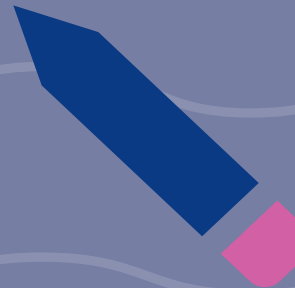


# Children with Intestinal Failure: Preparing for Matriculation

For school staff



Where the world comes for answers



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## What is intestinal failure (IF)?

Intestinal failure (IF) is a condition in which a child is unable to support their nutrition and hydration needs to grow and thrive by their gastrointestinal (GI) tract alone. Children with IF are at risk for malnutrition and dehydration, and often require additional advanced nutrition support. IF is an umbrella term encompassing several different diagnoses:

- **Short bowel syndrome (SBS)**, or simply “short gut,” is a condition caused by the loss of a functioning small intestine. The small intestine is an important part of the digestive tract — it’s where we absorb most of the sugars, proteins, fats, vitamins, and minerals from the food we eat. SBS can result from a variety of diagnoses, including gastroschisis, intestinal atresia, volvulus, and necrotizing enterocolitis (NEC).
- **Motility disorders**, such as chronic intestinal pseudo-obstruction (CIPO) and Hirschsprung’s disease, which impact the intestines’ ability to squeeze effectively.
- **Congenital enteropathies**, such as microvillus inclusion disease (MVID) and tufting enteropathy, which result in chronic diarrhea, severe dehydration, and malabsorption of nutrients.

## Can children with IF attend school? **Yes!**

Children with complex medical needs can attend school. The type of school and the setting of the classroom may vary depending on the child’s needs. However, most children with complex needs can be found in a traditional classroom setting with peers by their side. The following handout outlines important information to consider when caring for a child with IF:

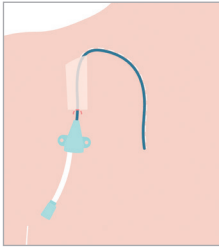
- medical devices they may use
- participation in sports and activities
- support offered from Boston Children’s Center for Advanced Intestinal Rehabilitation and Home Parenteral Nutrition Program

## What medical devices may children with IF use?

Children with IF may attend school with different devices.

Here is a review of potential devices they may use:

Central Venous Catheter



Ostomy Bag



Enteral Nutrition Pump



Parenteral Nutrition Pump



Gastrostomy Tube (G-Tube)



## Can children with IF participate in sports and activities?

Children with IF may participate in physical activity and recess. You should limit their participation in contact sports or activities that pose risk of blunt trauma to the abdomen or the central line site, and offer the child an alternate activity. Protective gear can be useful during physical activities.

**Scan here for an example of a protective gear:**



## What about water activities?

The central line site cannot encounter water. If water activities (e.g. sensory tables) are offered, the child must wear a protective plastic smock to protect the central line dressing or be offered an alternate activity. For outside water play on hot days, consider using a short-sleeved smock. For inside water play, consider using a long-sleeved smock.

Please monitor the central line dressing site during and after water activities and change the dressing immediately if it becomes wet.

**Scan here for an example of a protective smock:**



\*The use of these links is to provide an example. The CAIR and HPN Program do not endorse these products.



## How can I support a child with IF while they participate in sports and activities?

Children with IF are at an increased risk for dehydration. Please allow the child access to their water bottle for oral hydration.

Please monitor the child closely for signs of dehydration, including:

- decreased urine output
- concentrated urine
- decreased energy level
- dry or cracked lips
- dry tongue or walls of the mouth
- sunken appearance to the eyes
- increasing complaints of thirst

## How do I care for a child with IF?

We can provide individualized school orders with care instructions for the child, including:

- timing of medications, if needed during the school day
- enteral nutrition (continuous and/or bolus) schedule
- timing of parenteral nutrition and/or IV fluid infusions if needed during the school day
- how to react to urgent needs or emergencies that can happen during the school day

Emergencies may occur. Be on the lookout for the following signs and refer to the child's written school orders for an action plan:

- broken or occluded central line
- fever of 100.4F or higher in a child with a central line
- lethargy, chills, vomiting, dehydration

In addition to the written school orders, we will also provide the school staff with Boston Children's educational videos on:

- central venous catheter care
- mixing formula
- additional skills if needed

### Watch our videos here



**If your staff requires further training to ensure safety and success at school, we can provide this via Zoom or in-person on a case-by-case basis.**



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