



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.



SCAN QR to download the Let's Talk SBS tool

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.

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

Your most important goal:

Over the next few weeks

Over the next few months

Over the year

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?

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



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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

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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.

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



Large empty rectangular area for writing notes.

“
 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
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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?

Large empty rectangular area for writing questions.

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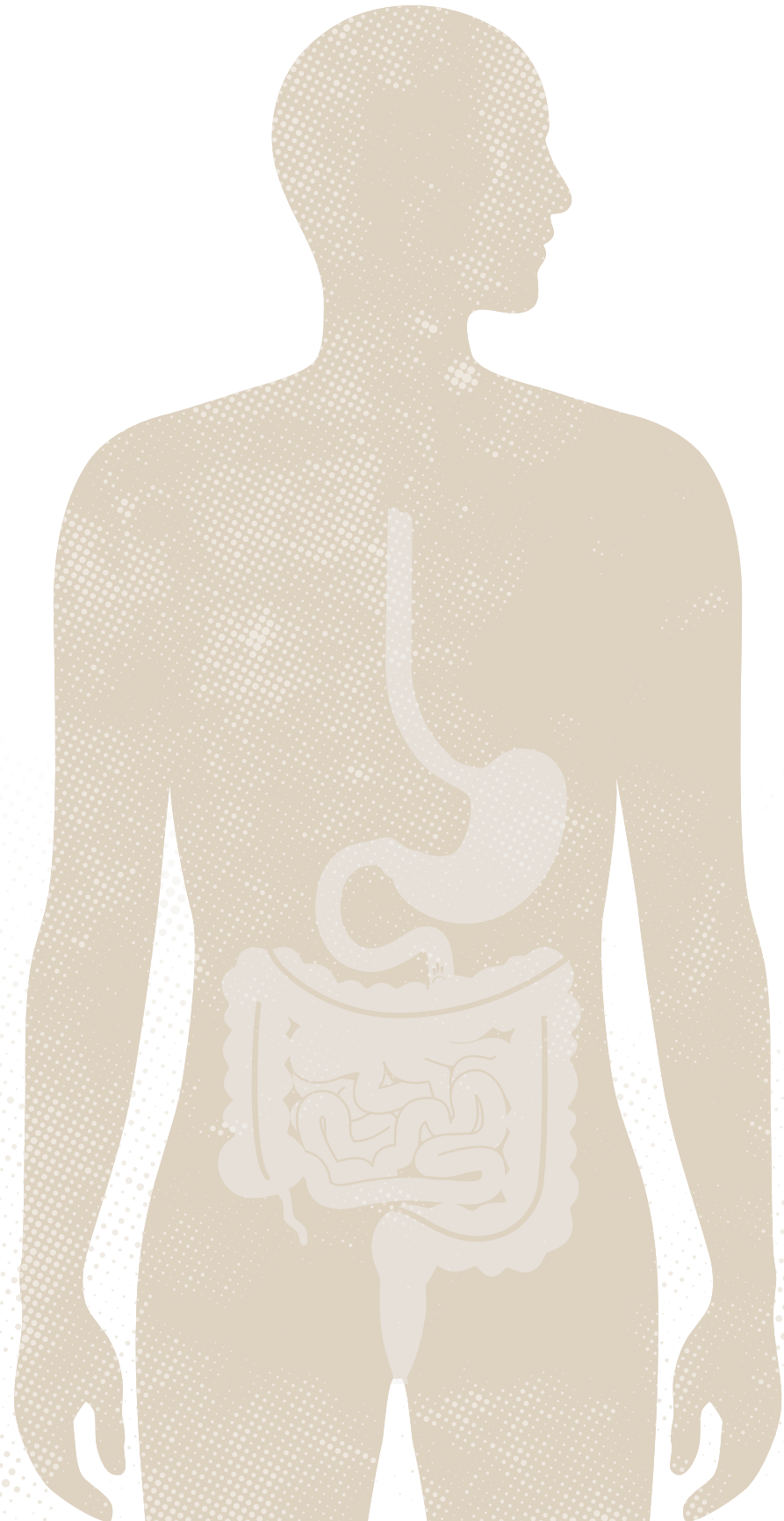
Could you describe which parts of my bowel have been removed and what's left/still working?

[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.]



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Additional notes



A large, empty rectangular area with a light beige background and a subtle halftone dot pattern, intended for writing additional notes.