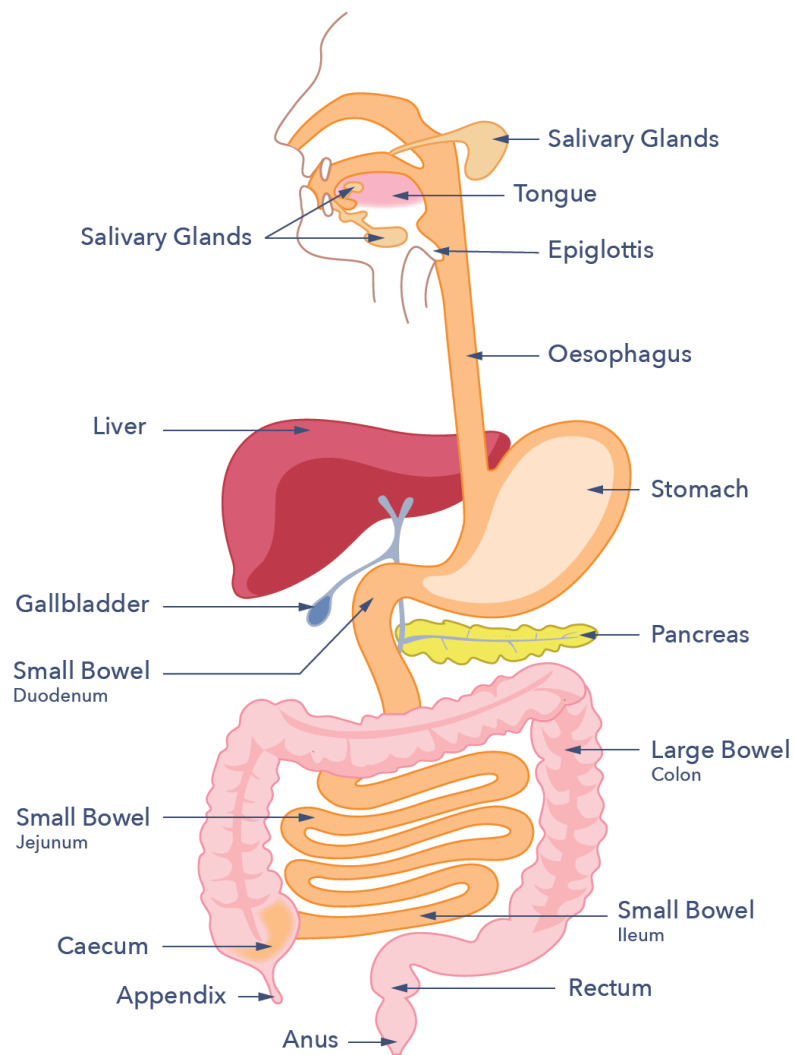




FUNDING RESEARCH TO FIGHT DISEASES OF THE GUT, LIVER & PANCREAS



THIS FACTSHEET IS ABOUT PELVIC RADIATION DISEASE

OVERVIEW

Pelvic Radiation Disease is a term used to describe a collection of symptoms that can arise in non-cancerous body tissues after radiotherapy treatment. The radiotherapy that causes pelvic radiation disease to the abdomen or pelvis is used for cancers such as: cervical, vaginal, endometrial (womb), prostate, bladder, anal, and bowel cancers. If the damage is to the bowel, you may hear other terms used to describe pelvic radiation disease, such as radiation enteritis, radiation proctitis, radiation colitis or radiation enteropathy.

CAUSES

CAUSES OF PELVIC RADIATION DISEASE

Radiotherapy is a treatment that is directed towards a part of the body, aiming to destroy cancer cells that are present there. However, during treatment, damage to nearby healthy cells can occur. This damage can vary from person-to-person and may depend on the type of cancer, location and how much radiation is used. This can result in pelvic radiation disease.

The effect of radiotherapy on the pelvic area can be acute (immediate) or chronic (long term). Between 6-8 in 10 people undergoing radiotherapy will experience acute side effects. These generally start 2 weeks into radiotherapy but can often settle between 2 to 6 months after the treatment is given¹. Symptoms which last longer than six months or develop afterwards, are described as chronic. 9 in 10² people reported chronic side-effects ranging from mild to severe in nature. 1 in 2 people had significant changes to their bowel function².

HOW IS PELVIC RADIATION DISEASE DIAGNOSED?

Many of the symptoms of pelvic radiation can also be caused by other conditions that need to be excluded first.

Bowel symptoms: the main investigations include an examination of the large bowel lining using an endoscope (where a small tube with a camera on the end is inserted into the bowel via the back passage). [www.myendoscopy.co.uk] An MRI (Magnet Resonance Imaging) scan can be used to investigate the small bowel. Stools can be tested to exclude certain infections or conditions, and the muscles that help stools to control continence can also be checked for any weakness.

Bladder symptoms: a cystoscopy (a procedure to look inside the bladder using a thin camera called a cystoscope) will be carried out, along with tests on urine samples that could help to exclude other conditions.

HOW CAN PELVIC RADIATION DISEASE AFFECT YOU?

The condition can impact a person in many ways. Pelvic radiation disease can have a significant impact on your day-to-day quality of life. Problems experienced range from practical problems of a frequent need or urgency to empty the bowel and the need to quickly find a toilet, to more emotional issues, such as being reminded of a cancer diagnosis. As a result, many patients suffer with feelings of hopelessness: living with bowel disorders can result in low mood and anxiety. It is important to discuss any feelings of hopelessness or changes to your mood with your doctor, so that appropriate support can be organised. Some symptoms can clear up on their own but, unfortunately, others do not completely go away and may last for years after radiotherapy treatment has finished. The effects may be very mild, with minimal impact on day-to-day living, but sometimes they may be very troublesome and interfere with daily activities.

SYMPTOMS

Symptoms can begin during radiation treatment or not appear until years after the treatment is finished and, likewise, can range from very mild to debilitating. Symptoms vary, depending on which organ is affected, therefore we have separated the symptoms into those of the bowel, bladder, and reproductive organs. Your doctor or specialist nurse should be able to help you identify and define your symptoms using a questionnaire, such as the [ALERT-B questionnaire](#).

Symptoms may include:

- Diarrhoea
- Faecal incontinence (soiling underwear)
- Urgency to use the toilet
- Waking at night to pass poo (stools)
- Urgency to pass urine
- Difficulty holding urine
- Pain when passing urine
- Loss of sexual desire
- Abdominal and/or rectal pain
- Fatigue

Bowel symptoms:

Radiotherapy can result in scarring of the bowel lining and/or weakening of the muscles that control stool movement. This can lead to the contents of the bowel (poo) passing through the bowel too quickly. Symptoms of this may include soiling underwear (faecal incontinence) and needing to rush to the toilet during the day, or waking up at night to pass stools. Excessive diarrhoea may also be caused by the

adverse effect of radiotherapy on certain vital bowel functions. These include the poor breakdown of carbohydrates such as lactose and fructose, a reduction in the amount of bile acids the bowel can re-absorb and bacterial overgrowth. The bowel may become narrowed by scar tissues, causing constipation or cramping pain. The blood vessels in the bowel can become more fragile, causing bleeding which can be seen in the poo. Sometimes the poo can be greasy and difficult to flush down the toilet (this is called steatorrhoea).

Bleeding from the back passage: may not need treatment, particularly if it is a small amount. However, if the bleeding is enough to cause a low blood count (anaemia) or is interfering with day-to-day activities, then medications or procedures can be used to help reduce or stop the bleeding. These may require a referral to a specialist gastroenterology centre.

This symptom can be challenging to manage, but treatments offered may include:

- No treatment, if the symptom is not resulting in a significant impact on the person, or there is no anaemia.
- Treatment for constipation, if the passage of hard poo is making bleeding worse.
- Self-administered sucralfate enemas, your healthcare professional will advise you on how to apply the enema.
- Argon plasma coagulation therapy by colonoscopy can stop small blood vessels bleeding, but this treatment is only suitable for some people. If this option is offered to you, there are risks involved that your doctor will discuss with you.
- For people with more severe symptoms, hyperbaric oxygen therapy may be considered. This treatment is only available in a few specialist units and the treatment may need to be provided daily for a few weeks.

Where an additional diagnosis has not been found to explain the bowel symptoms, then medication and lifestyle modifications can help to improve symptoms and quality of life.

Bladder symptoms:

Radiotherapy can cause scarring to the bladder and may also weaken the pelvic floor muscles. Symptoms include a need to rush to pass urine, being unable to hold urine in, having accidents (urinary incontinence) and/or pain when passing urine. Sometimes the blood vessels in and around the bladder and/or prostate are fragile, which causes bleeding which can be seen in the urine.

Reproductive organ symptoms:

Radiotherapy can result in the loss of sexual desire. Women can experience changes in the vagina including drying and loss of elasticity (caused by formation of scar tissue) which can make intercourse painful. Increased vaginal discharge may be noticed. For men, their ability to experience and/or maintain an erection may be affected.

TREATMENT

The treatment available will depend upon the symptoms and the organ affected.

Altered bowel habit:

Treatment depends on the cause of the change in bowel symptoms and your doctor will advise you based on the cause of the symptoms. If [bile acid diarrhoea](#) is diagnosed, then bile acid binding medications are available.

For [diarrhoea](#), anti-diarrhoeal medications can be used, and for [constipation](#), laxatives.

A referral to a dietitian may be useful, as dietary modifications: altering fibre intake and increasing fluid intake can help with diarrhoea, constipation and wind. Dietitians can also assist with food intolerance such as lactose intolerance and other elimination diets that might be useful to help with symptoms. Please do not attempt any elimination diet yourself, as restricted diets can result in malnutrition.

Pelvic floor: The pelvic floor muscles support the bladder and bowel, allowing for control of urination and defecation. Pelvic floor exercises can help increase this support, improve co-ordination and provide more control of the bowels and urination. A referral to a specialist bowel nurse or specialist pelvic physiotherapist can be helpful. Ask your doctor for a referral.

Bladder: pelvic floor exercises can help with urine leakage and incontinence, but if these measures do not help, medications can sometimes be used. Radiotherapy can cause narrowing (scarring) in the urethra, the tube that drains the bladder to the outside, which can make passing urine difficult. This narrowing can be treated using dilators to widen the affected area. Fragile blood vessels which cause blood in the urine can be sealed with a heat treatment and the bladder can be washed out to remove any blood clots. These procedures are usually available via referral to a urologist or a continence nurse specialist.

Reproductive organs: there are several treatment options which can help with pain during intercourse, bleeding, vaginal dryness or symptoms of early menopause (mood swings, hot flushes, low sex drive) after radiotherapy. Your doctor can advise you on these. Some symptoms may require referral to a specialist who can discuss different treatment options, such as use of hormone replacement therapy, hormone

creams or dilators. Men who have problems with erections can also be referred to an appropriate specialist.

For some people, symptoms can start many decades after treatment, it is therefore important that any changes are discussed with your doctor, who may suggest investigations to ensure that there is no other cause for your symptoms.

OTHER TREATMENTS

HOW CAN I SELF MANAGE MY PELVIC RADIATION DISEASE?

Being in control and organised can help you to manage the day-to-day symptoms of bowel and bladder problems, including planning ahead when leaving the house. For example, knowing how long the outing will be, finding out where toilets are, taking a bag of spare clothes and wearing products such as pads to help absorb any leakage. It is also important to protect the skin around the back passage by keeping it dry and clean.

A 'just can't wait – please help' card can be helpful in accessing toilet facilities when you are out. The Pelvic Radiation Disease Association can provide one [here](#).

Planning visits can be useful and the [Great British Public Toilet Map](#) can be of assistance.

SUPPORT

The Pelvic Radiation Disease Association is the charity that supports people with a diagnosis of pelvic radiation disease.

Website: <https://www.prda.org.uk/>

If you have been diagnosed with bile acid diarrhoea there is a charity where you can find out more information called: BAD UK

Website: <https://www.bad-uk.org/>

WHAT TO ASK YOUR DOCTOR?

These are some useful questions you can ask your doctor:

- Have I been assessed using the **ALERT-B questionnaire** to identify if I may benefit from seeing a specialist for any of my symptoms?
- May I be referred to a dietitian to see if there are any changes to my diet that may help with my symptoms?
- How often do I need follow-up?

- Would it be appropriate for me to be referred for counselling or other psychotherapy support to help me cope with my feelings?

Macmillan produce a really useful document that healthcare professionals use which lists a full range of bowel symptoms and you can find a copy by clicking on the link [here](#).

Research

Further research into the underlying mechanisms that cause pelvic radiation disease could lead to discovery of a reversible factor; treatment could then target the underlying changes, rather than just treatment of symptoms.

[For further information, visit gutscharity.org.uk](http://gutscharity.org.uk)