

Gastrostomy Button (MIC-KEY) Home Care Manual

Physician who placed gastrostomy: _____

Date of gastrostomy placement: _____

Size of the gastrostomy:

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

Your child has a _____ Fr. Button with a length of _____ centimeters (cm)

Phone number to ask questions after discharge: _____

Call the Surgery Team night or day if your child has any of the following symptoms:

- If the gastrostomy comes out. Call now and look at page 14 of this manual.
- Has purulent, bloody, bright green, or brown drainage that smells like stool coming from the gastrostomy.
- Has a temperature over 101°F (38.4°C)
- Has any of the following for more than 48 hours (2 days):
 - drainage or leakage around the gastrostomy.
 - redness larger than the size of a quarter around the gastrostomy.
 - skin irritation or rashes.
 - swelling or tenderness.

Note: Call the General Surgery Office 314.454.6022 during office hours. If after hours (nights, weekends, and holidays) call 314.454.6000 and ask for the Surgery Resident on-call to be paged.

Call your child's regular doctor if:

- Has a swollen or hard stomach.
- Is throwing up with feeds.
- Has pain or cramping with feeds.
- Is crying without tears.
- Has a dry mouth or cracked lips.
- Is an infant and has a sunken soft spot.
- Is more sleepy than normal.
- Is dizzy.
- Is an infant and has no wet diapers in 8 hours.
- Has no urine in 12 hours at any age.

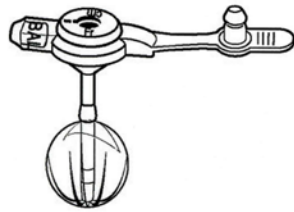
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A. Introduction

- Feedings and/or medications can be given to your child through the gastrostomy.
- Your child may need the gastrostomy for a short time or for a lifetime.
- A Home Care company delivers supplies to care for the gastrostomy at home.

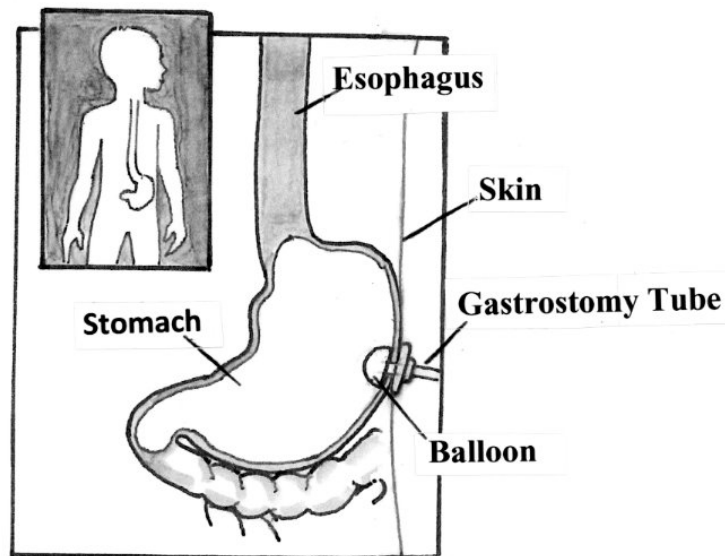


B. Placement of the Gastrostomy

Note: Children usually do not have to go to surgery if the button needs to be replaced.

- Your child's medical provider or surgeon will decide how the gastrostomy is placed.
- A small opening called a stoma is made on your child's abdomen.
- The gastrostomy goes into the stomach, passes through the muscle and fatty layers, and comes out the stoma.
 - The path (tract) from the stomach to the abdominal wall forms around the gastrostomy in **6 to 8** weeks.
 - The healing around the gastrostomy is similar to the tract formation after a body piercing.
 - **Do not turn the gastrostomy unless it is causing pressure on the skin.**
 - **Unnecessary movement of the button will interfere with healing.**
- The balloon on the button is usually filled with 5ml of water after the button is in the stomach.
***Note:** If your baby is being discharged from the NICU, check with the NICU staff about the amount of water in the balloon.
- The inflated balloon keeps the gastrostomy up against the stomach wall.

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After the Gastrostomy is placed:

- The area around the gastrostomy may be tender for several days.
- It is normal to see drainage around the gastrostomy after it is placed.
- A small plastic container may be attached to the gastrostomy after surgery.
 - Stomach contents drain into the container.
 - The container is removed when your child starts feeding.

C. General Guidelines for Care

- 1. Prevent the gastrostomy from being pulled or turned.**
 - Dress infants in onsies.
 - An ace wrap placed around the abdomen may be used on active toddlers.
- 2. Keep the balloon up against the stomach wall to create a seal.**
 - The balloon works like a sandbag in a flood wall.
 - If the balloon is not up against the stomach wall, the seal is broken and formula and gastric juices may leak onto your child's skin.
- 3. Age appropriate mouth care should be given to a child with a gastrostomy.**

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D. Call the Surgery Office or the Surgical Resident On Call:

1. If the gastrostomy button comes out before 2 months after surgery or before your child's surgery clinic appointment (**also see section M**).
2. If the drainage from the button looks:
 - Purulent (pus)
 - Bloody
 - Bright green
 - Brown and smells like stool

E. General Feeding Guidelines

1. Feeding Orders:

- In the hospital, your child's medical provider will order the:
 - Type of feeding
 - Schedule for feedings
 - Method of feeding
- Your child's Primary Health Care Provider will monitor the feedings after your child is discharged from the hospital.

2. Helping children adapt to the volume of gastrostomy feedings.

- Give feedings slowly. Never push in feedings with a syringe.
- Giving the feedings too fast may cause your child to cramp, wretch or vomit.
- Children who were fed through an NG tube before getting the button usually have no problems adapting to the volume of the gastrostomy feedings.
- Children who are not used to a full stomach may have more difficulty adapting to the increased volume of feedings through the gastrostomy.
- Discuss any concerns you may have about feeding with your child's physician.

3. The Feeding Experience

- Children can be held or placed in an infant seat, wheelchair or chair.
- Lay the child on the right side when in bed for feedings to help the stomach empty.
- Provide comfort to your child by talking or playing music.
- Increase oral stimulation with a pacifier and massage your child's lips and cheeks.

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F. Attaching the Extension Set for Feeding to the Button

There is a one-way valve inside the gastrostomy. To open the valve for feeding:

1. Clamp the extension set for feeding.
2. Lift up the plug on the button.
3. Hold the button and line up the black line on the extension set to the black line on the button.
4. Gently push the extension set into the button.
5. Turn the extension set clockwise at least one quarter of a turn to open the valve in the button.

G. Flushing the Gastrostomy after Feedings

- Flush the gastrostomy with 5 to 10 ml of tap water after every feeding and medications to clean the extension set and button.
- Flush the gastrostomy **once a day** with 5 to 10 ml of tap water if the gastrostomy is not needed to give your child feedings or medications.

H. Relieving Excess Air in the Stomach: Venting Air (Burping)

- Most children with gastrostomies can burp or pass gas to relieve air in the stomach.
- However, some children do have problems with excess air in the stomach.
- 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. Clamp the extension set and attach it to the button.
2. Place the feeding syringe (without the plunger) into the extension set.
3. Hold the syringe above the level of your child's stomach.
4. Unclamp the extension set.
5. Excess gas will bubble up in the syringe. It is normal if formula or stomach contents rise into the syringe.
6. Once the gas is relieved, allow the formula or stomach contents to slowly flow back into the stomach.
7. Add 5 to 10 ml of tap water to the syringe and flush the gastrostomy.
8. Clamp and remove the extension tubing.

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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 excess gas to come out of your child's stomach while your child is being fed.
- **Refer to the Farrell Bag Teaching Tool.**

I. How to Feed Your Child Through the Gastrostomy

- **Feeding by gravity (bolus feeds):**
 - Amount of formula: _____
 - Frequency of feedings: every _____ hours
- **Feeding by a feeding pump:**
 - Continuous feedings:
 - Volume of feedings _____
 - Time of infusion: Start time _____ End time _____
and/or
 - Intermittent (several times a day):
 - Volume of feeding _____
 - Infused over _____ minutes every _____ hours

***Note:** Clean supplies with warm water. Rinse and air dry. Do not boil or place them in a dishwasher.

Feeding by Gravity

1. Gather supplies:
 - ✓ formula
 - ✓ feeding syringe without the plunger
 - ✓ water (5 to 10 ml) for flushing
 - ✓ extension set for feeding
2. Wash your hands.
3. Attach the extension set to the button.
4. Connect the feeding syringe to the extension set.
5. Pour the feeding into the syringe and hold the extension set at the level of the child's stomach.
6. Open the clamp.

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7. Raise the syringe until the formula flows in slowly.
8. Raise the syringe to increase the flow of feeding. Lower the syringe to decrease the flow of the feeding.
9. Feedings should go in over 15 to 20 minutes.
 - The feeding will come back into the syringe if your child is crying or fussy.
 - Wait a few minutes and comfort your child. The feeding will go in again once your child is quiet.
 - If the formula is not going down and your child is quiet, put the plunger into the syringe and gently push the plunger about one-half inch to start the flow of the formula. **Do not push hard.** Take the plunger out after the feeding starts to flow in.
10. Pour 5 to 10 ml of tap water into the syringe to flush the gastrostomy after the feeding is finished.
11. Clamp the extension tubing.
12. Line up the black marks of the button and the extension tubing. Gently pull out the extension set.
13. Close the plug on the button.



Intermittent pump feedings for (several times a day) feedings

NOTE: Your child's home health company will review the pump with you.

1. Gather supplies:
 - ✓ feeding pump and tubing
 - ✓ extension set for feeding
 - ✓ formula
 - ✓ feeding syringe without the plunger for flushing
 - ✓ tap water (5 to 10 ml) for flushing

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2. Wash your hands.
3. Pour formula into the feeding bag.
4. Open the clamps on the feeding bag and the extension set. Fill the both tubings with formula then close the clamp on the extension set.
5. Place the pump tubing into the pump and attach the extension set to the button.
6. Make sure the tubing connections are secure.
7. Open the clamp on the extension set.
8. Check the feeding rate on the pump.
9. Start the feeding pump.
10. Flush after the feeding is done:
 - Clamp the extension set.
 - Turn off the pump
 - Remove the pump tubing from the extension set.
 - Attach the feeding syringe (without the plunger) to the extension set.
 - Open the extension set.
 - Pour 5 to 10 mls of water into the feeding syringe.
 - Unclamp the extension set. Allow the water to flow in.
 - Clamp the extension set.
 - Gently pull out the extension set and close the plug on the button.

Continuous feedings (during the day and/or night time) by the pump.

NOTE: Your child's home health company will review the pump with you.

Use the syringe method to relieve gas before continuous feeds if your child is not using the Farrell bag.

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 hands.
3. Pour formula into the feeding bag.
4. Open the clamps on the feeding bag and the extension set. Fill the both tubings with formula then close the clamp on the extension set.
5. Place the pump tubing into the pump and attach the extension set to the gastrostomy.
6. Make sure the tubing connections are secure.

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7. Open the clamp on the extension set.
8. Check the feeding rate on the pump.
9. Start the feeding pump.
10. Flush after the feeding is done:
 - Clamp the extension set.
 - Turn off the pump
 - Remove the pump tubing from the extension set.
 - Attach the feeding syringe (without the plunger) to the extension set.
 - Open the extension set.
 - Pour 5-10 mls of water into the feeding syringe.
 - Unclamp the extension set. Allow the water to flow in.
 - Clamp the extension set.
 - Gently pull out the extension set and close the plug on the button.

J. How to Keep the Button From Turning When Using a Feeding Pump

Tape the extension set on your child's skin during continuous feedings to prevent:

- Disconnection of the extension set from the gastrostomy.
- Turning of the gastrostomy during the feeding.

How to Tape

1. Gather supplies:
 - ✓ Scissors
 - ✓ Stomahesive wafer: a light tan wafer applied to the skin.
 - ✓ Skin Barrier Wipe (skin prep): a moist pad applied to the skin under the stomahesive wafer
 - ✓ Tape of choice
2. Wash hands.
3. Clean and dry the area on your child's abdomen where you will tape the extension set.
4. Cut the stomahesive wafer to fit under the extension set. Warm the wafer in your hand.
5. Wipe a skin prep pad on the skin where the tape and stomahesive wafer will go.
6. After the skin prep gets sticky, gently press the wafer onto your child's skin.
7. Lay the extension set on the stomahesive wafer and cover it with tape.
8. Remove the stomahesive wafer once a week and replace with a new one. Put it on a different spot on your child's skin.



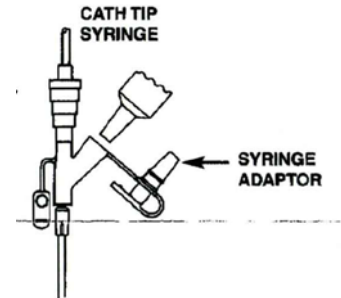
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K. Giving Medications

- Flush the gastrostomy with 5 to 10 ml of tap water after giving medications.
- Ask your pharmacist to dispense all medications in a liquid form if possible.
- If your child's Primary Care Provider or Pharmacist tells you to crush pills or open capsules, dissolve the medications in water before giving.

Using the medication port on the extension set for feeding

1. Be sure the feeding port is closed when using the medicine port.
2. Attach the extension set to the gastrostomy.
3. Open the med port and attach the medicine syringe.
4. Unclamp the extension set and slowly push in the medicine.
5. Clamp the extension set.
6. Disconnect the medicine syringe and close the med port.
7. Open the med port and attach the syringe with 5 to 10ml of water for flushing.
8. Unclamp the extension set and push in the flush.
9. Clamp the extension set.
10. Remove the syringe and close the med port.
11. Remove the extension set and plug the button.



L. Skin Care

- Clean the skin around the gastrostomy 3 times a week with soap and warm water or as needed. Rinse well and pat dry.
- Clean the gastrostomy site more often if you see drainage or redness.
- Your child may bathe two weeks after the button was inserted.
- **Do not turn the button unless it is causing pressure on the skin.**
- Gastrostomy sites very seldom get infected. However, look at your child's gastrostomy site daily for:
 - Drainage or leakage around the gastrostomy
 - Redness 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

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M. Leaking

**Important Note:*

- If your child **returned from surgery** with a button and if the button has been in less than 2 months, call the **Surgery Office** (314-454-6022) if you see leakage around the button.
- If your child has had the button in **longer than two months**, you can try the following steps to prevent leaking.

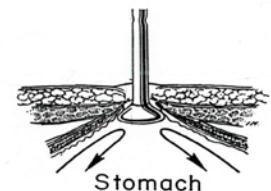
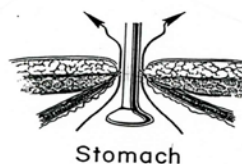
Why does leaking occur?

- The balloon may not be up against the stomach wall to create a seal
 - The balloon works like a sandbag in a flood wall.
 - If the balloon is not up against the stomach wall, the seal is broken and formula and gastric juices may leak onto your child's skin.
 - If the gastrostomy easily moves up and down, put a gauze or panty liner under the button as needed to keep the balloon up against the stomach wall.
- The balloon in the stomach may have lost some water
 1. Check the amount of water remaining in the gastrostomy balloon.
 2. The balloon is usually filled with 5mls of water. ***Note:** If your baby is being discharged from the NICU, check with the NICU staff about the amount of water in the balloon.
 3. Have another person hold the gastrostomy in place.
 4. Attach a 5 ml syringe to the port marked "BAL" (balloon) on the gastrostomy and pull out the water from the balloon.
 5. If you pull out 5ml from the balloon, push all 5 ml back into the balloon. (Do not complete step 4).

If you pull out less than 5mls from the balloon:

- Push the water in the syringe back into the balloon.
- Detach the syringe and draw the correct amount of tap water needed to fill the balloon to 5mls.

- **Call the surgery office if the leaking persists.**



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Leaking from the valve

- Valves can malfunction.
- Keep the gastrostomy plugged to prevent leaking of fluid onto your child's skin.
- Call the surgery office to replace the button.

N. Products that Can Protect Your Child's Skin from Leaking

1. Stomahesive powder

- Stomahesive powder can be sprinkled around the button.
- The powder absorbs some of the drainage and helps protect your child's skin.
- Use a small amount of powder to prevent clumping on the skin.
- It will not hurt your child if some of the powder goes into the gastrostomy site.

Call the surgery office if the leaking persists.

- The nurse may discuss the use of the following supplies to protect your child's skin.
- **Do not use any of these supplies without talking to a nurse from the surgery office.**

2. Dressings

- A dressing may be placed over the powder to absorb leakage around the gastrostomy (2x2 split gauze or panty-liner (cut to fit).
- Foam dressings may be ordered to place around your child's gastrostomy.

3. Stomahesive paste (Looks like putty)

- Do not use stomahesive paste unless you are told to do so by the Surgery Office.
- The paste is used around the gastrostomy to help prevent persistent leaking.

How to apply the paste:

1. Take the plunger out of a small syringe.
2. Squeeze the paste from the tube into the barrel of the syringe.
3. Replace the plunger.
4. Use stomahesive powder before you apply the paste if the skin is irritated.
5. Push the plunger and put a small dab of paste around the gastrostomy.
6. Do not smooth the paste with your finger. This removes the paste.
7. Too much stomahesive paste is difficult to remove from the skin.
8. Replace the cap on the syringe. You can save this for another time.

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O. Granulation Tissue

- Sometimes, “extra tissue” called granulation tissue grows around the gastrostomy.
- Granulation tissue is more likely to form if the gastrostomy is turned a lot.
- If the button gets turned frequently, it may have to be taped to your child’s abdomen.
- **You can not always prevent granulation tissue from forming.**
- 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/green drainage that smells like stinky feet.
- Do not worry if you see tiny spots of blood if the tissue becomes irritated.
- Granulation tissue may go away but it can return.
- 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 q-tip with medicine (silver nitrate) on the granulation tissue or use a special dressing around the button.
- Silver nitrate helps the granulation tissue shrink and dry up. The tissue may turn dark or white.

P. What if the gastrostomy button or tube comes out before 2 months after surgery or before your child’s surgery clinic appointment?

- Gastrostomy buttons, on very rare occasions, may come out. Formula or food may leak from the stoma and you may see a small amount of blood.
- There is no immediate danger to your child.
- Cover the opening with a washcloth or towel and prepare to insert the replacement tube.
- **Do NOT place the old button back in!**
- You will be sent home with two replacement tubes (foley catheters). One that is the same size as your child’s old button and a smaller one.
- The replacement tube is inserted to keep the stoma and gastrostomy tract open.
- When you get home with your child, take the replacement tubes (foley catheters) and lubricant out of the take- home bag and put them in a handy location.

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How to place the foley tube into the gastrostomy stoma

1. Get the foley (same size as you child's button) and put a dab of water soluble lubricant on the tip (use the package of lubricant in the take home package or KY Jelly).
2. Gently insert the tip of the foley **1¼ inch (3 cm)** into the gastrostomy stoma.
3. Your child may cry, wiggle, or kick causing the abdominal muscles to contract.
4. Take a deep breath, try to relax and comfort your child. When your child breathes out, the abdominal muscles relax and the foley should slide into the stoma.
5. **Never force the tube into the stoma.** Try the smaller size foley if needed.
6. Do not take more than 10-15 min to try to insert the replacement tube.
7. Tape the replacement tube to your child's abdomen after it is in the stoma.
8. **Do NOT blow up the balloon on the foley!**
9. **Do NOT feed, give water or, give medicine to your child.**
10. Call the Surgery Office or the Surgical Resident on Call (after office hours and on the weekends) when the replacement tube is in the stoma.
11. Take your child to **St. Louis Children's Hospital.**
12. If you are **unable** to insert the tube, take your child to **the nearest emergency room.** Have the local Emergency Room physician call the Surgical Resident on Call.

Q. Frequently Asked Questions

1. **Can my child swim or take a bath?**
 - After 2 weeks, the gastrostomy site should be healed and your child can take a bath or swim in chlorinated water.
 - After 4 weeks, your child can swim in lakes, rivers or the ocean.
 - Clean the gastrostomy site immediately after swimming.
 - Water may leak into your child's stomach. This is okay for most children.
2. **Can my child lay on the gastrostomy?**
 - Yes, after the site is no longer tender after placement.
 - Infants can lie on their stomachs for tummy time.
 - Older children can sleep on their stomachs.
3. **Does my child have to go back to surgery to remove the gastrostomy?**
 - No. Most gastrostomies are removed in the Surgery Office.
 - Some leaking from the stoma is normal after the gastrostomy is removed.
 - The nurse from the Surgery Office will show you how to put a dressing over your child's old gastrostomy site.

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- The stoma usually closes in several weeks.
- Your child may need to have surgery to close the stoma if the gastrostomy has been in place over a year.

R. Call Your Child's Medical Provider if:

- Your child's abdomen (stomach) is hard or distended (bulging) or your child vomits with feedings.
- Your child has pain or cramping with feeding.
- Your child has a fever.
- Your child has signs and symptoms of dehydration:
 - No urine in 12 hours for toddlers
 - No urine in 8 hours for infants
 - Crying without tears
 - Very dry mouth or cracked lips
 - Sunken soft spot (infants less than 1 year)
 - Your child is more sleepy than usual
 - Your child feels dizzy

S. Home Care Supplies

- Replacement gastrostomy tube.
- For Skin Care
 1. Stomahesive powder
 2. Stomahesive paste (optional)
 3. 2X2 gauze
 4. Skin barrier wipes
 5. Tape of choice
 6. Adhesive remover
- For feedings
 1. Extension set for feeding (2)
 2. Feeding syringe
 3. Farrell bag as ordered.
 4. Feeding pump as ordered

For General Health Information and Resources:

Call or visit the [Family Resource Center](#), a health information library on the 3rd floor of the hospital. Call 314.454.2350, email at frc@bjc.org, or check out the FREE [St. Louis Children's Hospital Kid Care App](#).

