



# **Caring for your baby after bowel surgery**

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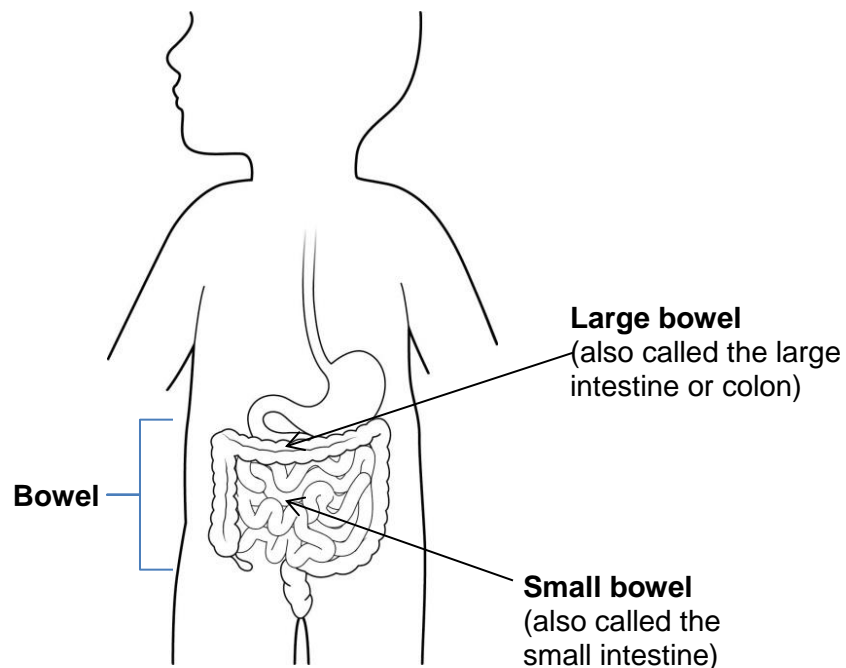
## The digestive system

Your child's digestive system is made up of a group of organs that work together to change food and fluids into energy and nutrients (calories, vitamins, minerals) to feed their bodies and help them grow.

Part of the digestive system includes an organ called the bowel. The bowel is shaped like a long tube and is made up of the small and large bowel. The bowel can also be called the small intestine and the large intestine. The bowel is where nutrients are absorbed.

Following bowel surgery, the bowel may not be long enough or working well enough to absorb all nutrients and fluids. This may affect your child's growth and nutrition. When a baby is not able to absorb enough nutrients from feedings, the medical term to describe this is "Intestinal Failure".

The picture below shows where the small and large bowels are in your baby's body.



## The cause of intestinal failure is anatomical or functional

- **Anatomical** means short in size. A section of the bowel has been removed, making it physically short so there is less surface area to absorb nutrients. This may be caused by surgery for conditions like intestinal atresia, gastroschisis or volvulus, or a bowel injury called Necrotizing Enterocolitis.
- **Functional** means there is a loss in function. This is because sections of the bowel are not working and are not absorbing nutrients well enough, even if all sections of the bowel are still there.

## Nutrition is important because ...

Babies with intestinal failure who cannot absorb enough nutrients can:

- become malnourished or dehydrated, and
- have serious growth and development problems.

However, over time your baby's bowel will adjust and get better at absorbing nutrients and fluids. This process is called bowel rehabilitation.

## What to expect:

After surgery, babies with intestinal failure go through 3 stages:

- **Stage 1 (acute phase)**  
This is when your baby will have many watery bowel movements (diarrhea) causing them to lose a lot of important fluids and minerals. To make up for these losses, your baby will probably need to have nutrition and fluids given to them through an Intravenous (IV) line also called parenteral nutrition (PN) or IV feeding (see next page for more information).

During this time, some babies might also need help from medications to decrease the amount of acid made by their stomach.

- **Stage 2 (recovery)**

Over many weeks to months, you can expect your baby's bowel movements to slowly improve and become more normal. You will see that the ostomy output or stools (poop) will become more normal with less diarrhea. Your baby may also slowly start to be given more enteral nutrition (tube feeds) and need less IV feeds. Some babies might need to stay on total IV feeds for a longer amount of time. Bottle or breastfeeding will be started as early as possible. Some babies need to stay on tube feeding while also eating by mouth in order to give enough food to help them grow.

- **Stage 3 (maintenance phase)**

The time it takes for a baby to make it to stage 3 is always different. It depends on how long it takes your baby to heal. Your baby will enter this stage when they can get enough nutrition from tube feeds and no longer need IV feeds.

## **Nutrition**

### **What is Parenteral Nutrition?**

Parenteral Nutrition (PN) is a way of providing nutrition directly into your baby's blood stream so that their bowel does not have to work to try and break down the nutrients. It is also called intravenous (IV) feeds or total parenteral nutrition (TPN).

Your baby will receive a carefully balanced mixture of fluids and nutrients such as protein, fats, sugars, vitamins and minerals that is right for them.

Parenteral Nutrition or IV feeds are used along with tube feeds until your baby's bowel is able to absorb all nutrients from tube feeds, breast and/or bottle feedings.

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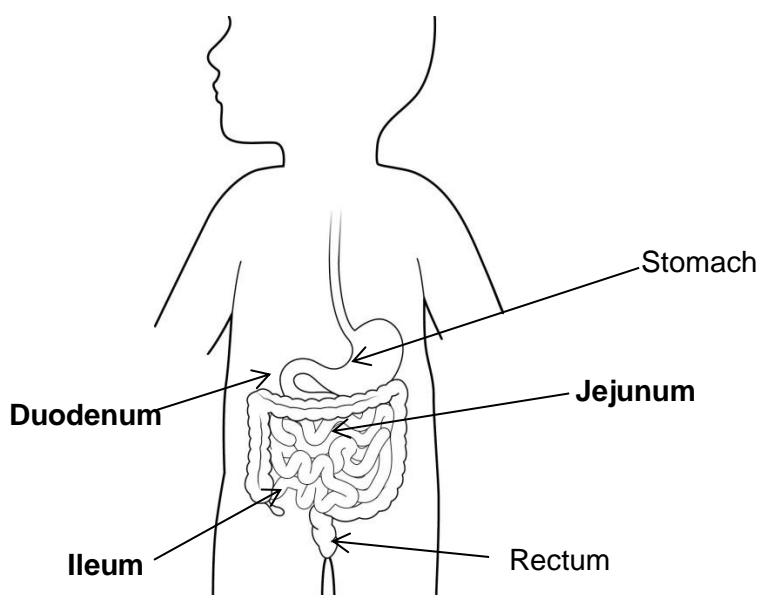
## What is Enteral Nutrition (EN) or tube feeding?

Enteral nutrition includes all feeding going into the stomach or intestines. It includes oral feedings (bottle or breastfeeding), and tube feeding. Tube feeding is when pumped breastmilk or a special baby formula is given through a tube into the stomach or small bowel. One type of feeding tube is a nasogastric (NG) tube, which passes from the nose into the stomach. Another type is the gastrostomy tube (G- tube) that is put into the stomach through a surgical incision. Some babies might have a tube put into the small bowel (jejunostomy tube or j-tube) instead of the stomach.

## What does the small bowel do?

The small bowel is a part of the digestive system where the body absorbs nutrients. It has 3 sections:

- 1) **Duodenum** – the first section after the stomach (shortest section)
- 2) **Jejunum** – the middle section between the duodenum and the ileum
- 3) **Ileum** – the last section that connects to the large intestine (colon)



Fluids, proteins, carbohydrates (starches and sugars), fats, vitamins, and minerals (such as iron, calcium, sodium, and potassium) are absorbed in the small bowel.

If the duodenum and part of the jejunum have been taken out by surgery, the ileum can gradually adapt to absorb nutrients.

If a large part of the jejunum or the ileum is taken out, it will be harder for your baby to absorb nutrients. This means that your baby may not get enough nutrition from the food they are given through tube feeding, bottle or breast, and need more IV.

## What does the large bowel do?

The large bowel (colon) is a muscular tube that connects the small bowel to the rectum (see diagram on page 2). The colon is very important for processing waste so that it is easy for your baby to empty their bowel. A major job of the colon is to absorb water and sodium from the waste so by the time it reaches the end of the colon the waste is more solid (stools or poop). If a large section of the colon is taken out, less water and sodium will be absorbed. This means your baby might get dehydrated and not get the sodium they need.

The rectum connects the colon to the anus. The rectum holds stool from the colon until a bowel movement happens.

## What is an ostomy?

An ostomy is a surgically created opening that connects part of your baby's bowel to the outside of their body. The purpose of this opening is to get rid of stool. This is called **ostomy output**.

There are different types of ostomies depending on where your baby needs the ostomy opening:

- Jejunostomy – in the jejunum
- Ileostomy – in the ileum
- Colostomy – in the colon

Often, if your baby has an ostomy, they will also have a mucous fistula. A mucous fistula is an opening for mucous to drain (from the part of the bowel that is not working properly).

The amount of ostomy output can change for different reasons, including:

- What and how much your baby is being fed.
  - Where the ostomy is in your baby's body.
  - How your baby's bowels are working.
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## What is dumping?

“Dumping” is a word used by staff to describe high or increasing ostomy output or stool loss.

## What causes “dumping”

- Dumping can happen in a baby with an ostomy or after the baby’s intestines have been reconnected and the ostomy has been closed.
- When food moves from the stomach into the first section of the small bowel (jejunum) too quickly, water rushes in and can cause bloating, abdominal pain, and fast ostomy output or bowel movements .
- Dumping is sometimes caused by increases in the total amount of food the baby is eating or how much the baby is eating at one time.
- To correct high ostomy output, the type of feed may need to be changed, the amount of feeds may need to be lowered, and/or the speed the feeds are given may need to be slowed.
- Medicine can also help manage dumping.

## What are “re-feeds”?

In babies with an ostomy that is placed higher up in the bowel, the ostomy output can be re-fed back in to a lower part of the bowels to give the baby another chance to absorb more nutrients.

Refeeding is used in certain situations. These situations are:

- When the ostomy is higher up in the bowel.
- The baby has a high ostomy output.
- The baby’s blood values are not normal.

Refeeding is done in the hospital. It is good for the bowel because it gives unabsorbed nutrients a “second chance” to be absorbed by the bowel. This decreases the amount of nutrients that need to be given through IV feeds.

## Choosing the type of feed for your baby

When available, mother's own breastmilk is always the first choice for feeding your baby. Pumped breastmilk can be given through a feeding tube before your baby is able to feed at the breast or by bottle.

If mother's own breastmilk is not available, your baby, with your consent, may be eligible to receive human donor milk for a short time before slowly switching to a formula to meet your baby's needs.

## Supplements

Based on what area of the bowel is affected or removed, your baby may need nutrient supplements. Your baby's need for nutrient supplements will be decided by regularly checking the nutrients in their blood.

Checking the nutrients in your baby's blood is also very important when your baby is decreasing IV feeds and changing to enteral feeding, including bottle or breastfeeding.

## Starting oral feeding

Once your baby is doing well with small amounts of enteral feeds and shows signs they are ready to take food by mouth, bottle feeding will be started using mother's breastmilk (if available) or infant formula. Bottles may be used first to closely keep track of how much your baby is eating.

When your baby is tolerating enteral feeds well, you may be able to start some breastfeeding.

Sometimes babies are not able to digest any feedings, but we still want them to practice oral feeding. These babies may be fed small amounts by breast or bottle and then the nurse will pull the feeding back out of the stomach via the feeding tube. These are called sham feeds.

## Long-term follow-up

- Your baby may be followed by our Short Bowel Rehabilitation Team ("SHORT"). This team includes doctors, nurse practitioners, social workers, child life workers and registered dietitians from Surgery, Gastroenterology, NICU and Pediatrics.
- Some babies with intestinal failure stay on long-term IV feeds after going home.