Intestinal Rehabilitation Education Guide

Designed for families journeying through the unique challenges of intestinal failure

Texas Children's
Hospital®

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Welcome

Caring parents and their resilient children to our intestinal rehabilitation team. At Texas Children's Hospital, we offer compassion and expertise to support families through the unique challenges of intestinal failure.

Short Bowel Syndrome (SBS) is a condition when a large portion of your child's intestines have been damaged or surgically removed, causing them to not work properly. This condition affects the body's ability to absorb nutrients, water, and electrolytes. This can lead to intestinal failure, where the intestines are unable to absorb nutrients and fluids necessary for your child's growth and development leading to challenges such as malnutrition, dehydration, and overall poor growth. Managing Short Bowel Syndrome and intestinal failure often involves specialized nutritional support, which may include a combination of intravenous (parenteral) and enteral (directly into the stomach or small intestine) nutrition.

Intestinal Rehabilitation requires a multidisciplinary team of experts involving pediatric gastroenterologists, surgeons, neonatologists, nurse practitioners, specialized nurses, dietitians, social workers, child life specialists, vascular access team, and other healthcare professionals that will work together to develop a treatment plan that is specific to your child's needs.

Remember you are not alone. Our team is here to provide the support, understanding, and resources you need to help you along this journey. You will learn about different treatment options, including special nutrition plans, medications, possible surgical procedures, and potential complications. The healthcare team will provide complete education and training in the use of equipment, preparing solutions, managing feeding ports, central line care, hygiene practices, recognizing potential problems and complications. During discharge planning, case management will set you up with an infusion company and home health agency to meet your needs.

This packet is an introduction about intestinal failure in children to provide general and supportive information about your child's intestinal condition. Transitioning from hospital care to home marks a significant step in your child's journey.

Introduction to Intestinal Rehabilitation

Intestinal Rehabilitation is the process of allowing the bowel/ intestines to work better by improving the function of the remaining intestines. The goal is to make up for the missing or non-working portion of the small bowel to improve absorption and provide the nutritional support necessary to grow. Nutrition that is given through the feeding tube or by mouth stimulates the intestines to absorb the nutrients and fluids to promote growth and development.

The goals of intestinal rehabilitation include:

- Maximize the function of the remaining intestines through intestinal adaptation
- Optimize nutrition to promote adequate growth and development
- Prevent potential complications
- Reduce or eliminate the need for total parenteral nutrition (TPN)

Treatment for intestinal rehabilitation includes:

- Nutrition modification
- Oral rehydration therapy
- Vitamin and mineral supplementation
- Medication therapy
- Surgeries to improve intestinal function
- Intestinal transplantation

About your Intestinal Rehabilitation care team

Our pediatric intestinal rehabilitation team is a dedicated group of healthcare professionals committed to providing total care to children with intestinal disorders, including short bowel syndrome (SBS) and intestinal failure. Here are some key members of our team:

Pediatric Gastroenterologist

Pediatric Gastroenterologists are doctors who specialize in diagnosing and treating gastrointestinal disorders in children, including intestinal failure, short bowel syndrome, and other conditions requiring intestinal rehabilitation. The digestive system includes the esophagus, stomach, intestines, liver, gallbladder, pancreas, rectum, and anus. Gastroenterologists oversee the medical management of intestinal failure and collaborate with other specialists to provide ongoing care and support to meet your child's complex medical needs. They may perform procedures such as endoscopies and colonoscopies.

Pediatric Surgeon

Pediatric surgeons perform a variety of surgical procedures to treat GI diseases and disorders. This may include surgeries to remove, diseased or damage portions of the intestine, reconnect or modify the intestine to improve absorptive function, and may need to create an opening in the stomach or intestines to assist with feeding.

Nurse Practitioner

Nurse Practitioners will work closely with the gastroenterologist and other healthcare providers to manage your child's care, develop treatment plans, and prescribe medications.

Nurse

Gastroenterology Registered Nurses will provide patient education, communicate and coordinate care for families and healthcare providers.

Registered dietician

Dietitians specialize in creating nutrition plans customized to your child and providing nutritional care and support through close monitoring of your baby's weight and growth.

Social worker

Social Workers provide support and assistance to patients and families facing challenges of living with a chronic medical condition. They will help connect families with resources in the community to get the support needed for you and your child.

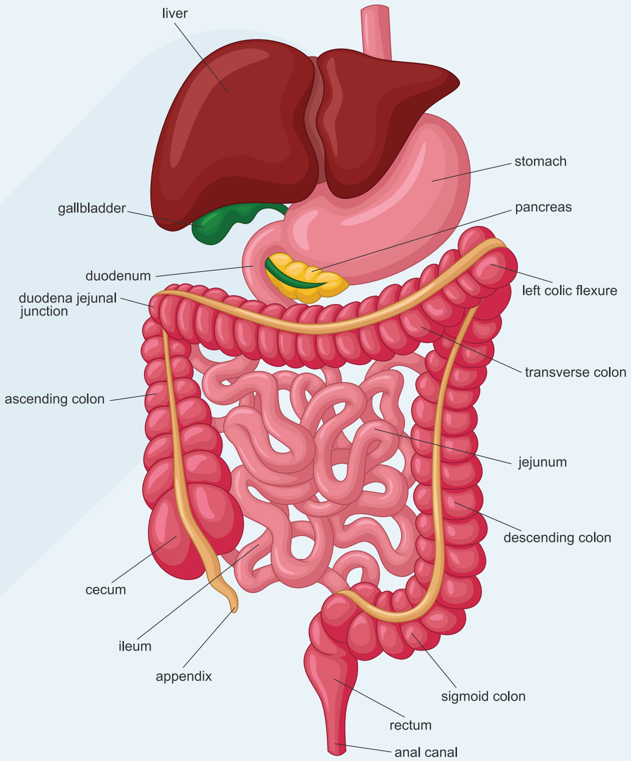
Meet our team

Scan the QR code to learn more about the Outpatient Intestinal Rehab team.

The Digestive System: How food moves through the body

Every part of the digestive tract plays a special role in helping your baby grow and stay healthy. It starts at the mouth, where food is chewed and swallowed. Then the stomach starts breaking down food even more. The small intestine is the most important part for babies with intestinal failure. This is where most nutrients like vitamins, proteins, and fats are absorbed into the body. If parts of the small intestine are missing, shorter than usual, or not working well, it can be hard for the baby to get enough calories to grow. The large intestine helps with water balance and form stool. If it's missing or not working properly, your baby may have watery stools and may lose too much fluid and electrolytes through diarrhea, which can lead to dehydration and electrolyte imbalance.

Babies with intestinal failure need extra support through special nutrition, medicines, and close monitoring from their medical team to help their intestines to work better and give them what he/she needs to grow healthy.



What is intestinal failure?

Intestinal failure is when your child's intestines cannot absorb the nutrients, fluids, and electrolytes that are necessary for survival.

Common symptoms of Short Bowel Syndrome:

- Diarrhea
- Vomiting
- Belly pain/bloating/discomfort
- Poor weight gain

The many causes of intestinal failure include:

- Necrotizing enterocolitis (NEC)
- Midgut volvulus
- Intestinal atresia
- Gastroschisis
- Malrotation
- Hirschsprung's Disease
- Tufting enteropathy
- Chronic intestinal pseudo-obstruction
- Radiation enteritis
- Trauma or injury
- Many more

Complications of Short Bowel Syndrome:

- Trouble absorbing nutrition and fluids
- Electrolyte abnormalities
- Low vitamin and mineral levels
- Blocked intestines (bowel obstruction)
- Liver problems from long-term TPN
- Kidney problems
- Too much bacteria in the small intestines
- Infections, especially from central lines
- Weak bones (low density)

Medical management

The team of specialists works together to develop a treatment plan that is customized to your child's specific symptoms, part of the intestines that were affected, the presence of the colon, overall condition of your child's health, tolerance to medications and procedures.

Key aspects of medical management include:

- A customized nutrition plan to meet your baby's specific needs
- Close monitoring of nutritional status, weight and growth, blood tests, and diagnostic tests
- Prescribed medications to control acid reflux, improve intestinal motility, prevent infections
- Monitoring fluid and electrolytes to prevent dehydration and imbalances
- Surgical procedures to improve function of the intestines and/or length
- Management of complications such as infections, nutritional deficiencies, and addressing issues like liver disease that can occur from intestinal failure
- Home health care needs
- Providing support services and access to support groups to help families cope with the challenges

Nutrition

Nutrition is important for your child's growth and development. It is important that your child gets the nutrition and fluid that they need such as proteins, carbohydrates, fats, vitamins and minerals to gain weight and grow. Each child has different nutritional needs and the way they receive it. Nutrition plays a key role in managing and treating short bowel syndrome.

When your child leaves the hospital, they will most likely have a central line for feeding through the veins and/or a gastrointestinal tube for feeding into the stomach or small intestine.

What are the types of nutrition?

- IV nutrition called Total Parenteral Nutrition or TPN
- Enteral Nutrition is breast milk or specialized formula given by mouth or feeding tube

Enteral nutrition

Enteral nutrition is a way to give your baby the important nutrients they need by delivering breast milk or specialized formula directly into their mouth, stomach or small intestine. Tube feeds are used when babies have difficulty feeding by mouth or when they need extra support. The formula is given slowly to help the intestines to adapt and absorb the nutrients to help your child gain weight and grow, with the goal of reducing parenteral nutrition.

About the feeding tube for Enteral Nutrition

A small, flexible tube placed through the nose or mouth guided into the stomach, or surgically placed directly into the stomach or small intestine for long-term use. This allows you to give food and medicine when your child has difficulty swallowing. Education and instructions will be provided on how to use and care for the feeding tube if it is needed.

Watching for problems related to g-tube or g/j tube

- Leaking of fluid around the stoma on the skin
- Soft, moist, pink-red tissue (granulation tissue), coming out from the g-tube site
- Bleeding at the tube site
- Fever, redness, swelling, warm to touch, pain, foul-smelling discharge (pus)

When to take your child to the emergency center:

- Belly pain, bloating or hard stomach
- Unable to poop
- Vomiting
- Difficulty breathing
- Fever

Total Parenteral Nutrition (TPN) and your child

Total parenteral nutrition (TPN) is a way for your child to get the correct amount of nutrients when your child's digestive tract can't digest food. TPN is given through a soft catheter, called a central line that is put into a large vein. This allows liquid nutrition to go directly into your child's bloodstream and absorbed into the body. TPN is a sterile solution that contains vitamins, minerals, fats, protein, and sugar that is usually in the foods we eat, that is needed to promote growth and development.

How long will my child require TPN?

The amount of time your child will require TPN varies from short-term to a life-long requirement to sustain life. Long-term use of TPN can lead to complications. The goal is to wean your child off IV nutrition and slowly advance to full tube feeds and eating by mouth. It is important to know that even if your baby is weaned off nutritional support, there is always a chance that they will need it again if nutrition needs are not met.

What are the complications of long-term TPN?

- Infections
- IV catheter problems
- Blood clots
- Gallbladder disease
- Liver disease

What is a central line?

A central line is used to deliver intravenous nutrition directly into his/her bloodstream.

Where the catheter enters your body, it's covered with a bandage (dressing). The dressing is often made of clear (transparent) plastic. This helps keep the area germ-free (sterile). To prevent infection, you need to keep the dressing clean and dry. Before your baby is discharged home, the nurses will prepare and teach you how to care for the central line, prevent infection, change the dressing, how to troubleshoot the line, and recognize emergencies.

Preventing infection when your child has a central line

The central line provides a direct path into your bloodstream, so the chance of a serious infection is high. Don’t touch the catheter where it enters the skin. And be very careful to keep your work area and supplies clean. Following the steps on this sheet will help. Keep in mind that some supplies come in sterile (germ-free) packaging. Make sure to keep these sterile during the dressing change.

- Wash your hands often with soap and clean water
- Try not to touch the catheter. Anyone who needs to touch it should wash their hands first and wear new, disposable gloves
- Don’t let anything (such as clothing) rub or pull on the catheter
- Don’t get your catheter wet. Ask your healthcare team for tips on how to shower or bathe
- Regular catheter site care and dressing changes as ordered by the healthcare provider

Watching for problems

Call your healthcare provider right away if your child has any of these problems:

- Catheter falls out, breaks, cracks, leaks, or has other damage
- The skin around the line bleeds, oozes, or becomes red or sore
- A fever of 100.3°F (37.9°C) or higher checked under the arm (axillary) or forehead (temporal)
    - **NOTE: Bring your child to a Texas Children’s Emergency Center. Do not give your child acetaminophen (Tylenol®) for the fever.**
- Stitches (sutures) or dressing over the catheter become loose or the catheter falls out
- Site becomes swollen or tender
- Chills
- Shortness of breath
- A racing or irregular heartbeat
- Muscle stiffness or trouble moving

Complications of Short Bowel Syndrome

Small bowel obstruction

An obstruction occurs when part or all of the small intestine is blocked and digestive contents are not able to move from the stomach through the bowels and out of the body properly. Immediate treatment is necessary to remove the blockage in the emergency center. Without treatment, the condition can cause serious complications like damage to the intestines, infection, and can be life threatening.

What are the symptoms of small bowel obstruction?

- Nausea and vomiting (especially if vomit is green or brown and smells like stool)
- Unable to poop or pass gas
- Severe belly pain
- Swollen and firm belly

Small intestinal bacteria overgrowth (SIBO)

SIBO occurs when food does not move through the digestive tract properly. There is a buildup of bad bacteria in the small intestine that can cause belly discomfort.

What are the symptoms of SIBO?

- Belly pain
- Bloating
- Gas
- Diarrhea
- Poor weight gain

D-Lactic Acidosis

D-lactic acidosis occurs when carbohydrates are not fully absorbed and causes a buildup of bad bacteria in the intestinal tract, which then gets absorbed into the blood and lead to impaired mental status or behavior changes.

What are the symptoms of d-lactic acidosis?

- **Confusion**
- **Difficulty walking**
- **Slurred speech**
- Feeling very tired or sleepy
- Belly pain
- **Nausea and vomiting**
- Breathing faster than usual
- **Dehydration**

NOTE: Bring your child to a Texas Children's Emergency Center if the above symptoms are present.

Preparing for your first outpatient visit

Congratulations you are going home! Preparing for your first intestinal rehabilitation clinic visit after your hospital discharge involves several key steps to ensure a smooth transition and follow-up care to confirm your child's treatment plan supports their needs.

1. Review discharge instructions to understand medical diagnosis, surgical history, feeding method, medications, etc.
2. Make a list of your child's symptoms, concerns, and questions to include any changes in stools
3. Bring a list of your child's medications, vitamins and over-the-counter medications. Include: name of medication, purpose, dosage, frequency, side effects
4. Feeding schedule (type of formula, amount, method of feed, any reaction or concerns)
5. Questions and concerns about diagnosis, treatment options, potential complications you may have since leaving the hospital
6. Discuss any goals that you would like to address with your healthcare provider
7. Expect routine follow-ups with Intestinal Rehabilitation Clinic

Visit checklist

Make sure to bring:

- Medication list
- Feeding schedule
- Equipment and supply list
- List of questions and concerns for your doctor

Intestinal Rehabilitation Outpatient Clinic
Texas Children's Texas Medical Center
Gastroenterology, Hepatology and Nutrition

6701 Fannin St., Mark Wallace Tower, 11th floor
Houston, TX 77030

832-822-3131

Additional references

Oley Foundation
oley.org

Short Bowel Syndrome in Children
shortbowelsyndrome.com/sbs-in-children

Emergencies:

If your child has a fever of 100.3°F
or higher and a central line in place, go to the
nearest Texas Children's Emergency Center for care.
Your child may have an infection that could progress quickly.

Do not give acetaminophen (Tylenol®) or ibuprofen (Advil®).
This could mask the fever or infection when testing.

Texas Children's Hospital
Texas Medical Center
6621 Fannin St.
Houston, TX 77030
832-822-2778

Texas Children's Hospital
West Campus
18200 Katy Fwy.
Houston, TX 77094
832-227-1440

Texas Children's Hospital
The Woodlands
17600 I-45 S.
The Woodlands, TX 77384
936-267-7555

Texas Children's Hospital
North Austin Campus
9835 North Lake Creek Pkwy.
Austin, TX 78717
737-229-3504

Texas Children's Gastroenterology, Hepatology and Nutrition
6701 Fannin St., Mark Wallace Tower, 11th floor
Houston, TX 77030
832-822-3131

texaschildrens.org/gi