

# Regaining bowel control

After Bowel Cancer Treatment

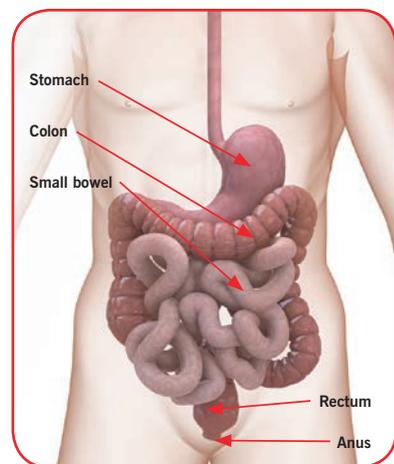
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# Introduction

Regaining bowel control can be one of the biggest challenges that you face after surgery for bowel cancer. Patients believe – and hope – that their bowel habits will return to how things were before they became ill, and this is true for some people. However, the reality is that even with a successful operation there will still be a piece of your bowel missing and this will change the way your bowel works, either in the short term or longer term.

To understand these changes to your bowel function, it is helpful to know more about the colon and rectum (which make up the bowel) and to find out how and why surgery can change the way they work. The colon and rectum are all one continuous tube, but because treatment (and the effects of treatment) can differ depending on whether your cancer is in the colon or rectum, we will discuss them separately in this booklet.



The digestive system

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# How does surgery affect the colon?

The main function of the colon is to re-absorb water from undigested food matter and then rid the body of remaining waste material as stools (poo).

The rectum is the last part of the bowel and it acts as a temporary storage chamber, which can stretch to accommodate stools. A full rectum sets off messages to our brain to let us know that we need to open our bowels.

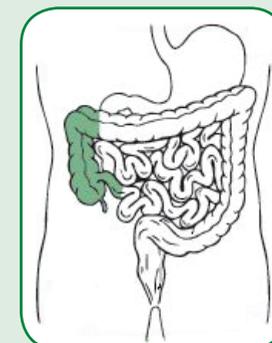
Below the rectum is the anal canal, which is approximately 4cm long and has complex nerve supplies, which help us tell the difference between flatus (wind) and stool.

If you have had part of your colon removed, the remaining ends will usually have been joined back together again and, after a period of adjustment, your bowel habits will settle down. While your stools may be a bit looser and more frequent straight after surgery, this usually calms down after a few weeks and most symptoms can be controlled with medication (see page 12). You can find further information on the different types of bowel surgery you may have in our booklet **'Bowel Cancer Surgery – Your Operation'**.

### Bile acid malabsorption

Up to 80% of people who have surgery to remove a tumour in the right side of the colon (known as a right hemicolectomy) can develop a condition called bile acid malabsorption. The end of the small bowel and first part of the large bowel are responsible for reabsorbing bile

acids and if you lose this section of bowel, it can cause chronic diarrhoea that does not respond to usual medication. If your doctor suspects that you have this condition, it can be diagnosed by a test called a SeHCAT scan and specific medication can be prescribed.



Right hemicolectomy

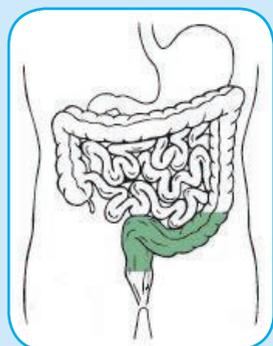
# How does surgery affect the rectum?

Following surgery for rectal cancer, issues with bowel control can be more complex and you may need a more detailed assessment and treatment plan to address the problem. If you have a cancer in your rectum, you may be advised to have an operation called an anterior resection. This involves removing a section of the rectum and colon, as shown in the diagram below.

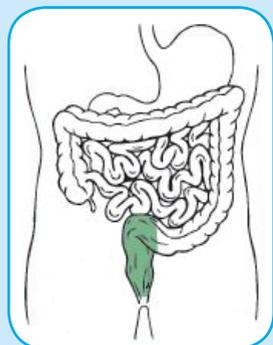
The two ends of the bowel are then joined together. This join is called an anastomosis. A temporary stoma (ileostomy) is sometimes formed to protect this join while it heals. See our booklet **'Bowel Cancer Surgery – Your Operation'** for more information about stomas. If an ileostomy was formed during the operation, then in due course it is reversed with another operation (stoma reversal) and you go back to using your bowels in the usual way.

After rectal cancer surgery (or once your ileostomy has been reversed), most people experience at least several weeks of problems with their bowel habit. For many people this is likely to continue for up to a year after surgery and while the severity of the side effects should reduce over time, it is unlikely that your bowel habit will fully return to what it was before your diagnosis.

Although in many cases symptoms do settle within a year of surgery, for some people this can become a chronic condition known as anterior resection syndrome.



**High anterior resection**



**Low anterior resection**

# Anterior resection syndrome

Anterior resection syndrome, sometimes referred to as low anterior resection syndrome or LARS, is the name given to a combination of bowel symptoms following surgery to remove all or part of the rectum. This can include frequency, urgency, leakage, tenesmus (a feeling of wanting to go but not passing anything), or clustering (several frequent, incomplete bowel actions).

Low anterior resection syndrome is now widely recognised as a significant problem following rectal cancer surgery, affecting up to half of patients.

Many hospital teams address this issue as part of their follow-up care by asking questions such as:

- Do you ever have occasions when you cannot control your flatus (wind)?
- Do you ever have any accidental leakage of liquid stool?
- How often do you open your bowels?
- Do you ever have to open your bowels again within one hour of the last bowel movement?
- Do you ever have such a strong urge to open your bowels that you have to rush to the toilet?

If you experience these symptoms regularly, or frequently, you are likely to have low anterior resection syndrome and your hospital team should work with you to find ways to help you regain bowel control.

Managing anterior resection syndrome is often a question of trial and error, as symptoms vary greatly from person to person. Your healthcare professional will suggest things for you to try; it's important to introduce changes step by step to see what works best and go back for more help if necessary.



# Why chemotherapy affects bowel control

Many chemotherapy drugs are known to cause diarrhoea. When these treatments are given following surgery to remove part of the colon or rectum, problems with looser stools, leakage of stool and burning (acidic) stools which can irritate the sensitive skin around the bottom can be made worse as the bowel struggles to compensate.

## Things you can do to minimize or avoid the effects of diarrhoea caused by chemotherapy:

- Drink plenty of fluids to prevent dehydration.
- Limit milk and lactose products temporarily to see if this improves symptoms.
- Avoid high fibre foods such as high fibre cereals, wholemeal or granary breads, brown rice and pasta, dried fruit, seeds and nuts.
- Avoid spicy, fried, greasy, fatty foods, raw vegetables, caffeine (tea, coffee, alcohol) and carbonated drinks.
- Limit fruit and vegetables (two portions per day), remove peel and skins.
- Limit lentils and pulses (peas and beans).
- Stop the use of laxatives.
- Use anti-diarrhoeal medications such as loperamide but discuss with your GP, consultant or nurse specialist before taking this medication.
- Speak to your doctor about using an appropriate barrier cream to protect the sensitive skin around the bottom (see page 15).

### If diarrhoea is accompanied by

- fever
- abdominal cramps
- pain
- bloating
- blood in stools
- and/or inability to drink adequate amounts of fluid

**then contact your hospital team**

# Patient story

## Paul, 48

"I am a self-employed builder and joiner and I was diagnosed with Stage 4 bowel cancer in 2008. Things seemed to get bad quite quickly. I was on the toilet a lot; I had bad diarrhoea for four months and I had zero energy. I used to go home and sleep through my lunchbreak. Eventually I went to my GP, although it was a locum doctor at the time. I saw her three times. I felt like no one would take me seriously. I decided to take matters in to my own hands and pay to be tested privately. Within 13 days I had been told I had a tumour in my large bowel. I had a huge chunk of my bowel removed and had to have an ileostomy bag. The cancer had spread to my lymph nodes, liver and lungs.

After I'd recovered from the bowel surgery I had nine months of FOLFOX chemotherapy. Chemo made me so tired, my brain was foggy, and I had a sore mouth and tingling in my hands and feet. It was a really tough time; you don't know if you're going to live, you have to take each day as it comes.

Once I had the reversal of the bag, which was around 12 months after the initial bowel surgery I needed to wear a nappy pad for a while in case of accidents. I could eat like an angel and still be on the toilet for most of the day. I went back to work slowly after the reversal. Everything had to revolve around the toilet. I would either have to ask people if I could use



their toilet, or make sure there was a Portaloos on site. These days I still have to have undies in the car, undies in my bag, I have to always be prepared and just get on with it really.

I still struggle daily with controlling my bowels; they are unpredictable. Some days I can go four times and others it can be 24. I do take loperamide to try to manage it sometimes, but I find that this can dehydrate me and give me stomach cramps. I try to eat a balanced diet, although vegetables can make things worse and I do like chocolate!

I am never going to be exactly the same as I was before, nobody with cancer is I don't think. I am not as physically strong as I was and I get very tired but I don't let it dictate my life and still lead an active life. I go out on my bike, I go to the gym."

# Why radiotherapy affects bowel control

**Radiotherapy on your rectum and surrounding tissues often causes side-effects that get better within a few weeks of treatment ending, but you may also start to experience side-effects months or even years later.**

Radiotherapy makes the lining of your bowel more fragile, which can cause bleeding from your anus (back passage). Passing a small amount of blood from your back passage is quite common for most people from time to time and may not need any treatment. This inflammation of the lining caused by radiotherapy can also cause your stool to become looser and you may open your bowels more frequently.

On the other hand, radiotherapy can thicken the lining of your bowel over time, making it less flexible and unable to hold as much stool as before. This can cause the stool to pass through more quickly and may give you less control of your bowel.

Experiencing a slow leakage of stool or mucus from your bottom can be a very distressing symptom. If this is a problem for you, it may be helpful to use some

sort of padding, such as an incontinence pad or pants. This will allow you to get on with daily activities with less worry and embarrassment, especially when out and about. The use of a good barrier cream (e.g. Cavilon) can help protect the delicate skin around the bottom.

## Problems that may develop at any time after your radiotherapy include:

- passing blood or mucus from your anus
- abdominal cramps
- a feeling of incomplete emptying
- diarrhoea or constipation
- increased frequency of bowel motions
- urgent need to empty your bowels
- incontinence (leaking of stool)
- passing more wind.

You may be able to manage these symptoms in the short term, but if you feel that you are struggling to cope, you should speak to your GP or your colorectal team.

# Patient story

## David, 61

*"I was diagnosed in late 2004 with a tumour in my rectum and was booked in for surgery to create an ileostomy (stoma) soon afterwards. I had a six week course of radiotherapy and two lots of chemotherapy to shrink the tumour, and then I had a low anterior resection in May 2005.*

*My stoma was reversed in November 2005. I was told that my bowel habit would never be the same again and I should expect three to four motions a day. In fact the urgency and frequency took me by surprise - I could go three times within the first hour of getting up and some of the early days were so bad I thought about asking for the stoma back in the form of a permanent colostomy.*

*I mentioned my problems to my colorectal nurse when I was having a check-up and she offered to refer me for biofeedback treatment. At the time the nearest bowel control clinic was an hour's train ride from my house, so I didn't take it any further and I have put up with the symptoms ever since.*

*I am fortunate that I can mainly work from home, I am a semi-retired photographer, and therefore can easily get changed when I have an accident, which is now not as bad as it once was. I hate to think how I would have coped had I had to do a daily commute.*

*I manage my urgency and frequency by taking up to two capsules of loperamide before I leave home if I am going where there is little likelihood of finding a nearby toilet. In the past I tried Fybogel, but gave up on it as I felt that it was not really making any difference. I occasionally take Buscopan, which I was prescribed when I went to my GP with bowel spasms.*

*Whilst I enjoy spicy food I know that it can upset my system and I no longer eat so much of it. I've now cut down on fruit and vegetables and no longer have my five a day. This also helps to keep things under control. These days, I reckon I am fairly active for my age, as we have a dog and I walk him at least twice a day. I also play golf and ride my bike regularly and help raise pigs on a local smallholding. It's taken a long time, but I now feel I have my life back under control, with the occasional lapse."*



# How your hospital team can help you

**It's important that you tell your doctor or nurse specialist what is going on. Don't suffer in silence. Many bowel control issues have very easy, straightforward solutions, but you need to tell your team so that they can help you.**

## Assessment

The key to beginning to manage your bowel control issues is assessment. It is important that your doctor or nurse specialist carries out a full assessment, which will help pinpoint exactly what the troublesome symptoms are for you, as this can vary greatly from patient to patient. This assessment will include an examination of your anus and rectum and a review of any medications you are taking, as well as looking at your diet. Keeping a food diary can be very useful to identify potential triggers that may be contributing to your symptoms.

Depending on the outcome of this assessment, your healthcare professional can then provide basic advice and treatment. This may include dietary advice, use of anti-diarrhoeal or bulking agents, management of stress and practical advice such as bowel training and pelvic floor exercises.

## Further investigation and management

It is important to exclude other causes for your symptoms that may not be related to your cancer surgery. Common problems such as haemorrhoids (piles) or fissure (a tear in the anal canal) can be treated quickly and easily. Further investigations and management will depend on the nature of your symptoms but may include blood tests, colonoscopy or sigmoidoscopy (examination of all or part of the bowel with a camera), stool samples or biofeedback (see page 20).

## Referral to a gastroenterologist or other specialist

If initial steps taken do not help resolve the problems, then your team may decide to refer you on to another specialist such as a gastroenterologist (a non-surgical doctor who specialises in disorders of the gastrointestinal system), a dietician, specialist continence service or physiotherapist.

# Managing your bowel function through diet

Different things help different people. Here's a list of things you might want to consider.

- Many bowel symptoms can be eased by adjusting your diet and fluid intake.
- Identify triggers by keeping a food diary, noting what you have eaten and how your bowels have behaved that day.
- If **diarrhoea** is a main symptom, exclude or reduce foods known to stimulate the bowel, such as caffeine, fizzy drinks, alcohol, sugar-free sweets (mints and gums) and foods that contain sorbitol. Avoid fatty and deep-fried foods.
- Limit insoluble fibre intake from foods such as wholegrain breads, brans, cereals, nuts and seeds (you can eat oats and golden linseed).
- Increasing the amount of dietary fibre in your diet may help with **constipation** but tends to generate gas, stimulate contractions and make pain, bloating, flatulence

and diarrhoea worse. If you do increase your fibre intake, do so gradually, because any sudden increase may make symptoms worse. Oats and golden linseeds are good sources of soluble fibre, which help to soften the stool and make it easier to pass; they may also help with symptoms of wind and bloating.

- Drink at least 8 cups of non-caffeinated fluid a day.
- If you are finding **flatulence** (wind) a problem, you may find that peppermint oil, charcoal tablets, mint tea or cardamom seeds help. Try also eating more slowly, chewing your food really well and not drinking during meals.
- Try probiotics – there's more information about this in our '**Living with Bowel Cancer – Eating Well**' booklet.



# Managing your bowel function through medication

## Diarrhoea

**Loperamide (Imodium)** works by slowing down the passage of stool through your bowel, which gives it time to absorb more water. This will help form stools and reduce the amount of times you need to go.

You will need to experiment to find the dose that will control your bowels without constipating you. It is usual to start on a low dose and build it up slowly over a few days so that you can judge how your body is responding.

Loperamide is a very safe drug which is not addictive. It can be taken in doses of up to eight capsules (16 milligrams) per day over long periods of time. It can be prescribed as capsules or as a syrup (a 5ml teaspoon of syrup = half a capsule).

It is best to take loperamide half an hour before a meal. This will help to slow down the usual gut activity that is stimulated by eating. Most people find that their bowel is most active in the morning and so loperamide will help most if taken before breakfast. A dose last thing at night may help with early morning frequency.

**Fybogel and Normacol** can be useful to try to bulk up loose stools, particularly if you are having frequent, small amounts of stool. The bulking agent comes as powder in a sachet which is dissolved in a glass of water. You can take this once or twice a day. It can also be used in conjunction with loperamide, but you should speak to your Colorectal Nurse Specialist or GP first to get further advice.

**Codeine** is a drug used for mild to moderate pain relief. It also acts on the gut to slow the passage of the stool down (similar to loperamide). As with loperamide it is important to start with a very low dose to avoid sudden constipation. Codeine should be used with more caution after bowel surgery and only following discussion with your hospital consultant or GP.

**You can buy these medications from a pharmacy, but you will be entitled to free prescriptions as you are having treatment for cancer. Your GP or hospital Colorectal Team will be able to organise a prescription for you.**

## Constipation

There are many medicines available to help manage symptoms of constipation, all with different ways of working and a general guide is outlined below. However, before taking regular medication it is advisable to firstly increase your fluid intake (preferably water), adjust your dietary fibre intake (see page 11) and take regular moderate exercise.

Simply getting up and moving can help constipation. One of the best ways to exercise for constipation relief is a brisk 10 to 20 minute walk at least once a day.

Types of laxatives include:

- **bulking agents** – absorb liquids in the intestines and swell to form a soft bulky stool e.g. Fybogel
- **stool softeners** – help liquids mix into the stool and prevent dry hard stool e.g. Milpar/docusate sodium
- **stimulant laxatives** – encourage bowel movements by acting on the wall of the bowel e.g. senna
- **osmotic agents** – draw water into the bowel from surrounding body tissues, providing a soft stool e.g. Lactulose, Movicol



## Patient story

### Sheena, 47

*"I have always found it hard to go to the toilet, going two or three times a week at best. In April 2015, I saw my GP, as I was really struggling to go to the loo. We put this down to stress initially, but things moved very quickly once I saw my consultant and had an endoscopy. We were blown away to be told that I had Stage 4 rectal cancer which had spread to my liver.*

*I took the bold step and opted to have a stoma, as this would make my life easier during treatment. We named her Fanny – it was part of me and would become a way of life. She was with me for almost 18 months until, just three months ago, we said our goodbyes.*

*The first few days after my stoma was reversed, things were OK, not much movement, but I could eat what I wanted, with no restrictions like with the stoma. Then on day 3 when I was about to be discharged, the cramps and pain kicked in as my bowels came back to life. I am*

*a very quick healer and was back on my feet the very next day after the operation, so was very downhearted that this had happened. I didn't want to eat at this point as I felt so full, but I needed to eat to get things moving – a vicious circle. After a few days, the pain died down a little and I was allowed home with pain relief to hand.*

*Once home things really got moving, I didn't leave the house for almost two weeks, as the urgency to go to the toilet was overwhelming and I had to get up in the night for a while.*

*At one point, when I hadn't been to the toilet for four days, it was time to seek help from my consultant. He checked that my bowel was not blocked and recommended some laxatives. So 12 laxatives later, we had movement, oh yes we did. It came to a point where it was easier to leave the light on and the loo seat up, because I didn't have time to do both. This went on for about 10 days. After a while I felt ready to venture out into town, but I did wear a very large pad, just in case I had a little accident, each time looking where the toilet was and sitting close to the toilet in restaurants.*

*Today, I try and eat a high fibre diet, drink lots of fluids and only eat about twice a day as that seems all my body can cope with at the moment. Life is good, back on track. Cancer was just a blip in my life plan. I had cancer, it didn't have me."*



## Skin care

**If you have frequent bowel motions, diarrhoea or accidental leakage you may get sore skin around your back passage from time to time. This can be very uncomfortable and distressing. Taking good care of the skin around your back passage can help to prevent these problems from developing.**

### Here are some tips:

- After a bowel action, always wipe gently with soft toilet paper or, ideally, cotton wool. You can use the newer moist toilet paper but make sure it is the unfragranced, simple variety as perfumed wipes should be avoided.
- Discard each piece of paper after one wipe, so that you are not re-contaminating the area you have just wiped.
- Whenever possible, wash around the anus after a bowel motion.
- Don't be tempted to use disinfectants or antiseptics – warm water is best.
- Pat the area dry gently. Do not rub the area as this can cause tiny abrasions (tears) in the skin that can then make the sore skin worse.
- If you do need a barrier cream, choose a simple one, such as zinc and castor oil, Sudocrem or Vaseline. Use just a small amount and gently rub it in. If you are having radiotherapy you should check with your healthcare professional first that the product is suitable.
- Ask your healthcare professional to have a look at your skin if the discomfort remains.

“Don't be tempted to use disinfectants or antiseptics – warm water is best.”

# Controlling your bowels through muscle training

There are two rings of muscle wrapped around the anus, called 'sphincters'. When a stool comes into the rectum, one of the muscles relaxes and allows the stool to enter the anus. Sensitive nerve endings in the anus can tell you if it is gas or stool waiting to come out. If it is stool, you squeeze the second muscle to stop it from coming straight out. The squeezing moves

the stool back into the rectum, where it waits until you get to the toilet. However, you may not be able to squeeze enough to hang on if your muscles are weak, have been damaged by surgery or radiotherapy, if they do not squeeze in the correct order or the nerve supply to the muscles is damaged.

## Learning to control your sphincter muscles

Having a problem controlling your bowels can be upsetting. If you have had the distressing experience of a bowel accident in public, you will be acutely aware of the feeling of any pressure or filling sensation in your rectum which might mean you will need to find a toilet quickly. It is a natural reaction to try and prevent an accident by either tensing all your muscles and holding your breath or rushing to find a toilet. A better course of action is to sit or stand still, breathe deeply and contract your anal sphincter until the urge passes.

Most people find that their emotions have an influence on their bowels. If you are worried or anxious it can lead to more frequent, more urgent, and looser bowel actions. If you panic when your bowel is full, this can cause the sense of urgency to become even stronger. Your rectum, your sphincter muscles and your confidence need retraining to help you overcome this problem.

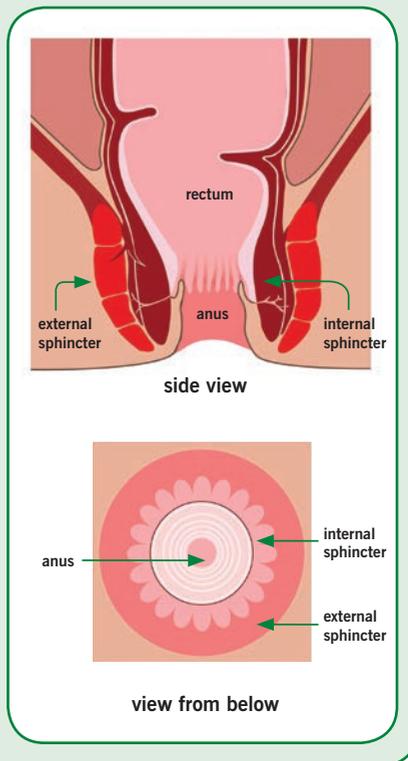


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Exercises can strengthen your anal sphincter muscles so that they give support again. This will improve your bowel control and improve or stop leakage of gas or stool. Like any other muscles in the body, the more you use and exercise them, the stronger they will be.

- 1 Imagine that your sphincter muscle is a lift. When you squeeze as tightly as you can, your lift goes up to the fourth floor. But you cannot hold it there for very long, and it will not get you safely to the toilet as the muscle will get tired very quickly. So now squeeze more gently and take your lift only up to the second floor. Feel how much longer you can hold it than at the maximum squeeze. You may not be able to do this at first. If the urge is too strong, start by trying to delay bowel emptying once you are sitting on the toilet. See how long you can wait until you really have to let go.
- 2 Sit on the toilet and hold on for as long as you can before opening your bowels. If you can only manage a few seconds, don't worry, it will become easier with practice. You might find it easier if you try to relax and concentrate on breathing very calmly. It may be helpful to take something to read.
- 3 Once you are able to delay opening your bowels for a few minutes, the unpleasant urge to go then disappears. Get up and leave the toilet. Return a few minutes later when there is no urge and try to open your bowels. Gradually you will find that you can increase the distance and time away from the toilet. The more you practise this and the sphincter exercises overleaf, the sooner it will happen.

Eventually you should find that you are regaining control of your bowels. The longer you can hold on, the more fluid is absorbed from the stools and so the firmer and less urgent they become.

“ When you have some successes, you will become more confident. ”

# Sphincter exercises

**1** Sit, stand or lie with your knees slightly apart. Now imagine that you are trying to stop yourself passing wind from your bowel. To do this you must squeeze the muscle round your back passage. Try squeezing and lifting that muscle as tightly as you can, as if you are really worried that you are about to leak. You should be able to feel the muscle move. Your buttocks, tummy and legs should not move much at all. You should be aware of the skin around your back passage tightening and being pulled up and away from your chair. You should not need to hold your breath when you tighten these muscles.

**2** Tighten and pull up the sphincter muscles as tightly as you can. Hold for at least five seconds and then relax for at least 10 seconds. Repeat at least five times. This will work on the strength of your muscles.

**3** Pull the muscles up to about half of their maximum squeeze. See how long you can hold this. Then relax for at least 10 seconds. Repeat at least five times. This will work on the endurance or staying power of your muscles.

**4** Pull up the muscles as quickly and tightly as you can, then relax, and then pull up again. See how many times you can do this before you get tired. Try for at least five quick pull-ups.

Do these exercises a few times every day. As the muscles get stronger, you will find that you can hold for longer than five seconds, and that you can do more pull-ups each time without the muscles getting tired. Remember that you cannot hold your tightest squeeze for very long, so it is better to use a gentle squeeze that you can hold for longer. Your control will gradually improve. You may need to exercise regularly for several months before your muscles gain their full strength; after you have achieved that, continue to do these exercises to maintain your bowel control.

“ Do these exercises a few times every day. ”

# Other solutions

**If you are still having problems after trying some of the advice in this booklet, you could ask for referral to a bowel control clinic for specialist treatment. After a thorough assessment, you may be offered some of the treatments described here.**

## Irrigation

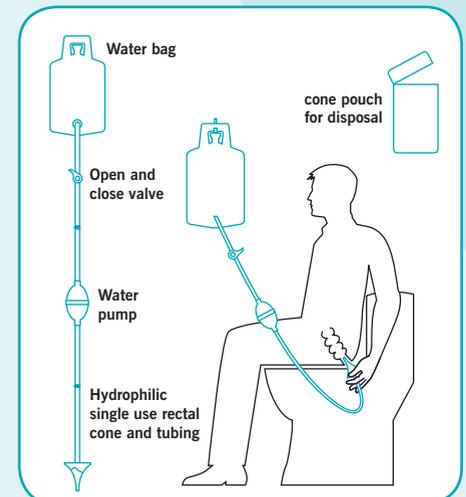
Rectal irrigation (also called transanal irrigation) is increasingly being used to manage the symptoms of anterior resection syndrome and other bowel symptoms after surgery. It is a convenient way to aid evacuation of stool from the bowel and is used to manage stool incontinence, bowel leakage, chronic constipation and difficulties with passing stools.

Rectal irrigation can help reduce the physical discomfort and worry of bowel leakage and constipation, making it easier to take part in social activities, go to work or travel. These systems can be very flexible; for example, if you are going away from home for several hours you can judge exactly when to use the equipment and it is also convenient to pack and take with you.

All irrigation systems work similarly. While sitting on the toilet, warm (tap) water is introduced from a reservoir via a rectal catheter. The water stimulates the bowel and flushes out the stool, leaving the lower half of the bowel empty. After an initial period of regulating the bowel, the number of times you need to irrigate can be reduced and need not be done every day. Rectal irrigation should only be used

following consultation with a continence nurse specialist or other expert.

**You must receive thorough instruction from a healthcare professional before using this product.**



## Other solutions

**Percutaneous tibial nerve stimulation** (PTNS) and **sacral nerve stimulation** (SNS) are both treatments for people with bowel problems. Bowel function is regulated by a group of nerves at the base of the spine, called the sacral nerve plexus. Stimulating these nerves through gentle electrical impulses can cause an improvement in bowel symptoms.

**Percutaneous tibial nerve stimulation** is a minimally invasive procedure, during which a very slim needle is inserted just above your ankle (for 30 minutes at each session). This is attached to a stimulator which delivers a mild electric current to stimulate the tibial nerve, which in turn stimulates the sacral nerves. The initial course of treatment will probably be 8 sessions, typically a week apart, after which your progress will be assessed. If there is an improvement you will continue to attend for PTNS but much less frequently.

With **sacral nerve stimulation**, a trial will first be carried out to assess if permanent treatment is right for you. This involves placing a thin wire under the skin in your lower back. The wire is connected to a small external test stimulator, which is worn on a belt. The surgeon can alter the strength of stimulation needed until the optimum level is reached. The trial typically lasts for two weeks and you can continue most daily activities, with care.

If your bowel control is sufficiently improved during the trial, inserting a permanent implant requires a short operation, usually performed under a general anaesthetic. Small incisions will be made in the upper buttock, where the surgeon will insert a pulse generator under the skin and in the lower back, where an electrode will be inserted next to the sacral nerves.

### Biofeedback therapy

Biofeedback is a non-invasive treatment which can be used to retrain your bowel and anal sphincter muscles to help manage problems such as constipation, problems with passing a motion and stool incontinence.

In some centres, the therapy will involve placing a small sensor into your bottom. The sensor relays detailed information about the movement and pressure of the muscles in your rectum to a computer. Sometimes a small balloon is inserted into your back passage and inflated with a little air. You will be asked to push down on the sensor or balloon to assess how you are using the muscles in your rectum and anus. You will be shown a more effective way of doing this, if required, or reassured that you are using the muscles correctly. The therapy includes a full assessment of your symptoms, changing toilet behaviour, sphincter exercises, medication advice and follow up review.

## Returning to work

**Returning to work can be quite daunting if you are having ongoing problems with your bowel control, especially the thought of having to talk to someone about changes you may need to make in order to accommodate your toilet needs.**

The Equality Act 2010 and the Disability Discrimination Act 1995 protect you from discrimination at work and employers must not treat you less favourably for any reasons relating to your cancer. Your employer must make 'reasonable' arrangements to help you return to your job. 'Reasonable' depends on the type of work you do and will take into account cost, practicality and how much any arrangement will be effective in helping you perform your role.

You may find the following helpful:

- If your organisation has an Occupational Health department, make an appointment to see an advisor to discuss your needs.
- If you feel able, discuss the issue with your line manager or a trusted office colleague.
- If you are office-based, it is reasonable to ask if you can relocate to a desk nearer the toilets.
- You may find it less stressful to commute outside of normal 'rush hour' times – ask your employer about flexible working.
- If you are self-employed, you may need to find different ways of managing your day-to-day activity and workload. Citizens Advice and local business networks can often give you support to work through the issues you are facing.
- A large make-up bag or 'man bag' is useful to keep some spare pads, underwear and wipes in case of any accidents. Sometimes having these with you gives you confidence even if you never need to use them.
- Smartphone apps such as 'Flush' and 'Toilet Finder' can be useful in locating nearby toilets.
- Carry a 'Just Can't Wait' card (details on page 22).
- Disability Rights UK has lots of information and access to the national toilet key scheme (details on page 22).

# Useful contacts

## Bladder & Bowel Community

'Just Can't Wait' toilet cards

**W:** [bladderandbowelfoundation.org](http://bladderandbowelfoundation.org)

**T:** 01926 357220

## British Dietetic Association

To find a registered dietician in your area

**W:** [bda.uk.com](http://bda.uk.com)

**T:** 0121 200 8080

## Disability Rights UK

Specialist keys for secure public toilets, and regional lists of locations

**W:** [disabilityrightsuk.org](http://disabilityrightsuk.org)

**T:** 020 7250 8191

## Colostomy Association

For people with a colostomy

**W:** [colostomyassociation.org.uk](http://colostomyassociation.org.uk)

**T:** 0800 328 4257

## IA Support Group

For people with an ileostomy or internal pouch

**W:** [iasupport.org](http://iasupport.org)

**T:** 0800 0184724

## Pelvic Radiation Disease Association

Support for the effects of radiotherapy

**W:** [prda.org.uk](http://prda.org.uk)

**T:** 01372 744338

Please also visit our online patient forum to make contact with a lively community of people who, like you, are living with and beyond bowel cancer. Friends and relatives are also welcome.

[community.beatingbowelcancer.org/forum](http://community.beatingbowelcancer.org/forum)

Beating Bowel Cancer booklets and factsheets can be downloaded or ordered in hard copy at [www.beatingbowelcancer.org/booklets-factsheets](http://www.beatingbowelcancer.org/booklets-factsheets)

## Gary Logue Colorectal Nurse Awards

These awards were set up in memory of our nurse advisor, Gary Logue, who passed away in 2014. Bowel cancer patients are warmly invited to show recognition of the fantastic work that nurses do by nominating their colorectal cancer nurse specialist for an award. Each year, two nurses will receive £500 each towards their personal development.

Please visit [beatingbowelcancer.org/nurse-awards](http://beatingbowelcancer.org/nurse-awards) and tell us why your nurse deserves this special recognition.

# Support our work

## We provide practical and emotional support

- We provide specialist support and information to anyone affected by bowel cancer.
- Our online forum which is free to join enables all those affected by bowel cancer, patients, relatives and carers to share information and experiences and gain support from one another. It includes a private area for relatives and friends. For many people talking to others who have been through similar experiences can be very helpful.
- You may need support at any stage of the bowel cancer journey, but many find us of particular help and comfort when they are having a break from treatment, or have finished treatment and are no longer receiving that day-to-day support from the hospital.

## We bring people with bowel cancer together

- Bowel cancer affects people physically and emotionally and a problem shared can make a world of difference.
- We connect people through the power of our website, social media and major events such as our Patient Days.

## We promote early diagnosis

- 9 in 10 people with bowel cancer will survive if they're treated early. That's why we campaign to promote and extend bowel cancer screening.

- We work tirelessly through innovative campaigns to promote greater awareness of symptoms, and the key message that bowel cancer can be beaten.

## We campaign for the highest quality treatment and care

- Everyone affected by bowel cancer, no matter who they are or where they live, should get the best possible support, care and information. We campaign nationally and locally to make sure Governments and health services do better by providing the highest quality care and treatments, and by making beating bowel cancer a priority.

## We raise money to fund our vital work

- We are a charity that relies entirely on voluntary donations and gifts in Wills. By giving a donation you will help fund a range of vital services that give people affected by bowel cancer help, hope and reassurance.
- We need you to help us continue our work. Please join us and together we can beat bowel cancer.

To make a donation please visit [beatingbowelcancer.org/donate](http://beatingbowelcancer.org/donate) or call **020 8973 0000**.

## Beating Bowel Cancer is the support and campaigning charity for everyone affected by bowel cancer.

We provide practical and emotional help – digitally, by phone and email, and face to face.

We bring patients together to share invaluable experience and support, through our website, social media and major events.

Our high impact campaigns have led to the introduction of the bowel cancer screening programme, which is helping save lives, as well as new funding and greater patient access to life-changing cancer treatments.

**beatingbowelcancer.org**

**Nurse Advisory Service**

24 hour answerphone and callback service

**020 8973 0011**

**nurse@beatingbowelcancer.org**

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If you have any questions or comments about this publication, or would like information on the evidence used to produce it, please write to us, or email **info@beatingbowelcancer.org**

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