About this Patient Guide

This patient guide is written for patients by patients. **It is not intended to be expert medical advice** or a “how to cure” the condition known as LARS. Our hope is that from reading this booklet, patients will gain an understanding and collective reasoning of the condition; along with some tips for management and connections to other resources.

LARS is unique for each patient. There are no two patients with the exact symptoms and response to treatments. There are patients who gain better function and quality of life within a short time frame and others who have seen little improvement after many years. Most of us have had various treatments (chemo and radiation) for rectal or other cancers and some have little or no rectum left after anastomosis. Some of us have major LARS even though treatment was limited and some of us have minor or no LARS although we had many and major treatments. The human body is complex and no two people are identical. Some patients have had the entire rectum removed and some only part of the rectum. Some patients were able to have a LAR without an ostomy and others have had ostomy with a later reconnect. There does not seem to be any connection between patients, protocols for treatment and the severity of LARS symptoms. LARS is difficult for anyone who is living with the condition.

What makes this booklet unique is that the content is written by two different patients, but with advice and learning from a large patient group who have connected online and who are living with LARS. This makes this information from the perspective of those who know very well what it is like to live with LARS. This patients group have also found hope and progress through management and care.

There are other cancer surgeries that can mimic the symptoms of LARS, but LARS is a condition that is affiliated with those who have had a low anterior resection or LAR. Millions of patients have undergone this surgery, and there are no exact numbers on how many of the patients who have had this surgery end up with LARS. Many do not. If you are reading this booklet to help you decide whether or not to forego a life saving surgery, we implore you to not let unwarranted expectations of the unknown, inform your decision on whether or not to take life saving treatment options. You cannot deal with anything if you do not beat the cancer. Take care of that first!

Perhaps you have gone to your doctor and care team and they have provided you with little help or hope for treatment or any guarantee of improvement. We understand how frustrating this can be. Remember, many doctors (but not all) are not totally familiar with LARS issues and outcomes. Even if they are aware and familiar with LARS, with no two patients being alike, it is impossible for a doctor to tell you the exact outcome and prognosis of your new digestive system and bowel function. We implore and encourage you to educate and inform your doctor and care team so that you can help them better understand the symptoms and treatments available for LARS. Care providers know as much as we tell them. Update them and talk to them often! Knowledge is power and hope for future patients!

So let's get into it, shall we?

What is LARS?

LARS, or Low Anterior Resection Syndrome, is a varying array of symptoms or issues resulting from the surgical procedure known as a Low Anterior Resection. Symptoms and issues may include some or all of the following:

Bowel Frequency: Frequent movements in a day- some patients report an average of 6-10 bowel movements or as many as 20 per day.
Clustering: This refers to the bowel not being able to empty completely. You may go and eliminate small partial stools, think you are done, only to find you have to move your bowels again within a short amount of time. Stools may vary in consistency and size. Some stools are small and pellet like, some are thin and pencil like and other stool lacks any formation and seems to have a pasty consistency.
Flatulence: Frequent uncontrolled passing of gas. You may notice that the gas is very smelly and often loud and uncontrollable.
Incontinence: Inability to control stool resulting in defecation- sometimes in small accidents and other times substantial.
Tenesmus: A feeling that you need to empty your bowels even when they are empty. This sensation can lead to painful spasms. Tenesmus is different than clustering as with tenesmus, the bowels are empty.
Constipation- Not being able to have bowel movements for a period of time. This can lead to bloating and discomfort and pain.

Additional challenges that affect those of us who live with LARS

Digestive Paralysis and Blockages- The digestive tract either freezes up or is blocked. Signs of this happening are extreme bloating, abdominal pain and lack of bowel movements.

Skin issues- Itching and irritation- This can come from excessive bowel movements and/or constant wiping.

Quality of Life Effects of LARS

The following list of issues are a sampling of what patients have reported for quality of life issues as a direct result of living with LARS.

- ❑ **Ability to function effectively at work-** The lack of bowel control often makes it difficult to manage plans for a successful day of work. Also, fear that employers and co-workers will not understand or become aware of embarrassing flatulence and/or incontinence is a concern for returning to work or changing jobs.
- ❑ **Ability to exercise**- Concern that any movement that causes physical strain may lead to increased bowel movements and incontinence.

- **Impact on sex life**- Some may find diminished sexual drive, an overall fear of sexual intimacy or fear that partners have lost interest due to LARS.
- **Ability to travel any amount of distance-** Some fear travel with concerns of not knowing where bathroom is located, being able to make it to the bathroom in time and/or dealing with flatulence in public places.
- **Ability to go out with family and friends-** Similar to travel, fear of not knowing where bathroom is located, being able to make it to the bathroom in time as well as dealing with flatulence in public places.

Anxiety and depression are very common, if not certain, for with those living with LARS. Anxiety and depression are a direct result of living with LARS symptoms and the impact of the quality of the patient's life. Anxiety and depression are also very common for caretakers of those who are living with LARS.

You will find more details on each of these symptoms/issues under the section on remedies and treatments.

How do I know if I have LARS?

If you have had the LAR surgery and can identify with some or all of the symptoms mentioned above you likely have LARS. Some people have minor LARS and some have major LARS. You can use this scoring chart below to see where you are. A good idea is to use this chart every 6 months to see if there has been any improvement. This would be a good thing to do before any follow up appointments with your doctor as a means of discussion for treatment options.

LARS Score chart (soon to be updated)

The aim of the questionnaire below is to assess your bowel function. Please check the box that represents your current situation. It may be difficult to select only one answer; do your best to look at daily life for you as of recent days. If you have had a recent illness or infection or have eaten foods known to disrupt your bowels, please take that into account and answer to reflect your usual daily bowel function.

Question 1: Do you have have times when you cannot control your gas (flatulence or wind)?

☐ **No, never**	**0**
☐ **Yes, but less than once per week**	**4**
☐ **Yes, at least once per week**	**7**

Question 2: Do you ever have bowel incontinence (any leakage)?

☐ **No, never**	**0**
☐ **Yes, but less than once per week**	**3**
☐ **Yes, more than once a week**	**3**

Question 3: How often do you have bowel movements?

☐ **More than 7 times in a 24-hour period**	**4**
☐ **4-7 times in a 24-hour period**	**2**
☐ **1-3 times in a 24-hour period**	**0**
☐ **Less than once per day**	**5**

Question 4: Do you have have a bowel movement within one hour of your last bowel movement?

☐ **No, never**	**0**
☐ **Yes, but less than once per week**	**9**
☐ **Yes, more than once a week**	**11**

Question 5: Do you ever have to rush to the bathroom to relieve your bowels due to sudden strong urge?

☐ **No, never**	**0**
☐ **Yes, but less than once per week**	**11**
☐ **Yes, more than once a week**	**16**

Add up your total score and use this interpretation:
0-20= no LARS   21-29= minor LARS   30-42=major Lars

Why Do I have LARS?

Some of you may be asking yourself why you are dealing with the symptoms of LARS. The answer to that question may be different for each patient. The body has been through major changes and disruption and many nerve systems have been disrupted. It is likely that rectal surgery to remove the cancer- the low anterior resection- played a major role in the development of this condition. Some rectal cancer patients also undergo chemotherapy and radiation, both which may play a small or a significant part in LARS. Let’s face it, our bodies have been through a trauma or numerous traumas, and our digestive systems have been permanently changed and impacted.

Understanding how the digestive system works may help you see how the body functions have been changed with surgery and treatment. For more on how the digestive system relates to LARS- see Appendix A.

In all honesty, it is important to not get too caught up in trying to figure out why you have LARS and focus more on management of LARS so that you can get back to a decent quality of life.

What Can I do to Manage LARS?

Remedies and potential treatment of issues and symptoms.

Although not all who have LARS have the same symptoms and responses, there are many similarities in how people manage these issues and symptoms. This overview of management options may help you find some improvement or may at the least give you some items to talk about with your doctor. Remember, before trying anything, you should talk with your doctor if it is outside of what has already been recommended. With many options available and because the range of symptoms vary greatly, the best combination of strategies can only be determined with medical consultation and by trial/error.

Common Management Strategies

Strategy 1- Diet

Aids in the Management of Clustering, Frequency, Flatulence, Incontinence and Constipation:

What you eat plays a critical role in almost all symptoms of LARS. Not every patient has the same digestive tract (some people have sensitivities and other GI issues) and some people have slower or faster transit time. Keeping a food journal is a great tool for early recovery. In the first few months, it is best to avoid all foods that are known to pose a problem for people living with LARS. The following is a list of common food items that those who live with LARS may find pose an issue if eaten:

Corn	Alcohol
Cabbage	Red Meat
Popcorn	Nuts /seeds
Fried Food	Spinach
Fruit and vegetables with skins and seeds	Melons
Broccoli/Cauliflower	Spicy Food
Sugar Substitutes	Caffeine/Chocolate
Dairy (milk/ice-cream)	Pork
Legumes	Onions/peppers

Some people report that they can eat some of these foods with no problem and others report that over time, they have been able to introduce some of these foods back into their diet in time, with good result. If you are going to try and add foods back to your diet, be sure to only introduce one challenging food back at a time. This way you can get a good sense of how your body is going to react to it! Remember, transit time can make a difference. A good rule of thumb is to wait three days to make sure there is no negative response. Adding another forbidden food too soon can create confusion and misery!

Strategy 2- Exercise and Exercises

Aids in Management of Frequency, Clustering, Constipation and incontinence

Physical Exercise- Strengthening our bodies can help LARS in many ways. Routine physical exercise is a vital part of both physical and emotional well-being. Exercise can strengthen the body and the mind. Many patients ease themselves into exercise as to ensure that the body will respond well. Those living with LARS suggest that you start with a small program and slowly and gradually increase time and impact. Exercise is not going to negatively affect LARS. If you have recently had surgery, check with your doctor about beginning exercise.

Pelvic Floor Therapy- Some patients find that working with a physical therapist to strengthen pelvic muscles, for the right person, may help align bowel rhythm and help you gain better control of your bowels. Talk with your doctor about the possibility of working with a physical therapist for pelvic floor therapy if you think this is something that may help you.

Strategy 3- Biofeedback

Aids in the Management of Clustering, Frequency, and Incontinence

Often used in conjunction with pelvic therapy, biofeedback uses sensors to monitor specific muscle and body functions. This can help the patient learn to regain control over pelvic floor muscles. With training, patients will learn to relax their pelvic floor muscles to improve bowel control. Speak with your doctor and/or pelvic therapist to determine if biofeedback is an option for you.

Strategy 4- Sacral Nerve Stimulator

Aids in the Management of Clustering, Frequency, and Incontinence

Some individuals living with LARS have found that Sacral Nerve Stimulation can help improve LARS. A small device is surgically implanted into the tailbone area and sends electrical impulses, similar to a heart pacemaker, to the sacral nerves. These nerves affect sphincter and pelvic floor muscles so as these are stimulated by the device, colon function is improved in some patients.

Your doctor will be able to make a determination if Sacral Nerve Stimulation is a suitable option for you.

Strategy 5- Mindfulness practice

Aids in all symptoms of LARS but most specifically, anxiety and depression

There is a lot to be said about mindfulness and the symptoms of LARS. The mind is a powerful thing and can have a direct effect on symptoms. Have you ever noticed that your bowels correlate certain events with evacuation? As soon as you get home? A certain time of the day? Your mind can trigger and associate stimuli in the body to have a response to nerve endings. For this reason, meditation, a positive attitude (yes, we know if it hard), faith and prayer as well as getting into a regular routine will all have positive impact on your condition. If you are struggling with anxiety and depression, seek help so that you can work on mindfulness at your full capacity. Many patients report that mindfulness and getting back to regular things like work and exercise, have the biggest impact on improvement of symptoms. Here are a few small suggestions for mindful practice:

Yoga- Yoga can help strengthen your mind and body. Yoga can be simple or intense but can be done in the comfort of your own home.

Meditation- Stress and brain fog can have serious impact on how our bodies function. Spending time each day in an effort to relax the mind and focus on breathing has been known to provide significant improvements in function and lesson symptoms. A suggestion is to start with 5 minutes a day. Clear your mind completely and take deep full breaths. Sometimes looking at tangible things around you while doing this can help with mind distraction. Many books and videos on mindfulness and meditation can be helpful. Remember they call it a practice for a reason.

Nature walks- Taking a walk outside and focusing on your surroundings can help reduce stress and improve your overall sense of well-being. Many people living with LARS incorporate this into their daily regimen.

Gratitude list- It may sound silly- but taking the time to write down things that are going well can help get away from the insanity that comes with living with LARS. Start your list with being a cancer survivor- and go from there.

Peer to Peer support- Connecting with those who share in your challenges with LARS can help you feel supported and understood. People who share common challenges can often be the best form of wellness. For more information and links to peer to peer support- see section on peer to peer support below.

Strategy 6- Medications and Supplements

Aids in the Management of Clustering, Frequency, Flatulence, Incontinence and Constipation

There are medications and supplements that may ease and control symptoms. Most people living with LARS have reported that they use some or a combination of the following medications. The medications listed here are not known to cause serious side effects or health risks due to long term use, but some may cause the body to become dependent on them. Keep in mind every person is different and you should talk with your healthcare providers and check for interactions with any other medications you are taking. The list below is a list of most common medications and supplements that patients have tried. There may be other medications and also many natural and homeopathic supplements that can aid in in the relief of symptoms.

Dosage may vary from patient to patient and you should always start with the recommended dose. For more guidance discuss with your doctor and health care providers.

Medication or Supplement	**How it Helps/Works**	**Further information**
Lomotil- (diphenoxylate hydrochloride and atropine sulfate)	This is an anti-diarrheal and helps with nerve impulses. It works by slowing down the movement of the intestines which can help with less frequent movements.	Only available by prescription. Dosing is per your doctors advice. Considered a narcotic and there is a slight risk of dependance.
Imodium- (loperamide hydrochloride)	This is an anti-diarrheal -It works by slowing down the movement of the intestines. This decreases the number of bowel movements and makes the stool less watery.	Your gut can become adapted to a daily dose but with careful planning you can retrain your system. Some of those living with LARS take this daily for maintenance of symptoms. Some take as many as 5-6 a day, although that is not the norm.
*Fiber Soluble- absorbs water, turning into a gel.	This can bulk up stool and help move it through the digestive tract- this can help with frequency and transit time.	Forms of Soluble Fiber- Citrucel, Metamucil and other psyllium husk supplements. These all come in powder, pill or wafer form.
*Fiber Insoluble- does not absorb in water.	This does not digest and can help with constipation by bulking stools.	Forms of Insoluble Fiber- Nuts, seeds and leafy green vegetables among other foods.
Probiotics	Work to restore the good bacteria in the gut and could help with gas and stool consistency	Many different kinds available- do some research and try a few before deciding which is right for you.
Slippery Elm Bark	Soothes inflammation in the intestines	All natural and can be found online.

Simethicone	This can help with gas/flatulence by changing the levels of gas in the stomach	GAS-X is one example of this type of medicine. May have effects on stool output, use wisely.

*A note on Fiber- Some people have reported that soluble fiber did not work for them and/or aggravated symptoms. It may be best to try different brands and types (wafer, powder, pill form) of soluble fiber to see if one is right for you. Most insoluble fiber found in food can cause major stomach and intestinal distress for many living with LARS. Be cautious when consuming foods rich in dietary fiber.

Strategy 7- Lower Colon Irrigation

Aids in the Management of Clustering, Frequency, Flatulence and Incontinence

Important note: If you have had surgery recently and are still in a period of healing, it is highly suggested that you wait to try any form of irrigation. Allow your body time to heal and recover before considering this option. You want your body to regain as much function as possible before introducing irrigation. Not waiting could affect long term outcomes. As with any other treatment, consult with your doctor before attempting irrigation.

Lower Colon irrigation is a common strategy for many living with LARS. There are a few options for this and knowing the differences and challenges associated with each system, can help you determine the best possible system for you. Rectal irrigation refers to the use of water, introduced into the lower colon via the anus, to assist with the evacuation of feces from the lower colon. This is commonly referred to as a “clean out”. By doing so, the lower colon remains empty for a period of time, offering relief from clustering and frequency.

Warm Water Enemas- Warm water enemas are the most common irrigation system used by those living with LARS. It it important to note that this system refers to the use of a medical grade enema kit, 4-6 cups of warm water, a proper nozzle and a lot of patience and practice. Most patients who have established this routine report that they can go 24- 48 hours between bowel movements. In some cases, people find that using frequent enemas allows them to eat foods that once posed problems.This seems to vary from person to person.

There is a lot of internet talk promoting the use of additives with the warm water, including salts, soaps, coffee, etc.. Warm water alone has shown to be effective and safe and using additives is not recommended without medical advice.. If you are considering using additives, please speak with your doctor beforehand.

See Appendix B for more details and instructions about warm water enemas.

Peristeen System- This system is available through your medical provider and requires purchase of the delivery system and replacement supplies including a one-time use catheter nozzle. The catheter includes an inflatable rubber balloon that is filled with air once inserted into the colon, creating a seal and therefore preventing water leakage. With this system, a person can perform the enema while sitting on the toilet rather than lying on the floor. Some people living with LARS have found this system for lower bowel irrigation to be quite good, but the system is also costly. This may be a viable option if covered by your insurance provider. As an alternative, warm water enemas can provide a similar sitting experience by using an inflatable nozzle, also referred to as a "retention" nozzle. See Appendix B for further information.

Other Irrigations Sources- There are other irrigation devices and systems available, such as saline enemas (such as Fleet), suppositories and hand held bulb syringe devices. Some of those living with LARS have reported that these systems have been used and in some cases work, but in most cases they are not as effective as the warm water full enemas. Some have reported that they have tried these and they can be no help at all. Saline enemas contain saline (salt pulls water out of the bowel) and can only likely provide a clean out of the very lowest portion of the colon/rectum. The same is true for a bulb syringe enema and it may be a good backup system when warranted, but give only temporary, short-lived relief.

Again, if you are considering performing any enemas soon after cancer treatment, it is important to consult your doctor to determine if irrigation is safe for you.

Strategy 8- Bowel Training Program

Aids in the Management of Clustering, Frequency, Flatulence, Incontinence and Constipation

Some individuals living with LARS have found that using a bowel training program works well for them and by inducing a regular bowel movement daily, decreases or eliminates the symptoms of LARS. You can find more information on such a bowel training program here.

Strategy 9- Skin care- Prevention and Management

Aids in the Management of Skin irritation

As mentioned previously in this guide, skin irritation can be a concern and can arise from constant wiping and bowel movements. Here are some of the items you may wish to try to help with skins concerns:

- Bidet- A bidet is a warm water cleanse that can be either handheld or installed on a toilet. BIdets provide a way to wash with pressurized warm water and can reduce the need for too much wiping.
- Creams and Ointments -Calmoseptine, Desitin, A&D OIntment and Aquaphor may provide relief from irritation as well as barriers for future irritation. Be cautious to use over the counter itch relief creams without first consulting your doctor. These may create more irritation.
- Paper- Buy high quality toilet paper that is multi layers for softness and absorbency,

- Wiping tips- If you are dealing with irritation- use water as a spray to clean and pat dry with a soft cloth or soft toilet paper.
- Bathing- Use sitz baths with epsom salts for relief. Avoid using soap on sensitive skin.

Strategy 10- Practicality Tips

Aids in the Management of Quality of Life Issues related to LARS

- **Adult Diapers and Flatulence Undies-** Many people living with LARS use adult diapers in case of incontinence. These are made today with very seamless designs that allow you to wear them and go undetected. There is also underwear made with charcoal filters that make claims to hide the odor from flatulence.
- **Travel Bag-** Those living with LARS should keep an emergency travel bag with them even for short trips. A change of clothes, wipes and barrier ointments are good things to have on hand in emergencies. If you use enemas, always travel with your enema kit. It may be wise if you are flying to keep the kit and travel bag in your carry on instead of your checked luggage. This way if luggage gets lost or delayed you will be prepared. Do not think twice about TSA seeing these kits- incontinence and bowel dysfunction are more common than we think.
- **Bathroom location-** People living with LARS need to know where bathrooms are located! Be OK with asking businesses, schools, places of work and friends and family where all of the bathrooms are as soon as you arrive. When traveling there are apps available that can locate rest areas and toilets along the way. See the resource section of this booklet for links to some of these services.
- **Meal timing-** Some of those living with LARS find that small and more frequent meals can help minimize LARS symptoms. Others report that large meals can help the bowels to evacuate fully. It might help to journal your food intake and assess which works best for you.
- **Hydration-** Dehydration seems to be a factor in bowel paralysis and blockages.
  The intestines need to be hydrated to function at best capacity. It is very important that those who are living with LARS drink plenty of fluid to ensure that digestive function does not fail.

Strategy 11- Returning to Work

Many patients return to work a few months after surgery. Others have found that working is not an option due to incontinence and unmanageable symptoms. Some have had to find work that allows them to be able to visit the bathroom frequently- and that is not always easy. LARS is not a published disorder and if you are seeking payment from your government to support you financially- it would likely make a better case to report incontinence. As overall well-being plays a vital part in improvement, it is highly recommended that you try and work as normal as possible. Talking with employers and asking for accomodations is not only reasonable, but in most countries there are laws that protect employees. Talk with your doctors or other support professionals to plan for your future working environment or disability claim.

Strategy 12- Sex and Intimacy with LARS

As one would imagine- having sex after LARS may seem like a huge task and many may fear that they would have challenges with physical human interactions and intimacy. Talking with your spouse or partner about those fears and finding ways that you can both enjoy intimacy together is a natural and important part of your well-being. Incontinence support groups may be very helpful in providing suggestions and counseling around intimacy.

Strategy 13- Alternative Medicine

This guide was created to provide an overview of common strategies for symptoms and is not intended to be a comprehensive guide with every potential remedy. Many people try and have seen success with alternative and holistic treatments. Alternative options are likely something you should research to help to support your specific needs. You may find different sources of alternative treatments based on symptoms, medical history, as well as environmental and genetic makeup. As modern medicine evolves, we can expect to have access to a wider array of options with these types of treatments.

Strategy 14- Professional Support

As previously mentioned, anxiety and depression are common for those living with LARS and their caretakers. Physical and emotional health can play a huge factor in the healing process. If you are struggling to find joy and hope in any situation, you may benefit from professional counseling and/or medication. Without mental health your body likely will not improve. Do not wait to seek help. The sooner you gain mental health, the sooner you can address physical health.

Is there a cure for LARS?

Perhaps you are wondering if anyone has ever been cured of LARS. Perhaps you are wondering if your LARS will improve. Truth be told there is no known cure for LARS. What we do know is that symptoms can improve over time. Some patients report that over time they gain almost total freedom from symptoms. Management over cure is likely the better mindset to have regarding our condition.

The good news is that you are not alone or without hope. There are many of us living with this condition and at the end of this booklet you will find out more about how you can connect with us. See section on peer to peer support.

Permanent Colostomy

When none of the strategies listed above provide sufficient relief from your LARS symptoms, a permanent colostomy may be a suitable option. As scary as that sounds, people live very full lives with a colostomy bag and the symptoms of LARS are no longer an issue when you choose this route. As you would have likely had a temporary (reversible) colostomy with the initial LAR, a permanent colostomy is similar in that an exit port will be surgically implanted on the colon so that stool can be drained into an externally mounted bag. If you are feeling like there is no improvement with time and your quality of life is severely diminished, talk to your doctor about this option.

Note To Caretakers

If you are a caretaker (spouse, friend, family member or other) of someone living with LARS, please know that your role is important and critical. Although the symptoms of LARS create some intimate and private challenges, a kind word of encouragement and understanding, patience and support can go a long way to help with quality of life for us. It may be hard to watch your partner, friend, or family member go through something that you have absolutely no control over. It is very important that you take the time to do some self care and seek support from professional or personal outlets if you need to. The time that you take to care for yourself will be the greatest help that you can give to those of us who live with LARS. There are days when we will need your strength, as ours is completely diminished. Know that most patients will gain improvement and hope is something that grows stronger with your care and support.

Patient to Patient Support

The best way to pull all of this together and get support for LARS will come from patients who know and understand the condition. There is a large group of people who are living with LARS and connected on social media through a private group on Facebook. The group is growing every day and it is an excellent source of information and support. There are protocols and guidelines for the group so that the focus remains patient to patient support. Please understand that to keep that focus foremost, only patients and sometimes caregivers (if the patient cannot join) are permitted to join the group.

You can request to join the page using this link: https://www.facebook.com/groups/lwlars/

Additional Resources

Colorectal Cancer Site: on LARS
UK Bowel Cancer Site
Clinical Report on LARS
Podcast Discussing LARS
National Association for Continence
International Continence Society
Bathroom Scout- Worldwide Bathroom Finder App
Got to Go Restroom Finder App
Charmin’s Sit or Squat Restroom Finder App

Suicide and Depression Lifeline

Final Comments

If you are reading this document, it is likely that you or someone you know has gone through a tremendous health experience involving surgeries, radiation, chemotherapy, many tests and medical appointments. On the other side of that treatment you or they have come face to face with some minor or even sometimes severe day-to-day challenges. Whether you feel that these experiences qualify you as a soldier or a victim, our message to you is that your life will improve by following some of the suggestions in this guide and by connecting with others who have and do share this journey. Take heart in knowing that the information and knowledge of LARS is improving all the time. Even better, further improvements are coming as our voices are being heard by the medical community. We encourage you to continue to be a voice of advocacy for LARS with your care team. Keep the conversation going with them and provide a copy of this patient to patient guide to all of them!

This guide was created with the intention to give those of us with this similar condition some much needed information and encouragement. Living with the aftermath of cancer is a continuing challenge. We hope that this guide has provided you with some useful tools to help you with your fight.

About the Authors

Jeanee Wright - I was diagnosed in 2009 at the age of 40. An early routine colonoscopy due to family history was the only reason for the detection. After chemotherapy combined with radiation and surgery to remove the tumor and resect (LAR), I was told I would have a “new normal”. I had no idea that meant all of the symptoms listed above in this booklet! I lived for years with little advice or answers from my doctor regarding my sometimes unbearable symptoms. My surgeon seemed surprised that I was having such severe issues (considering my tumor was high up). I researched online and found very little in the first few years. I will never forget the first time that I did not make it to the bathroom. I was out to dinner and on my way home, I was mortified and thought my life was over. Thanks to a very supporting and loving husband, some much needed lifestyle changes, and a ginormous faith in God, I slowly began to see improvement. Thankfully, I was always able to figure out how to live my life; work, travel and exercise, although I still had many things to learn about management of symptoms. In 2014, while still searching the internet, I began to find information about something called LARS, a syndrome caused by the surgery I had. That was my first glimmer of hope. In 2017, I decided that I would start an online Facebook Group page to see if I could connect with others who were living with the condition. I was amazed at how many people quickly joined this group and also how quickly I was learning from others about similarities and differences with symptoms and remedies for LARS. The best thing that I realized was that my heart was full and I was no longer alone in my journey. I decided right around the same time I started that online community that I wanted to offer something in writing to doctors and other patients. I realized once I began writing this that the patient to patient connection was the most important resource, and doctors were only a reference for us to seek medical advice. We are the experts in LARS. We can also be the educators and voice on behalf of those living with LARS worldwide. I hope you find this guide useful. I brought my friend Joe into the project when I saw his amazing ability to lay out technical advice on enemas and other detailed therapies. He is an engineer, he is GOOD at it!

The therapies and management that work for me are daily imodium and psyllium husk fiber supplements, regular exercise and a low carb healthy diet, regular warm water enemas and prayer and meditation. I still avoid red meat and anything with skins because they still give me pain and gas!

I live in New Hampshire, USA, with my husband, adult son, two cats and a granddog. I work a full time job as a Cooperative Housing Specialist, which requires a lot of car travel and client meetings. I have a can-do attitude and plan to live my life to the fullest; working, traveling and not letting LARS slow me down one bit! Feel free to email me with any thoughts, comments or suggestions at braelyn1969@aol.com

Joe Grasso - I received my rectal cancer diagnosis in May, 2016 and have been living with LARS June 2017.

Like many others that have gone through this experience, my initial reaction to the cancer diagnosis was a silent shock followed by a mental struggle to understand the scope of this news and coming to grips with how this would affect my life and my family. Up until my diagnosis, I had a vibrant work and family lifestyle but upon hearing the “news”, all of that appeared to be in jeopardy.

But once I decided that I would face the treatments with all of my strength, I endured and accepted the surgeries and chemo treatments despite the pain, discomfort, and struggles demanded on me and my loved ones. However nothing prepared me for the challenge faced once my ostomy reversal was completed…… the highly skilled and wonderful doctors and healthcare professionals that attended my treatments didn’t advise me of what was to come and I had no other immediate resources to help understand this thing that I would eventually learn, was called LARS.

The next 6 months after reversal was a period of significant confusion and hardship trying to cope with work and interacting with friends and family as LARS continuously invaded my mind. I needed to think about the location of the nearest toilet, how to excuse myself from important meetings, decide whether I was able to leave my home, what I could or couldn't eat and very importantly, whether I could travel which constituted a significant component of my work responsibilities. Everything that I was capable of doing before now seemed to be nearly impossible and this was not a situation that I felt was acceptable to me.

After an exhaustive search for answers and interacting with some truly wonderful people like Jeanee, I found that several of the strategies listed in this guide, including mindfulness training, exercising, low-dose loperamide and regular warm-water enemas, have had a dramatic and positive affect. With daily focus and care, I've been able to resume normal work and life activities. Life is great once gain.

https://www.facebook.com/joe.grasso.90

End of Patient Guide- Appendix A and B on Next pages

Appendix A- Digestive System Function

Function Of The Digestive System

The are seven main functions:

(1) *Ingestion* - eating/consuming food and liquid

(2) Propulsion - the method of moving food through the digestive system which is called peristalsis. This occurs via the contractions and relaxations of muscles around the walls of the digestive organs causing food and waste materials to move forward through the system.

(3) Secretion of digestive enzymes and other substances liquefies, adjusts the pH of, and chemically breaks down the food.

(4) Mechanical digestion is the process of physically breaking down food into smaller pieces. This process begins with the chewing of food and continues with the muscular churning of the stomach. Additional churning occurs in the small intestine through muscular constriction of the intestinal wall. This process, called segmentation, is similar to peristalsis, except that the rhythmic timing of the muscle constrictions forces the food backward and forward rather than forward only.

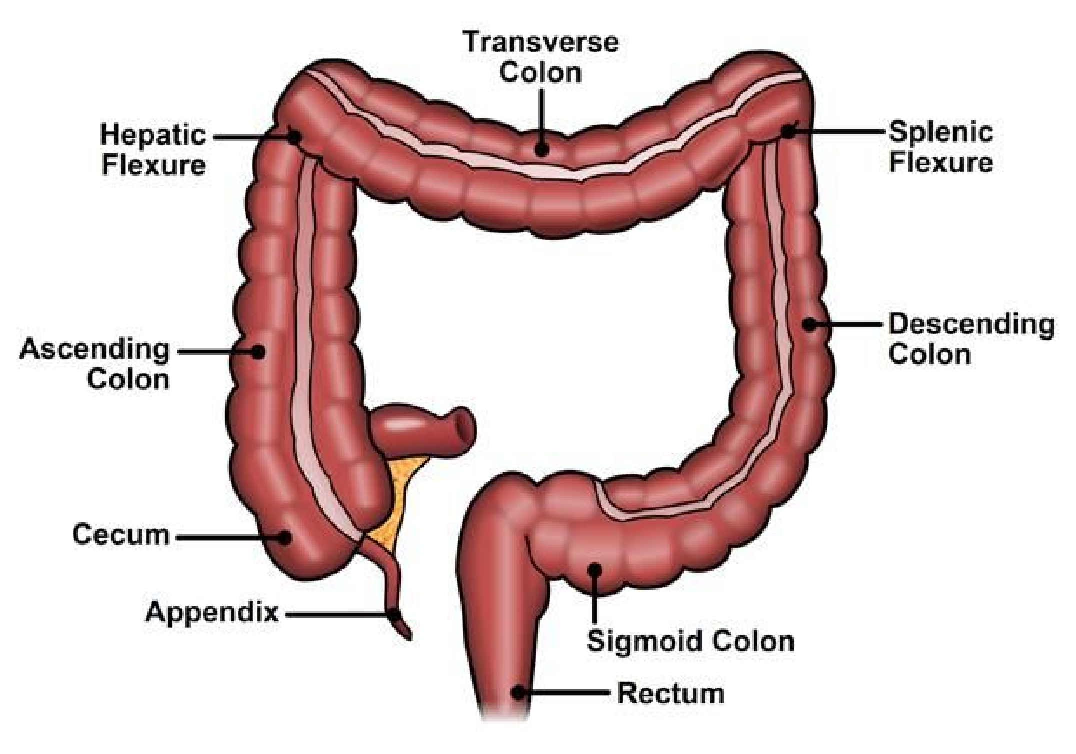
(5) Chemical digestion is the process of chemically breaking down food into simpler molecules. The process is carried out by enzymes in the stomach and small intestines.

(6) Absorption is the movement of molecules (by passive diffusion or active transport) from the digestive tract to adjacent blood and lymphatic vessels. Absorption is the entrance of the digested food (now called nutrients) into the body.

(7) Defecation is the process of eliminating undigested material through the anus.

Digestions and nutrient absorption occur in the stomach and small intestines. After absorption, the resulting waste material moves through our large bowels, or more commonly known as the colon, before it is released from the body. Let’s understand what happens in the colon:

An illustration of the colon is shown below. Imagine your belly-button in the center of the illustration with the Cecum, which is the transition from your intestines into the colon, being on your right side.



So we have 5 main sections of the colon as follows:

- Ascending colon
- Transverse Colon
- Descending colon
- Sigmoid
- Rectum

The main function of the colon is to absorb water and to breakdown any remaining materials by the action of bacteria. Material continues to moves along the colon via peristalsis and this waste material becomes thicker as water is absorbed back into the body. Thick or formed stool is easier for our bodies to expel.

Let's focus on the 2 areas that directly affect LARS; the Sigmoid and the Rectum. When these are working normally, both the Sigmoid and the Rectum are essentially holding tanks for waste material. The signaling for when the material is moved is controlled by our brains which depends on information from nerves, or sensors inside our colons .

The Sigmoid is capable of holding waste for 7 hours or longer and once it is full or when the rectum is empty, as determined by our nerves, the material is moved into the rectum. Nerves in our Rectum now tell our brains that waste is present and now need to expel it from our bodies. Typically, the Rectum can store this waste for 2 hours or more giving us time to plan ahead to find a toilet.

Once we’re ready to expel this waste, we can consciously relax and open our sphincter muscles causing normal evacuation of solid waste via peristalsis as the Rectum muscles contract and relax. Once the waste is eliminated, the colon sensors inform our brains that the process is completed, our Rectum is empty, and then peristalsis stops and we have a general sense of completion.

However after a LAR, there is major disruption to the nerves and muscles in the Sigmoid and Rectum. Surgeons have typically assumed that Colon function, as a result of a LAR, returns naturally over time however for the majority of cases, normal bowel function as described above does not return.

Instead, the following may occur depending heavily on the specific surgery, amount of Rectum and/or Sigmoid removed, and general success of the surgery, ie which nerves or muscles were compromised and to what extent; damaged sensors and muscles in the Rectum heavily influence the brain’s ability to control the necessary actions to push out the waste and monitor whether the waste is fully ejected. The normal control “circuitry” is simply impaired and LARS patients then suffer incontinence, clustering and tenesmus and a consequence of the disruption. Because of the various factors noted above, we can expect that the loss of function and severity will be different between patients and likewise, the treatments to this condition cannot be universally applied. The treatments therefore require trial/error before the symptoms can be reduced to tolerable levels.

Appendix B- Warm Water Enemas

Warm Water Enemas
The first important step for people considering enemas as a means to manage LARS symptoms is to consult your doctors and seek their advice and recommendations. Your doctor is the only professional that understands your specific health condition and status and can therefore advise if enemas, which require the insertion of a plastic nozzle into the rectum, is a safe and viable option for you. This is particularly important if you are considering enemas within the first 6 months after surgery the colon is still recovering from inactivity and your anastomosis may not be fully healed.

Also be aware that many doctors are not specifically experienced with the option of using enemas for LARS as LARS itself is not fully understood by the medical community at large. In this case, be prepared to have an open discussion with your doctor by learning all that you can about how enemas work, what the risks and benefits are, and most importantly, communicate clearly your specific symptoms and the effect these are having on your quality of life. Use this guide as a learning tool and read as much medical literature as possible in order to raise your level of understanding.

There are several means of administering an enema but we will describe the most common method here as well as provide additional information of other methods that you can review. All these methods basically deliver warm water into the colon and this stimulates peristalsis which then causes the water and stool in the lower colon to be pushed out of your body. When this process is performed properly, stool is typically removed without straining and excessive stress or pain. However, because LARS is not the same for everyone, enemas do not work for everyone and has shortcomings as described below. More typically, enemas are often used in combination with the other management tools noted in this guide. The frequency of enemas and combination with the other treatments are patient specific and can only be determined by trial/error and advice from you doctor or health professional.

The enema process starts with a kit comprised of a water container, typically a rubber bag or bucket, a hose with flow control and a nozzle.

Typical enema bag

Typical flow control

Typical Nozzle

There are many kits and options available. Successful users recommend silicon bags or stainless steel (bucket) materials be used and the nozzle be as soft as possible.

Here is a brief summary of the process however follow the manufacturer's recommendations and follow the advice from your doctor or medical team.

The water container is positioned approximately 2 feet above your abdomen usually by hanging it on a shower curtain bar or hook. The hose is attached to the bottom end of the container and the nozzle is at the outlet end of the hose. The container is filled with 4-8 cups of clean warm water at body temperature of approximately 100 F while the flow control is closed. The tip of the nozzle is coated with a suitable lubricant such as KY or similar material. Open the flow control and allow some water to flow into a toilet to remove air bubbles that may be in the hose. While lying on the floor or bath tub on your left side and on a towel, insert the nozzle into the rectum about 2-3 inches and open the flow control slowly to allow water to flow via gravity into the colon. The flow control needs to be adjusted so that it takes 2-5 minutes for all of the water to flow through.

Once all the water has been injected, close the flow control and remove the nozzle. Try to continue lying on your left side for a few minutes until the urge to evacuate is strong at which time you will need to sit on the toilet and evacuate. Do not push out the water and stool as this will occur naturally through peristalsis. It may take 30 minutes or longer for all of the material to be evacuated as there will be typically several “waves” of peristalsis. Again, do not force evacuation as these waves will occur naturally and normally without effort or strain. Stay within close proximity of the toilet during this time.

Here are some typical questions and answers (FAQs) regarding enemas:

What are the benefits?
For those that successfully administer enemas, most reported that the severity of LARS symptoms are eliminated or significantly reduced, including clustering and incontinence, for the period between enemas. Some of those living with LARS report that they can go up to 48 hours without a bowel movement and a need to perform another enema.

What are the goals?
While each individual must determine their goals, clearly we want a reduction and hopefully elimination of the severe LARS symptoms and improved quality of life. For you, this may mean the ability to return to work, reduce the time on the toilet, minimize the time “thinking about it,” etc.. An enema, in combination with diet, medication, physical activity and mindfulness training, is a tool available to help meet your goals.

Are enemas safe? Are there risks associated with enemas?

Enemas have been used to aid evacuation for centuries and when performed properly, are considered safe. However, inserting a foreign object into the rectum creates the possibility of causing physical injury to this area and therefore you must be certain, by speaking to a medical professional, that there are no physical issues in your specific case.

Always make sure that the enema equipment is clean before every use. Replace any components that have any sign of wear, stain or damage to avoid any possibility of injury or infection.

Are enemas painful?

Enemas should never be painful. If you encounter any pain, stop immediately and consult your doctor. Inserting the nozzle is generally not painful although it is uncomfortable for most people. With time and practice, this discomfort decreases.

What should I do if I get cramping?

Cramping is common as the water is flowing into the colon. To help prevent cramping, ensure that there are no air bubbles in the enema hose by releasing some of the water into the toilet before inserting the nozzle. Also, make sure that the water temperature is near body temperature but not higher than 105F. Use a thermometer to help determine the correct water temperature if you are unsure. If you get cramping during the enema, it can usually be halted quickly by stopping the flow of water for a few seconds. Once the cramps end, allow the water to flow again. Most importantly- relax your mind and body and take deep cleansing breaths.

I have painful hemorrhoids so can I do enemas?

If you have hemorrhoids consult your doctor about them. In most cases, external hemorrhoids are caused by excessive straining while having a bowel movement. If enemas are performed regularly and successfully, it is possible that external hemorrhoids will diminish or be prevented, as straining is normally eliminated. However, inserting the nozzle when an external hemorrhoid exists may be highly uncomfortable and cause bleeding. Again, speak with your doctor who may recommend a treatment for this condition.

How often should I do enemas?

Enema frequency is dependant on the transit time, ie the time it takes for food to pass through your digestive system after it has been eaten. Everyone is different as transit time can vary significantly and therefore the frequency requires some trial/error. If you normally need to go to the toilet daily prior to your cancer diagnosis, then start performing enemas every 24 hours. Ideally, the timing of the enema should occur before stool has travelled to the “rectum” area as after this time, it will be more difficult for enema water to flow into the colon and you will likely start to cluster.

However depending on your physical/medical condition, diet, amount of exercise, etc, many people can perform the enema every 36 or 48 hours. Be patience and “listen” to your body in order to determine the best cycle for you.

When is the best time of day to do enemas?

Most people that perform enemas report that the time of day has little/no effect on the success of the enema. Therefore, decide what is best for you after some experience. Again, practice and "listening" to your body will guide your schedule.

Is there a risk of dependency?

This is a difficult and complex question to answer as very little evidence exists to confirm or refute the matter. For LARS patients, the symptoms and their severity change over time. Doctors have advised that changes can be expected for the first 2 years after reversal and therefore many hope that normal bowel function will return within this period of time and therefore, many patients will endure LARS symptoms in hopes of regaining normal function. It can also be stated that very few LARS patients that have severe symptoms for at least 6 months have actually reported a normal return of bowel function. So while it can be reasonably assumed that frequent enemas can and likely will alter "normal" bowel function and lead to dependency, the alternative appears to be continued LARS symptoms. Our recommendation for you is to speak with other people who are living with LARS, and read all the medical literature available. You should also speak with your doctor to determine the best strategy for you.

How much water is required?

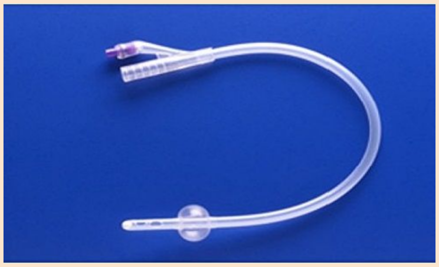
Typically, use 4-6 cups of clean water. Some people have success with 8 cups and others are fine with as little as 2 cups. The amount of water that you can hold in your lower colon that will result in a successful enema is highly individual. Feel free to experiment.

What can I do if the water leaks out too soon?

This is a common issue particularly soon after reversal as your pelvic muscles are not yet strong enough to properly close the anal canal. Pelvic floor therapy and exercise will improve this.

You can also use a retention nozzle which has an inflatable bubble at the tip. Air is used to inflate this tip once it is inserted so that it creates a seal. This also has the benefit of allowing the user to sit on the toilet, rather than lying on the floor, as the water flows in.

Here is an image of a typical retention nozzle showing the balloon in the inflated position. There are 2 inlet ports, 1 for the warm water and the other for connection to an air syringe to inflate or deflate the balloon.



I have difficulty lying down on the floor to do an enema. What can I do?

Lying down can be difficult for some people while others do not have a suitable space available in their homes. The alternative is to use a retention nozzle, as described immediately above, which allows you to sit on the toilet during the enema process. This system relies on either a bag or bucket to hold water above your abdomen, a hose with a clamp to control the water flow, and the inflatable nozzle to seal the nozzle once inserted into the rectum.

How do I clean-up after the enema?

Follow the recommendations of the manufacturer but in general, thoroughly clean the bag, hose and nozzle with clean soapy water before and after each use. Allow these to air-dry after each use. If there are any signs of discoloration or odor, dispose of these items and replace with new components. Always have spare components available.

Where can I buy an enema kit and what should I use?

Online retailers sell enema kits. Silicon is generally an excellent material. Check the reviews before purchasing. Ask others who are using enemas successfully for examples and suggestions on which they are using.