



## What is Short Bowel Syndrome or SBS?

Short Bowel Syndrome or SBS is a medical condition that affects people who have a sizable piece of their small intestine missing. The large intestine is sometimes called the *large bowel*, and the small intestine is sometimes called the *small bowel*. The small intestine and large intestine are parts of your digestive tract (see Figure 1).

People with SBS have trouble absorbing nutrients, including water, from food and drink. Nutrients keep the body healthy and provide energy. Some examples of nutrients are vitamins, minerals, electrolytes, proteins, carbohydrates, and fats. Water is also a nutrient. Your body needs the right amount of water, too, in order to keep working right.

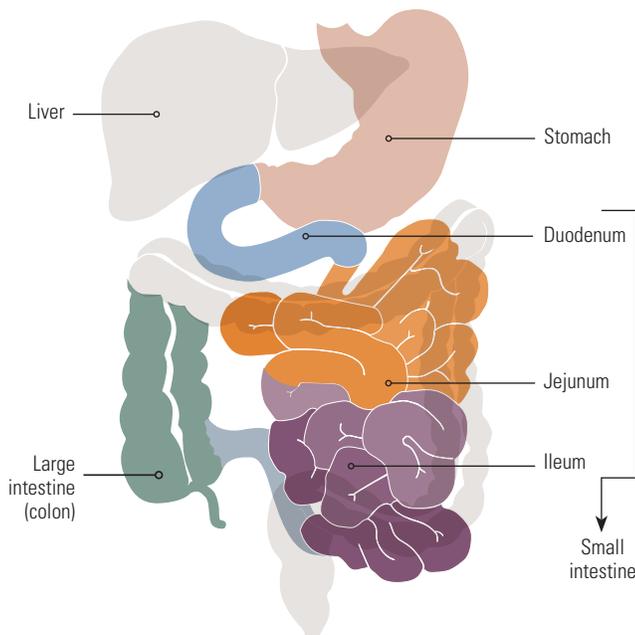
### SYMPTOMS OF SBS

Because people with SBS have trouble absorbing the right amounts of nutrients and water, they can develop symptoms. Not every person with SBS has the same symptoms, but some symptoms are more common than others.

In most patients, the main symptom of SBS is diarrhea. Other common symptoms include:

- Dehydration
- Malnutrition
- Weight loss
- Fatigue
- Excessive stomach or intestinal gas
- Oily, fatty, or sticky stool that can smell foul

Figure 1. Parts of the digestive tract.



Patients, like you, who have had surgery and do not have a large intestine, may be more likely to have problems with fluid losses than patients who do have a large intestine, because the large intestine absorbs most of the water your body needs.

## What is parenteral nutrition and what do I need to know about It?

Parenteral nutrition is a special liquid form of food delivered intravenously into the blood through a catheter placed in a large vein near the heart.

These catheters are called *central venous catheters*.

Parenteral nutrition does not go through the normal pathway of food through the stomach and the intestine because it is a special liquid form of food that must be delivered into the blood. Parenteral nutrition contains the nutrients your body needs to keep working correctly. Examples of nutrients delivered in the liquid food mixture include proteins, carbohydrates (or sugars), fats, vitamins, electrolytes, and minerals.

### WHAT IS THE DIFFERENCE BETWEEN COMPLETE AND PARTIAL PARENTERAL NUTRITION?

Types of parenteral nutrition	
Complete	Partial
<ul style="list-style-type: none"> <li>• Patient relies totally on delivery of nutrients through the vein</li> <li>• Little to no digestion of oral food</li> </ul>	<ul style="list-style-type: none"> <li>• Patient gets some but not enough nutrition from oral food</li> <li>• Requires some nutrition intravenously</li> </ul>

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People can live on complete parenteral nutrition for as long as it is needed. However, in many patients with SBS, parenteral nutrition is required for only a short time, usually right after surgery. As patients begin to recover, parenteral nutrition is gradually reduced and replaced with oral eating. In some patients who begin to eat normally again, parenteral nutrition may be stopped entirely.

### ORAL REHYDRATION SOLUTIONS

Maintaining proper hydration is important when you have SBS, especially if you are on complete or partial parenteral nutrition. You should talk with your health care team about hydration. They might recommend a specific oral rehydration solution if you are dehydrated. Some examples of recipes for homemade solutions appear in **Table 1** on page 2.

## Is there anything I need to look out for with SBS?

Yes, SBS may cause complications in some patients. By keeping a look out for symptoms of these complications, you can alert your health care provider early. Your health care provider can help you manage complications, which may help prevent them from becoming something serious.

Keep in mind, though, that not all patients with SBS will have all of

Table 1. Recipes for oral rehydration solutions.

World Health Organization Formula	Washington University Formula	Homemade Cereal-Based	Basic Homemade Recipe
1/2 teaspoon salt 1/2 teaspoon potassium chloride 8 teaspoons sugar 1/2 teaspoon sodium bicarbonate (baking soda) 1 liter water (4 1/2 cups) • Combine and stir until well mixed and dissolved	1/2 teaspoon salt 1/2 teaspoon sodium citrate 3 tablespoons + 1 teaspoon powdered polyose 1 liter water (4 1/2 cups) Crystal Light® to taste (especially lemonade, orange, or pineapple flavors) • Combine and stir until well mixed and dissolved	1/2 cup dry, precooked baby rice cereal 2 cups water 1/2 teaspoon salt • Combine ingredients and mix until well dissolved and smooth • Refrigerate. Solution should be thick, but pourable and drinkable	1 liter water (4 1/2 cups) 1 cup orange juice 8 teaspoons sugar 1/2 teaspoon baking soda 1/2 teaspoon salt • Combine and stir until well mixed and dissolved

these complications, and every patient will experience different symptoms to a different degree.

## COMMON COMPLICATIONS OF SBS

### Acidosis

Acidosis is a condition in which the level of acid in the blood is too high. People with SBS may sometimes produce more acid than normal or lose more bicarbonate than normal because of increased diarrhea. Acidosis can also result from abnormal growth of certain bacteria in the intestine (see *Bacterial overgrowth* below). Notify your health care provider if you experience symptoms of acidosis.

#### Symptoms of acidosis include:

- Confusion
- Blurred vision
- Slurred speech

### Increased amounts of stomach acids

Patients with SBS often produce increased amounts of stomach acids. High levels of stomach acids can increase the amount of secretions entering the shortened bowel, which can interfere with normal absorption of nutrients.

#### Symptoms of increased stomach acids include:

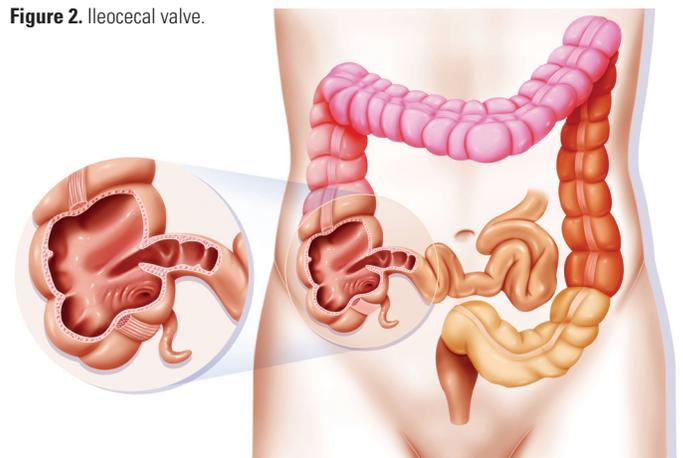
- Diarrhea
- Abdominal pain
- Discomfort
- Nausea or vomiting

### Bacterial overgrowth

SBS can result in an unusually high amount of bacteria in the small bowel because of undigested or unabsorbed food. It can also result when the ileocecal valve has been removed and bacteria from the large bowel can backflow into the small bowel. Bacterial overgrowth can cause acidosis (see *Acidosis* above).

The ileocecal valve connects the small and large intestines and normally blocks bacteria from the large intestine from back flowing into the small intestine (see **Figure 2**). Patients who have had their ileocecal valve surgically removed may be at greater risk for developing small bowel bacterial overgrowth. When the ileocecal valve is removed, the flow of bacteria between the large intestine and small intestine goes unchecked and more bacteria may get into the small intestine.

Figure 2. Ileocecal valve.



#### Symptoms of bacteria overgrowth include:

- Diarrhea
- Bloating
- Nausea
- Vomiting

## What should I be on the lookout for with parenteral nutrition?

It is important to be aware of some complications that can occur with parenteral nutrition so that you can better understand steps your health care provider may take, or ask you to take, to prevent or manage these complications.

For some patients, parenteral nutrition is needed for nutrition only in the period immediately following bowel surgery. For other patients, parenteral nutrition may be required for a longer time.

When you are in the hospital, your health care provider will monitor you for certain complications that might occur while you are receiving parenteral nutrition. Some of these complications are related to the central venous catheter used to deliver the parenteral nutrition into the large vein. Other complications are related to the parenteral nutrition.

Some common complications of parenteral nutrition are infections, venous thrombosis (or blood clots in a vein), and liver disease. In addition, some patients—particularly those who have a colon—are also at increased risk for kidney stones because they are more susceptible to dehydration. The increased risk of kidney stones is just one of the many reasons that staying hydrated is important for patients with SBS.

## Infections

Infections may be due to bacteria or fungal contamination of the central venous catheter used to administer the parenteral nutrition. Your health care provider will measure your temperature and carefully inspect your catheter to make sure it is not infected. You will also likely receive instructions on how to care for your catheter and how to keep it clean.

 **Notify your health care provider immediately** if you have any fever, chills, or pain, or redness or swelling at or around the catheter insertion site.

## Venous thrombosis

Venous thrombosis is a medical term for a blood clot that forms in your veins. These blood clots can sometimes occur in patients who are receiving parenteral nutrition through a central venous catheter. When venous thrombosis does occur, it most often forms in the blood vessel or vein with the central venous catheter. Your health care provider will monitor you for venous thrombosis. But you can also monitor yourself for any signs of a blood clot.

### Some signs of a venous thrombosis include:

- Warmth and tenderness over a vein
- Pain or swelling in the part of the body affected
- Skin redness

 **Notify your health care provider immediately** if you have any of these symptoms or suspect that you have a venous thrombosis.

## Liver disease

Liver disease sometimes develops in patients with SBS who are receiving parenteral nutrition. Some patients may be at greater risk for liver disease than others. Factors that increase the risk of liver disease include recurrent infections, bowel surgeries that affect the blood vessels connecting the liver and the bowel, bacterial overgrowth, and poorly regulated nutrition.

Your health care provider will use a number of different strategies to help prevent and treat liver disease associated with parenteral nutrition. Some strategies include adding tube feeding and adjusting the parenteral nutrition composition.

## What do I need to know about weaning off parenteral nutrition and eating regular food?

An important goal for almost all patients with SBS is to reduce the amount of parenteral nutrition that they need over time. Some patients with SBS on parenteral nutrition can be gradually weaned off it relatively soon after surgery. Other patients will require longer term partial parenteral support.

### WHAT ARE ADAPTATION PHASES?

After surgery to remove a section of the small bowel, the remaining section of the small bowel can sometimes adjust to the shorter bowel length. It does this by working harder than before. There are 3 general phases of intestinal adaptation, which can overlap and vary by patient (see **Table 2** on page 4).

### WHEN DOES WEANING OFF PARENTERAL NUTRITION TO EATING REGULAR FOOD OCCUR?

Weaning off parenteral nutrition most often takes place during the adaptation and maintenance phases.

### WHAT FACTORS CAN INFLUENCE THE SUCCESS OF THE ADAPTATION PHASE AND THE WEANING OFF PARENTERAL NUTRITION TO AN ORAL DIET OR TUBE FEEDING?

Every patient is different. But some factors can affect the success of the adaptation phase and switching from parenteral nutrition to tube feeding or eating food. These factors include:

- Overall health and age
- Length of the remaining small intestine
- Presence or absence of inflammatory disease in the remaining portion of the small intestine
- Presence or length of the large intestine
- Presence or absence of the ileocecal valve

### How will I be weaned off parenteral nutrition?

Your health care team will decide when and how you will be weaned off parenteral nutrition. Depending how rapidly your bowel adapts to oral nutrition, parenteral nutrition may be weaned off in a short time. If your bowel is slower to adapt to oral nutrition, you may require a longer time to wean off parenteral nutrition.

If your health care team decides that you are ready to begin tapering off parenteral nutrition, you will likely be gradually switched to tube feeding and/or oral eating. You should expect this process to be slow and gradual, much like a baby shifts from consuming milk to pureed foods, to solids over a period of months to years.

### What is enteral nutrition?

Enteral nutrition usually refers to delivery of liquid food to the stomach or small intestine through a feeding tube. The tube may be threaded through the nose and down into the stomach or small intestine, or the tube may be placed through the skin into the stomach or small intestine. Sometimes some health care providers will refer to oral eating of food as “enteral nutrition,” too, because the food is entering the gastrointestinal tract rather than the bloodstream (as it is for parenteral nutrition). But in most cases, enteral nutrition means tube feeding.

### What is oral eating?

Oral eating means just what it sounds like—ingesting food by mouth.

Small but frequent increases in enteral feeding and oral eating enable the small intestine to adapt better.

### HOW WILL MY HEALTH CARE TEAM MODIFY MY DIET TO HELP DURING ADAPTATION?

Your health care team will adjust your diet as your digestive tract adjusts after surgery. Your diet will depend on the length of the remaining small intestine and how well it is functioning. Your health care team will provide you with general guidance on foods that are good choices for you once you are ready to start eating regular food.



Table 2. The 3 phases of intestinal adaptation.

	Acute phase	Adaptation phase	Maintenance phase
<b>Timing</b>	<ul style="list-style-type: none"> <li>Occurs immediately after surgery</li> <li>Can last to 3 to 4 months after surgery</li> </ul>	<ul style="list-style-type: none"> <li>Begins soon after surgery</li> <li>During this period the bowel adapts to the loss of the removed section</li> <li>Can last up to 2 years following surgery</li> </ul>	<ul style="list-style-type: none"> <li>2 or more years after surgery</li> </ul>
<b>What to expect</b>	<ul style="list-style-type: none"> <li>Increase in stool output</li> <li>Patients will need extra fluids</li> </ul>	<ul style="list-style-type: none"> <li>Reduced stool output</li> <li>Patients typically experience an increase in the ability to take oral nutrition</li> </ul>	<ul style="list-style-type: none"> <li>Patients require fewer changes to their nutrition therapy, whether it is oral eating or parenteral nutrition</li> </ul>

**Note:** Full intestinal adaptation is reached when a patient can successfully digest and absorb all necessary nutrients through the gastrointestinal tract.

### ARE THERE ANY MEDICATIONS THAT CAN HELP ADAPTATION AND THE TRANSITION FROM PARENTERAL NUTRITION TO REGULAR FOOD?

Yes, for some patients, medications may help the digestive tract adapt and enable them to gradually change from parenteral nutrition to oral eating. Your health care provider will prescribe medications depending on how well your intestine is working. Your medications may change as your intestine continues to adapt over time. Some of these medications include antidiarrheal or antimotility medications, gastric acid reducers, bile acid/salt resins, teduglutide, somatropin, human growth hormone, L-glutamine powder, and other medications.

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### SELF-MONITORING

The Oley Foundation, an organization dedicated to providing education and advocacy for patients living with home intravenous nutrition and tube feeding, has a number of different tips for monitoring your progress and health at home.

More information for patients can be found at the Oley Foundation website: <http://oley.org/>

### How do I stay on track with treatment?

Staying on track with your treatment is the most important step you can take to improve your SBS symptoms, help your intestine regain function, and reduce your symptoms. Here are some tips to help you:

- **Wash your hands** with soap and water before handling your central venous catheter
- Follow directions provided by your health care team about caring for your central venous catheter and administering your parenteral nutrition
- **Notify your health care provider immediately** of any symptoms of fever, chills, or redness and swelling around the central venous catheter

**Take your medications as your health care team instructs.** Medications are an important part of helping your intestines regain as much function as possible. Medications can also help manage your symptoms and enable you to live your life more fully. But medications work only if you take them as instructed. Some hints for remembering to take your medications include:

- Using pill boxes
- Setting alarms on your phone or computer, or using an alarm clock
- Keeping a medication calendar or diary that you check off every day

**Ask your health care team for other ideas and tips for staying on track with your treatment. They are there to help you.**

