

Understanding

# **Low Anterior Resection Syndrome**



## A special message for you and your family

This booklet will explain what Low Anterior Resection Syndrome (LARS) is. The more you understand, the more you can get involved with your own treatment. We want to help you have more control over your LARS. This should make daily life less stressful and more comfortable for you.

Share this booklet with family members and caregivers. It is important for them to understand what to expect and how to help you manage your symptoms.

Your LARS treatment team



**Welcome** to this educational booklet on Low Anterior Resection Syndrome (LARS).

**We** have designed this booklet for you because you have had surgery for rectal cancer. How you go to the bathroom now has probably changed a lot. The symptoms that you might be feeling after this surgery are called LARS.

**We** want to help you learn how to control your LARS symptoms. This booklet was written by Colorectal Surgeons, Nurses and Physiotherapists who specialize in rectal cancer. We also asked patients who have had rectal cancer surgery to review this guide. They have shared their experiences with us to help improve this booklet for you.

**We** will review rectal cancer surgery, what LARS is, why LARS happens, and most importantly, how to best manage your LARS. Check out the chapters below for a full overview of LARS, or skip ahead to the chapters that directly answer your questions.

**We** have included a list of some of the references we used so that you can understand where our up-to-date knowledge comes from. We also included a link to online health resources just for patients, so that you can read what other people are saying about how they manage their LARS.

**It** is important to remember that you may, or may not, have the symptoms listed in this booklet. But it is better to know how to manage them. This way, if they do happen, it is less stressful and anxiety-provoking.

**This** booklet is not a prescription! It does not replace a doctor, nurse, or physiotherapist! This should complement discussions you have with your colorectal specialist. Speak to us if you have questions or concerns.

**We** will be there each step of the way.

# Table of content

- 1 **Introduction**
- 2 **Surgery for rectal cancer**
  - 2 What is the rectum?
  - 3 What is rectal cancer?
  - 4 How is rectal cancer treated?
  - 5 **Summary**
- 6 **What is LARS**
  - 6 What is LARS?
  - 6 Symptoms of LARS
  - 8 **Summary**
- 9 **Common Questions about LARS**
  - 9 Why does LARS happen?
  - 11 Who gets LARS?
  - 13 How common is LARS?
  - 13 How is LARS diagnosed?
  - 13 How long will my symptoms last?
  - 14 **Summary**
- 15 **Overview of treatment options**
  - 15 A word on treatment of LARS
  - 15 What can you do to help manage your LARS?
  - 16 **Summary**
- 17 **Slow down colonic transit**
  - 17 Stool consistency
  - 18 Dietary changes
  - 20 **Summary**
  - 21 Medication
  - 22 **Summary**
  - 23 Stool bulking agents
  - 24 **Summary**

- 25 **Improve your ability to “hold-on”**
  - 25 Pelvic floor exercises
  - 26 Pelvic floor biofeedback
  - 27 **Summary**
  
- 28 **Improve your ability to fully empty your bowels**
  - 28 Proper toileting habits
  - 29 Rectal irrigation and enemas
  - 30 **Summary**
  
- 31 **Managing the current situation**
  - 31 Perianal skin care
  - 33 **Summary**
  - 34 Self-management strategies
  - 35 **Summary**
  
- 36 **Surgical options to manage LARS**
  - 36 When to consider these?
  - 36 Neuromodulation
  - 37 Permanent Stoma
  - 38 **Summary**
  
- 39 **Some final thoughts**
  
- 40 **References and other materials**
  - 40 References
  - 41 Patient materials
  
- 42 **Support services**
  
- 43 **Diaries**

# INTRODUCTION

## What is LARS?

If you have had surgery for rectal cancer, how you go to the bathroom now has probably changed a lot. The symptoms that you might be feeling after the bowel surgery are called **LARS**.

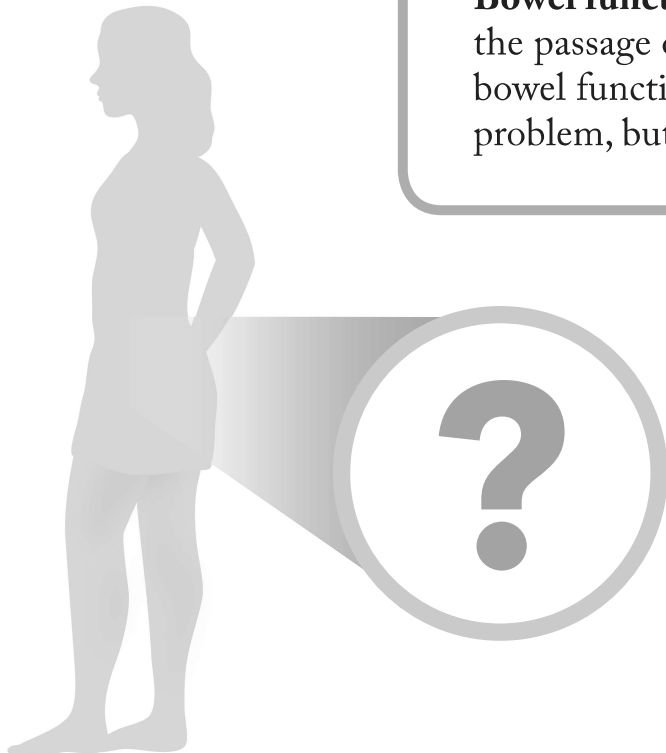
LARS stands for **Low Anterior Resection Syndrome**.

It refers to changes in bowel function after Low Anterior Resection surgery.



What do we mean by bowel function?

**Bowel function** is how the body controls the passage of stool and gas. We often take bowel function for granted until there is a problem, but it is a complex process.



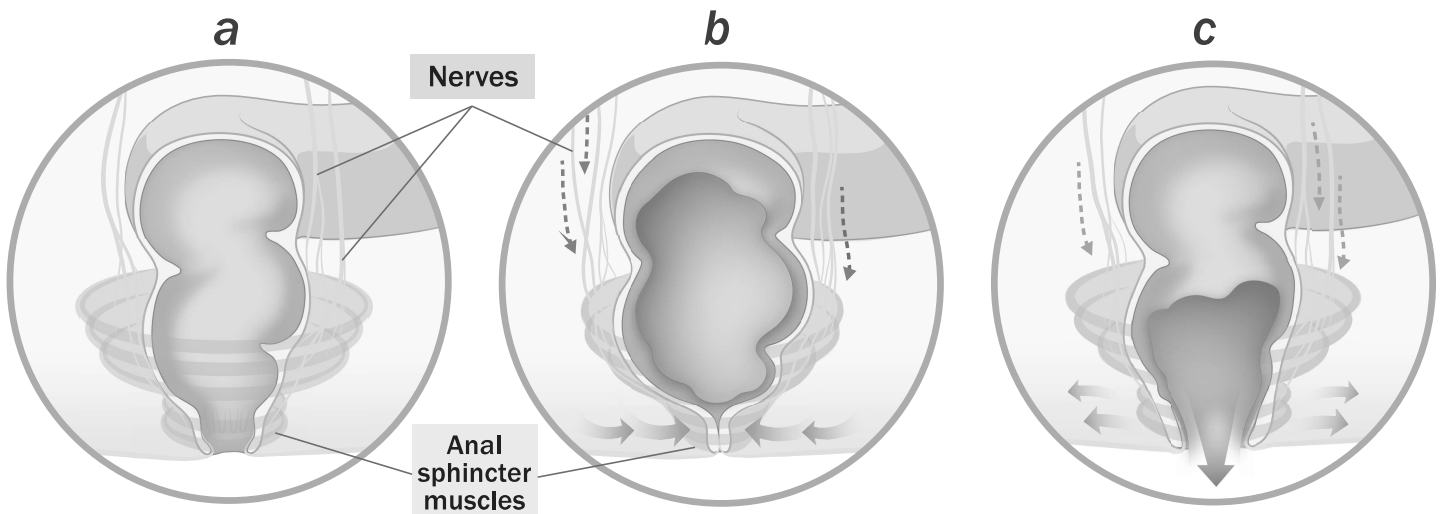
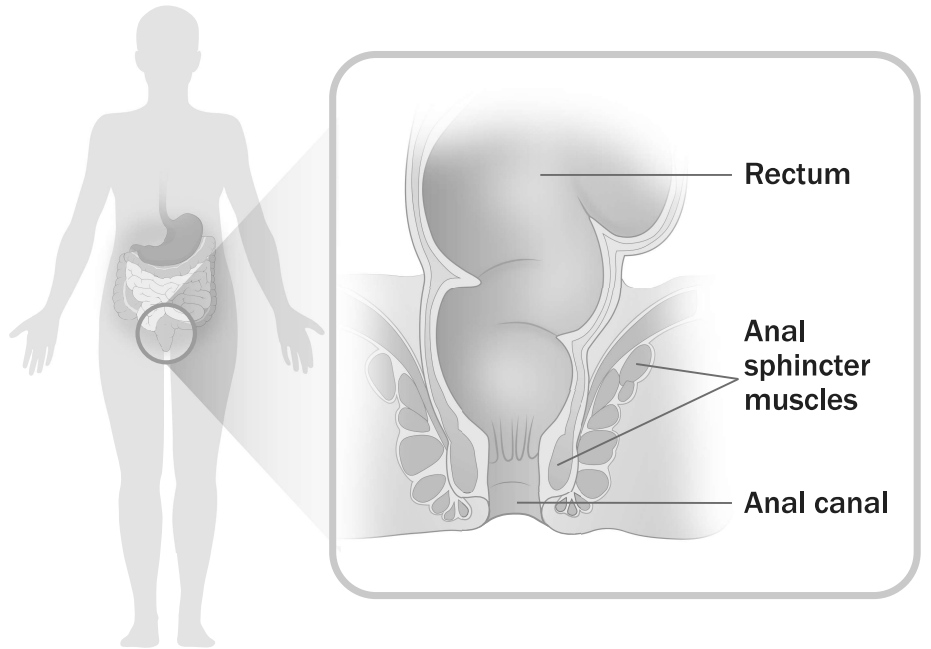
Let's begin by reviewing the changes in your body that occurred with surgery before we talk more about LARS.

# SURGERY FOR RECTAL CANCER

## What is the rectum?

The rectum is the last part of the digestive tract that ends at the anus, the opening where stool exits the body. Its main role is to store stools.

The rectum is surrounded by the **anal sphincter muscles**. These muscles tighten up to help us hold our stool in (*b*) and relax when we empty our bowels (*c*). This allows us to have control over our **bowel movements**.



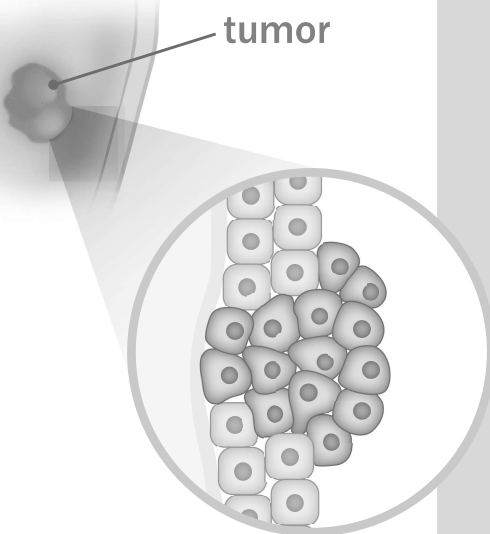
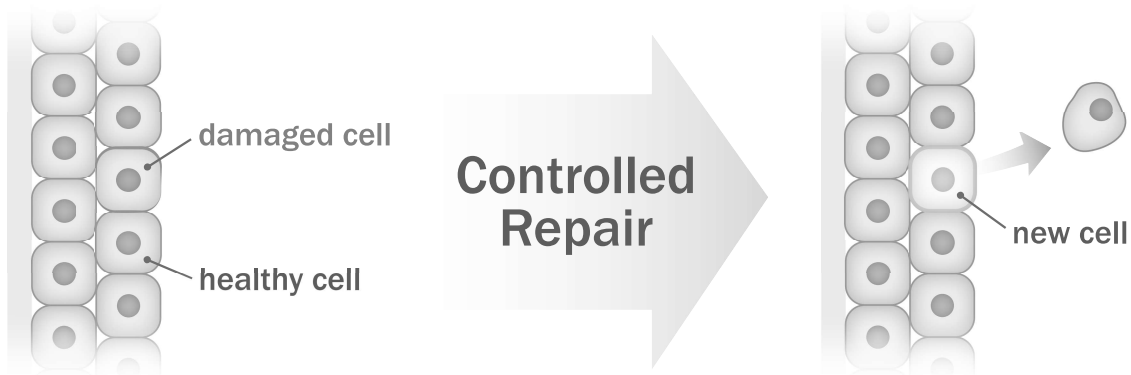
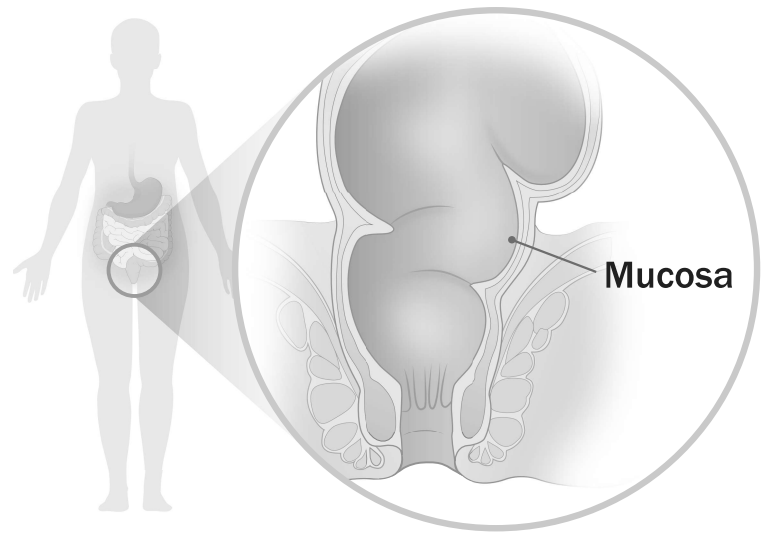
There are also special **nerves** that control the rectum's ability to stretch, and which control our anal sphincter muscles. These nerves play an important role in controlling how the rectum works.

The rectum is also very stretchy, which allows it to store a lot of stool before we decide to empty.

## What is rectal cancer?

**Cells** are the building blocks that make up the tissues and organs of your body.

When a cell gets old or damaged, your body either repairs the cell or gets rid of it, and a new cell grows in its place. This process of cell repair and growth is very regulated and controlled.



Sometimes, this process *is not* regulated and controlled. If this happens, the damaged cells in the rectum stick together to form a polyp. This is a benign (non-cancerous) growth in the rectum.

Over time, the cells in the polyp can become abnormal. These cells are now considered malignant (cancerous).

When the cells are cancerous, the growth is no longer called a polyp, and instead is called a **cancer**.

## How is rectal cancer treated?

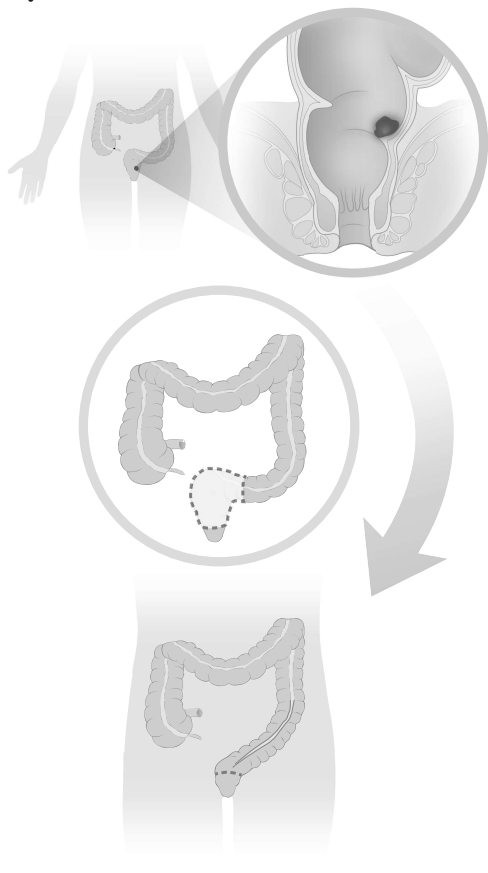
Rectal cancer is usually treated by surgery. The operation involves removing part of, or all of, the rectum. Before surgery, **radiotherapy** is sometimes used to try and shrink the tumor and make it less likely to come back after surgery.

There are two different types of surgery:

### 1. LAR surgery

If the cancer does not touch the anal sphincter muscles, these muscles stay, and the colon above can be connected to the lower rectum or anus. This way, you will be able to empty your bowels through your anus.

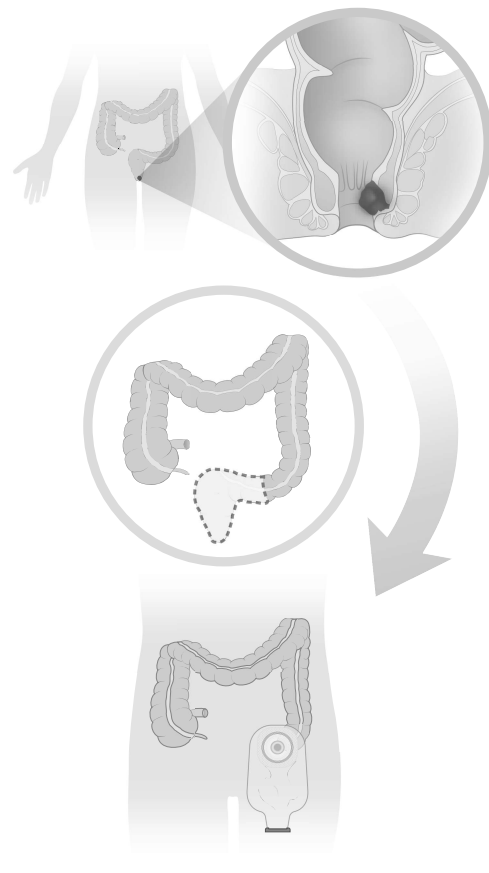
This is called a **Low Anterior Resection (LAR) surgery**. Some patients might get a temporary stoma (“bag”), usually known as an ‘ileostomy’. But this is usually removed later.



### 2. APR surgery

If the cancer touches the anal sphincter muscles, then these muscles are removed with the rectum. Without sphincter muscles, we don't have control over when we empty stool. The solution is to create a permanent stoma, known as a ‘colostomy’.

This is called an **Abdominoperineal Resection (APR) surgery**.



# Summary

- The rectum is the last part of the digestive tract before the anus.
- Rectal cancer is treated with surgery, and sometimes radiotherapy.
- There are two types of surgery:
  1. Abdominoperineal Resection (APR): Patients will have a permanent stoma after.
  2. Low Anterior Resection (LAR): Patients will have a new connection made so that stool exits through the anus.
- The rest of this booklet will focus on patients who have Low Anterior Resection surgery. The next chapter will explain what LARS is and what sort of symptoms it can lead to.

## WHAT IS LARS?

LARS stands for Low Anterior Resection Syndrome. Remember what a Low Anterior Resection surgery is from the previous chapter?

After you have Low Anterior Resection surgery, how you go to the bathroom will change. LARS refers to some of these changes.

### Symptoms of LARS



#### Frequency

This means emptying your bowels often. Since everyone is different, when we say “frequent”, we mean more than what is normal for you.

#### Urgency

This means that when you feel the need to go, you *really* need to go. There is little to no warning time to give you a chance to get to the bathroom.



#### Incontinence to liquid stools

This is accidental leaking of liquid stool.

## Symptoms of LARS

### Incontinence to flatus

This is accidental passing of gas.



### Clustering

This means having to go to the bathroom many times because there is still more stool that has to come out.

For example, as you leave the bathroom thinking that you are done, you need to go back to the bathroom to empty your bowels again. It is often called “fragmentation” of bowel movements as well.

You may also have **OTHER** bowel-related symptoms because of your surgery (e.g. bloating, belly cramps, difficulty emptying your bowels, constipation, increased gas), and these symptoms may also trouble you.

It is important to understand that every patient experiences LARS differently. You may experience some symptoms associated with LARS, while another patient may experience more or fewer symptoms.

Also, some symptoms may bother you more than others. You may find that frequency is the most bothersome symptom that interferes with your day-to-day life, while the next patient may feel that clustering of bowel movements is the most bothersome. Everyone is different.

How can you figure out which symptoms are bothering you?

Use our **BOWEL TROUBLE** diary at the end of this booklet.



The goal of this diary is to understand what symptoms you are having, how severe they are, and what time of day they are happening, to give you and your doctor or nurse specialist the best idea of how to intervene.

## Summary

- LARS refers to changes in bowel function after Low Anterior Resection surgery.
- There are 5 major symptoms associated with Low Anterior Resection surgery.
- You may have a few or more of these symptoms.
- Use our **BOWEL TROUBLE** diary to explore which symptoms are affecting you most.
- The next chapter gives more background information on LARS to understand why it develops.

# COMMON QUESTIONS ABOUT LARS

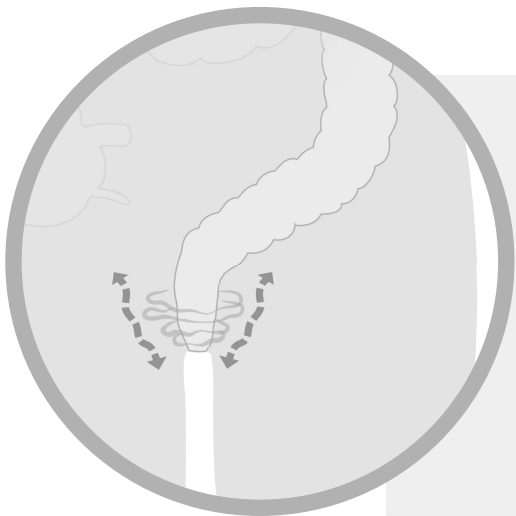
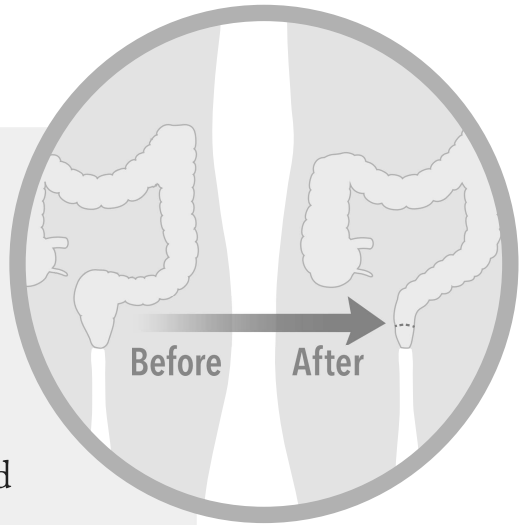
## Why does LARS happen?

There is no single cause for LARS. For most patients, it is probably a combination of things. Here we list some of the common causes that we think about, but others may exist too.

### Loss of storage

After surgery on the rectum, the rectum is removed. Unfortunately, the colon is not a good replacement for the rectum. The colon simply cannot store as much stool as the rectum. Plus, the colon's normal job is to absorb water and and move stool downward.

When the colon is used to replace the rectum, it can lead to feeling the need to empty your bowels often.



### Weak sphincter muscles

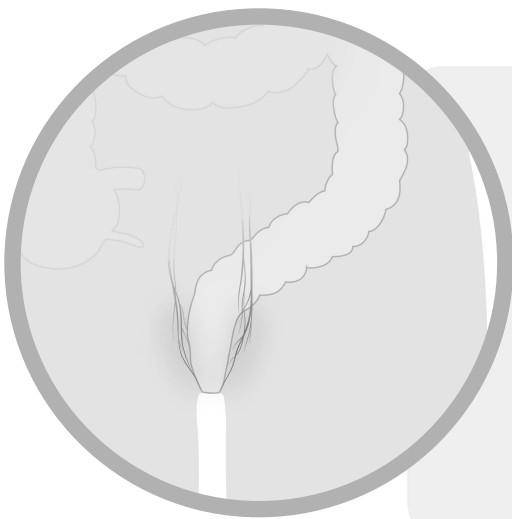
If your sphincter muscles were weak to begin with (even without you knowing!), this weakness will start to show once the rectum is removed. The sphincters can also get weak with radiotherapy.

## Faster colonic transit

The movement of stool from the beginning of the colon to the anus is called “colonic transit.”

After rectal cancer surgery, because the stool is moving through the colon faster, the colon has less time to absorb fluid. This means that the stool comes out soft, or is liquid. It can also leak accidentally and make you want to *go* often.

Also, with things moving faster, more stool is being delivered than can be stored, which makes you have to empty your bowels more often.



## Nerve damage

Both surgery and radiotherapy can irritate the nerves that control your sphincter muscles. When this happens, it can lead to accidental leakage, the urge to go often, and not emptying your bowels completely.

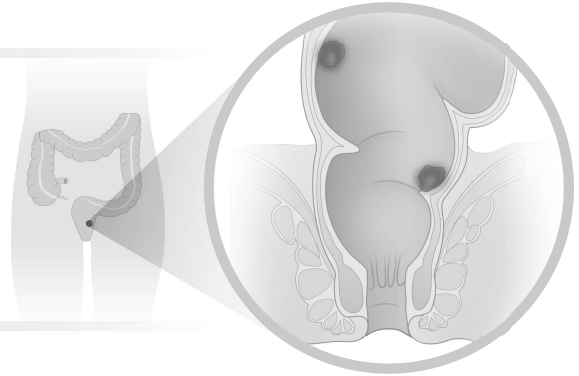
With what you just learned, can you think of some of the important factors that might *increase* or *decrease* your risk for LARS?

## Who gets LARS?

Here are some of the main factors:

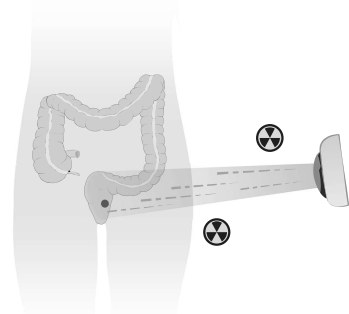
### Low rectal tumors

The more rectum that is removed, the **MORE** likely you are to get LARS.



### Radiotherapy

While radiotherapy helps to shrink the tumor, it can cause damage to the nerves and the bowel. This can affect the bowel's ability to stretch and store stool properly.



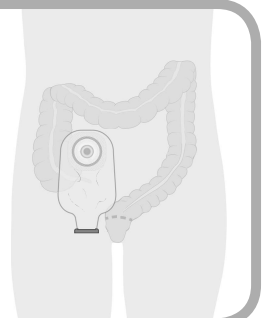
### Age

We don't completely understand why, but studies show that **younger** patients tend to have more problems with LARS.



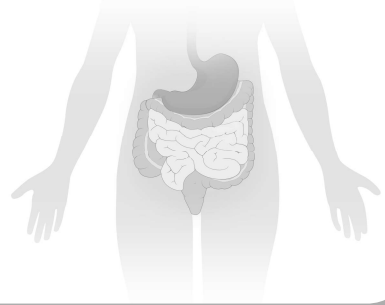
### Temporary Ileostomy

When the temporary stoma is there, the colon is not being used. During this time the colon gets weaker. It does not respond in the same way to having stool pass through.



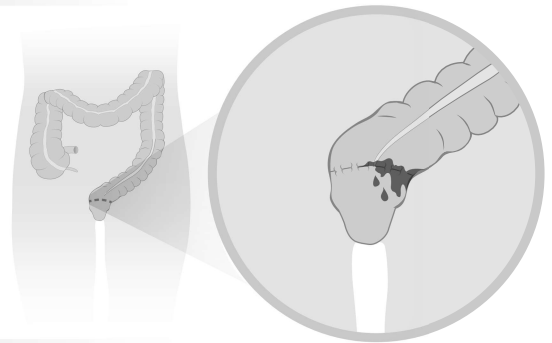
## Bowel function before getting rectal cancer

Your bowel function before surgery is important. If you already had some bowel issues before surgery, you are more likely to have symptoms after surgery.



## Anastomotic leak

After the rectum is removed, the colon is reconnected to the lower rectum or anus. Sometimes, you can develop a “leak” of stool at this connection, which can worsen LARS.



## The size of the storehouse

There are different ways that the colon can be reconnected to the lower rectum or anus. Depending on the type of reconnection, you may have a bit more or less storage room.

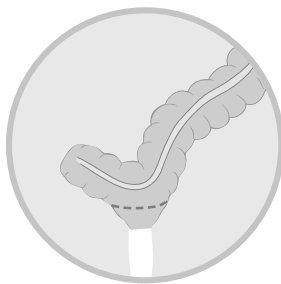
Some of these connections tend to function better than others at the start (e.g. “J-pouch” or “side-to-end” or “coloplasty” connections). However, most research shows that no matter what type of reconnection you have, they will likely all work the same after 2 years.



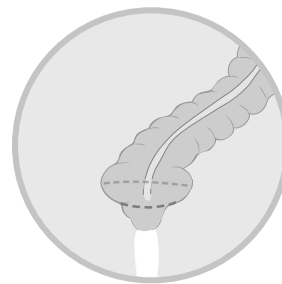
straight



J-pouch



side-to-end

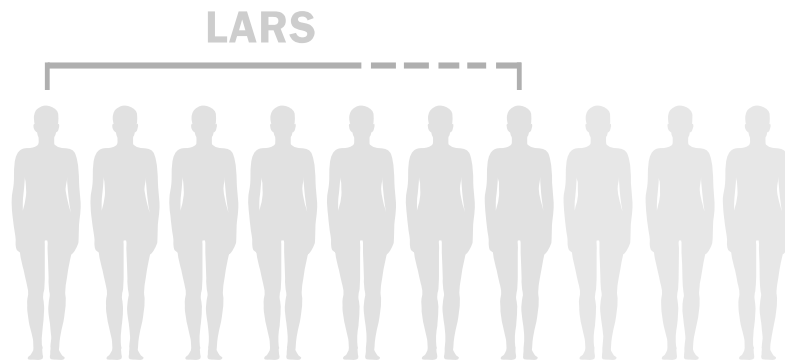


coloplasty

## How common is LARS?

LARS seems to affect 5 to 7 out of every 10 patients after Low Anterior Resection surgery, with more than half of patients saying that it affects their quality of life.

Even people who DON'T have rectal cancer surgery can have these types of symptoms (e.g. accidental leakage, frequent bowel movements). So you are definitely not alone if you experience LARS.



## How is LARS diagnosed?

Unlike other medical problems, LARS is not diagnosed with blood tests, x-rays, or biopsies. The diagnosis of LARS is based on your symptoms.

We normally say that you have LARS if your bowel symptoms have lasted more than 1 month since your Low Anterior Resection surgery (or the removal of your temporary stoma).



Questionnaires can give us more information about your symptoms that can help to diagnose you and to follow your symptoms over time. There are a couple of questionnaires that can be used; one is called the “**LARS Score.**”

Your doctor might also order tests to investigate other conditions that might be similar to LARS.

## LARS score - Scoring Instructions

Add the scores from each 5 answers to one final score

Do you ever have occasions when you cannot control your flatus (wind)?

- No, never 0
- Yes, less than once per week 4
- Yes, at least once per week 7

Do you ever have any accidental leakage of liquid stool?

- No, never 0
- Yes, less than once per week 3
- Yes, at least once per week 3

Interpretation:

0-20: No LARS  
21-29: Minor LARS  
30-42: Major LARS

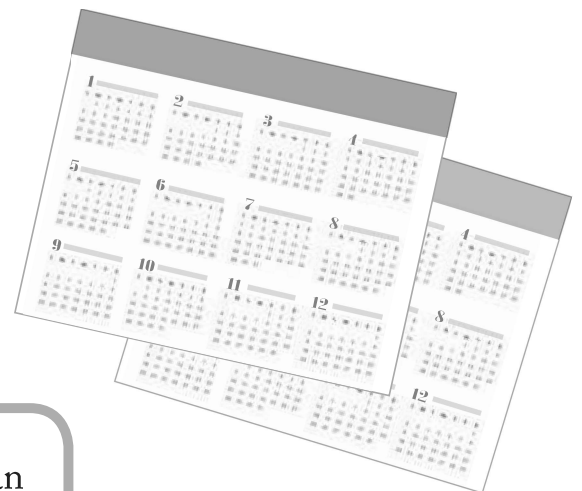
Total Score: \_\_\_\_\_



## How long will my LARS symptoms last?

For most patients, LARS symptoms are usually worse immediately after surgery, and improve slowly during the first 2 years after surgery. It is hard to know for sure what your experience will be, if your symptoms will improve and how long they might last.

Even if LARS might be long term, generally, you can expect to reach a new baseline after about 2 years.



Why do things settle down after 2 years?  
It is tough to tell. Some research shows that these two things can improve over time:

- The ability of the colon and anus to ‘speak’ with the rest of the digestive tract.
- The ability of the colon and anus to slow things down coming from above.

It could also be that your bowels (the colon from above that is reconnected to the lower rectum or anus) adapts over time to be able to accommodate more stool and act as a better storehouse.

In addition, patients learn to live with their LARS and find strategies to deal with their “new normal”.

This booklet will hopefully provide you with some suggestions of how to deal with your LARS symptoms, reduce the symptoms, and manage the problems associated with LARS.

## Summary

- There are several possible explanations for why LARS occurs, but it is hard to show a single cause.
- We are getting better at predicting who will get LARS. Patients with tumors lower down in the rectum and patients who received radiotherapy are at highest risk.
- LARS is diagnosed by listening to the patient’s symptoms - so speak up!
- LARS usually improves over the first 2 years after surgery, but some people may continue to have symptoms long term.
- The next few chapters will focus on how to best treat and manage LARS.

# OVERVIEW OF TREATMENT OPTIONS

## A word on treatment of LARS

LARS is a tricky condition to treat. Every patient is different.

For this reason, the treatment of LARS sometimes requires a bit of trial and error, to find the best possible solution for you. If at first the treatment does not provide you relief in your symptoms, do not despair! Your doctor and nurse can continue working with you to find the best solution.

While LARS is not always “curable” and may be a long-term condition, our hope is to offer suggestions that can make your symptoms better.

## What can you do to help manage your LARS?

Here are some strategies to control your LARS. In the next few chapters, we will go over each strategy in detail.

Remember, every patient is different! Use the methods that work best for you.

**1.**

### Slow down colonic transit

As we explained earlier, part of the reason LARS develops is because stool moves through the colon too quickly.

Some ways you can slow down colonic transit are:

- a. Changes in what you eat and drink (dietary changes)
- b. Medication
- c. Stool bulking agents

**2.**

### Improve your ability to “hold on”

You can train your body to deal with the urge of always having to go to the bathroom:

- a. Pelvic floor exercises
- b. Pelvic floor biofeedback

### 3.

#### **Improve your ability to fully empty your bowels**

Some things you can do to make sure you fully empty your bowels are:

- a. Proper toileting habits
- b. Enemas and transanal irrigation

### 4.

#### **Managing the current situation**

To avoid LARS from impacting your day-to-day life, it is important to know about:

- a. Perianal skin care
- b. Self-management strategies

### 5.

#### **Surgical procedures for LARS**

IF you've tried the strategies mentioned, and you **STILL** have no relief from your LARS, there are other treatment options.

Speak to your colorectal specialist about:

- a. Neuromodulation
- b. Permanent stoma

## Summary








- There are different strategies to manage LARS.
- Try as many strategies as you need to give yourself the best possible chance at gaining control of your LARS.
- Need more information about the treatments?
- The next few chapters will explain more about each one!

# SLOW DOWN COLONIC TRANSIT

## Stool consistency

When colonic transit is fast, stool comes out too soft. Slowing down colonic transit lets the colon absorb more water, and helps to get stools more firm.

The **Bristol Stool Chart** shows what your stool consistency can be like.

Type 1		Separate hard lumps, like nuts (hard to pass)
Type 2		Sausage-shaped but lumpy
Type 3		Like a sausage but with cracks on its surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges (passed easily)
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces, entirely liquid

**Type 4** (smooth and soft, like a sausage or snake) is the ideal consistency.

**Type 6** (fluffy, mushy stool, like oatmeal) or **Type 7** (completely liquid) happen a lot in patients with LARS. If that's the case for you, then colonic transit is certainly something that you need to work on.

## Dietary changes

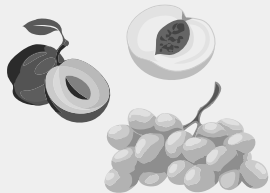
### How can diet improve my LARS?

Many of the symptoms related to LARS can be made worse with certain foods or drinks.

For example, some foods might make you feel full of gas. Other foods may travel through your digestive system quickly. Others may activate your bowels to move.

You can help manage your LARS by figuring out which foods trigger your symptoms, and trying to remove them from your diet.

### What are some examples of foods that might trigger my LARS?



#### Fruits

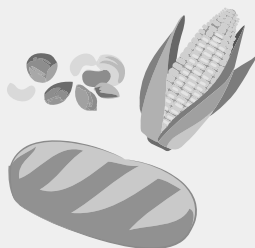
Grapes, peaches, plums, berries, dried fruits may activate the bowel and make your stool softer.



#### Vegetables

Many vegetables, such as broccoli, cauliflower, cabbage, onions and beans may activate the bowel, and can cause gas and “explosive windy stools”.

First, try eating vegetables that have no seeds, like cooked carrots, potato, puréed or canned vegetables. Later, you can try lettuce or tomatoes in small amounts. Remember, the key to finding out which foods you can manage is trying them out one at a time and making sure you always chew your foods well.



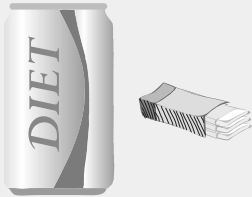
#### “Insoluble” dietary fibre

Nuts, seed, certain rice or bran cereals, wholegrain breads, corn, and vegetables with peel and stringy parts can all activate the bowel and make stools softer (more on fibre in the Stool Bulking Agents chapter).



### Spicy foods

Many spicy foods, such as curry and chilli, can make your bowels move more and make your stools softer.



### Sorbitol

A sweetener that is often found in “sugar-free” foods (example: diet drinks, sugar-free gum, some candy or snack bars) can lead to looser stools, bloating and gas.

## Are there any drinks that might trigger my LARS?



### Caffeine

Any drink that has caffeine, such as coffee or certain teas, can activate the bowel and make your stools softer.



### Alcohol

Beer and wine are examples of alcoholic drinks that can activate the bowel.



### Moderate fluid intake

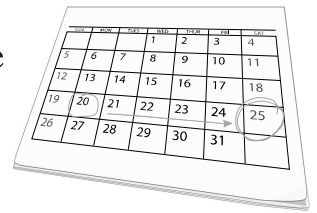
Drink about 8 cups of water per day. Drinking more water may make your bowel movements too loose and drinking less water may result in small pellet-like stools (Type 1 on the Bristol Stool Chart).

## Figuring out which foods are bothersome

Use our **DIET diary** to help you figure out which foods affect your LARS (see next section for more).



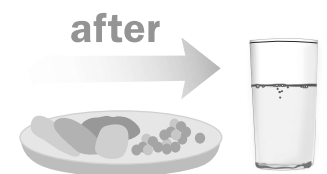
Eliminate foods one at a time. When you make a change to your diet, wait at least one week to really see the effect.



Do not reduce your total amount of food intake – that will not help! Some people find it better to have 6 small meals instead of 3 meals a day. You can try this.



We also recommend that you drink at the end of your meals or in between meals instead of during them, so as not to over-activate your bowels.



It can be tough to know for sure which foods are causing your symptoms. The food that you eat can take anywhere from a few hours to 2-3 days to come out the other end! Use the DIET diary to help you identify types of foods that affect your symptoms.

## Summary

- The foods you eat can trigger symptoms of LARS.
- This list provides some common examples but is not a complete list.
- It is important for **YOU** to discover what bothers **YOUR** LARS in order to improve **YOUR** symptoms.
- Use our **DIET diary** to keep track of your progress!

## Medication

### Loperamide

Loperamide (also known as **Imodium®**) is the first-line medication used to slow down colonic transit. You don't need a prescription to take it.

Loperamide works by slowing down how food moves through the intestine. This allows more fluid to be absorbed by the intestine along the way, so that your stool is thicker and the amount of stool is less. This can help some of the LARS symptoms you might be having, especially frequency and urgency.

The best time to take loperamide is **30 minutes before a meal**. This will help the intestine prepare for incoming food. After your meal, if you don't empty your bowels, do not take loperamide again until you have a bowel movement.

You may also find that loperamide helps you more with certain foods, and you may want to always take it before those foods.

If you wake up often at night to empty your bowels, you may also take loperamide **before you go to bed**.



Loperamide usually come in **2 mg pills**. Start by taking one pill at a time to see how it works and to make sure you don't have side-effects. If it doesn't improve your symptoms, you can take it several times during the day. **Do not take more than 8 pills in one day (total of 16mg)**.

Taking too much loperamide can lead to difficulty having a bowel movement (because your stool is hard), cramps in your stomach or feeling sick to your stomach (nausea).

Loperamide can help some people. If you are taking it to treat your LARS, it is perfectly fine to take it long-term.

Not sure how much loperamide to take? Is it *really helping*? Are you taking it at the right times? Use our **LOPERAMIDE diary** at the back of the booklet to keep track of how you are using loperamide, and to make sure you are using it according to **YOUR** symptoms.

## Other prescription medications

Diphenoxylate (also known as **Lomotil**<sup>®</sup>) also works by slowing down how food moves through your intestines.

Some side effects can include feeling dizzy, flushed, feeling like you have to vomit or having stomach cramps.

Cholestyramine (also known as **Questran**<sup>®</sup> or **Cholamine**) is a prescription medication that stops the stool from getting too liquid by decreasing a type of salt product from building up in your stools. This can help with frequency and urgency.

Amytriptyline (also know as **Elavil**<sup>®</sup>) is another prescription medication that is sometimes used to help with frequency and urgency. It works by slowing down contractions in the digestive tract. Side effects include constipation, dry mouth, and others if used inappropriately.

**Codeine**, which is usually used as a pain-killer, can be used as well, but may cause nausea and constipation. It is also a “narcotic” pain-killer. Patients can become addicted if they do not use it carefully and as prescribed by their doctor.

## Summary

- Loperamide is a medication that is often used to slow down intestinal transit and harden stool.
- It might improve your LARS symptoms, especially frequency and urgency.
- Sometimes it takes a while to figure out the best dose for you. Use our **LOPERAMIDE diary** to make sure you are using it correctly.
- There are other medications you might be able to use (such as diphenoxylate, cholestyramine, amitriptyline, and others).
- Always consult with your doctor before starting any medication.

## Stool bulking agents

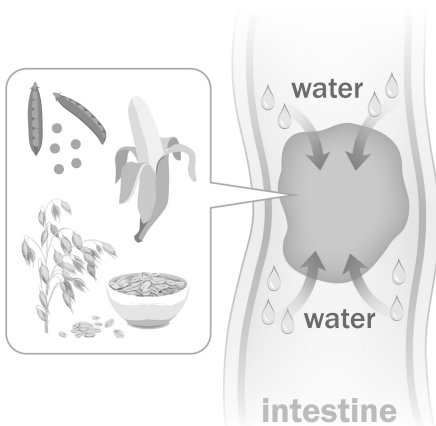
### Is fiber good or bad for LARS?

Fiber is a tricky subject to master! There are two types of dietary fiber: “insoluble” and “soluble”.

#### “Insoluble” fiber

speed up bowel activity and is often used to treat constipation (difficulty having a bowel movement because of hard stool). Foods with “insoluble” fiber include those listed in the Dietary Changes chapter (wholegrain breads, bran, corn, some nuts and seeds, etc.).

These insoluble fibers are usually foods that you want to **avoid** because they might worsen your LARS.



#### “Soluble” fibre

act more like a sponge, soaking up extra water and becoming a gel-like substance.

This in turn makes your stools bulkier (hence, the name “stool bulking” agents!), which can improve some LARS symptoms.

Foods high in “soluble” fibre include oats, barley, rye, legumes (lentils, peas), and peeled fruits.

### “Soluble” fibre supplements

You can add soluble fibre to your diet by taking fibre supplements. Psyllium has “soluble” fibre. It usually comes as a powder that you can mix with water or food.

Some brands on the market are **Metamucil**<sup>®</sup>, **Benefiber**<sup>®</sup>, **Konsyl**<sup>®</sup>, etc.

These products can really help your LARS symptoms. They are usually available in a powder form, although you can also find them as pills or wafers (powders are more effective).

You might hear that you should take psyllium with lots of water. While this is not wrong, it may not be best for treating LARS symptoms. Why is that?

Psyllium and other “soluble” fibres work by attracting water like a sponge and becoming a gel-like substance. You want it to “sponge-up” the extra water already in your stools and not to add more water for it to absorb.

So, do not take psyllium with too much water. Instead, sprinkle it on your food (for example: oatmeal, peanut butter, banana, yogurt). Make this part of your morning breakfast routine.

You should start to see a change in your stool consistency in a couple of days. If not, you can increase the dose. For example, if you started with one tablespoon, try using two.

Just make sure not to take more than 10g per day (look at the labels to see how many grams are in one tablespoon or scoop). Taking too much psyllium can give you stomach cramps or constipation. Psyllium can also have the opposite effect in some people, and can worsen diarrhea. Give yourself at least 2 weeks to see if the psyllium is helping you.



## Summary

- “Soluble” fibre acts like a sponge to soak up excess water in the intestine, which makes your stool thicker.
- Fibre supplements can be added to your diet, but must be taken properly in order to work well.

# IMPROVE YOUR ABILITY TO “HOLD-ON”

## Pelvic floor exercises

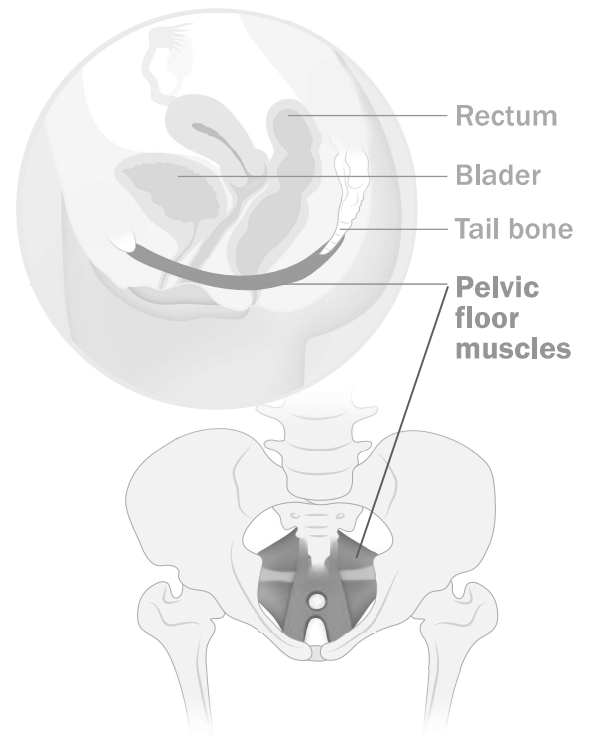
### What is the “pelvic floor”?

The **pelvic floor** is made up of muscles that stretch like a hammock from your tailbone in the back to the pubic bone in the front. In a man, the pelvic floor supports the rectum and bladder. In a female, the rectum, bladder, and uterus lie on the pelvic floor.

### What do the pelvic floor muscles do?

Because the pelvic floor muscles support the rectum, they can affect how your bowels empty.

Just like any other muscle in the body, the pelvic floor needs to be worked out (trained) if you want it to be strong and well controlled.



First you need to figure out where your pelvic floor muscles are. Sit or lie down. Try to relax your thighs, buttocks, and belly muscles.

Now try to squeeze and lift the anus up into your pelvis as if you were holding in gas or stool. Then relax, allowing the anus to drop down to its normal position. Do this a couple of times to make sure you’ve found the right muscles. Try **NOT** to squeeze your buttock muscles or belly muscles.

Each time you “squeeze and lift”, try to hold that feeling for up to 8 seconds. If you can’t get to 8 seconds because it is too difficult, hold it for as long as you can. With time, you will get better at this.

After 8 seconds, release the “squeeze and lift”. Take a break for 10 seconds. Then repeat the same thing.

Do this 10 times, and repeat this exercise 3 times a day.

If you are not sure if you are working the right muscles, sit comfortably in bed or on the floor with your back supported and your knees bent. Use a mirror to see the anus and watch for it to tighten and move inward.

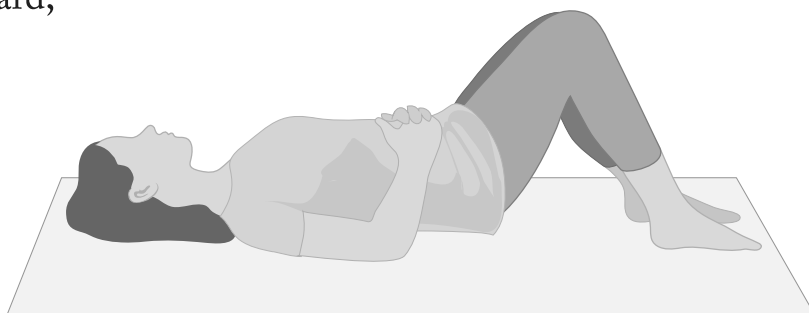
Alternately, you can place your index finger over the anus. When you squeeze you should feel the anus move inward and away from your finger.

If you see or feel the anus bulge outward, you may be pushing instead of lifting which may worsen symptoms.

If you are having trouble getting the hang of this exercise, you can ask your doctor or a pelvic health physiotherapist.

We generally recommend continuing exercising, especially if it has given you some relief.

Remember, like any muscle, when you stop working out, the results may disappear.

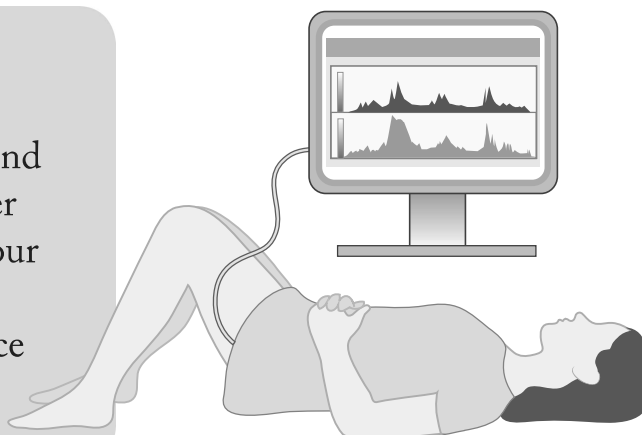


## Biofeedback

**Biofeedback** is another tool that can help you find and control your pelvic floor and sphincter muscles to improve how well you can hold back stool. It can only be performed with specialized pelvic health physiotherapists. There are two common types.

### Pelvic floor biofeedback

Pelvic floor biofeedback uses electrodes and sensors to measure the way your sphincter muscles contract and allows you to see your contraction on a screen. The goal is to improve isolation, strength, and endurance of the sphincter muscles.



## Rectal balloon training

Rectal balloon training involves a health care professional gently inserting a small balloon into the anus which can be inflated with water or air. The balloon can be inflated until the point where you start to feel the urge to have a bowel movement.

With each session, your health care professional will gradually increase the amount it is inflated to slowly improve the amount of balloon (and hopefully, stool) that your anus can accommodate before the urge “to go” kicks in.



Pelvic floor muscles

Rectum

The goal is to improve the storage of stool and to give you more time to reach the toilet before you leak.

## Summary

- The pelvic floor plays a big role in normal bowel function.
- In patients with LARS, pelvic floor exercises can be performed at home to improve symptoms.
- Pelvic floor biofeedback is a way to help train the pelvic floor. These need to be performed with a colorectal specialist, pelvic health physiotherapist or nurse.

# IMPROVE YOUR ABILITY TO FULLY EMPTY YOUR BOWELS

## Proper toileting habits

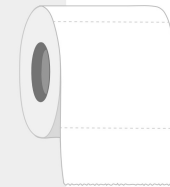
People often take for granted the simple action of sitting on the toilet and emptying their bowels. However, for people with LARS, this can sometimes be difficult.

Here are several tips for going to the bathroom that will help you fully empty your bowels.



### Only go to the bathroom when you really have to go!

Remember the chapter on pelvic floor exercises and training? Well, if you allow stool to build up in the anus until you absolutely need to go, you will train yourself to be able to hold-on more, which will hopefully lead to less frequent episodes of urgency.



It is time!

### When on the toilet, it is important to position yourself correctly to fully empty your bowels.

This includes leaning forward, resting your elbows on your thighs, and lifting up your knees above the level of your hips (putting your feet on a foot-stool might help). This should help the stool exit.



### Do not sit on the toilet for a long period of time. Do not strain hard.

Straining on the toilet can actually weaken the pelvic floor muscles and cause swelling around the anus that bleeds easily (hemorrhoids).



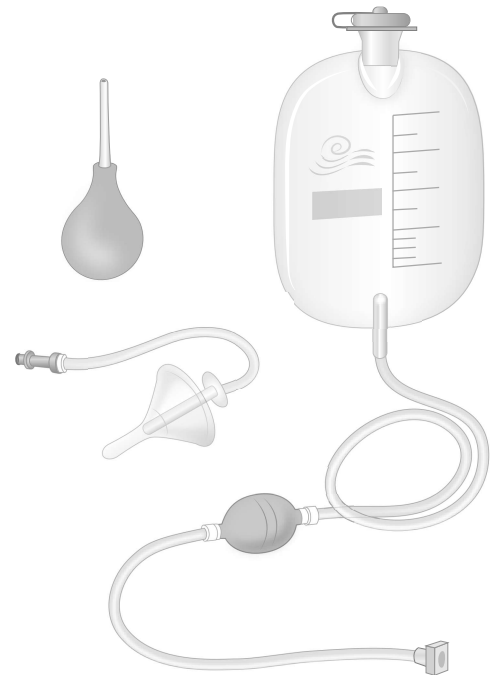
## Enemas and rectal irrigation

If you are still having some difficulties even after trying these methods, **enemas** and **rectal rinses** may provide extra relief.

Both of these work by flushing water up your anus to help empty your bowels.

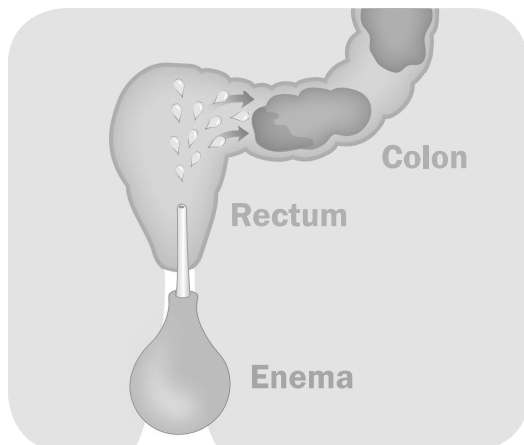
It can help with many of the symptoms of LARS, especially clustering and incontinence.

A rectal irrigation system is simple to use. You need a bag filled with lukewarm tap water, a tubing system, a pump, and small balloon catheter that is inserted into the anus.



While sitting on the toilet, you can start the pump, and the system will spray water up your anus, which flushes out the stools and activates the bowels to empty fully.

In the beginning, you can do this once or twice a day, but after a while you might not have to do it so often.



Enemas are similar to rectal irrigation systems and are simpler to use. They deliver either water or a water-like medication up the anus.

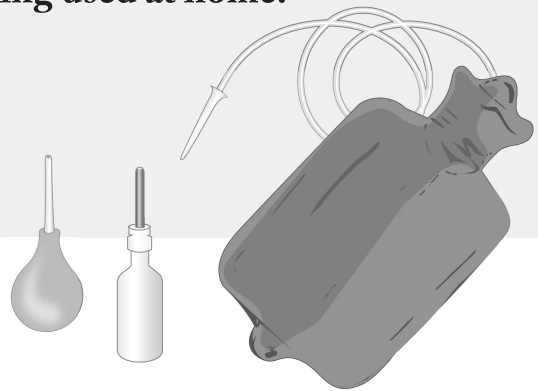
Enemas can usually be found at any local pharmacy. Rectal irrigation systems may be more difficult to find, **and you should** ask your colorectal specialist, nurse, or pharmacist for help.

While they are rare, some people can have complications with either enemas or rectal irrigation systems.

Some of these rare complications include abnormal heart rhythms due to the bowel filling up rapidly with water, injuries to the bowel, and possibly changes in the level of electrolytes (chemicals in your blood).

**Before beginning enemas or rectal irrigations, it is important to speak with your colorectal specialist or nurse.**

**Both methods should be explained in-person by a nurse before being used at home.**



## Summary

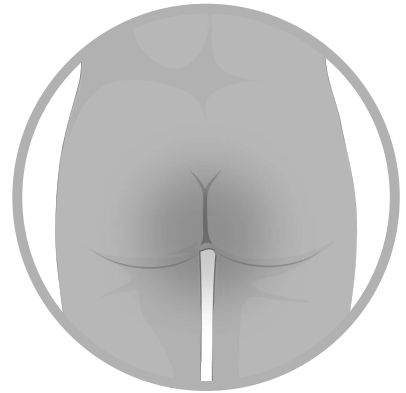
- Fully emptying your bowels is important to improve LARS symptoms.
- Proper toileting habits include only going when you really have the urge to go, getting in a good position on the toilet, and trying not to strain.
- Enemas and rectal irrigations work by flushing water up your anus to empty out the bowels.
- Discuss this with a colorectal specialist to decide if it is safe for you.

# MANAGING THE CURRENT SITUATION

## Perianal skin care

### Why perianal skin care?

Frequent or loose bowel movements can cause the skin around your anus, genital areas and bum to become irritated. Your skin may be red, sore and itchy.



### What factors cause skin irritation?

#### Extra moisture

from leakage of stool or if you are wearing pads that are wet.

#### Mechanical irritation

from constantly wiping with rough toilet paper.

#### Chemical irritation

caused by leakage of stool or using the wrong type of products to clean your bum.

#### Infection

we are all at higher risk for skin infections (fungus and bacteria) in conditions of extra moisture, chemical irritation, or mechanical irritation.

### Goal 1 – Clean the skin

Use warm water to wash the area gently once or twice a day, or after each bowel movement.

You can also wash the area gently by using a hand shower, a bidet or sitzbath basin.

If you feel sore in the bum area from passing stools often, sitting in water (room temperature) can help.

If you use a product to clean the skin, it should be “pH-balanced” (not acidic or basic), and should not include alcohol, soap, or fragrances. These products can cause more harm than good.



To dry the area, pat it with a soft cloth rather than wiping. Do not use dry toilet paper or rough cloths. Try wetting the toilet paper before wiping, or using washable reusable J-cloth type of tissue or soft cotton material.

**Do not** use pre-moistened toilet wipes as they often contain chemicals that can irritate the skin.

If you still choose to use wipes, use non-alcoholic, fragrance-free baby ones. Make sure to check if they can be flushed down the toilet.



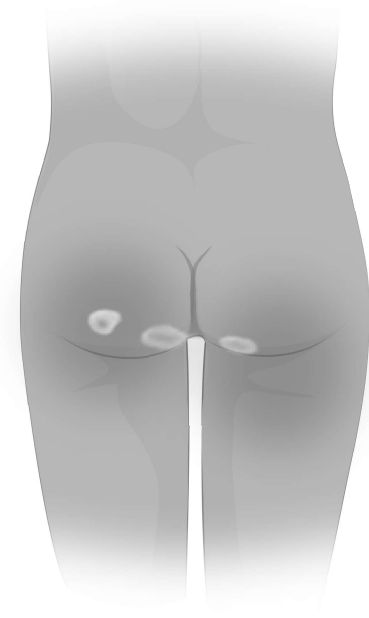
## Goal 2 – Prevent skin breakdown

If the skin is irritated, it is at risk of “breaking down”.

Skin breakdown means that the first layer of skin (or even deep layers) is destroyed, and a cut or sore develops.

The best treatment to prevent skin breakdown is to reduce the contact between the skin around your bum and stool, by treating things like stool frequency and incontinence.

If you are already following some of the recommendations from the previous chapters, here are some other ways to prevent skin breakdown.



### **Use a skin cream like a diaper-rash type.**

Zincofax<sup>®</sup> without fragrance, ihle's paste, Sudacream<sup>®</sup>, Calmoseptine<sup>®</sup>, Coloplast Citrix Acid barrier ointments are some examples.

### **Wear cotton underwear**

instead of synthetics (nylon, polyester) so that you don't perspire in that area.

If it is hard to control when you pee or have a bowel movement, you can wear disposable pads or disposable underwear.

Just make sure to throw out the pad or underwear when it gets wet.



If you notice foul smelling odors or discharge from the skin around your bum, you might have an infection, and might need antibiotics. Consult a doctor if you are concerned about this.

## Summary

- LARS can irritate the skin around your anus and bum, which can cause discomfort and skin breakdown.
- The goals of skin care are: cleaning the skin, and preventing skin breakdown.
- Creams, protective barriers, and disposable pads are just a few ways that you can keep your perianal skin healthy.

## Self-management strategies

### What are self-management strategies

While you are starting to use some of the treatment strategies covered in this booklet, it will take time for your LARS to improve. In some cases, even after months of treatment, your LARS will only improve slightly.

Self-management strategies are ways to prepare for every situation and ways to regain control when dealing with LARS.

Some self-management strategies were already covered in previous chapters – for example, properly taking loperamide, avoiding certain foods, keeping a food diary, and good perianal skin care with the use of appropriate products.

Here are some other important tips that can help maintain your quality of life.

### Social self-management strategies

Some patients with LARS stay at home because they worry that their symptoms can flare up at any time. **So much as possible, don't let LARS stop you from your daily activities.**

One helpful tip is to always know the location of the closest bathroom, whether inside a building or walking around outside. Some cities even have mobile-phone or Internet Apps for this.



Another is to try and arrange your activities according to your bowel habits.

For instance, if you know that your LARS is worse in the morning or after certain meals, plan your activities in the afternoon.

Also, get used to carrying a “**survival pack**” with you when you leave the house. Your pack might include non-alcoholic baby wipes, extra underwear, skin creams, and loperamide medication.

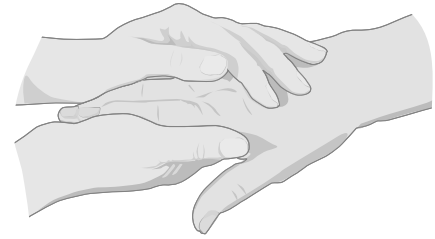
## Emotional self-management strategies

Some people find that there is a link between their emotional state and their bowels.

During times of high stress, some people go to the bathroom more often and have looser stools.

While you might not be able to completely remove stress for your life, try to engage in activities that keep you relaxed.

Reading, yoga, taking a bath, and listening to music are some examples that you might find helpful.



It is also important to express your emotions related to your frustration about LARS.

Speak to your nurse, family or friends about what you are going through.

Some people find it more helpful to speak with other patients who are experiencing similar problems.

They may relate to you better, and might offer some personal solutions that they've discovered.

Online blogs and chat rooms can be easily found on the Internet, and are encouraged. You can also ask your surgeon if he/she knows a patient that you could speak with!

Remember that everyone is unique; you will learn what works best for you to cope with LARS.

## Summary

- Self-management strategies give you some control over your LARS.
- It is important to plan for social situations so that you are not limited in what you can do or where you can go.
- It is also important to limit stress and express your feelings of frustration when needed.

# SURGICAL OPTIONS TO TREAT LARS

## When to consider these?

If you have tried all other treatment strategies for your LARS with no improvement, and your symptoms are still having a big impact on your quality of life, there are other options to consider.

These all involve **surgery**. There are risks associated with all surgical procedures, so make sure to be well informed and speak to your colorectal specialist about the risks and benefits for you.

These treatment options require a serious discussion with your colorectal specialist. This chapter will only cover the basics of these procedures.



## Neuromodulation

For severe LARS, if more conservative treatment strategies have not helped, you may be considered for neuromodulation. What's neuromodulation?

Neuromodulation is a form of treatment that affects the nerves that control the bowel and muscles around the anus.

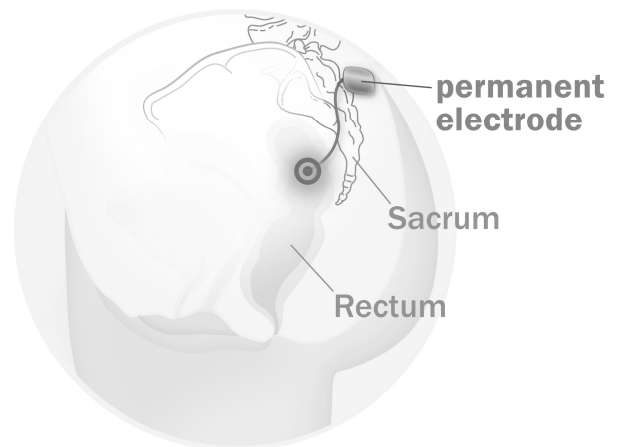
Remember at the beginning when we spoke about the nerves that control the bowel and the sphincter muscles? These nerves can be targeted as a treatment.

There are two main sets of nerves that can be targeted: 'sacral' and 'posterior tibial.'

**"Sacral neuromodulation"**, or SNM, is the most widely studied form of neuromodulation used for LARS.

SNM involves placing an electrode near the spine, which can electrically stimulate the nerves that control the bowel and sphincter muscles.

The first step of SNM is to implant a temporary electrode for 2 weeks. If there is improvement, a permanent electrode can be placed.



Remember that this is a surgery, meaning that there are risks such as infection or surgical complications. Also, SNS may not be covered by insurance for LARS treatment.

If you want to learn more about SNS, speak to your colorectal specialist to see if you would qualify for this treatment.

Not everyone will improve with the temporary electrode, so SNS is not for everyone.

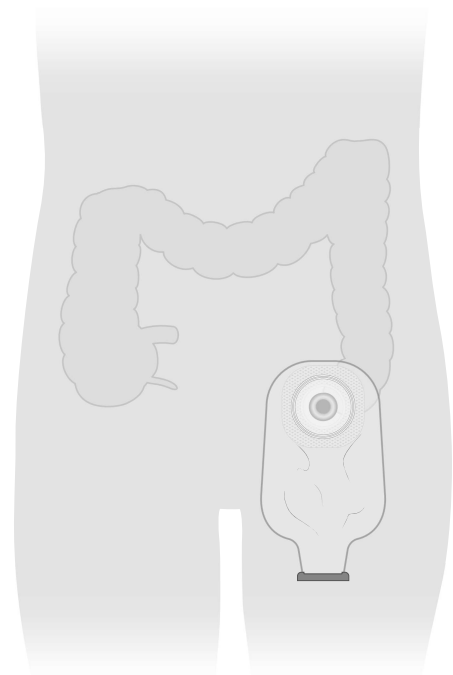
When it works, SNS has been shown in research studies to improve incontinence, urgency, and clustering of bowel movements.

## Permanent Stoma (Colostomy)

If LARS is seriously affecting your quality of life, you can speak to your colorectal specialist about undergoing surgery to create a **permanent colostomy**.

You may have had a temporary stoma (an ileostomy). A permanent stoma (colostomy) involves the colon. A colostomy is usually easier to manage than an ileostomy because the stool that empties into the bag is thicker.

We understand that passing stool from the anus is more natural and typically more convenient. Having a stoma seems like an odd thing to “choose”, but it does offer you relief of your LARS and a way of emptying your bowels that you can more or less be in control of.



Remember that choosing a permanent colostomy requires another surgery. This can lead to any number of complications, such as wound infections, blood clots, serious infections in your belly, and the risks of anesthesia (being put to sleep during surgery). There are also late complications that can happen from having a colostomy, such as a hernia (bulge) around the stoma.

If a permanent colostomy seems like a better alternative to your current situation dealing with LARS, speak to your colorectal specialist to learn more about the risks and benefits.



## Summary

- Neuromodulation (SNS) and surgery for a permanent colostomy are both invasive procedures that can be considered in cases of severe LARS.
- This is a brief overview of the risks and benefits of either treatment – both require a discussion with your colorectal specialist to properly review all options.

## SOME FINAL THOUGHTS

LARS is a common condition facing rectal cancer survivors, and its management can be tricky. It may seem that despite your best efforts, your bowel symptoms continue to affect your daily activities.

Don't despair!

Our goal is to help you understand your LARS, reflect on your symptoms, and find some solutions that work for you.

If you can do this, you will almost certainly see some degree of improvement.

Remember, you are not alone! There are many rectal cancer patients going through the exact same experience.

We wish you success!

## REFERENCES AND OTHER MATERIALS

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### References

Here is a list of some of the medical articles that we used to make this module. We do not expect you to be able to understand these articles, as they are written for doctors and not for patients.

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## Health Professionals for LARS

There are many people that you can reach out to for questions about your LARS. Some of them are listed here. Speak to your colorectal specialist to get a referral.

- Your physician (surgeon or oncologist)
- Nurse specializing in cancer care or Colorectal Surgery
- Pelvic physiotherapist
- Dietician
- Pharmacist
- Other patients!

## Patient materials

Here are some additional online patient materials on LARS that you may find helpful.

### **Bladder Bowel**

[www.bladderbowel.gov.au/assets/doc/ImproveBowelAfterSurgery.html](http://www.bladderbowel.gov.au/assets/doc/ImproveBowelAfterSurgery.html)

### **Beating Bowel Cancer**

[www.beatingbowelcancer.org/understanding-bowel-cancer/living-with-bowel-cancer/long-term-changes-bowel-habit/](http://www.beatingbowelcancer.org/understanding-bowel-cancer/living-with-bowel-cancer/long-term-changes-bowel-habit/)

### **National health Services**

[www.eastcheshire.nhs.uk/Patient%20Information%20Leaflets/On%20theA-Z/Managing%20bowel%20after%20Anterior%20Resection%2011453.pdf](http://www.eastcheshire.nhs.uk/Patient%20Information%20Leaflets/On%20theA-Z/Managing%20bowel%20after%20Anterior%20Resection%2011453.pdf)

### **Coloplast**

[www.coloplast.co.uk/Global/UK/Continence/Peristeen/Managing-your-bowel-function-Patient-Booklet.pdf](http://www.coloplast.co.uk/Global/UK/Continence/Peristeen/Managing-your-bowel-function-Patient-Booklet.pdf)

# BOWEL TROUBLE DIARY

Date							
Number of bowel movements							
Average stool consistency (Bristol)							
Time of symptoms (please circle)	AM Noon PM	AM Noon PM	AM Noon PM	AM Noon PM	AM Noon PM	AM Noon PM	AM Noon PM
Number of incontinence episodes:	Gas	Gas	Gas	Gas	Gas	Gas	Gas
	Mild liquid	Mild liquid	Mild liquid	Mild liquid	Mild liquid	Mild liquid	Mild liquid
	Major liquid	Major liquid	Major liquid	Major liquid	Major liquid	Major liquid	Major liquid
	Stool	Stool	Stool	Stool	Stool	Stool	Stool
Did you have to rush to the toilet because of a sudden urge?	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No
Did you have to go to the toilet twice, or more, in the same hour?	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No	Yes No
What other symptoms did you have? (circle all that apply)	Difficulty emptying	Difficulty emptying	Difficulty emptying	Difficulty emptying	Difficulty emptying	Difficulty emptying	Difficulty emptying
	Constipation	Constipation	Constipation	Constipation	Constipation	Constipation	Constipation
	Cramps	Cramps	Cramps	Cramps	Cramps	Cramps	Cramps
	Bloating	Bloating	Bloating	Bloating	Bloating	Bloating	Bloating

# DIET DIARY

Date							
Bothersome symptom	Frequency	Frequency	Frequency	Frequency	Frequency	Frequency	Frequency
	Urgency	Urgency	Urgency	Urgency	Urgency	Urgency	Urgency
	Incontinence	Incontinence	Incontinence	Incontinence	Incontinence	Incontinence	Incontinence
	Clustering	Clustering	Clustering	Clustering	Clustering	Clustering	Clustering
	Constipation	Constipation	Constipation	Constipation	Constipation	Constipation	Constipation
	Bloating	Bloating	Bloating	Bloating	Bloating	Bloating	Bloating
Possible troublesome food today: (please circle all that apply)	Fruits	Fruits	Fruits	Fruits	Fruits	Fruits	Fruits
	Vegetables	Vegetables	Vegetables	Vegetables	Vegetables	Vegetables	Vegetables
	Spicy Food	Spicy Food	Spicy Food	Spicy Food	Spicy Food	Spicy Food	Spicy Food
	Sweets	Sweets	Sweets	Sweets	Sweets	Sweets	Sweets
	Nuts	Nuts	Nuts	Nuts	Nuts	Nuts	Nuts
	Other:	Other:	Other:	Other:	Other:	Other:	Other:
Possible troublesome beverages today: (please circle all that apply)	Coffee	Coffee	Coffee	Coffee	Coffee	Coffee	Coffee
	Tea	Tea	Tea	Tea	Tea	Tea	Tea
	Alcohol	Alcohol	Alcohol	Alcohol	Alcohol	Alcohol	Alcohol
	Other:	Other:	Other:	Other:	Other:	Other:	Other:
Foods or beverages eliminated since last diary entry							

# LOPERAMIDE DIARY

Date							
How many Loperamide pills did you take today?	Morning 0 1 2	Morning 0 1 2	Morning 0 1 2	Morning 0 1 2	Morning 0 1 2	Morning 0 1 2	Morning 0 1 2
	Noon 0 1 2	Noon 0 1 2	Noon 0 1 2	Noon 0 1 2	Noon 0 1 2	Noon 0 1 2	Noon 0 1 2
	Evening 0 1 2	Evening 0 1 2	Evening 0 1 2	Evening 0 1 2	Evening 0 1 2	Evening 0 1 2	Evening 0 1 2
	Before bed 0 1 2	Before bed 0 1 2	Before bed 0 1 2	Before bed 0 1 2	Before bed 0 1 2	Before bed 0 1 2	Before bed 0 1 2
Did you take Loperamide 30 minutes before your meal?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	No	No	No	No	No	No	No
Do you think it helped with your symptoms?	Yes	Yes	Yes	Yes	Yes	Yes	Yes
	No	No	No	No	No	No	No

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## IMPORTANT

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you are having a medical emergency or need medical assistance.

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