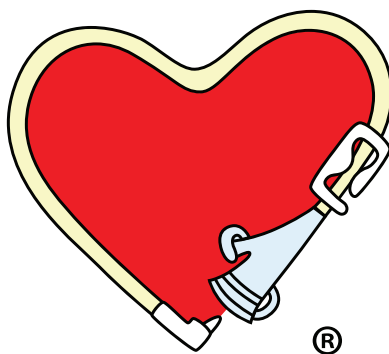




What You **Need** to Know Now

A Parent's Introduction to Tube Feeding



Feeding Tube Awareness Foundation®

Raising Awareness and Sharing Knowledge

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Introduction

Being told your child needs a feeding tube can be overwhelming. We understand. We have been in your shoes. You may not know anyone else who has a child with a feeding tube. And the unknown can be frightening, especially when it concerns your child. You may have mixed emotions. It is a lot to take in, particularly if your child is experiencing other medical issues.

You are not alone.

In the United States, there are tens of thousands of children who rely on tube feeding due to hundreds of different medical conditions.

There is support.

The Feeding Tube Awareness Foundation is a non-profit organization founded and run by parents of children who are tube fed. Our mission is to provide parents and caregivers with the information they need in day-to-day life caring for a child who is tube fed. We also raise awareness of tube feeding as a positive life-saving medical intervention, so that parents can get the support and understanding they need.

Our Facebook page is the largest online support group for tube feeding in the world. Thousands of parents and caregivers are available to offer support, resources, knowledge, and experience. We make it possible to connect with other people in similar situations.

It isn't as scary as you think it will be.

With all the equipment and supplies, it can seem like tube feeding your child is a very medical process. It is common for parents to be hesitant about it. But most often we find that once parents see the benefits of tube feeding, they wish they had started sooner. Tube feeding helps so many children grow, develop, and thrive. It becomes just another way for a child to eat. Even though there is a lot to learn in the beginning, it does get easier.

You will be receiving a lot of information from a variety of medical professionals. It is hard to remember everything. We created this introduction based on the information that we, as parents, wished we had to supplement what we learned when our children's feeding tubes were placed. This information is meant to supplement, not replace, the information you receive from your doctor and other medical professionals.



In Parents' Words

I wish that I had realized that having a tube placed did not make me a bad mom. We love our children dearly, but sometimes accepting that no matter what you try, your child needs a doctor's help can be very difficult. Those first few weeks after surgery were hard, but seeing her start to thrive, and laugh, I've realized that I made the best decision I could. Trust your instincts, keep your faith and remember that you're giving your child every tool possible to help them. A tube is no different. It's just another tool to help them eat, and it's my daughter's path to a happier and healthier life.

Jennifer, Parent

Myths and Facts About Tube Feeding

Myth: *You didn't try hard enough to make your child eat.*

Fact: In our experience, parents try everything to get their children to eat. It is a natural instinct for a parent to feed his or her child. Some children require extra nutritional support to stay healthy. Tube feeding is a last resort. Tube feeding allows children to get the nutritional support they need to grow and develop, either when eating orally is not possible, or while exploring the medical reasons a child cannot eat and drink enough.

Myth: *You can't eat by mouth when you have a feeding tube.*

Fact: Some children benefit from tube feeding because they can't eat enough by mouth. Others need tubes because they can't eat some or all types of food safely. If your child can eat safely by mouth, oral eating should be encouraged as much as possible to maintain and develop oral eating skills.

Myth: *Tube feeding is forever.*

Fact: Some children have medical conditions that will require them to have feeding tubes their whole lives. But for many children, tube feeding is temporary. Children are able to wean off their feeding tubes once they are no longer medically necessary. It is often difficult to estimate how long a feeding tube will be needed, especially if the child's medical condition is not yet fully understood.

Myth: *You have to get everything right, right away!*

Fact: Just like everything in parenting, you will make mistakes and learn from them. Don't panic when you do. We all have made mistakes. There can be a bit of trial and error in the beginning. Tube feeding isn't one size fits all. Learning what is best for your child is a step-by-step process, particularly with infants and children who are unable to tell us what they are feeling.

Myth: *A child's physical activity will be limited by having a feeding tube.*

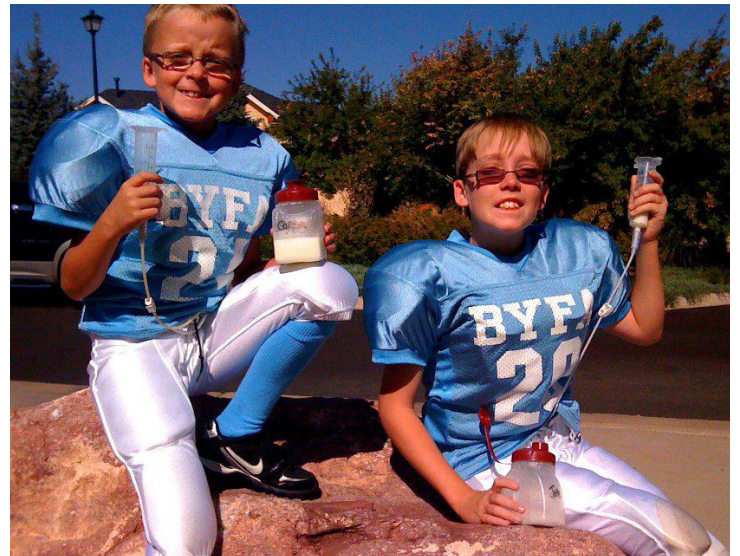
Fact: Tube feeding itself does not limit a child's ability to roll around, play, climb, run, swim or play sports. A child's physical ability will not be impacted by having a feeding tube. Even children who feed continuously can wear feeding pumps in backpacks and still be active.

Myth: *You will need a nurse to care for your child if you tube feed at home.*

Fact: It is easy for parents and caregivers to learn how to use the feeding tube safely at home. Very few parents have any medical background before they begin the feeding tube journey.

Myth: *You must use formula for tube feeding.*

Fact: You can tube feed breast milk, formula, or blended foods. The diet can vary based on your child's medical condition and tolerance.



When your child is unable to eat, swallow or get enough nutrition orally, the tube takes away so much worry — you know that they are getting the nutrition, hydration, and medication that they need to grow and stay healthy. The thing I wish I would've known is that tube feeding sounds a lot more scary than it actually is — once you learn the equipment and the schedule, it's really just an alternative way to feed your kid.

Erin, Parent

At first you're going to feel frazzled and overwhelmed but just keep your head up. A feeding tube is an adjustment but it's also the gift of life. :)

Ann, Parent

My only regret is my hesitation. Seeing Ava finally THRIVE, both physically and developmentally, after the tube was placed was amazing. I fought tooth and nail for as long as I could, but looking back, we have probably made no better decision in Ava's care than placing her first G-tube.

Lindsay, Parent

Terms to Know

Flush:

Administering water into the feeding tube, usually with a syringe, to clear food, formula, or medication in order to keep it from clogging is called a flush.

The amount of the flush is dependent on the length of the tube, but is usually between 10–20ml (about half an ounce) of water. It is generally advised to flush both before and after giving medications; however, in infants and children who can only take small amounts, parents often flush only after medications. You always need to flush at the end of a tube feed.

Vent/Venting:

Venting is letting the air out of the stomach with a feeding tube, usually through an open 60ml syringe.

Farrell Valve Bags:

Farrell Bags allow for venting the stomach while feeding. The food and air first passes through the bag, where the air is vented, and the food is then gravity fed back into the stomach.

Feeding Tolerance and Intolerance:

How a child reacts to tube feeds is referred to as feeding tolerance or intolerance. If a child seems happy or content during and after feeding, he is tolerating feeds well. If there is discomfort, coughing, vomiting, or retching during or after feedings, then there is feeding intolerance.

Motility/Dysmotility:

Motility is the movement of food and liquids through the GI tract. If there is a motility issue, which is referred to as dysmotility, then food isn't moving through as it should (either too slowly or quickly). There can be dysmotility at any point in the GI tract, from the esophagus all the way to the stomach, intestines, and bowels.

Stoma:

The stoma is the tube site itself for G-, GJ- and J-tubes. It is the opening that connects the feeding tube on the outside of the body to the stomach or intestine on the inside.

Ways to Give Tube Feedings

How much food and how quickly that food is given will depend on your child's feeding tolerance and nutritional needs. You should observe how your child is tolerating feeds and discuss with your feeding team the best way to deliver all the appropriate nutrition to your child as comfortably as possible.

Bolus Feedings:

A bolus is a tube feed that is given like a meal. Typically, a larger amount is given in a short period of time, usually less than 30 minutes. There is often a break of several hours between feeds.

There are multiple ways to administer bolus feeds. One uses a 60ml syringe to push the food into the stomach using the plunger of the syringe. Another is pouring the food in to the open syringe with the plunger removed and letting it flow in to the stomach by gravity. When doing a bolus feed via gravity, the higher you hold the syringe above the child, the faster it will flow. To slow the rate of flow, lower the syringe so it is closer to the child's stomach. If you hold the syringe below the level of the stomach, or if your child arches or coughs, formula may back up into the syringe. Simply raise the syringe to reverse the flow.

Bolus feedings can also be given using a gravity bag that hangs above the child. Gravity bags have roller clamps on the tubing that can be moved up or down to control the rate of flow. Fifteen drips into the chamber above the roller clamp equals 1ml of formula. Some parents give bolus feedings using a feeding pump at a faster rate over a shorter period of time than continuous feeding. These can be scheduled to run automatically using the interval setting on the feeding pump, or you can turn the pump off in between feedings.

Continuous Feedings:

Continuous feeding is done using a feeding pump to deliver a slow and steady amount of formula, over many hours (typically 18-20 hours). Some children with a G-tube tolerate a continuous feed better than bolus feedings. When using a GJ-tube or a J-tube, you must use a continuous feeding schedule.

Combination:

Many children use a combination of feeding methods, such as bolus for day time and continuous for overnight.

What You Need to Know About Nasal Tubes

About Nasal Tubes (NG-, ND-, and NJ-tubes)

Nasal tubes are non-surgical and temporary. The choice between nasogastric (NG), nasoduodenal (ND), and nasojejunal (NJ) depends on whether your child can tolerate feeding into the stomach or not.

NG-tubes

NG-tubes enter the body through the nose and run down the esophagus into the stomach.

ND- or NJ-tubes

ND-tubes are similar to NG-tubes, but they go through the stomach and end in the first portion of the small intestine (duodenum). NJ-tubes extend even further to the second portion of the small intestine (jejunum). Bypassing the stomach can be beneficial for those whose stomachs don't empty well, who have chronic vomiting, or who inhale or aspirate stomach contents into the lungs.

Questions to Ask

- Will it be an NG-, ND-, or NJ-tube?
- Will we leave the hospital with this tube?
- What should I do if the tube is pulled out?
- How long will this tube be in place?
- How often do we need to replace it?
- How do we replace it?
- At what point do we need to consider a more permanent tube, such as a G-tube?
- Do I need to check placement before feeding or giving medication?
- How do I check the placement?



Tips for Little Hands and Nasal Tubes

Babies and small children will often try to pull their nasal tubes out. At night, try putting mittens or socks on your child's hands to keep him/her from pulling the tube out. You can tape the nasal tube (or feeding bag tubing) down the back of the shirt during the day to keep it out of the child's way. At night, you may want to tape it further down the pajamas. If the pajamas are two-piece, you can run tubing inside the pajama leg to keep children from tangling. (See page 22 for more information about overnight feeding.)

Nasal Tube Considerations

- They are non-surgical and temporary.
- They are a good way to quickly get infants and children the nutritional benefits of tube feeding.
- They can be helpful in determining if longer-term tube feeding will be beneficial.
- Nasal tubes need to be taped to the cheek, which can be irritating to some children.
- Little hands often succeed in pulling nasal tubes out. Make sure you discuss accidental removal with your doctor and have a replacement plan, because it will happen.
- You may see increased nasal congestion, especially in infants.
- Nasal tubes can make reflux, gagging, and oral aversions worse.
- Nasal tubes can clog easily because they are very narrow. This is unlikely to happen with regular feeding, but may happen with medications that aren't in liquid form. If your child has any medications that need to be crushed, discuss with your doctors if there is a liquid, compounded, or dissolvable form that can be used.
- Some hospitals do not let infants or children go home with nasal tubes. Discuss this with your doctor in advance (if possible).
- Nasal tubes are intended for short-term use. They need to be changed every 3 days to 4 weeks, depending on the type of tube. If longer-term tube feeding is needed, it may be time to discuss a G-tube (gastrostomy tube) that is placed directly into the stomach (See page 9).
- Nasal tubes are highly visible since they are taped to the face. They may draw unwanted attention because few people know what they are. They may also be confused with oxygen, since that is the reference point most people have when they see a tube near the nose.

Life at Home with a Nasal Tube

Parents and caregivers can learn how to place, or “drop,” an NG-tube at home. You will need to be taught by a medical professional, because the correct placement is very important. Learning to replace the tube yourself makes it a lot easier to do routine changes and replace a tube that gets pulled out at home.

You will need to check the placement of the nasal tube after you insert it. It is a good idea to confirm placement before the start of each feed and if your child vomits forcefully.

Some NG-tubes have numbers on the side that allow you to see if they have moved. Or you can mark the tube before placement so that you can tell if it has been partially pulled out.

Your doctors and nurses will discuss different methods for confirming tube placement. A common way to check placement is to fill a syringe with 1 to 2 ml of air and rapidly push it into the tube while listening to the stomach with a stethoscope. If you hear a “whoosh” or “burp” as the air goes in, the NG-tube is in the stomach. You may also be told to draw back stomach contents using a syringe.

NJ-tubes, and some ND-tubes, need to be placed by a radiologist with X-ray guidance to ensure correct placement. They cannot be changed at home.





How to Tape a Nasal Tube

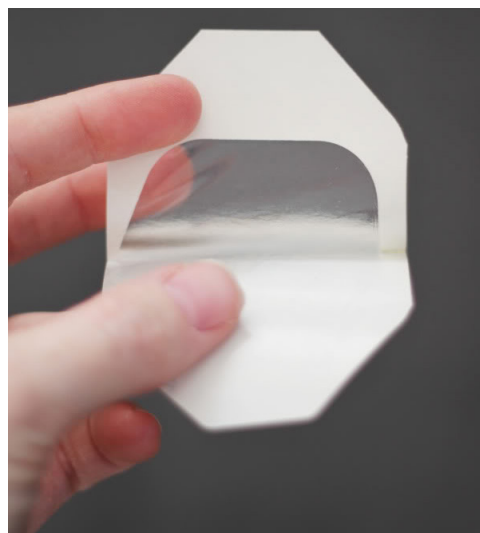
Taping is an art, and there is definitely a process of trial and error to find what works best for you and your child. Often a piece of an extra thin dressing called Duoderm is placed on the skin, the nasal tube is run on top of it, and then a clear Tegaderm dressing is applied on top.

Here is a common method:

1. Prior to placing the NG-tube, clean and dry the cheek and apply a piece of Duoderm Extra Thin to the cheek.
2. Insert the tube and lay it on top of the Duoderm.
3. Secure the tube to the Duoderm with a piece of Tegaderm.
4. Add a small strip of tape closer to the nose (Durapore works well for this).
5. Tape tube to clothing at the back of the neck to keep the end of the tube accessible.



Duoderm



Tegaderm



Durapore

Please note: Specific products may not be available from all home care companies or covered by every insurance plan.

What You Need to Know About Gastrostomy Tubes



The most common type of feeding tube is the gastrostomy (G) tube. G-tubes are placed through the abdominal wall into the stomach. This sounds scarier than it is. The G-tube surgery can be performed in three ways: surgically through small incisions using a laparoscope, surgically using a larger open incision, or endoscopically using a scope into the stomach to create the stoma from the inside. The endoscopic method has become the method of choice at many hospitals; however, some institutions still place tubes surgically, and children with anatomic abnormalities or who need other procedures may require a surgical placement.

There are a number of types of G-tubes. Any kind of G-tube can be placed initially. Often it is the surgeon or the gastroenterologist who determines the first type of G-tube placed. Below are some of the most common types of G-tubes you may encounter.

PEG and Long Tubes:

These are one-piece tubes held in place either by a retention balloon or by a bumper. They are often used as the initial G-tube for the first 8-12 weeks post-surgery. PEG specifically describes a long G-tube placed by endoscopy, and stands for percutaneous endoscopic gastrostomy. Sometimes the term PEG is used to describe all G-tubes. Surgeons may place other styles of long tubes.



Low Profile Tubes or Buttons:

These tubes do not have a long tube permanently attached outside the stomach. Instead, they have a tube called an extension set that is attached for feeding or medication administration and then disconnected when not in use. When an extension set is not attached to the button, it lies fairly flat against the body. There are two types: balloon and non-balloon.



Balloon Buttons: Balloon buttons are held in place by a water-filled balloon. Balloon buttons are the most common G-tube for children once the stoma (G-tube site) is fully healed, usually in 2-3 months. The use of balloon buttons as a first G-tube is increasing among medical professionals. Balloon buttons can be replaced at home after caregiver training.

Non-Balloon Buttons: Some surgeons and gastroenterologists prefer the first G-tube to be a non-balloon button. Non-balloon buttons are harder to pull out than balloon buttons. Non-balloon buttons cannot be replaced at home. They are placed in the doctor's office or at the hospital, sometimes with sedation or a topical pain reliever.



Questions to Ask

- Is this an open or laparoscopic surgery procedure or will it be performed by endoscope? Why are you choosing to do it that way?
- Will you be doing a fundoplication? If so, will it be a full Nissen or partial fundoplication? Why or why not? (See sidebar for more information.)
- Will my child be receiving a long tube or a button? Will it be a balloon tube or a non-balloon device? Why are you recommending this type of tube? If you are recommending a long tube, when can it be changed to a button?
- What is your plan for pain management after surgery? What pain meds will be given, and how will they be given? *NOTE: Adequate pain management after surgery is very important and will lessen recovery time. Do not be afraid to be an advocate for your child to make sure pain is well controlled. Having a plan ahead of time is especially helpful.*
- What should my child expect as far as recovery? How long do you expect my child to be in the hospital?
- How soon after surgery should we expect to start feeding through the tube?
- Who will determine the feeding plan, and can I be a part of those decisions? *NOTE: Some children need to start out with slower or smaller feedings, especially if they have had a Nissen fundoplication. It is important to try to avoid retching (dry heaves) from feeding too fast, too much, or too soon.*



What is a Fundoplication?

Fundoplication is a surgical procedure where the top of the stomach is wrapped around itself to prevent reflux. When the stomach is wrapped fully, it is referred to as a Nissen fundoplication (also called a Nissen, Nissen fundoplication, fundoplication, or just fundoplication). When the stomach is only partially wrapped, it is called a partial fundoplication.

This surgery is not required when getting a G-tube placed. It may be advised in instances when a child has severe reflux-related airway problems or when there is severe damage to the esophagus from reflux. Children who vomit a lot or who have delayed gastric emptying are often not good candidates for a fundoplication. In these cases a gastrojejunal tube (GJ-tube) may be an alternative to a fundoplication.

Parents should discuss the procedure with their doctors and research the procedure before committing to a fundoplication.

Fundoplications often inhibit a child's ability to burp and vomit, at least temporarily. Many children require frequent venting for gas, as well as for stomach fullness that would lead to vomiting in a child without a fundoplication.

Life at Home with a G-tube

How to Vent Air from the Stomach Via G-tube

Some children get uncomfortable when there is air in the stomach. You can vent air out of the stomach every few hours as needed. You may want to vent before each feeding, around the time of each diaper change, or after feeding. Children who receive fundoplication surgery may need to be vented more often. You will learn how often your child needs to be vented.

In order to vent, you need a large syringe with the plunger removed, a cup, and towel because sometimes stomach contents comes out with the air. If your child has a button-style tube, you will need an extension set (preferably a straight/bolus extension). Note that the Bard Button has a special extension set for venting called a decompression tube.

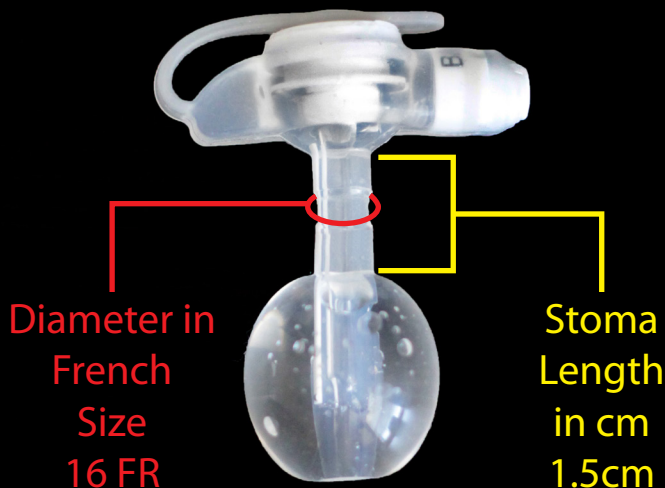
Insert the open syringe into the end of the long tube or into the extension set, then unclamp the tube. Gently pushing on the stomach (or raising your child's legs to the chest) will help to move the air towards the tube and allow it to move out. Food may also come out. You should let it slowly run back in when finished. This is often referred to as re-feeding. The Feeding Tube Awareness Foundation has videos on different venting techniques. These are available on line. For more continuous venting, even while feeding, you can use a Farrell valve bag.

Gastric Tube Considerations

- G-tubes can be more comfortable than nasal tubes and are a safer option for longer-term tube feeding.
- There are low profile, button-style G-tubes that aren't as noticeable under clothing.
- The balloon button G-tubes can be replaced at home by a trained parent or caregiver.
- Balloon buttons and tubes typically need to be replaced every 3 months, while non-balloon buttons need to be changed less often, between every 6 months to a year.
- G-tubes need to be placed surgically or endoscopically, and there is a recovery period after.
- Little hands may also pull out G-tubes.
- A common complication of G-tubes is the formation of granulation tissue (which looks like red, overgrown tissue around the tube site) during the healing process. It isn't dangerous but it can be painful and irritating. It may also bleed easily. (See *troubleshooting*, page 23.)



Feeding Tube Size



Sizing for G-tubes

All G-tubes are sized by the width of the tube, which is measured using the French scale, across the diameter of the tube. G-tube buttons require a second measurement, in centimeters, based on the length of the tube's stem (the part of the tube that is placed in the stoma or tube site). For example, a 16Fr 1.5cm tube has a French size (diameter) of 16 and a stem length of 1.5cm. The size is listed on MIC-KEY and AMT button G-tubes. G-tubes should have enough room between the tube and the skin to allow one or two coins to slide under. If the tube is pressing tightly against the skin or has much more room, your child may need a different stem size.

Caring for the New Stoma

Less is more with tube site care, particularly in the beginning.

New stomas often ooze cream-colored secretions. Initially, you may use gauze or another dressing around the site. You should change the gauze as often as needed to keep the site dry. Keeping the site dry is important to healing.

The dressing usually can be removed after a few days. Keeping the site open to the air is good for healing. You may continue to see leakage that is clear or tan in color, which may become crusty as it dries. There may be small amounts of blood. You can gently wash the site with warm water and gauze or cotton swabs as needed throughout the day. Dry the site with clean gauze or a towel after.

New tube sites should not be submerged in water for at least a week or two unless otherwise directed by your doctor. Ask your doctor about any restrictions your child may have.

Think of the G-tube like an earring. In order to form the stoma, the new G-tube needs to be spun daily. (*See the troubleshooting section, page 23, for more information on granulation tissue and stoma complications.*)

Securing the PEG or Extension Set

Other than the daily spinning of the G-tube, movement and pulling on the site should be minimized to prevent trauma and leakage.

Many parents use medical tape, such as Micropore (paper tape) or Hypafix, or a securement device, such as a Grip-Lok, to secure tubes and extension sets, especially for continuous feeders. You can secure the tube to the stomach with tape. Or you can form a tab to pin to the child's clothing or diaper by wrapping tape around the tubing and folding it back onto itself.



What You Need to Know About Gastrojejunal Tubes

GJ-tubes are placed in the stomach just like G-tubes, but a thin, long tube is threaded into the jejunal (J) portion of the small intestine. The vast majority of children who get GJ feeding tubes begin with G-tubes; it is rare for a GJ-tube to be placed initially. Most GJ-tubes have separate ports to access both the stomach (G-port) and the small intestine (J-port), though some tubes, often called Transjejunal (TJ) tubes, only allow access to the small intestine. GJ-tubes are available both as buttons or long tubes.

Most often the J-port is used for feeding and the G-port is used for venting and sometimes for medications.

Life at Home with a GJ-tube

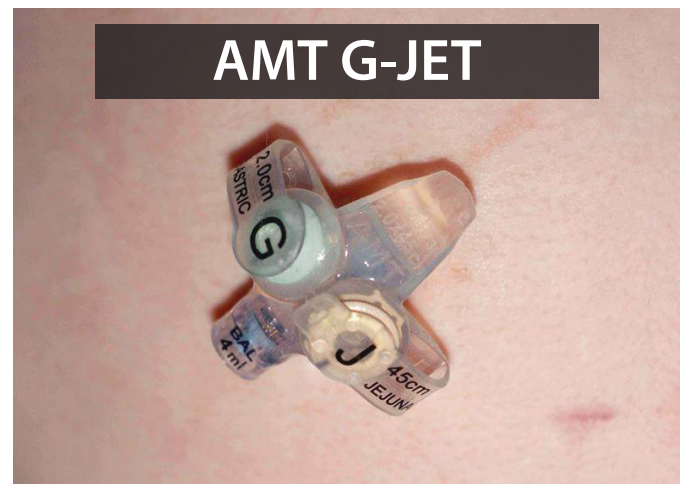
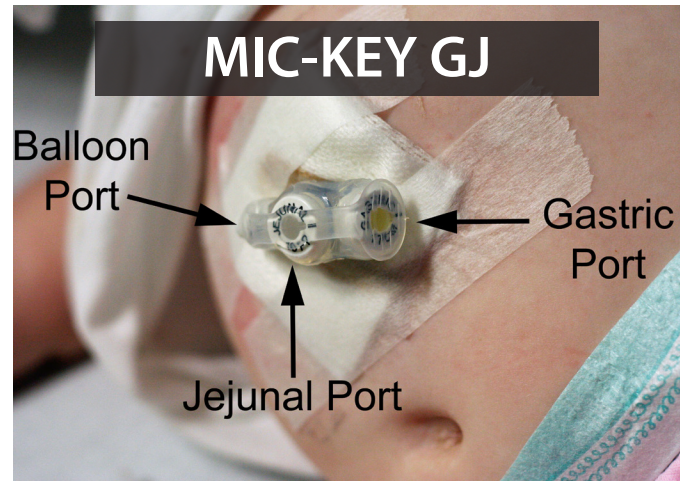
You may need to vent air from the stomach via the G-port:

You will most likely still need to vent the G portion of the GJ-tube. In the beginning, you may need to vent every 3 to 4 hours. One of the challenges of a GJ-tube is that the J tubing holds the pylorus (entry to the intestines) partially open, and that may allow bile from the small intestine to seep into the stomach. If bile reflux occurs, the stomach can be vented to prevent the bile from being vomited or refluxed. In rare cases, the stomach needs to be continuously drained. What is drained out can be replaced with a hydration solution as directed by your physician, or re-fed into the intestines via the J-port. Talk to your child's medical team if there is a problem with bile in the stomach.

Keep the GJ-tube from spinning: Unlike a G-tube, the GJ-tube should not be rotated. Rotating a GJ-tube can result in the tubing becoming kinked or dislodged from the intestines.

GJ-tubes need to be flushed: GJ-tubes need to be flushed more often than G-tubes. The J-port is particularly likely to clog because of the longer length and smaller diameter of the tube. The J-port should be flushed every 4-6 hours, especially after medications have been given, and after feeds have ended. Water should be flushed slowly into the J-port each time. It is usually OK for parents not to wake in the middle of the night to flush the J if feeds are running continuously.

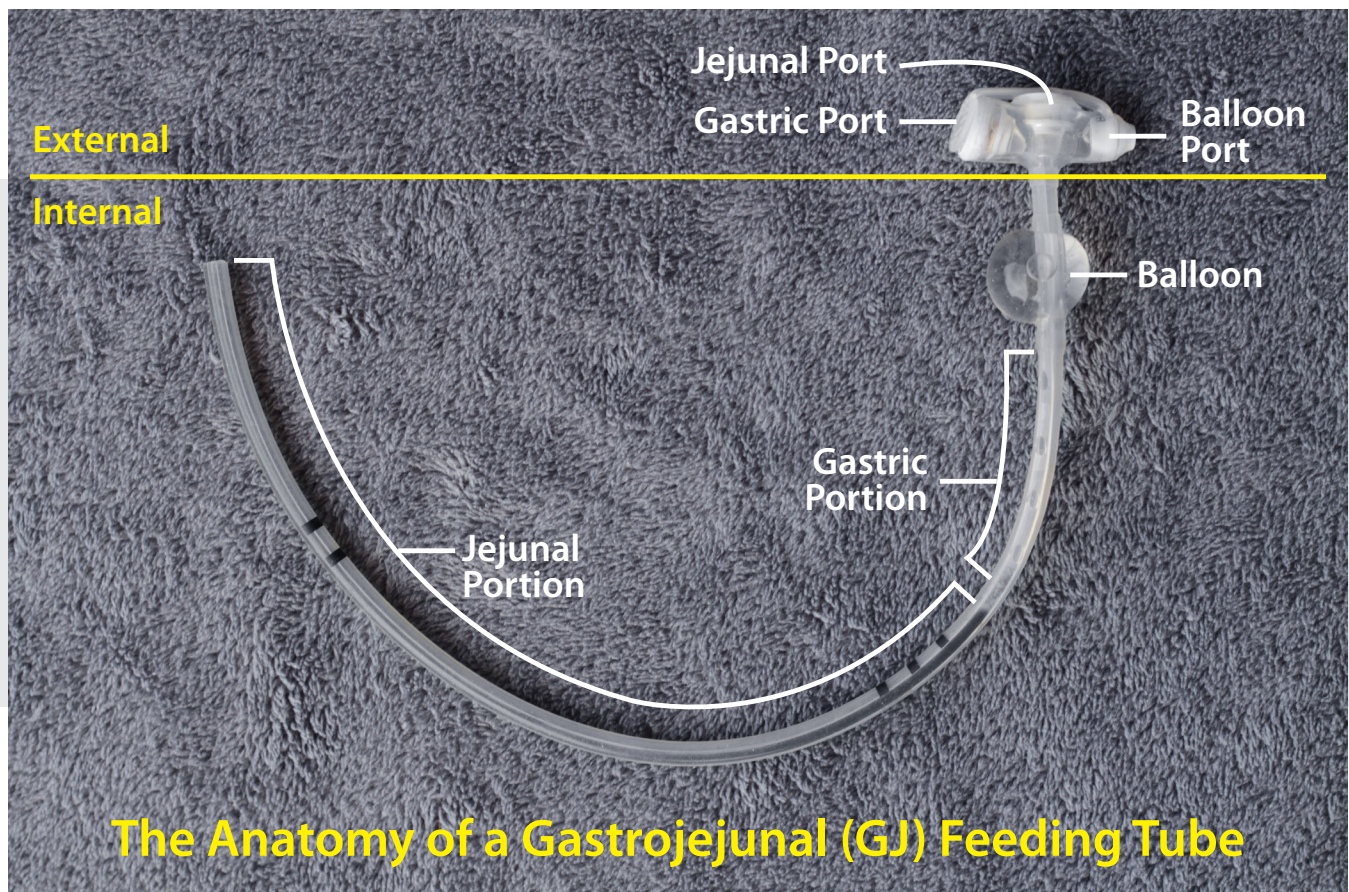
Many medications can be given using the J-port: Most can be given in either the G- or J-port, though there are a few that must be given through the G-port. A doctor or pharmacist can determine which medications should be given through which port. Some kids are highly sensitive to volumes in either the G- or the J-port, so medications and flushes may need to be spaced apart and given slowly.



There may be changes in stool with J feeds: Be aware that there may be drastic changes in stools for the first few days. The body needs time to adjust to formula bypassing the stomach and going directly into the intestines. If your child is having diarrhea or constipation issues, it is important to let your doctor know so he or she can help manage stooling problems.

You should never see formula in the stomach when feeding to the intestines: If you see formula when venting the stomach or if your child vomits formula, you should contact your doctor immediately. This can be a sign that the J-tube has migrated to the stomach.

It is important to check which medications should be given through the G-port and which through the J-port: Some medications can only be absorbed in the stomach and must be given through the G-port. Others can be given safely through either port.



GJ-tube Considerations

- GJ tubes may be a good option for individuals with poor stomach function or motility, chronic vomiting and respiratory problems from reflux. Feeding the intestine (through the J-port) may alleviate these problems.
- Individuals who feed into the Jejunal (J) port must be fed continuously.
- Part of the benefit of GJ feeds comes from getting the formula slowly. If your child has never tried continuous feeds through the G-tube, you should try this before converting to a GJ.
- For some, the GJ-tube can be an alternative to a Nissen fundoplication.
- Start J feeding slowly, and gradually increase the rate over hours or days. If you increase rates too quickly with J feeds, you may see retching, discomfort, or diarrhea. Often J feeds are started with Pedialyte before formula is added in. It may take 24 hours or more to get to the goal rate. It is not uncommon for continuous feeds to run for 20 hours a day or more with GJ-tubes, especially in the beginning.
- GJ-tubes can allow for continuous feeding through the J-port, and frequent or continuous venting and drainage from the G-port, if necessary.
- Like ND- and NJ-tubes, GJ-tubes must be inserted by a radiologist to make sure they are placed correctly. Sometimes a sedative or anesthesia is used. In some cases, the procedure can be done with the child awake.
- Like other balloon buttons, button GJs need to be changed about every 3 months. They are more likely to clog than G-tubes and must be flushed well after feeds and medications are administered.

Separate Jejunal (J) Tube

It is sometimes necessary to place a separate J-tube that has a stoma directly to the intestine. This is not usually an initial feeding tube placement for a child.

J-tubes are placed by a variety of methods, including a Roux-en-Y technique and a direct placement. Most are surgically placed, but they can also be placed endoscopically. Initial tubes can include long tubes or buttons. Most children can eventually move to a button style tube, identical to the ones placed as a G-tube, once the tract heals.

What You Need to Know About Your Supplies

Getting a feeding tube means getting a lot of new equipment and supplies. Be sure you know what all the supplies are for. Try out everything yourself before leaving the hospital. Make sure you ask a lot of questions. The equipment in the hospital, especially the feeding pump, may not be the same type you will receive at home. Ask that your home pump and supplies be delivered to the hospital before you are discharged, and that someone from the medical supply company or a nurse shows you how to use and program your pump before you leave the hospital.

Feeding Pump and Bags:

Many children use a feeding pump for continuous feedings, overnight feedings, or on-the-go feedings. There are two main pumps available in the United States: the Moog EnteraLite Infinity and the Covidien Kangaroo Joey.

The Moog Infinity is a small, lightweight pump that can run in any position. It can use bags that hold either 500ml (about 17 ounces) or 1200ml (about 41 ounces) of formula or liquids. There is also a Moog Infinity Orange pump designed for small feedings, which has bags that hold 100ml (about 3 ounces).

The Covidien Kangaroo Joey is larger and heavier, and has more adaptable features. Kangaroo Joey bags come in 500ml (about 17 ounces) and 1000ml (about 34 ounces) sizes.

Which pump is right for you will depend on your child's size and your child's feeding requirements. Some suppliers also only carry one brand of pumps, and some insurers only cover one brand.

Make sure your medical supplier gives you the pump manual. Pump manuals can be found online at the manufacturer's website and on the Feeding Tube Awareness Foundation's website (www.feedingtubeawareness.org/Resources).

You should receive enough feeding bags so that you can use a new one every 24 hours. Most supply companies deliver 30 days' worth per shipment.

You do not need to rinse the bag between feeds. You can place the bag in the refrigerator between uses at home.



The Moog Infinity



The Kangaroo Joey

Rate and Dose:

The rate is the amount given per hour. The dose is the total amount of the feed (given over the duration of the entire feed). To find the correct pump rate simply divide the dose by the feed time in hours. If you wanted to give a dose of 100ml over one hour, your rate would be 100ml. Adjusting that dose over different times, for example:

Over 15 minutes: pump rate = 400 (100ml/0.25hours)
Over 30 minutes: pump rate = 200 (100ml/0.5hours)
Over 45 minutes: pump rate = 133.3 (100ml/0.75hours)
Over 120 minutes: pump rate = 50 (100ml/2hours)

Backpacks:

Backpacks are extremely convenient for feeding while out of the house. Mobile children are able to wear a feeding backpack and be fed on-the-go. Ask if your pump can be delivered with a backpack. Often insurance will cover a backpack for the feeding pump.

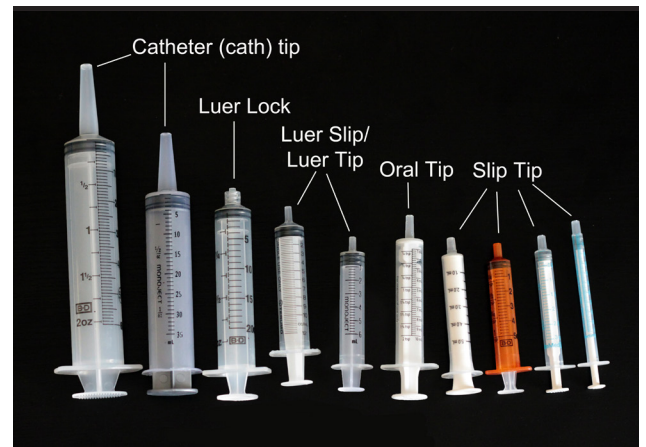
Moog makes a Super Mini backpack for the Infinity, which holds a 500ml feeding bag, allowing even young children to wear their pumps. The Mini backpack for the Infinity pump, for a larger child, holds a 500ml or 1200ml bag. The Kangaroo Joey also has backpacks that hold either size feeding bag. Many parents opt to convert a child's regular backpack to accommodate the pump and feeding set, and there are also several small companies that sell custom or converted backpacks online.



Syringes:

There are many different types and sizes of syringes. Many families who use a syringe for feedings or venting prefer larger 60ml syringes. Most medications can be dosed using 1, 5, or 10ml syringes. Catheter (large, long tip) or slip tip (short, thin tip) syringes are good choices to start.

Syringes may or may not be covered by insurance. Some pharmacies will give them out for free with medications. Syringes can be reused at home. They can be washed with soap and hot water and rinsed well. Do not put syringes in the dishwasher.



Tape:

There are many types of tape with varied uses.

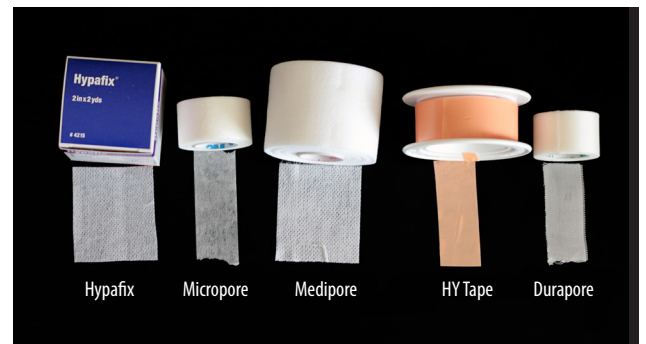
Hypafix: This is a flexible, breathable cloth tape that must be cut with scissors. It has a strong hold even when wet but is gentle on skin. It works well for securing NG-tubes and G-tube/GJ-tube extension sets.

Micropore: Micropore (paper tape) is a gentle adhesive that comes off easily when wet. It is the most versatile kind of tape and it works well for securing G-tube or GJ-tube extension sets to the skin.

Medipore: Medipore is a flexible, breathable cloth tape similar to Hypafix except that it is pre-perforated so no scissors are necessary. The adhesive is not quite as strong as Hypafix.

HY tape: This is a non-breathable waterproof tape that works well for sensitive skin and for taping NG-tubes.

Durapore: Durapore is a silky cloth tape with a very strong adhesive. It is not good for sensitive skin but has a strong hold unless it gets wet. It works well for taping NG-tubes and extension sets to clothing.



Note: Not all specific products will be supplied by every supplier or covered by every insurer. You may be able to get specific products covered or request more of a particular product (such as extension sets) by requesting a letter of medical necessity from your doctor or nurse practitioner.

Extension Sets:

If you have a button style feeding tube, rather than a nasal or long tube, you will need extension sets that attach to the button. These extension sets connect from the button to a syringe or a feeding pump bag to allow you to feed, give medications, and administer liquids.

Each button manufacturer produces extension sets that fit their buttons, and offers multiple styles in terms of length and port options. Know there are many options available, so you can request what will work best for your needs.

Before using the extension set, prime it (fill it) with water or food/formula to get the air out. Priming should always happen prior to connecting the extension set to the button, otherwise the air in the empty extension will be pushed into the stomach. The easiest way to prime the set is to open the straight-port on the top, hold it under a faucet, and run water directly into it. Be sure to close the side medication port first (if one is present), and pinch the clamp closed once there is no more air in the extension set. You can also fill the extension set by using a syringe if the extension set is not connected. Another option is to connect the extension set to the feeding set and prime the entire length of tubing at one time.

After use, extension sets can be cleaned with dish soap and hot water. They should be rinsed well so that no soap remains in the tubing. Extension sets are usually replaced every 1 to 2 weeks, but can be used up to a month, if necessary.



Straight vs. Right Angle

Right Angle: Connects at a 90 degree angle laying flat against the body; smaller diameter tube; best for continuous feeds and giving medications.

Straight: Connects straight into the button and sticks straight out; has a larger diameter tubing to accommodate larger volumes and thicker formulas; best for bolus/gravity feeds and venting.

**Exact product names will vary by manufacturer.*



Bard Compatible Extension Sets

There are two types of Bard Extension sets.

Decompression/Venting Extension: The extension on the left is the decompression extension, which is used to vent.

Feeding Extension: The two extensions on the right are both used for feeding.

Non-Medical Supplier Products:

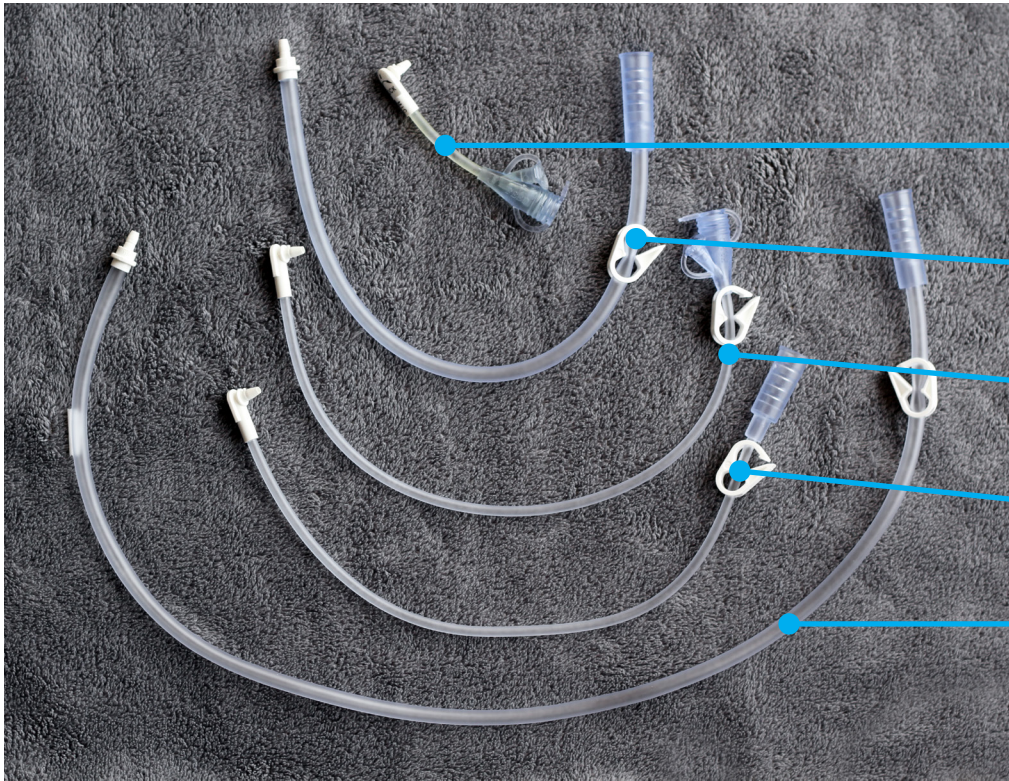
There are many tube-related products made by small companies and fellow tube feeding parents. These include backpacks, cloth G- and GJ-tube pads, protective belts, adapted clothing, med port covers, stuffed animals with tubes of their own, books about tube feeding, incline wedges for sleeping, medical beds, cloth diaper covers to help with overnight feeds, stickers to make NGs more kid friendly, and much, much more. You do not need any of these things right away. Just know that they are available. Many of them are listed at:

www.feedingtubeawareness.org/useful-products.html



AMT Extensions:

- 12" Straight Single Port
- 12" Right Angle Y-Port
- 12" Right Angle Single Port
- 12" Right Angle Y-Port (Clear)
- 24" Right Angle Single Port



MIC-KEY Extensions:

- 2" Right Angle Y-Port
- 12" Straight Single Port
- 12" Right Angle Y-Port
- 12" Right Angle Single Port
- 24" Straight Single Port

24" Right Angle Extensions are also available for AMT and MIC-KEY (not pictured)

AMT Mini One and MIC-KEY Extensions are compatible for the AMT Mini One G-tube button and the MIC-KEY G-tube and GJ-tube buttons.

Questions to Ask

The following is a list of questions for you to ask prior to discharge to make sure you have all the details about your child's feeding tube and feeding schedule.

What kind of feeding tube does my child have?

Circle one: NG ND NJ G GJ/TJ J Other: _____

Brand/Style: _____

Size (French size, stem length, tube length): _____

What medications is my child taking? *Include concentration, dose, method, and time of administration.*

Who do we contact for help/questions once we are discharged? *Note contact info for doctors, and who to contact for what types of issues. This could include the surgeon, GI doctor, pediatrician, nurse practitioner, or dietician.*

What should we expect during recovery (including pain and complications)?

How should I care for the surgery site? When can my child take a bath?

What should I do if my child's feeding tube accidentally comes out? *Ask for details on how quickly you need to act, or if you should insert something in the stoma to keep it open, such as a spare G-tube or Foley catheter.*

Accidental removal before ____ weeks:

Accidental removal after ____ weeks:

What should I feed my child (such as breast milk, formula, blended food or supplements)? *Include mixing instructions, if applicable, how long the food can be left out without refrigeration, and instructions for oral feeding.*

How should I feed my child? Include details on how much, how often, bottle or oral eating, pump, gravity or by syringe push. If you are using a pump, be sure to note the rate and dose.

What equipment or supplies am I taking home with me?

Who is my supply company and what is their contact information?

How do I reorder when I need more supplies?

Which doctor or nurse practitioner is writing the orders, in case I need to request something different?
(Examples: feeding pump, IV pole, backpack, delivery sets, feeding extensions, syringes.)

Other Important Information (e.g. follow up appointments):

Basic Troubleshooting at Home

It is impossible to learn everything right away. There are many things you learn as you go. The best advice we can give as parents is to ask questions of other parents who have been through it.

When should I call my child's doctor?

Fever over _____
Feed intolerance (*increased vomiting or retching*)
Changes in bowel movements (*diarrhea, constipation*)
Tube is pulled out or falls out
Stomach becomes distended

Specifically For G-/GJ-tubes:

Signs of infection around stoma
Excessive leakage or blood
Granulation tissue around stoma
Tube is too tight/too loose
Specific to my child: _____

How do I know if my child is not tolerating feeds?

Tube feeding can be viewed as an art rather than a science. Eventually, you will learn to read your child's signs, but those signs can be hard to spot at first. Typical signs of problems with feeding, referred to as feeding intolerance, include coughing, retching, dry heaving, swallowing hard, sounds of "rumbling" or sloshing in the stomach, vomiting, appearing uncomfortable, diarrhea, and sometimes even sneezing. You should let your doctor or dietitian (whomever is managing your child's diet) know if your child is experiencing feeding intolerance. You will likely have to adjust when, how, or what you are feeding your child, with guidance from your medical professionals.

The most common culprits of feeding intolerance are:

Too much food, too fast. Try decreasing the volume per feed, and/or give the feed a little slower. It can take a long time to build up tolerance in children who are fed by tube. If you are using a pump to feed, you can decrease the rate and feed over a longer period of time. If you are using an open syringe or gravity bag, remember that the height of the food (relative to the stomach) controls how fast the formula flows. The higher the food is above the stomach, the faster the formula flows. If you hold the food below the stomach, flow will stop or reverse.

Caloric density of the formula is too high. Breast milk averages 20 calories per ounce and this is a caloric density that most babies and children can digest easily. When the decision is made to place a feeding tube, your child may be underweight or losing weight, and the natural tendency is to

increase the calories per ounce of formula. Unfortunately, this may result in reflux and vomiting. Just as you need to slowly increase the amount and rate of each feeding, you may need to slowly increase the amount of calories in each ounce of food or formula, too.

It's not the right food/formula.

Dairy-based formulas and very high calorie formulas can be harder to digest and can result in feeding intolerance for some children. Formula that is partially broken down (peptide-based) or fully hypoallergenic (amino acid-based) may be tolerated better. Many parents also puree whole foods and feed a blenderized diet through the tube. A supportive dietitian and GI doctor are key team members in the decision about what to feed your child. It is also important to make sure that your child doesn't have food allergies or a medical condition that is contributing to intolerance.

What do I do if the tube gets pulled out?

Talk with your doctor about what to do if your child's G-tube is pulled out in the first few months after surgery. Your child may need an X-ray to confirm proper placement, as the stoma is still healing during that time. Stomas can close very quickly, so you want to have a plan in place ahead of time that will allow you to act quickly. Once your child's stoma is healed, children with balloon buttons can have their buttons changed at home. Your child's doctor or nurse will teach you how to change the button yourself, and you should always have an emergency kit with water-based lubricant, an extra G-tube or Foley catheter, tape, and a 5ml slip tip syringe for deflating and filling a balloon button with water. It is very important to be well trained on placement before attempting an emergency replacement yourself!

For those with a GJ-tube, common symptoms of a GJ-tube being out of place include vomiting formula, feeding intolerance, GI pain, or formula coming out the G-port when venting. If you see these signs call a doctor or go to the hospital immediately. The best way to determine if your child's GJ-tube may be out of place is to have the tube X-rayed using contrast or dye.

Basic Troubleshooting at Home

What if the tube gets clogged?

If the tube becomes clogged, flush with warm water, just like you would if you were administering medication.

Try alternately pushing and pulling on the syringe with different size syringes, as you may be able to pull back with more force depending on the type of syringe.

For severe blockages, especially in children with GJ-tubes or tubes that cannot be changed out, your doctor can prescribe pancreatic enzymes to put into the tube to eat away the blockage.

How do I know if my child is getting enough calories and fluids?

You should speak with your medical professional about the hydration and calorie needs of your child. Knowing how many calories your child needs is helpful when designing a tube feeding plan.

Also be mindful of your child's hydration needs. Ask how you should be monitoring and calculating hydration. Remember that formula is not 100% water, and you might need to add extra water in addition to feedings, especially if you are feeding higher calorie formula. Know the signs of dehydration: reduced amount of urine, which is also dark yellow in color, dry membranes in the mouth, no tears when crying, sunken eyes, and restlessness, irritability, lethargy, or strong smelling urine.

My Child's Target Calorie/Fluid Intake:

How do you do overnight feeds?

If you have a backpack, you can hang it on the end of the crib or bed, using a link or carabineer clip. Your home health care supplier may provide an IV pole for you to attach the pump and hang the bag. For children who sleep in cribs, be sure to drape the tube over the top of the crib rail, and not through the side of the crib, so you are able to pick your child up easily without pulling the tubing.

You don't need to refill formula in the middle of the night! Most formulas, as well as breast milk, can be hung for 4-6 hours without refrigeration (check the label). But with a good ice pack tucked in the backpack or rubber-banded to the feeding bag, they can hang for at least 8-10 hours.

Parents are often concerned about tubing getting tangled around a child's neck. For an NG-tube, you can tape the tubing down the child's back, and then down the pajama leg. If the pajamas are two-piece, you can run the tubing inside the pants leg. For G- and GJ-tubes, you can tape the extension set to your child's stomach or clothing, and then run it down the inside of a pants leg.

You can use a section of a pool noodle, pipe insulation, or even an empty paper towel roll to tame tubes and prevent tangling, especially if you have multiple tubes. There are also products sold as line tamers to corral multiple lines.

If reflux is a concern, you can rig a crib, toddler bed, or twin bed to be inclined using comforters, quilts, or towels **under** the mattress, to raise it to a 30-degree angle on one end. There are also medical inclines available, but check with your doctor before putting anything on top of a child's mattress.



Basic Troubleshooting at Home

What is this red, bubbly tissue around the tube site?

Granulation tissue is typically red or pink soft tissue that appears bumpy or almost bubbly in nature. It is the body's attempt to heal the tube site. It can bleed very easily and may grow quite rapidly. However, while granulation tissue may be bothersome, it is not dangerous.

Your doctor can use Silver Nitrate to cauterize (or remove) the tissue, or may prescribe creams, such as Triamcinolone (Kenalog) ointment. Calmoseptine ointment is an over-the-counter product that many parents use to help treat mild granulation tissue and soothe irritated skin.

Stabilizing tubes and extensions can help by reducing friction at the tube site. You can tape them to the stomach or create a tab that can be pinned to a diaper or clothing by folding the tape back onto itself.

Keeping the area dry is extremely important to prevent granulation tissue. Some families prefer to keep the tube site open to air, some use gauze under the button, and some use cloth tube pads. At first the site may leak. But within 4-6 weeks, the leakage should diminish.

Have your doctor check the sizing of the feeding tube, as an incorrectly sized tube can make granulation tissue worse.

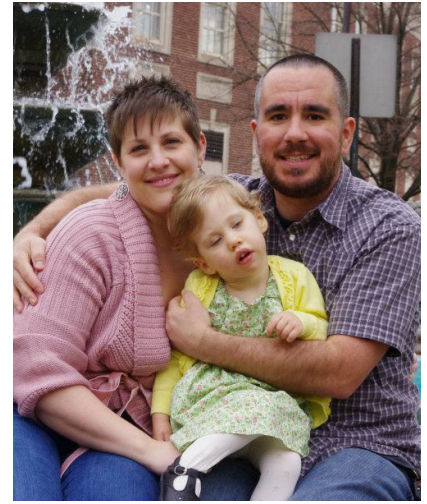
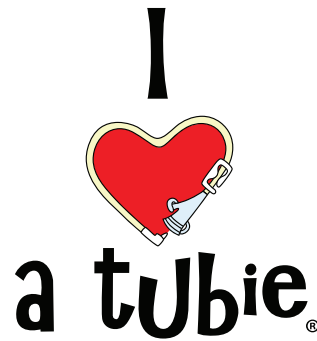
What if the tube site (stoma) looks infected?

The signs of infection are:

- Angry, red, or red-streaked stoma
- Weepy, oozing, or pus-filled stoma
- Foul or unusual smell
- Pain or sensitivity when the feeding tube is touched
- Fever

Sometimes stomas can be infected in the tract on the inside, so there may be no visible signs besides pain and tenderness. Consult your child's doctor if you suspect an infection. The doctor may perform a culture of the site, and may prescribe topical antibiotics, and in some cases oral antibiotics, to treat the infection.





Feeding Tube Awareness Foundation®

The Feeding Tube Awareness Foundation was founded in 2010 by parents of children who are tube fed, who understand the emotional and practical challenges associated with raising a child who is complex.

The mission of the organization is to raise positive awareness of tube feeding, to increase the visibility and acceptance of tube feeding in our communities, and to help parents get the practical knowledge and support they need. The Feeding Tube Awareness Foundation is a registered 501(c)(3) charitable organization that is run 100% by volunteers who currently have children who are tube fed.

The organization's website (www.feedingtubeawareness.org) is an unparalleled resource for parents and caregivers. We provide knowledge and experience that only parents who are tube feeding their children in a home environment can have. The site provides answers to frequently asked questions, has video tutorials, and links to useful products and resources.

Our Facebook page is the world's largest online support group for tube feeding. Thousands of parents, caregivers, and older tube feeders exchange information and share their experiences in real-time. It is a source of support and understanding that is especially beneficial to parents who are new to this.

Remember, you are not alone! We, along with thousands of other parents and caregivers of children with feeding tubes, are here to help.

www.feedingtubeawareness.org
www.facebook.com/FeedingTubeAwareness



Feeding Tube Awareness Week®

In 2011, Feeding Tube Awareness launched the first annual Feeding Tube Awareness Week®. The mission of Awareness Week is to promote the positive benefits of feeding tubes as a life-saving medical intervention. The week also serves to educate the broader public about the medical reasons that children are tube fed, the challenges that feeding tube families face, and day-to-day life with a feeding tube. Feeding Tube Awareness Week connects feeding tube families. Seeing how many other families are going through similar things helps us all feel less alone.

The second week in February was selected because of its proximity to Valentine's Day, because we love our tubies. The negativity surrounding the medical device that is keeping our children alive can be challenging. This week, in particular, is an opportunity to embrace the positives and be thankful that feeding tubes help our children to live, grow and thrive.

Thousands have participated in Feeding Tube Awareness Week. Millions have been reached through TV, newspapers, online media, websites, blogs, social media, and outreach from companies and organizations.

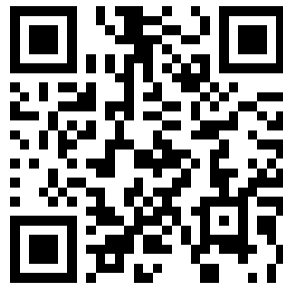


What You **Need** to Know Now

A Parent's Introduction to Tube Feeding

Feeding Tube Awareness Foundation®

Raising Awareness and Sharing Knowledge



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