

A practical guide to tests and treatments

PELVIC RADIOTHERAPY IN WOMEN – MANAGING SIDE EFFECTS DURING TREATMENT



About this booklet

This booklet is for women 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.

Radiotherapy is an effective treatment that can be used to cure or control certain cancers that start in the pelvic area. Like any cancer treatment, it can cause side effects. In this booklet, we explain:

- the possible immediate side effects of pelvic radiotherapy
- how they can be controlled or reduced
- what you can do to help yourself.

This booklet is about side effects that happen during or shortly after treatment.

We've also included some information about late effects. These are side effects that don't go away or that develop some time after the treatment finishes.



If you've had pelvic radiotherapy in the past and now have late effects, our booklet **Managing the late effects of pelvic radiotherapy in women** has more information.

We can't advise you about the best treatment for you. This information can only come from your doctor, specialist nurse or radiographer, who know your full medical history.

Turn to pages 55–59 for some useful addresses and websites. On page 60 there is space for you to write down any notes or questions you want to ask your doctor, nurse or radiographer.

In this booklet, we've included some quotes from women who have had pelvic radiotherapy, which you may find helpful. Quotes are from the website **healthtalk.org** and some names have been changed.

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

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

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THE PELVIS AND PELVIC RADIOTHERAPY

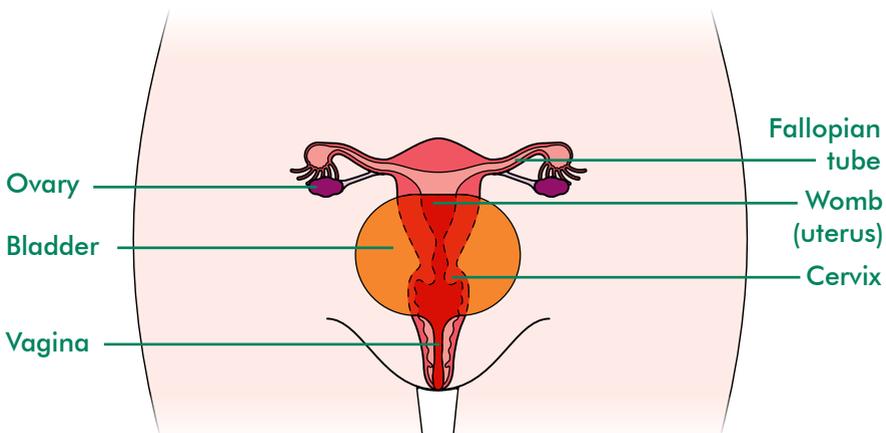
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The pelvis

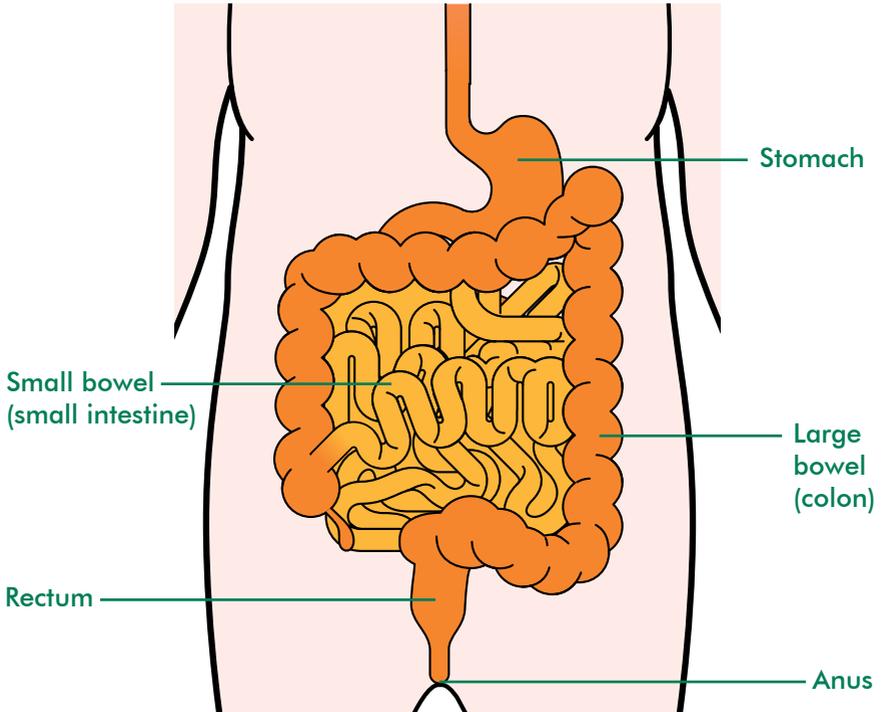
The pelvis is the area in the lower part of the tummy (abdomen) between the hips. In women it contains:

- the reproductive system, which includes the ovaries, fallopian tubes, womb (uterus), cervix and vagina (see diagram below)
- the bladder (see diagram below)
- the lower end of the large bowel (the colon, rectum and anus), and part of the small bowel (see diagram opposite)
- lymph nodes (glands)
- the pelvic bones.

The female reproductive system and bladder



The digestive system





Radiotherapy

Radiotherapy uses high-energy rays to destroy cancer cells, while doing as little harm as possible to healthy cells. In women, pelvic radiotherapy can be used to treat cancer of the cervix, womb, vulva, vagina, bladder, rectum or anus.

Radiotherapy can be given either from outside the body (externally) or from inside the body (internally). Some women are treated with a combination of both methods.

Your course of radiotherapy will be prescribed by a cancer specialist (clinical oncologist). This is a doctor who specialises in the use of radiotherapy and chemotherapy. The person who operates the machines and helps position you before each treatment is called a radiographer.

External radiotherapy

This is normally given as a series of short, daily treatments in the radiotherapy department at the hospital. It uses equipment similar to a large x-ray machine. You often have treatment over a number of weeks as an outpatient. It's most commonly given once a day from Monday to Friday, with a rest at the weekend.

Each treatment takes a few minutes and is painless. It won't make you radioactive and it's safe for you to be around other people, including children and pregnant women.

There is a photo of someone having external radiotherapy on page 4.

Internal radiotherapy (brachytherapy)

Internal radiotherapy gives a high dose of radiation to the area being treated, but only a low dose to the surrounding normal tissue. It's also known as brachytherapy. A radioactive material (source) is placed inside the body, close to the area being treated.

There are different ways of giving internal radiotherapy, depending on the type of cancer you have. You may have a few separate treatments as an outpatient, or as an inpatient over a few days. You may be given an anaesthetic (so you are asleep) or sedation (to help you relax) while you are given brachytherapy.



If you have cancer of the cervix or womb, the treatment is given by a machine. The machine delivers the radioactive source to the correct place in the body through tubes (applicators) placed in the vagina and/or womb. The machine is programmed to give you the exact dose you need. At the end of the treatment, the radioactive source is withdrawn from the applicator into the machine. After this, the nurse removes the applicators.

For other types of cancer, the doctor may put the radioactive source in place and then remove it when the treatment is finished.

We have booklets on different cancer types, which have more specific information about internal radiotherapy. To order them, call us on **0808 808 00 00**.

Special safety measures are taken while the radioactive source is in your body, to make sure other people aren't exposed to radiation. Having internal radiotherapy may feel uncomfortable at times, but you'll be given painkillers and the nurses will check on you regularly.

Once the treatment is over, there is no risk of exposing your family or friends to the radiation.



You can read more information about external and internal radiotherapy in our booklet **Understanding radiotherapy**.

You also may find it helpful to watch the video at macmillan.org.uk/radiotherapy which explains how radiotherapy works.



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How radiotherapy might affect you

Radiotherapy destroys cancer cells in the treated area, but it can also affect some of the surrounding normal tissue.

Radiotherapy affects people in different ways. It's difficult to predict exactly how you will react to it. The side effects you have will depend on different factors. These include:

- the type of cancer you have
- the dose of radiotherapy you have
- whether it's external or internal radiotherapy.

Women having internal radiotherapy on its own will not have as many side effects as women having a course of external radiotherapy.

If you also have other types of cancer treatment, such as surgery, chemotherapy or hormonal therapy, this can affect the side effects you have. Having chemotherapy at the same time as radiotherapy (called chemoradiation) may cause more severe side effects.

Your cancer specialist, specialist nurse or radiographer will explain the most likely side effects. Let them know about any concerns or questions that you have.

Most side effects are temporary and start a week or two into the treatment. They may continue to get worse for a couple of weeks after treatment finishes, before they begin to get better. They will usually improve gradually over the next few weeks or more.

Occasionally, some side effects don't completely go away. And sometimes side effects may develop months or years later. These are called long-term or late effects (see pages 41–46).

During treatment, you may have some of the side effects described in this chapter. It's important to tell your radiographer, cancer specialist or specialist nurse if you do. They can give you advice on how to manage them and tell you about treatments that can help.



Tiredness (fatigue)

Radiotherapy often makes you feel tired, especially towards the end of the course of treatment. The tiredness continues after the treatment has finished and may last for a few months. You'll find that your energy levels will gradually improve. However, it can take a while to recover, so don't be too hard on yourself.

There are some things you can do to help manage tiredness:

- Pace yourself so you don't overdo it, and take regular rests.
- If you're able to, plan some physical activity into your day, such as a short walk. This will help to build up your energy levels (see page 38).
- Ask family and friends to help out, perhaps with things like household tasks and taking care of children.
- Make sure you get enough sleep.



We can send you more information about coping with tiredness, keeping physically active during treatment and getting a good night's sleep.

Effects on the skin

Sometimes, radiotherapy can cause a skin reaction in the area being treated. The skin may redden or get darker and become dry, flaky and itchy. Towards the end of treatment, the skin sometimes becomes moist and sore. There may be breaks in the skin, especially around the back passage (anus) and groin.

Your radiographer or nurse will check your skin regularly. Tell them if your skin is sore or you notice any other changes. They will check your skin and may prescribe a cream or dressings to help. They can also prescribe painkillers, if needed.

Skin reactions may be at their worst up to two weeks after radiotherapy finishes, before beginning to improve. If you're sore or have any problems with your skin during this time, contact the radiotherapy department for advice.

Pelvic radiotherapy may make the hair around your genital area (pubic hair) fall out. It should start to grow back again within a few weeks after radiotherapy finishes, but it may be thinner. Occasionally, hair loss can be permanent.

Skin care

Your radiographer or specialist nurse will tell you how to look after the skin in the treated area. They will usually give you the following advice:

- Keep the skin in the area clean. Wash it gently with lukewarm water and carefully pat it dry with a clean, soft towel.
- Check with the radiographer or nurse before you put anything on the skin in the treated area.
- It is better to have a shower than a bath, as soaking in a bath can make the skin too moist. When having a shower, use a very gentle stream of lukewarm water. If you have a bath, don't soak in the water for longer than a minute or two.
- Use a simple moisturiser on the skin. Your radiographer or specialist nurse will be able to suggest moisturisers you can try.
- Wear underwear made from natural fibres, such as cotton or silk. They should be loose-fitting (such as shorts) so they don't rub against the skin. Avoid wearing tights or tight-fitting trousers.
- Don't shave, wax or use hair removal creams until a few weeks after radiotherapy is over and any skin reaction has healed.
- Protect the skin in the treatment area from the sun for the first year after radiotherapy. Even after any skin reaction has settled, you should always wear sunscreen with a high sun protection factor (SPF) of at least 30.
- Wash your underwear, bed linen and towels using a non-biological powder or liquid for people with sensitive skin.
- Avoid smoking, as it can make skin reactions worse (see page 36).

Bladder side effects

Pelvic radiotherapy can cause irritation and inflammation of the lining of the bladder. You may find that you have some of the following symptoms:

- a need to pass urine often (frequency)
- a need to pass urine during the night (nocturia)
- a burning sensation when you pass urine (similar to cystitis)
- a feeling that you can't wait when you need to empty your bladder (urgency)
- blood in your urine (haematuria)
- leaking small amounts of urine (incontinence).

Your doctor may prescribe painkillers or anti-inflammatory drugs to ease these symptoms. Sometimes drugs called anticholinergics are also used. Your doctor or specialist nurse can give you more information.

What you can do

- Drink at least 2–3 litres of fluids (3.5–5.5 pints) a day. Urine that’s concentrated irritates the bladder and makes symptoms worse. Drinking more reduces this.
- Avoid smoking, which can make the symptoms of bladder irritation worse (see page 36).
- Avoid drinks that might irritate the bladder. These include drinks containing caffeine (tea, coffee, drinking chocolate and cola), alcohol, fizzy drinks, acidic drinks (orange and grapefruit juice) and drinks with artificial sweeteners (‘diet’ or ‘light’ drinks).
- Cranberry juice or capsules may help reduce symptoms.
- Let your nurse or radiographer know if you have any incontinence.

If symptoms get worse, you have a high temperature, or you feel you can’t pass urine, contact the hospital straight away.

If you have incontinence, your nurse will take a urine sample to check for signs of infection. This is a common and easily treatable cause of incontinence. They may also arrange for you to have pads if needed and give you advice on looking after your skin. If the problem doesn’t settle within a few weeks, the nurse can refer you to a continence specialist for advice and treatment.

Sometimes you’ll have further tests to assess the incontinence. Your specialist team will discuss these with you if you need them.

It is usually possible to improve incontinence. So it is important to let your doctor or nurse know if it is a problem for you.

You can get a card to show to staff in shops and other public places if you need to use their toilet urgently – see page 23.

Bowel side effects

Pelvic radiotherapy can cause some of the following side effects:

- loose stools, diarrhoea or sometimes constipation
- a need to open your bowels urgently
- cramping pains in your tummy (abdomen) or back passage
- passing a lot of wind.

Some other, less common side effects are:

- feeling as if you need to go to the toilet although your bowel is empty (tenesmus)
- passing mucus or blood when you empty your bowels
- slight soiling of your underwear or some leakage (incontinence), although this is rare.

Tell your cancer specialist, specialist nurse or radiographer about any bowel side effects you have.

Diarrhoea is the most common side effect and usually starts during or after the second week of radiotherapy. If you have diarrhoea, your specialist will prescribe anti-diarrhoea tablets to help reduce it.

Some people are advised to make changes to their diet during radiotherapy. This may involve eating a bland diet and cutting down on fibre. Your specialist nurse or radiographer will tell you if this is right for you. If you have diarrhoea, you should drink plenty of fluids.

If you have tummy cramps, tell your cancer specialist or nurse. They can prescribe drugs to help with this. If you're constipated, your doctor will usually prescribe a laxative and give you advice on diet.

Let your nurse or radiographer know if you have any soiling or leakage. They will give you advice on coping with this and looking after the skin in the area.

Bowel side effects usually start to improve about two weeks after radiotherapy has finished. Sometimes, it may take a few months for the bowel to settle down.

What you can do

- Drink at least 2–3 litres of fluid a day (to replace fluid lost through diarrhoea) and avoid caffeine and alcohol.
- Follow any dietary advice given by the hospital.
- Take your anti-diarrhoea tablets or other medicines you have been prescribed.
- Avoid foods and drinks that give you wind, such as pickles, beans, curry and fizzy drinks.
- Gentle exercise may help if you have a lot of wind. Or you could try charcoal tablets, which you can buy at the chemist.
- If side effects don't get better, tell your specialist nurse or doctor.
- Avoid smoking, which stimulates the bowel and can make diarrhoea worse (see page 36).

There is more information about coping with bowel problems in our booklet **Eating problems and cancer**.

'Just Can't Wait' toilet card

If you need to go to the toilet more often, or feel that you can't wait when you do want to go, you can get a card to show to staff in shops, pubs and other places. The card allows you to use their toilets without them asking awkward and embarrassing questions.

You can get a card from the Bladder and Bowel Foundation (see page 55). There is a small charge for the card.

Macmillan also has a toilet card that you can order from be.macmillan.org.uk

'The medication sorted the diarrhoea out – it wasn't bad. It doesn't matter really in the end, if it's going to do you good. You know if it's getting rid of cancer, six weeks of diarrhoea is nothing.'

Frances

Effects on the vagina

During radiotherapy, you may have a skin reaction in the treated area. There's more information on skin care on page 18.

Radiotherapy to the pelvis can make the vagina narrower, less stretchy and drier. This may make having sex uncomfortable.

It may also be more difficult for you to have internal examinations.

Narrowing of the vagina

Your specialist nurse may recommend that you use vaginal dilators to try to prevent the vagina from narrowing. Dilators are tampon-shaped, plastic rods of different sizes that you use with a lubricant. Using a vibrator or having regular penetrative sex may also help prevent vaginal narrowing.

You may be advised to gently start using the dilator shortly after your radiotherapy has finished.

Your specialist nurse or radiographer will advise you on how helpful a dilator may be for you and explain how to use them.

Vaginal dryness

This can make having sex uncomfortable, but there are lots of vaginal lubricants and creams that can help. You can buy them from chemists and some supermarkets.

Creams that contain a small amount of the female hormone oestrogen can also be used to help with dryness and vaginal narrowing. These are available on prescription from your doctor. Hormone creams are not recommended if you have had womb (endometrial) cancer. Your specialist nurse can give you advice.

Moisturising creams and lubricants

There are creams you can use regularly to help with dryness, as well as lubricants you can use during sex to make it more comfortable and pleasurable.

Replens MD[®] is a cream that binds to the wall of the vagina and helps rehydrate cells and make the vagina less dry. Hyalofemme[®] helps to hydrate the cells giving a moisturising effect. Both creams are applied every two or three days.

Water-based lubricants including Senselle[®], Astroglide[®], Sylk[®], Vielle[®] or Durex[®] Lube can be bought at chemists or some supermarkets. Organic lubricant products such as Yes[®] or V Gel[®] are available to buy online. Not all water-based products are the same and some can cause skin irritation. You may need to try a few different ones until you find one that suits you.

Oestrogen creams or pessaries

These contain very small amounts of oestrogen and can be used as a cream or as a tablet that's inserted into the vagina (pessary). They help with dryness and may prevent the vaginal wall from becoming thin. They are not recommended in all situations, so always check with your cancer specialist first.

Effects on your sex life

You may be advised to wait a few weeks after radiotherapy before having sex. This is to allow any inflammation and side effects to settle. Ask your doctor or nurse for advice on this, as it can vary.

You may find that you don't feel like having sex for a while. This may be because of ongoing side effects, anxiety, or how you feel about yourself sexually. You, and your partner if you have one, may need a period of time to adjust.

It's not unusual to feel nervous about having sex for the first time after pelvic radiotherapy, but it's perfectly safe for both you and your partner. Taking your time, making sure you're relaxed and using vaginal lubricants or creams will help to make it feel more comfortable. If you have sexual difficulties that don't improve, it's important to let your cancer specialist and specialist nurse know.

It can be embarrassing to talk about your sex life and any problems you're having, but doctors and specialist nurses are used to dealing with intimate problems. They can often give you advice and support if things aren't going well. Your hospital doctor or GP can also refer you to a counsellor or sex therapist.



There's more information about coping with the impact cancer and its treatment can have in our booklet **Sexuality and cancer – information for women**. You may also want to watch the video at macmillan.org.uk/sexuality to hear a sex therapist discuss some common sexual problems and solutions for people after cancer treatment.

Contraception

Some hospitals may advise that you can still have penetrative sex during radiotherapy. Pelvic radiotherapy will bring on the menopause (see pages 28–30), but your periods may not stop completely until after treatment is over. If you're having sex during treatment, it's very important to use effective contraception to prevent pregnancy until your periods stop completely. This is because radiation may cause damage to a baby conceived during or shortly after radiotherapy.

If you have problems with your bowels, such as loose stools or diarrhoea, you should use a barrier form of contraception instead of the contraceptive pill. This is because diarrhoea can affect the way that the contraceptive pill is absorbed.

You should always talk to your specialist nurse or doctor before you stop using contraception.

Early menopause

Pelvic radiotherapy stops the ovaries producing oestrogen and progesterone and brings on the menopause. Early menopause as a result of radiotherapy may cause more noticeable symptoms than a natural menopause. Symptoms can include:

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

The menopause also means your ovaries no longer produce eggs, so you will not be able to get pregnant. There's more information about this on page 31.

Hormone replacement therapy (HRT)

You may be able to have HRT to replace the hormones your ovaries are no longer producing. This can improve some menopausal symptoms, although you will not be able to get pregnant.

Early menopause at a young age can increase the risk of bone thinning (osteoporosis) and heart problems later in life, so HRT can also help protect against these.

HRT is not usually recommended after some types of cancer, as it may increase the risk of the cancer coming back. Ask your cancer specialist or nurse if it is suitable for you.



Managing menopausal symptoms

If HRT is not advised, or you don't want to have it, there are other ways to manage menopausal symptoms. You can ask your doctor or specialist nurse for advice.

Low doses of antidepressant drugs, an anti-epilepsy drug called gabapentin (Neurontin®) or a drug called clonidine (Catapres®, Dixarit®) can reduce hot flushes and sweats. Some women find that using slow, controlled breathing techniques, yoga or acupuncture helps with hot flushes.

You can use different vaginal lubricants or creams to help reduce discomfort from vaginal dryness (see page 25), which can be caused by the menopause.

Making lifestyle changes may help reduce some of your symptoms and improve your general health. There's more information about this on pages 36–39.

The Daisy Network (see page 56) is a support organisation for women who've had an early menopause. It can give you more information. Ask your specialist nurse for advice if you're finding menopausal symptoms difficult to manage.

You can call our cancer support specialists on **0808 808 00 00** for more information.



We can send you more information about managing menopausal symptoms. There's also a video on our website of one woman's experience of early menopause due to cancer treatment. Visit [macmillan.org.uk/menopausalsymptoms](https://www.macmillan.org.uk/menopausalsymptoms)

Effects on fertility

Pelvic radiotherapy stops the ovaries producing eggs and also affects the lining of the womb. As a result, you won't be able to get pregnant. Infertility can be very distressing and hard to come to terms with, especially if you had planned to have children or add to your family.

Getting the right support can help you to cope. 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 professional fertility counsellor or therapist. Our cancer support specialists on **0808 808 00 00** can also give you further help and advice.

Talking to other women in a similar position may be helpful. Some of the organisations on pages 55–58 offer this, as well as counselling.

Before having radiotherapy, some women may want to see a fertility specialist to discuss the possibility of storing eggs or embryos (fertilised eggs). This is if they are considering trying to have a child through surrogacy (when another woman carries a baby for you) in the future.



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



AFTER PELVIC RADIOTHERAPY

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Follow-up

Most of the side effects of radiotherapy should gradually disappear once the treatment has finished. But it may take you some time to recover. Looking after yourself by getting enough rest and gradually increasing your physical activity will help with your recovery. If you smoke, it's advisable to stop.

Your cancer specialist or nurse should give you specific advice to help with your recovery. For example, they may give you information on:

- when you can expect to go back to work
- how to gradually build up your activities
- how to use vaginal dilators (see page 24).

Some women who had a gynaecological cancer may be taught to do regular exercises to strengthen their pelvic floor muscles (see page 38).

There's more information about recovery on pages 36–39.

After treatment, you'll be seen at the hospital every few months for regular check-ups. Let your cancer specialist or nurse know if the side effects don't get better, or if you develop new symptoms, even if it's between appointments.

Share your experience

When treatment finishes, many people find it helps to share their thoughts, feelings and advice with others. This can be especially helpful for other women about to start their treatment. Just hearing how you've coped can be very helpful to someone in a similar situation.

We can help you share your story. Call us on **0808 808 00 00** or visit **[macmillan.org.uk/cancervoices](https://www.macmillan.org.uk/cancervoices)** for more information.



Well-being and recovery

After radiotherapy, you may want to think about ways you can help your own recovery. Here we've included some ideas for improving your overall health. Some of these suggestions may help to reduce any ongoing side effects and the risk of developing certain late effects (see pages 41–46), other health problems and some cancers. These may be things you have always done or are already doing for yourself.

If you smoke, get help to stop

Smoking increases side effects during radiotherapy, so the best time to stop is before you start treatment. But it's never too late to benefit from giving up smoking.

Smoking makes side effects worse, increases the risk of developing late effects and makes any late effects more severe. For example, smoking increases bladder symptoms and makes problems with diarrhoea worse. It can also increase the risk of bone thinning (osteoporosis).

Continuing to smoke also puts you at risk of developing a new cancer.

Giving up smoking is one of the healthiest decisions you can make. It can be hard to stop when you're already feeling stressed, but there's a lot of support available. If you want help and advice on how to stop, you can talk to your cancer specialist, specialist nurse or GP. You can also contact one of the national helplines – see page 59 for more details.

Eat healthily

Eating healthily will help you feel better and give you more energy. In general, a healthy diet includes five portions of fresh fruit and vegetables every day and not too much red or processed meat.

However, after pelvic radiotherapy, some people may not be able to cope with as much fruit and fibre in their diet. If changes in your bowel habit are affecting what you can eat, talk to your cancer specialist or nurse. They can refer you to a dietitian for advice.

Keep to a healthy weight

Being overweight is a risk factor for some cancers and other health conditions such as heart problems and diabetes. It also puts pressure on your pelvic floor muscles and your joints.



We can send you more information on healthy eating, giving up smoking, and keeping to a healthy weight.

Look after your pelvic floor muscles

Pelvic floor muscles support the organs in the pelvis and are important for bladder and bowel control. Radiotherapy to the pelvis can weaken these muscles. They are also naturally weakened by childbirth, the menopause and getting older.

Some women are advised to do regular pelvic floor exercises after radiotherapy for a gynaecological cancer. It's important to do pelvic floor exercises correctly, so you'll usually be referred to a physiotherapist or nurse specialist who will teach you how to do them. The Bladder and Bowel Foundation (see page 55) has leaflets explaining how to do pelvic floor exercises.

Keep physically active

Keeping active will help build up your energy levels. It will also help you to keep to a healthy weight, strengthen your bones and protect your heart. Regular physical activity reduces stress and can help you sleep better.

Walking is a good way of staying physically active. You don't need any special equipment and you can gradually build up how much you do. There are lots of other types of physical activity you can try too. There's more information in our booklet **Physical activity and cancer treatment**.

Stick to sensible drinking guidelines

Alcohol can make bladder and bowel side effects worse. Current guidelines recommend women should drink no more than 14 units of alcohol a week and have some alcohol-free days every week.

Reduce the risk of lymphoedema

If you have radiotherapy to the lymph nodes in the pelvis you are at risk of developing swelling of the leg or legs (lymphoedema). The risk depends on the type of cancer you have had and the treatment you received. It is more likely if you have had surgery to the pelvis as well as radiotherapy. If you are at risk, it's important to protect the skin on your legs and feet by doing the following things:

- Keep the skin clean and use moisturisers to keep it supple.
- Clean grazes or cuts straight away and see your GP if the area gets red, hot or swollen.
- Use an electric razor if you want to shave your legs.
- Wear well-fitting shoes.
- Use nail clippers instead of scissors to cut toenails.
- Try to keep to a healthy weight.
- Keep physically active and avoid standing for too long in the same position.
- Avoid having injections in the buttocks or legs.

If you notice any swelling in your foot or leg, always get it checked by your cancer specialist or nurse.



Our booklet **Understanding lymphoedema** has more detailed information.



Late effects of pelvic radiotherapy

This section explains some possible late effects. Late effects are side effects that don't go away within six months (long-term), or new side effects that develop months or sometimes years later as a delayed response to treatment.

Many women who have pelvic radiotherapy never develop late effects. Or, if they do, the side effects are mild and don't 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 factors, including the type of cancer you had, the dose of radiotherapy and any other cancer treatments you have had. Late effects are also more common in people who smoke. Your cancer specialist or nurse can tell you more about your risk.

If late effects do develop, they can often be treated effectively or managed 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 the function of the bowel and bladder.

Changes in bowel habits

Some women continue to have changes in their bowel habits. They may have:

- loose bowel movements
- diarrhoea
- urgency (feeling they can't hold on)
- constipation.

Sometimes, medication is needed to control symptoms and regulate the bowel.

Rarely, some women find it difficult to control their bowels and some leakage (incontinence) can occur. 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.

'You can let it stop your life or embarrass you horribly, or you can get on with it. As far as I'm concerned, my friends aren't bothered by it, and I'm not either.'

Janet

Bladder changes

Some women find they need to pass urine more often than before. This can happen because radiotherapy can cause the bladder to shrink. Occasionally, women may have some problems with leaking urine (incontinence).

It's important to let your doctor know if you have ongoing bladder symptoms, or develop new symptoms. You can then be assessed by an expert who can give you the right treatment and advice. Bladder problems due to pelvic radiotherapy can usually be well managed or treated.

Bleeding

About a year after radiotherapy, fine blood vessels may develop in the vagina, the lining of the bladder or the bowel. You may notice slight vaginal bleeding, particularly after sex, or you may have small amounts of blood in your urine or bowel motions. Although this doesn't usually cause any problems, it can be worrying when it first happens. Some women may feel anxious that the cancer has come back.

It's very important to let your doctor know if you have vaginal bleeding, or blood in your urine or bowel motions, as it can be due to other causes. You can have tests to find the cause and have treatment if needed.

Other possible late effects

Some women have changes to the vagina that can make having sex difficult or affect how they feel about themselves. However, there are ways of reducing these changes and treatments that can help – see pages 24–25.

Ongoing tiredness can also be a problem for some women.

Occasionally, some women develop swelling in one or both legs, called lymphoedema. This is more common in women who've had their pelvic lymph nodes removed during surgery. There are ways you can reduce the risk of lymphoedema (see page 39).

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



We can send you more information about coping with fatigue and controlling pain or lymphoedema.

Things to look out for

Always tell your cancer specialist or nurse if any side effects don't go away, or if you develop any new symptoms or problems after treatment is over.

You should tell them if you:

- bleed from the vagina, back passage, 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
- wake from sleep to open your bowels, need to rush to open your bowels (urgency), or have accidents (incontinence)
- need to pass urine often or urgently, leak urine (incontinence), or have pain or difficulty passing urine
- have swelling in your leg(s)
- have pain or difficulty having sex, or problems getting back to your usual sex life
- notice pain in your hips or pelvis when you're walking.

You may feel embarrassed talking about problems related to your bowel, bladder or sex life. But doctors and nurses are used to discussing intimate problems like this, so don't be put off. Your cancer specialist will assess your symptoms and explain if they're likely to be a result of the radiotherapy. Sometimes, tests are needed to find out the cause of your symptoms.

Getting expert help

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

There are also some expert doctors who specialise in treating late effects of radiotherapy. But this is a specialised area, so there aren't many of these doctors and you may have to travel to see one. A few hospitals have special clinics for people with late effects.

Your doctor or nurse can refer you to other specialists if needed. The organisations listed on pages 55–58 can also put you in touch with specialists.

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

Your feelings

It's common to feel a range of emotions during and after cancer treatment, and it's not unusual to have a low mood at first. As you recover and get back to your everyday life, these feelings usually get easier to deal with. Talking to family and friends often helps. If things don't improve or you feel anxious or depressed, let your doctor or nurse know so that they can arrange for more support for you.

Some people find meeting others in a similar situation helpful. There may be a local support group near you. Our cancer support specialists on **0808 808 00 00** can tell you what's available in your area.

You may also like to join our online community, where you can get and give advice and support based on your experiences. Visit [macmillan.org.uk/community](https://www.macmillan.org.uk/community)

'Mentally it doesn't upset me any more.
I just know that it's going to be a part
of my life. It's a small price to pay.'

Kate



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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](https://www.be.macmillan.org.uk) or call us on **0808 808 00 00**.

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

All of our information is also available online at [macmillan.org.uk/cancerinformation](https://www.macmillan.org.uk/cancerinformation)

org.uk/cancerinformation

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

Other formats

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

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

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

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

Help us improve our information

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

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

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



Other ways we can help you

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

Talk to us

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

Macmillan Support Line

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

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

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

Talk to others

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

Support groups

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

Online community

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

The Macmillan healthcare team

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

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

Mal

Help with money worries

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

Financial advice

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

Help accessing benefits

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

Macmillan Grants

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

Call us on **0808 808 00 00** to speak to a financial guide or benefits adviser, or to find out more about Macmillan Grants. We can also tell you about benefits advisers in your area. Visit [macmillan.org.uk/financialsupport](https://www.macmillan.org.uk/financialsupport) to find out more about how we can help you with your finances.

Help with work and cancer

Whether you're an employee, a carer, an employer or are self-employed, we can provide support and information to help you manage cancer at work. Visit [macmillan.org.uk/work](https://www.macmillan.org.uk/work)



Macmillan's My Organiser app

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

Other useful organisations

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

Action on Bladder Cancer

6 Trull Farm Buildings,
Tetbury,
Gloucestershire GL8 8SQ

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

actiononbladdercancer.org

www.

actiononbladdercancer.org

Helps people to understand more about bladder cancer, through raising awareness, supporting research, and campaigning.

Bladder and Bowel Foundation

SATRA Innovation Park,
Rockingham Road,
Kettering NN16 9JH

Helpline 0845 345 0165

Email

info@bladderandbowelfoundation.org

www.bladderandbowelfoundation.org

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

Bowel Cancer UK

Willcox House,
140–148 Borough High Street,
London SE1 1LB

Tel 020 7940 1760

Email

admin@bowelcanceruk.org.uk

www.bowelcanceruk.org.uk

Raises awareness of bowel cancer and aims to improve the quality of life of those affected. Provides information about bowel cancer prevention, screening and symptoms through its website, leaflets and a helpline run by specialist colorectal nurses.

Bowel Cancer UK in Scotland

20 Queen Street,
Edinburgh EH2 1JX

Tel 0131 225 5333

Email [scotadmin@
bowelcanceruk.org.uk](mailto:scotadmin@bowelcanceruk.org.uk)

Bowel Cancer UK in Northern Ireland

Tel 07798 523668

Email [bernadette.mcgarry@
bowelcanceruk.org.uk](mailto:bernadette.mcgarry@bowelcanceruk.org.uk)

The Daisy Network

PO Box 71432,
London SW6 9HJ

Email

daisy@daisynetwork.org.uk

www.daisynetwork.org.uk

A nationwide support group for women who have had a premature menopause.

Jo's Cervical Cancer Trust (Jo's Trust)

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

Tel 020 7936 7498

Helpline 0808 802 8000

Email info@jostrust.org.uk

www.jostrust.org.uk

The only UK charity dedicated to women and their families affected by cervical cancer and cervical abnormalities. Offers information, support and friendship to women of all ages.

Menopause Matters

[www.](http://www.menopausematters.org.uk)

[menopausematters.org.uk](http://www.menopausematters.org.uk)

A website providing information about the menopause, menopausal symptoms and treatment options.

Pelvic Radiation Disease Association

Tel 01372 744338

www.prda.org.uk

Raises awareness of the late effects of pelvic radiotherapy, provides information, and has a network of support groups across the UK.

Sexual Advice Association

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

Tel 020 7486 7262

Email info@sexualadviceassociation.co.uk

www.sexualadviceassociation.co.uk

Charity aiming to help people improve their sexual health and well-being. Has a helpline and lots of information on its website.

General cancer support organisations

Cancer Focus

Northern Ireland

40–44 Eglantine Avenue,
Belfast BT9 6DX

Helpline 0800 783 3339
(Mon–Fri, 9am–1pm)

Email hello@cancerfocusni.org

www.cancerfocusni.org

Offers a variety of services to people affected by cancer, including a free helpline, counselling and links to local support groups.

Cancer Research UK

Angel Building,
407 St John Street,
London EC1V 4AD

Tel 0300 123 1022

www.cancerhelp.org.uk

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

Cancer Support Scotland

The Calman Centre,
75 Shelley Road,
Glasgow G12 0ZE

Tel 0800 652 4531

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

cancersupportscotland.org

**www.cancersupport
scotland.org**

Runs cancer support groups throughout Scotland. Also offers free complementary therapies and counselling to anyone affected by cancer.

**Macmillan Cancer Voices
www.macmillan.org.uk/
cancervoices**

A UK-wide network that enables people who have or have had cancer, and those close to them such as family and carers, to speak out about their experience of cancer.

Maggie's Centres

20 St James Street,
London W6 9RW

Tel 0300 123 1801

Email enquiries@
maggiescentres.org

www.maggiescentres.org

Provides information about cancer, benefits advice, and emotional and psychological support.

Tenovus

Head Office,
Gleider House,
Ty Glas Road,
Cardiff CF14 5BD

Helpline 0808 808 1010
(Mon–Sun, 8am–8pm)

Email info@

tenovuscancercare.org.uk

www.tenovus.org.uk

Aims to help everyone get equal access to cancer treatment and support. Funds research and provides support such as mobile cancer support units, a free helpline, an 'Ask the nurse' service on the website and benefits advice.

**Counselling and
emotional support**

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

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

Tel 01455 883 300

Email bacp@bacp.co.uk

www.bacp.co.uk

Promotes awareness of counselling and signposts people to appropriate services. You can search for a qualified counsellor at **itsgoodtotalk.org.uk**

Support for carers

Carers Trust (Princess Royal Trust for Carers in Scotland)

32–36 Loman Street,
London SE1 0EH

Tel (England)

0844 800 4361

Tel (Scotland)

0300 123 2008

Tel (Wales)

0292 009 0087

Email info@carers.org

www.carers.org and

www.youngcarers.net

Provides support, information, advice and services for people caring at home for a family member or friend. You can find details for UK offices and search for local support on the website.

Support to stop smoking

Smokefree

Tel 0300 123 1044

(Mon–Fri, 9am–8pm,

Sat–Sun, 11am–4pm)

www.nhs.uk/smokefree

Offers free information, advice and support to people who want to give up smoking, or who have given up and do not want to start again.

Smokeline

Tel 0800 84 84 84

(Daily, 8am–10pm)

www.canstopsmoking.com

Scotland's national stop-smoking helpline.

Stop Smoking Wales

Tel 0800 085 2219

www.stopsmokingwales.com

A free NHS service to help people quit smoking.

Want2stop

Tel 080 812 8008

www.want2stop.info

Website run by the Northern Ireland Public Health Agency. Offers a range of information and advice for those wanting to quit smoking.

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 photographs are of models.

Thanks

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

With thanks to: Dr Susan Davidson, Clinical Oncologist; Heather Dias, Macmillan Specialist Radiographer; Lynn Holmes, Gynae-oncology CNS; and the members of the Pelvic Radiation Disease Association. Thanks also to the people affected by cancer who reviewed this edition, and to those who shared their stories.

Sources

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

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UpToDate online. May 2014.

Can you do something to help?

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

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



Share your cancer experience

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

Campaign for change

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

Help someone in your community

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

Raise money

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

Give money

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

Call us to find out more

0300 1000 200

macmillan.org.uk/getinvolved

Please fill in your personal details

Mr/Mrs/Miss/Other

Name

Surname

Address

Postcode

Phone

Email

Please accept my gift of £

(Please delete as appropriate)

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

OR debit my:

Visa / MasterCard / CAF Charity
Card / Switch / Maestro

Card number

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Signature

Date / /

Don't let the taxman keep your money

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

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

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

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

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



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

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

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

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

Together, we are all Macmillan Cancer Support.

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

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.

Non-English speaker? Interpreters available. Braille and large print versions on request.

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CANCER SUPPORT**