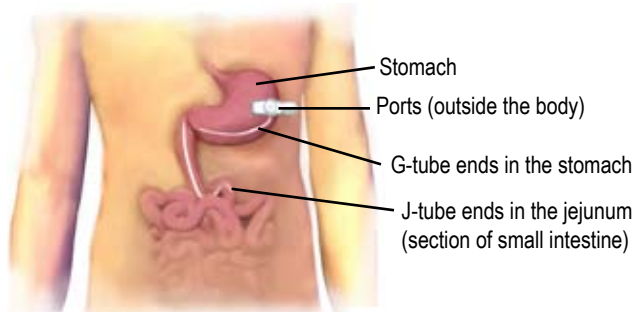


A Guide for
Parents
G-J tube
Care at Home

Gastrostomy Care for G-J Tubes

What is a gastro-jejunal tube?

A gastrostomy (stoma) is a surgical opening made through the skin of the abdomen (belly) and into the stomach. A gastro-jejunal tube (or G-J tube) is a “tube within a tube” placed through this opening. One tube ends in the stomach and the other extends into the jejunum (the small intestine).



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

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

- cannot swallow safely
- blockage of the esophagus
- abnormal function of the stomach
- cannot take enough food by mouth
- _____

Understanding units of measure

- Cans of liquid food are measured in fluid ounces (fl. oz.) and milliliters (ml).
 - Measuring cups can show amounts in ounces (oz.) or milliliters (ml).
- 1 ml = 1 cc
1 fl. oz. = 1 oz. = 30 ml
1 cup = 8 oz. = 240 ml

Your child's information

Tube information

Brand: _____
Size: _____ Date of insertion: ____ / ____ / ____
Balloon volume: _____ ml (if applicable)

Feeding method and schedule

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

- Continuous feedings:
What to feed: _____
Amount: _____
How often: _____
Type of pump: _____
Pump rate: _____
Connect to the **jejunal** port, unless otherwise noted: _____
- Bolus feedings (feed into the **gastric** port):
What to feed: _____
Amount: _____
How often: _____
- After feeding, flush tube with _____ ml of room-temperature water
- After feeding, vent for _____ min.
- If you give extra water: _____ ml _____ times per day.

Medicine

See your discharge summary for your child's list of medication information.

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

Who to contact

When should I call for help?

Call the doctor if:

- redness, pus-like drainage, or bad smell around the stoma
- temperature higher than 101°F
- continued upset stomach, vomiting, or gas
- diarrhea for longer than 24 hours
- constipation (hard, painful bowel movements)
- bleeding around stoma
- fussiness, hard to console
- coughing that does not stop
- continued increase in abdomen size
- tube is accidentally pulled out
- tube breaks off or is cut off
- tube is too short or too long
- leaking around stoma (more than a quarter-sized amount between cleanings)
- tube is clogged and you cannot unclog it
- trouble breathing - Call 911
- rash or irritated skin around the gastrostomy site
- increase in granulation tissue around stoma

Phone numbers

Primary doctor _____

Gastroenterologist _____

Surgeon _____

Dietitian _____

Emergency room _____

Feeding clinic _____

Home care nurse _____

Medical equipment company _____

Occupational therapist _____

Speech-language pathologist _____

Resources

Family Resource Centers
Minneapolis campus
Phone: (612) 813-6816

St. Paul campus
Phone: (651) 220-6368

National Digestive Diseases Information Clearinghouse

- www.digestive.niddk.nih.gov

Oley Foundation

- www.oley.org

Others:

What kind of feeding tube does my child have?

There are many kinds of feeding tubes, but they all have the same basic parts.

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

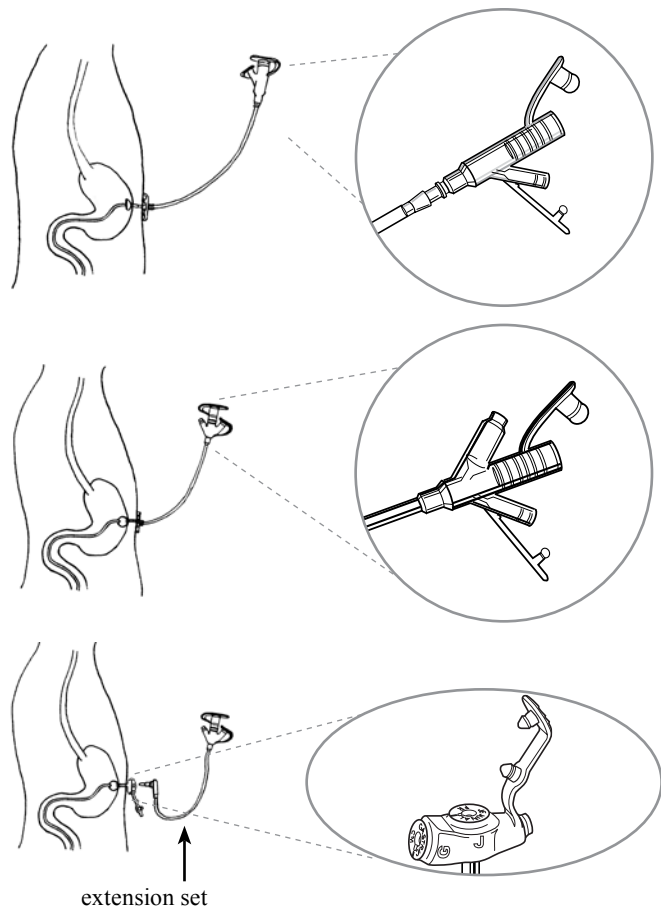
Ask your nurse to go over the type of device your child has and what each port is for.

Your child has this type of device:

- Percutaneous endoscopic gastrostomy (PEG-J): the first gastro-jejunosomy tube placed in surgery. It has 2 ports and a plastic bumper inside the stomach to secure it. A smaller tube that ends in the jejunum may be threaded through the PEG tube.
- G-J tube (gastro-jejunal tube): a tube placed into the stomach through the gastrostomy, and threaded into the jejunum (the first part of the small intestine). It is used to bypass the stomach if vomiting is an issue. It usually has a balloon inside the stomach and has 3 ports. It is placed after the PEG is removed.
- G-J button (or skin-level gastro-jejunal tube): a tube placed into the stomach through the gastrostomy, and threaded into the jejunum. The G-J button lies flat against the skin and has a balloon inside the stomach. An extension set is used to give the feedings and medicines.

side view

close up



Jejunal tube precautions

- Jejunal feedings are always given with a pump.
- Never give a jejunal feeding by the bolus method.
- Never give formula in the gastric port unless instructed to by your doctor.
- Never give medicine in the J-tube unless instructed to by your doctor.
- Never rotate the tube.

Notes about your child's device:

How will I care for my child?

What can I expect after surgery?

The anesthesiologist and surgeon will prescribe and explain the medicine that will be used to keep your child comfortable. Your child will have an intravenous line (IV) to provide fluids and pain medicine.

At first the gastrostomy tube will not be used for feeding. This is because anesthesia makes the intestines stop working for a while. The doctor will decide when feedings can be started depending on what other procedure may have been done in surgery. Once started, feedings will progress slowly.

Caring for a child with a feeding tube may be a little scary at first. With practice, feeding and caring for your child can be simple and comfortable for you both. Your nurse will teach you and help you become comfortable with your child's care before you take him or her home.

These are the things you will need to learn how to do before going home:

- clean the gastrostomy site
- stabilize and protect the gastrostomy
- give feedings through the feeding tube
- give medicines through the feeding tube
- care for the equipment
- help your child develop oral skills
- watch for problems and know what to do if they occur

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

Caring for your child with a gastrostomy tube will require supplies. Here is a list of items that you will need to keep on hand at home.

Supply List

Keep these items on hand at home:

- clamp or gastrostomy plug
- clog zapper, if used
- cotton-tipped applicators
- extension set (for skin-level devices only)
- feeding bag, tubing, and pump
(for continuous feeding)
- gauze drainage sponges
- clean cloths
- lubricant, if desired
- measuring container with pouring spout
- mild, pH-balanced soap
- stabilizers, if used
- syringe, _____ml (catheter-tip)
- syringe, 5 ml
- white vinegar
- wipes or waterless cleanser
- Y-adapter repair kit, if used

Safety Precautions

Be aware the feeding set tubing can get wrapped around a child's neck, which could lead to strangulation or death.

When running a feeding for your child, place the tubing in a way the tubing cannot get tangled around your infant or child. Place the tubing through your child's clothing or towards the foot of the bed. This will help the tubing from getting wrapped around your child's neck if they are to turn or move.

If your child is injured by feeding set tubing, report the event to the FDA at DICE@FDA.HSS.GOV or call 1-800-638-2041.

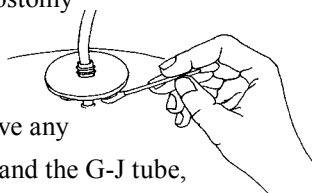
Gastrostomy site care

Cleaning the gastrostomy site

The stoma, or opening in the skin, heals very slowly. It may take several months. Stabilizing the tube can help healing.

Never rotate the tube. Careful skin care is essential. Until the site is healed, the skin around your child's stoma needs to be cleaned twice a day, such as with the bath, before a feeding, and as needed if drainage occurs. Once the site is healed, it can be cleaned once a day, and as needed.

1. Wash your hands well with soap, using friction.
2. Have all supplies together, ready to use:
 - cotton swabs such as Q-Tips®
 - mild, pH-balanced soap and water
 - washcloth and dry towel
 - gauze drainage sponges (if applicable)
3. Remove the old gauze, if present.
4. Check for drainage. A smear of blood or a bit of clear yellow drainage is normal. If drainage has increased, is cloudy, yellow or green, or smells bad, call the doctor.
5. Gently clean around the gastrostomy site with water and mild, pH-balanced soap, rolling a cotton swab around it to remove any drainage. Clean the stabilizer and the G-J tube, too. Rinse and dry the area well.
6. Check the skin around the stoma. If there is increased redness or skin growth, call the doctor.
7. If there is a little bleeding or drainage at the site, place gauze under the bumper. Change it as needed to keep the site dry.
8. Clean the feeding port by vigorously swishing it in warm soapy water. Rinse with clean water.
9. To keep the tube from being pulled, wrap a piece of tape around tube, leaving a tape tag. Use a safety pin to pin the tag to the child's clothing. Wrap a piece of tape around the clasp of the safety pin to keep it from popping open. (Your child's health care team may recommend another type of tube stabilizer.)



Protecting the gastrostomy site

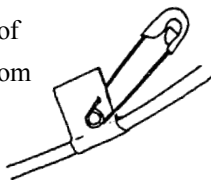
It is important to keep the tube stable so it does not shift. Movement prevents healing, and can lead to leaking or tube slippage too far into the body. Some tubes have a stabilizer that rests on the skin to keep the tube from sliding in and out of the opening. If your child's tube does not have one, a separate stabilizer can be used, such as Flexi-Trak®. The stabilizer may be used for the first 4 weeks after the tube is placed to promote healing. It may also be used if your child develops problems such as skin redness or drainage. The replacement feeding tube and the skin-level device have their own stabilizing devices and you will be shown how these work.

Changing a stabilizer

Do this once a week, or sooner if it is coming off.

1. Wash your hands well with soap, using friction.
2. Have all supplies together, ready to use:
 - supplies for cleaning the site (see left)
 - stabilizer
 - gauze drainage sponges, if applicable
3. Remove the old stabilizer, and gauze if present.
4. Open the stabilizer package and have it ready.
5. Clean the gastrostomy site (shown on left).
6. Pull gently on the tube to snug the bumper against the stomach wall.
7. Apply the stabilizer, following package directions. There should be no pulling on the tube.

To give your child a tub bath with the stabilizer in place, you may want to use waterproof tape to secure the edges.



Preparing for feedings

Giving gastrostomy or jejunostomy feedings

There are several ways to give a gastrostomy feeding. The type, amount of formula, and length of feeding time will be decided by the doctor and dietitian, depending on your child's needs. See page 1 for your child's specific information. **Do not** change the diet without approval from your health care team.

Bolus feedings are given over a short period of time.

Continuous feedings are given over a long period of time. A feeding pump is used to make the tube feeding go into the stomach or jejunum at a slow, steady rate. A child may be fed day and night using a pump. Some children are fed only during waking or sleeping hours.

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

Getting ready

1. Wash your hands well with soap, using friction.
2. Gather all equipment:
 - medicine (if it is to be given with food)
 - syringe, _____ ml (see page 1)
 - extension set (for skin-level G-J tubes)
 - clamp or gastrostomy plug, if used.
 - measuring container with pouring spout
 - formula or breast milk
 - warm water to flush the G-J tube (if ordered)

If you give continuous feedings, you will also need:

- enough breast milk for up to 4 hours, or formula for up to 8 hours. (Breast milk, whether fortified or not, may separate. Gently shake to mix before use.)
- feeding pump
- feeding bag and tubing

Measure the correct amount of formula or breast milk. If it is cold, warm it to room temperature. If you will be giving any water, let it warm to room temperature as well.

Giving medicines

Giving medicines before the feeding

- **Never** give medicines in the jejunal tube unless directed by a doctor.
- **Do not** give non-prescription medicines unless they are approved by a doctor or nurse.

Give medicines before feedings. Do not mix a medicine with other medicines or with the feeding unless you have been directed to do so by your doctor or pharmacist. If mixing together, try them together in a cup (stir for 1 minute) to see that they do not clump, curdle, or become flaky.

Use liquid medicines when available. If a medicine is a tablet or capsule, ask the pharmacist whether it can be crushed or opened. If the medicine is a:

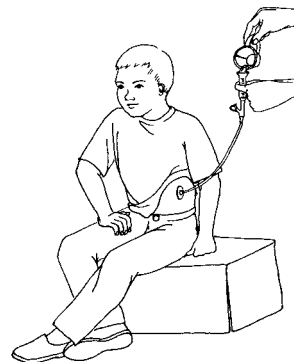
- tablet: crush between two spoons to make a powder, then dissolve in _____.
- capsule: open capsule, pour contents into a cup and dissolve in _____.
- liquid: dilute medicines with an equal amount of water, if instructed.

Ask the pharmacist whether the medicine should be given with or without food. If your child is receiving continuous feedings and the medicine you need to give cannot be given with food, stop the feeding, flush the tube, wait one hour, give the medicine, and wait one more hour before starting the feeding again.

Unless otherwise directed, flush the tube before and after medicine with ___ ml of warm water (see page 1 for the amount). If giving several medicines, flush the tube after each medicine.

Positioning for the feeding

To prevent choking, particularly for bolus feedings, have your child's upper body raised at least 30 degrees. An infant can be held in the curve of your arm (cuddling position), or you may find it easier to use an infant seat or a bed with the head end raised. The upper body should stay raised throughout the feeding and for at least 30 minutes afterward.



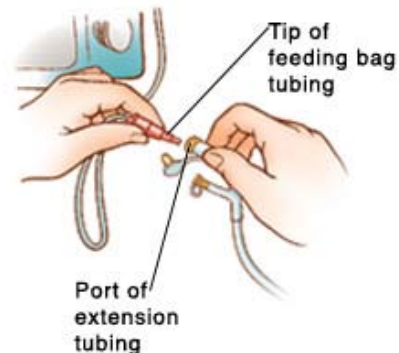
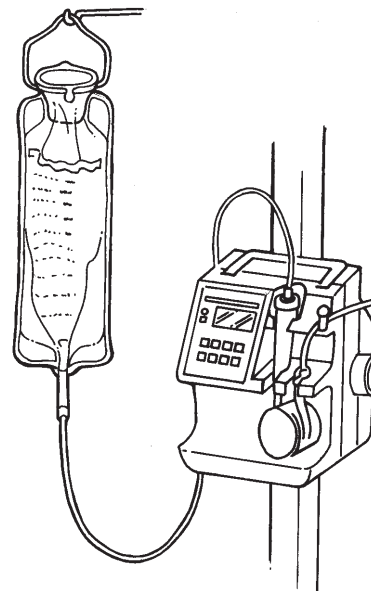
Checking the G-J tube

- Check the length of the G-J tube. Call the doctor if the length of the tube has changed.
- Check that the stabilizing device is secure, but not too tight against the skin. There should be no pulling on the tube.

Continuous feeding with a pump

Continuous feedings are given over a long period of time. See the your child's feeding details on page 1 and follow these instructions to give your child a continuous feeding.

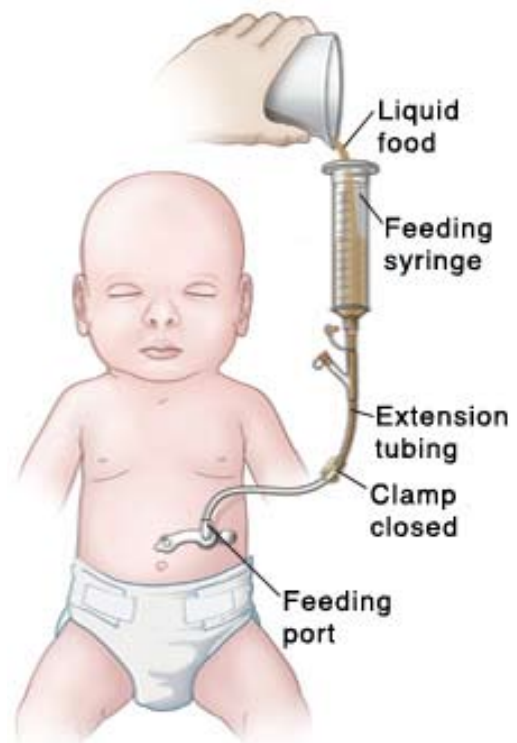
1. If your child has a skin-level device, insert the extension set into it.
2. Pour formula or breast milk into the feeding bag. Run formula through to the end of the tubing.
3. Set up the pump and feeding bag tubing according to the directions from the medical supply company. Be sure the rate is set correctly.
4. Connect the feeding bag tubing to the **jejunal** port.
5. Unclamp the tube.
6. Turn on the pump. Check to make sure the formula is dripping.
7. As the bag empties, add more formula.
8. When the last part of the feeding is in the tube, flush it with _____ ml warm water (see page 1 for the amount) to keep it from clogging.
9. Plug or clamp the tube.



Bolus feedings

Bolus feedings are given over a short period of time. **Follow these steps only if you have been told to give your child bolus feedings.**

1. If your child has a skin-level device, insert the extension set into the gastric port.
2. Put the syringe (without plunger) into the **gastric** port.
3. Pour part of feeding into the syringe.
4. Unclamp the tube.
5. A gentle push of the plunger may be needed to start the flow. Try to start the feeding when the child is calm.
 - A pacifier may help calm an infant.
 - For older children, use activities to distract them, or involve the child with the feeding, such as holding the syringe.
6. Allow the feeding to flow by gravity. Do not force it.
 - During the feeding, the bottom of the syringe should never be held higher than 6 inches above the child's stomach.
 - Lower the syringe at times to allow air bubbles to escape, or to slow the feeding.
 - If your child is crying, you may need to repeat the gentle push with the plunger several times.
7. Continue adding formula to the syringe (without letting it empty) until the entire amount is given.
8. When the last part of the feeding is in the syringe tip, flush it with ___ ml warm water to keep it from clogging (see amount on page 1).



(Note: Conventional G-J tubes do not have the extension set - the feeding port is directly connected to the tube.)

After the bolus feeding

- If directed by your doctor, allow air to escape by venting (leaving the tube open to air). Tape a piece of gauze over the syringe to keep fluids from splashing out. Vent for _____ min. (see page 1).
- Plug or clamp the tube.
- Burp your child, unless a nissen fundoplication has been done.

The upper body should stay raised for at least 30 minutes after feedings, whether your child is sleeping or awake.

Care of the equipment

Cleaning the equipment

Formula container and syringe:

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

Feeding bag and tubing:

1. After each use, wash with warm water and dish soap.
2. Rinse well with clear water.
 - If the bag and tubing do not become clean easily, try using a solution made of white vinegar and cool water (equal amounts of each, for example, 1 cup vinegar with 1 cup water). Then, rinse well.
3. Store in a plastic bag or covered container in the refrigerator to keep germs from growing.
4. Throw away the feeding bag and tubing:
 - Every day.
 - After 1 week, or sooner if it becomes cracked, cloudy, or hard to clean.

Problem solving

What if the gastrostomy tube comes out?

The opening in the skin (stoma) will not close up right away, but a new tube should be put in within 2 to 3 hours.

1. Place a diaper or cloth over the stoma to absorb any fluid. Some stomach contents might ooze out of the opening, and the site may bleed a very small amount, especially if the tube was accidentally pulled out. Apply gentle pressure to stop the bleeding.
2. Call the doctor's office. You will be instructed to take your child to the office or emergency room to have a new tube put in. Bring the tube that came out, along with your gastrostomy travel kit. The doctor will need to know the type and size your child uses.

Other problems:

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

Problem solving

Stoma problems	What to do
Leaking around stoma (more than a small amount)	<ul style="list-style-type: none"> • Check the amount of fluid in the balloon. • If leaking continues, call the doctor.
Bleeding	<ul style="list-style-type: none"> • Apply gentle pressure with a clean cloth for 5 minutes. • Call the doctor.
Tube problems	What to do
Change in length of tube	<ul style="list-style-type: none"> • Call the doctor.
Clogged tube: Follow only the checked instructions	<ul style="list-style-type: none"> • Check tube for kinks, closed clamps. <input type="checkbox"/> Try to slowly push warm water into tube with a catheter tip syringe, using slow, easy pushing. <input type="checkbox"/> Use clog zapper (follow directions on package).
Feeding tube does not stay connected to port	<ul style="list-style-type: none"> • Clean port by swishing in soapy water, then rinsing in clear water.
Port cap breaks off	<ul style="list-style-type: none"> • Replace with Y-adapter repair kit, following package instructions.
Tube is accidentally pulled out or tube breaks off or is cut off	<ul style="list-style-type: none"> • Cover the stoma with a clean soft cloth. • Call the doctor for directions on where to have the tube replaced. • Take your gastrostomy travel kit with you.

Contact your doctor if you suspect the tube has moved.
The doctor may order an X-ray.

General Care

Activity

Your child should be able to do normal activities. Be sure to protect the tube from being pulled out. Children may enjoy being in a swimming pool once the site has healed. Be sure to dry the site well afterwards.

Mouth care

Whether or not your child is eating by mouth, the mouth needs to be cleaned. The mouth may become dry and sore, or mucus may pool in it. You can wipe out and moisten the mouth with a washcloth and plain water. Use lip balm (such as Vaseline®) to keep the lips moist. If your child has teeth, clean them with water or a soft toothbrush. No toothpaste is needed for children younger than one year of age. If your child does not like a toothbrush, begin with a wet washcloth over your finger. Work toward your child getting used to a variety of textures in the mouth. Begin regular dental checkups as you would for any child.

Bathing

Children can take a tub bath once the gastrostomy is healed, about 14 days after a G-J tube has been placed. Until tub baths are allowed, sponge baths may be given. Be sure to dry the skin around the G-J tube well after the bath.

Clothing

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

Babysitters

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

Safety

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

Siblings

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

Travel

Take a gastrostomy travel kit everywhere you take your child. The kit should contain:

- clamp or gastrostomy plug, if used
- clog zapper, if used
- cotton-tipped applicators
- extension set (for skin-level devices only)
- extra G-J tube (in case it needs to be replaced)
- feeding supplies
- gauze or clean cloths
- lubricant, if desired
- measuring container with pouring spout
- mild, pH-balanced soap
- stabilizers, if used
- syringes
- wipes or waterless cleanser
- Y-adaptor repair kit, if used

Developing oral skills

A child who cannot eat by mouth misses the oral touch that normally happens with eating. The child does not learn that the mouth can give pleasure. It is important to provide activities that provide touch and pressure to the mouth and face to help prevent your child from developing oral aversion. After your child goes home, ongoing therapy is available through Children's, local school early intervention programs, or county agencies.

Giving food by mouth

Some children with a G-J tube are allowed to take food by mouth, while others cannot. Your doctor will decide if it is safe for your child to take any food by mouth.

Children's feeding clinic can help you work on balancing oral feedings and gastrostomy feedings. The feeding clinic consists of a nurse practitioner, speech-language pathologist, occupational therapist, and a dietitian. Working with you, your child and your doctor, the team will develop a treatment plan that allows for safe feedings — orally and using the G-J tube. If interested, talk to your doctor or call the feeding clinic at (651) 220-6372.

If your child can take food by mouth, offer oral feedings first, before the gastrostomy tube feeding. This will allow your child to learn that eating makes hunger go away. Use the gastrostomy tube to finish the feeding if your child has not taken the entire amount.

If possible, give your child the tube feeding while at the table with you to encourage an eating routine and schedule. If your child is able to eat by mouth, give food at the same time as the tube feeding. This plan will allow your child to share meals with the family as often as possible.

Oral stimulation

Here are some things you can do with your child to promote normal touch to your child's face and mouth. Try to make these activities a part of your child's daily routine. Also, it is important to do oral stimulation during the tube feedings to help associate using the mouth with satisfying hunger. This is especially important if your child receives no food by mouth. Try to keep oral stimulation enjoyable for your child. Although it may not be received well at first, it will improve with time. It is important to be persistent without forcing.

1. Give a pacifier to your child to suck on during and between gastrostomy feedings (if age appropriate). This will help your child learn to connect sucking to feeling full. Sucking is a normal activity for infants and young children that helps calm them when they are "fussy" or tired. It also aids in the digestion of food by stimulating the making of saliva.
2. Encourage your child to bring his or her fingers up to his or her mouth for exploration or sucking.
3. Encourage and help your child to explore a variety of toys and textures with the mouth. Children should be allowed to do this at their own speed and in their own way. Never force them to do it.
4. Encourage your child to enjoy the face and mouth. Do this by kissing the lips and cheeks, patting the lips as he or she makes noises, and blowing "raspberries" on the cheeks to make funny sounds.
5. Your child's speech-language pathologist or occupational therapist may teach you some other activities.

If you have any questions or concerns, see page 2 for a list of contacts and resources.

