

# Intestinal Failure

## *[Short Bowel Syndrome]*

### What is intestinal failure?

Intestinal failure occurs when a significant portion of the small intestine is not present or does not function normally. This can occur if a large part of the small intestine has been surgically removed or if a baby is born with an abnormal intestine. The presence or function of the large intestine (colon) can also play an important role in how well a child with shortened small intestine does.

### Who is at risk for intestinal failure?

- ◆ Babies (usually premature) who have had surgery for NEC (necrotizing enterocolitis)
- ◆ Babies born with their intestines damaged by being outside the body (gastroschisis)
- ◆ Babies born with narrowed or obstructed intestines
- ◆ Patients who have had some intestine surgically removed due to Crohn's disease
- ◆ Patients with intestinal pseudo-obstruction or abnormal motility of the bowel
- ◆ Patients who have had surgery for volvulus (twisting of the intestine)
- ◆ Patients who have had parts of the intestine removed for other reasons (e.g. tumors, abnormal blood supply, strictures, etc.)
- ◆ Patients born with abnormalities of the absorptive cells lining the intestine

#### SPECIAL INSTRUCTIONS:



### What are the symptoms of intestinal failure?

- ◆ Diarrhea
- ◆ Poor weight gain or weight loss
- ◆ Bloating
- ◆ Poor appetite
- ◆ Increased gas, foul smelling stools
- ◆ Fatigue, pallor
- ◆ Vomiting

### What are the complications of intestinal failure?

- ◆ Malnutrition
- ◆ Dehydration
- ◆ Vitamin deficiencies as a result of poor absorption in the intestine
- ◆ Electrolyte and mineral deficiencies due to losses in the stool
- ◆ Bacteria moving up from the colon and multiplying in areas of dilated small intestine (bacterial overgrowth)
- ◆ Liver disease due to TPN (Total Parenteral Nutrition)
- ◆ Infections of the blood from the intravenous catheter used for TPN

# Intestinal Failure continued

- ◆ Severe diaper rash from frequent loose stools
- ◆ Abnormal oral eating behavior due to need for long-term tube feedings
- ◆ Narrowing or bleeding at the area where the intestine was reconnected
- ◆ Kidney stones or gallstones due to poor absorption of calcium or bile

## How is intestinal failure treated?

The diet needs to be adjusted according to the intestine's ability to absorb nutrients. TPN is usually required at the beginning to maintain nutrition and good hydration although it is hoped that the small intestine will adapt over time in order to allow intestinal (enteral) nutrition alone. Since the biggest problems are related to TPN and intravenous (IV) nutrition, the first goal is to try and gradually decrease the TPN while increasing enteral nutrition.

Pre-digested and hypoallergenic formulas improve intestinal absorption, and extra vitamins and minerals are often added. These formulas are usually given slowly by a feeding tube and a pump, sometimes just at night. Dripping the formula in slowly gives the intestine more time to absorb nutrients. Portable pumps are available for children who also need drip feeds during the day. Allowing the child to eat small amounts by mouth minimizes the loss of oral feeding skills.

If steady progress is not being made in decreasing the TPN, additional surgery is sometimes performed. Intestinal and/or liver transplantation can be considered for severe forms of intestinal failure or when long-term TPN has resulted in severe liver disease.

## What can you expect?

The prognosis of intestinal failure depends on many factors, including the length and specific section of intestine lost, the complications experienced by the child (particularly infections and liver dysfunction) and whether other parts of the body (eg heart, lungs, kidneys) are working well. A good proportion of children can have their TPN and enteral formula feedings discontinued and have a normal quality of life.

For more information or to locate a pediatric gastroenterologist in your area please visit our website at: [www.naspgghan.org](http://www.naspgghan.org)

**IMPORTANT REMINDER:** This information from the North American Society for Pediatric Gastroenterology, Hepatology and Nutrition (NASPGHAN) is intended only to provide general information and not as a definitive basis for diagnosis or treatment in any particular case. It is very important that you consult your doctor about your specific condition.



### LINKS:

**National Digestive Diseases Information Clearinghouse:**  
<http://digestive.niddk.nih.gov/ddiseases/pubs/shortbowel/>

**American Society for Parenteral and Enteral Nutrition:**  
<http://www.nutritioncare.org/wcontent.aspx?id=256>

**The Oley Foundation**  
<http://www.oley.org/>