

## A SHORT GUIDE TO UNDERSTANDING

# SHORT BOWEL SYNDROME

Are you living with or caring for someone who's been diagnosed with short bowel syndrome (SBS), or curious to understand more about this rare condition?¹

Check out the information and real-life perspectives below to learn more about SBS.



## What is SBS?

SBS is a serious and chronic malabsorption disorder, that most often occurs when parts of the intestine are removed surgically and the remaining intestine may not be able to absorb enough nutrients from food and drink. This results in malabsorption.

SBS affects about

10K - 20K people in the U.S.<sup>1,2,3,4</sup>

“When describing SBS to others, I share that my daughter was born missing most of her small bowel and half of her colon, so she doesn’t receive nutrition as well as she should.”

– Ashley K., Mother of a child with SBS

People sometimes talk about having:

- “short bowel”
- “a short gut”
- “short gut syndrome”

but the medically accurate term is **short bowel syndrome**, or SBS for short.

SBS can vary from person to person, and malabsorption can put people at risk for:<sup>2,5</sup>

- Malnutrition
- Electrolyte disturbances
- Dehydration
- Diarrhea/ increased outputs

“My son doesn’t look sick, so people may not understand how easily his condition can turn on a dime. It can be hard for people to recognize how much this impacts his whole life.”

– Gabriela L., Mother of a child with SBS

## The Long Road to Short Bowel

There are many diseases and conditions that could require surgical removal of intestines, which may increase the risk for SBS. Examples may include:<sup>2,6,7</sup>



### Crohn's Disease

Chronic disease causing inflammation and injury to the intestines. Treatment for severe cases of Crohn's disease can include surgery



### Bariatric OR Gastric Bypass Surgery Complications

Gastric bypass and bariatric surgery are designed to help people lose weight<sup>7,8</sup>



### Trauma

A traumatic injury to the intestine may require a bowel resection



### Injury to Blood Vessels

When blood vessels in the intestines can't deliver enough blood (and consequently oxygen and nutrients) to the organ to allow it to function properly (also referred to as intestinal ischemia)



### Cancer Surgery

During certain cancer treatments, it may be necessary to have tumors in the intestine removed or undergo radiation therapy



### Volvulus

A twisting of the intestine that can cause a blockage and cut off blood flow



**SBS in Children:** The majority of SBS cases in children stem from genetic or birth conditions that can lead to bowel resection surgery.<sup>9</sup>

“My son was born with a birth defect known as gastroschisis, which I was told rarely leads to SBS. However, when he was born, he had lost most of his small and large intestines. I wasn't prepared for him to lose so much of his intestine, and also didn't know how important the intestines were or how rare SBS was.”

– Gabriela L., Mother of a child with SBS

“I arrived at my diagnosis after my family car was hit head on by a driver who had crossed the middle line of a two-lane highway. The trauma caused me to lose blood flow to my intestines, which then had to be removed.”

– Matt B., Living with SBS

## Managing SBS

Though every individual may manage SBS differently, some primary SBS management goals include:

- Improving daily life with SBS
- Maintaining essential nutrition and hydration
- Improving intestinal adaptation
- Reducing or eliminating long-term parenteral support (PS)



**Parenteral support (PS) delivers fluids and/or nutrition intravenously; it can range from fluid electrolytes to a complete mix of nutrients.<sup>7</sup> This mix can also be customized to person's specific nutritional needs, known as total parenteral nutrition (TPN).<sup>10</sup>**

“I want to encourage my daughter to become independent in every aspect of her life and to be curious about her SBS management. She already likes to gather her own TPN supplies!”

– Ashley K., Mother of a child with SBS

“We can't control what happens to us, but we can choose how we respond. I chose to focus on what I can control, and that mindset changed everything about my SBS management for me.”

– Matt B., Living with SBS

“Ask lots of questions. The better informed you are, the better you can manage your health.”

– Monica W., Living with SBS

## Never Short on Support

SBS care is not just about managing physical symptoms. Strong relationships and connections with family, friends and members of the SBS community can make a big difference.

“When I talk to other parents in the community about our experiences, they get it! I can ask, ‘Do you experience this?’ and they say, ‘Yes!’ So, I feel less crazy and less alone.”

– Ashley K., Mother of a child with SBS

“My family is incredibly healthy, so it was a struggle at first for them to understand my condition. However, they never made me feel bad about my SBS and have kept me motivated.”

– Monica W., Living with SBS

People living with or caring for others with SBS can find themselves asking new questions every day. Thankfully, support is never far to help find the answers. Find resources here for discussing SBS with your healthcare team and join the short bowel syndrome community for more support.

[Learn More](#)

### References

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