



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 from food and drinks. 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 to keep working correctly.

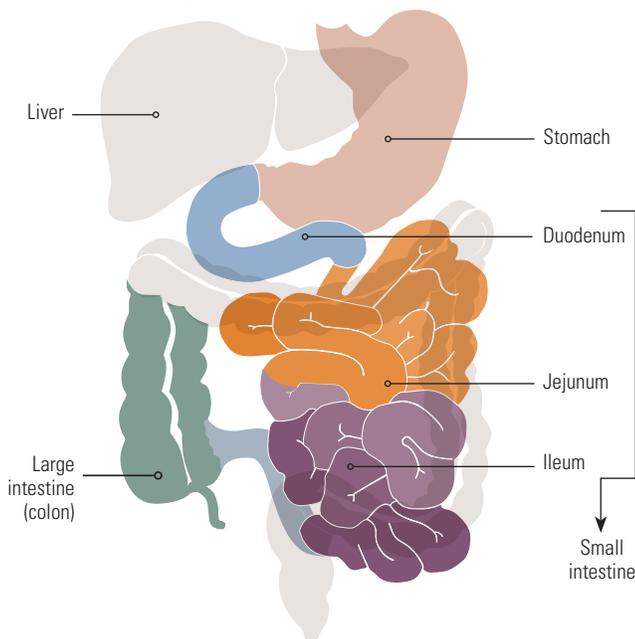
SYMPTOMS OF SBS

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.



What can I eat and drink?

Parenteral nutrition is a special liquid form of food delivered intravenously into a central vein. Intravenous means that it is delivered directly 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 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. Some patients are also given enteral nutrition. Enteral nutrition is described in more detail on page 4.

WHAT IS THE DIFFERENCE BETWEEN COMPLETE AND PARTIAL PARENTERAL NUTRITION?

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

Your health care team will give you specific oral diet recommendations that will help you digest and absorb as much as possible, in addition to stimulating your remaining intestine to grow. But there are some general guidelines you can follow on what to eat and drink (see section below for information on oral rehydration solutions):

- Avoid concentrated sweets and fluids (for example, fructose, high fructose corn syrup, and sugar alcohols such as sorbitol)
- Chew foods well
- Eat 5 or 6 smaller meals per day
- Limit fluids with meals
- Separate solids and liquids at meals as much as possible (solids before liquids)
- Limit or avoid alcohol and caffeine
- Limit fat intake to less than 30% of your diet; make protein about 20% to 30% of your diet; keep complex carbohydrates to more than 50% of your diet
- Eat foods with soluble fiber (for example, oatmeal, oat cereal, oat bran, lentils, apples, oranges, pears, blueberries, nuts, legumes, ground flaxseeds, chia seeds, carrots, psyllium, guar gum, pectin, and rinds)
- You may eat salty snacks
- Depending on your health care team's recommendations, you may need to monitor your intake of water and other drinks
- Depending on your health care team's recommendations, you may need to limit your intake of foods that have a high concentration of a substance called oxalate: beets, spinach, rhubarb, strawberries, nuts, chocolate, tea, wheat bran, and all fresh, canned, or cooked dry beans

ORAL REHYDRATION SOLUTIONS

Maintaining proper hydration is important when you have SBS, especially if you are on complete or partial parenteral nutrition. Talk with your health care team about hydration. They may recommend a specific oral rehydration solution if you are dehydrated.

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 more serious. Some common complications of SBS are shown in **Table 1**; others are listed below.

Keep in mind, though, that not all patients with SBS will have all of these complications, and every patient will experience different symptoms to a different degree.

➔ **Notify your health care provider** if you notice any new symptoms or a change in symptoms.

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* in **Table 1**).

The ileocecal valve connects the small and large intestines and normally blocks bacteria from the large intestine from flowing back 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.

Symptoms of bacterial overgrowth include:

- Diarrhea
- Nausea
- Bloating
- Vomiting

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Kidney stones are solid masses made up of tiny crystals. Patients with SBS can develop kidney stones because they have decreased intestinal absorption of fats, calcium, and bile salts. Patients can have more than one kidney stone in the kidneys or in the tubes (also called *ducts*) leading from the kidneys that carry urine to the bladder.

The main symptom of kidney stones is severe pain that may come and go suddenly. The pain:

- Is usually in the lower back, side, or abdomen
- May move to the groin area

Other symptoms of kidney stones can include:

- Abnormal urine color
- Blood in the urine
- Chills

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

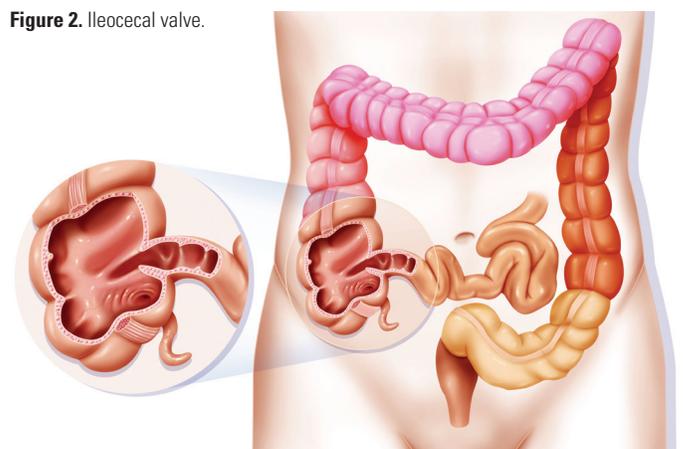
It is important to be aware of some complications that can occur with parenteral nutrition so that you can better understand steps your health care provider may take, or ask you to take, to prevent or manage these complications.

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

Figure 2. Ileocecal valve.



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 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 that 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 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 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.

Table 1. Common complications of SBS.

Malnutrition	
<p>What it means: Malnutrition means that the body is not getting all the nutrients it needs in the right amounts, and this is causing problems in how the body normally functions. You can develop malnutrition even if only one nutrient is missing from your diet.</p>	<p>Symptoms of malnutrition are different, depending on what nutrients your diet is lacking.</p> <p>Common symptoms include:</p> <ul style="list-style-type: none"> • Fatigue • Weight loss • Dizziness • Changes in skin, such as rashes and sores • Changes in vision
Dehydration	
<p>What it means: Dehydration means that your body does not have enough water to function properly. Dehydration can be either mild to moderate, or severe. Diarrhea and vomiting can cause dehydration. You can also become dehydrated if you aren't drinking enough water or other fluids because you feel sick or nauseated.</p>	<p>Signs of mild to moderate dehydration include:</p> <ul style="list-style-type: none"> • Thirst • Dry or sticky mouth • Not urinating much • Darker yellow urine than usual • Dry, cool skin • Headache • Muscle cramps <p>Some symptoms of severe dehydration include:</p> <ul style="list-style-type: none"> • Not urinating, or very dark yellow or amber-colored urine • Dry, shriveled skin • Irritability or confusion • Dizziness or lightheadedness • Rapid heartbeat • Breathing rapidly • Feeling a lack of energy or interest in anything
Electrolyte abnormalities	
<p>What it means: SBS can affect how well your body absorbs electrolytes. Electrolytes are minerals that help regulate important functions in the body. Examples of electrolytes are potassium, sodium, phosphorus, and magnesium. Normally, electrolytes are balanced in the body. When you have too much or too little of one or more electrolyte, you can develop different symptoms.</p>	<p>Symptoms of electrolyte abnormalities include:</p> <ul style="list-style-type: none"> • Irregular heartbeat • Muscle weakness or muscle cramps • Headache • Nausea
Vitamin and trace element deficiencies	
<p>What it means: SBS can affect how well your body absorbs vitamins and trace elements. Vitamins are necessary for metabolizing food in your body. Sometimes, your body doesn't absorb enough of one or more vitamins, leading to vitamin deficiencies. Some vitamin deficiencies can cause serious problems, such as damage to the brain and nerves, confusion, and night blindness.</p> <p>Your body needs small but important amounts of trace elements, such as zinc, chromium, and manganese.</p>	<p>When deficiencies occur, you may experience such symptoms as skin rashes, muscle cramping, and irregular heart rhythms.</p> <p>It is important to catch vitamin and trace element deficiencies early. Your health care team will monitor you for them, but if you notice a change in how you feel, or you have increased fatigue, weakness, visual changes, skin rashes, or muscle cramps, or your heartbeat feels different, call your provider.</p>
Acidosis	
<p>What it means: 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 <i>Bacterial overgrowth</i> on page 2). Notify your health care provider if your stool output increases or you experience symptoms of acidosis.</p>	<p>Symptoms of acidosis include:</p> <ul style="list-style-type: none"> • Confusion • Blurred vision • Slurred speech
Increased amounts of stomach acids	
<p>What it means: Patients with SBS often produce increased amounts of stomach acids. High levels of stomach acid can increase the amount of secretions entering the shortened bowel, which can interfere with normal absorption of nutrients.</p>	<p>Symptoms of increased stomach acids include:</p> <ul style="list-style-type: none"> • Diarrhea • Abdominal pain • Discomfort • Nausea or vomiting

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 OCCUR?

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

WHAT FACTORS CAN INFLUENCE THE SUCCESS OF WEANING?

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

- Overall health and age of the patient
- Length of the remaining small intestine
- Presence or absence of inflammatory disease in the remaining portion of the small intestine



Table 2. The 3 phases of intestinal adaptation.

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

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

- 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, you may be weaned off parenteral nutrition 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 enteral nutrition and 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.

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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.

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 general guidance on foods that are good choices once it is time to start eating regular food. Patients with SBS who have a colon should eat small meals, avoid concentrated sweets, avoid too much fat, and focus on a diet rich in whole grains.

ARE THERE ANY MEDICATIONS THAT CAN HELP ADAPTATION?

Yes, for some patients, use of medications may help the digestive tract adapt and enable them to gradually change from parenteral nutrition to oral eating. Your health care team 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.

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?

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:

Follow directions provided by your health care team about caring for your central venous catheter and administering your parenteral nutrition.

- **Inspect the injection site every day for signs of swelling, redness, or leakage**
- **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.

Follow your prescribed diet.

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

