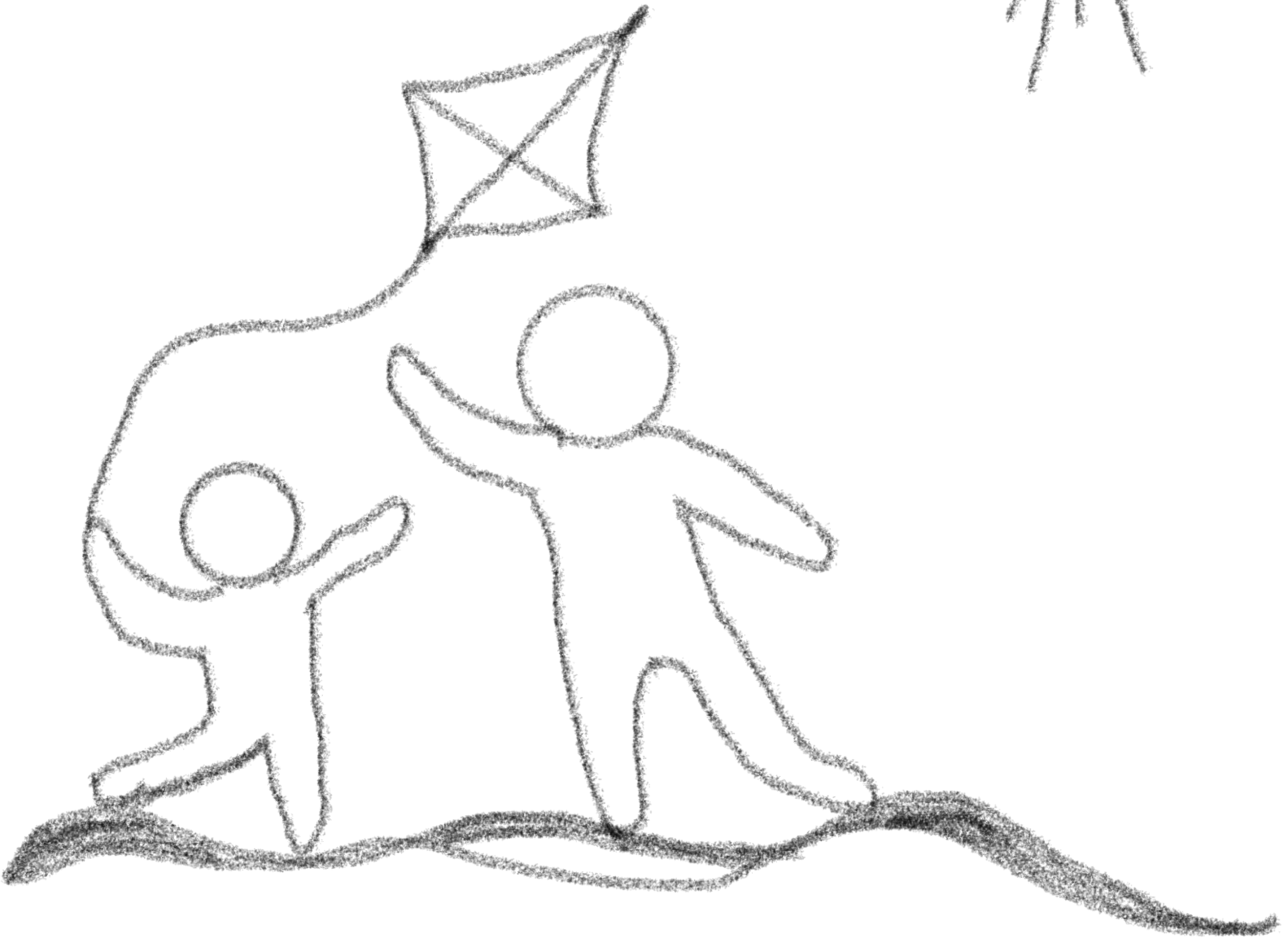


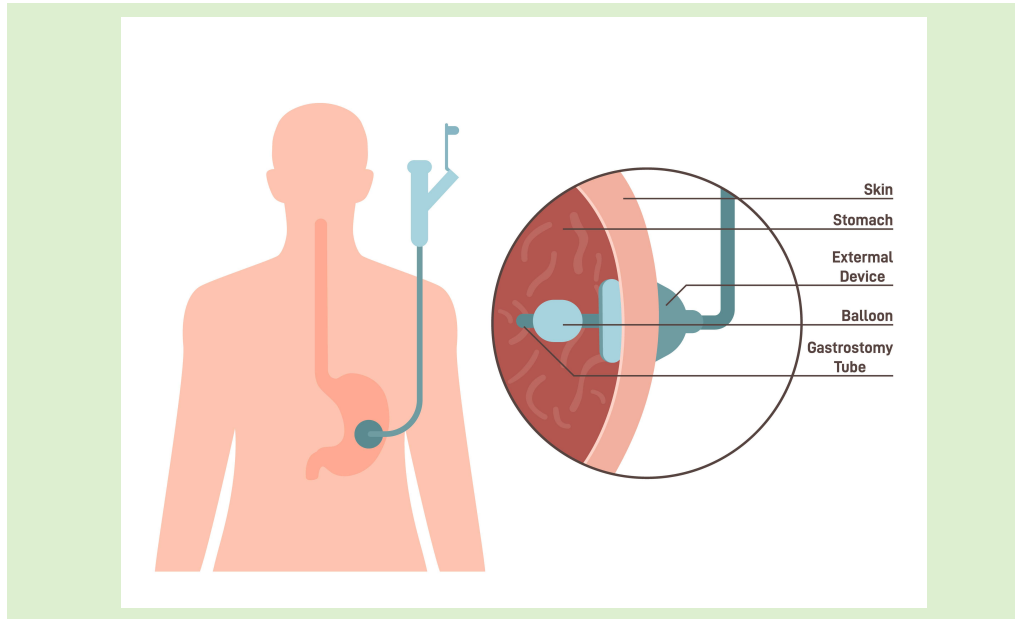
Parent's Guide for Going Home with a Gastrostomy Tube



 KAISER PERMANENTE. PEDIATRIC CARE

What is a Gastrostomy?

A gastrostomy (stoma) is a surgical opening made through the skin of the abdomen (belly) and into the stomach. A feeding tube (called a gastrostomy tube or G-tube) is placed through this opening.



This allows food and medicine to be given directly into the stomach instead of through the mouth. Giving feedings this way can be done safely at home. The gastrostomy tube can be permanent or temporary. Tube feedings will help your child get enough nutrition to grow, develop, recover from illness, play and learn.

What will I learn in caring for my child with a gastrostomy tube?

Caring for a child with a feeding tube may be a little scary at first. Your child's nurses will help you learn and practice how to care for the gastrostomy tube (G-tube). We want you to feel comfortable with your child's care before you take them home.

These are special things you will learn how to do:

- Care for the gastrostomy tube
- Protect the gastrostomy tube
- Clean the gastrostomy site
- Give feedings through the feeding tube
- Give medicines through the feeding tube
- Help your child develop oral skills
- Watch for problems and know what to do if they occur

FAQs

There are many variations in these tasks. Please follow the instructions specific to your child. Sometimes changes must be made based on your child's needs.

Your child may need a gastrostomy tube for any of the reasons below:

- Cannot swallow safely
- Blockage of the esophagus
- Abnormal function of the stomach
- Cannot take enough food by mouth

How is the gastronomy tube placed?

- In the operating room by a surgeon or pediatric gastroenterologist
- Usually, your child is in the operating room for 1 to 2 hours

What will happen after surgery?

- Your child will have nothing to eat or drink for up to 24 hours after surgery but will have fluids through an IV
- You child may feel sore for a day or two and the area may be swollen
- We will give your child medications for pain
- There may be some sutures near the G-tube
- You will start to learn about caring for the G-tube right away
- We will clean the skin around the tube with saline and gauze or cotton tip applicators at first
- The new site may have some drainage until it heals
- As the stoma heals, a tract connecting the stomach to the outside skin develops around the tube
- Do not rotate the G-tube until the tract is healed
- Your child may only have sponge baths for the first 2 weeks

What kind of feeding tube does my child have?

There are different kinds of feeding tubes, but they all have the same basic parts:

- A bumper or balloon inside the stomach to keep the tube from coming out
- A stabilization device against the skin to keep the feeding tube from moving
- Numbers or marks on the feeding tube so you can tell whether the tube has moved
- Ports: openings on the outside of the G-tube, used to give food or medicines, or to fill the inside balloon with water. There may be 1, 2, or 3 ports. Ports have a flip-top cap that can be closed off when not in use

Ask your nurse to go over the type of device your child has and what each port is for.

Gastrostomy tube (or "G-tube"): has 2 or 3 ports, and a balloon filled with water inside the stomach to secure it. There are several types of gastrostomy tubes. The doctor will choose the best one for your child. It may be necessary to change the type or size of the G-tube as your child grows and his/her medical needs change.



Home Care

- Keep the G-tube and the stoma (the skin around the tube) clean and dry
- Clean the skin around the G-tube 1 to 2 times each day with soap and water
- The G-tube is replaced about every 3 to 6 months
- At your follow-up appointment, the clinic staff will teach you how to change the G-tube at home, and how and when to check the water in the balloon
- A dressing under the extension set can help stabilize and prevent movement, but is not required

How to care for your child's gastrostomy Site

The stoma, or opening in the skin, heals very slowly and may take several months. Careful skin care is essential until the site is healed. The skin around your child's stoma needs to be cleaned twice a day, such as with the bath, before a feeding, and as needed if drainage occurs. Once the site is healed, it can be cleaned once a day, and as needed

1. Wash your hands well with soap
2. Gather supplies needed:
 - o Cotton swabs
 - o Mild, pH-balanced soap and water
 - o Washcloth and dry towel
 - o Gauze drainage sponges (if needed)
3. Remove the old gauze, if present
4. Check for drainage. A smear of blood or a bit of clear yellow drainage is normal. If drainage has increased, is cloudy, yellow or green, or foul smelling, contact the doctor
5. Check the skin around the stoma. If there is increased redness or skin growth, call the doctor
6. If there is a little bleeding or drainage at the site, place gauze under the bumper. Change it as needed to keep the site dry
7. Clean the feeding port by vigorously swishing it in warm soapy water. Rinse with clean water
8. To keep the tube from being pulled, wrap a piece of tape around the tube, leaving a tape tag. You may use a safety pin to pin the tag to the child's clothing.

It is very common for some children with G-tubes to get hypergranulation tissue (also called granulation tissue or granuloma) around the stoma. Granulation tissue typically looks pink to dark red, it appears open, shiny or wet, and appears puffy. Causes of granulation tissue include too much movement of the feeding tube, the stoma is wet, too much pressure on the stoma, trauma to the stoma, or an infection. Preventative measures are:

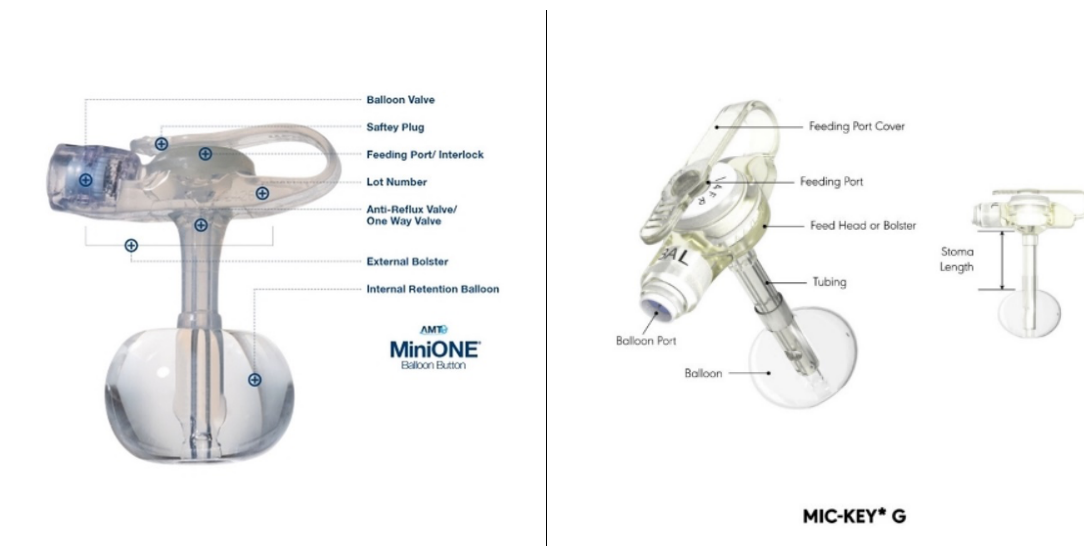
- Keep stoma clean and dry
- Clean site with soap and water every day
- Prevent pulling on the G-tube

If the granulation tissue and surrounding area has pain, redness or swelling, contact your healthcare provider for an appointment. They may prescribe Triamcinolone cream to apply to the G-tube site, or they may treat it in the clinic with a medicine called silver nitrate. These medicines shrink granulation tissue.

Granulation tissue may return and need to be treated with medicine again.

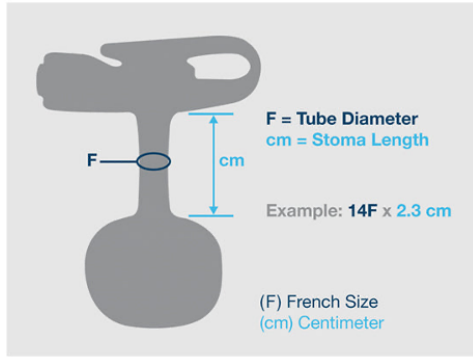
Home treatment for G-tube granulation is applying Tea Tree oil to the affected area (s). You can purchase tea tree oil online or in most health food stores. The directions are as follows: Add 10 drops of Tea Tree Oil to 1oz water. Moisten a cotton swab or gauze with the solution and apply to granulation tissue 2-3 times per day.

Skin-level Gastrostomy tube (or "button"): this device lies flat against the skin and has a balloon inside the stomach. This device is sometimes called a "MiniONE Balloon Button" or a "MIC-KEY" which are brand names. An adapter tube called an extension set has 2 or 3 ports and is used to give the medicines



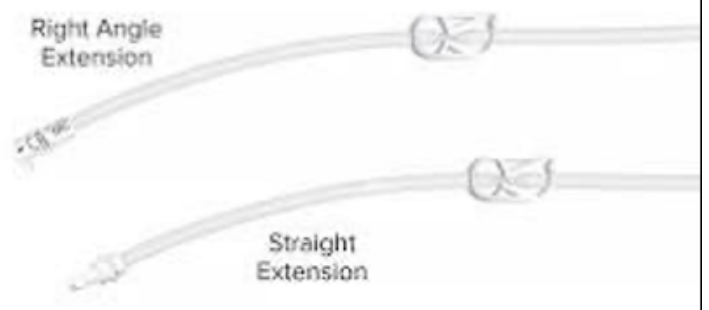
- The balloon port is the little opening labeled "BAL" on the side of the G-tube
- Amount of water in the balloon should be checked once a week, same day each week
- An extension set is attached to the key shaped opening to give fluid and feedings
- When not in use, the feeding port is covered with an attached cap
- An anti-reflux valve is located inside the G-tube to help prevent the stomach contents from leaking out of the G-tube
- The extension set will open the valve
- Flush thoroughly with water to keep the valve clean and working properly
- Extension sets are disposable and should be changed every week

What do the numbers on a GT mean?



Extension sets

- Remove extension set from GT when not in use
- If your child is receiving feedings over more than an hour, secure the extension set to the skin with tape to prevent pulling on the g-tube
- Extensions sets are disposable and should be changed every week
- The supply company providing our G-tube supplies should send you 5 extension sets every month
- Clean the extension set with soap and water after every use
- Do not use if clogged or dirty
- The most used extension for feeding has a right-angle connector and a y-port
- The straight bolus extension set is useful for venting the G-tube or for large volume bolus



When should I call the Doctor?

Call the doctor if:

- Temperature higher than 101° F
- Redness, pus-like drainage, or bad smell around the stoma
- If there are any large bumps under the skin around the G-tube
- Rash or irritated skin around the gastrostomy site
- Leaking around stoma (more than a quarter-sized amount between cleanings)
- Bleeding around stoma
- Increase in granulation tissue around stoma
- Continued upset stomach, vomiting, or gas
- Continued increase in abdomen size
- Residuals are more than the recommended amount for 2 feedings in a row
- Blood in the residual
- Diarrhea for longer than 24 hours
- 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
- Tube is accidentally pulled, and you don't know how to replace it
- Tube breaks off or is cut off
- Trouble inserting the tube
- Tube is too short or too long and you cannot adjust it
- Tube is clogged and you cannot unclog it
- If the G-tube falls out and it is less than 2 months since surgery
- If the G-tube falls out before the first tube change (follow the instructions for the emergency tube and call the surgeon)

Home Emergency Kit for your Child's G-tube



Why is it important?

The opening will start to close within 30 minutes and may be closed completely closed by 24 hours. If the tube is newly placed, and you have not yet been seen in the Pediatric Gastroenterology (GI) clinic, call Pediatric Surgery _____. After 5 pm or on weekends or holidays, call _____ and ask for the on-call pediatric surgeon to be paged.

G-Tube Emergency Kit Supplies

- 2 tubes, 1 the size of current G-Tube and 1 a size smaller (this tube is often called a Foley)
- Water soluble lubricating jelly
- Tape
- Catheter plug

Steps if G-tube falls out

1. Wash your hands
2. Put a small amount of water-soluble lubricating jelly on the end of the emergency tube
3. Gently insert the emergency tube 2-3 inches into the stoma (Do not take more than 10-15 minutes to try to insert the Emergency tube
(the emergency tube is inserted to keep the stoma and gastrostomy tract open)
4. Tape the tube to the skin so that it won't fall out
5. Do not give ANYTHING (formula, water or medications) through the emergency tube. Do not inflate the balloon on the emergency tube.
6. Call the doctor or go to the nearest emergency room

Important information

- **Always carry your emergency kit**
- Be sure your child's teachers, school nurse, and PE teacher know about the gastrostomy tube
- Do not use medications that are out of date

How do I replace the G- tube?

Once the gastrostomy site has healed, the nurse may teach you how to replace the tube or skin level device at home.

When to change G-tube

- It is plugged and you cannot unclog it
- The tube comes out
- Your child has pulled the tube out

Steps to Replacing the G- tube:

1. Wash your hands well with soap
2. Gather all supplies needed:
 - Extra gastrostomy tube
 - Water based lubricant (it is important to AVOID oil-based lubricants such as mineral oil)
 - Stabilizing device, if used
 - 5-ml syringe
 - Tape
 - 2 clean cloths
 - Water
3. Check the new gastrostomy balloon for leaks by filling it with the volume recommended by the manufacturer
4. Remove the water from the balloon
5. Wet the tip of the tube in lubricant
6. Put the tip into the stoma
7. Gently push tube into the stomach until the mark is at skin level
8. Fill the balloon with the correct amount of water
9. Gently pull tube to position the balloon against the wall of stomach. Pulling the tube too tightly will cause the opening to enlarge and formula may leak out around the tube (not applicable for skin-level tubes)
10. Clamp or plug the tube
11. Apply stabilizing device (not applicable for skin-level tubes)
12. Check the tube for correct placement. For a skin-level device, insert an extension set and listen for air and check for residual stomach content

Tube Feedings

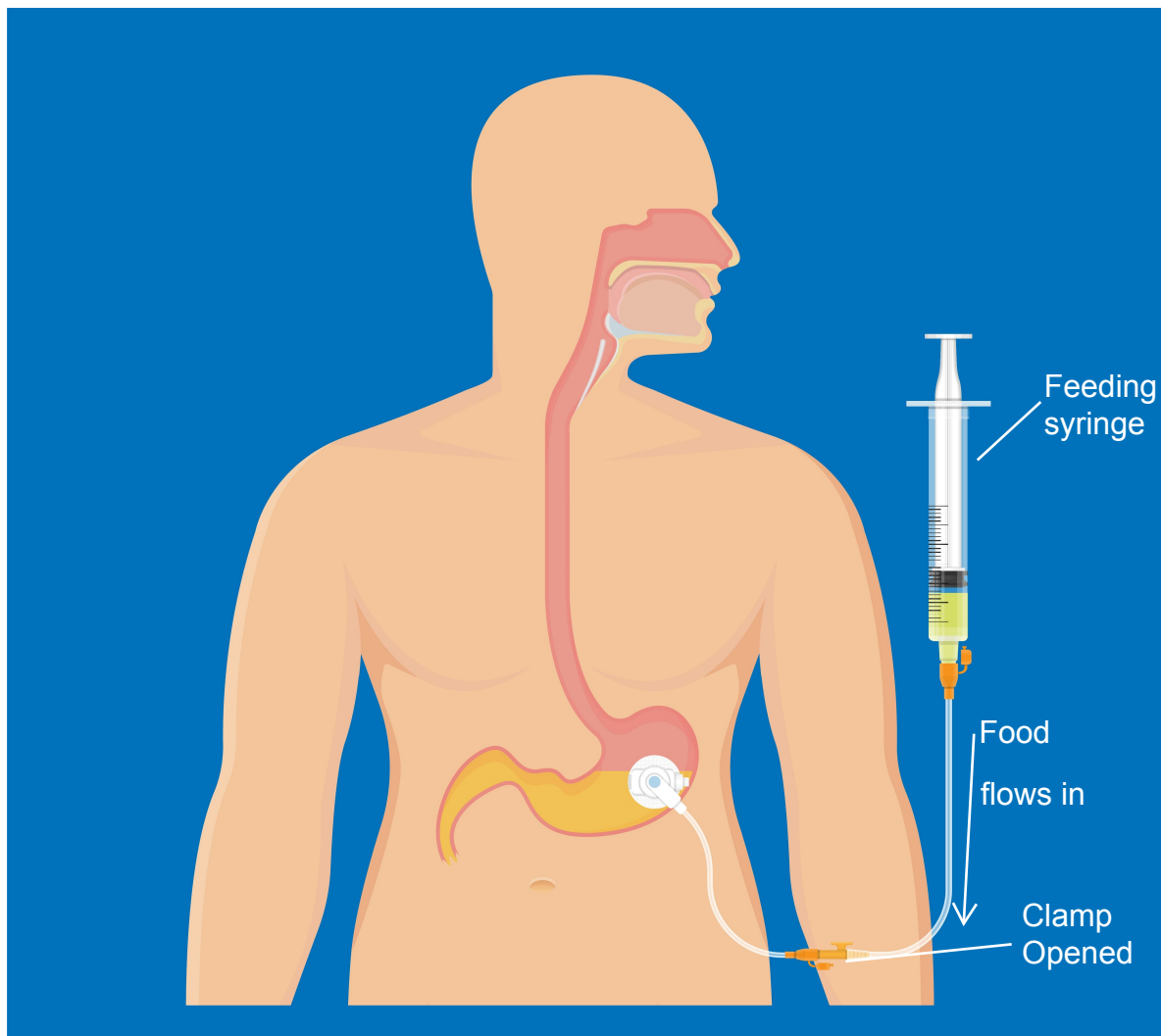
There are several ways to give a gastrostomy feeding. The type, amount of formula, and length of feeding time will be decided by the doctor and dietitian, depending on your child's needs. DO NOT change the diet without approval from your health care team.

Bolus feedings (also called gavage feed)

- With this method, formula flows out of the syringe into the feeding tube and the stomach
- The bolus is given like a meal, usually over 20-30 minutes
- Larger amounts can be given over a short period of time
- To prevent choking, particularly for bolus feedings, have your child's upper body raised at least 30 degrees. The upper body should stay raised throughout the feeding and for at least 30 minutes afterward

Supplies:

- Formula
- Water
- 60 ml syringe with plunger removed
- 5- or 10-ml syringe for water flush
- Extension set (if used)



Steps for feeding:

1. Wash your hands
2. Attach extension set (if used)
3. Make sure G-tube or extension set is clamped
4. Attach syringe to G-tube or extension set
5. Pour desired amount of formula into syringe
6. Unclamp extension set or tube
7. Allow formula to flow in by gravity
8. The higher you hold the syringe, the faster it flows
9. If formula doesn't flow, push gently with the syringe plunger. Do not force
10. Add more formula to the syringe before it empties to prevent unnecessary air from entering the stomach
11. Adjust the flow rate by raising or lowering the syringe in relation to your child's stomach
12. Add ____ ml warm water to syringe for flush at end of feeding to keep it from clogging
13. When feeding is finished, clamp tube
14. Disconnect and wash extension set and syringe, allow to air dry
15. Refrigerate any unused formula and use within 24 hours

Continuous feedings (Enteral pump feeding): A feeding pump is used to make the tube feeding go into the stomach at a slow, steady rate. A child may be fed day and night using a pump. Some children are fed only during waking or sleeping hours.

Whether or not your child is eating by mouth, their body may need extra water. Your doctor and dietitian will decide whether extra water is needed and how much should be given to your child every day.

There are multiple ways of giving feedings with a pump:

- Bolus: Feeding given over 30 minutes to several hours
- Continuous: Feedings given over a longer time period, for example, overnight or 24 hours per day
- Cycled: Feedings given over a longer time period with breaks in between

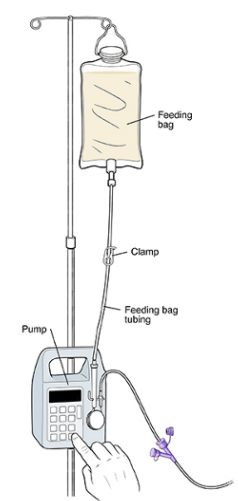
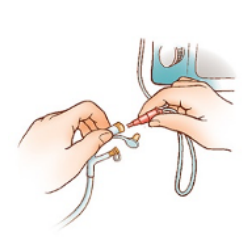
Supplies:

- Formula
- Water

Steps for feeding with pump: > > > > > > > > > > > > > > > >

1. Wash your hands
2. Fill feeding bag with formula
3. Connect feeding bag to pump and prime according to pump instructions
4. Program pump settings as instructed
5. Attach extension set (if used) to G-tube and flush with water
6. Attach pump tubing to G-tube or extension set
7. Unclamp G-tube or extension set
8. Start pump and watch to make sure feeding has started properly
9. For bolus or overnight feedings:
 - At the end of the feeding, flush G-tube/extension set with water
 - Pump feeding bag
 - Disconnect and wash extension set, and allow to air dry
 - Your child's nurse will instruct you on how to care for the feeding bag
 - Use a new feeding bag every 24 hours
10. Refrigerate any unused formula and use within 24 hours

It is recommended to flush the G-tube/extension set with 5-10 mls of water before and after feedings to keep tube from clogging



What is "Venting"?

Venting allows air to escape from the stomach. Your child may get uncomfortable due to excess air or gas in their stomach. Some children may need venting more frequently and /or during feeds.

When you may vent the tube:

- Before and after feeds
- With diaper changes
- As needed

How to vent your child's G-tube

1. Wash your hands
2. Remove plunger from 60 ml syringe
3. Attach syringe (without plunger) to clamped feeding tube or extension set
4. Hold syringe above the level of our child's stomach
5. Unclamp tube or extension set
6. Press lightly on the stomach or lift the legs
7. Excess gas will bubble up into the syringe. It is normal for formula/stomach contents to rise into the syringe
8. If liquid is seen in the syringe, allow it to flow back by gravity before clamping the tube/extension set and removing the syringe

Cleaning feeding equipment

Formula container and syringe:

1. After each use, wash well with warm water and dish soap
2. Rinse well with clear water
3. Air-dry on a clean towel
4. When completely dry, store in a clean, covered container

Feeding bag and tubing:

1. After each use, wash with warm water and dish soap
2. Rinse well with clean water

If the bag and tubing do not become clean easily, try using a solution made of white vinegar and cool water (equal amounts of each, for example, 1 cup vinegar with 1 cup water). Then, rinse well

Store in a plastic bag or covered container in the refrigerator to keep germs from growing

Throw away the feeding bag and tubing

- o Every day
- o After 1 week, or sooner if it becomes cracked, cloudy, or hard to clean

Giving medications

Steps for giving medications

1. Wash your hands
2. Pull up medications in separate syringes
3. If tubing or extension set has 2 ports, always ensure that they are capped to prevent meds from spilling
4. Prime extension set with water
5. Add extension set (if used) to G-tube
6. Attach syringe with medicine to G-tube/extension set port
7. Unclamp G-tube/extension set
8. Give medicine through medicine port. Medication should go in easily, do not force
9. Clamp between medications and water flushes
10. Flush with a small amount of water (1-2 ml) in between each medication
11. Flush afterward with recommended amount of water
12. Remove and wash extension set (if used)
13. Wash syringes with soap and water and allow to air dry

Medications are the most common cause of a clogged tube

- Only give one medication at a time
- Flush with water between and after meds
- Use liquid medications whenever possible
- Check with MD or pharmacist before crushing pills
- If crushing pills do so into a fine powder and mix with warm water to dissolve
- If medications are thick, dilute in water
- Pull medications in separate syringes
- Wash extension sets after each use
- Throw away the extension set if it becomes stiff or cannot be cleaned well
- Change extension sets at least weekly

Adjusting to your child's G-tube

Activity – the healthcare team will work with you to develop a plan that fits your family's needs and fits with your child's school, appointment, and sleep schedule

Most activities including tummy time are allowed. Children may enjoy being in a swimming pool once the site has healed. Be sure to dry the site well afterwards

Mouth care – if your child is not taking food by mouth, it is still important to keep the mouth clean. If your child has teeth, clean them with water or a soft toothbrush. No toothpaste is needed for children younger than one year of age. If your child doesn't like a toothbrush, begin with a wet washcloth over your finger. Work toward your child getting used to a variety of textures in the mouth. Begin regular dental checkups you would for any child

Clothing – Your child can wear almost any kind of clothing. Infant outfits that have snaps or fasteners all the way down the front give easier access to the gastrostomy site. As babies get older, they sometimes like to play with the G-tube. If our child does this, you may want to use one-piece outfits and shirts that tuck into pants. Or can tuck the tube under the shirt or under an elastic waistband. If your child does not see the tube, there will be less temptation to play with it.

Development – your child needs to keep the connection between the mouth being used and the stomach getting full. If your child is allowed to have food or liquids by mouth, it is important to offer an oral feeding each time your child gets a tube feeding. If your child is not able to eat by mouth, oral stimulation (or a pacifier for infants) can be offered during tube feedings. Talk to your healthcare team about other ways to provide for your child's oral development

Safety -keep sharp objects away from the G-tube. Protect the tube from being pulled on. Do not put anything in the tube that has not been approved by the health care team

Preventing Infection:

- Wash your hands every time you handle the tube, formula, or supplies
- Wash out the bag or place it in the refrigerator between feeds as instructed by your enteral supply company
- Use a new bag every day
- Good oral hygiene prevents bacteria from moving down the airway and causing pneumonia

Babysitters/Caregivers – all caregivers should be trained in gastrostomy care. The hospital or home care staff can help you teach other caregivers how to care for your child. Be sure to provide the babysitter with emergency phone numbers and enough extra supplies

Siblings - it is important to help other children in the family understand why and how the child is fed through a G-tube. It may be helpful to involve brothers or sisters in small tasks, such as getting or holding things, or helping to clean the equipment. Be sure to watch children so they do not put anything into the gastrostomy tube or pull it out

Supplies – be prepared and always make sure you have enough formula and supplies

Travel – Take a gastrostomy travel kit everywhere you take your child

Gastronomy travel Kit:

- Clamp or gastrostomy plug, if used
- Cotton-tipped applicators
- Gastrostomy tube
- Extension set (for skin-level devices only)
- Feeding supplies
- Gauze or clean cloths
- Lubricant, if desired
- Measuring container with pouring spout
- Mild, pH-balanced soap
- Stabilizers, if used
- Syringes



Stoma Problem Solving

Stoma problems	What to do
Leaking around stoma (more than a small amount)	<ul style="list-style-type: none"> Try to adjust tube and stabilizer. Check amount of water in the balloon. Slow the feeding rate. If leaking continues, call the doctor.
Bleeding	<ul style="list-style-type: none"> Apply gentle pressure with a clean cloth for 5 minutes. Call the doctor.
Tube problems	What to do
Change in length of tube	<ul style="list-style-type: none"> If it is too short, gently pull it to the right length. If it is too long, push it in slightly (1/2 -1 inch). Check the balloon volume. Then gently pull it to the right length. If you cannot adjust it, do not feed. Call the doctor.
Clogged tube	<ul style="list-style-type: none"> Check tube for kinks, closed clamps. Attach syringe with warm water and use slow Push-pull method to try to unclog G-tube. Repeat every 10-15 minutes. Call the doctor
Feeding tube does not stay connected to port	<ul style="list-style-type: none"> Clean port by swishing in soapy water, then rinsing in clear water.
Port cap breaks off	<ul style="list-style-type: none"> Replace with Y-adapter repair kit, following package instructions.
Tube is accidentally pulled out and you don't know how to replace it	<ul style="list-style-type: none"> Cover the stoma with a clean, soft cloth. Call the doctor for directions on where to have the tube replaced.
Tube breaks off or is cut off	<ul style="list-style-type: none"> Take your gastrostomy travel kit with you.

Stoma Problem Solving

Feeding Problems	What to do
Residual is more than ____ml right before a feeding	<ul style="list-style-type: none"> ▪ Check again before the next feeding. ▪ Call the doctor if residuals are more than recommended for 2 feedings in a row.
Vomiting	<ul style="list-style-type: none"> ▪ Stop the feeding ▪ Place child in side-lying or sitting position with head tilted forward. ▪ Flush tube with water or air to prevent clogging. ▪ Start feeding again when the child feels better. ▪ If child vomits again, call the doctor
Gas or upset stomach	<ul style="list-style-type: none"> ▪ Make sure food is at room temperature. ▪ Give feeding more slowly. Do not force a feeding. ▪ If slowing does not help, stop the feeding and vent the tube. ▪ Wait until child feels better, then restart the feeding. ▪ If gas or upset stomach happens again, call the doctor.
Cramping Diarrhea	<ul style="list-style-type: none"> ▪ Be sure the formula has not been open longer than 2 hours. ▪ Check for correct pump rate. ▪ Check for correct formula concentration. ▪ If formula is cold, warm it to room temperature. ▪ Stop the feeding and vent the tube. ▪ Flush the tube with water or air to prevent clogging ▪ If the child feels better, feed at the next scheduled time. ▪ If diarrhea lasts more than 24 hours, call the doctor
Increase in abdomen size	<ul style="list-style-type: none"> ▪ Leave tube open to air. ▪ Call the doctor if it does not decrease.

Feeding Problem Solving

Feeding Development

A child who cannot eat by mouth misses the oral touch that normally happens with eating. The child does not learn that the mouth can give pleasure. It is important to provide activities that provide touch and pressure to the mouth and face to help prevent your child from developing oral aversion. It is common for tube fed children to show no interest in eating; in fact, they may gag and cry when offered foods or liquids.

Ways to Support Oral Development (Age appropriate)

0-3 months	3-6 months	6-12 months
<ul style="list-style-type: none">▪ Tummy time▪ Using exaggerated facial expressions when interacting with your baby▪ Encourage your child to bring their fingers up to their mouth for exploration or sucking	<ul style="list-style-type: none">▪ Floor time▪ Teethers▪ Textured spoons▪ Silicone safety feeder▪ Straw cup/sippy cup/open trainer cup▪ Encourage your child to bring their fingers up to their mouth for exploration or sucking	<ul style="list-style-type: none">▪ Teethers▪ Textured spoons▪ Silicone safety feeder▪ Silicone puree feeder▪ Straw cup/ sippy cup/open trainer cup

Eliminate All Tubes (E.A.T.) Well Program

E.A.T. Well is a program developed to wean your child off tube feedings. Your GI Team will determine if your child is eligible when they meet the following criteria: medically stable, has adequate growth and showing developmental readiness. In this program, the team will work with you on slowly decreasing the amount of nutrition that is offered in the G-Tube, thereby create more of an interest and appetite for eating/drinking by mouth. Your child's nutrition and growth status will be closely monitored. The Occupational Therapist will work with you and your child to support their feeding skill development by assessing their oral motor skills to increase their oral intake.

Your Child's Gastrostomy information

Tube information

Brand: _____

Size: _____ Date of insertion: ____/____/____

Balloon volume: _____ml (if applicable)

Feeding method and schedule

See your child's discharge summary for details on the following. Be sure to ask if you do not have this information:

☐ Bolus feedings:

What to feed: _____

Amount: _____

How often: _____

☐ Continuous feedings:

Type of pump: _____

What to feed: _____

Amount: _____

How often: _____

Pump rate: _____

☐ After feeding, flush tube with ____ml of room-temperature water.

☐ After feeding, vent for _____ minutes

☐ If you give extra water: _____ml times/day

☐ Check residual every _____; call if more than _____ ml

Medicine

See your child's discharge summary for medication information.

- If medication and feeding are due at the same time, give medication first then feed your child
- Prepare medication according to pharmacy guideline
- Flush tube with ____ ml of water

Phone numbers

Call 911 if you child is

- ❖ Pale, Blue or Gray
- ❖ Having trouble breathing or rapid breathing
- ❖ Coughing or choking repeatedly and/or unable to get their breath

Primary doctor _____

Gastroenterologist _____

Surgeon _____

Dietician _____

Occupational therapist _____

Nurse Case Manager _____

Emergency room _____

GI Clinic Line (Business hours) 408-851-1240

Kaiser Nurse Advice line (24/7) 866-454-8855