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Short Bowel Syndrome

What is short bowel syndrome?

Short bowel syndrome (SBS), or “short gut”, is a condition in which part of the small intestine is missing or does not function properly. This makes it hard for the digestive tract to absorb nutrients from food.

SBS is often due to surgery to remove part of the digestive tract or simply how the digestive tract formed. This can lead to **intestinal failure**, in which the digestive tract cannot support proper nutrition or hydration. Intestinal failure also can occur even if the intestine is the correct length. In these cases, the intestine may not function properly due to issues like poor muscle movement (called dysmotility), nerve problems, or the intestinal lining not absorbing nutrients properly.

What is the small bowel?

The small bowel, also known as the small intestine, is an important part of the digestive system. It is a long, tubular organ located between the stomach and the large intestine. The small intestine is where many important nutrients like fats, proteins, sugars, vitamins, and minerals are absorbed in our bodies. Without a properly functioning small intestine, the body struggles to get all required nutrients from food, potentially leading to malnutrition and other complications.

What causes SBS?

- **Surgery:** Surgery is often the main cause of SBS. Doctors sometimes need to remove a large section of the small intestine because of conditions such as:
 - **Necrotizing enterocolitis:** This most often occurs in premature babies and causes damage to parts of the digestive tract, which then need to be surgically removed.
 - **Crohn’s disease:** This is a condition in which the digestive tract is inflamed, and sections may need to be removed.
 - **Intestinal tumors:** Growths, whether cancerous or not, can require surgical removal.
 - **Volvulus:** This is when the intestine twists and cuts off its own blood supply, requiring removal of parts of the tissue.
 - **Accidents:** Injuries that damage the intestine might require surgery to remove the damaged tissue.

- **Birth defects:** Some people are born with a shorter or malfunctioning digestive system because of conditions like:
 - Intestinal atresia: A blockage in the intestine because it did not develop correctly.
 - Gastroschisis: When a baby is born with its intestines poking outside its body through a hole near the belly button.
- **Other diseases:** Some diseases can damage the digestive tract or make it function poorly:
 - Radiation enteritis: This is when radiation treatments damage the intestines.
 - Vascular disorders: Diseases that affect the blood vessels in the intestine can cause loss of intestinal tissue.

What are the symptoms of SBS?

- Diarrhea: Having many loose or watery bowel movements.
- Bloating and gas: Sensation of feeling full or having a distended abdomen, and maybe passing gas more often.
- Steatorrhea: Stool that is oily and might smell bad because the digestive tract is not absorbing fats well.
- Abdominal pain: Cramping or aches in the abdomen.
- Weight loss: Losing weight even if eating normally.
- Poor growth: Not growing as much as other children of the same age.
- Dehydration: Feeling very thirsty or not urinating enough because the body is not absorbing enough water.
- Fatigue: Being exhausted or worn out all the time.
- Swelling: Areas of the body, such as legs, might puff up with extra fluid.

How do we manage SBS?

- **Total parenteral nutrition (TPN):**
 - When the intestines struggle to absorb nutrients, TPN provides nutrients directly into the bloodstream via a special long-term intravenous (IV) tube. The nutrition includes proteins, fats, sugars, and vitamins.
 - Based on individual needs, the doctor will adjust TPN and provide guidance to prevent IV-related infections.
 - Initially, many patients rely on TPN, but the goal is to transition from TPN to full enteral nutrition over time. Prolonged TPN and IV nutrition can cause complications.
- **Supplemental enteral nutrition:**
 - This involves feedings administered directly to the stomach or intestine via a tube. This nutrition supports intestinal growth and adaptation. Formulas enriched with pre-digested, hypoallergenic ingredients and additional vitamins and minerals improve absorption. They

are often introduced slowly using a pump, sometimes only during nighttime, allowing ample nutrient absorption. Portable pumps are an option for daytime feeding. At the same time, limited oral feeding continues so that the child keeps their feeding skills.

- **Dietary management:**
 - Short bowel patients may need a change in diet to get optimum nutrition. This can include eating smaller amounts more often and avoiding lots of sugar.
 - Drinking enough fluids is crucial, especially when diarrhea is present.

- **Medicines:**
 - **Anti-diarrheal:** Reduces frequent bathroom trips.
 - **Acid suppressors:** Controls excess stomach acid, which can make diarrhea worse.
 - **Growth factors and hormones:** Can help the intestine function better and depend less on TPN.
 - **Antibiotics:** Treats excessive amounts of bacteria in the small intestine.
 - **Vitamins and minerals:** Ensures the body gets what it needs.

- **Intestinal transplant:**
 - In difficult cases, surgically replacing the patient's bowel with bowel from a donor may be considered.

- **Regular check-ups:**
 - It is essential to see your child's doctor often for tests and check-ups to make sure the treatment is working and catch any problems early.

Can SBS be reversed?

Yes! The remaining intestine can adapt to increase its ability to absorb nutrients from food. This process is called intestinal adaptation. This process can take some time and can vary depending on how much intestine is missing or nonfunctioning. Many children can eventually have their TPN and enteral feedings discontinued and have a good quality of life.

Navigating the SBS journey:

- **Prioritize education:** The more you understand about SBS, the more proactive you can be in seeking optimal care for your child.
- **Build a support network:** Connect with other families dealing with SBS. Their experiences, insights, and emotional support can be invaluable.
- **Maintain detailed health logs:** Keeping records of your child's daily health, including diet, symptoms, and medications, can help your healthcare provider tailor a care plan for your child.
- **Harness hope and resilience:** Though the journey may be tough, remember that children are remarkably resilient. With love, support, and the right care, they can thrive and lead fulfilling lives.

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