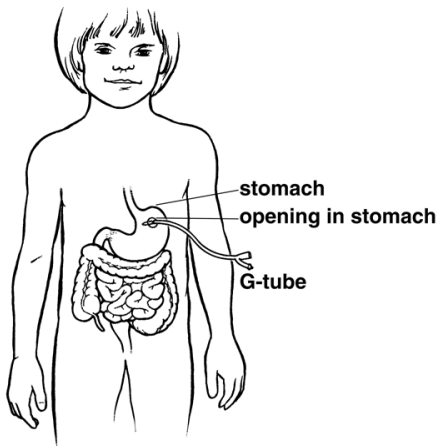


Caring for Your Child's Gastrostomy Tube

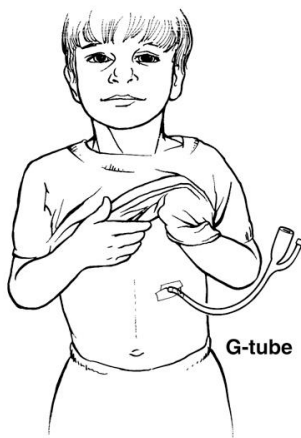
This booklet is meant to answer questions parents and caregivers have about feeding children with gastrostomy tubes (G-tubes). Your health care team will work with you to find a care plan that is best for your child.

What is a gastrostomy tube (G-tube)?

A gastrostomy tube (G-tube), is a soft plastic tube that is placed into your child's stomach through a small hole in the abdomen. The G-tube lets you give formula, water, and medicine right into the stomach. It also lets extra air or fluid drain out of the stomach.



Food, fluids, and medicine go into the G-Tube instead of the mouth and pass down the tube into the stomach.



Why would a child need a G-tube?

Reasons children may need a G-tube include:

- Helping them get the calories and fluids they need to grow when they cannot eat or drink enough.
- Food or fluids getting into the lungs when eating or drinking which causes aspiration pneumonia.
- Being on a special diet that tastes bad and causes children not to want to eat or drink.
- Not being able to take medicine by mouth.
- Other health problems that make it hard to eat, chew, or swallow food.
- Health concerns that make it hard to eat enough food.

Will our lives change with tube feedings?

Yes, getting used to tube feedings takes time. Most parents and caregivers have lots of questions about how tube feedings will affect their daily lives.

There are many reasons G-tubes help. A G-tube makes it easier to give your child the nutrition and fluids he needs. For children who have a hard time eating, tube feeding will take less time and cause less stress than feeding by mouth. For children who can eat food, having a G-tube allows them to enjoy mealtime better. Parents can give foods the child likes, rather than having to give certain high calorie foods the child may not like. Parents also do not need to “force” the child to eat more than he wants.

There are some cons to having a G-tube. Some children eat less food by mouth after starting G-tube feedings. This does not happen with all children. Travel can be a challenge. Yet, with good planning, you will be able to enjoy going on outings and trips with your child the same as you did before.

the G-tube was placed. There are some problems that can occur with a G-tube. These will be discussed later in this booklet.

Try to make tube feeding a part of your family's routine. All parents and other caregivers should learn to give feedings and care for the equipment. This prevents one person from having to do all the work.

Types of Feeding Tubes

There are many types of feeding tubes. The type of tube your child uses may change. This will depend on his or her needs. Types of tubes used are listed below.

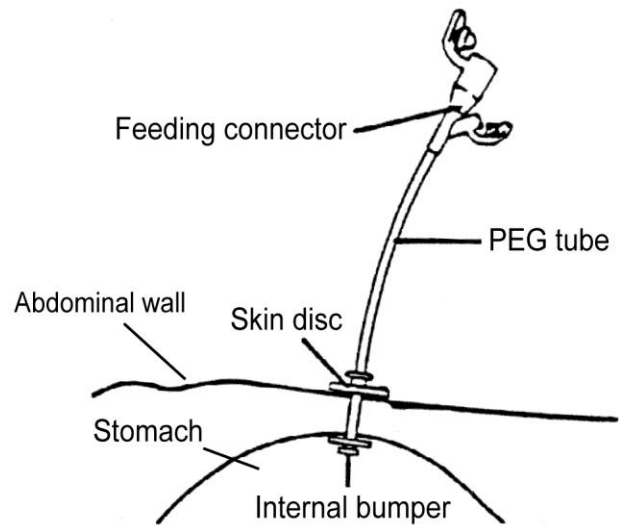
- Nasogastric tubes (NG).
- Percutaneous gastrostomy tubes (PEG).
- Skin-level devices (buttons).
- Single piece balloon or mushroom tip catheters.

Nasogastric (NG) Tubes

NG tubes are short-term feeding tubes. NG tubes are small tubes placed through the nostril and into the stomach. The tube is secured to the child's face with tape. This type of tube is changed every 1 to 4 weeks. How often it is changed will depend on the brand of the NG. They can be changed by health care providers or parents (after they have been trained). There are times that a NG will be used to supplement feedings before a child has a more long-term type of G-tube. They are sometimes used as a trial. This is done to see if a child can handle feedings and gain weight with added feedings.

NG tubes are easy to place and use. They are not good for long-term use. With the tube being taped to the child's face it becomes an easy target for the child to grab and pull out

of place. The tape used to secure the tube can sometimes irritate the skin. These tubes also tend to become clogged with formula and medicines. This is because they are smaller than more permanent types of feeding tubes.



Percutaneous G-tube (PEG)

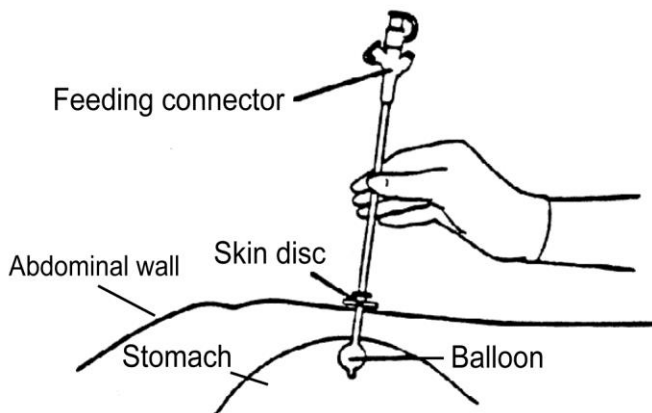
These are soft plastic tubes that are placed during a surgery. PEG tubes are held in place with a clamp or disc that sits outside of the body and an internal bumper.

A gastroenterology (GI) doctor and surgeon will place this tube in the operating room. They will use a small tube with a camera and light to guide the placement of the tube. This is called endoscopy. The only incision or cut will be the opening for the tube.

The tube will remain in place for about 2 months. This will allow the opening to heal. It is at this time that the tube can be changed to a "skin-level" tube.

Balloon-Type G-Tube (Foley Catheter or Replacement Tube)

This is a long tube with a clamp and a feeding or medicine port at one end. It does not have a detachable feeding adapter. An inflatable balloon holds it in place. There may also be a disc or clamp that lies against the skin. This helps to steady the tube. This type of tube is changed every 3-6 months. The first tube is placed during surgery. After this first tube is changed, the people caring for the child can be taught how to change the tube.

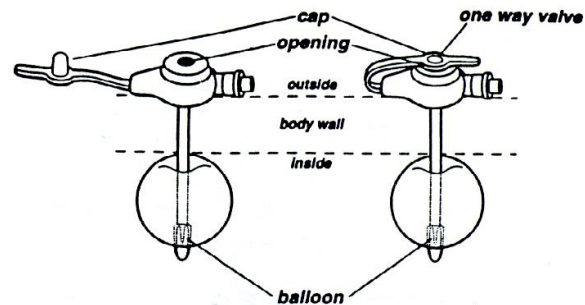


Skin-Level Devices

These tubes are also referred to as “buttons.” Sometimes they are called by their brand names, such as “Mini/AMT”, “MICKEY.” A balloon that inflates holds this type of tube in place. They lie flat against the skin. There is no external tubing attached. A person will connect an adapter tube only as needed for feedings and giving medicines.

Sometimes, a surgeon can place this type of G-tube in the operating room using laparoscopy. This uses small incisions in the skin to insert a camera and small instruments to place the tube without a larger incision. The surgeon uses stitches to secure the tube for the first 2-5 days. Then, your doctor or nurse removes the stitches. The internal balloon which is filled with water holds in place. The first tube change will be 2-3 months after surgery by a doctor or trained nurse. Caregivers learn how to

change the balloon button at home after the first tube change. You will change the balloon type button every 3-6 months, as needed.



Balloon Type Button
(AMT mini or MIC-KEY)

Care of the Button After Surgery

You need to prevent the G-tube from being tugged on, especially before the first tube change. Keep the adapter secured at all times with a “grip-loc” securement device, or medical tape.

Until the first tube change you should not use the balloon port on the G-tube. Do not check the water in the balloon until after the first tube change. Doing so can cause the stomach lining to fall away from the abdominal wall if the site is not well healed.

If the G-tube falls out before the first G-tube change, you should call the pediatric surgery clinic and either come to the clinic or emergency room to have the tube replaced. If we gave you a red rubber catheter at hospital discharge you may gently insert that catheter into the stoma (hole) and tape it in place to keep the hole open until you arrive. If the tube does not easily insert do not force it. Once you arrive, we will replace the G-tube. We will do an x-ray with contrast to make sure that it is in the correct position.

Cleaning the Gastrostomy Site

You should clean the site once a day. You will need to do it more often if your child has drainage around the tube. One of the best ways to clean the site is in the shower or during a bath. Be sure to rotate the tube and allow water to flow under the skin disc to clean the area. If your child cannot shower or take a bath, please use the steps below. The tube site should not be submerged or soaked under water until 2 weeks after surgery. Your child may shower or sponge-bathe until then.

For PEG tubes and one-piece tubes (non-skin level tubes), the external bolster should not be loosened except by the doctor or nurse who placed the tube until after the first tube change.

Steps for Cleaning the Site

1. Wash your hands.
2. Clean the skin and tube with cotton swabs, mild soap, and water. If there is crust around the tube, dip a clean, soft cloth or paper towel in warm water. Wrap it around the crusted area. After about 5 minutes, remove the cloth and wipe away the crusting. Dry the area well. Do not use hydrogen peroxide to clean your child's G-tube site.
3. Look at the skin around the site. A little clear drainage around the opening is normal. When this drainage dries, it becomes a light brown crust. Call your doctor or nurse practitioner if you notice:
 - Drainage
 - Bleeding
 - Excess tissue
 - Redness
 - Swelling
4. Secure the tube to prevent tugging. G-tube buttons should have the

adapter detached when not in use to prevent tugging, if you can. When the adapter is attached or for any other one-piece tube, secure the tube to the abdomen using "grip-locs" or medical tape. One piece clothing (onesies) for infants can help to keep your child from tugging on the tube.

5. Wash your hands when you are done.

Moisture can irritate skin. Avoid dressings. If your child needs a dressing, gently place it between the tube and the skin. Change it every morning and night or when it gets dirty.

Gastrostomy Feedings

There are many ways to feed your child with the G-tube. Your health care team will talk with you about your child's nutrition needs, your child's daily routine, the family routine, and school needs. They will decide which type of G-tube feeding and feeding schedule is best for your child.

Formula name _____

Names of similar products _____

Name of manufacturer _____

Total amount of formula per day _____

Total amount of water per day _____

Vitamins/Minerals/Supplements _____

Feeding Schedule

Give ___ can or ___ ml of _____
every ___ hours or ___ times per day.

Flush the tube with ___ ml water after each feeding.

If your child has nausea, feels full, or the tube does not flush freely. Wait one hour and try again. Call your doctor if this does not improve.

Other Instructions

How to Give a Feeding

1. Wash your hands with soap and warm water for 30 seconds.
2. Connect the syringe or the feeding bag to the G-tube. If using a skin level device, connect the adapter tube to the device and then the syringe or feeding bag.
3. Your child should be sitting up or lying with head raised 30° - 45°.
4. Infuse the formula. It can be given at room temperature.
5. Flush the G-tube with 5-10 ml of tap water. You may be told to give your child a larger amount in order to meet your child's daily water needs. If the volume of water you need to give is quite large you may need to give it as you would a feeding.
6. Clamp or cap the G-tube. If your child has a skin level device remove the adapter. The adapter tubes and feeding bags are reusable.
7. Clean your supplies by rinsing the syringe, bag, and adapter tube with cool water. Then swish with warm water and a small amount of liquid dish soap. Rinse. Hang to dry.

Change tube feeding bags every 3 days. If you cannot easily insert the plunger into the syringe, try a few drops of vegetable oil. Change syringes weekly.

If Using a Pump

1. Fill the feeding bag with the desired amount of formula.
2. Connect the G-tube to the pump tubing, open the flow clamp, and turn on the pump. Be sure the pump is set at the correct rate. The correct rate is _____. (We will teach you how to use the pump.)

Syringe Method

1. Remove plunger from syringe and connect syringe to the G-tube.
2. Raise the syringe 4-5 inches above the stomach and pour the feeding into the syringe. Allow the feeding to flow into the stomach by itself. Feedings should take 15-30 minutes. This will depend on what your child can handle.
3. You may need to gently push the feeding with the plunger to start the flow. Never force feedings into the G-tube.
4. When feeding is complete, remove the syringe from the G-tube.

Feeding Bag Method

1. Fill the feeding bag with the desired amount of formula.
2. Hang the feeding bag at least two feet above your child's head.
3. Attach the feeding bag tubing to the G-tube.
4. Open the clamp and use it to adjust the flow. Feedings will take 15-30 minutes. This will depend on what your child can handle.
5. When done, clamp the feeding bag tube and remove it from the G-tube.

Giving Medicines

You can give medicine with a syringe through the G-tube. Liquid medicines work best. If the medicine does not come in liquid form, crush and dissolve the pills in water (not formula) so that they do not clog the tube. **Never crush enteric-coated or time-release capsules.** Flush the tube with 5-10 ml of water after giving medicine.

G-tube Feedings at Daycare and School

You will need to plan for your child's return to daycare or school with a new G-tube. Some caregivers already know how to use a G-tube. Others may need training. Meet with your child's teacher to discuss the items listed below.

- Your child's feeding schedule.
- The name of the formula.
- The time your child needs feedings.
- How fast your child needs the feeding.
- The position your child needs to be in while being fed.
- Any special instructions.
- Care of the equipment.
- Medicine schedule.
- Plan for the G-tube coming out.
- How to contact you in an emergency.

It may be helpful to show the teacher how to do a feeding. If your child can eat foods, talk with your child's teacher about what foods your child eats, how much, and when he eats.

Decide where the extra G-tube kit will be kept. Some parents keep one at school. Others keep one with their child in a backpack.

Decide how you and your child's teacher will communicate with each other. Many parents and teachers find a notebook is

helpful. Both you and your child's teacher can write in it every day.

Changing a Balloon-Type Gastrostomy Tube Button

The first tube change must be done by your doctor or nurse practitioner. They will then teach you how to change the tube in the future as needed.

You will need to change it if:

- It becomes plugged.
- It falls out.
- Your doctor or nurse suggests a routine change, about every 3 to 6 months.

Supplies

- G-tube kit with inflatable balloon as ordered by your child's doctor.
- Tap water.
- Lubricating jelly that is water-based such as KY[®] jelly or Surgilube[®]. **Do not use Vaseline[®].**

How to Change Your Child's G-Tube

1. Wash your hands.
2. Take a new G-tube and test the balloon for leaks. Using a syringe, draw up 5 ml of tap water. Inject the water into the balloon port. If there is no leak, withdraw the water. If the balloon leaks, save the tube and the box it came in. Bring it to our clinic. We will replace it.
3. Using a syringe, withdraw water from the balloon of the old G-tube.
4. Remove the old G-tube.
5. Coat the tip of the new tube with a water-based lubricant. **Do not use Vaseline[®].**
6. Insert the new tube. **If you cannot insert the tube, call your doctor.**
7. Using the syringe, inject the amount of water as stated on the G-tube

- package into the balloon port.
8. Clean the site.
 9. Wash your hands.

Tips

It is normal for some stomach juices to spill out during the tube change. It is also common for a few drops of blood to ooze from the site during the change. **If there are more than a few drops of blood, call your doctor.**

Removing Your Child's G-tube for Good

Before the tube can be removed, your child will need to be able to:

- Eat all their calories by mouth and gain weight.
- Drink enough fluids every day.
- Take all medicines by mouth.
- Get through an illness without using the tube.

You and your health care team will decide together when to remove the G-tube. In most cases, once your child meets these requirements for about 3 months you can talk to your provider about removing the tube.

When the time comes, you can easily remove it. In most cases, we suggest you do this at home, just before bedtime.

1. Remove the tube as you do when changing tubes.
2. Cover the hole with a small piece of gauze.

The stomach and skin close in about 24 hours. Sometimes the site may take several weeks to close. In most cases, your child will not need surgery to close the G-tube site.

Common G-Tube Problems

- Plugged tube
- Leaking around the tube
- Redness around tube
- Bleeding around tube
- Tissue buildup around tube
- Broken tube
- Tube falls out
- Vomiting
- Diarrhea
- Dehydration
- Constipation
- Gas, bloating, cramping

Plugged Tube

Food particles, lumpy formula, or residue from sticky medicines can cause a plugged tube. Prevent clogging by flushing the tube with 5 ml of water after all medicines and feedings.

If the tube is plugged:

1. Check that the tube is not kinked or clamped.
2. Squeeze the tube between your fingers. Start at the top and work down toward the stomach.
3. Flush the tube with 5 ml of warm water. Do not use force when flushing. If the tube has been changed before and you have been taught how to do so, you may change the tube.
4. Call your doctor or nurse if you are not able to use the tube.

Leaking Around the Tube

There are many causes of a leak, such as:

- A poor fitting tube.
- Extra tissue that prevents the tube from fitting the way it should.
- A deflated balloon.
- Increased pressure in the stomach. Constipation or retching can force formula out around tube.

If your child's tube is leaking:

1. If your child's tube has a balloon and your child has already had the tube changed before, check the water level. (Do not check the water in the balloon of a new G-tube that has not been changed before.) Using a syringe, withdraw the water from the balloon. If the balloon did not contain enough water, add the amount that should be in it. If the balloon keeps leaking water, you may need to replace the tube.
2. Secure the tube to avoid movement that could widen the opening.
3. Protect skin with barrier creams such as Aquaphor® or Proshield®.
4. Apply and change gauze dressings as needed to keep the skin dry.
5. Apply Maalox on the skin. This will prevent and treat irritation caused from leaking stomach acid.
6. Call your doctor or nurse if the leaking persists.

Redness Around Tube

Redness can be caused by an infection, irritation from tape, drainage or movement of the tube.

Call your doctor or nurse if you notice redness, swelling, and warmth at the site, tenderness, or unusual drainage. This may be a sign of infection.

Keep skin at the site clean and dry. Change the gauze as needed to keep the skin dry. If you are able, allow the red areas to be open to air. If the site is leaking, treat the cause of the leak, if you can. Secure the tube to prevent excess movement. You could try tape or try to cover the tube with clothing such as a "onesie."

Bleeding

A few drops of blood can be normal. Large amounts of blood could be a sign of injury.

If you have bleeding that is more than a few drops of blood, call your doctor or nurse. Secure the tube to avoid any excess movement.

Tissue Buildup

Some growth of extra tissue is normal. The body wants to heal the opening. Excess movement of the tube can also cause tissue buildup.

If you notice tissue buildup, secure the tube to prevent excess movement. If the tube is a skin level or "button" tube, detach the adapters when not in use. This will help prevent extra weight and tugging at the G-tube site.

Call your doctor or nurse if the tissue builds up and causes drainage or bleeding.

Tube Breaks

Sometimes the tube breaks. The tube may have been cut. The clamp and feeding port can also break.

If the tube breaks, you may be able to replace the tube at home if the tube has been changed before.

If the tube is new or needs a health care provider to change it, call your doctor or nurse. They may be able to repair the broken section of the tube or they will replace the tube.

Prevent cutting the tube. Do not use a scissors anywhere near the tube.

The Tube Falls Out

The tube may fall out if the child pulled the tube out, the tube was caught on an object or the balloon ruptured.

If the tube falls out, do not panic. The tube will need to be replaced as soon as you can. The opening will start to close after the tube has been out for 30 minutes. Replace the tube if the tube has been changed before. (See page 11)

If the tube is new and has not been changed, cover the opening with a clean bandage and go to the ER to have the tube replaced. If your nurse or doctor gave you a red rubber catheter and you feel comfortable, insert it into the opening. This will keep the hole open until you can get to the clinic or ER.

If you do not have a new tube at home, you will need to use the one that fell out. Rinse the old tube under water and put it back in. This will keep the hole open until you have a new one. Secure the tube in place with tape. Replace with the new tube as soon as you can. Call your doctor or nurse if you do not have access to a new tube.

Call your doctor, nurse, or go to the ER if you cannot replace the tube.

Vomiting

Your child's vomiting may be caused by not having your child in an upright position during and after a feeding. It can also be caused by infection or other illness. Be sure equipment is well cleaned and rinsed between feedings. Wash your hands between contacts with persons who are ill.

If your child is vomiting, be sure that your child is sitting upright or propped up on pillows at least 45° when lying down.

Try giving smaller feedings more often. You will need to make sure that your child gets the amount of feedings needed for each day.

Call your doctor if vomiting doesn't go away. The strength of the formula or the contents may need to be changed.

Diarrhea

Diarrhea means frequent, loose, watery stools. Vomiting, diarrhea, a fever, and sweating cause the body to lose fluids can cause dehydration. Stools that are loose may be normal with certain types of tube feeding. Having loose stools a couple times in a 24-hour period is not a problem.

If your child has loose stools:

- Avoid having formula hang for longer than 6-8 hours.
- Give the tube feeding more slowly, yet make sure the total amount for the day is still the same.
- Watch for signs of dehydration.
- Call your doctor or nurse if the diarrhea does not stop after 24-48 hours. They may choose to adjust the strength or type of formula.

Dehydration

Signs include:

- Decreased amounts of urine.
- Urine that is a darker yellow or more concentrated looking.
- Crying with no tears.
- Dry skin that does not bounce back when squeezed.
- Fatigue or crankiness.
- Dizziness.
- Dry mouth and lips.
- Sunken eyes.
- Headache.

Call your doctor if you notice any signs of dehydration. The doctor will tell you what kind and how much extra fluid you will need to give. Keep in mind that your child may not feel thirsty.

Constipation

Constipation may be due to a low fluid intake, too little fiber in the diet, or a side effect of medicine. This is common in those with limited activity.

Call your nurse or doctor if you notice that your child has chronic constipation. They may want you to try a different formula or prescribe new medicines.

Gas, Bloating or Cramping

Try to get rid of all air from the tube feeding system before connecting it to the G-tube. You may open the tube while it's raised to allow extra air to escape. Do it lying down with the tube held straight up. Be sure to have a towel handy in case fluid is released. Recap once the air is out and fluid starts to come out. Do not drain excess fluid from the stomach.

Call your nurse or doctor if your child's gas, bloating, or cramping doesn't go away.

Your Growing Child

Infants explore their world by grasping, pulling and sucking the objects around them. To keep your child from pulling the tube out, tape the G-tube to the stomach and tuck it under clothing. Overalls and shirts that snap between the legs keep infants from playing with the tubes.

Toddlers love routine. Come up with a special routine during the feeding such as sitting in a favorite chair. Keeping a routine makes your child feel safer. If you can, have your child sit at the table and get the G-tube feeding during the family meal. If your child

takes food by mouth, meals are a great time to practice feeding skills.

Preschoolers love playing "make believe."

Tape a tube like your child's tube to the stomach of a doll or stuffed animal. When your child gets her feedings or other tube care, tell your child to do the same with the doll. Children of this age can help with their own care such as handing Mommy or Daddy the tape or holding the syringe during the feeding. This helps them improve their skills, learn about their own care, and feel proud.

School-aged children can learn to do their own feedings and G-tube care. Children at this age like to know how things work. A picture book that talks about the digestive system may help teach your child how the G-tube works and why your child needs it. Self-care activities for school-aged children make them feel better about themselves.

Teenagers are very worried about how their bodies look. Most teens prefer a skin level device because it is less likely to be seen under clothing. Teenagers may also work with their health care provider to create a plan for weekends or parties. Some will change the feeding schedule and not give a tube feeding during a sleepover.

Common Questions

Can my child sleep on his stomach?

Yes. After the tube site has healed, most children sleep well on their stomachs. Infants should never sleep on their stomachs due to risk of SIDS (sudden infant death syndrome).

Can my child go swimming?

Yes, once the g-tube site is well healed and the tube has been in place for at least 2 weeks. A pool with chlorine is better than a lake. The chlorine will decrease the risk of infection

Home Supplies List

- Pump
- Feeding bags
- Tube feeding formula
- _____.
- 60 ml ENFit syringe.
- Feeding bag (optional).
- 1 inch plastic adhesive tape or “grip-locs.”
- Cotton swabs.
- Smaller syringes for medicines.
- ENFit adapter tube if you child has a skin level devices.
- Split 2X2” gauze if needed.

The nursing staff will give you a 3-day supply before your child is discharged home. You can get future supplies through your home care provider. You can order the special G-tubes, buttons, and other G-tube supplies from your clinic. Please check with your nurse or doctor.

Your health care team may have given you this information as part of your care. If so, please use it and call if you have any questions. If this information was not given to you as part of your care, please check with your doctor. This is not medical advice. This is not to be used for diagnosis or treatment of any medical condition. Because each person's health needs are different, you should talk with your doctor or others on your health care team when using this information. If you have an emergency, please call 911. Copyright © 7/2020 University of Wisconsin Hospitals and Clinics Authority. All rights reserved. Produced by the Department of Nursing. HF#4277