

# Let's Talk SBS

A guide to discussing Short Bowel Syndrome (SBS) with your care provider



This resource was created by a collaboration of SBS patients, community organization leaders and medical professionals, working together with Ironwood. The educational taskforce was organized and funded by Ironwood Pharmaceuticals, who also provided design and editorial support.



The following groups endorse this guide:





# How to Use This Guide

Welcome! The ‘Let’s Talk SBS’ guide has been developed to help you discuss your condition with your care provider. Created with people who have been diagnosed with Short Bowel Syndrome (SBS), caregivers, community organization leaders and specialist healthcare providers, we know how important it is you feel heard and understood as you navigate life with SBS.

**This ‘Let’s Talk SBS’ tool includes:**

- Frequently Asked Questions to increase your SBS knowledge
- Checklists to help you identify topics to discuss with your care provider – it’s important you have the chance to explain your goals, concerns, and what matters most when managing life with SBS
- Notes sections to capture and reflect on your conversations with your care provider

The guide is intended to help you identify your priorities for each appointment, and to gather the information you need to make choices and decisions that are best for you. Setting goals with your care team and making a shared decision on a care plan that works for you can take time. Doing this together can help you feel more in control of SBS.



*Attending an appointment prepared with questions and feedback on how we are managing day-to-day with SBS is important. It gives our healthcare provider the information they need to help us manage our symptoms, live comfortably with SBS, and maintain our quality of life.*

- Lori Plung, SBS and IBD Patient Expert



**Next steps:**



Get the facts



Share personal goals



Understand key takeaways



Ask other questions about my SBS



Prioritize what’s impacting life the most

<sup>2</sup> This resource is focused on adult SBS.

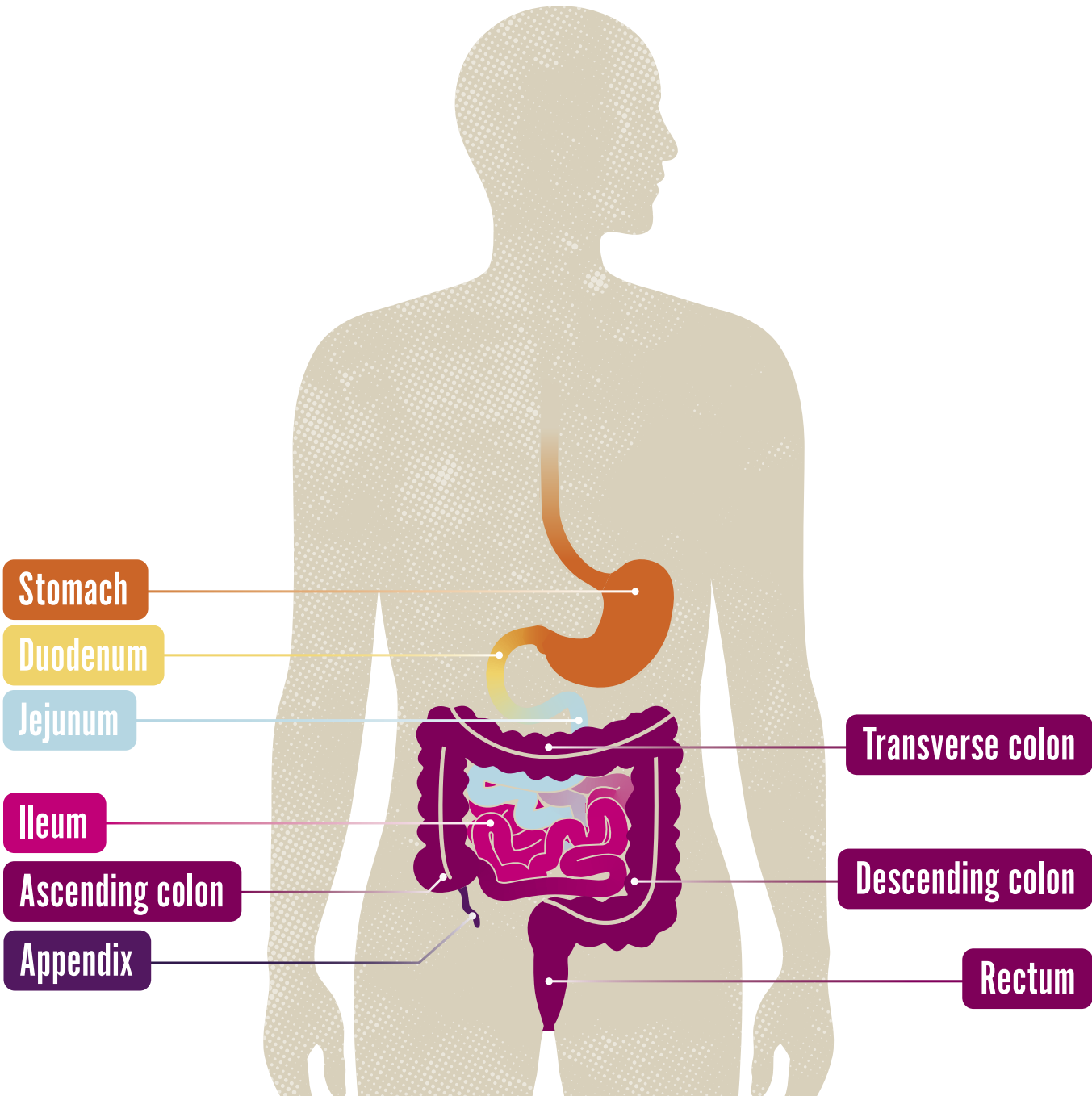
# Frequently Asked Questions About Short Bowel Syndrome (SBS)

Here is some information about the basics of SBS. Since no two people with SBS are alike, you will have your own specific questions.

For additional resources and support, please check out the link on [page 7](#).

## 1 How does the bowel work?

The bowel is an essential organ. Its role is to absorb nutrients and fluids to ensure your body can function. It slowly breaks down food, passing it from the stomach through the small and large intestine to the rectum using hormones, muscles, and nerve signals. It also helps to protect the body from infection.





2

## What is SBS?

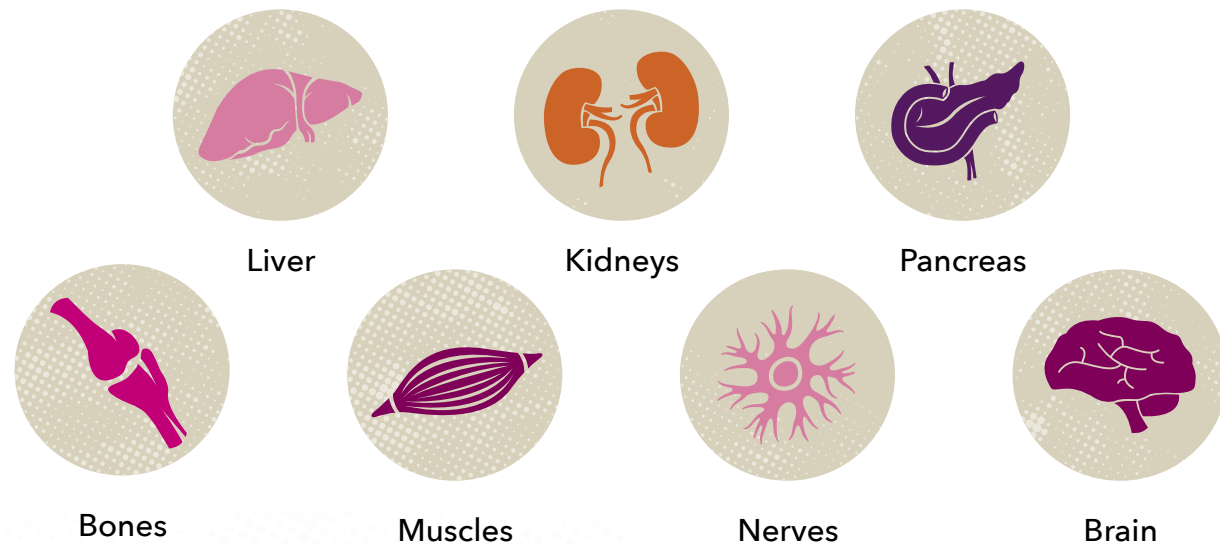
SBS, also known as short gut, is a rare condition in which a large part of the small intestine has been removed or isn't working. As a result, your body cannot properly absorb the vital nutrients and minerals it needs from eating and drinking and you may require nutrition support, such as tube feeding or intravenous (IV) nutrition and/or IV hydration (known as parenteral support\*). With parenteral support, nutrients, electrolytes, and/or fluids pass directly into the bloodstream via a vein. This type of SBS can be referred to as SBS with intestinal failure (SBS-IF). This doesn't mean things can't improve. It indicates your body can't obtain the nutrients and fluids it needs to stay healthy without extra help.

3

## SBS symptoms

An inability to absorb nutrients and fluids properly can lead to malnutrition, dehydration, and electrolyte loss. Symptoms can include diarrhea, weight loss, fatigue, nausea, cramping, pain, bloating, and problems eating.

Many parts of your body can be affected by SBS:



Blood, stool, and urine tests may be done to check your nutrition status and your pancreas, liver and kidney function.

4

## What causes SBS?

The main cause of SBS in adults is the surgical removal of half or more of the small intestine. The colon may still be intact or removed. Surgical removal may result from Inflammatory Bowel Disease (IBD), cancer, radiation damage, sudden twisting of the gut (volvulus), damage to the gut's blood flow (ischemia), complication of weight loss surgery or because of traumatic injury to the abdomen. In some cases, SBS is caused by a defect in the bowel from birth or hereditary diseases.

**\*Intravenous (IV) nutrition and/or IV hydration go by various names:**

- Total Parenteral Nutrition (TPN): A method of feeding that provides nutrients to the body through a vein. This can also be known as parenteral nutrition (PN) or Home Artificial Nutrition (HAN).
- Parenteral Support may be used to refer to IV nutrition and/or IV hydration. Total Parenteral Support (TPS) is more commonly used outside of the United States.

5

## Understanding your SBS

It can be helpful to ask your healthcare provider to draw a picture of your remaining bowel anatomy, explain the function of what remains, and the impact on you and your body.

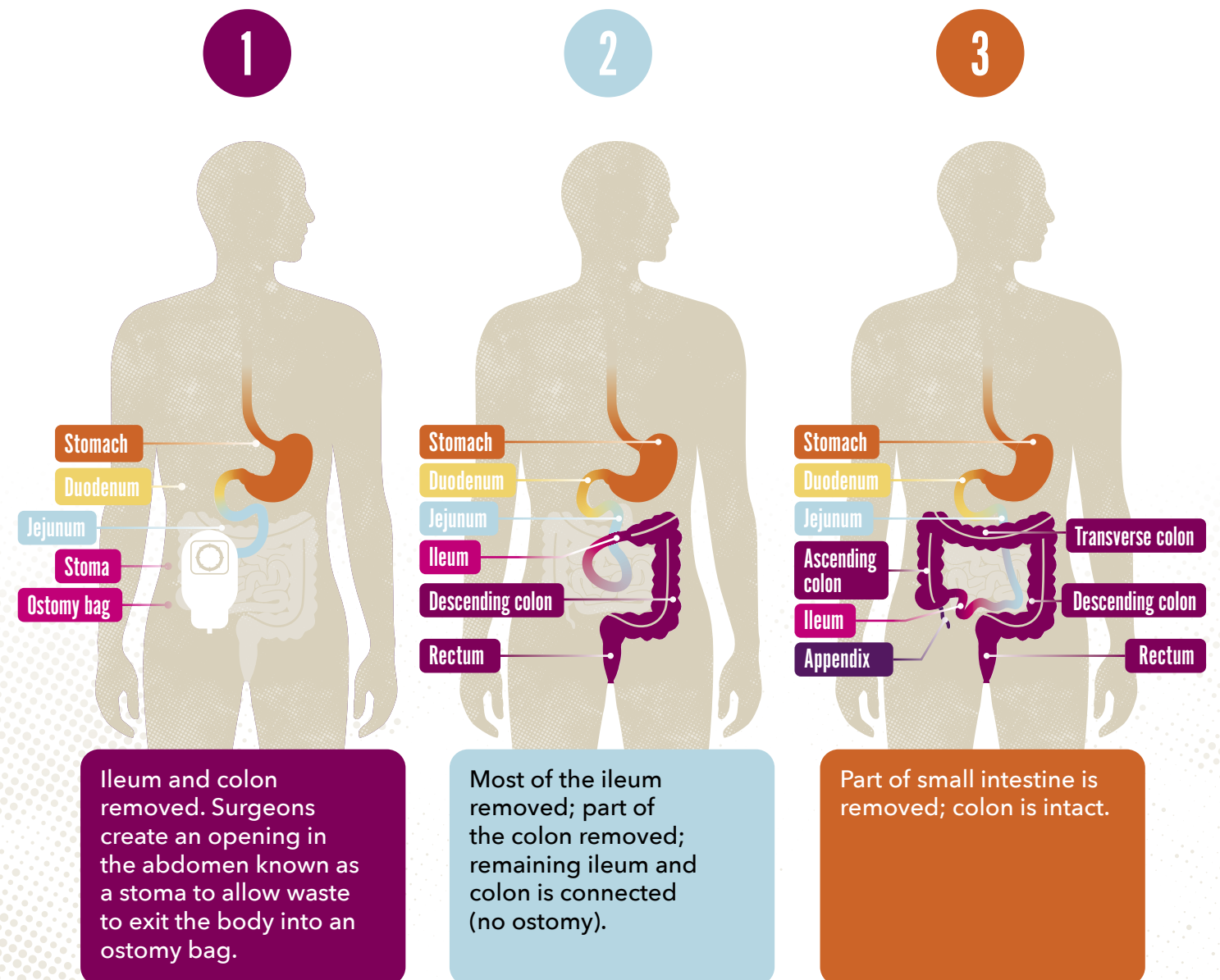
This can help you understand your treatment options, symptoms, ability to absorb certain nutrients and risks, such as malnutrition or dehydration.

There are three general types of SBS, but every individual is unique and will differ in their bowel anatomy, gut function and symptoms.

### Questions to consider:

- What parts of my bowel remain?
- Do I have a colon? Do I have an ileocecal valve? (can enhance absorption of digested food from your small intestine to colon)
- If not known, how do we find out?

## General SBS Types after surgery



## How is SBS managed?

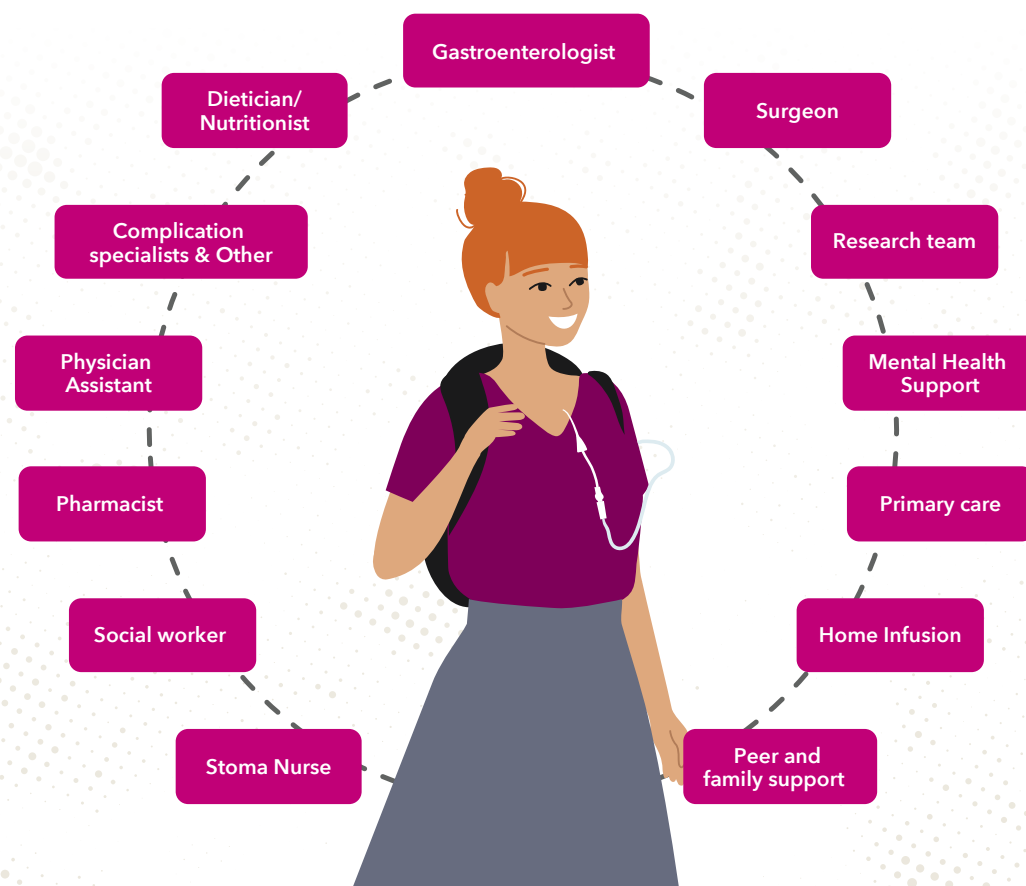
SBS management options commonly include a combination of medications, diet changes, nutrition support and surgery. You may be able to eat but require nutrition support to obtain sufficient nutrients and fluids. Nutrition support can include tube feeding, parenteral support (IV nutrition and/or IV hydration) and sometimes both. The type and amount will depend on how well your remaining intestine works, your health, and how recently you've had surgery.

You may hear the term 'intestinal rehabilitation' - a process intended to improve the function of your remaining intestine. Treatment options may change over time as your body and intestine adapt. For more information, please consult with your care provider.

## Who manages SBS care?

Care providers for SBS can vary. At an academic medical center, which specializes in conditions like Short Bowel Syndrome, you are more likely to be looked after by a team of experts led by a gastroenterologist or surgeon who partners closely with a registered dietitian, nurse, and pharmacist. Extended team members can include a psychologist and social worker. If you live far away from such a hospital, you may be looked after by a local care provider, or rely on your home infusion company. It's important you feel confident and supported. At any time, you and your care provider should be able to consult with a clinical specialist in Short Bowel Syndrome. Check out professional directories from patient groups and medical societies or speak with your local support network.

**SBS Care Teams can differ and change over time. They may include:**



## Where can I find more information and connect with others like me?

As you navigate your journey with SBS, it can be helpful to find services and resources offered by patient groups, medical societies, and specialist clinics, and connect with those who understand and share your experiences. We've pulled together some peer-to-peer resources within an SBS Community Guide. In addition, check out intestinal rehabilitation center websites for patient resources.



*Speaking to someone who experiences all the same things and walks in the same shoes is powerful. It helps me not feel alone or isolated in my experience living with SBS.*

- Bethany Johnson, SBS patient expert,  
Intestinal Rehab & Transplant Unwrapped





Adjusting to your life with SBS can feel daunting, but it's important to know that you can live a full and productive life with the condition. With the proper support and care plan, many people with SBS can travel, work, exercise, and participate in their hobbies in a meaningful way. Check out the [Let's Talk SBS Conversation Guide](#) for tips on how to talk to your care provider about your personal journey and goals.



*It can be daunting to find yourself in a situation with a condition that is potentially life changing. You're not alone, there is a wealth of knowledge out there for you to access from people who were once where you are now!*

- Carolyn Wheatley, Chair, PINNT and IF Patient Expert



*Managing life with short bowel syndrome (SBS) can be complex and challenging. I find it helps to shift my thinking from the limitations of SBS to focus on the possibilities of how to enjoy life despite the disruption caused by this condition.*

- Marek Lichota, SBS and IBD Patient, President, 'Appetite for Life' - Stowarzyszenie "Apetyt na Zycie"



*I like to think of managing any chronic illness, including SBS, as a team sport. Our healthcare provider is the coach, and we as the patient are number one on the team. Cultivating a relationship with our healthcare provider and their team is essential for communicating our needs, fears, and wins.*

- Lori Plung, SBS and IBD Patient Expert



*Short Bowel Syndrome is part of me, but does not define me. It is completely possible to live independently, work, and travel, while living with SBS. With nutrition support, I have been able to go to school away from home, accomplish my education goals, work in different cities, and travel regularly. Although it takes time and energy to manage the various aspects of this chronic disease, taking ownership of my SBS management with my multiple providers, has been critical to my clinical outcomes and my life goals.*

- Swapna Kakani, Patient Expert, Rare Disease Advocate, Co-Founder/Researcher, The gutsy perspective



*Understanding what's most important to a patient provides the roadmap for our work together. From these honest conversations, realistic goals can be created.*

- Maria Karimbakas, Registered Dietitian and Certified Nutrition Support Clinician



### SBS Facts Summary

- SBS typically occurs after surgery that has removed significant length of intestine.
- Some people with SBS have an ostomy.
- Symptoms can include: Diarrhea, weight loss, fatigue, nausea, cramping, pain, bloating, and problems eating.
- SBS has many causes, including: Inflammatory Bowel Disease (IBD), such as Crohn's disease; cancer; sudden twisting of the small bowel (volvulus); damage to the bowel's blood flow (ischemia); complications of weight loss surgery; and traumatic injury to the abdomen.
- In certain cases, SBS is caused by a condition from birth.



# Let's Talk SBS

As someone with Short Bowel Syndrome (SBS), you know your disease process better than anyone so it's important you feel heard and understood. It can take time for you and your healthcare team to work out a care plan that meets your needs.

This tool will help guide conversations with your healthcare team about your personal journey and goals. You may wish to share your responses with your care team and revisit over time to see if things change. It can also be helpful to involve a loved-one who can support you in these conversations.

Don't feel you need to cover everything in one go. Try to focus on one or two topics at each appointment - take it one step at a time.



## Before your appointment, consider:

- What has prompted this appointment?
- How much time do I have at this appointment?
- What do I need help with the most? (What are my top priorities?)
- What are my symptoms?
- What was the follow up from my last appointment? (Do we need to revisit?)
- Do I know who to contact if I want to learn more or am worried about my SBS?
- What caused my SBS and which parts of my intestine do I have still?
- What's working and what's improved since we last met?

DATE: \_\_\_\_ / \_\_\_\_ / \_\_\_\_

You may wish to complete before your appointment and either print or download.



## 1 Your Goals with SBS: What are the things you want to do in life?

*It's important to understand this for your ongoing care plan. Goals can be small, daily wins specific to daily activities or something you want to accomplish or strive for in the future. You can revisit these throughout the year.*

- |                                                                                       |                                                                        |
|---------------------------------------------------------------------------------------|------------------------------------------------------------------------|
| <input type="checkbox"/> I want to be able to leave the house when I want             | <input type="checkbox"/> I want to be able to do more with my children |
| <input type="checkbox"/> I want to eat a more varied diet                             | <input type="checkbox"/> I want to go out socially                     |
| <input type="checkbox"/> I want more freedom from rushing to the toilet and accidents | <input type="checkbox"/> I want to work or study                       |
| <input type="checkbox"/> I want to travel                                             | <input type="checkbox"/> I want more time for hobbies                  |
| <input type="checkbox"/> I want to sleep better                                       | <input type="checkbox"/> I want to plan for a family                   |
| <input type="checkbox"/> I want to play sport or exercise or swim                     | <input type="checkbox"/> I want to do my own chores                    |
| <input type="checkbox"/> I want more quality time with family                         | <input type="checkbox"/> Other [Please list]                           |

### Your most important goal:

Over the next few weeks

Over the next few months

Over the year

## 2a How often do your gut problems prevent you from doing what you want?

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Never

## 2b How often do your gut problems make you rearrange plans?

- ☐ Daily
- ☐ Weekly
- ☐ Monthly
- ☐ Never





What aspects of SBS are bothering and impacting you the most?



If your current symptoms don't prevent you from achieving your goals, feel free to skip this section.

For example:

- ☐ Diarrhea
- ☐ Dehydration
- ☐ Ostomy output/ leaks
- ☐ Incontinence and accidents and/ or fear of an accident
- ☐ Frequent urination
- ☐ Line infections
- ☐ Difficulty sleeping
- ☐ Fatigue/ lack of energy
- ☐ Pain
- ☐ Nausea or vomiting
- ☐ Memory problems/loss in focus
- ☐ Anxiety/depression
- ☐ Feeling unwell/bouts of ill-health
- ☐ Fear of no improvement or feeling worse
- ☐ Fear of being hospitalized
- ☐ Treatments/medication and potential side-effects
- ☐ Time on TPN
- ☐ Financial burden of SBS
- ☐ Stigma
- ☐ Ongoing medical procedures and SBS management
- ☐ Lack of peer or caregiver support
- ☐ Poor gut motility/ function
- ☐ Other

What do you want to discuss and focus on during your appointment?



Try to prioritize one or two things. Considerations are provided but list what is relevant to you.

Daily Life:

- ☐ Aspects of my life that are impacted by SBS, e.g., daily activities, work, family
- ☐ Any practical or financial concerns linked to your SBS
- ☐ Ability to travel (for work, family or holiday)
- ☐ How my care partner can support me

Clinical care and symptoms:

- ☐ My gut symptoms (e.g., pain, diarrhea, ostomy leaks, gas, bloating, constipation, slow digestion, etc.) and how to manage them
- ☐ Symptoms of nutrient imbalance (e.g., muscle weakness, fatigue, nausea, bone tingling, headaches, cramps, and irregular heartbeats)
- ☐ Hydration and thirst
- ☐ Weight (drop or gain, list by how much)
- ☐ Line infections
- ☐ Symptoms to look out for and what to do if worried
- ☐ Diet
- ☐ My TPN, my central line
- ☐ Treatment options (e.g., surgery, medications, new research)
- ☐ Lab tests and results
- ☐ Hormonal and sexual health, family planning
- ☐ Other related symptoms (e.g., rashes, acne breakouts, etc)

Emotional wellbeing:

- ☐ Regular ups and downs, anxiousness, bouts of sadness
- ☐ Feeling isolated or lonely
- ☐ Body image (scars, tubes, ostomy, fistulas, other)
- ☐ Feeling overwhelmed and fatigued

Your Notes and Discussion List:

1.
2.
3.
4.



5

From today's appointment, what are your key takeaways and next steps?



6

Do you have any other questions for your care provider?



If there's anything you don't understand, or if you need more information, don't hesitate to ask. Write down your questions now so you remember these for your next appointment.

My Questions (for example)

SBS experience:

- How many patients with SBS do you see?
- Do you consult with other healthcare professionals about my care?
- How many patients on my same treatments do you see?

My treatment:

- Do I have a written care plan that you can share with me?
- Could I need any additional surgeries?
- What tests should I be having next and why?
- Are my kidney, liver and bone health being monitored?
- Could I benefit from any other food and nutrition, mental health or social worker support?

About Me:

- What caused my SBS?
- How much working intestine do I have left and what does this mean for my symptoms and treatment options?
- What should I be paying most attention to?



Taking ownership in your SBS disease journey and decision-making with your clinician has the potential to transform your quality of life and clinical outcomes.

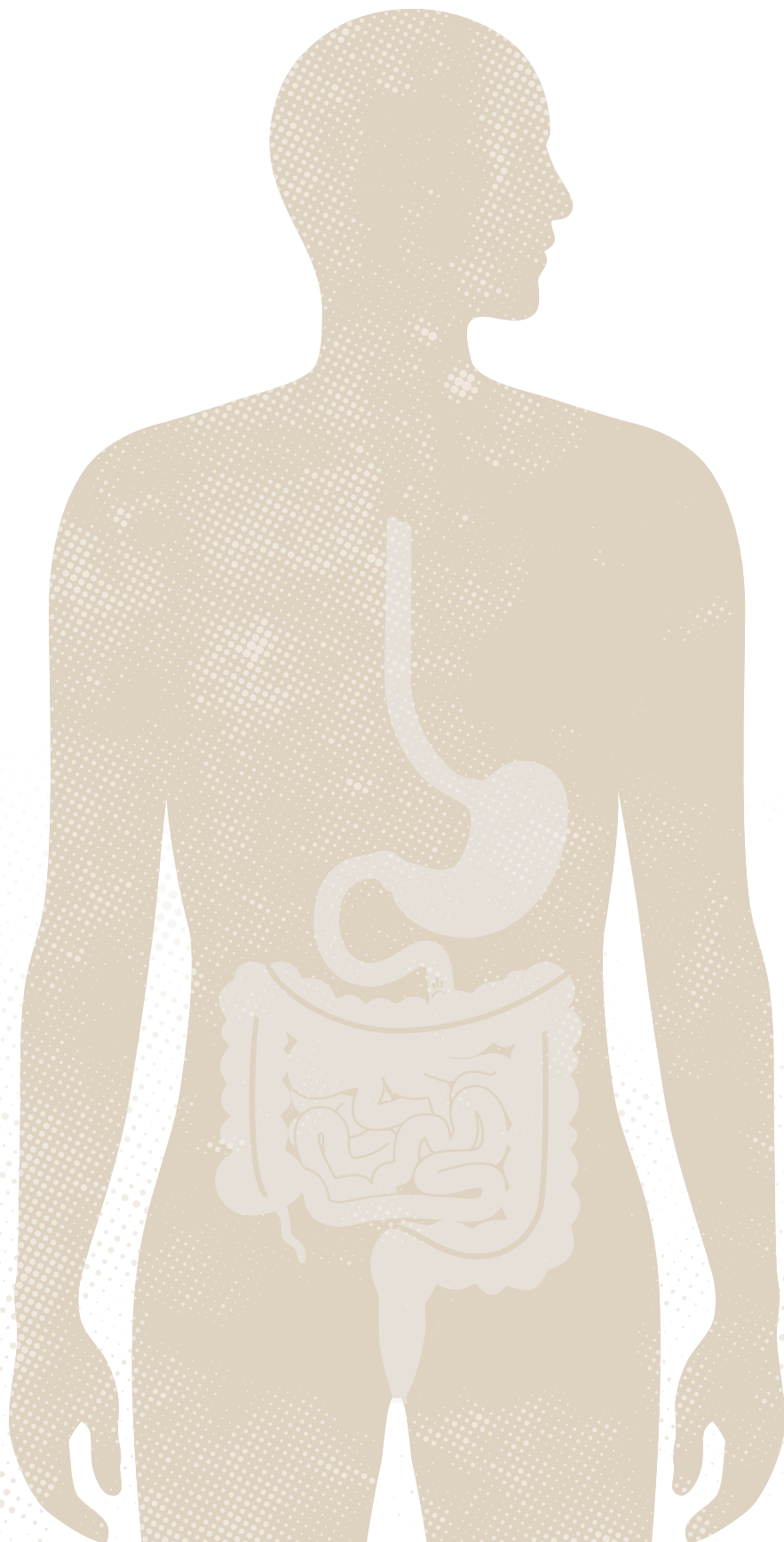
- Swapna Kakani, Patient Expert, Rare Disease Advocate, Co-Founder/Researcher, The Gutsy Perspective



7

Could you describe which parts of my bowel have been removed and what's left/still working?

*[Ask your care provider or surgeon to color the diagram, showing the parts of your bowel that remain and confirming what's been surgically removed.]*



8

Additional notes



A large, empty rectangular area with a light beige background, intended for additional notes or information.

# Authors



**Oley Foundation**  
*Represented by **Beth Gore**, PhD,  
Executive Director and parent of  
child with intestinal failure*



**Bethany Johnson**  
*SBS Patient Expert  
and Board Member,  
Intestinal Rehab &  
Transplant Unwrapped*



**Swapna Kakani**  
*MPH, SBS Patient Expert,  
Rare Disease Advocate, and  
Co-Founder/Researcher,  
the gutsy perspective*



**Carolyn Wheatley**  
*Chair, PINNT and  
IF Patient Expert*



**International Foundation  
for Gastrointestinal Disorders  
(IFFGD)**  
*Represented by  
**Ceciel T. Rooker**, President*



**Lori Plung**  
*SBS and IBD  
Patient Expert*



**Marek Lichota**  
*SBS and IBD Patient Expert  
President, Stowarzyszenie  
"Apetyt na Życie"*



**Laurie Reyen**  
*RN, MN, CNS,  
Clinical Nurse Specialist,  
formerly UCLA Health*



**Maria Karimbakas**  
*RD, CNSC, Optum Intestinal  
Rehab Program Manager,  
Optum Infusion Pharmacy*



**Monika Malíčková**  
*SBS Patient Expert,  
Vice President,  
Život bez střeva z.s.*



**Marion Winkler**  
*PhD, RD, LDN, CNSC,  
Independent Nutrition Consultant,  
Rhode Island, USA*

This resource is compiled in collaboration with a group of patients, community organization leaders, medical professionals, and Ironwood who are working together to improve SBS education and awareness. Authors are compensated as advisory members of an SBS educational taskforce convened and funded by Ironwood Pharmaceuticals.





The following groups endorse this guide:



the gutsy perspective



Intestinal Rehab  
&  
Transplant  
UNWRAPPED



Život bez střeva

