



Short Bowel Syndrome and Crohn's Disease





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Short Bowel Syndrome (sometimes referred to as SBS) is a disorder that affects people who have had large portions of their small intestine surgically removed as a result of a digestive illness, such as Crohn's disease. Approximately 10,000–20,000 people in the United States have short bowel syndrome.

The bowel consists of two parts, the small and large intestines. The large intestine, also known as the *colon*, is about five feet long. It is the thicker, lower end of the digestive tract. Its main purpose is to absorb water and electrolytes from solid waste before the waste is eliminated from the body. The body can safely live without some (or all) of the colon. The small intestine makes up the narrower portion of the bowel and is approximately 23 feet in length for a full-grown adult. Nearly all digestion of food and absorption of nutrients takes place in the small intestine. Because of its essential function in nutrition, losing portions of the small bowel to surgery can have significant negative effects.

The small intestine has three sections—the duodenum, the jejunum, and the ileum. Each segment performs a specific role in the digestion and absorption of nutrients. When large amounts of the small intestine are removed the body is unable to absorb adequate amounts of water, vitamins, and other nutrients from food in order to stay healthy and survive. The effects of short bowel syndrome can range in seriousness from mild to life-threatening.

Crohn's disease is one of the two major inflammatory conditions that affect the gastrointestinal (GI) tract.

Causes of Short Bowel Syndrome (SBS)

Crohn's disease is one of two major inflammatory conditions that affect the gastrointestinal (GI) tract. Together with ulcerative colitis, they are commonly known as inflammatory bowel diseases, or IBD. The major cause of short bowel syndrome for Crohn's disease patients is the surgical removal of large amounts of the small intestine. In others, short bowel is present at birth. It is also possible for a person with a small intestine of normal length to develop SBS if injury, disease, or other conditions prevent it from working as it should.

Surgery for Crohn's Disease

Crohn's disease can affect any part of the gastrointestinal tract, from the mouth to the anus. When medications are no longer effective at controlling the inflammation and managing the symptoms of Crohn's disease, or when complications develop, treatment sometimes includes the removal of affected sections of the small intestine. This type of operation is known as a *resection*. This surgical resection can result in a diminished surface area, thereby reducing the body's ability to effectively absorb fluid and nutrients. Most people can adapt to losing short segments of their small bowel.

Surgery is also sometimes necessary to treat complications that arise from chronic inflammation and scarring. Examples include *stricture* (a narrowing of the intestinal wall), *perforation* (when the intestinal wall is punctured or torn), or *hemorrhage* (excessive bleeding). Other complications can include the development of an *abscess* (a localized collection of pus and/or infection) or a *fistula* (an abnormal pathway leading from one part of the intestine to another part, to another organ in the body, or sometimes outside the body through the skin).

After a diseased part of the intestine is removed, the two remaining ends are sewn together. This is called an *anastomosis*. Although resection may provide symptom relief

for many years, the disease can recur at or near the site of the anastomosis, generally concentrating around areas of scar tissue.

Another type of surgery for Crohn's disease is called a *stricturoplasty*. This is an operation performed to open up a blockage, or *stricture*. The goal of this procedure is to widen the narrowed section of intestine without removing



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it. Surgeons make an incision along the length of the affected portion of intestine, then pinch it closed in the opposite direction (perpendicular to the original incision), and seal it shut. The result is a widened, but slightly shortened area with no loss of intestinal length. There are some situations in which stricturoplasty cannot be performed. In these cases, the doctor and patient must discuss other options.

Particular nutritional deficiencies can be linked to the specific section of the small intestine that is damaged, surgically removed, or working inadequately.

About two-thirds to three-quarters of people with Crohn's disease will eventually undergo surgery at some point in their lifetime. Of those, about half will require multiple surgeries to remove additional sections of the small intestine as a result of the disease and other complications from previous surgeries.

In addition to Crohn's disease, there are other causes of short bowel syndrome. These include:

- **Radiation damage.** Radiation therapy may damage the small intestine (*radiation enteritis*).
- **Volvulus.** This is a twisting or tangling of the small intestine that restricts blood flow, thereby damaging intestinal tissue. Surgery is required to remove permanently damaged tissue.
- **Vascular injury or disease.** If the blood vessels of the small intestine are injured or diseased, blood flow may be impaired.
- **Adhesions.** Scar tissue can form outside the bowel, causing periodic blockages that require surgical management.
- **Chronic pseudo-obstruction.** This is a nerve and muscle disorder that impairs intestinal contractions, resulting in malabsorption of nutrients and other complications.
- **Bypass surgery** to treat obesity.
- **Intestinal cancer.** Surgical resections may be necessary to remove tumors.
- **Trauma.**
- **Congenital defects.**

Signs and Symptoms

Patients with short bowel syndrome can experience a variety of symptoms. All of these are related to their body's inability to absorb enough nutrients, fluids, electrolytes, vitamins, and minerals from the food they eat. Particular nutritional deficiencies can be linked to the specific section of the small intestine that is damaged, surgically removed, or working inadequately:

- **Duodenum:** The upper section of the small intestine, where iron, calcium, and magnesium are absorbed.
- **Jejunum:** The middle section of the small intestine, where the absorption of proteins, fat, carbohydrates, vitamins, and minerals occurs.
- **Ileum:** The lower section of the small intestine, where vitamin B12 and bile acids are absorbed. Bile acids help the body absorb fat-soluble vitamins (A, D, E, and K).
- **Colon:** The presence or absence of the colon will have an impact on SBS. Although the colon is not generally thought of as part of the GI tract where nutrients are absorbed, in SBS, it may be able to recover 10%–20% of malabsorbed carbohydrates. This may provide a critical caloric buffer for some patients. Additionally, the colon may be able to absorb significant amounts of water and electrolytes.

The most common symptom of short bowel syndrome is *chronic* (long-term) diarrhea. This, in turn, can cause malnutrition, dehydration, and weight loss. These problems can become life-threatening if not treated properly.

Other symptoms of short bowel syndrome may include:

- Abdominal pain and cramping
- Bloating
- Heartburn
- Flatulence (intestinal gas)
- *Steatorrhea* (oily and/or foul-smelling stool)
- Fatigue
- Weakness
- Bacterial infections
- Food sensitivities

Additional signs of nutrient and vitamin deficiencies caused by SBS include:

- *Anemia* (low blood counts)
- Easy bruising
- *Osteoporosis* (thinned/fragile bones) and bone pain

The most significant indicator that points toward short bowel syndrome is a history of surgical resection of the small intestine.

Making the Diagnosis

The most significant indicator that points toward short bowel syndrome is a history of surgical resection of the small intestine. A medical history of digestive ailments also may indicate that the small intestine is not working properly. The following tests are commonly used to confirm a diagnosis:

- **Blood tests.** These can reveal anemia and assess the levels of vitamins, minerals, electrolytes, and other chemicals linked to metabolism and digestion. Elevated liver enzymes and low potassium levels may also point to SBS.
- **Physical examination.** *Jaundice* (yellowing of the skin), loss of muscle mass, skin rashes, and scaly skin (due to vitamin A deficiency) can be indicators of SBS. Also, vitamin deficiencies may cause reduced feeling in hands and feet.
- **Stool examination.** Testing solid waste can determine whether a person is absorbing the amount of dietary fat and carbohydrates necessary for proper nutrition.

Complications

Short bowel syndrome can be accompanied by a number of complications. These include:

- **Kidney stones.** Decreased absorption of fats, calcium, and bile salts in the bowel can cause kidney stones, which are known to decrease urine flow from the kidneys to the bladder, impair kidney function, and cause pain.
- **Electrolyte abnormalities.** *Electrolytes*—such as potassium, sodium, and magnesium—are minerals that control important functions in the body. Unbalanced electrolytes can result in irregular heartbeat, muscle weakness, headache, and nausea.
- **Vitamin and mineral deficiencies.** Short bowel syndrome can affect the amount of vitamins that the body absorbs, sometimes with serious consequences. For instance, a lack of vitamin B12 can result in damage to the brain and nerves in the spinal cord, while a deficiency in vitamin E can cause swelling and poor muscle coordination. Too little vitamin C can lead to problems with the gums and skin. Reduced absorption of vitamin D and calcium can cause osteoporosis and lead to

fractures. In addition, the diarrhea commonly associated with short bowel syndrome can result in low mineral levels such as zinc and magnesium, sometimes leading to skin rashes, muscle cramping, and irregular heart rhythms.

- **Acidosis.** *Acidosis* is an unusually high level of lactic acid in the bloodstream. People with short bowel syndrome may be unable to digest carbohydrates well. Undigested carbohydrates create lactic acid. When the body absorbs more lactic acid than it can use and dispose of, acidosis may result. Symptoms include confusion, blurred vision, and slurred speech.
- **Bacterial overgrowth.** In contrast to the large intestine, which is rich in bacteria, the small intestine normally hosts a minimal amount of bacteria. In people with short bowel syndrome, those bacteria may multiply by feeding on unabsorbed nutrients. Patients who have had their *ileocecal valve* surgically removed (typically during a resection procedure) may be at heightened risk for developing small bowel bacterial overgrowth. This valve, which connects the small and large intestines, normally prevents the flow of bacteria from the large intestine to the small intestine, and without it, the movement of bacteria goes unchecked. Symptoms of small bowel bacterial overgrowth include diarrhea, bloating, nausea, and vomiting.
- **Gastric hypersecretion.** Acid production is increased in patients with short bowel syndrome. High levels of stomach acid can raise the amount of secretions entering the shortened bowel, and interfere with normal absorption.

Impact of SBS on Children

In children, as in adults, short bowel syndrome is the result of too little intestinal surface to absorb nutrients from food. Typically, an affected child was either born with an abnormally short intestinal length, or much of the small intestine was surgically removed to correct another condition such as *necrotizing enterocolitis* (intestinal infection and inflammation).

In either case, this can reduce the child's ability to extract sufficient nutrients from food. Because children are still growing, they require a higher caloric intake than adults.

Supportive measures exist to treat the complications of short bowel syndrome.

Many children with short bowel syndrome must utilize *total parenteral nutrition* (TPN), a system of providing nourishment *intravenously* (through a vein), thereby bypassing the GI tract. While some children stay on TPN for an indefinite period, others can be switched over to *enteral* (through a feeding tube) nutrition. With this approach, nourishment is delivered through a feeding tube that is inserted through the nose into the stomach in the case of a nasogastric tube. Other types of feeding tubes are available.

The severity of short bowel syndrome in children can vary depending on how much small intestine remains. However, long-term follow-up care is necessary in most cases. Children with SBS need to be monitored regularly for nutritional deficiencies and other conditions associated with prolonged parenteral or enteral nutrition. These include infections and complications in the liver and *biliary tract* (the pathway that carries bile from the liver to the small intestine).

Impact of Short Bowel Syndrome on Pregnant Women

Women who have had previous resection surgery do not appear to have any special problems while pregnant. However, adequate nutrition is always a concern both before and during any pregnancy. For that reason, a chronic condition that affects absorption of nutrients—such as short bowel syndrome—warrants special attention.

Intestinal Adaptation

For some people, short bowel syndrome is a temporary problem. Even after extensive surgery, the remaining small intestine is sometimes able to adjust to the short bowel length. It does so by working harder than before. Although intestinal adaptation may begin soon after the onset of short bowel syndrome, it may take as long as two years before the small intestine has fully adjusted.

True intestinal adaptation is achieved when a person can successfully digest and absorb all necessary nutrients through the GI tract. The adaptation capacity depends on several factors, including:



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

Treatment

Supportive measures exist to treat the complications of short bowel syndrome. Even for patients who eventually achieve intestinal adaptation, treatment is typically necessary to bridge the gap. Treatment varies, depending on a number of factors—including the amount and location of small intestine that is left after surgery, the severity of symptoms, and how well the remaining intestine adapts over time. Because the treatment plan is designed for each person, it also shifts as the person's needs change. Regardless of the particular approach, the primary goals are the same for everyone: to relieve symptoms and ensure adequate nutrition (including proteins, carbohydrates, lipids, vitamins, minerals, and salts). The secondary goal is to treat and prevent complications resulting from short bowel syndrome, including infections and liver injury (sometimes related to total parenteral nutrition).

Treatment often proceeds in small steps, beginning with the simplest options first. This typically means minimizing the use of drugs and maximizing the ability of the person's small intestine to absorb food and fluids.

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Nutrition

The first step is to make dietary adjustments, bearing in mind that there is no single specific diet for people with short bowel syndrome. As with any change in treatment, the patient should consult with their doctor. Working with a registered dietitian can be helpful in creating an effective eating plan based on the length and location of remaining small intestine and the degree to which it is functioning. Eating small, frequent meals (six to eight) throughout the day—rather than fewer larger ones—may enhance digestion and absorption. Keeping a food diary is helpful in determining which foods are causing diarrhea and other symptoms. In general, people with short bowel syndrome should eat meals that are:

- **High in protein** (fish, meat, poultry, eggs, dairy products, tofu)
- **Moderate in fat** (butter, margarine, oils, mayonnaise)
- **High in low-fiber complex carbohydrates** (white rice, pasta, white bread, unsweetened cereals)
- **Low in concentrated sweets** (sugar, honey, corn syrup, molasses, sodas and fruit juices)

Other recommendations:

- Include beverages but limit intake during meals. Large amounts of fluid intake push food faster through the bowel, decreasing absorption of nutrients and increasing diarrhea. Water may not be absorbed as well as oral rehydration solutions that contain salts and sugar.
- Low-oxalate diet. People who have had their ileum removed and still have an intact colon should consider a diet low in *oxalates* (compounds found in plant-based foods) in order to prevent the formation of kidney stones. Foods that are high in oxalates and should be avoided include alcohol, tea, coffee, cola, chocolate, nuts, soy, green leafy vegetables, sweet potatoes, beets, rhubarb, berries, tangerines, and wheat germ/bran.
- Eat a low-lactose diet (or use lactase supplements) if the patient is lactose intolerant.
- In some cases, people with short bowel syndrome will need to consume more calories to maintain their weight than those with normal bowel length.

In addition to dietary adjustments, other recommendations may include the following:

Vitamin and mineral supplements. A daily multivitamin is a good place to start, making sure that it contains all the recommended daily allowances (RDA). Delayed- or extended-release vitamins should be avoided in short bowel syndrome because the shortened transit time may lead to inadequate absorption. A doctor or dietitian can suggest particular multivitamins or other specific vitamin or mineral supplements. Folic acid, vitamin B12, and iron can be used in the treatment of or prevention of anemia. Injections of B12 are given if more than about one and a half feet of the ileum have been surgically removed. Calcium, potassium, and zinc may be necessary, but should only be taken if recommended by a doctor.

Oral rehydration solutions. These solutions (specific mixes of water, sugar, and salts) are particularly helpful for people with short bowel syndrome who experience excessive diarrhea. They restore the fluid, potassium, and sodium that are lost in watery stool and help the intestines to better absorb the water. Commercial products such as Pedialyte®, Ceralyte®, or Liquilyte® are viable options, and homemade solutions are simple to make. The World Health Organization (www.who.int/en/) publishes a popular recipe. It is important to note that while oral rehydration solutions are effective for fluid replacement, they do not decrease diarrhea.

Nutritional supplements. These high-calorie drinks are useful for patients who are losing or having difficulty sustaining weight. Specialty supplements are commonly recommended over the commercially available versions, which have high sugar content.* Semi-elemental and soluble fiber-based formulas often work better than typical over-the-counter supplements and are usually well tolerated.

Electrolyte supplements. These are preparations used to correct imbalances in the body's electrolyte levels. Available as drinks, the supplements can also be mixed with enteral or parenteral formulas (for enteral tube feedings or intravenous feedings, respectively). *(Please note: Although sports drinks are often marketed as electrolyte replacement solutions, they are formulated differently, are often high in sugar, too low in salt, and are not appropriate for people with short bowel syndrome.)*

*High sugar content supplements can worsen diarrhea and other symptoms.

In addition to nutritional support, oral medications may also be used to relieve symptoms of short bowel syndrome.

Oral Medications

In addition to nutritional support, oral medications may also be used to relieve symptoms of short bowel syndrome. (*Please note: It is essential to check with a doctor before taking medications of any kind, whether they are prescription or over-the-counter.*)

Medications for short bowel syndrome include:

- **Anti-diarrheal or anti-motility medications.** These slow down the normal movement of food through the small intestine. This allows the small intestine more time to absorb water and nutrients. Commonly used products for this purpose include:
 - » **Loperamide** (Imodium®)
 - » **Diphenoxylate/atropine** (Lomotil®)
 - » **Narcotic agents** (codeine and tincture of opium)
 - » **Somatostatin:** This relatively new treatment option is based on a naturally occurring hormone produced in the body known as somatostatin. This hormone works to slow down the action of the small intestine. *Octreotide*, the man-made form of somatostatin, has the same effect. It reduces secretion of gastric acid and decreases small bowel secretions. In addition, octreotide may enhance absorption of water and salts.
- **Gastric acid reducers.** H₂ blockers such as famotidine (Pepcid®) and ranitidine (Zantac®) and proton-pump inhibitors such as omeprazole (Prilosec®, Losec®) can help ease the discomfort and pain caused by excessive amounts of gastric acid in the stomach and intestines. These products may also aid in reducing intestinal fluid and possibly help with diarrhea.
- **Bile acid/salt resins.** Cholestyramine and similar products work by binding excess bile salts, which can worsen short bowel syndrome. These products can reduce bile-salt diarrhea after a small resection, but may be less effective after a larger resection.

Delayed- or extended-release medications should be avoided because absorption rates of these products are based on a normal-length intestine. Depending on the type of delivery system used, some medications may be

eliminated from the intestinal tract prior to releasing the active ingredient.

Other Medications Used to Treat SBS

- **GLP-2** (glucagon-like peptide-2) is a hormone made in the small and large intestine that may result in improved absorption and increased fluid absorption by enhancing intestinal growth function. The pharmaceutical form is called teduglutide. Teduglutide (Gattex®) has been approved by the Food and Drug Administration (FDA) for the treatment of adult patients with Short Bowel Syndrome who are dependent on parenteral support. Teduglutide enhances absorption and increases the surface area of the lining of the small intestine.
- **L-Glutamine powder.** This is a man-made form of glutamine, the most plentiful amino acid (building block of protein) in the body. Glutamine helps regulate cell growth and can help to maximize absorption in the shortened intestine. Among its other functions is to protect the lining of the GI tract. The powder is mixed with water and made into an oral solution. L-Glutamine may be used together with human growth hormone (*see below*) and a specialized diet to treat short bowel syndrome.
- **Somatropin.** Somatotropin, or human growth hormone, is made by the pituitary gland in the brain. It stimulates body mass growth and maintains organs and tissues. Somatotropin (Zorbtive®) is a man-made injectable form of human growth hormone that, when used with a diet high in complex carbohydrates, may enhance the intestinal adaption process and help to increase the flow of water, electrolytes, and nutrients into the bowel.

None of these three compounds will cure SBS, but they may result in some modest improvement in overall intestinal function. The timing of when these medications are given may determine how effective they are. A combination of these therapies may have an added effect.

Nutritional Support Therapy for SBS

If the normal method of nutrition—by mouth—is not allowing enough nutrients to be absorbed, then another method must be used. These include *enteral* (through a feeding tube) and *parenteral* (through a vein) delivery.

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Many people will use a combination of these methods over time while living with SBS. Both enteral nutrition and normal eating stimulate the remaining intestine to function better and may allow patients to discontinue parenteral nutrition over time. Some people with severe short bowel syndrome require parenteral nutrition indefinitely.

Enteral nutrition

This form of nutrition is delivered through a feeding tube that is inserted directly into the stomach or small intestine. “Enteral” means “by way of the intestine.” A special liquid food mixture contains protein, carbohydrates (sugar), fats, vitamins, and minerals. Feeding can be administered through several different types of tubes. A nasogastric (NG) tube leading down to the stomach or bowel can be placed through one of the nostrils. Another kind of tube is placed through a surgical incision in the skin into the stomach or bowel. This is called a *gastrostomy* or *jejunostomy* tube. Enteral nutrition provides food in a form that is easily digested. Most patients find the raw nutritional product to have an unpleasant taste, therefore, the feeding tube offers a more palatable delivery method.

Intake of oral and/or enteral nutrition can help preserve or improve the absorption ability of the remaining small intestine. Whenever possible, enteral nutrition is preferred over parenteral nutrition (*see below*). In addition, enteral nutrition is considered less expensive and safer

than parenteral nutrition. However, certain situations prevent the use of enteral nutrition. Under those circumstances, parenteral nutrition is required.

Parenteral nutrition

For situations in which the GI tract cannot be used, feeding is accomplished through a thin intravenous (IV) tube called a *catheter*. It is surgically inserted directly into a large vein—either in the chest, neck, or arm. This is called parenteral nutrition (PN). “Parenteral” means “outside of the digestive system.” The liquid nutrients are delivered directly into the bloodstream, instead of through the stomach or small intestine. The liquid mixture contains all the necessary proteins, carbohydrates, sugars, fats, vitamins, minerals, and other nutrients. In cases in which this is the exclusive form of nutrition, this method is referred to as total parenteral nutrition, or TPN. Parenteral nutrition is often tailored to deliver specific nutritional needs to the individual. Although TPN may be started in the hospital, many people with short bowel syndrome receive it at home. In these situations, it may be referred to as home parenteral nutrition, or HPN.

A convenient way to administer parenteral nutrition is to do so at night. A pump and IV bag containing the liquid mixture are placed near the bed. Delivery of TPN usually takes 12 hours, or longer in some cases.

Caring for the TPN catheter appropriately can be a significant challenge. In the hospital, nurses attend to the catheter. They will examine the insertion site, check the dressing, inspect for signs of leakage, and perform flushing of the catheter after each use. Once the person is discharged, however, those responsibilities fall to a caregiver at home, or in some cases to the patient. A home care service provider or infusion center is generally able to assist with training, care, and maintenance of the catheter. The dressing must stay dry to reduce the chance of infection. To prevent clogging, the catheter must be flushed every 12 hours and after each use. The insertion site requires daily inspection for signs of swelling, redness, or leakage.

Some patients’ intestines never fully adapt to short bowel syndrome and require TPN for the rest of their lives in order to prevent malnutrition and eventually death. When a person’s intestine is not able to adapt, it is referred to as *intestinal failure*.

A variety of surgical approaches are used to improve intestinal absorption and function.

Surgical Intervention for Short Bowel Syndrome

A variety of surgical approaches are used to improve intestinal absorption and function and reduce dependence on parenteral nutrition. These include the following procedures:

- **Serial transverse enteroplasty (STEP).** In this procedure, surgeons take a small section of intestine that is stretched too wide to be effective. They make a series of V-shaped cuts on either side of this section, creating an accordion-like or zigzag appearance. This approach increases bowel length and makes it into a narrower, longer, and more effective part of the digestive tract.
- **The Bianchi procedure.** In this approach, surgeons cut the small intestine in half longitudinally (down its length). The pieces are then sewn into two narrower tubes and joined end to end. The result is a longer, narrower intestine.
- **Intestinal transplantation.** In small bowel transplantation, surgeons replace a diseased small intestine with a healthy one from an organ donor. Transplant surgery can involve just the small intestine, or the entire bowel plus the liver. Transplant surgery may be an option when other treatments have failed or for people who experience serious complications from long-term parenteral nutrition. Such complications include blood clots, infections, and liver failure—which may sometimes require liver transplantation.

Coping with Short Bowel Syndrome

Each person handles physical illness differently. Some experience an extreme emotional reaction, while others absorb the news gradually. The best way to cope with SBS is to focus on seeking effective treatment.

A good patient-physician relationship is essential. It fosters more productive medical results and provides peace of mind when there is open communication. The symptoms of SBS can become quite challenging. There is no question that diarrhea, the most common symptom of short bowel syndrome, can have a major impact on a person's lifestyle. Virtually all activity focuses on access to bathrooms. Knowing where they are when away

from home becomes an important concern. But diarrhea doesn't necessarily have to dominate a person's life. With proper medical care and the appropriate adjustment, many can return to a normal lifestyle.

Other coping strategies include:

- Staying active is an important part of staying healthy. Doctors can offer guidance on the appropriate level of activity for each patient, which can benefit both body and mind. Some people even take their parenteral nutrition "to go," using a portable backpack system for delivery.
- Create a support network of people who can be called upon to help out during difficult times. These people should understand the occasionally serious nature of your disease and be ready to take you to the hospital or doctor if necessary. They may also be called upon to take care of tasks you are temporarily unable to handle, such as child care and grocery shopping.
- Join CCFA's online community (www.ccfacommunity.org) where you can share your story with others and participate in discussion boards.
- Support groups can be especially helpful. Probably the best help, advice, and understanding will come from people who know what you are going through from personal experience. Local CCFA chapters offer support groups as well as informational meetings. To find your local chapter, go online to www.cdfa.org/chapters.

Still, for patients who experience significant emotional distress with SBS, or those who are eager to find more effective ways of coping, a referral to a psychologist or psychiatrist might be helpful. For more information and support regarding living with short bowel syndrome, please contact the Crohn's & Colitis Foundation of America's *Irwin M. and Suzanne R. Rosenthal IBD Resource Center* (IBD Help Center) at 888.MY.GUT.PAIN (888-694-8872) or at info@ccfa.org.

Resources

Crohn's & Colitis Foundation of America
733 Third Avenue, Suite 510
New York, NY 10017
Phone: 800-932-2423
www.ccfa.org

The Oley Foundation
214 Hun Memorial, MC-28
Albany Medical Center
Albany, NY 12208-3478
Phone: 800-776-OLEY (6539)
www.oley.org

Short Bowel Syndrome Foundation, Inc.
285 South 68th Street Place, Suite 307
Lincoln, Nebraska 68510
Phone: 888-740-1666
www.shortbowelfoundation.org

Short Bowel Support
www.shortbowelsupport.com

Social Security Administration
Disability Evaluation Under Social Security, 5.07
Short Bowel Syndrome
<http://www.socialsecurity.gov/disability/professionals/bluebook/5.00-Digestive-Adult.htm>

American Society for Parenteral and Enteral Nutrition
(A.S.P.E.N.)
8630 Fenton Street, Suite 412
Silver Spring, MD 20910
Phone: 301-587-6315
www.nutritioncare.org

United Ostomy Associations of America, Inc.
P.O. Box 512
Northfield, MN 55057-0512
Phone: 800-826-0826
www.ostomy.org

"A Patient's Guide to Managing a Short Bowel,"
© 2011 Carol Rees Parrish, MS, RD
www.shortbowelsupport.com/register.htm



This information is supported by an unrestricted educational grant from NPS Pharmaceuticals, Inc.

About CCFA

Established in 1967, the Crohn's & Colitis Foundation of America (CCFA) is a private, national nonprofit organization dedicated to finding cures for IBD. Our mission is to cure Crohn's disease and ulcerative colitis, and to improve the quality of life of children and adults affected by these diseases.

Advocacy is also a major component of CCFA's mission. CCFA has played a crucial role in obtaining increased funding for IBD research at the National Institutes of Health, and in advancing legislation that will improve the lives of patients nationwide.

Contact CCFA for the latest information on symptom management, research findings, and government legislation.

E-mail us at info@ccfa.org, call us at 888.MY.GUT.PAIN (888-694-8872), or visit us at www.ccfa.org.





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11/2013