

# Bowel changes after rectal cancer treatment



Understanding and managing LARS (low anterior resection syndrome)

Written for people who have had an anterior resection (with or without a stoma)

“They need to prepare you better for survival because it's a big deal” (Stan aged 52)

Written with many thanks to all the people who took time out of their lives to talk to me about problems and solutions. Their words (some of which are included) led me write this booklet (Jennie Burch 2023)

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## **Introduction**

### **In brief**

People after a rectal cancer operation have said that having facts is helpful. This booklet is designed with three purposes in mind. One, to give you a few facts about a topic (in brief). Two, to give you more facts about the topic (looking in-depth). Three, to give you other places to look for other facts (signposting).

This booklet is not meant to scare you. This booklet hopes to give you facts. Having facts can help you cope with changes that can happen after your rectal cancer operation.

This booklet can be read in full. Or you can read just the bits relevant to you. The booklet can wait until you are ready to look. Or you can read the booklet if you come across a particular problem. Or you can share the booklet with friends and family.

If the help you want isn't in this booklet, look in the signposting section. These facts might suit you better.

### **Looking in-depth**

The focus of this booklet is bowel problems. Bowel changes after rectal cancer treatment can be called LARS. This stands for low anterior resection syndrome. Bowel changes might include needing to get to the toilet faster than before. Or going to the toilet more often than before the cancer. People with bowel changes have said they belong to the "LARS community."

"Obviously it helps when it's got a name [LARS] because then it's a bit more clearly defined" (Mike aged 50)

It is helpful to know bowel function might change after rectal cancer treatment. When you have facts, you can set your expectations. Reading this booklet should help you know what might happen. Also, why it might happen and what you can do about it, to make things better.

"I remember some weird thing about there might be problems after it [the stoma reversal]. I know what I'm dealing with right now and having a stoma isn't great. But I know where I am at with it. And then there's this great big unknown. And I've got to make a decision on an unknown. And if someone could have sat me down at that point and said: 'If you have the reversal, this is the range of

symptoms you could have. We obviously can't tell you where you'll fall in that range, but these are the potential consequences. These are the potential things we can do to address some of these complications if you were to get them.' So, you get an informed decision" (Kylie aged 46)

People who have been through rectal cancer, said they would have liked to have more facts. More facts would not have changed their choices, but it would have helped them to know what to expect. People said it would have been helpful to know problems might occur. For some people it can feel like too many facts. Other people want a booklet to remind them about facts, so they could look at it later. We are all different and have different needs.

### **Signposting**

This list may not include all facts. These are some useful websites:

- The Association of Coloproctology of Great Britain and Ireland. Go to: <https://www.acpgbi.org.uk/patients/default.aspx>
- Macmillan Cancer Support (United Kingdom). Go to: <https://www.macmillan.org.uk/>
- Bowel Cancer UK. Go to: <https://www.bowelcanceruk.org.uk/>
- Colorectal Cancer Alliance (United States of America). Go to: <https://www.ccalliance.org/>
- Cancer Council (Australia). Go to: <https://www.cancer.org.au/>
- Cancer Society (New Zealand). Go to: <https://www.cancer.org.nz/>
- Canadian Cancer Society. Go to: <https://cancer.ca/en/about-us>
- Bowel Cancer UK, regaining bowel control after bowel cancer treatment. Go to: [Regaining bowel control | Our publications | Bowel Cancer UK](#)
- Bowel Cancer UK, stoma reversal. Go to: [Stoma reversal | Our publications | Bowel Cancer UK](#)
- St Mark's Hospital website. Go to: <https://www.stmarksdigital.com/education/patient-information/>

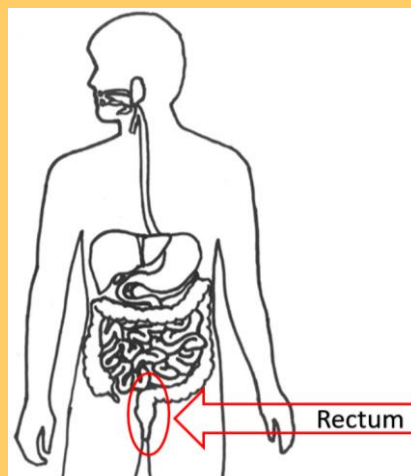
## How the gut works

### **In brief**

The job of your gut is to take in and break down food. You absorb what is needed into your body and get rid of any waste by having a poo. Having a poo requires co-ordination between your back passage (rectum), brain, nerves and muscles. After rectal cancer treatment there are likely to be temporary or long-lasting changes to your bowel function.

### **Looking in-depth**

The gut (gastrointestinal tract or alimentary canal) begins at the mouth and continues inside of you, via a long tube (your bowel) to your bottom (anus). The main parts of the gut are the mouth, stomach, small bowel, large bowel (colon) as well as the rectum (back passage), anal canal and anus.



Most of the absorption of nutrients and fluids occurs in the small bowel. Movement through the gut happens when the muscles in your gut wall squeeze the food and waste towards your bottom. Movement through your gut is controlled by several things. When you eat, signals are sent to your gut. These signals tell the gut to move what is inside along to make room. This is termed the gastrocolic reflex. In your large bowel, your waste usually becomes a brown, sausage shaped poo. Poo is stored in the rectum before it is passed out of the body.

Having a poo is more complicated than you would image. When poo reaches your rectum, it is stored until there is a good amount to pass into the toilet. A small amount of poo can usually be stored in the rectum unnoticed. Once a good amount of poo is collected in the rectum, the rectal walls stretch. This stretching

sensation tells the body it is time for a poo. The body needs to tell the brain that a poo is needed. This happens via the nerves and the spinal cord. Once the brain knows there is poo waiting to come out, the brain needs to decide if it is the right time to go to the toilet.

When you are ready for a poo, everything inside needs to co-ordinate so you can push the poo out. There needs to be co-ordination of the rectum, nerves, pelvic floor and anal sphincter muscles. This used to happen automatically without you thinking about it. After your operation you may need to re-learn this again.

### **Signposting**

If you want to have going to a poo explained in more detail, watch this video:

- Dr John Campbell has made a video that explains 'gastrointestinal system, defecation' Go to: <https://www.youtube.com/watch?v=bu7R2gwO6H0> (17 minutes long)

## **Rectal cancer**

### **In brief**

Rectal cancer can also be called colorectal cancer or bowel cancer. Rectal cancer is cancer in the last part of the bowel (rectum) the area that stores the poo. Cancer is an uncontrolled growth of cells. Rectal cancer can spread by growing bigger or it can spread into the blood vessels, lymph nodes or distant places in the body such as the liver.

### **Looking in-depth**

Rectal cancer can occur in anyone at almost any age, although it is more common in people over 60 years old. The signs and symptoms of rectal cancer include a change in bowel habit such as diarrhoea or constipation. Also, passing blood with a poo or the poo becomes narrower. Other symptoms can include pain in the tummy or losing weight without meaning to. If any of these symptoms are noticed, speak to your doctor.

“I went to my doctor and I said I'm doing flat poo. It's not normal, is it? The reason they were flat was because I had a huge tumour and it was squeezing past like toothpaste” (Scott aged 63)

Diagnosing rectal cancer can be hard as symptoms can be the same for other reasons such as piles (haemorrhoids). Blood tests might be needed to look for anaemia. A colonoscopy is a camera test that can look inside your bowel for cancer or other problems. The clinician can take a sample (biopsy) to look for anything of concern. Scans such as a CT (computed tomography) are usually needed before your operation to help the clinicians determine the best treatment for your rectal cancer.

Rectal cancer can also be diagnosed in a screening programme. In the UK there are screening programmes that post a poo test to people in their 50's, 60's and 70's. The poo test (FIT) is looking for bleeding, one sign of bowel cancer. Even if you have no signs of cancer, you should do a screening test if you are sent one.

### **Signposting**

Cancer Research UK website has useful for facts on bowel cancer. Go to:

<https://www.cancerresearchuk.org/about-cancer/bowel-cancer>

The Australian government have produced facts on bowel (colon and rectal) cancer. Go to: <https://www.healthdirect.gov.au/bowel-cancer>

For more help about bowel screening there is a short video from the Scottish government: <https://www.youtube.com/watch?v=nRa7oj0478Q> (1 minute)

Hear Joan's experience of bowel cancer screening:

<https://www.health.gov.au/resources/videos/joans-story-i-do-everything-right-and-i-still-had-bowel-cancer> (3 minutes)

The American Society of Colon and Rectal Surgeons has produced a short video about rectal cancer: <https://fascrs.org/patients/diseases-and-conditions/a-z/rectal-cancer> (7 minutes)

A general rectal cancer overview from Canada explores your operation, side effects and recovery: <https://colorectal.providencehealthcare.org/patient-info/cancer-information> (23 minutes)

## **Rectal cancer treatment options**

### **In brief**

There are three main treatments for rectal cancer. These are an operation, chemotherapy and radiotherapy. Some people need one, two or all three treatments depending on their cancer and where it is. Treatment for cancer is likely to cause temporary or lasting changes to how your body works.

“There is nerve damage from the infusion chemo[therapy] and some of it’s permanent. I know its permanent because eight years is long enough to be permanent” (Brendan aged 65)

### **Looking in-depth**

The Surgeon can operate to remove the cancer. The Surgeon will also cut out nearby tissues to make sure all the cancer is removed.

Chemotherapy is used to kill tiny cancer cells. Tiny cancer cells might be in the lymph nodes or be left after the operation. Chemotherapy might be needed to treat this.

Radiotherapy may be used before your operation to shrink the cancer, to make it easier to remove. Radiotherapy may be used after your operation to make sure all the cancer has gone.

Although everything will be explained to you, it can be hard to retain the facts. You need to expect that having an operation and/or chemotherapy and/or radiotherapy will change your body.

“My Surgeon in the initial diagnosis appointment, said something to me about the implications of surgery. I had no choice about the surgery. I didn’t want to die. ‘Just do whatever it will take for me not to die.’ So, anything else, you just didn’t take it in. There was already so much to take in” (Kylie aged 46)

Cancer treatment can lead to visible scars as well as unseen changes. Unseen changes might include changes to the way you go to the toilet such as going more often or needing to go in a rush. It is helpful to know about these changes to help you cope with them.

“No-one told me that before all of this. It wouldn’t have changed my path, but it might have helped” (Angela aged 44)



You can feel overloaded by all the things you are told in the hospital. It can be hard to remember everything. Re-read facts you were given, write a list of questions or ask your healthcare team to repeat facts.

“You have two [brain] cells ... and they’re both going ‘I have cancer. What do I do?’ I remember nothing from my consult” (Julie aged 53)

### **Signposting**

The Association of Coloproctology of Great Britain and Ireland explain an anterior resection. Go to:

[https://www.acpgbi.org.uk/patients/procedures/7/anterior\\_resection](https://www.acpgbi.org.uk/patients/procedures/7/anterior_resection)

The National Health Service explains about bowel and rectal cancer treatment options. Go to: <https://www.nhs.uk/conditions/bowel-cancer/treatment/>

Cancer Research UK has facts about treating rectal cancer. Go to:

<https://www.cancerresearchuk.org/about-cancer/bowel-cancer/treatment/treatment-rectal>

## **Rectal cancer operation**

### **In brief**

The most common treatment for rectal cancer is an operation, used alone or with other treatments such as chemotherapy. The Surgeon will perform your rectal cancer operation. There are different options that the Surgeon will discuss with you.

### **Looking in-depth**

The surgeon’s role is to operate and remove the cancer. The Surgeon will request tests and tells you test results. Tests before your operation are needed to check the cancer stage. Tests after your operation might be to check that the cancer has not come back. The Surgeon might not be the best person to help with bowel changes but may be able to signpost or refer you to people who can help.

The common treatment to remove a rectal cancer is an operation to cut out the part of the rectum with the cancer in it. The different operations might be better suited to different people and the Surgeon can discuss this with you.

The most common operation is an anterior resection. Anterior means front and resection means removal. The Surgeon will make one or more cuts on the front of your tummy and remove part or all your rectum. How much rectum is removed depends on things such as where the cancer is growing. The two ends of the bowel are then joined back together. The amount of bowel that is removed might seem a lot. This is to make sure the Surgeon removes enough bowel to take all the cancer away. Also, to make sure there is a good blood supply to the remaining bowel.

An anterior resection may also involve removal of the outer coating around the rectum (mesorectum). This operation is called an anterior resection with a total mesorectal excision (TME). A TME is more commonly performed if the cancer is low down, at the end of the rectum. A TME often needs a temporary stoma, usually an ileostomy. The ileostomy will usually be reversed at least three months after the operation, longer if you need chemotherapy.

A less common operation is an abdominoperineal excision of the rectum. This operation will result in a permanent stoma, usually a colostomy.

## **Signposting**

If you want to know more about cancer treatment there is help available.

Cancer Research UK has facts about rectal operations. Go to:

[https://www.cancerresearchuk.org/about-cancer/bowel-cancer/treatment/treatment-rectal/surgery-rectal/types-surgery-rectal?\\_gl=1\\*6b7bxy\\*\\_ga\\*MzI4NjU3MzMxLjE2MTg5OTkwNTk.\\*\\_ga\\_58736Z2GN N\\*MTY3MTcyNjc1Ni4xNC4xLjE2NzE3MjY5MTAuNTAuMC4w&\\_ga=2.190272299.1016864704.1671726757-328657331.1618999059](https://www.cancerresearchuk.org/about-cancer/bowel-cancer/treatment/treatment-rectal/surgery-rectal/types-surgery-rectal?_gl=1*6b7bxy*_ga*MzI4NjU3MzMxLjE2MTg5OTkwNTk.*_ga_58736Z2GN N*MTY3MTcyNjc1Ni4xNC4xLjE2NzE3MjY5MTAuNTAuMC4w&_ga=2.190272299.1016864704.1671726757-328657331.1618999059)

Ileostomy and internal pouch association has facts about stomas. Go to:

<https://iasupport.org/>

## **Radiotherapy and chemotherapy for rectal cancer**

### **In brief**

The Oncologist may suggest that you have chemotherapy and / or radiotherapy.

### **Looking in-depth**

The Oncologist is the cancer specialist who oversees treatments such as radiotherapy and chemotherapy. The Oncologist will explain what treatment, if any, is best for you. If problems occur when you have radiotherapy or chemotherapy it is best to speak to your Oncologist.

Radiotherapy can be used to shrink the cancer. Radiotherapy might cure cancer. Radiotherapy might reduce the chances that the cancer will come back (recurrent cancer). Radiotherapy can also be used to help improve symptoms. Radiotherapy is linked with having long-term changes to bowel function.

There are a lot of different types of chemotherapy. Chemotherapy can be given before or after your operation. Chemotherapy may be given before your operation to shrink the cancer and make it easier to remove (neoadjuvant chemotherapy). Chemotherapy can be given after your operation (adjuvant chemotherapy) to reduce the chances of the cancer coming back.

### **Signposting**

If you want to know more about cancer treatment.

Cancer Research UK has facts about radiotherapy. Go to:

[Pelvic radiotherapy - treatment, side effects, follow-up | Macmillan Cancer Support](#)

Cancer Research UK has facts about chemotherapy. Go to:

<https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/chemotherapy>

Pelvic radiation disease association has facts on different topics related to pelvic radiation. Go to: <https://www.prda.org.uk/>

## **Recovery after rectal cancer treatment**

### **In brief**

Recovering from your rectal cancer operation can take a while. Bowel changes are usually at their worst soon after your operation. It is helpful to know that most people do get better over time. Be patient but do not just put up with symptoms that bother you. Bowel changes can get better faster if you try a plan to help such as taking medicine. You might need to be guided by your healthcare team.

“[It took] a year before you really kind of feel your way with it” (Kate aged 45)

### **Looking in-depth**

Cancer treatment can take about a year to complete, if you need an operation, chemotherapy, radiotherapy and a temporary stoma (ileostomy).

Recovery after rectal cancer treatment takes a while and will depend upon the type of cancer treatment you had. People report that recovery takes many months but for some people it can take more than a year. The first few weeks can be hard to cope with but things generally improve. Most people see most change in the first three months after the operation. If you do not try any plans to help, you will improve for about three months. Without trying other plans, it is not likely you will get much better after three months and any changes will probably be small. If you use treatments, such as medicine, you are likely to get better faster. Plans to help are more likely to improve symptoms than trying nothing. Plans to help can be tried at any time and can be effective. It can take a while to adapt both physically and emotionally after cancer diagnosis and treatment.

“At the beginning it was very tough” (Seb aged 56)

Most people will not ever quite get back to where they were before the cancer. But people report that they have reached a ‘new normal’ for them. This new normal might include some changes in bowel function. Also, people might need to learn to live with taking medicine or changing their diet.

If recovery is not as good as you want it to be, contact your healthcare team for more advice. You might need to try several different treatments, which are discussed later.

Most people can do the things that they want to do, once they recover. This includes physical activities.

“I’m totally happy and fine with the way things are, I can deal with [the bowel symptoms], I’ve been out running this morning” (John aged 39)

### **Signposting**

Macmillan Cancer support have facts about life after treatment. Go to:

<https://www.macmillan.org.uk/cancer-information-and-support/after-treatment>

## **Getting back to normal**

### **In brief**

It is helpful, when you are ready, to get back to your usual routines. Friends and family can be helpful, but it can be hard to talk to people or ask for help. What you say may depend upon how comfortable you feel telling others. It can also depend on how close you are to the person. You might need someone professional to speak to, such as a counsellor, to help you adjust. You might want to contact someone who has shared your experience, such as on a patient forum.

### **Looking in-depth**

Telling other people about cancer or your bowel problems can be hard. It can be embarrassing. You might not be ready to tell people. You might only want to talk about your problems with a close friend, partner or family member. Or, you might feel comfortable talking about your cancer experiences.

“I don’t feel like I wanna heap too much onto her” (Sandra aged 56)

You might be worried about who to talk to about your problems, because talking about poo is not common in most societies. People that you live with may know more, as they can see some of the problems you face, like going to the toilet more often. Unfortunately, some people might not know. Other people might think everything is ok now the rectal cancer has been removed. They may not realise other problems have occurred because of the cancer treatment.

“I really can’t physically eat all this food; I’ve got to have slightly smaller meals”  
(Alison aged 38)

Leaving the house can be stressful initially. Small trips can be useful to help you gain confidence.

Seeing friends and family might seem hard at first. You might find when you go out, you need to have a poo soon after eating or during the meal. You might not be able to eat the same foods that you used to. You might need to eat smaller meals. Telling people can be useful, so they know why you are different. It can be hard to know how much to tell people. Some people choose to tell just people who are close to them. Others might be more open, perhaps using humour to make light of these changes.

“I like to joke with people. I literally have 50% less capacity for sh\*t in my life, physically and metaphorically” (Angela aged 44)

It is helpful to have realistic expectations. Some people find they cannot do as much as they used to do. They readjust their lives to do the things they care about. Other people find new ways to cope with changes, such as planning activities more than they did before. If you are finding it hard to get back to normal speak to your Specialist Nurse or General Practitioner (GP).

“I understand I’m not going to be able to do everything I want to do every day. So, I do what I can and let go of the expectations of the other stuff” (Charlotte aged 53)

A 20 minute walk each day is good for your wellbeing. A walk with someone else can be a nice way to catch up.

## **Signposting**

Macmillan cancer support have facts about getting active again after treatment. Go to: <https://www.macmillan.org.uk/cancer-information-and-support/after-treatment/being-physically-active>

The National Health Service has facts about living with cancer. This includes facts about talking to others. Go to: <https://www.nhs.uk/conditions/bowel-cancer/living-with/>

A healthcare company called Wellspect have some online education about bladder issues. Go to: <https://www.wellspect.co.uk/bowel/rectal-surgery>

Bowel Cancer UK have an online patient forum. Go to:

<https://community.bowelcanceruk.org.uk/forum/welcome-to-our-forum>

## **Emotional well-being**

### **In brief**

Having cancer or adapting to life after cancer can be hard. Some people worry about the cancer returning. People may have side-effects of their cancer treatment. Alternatively, people after cancer treatment may feel enthused to focus on the good things in their life. They might choose a healthier lifestyle such as to stop smoking, stop drinking alcohol, eat better or do more exercise.

### **Looking in-depth**

Having a rectal cancer diagnosis can be hard to cope with. When bowel changes first occur, things can be overwhelming. It is helpful to know things will usually improve.

Trying to cope with bowel problems can be hard and it takes time. There are things that can help your symptoms.

There will be good and bad days. It can be hard not knowing whether it is going to be a good day or not. When bowel changes are bothersome this can be a bad day. Stress can also affect your bowels. It can help to think back, about how things have improved, maybe keep a diary.

Going forward, having tests after your operation to check for a cancer recurrence, can be stressful. It can help to have someone come to appointments for results with you.

If new symptoms occur it can increase concerns. Symptoms might make you worry that the cancer has come back. Bleeding from the bottom should always be checked, but it is not always a cancer recurrence. If you see bleeding you need to see your General Practitioner and possibly have some tests.

Having cancer can be emotional. It can help to acknowledge your emotions and talk about them. There are various stages that people report going through.

Initially there may be feelings of shock or denial at the cancer diagnosis. 'Why me?' There might be grieving about what has changed. Alternatively, there may be feelings of guilt, that the cancer was somehow your fault. 'What did I do wrong?' Feelings may change to anger. 'It is not fair. I've always been healthy!' Some people may feel depressed. Some people may feel unmotivated. Some people may push themselves to do things you might not have done before, good or bad things. At the end of this process is acceptance. To get through these stages you need hope and time. But it is not always easy. You can go backwards and forwards a bit. You might need help with your emotions.

"I don't want to get upset or angry about it, but that's where I am with this. So, I've not really told anyone [about bowel symptoms, but] I've been pretty open, when it comes to the cancer" (Debbie aged 56)

You may worry about changes in how your body looks. Your body may change because of surgical scars. These concerns will usually reduce with time. Some people have long-lasting anxiety. It is useful to ask for help if you think your emotions are stopping you getting on with your life.

"I found myself engaging in risky behaviour and doing stupid things" (Barry aged 57).

Some people after chemotherapy report they have changes in the way their brain works. Chemotherapy might affect concentration.

Some people cope by thinking positively and developing coping mechanisms to adapt to changes that happen. Being optimistic and focusing on the good parts of life can be useful. Be kind to yourself. Take each day at a time. Enjoy the small things.

"I'm truly grateful to being alive. I ensure that I have a full, normal and active life" (Adam aged 75)

If you feel you need more help, ask your General Practitioner. You might need a counsellor to talk through your concerns and improve your emotional well-being.

## **Signposting**

Macmillan offer free, short courses. Go to:

[https://learnzone.org.uk/courses/index.php?q=HOPE&\\_ncforminfo=AUuNldLCv](https://learnzone.org.uk/courses/index.php?q=HOPE&_ncforminfo=AUuNldLCv)



[sZszBml490cgnUbRnR4gFUw1zx-](https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/bupa-counselling-and-emotional-well-being-support)

[vuWdTHJ3jpmOLyJgSpdeMKkDE6sfvllRe9bjupxcSEulsHr9YLyrNSfDPbF](https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/bupa-counselling-and-emotional-well-being-support)

<https://www.macmillan.org.uk/cancer-information-and-support/get-help/emotional-help/bupa-counselling-and-emotional-well-being-support>

Bowel Cancer UK have some real life stories:

<https://www.bowelcanceruk.org.uk/how-we-can-help/real-life-stories/younger-people-with-bowel-cancer/carla-mitchell,-kent/?s=03>

## **Changes to your body after your operation**

### **In brief**

The rectal cancer treatment might cause changes to the way you go to the toilet for a poo or a pee. It might change how you function sexually. You might not have any problems but most people will have some bowel changes. Bowel changes will usually improve with time. To help them to improve faster you can make changes. There are lots of things that can be done to help.

### **Looking in-depth**

Clinicians do not know exactly how many people will have changes or what these changes might be. Some research suggests that up to four out of every five people after a rectal cancer operation will have some bowel changes. This means most people will have some changes to their bowel function after rectal cancer treatment. But it is not certain what problems people will have. Some of these changes will be temporary and some long-lasting.

“I think statistically it’s about 80% of people are going to have LARS” (Barry aged 57)

There is no way to determine exactly which people will have which (or any) problems. But it is likely that people who have a cancer low down in their rectum will have more problems than people with cancer at the top of the rectum. Similarly, people who need to have radiotherapy will probably have more

problems than people who do not need radiotherapy. People who have both a low rectal cancer and radiotherapy are very likely to have bowel problems.

In summary, people most likely to have bowel problems will have a low rectal cancer as well as radiotherapy.

“If you’ve had radiation to your pelvis. You’re higher risk [of having bowel problems]” (Kaylee aged 50)

Having bowel problems is called having LARS (low anterior resection syndrome). The most common bowel problems that can happen are:

- Variable and unpredictable bowel function
- Changes in the poo consistency
- Difficulty having a poo
- Having to run to the toilet (urgency)
- Having to go to the toilet more often (frequency)
- Having accidents (incontinence)
- Discomfort when having a poo
- Poo stains on their pants
- Increased or smelly wind

### Signposting

Macmillan Cancer Support have a huge range of topics in their impact of cancer section. Go to: <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer>

Macmillan Cancer Support have bowel specific data. Go to: <https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/late-effects-of-bowel-cancer-treatment/bowel-changes>

Disability Rights UK, sell keys to disabled toilets. Using a disabled toilet can be useful as there is a sink in the room with the toilet, helpful if you urgently need the toilet. Go to: <https://shop.disabilityrightsuk.org/products/radar-key>

## **Poo problems - low anterior resection syndrome (LARS)**

### **In brief**

Having rectal cancer treatment often makes going for a poo different to how it was before your operation. A term for your bowel changes is low anterior resection syndrome (LARS). There are things that can be done to help. You need to decide what (if any) treatment is right for you.

### **Looking in-depth**

Going for a poo might be less predictable than before the cancer treatment. There may be problems emptying your bowels. The poo consistency might change. You might need to rush to the toilet. Or go more often than before and for longer. Some people have poor control of wind or poo. Some people feel they produce more wind than before. Going to the toilet (bathroom) might feel uncomfortable. There might be some poo staining on your pants. Or you might need to go to the toilet more often.

“Some days I don’t go at all and some days I go like double figures” (Martin aged 50)

Removing your back passage means your poo storage area is removed. This means poo is not stored as well as it was. So, you may go to the toilet more to pass small poos. Over time this usually improves.

“I got what I call poo cystitis, I went nine times in an hour” (Angela aged 44).

Going to the toilet a lot can mean cleaning your bottom more. This can result in redness, soreness, burning or irritation around your anus.

After radiotherapy the walls of the rectum can become scarred (fibrosis). This means your rectum cannot expand when poo comes into it. This means you may need to go to the toilet more often.

The join in the rectum can heal with a tight scar. This can cause the width of the rectum to be narrow. This means it can be difficult or uncomfortable to poo.

The signals from your bowel might not work in the same way as before. The nerves needed to go for a poo can be damaged during your operation, chemotherapy and / or radiotherapy. Nerve damage can be temporary or long-lasting. Temporary changes last from months up to a couple of years. Getting better is usually slow and gradual. Permanent damage will not improve.

Nerve damage can make your anal sphincter muscles, that control when you have a poo, less reliable. The muscles may not close properly after a poo. This means you might get soiling on your pants. Your sphincters might ‘forget’ how to work with your other muscles and nerves. This may mean it is harder to start to have a poo. Or it may mean it is hard to completely empty when you go for a poo. Your anal sphincter muscles may be weak. Your sphincters might have been weak before the operation. Alternatively, having an operation might weaken the muscles. If you had a temporary stoma, the sphincter muscles may become weaker. Weak sphincter muscles mean you might not be able to hold back poo. You might have accidents, especially if your poo is soft or loose.

People may have reduced time between the first feeling they need the toilet and needing it urgently. In the first few weeks after your operation, you may only get a few minutes warning. This means you need to get to the toilet fast.

It might be hard to know the difference between wind or poo. This is because of changes in how the nerves work. Some people report they learn their new sensations (body cues).

People may feel they need a poo but nothing is there. This might be because the staples used re-join the bowel ends are causing unfamiliar sensations.

Some people report that they are not emptying out properly and feel there is more poo to come out. This feeling usually goes away over time.

“Never really feel that I’ve completely emptied myself ... I always feel that I could do more but I sit on the toilet long enough as it is” (Simon aged 63)

Some people report that the consistency of the poo has changed. The poo becomes stickier, which can be hard to clean up.

“That peanut butter nastiness that doesn’t wipe off” (Charlotte aged 53)

After a rectal cancer operation, the response to the gastrocolic reflex can change. The gastrocolic reflex usually tells the body to move waste along after eating a meal. This can result in needing a poo soon after eating or even during a meal.

The bowel might also be affected by an imbalance in the normal gut bacteria. This might improve over time.

## **Signposting**

A healthcare company called Wellspect have produced online education about having bowel accidents (incontinence). Go to:

<https://www.wellspect.co.uk/education/articles/fecal-incontinence/>

Bowel Cancer UK have facts about change in bowel habit after treatment. Go to:

<https://www.bowelcanceruk.org.uk/about-bowel-cancer/living-with-and-beyond-bowel-cancer/change-in-bowel-habit-after-treatment/>

Some people report buying a portable toilet. Some people have bought a bidet that can be attached to the toilet.

Sarah tells her story of having an accident, on Bowel Research UK website: Go to:

[Sarah, 57 #Auguts Story - YouTube](#)

## **Managing LARS (initial plans to help)**

### **In brief**

People after a rectal cancer operation can have a lot to deal with emotionally or physically. It can take a while to adjust to changes that might have occurred, which may be temporary or long-lasting.

You might choose to make a few changes to your life to help you adjust to your new bowel habit. You might make changes on your own. You might need help from your healthcare team. If you need assistance ask your Cancer Specialist Nurse, your Surgeon or General Practitioner.

Most people need to make more than one change to help them adjust. There is not much research about treating LARS. This means not all healthcare professionals will be able to offer you all the treatments discussed in this booklet.

One common change people make is planning more. This is harder at first when you are getting used to the changes.

“Trying to find a bowel regime ... it just seemed to be my whole life at that time [just after surgery]” (Alisha aged 65)

## Looking in-depth

You must decide what bowel changes you can live with and what cannot live with.

At first, it can be hard to adjust to the bowel changes. It can be useful to set small goals and increase your confidence. Things might feel different, but you can often learn what these new feelings mean. Some people use the term my 'new normal.' This is the changes that have now become 'normal' for you.

It is helpful to remember that by making some adjustments it can help you cope more easily with bowel changes than before. As you make changes, make sure you are happy with the adjustments you have made. If you need more help, ask your healthcare team.

It is useful to realise most people try more than one thing to help manage their symptoms to their liking. What you try may relate to your bowel changes, your personal choices or what is available to you. Some people need to use treatments for ever. Some people need to do them only for a few weeks or months. If you have had bowel changes for a long time and you are only just trying these ways to help, they can still potentially help.

Ways to help include:

- Lifestyle changes
- Exercises
- Adjusting your diet
- Taking medicine

We are all different. So, it is not possible to be certain what management options will work for each person. Most people do try more than one treatment at the same time. But most people do not need to try more than these ways to help. There are other options if these do not work well enough for you (see specialist ways to help). Most people report having to try and see what works best for them. Most people need to try things for about four weeks to see if things are slowly getting better.

"One thing I have learned with talking to literally hundreds of people about this [managing bowel symptoms], everyone is different. So, what works for me, won't work for the next person (Stuart aged 52)

Most people say they get better faster in the first three months than after three months. Some people get a little bit better for a few years but this will be much smaller changes. Do ask for more help if you do not think you have got better enough.

Please remember the treatments are to improve your life. You do need to try each option for about four weeks to see if it works for you. But, don't try a treatment for more than three months if it is not helping, as it is probably not the right one for you. If a treatment does not help you, you might need to consider something else. Ask your Cancer Nurse Specialist, Surgeon or GP for more help. If the intervention helps a bit, you can continue with it and add another one. Some people say the treatments are worse than their bowel changes. If you are happy with things as they are (or do not want to try new things) you do not need to. It is your choice.

## **Lifestyle changes**

### **In brief**

Lifestyle changes might include making more plans than usual. Careful planning when leaving the home can reduce anxiety.

### **Looking in-depth**

There are many things that might help adjustment to your bowel changes. If you do not want to take medicine that is ok, but you might need to make bigger changes with your diet (see diet section) such as avoiding spicy food and alcohol.

While learning how your body now works, some people do not feel confident to leave their home. Other people choose to wear a pad or continence pants when they go out, in case they have an accident. Some people choose to wear a pad in bed to give them added security. People might have a 'kit' when they leave their home. The kit might include cleaning cloths, rubbish bags, pads or a clean set of clothes in case of accidents. This kit might be put in a bag, left in the car or stored at work. Here are a few suggestions from people with LARS:

"Buy black underwear instead of white" (Stuart aged 52)

“Know where all the good toilets are” (Kathy aged 61)

“[Get] really big, really cheap pants, pads, some baby wipes, Sudocrem” (Kate aged 45)

“[Being] mindful when going for a swim and how I feel before I go. I would not go for a swim feeling like I need to do another poo” (Angela aged 44)

Planning can give you confidence. Travelling for work or pleasure will become easier after success with short trips. Undertaking activities such as sport may need planning. Eating out or meeting friends and family might need planning.

“If I know for example that we were going out for dinner tonight, I’ll take a couple of loperamide today because I know that otherwise I’ll have a problem later on” (Simon aged 63)

The position that you adopt on the toilet can help you to poo a bit more easily. This includes having your knees higher than your hips. You can do this by using a small stool under your feet. Allowing sufficient time and relaxing can also help when going for a poo.

Stress can affect your bowels. Learning to deal with your stress can help prevent some bowel problems.

Looking after the skin around your bottom is needed in the first few days and weeks after having your operation. Some people get a sore or itchy bottom. If pain is due to skin damage from cleaning up after a poo, this can be helped in several ways. Using soft or wet tissues can help prevent the skin being rubbed. To help prevent skin from becoming sore use a barrier cream (ask your chemist / Pharmacist) on your bottom once it is cleaned. If the skin is sore, you can use a nappy rash cream, ointments or Vaseline to soothe the skin.

Simple measures can prevent skin from getting sore. Changing the way that you clean your bottom after a poo can help such as using a bidet or shower. If skin is sore, people report using a sitz bath or bidet to help reduce discomfort. Here is what people with LARS have said:

“I tend not to wipe, I ended up dabbing, because wiping just scraps you raw and I was washing every time” (Russell aged 59)

“I just want to sit in a warm bath, it sorts out all cramps” (Samantha aged 50)



“It [bidet] ought to be prescribed, honestly, that’s how much difference it is”  
(Brendan aged 65)

If your skin is very sore, ask your Specialist Nurse or GP for advice.

Accepting and adapting to your new changes is helpful. Changes you cannot accept you need to speak to your healthcare team.

### **Signposting**

The squatty potty video helps to explain why the right toilet position is helpful.

Go to: [www.youtube.com/watch?v=YbYWhdLO43Q](https://www.youtube.com/watch?v=YbYWhdLO43Q) (3 minutes)

## **Exercises**

### **In brief**

It can be useful to strengthen the muscles of your pelvic floor and anal sphincters. These muscles can get weakened by rectal cancer treatment. Or muscles may have been weak before the cancer. Exercises can be started when you have a temporary stoma.

“Pelvic exercises, right. I think it might be useful to start before the [stoma] reversal” (Seb aged 56)

### **Looking in-depth**

Doing pelvic floor exercises is reported to help urgency and reduce accidents. Pelvic floor exercises may also help reduce the number of times that you go to the toilet each day. Pelvic floor exercises may help you gain more control of your bowels, so that you can delay the urge to have a poo.

“Work on it as a muscle and learn to control ... you might not stop the urge of needing to go to the loo but you’ll be able to make it to the loo, which is important” (Angela aged 44)

We should all do pelvic floor exercises each day, especially as we get older. If simple exercises are not helping your problems to your liking and you have tried them for two to three months you might need to add in another way of managing your bowels. If you would like more help, ask your Surgeon or GP for

referral to specialist services such as biofeedback, pelvic floor or to the continence team.

Exercise in general can help to move your bowels. A walk may help to relieve wind. A run might stimulate your bowels to work.

### **Signposting**

The NHS explains a bit more about pelvic floor exercises. Go to:

<https://www.nhs.uk/common-health-questions/womens-health/what-are-pelvic-floor-exercises/>

The Memorial Sloan Kettering Cancer Centre explain how men should perform pelvic floor exercises. Go to: <https://www.mskcc.org/cancer-care/patient-education/pelvic-floor-muscle-kegel-exercises-males>

Macmillan explain pelvic floor exercises (Kegel exercises). Go to:

<https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/pelvic-floor-exercises>

## **Diet**

### **In brief**

It is possible that different foods or drinks will affect how your bowels work. Most people will change their diet to try and improve their bowel function. Unfortunately, as we are all different it can be hard to say which foods might have a good or bad effect. People report that food needs more consideration than it did before rectal cancer treatment. Also, foods that might have given bad effects before surgery, might give worse effects now, such as causing more wind.

People who are diabetic, vegetarian or have a special diet may find that it can be hard to know what to eat. It might be useful to ask your GP or Surgeon for a referral to see a Specialist Dietitian. The Dietitian can help you know about your dietary choices.

“It's hard for vegetarians, you're overwhelmed with this difficulty” (Julie aged 53)

## Looking in-depth

## African & Caribbean Eatwell Guide

Use this Eatwell Guide to help you understand some cultural foods and help get a better balance of healthier and more sustainable food. It shows how much of what you eat overall should come from each food group.

**Check the label on packaged foods**

Each serving (50g) contains

	Energy (kcal)	Fat	Carb	Salt
100g	2,000	10g	100g	10g
100g	1,000	5g	50g	5g

of an adult's reference intake  
Typical values (as sold) per 100g: 687kJ/ 163kcal

**Choose foods lower in fat, salt and sugars**

**Eat at least 5 portions of a variety of fruit and vegetables every day**

**Fruit and vegetables**

**Choose a wholegrain or higher fibre version with less added fat, salt and sugar**

**Potatoes, bread, rice, pasta and other starchy carbohydrates**

**Eat less often and in small amounts**

**Patties/Meat Pies**  
**Malt beverages**  
**Fried doughs (puff puff, dumpling, festival, phourorie)**

**Eat more beans and pulses, 2 portions of sustainably sourced fish per week, one of which is oily. Eat less red and processed meat**

**Beans, pulses, fish, eggs, meat and other proteins**

**Choose lower fat and lower sugar options**

**Dairy and alternatives**

**Choose unsaturated oils and use in small amounts**

**Oil & spreads**

**Water, lower fat milk, sugar-free drinks including tea and coffee all count.**

**Limit fruit juice and/or smoothies to a total of 150ml a day.**

**Water**

**THE DIVERSE NUTRITION ASSOCIATION**

Melissa Saint Hill, Amaeze Madukah & Ashleigh Simpson

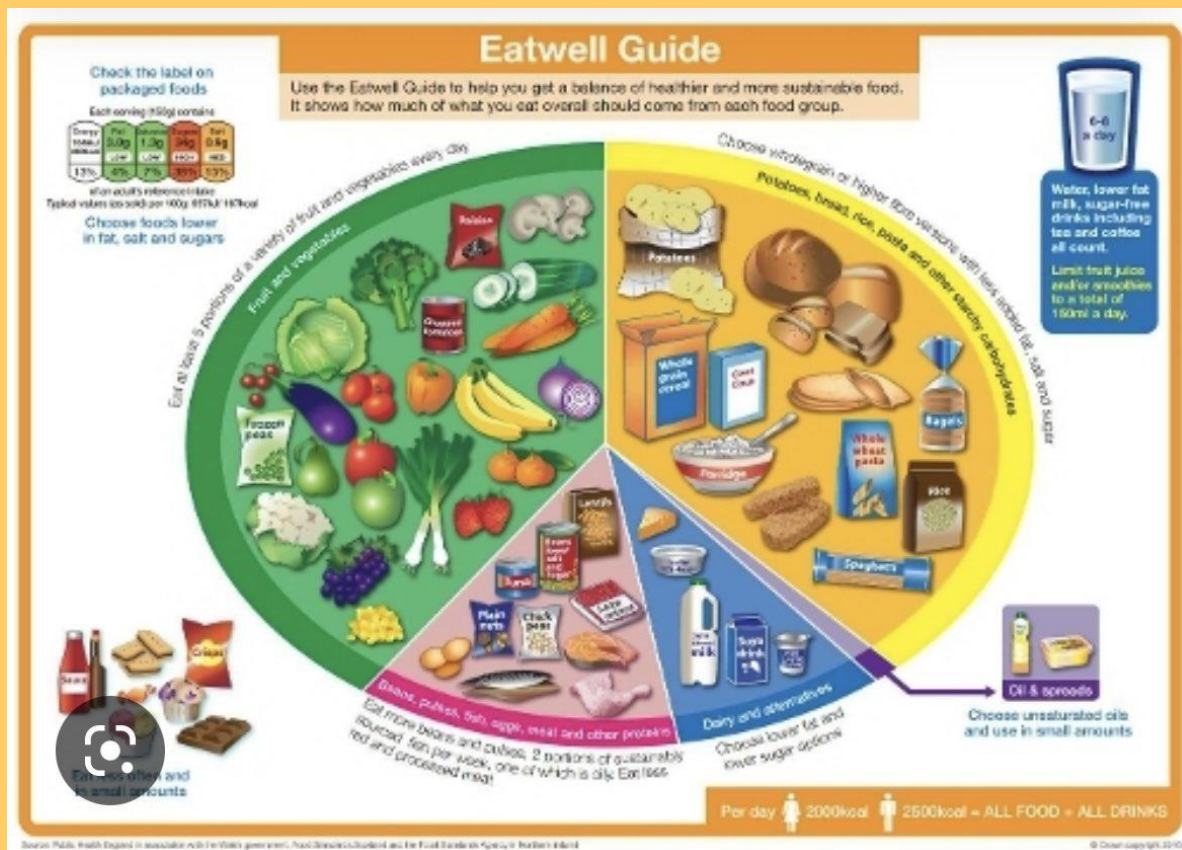
Source: Public Health England in association with the Welsh Government, Food Standards Scotland and the Food Standards Agency in Northern Ireland

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- Spicy food
- Rich, fatty foods
- Caffeine (coffee, tea, cola and chocolate)

- Alcohol
- Very fibrous foods – consider removing skins and pips, well cooking fruit and vegetables or eating tinned versions

You can choose to avoid these foods and drinks. But you do need to be careful not to avoid too many foods and to try to have a balanced, healthy diet.



Here are some dietary changes that people with LARS suggest:

“Alcohol, I try not to have it very often” (Sally aged 57)

“Most fruits I no longer have a problem with, [but] I only eat small amounts of melon” (Brendan aged 65)

“I’ve started white bread instead of brown bread” (Russell aged 59)

Getting the balance right with food can be hard. Fibre can help some bowel problems but make others worse. If you are uncertain what to do, speak to a Dietitian. Soluble fibres such as oat-based fibre, can help bulk your poo and make it a thicker consistency. Soluble fibre needs to be increased slowly into your diet over a few weeks or you might find you get bloated or a lot of wind.





If you choose to manage your bowel changes with diet alone and do not want to take medicine this is possible. But you will probably need to eat more carefully, such as avoiding spicy foods.

## Signposting

Bowel Cancer UK have produced a booklet called Eating well. Go to:

<https://www.bowelcanceruk.org.uk/about-bowel-cancer/our-publications/eating-well/>

For facts about Dietitians and advice. Go to: [https://www.bda.uk.com/specialist-groups-and-branches/gastroenterology-specialist-group/what-do-gastroenterology-dietitians-do.html?utm\\_content=buffer8d90d&utm\\_medium=social&utm\\_source=twitter.com&utm\\_campaign=buffer&s=03](https://www.bda.uk.com/specialist-groups-and-branches/gastroenterology-specialist-group/what-do-gastroenterology-dietitians-do.html?utm_content=buffer8d90d&utm_medium=social&utm_source=twitter.com&utm_campaign=buffer&s=03)

World Cancer Research Fund have produced data, such as about fibre. Go to:  
<https://www.wcrf-uk.org/health-advice-and-support/health-advice-booklets/facts-about-fibre/>

A short video (3 minutes) on diarrhoea during cancer treatment. Go to:  
[https://m.youtube.com/watch?v=Tn4OTIIRcZs&list=PLjlz7M\\_yg9uxbDDSnD94AYWW8jswruvqw&index=7&s=03](https://m.youtube.com/watch?v=Tn4OTIIRcZs&list=PLjlz7M_yg9uxbDDSnD94AYWW8jswruvqw&index=7&s=03)

Unsure if it is a fact or not? Look at the British Dietetic Association fact sheet. Go to: [Cancer Diets: Myths and More | British Dietetic Association \(BDA\)](#)

## **Medicines**

### **In brief**

There are over-the-counter medicines that can help your bowels: antidiarrhoeal medicine, bulking agents and / or laxatives. Which medicine you might need depends upon your symptoms. You might need more than one medicine at a time. You might need to try other ways as well as medicine. Over-the-counter medicine might also be prescribed by your General Practitioner. It is common to need advice from a clinician about which medicine is best for you and how best to take the medicine.

“I add psyllium husk to my porridge every morning, I couldn’t go out for a run if I wasn’t using the psyllium” (Kate aged 45)

### **Looking in-depth**

Antidiarrhoeal medicine such as loperamide (Imodium) or Lomotil, helps to slow down the poo as it moves through the gut. Antidiarrhoeal medicine makes the poo more solid so it is less likely to leak out of your bottom causing accidents. Not everyone can take loperamide, it can make you bunged up (constipated). If this happens speak to your healthcare team about ways to have smaller doses. People can take antidiarrhoeal medicine every day, 30-60 minutes before eating and/or before going to bed. Alternatively, antidiarrhoeal medicine can be taken before going out for food and drinks. Antidiarrhoeal medicine can be safely

taken for years (up to 8 capsules, 16mg) without bad effects, so long as it does not constipate you too much. Loperamide is effective for about 8-12 hours

Bulking agents such as psyllium husk or Fybogel can help to add bulk to the poo. A bigger poo can help people who have the urge to poo but find it difficult to pass. Bulking agents can also help people who pass lots of small poos to make fewer, larger poos.

“I was taking Imodium and Fybogel and slowly it went down, the number of daily visits [to the toilet]. It became a better emptying as well” (Seb aged 56)

Laxatives help you to pass poo more easily. Laxatives can be taken by mouth and work gradually over a day or so. Laxatives such as a suppository or enema are inserted into the bottom. You should check with your Surgeon if you can put medicine into your bottom. An enema or suppository might help prevent accidents (incontinence) by keeping the rectum empty. Using an enema or suppository can become part of your daily toilet routine.

Changes in your gut bacteria might affect your bowel function. Currently there is no good evidence that probiotics (“good bacteria”) improve bowel function. But, unless you are on chemotherapy or are immunosuppressed, probiotics are probably safe to take. If you tried probiotics for 12 weeks and they are not helping, then stop taking them as they are not likely to work for you.

If these medicines do not help, you could see your GP or ask to see a Gastroenterologist for more specialist medicines.

### **Signposting**

The NHS website explains about loperamide:

<https://www.nhs.uk/medicines/loperamide/>

The NHS website explains about bulking agents, such as Fybogel:

<https://www.nhs.uk/medicines/fybogel-ispaghula-husk/>

The NHS website explains about laxatives:

<https://www.nhs.uk/conditions/laxatives/>

## **Pee problems**

### **In brief**

Going for a pee (wee) to pass urine, can be a problem after rectal cancer treatment for some people. Urinary problems are more common after radiotherapy. It is possible that problems will improve over time.

“Nobody mentioned anything that your life would never really be the same ... this was all quite shocking” (Kathy aged 61).

### **Looking in-depth**

Research has found that about one in every six people after rectal cancer treatment may have changes going for a pee. One problem is passing pee without meaning to (urinary incontinence). People also report going for a pee more often, at night or needing to rush to the toilet for a pee.

Urinary incontinence can be the result of nerve damage from the rectal cancer treatment. Urinary incontinence may be improved by avoiding things that irritate the bladder. Bladder irritants include caffeine (in coffee, tea, cola, energy drinks and chocolate), alcohol and smoking. Pee problems may also improve with pelvic floor exercises or medicine.

### **Signposting**

Your General Practitioner may be able to assist with your problems. Alternatively, your GP may make a referral to a urologist or urinary continence specialist.

A useful website is Bowel & Bladder UK: <https://www.bbuk.org.uk/adults/adults-resources/>

A healthcare company called Wellspect have some online education about bladder issues. Go to:

<https://www.wellspect.co.uk/education/articles/treatment-options-for-incomplete-bladder-emptying/>

National Association for continence has produced some facts on management and support. Go to: <https://nafc.org/management-support/>

A useful website is Continence Foundation of Australia. Go to: [Bladder & bowel resources | Continence Foundation of Australia](#)



## **Sexual relations**

### **In brief**

Rectal cancer operations and radiotherapy can affect sexual function. There can be problems with sexual function for both men and women. Getting older can also affect sexual function. After treatment for rectal cancer there may be changes in sexual desire. There are things that can be done to help these problems.

“Intimacy is actually a real challenge” (Julia aged 43)

### **Looking in-depth**

There are several sexual changes that may occur because of a rectal cancer operation. Sexual changes may be psychological such as a lack of desire or less satisfaction associated with sexual activity. People with pee or poo control (incontinence) may have concerns about accidents during sexual relations and thus may avoid sexual activity.

Sexual changes may be physical. Problems are probably the result of changes to the nerves during cancer treatment. For men it may be difficult to obtain or maintain an erection. Or there may be problems with ejaculation. For women there can be dryness or discomfort during intercourse.

There are ways to help sexual problems. Sexual counselling or couple counselling can be helpful to explore issues with sexual relations. Medicine can be useful for men to gain or sustain an erection. For problems with gaining an erection there are also vacuum devices. For women lubrication may be useful. Or, if the vagina has become scarred a vaginal dilator may help.

For more help speak to your General Practitioner. For counselling your GP will need to make a referral.

“People’s sexual drive changes dramatically with this [rectal cancer treatment]” (Stuart aged 52)

### **Signposting**

Cancer Research UK has facts on their website about your sex life and bowel cancer: <https://www.cancerresearchuk.org/about-cancer/bowel-cancer/living-with/sex->

[life#:~:text=Sexual%20problems%20are%20quite%20common,can%20affect%20your%20sex](#)

Sexuality data can also be accessed at the Continence Foundation of Australia website. Go to: <https://www.continence.org.au/continence-health/sexuality>

## **Asking for help**

### **In brief**

In general, in the first few days after your operation it is advisable to contact the hospital where you had your operation if you have a problem such as bleeding or pain. The best person to contact is usually your Surgeon or Specialist Nurse. In the first year and in the long-term, it might be the Specialist Nurse, Surgeon or General Practitioner. They might be able to help or they might need to make a referral to specialist services.

You should always seek advice if you pass blood from your bottom. Although it could be piles (haemorrhoids) it needs to be checked. Go to the General Practitioner (GP) within a week or so and tell them you are passing blood and remind them that you have had rectal cancer treatment.

### **Looking in-depth**

Some people initially go for a poo up to 10 times a day, a few people go even more often. Going for a poo this often should settle within a few weeks. If you are passing more than ten poos a day after the first week you need to contact your Surgeon or Specialist Nurse for some advice. If you are not happy with your bowel function, tell your Surgeon, GP or Specialist Nurse.

There are many things that might help you. Remember everyone is different with different needs, so you need to find out what works for you.

You might see many different clinicians in your cancer journey. Some clinicians use medical jargon and words that are hard to know what is meant. Please ask if you are uncertain about what you have been told.

There are many different nurses involved in rectal cancer treatment. Nurses that specialise in cancer or stomas might be the best people to contact if you have bowel problems.

Not all healthcare professionals know or use the term LARS (low anterior resection syndrome). They can still help with your bowel problems if you explain your needs. If they cannot help, they may refer you to someone who can.

It can be useful to ask your healthcare team questions at different stages of your cancer pathway or LARS pathway. You need to know what options you have and what drawbacks these options have. You can ask three questions:

1. What are my choices?
2. What are the benefits of these choices?
3. What are the drawbacks of these choices?

In summary:

- Bleeding from your bottom is not normal (except a little just after your operation) and you should seek help
- Going to the toilet 10 or more times a day can often be improved
- If you would like things to be better with your bowels ask your Surgeon, GP or Specialist Nurse for help

### **Signposting**

The National Health Service has a site that can find cancer help in your UK-based local area. Go to: <https://www.nhs.uk/service-search/other-services/Cancer-information-and-support/LocationSearch/320>

## **Carers facts**

### **In brief**

If you are the carer, friend, family or significant other for a person with LARS you will have some needs as well. You will have concerns about the person with rectal cancer. You may also have concerns about how your life and their life has changed.

## Looking in-depth

You might find that you are watching your partner more than you used to, looking to see if they are doing ok. You might feel lonely because your partner is not there in the same way as they were before. You are also adjusting to changes in your lives resulting from the bowel changes.

You might find it exhausting to be watching over them. You can be both physically and emotionally exhausted. You might feel tired because you are doing more jobs in the house than before.

Talking to each other can be a problem. You might not want to talk about problems. Or your partner might not want to discuss their problems.

You might be worried about changes that occur to your personal lives due to LARS. You might find it frustrating. You might feel lonely. You might feel guilty for your feelings because your partner had cancer and you don't want to seem selfish. You will want to help and support your partner but might not know how to do this.

It is normal for some people after they have a cancer diagnosis to focus on themselves. It is a way to cope.

People also report that they feel alone after a cancer diagnosis. This doesn't mean that you are not being supportive enough. It might mean that the person with cancer would find it helpful to speak to another person with cancer in a support group or online.

You might try to encourage your partner to do things. Or you might worry that you are pushing them too hard. You might worry about when or if things will improve and return to normal. This booklet will help you know that some things will change back to normal but others might not and you need to try and find ways for you both to adapt.

It is normal for the healthcare team to focus on your partner and their needs rather than those of the carer. You might find your partner's nurse is the person that you are best able to approach to ask questions.

You might choose to speak to your GP for counselling for yourself. You can also have counselling as a couple.

## Signposting

Macmillan have data for people who care for someone with a cancer; Go to: <https://www.macmillan.org.uk/cancer-information-and-support/supporting-someone>

Maggie's also offer support: [Friends and family](#) | [Maggie's \(maggies.org\)](#)

## Returning to work

### In brief

Working after cancer treatment is a personal choice for some people. Some people need to return to work, to get paid. Some people want to. Some people do not.

### Looking in-depth

Going back to work can take a while. This can be due to concerns about bowel function. For others getting back to work is expected by their employer. Some people want to go back to work.

When returning to work it can be useful to explain to work colleagues that you might need to go to the toilet more than before. This can help them know why things might be different with you after your cancer treatment. Often people at work do not want to hear too many details.

"I'm probably quite sanitised when I tell my work ... I just don't want to overwhelm them" (Jessica aged 53)

## Signposting

Macmillan cancer support have data about making decisions about work after treatment. Go to: <https://www.macmillan.org.uk/cancer-information-and-support/after-treatment/being-physically-active>

## **Is the cancer coming back?**

### **In brief**

It is normal to worry about the cancer coming back. Your healthcare team will do tests such as scans and blood tests to check. It can be scary waiting for tests and test results.

### **Looking in-depth**

If the cancer is going to return it will usually do so in the first one to two years. Your healthcare team will probably perform tests for longer than two years. It is not usually needed to keep doing tests after five years.

“I think, by definition, if you've had rectal cancer, anything that goes weird with your bowels takes you, even if there's another explanation for it, takes you back there. It must be the cancer” (Gail aged 42)

There are a few things to be worried about at any time. Passing blood from your bottom is not normal. If you see blood, urgently (within a week or so) go to your General Practitioner for tests. It might be nothing but it needs to be checked.

If the cancer does come back there are treatment options. You should speak to your Surgeon, Oncologist or Cancer Specialist Nurse.

### **Signposting**

Bowel cancer UK has facts about should the cancer come back. Go to:

[https://www.bowelcanceruk.org.uk/about-bowel-cancer/advanced-bowel-cancer/treating-advanced-bowel-cancer/when-cancer-comes-back-after-treatment/#:~:text=Bowel%20cancer%20that%20comes%20back,called%20meta stases%20\(metastatic%20disease\).](https://www.bowelcanceruk.org.uk/about-bowel-cancer/advanced-bowel-cancer/treating-advanced-bowel-cancer/when-cancer-comes-back-after-treatment/#:~:text=Bowel%20cancer%20that%20comes%20back,called%20meta stases%20(metastatic%20disease).)

## **Specialist ways to help**

### **In brief**

Most people cope ok with treatments such as lifestyle changes, pelvic floor exercises, dietary changes and medicine, as described above. If these ways to

help do not work to your liking, there are other options. You usually need a referral from your Surgeon or GP to a specialist service to access specialist ways to help. There is limited evidence for using these treatments for people with LARS. Also, not all treatments might be offered in all areas.

### **Looking in-depth**

If you would like to try specialist ways to help there are many that might be useful.

**Pelvic floor rehabilitation** can be provided by Specialist Biofeedback Nurses or Pelvic Floor Physiotherapist. Pelvic floor rehabilitation can help to improve muscle control. Treatment can include pelvic floor and sphincter exercises but depending on the care centre, other things might also be included.

**Transanal irrigation (water enema)** can be useful to treat bowel incontinence or difficulty emptying your bowels. Irrigation involves putting warm water into your bottom using specialist irrigation equipment. The water then washes out the poo and wind. It is sensible to have an assessment by your healthcare professional prior to starting irrigation. This assessment may include a check of the join in your rectum to ensure that it is not too tight (stenosed).

**Specialist dietary advice** can be provided by a Specialist Dietitian. A Specialist Dietitian is useful if you have additional dietary needs such as diabetes or are a vegetarian. A Specialist Dietitian can help with persistent IBS (irritable bowel syndrome) symptoms such as bloating, constipation or going to the toilet a lot.

**PTNS** (percutaneous tibial nerve stimulation) is the use of needles, inserted into the skin near your ankle to stimulate your bowel nerves to work. PTNS might be useful for people with bowel incontinence. You will need several sessions of PTNS.

**Specialist medicines** might be prescribed by Gastroenterologists, but you may need additional tests to diagnose or rule out other problems. Specialist medicines can help with problems such as small bowel bacterial overgrowth (SIBO) or bile salt malabsorption.

**Sacral neuromodulation** (SNM / SNS - sacral nerve stimulation) can be used to stimulate your nerves and help improve bowel control. A small electrode (wire) is inserted under the skin in your lower back. A trial is needed for up to two

weeks. If the trial is successful, permanent wires can then be inserted. You must have tried other ways to help first before trying SNM.

**A colostomy** can be formed if you have tried other things and they have not helped your bowel problems. A colostomy is usually different to the temporary stoma you had, which is usually an ileostomy. A colostomy will pass the poo that would usually come out of your bottom each day into a bag. Most people need to change the bag once a day. Or you can irrigate the colostomy. A colostomy formation requires an operation and a few days stay in hospital to recover.

### **Support groups**

There are peer support groups for people with LARS, such as on Facebook. These support groups are run by people who have undergone rectal cancer treatment. Peer support can be invaluable because these people have also encountered rectal cancer and its treatment.

“[The] Facebook group, it helps me enormously” (John aged 39)

### **Signposting**

There are many support groups. One Facebook group that people have mentioned is useful for advice is called: Living with Low Anterior Resection Syndrome

Bowel Cancer UK has a forum for people with rectal cancer. Go to:

<https://community.bowelcanceruk.org.uk/forum/>

A podcast with two Surgeons and two patients discussing LARS and transanal irrigation. Go to:

[https://www.podomatic.com/podcasts/gagliarg21430/episodes/2018-11-14T08\\_43\\_53-08\\_00](https://www.podomatic.com/podcasts/gagliarg21430/episodes/2018-11-14T08_43_53-08_00) (34 minutes)



## **FAQ (frequently asked questions)**

### **I feel I want to poo but there is nothing there, why is that?**

The nerves in your bottom can give you the feeling that you need a poo when they are damaged during your operation. The nerves might get back to how they were before your cancer. Or over time (a few months to a year) you get to learn what your new signals mean.

### **I feel I want a poo but it will not come out, what should I do?**

After your cancer treatment the parts of your body that are involved in having a poo may forget how to communicate properly. Getting the right position on the toilet can help (see lifestyle changes section). Using a bulking agent or psyllium husk can help bulk the poo and make it easier to pass (see medicine section). Transanal irrigation might help (see specialist ways to help).

### **My poo is loose and difficult to hold on to, how can I help?**

Try to thicken the consistency of your poo. You can do this with diet (see diet section) or anti-diarrhoeal medicine (see medicine section). You can try doing pelvic floor exercises to strengthen your muscles (see exercise section). Or, know the location of toilets when you are out.

### **After I have cleaned my bottom, I notice a tiny bit more poo comes out when I move, what can I do?**

You can do pelvic floor exercises to strengthen your muscles (see exercise section). You could give a little 'jiggle' to move any poo before you wipe. You could stand up and sit down again and see if that last bit of poo comes down as you move and then clean. You could use a bidet or shower head (see lifestyle changes).

### **My poo is sticky and hard to clean up, what should I do?**

Try using wet cleaning tissues. Or try using a shower head or a bidet to help you clean.

**When I feel I need a poo, I must get to the toilet fast, what can I do?**

This urgent need to get to the toilet will usually improve over time (within the first year) but it might not totally go back to how you were before your cancer treatment. You can try an antidiarrhoeal medicine to thicken your poo and slow down your gut (see medicine section).

**I go to the toilet about 10 times in an hour what can I do?**

A bulking agent might help (see medicine section).

**I go to the toilet a lot every day, what can I do to help?**

You could try antidiarrhoeal medicine or bulking agents or both (see medicine section). Try one at a time and use it for a few weeks to see if it works for you.

**I go for a poo so often my bottom is sore, what can I do?**

Try to prevent your bottom getting sore by using a cream (see lifestyle changes). Also clean your bottom carefully. Be careful not to rub your skin too hard or try using wet wipes for cleaning. If it does get sore sitting in a warm bath can help (sitz bath) and use cream afterwards.

**I want to go out but I am worried I might need the toilet when I am out, help me please?**

Consider taking an antidiarrheal medicine to slow down your bowels. You can plan your trip. You can check out where toilets are (see lifestyle section).

**I am worried about having accidents what should I do?**

You can try wearing a pad or continence pants when you are worried (see lifestyle changes section). You could try an antidiarrhoeal medicine to slow down your bowels (see medicine section). You could plan where toilets are when you leave the house to give you more confidence. You could try having a clean-up kit in the car or at work (see lifestyle changes).

**It feels like passing glass when I have a poo, why is that?**

You might have a small split called a fissure. Go and see your GP for help.

**I have a pain in my bottom, what should I do?**

Pain in your bottom might get better with medicine such as a pain killer like paracetamol. If it does not or if the pain is new, please see your GP.

**How can I tell if it is wind or poo in my bottom?**

The signals from your bottom you had before your cancer treatment have changed. They get back to normal but you might need to learn what the new signals mean. This usually takes a few months (up to a year). If you are not sure sit on the toilet in case it is a poo.

**My bowel function changes every day, how can I cope?**

It can be hard to know how your bowels will be each day. If you are stressed or if you eat different things or do different activities, this can affect how your bowels function. If you have loose poo, you might need an antidiarrhoeal medicine. If you cannot go for a poo, you might need a laxative or bulking agent (see medicine section). Trying to do similar things each day can help to regulate your bowels such as eating regularly and taking a walk each day.

**I have blood in my poo is that ok?**

No, it is not normal to see blood, go and see your GP.

**I just don't know what to do.**

Please contact your Nurse, Surgeon or GP for help.

## **Summary**

Revisit this booklet if you have new needs or concerns. Or revisit the booklet as a reminder.

Living with LARS takes a while to adjust to. Things that you cannot adjust to can often be improved by making changes such as:

- Changing your diet
- Taking medicine
- Undertaking exercises
- Planning ahead
- Learning where toilets are
- Learning how your body works after the cancer treatment

You need to expect things to be hard initially but over time they do improve. You will probably get better if you do nothing. You are likely to get better faster if you do something. Ways to help might be to change your diet or take medicine or often both. If your problems don't improve enough to your liking after three months, speak to your healthcare team, often a Nurse, Surgeon or GP for advice.

**Please don't just put up with things if they bother you.**