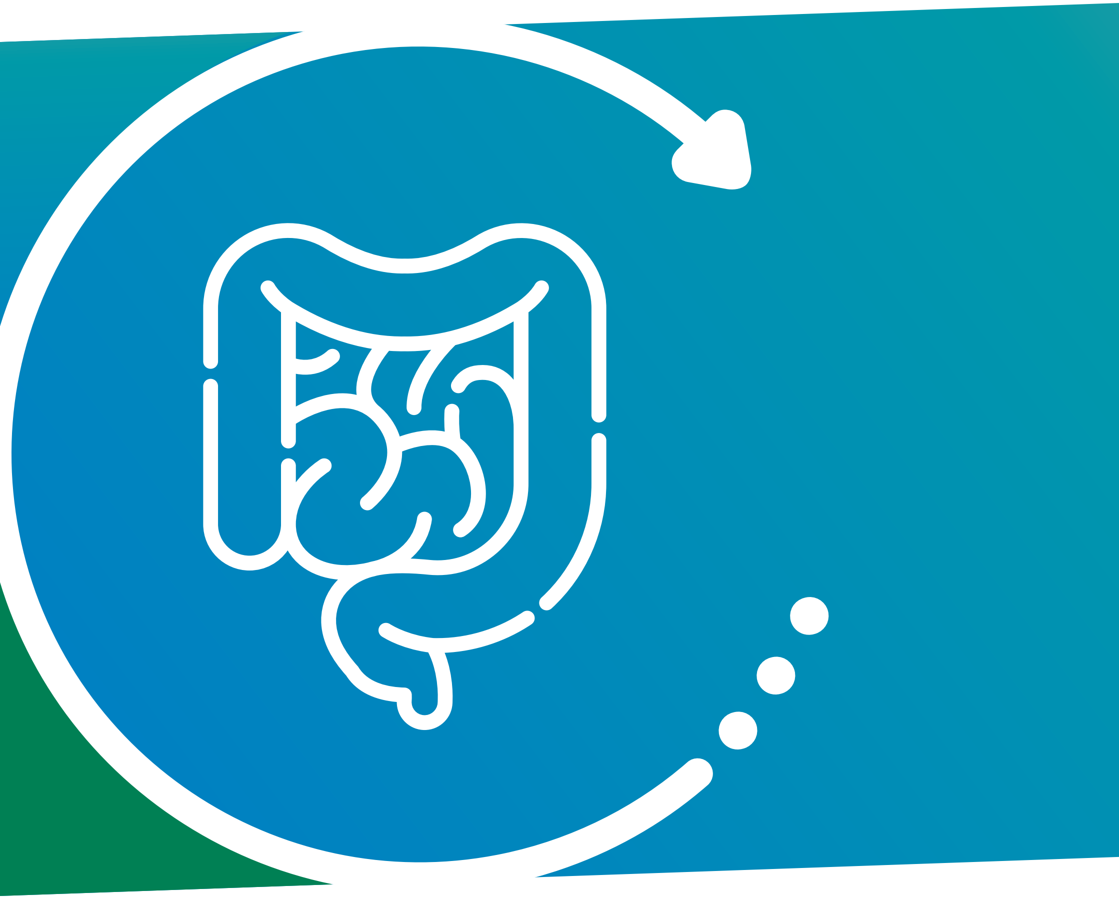


Living with Short Bowel Syndrome

Information for patients

Dear Reader,

You probably came across this booklet because you or someone important to you has **short bowel syndrome with chronic intestinal failure**. This booklet is intended to help you better understand what this diagnosis means for you or your loved one.

When someone develops a severe disease or has an accident with long-term health consequences, they and their loved ones usually have many questions, especially: How will this condition affect my family and me? How can we learn to live with this condition, how can I learn to work with it? Who can help us manage our day-to-day lives? Where do we go from here?

It is not possible to answer all of these questions in one single booklet. But hopefully we can help guide you toward the answers by providing some basic information in a concise and easy-to-read manner. Feel free to come back to this booklet whenever you want or need to learn more about a specific topic in order to better manage this condition or provide support to your loved one. This booklet is also designed to help you prepare for the many conversations you will likely be having with your healthcare team in the near future.

This booklet contains:

+ Information about **short bowel syndrome**
+ **An introduction** to digestion and the bowel
+ **Real-life stories** from people with short bowel syndrome
+ Links to more **information and support resources** for patients
+ A **Glossary** explaining the most important terms (written in *italics* in the booklet)
+ A **Checklist** for conversations with your healthcare team

We recommend you read this booklet all the way through at first to familiarize yourself with short bowel syndrome. If you are just interested in one specific topic, you can find it in the **Table of Contents**. The **Glossary** is designed as a reference in case you come across words you don't understand while reading other resources. Use the **Checklist** to prepare specific questions for your next doctor's appointment.

Table of Contents

What is short bowel syndrome?

Short bowel syndrome with chronic intestinal failure is a complex and sometimes life-threatening disease. Its name provides us some clues about its nature: the term “bowel” is another word for the intestines. When the **intestines are abnormally short**, they can lose the ability to carry out their vital function of delivering **nutrients, minerals and fluids** to the body – a situation called intestinal failure or intestinal insufficiency. Because having a short bowel is a persistent condition, the disorder it causes is chronic, or long-lasting. With short bowel syndrome (SBS), the intestines are no longer able to digest nutrients eaten by mouth or taken by feeding tube enough to keep the body healthy. Instead, a type of nutrition called ***parenteral support*** is often needed, which means that nutrients and fluids are provided through a thin tube called a *catheter*. This *catheter* delivers nutrition directly into the bloodstream rather than it being absorbed by the digestive system. *Parenteral support* can be used to replace some nutrients and fluid, or all of it when given in a form called *total parenteral nutrition (TPN)*.

Short bowel syndrome can be caused by a number of different conditions. Its impact is determined by several factors, including:

- How much intestine is missing,
- What part(s) of the intestine are missing,
- How old someone is when SBS starts, and
- What the underlying cause of SBS is.

People experience different **symptoms** and **complications** depending on what type of SBS they have and what originally caused it. Diarrhea and fluid loss are common problems at first, and often require extra medications in addition to *parenteral support*. Even though short bowel syndrome is a **chronic (meaning long-term) condition,** that doesn’t mean it will always stay the same. In some people, the bowel is **able to adapt to the condition over time.** Certain **medications** can promote this process in some cases.

Your healthcare team will talk with you about how short bowel syndrome will affect you, what you can expect, and the outlook for your condition.

Short bowel syndrome is often abbreviated as *SBS*, while chronic intestinal failure is abbreviated as *CIF.*

How does the bowel work?

The human intestine, or bowel, is a tube-shaped organ that is divided into the small intestine and the large intestine.

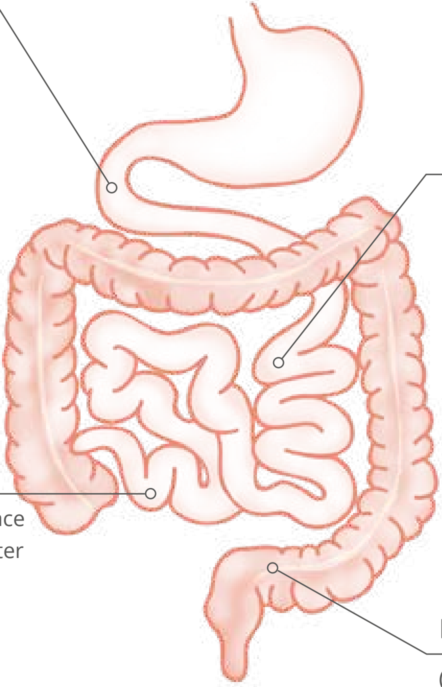
The **small intestine** is the longer segment, and is 5 to 6 meters long in adults. The small intestine lies between the stomach and the large intestine in the abdomen and winds back and forth as shown in Figure 1. It is divided into 3 segments: the *duodenum*, the *jejunum* and the *ileum*. While these segments have slightly different functions, they are all key sites for absorbing vital nutrients from food and drink and supplying them to the body through the bloodstream. Although it may look like a smooth tube in pictures, in reality the lining of the small intestine is made up of many small folds that form finger-like structures called *villi*. On top of the *villi* are even smaller hair-like structures called *microvilli* that give the surface of the small intestine a brush-like appearance. All of these folds and bulges increase the surface area of the small intestine tremendously: in fact, it is 100 times larger than the surface of the skin! In people with a healthy small intestine, this large surface is what makes digestion possible.

The **large intestine** (also called the *colon*) is the shorter segment of the bowel. It is about 1.5 meters long and is located downstream of the small intestine. At the end of the large intestine is a segment called the *rectum*, which is the final part of the bowel and connects to the *anus*. Between the small and large intestines is a gate called the *ileocecal valve* that prevents the contents of the large intestine from flowing back into the small intestine. Figure 1 on the next page shows a conventional depiction of the large intestine as a series of small pouches that develop when the muscles around the large intestine squeeze together. These muscle movements are what slowly propel portions of partly-digested food through the large intestine. During this process, water and minerals are absorbed from the food into the body. This makes them ever more dense until they finally form the stool which is passed from the anus as a bowel movement.

Figure 1 shows the structure of the small and large intestines and lists which nutrients are primarily absorbed in each segment. See the next section on digestion for more information.

Which segments of the intestine absorb which nutrients?

A selection of nutrients absorbed by the bowel is shown below.



Duodenum

First part of the small intestine

Fat, sugar, *protein*, iron, folate, calcium, trace elements, water

Jejunum

Middle part of the small intestine

Sugar, iron, calcium, *protein*, trace elements, fatty acids, fat-soluble vitamins, water

Ileum

Last part of the small intestine

Bile salts, vitamin B12, trace elements, *electrolytes*, water

Large intestine

(*Colon*)

Water, trace elements, *electrolytes*, *amino acids*, short and medium chain triglycerides, calcium

Figure 1

How does digestion work?

Digestion is the process by which the **food** we eat is broken down and supplied to the body for it to use as **energy** and **building blocks**. Our bodies need energy to carry out all of the processes important for living. The body is continuously building new cells and tissues, not only during childhood but across our entire lives since tissues are constantly being regenerated.

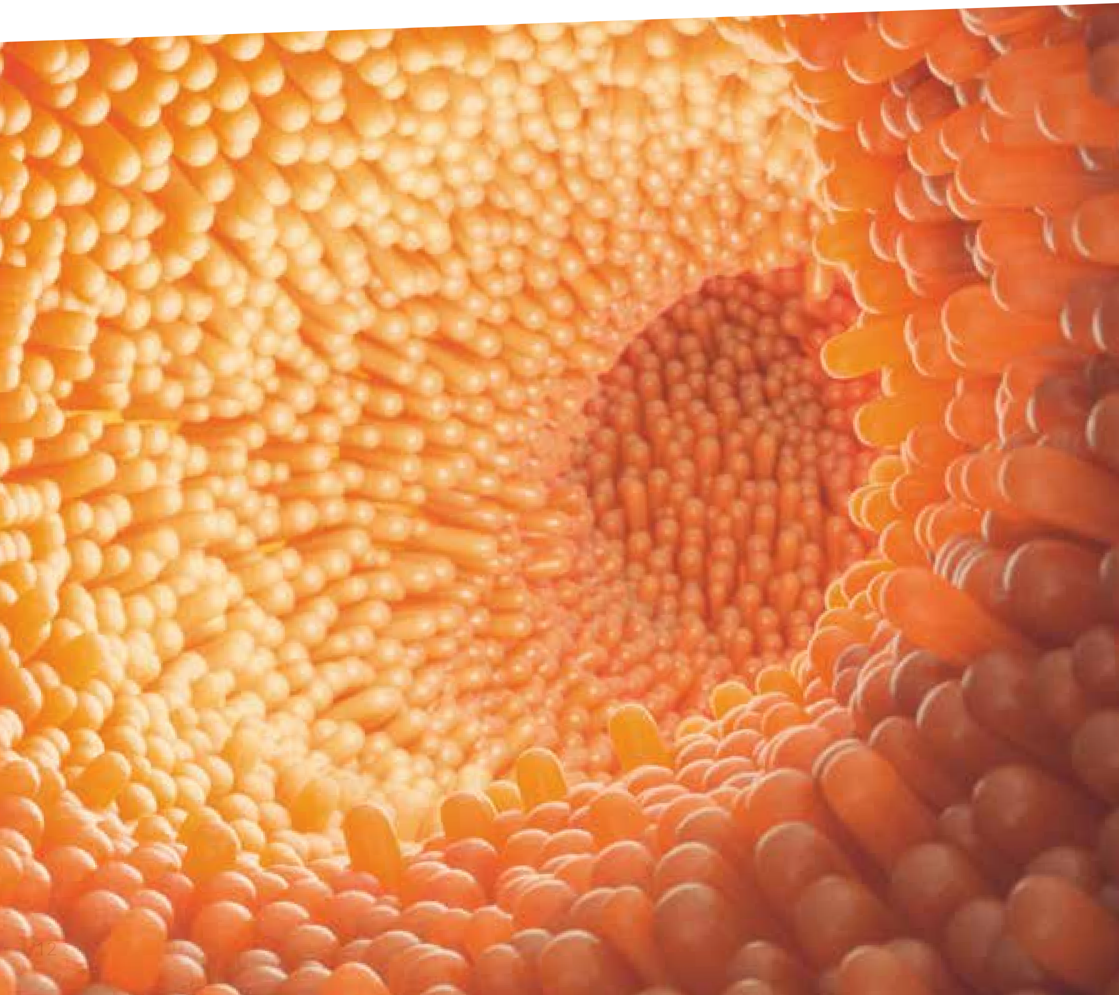
Digestion starts in the **mouth** when large bites of food are broken up by chewing and mixed with saliva. Saliva itself contains *enzymes* that are involved in the chemical reactions of digestion. The tongue then pushes a small lump of food into the back of the mouth. There, it presses against the gums, triggering a swallowing reflex that propels the food through the throat and into the stomach.

Once in the **stomach**, the lump of partly-digested food is mixed with stomach acid containing even more ***enzymes***, transforming it into a soft mass. The muscles of the stomach then grind this mass further and gradually supply it to the small intestine, which is where the majority of digestion actually takes place. There, the individual nutrients from the food and fluids are absorbed into the bloodstream, which delivers them throughout the body.

The most important nutrients in the diet are energy sources like **fats*, carbohydrates* and *proteins***, as well as ***essential amino acids*, fatty acids, vitamins, minerals** and ***trace elements*.** All of these nutrients play crucial roles in metabolism, growth and tissue *regeneration*. Without them, life is not possible. And when digestion is restricted by a medical condition, some or all of the required nutrition must be supplied by a different route.

Once most of the nutrients have been absorbed by the small intestine, the mass of digested food passes into the **large intestine**. There, water as well as stomach acid and other substances produced by the body to aid digestion are absorbed back into the body. This turns the partly-digested food more solid, and allows the remaining undigested food to be eliminated from the body as stool. Stool also contains a great deal of dead **bacteria from the digestive tract**, which usually live in the small and large intestines and help promote digestion in healthy people.

Although this explanation of digestion is only a basic overview, it still illustrates how complex this process is. In order for nutrients to enter the body, it is not enough to eat the right amount of high-quality food: all of the digestive organs also need to work the way are supposed to! The body has to produce *enzymes* and stomach acid, and the right bacteria have to thrive in the intestines. There are a large number of medical conditions that can disrupt this complex process – including the rare and very severe condition of short bowel syndrome which is the topic of this booklet.



What causes short bowel syndrome?

Short bowel syndrome (SBS) usually occurs after a major section of the bowel (typically the small intestine) is **surgically removed** in a procedure called *bowel resection*. This surgery is necessary to treat a different condition or accident.

SBS can also be caused by medical conditions where the intestines have a normal length but do not work properly, meaning the intestines are unable to adequately absorb nutrients and fluids. This situation is sometimes called **"functional" short bowel syndrome.** Adults may require *bowel resection* surgery in the following situations:

+ Inflammatory bowel disease, for example *Crohn's disease* and severe forms of *ulcerative colitis*
+ Acute *mesenteric ischemia* (when the blood supply to the intestines is suddenly blocked)
+ Colorectal cancer
+ Severe abdominal injury
+ Radiation therapy of the abdomen to treat cancer
+ Complications of abdominal surgery

Nutrition in short bowel syndrome

As shown in Figure 1, different segments of the bowel are specialized to absorb different nutrients. The table below provides a brief overview of which foods contain these nutrients and what roles they play in the body. Since this table can only serve as a rough guide, please talk with your healthcare team about your nutrition.

Nutrient	Major sources (examples)
Fats	Animal fats: butter, cream, fat-rich meat/bacon, fat-rich types of fish; Plant fats: oils, margarine, avocado
Medium chain triglycerides (MCT)	Coconut oil, palm oil, special products for high-MCT diets
Carbohydrates (sugar)	Table sugar, honey, as well as starch breakdown products (potatoes, bread, rice, pasta), fruit, juices
Protein	Animal protein: meat, fish, eggs, yogurt; Plant-based protein: beans, peas, tofu, oats
Iron	Animal sources: liver, some types of sausage; Plant sources: some nuts, some types of mushrooms, spinach, chick-peas
Calcium	Animal sources: milk and dairy products; Plant sources: broccoli, spinach, kale
Folate	Animal sources: liver, egg yolks; Plant sources: wheat germ, lettuce, spinach, broccoli
Cholesterol	Animal sources: fat-rich meat, offals; Plant sources: seed oils (corn oil, pumpkin seed oil)
Vitamin B12	Animal sources: dairy products, liver; Plant sources: not found
Trace elements	Iodine, zinc, selenium, iron, etc.: various sources

Parenteral support

Patients with short bowel syndrome may need a type of *parenteral support* called *total parenteral nutrition (TPN)* as a short-term or long-term treatment, depending on how severe their condition is and what digestive functions are affected. Long-term *parenteral support* may also be necessary to replace only some, but not all, nutrients and fluids. *Total parenteral nutrition* ensures that the body receives all of the nutrients and fluids it needs. Unlike normal eating by mouth, *parenteral support* is not taken at fixed meals but is given all day long, or sometimes only at night. *Parenteral support* uses special mixtures that are tailored to your individual needs. These mixtures need to be adjusted regularly as your bowel's ability to absorb nutrients changes.

The role of eating in parenteral support

Many patients with SBS still have enough intestinal function to get some of their nutrition from eating normally or from feeding tubes. While *parenteral support* through a *catheter* in a vein is still the main source of nutrition and fluids, eating additional nutrition by mouth can help maintain and sometimes even increase the ability of the remaining intestine to absorb nutrients. The aim is to meet as much of your nutritional needs this way as possible. By increasing the ability of your remaining bowel to deliver nutrition through training, your requirement for *parenteral support* can hopefully be reduced, which could also reduce the risk of its complications. One of the risks with *TPN* is that the lining of the small intestine may deteriorate when not used, further decreasing the surface available for digestion and absorption of nutrients and fluids. Keeping the colon trained (when it is still present) also helps prevent painful constipation you are again able to eat more.

People on *parenteral support* who also receive some nutrients by mouth or feeding tube must plan their nutrition carefully and adjust it regularly. Your care team can support you with this task. Some general tips include:

- Eat small but frequent meals (about every 2 hours)
- Always eat slowly and chew well
- Eat and drink separately (ca. 30 minutes in between)
- Each meal should contain fats (you may need to determine which fats you tolerate and buy special groceries containing fats that are more easily digestible)
- SBS patients tolerate fruit and vegetables better when cooked or blended (like applesauce)
- Eat lots of meals with potatoes and noodles
- Pay special attention to any food intolerances you may have (like lactose intolerance)

Eating is a central activity in life and is closely linked to quality of life and physical well-being. Seek out the advice of a dietician or other nutritional specialist, as they can play a key role in managing your condition.

Symptoms and complications

Losing large quantities of fluids – together with the *electrolytes* in the fluids – is a major complication of SBS that can even be life-threatening. The risk of this complication is particularly high right after *bowel resection* surgery, a period called the acute phase. Other symptoms of SBS can also have serious consequences, even if they are somewhat less dramatic.

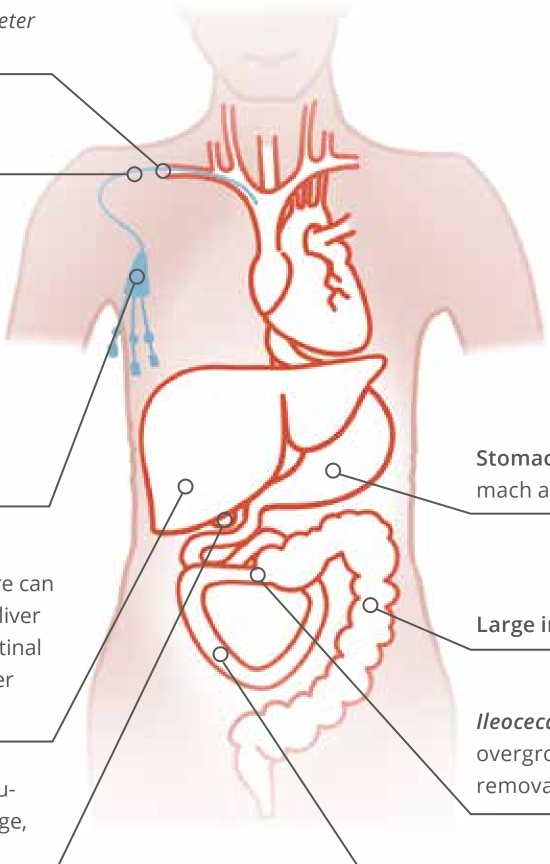
Chronic malabsorption: a lack of nutrients

When one or more sections of the bowel are missing or do not function properly, the body cannot receive the nutrients that would normally be supplied by those sections – a condition called *malabsorption*. The bowel also cannot absorb healthy volumes of fluids when it is abnormally short, raising the risk of *electrolyte* imbalance. In order to compensate for this lack of nutrients and fluid, SBS patients require *parenteral support*, sometimes even *total parenteral nutrition*.

Signs and symptoms of chronic *malabsorption* include:

+ Frequent, runny **diarrhea**
+ Constant *dehydration*, meaning **not enough fluids in the body**
+ **Weight loss**
+ **Bone density issues** and fractures
+ **Apathy** and depression
+ **Wound healing** issues

Short bowel syndrome with chronic intestinal failure is a complex condition



Insertion of the *catheter* into the vein

Incision in the skin for the *catheter*

Central venous catheter for parenteral support
Potential problems:

+ Infections
+ *Thrombosis*
+ Loss of access

Liver: Intestinal failure can cause some types of liver diseases (*IFALD*: intestinal failure-associated liver disease).

Gallbladder: Bile accumulation, biliary sludge, enlarged gallbladder

Stomach: Excessive stomach acid secretion

Large intestine

Ileocecal valve: Bacterial overgrowth possible after removal

Small intestine: longterm *parenteral support* and lack of food/tube feeding may cause the intestinal lining to deteriorate

Figure 2

Parenteral support: a blessing, but also a curse

There is no question that *parenteral support* is a blessing for anyone with SBS. It is quite often the only short-term or long-term option for providing vital nutrients and fluids to the body and ensuring patients' survival. However, these benefits also come with their own drawbacks.

+ Because *parenteral nutrition* is delivered through a **central venous catheter**, a foreign object (the *catheter*) is in continuous contact with the bloodstream. This poses an ongoing risk of infections that require antibiotics and could even become life-threatening.

+ **Blood clots** (*thrombosis*) can form in the *catheter* and in the vein the *catheter* is placed in. These clots block the vein and can make access to it difficult or even impossible.

+ The nutrient solutions and fluids used must be measured precisely and continuously adjusted as needed.

+ You must always have the equipment required for *parenteral support* with you whenever you leave your home for any extended amount of time. This can be a real burden, especially at the beginning.

Complications can occur even with the best management

Many factors determine which complications of SBS and long-term *parenteral support* you can expect to experience. The human bowel is divided into several sections which have different functions and absorb different nutrients. For this reason, your outlook after *bowel resection* surgery will depend on which functional sections are still remaining. In addition to the complications shown in Figure 2, a condition called ***enterocolitis*** is another possible complication. *Enterocolitis* is when the linings of the small and large intestine are inflamed at the same time.

When the digestive system is not working properly, issues also frequently develop in the liver, gallbladder and kidneys. These organs are often affected because they play a role in normal digestion and may have too much or too little work to do when the intestine is no longer working as it should. If you develop liver problems resulting from intestinal failure, this condition is called *intestinal failure associated liver disease*, abbreviated as *IFALD*. Several different factors may be partly responsible for liver disease: the **composition of *parenteral support*** as well as abnormal absorption of **bile salts** by the *colon* both play roles. A form of major liver damage called fatty liver can even develop within a year in the worst case. It is therefore important that you have your liver and kidneys checked regularly.

Medications for the symptoms of SBS

Most of the symptoms described in previous sections can (and sometimes must) be treated with medications. The table below provides a brief overview of which drugs may be prescribed and what effects they have. Some of these medications are intended for long-term use while others will only be prescribed for acute issues. Close coordination with your healthcare team is also important if you are taking medications for SBS: the dosages of your medicines may need to be adjusted as your situation changes, and any side effects need to be identified as early as possible. Your team will explain to you how to take each drug and what to do if you miss a dose.

Medications	Purpose
Antibiotics	Stop the growth of bacteria during an infection
Antidiarrheal drugs	Used to treat diarrhea
Stomach acid blockers	Reduce stomach acid production, fluid loss and diarrhea
Bile acid sequestrants	Prevent diarrhea caused by bile
Pancreatic enzymes	Improve the cleavage of fats and prevent fatty stool
Hormone therapy	Can improve the ability of the bowel to absorb nutrients

Living with short bowel syndrome

Just as short bowel syndrome can take a wide range of forms, there is also a wide range of journeys among the people living with SBS. In this booklet, we will share the stories of Martin, Erwin and Michael. Their stories are proof that a full life is possible with SBS, despite all of the hurdles, challenges and concerns it presents.

Michael (30): SBS due to Crohn's disease

Michael has been suffering from digestive problems and stomach pain since childhood. Even though these problems were occurring much too frequently to simply be caused by a stomach bug, it took years before Michael was properly diagnosed. By that point, his *Crohn's disease* was so advanced that he had major bleeding from his anus and needed to go to the emergency room. Although he was only 11 years old at the time, the doctors first suspected it might be end stage colorectal cancer. While his ultimate diagnosis of inflammatory bowel disease might seem almost harmless in comparison, Michael still had to go to the hospital quite frequently whenever his disease would flare up. He also suffered from the common Crohn's complication of fistulas, which required several operations. Each of these shortened the length of his bowel. After the first fistula surgery there was a gastrointestinal perforation, which is a hole in the intestine. This allowed the partly-digested food in the intestine to escape into his abdomen, causing a life-threatening case of *sepsis*. Michael fell into a coma, required numerous operations, and is convinced that he only survived thanks to the persistence of his mother, who fought to make sure the hospital didn't give him up. Michael was able to leave the hospital after 9 months and has since lived with a *stoma* (an opening in abdomen created surgically). At first he found the stoma disgusting. But the continuing operations he required for new fistulas were so difficult to bear that he quickly decided not to undergo even more surgery to restore his natural digestive tract. Since his most recent surgery in 2020, Michael only has 80 centimeters of his small intestine and none of his large intestine remaining.

In spite of the pain, the hospitalizations and the huge burden on his health, Michael has managed to complete not only school but also a professional degree, and now works as an administrator. And it doesn't end there: in 2020, he married his girlfriend of the past 10 years.

Transparency is important to Michael, and he tells everyone around him about his condition. He finds it important that his colleagues at work know about his challenges so they can support him when he needs it. Now, his motto is: "When you have an illness that is as nasty as this one is – when any day could be your last – you just live for today and don't think about tomorrow." But even with that outlook, he still hopes to buy a home with his wife and maybe even start a family one day.

Michael also has some advice for other people with short bowel syndrome: When it comes to medical care, he recommends always looking for information on your own, asking lots of questions during the diagnosis and treatment process, and taking lots of notes. When it comes to life in general, he advises patients to keep an open mind. His story shows that love and relationships are still possible with SBS, and that it's worth fighting for the important things in life.

Martin (55): Short bowel syndrome after mesenteric ischemia

Up until 10 years ago, Martin was doing great: a wonderful family (he has a wife and 2 kids), a job as a police detective that he loved, and in good physical shape. Before his children were born, his big hobby was riding his motorcycle with his wife. Unfortunately, his active lifestyle came to an abrupt halt one day when a very unlucky chain of events led to *acute mesenteric ischemia* that was not detected in time. He eventually needed *bowel resection* surgery to remove large portions of his small and large intestines. He now has only 30 centimeters of small intestine and two-thirds of his large intestine left. What does this mean for Martin and his family? Like many SBS patients, Martin's journey started with a crisis. He had to fight for his life – literally: he was resuscitated twice, and needed a long time to learn how to walk again after being hospitalized for such a long time. Overcoming the hurdles of each day forces him to plan every detail of his life. The first challenge in his daily life is his *parenteral support*: the infusions must be scheduled for specific times, as do bathroom visits, and he also needs to monitor his *electrolyte* levels closely. *Parenteral support* also means coordinating all of the medical equipment and solutions he needs: in Martin's case, this includes 10 liter bags of infusion solutions, boxes of intravenous magnesium and supplies for maintaining his *catheter*. On top of that, he takes 15 medications. Managing this complex self-care requires not only lots of storage space but also lots of attention, especially when it comes to reordering supplies and medications. Martin has managed to stay at work despite his SBS, although to his dismay his police department did transfer him to a desk job after his illness made him shorten his work hours. Nonetheless, between his job and his self-care, Martin's days are very long: he is busy from 5 in the morning to 7 in the evening with work, infusions and other tasks related to his condition.

Martin gets a lot of help from his wife. She is also the one who looked for and found a rehabilitation center specializing in SBS after Martin was misdiagnosed and inadequately treated at his original hospital. He is also assisted by a home care nurse specializing in *parenteral nutrition* who has become an indispensable part of his support group. This nurse takes care of his *catheter* and handles some of his infusion requirements. Martin has regained his physical fitness and his doctors are amazed that he can split enough firewood by hand to heat his home for the entire winter. He has also started riding his motorcycle again. Keeping in shape is very important to him, since it also improves his mental health. His advice to other SBS patients is to make sure you seek advice from SBS specialists for your medical care, even if this means traveling further to see them. Because short bowel syndrome is so rare, many smaller hospitals have no experience treating it. Since SBS is a lifelong condition requiring continuous care, having a trusting and cooperative relationship both with and within your healthcare team is crucial. One example from Martin's story is that after his specialist prescribes him a new medicine for the first time, his primary care physician takes charge of new prescriptions of the medication after just a brief phone call with the specialist. This saves Martin a lot of travel.

Erwin (82): SBS in an older person with a damaged ileocecal valve after rectal cancer

Although Erwin didn't have any digestive issues until later in life, when they appeared they came with a bang. Shortly before his retirement, he was diagnosed with rectal cancer that was successfully treated by surgery. However, the surgery resulted in bands of scar tissue developing in his digestive tract several years later, which also had to be removed by surgery. These bigger issues are probably the reason why another problem in Erwin's intestines was not correctly diagnosed until much later: his *ileocecal valve* wasn't working properly. The
ileocecal valve allows partly-digested food to pass from the small intestine to the large intestine but makes sure the food can't go back the other way. Because this valve could no longer open correctly, the digested food kept accumulating in Erwin's small intestine. This caused intense pain that was misdiagnosed several times before the real cause was identified. Erwin was initially prescribed medications for the pain, which had no effect. He was then referred to a dietician to make changes to his diet, which did lead to some improvement.

Unfortunately, these changes were not enough, and the intense pain returned after a few years. Once again, his doctors were probably led down the wrong path due to his previous intestinal issues, because this time his pain was being caused by the intestine twisting around itself. Even after this problem was finally recognized and treated by surgery, Erwin still did not feel better. However, his doctors didn't worry about it at the time since his surgery had gone successfully. Erwin eventually needed emergency surgery that shortened his bowel to 100 centimeters of small intestine and 40 centimeters of large intestine. After this surgery, Erwin now had short bowel syndrome. He still recalls how neither he nor his wife realized how much this diagnosis would impact their lives. Erwin was 74 when his SBS began. This meant it would no longer be possible to return to his “normal” life the way he had after his cancer diagnosis 15 years before. He now had to come to terms with living a much more restricted life, which included abandoning the plans he and his wife had for traveling all over the world. Instead of living a more active lifestyle, he was now faced with “around-the-clock” *parenteral support* and an uphill battle to regain strength after his body had become weak from long periods in the hospital and even longer periods of *malabsorption*. A nutritional specialist and a home care team were assigned to Erwin in the hopes of providing him needed support, but unfortunately he once again had bad luck. His nutritional specialist over-calculated the calories Erwin needed, while key blood tests to monitor his *parenteral support* were skipped. As a result, he developed a condition called fatty liver within a year. Although this is a well-known and dreaded complication of *parenteral support*, Erwin’s healthcare team did not respond properly until he sought advice on his own from a gastroenterology specialist at a large university hospital.

With all this experience, Erwin has some important advice for patients with SBS: it is very important to seek out information yourself, to listen to your gut feeling (literally and figuratively!), and to learn as much about your condition and nutrition as you can. By following this path, Erwin was able to recover much of his quality of life. Once it became clear that his planned trips would no longer be possible, Erwin dedicated himself to a completely new hobby that he can practice at home: he researches and writes books about a region in Germany that is near and dear to his heart. Between this hobby, support from his wife, new medications that have reduced his bowel movements to only a few each day, and some practical tips he learned at patient workshops, he now leads a very fulfilling life in spite of his SBS.

Help and support for patients and their families

Being able to find and talk with people who are dealing with similar problems can be very helpful when facing a chronic condition. Because SBS is such a rare disorder, you might not know anybody nearby who has it. There are several online platforms for finding and connecting with others: for example, visit leben-mit-kds.de or the Facebook community "Leben mit KDS" at https://www.facebook.com/lebenmitkds. Read the latest about living with SBS and connect with other SBS patients in these groups, which are an initiative of Takeda.

Specialized centers

Because SBS is so rare and yet so complex, it is important to seek medical care from specialists with experience treating the condition. This can be in addition to your local healthcare team if there is no specialized center in your area.

Visit leben-mit-kds.de to find a list of centers in Germany that specialize in treating and caring for people with SBS.

Scan this QR code to
jump directly to the list.

Self-help groups

A severe illness places a heavy strain both on the patient and on her or his entire family. While medical care from your healthcare team, dieticians and further specialists is essential, connecting with other families going through a similar situation can also provide comfort and community. Ask your doctors whether they can point you to a self-help group.

Glossary

Term	Definition
Amino acids	Amino acids are the building blocks the body uses to make proteins. When proteins are eaten in food, they are broken down by the digestive system into amino acids.
Bowel resection	Bowel resection is a type of surgery in which part of the intestine (bowel) is removed. The remaining parts of the bowel may be reconnected during surgery, or an artificial outlet may be created in the skin (called a stoma).
Broviac catheter	A long-term catheter that is placed into a large vein, such as the vein below the collarbone, and is frequently used for parenteral support since it is less prone to infection and is less likely to slip.
Catheter	A catheter is a thin tube than can be inserted into blood vessels and other hollow organs in the body. Parenteral support is delivered through a catheter that is inserted into a vein.
Carbohydrates	A group of biologically-important substances including sugars, starches, glycogen and cellulose. Carbohydrates are important sources of energy in the diet.
CIF	Abbreviation for “chronic intestinal failure”
Colon	Another name for the large intestine.
Crohn’s disease	An inflammatory bowel disease that can attack any part of the gastrointestinal tract and typically comes in waves called flares.
Dehydration	When the body does not have enough fluids, either because a person did not drink enough liquids or loses too much fluid, for example by diarrhea. Dehydration can be very severe or even life-threatening.
Duodenum	The first segment of the small intestine downstream of the stomach.
Electrolytes	Electrolytes are substances which have an electrical charge when dissolved in a liquid (like blood). The most important electrolytes in the human body are sodium, potassium and magnesium and are required for many metabolic processes.

Term	Definition
Enteral nutrition	While enteral nutrition technically means any type of nutrition that goes through and is absorbed by the bowel, including food eaten by mouth, in the setting of SBS treatment it usually refers to nutrition delivered by a feeding tube (sometimes called a gastrostomy button or G-button) directly into the stomach.
Enteral	The term enteral means “in the gut” and is used to describe any type of nutrition taken in through the stomach and/or intestines. For SBS patients, it often refers to enteral nutrition (see below).
Enterocolitis	Inflammation in the digestive tract.
Enzymes	Enzymes are a type of protein that carry out a wide range of functions in the body by accelerating biochemical reactions. During the digestive process, enzymes from the human body and from bacteria living in the bowel play important roles.
Essential amino acids	These are amino acids that the human body needs but cannot make by itself and therefore must obtain from the diet. Examples of essential amino acids: isoleucine, leucine and lysine.
Hormone therapy	Treatment with hormones that may help reduce the need for parenteral support.
IFALD	Abbreviation for “intestinal failure-associated liver disease”, an occasional complication of SBS.
Ileocecal valve	The ileocecal valve acts as a gate between the small and large intestines, preventing partly-digested food from flowing back into the small intestine. This is important because the bacteria that live in the colon should not enter the small intestine.
Ileum	The last segment of the small intestine before the large intestine.
Jejunum	The middle segment of the small intestine.

Term	Definition
Malabsorption	When nutrients are insufficiently absorbed by the bowel.
Mesenteric ischemia	An acute blockage in one of the blood vessels that supplies the intestine. The lack of blood flow to the bowel can cause intestinal tissue to rapidly die.
Microvilli	Hair-like protrusions that help expand the surface area of cells in the intestine, improving the exchange of substances into and out of the gut.
Motility	In the body, the term motility refers to involuntary muscle contractions in the bowel that propel partly-digested food through the intestines toward the anus.
Necrotizing	Necrotizing refers to the death of an area of tissue.
Oral	When something is eaten or taken by mouth.
Parenteral	Parenteral literally means “to bypass the intestines”. Parenteral nutrition bypasses the digestive tract by being delivered directly into the bloodstream.
Parenteral support	Parenteral support refers to any type of nutrition, including fluids, delivered through a catheter into a vein, and thus directly into the bloodstream. This nutrition can be a partial replacement of enteral nutrition, for example fluids or some nutrients, or it can be a way to supply a person’s complete nutritional needs (see Total parenteral nutrition).
Proteins	Proteins are complex biological molecules made of amino acids which serve many functions in the body, including as enzymes or structural molecules. In the diet, they can also serve as a source of energy.
Rectum	The last segment of the large intestine upstream of the anus.

Term	Definition
SBS	Abbreviation for “short bowel syndrome”.
Sepsis	A life-threatening situation which can occur when bacteria or other microorganisms get into the bloodstream.
Stenosis	An abnormal narrowing in a hollow organ such as the bowel or a blood vessel.
Thrombosis	A blood clot.
Total parenteral nutrition	When a person’s entire nutritional and fluid needs are delivered by catheter directly into the bloodstream.
Ulcerative colitis	Chronic inflammation of the mucosal lining of the large intestine that starts at the rectum and spreads up the colon to a differing degree in each patient.
Villi	Villi are finger-like folds in the lining of the small intestine. They are densely packed inside the small intestine, which expands the surface area of the intestine a great deal.
Volvolus	A twisting of the intestine around itself. It can be present at birth or occur after birth.

Checklist for doctors' appointments

Short bowel syndrome is a complex condition, and there will always be many topics to discuss at each visit with the doctor or other members of your healthcare team. It can be helpful to prepare for these conversations by writing down a few questions ahead of time and taking notes during the visit itself. You might also find it helpful to bring along a relative or good friend to help you process the wide range of information discussed with the doctor.

Some important questions might include:

+ Which segments of my intestine are affected by short bowel syndrome?

+ What type of nutrition will I need: is parenteral support necessary?

- What is the expected outlook? Is there a possibility that my intestines will recover enough for me to be free of parenteral support?

- How often will I need to see the doctor/go to the hospital? Is there a place near the hospital for patients to stay, and do any of the hotels offer special deals for patients and their relatives who live far away?

+ Should I expect to need more surgery?

+ Will I need a catheter or port for parenteral support? If yes, how will it be maintained?

+ Is there a home care service that can support me?

+ What medications do I need and how do I take/use them?

+ What signs or complications do I need to look out for? When is it okay to call the doctor's office, when is urgent care needed, and when do I need to call an ambulance?

+ Do you know of any self-help groups or other resources for families of SBS patients?

+ Where can I find resources to learn more on my own? Are there any events for patients?

Do you have any other questions? Write them here:

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