



Caring for your child
with a gastrostomy


**Intermountain
Primary Children's Hospital**
The Child First and Always®





Dear parents or caregivers,

Your child has received or may be getting a gastrostomy [gas-TRAW-stoh-mee]. This is a special surgery that creates a small hole from outside the skin into the stomach. After the hole is made, a feeding tube is placed into the hole. Healthcare providers call this a g-tube. The g-tube provides a way to give your child formula and medicine directly into the stomach. G-tubes are placed for many reasons. Some children will have the g-tube for a few months, and others may have it their whole lives.

The idea of a g-tube for your child may make you feel afraid. You may also be worried about taking care of the g-tube at home. These feelings are normal. At first, most parents are unsure about their ability to care for a g-tube at home. Below are a few ways you can learn to care for your child's new feeding tube while at the hospital:

- **Take time to be at your child's bedside.** Nurses will teach you, step-by-step, how to take care of the g-tube, give formula, and give medicine.
- **Watch the g-tube video.** You can find the video on the education channel at the hospital and hospital unit iPads. Ask your nurse to help you find it.
- **Go to the community g-tube caregiver class.** This class is free and open to all caregivers and is taught by the gastrostomy nurses. They will teach you how to care for your child's g-tube. Ask your bedside nurse how to sign up for the class.
- **Learn where to get the supplies.** Ask about the best suppliers, since you will need many supplies to care for your child's g-tube.

This booklet is yours to keep and use at home. The instructions inside are only guidelines. Your doctor may change the recommendations according to your child's individual needs.

As you learn about g-tubes, you will hear many new words. These words are explained in a glossary on the last page of this book. We encourage you to ask questions and practice skills so you feel comfortable with the g-tube when your child leaves the hospital.

Sincerely,

Primary Children's Hospital





Caring for your child with a gastrostomy

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What is a gastrostomy?

When we eat, food and drink moves from the mouth down to the stomach. Food and drink give our bodies the nutrients we need. When an infant or child cannot eat or drink, or a medical problem keeps the child from getting enough nutrients, a tube is placed directly into the stomach.

This is called enteral [EN-ter-al] feeding. It can help a child stay at a healthy weight.

To place a g-tube, your child's doctor will make an opening through the skin and into the stomach. This is called a stoma [STO-muh]. The g-tube is placed through the stoma and into the stomach. It takes about 8 weeks for the stoma to fully heal.

There are many different kinds of g-tubes. This booklet will go over the most common types of g-tubes and practices. Your doctor will choose the type of g-tube and best practice that will work best for your child's needs.

What's it like caring for a child with a g-tube?

"Generally speaking, having a child with a G-tube is pretty much like having any other child that has to be fed. Right at first it was pretty hard, and it was kind of hard to accept that I couldn't just feed her like anybody else or she couldn't drink water like anyone else or something, but after a while it just became normal. It's just our normal. It's our family's normal and we're used to it. It's just like feeding any of my other children."

Lana's mom

How does my child eat with a g-tube?

When your child has a g-tube, they will get their nutrition through the tube that goes directly into their stomach and not through their mouth.

Normal eating

Food goes through the mouth, down the esophagus [eh-SAH-fug-gus], and to the stomach. After the stomach has broken down the food a little bit, it moves into the small and large intestine so the body can absorb the nutrients it needs.

Feeding through a g-tube

When your child is fed through their g-tube, they may not need to eat through their mouth. The food goes directly into the stomach instead of going through the upper digestive tract.

Your child may be able to eat regularly along with their g-tube feedings, depending on why they have the g-tube.

There are many reasons why children need a g-tube. Why does your child have a g-tube?

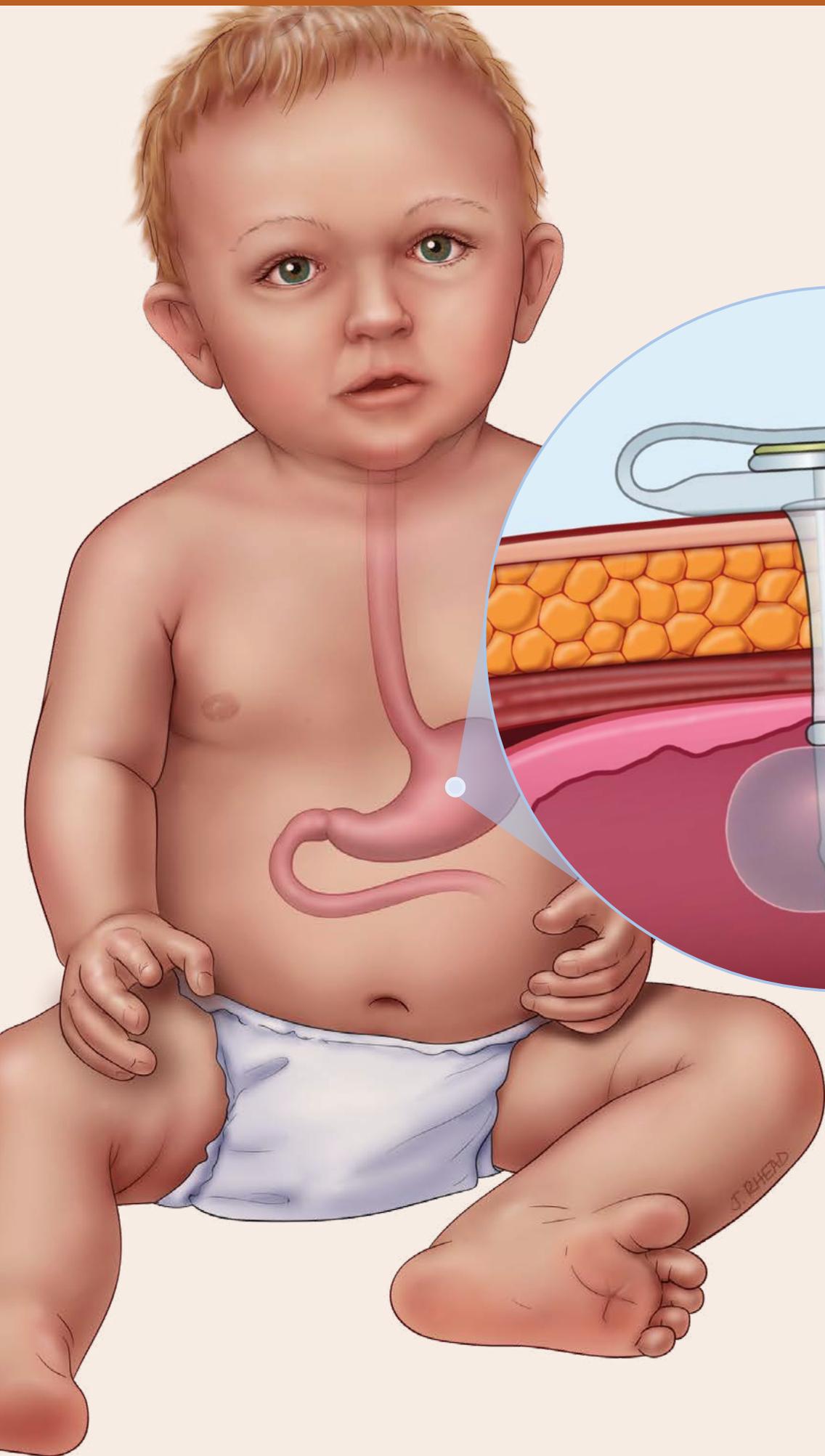
Write your answer in the box below.

My child has a g-tube because:

Gastrostomy checklist

Before you take your child home, the g-tube team will ensure you are ready to care for your child with confidence. At least 2 caregivers must be trained, but multiple caregivers can attend the hospital training sessions. You can also train other caregivers yourself once your child is at home.

- The g-tube team will assess your learning needs:**
 - Meet with your family and explain the g-tube teaching process and timeline
 - Schedule interpretation services as needed
 - Tell your medical team if caregivers need special learning techniques or help
- Go to the G-tube Caregiver Class and 6 week follow-up appointment**
 - Watch g-tube video on patient education channel or unit iPad
 - Review the written information, including Primary Children's Hospital's g-tube training booklet
 - Attend 1-hour g-tube class (only one session Monday through Friday)
 - Demonstrate g-tube cares on a doll (simulation)
 - Demonstrate g-tube cares on your child (bedside pass-off)
- Understand how to care for your child's new feeding tube.**
 - Take time to be at your child's bedside. Nurses will teach you, step-by-step what you need to know to care for your child's new g-tube.
 - Practice the skills you are taught often while you are at the hospital so you feel comfortable doing them once you leave the hospital.
 - Ask questions if you don't understand something.
 - Learn where to get the supplies you will need to care for your child's g-tube.
- Make sure you have the g-tube replacement kit before you leave the hospital. This kit should be with your child at all times.**







Types, parts, and supplies for a g-tube

There are many parts of a gastrostomy tube, but you'll soon learn to put it together correctly. Read on to learn about the different g-tube types and parts and how they all work together.

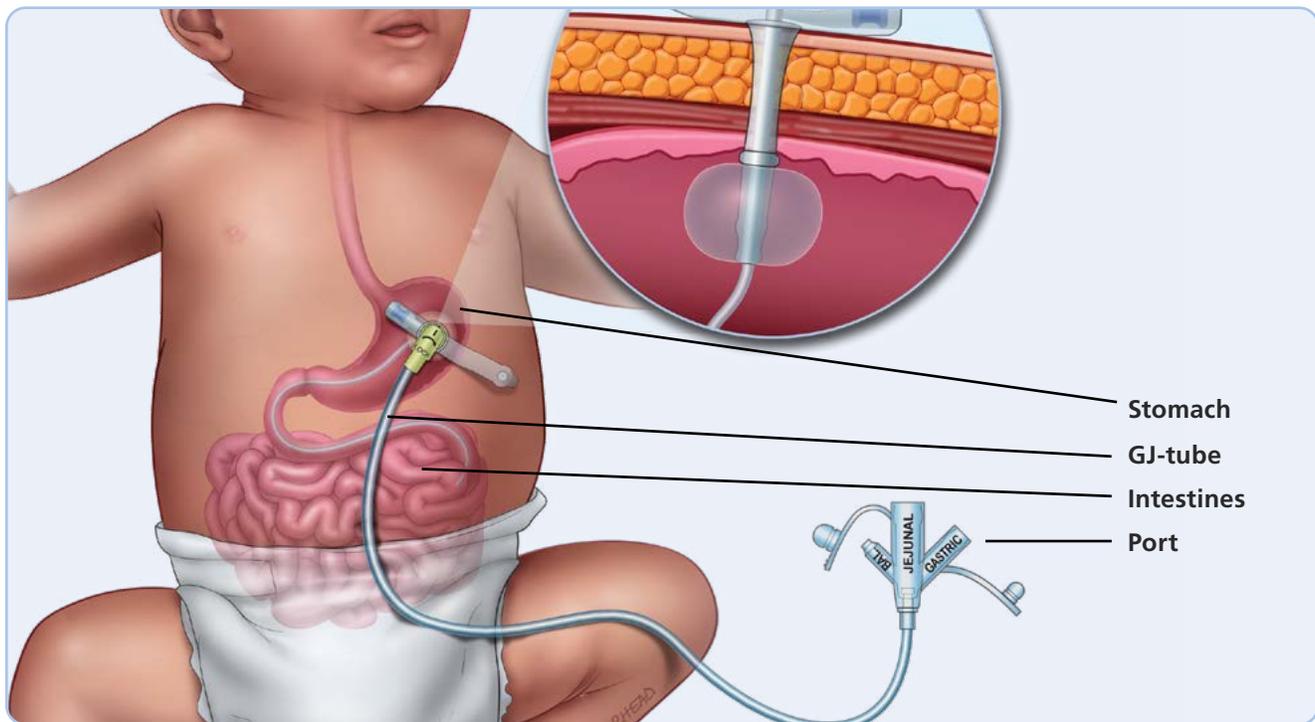
What's the hardest part of having a child with a g-tube?

"At the beginning, I think the biggest obstacle was accepting that my child needed a feeding tube. I felt kind of like a failure, that I couldn't feed her and do what I needed to do so that she could grow and stay hydrated appropriately. After I got over that, it was just learning all the different terminology, learning what different types of syringe tips we needed and learning what an extension was, and learning what terms all the doctors would be using, like gravity-feed or bolus-feed, or the pump and how to use a pump. There were a few things that I had to learn that I had never had to learn before with my other children."

Lana's mom

Types of g-tubes

A g-tube is a tube inserted through the abdomen that delivers nutrition directly to the stomach. It's one of the ways doctors can make sure kids with trouble eating get the fluid and calories they need to grow.



Gastrojejunal tubes

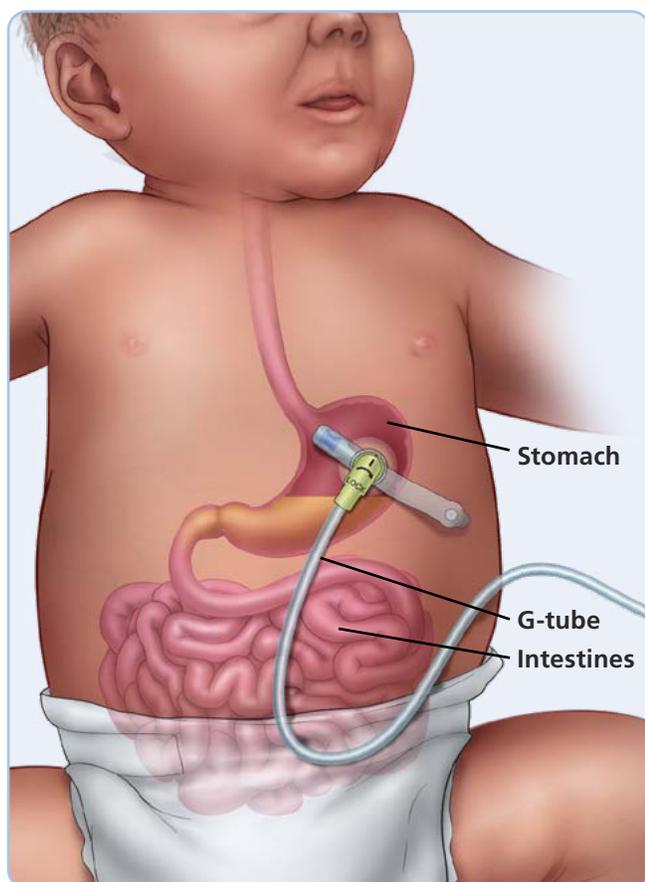
Gastrojejunal [gastro-jay-JOON-ul] tubes, or GJ-tubes, are used when emptying the stomach is a problem. The GJ-tube is a long tube with two openings. One opening goes to the stomach, and the other goes to a part of the small intestine called the jejunum. The GJ-tube is put into the stomach stoma and guided into the small intestine. The tube is held in place with a small balloon at the end of the tube inside the stomach. At the end of the tube, there are 3 ports labeled gastric, jejunal, and balloon. The gastric port is used for venting air or giving medicine. The jejunal port is used for giving formula. The balloon port is used to add or remove water from the balloon. A disk placed on the skin outside of the body helps to hold the tube in place.

GJ-tubes are also available as GJ-tube buttons. The only difference is what you see on the outside of the body. The button sits on top of the skin.

Two feeding tube extensions are attached to the button when your child is done with surgery. One extension is used for putting medicine into the stomach, and the other is used for putting fluids or medicine into the jejunum.

Whenever the feeding extensions are in place, they should be taped to your child's skin. The feeding extensions need to stay attached for 2 weeks after surgery. After that, you can remove the feeding extensions when your child is not getting a feeding or medicine.

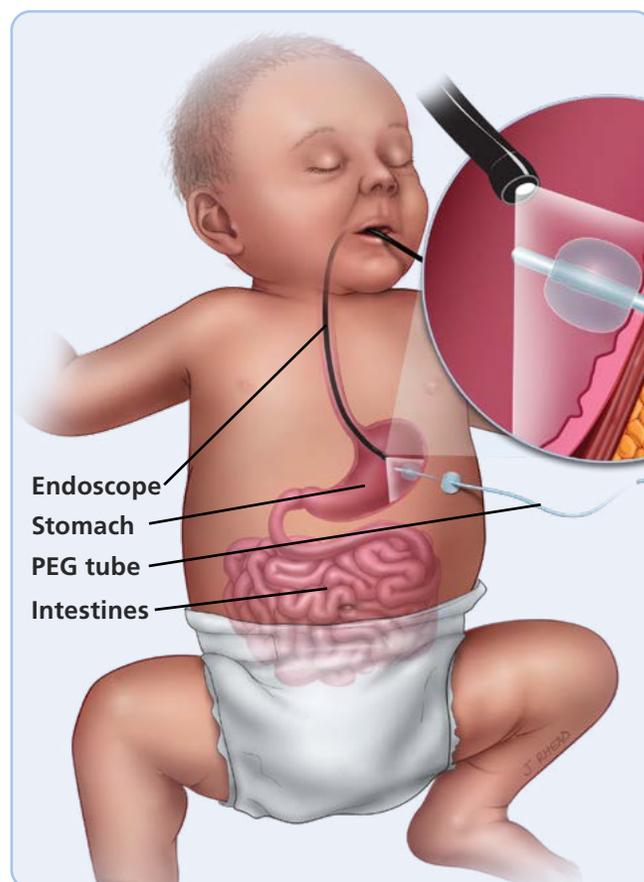
Never twist or turn a GJ-tube. This may cause it to move out of place.



Gastric tubes

A gastric [GAS-trick] tube is a feeding tube that fits into the stoma and is held in place with a water-filled balloon. The tube has 3 openings or ports. The larger port is used for feedings, and the smaller port is used for medicine. The remaining port is called the balloon port. This port is used to put water into the balloon. There is also a soft plastic disk that helps hold the gastric tube to the skin over the stomach.

Some children will have a gastric tube placed during surgery. It is usually removed 6 weeks later and replaced with a g-tube button. Changing the g-tube to a g-tube button does not require additional surgery and can be done at a doctor's appointment.



Endoscopically placed tubes

Percutaneous [per-cue-TANE-ee-yus en-doh-SKAH-pik] endoscopic gastrostomy tubes, or PEG tubes, are placed with an endoscope (a lighted telescope). The tube is moved down the esophagus and into the stomach. The stoma is made from the inside of the stomach to the outside of the skin. A short crosspiece of tubing or a soft plastic support called a bolster helps keep the tube in place. The PEG tube is kept in place for about 8 weeks.

It is important that you turn the PEG tube every day while it is healing.

PEG tubes are often changed out for a g-tube button at about 8 weeks. The button is held in place with an internal bolster. These tubes can only be changed by your child's doctor.

Parts of a g-tube button

A g-tube button resembles an actual button and is used as a path for food, fluids, and medicine to be inserted and ingested into the stomach. It fits into the stoma and sits close to the skin. The button is held inside the stomach with either a water-filled balloon or a soft plastic support called a bolster.

There are a few parts that you will learn once your child's g-tube type and size has been chosen. The picture below will help you identify the parts of a g-tube.

- 1 Safety plug:** A silicone cap that stops any flow of air or liquid from entering or exiting the g-tube button.
- 2 Feed port:** Opening to the g-tube button's soft external bolster.
- 3 Balloon port:** The port used to add or remove water in the balloon. This helps hold the g-tube in place.
- 4 Bolster or balloon:** A soft, flexible plastic bar or balloon that helps hold the g-tube snugly in place.



Supplies you need at home

Your child's home care company should provide you with many of the supplies you need to care for your child's g-tube at home. Each home care company is different, so the supplies may look a little different from what the staff uses at the hospital. This is okay. The first time the home care company visits, talk with the nurse about the supplies and services they will provide.

You should have the following supplies:

- 1 Feeding extensions
- 2 Tape to secure the tube or feeding extensions
- 3 Cotton-tipped swabs
- 4 Water-soluble lubrication jelly
- 5 60 mL syringes if you are giving gravity feedings
- 6 Smaller syringes for giving medicine and flushes
- 7 Slip-tip syringe
- 8 Foley catheter
- 9 Catheter plug

You should also have a replacement kit with you at all times. This will be helpful if the tube accidentally comes out when you are not at home. A replacement kit should have these supplies:

- Water-soluble lubrication jelly
- Foley catheter
- Catheter plug
- Slip-tip syringe
- Tape



1

Feeding extension



2

Tape



3

Cotton-tipped swabs



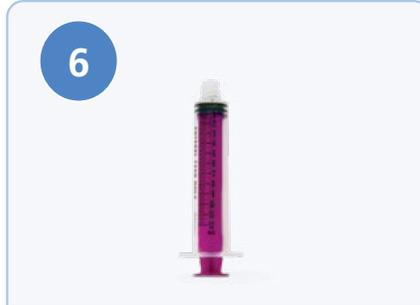
4

Lubricant



5

60 mL syringe



6

Smaller syringes



7

Slip-tip syringe



8

Foley catheter



9

Catheter plug

The replacement kit should have the following supplies:



Water-soluble lubrication jelly



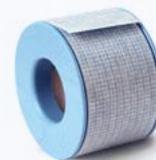
Foley catheter



Catheter plug



Slip-tip syringe



Tape



G-tube site care

Caring for the g-tube site helps prevent infection. It also helps you know if the g-tube is working right and whether any parts are broken.

What are the benefits of a g-tube?

“Once we got the feeding tube and we were able to get her the milk and water that she needed, I suddenly saw a child who had energy. I saw a child who could play and grow the way everybody else was. She has put on multiple pounds this year that she had lost before. She was able to just talk and laugh and smile and feed herself and do the things she hadn’t had energy for before. She suddenly had energy because she was getting calories. She was getting nutrition that she so badly needed that we could not get to her without the feeding tube.”

Lana’s mom

Cleaning the g-tube site

You should clean around the g-tube at least twice a day for the first 8 weeks. This area (the hole in the abdomen) is known as the stoma. After the stoma has healed (about 8 weeks) you should not need to clean the site everyday. You only need to clean with cotton-tipped swabs if the site is visibly dirty or when your child takes a bath.

Most g-tubes do not need a dressing. Moisture from the dressing can cause the skin to become weak (a condition called “breakdown”) and cause redness around the stoma. Other tubes need to have a dressing in place for a short time. The doctor or nurse will tell you if your child needs a dressing. If your child has a tube that needs a dressing, your child’s nurse will teach you how to change it.

It is important to keep the skin around your child’s g-tube site clean and dry. For the first few weeks after the tube is placed, you may see some wet or dried drainage around the g-tube. This should continue to decrease and stop after the first few weeks.

These 3 steps will guide you through the g-tube site cleaning process. Each numbered step coordinates with an image on the following page.

To clean the stoma:

Wash your hands well with soap and water.

Supplies you will need:

- Cotton-tipped swabs (Q-tips) **(a)**
- Warm water **(b)**



- 1 Wet the cotton-tipped swab with warm water.
- 2 Clean under the g-tube and around the stoma. (You may need more than one wet cotton-tipped swab if the site is really dirty)
- 3 Dry the skin with a cotton-tipped swab.

Each time you clean the site, look for signs of skin breakdown. Stomach acid can sometimes leak out of the stoma and cause skin burns and breakdown.

When fluid from the stomach sits on the skin around the stoma, the skin may become red and sore.

Skin problems can include:

- Leaking and skin breakdown
- Granulation tissue
- Infection
- Bleeding

For further details, go to page 48.

If you notice redness on the skin around the stoma, put a thin layer of diaper rash cream onto the skin. This helps to protect the skin and allows it to heal. You can put the diaper cream on the skin 2 to 3 times a day. The container of diaper cream that is used for the g-tube should only be used around the g-tube. Write on the diaper cream container “for g-tube site only.”

If there is a lot of leaking, you can put a piece of gauze or drain sponge, around the g-tube to soak up the drainage. Change the gauze every few hours to help protect the skin.

1



Wet swab with water

2



Clean skin

3



Dry skin





Checking the balloon

The balloon is important because it keeps the g-tube button in place and stops it from coming out. Because of its importance, you should check the amount of water in the balloon once a month.

What surprised you about caring for a child with a G-tube?

"When we first were introduced to the idea of a g-tube, I was expecting it to be really difficult. I was expecting it to be something where nobody else could feed her except me and maybe my husband. It would take a long time, and it would take a lot of things and a lot of cleaning. I expected it to just be really hard and really obvious that that's what I was doing, was feeding her with a tube.

After she got the g-tube, it was easier to take care of her because before she would have vomiting spells, and it was impossible for me to keep her fed. We had to thicken all of her liquids, and it made her feel full before she was actually getting enough calories. So after we had the g-tube placed, I was able to give her the calories and hydration and liquids that she needed in a day without a lot of fuss, without a lot of effort. It was a simple process. I knew exactly how many calories she had had. I knew exactly how many ounces or milliliters of fluid she had had that day, so it was no more guessing. It was just a measurable way for me to know that she was getting enough and that she was okay."

Lana's mom

Checking the balloon

Begin checking the water in the balloon after the site has healed all the way, or **in about 6 weeks**.

The amount of water in the balloon is specific to your child's tube. The balloon port should have this information printed on it. If you don't know how much water should be in the balloon, ask your child's doctor. If there is less water in the balloon than what should be there, you can add a little more water to make sure the amount of water is correct.

These 5 steps will guide you through checking the balloon process. Each numbered step coordinates with an image on the following page.

To check the balloon:

Wash your hands well with soap and water.

Supplies you will need:

- 1 slip-tip syringe with water in it
- 1 empty slip-tip syringe



- 1 Prepare a slip-tip syringe with the correct amount of water in it; set it aside.
- 2 Hold the button and attach an empty slip-tip syringe.
- 3 Pull back on the plunger of the syringe to remove the water.
- 4 Check the syringe to see if the correct amount of water is in it.
- 5 Slowly put the water back into the balloon. If there is less water in the syringe, add more water using the prepared syringe to make it the correct amount. Continue to hold the button while doing this so it doesn't come out.

If the amount of water was low, check the water again in 24 hours to see if there is a possible leak in the balloon. If there is less water in the balloon again, you need to replace the button.

Some doctors may want you to turn the g-tube once a day while the stoma is healing. Check with your child's doctor to see if you need to do this. If your child has a PEG tube, it should be turned once a day. GJ-tubes should never be turned.

It takes about 6 weeks for the stoma site to fully heal after surgery. After 2 weeks, you may put your child in a bathtub. After 6 weeks, you may allow your child to go swimming or allow water to cover the stoma site.

Protect the tube

All g-tubes need to be secured so your child doesn't pull it out of the stoma. This can be painful for your child. A lot of movement can also cause the stoma opening to get larger or form granulation [gran-u-LAY-shun] tissue. If your child's g-tube does not have a removable feeding extension, you need to tape the tube to your child's stomach. If your child is small enough, wearing a onesie will help protect the g-tube.

If your child's g-tube has removable feeding extensions, these need to be taped to your child's stomach whenever they are attached.

1



Fill syringe with correct amount of water

2



Attach the empty syringe

3



Pull back to remove water

4



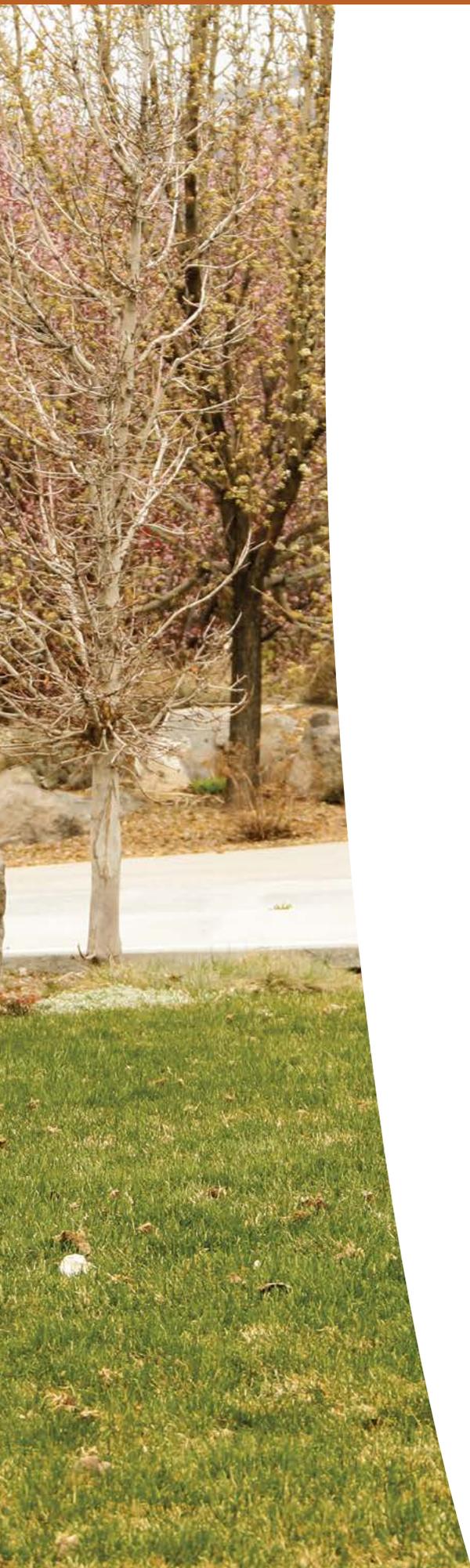
Check the amount of water

5



If the balloon needs more water, use the prepared water-filled syringe





Feeding your child

Some children who have g-tubes can still eat and drink but need the g-tube to make sure they get enough calories to grow. Depending on your child's needs, the doctors and dietitians will recommend a formula with the required nutrients. It is important to follow up regularly with the doctor and dietitian as your child grows to make sure they get the right amount of nutrition.

How have others helped you care for your child with a g-tube?

"In the beginning, I was a little worried that I wouldn't be able to leave her with anybody and that she would always have to be with me and me and my husband wouldn't get to live a more normal life with our other children.

It didn't take much time, and she learned out to do it. We've been able to leave her. Me and my husband can go on dates. I can take my older son to gymnastics and watch him at gymnastics while the babysitter stays home with her. We have a more normal life. We've even been able to go overnight, just me and my husband, and our nanny was able to take care of everything that she would need."

Lana's mom



Types of g-tube feeds

There are 2 basic ways to give formula to children with g-tubes.

Continuous feedings

During a continuous feeding, a machine called a feeding pump controls how fast the formula is given through the g-tube. Some children may need to have pump feedings for long periods of time, up to 24 hours a day. Other children may only have feedings during the night.

Each feeding pump is a little different. When the homecare company delivers the pump, they will help you set it up and show you how it works. They should also give you a copy of the manufacturer's instructions and information about how often to change the formula bag and tubing.

While your child is on continuous feedings, the g-tube should be flushed (cleared) every 4 to 6 hours with 3 to 5 mL of warm water. This helps keep the tube from becoming clogged. If your child is on tube feeds overnight, flush the g-tube with water before you go to bed and then again first thing in the morning. You may want to flush with 5 to 10 mL in the morning to help clear any small clogs that may have formed during the night.

Bolus feedings

Bolus feeding is a type of feeding method using a syringe to deliver formula through your child's feeding tube. It may also be called syringe or gravity feeding because holding up the syringe allows formula to flow down using gravity.

A Bolus feed can also be done with a machine. Your child's care team will work with you to determine the best feeding plan.



Feeding your child with a bolus gravity feed

During a gravity feeding, formula is given using a large syringe. The formula is poured into the syringe, and gravity allows the formula to slowly flow into the stomach.

These 14 steps will guide you through the bolus gravity-feeding process. Each numbered step coordinates with an image on the following page.

To give a bolus gravity feed:

Wash your hands well with soap and water.

Supplies you will need:

- Large syringe for the formula (a)
- Formula (b)
- Small syringe for flushing (c)
- Water (d)
- Bolus feeding adapter if needed (e)



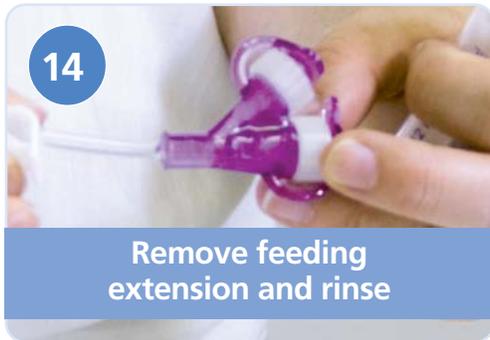
- 1 Clamp or kink the feeding extension.
- 2 Attach a small syringe with 3 to 5 mL of warm water to the feeding extension.
- 3 Unclamp or unkink the feeding extension.
- 4 Flush the g-tube with water.

- 5 Clamp or kink the feeding extension.
- 6 Remove the plunger on the large syringe, and attach the large syringe to the feeding extension.
- 7 Pour the formula into the syringe until it is about half to 3/4 full.
- 8 Unclamp the feeding extension.
- 9 The height of the syringe controls how fast the formula flows into the stomach. If you hold the syringe high, the formula will flow fast. If you hold the syringe low, the formula will flow slowly.
 - Hold the syringe high to start the formula.
 - Hold the syringe at a height that will let the feeding take about 20 minutes.
 - If the formula does not start to flow, put the plunger back into the syringe and push lightly. Then take the plunger back out.
 - If your child acts uncomfortable or gags as the formula is going in, slow the flow of the formula by lowering the height of the syringe.
- 10 Continue to add formula into the syringe until your child has received the full amount of formula ordered.
 - Do not allow the syringe to become completely empty until the end of the feeding. An empty syringe can let air into the stomach, which may cause your child to have gas pains.
- 11 When the feeding is finished, clamp or kink the feeding extension.
- 12 Remove the syringe.
- 13 Flush the feeding tube with 3 to 5 mL of warm water.
- 14 If your child's g-tube has a removable feeding extension, remove it and rinse the extension with soap and water.

Helpful hints:

Give an infant a pacifier to suck on. This will help them with the connection between sucking and getting a feeding.

If your child begins to cry during a feeding, the food will not flow easily into the stomach. It is best to stop the feeding, calm your child, and then continue the feeding.







Burping or venting

A g-tube can make it difficult to burp, causing air to build up in the stomach and cause a lot of gas pain. You may need to burp or vent the g-tube to get the air out.

How have others helped you care for your child with a g-tube?

"We found a babysitter. We had her come and learn how to do everything with the tube. We taught her how to give a tube feed. We taught her how to clean it. We taught her how to take care of it if it were to come out."

Lana's mom

How to burp or vent

Burp or vent your child's g-tube 30 minutes to 1 hour after a bolus feeding or if your child has been fussy, gagging, or retching. If your child is on continuous feedings, you should burp your child's tube every 2 to 3 hours.

These 5 steps will guide you through the burping or venting process. Each numbered step coordinates with an image on the following page.

To burp or vent:

Wash your hands well with soap and water.

Supplies you will need:

- Large 60-mL syringe



- 1 Remove the plunger from a large syringe.
- 2 Attach the syringe to the feeding extension or straight tube.
- 3 Unclamp the feeding extension.
 - This will allow the air to leave the stomach. You may hear a noise like a burp. If this does not work, continue to step 4.

Option 2: If you can't get the g-tube to burp or vent, continue to steps 4 to 6.

- 4 Clamp the feeding extension and remove the syringe.
- 5 Place the plunger back into the syringe and re-attach it to the feeding extension.
- 6 Slowly pull back on the plunger to remove the air.
 - If some formula or stomach contents come into the syringe while burping the tube, gently push them back into the stomach.
 - Make sure you stop before any air goes back into the stomach.

Gastroesophageal reflux (GER)

Some children who have a g-tube placed develop gastroesophageal [GAS-tro-ee-soff-uh-JEE-ul] reflux (GER). This means that stomach acid and contents flow back up into the esophagus. Some of the symptoms of GER are:

- Vomiting
- Heartburn
- Coughing
- Gagging
- Retching
- Respiratory symptoms
- Failure to gain weight

If you notice any of these symptoms, call your child's doctor.



1 Remove plunger



2 Attach syringe



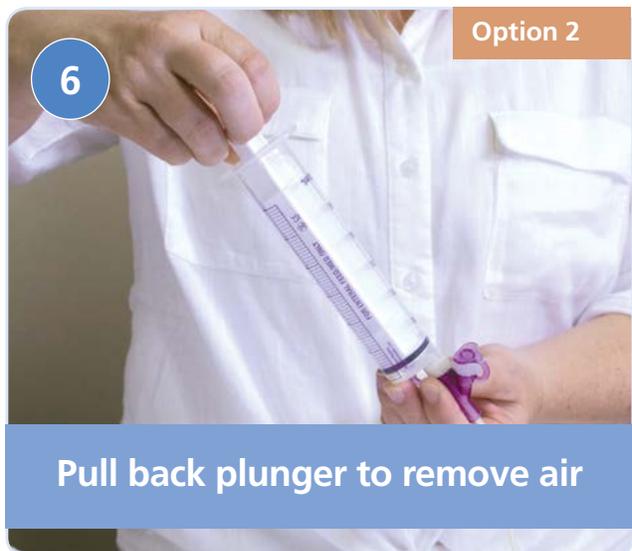
3 Unclamp feeding extension



4 Clamp feeding extension and remove syringe



5 Replace plunger and reattach it to the feeding extension



6 Pull back plunger to remove air





Giving medicine

Medicine can be given through the g-tube. When you get a prescription from your child's doctor, request the liquid form of the medicine from your pharmacist.

If the medicine is not available in a liquid form, request an uncoated tablet. This tablet can be crushed into a powder and dissolved in water. If you are giving more than one medicine, you will need to flush the g-tube between each medicine.

How is life the same since your child received a g-tube?

"Now that she has a g-tube, I have realized that there are a lot of things I was worried about beforehand that are just nothing to worry about. She can sit in the bathtub and take a bath with her brothers just like she could before. We go swimming as a family, and she has even been able to go play in the lake and do things that any other kid can do. She can ride a bike outside or ride a little scooter outside. She jumps on the tramp. She does everything that all my other kids do, and she can keep up with them. She can climb up on the couch and jump down. She can do anything that any other kid can do. It was comforting to me to know that this is just the way she gets fed and nothing else."

Lana's mom

Giving your child medicine

These 15 steps will guide you through giving your child medicine through the g-tube process. Each numbered step coordinates with an image on the following page.

To give medicine:

Wash your hands well with soap and water.

Supplies you will need:

- Medicine (a)
- Syringe for medicine (b)
- Syringe for water (c)
- Feeding tube extension (d)
(if your child has a g-tube button)



- 1 Put medicine into the syringe.
 - If you are giving more than one medicine, you will need a different syringe for each medicine.
- 2 Fill a syringe with water for flushing, and flush feeding tube with water.
- 3 Attach feeding tube to the g-tube button.
 - If your child is getting a feeding when you need to give them the medicine, pause the feeding. Follow steps 4 to 9 if you need to pause the feeding.
 - If you are just giving medicine, go to step 10.

If pausing feeding to give medicine:

- 4 Clamp or kink the feeding extension.
- 5 Attach a water-filled syringe to the medicine port.
- 6 Unclamp or unkink the feeding extension.
- 7 Give 1 mL of water to flush the formula out of the feeding extension.
- 8 Clamp or kink the feeding extension.
- 9 Remove the water-filled syringe.

You are ready to give the medicine:

- 10 Attach the medicine syringe.
- 11 Unclamp or unkink the feeding extension.
- 12 Give the medicine.
- 13 Clamp or kink the feeding extension.
- 14 Remove the medicine syringe.
- 15 Attach the water-filled syringe, and flush with 3 to 5 mL of water.

If your child does not have any other medicine, restart the feeding or remove the feeding extension.

If your child has more medicine to take, repeat steps 10-15 until you are done giving the medicine.

Important information about medicine given through a g-tube

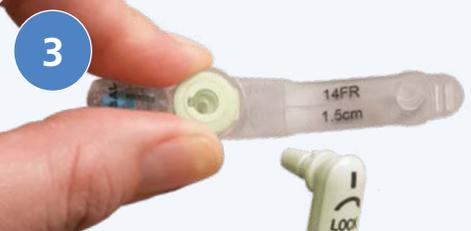
- Always ask your pharmacist if a medicine can be crushed.
- Do not crush coated or time-release tablets or capsules.
- The following medicines may clog the g-tube and should not be given through a g-tube:
 - Biaxin
 - Calcium carbonate
 - Carafate
 - Depakote sprinkles
 - Enzymes
 - Laxatives
- Do not mix medicine with the formula you are giving to your child.
- Do not mix two medicines together. Give each medicine one at a time.
- Never insert a syringe directly into the g-tube button. Always use the feeding extension.

1 

Put medicine in syringe

2 

Fill a syringe with water and flush feeding tube

3 

Attach feeding tube to button

4  Pausing feeding

Clamp feeding extension

5  Pausing feeding

Attach water-filled syringe to the medicine port

6  Pausing feeding

Unclamp feeding extension

7  Pausing feeding

Flush the formula out of feeding extension

8  Pausing feeding

Clamp feeding extension

9  Pausing feeding

Remove water-filled syringe

10 

Attach medicine syringe

11 

Unclamp feeding extension

12 

Give the medicine

13 

Clamp feeding extension

14 

Remove medicine

15 

Flush with water-filled syringe





Replacing a g-tube button

To ensure that the g-tube site, also known as the stoma, is healthy, keep it clean and dry. You will need to change the g-tube every few months or when the g-tube is not working correctly. Check with your insurance company so you know how many they will provide each year. The g-tube needs to be change out at least once a year.

Make sure you check the water in the g-tube button monthly. Keeping the correct amount of water in the balloon will help prevent it from accidentally coming out.

If the g-tube is accidently pulled out, put the g-tube back in place quickly. The stoma begins to close up in a short period of time (in some cases 20 to 30 minutes). This can make it difficult or dangerous to put the tube back in. Make sure the g-tube is secured to your child's belly with tape at all times. This may help prevent the tube from being pulled out.

In this section, you will learn what to do if a g-tube comes out, before and after the stoma has healed.

Replacing a button BEFORE the stoma has healed

If the g-tube comes out before the site is healed (within the first 2 months), you will need to place a Foley catheter into the stoma to keep it open. Call the doctor who placed the button and they will tell you what to do next. Do NOT use foley for feeds or medications until a provider has confirmed that the tube is in the stomach.

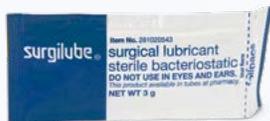
These 6 steps will guide you through the Foley catheter placement process. Each numbered step coordinates with an image on the following page.

Supplies you will need:

Before you start, gather the supplies:

- Water-soluble lubricant (a)
- Foley catheter (b)
 - Same size as your child's g-tube
 - One size smaller than your child's g-tube
- Catheter plug (c)
- Tape (d)

a



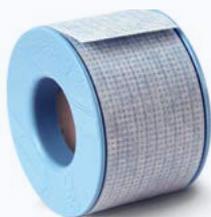
b



c



d



To place a Foley into the stoma:

Wash your hands well with soap and water.

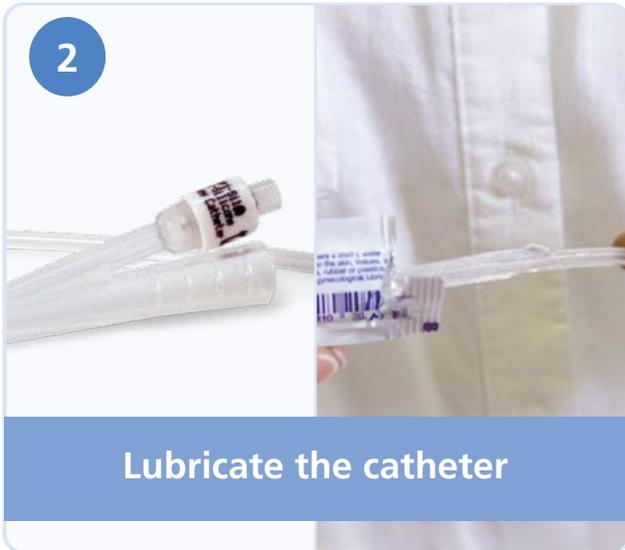
- 1 Lay your child flat on their back.
 - If needed, have someone hold your child's hands.
- 2 Lubricate the same-sized Foley catheter with a water-soluble lubricant.
- 3 Place the catheter about 1.5 inches into the stoma. Do not force the catheter into the stoma.
- 4 Once you get the catheter in place, secure it to the stomach with tape.
- 5 Cap the tube with the catheter plug.

If you can't get the same-sized Foley catheter in easily, use the smaller-sized Foley catheter. Follow steps 2-5

Replacement kit

Have your replacement kit with you at all times. In the case that your child's stoma has yet to heal, you may need to place a Foley catheter if your child's g-tube is accidentally removed. This kit will also continue to be a resource when the g-tube site has healed and replacing the g-tube is an option. The replacement kit should have these supplies:

- Water-soluble lubrication jelly
- 2 Foley catheters
 - Same size as your child's g-tube
 - One size smaller than your child's g-tube
- Catheter plug
- 10-mL syringe (for removing water from the balloon)
- Tape



Replacing a button AFTER the stoma has healed

You may need to replace the g-tube if the tube comes out accidentally or is due to be changed.

These 6 steps will guide you through the g-tube button replacement process. Each numbered step coordinates with an image on the following page.

To replace the g-tube button:

Wash your hands well with soap and water.

Supplies you will need:

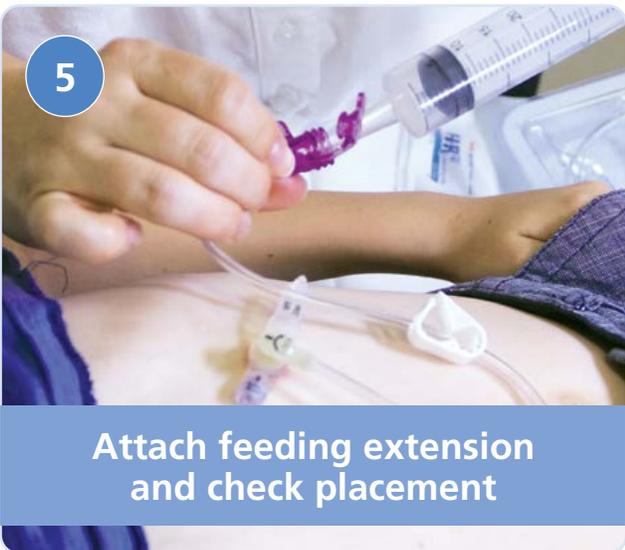
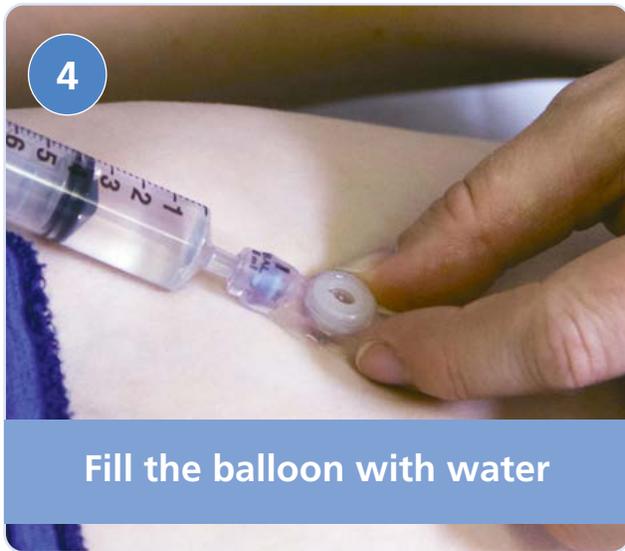
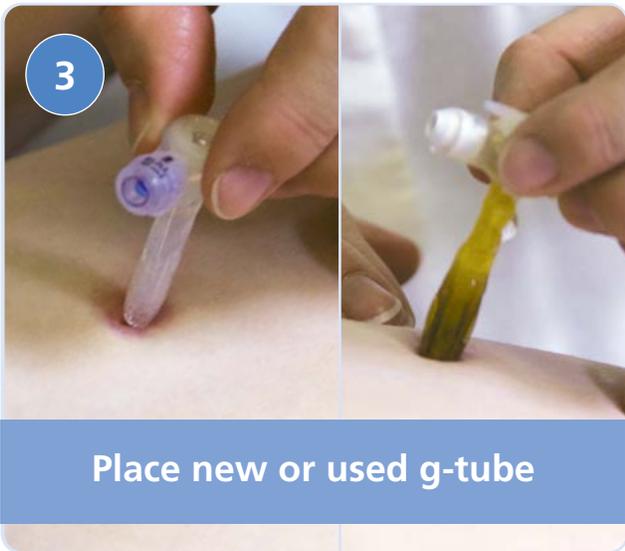
- New g-tube button if changing out button (a)
- Water-soluble lubricant (b)
- Foley catheter (c)
- Catheter plug (d)
- 10-mL syringe (e)



- 1 Lay your child flat on their back.
 - If needed, have someone hold your child's hands.
- 2 If replacing the g-tube, remove the water from the balloon. Then gently remove the old g-tube button.
- 3 Place the new or used g-tube
 - If it is time for a new g-tube, lubricate it with water-soluble lubricant and put it into the opening.
 - If it is not time to change the g-tube and the one that came out is in good shape, replace it with the button that came out of the stoma.
 - Make sure all of the water is out of the balloon before you replace the button.
 - Do not force the tube into the stoma.
- 4 Fill the balloon with water.
- 5 Check the placement of the g-tube to make sure it is in the stomach.
 - Attach the feeding extension and a 60-mL syringe, and gently draw back with the syringe. When you get stomach contents, you know you are in the right place.
- 6 Flush the feeding tube extension with warm water.

If the g-tube was removed accidentally and you can not get the g-tube back in place, use the one size smaller Foley from the replacement kit to keep the stoma open. See page 41 for details.

Call your child's doctor if you can't get the g-tube or the Foley back into the stoma.







Living healthy

You'll notice many changes in your family's lives once your child gets a g-tube. Your day-to-day routines may form around caring for the g-tube. However, you and your child should also be aware about other aspects of their health.

Many patients and their families struggle with physical development, social, and behavioral health issues. You should also recognize any problems with your child's skin or g-tube equipment.

Your child's care team can help you and your child manage these problems and offer resources for your family.

Dental and oral health

Children with g-tubes should have mouth care at least once a day. Gently brush the teeth, gums, and tongue with a soft toothbrush. This routine will help your child's mouth stay clean, but it will also help them get used to having things in their mouth. This helps them get ready to eat food by mouth. Make sure this time is a pleasant experience. An occupational therapist can give you other suggestions on how to help prepare your child to eat by mouth.

Social work

A dedicated social worker can share hospital and community resources to help your child and family cope with medical challenges and understand how your child's g-tube impacts the family.

Developmental and behavioral health

Feeding routines are important to help with family bonding and a child's development. You and your child should not miss out on this experience. Even though you're trying to start the g-tube feeding, it's important to hold and cuddle your child during feeding time.

When your child is old enough to sit up for feedings, interacting with caregivers will help your child develop socially. Playful contact is important for your child's development, and it can be fun for both of you. Parents often make silly faces or funny noises or play with babies and young children at mealtime. Once you feel confident in managing the g-tube feedings, relax and treat your child as normally as possible.





Tube maintenance

Plugged tube

To prevent the g-tube from getting clogged, make sure you flush the tube with warm water after every feeding. If your child has continuous feeds, you should flush the g-tube every 4 to 6 hours.

If the tube becomes clogged and you can't clear it with warm water, attach an empty 60-mL syringe and pull back gently on the plunger. This will create a little bit of suction, which may loosen the clog.

Do not pull too hard; this can hurt your child's stomach. Flush the tube with warm water again. If this still does not clear the clog, you may need to replace the g-tube.

Punctured, split, or damaged tube parts

If any part of the g-tube is broken or cracked, you will need to replace the tube.

If your child's g-tube is leaking and it has a balloon, you can check the amount of water in the balloon to see if the balloon is damaged. If there is less water in the balloon than there should be, put the full amount of water into the balloon.

Wait for 24 hours and check the water amount again. If it is less than what you put in, the balloon may have a hole in it. The g-tube will need to be replaced.



Skin health

Leaking and skin breakdown

Your child's g-tube may sometimes leak. The fluid from the stomach has acids that can hurt the skin. The skin around the stoma may become red and sore. If you notice redness on the skin around the stoma, clean the skin more frequently, apply a thin layer of diaper cream, and put a piece of clean gauze or other dressing around the tube. Leaking can happen for many reasons.

Check for any of these problems:

Broken or damaged g-tube. Check the balloon on a g-tube button.

Change in the size of the stoma. If the stoma has become larger, the tube may be moving back and forth. This can stretch the stoma and cause leaking. Secure the tube to your child's stomach with tape so it doesn't move around. This allows the stoma to heal back to the right size.

Illness. When your child gets sick, their stomach does not digest formula as quickly. This can cause the g-tube to leak at the stoma. Clean the skin often, apply a thin layer of barrier cream, and put a dressing around the g-tube.

Granulation tissue

Granulation tissue is the body's attempt to close the stoma opening. It looks red and spongy and may bleed easily. This may look painful but it does not hurt. Granulation tissue may cause leaking around the g-tube. If you keep the g-tube clean, dry, and secure, the tissue may heal on its own. If the tissue does not heal, call your child's doctor. They may prescribe 0.1% triamcinolone [try-am-SIN-ah-lone] cream. This is a steroid medicine that can sometimes help decrease the tissue. Triamcinolone cream should only be used for up to 10 days at a time.

If the tissue gets worse, you may need to treat it with silver nitrate. This needs to be applied by a trained healthcare provider. If there is a lot of granulation tissue around the stoma, a surgeon may need to remove it. The granulation tissue treatment depends on the amount of tissue. Call your child's doctor if you have used the triamcinolone and the granulation tissue has not gone away. Even with treatment, granulation tissue can come back.

Infection

Infection of the stoma or the skin around the stoma is not a common problem. However, redness from leaking may look like an infection. If the redness is not from leaking, or the skin under the redness is hard to the touch, call your child's doctor right away.

Signs of infection are:

- Pain at the site
- Fever
- Hard skin around the g-tube

Yeast infections are not common but can happen. They look like scattered red dots (rash) around the stoma. A yeast infection can cause pain and itching. If you notice a rash like this, call your doctor or one of the g-tube nurses.

Bleeding

A small amount of bleeding may occur around the stoma during a tube change. The stoma may also bleed a little bit if the tube is moving around a lot and irritating the stoma. Securing the tube to your child's belly with tape can help prevent this. A little bit of bleeding is not serious.

When to call

If you have any of the problems mentioned in this booklet and tried the remedies without improvement, call your child's pediatrician, the physician who placed the tube, or the enterostomal therapy nurse at Primary Children's Hospital for help.





Frequently asked questions

How long does a tube last?

The length of time a g-tube lasts will depend on what type of tube it is. Check the instructions from the manufacturer. Change the tube if it has a leaking balloon or access port or if the tube starts to crack or break. The tube does not need to be changed on any schedule, but it should be changed a least once a year.

Does the g-tube hurt?

A well-healed g-tube stoma will not cause your child any pain. However, if the skin around the stoma becomes red and irritated, the area may hurt or be uncomfortable.

Can my child still have tummy time?

After the tube has been in place for 2 weeks, your child may sleep on their tummy or back or roll from side to side. Be sure the tube is secured so it doesn't move around in the stoma while your child sleeps.

How active can my child be?

Your child can do anything as long as it doesn't yank or pull on the g-tube. Your child should avoid contact sports that might involve a blow to the stomach. It is important for your child's physical and emotional development to have as few limits as possible.

Can my child bathe or swim?

Your child may have a tub bath or shower after the surgery as long as the water does not cover the g-tube site. The water in the tub should only come up to your child's hip level.

Make sure you dry the skin around the stoma after the bath or shower is done. Keep the skin around the g-tube clean and dry to help prevent skin problems.

After the site has healed (8 weeks), your child can swim and have a bath with the water level above the g-tube.



Is the tube permanent?

Your child's need for the g-tube depends on their specific condition. They may need it for several months or for many years. Ask your child's doctor how long your child may need the g-tube.

How will the hole close when the g-tube is no longer needed?

Once the g-tube is removed, the stoma will usually close on its own. It takes about 2 to 3 weeks to close completely. Your child may need to wear a small dressing until a scab forms over the hole and the stomach contents no longer leak.

A stoma that has been in place for a long period of time should shrink in size right away. However, some openings may not close all the way. If this happens, your child will need a simple surgery to close the opening.

Glossary

Aspirate: To suction liquid or air with a syringe.

Bolster: A piece of soft plastic that supports a PEG tube and holds it in place in the stomach.

Bolus: A feeding given over a short period of time.

Dressing: A bandage.

Enteral feeding: A way of giving liquid nutrition directly into the stomach.

Gastrointestinal tract: The digestive structures stretching from the mouth to the anus.

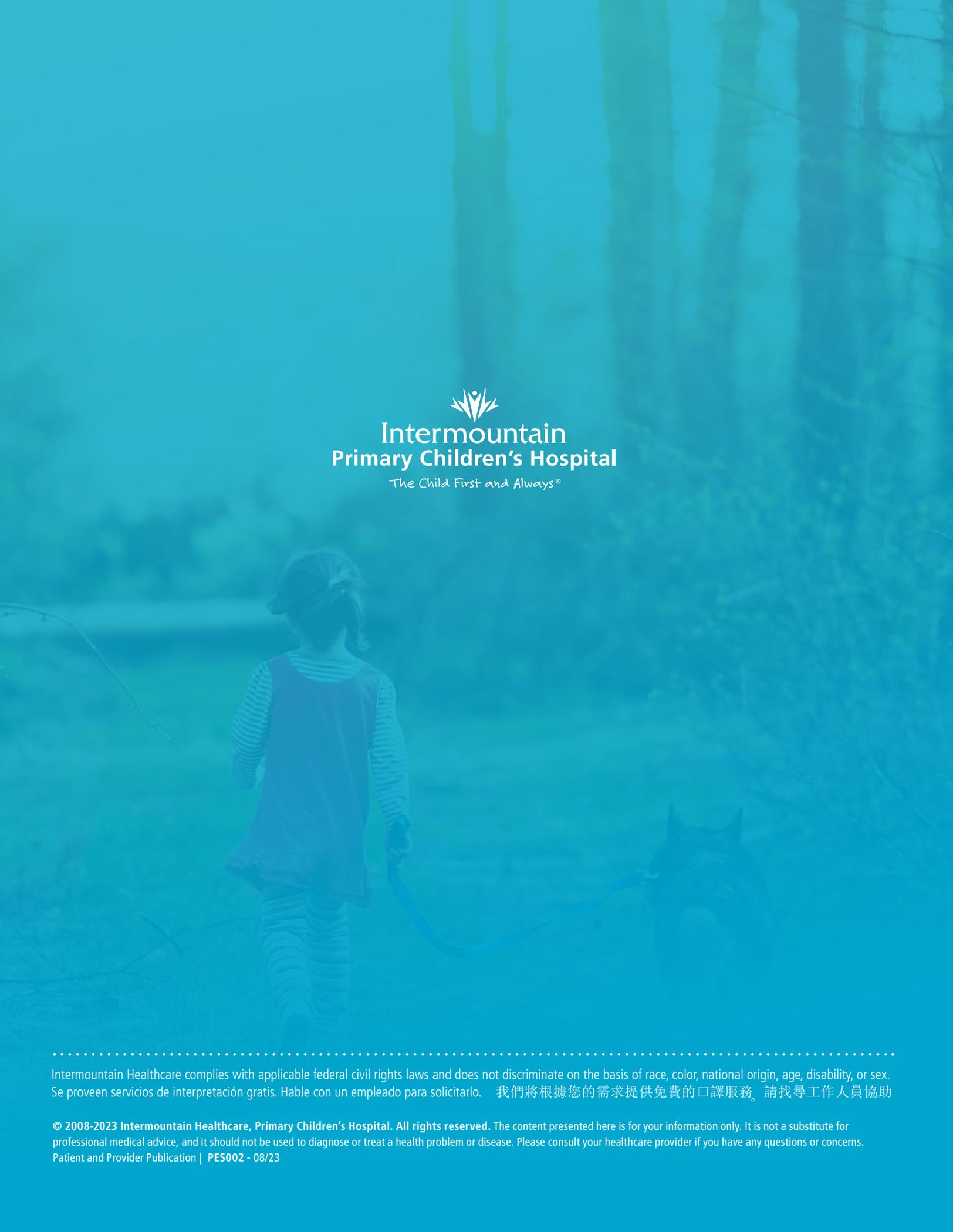
Gastrostomy: The surgical creation of an opening from the skin into the stomach wall for placing a feeding tube.

Gastrostomy button: A feeding tube placed into a stoma through which feedings can be given directly into the stomach.

Gastrojejunal tube (GJ tube): A feeding tube that fits through a stoma opening into the stomach and is then passed down into the small intestine.

Granulation tissue: Overgrowth of tissue around the base of the stoma.

Stoma: A surgically created opening into a body cavity.



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