Gastrostomy Tubes In Children: A Guide For Patients And Families - UCSF

What is a gastrostomy tube?
A Gastrostomy tube is a feeding tube placed through the abdomen into the stomach.

Why does my child need a gastrostomy tube?
A gastrostomy tube is used to give your child formula, liquids, and/or medications.

What type of gastrostomy tube will my child have?
There are several types of gastrostomy tubes. The types of tubes most commonly used are described in detail below.

What is a percutaneous or PEG tube?
A PEG tube, or Percutaneous Endoscopic Gastrostomy tube, is a silicone low profile gastrostomy tube. It is placed by a Pediatric Gastroenterologist (GI doctor) in the operating room.

The PEG tube is inserted using a telescopic instrument called an endoscope. The endoscope is a small flexible tube with a light and camera on the end that lets the doctor see into the esophagus (food tube) and stomach. The endoscope allows the doctor to choose the best location in the stomach to place the PEG tube. Once the location is chosen, a small opening is made on the outside of abdomen into the stomach. After the opening is made, the top part of the PEG tube is pulled up out of the stomach through this opening. The top of the tube rests on the skin. The bottom part of the PEG, which is shaped like a bulb, remains inside the stomach. This bulb anchors the tube in the stomach and prevents it from coming out.

What should I expect when the PEG tube is placed?
This procedure requires an intravenous (IV) line for administration of fluid and medications.

After the PEG tube is placed your child will stay in the hospital for observation, care and teaching. The hospital stay is usually three days.

Generally, feedings will be started through the PEG tube the day after it is placed.
When will the PEG tube be changed?

The PEG tube must stay in the stomach for at least three months to allow the tract (hole) to heal between the abdomen and the stomach. The tract must be well healed so it is safe for the gastrostomy tube to be changed if it needs to be, otherwise it can stay in place for one year.

After three months you may choose to replace the PEG with a low-profile gastrostomy tube. See below for more information about the low-profile g-tube. Talk with your nurse practitioner or doctor about the best tube for your child.

What supplies will I need to use with the PEG tube? (Figure 2,3,4)

You will receive three types of extension sets, as illustrated in figures 2, 3, and 4. An extension set is a tube that connects to the gastrostomy tube and allows formula, liquids and medicines to be given into the stomach.

Figure 2 is a right angle tube. This tube is used for feedings given slowly or continuously by a pump.

Figure 3 is a bolus tube, for feedings given by gravity, through a syringe.

Figure 4 is a decompression tube (which has a long tip to open a valve at the base of the tube to drain air and formula from the stomach, if needed. The decompression tube is used if a child has too much gas (which can’t be burped up) or if the child is very uncomfortable and appears to have a bloated or full abdomen.

The nurses taking care of your child will show you how to attach and remove each extension tube.

PEG tubes have two measurements, the diameter (width) measured in French (FR) size and the length measured in centimeters (cm). These numbers are printed on the inside flap of the PEG tube coverlet.

It is important to be aware that PEG extension tubes must be the same French size as the gastrostomy tube in order to fit.

The bolus set and the right angle set must be the same French size as the PEG tube.

The decompression tube must be the same French size and the same length (for example 24 Fr and 1.7 cm) in order to fit.

We recommend that you write down the size of your child’s tube on this document or some place where you can find it when needed. You will need to know the tube size to order supplies and and to talk with your child’s doctors and nurses. The GI office will also have a record of your child’s tube size.

How do I care for the skin around the PEG tube?

After placement you may clean the area around the PEG tube with sterile water or saline, as directed. Once home, clean daily with soap and water. Cleaning in the shower may occur starting day 5 and submerging in a bathtub may occur after 7-10 days. To clean the skin around the PEG tube, lift up the flap, inspect the area; wash the skin with soap and water and dry the skin completely. Most PEG tubes do not need a dressing. A small amount of drainage is normal. Turn the tube with each feeding to prevent skin irritation.

How is the PEG tube fit adjusted?

If the tube becomes too loose, spacers may be placed between the PEG and the skin to provide a better fit. If the tube gets too tight, and there are spacers in place, they can be removed. This can be done any time by your GI nurse practitioner or doctor.
What is a surgically placed gastrostomy tube?

The pediatric surgeon places a gastrostomy tube in the operating room under general anesthesia. This operation is done through a small incision or opening in the abdomen. In most cases the surgeon will place a balloon type gastrostomy tube sometimes called a “button”. These are low profile (Figure 4) or high profile (Figure 5) tubes made of silicone. They are held in the stomach by a water-filled balloon.

In some cases a temporary tube, called a Malecot® (Figure 7), will be placed instead. The Malecot® will be stitched to the skin and left in place for 2-3 months. The surgeon will determine the best type of tube for your child.

What should I expect when a surgical gastrostomy tube is placed?

This procedure requires an intravenous (IV) line for administration of fluid and medications.

After the gastrostomy tube is placed your child will be admitted to the hospital for observation, care, and teaching. The hospital stay is usually three days.

Generally feedings will be started through the gastrostomy tube the following day.

When will the surgically placed tube be changed?

The gastrostomy tube must stay in the stomach for at least 1-2 months to allow the tract (hole) to heal between the abdomen and the stomach. The tract must be well healed so it is safe for the gastrostomy tube to be changed.

The surgical nurse practitioner will teach you how to change the gastrostomy tube after 2 months. If your child has a high profile tube in place, the tract will have to be measured by the surgical nurse practitioner in the office and a low profile tube ordered from your home care company. The high profile tube will be placed until the low profile tube is available.

After the first gastrostomy change, the tube can be changed at home every 1-3 months (when you get a new one from your home care supplier). You must always have a new spare gastrostomy tube.
What supplies will I need to use with the low profile balloon gastrostomy tube?

You will receive two types of feeding extension sets, as illustrated in figure 8 and 9. An extension set is a tube that connects to the gastrostomy tube and allows formula, liquids and medicines to be given into the stomach. Please note, the extension set fits all low profile balloon gastrostomy tubes.

Figure 8 is the bolus set, used for feedings given by gravity through a syringe.

Figure 9 is the right angle set, used for slow or continuous feedings, given by a pump.

Either tube can serve as a venting/decompression tube to drain air or liquid from the stomach. The decompression tube is used if a child has too much gas (which can't be burped up) or if the child is very uncomfortable and appears to have a bloated or full abdomen.

If your child has a fundoplication, it is important to "vent" the gastrostomy tube routinely. This may need to be done every feeding, in the beginning. You will need to wait for the air to escape from the gastrostomy tube. This may take 15-30 minutes or longer.

How do I care for the skin around the surgical gastrostomy tube?

If there is a dressing from surgery, this can be removed 3 days after surgery.

Once home, clean daily with soap and water.

If there is a balloon gastrostomy tube in place, your child may be submersed in a bath and swim after 1 week.

If there is a Malecot® in place, make sure it is secured in place at all times with a Hollister Drain Tube Holder®. The device is usually changed every week. Your child may not be submersed in water (sponge bath is ok) until the Malecot is removed and replaced as described below.

Keep the skin around the gastrostomy tube dry. You may place a dry split gauze under the GT and change it at least every day or when moist or soiled.

What emergency supplies do I need to keep with my child after the surgical tube is inserted?

A spare gastrostomy tube of the same size.

Foley® catheters 14 French (or the size of the gastrostomy tube) and 12 French (or one size smaller).

Water

5 mL syringe

Lubricant jelly

Blue Clamp

How do I replace the balloon gastrostomy tube?

Check the balloon of your new gastrostomy tube by inflating the balloon with 4ml of water (unless otherwise specified) and then deflating it.

Dip the gastrostomy tube in lubricant jelly.
Place the gastrostomy tube in the hole (use a straight down motion).
Hold it in place, Insert the syringe into the “BAL” or balloon port of the gastrostomy tube.
Fill the balloon with 4ml water (unless other amount specified) to hold the GT in place.

**General information about all gastrostomy tubes**

**Tube sizes**
The diameter or width of the tube is measured in French (Fr) and the length in centimeters (cm). This is marked directly on the top of the tube.
Knowing the type and size of your child’s gastrostomy tube will help you when reordering supplies and talking with your child’s doctors and nurses.

**Use of the gastrostomy tube**
Give feedings and medications as directed by your nurse or doctor.
PEG extension sets must be the same size of the gastrostomy tube in order to fit. However extension sets made for the balloon gastrostomy tubes, fit all size tubes.
Flush the extension set and gastrostomy tube with 5-10cc’s of water after every feeding or medication. 3ml of water is sometimes used for small infants. This prevents clogging and keeps the tube as clean as possible.
We recommend you change the feeding extension set weekly.
If you are giving continuous drip feedings into a PEG tube you may want to tape connections to prevent disconnection of the extension set and spillage of feedings from the PEG tube. This is not necessary with a balloon gastrostomy device as it has a “locking mechanism” to keep the extension set in place.
For a balloon gastrostomy tube, after the first G-tube change with your child’s provider, you may begin checking the volume of water in the balloon every week and refill with water as necessary to maintain the amount of water prescribed by your child’s doctor or nurse.
After the first change, the gastrostomy tube can be replaced every 1–3 months depending how often replacement tubes are provided.

**Home care supplies**
Supplies will be ordered by the hospital discharge coordinator from a home care supply company.
The equipment and supplies will be delivered to your home or to the hospital when your child is discharged.
You will be taught to use the pump, if ordered, by a representative from the home care company or home nursing agency, as pumps differ from hospital to home.
Each month supplies will be delivered to your home. Keep your home care company name and phone number readily available. You will need to call the home care company monthly to reorder more supplies. We recommend you place your next order when you have about one week of supplies left. Do not wait until you are out of supplies. Supplies are rarely shipped without a phone call and it is possible to run out of supplies.
When your shipment arrives, check the order. If you are missing anything, or the supplies are not correct, call your home care company directly. If you cannot resolve the problem contact your GI or surgical nurse practitioner for help. Sometimes a new prescription from your child’s doctor is required.
Nursing visits
At hospital discharge, a referral will be made to have a nurse visit your home, if needed. The nurse will help you care for the gastrostomy tube and give feedings and medications and, in general, serve as a resource in your home.

What should I do for the following problems?

What if the tube comes out before the gastrostomy tract has healed?
This rarely happens with a PEG tube, but sometimes happens with the Malecot® or balloon gastrostomy tubes. If the tube becomes accidentally dislodged before you have been taught to change it, call your child's doctor at either the GI (415-476-5892) or surgical office (415-476-2538) for instructions. If you do not speak to a doctor or nurse after thirty (30) minutes take your child and gastrostomy supplies to the nearest emergency room.

If the emergency room doctors and nurses have questions, they can call the pediatric gastroenterologist, or surgeon who placed the tube (same phone numbers above).

If your child has a surgically placed gastrostomy tube, a new tube will need to be placed into the gastrostomy tract to prevent closure and the need for another operation.

If you have trouble inserting the gastrostomy tube, try placing the 14 fr foley tube or smaller foley if needed:
Place in about 4 inches deep. You can mark the tube with a pen first

While holding the foley tube in, place the syringe into the balloon port of the foley and fill the balloon with 3-5 ml of water. This will fill the balloon on the inside and hold the catheter in place.

After the balloon is inflated, gently pull the catheter up until you feel resistance and then secure the catheter in place with tape.

Clamp the foley catheter with a clip, as gastric contents will drain out of the tube.

When the tube is replaced, a special x-ray called a “gastrostomy tube dye study” will need to be taken to make sure the newly placed tube is in the stomach. Do not use the tube until the dye study demonstrates the tube is in the stomach.

If necessary, a foley catheter can be used for short-term feeding and stomach decompression at home until a new gastrostomy tube can be placed.

Redness around the site
The skin may be slightly pink after initial insertion. You should see a decrease in this pink color over time. If the skin becomes tender, warm or red, call your child’s doctor or nurse practitioner.

Crusting
Drainage that dries on the skin is called crusting. Crusting and drainage is common around gastrostomy tubes. You can remove crusting and drainage with warm water.

Bleeding
If the tube gets bumped, or is rubbed, there may be a small amount of bleeding from the skin around the tube. Applying pressure for up to ten minutes should stop the bleeding. If the bleeding does not stop, call your child’s doctor or nurse practitioner. Blood coming through the tube is not normal. If this happens call your child’s doctor or nurse practitioner or go to the nearest emergency room.
**Granulation tissue**

Granulation tissue appears in most children at some time after the gastrostomy tube is placed. This tissue is common and not dangerous. It grows directly around the gastrostomy hole and looks raised, red and may ooze fluid, mucous or bleed easily. Granulation tissue should be treated when it first appears. This can be done in the office by your child’s nurse practitioner or doctor. A special ointment or cream will be prescribed to apply to the granulation tissue (not the surrounding skin) up to four times a day until the granulation tissue goes away.

**Leaking around the tube**

This can have several causes. Contact the GI or surgical nurse practitioner for advice.

**Fever**

If your child has a fever, call your child's pediatrician.

**Not tolerating feedings**

If your child has vomiting and/or diarrhea, call your child’s pediatrician and the pediatric GI or surgical nurse practitioner or doctor for advice.

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**Follow-up appointment:** _________________________________________________

**Home care company:** ________________________________________________

**Nursing agency:** _____________________________________________________

**Tube type:** __________________________________________________________

**Tube size Fr:** _____________________________ cm________________________:_

**Placement date:** _____________________________________________________

**Date of First tube change:** ____________________________________________

**Amount of water in balloon (for surgically placed tubes):** __________________