Short Bowel Syndrome

A GUIDE FOR PATIENTS

WITH
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DVD INSIDE

AMERICAN COLLEGE OF GASTROENTEROLOGY
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A GUIDE FOR PATIENTS

Short Bowel Syndrome

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Watch the Video

The Short Bowel Syndrome: A Guide for Patients video (14 min) features the stories of three SBS patients, with expert commentary from Dr. Donald F. Kirby.
Introduction

Short Bowel Syndrome (SBS) is a rare condition that makes it hard for your body to use nutrients from the food you eat. SBS is not a one-size-fits-all condition, however. It takes many forms and affects people in many different ways.

In the United States, it is estimated between 10,000 and 20,000 people have SBS. It can affect people of all ages. Managing SBS is challenging! Special care must be taken to make sure the person with SBS gets the right kinds of fluids and nutrients to stay healthy.

The good news? SBS can be managed with a variety of treatments. The goals of treating SBS are to help the digestive system work better, to maintain good nutrition, and manage symptoms and complications.

This booklet and video program will help you learn more about SBS and how it can be managed. You’ll learn about:

- Causes of SBS
- Treatment options
- Ways to work with your health care team to help reduce symptoms

The contents of the book and video are not intended for disease diagnosis or as a substitute for information from your doctor. Always talk with your doctor about any symptoms you are feeling, or any questions you have.
The Digestive System

To understand SBS and how it is treated, you need to learn a little about your digestive system.

The food you eat gets broken down in your stomach. It is then passed to the small intestine, also known as the small bowel. The small intestine is a tube about 20 feet long, made up of three sections:

*Duodenum*: the short first part of the small intestine, where iron and other minerals are absorbed, and important digestive fluids are added.

*Jejunum*: the long middle section of the small intestine, where carbohydrates, proteins, fat, and most vitamins are absorbed.

*Ileum*: the end section of the small intestine that leads into the large intestine, where bile salts and vitamin $B_{12}$ are absorbed.

The contents of the small intestine contain many substances that can be reused by the body. The large intestine is where these substances, and water, are reabsorbed.

The two kinds of intestine (small and large) are separated by an important “gate” located at the end of the ileum—the *ileocecal valve*. This one-way valve helps control the amount, and slow the speed, of contents into the large intestine. It also helps to prevent bacteria in the large intestine from spreading backwards into the small intestine.
SBS typically occurs when at least half the small intestine, and/or part or all of the large intestine, have been removed. Often, some portion of the small intestine is surgically removed, to repair injuries due to accidents or a disease of some kind. (Note that sometimes there are cases where no bowel is actually missing, but the bowel doesn’t work as it should—a condition called functional SBS.)

SBS can result from surgery to treat:
- Crohn’s disease (swelling and irritation of the digestive system)
- Intestinal problems from loss of blood flow
- Intestinal injury from an accident
- Complications related to weight-loss surgery (also called bariatric surgery)
- Damage from radiation therapy
- Intestinal blockages

SBS can lead to many kinds of health problems, such as diarrhea, dehydration, weight loss, and malnutrition.
The severity and nature of SBS depends on many things, including:

- Length and health of the remaining bowel
- Which part of the small intestine and/or large intestine remains
- Presence of the ileocecal valve
- Presence of the colon
- Ability of the remaining bowel to adapt

After some portion of the small intestine is removed, the remaining intestine will begin to adapt to the loss. It becomes better able to absorb nutrients. In general, this adjustment is more likely to be successful in younger, healthy patients who still have intact the parts of their small intestine farthest from the stomach.

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If the ileocecal valve has been removed, bacteria can move up into the small intestine. The bacteria can cause cramps, bloating, and abdominal pain, a condition called Small Intestinal Bacterial Overgrowth (SIBO).

The specific kind, and severity, of symptoms you feel will depend on the amount and nature of the intestines removed.
Every patient—and every case—of SBS is different, so your health care team will work to find the treatments that are best for you. Often, treatments change as the remaining intestine adjusts after surgery. The main goals of treating SBS are to maintain adequate nutrition, and manage symptoms and complications. This may involve a combination of:

- Dietary education, with the possible need for special nutrition support
- Medications
- Surgery
Nutrition Support

After surgery to remove a portion of the intestine, nutrition can be provided either with a feeding tube into the stomach or small intestine (enteral nutrition) or with liquid delivered directly to the blood via an intravenous (IV) line (parenteral nutrition). These methods are vital while a patient recovers from surgery. Whether you will be able to slowly wean off enteral or parenteral nutrition depends on many factors, including the length and section of intestine remaining.

Patients not on either enteral or parenteral nutrition must still be careful about what they eat. For example, it is important to drink enough liquids, but these should be the right kinds of liquids. You should avoid very sugary drinks such as some sport drinks, sodas, and fruit juices.

However, plain water isn’t the right choice, either! Water isn’t easily absorbed and simply flushes out your system. Drinks with just a little bit of sugar and salt are preferred. These are called oral rehydration solutions. Talk with your health care professional (HCP) about which kind of oral rehydration solution might be best for you.

Here are some general nutrition and eating tips for SBS patients:

- Eat smaller meals, more often
- Follow a diet recommended by your HCP or dietitian. What you should eat depends on how much and what kind of intestine you have remaining. Avoid high-sugar foods and drinks (e.g., sugary cereals, donuts, pastries, fruit canned in syrup, highly sweetened yogurt, fruit juice, soda, syrups, jams, honey)
- Take small bites and chew your food well
- Eat solid foods first at meals, before liquids
- Avoid caffeine and alcohol

Your HCP or dietitian may have specific advice for you, or some extra restrictions based on your own needs. If you must use home-based enteral or parenteral nutrition, your HCP will explain the details of the equipment and how to use it.
Medicines

Many types of medicines may be used to treat patients with SBS. These medicines can include:

- Treatments to reduce stomach acid
- Enzymes
- Probiotics
- Treatments to slow the passage of nutrients through the digestive system and reduce diarrhea
- Antibiotics to treat excessive growth of bacteria
- Treatments to reduce fluid secretions in the digestive system
- Treatments that help the small intestine absorb nutrients

Your doctor will work with you to find the right medicines to best control your symptoms, and promote the health of your remaining intestines.

Surgery

Surgery may help some patients for whom other treatments have not worked. These techniques attempt to increase the ability of the remaining small intestine to absorb nutrients.

An option for people for whom other treatments have failed, and who have life-threatening complications, is **visceral (intestinal) transplantation**. A full discussion of surgical options is beyond the scope of this booklet, but it’s important to know these options exist.
Dealing with SBS may feel overwhelming. Not only do you need to adjust to new ways of eating/feeding, but the lack of nutrition caused by the condition can affect your energy level. Slowly, however, patients with SBS can adapt to their new normal, focus on wellness rather than illness, and adjust life goals and priorities in a positive way.

An important step can be to build a support team of family members, close friends, health care professionals, or others who have dealt with SBS. Support groups can be a great way to connect with others. This is easier than ever, thanks to the Internet.

You can find information about online or in-person support groups from some of the organizations listed in the Resources section of this booklet.
It may also be helpful to stay active. This can be challenging, especially early in recovery, but activity can benefit both body and mind. Talk with your doctor about what kinds of activity you can try.

Since people with SBS often need to use a toilet frequently, you should find out what laws your state has regarding use of private bathrooms. More than a dozen states have passed laws requiring stores to allow customers to use their bathrooms, if they have a medical condition that makes quick access to a toilet necessary.

As you continue to learn ways to cope with SBS, remember: although SBS is a rare condition, you are not alone! Your health care team is there to help every step of the way.

Conclusion

This booklet and DVD have given you some basic information about Short Bowel Syndrome. Although SBS can be challenging, you’ve learned it can be managed with a variety of treatments. Treatments include changing your diet and eating habits, the use of medicines and, less commonly, surgery.

Talk with your doctor whenever you have questions about SBS and your treatment options.
Resources

American College of Gastroenterology
www.patients.gi.org

American Society of Parenteral and Enteral Nutrition
www.nutritioncare.org

International Foundation for Functional Gastrointestinal Disorders
www.iffgd.org

Short Bowel Syndrome*
www.ShortBowelSyndrome.com

The Short Bowel Syndrome Foundation Inc.
www.shortbowelfoundation.org

The Oley Foundation
www.oley.org

American College of Gastroenterology

Founded in 1932, the American College of Gastroenterology is an organization with an international membership of more than 14,000 individuals from 86 countries. The College is committed to serving the clinically oriented digestive disease specialist through its emphasis on scholarly practice, teaching and research. The mission of the College is to serve the evolving needs of physicians in the delivery of high quality, scientifically sound, humanistic, ethical, and cost-effective health care to gastroenterology patients. For more information, visit www.gi.org.

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CREDITS

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…and the people who so generously share their SBS stories.
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Short Bowel Syndrome is a rare condition: in the United States, it is estimated between 10,000 and 20,000 people have SBS.

Managing SBS can be challenging for patients and their family members. Special care must be taken to make sure the person with SBS gets the right fluids and nutrients.

The good news? SBS can be managed with a variety of treatments. Treatments for SBS seek to control symptoms and include following specific diets, the use of medicines, and/or surgery.

This booklet and video will help you learn more about SBS, and how it can be effectively managed. Talk with your doctor if you have questions about SBS and your treatment options.