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International Foundation for Gastrointestinal Disorders ([www.iffgd.org](http://www.iffgd.org))

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**Short bowel syndrome (SBS)**, also referred to as short gut, is broadly described as a condition in which nutrients are not properly absorbed because a large part of the small bowel is missing. This is most often due to defects existing at birth (congenital), or surgical removal of part of the small bowel. There may not be enough functioning bowel or surface area left in the remaining bowel to absorb needed water and nutrients from food. Sometimes, loss of normal function may occur even when the bowel length is intact. Typically, a loss of half or more of the small bowel will result in SBS.

To learn more about Short Bowel Syndrome (SBS), see IFFGD Fact Sheet No. 290 *What is Short Bowel Syndrome (SBS)?*

### Symptoms of SBS

Symptoms of SBS result when fluids and nutrients are not properly absorbed. These will vary from person to person. Symptoms often include:

- diarrhea
- fatigue
- pale greasy stools (steatorrhea)
- swelling of lower extremities (edema)
- foul smelling stools
- weight loss
- dehydration
- electrolyte losses
- malnutrition

### Managing Short Bowel Syndrome (SBS)

Managing SBS is challenging for patients, families, and healthcare providers. In addition to dealing with multiple symptoms, special steps must be taken to ensure that fluid and nutrient requirements are met. These steps include high levels of healthcare provider-

patient communication, careful patient and/or caregiver education, and high health care utilization. Treatments for short bowel syndrome are aimed at controlling symptoms and maintaining nutritional status. This involves special dietary measures and regular use of medications. In some situations, surgery is required. Many people with SBS are unable to take in adequate fluids and nutrients by oral diet alone and must depend on parenteral nutrition (through a vein) or enteral nutrition (through a feeding tube).

### Treatment

The aims of treatment for SBS are to promote adaptation and get the best use out of the existing bowel, maintain adequate nutritional status, and manage symptoms and complications. Complications can arise not only as a result of the underlying condition, but also in connection with treatments. The goal is for the patient to resume daily life as well as possible. Treatment involves some combination of:

- Nutrition planning
- Managing gastric acid secretions, bacterial overgrowth, bile salt malabsorption, and diarrhea
- Medications
- Surgery

To learn more about Complications of Short Bowel Syndrome (SBS), see IFFGD Fact Sheet No. 292 *Complications of Short Bowel Syndrome (SBS)?*

Treatment of SBS begins immediately after bowel loss. It starts with restoring fluid and electrolyte balance and quickly progresses to nutritional support. Nutritional support includes individualized meal plans and may involve the use of supplements, oral rehydration solutions, enteral nutrition, or parenteral nutrition. Treatment will often include medications, and in some instances surgery. In situations where all other

treatment approaches have failed, intestinal transplant is considered. The course of treatment will depend on how well the bowel is able to support individual fluid and nutrient needs.

### Deciding on the Treatment

Deciding on a type of treatment requires knowledge about the remaining length of the small bowel. This may require diagnostic testing, which usually begins with x-rays and/or an enteroscopy (using an endoscope, a thin, flexible tube with a light and a lens on the end) to examine the esophagus, stomach, and small bowel.

In the average adult, the minimal length of small bowel required so that some nutrient absorption can be anticipated is 4 feet. Usually this is counted as 4 feet of jejunum beyond the point where the duodenum ends. Parenteral nutrition is always required if the remaining small bowel is less than 4 feet.

The **Esophagus** is the muscular tube through which food passes from the mouth to the stomach. The **Jejunum** is the middle part of the small intestine. It is between the **duodenum** (first part of the small intestine) and the ileum (last part of the small intestine).

The length required for adequate fluid absorption and avoidance of dehydration will be influenced by whether the colon is intact. Parenteral nutrition is still required on many days for remaining bowel length of less than 10 feet.

### Nutrition Strategies

Nutrition strategies aim to prevent malnutrition and dehydration and maintain the best possible nutrition status. This may include oral eating, enteral nutrition, and parenteral nutrition. All methods may be used by patients in their homes. Nutrition support specialists (registered dietitians, nurses, doctors) play a key role in helping manage SBS. Nutrition specialists will tailor the approach used to each person according to their individualized needs and provide detailed dietary guidelines. Nutritional needs may change over time.

Oral eating is preferred whenever possible. Recommended diet components and balance of nutrients will vary in each person with SBS. A number of

factors influence this including what part of the bowel was removed and how much of the bowel is remaining.

In most people with SBS the colon is intact. The general dietary guidelines for those with a colon involve a low fat, high carbohydrate diet. A diet that includes chopped, ground, or well chewed nutrient rich foods, with small frequent meals (up to 6–8 per day) is recommended. Fluids should be taken between meals rather than with meals.

With greater stool losses, recommendations are for beverages formulated to replace fluid and electrolytes. Oral rehydration solutions contain specific amounts of sodium, carbohydrate, and water, which increase fluid absorption in the small bowel.

Enteral nutrition is used when oral eating does not supply adequate nutrition. Enteral nutrition involves the delivery of liquid food to the stomach or small intestine through a feeding tube. While not without risks, it is associated with fewer complications than parenteral nutrition. Both enteral nutrition and oral eating stimulate the remaining intestine to function better (adaptation). This may allow patients to avoid or discontinue enteral nutrition.

IFFGD's **Dietitian Listing** is a resource that allows you to search for a dietitian that is in your area or treats a specific condition.  
<https://www.iffgd.org/resources/dietitian-listing.html>

The length of remaining and functioning small intestine is a key factor. The length needed for adequate absorption will be influenced by whether the colon is intact. When nutritional goals cannot be met by other means, medical management will likely rely on long-term use of parenteral nutrition.

Parenteral nutrition bypasses the digestive system. It involves the delivery of fluids, electrolytes, and liquid nutrients into the bloodstream through a tube placed in a vein (intravenous or IV). It is often needed short-term after resection while the remaining bowel adapts. It may be needed long-term depending on the bowel's ability to absorb nutrients. If there is greater than 4 feet of small bowel remaining, then attempts to go from

daily parenteral nutrition to a less frequent use can be tried.

## Medications

In recent years, pharmacological hormonal therapy (the use of hormones in medical treatment) has been introduced aiming to stimulate intestinal adaptation after intestinal resections. Clinical research involving growth hormone, glutamine, and glucagon-like peptide 2 growth hormone (GLP-2) have been studied for the treatment of SBS.

**The Food and Drug Administration (FDA)** is one of the U.S. government's regulatory agencies. This agency oversees a broad range of topics that pertain to food, drugs and other products used on a daily basis.

The FDA works to protect public health by assuring that foods and drugs for humans and animals are safe and properly labeled. The FDA also ensures that vaccines, other biological products, and medical devices intended for human use are safe and effective.

Products approved by the FDA have been deemed safe, with benefits that are worth the possible risks. This is done after reviewing studies and tests that have been done on a product.

- Teduglutide (Gattex<sup>®</sup>), a recombinant analog of human glucagon-like peptide 2, was approved by the U.S. Food and Drug Administration (FDA) for the treatment of adults with SBS who are dependent on parenteral support. Teduglutide works by regenerating cells in the intestinal lining, improving intestinal absorption of fluids and nutrients, and helping reduce the frequency and volume of parenteral nutrition.
- Apraglutide is a peptide analogue of GLP-2 which is currently under development for treatment of SBS-IF, which acts as a full agonist at the GLP-2 receptor.

Both of these medications are given by subcutaneous injection. A subcutaneous injection is a method of administering medication. Subcutaneous means under the skin. In this type of injection, a short needle is used to inject a drug into the tissue layer between the skin and the muscle. Medication given this way is usually absorbed more slowly, than if injected into a vein. Sometimes, it can take up to 24 hours to be fully

absorbed.

## Surgical Options

The main goal of surgery for SBS is to increase the capacity for absorption by the existing bowel. Surgery is considered in patients who are dependent long-term on parenteral nutrition when medications have failed and where the goal is to try to avoid intestinal transplantation.

Several different surgical procedures are available depending on the existing bowel length and function. The goal of these procedures is to improve function of the existing bowel by slowing transit or increasing surface area. Different methods include reconnecting the remaining small bowel to the colon when continuity has been lost, attempting to increase transit time by reversing a segment of bowel, and intestinal lengthening procedures.

Intestinal transplantation becomes a necessary option when required life-long parenteral nutrition begins to fail. When this happens, the patient may experience any of the following:

- Significant evidence of liver injury
- The inability to maintain central venous access. Central venous access is used for parenteral nutrition (a long thin and hollow plastic tube called a 'catheter' or 'line' is placed in a vein to provide nutrition, medications and fluids).
- Frequent bloodstream infections with the line used for central venous access, which are becoming life threatening.
- Inability to keep up with excessive fluid loss (dehydration).

Isolated intestinal transplants are the preferred procedure in patients who have adequate liver function. However, a combined liver and intestinal transplant is required for those with liver failure. Management strategies for intestinal transplantation, both before and after the operation, require careful consideration

For assistance in finding a center, contact IFFGD by phone at 414-964-1799 or by email at [iffgd@iffgd.org](mailto:iffgd@iffgd.org)

involving a multidisciplinary team of specialists available at only a few centers.

### **Working With a Healthcare Team**

Managing SBS requires the patient and often family members working together with a team of healthcare professionals. Members of the healthcare team may include primary care physicians (for example, family doctor, pediatrician, or gastroenterologist), surgeons, nutritional specialists, nursing specialists, and pharmacists. Often, the primary care physician will take the lead in managing and coordinating the patient's care. If an intestinal transplant becomes necessary, other specialists may be brought in including social workers, psychologists, and financial counselors to help deal with the complexities of organ transplants.

The most important member of the healthcare team is the person with short bowel syndrome. Family members or parents of children with SBS play essential roles as caregivers. Patients and caregivers need to have a thorough understanding of the condition and how it may best be managed based on individual needs. This will include recurring contact with healthcare providers, and use of outside resources, all aimed at helping navigate the complexities of managing SBS long term.

### **Manage Both Risk and Benefit of Treatments**

All drugs and procedures have inherent risks. Some are unavoidable, while others can be avoided and managed. It is important for patients and families to talk to healthcare team members about both the benefit and risk of any treatment. Working together helps make treatment decisions that best fit individual needs.

Here are some questions to consider:

- What are the possible benefits of the treatment?
- How much benefit can reasonably be expected?
- What are the possible side effects of the treatment?
- What are the chances of experiencing a side effect?
- How can the chances of a side effect be reduced?
- What action should be taken if a side effect occurs?

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