

Gastrostomy Tube Care

Making the decision

Your child’s medical provider is recommending a gastrostomy tube (G-tube). You may be questioning if this is the right decision. It is important to understand why this recommendation is being made.

Some things to consider when making this decision:

- What type of nutritional support is your child getting right now?
- What type of nutritional support will your child likely need in the future?
- How is your child’s quality of life right now?
- Will the G-tube help your child’s quality of life?
- What are your hopes and goals for your child and your family moving forward?

Pros of a G-tube	Cons of a G-tube

What else do you feel needs to be considered or explored before making this decision?

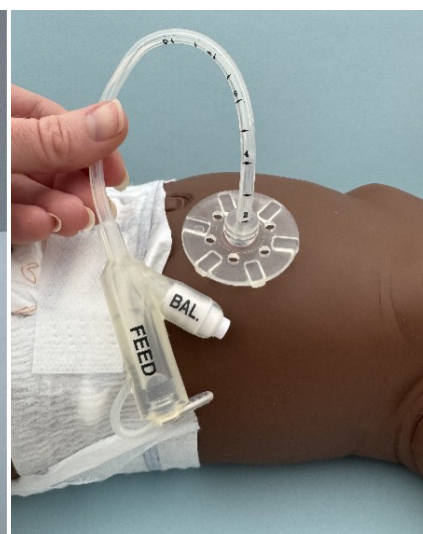
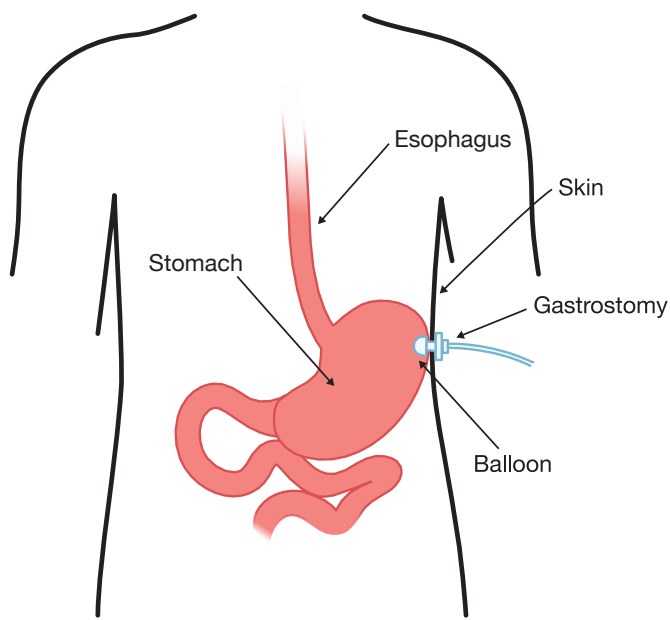
Introduction to Gastrostomies

A gastrostomy is a surgical procedure where a small opening is made from the outside of the abdomen to the stomach. This opening is called a stoma.

A gastrostomy tube (G-tube) is a device that is placed through the stoma and into the stomach. A low-profile version of this tube is often called a gastrostomy button (G-button).

G-tubes are often used to provide hydration (water), nutrition (food), and medicine directly to the stomach. Your provider will talk to you about why a G-tube was recommended for your child. Some reasons to get a G-tube include:

- Differences in your child’s mouth, esophagus, stomach, or intestines that make it hard or impossible for them to eat and drink. These may be present at birth.
- Feeding difficulties or oral aversions.
- When a child is unable to eat enough or has digestive problems that affect their ability to grow appropriately for their age.
- A G-tube can be used for a long time, but it does not need to be permanent if it is no longer needed.



My Gastrostomy Information

Type

My gastrostomy is a:

Size

I have a _____ Fr. G-button with a length of _____ centimeters (cm)

- Gastrostomy tubes are measured in French (Fr.) sizes. This is the diameter of the tube.
- A size 16 Fr. gastrostomy is larger than a 14 Fr. gastrostomy.



Balloon

My balloon volume is _____ milliliters (mL)



My doctor who placed my gastrostomy:

Date of gastrostomy:

Phone number to ask questions after discharge: 314-454-6022

Surgery

Several tests may be done before a gastrostomy is placed. The most common test is an upper GI—an X-ray of the upper gastrointestinal (GI) system. This includes the esophagus, the stomach, and the first part of the small intestine.

The doctor or surgeon will describe the procedure specific to your child.

- A **path** (tract) from the stomach to the abdominal wall forms around the gastrostomy in 6–8 weeks.
- Healing around the gastrostomy is similar to tract formation after a body piercing.
- The end of the gastrostomy in the stomach may have a small balloon.
- The balloon keeps the gastrostomy up against the stomach wall.
- A percutaneous endoscopic gastrostomy (PEG) tube may be held in place by a bolster.

After surgery:

- The area around the gastrostomy may be tender for several days.
- It is normal to see drainage around the gastrostomy after it is placed.
- Most buttons and tubes are clamped after surgery. Sometimes, the surgeon will have the gastrostomy drain by gravity while the site is healing.

When to call the surgery office or the surgical resident on call:

1. If the G-tube comes out before the surgery team has taught you how to replace the device.
2. If your child had gastrostomy surgery in the last 2 months and they now have new drainage.

Gastrostomy sites do not get infected often. However, look at your child's gastrostomy site daily for:

- Drainage or leakage around the gastrostomy
- A red area larger than the size of a quarter
- Skin irritation or rashes
- Swelling or tenderness

Call the surgery office if any of the above lasts longer than 24 hours.

When to call your child's primary medical provider:

- Your child's abdomen (stomach) is hard or distended (bulging).
- Your child vomits with feedings.
- Your child has pain or cramping with feedings.
- Your child has a fever.
- Your child has signs and symptoms of dehydration:
 - No pee from a toddler for 12 hours
 - No pee from an infant for 8 hours
 - Crying without tears
 - Very dry or cracked lips
 - Sleepier than usual
 - Sunken soft spots (in infants younger than 1)
 - Dizziness

Important phone numbers:

Surgery office phone number:

314-454-6022

(Monday–Friday, 8 a.m.–4 p.m.)

Surgical resident on-call:

314-454-6000

(Outside of office hours.)

General Care and Guidelines

1. Keep the position of the button or tube stable.

- Do not turn the gastrostomy unless it is causing pressure on the skin. Unnecessary movement of the button will interfere with healing.
- Dressing your baby in a onesie can help keep the tube secure. Using snap-up clothes or footless pajamas provide safe access for tubing to pass through. A compression bandage can be used around the abdomen for more active toddlers.
- To prevent pulling on the tube, detach the extension piece when it is not being used.
- Cinches are available to help stabilize the gastrostomy tube or extension sets when a child is on a continuous feed, or if their bolus feeding extends for a long period of time.



2. Flushing the gastrostomy

- If the child is older than 12 months, flush the gastrostomy with 5–10 mL of tap water after every feeding and anytime you give medication through the tube to clean the extension set and button.
- If the child is older than 12 months, flush the gastrostomy **every 1 to 2 days** with 5–10 mL of tap water when the gastrostomy is not needed.
- If the child is **less** than 12 months old, **ask their medical team** about flushing needs.

3. Age-appropriate mouth care:

Even if your child receives nutrition through a gastrostomy tube, daily mouth care is important.

4. Skin care and bathing

- For the first 2 weeks, clean the skin around the gastrostomy 3 times a week with gentle soap and warm water, or as needed. Rinse well and pat dry.
- Clean the gastrostomy site more often if you see drainage or redness.

Attaching the Extension Set

There is a one-way valve inside the gastrostomy. To open the valve and attach the extension set, follow these steps:

1. Use the feeding (right angle) extension set.
 2. Prime the extension set with formula or water.
 3. Clamp the extension set.
 4. Open the plug on the button.
 5. Hold the button and line up the black line on the extension set with the black line on the button.
 6. Gently push the extension set into the button.
 7. Turn the extension set clockwise at least three-quarters of a turn to lock into the button.
- *Do not push past resistance because this will break the valve.



Feeding

There are different ways to get food with a G-tube. While in the hospital, the medical team will decide the best type of feeding for your child. After you go home, your primary care provider or GI provider will take over this care.

Continuous

Continuous feeds are when a pump is continuously delivering a set volume of liquid nutrition over many hours.

Bolus

Bolus feeds are when the feeds are divided up throughout the day, like meals. Bolus feeds can be given over a pump, with a syringe, or using a gravity bag.

Before starting a feed: It can help to relieve gas from the stomach if they are not using a Farrell bag. See the “venting” section for information on how to do this.

1. Gather your supplies.
2. Wash your hands.
3. If you are using a G-button, attach the primed extension set.
4. Measure the amount of formula or milk you need.

Gravity

1. Connect the feeding syringe to the extension set.
2. Pour the formula into the syringe and hold the extension set at the level of the child’s stomach.
3. Open the clamp.
4. Raise the syringe until the formula flows in slowly.
 - Feeds should go in over 15–20 minutes.
 - To have the feed go in faster, raise the syringe. To slow down the feed, lower the syringe.
 - If your child is upset or crying, the feed may back up into the syringe. It will flow out when they calm down.
 - If the formula is not going down and your child is quiet, put the plunger into the syringe and gently push the plunger about a 1/2 inch to start the flow of the formula. **Do not push hard.** Take the plunger out after the feeding starts to flow in.
5. Pour 5–10 mL of tap water into the syringe to flush the gastrostomy after the feeding is finished.
6. Clamp the extension tubing.
7. Line up the black marks of the button and the extension tubing. Gently pull out the extension set.
8. Close the plug on the button.

Pump feedings

1. Gather supplies:

- Feeding pump and tubing
- Extension set for feeding
- Formula
- Feeding syringe without the plunger for flushing
- Tap water (5–10 mL) for flushing

2. Wash your hands.

3. Pour formula into the feeding bag.

4. Open the clamps on the feeding bag and the extension set.

5. Prime the feeding bag and extension set with formula.

6. Place the pump tubing into the pump and attach the extension set to the button.

7. Make sure the tubing connections are secure.

8. Check the settings on the pump to make sure they are correct.

9. Start the feeding pump.

10. Flush after the feeding is done.

- Clamp the extension set.
- Turn off the pump.
- Pull up 5–10 mL of water into the feeding syringe.
- Remove the pump tubing from the extension set.
- Attach the feeding syringe to the extension set.
- Open the extension set.
- Flush the water in the feeding syringe into the extension set.
- Clamp the extension set.
- Gently remove the extension set and close the plug on the button.

Venting

Most children with gastrostomies can burp or pass gas to relieve air in their stomach. However, some children still have problems passing gas. Usually, gas is the biggest problem the first few days after surgery. A syringe or Farrell bag may be used to relieve gas from the stomach.

Using a syringe to relieve gas in the stomach:

1. Use the venting (straight) extension set.
2. Clamp the extension set and attach it to the button.
3. Place the feeding syringe (without the plunger) into the extension set.
4. Hold the syringe above the level of your child's stomach.
5. Unclamp the extension set.
6. Gas will bubble up in the syringe. It is normal for formula or stomach contents to rise into the syringe.
7. Once the gas is relieved, allow the formula or stomach contents to slowly flow back into the stomach.

Using a Farrell bag to relieve excess gas in the stomach:

- Your child's medical provider may order a Farrell bag if your child had a Nissen fundoplication (anti-reflux procedure).
- The Farrell bag attaches to the gastrostomy and allows gas to come out of your child's stomach while your child is being fed. This is often used when a child is on continuous feeds.
- Refer to the Farrell Bag Teaching Tool provided by your care team.



8. Add 5–10 mL of tap water to the syringe and flush the gastrostomy.
9. Clamp and remove the extension tubing.

Medicine

- Ask your child's pharmacist to dispense all medications in a liquid form for the first 3 months after surgical placement, if possible.
- If your child's primary care provider (PCP) or pharmacist tells you to crush pills or open capsules, dissolve the medications in water before giving.
- Flush the gastrostomy with 5–10 mL of tap water after giving medications. If the child is less than 12 months old, ask their PCP how to flush.

Using the medication port on the extension set for feeding:

1. Attach the extension set to the gastrostomy.
2. Open the med port (make sure the feed port is still closed) and attach the medicine syringe.
3. Unclamp the extension set and slowly push in the medicine.
4. Clamp the extension set.
5. Disconnect the medicine syringe and close the med port.
6. Open the med port and attach a syringe with 5–10 mL of water for flushing.
 - If the child is under 12 months of age, ask their medical team for directions on flushing.
7. Unclamp the extension set and push in the flush.
8. Clamp the extension set.
9. Remove the syringe and close the med port.
10. Remove the extension set and plug the button.



Troubleshooting

Leaking

Leaking around the stoma site can happen when the balloon does not form a seal against the inside of the stomach wall. This can happen as children grow, if the balloon loses too much water, or if the valve breaks.

*Important notes:

- If your child has leakage around the button and they **returned from surgery** for button placement within the last 2 months, **call the surgery office**.
- If your child has had the button in **longer than 2 months**, and you have been trained, check the amount of water in the gastrostomy balloon to see if it is correct.
 - The balloon on the **14 Fr. AMT** button is usually filled with 4 mL of water after the button is in the stomach.
 - The balloon on the **12 Fr. AMT** button is usually filled with 2.5 mL of water after the button is in the stomach.
 - The balloon on the **Mickey** button is usually filled with 5 mL of water after the button is in the stomach.

1. Fill a syringe with the amount of water ordered by your surgery team.
2. While holding the button in place, attach an **empty** syringe to the port marked “BAL” (balloon) on the gastrostomy and pull out the water from the balloon.
3. Disconnect the syringe you used to remove the old water and attach the new syringe with the correct amount of water.
4. Push the water into the balloon.

Call the surgery office if the leaking persists. They will work with you to figure out the best dressing or skin care for your child.



Granulation tissue

Sometimes, “extra tissue” called granulation tissue grows around the gastrostomy. You cannot always prevent granulation tissue from forming, but it is more likely to be a problem if:

- The gastrostomy is turned a lot.
- There is a lot of movement on the stoma.
- The stoma is frequently exposed to moisture.

What does granulation tissue look like?

- Granulation tissue contains many capillaries (small blood vessels).
- The tissue may be red or pink. It looks like the inside of the mouth.
- Granulation tissue is not an infection, but it can have yellow or green drainage that smells.
- Do not worry if you see tiny spots of blood if the tissue becomes irritated.
- Granulation tissue may go away, but it can return.

What can we do about granulation tissue?

- If the button gets turned frequently, it may have to be H-taped or secured to your child’s abdomen.
- Call the surgery office if the granulation tissue becomes tender and painful to your child or if the drainage increases.
- A nurse from the surgery office or home care may use a small cotton swab and apply medicine on the granulation tissue or use a special dressing around the button.
- Some medicines they might use:
 - Silver nitrate helps the granulation tissue shrink and dry up. The tissue may turn dark or white.
 - Topical steroid creams or ointments
 - GranuLotion™





Dislodgement

At your child's follow-up appointment with surgery (2–3 months after surgery), you will be taught how to replace the button or tube if it is dislodged.

What if the gastrostomy button or tube comes out before my child's surgery clinic appointment?

- **Cover the opening with a washcloth or towel. Do not push the gastrostomy back in.**
- There is no immediate danger to your child. Gastrostomy buttons usually stay secure, but sometimes they come out.
- Formula or food may leak from the site, and you may see a small amount of bloody drainage.
- **2 Foley tubes** will be in your take-home bag. **The Foley tube is inserted to keep the stoma and gastrostomy tract open.**
 - One Foley tube is the same size as your child's old gastrostomy, and the other tube is one size smaller.

When you get home with your child, take the Foley tubes and lubricant out of the take-home bag and put them in an easy-to-find place.

Placing the Foley tube into the stoma:

1. Get the Foley tube that is the same size as your child's gastrostomy.
2. Put a dab of water-soluble lubricant from the take home package or KY Jelly® on the narrow tip of the Foley tube.
3. Gently insert the appropriate length of the Foley tube into the gastrostomy stoma.
 - A. **1 ¼ inches (3 cm)** for a child **under 66 lbs (30 kg)**
 - B. **2 ½ inches (6 cm)** for a child **over 66 lbs (30 kg)**
4. Your child may cry, wiggle, or kick causing the muscles to contract.
5. Take a deep breath and try to relax your child. When your child breathes out, the abdominal muscles relax, and the Foley tube should slide into the stoma.
6. Never force the tube into the stoma. Try the smaller sized Foley tube if needed.
7. Do not take more than 10–15 minutes to try to insert the Foley tube.
8. **If you are unable to insert the Foley tube, take your child to the nearest Emergency Department (ED).** Have the local Emergency Department physician call the St. Louis Children's Hospital surgical resident on call.

After the Foley tube is in the stoma:

1. Tape the Foley tube to your child's stomach.
2. Do not blow up the balloon on the Foley tube.
3. Do not feed, give water, or give medicine to your child.
4. Call the **surgery office at 314-454-6022.** On nights, weekends, or holidays, call **314-454-6000** and ask for the surgical resident on-call to be paged.
5. **Take your child to St. Louis Children's Hospital. If you are having any problems, call the surgery team or bring your child to the Emergency Department.**

St. Louis Children's Hospital has 5 pediatric Emergency Department locations across the St. Louis and southern Illinois region.

Scan QR code to view locations:



Living With a G-Button

Baths and swimming

- After 2 weeks, the gastrostomy site should be healed. The child's gastrostomy site can be submerged in water, and your child can take a bath or swim. Chlorinated water or salt water are OK for them to swim in.
- After 4 weeks, your child can swim in lakes, rivers, or ponds.
- Clean the gastrostomy site immediately after swimming.
- Water might leak into your child's stomach. This is OK for most children.

Clothing

- Dressing infants in onesies can help keep the tube secure. Snap-up clothes or footless pajamas provide safe access for tubing to pass through.
- A compression bandage can be used around the abdomen for more active toddlers.
- Protective gastrostomy belts are another option that can be used 2 to 3 months after surgery.

Activity or positioning

Once the gastrostomy has healed, children are encouraged to participate in all normal activities for their age. Make sure that the device is secure to prevent it from getting pulled on.

It is OK for infants and children with G-tubes to lay on their stomachs when the site is no longer sore.

- Infants should always be supervised for tummy time, and they should not be placed in an infant lounger while on their stomachs.

For non-mobile children:

- Child can be held, placed in an infant seat, high chair, wheelchair, stroller, or other seated position.

For children who are crawling, scooting, and rolling:

- Child can be placed in a seated position, such as in a high chair, but it is not required.
- Consider placing the child in a play yard that is large enough to allow for movement and exploration. If they are being fed through a pump, the device can be hung along the railing or on an IV pole while the child moves about the play space. It is important that the tubing can freely extend with your child without placing tension on the G-button.





For feeding with toddlers and young children who walk:

- Child can be placed in a seated position, such as in a high chair, if they are on bolus feeding running less than 1 hour.
- Consider placing a tube feeding backpack on the child to allow them to be mobile during tube feedings.



For feeding while transporting your child in a vehicle:

- Your child should always be supervised, especially if they are in a rear-facing seat.
- Make sure the feeding pump, bag, and tubing are secured to avoid disconnections or spills.

For feeding while in a stroller or wagon:

- Avoid laying the child flat.
- Make sure the feeding pump, bag, and tubing are secured to avoid disconnections or spills.



For feeding while in a crib or bassinet:

- Make sure tubing and equipment is at the foot of the crib or bassinet to make tubing cannot reach the child's head or neck area.
- Consider laying the child on their right side when in bed for feedings to help the stomach empty. If the child is under 1 year old, always practice safe sleep.

Provide a positive feeding experience during tube feedings

- For infants, provide positive oral stimulation by using a pacifier, teething toy, or bring the child's hands to their mouth.
- For toddlers, provide positive oral stimulation using teething or other oral motor tools.
- If the child eats some by mouth, coordinate tube feedings with scheduled mealtimes.
- Provide comfort to your child by talking or playing music.