A GUIDE FOR FAMILIES

Enteral Tubes





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A Guide to Enteral Device Tubes for Families

Who needs enteral tubes?

Children who live with a variety of diagnoses require enteral tubes. Some of these diagnoses include:

- Failure to thrive
- Oral aversion
- Gastroesophageal reflux
- Neuromuscular disorders
- Cerebral palsy
- Traumatic brain injury
- Severe constipation

What is a G-tube?

A gastrostomy tube (G-tube) is a special enteral tube that is inserted surgically through your child's abdominal wall into the stomach to allow them to receive formula, food and medications. This tube is used for children who have a difficult time eating enough calories by mouth to allow them to grow appropriately. A small surgical opening will be made into the stomach and an enteral tube will be placed in this opening. This is referred to as a stoma.

What is a GJ-tube?

A gastrostomy/jejunal tube (GJ-tube) is a special enteral tube that is inserted surgically through your child's abdominal wall into the stomach with an additional extension that goes into the small bowel. This differs from a G-tube as there are two ports to instill formula, food and medication. One port enters into the stomach and one port enters into the small intestine. This tube is typically used for children who have had a difficult time handling formula or food in their stomach. Your gastroenterologist and surgeon will help to identify which tube (G- or GJ-tube) is appropriate for your child. Similar to a G-tube, this tube is placed surgically through a small opening in the stomach. This is also referred to as a stoma.

What is an NG-tube?

Nasogastric tubes (NG-tube) are temporary enteral feeding tubes that enter the body through the nose and travel down your child's esophagus into the stomach. These tubes do not require anesthesia or surgery to insert but do need to be changed every two weeks. Some side effects of having an NG-tube for long periods of time include sinusitis, recurrent gagging, oral aversion to drinking and eating as well as a runny nose.

What is a C-tube?

A cecostomy tube (C-tube) is a special enteral tube that is inserted surgically through your child's abdominal wall into their large intestine (cecum) to allow them to receive antegrade enemas. This tube is used for children who have chronic medically refractory constipation. A small surgical opening (stoma) will be made into the large intestine under visualization by a camera that is inserted through the belly button. From there an enteral tube will be placed into the intestine.



Types of enteral tubes

There are a number of types of enteral tubes. Each type of tube has variety of pros and cons. Your child's gastroenterologist and surgeon will help determine what tube is best for your child.

PEG and long tubes

These are one-piece tubes that are held in place within the stomach by a balloon or a bumper. PEG stands for percutaneous endoscopic gastrostomy. This tube is placed by by a surgeon in the endoscopy suite.

Low profile tubes or buttons

These tubes do not have a long extension tube permanently attached to them outside of the stomach like the PEG tube. Instead, these tubes have an additional extension set which the child or family member attaches to the button when the child requires a feeding, enema or medication. When an extension set is not connected to the button, the enteral tube lies fairly flat against the body. These tubes are held in place in the stomach by either an inflatable balloon or a plastic bumper.

Enteral tube myths debunked

There is a lot of information on the internet regarding enteral tubes. After your child's enteral tube site heals they will have very little limitations and can participate in nearly all activities. Here are some common myths.

"My child can't swim or take baths with an enteral tube." They sure can! Your child must wait one to two weeks following surgery and then they can splash away.

"My child can't lie on their stomach." Immediately following surgery it may be uncomfortable to lie on their stomach, but after a few days this should go away. Your child can sleep or lie on their stomach for as long as they would like.

"My child can't play sports with a tube." Your child will have to avoid gym class, rough play and sports immediately after surgery. Following a full recovery, your child will have no activity restrictions.

"My child will have their tube for their entire life." Enteral tubes can be removed after your child no longer needs them. In some instances these tubes are used for months and other kids will use them for a lifetime. G-tubes and G/J-tubes commonly do not require any surgery for closure of the stoma. Unfortunately, C-tubes always require surgery to close the stoma.



Caring for the enteral tube

Enteral tubes should be cleansed twice daily with mild soap and water. This should not be uncomfortable for your child and should become part of your daily routine.



Gather equipment.

- a. Unscented soap
- b. Warm water
- c. Cotton tipped applicator
- d. Soft cloth or gauze pad
- e. Stoma adhesive powder or diaper cream (if indicated)



Wash hands.



Use mild soap and warm water on a soft cloth to clean stoma site and skin around the site. A good time to do this would be during your child's bath.



Gently lift the enteral tube and clean around the stoma site. Dip the cotton tipped applicators into warm soapy water and gently wipe around the stoma site. There may be crusting around the site. Gently remove this with the cotton tipped applicator.



After cleaning the area, pat dry. Keeping the area clean and dry helps to prevent bacteria from entering the site. If indicated, a dressing can be applied to keep moisture from sitting on your child's skin.



If your child's skin is red or irritated, apply a stoma adhesive powder or diaper cream.



To dress or not to dress, that is the question

It is normal for a stoma to ooze a small amount of secretions. These secretions are coming from the stomach or intestines and can irritate your child's skin. A split gauze or split cloth can be placed around the enteral tube to help absorb the moisture and prevent skin breakdown. If your child's skin becomes irritated or red, you can apply an over-the-counter diaper cream to the area.

It is normal for infants or small children to pull on their enteral tube. It is important to keep your child from pulling the tube out. Here are a few suggestions:

- Use snuggly fitted shirts.
- Dress your child in a one piece outfit for sleeping or when not supervised.
- Wrap spandex or an ACE bandage/abdominal binder around the enteral tube.
- Use mittens or socks on your child's hands when they are sleeping or unsupervised.

Connecting the button to an extension set

If your child has a button-style enteral tube, you will need to attach an extension set prior to instilling formula, enema or medications. Each manufacturer has their specific extension sets which must be used with their device. Extension sets are typically replaced every one to two weeks, but can be used for longer periods of time if necessary.



Gather equipment.

- a. Extension set
- b. Tap water
 - c. Syringe



Wash your hands.



Prior to attaching an extension set to your child's button, it should be primed with water. This prevents your child from inadvertently getting air into their stomach when attaching the extension. Large amounts of air can result in gas pain.



While holding the button securely in your hand, line up the lock and key with the button and extension. Once you feel it settling into the button, turn the extension clockwise to lock in place. If you do not feel the extension set settle into the button, do not force it.



After instilling the formula, enema or medication through the extension set, flush the tube with 10 ml of tap water to make sure the child has received the full volume of the intended solution.



To remove extension, hold button securely in one hand. Turn extension set counterclockwise to line up lock and key with button and extension set. Once aligned, lift the extension set up lightly. This should easily disconnect.



Flush extension set with water, clamp and allow to dry.

A Guide for Families

Feeding time!

Bolus feeding with Gastronomy Tube

Bolus feeding is a method of giving formula over a short period of time at specified intervals throughout the day. *This type of feeding is given like a meal and can be used only with a G-tube.* It cannot be done through a GJ-tube. A gravity feeding bag or feeding bag with pump is connected to your child's extension set and the formula is instilled into the stomach.



Gather equipment.

- a. Formula (premeasured)
- b. Tap water
- c. Extension tubing (if indicated)
- d. Syringe
- e. Feeding bag and pump (if indicated)



Wash your hands.



Prepare the formula as instructed.



Tell your child what you will be doing.



If your child is awake, place them in a sitting or semi-reclining position. Infants can be held or placed in an infant seat.



Attach the extension set as instructed on page 9.



Check to make sure the tube is free of any clogs. Administer 5 ml of water through the attached extension set using a syringe. If the tube is clogged please refer to the troubleshooting section on page 15.



Insert the feeding syringe tip (without the plunger) or feeding bag into the extension set. Add the premeasured volume of formula into the syringe or bag. If you are using a syringe and the entire volume of formula doesn't fit in the syringe, pour more formula in before it empties to prevent your child from getting excess air in the stomach.



Begin feeding. If using the gravity technique, elevate the feeding setup above the level of the stomach to promote gravity flow into the stomach. Raising the setup increases flow and lowering the setup decreases flow. If using this method, the syringe or bag should not be lowered below the child's abdomen. This will result in a backflow of feeds and gastric juices. Giving the formula too fast may cause stomach upset or diarrhea.



When feeding is finished, flush the extension set with water to flush in any residual formula. This will prevent the extension set and G-tube from becoming clogged. Volume of flush is dependent on the age of your child.

- Infants: 5-10 ml water
- Children: 10-20 ml water



Remove syringe and extension from G-tube and wash with warm soapy water. Allow to air dry before next use.



Cover and refrigerate any unused formula.

Continuous feeding through Gastrostomy or Gastro/Jejunal Tube

The continuous feeding method allows formula to flow slowly into the stomach or small intestine over a longer period of time. Some children tolerate continuous feeding better than bolus feeding. A feeding pump is required for this method of feeding to control the speed at which the formula flows into the tube. **Remember, if your child is using a J-tube for their feeding, continuous feeding is required.**



Gather equipment.

- a. Formula
- b. Water
- c. Extension tubing if indicated
- d. Feeding bag
- e. Feeding pump
- f. Syringe

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Wash your hands.



Prepare the formula as instructed. Prepare only enough formula for four hours at a time.

Position your child for feeding. The best feeding position is sitting or semi-sitting. Avoid allowing your child to lie flat as this can result in gastroesophageal reflux and feeding intolerance.

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Clamp the tubing connected to the feeding bag. Pour the formula (only enough for four hours) into the feeding bag and open the clamp to let the formula run through the tubing to the end, then clamp again.



Connect the feeding bag set to the feeding pump. Set the pump according to the manufacturer and provider instructions.



Connect the extension to the enteral feeding tube as per the previously described instructions. Check to make sure the tube is free of any clogs. Administer 5 ml of water through the attached extension set using a syringe. If the tube is clogged please refer to the troubleshooting section on page 15.



Connect the feeding bag to the extension tubing and start the feeding by pressing the start button on the pump.



The tubing and pump can be safely used continuously for 24 hours. Continue to pour more formula (no more than four hours) into the bag as it empties. Once your child has completed 24 hours of feeds, prepare another feeding bag as described in step number five. The old feeding bag and tubing should be washed in warm soapy water and allowed to air dry.



You can then use this setup for the following day.

Enema administration

Gather equipment.

C-tubes are used for antegrade enema administration. The tube allows easy administration of a mixture of saline and additional medications to wash the colon of stool. Children tend to tolerate enema administration through the C-tube if it is given slowly (at least 10 minutes) and the solution is lukewarm.



It is important to elevate the enema setup above the level of the child's body to promote gravity flow into the intestines. Raising the setup increases flow and lowering the setup decreases flow. It is important that the enema bag not be lowered below the child's abdomen as this will result in backflow of enema contents and stool. Enema should be administered over about 10 minutes. If your child experiences nausea or cramping, slow the administration down by lowering the setup or closing the clamp on the feeding bag.



When enema is finished, flush the extension set with water to flush any residual solution. This will prevent the extension set and C-tube form becoming clogged. Volume of flush is dependent on the age your child.

- a. Infants: 5-10 ml water
- b. Children: 10-20 ml water



Remove syringe, bag and extension from C-tube, wash with warm soapy water and allow to air dry before next use.

e. Extension tube c. Prescription medications f. Syringe

d. Gravity feeding bag

Wash your hands.

Prepare the enema solution as instructed by your child's provider.

a. Warm water

b. Salt

Position your child for enema administration. The child should be relaxed in a sitting or lying position. This can be done in any location as long as the child has easy access to the bathroom.

Clamp the tubing connected to the gravity feeding bag. Pour the solution into the bag and open the clamp to let the solution run through the tubing to the end, then clamp again.

Connect the extension to the cecostomy tube as per the previously described instructions. Check to make sure the tube is free of clogs. Administer 5 ml of water through the attached extension set using a syringe. If the tube is clogged please refer to the trouble shooting section on page 15.







Burping and venting G-tubes

It is natural for children to swallow air. It becomes worse when they cry or have it accidentally instilled through a G-tube. Many children become uncomfortable and full when there is a large amount of air in their stomach. G-tubes allow a child to passively release stomach air, similar to a burp. Many parents burp or vent their child's G-tube throughout the day, before a feeding, if the abdomen looks large, or the child is especially fussy or has cried for an extended period of time.



Remove plunger from 60ml syringe and attach to extension set. Open the extension set clamp.



It is normal to hear air released and a small amount of gastric contents come into the syringe.



Clamp the extension set and remove syringe and extension set.

Routine medical care of the enteral tube

As children grow, their enteral tube must grow as well. Your gastroenterology or surgical office will help determine what size enteral tube your child needs. It is important that your child sees the provider at scheduled intervals to measure the enteral tube and replace it as needed.

- Infant 8 years: Provider visit every three months
- 8 years 18 years: Provider visit every six months

Complications and troubleshooting

Clogged enteral tube

The enteral tube may become blocked or clogged by accumulation of formula, intestinal contents or medications. For this reason, it is very important to flush the enteral tube before and after every use. Resistance during flush may indicate a blockage. To clear the tube, flush the tube with warm water. If unsuccessful, flush the tube with diet cola. Never use force to clear a clogged tube. If the diet cola doesn't work to clear the blockage, call your provider's office. Volume of flush is dependent on the age of your child.

- Infants: 5-10 ml
- Children: 10-20 ml

Leakage of stomach or intestinal contents around the tube or through the tube

A small amount of leakage around your child's enteral tube is normal. Often times this dries up and becomes crusty. This should be removed with daily cleaning. A large amount of leakage is abnormal and can result from incorrect tube position (too short or too loose), a deflated balloon or an enlarged stoma.

If you note a large amount of stomach or intestinal contents leaking through the stoma, gently pull on your child's enteral tube. If the balloon is still inflated, you should not be able to pull the tube up very far. You can also check the volume of water in the balloon. Refer to your child's enteral tube information sheet as to the volume of water which should fill the balloon. Hold your child's tube secure with one hand, with the other, attach a luer lock syringe to the balloon access valve. Withdraw the fluid and compare to the documented volume of the balloon. If the fluid is less than the anticipated volume, then the balloon is likely leaking. Refill the balloon with the balloon is less than what was put in, the tube will need to be replaced. Call your provider's office.

If your child's tube is too short or too large it can result in significant leaking of stomach or intestinal content around the tube. The safest way to determine the correct size tube for your child is at the provider's office.

As enteral tubes age, they can malfunction. If you notice that stomach contents are leaking through the enteral tube port itself, the extension locking system has likely malfunctioned. Please call your provider's office for replacement.

Redness or soreness at stoma site

Leakage of stomach or intestinal fluids may cause redness around the stoma. This is a problem that can typically be solved with frequent cleaning and changing of the dressing to make sure the site is kept dry. If the skin is still red and sore, you can apply over-the-counter diaper cream or stoma powder. If the pain worsens or redness grows, call your provider's office.

Diarrhea

Children can get diarrhea from tube feeds for a variety of reasons including quick administration or spoiled formula. Remember to give bolus feeds over a minimum of 20-30 minutes, only put a maximum of four hours of formula into a feeding bag at a time for continuous feeds and always refrigerate your child's formula between feedings.

Medication, a change in formula or a change in feeding routines can also cause diarrhea. It is important to take note of these changes so your provider team can help to determine the cause of your child's diarrhea.

Constipation

Change in formula or medications may cause constipation. If your child has constipation for more than three days, call your provider and they will help determine the best management strategy.

Gas

Gas, or air, in the stomach can make your child feel uncomfortable or full. This can easily be relieved by venting the enteral tube for gas to escape.

Nausea or vomiting

Nausea or vomiting can be a result of a variety of issues including rapid formula or enema administration, formula intolerance and spoiled formula. To help relieve your child's nausea or vomiting you can try slowing down your child's feed/enema or venting your child's tube to relieve them of gas. If your child is on continuous feeds, try stopping their feeds for one to two hours and then restart the formula at a slower rate. If the nausea and vomiting persists, contact your provider.

If your child's vomit is green, brown or red it is considered a medical emergency and he or she should be seen at the nearest emergency room.

Granulation tissue

Granulation tissue is a red or pink bumpy tissue that can erupt out of the stoma. It can be uncomfortable and bleed very easily. It is a common reaction that the body has to a foreign device. This tissue is not dangerous. There are a variety of treatments that you can do at home to prevent granulation tissue from forming or becoming worse.

- Stabilize your child's enteral tube and extension to prevent excess movement or weight on the enteral tube. You can tape them to the abdomen or create a tab to pin the extension to your child's diaper.
- Keep the stoma area dry. This is very important when it comes to reducing the formation of granulation tissue. If the granulation tissue gets worse, causes discomfort or bleeds frequently your provider can prescribe a variety of different treatments that can reduce the tissue over time.
- Granulotion[®]: This is an over-the-counter cream that can be applied for an extended period of time to reduce granulation tissue. This can be used preventively as well.

- Silver Nitrate: This is a medication that is applied in a provider's office to cauterize the tissue. Following the application of silver nitrate the granulation tissue will turn into a scab and then fall off.
- Steroid cream: This is a prescribed cream that can be applied to granulation tissue for short periods of time to reduce or shrink the granulation tissue. This medication should not be used preventively, as it can cause your child's skin around their stoma to thin.

Infected stoma site

While post-operative infections are rare, they are a risk of surgery. An infection can affect the skin or the stoma tract or your child may develop a pocket of infection directly beneath the skin. If you suspect your child has an infection anywhere related to the enteral tube, it is important to contact your provider's office.

Signs and symptoms of infection include:

- Weepy, oozing or pus-filled stoma
- Foul or unusual smell from stoma
- \cdot $\,$ Pain or sensitivity when the enteral tube is touched
- Fever

Accidental dislodgement of enteral tube

If your child's tube falls out it is important to maintain patency of the stoma. This is done by placing a Foley catheter or replacement tube into the stoma until your child can be seen by a member of their care team. The stoma can shrink within hours making replacement of your child's enteral feeding tube difficult if the patency of the stoma is not maintained. If the tube becomes dislodged please follow these steps:



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Place your child in a comfortable position where he/she is lying on their back. It is common for a child to be anxious when replacing their tube. We recommend explaining the procedure in a developmentally appropriate way and using distracting devices such as a tablet, book or favorite television show.

Lubricate the tip of the Foley catheter



Hold the catheter at the tip with just 1-2 inches exposed. While placing your hand on your child's stomach guide the catheter into the stoma. Continue to pass the catheter until 6-12 inches are within the abdomen.

Who to contact and when

G-tubes, GJ-tubes and C-tubes are managed by multiple teams of providers. The surgical team, gastroenterology team and your primary care provider work together to help determine what type of enteral tube is the best for your child. The surgical team will place your child's enteral tube and manage the tube during the immediate post-operative phase. The gastroenterology team and/or primary care provider will manage your child's long-term feeding plan, formula and other gastroesophageal diseases.



Pediatric Surgery

Logan Health Children's Specialists 202 Conway St., Suite 200 Kalispell, MT 59901 p: (406) 758-7490

Pediatric Gastroenterology

Logan Health Children's Specialists 202 Conway St., Suite 202 Kalispell, MT 59901 p: (406) 758-7490

Great additional resources

There are so many great resources on the internet for children with enteral feeding tubes. These are some that we recommend: Feeding Tube Awareness Foundation – feedingtubeawareness.org The Oley Foundation – oley.org GI Kids – gikids.org Granulotion – granulotion.com

Enteral Feeding Tube Information Sheet

hild's name
urgeon
pate of initial placement
ype of enteral tube
ize of enteral tube
alloon fluid volume

Discharge supplies/prescriptions

- □ Formula □ Feeding pump (if indicated)
- □ IV pole (if indicated) □ 60 ml syringe
- Foley catheter

□ Water-based lubrication

- □ Feeding tube extension supplies (if indicated)
- Prescription for additional enteral tube
- □ Follow up appointment with surgery clinic
 - · 5-7 days for suture removal (if indicated)
 - · 6 weeks 3 months for first enteral tube change





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