There are some things you can do that may help with bowel side effects:

- Try drinking less of drinks that could make bowel side effects worse. These include drinks containing caffeine (tea, coffee, drinking chocolate, cola) and alcohol.
- Avoid foods and drinks that give you wind, such as pickles, beans, curry and fizzy drinks.
- Try doing gentle exercise to help if you have a lot of wind. Or try taking charcoal tablets, which you can buy at the chemist. These can affect other medicines so always ask your doctor or pharmacist first.
- If you smoke, try to stop. Smoking can make bowel side effects worse.
- Look at our tips for finding a toilet when you are out in public (see next page).

We have more information about coping with bowel problems in our booklet **Eating problems and cancer** (see page 56).

Finding a toilet in a hurry

Bladder or bowel side effects may mean you need to go to the toilet more often. Or that you sometimes need to use the toilet urgently. Some people feel anxious about going out in public because of this. It may help to do some of the following things.

Plan ahead

Think about where you can find a toilet when you are not at home:

- Many areas have lists, or maps of the local public toilets. Try typing 'public toilets' and the name of the place you are visiting into an internet search engine, such as Google.
- Visit the website toiletmap.org.uk to see a map with details of public toilets.
- Download a phone app that can help you find a public toilet.

Get a toilet card

You can show this quickly and easily to staff in shops, pubs and other places. It explains that you have a medical condition and need urgent access to a toilet.

We have a free toilet card you can use (see page 56 for contact details). The Bladder and Bowel Community also offer a free 'Just Can't Wait' toilet card and phone app (see page 61).

Use disabled toilets

These often have more privacy and space. The National Key Scheme offers access to about 9000 locked disabled toilets across the UK. You can buy a key from Disability Rights UK (see page 63). They also have a guide that explains where the toilets are.

> 'I couldn't hold a full bladder for a long period of time. I did all the pelvic floor exercises and started to do okay. I always made sure I wasn't far from a loo.'

John

Effects on your sex life

It can be difficult to talk about your sex life. But if you have any problems during or after your treatment, there are usually things that can help. You may have side effects that:

- mean you do not feel like having sex
- make having penetrative sex uncomfortable or painful
- make it difficult to get, or keep, an erection.

Do not let embarrassment stop you from getting information that can help. Your team can give advice and support. If you need expert advice, they can often arrange this for you.

'I can experience sex but it's different. I went to see a nurse who deals with sexual problems. I wouldn't have spoken openly about before, but it was quite helpful."

Tyrone

If you identify as gay, bisexual, transgender or LGBT+, you may worry about your healthcare team treating you insensitively. Many sexual difficulties caused by pelvic radiotherapy are similar whatever your sexuality. But you may have some specific questions. Having your sexual or gender identity acknowledged may help you feel more supported. It also means your healthcare team can give you the right information and advice.

If you feel unable to talk to your healthcare team about your sexuality, contact the LGBT Foundation. They have a helpline that can give you confidential advice and support (see page 63).



Having sex after treatment

Your team may advise you to wait a few weeks after radiotherapy before having sex. This is to allow any irritation and side effects to improve. Ask your doctor or nurse for advice about this, as it can depend on the treatment you are having.

It is normal to feel nervous about having sex after pelvic radiotherapy. You may have ongoing side effects. Or you may be coping with changes that affect your feelings about your body. If you are ready to have sex, take your time and make sure you are relaxed. If you have any problems that do not improve, talk to your cancer doctor or nurse.

We have more information in our booklet Cancer and your sex life – information for men (see page 56).

Protecting your partner

You may have had brachytherapy, with radioactive seeds placed in the prostate gland as part of your treatment (see page 10). After having this treatment, you should use condoms during sex for the first few weeks. This is in case a radioactive seed moves from the prostate into the semen. But it is very rare for this to happen.

Contraception

It may be important that you do not make someone pregnant during radiotherapy, and for a few months after it has finished. Some treatments can be harmful to an unborn baby.

Your radiotherapy team can give you more information about this. They may tell you to use contraception to prevent a pregnancy during your treatment and for a time after. There are different types of contraception. Ask them to explain which type is best for you.

Preventing pregnancy may be important even if you have been told that radiotherapy might affect your fertility. It is difficult to know exactly when this will happen. You may still be able make someone pregnant.

Erection problems

Radiotherapy to the pelvic area can cause problems getting or keeping an erection. This is called erectile dysfunction or ED. You may find your erections are not as strong as they were before the treatment. You may get an erection, but then lose it. Or you may be unable to get an erection at all. Your radiotherapy team can explain what is likely to happen.

Although you may feel embarrassed, talk to your doctor if you are having problems. There are treatments for ED that may help. We have more information about ED after cancer treatment in our booklet Cancer and your sex life – information for men (see page 56).

It is natural to worry about how ED will affect your sex life. It may help to remember there are lots of ways to give and receive pleasure. Sex is not only about penetration. There are other ways to be intimate with your partner, such as oral sex, mutual masturbation or using sex toys. Sometimes, both you and your partner may enjoy just hugging and kissing as ways of being intimate during this time.

Changes in ejaculation

You may have a sharp pain when you ejaculate. This is because radiotherapy can irritate the tube that runs through the penis from the bladder (the urethra) – see the illustration on page 6. The pain should get better a few weeks after treatment finishes.

After treatment, pelvic radiotherapy reduces the amount of semen you produce. This means when you ejaculate, you may only notice a small amount of fluid. Some men do not produce any semen at all. This is called a dry ejaculation. But you will still be able to orgasm (climax). You may find the sensation of an orgasm feels different from before.



Effects on fertility

Pelvic radiotherapy may make you unable to make someone pregnant (infertile). Before you decide to have treatment, your team will explain any risks to your fertility. For some people, radiotherapy causes changes that may get better with time. For others, the treatment they have to the pelvic area causes permanent infertility.

Your team may talk to you about persevering your fertility, if this is possible for you. For men, preserving fertility usually means collecting and freezing sperm.

Preserving fertility is not always possible. But it may mean some people who lose their fertility are still able to have a baby in the future. We have more information about fertility preservation for men in our booklet Cancer treatment and fertility information for men (see page 56).

Losing your fertility can be hard to cope with, especially if you had planned to have children. It can help to get the right support. If you have a partner, it may be a good idea to include them in this too.

Your doctor or nurse can usually arrange for you to talk to a fertility counsellor or therapist. Talking to other people who are in a similar position may be helpful. Organisations such as the British Infertility Counselling Association (BICA) can offer support and counselling (see page 61). If you are not sure where to start or just want to talk, you can contact our cancer support specialists (see page 58).



AFTER PELVIC RADIOTHERAPY

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Follow-up

Your team will plan your treatment carefully to reduce the risk of side effects. But most people will have a few side effects during, or after, radiotherapy.

After your radiotherapy has finished, your oncologist or radiographer will tell you about your follow-up care. It will depend on the type of cancer and the type of radiotherapy you had. Your follow-up care may involve one of the following:

- You may not need follow-up appointments. Instead you might get advice about problems to watch for and the details of someone to contact, if needed.
- You might have regular follow-up appointments at the radiotherapy department, or your original hospital. These may be with the specialist who recommended the radiotherapy. The first appointment is usually 4 to 8 weeks after treatment finishes.
- A nurse or radiographer may follow-up by telephone. They will check how you are by asking you questions. If they are worried about anything, they will arrange an appointment for you at the clinic.
- You may have patient led follow-up. This means you do not have set appointments, but can contact the team and arrange one if you are worried. This may not be suitable for everyone. You still have any tests or scans that you need as normal.

Follow-up appointments are a good opportunity to discuss any problems or worries you have. It may help to make a list of auestions beforehand so you do not forget anything important. There are some notes pages at the end of this booklet (see pages 64 to 65). If you feel anxious, it can help to have a friend or family member with you.

If you have any ongoing side effects or new symptoms, contact your specialist nurse, cancer doctor or the person you have been told to contact. You should do this at any time, even between appointments. Do not wait until your next scheduled appointment. You can just ask for an earlier one.

> 'The only problems I have now are a bit of wind trouble, slight pains in my tummy, and some problems with my bowel. I have a fantastic support network and set myself targets to get to.'

John

Well-being and recovery

You may have mixed emotions when you come to the end of your radiotherapy treatment. You will probably feel relieved, but you may also feel anxious and uncertain. Some people find they feel low after finishing the treatment. It can take time to get your confidence back, and accept what you have experienced.

It may also take time to recover from treatment. You may feel tired for a while, and you may have lots of emotions to deal with. It is important to give yourself time to recover and adjust. You can call our support line and talk to one of our cancer support specialists (see page 58). You can also ask your healthcare team for details of local support groups that may be able to help (see page 59).

We have more information about dealing with your emotions in our booklet **How are you feeling?** (see page 56).

Lifestyle changes

When your treatment has finished, you may want to make some positive changes to your lifestyle. You may have already followed a healthy lifestyle before your treatment. But maybe now, you want to focus more on being as healthy as you can.

There are things you can do to help your body recover. These can also help improve your well-being, and lower your risk of getting other illnesses and other cancers.



Giving up smoking

If you smoke, it is important to try to stop. Smoking can delay your recovery, and increases your risk of developing a second cancer.

Giving up smoking can be difficult, but there is lots of support available (see page 63).

Healthy eating

After pelvic radiotherapy, some people may not be able to cope with as much fruit and fibre in their diet. But it is important to have a well-balanced diet that includes fresh fruit and vegetables. You should try to do this even if your appetite and interest in food has reduced. If changes in your bowel habits affect what you can eat, tell your cancer doctor or specialist nurse. They can refer you to a dietitian for advice.

You can find more details about healthy eating in our booklet Healthy eating and cancer (see page 56).

'I found that eating in small quantities when I was hungry, rather than sticking to meal times, seemed to help."

Andrew

Maintaining a healthy weight

Being overweight is a risk factor for some cancers and other health conditions. These include heart problems and diabetes.

We have more information in our booklets (see page 56 for ways to order these booklets):

- Heart health and cancer treatment
- Cancer and diabetes
- Managing weight gain after cancer treatment.

Physical activity

Physical activity can be an important part of your recovery after treatment. It can:

- help you feel better in yourself
- help increase your energy levels
- reduces the risk of heart disease, strokes and diabetes.

Talk to your cancer doctor or GP before you start exercising. Start slowly and increase your activity over time. You may find our booklet **Physical activity and cancer** helpful (see page 56).

Stick to sensible drinking guidelines

NHS guidelines suggest that both men and women should:

- not regularly drink more than 14 units of alcohol in a week
- spread the alcohol units they drink in a week over 3 or more days
- try to have several alcohol-free days every week.

A unit of alcohol is:

- half a pint of ordinary strength beer, lager or cider
- one small glass (125ml) of wine
- a single measure (25ml) of spirits.

There is more information about alcohol and drinking guidelines at drinkaware.co.uk

Complementary therapies

Complementary therapies may help you feel better and reduce any stress and anxiety you might have. Relaxation, counselling and psychological support are available at many hospitals. Some hospitals also offer:

- visualisation
- massage
- reflexology
- aromatherapy
- hypnotherapy.

Complementary therapies are sometimes available through cancer support groups (see page 59) or your GP. Many complementary therapists also have private practices.

Not all complementary therapies are suitable for people who have just finished radiotherapy. It is important to check with your healthcare team first if you are thinking of having one.

We have more information about the different types of complementary therapies and advice on choosing a therapist on our website (see page 56).

Look after your pelvic floor muscles

Pelvic floor muscles support the organs in the pelvis. They are important for bladder and bowel control. Radiotherapy to the pelvis can weaken these muscles. They are also naturally weakened as you get older.

You may be advised to do regular pelvic floor exercises after pelvic radiotherapy. It is important to do pelvic floor exercises correctly. So you will usually be referred to a physiotherapist or specialist nurse, who will teach you how to do them.

Reduce the risk of lymphoedema

Lymphoedema is swelling that happens because of a build-up of fluid in the body's tissues.

Surgery to remove lymph nodes, or radiotherapy to the lymph nodes can cause lymphoedema. If you have both treatments, the risk is higher.

There are things you can do to lower your risk of lymphoedema. These include protecting the skin on your legs and feet, being active and keeping to a healthy weight. Here are some things you can do to help:

- Keep skin clean and supple by moisturising regularly. Your specialist nurse or cancer doctor can tell you which creams to use.
- Wear long trousers if you are gardening.
- If you get any cuts or grazes on your feet or legs, use antiseptic cream and cover them up. If the area becomes red, warm or swollen, see a doctor straight away.
- Wear well-fitting footwear and do not walk around barefoot.
- To avoid cuts, use nail clippers instead of scissors to cut your nails.
- Avoid standing for long periods and put your feet up if you are sitting down.
- Use a high factor sun cream (SPF 30) and cover up in the sun. This will protect the skin on your leas and feet.

Always tell your cancer doctor or specialist nurse if you have a swelling in your feet or legs. The earlier lymphoedema is diagnosed, the easier it is to manage. We have more information in our booklet **Understanding lymphoedema** (see page 56).



Late effects of pelvic radiotherapy

Late effects are side effects that either:

- begin during, or shortly after treatment and last longer than 6 months – these are sometimes called long-term effects and might become permanent
- begin months, or even years after treatment.

Many people who have pelvic radiotherapy never develop late effects. Or if they do, the late affects are mild and do not interfere with their daily lives. Newer ways of giving radiotherapy are designed to reduce the chance of developing late effects as much as possible.

The risk of getting late effects depends on different things. These include the type of cancer you have had, the dose of radiotherapy you have had and other cancer treatments you have had. Your cancer doctor or specialist nurse can tell you more about your risk.

If late effects develop, you can often have effective treatment. Or you can manage the effects to make them easier to deal with. Some late effects improve over time, and may eventually go away on their own. The most common late effects after pelvic radiotherapy are changes to how the bowel and bladder work.

Changes in bowel habit

You may continue to have changes in your bowel habit after treatment has finished. You may have:

- loose stools (poo), diarrhoea or sometimes constipation
- a need to poo urgently.

Sometimes, you need medication to control symptoms and regulate the bowel.

Rarely, some people find they have problems with leakage (incontinence). There are many effective treatments and ways of managing changes in bowel habits after pelvic radiotherapy.

Talk to your doctor or specialist nurse if you have any of these ongoing problems.

Bladder changes

After radiotherapy, you may:

- pass urine (pee) more often
- need to get up during the night to pass urine
- feel discomfort when passing urine
- sometimes, have problems with leaking urine (incontinence).

It is important to let your cancer doctor know if you have ongoing bladder symptoms, or develop new symptoms. An expert can assess you and give you the right treatment and advice.

Bleeding

About a year after radiotherapy, fine blood vessels may develop in the lining of the bladder or bowel. This can cause small amounts of blood in your urine or stools. This does not usually cause problems, but it can be worrying when it first happens. You may worry that the cancer has come back.

It is important to tell your doctor if you notice any blood in your urine or stools. Something else may be causing this, not the cancer or radiotherapy. You can have tests to find the cause and have treatment if you need it.

Other possible late effects

Some men develop sexual difficulties (erectile dysfunction) months or years after having pelvic radiotherapy. This may happen if there is scarring to the nerves. Or it may happen if radiotherapy has caused narrowing of the blood vessels that supply blood to the penis. If this happens there are treatments that can help. We have more information about these effects in our booklet Cancer and your sex life - information for men (see page 56).

Ongoing tiredness can be a problem for some men. Get plenty of rest, but balance this with some gentle exercise, such as short walks. This will give you more energy and keep your muscles working. It also helps to eat a healthy diet (see page 42) and drink plenty of fluids.

Save some energy for doing the things you enjoy. You can also ask others for help doing daily tasks, if these are making you too tired. We have more information about coping with tiredness in our booklet Coping with fatigue (see page 56).

Rarely, men develop pain in their pelvis or hips. This is because radiotherapy may have caused some fine cracks in the bones of the pelvis. These usually heal on their own, but you may need to take painkillers.

Things to watch for

Always tell your cancer doctor or specialist nurse if any side effects do not go away. You should also contact them if you develop any new symptoms or problems after you finish treatment.

You should tell them if you:

- have any bleeding that looks like it is in your stools, or have blood in your urine
- have loose stools, diarrhoea or constipation
- feel you need to go to the toilet although your bowel is empty (tenesmus)
- have difficulty emptying your bowel
- need to empty your bowel (poo) at night, need to empty your bowel urgently, or have accidents (incontinence)
- need to pass urine often or urgently, leak urine (incontinence), or have pain or difficulty passing urine
- have pain or difficulty having sex, or problems getting back to your usual sex life.

You should also tell them if you notice symptoms in other parts of the body, including:

- swelling in one or both legs
- pain in your hips or pelvis when you are walking.

You may feel embarrassed talking about problems related to your bowel, bladder or sex life. But doctors and nurses are used to talking about intimate problems like these. Do not let embarrassment stop you getting help. Your cancer doctor will assess your symptoms to see if radiotherapy is causing them. Sometimes, you may need tests to find the cause of your symptoms.

Getting expert help

To help with late effects, you may be referred to a doctor or nurse who is an expert in that area. This depends on the late effects you have and how they affect you. For example, if you have bowel problems, you may see a gastroenterologist. This is a doctor who specialises in bowel problems.

There are also some expert doctors who specialise in treating late effects of radiotherapy. But this is a specialised area, so there are not many of these doctors. You may have to travel a longer way 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.

For more information on the help available, contact the free Macmillan Support Line **0808 808 00 00** (see page 58).

Your feelings

It is common to feel lots of different emotions during and after treatment. It is normal to have a low mood at first. As you recover and get back to your everyday life, any negative feelings usually get easier to deal with. Talking with family and friends often helps. If things do not improve, or you feel anxious or depressed, tell your doctor or nurse. They can arrange more support for you if you need it.

Some people find meeting others in a similar situation helpful. There may be a local support group near you. Our cancer support specialists can tell you about what is available in your area (see page 58).

Or you may like to join our Online Community (see page 59). You can get advice and support from others, or give advice based on your own experiences.

'I was working, playing golf again, and slowly using less incontinence pads. I would go out most days without one with just a slight leakage - I could see the end of the tunnel."

John



FURTHER INFORMATION

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About our information

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

Order what you need

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

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

Online information

All of our information is also available at macmillan.org. uk/information-and-support There you'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
- eBooks
- 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.



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Information centres

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

Visit one to get the information you need, or if you'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

Online Community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

Having cancer can bring extra costs such as hospital parking, travel fares and higher heating bills. If you've 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/ financial support 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

Other useful organisations

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

Pelvic radiotherapy support organisations

Action Bladder Cancer UK Tel 0300 302 0085 Email info@ actionbladdercanceruk.org www.

actionbladdercanceruk.org Online information and support for people affected

by bladder cancer.

Bladder and **Bowel Community** Tel 01926 357 220 **Email**

help@bladderandbowel.org www.bladderandbowel.org Supports people living with conditions that affect their bladder or bowel. Supplies the 'Just Can't Wait' toilet access card and phone app.

Bowel Cancer UK Tel 020 7940 1760 **Email**

nurse@bowelcanceruk.org.uk www.bowelcanceruk.org.uk Provides information and support for everyone affected by bowel cancer.

British Infertility Counselling Association www.bica.net

Professional infertility counselling association. Provides information and contact details for counsellors listed on their website.

Orchid Tel 0203 745 7310 Helpline 0808 802 0010 **Email**

nurse@orchid-cancer.org.uk www.orchid-cancer.org.uk Works on behalf of anyone affected by male cancer - prostate, testicular and penile cancer. Orchid exists to save men's lives from male cancer through a range of support services, education and awareness campaigns and a pioneering research programme.

Pelvic Radiation Disease Association Helpline 01372 744338 (hours vary) www.prda.org.uk Support people affected by the late effects of pelvic radiotherapy.

Prostate Cancer UK Tel 0203 310 7000 **Specialist Nurses** 0800 074 8383

www.prostatecanceruk.org Help campaign for men with prostate cancer to receive the best treatment and care wherever they live in the UK, based on the latest evidence. Provide information and support for men affected by prostate cancer.

Sexual Advice Association sexualadviceassociation. co.uk

Organisation that aims to help improve people's sexual health and wellbeing.

LGBT-specific information

LGBT Foundation

Tel 0345 330 3030 (Mon to Fri, 9am to 9pm, Sat and Sun, 10am to 6pm) 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.

Equipment and advice on living with a disability

Disability Rights UK Tel 0330 995 0400 **Email** enquiries@ disabilityrightsuk.org www.disabilityrightsuk.org Provide information and support for disabled people. Sells Radar keys that allow

disabled people to access the National Key Scheme's locked

public toilets.

Support with stopping smoking

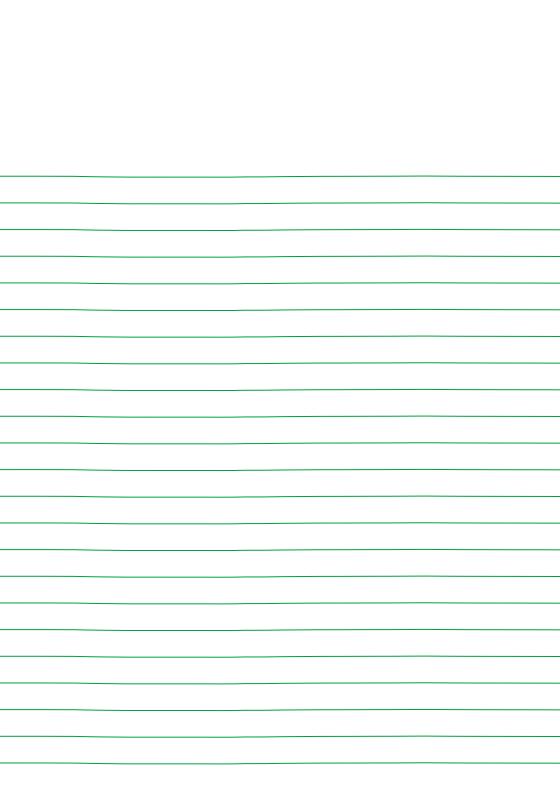
Smokefree (England) Tel 0300 123 1044 (Mon to Fri, 9am to 8pm, and Sat and Sun, 11am to 4pm) www.nhs.uk/smokefree

Smokeline (Scotland) **Tel** 0800 84 84 84 (Mon to Fri, 8am to 10pm, Satand Sun, 9am to 5pm) www.canstopsmoking.com

Stop Smoking Wales (Help me quit) Tel 0808 252 8937 **Text** 'HMQ' to 80818 www.helpmequit.wales

Want2stop (Northern Ireland) Text 'QUIT' to 70004 www.want2stop.info

YOUR NOTES AND QUESTIONS



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 our Chief Medical Editor, Prof Tim Iveson, Macmillan Consultant Medical Oncologist.

With thanks to: Katherine Aitken, Clinical Oncologist; Tracey Ellis, Macmillan Consultant Radiographer; and Chris O'Sullivan, Therapy Radiographer and Lecturer. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

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

Sources

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

Andreyev HJN, et al. Practice guidance on the management of acute and chronic gastrointestinal problems arising as a result of treatment for cancer. Gut, 61: 179-192. 2012.

Nicholas S, et al. Pelvic radiation and normal tissue toxicity. Seminars in Radiation Oncology. 27:358-369. 2017.

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 Valid from Expiry date

Don't let the taxman keep your money

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

I am a UK tax payer 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.

Registered with FUNDRAISING

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

Security number

Issue no

Signature

Date

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

REGULATOR

This booklet is for men who are having, or are going to have, radiotherapy to the pelvic area. The pelvic area is the lower part of the tummy (abdomen), between the hips.

The booklet explains side effects that may happen during, or shortly after, pelvic radiotherapy, and how these can be controlled or reduced. It also has information about what you can do to help yourself.

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

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

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

MACMILLAN CANCER SUPPORT

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