Regaining bowel control
After bowel cancer treatment
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 large bowel (colon and rectum), and to find out how and why surgery can change the way it works. 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.
How does surgery affect the colon?

The main function of the large bowel 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 large 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 go to the toilet.

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

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).

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 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 diagrams below.

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 habits. 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.
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 wind?
- do you ever have any accidental leakage of liquid poo?
- how often do you go to the toilet?
- do you ever have to go to the toilet again within one hour of the last bowel movement?
- do you ever have such a strong urge to go 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 poo, leakage of poo and burning (acidic) poo, which can irritate the sensitive skin around the bottom can be made worse as the bowel struggles to compensate.

Things you can do to minimise 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 (for example 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 14)

Please note

If diarrhoea is accompanied by fever, abdominal cramps, pain, bloating, dizziness, blood in poo, and/or inability to drink adequate amounts of fluid, then contact your hospital team.
Regaining 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 poo 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 poo as before. This can cause the poo to pass through more quickly and may give you less control of your bowel.

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 poo)
- passing more wind

Experiencing a slow leakage of poo 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, like Cavilon, can help protect the delicate skin around the bottom.

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.

Why radiotherapy affects bowel control

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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 basic assessment, which will help pinpoint exactly what the troublesome symptoms are for you, as this can vary greatly from patient to patient. This will include 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

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 cut 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 19).
Referral to a 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.

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 poo and make it easier to pass; they may also help with symptoms of wind and bloating.
- Drink at least eight cups of non-caffeinated fluid a day.
- If you are finding 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.
- You could try probiotics, but always check with your healthcare team first.

Within a month of having my stoma reversed I had chemotherapy, which played havoc with my digestion. It’s more under control than it was, but I’m still having problems a year later. I’m due to see a specialist cancer nutritionist and a colorectal consultant to discuss what else we can do.

Richard
Managing your bowel function through medication

Diarrhoea

Tell your doctor about any medicines and any nutritional supplements you’re already taking. They may suggest you stop taking any medicines that may be making your diarrhoea worse.

Always speak to your doctor before taking any medicines for diarrhoea. They will need to find out what is causing your symptoms before deciding on the best treatment for you.

Your doctor may offer you medicines that slow down the movement of the large bowel, such as loperamide or codeine phosphate. They will give you information on how and when to take these drugs.

If your bowel cancer treatment is likely to cause diarrhoea, your doctor may give you diarrhoea medicine to keep at home in case you need it.

If you’re having chemotherapy or chemoradiotherapy, your doctor may give you a medicine called octreotide to treat diarrhoea caused by your cancer treatment. Your healthcare team and GP can tell you about products and local services that can help you cope with diarrhoea.

Constipation

Your GP or healthcare team can give you medicine to help with constipation. They may give you stool softeners for hard poo that is difficult to pass or laxatives for a slow bowel habit. Only take these under medical guidance.

"I’m now living without a bowel and I’m taking tablets daily to manage the diarrhoea. I have to be careful about what I eat. I’ve recovered really well from the surgery and I’m managing to work and have started to exercise again. The entire clinical team during this journey has been amazing. They have been supportive, provided really high levels of care and explained every step of the process so I was well informed enough to make decisions about my treatment."

Kate
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 bottom 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 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.

Controlling your bowels through muscle training

Your healthcare team may give you exercises to help you regain control of your bowels. You could also do pelvic floor exercises to help strengthen the muscles you use to go to the toilet and pass urine.

Learning to control your anal sphincter muscles

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.

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.
Regaining bowel control

If you are still having problems after trying some of the advice in this booklet, you could ask for a referral to a bowel control clinic for specialist treatment. Some of these treatments are 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 removal of poo from the bowel and is used to manage stool incontinence, bowel leakage, chronic constipation and difficulties with passing poo.

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.

Please note

Pelvic floor exercises might also help. You can find more information on NHS Choices website or by speaking to your healthcare team.

Remember

Always speak to your healthcare professional before using this product.

Other solutions

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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 bottom 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.

Sacral nerve stimulation (SNS)

With SNS, 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.

Percutaneous tibial nerve stimulation (PTNS)

PTNS 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 eight 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.

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.
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.

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 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)

I’ve now got a real balance to my life despite being on lifetime chemotherapy – I work, I’m back training in the gym regularly, I’ve qualified as a yoga teacher. I also travel a lot, going to Europe and the US regularly and I’ve even been as far as Bali. I’ve just passed the all-important five-year milestone since my stage four diagnosis.

Steve
Useful contacts

Bladder & Bowel Community
W: bladderandbowel.org
T: 01926 357 220
‘Just Can’t Wait’ toilet cards

British Dietetic Association
W: bda.uk.com
T: 0121 200 8080
To find a registered dietician in your area

Disability Rights UK
W: disabilityrightsuk.org
T: 0330 995 0400
Specialist keys for secure public toilets and regional lists of locations

Colostomy UK
W: colostomyuk.org
T: 0800 328 4257
For people with a colostomy

IA Support Group
W: iasupport.org
T: 0800 018 4724
For people with an ileostomy or internal pouch

Pelvic Radiation Disease Association
W: prda.org.uk
T: 01372 744338
Support for the effects of radiotherapy

Further support

Online community
Our online community is a welcoming place for everyone affected by bowel cancer to ask questions, read about people’s experiences and support each other. Join us at bowelcanceruk.org.uk/community

Ask the Nurse
If you have any questions about bowel cancer, contact our nurses at bowelcanceruk.org.uk/nurse

Publications
We produce a range of expert information to support anyone affected by bowel cancer. Order or download our free publications at bowelcanceruk.org.uk/ourpublications

Website
Visit our website for a range of information about bowel cancer including symptoms, risk factors, screening, diagnosis, treatment and living with and beyond the disease. Visit bowelcanceruk.org.uk
Bowel Cancer UK is the UK’s leading bowel cancer charity. We’re determined to save lives and improve the quality of life of everyone affected by the disease.

We support and fund targeted research, provide expert information and support to patients and their families, educate the public and professionals about bowel cancer and campaign for early diagnosis and access to best treatment and care.

To donate or find out more visit bowelcanceruk.org.uk

/facebook/bowelcanceruk
/twitter/@bowelcanceruk

Please contact us if you have any comments about the information in this booklet: feedback@bowelcanceruk.org.uk