

Feeding Tube Education Workbook



**NATIONWIDE
CHILDREN'S**

When your child needs a hospital, everything matters.SM

Table of Contents

When your child has a feeding tube.....	4
Important information about my child’s feeding tube.....	5
Journey Board.....	6
Why does my child need a feeding tube?	7
What is a feeding tube?.....	7
How do I take care of my child?.....	10
Clothing	10
Bathing.....	10
Mouth care	10
Activities	11
Health care.....	11
Traveling.....	11
How do I take care of the skin around the tube?	12
Cleaning the skin	12
Dressings.....	13
Securing the tube	14
What do I do if the feeding tube falls out or is pulled out accidentally? ...	14
If it has been less than 3 months since the tube was placed.....	14
If it has been more than 3 months since the tube was placed.....	15
How do I change or replace the feeding tube?	16
Removing a G-tube.....	16
Putting a new G-tube in the stomach.....	17
How do I get the feeding equipment and formula?	19
How do I prepare the feeding?	20

How do I feed my child?	21
Feeding methods.....	21
Getting ready to feed.....	22
Feeding your child by gravity with a syringe (bolus)	22
Feeding your child by gravity with a feeding bag.....	26
Feeding your child by pump	27
How do I get ready for oral (by mouth) feedings?	31
Reasons for oral feeding	31
Helping your child get ready for oral feedings	31
When to change to oral feedings	31
How do I give my child medicines?	32
Preparing to give medicine	33
Preparing liquid medicines	33
Preparing pills or tablets.....	34
Preparing capsules	34
Flush before giving the medicine.....	35
Give the medicine	36
Flush after giving the medicine.....	37
How do I take care of the equipment?	38
How can I prevent and manage problems?	38
Feeding and flush schedule	43
Glossary	45

When your child has a feeding tube

A guide for parents and families

While your child is in the hospital, the health care team will teach you how to feed your child using the feeding tube. You may feel anxious at first, but we will give you lots of support. With a little time and practice, you will begin to feel more comfortable.

When you leave the hospital, you will be able to:

- feed your child using the feeding tube
- give your child any needed medicines through the feeding tube
- take care of the feeding tube and the skin around the tube
- know how to manage some common problems and who to call for help

This workbook will answer your questions and give you the information you need to care for your child at home.

Important information about my child's feeding tube

Child's Name: _____

Date of Tube placement: _____

Tube Type: _____

Tube Size: _____ French

Tube Length: _____ cm (low profile tubes only)

Balloon Volume (if applicable): _____ mL

Where does the tube end: Stomach Past Stomach (Jejunum or Small Intestine)

Care Team Member	Doctor/Service	Phone Number
Who do I call if we have problems with feeding? (This is also the doctor managing your child's nutrition needs).		
Who do I call if we have problems with the tube or the skin around the tube?		
Who is our family doctor?		
Which home care company provides our feeding supplies?		
Which home care company provides our home nursing?		
Who do we call if we need more formula?		

Journey Home

We know why our child needs a feeding tube.

We know what to expect after surgery.

We have received the printed feeding tube handouts.

We have watched the "Edutainment" assigned videos.

We have observed the nurses performing care on our child's feeding tube.

We know when and how to give medicine through the feeding tube.

We know when and how to flush our child's feeding tube.

We have performed daily skin care on our child's feeding tube.

We have changed the dressing around our child's feeding tube (if needed).

We have scheduled a class with the Family Resource Center.

We know when and how to vent the feeding tube.

We know our child's formula and feeding schedule.

We know our child's formula and feeding schedule.

We know the name and number of our homecare company.

We are scheduled to meet with our homecare company for equipment training.

We know what to do if our child's feeding tube comes out or gets clogged at home.

We have our "Back-up Tube Kit."

We know our child's formula and feeding schedule.

We know the name and number of our homecare company.

We are scheduled to meet with our homecare company for equipment training.

Hospital Feeding Team:

- Doctor: _____
- Care Coordinator: _____
- Dietitian: _____
- Social Worker: _____
- Other: _____
- Other: _____

We can go home when:

- We can take care of our child's feeding tube by ourselves
- We know when to call the doctor
- We have all of our follow-up appointments
- We have all of our prescriptions and medicines
- We have had all of our questions answered

Why does my child need a feeding tube?

Your child's doctor will tell you the reasons your child needs a feeding tube and how long he or she may need to feed through the tube. The feeding tube will not affect your child's ability to eat or drink.

The feeding tube can be used for the following reasons:

- to give your child liquid food for nutrition
- to give your child water for hydration
- to give your child medicines
- to remove excess air and fluid from your child's stomach (this is called venting)

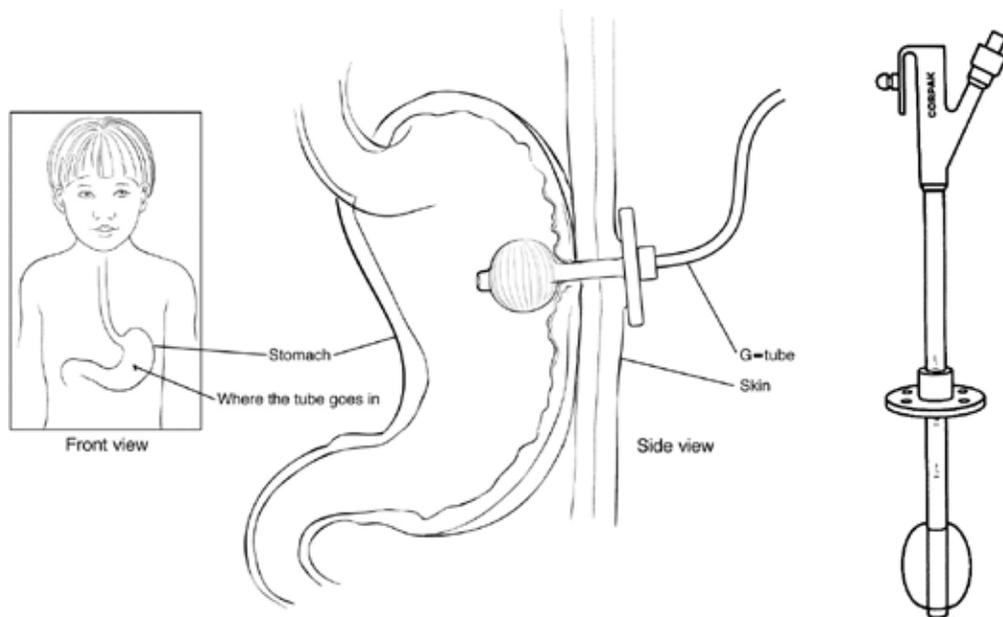
My child needs a feeding tube because:

What is a feeding tube?

A feeding tube is a thin, flexible tube that goes through the skin and muscle into the stomach. Liquids go through the tube directly into your child's stomach or intestine.

There are different kinds of feeding tubes (see pictures 1-7). Your child's doctor has chosen the one that best meets your child's needs at this time. As your child's needs change, the doctor may recommend a different type of feeding tube.

The feeding tube my child has now is called:



Picture 1. Gastrostomy feeding tube inside the stomach



Picture 2. Gastrostomy feeding tube



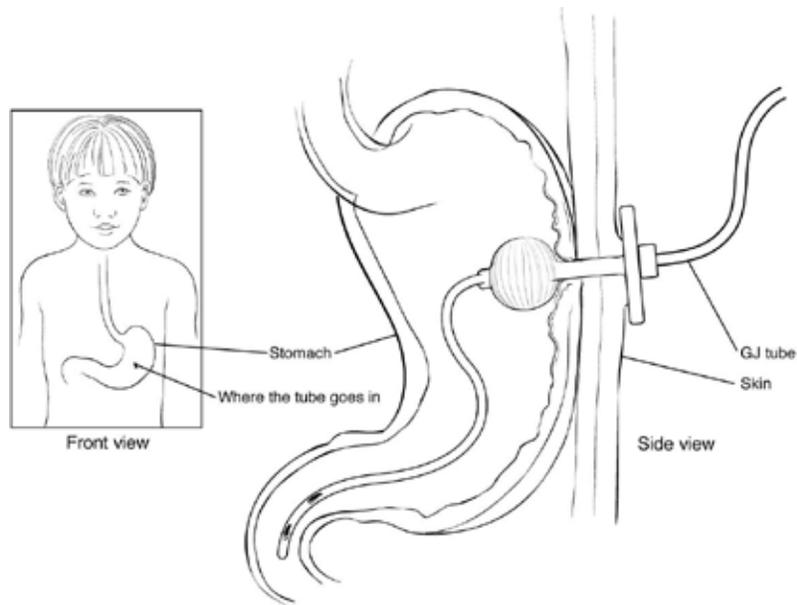
Picture 3. Low profile gastrostomy feeding tube



Picture 4. PEG feeding tube



Picture 5. Foley feeding tube



Picture 6. Gastrojejunostomy feeding tube inside the stomach and intestine.



Picture 7. Two piece gastrojejunostomy (GJ) feeding tube

How do I take care of my child?

Clothing

- Secure the tube in place to protect the opening (called the stoma) and prevent the tube from coming out.
- Cover the feeding tube with a sleeper or undershirt. This holds the tube close to your child's body. Then put on your child's usual clothing over the top.

How I can secure my child's feeding tube:

Bathing

- After the site heals (usually about 2 weeks), it is safe to put your child in the bathtub. The doctor or nurse will tell you when your child can have a bath.

My child can have a bath on _____.

- Before a bath, make sure the plug to the feeding tube is closed. The plug will keep bath water from going into the opening in the abdominal (stomach) wall where the feeding tube enters the body (called the stoma).
- If there is a dressing around the tube, take it off before bathing.
- After the bath, follow steps on page 12 to clean the skin around the feeding tube.

Mouth care

- You need to care for your child's mouth, even if he or she is not eating or drinking. Mouth care can prevent a dry mouth, cavities and gum problems.
- Mouth care depends on your child's age. Before teeth grow, massage your baby's gums. As teeth develop, brush and floss your child's teeth.

How do I take care of my child?

Activities

- Your child can do regular activities such as crawling, walking, running, swimming and lying on his or her stomach. Please check with the doctor before your child plays any rough sports.
- Before your child has a bath or goes swimming, be sure to plug or clamp the feeding tube.
- If your child goes to school, talk with your child's teacher and the school nurse about the feeding tube. The school staff should know what to do and who to call for common problems and emergencies.

Health care

- The health care team will check the feeding tube and your child's nutrition, hydration and growth.
- It is important that your child continues to have regular check-ups with your family doctor or pediatrician.
- If your child needs to go to the hospital, take the formula, feeding equipment, feeding adapter, supplies and information about the feeding tube.

Traveling

- When leaving your home, take your child's formula, equipment and extra supplies with you. You may want to keep a checklist of things to pack so you do not forget anything. You can use a clothes hanger, lamp pole or a hook to hang up the feeding bag.
- Long trips and trips out of the country take some planning. If you are flying, put 2 days of supplies in your carry-on bag. Always keep these supplies with you. You can check the rest of your supplies with your luggage.
- If you are leaving the country, check with your insurance company about your coverage for health care and medical expenses. Find out how and where you can get supplies and what they will cost.
- If you are planning a long vacation, talk with the doctor, nurse and dietitian. The health care team can help you with the details.

Supplies to carry with you:

- Two back-up tubes (one the same size and one that is a size smaller)
- Cotton tipped applicators
- Syringes
- Feeding tube extension set (for low profile feeding tubes only)
- Gauze dressing (if applicable)
- Tape (if applicable)
- Rubber gloves
- Medicines
- Soap for cleaning
- Sterile water for cleaning (if applicable)
- Formula
- Water for flushing
- Pump (if applicable)
- Feeding Bag (if applicable)
- _____
- _____
- _____
- _____
- _____

How do I take care of the skin around the tube?

Cleaning the skin

- Keep the feeding tube site clean and dry. Clean the skin around the feeding tube every day. Clean the skin two times a day if the feeding tube site is red or is draining.
- Be sure to wash your hands.
- If the feeding tube has tape and a gauze dressing, remove the tape and dressing before cleaning around your child's feeding tube.



Picture 8. Cleaning around the tube and under the external bumper of the gastrostomy feeding tube.

- Each time you clean the site, check the skin for any discomfort, redness, swelling, or green or yellow drainage. A small amount of pale (clear or tan) drainage is normal. You may notice some pink-red skin growing around the tube. This is granulation tissue. This is normal. If this tissue builds-up or bleeds easily, the doctor will treat it at your follow-up visit. Call the doctor who takes care of the skin around your child's tube (listed on page 5) if the skin is sore, red, swollen or there is a lot of drainage.
- **For the first two weeks** after surgery, you should wash your child's skin everyday with sterile water. The doctor or nurse will tell you what you should use to wash your child's skin.
- **After the first two weeks**, wash your child's skin everyday with mild soap and water.
- Clean around the tube and under the external bumper using cotton-tipped swabs. If the doctor took out stitches, be sure to turn the external bumper or low profile feeding tube in a full circle to clean all of the skin underneath (see Picture 8).
- Rinse the skin using clean tap water. If there is crusted drainage on the skin or the tube, use half strength hydrogen peroxide to help clean the site.
- Pat the skin dry with a soft cloth or towel.
- Do not use any creams or powders on the skin, unless directed by the health care team.

Dressings

- If there is drainage around the tube, your child's doctor may tell you to put a gauze dressing around the tube. Change the dressing every day or as needed. Clean the skin with each dressing change.
- To replace the dressing, place a 2x2 split gauze pad around the tube and under the external bumper. Cut four 3-inch pieces of tape and secure the gauze and the external bumper to the skin.
- Otherwise, leave the feeding tube site open for better air exposure if the doctor tells you to.

Securing the tube

- If your child has an external bumper (long tube), the health care team will secure the tube during your child's hospital stay. Talk to the doctor who placed the tube about how to secure the tube at home.
- If your child's first tube is a low profile feeding tube, you will tape the feeding tube to the skin for the first two weeks (see Pictures 9A and 9B). Talk to the doctor who placed the tube about how to do this at home.



Pictures 9A and 9B: Taping the external bumper for a gastrostomy feeding tube.

What do I do if the feeding tube falls out or is pulled out accidentally?

If it has been less than 3 months since the tube was placed (any tube type)

- Cover the opening with gauze (see Picture 10) or a clean cloth.
- If the feeding tube is new or has not yet been replaced by a clinician and comes out accidentally, **call the doctor listed on page 5 who takes care of problems with your child's tube.**
- If you cannot reach the doctor, take your child to the local emergency department. The opening should have a tube of similar or smaller size placed within 4 hours or less so the opening does not close. Be sure to take the tube that fell out with you to the doctor or the emergency department.



Picture 10. Covering the stoma with a gauze.

If it has been more than 3 months since the tube was placed (any tube type)

- If it has been more than 3 months since your child's G-tube was placed and your child's doctor says that you can change the tube on your own, follow instructions for "Putting a New G-tube in the Stomach" on page 17.
- If the doctor has NOT shown you how to change the tube, call the doctor listed on page 5 who takes care of problems with your child's tube.
- If you are unable to put the new feeding tube in, cover the opening with gauze (see Picture 11) or a clean cloth and call the doctor listed on page 5 who takes care of problems with your child's tube. If you cannot reach the doctor, take your child to the local emergency department. The opening should have a tube of similar or smaller size placed within 4 hours or less so the opening does not close. Be sure to take the tube that fell out with you to the doctor or the emergency department.



Picture 11. Covering the stoma with a gauze.

Important Note about GJ tubes:

- If your child had a GJ tube placed more than 3 months ago, you'll need to replace the G-tube to keep the stoma open. Please follow instructions for "Putting a New G-tube in the Stomach" on page 17. **Don't try to put the jejunostomy tube back in place – the doctor will need to do this.** Call the doctor listed on page 5 who takes care of problems with your child's tube.

How do I change or replace the feeding tube?

The first scheduled tube change will happen about 3 months after surgery.

My child's first tube change is due in ____ weeks. _____ will change the tube.

I will change the tube for the first time on _____.

If your child has had the feeding tube for more than 3 months and your child's doctor says that you can change the tube on your own, follow the instructions below to change or replace the feeding tube. If the doctor has NOT shown you how to change the tube on your own, check with the doctor who takes care of problems with your child's tube.

Removing a G-tube

Supplies you'll need:

- Catheter-tip syringe
- Gauze or a clean washcloth

1. Remove the G-tube dressing (if your child's tube has a dressing).
2. Put the tip of an empty syringe into the balloon port of the G-tube. Pull back gently to remove the water from the balloon (see Picture 12 or 13).
3. Gently remove the G-tube.
4. Hold a piece of gauze or a washcloth over the opening to absorb the stomach contents.



Picture 12. Removing water from the balloon of the gastrostomy feeding tube



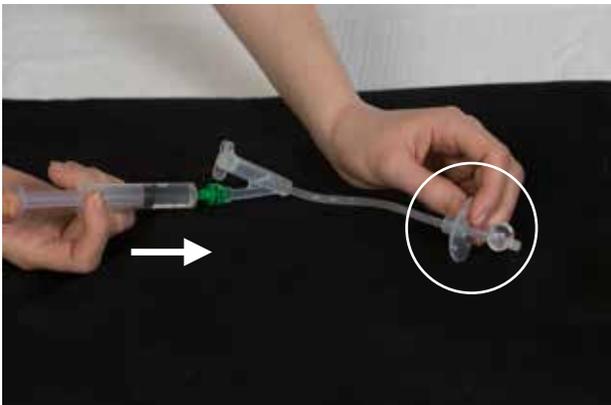
Picture 13. Removing water from the balloon of the low profile feeding tube.

Putting a New G-tube in the Stomach

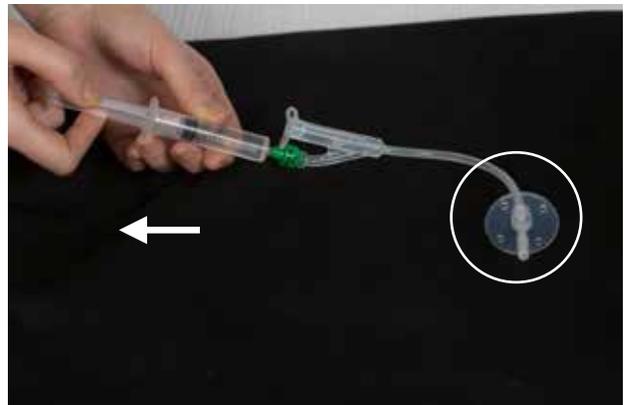
Supplies you'll need:

- Catheter-tip syringe
- 3-5 mL of water
- Water Soluble Gel (such as K-Y Jelly®)
- Feeding tube
- Split 2x2 gauze dressing (if applicable)
- Tape

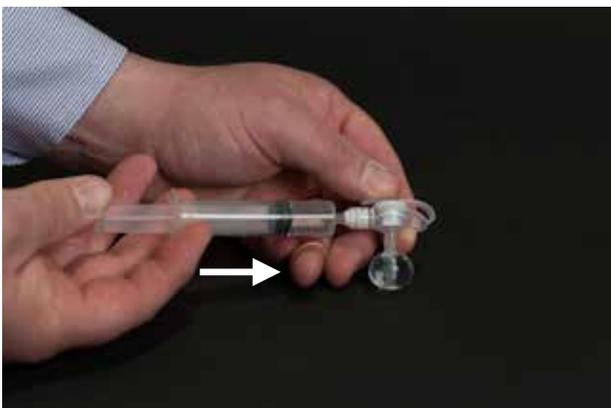
1. Check the balloon of the new G-tube for leaks. Use a syringe to put 3 to 5 mL of water into the balloon port (see Picture 14A or 15A). Then check for leaks. Do not use salt water or air, this would cause the balloon to break. If there is a leak in the balloon, the tube is not working. Do not use it. Pull back on the plunger to remove the water from the balloon (see Picture 14B or 15B).



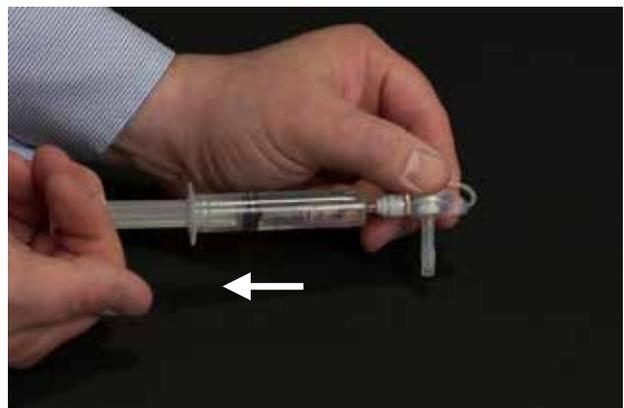
Picture 14A: Check the gastrostomy feeding tube balloon for leaks by filling with water.



Picture 14B: Remove the water from the gastrostomy feeding tube balloon after checking for leaks.



Picture 15A: Check the low profile feeding tube balloon for leaks by filling with water.



Picture 15B: Remove the water from the low profile feeding tube balloon after checking for leaks.

2. Put a dab of water soluble gel, such as K-Y Jelly®, on the tip of the G-tube.
3. Gently put the tube into the stoma (stomach opening) about one inch (see Picture 16).



Picture 16. Inserting the gastrostomy feeding tube into the stoma.

4. Inflate the balloon with 3-5 mL of water (see Picture 17 or 18). Never use more than 5 mL of water.



Picture 17. Inflating the balloon on a gastrostomy feeding tube.



Picture 18. Inflating the balloon on a low profile feeding tube.

5. Gently pull up on the G-tube until you feel tension from the balloon against the stomach wall.

6. Pull the external bumper snugly on the skin to keep the tube from moving (see Picture 19).
7. If you are using a gauze dressing, place a 2x2 split gauze pad under the external bumper around the G-tube.
8. Tape the gauze and external bumper to the skin to hold the tube in place (see Picture 20).
9. Check to be sure that stomach content or gas comes out of the new tube.
10. Flush the new tube with water.



Picture 19. Gently pulling the external bumper of a gastrostomy feeding tube snugly on the skin.



Picture 20. Taping the external bumper for a gastrostomy feeding tube.

How do I get the feeding equipment and formula?

The doctor or dietitian will tell you which formula to give your child. They will write it on the Feeding and Flushing schedule on page 43. Formula can provide all the nutrition your child needs. As your child grows, you may need to change formulas.

You will receive feeding supplies and formula from your child's home care company(ies). The companies are on page 5.

How do I prepare the feeding?

Make sure you check the expiration or “best before” date on the container of formula. Mark the date on powdered formula when opened. Throw it away if it is not used within 30 days of opening. Be sure to wash your hands before making formula for your child.

Liquid Formula	Powdered Formula	Expressed Breastmilk (EBM)
<ul style="list-style-type: none"> • Store unopened containers of liquid formula at room temperature. • Cover and store open containers in the refrigerator. Use within 48 hours. • Warm the formula by putting the container or bottle in a bowl of warm water. Do not use hot water or a microwave oven. 	<ul style="list-style-type: none"> • Prepare formula following instructions given by the dietitian or the physician. • Warm the formula by putting the container or bottle in a bowl of warm water. Do not use hot water or a microwave oven. 	<ul style="list-style-type: none"> • You can give your child fresh or thawed EBM through a feeding tube. • Use fresh EBM within 48 hours. • Use thawed EBM within 24 hours. • Warm the EBM by putting the container or bottle in a bowl of warm water. Do not use hot water or a microwave oven.

Important information about water used to prepare the formula:

- Do NOT use well water.
- You should boil your city water.
 - Boil for 1 minute with the lid on the pan. Cool before using.
 - It is recommended to boil water for the first 3 months of life (past baby’s due date), unless your medical team recommends differently.
- If your house was built before 1986 (although the risk is low), lead could be in the water system. Run cold water for 1-2 minutes before using it to prepare formula.
- Distilled or purified water can be used without boiling first. (All other bottled water should be boiled.)

How do I feed my child?

The health care team will help you make a feeding plan that meets your child's needs and fits your family's daily life. They will write the details of the plan on your "Feeding and Flushing Schedule" (page 43). The plan will change to meet the needs of your growing child.

If your child is very young, he or she can suck on a pacifier during feedings. This helps your baby relate sucking with the pleasant feeling after a feeding. Hold and talk to your baby while feeding.

Feeding Methods

There are several ways to feed your child using the feeding tube. You and your child's health team will decide which method is best for your child. You may change methods as your child's needs change.

- By gravity: Formula flows down from a large syringe or feeding bag through the feeding tube. You control the flow of the formula by the location of the large syringe or the roller clamp on the feeding bag tube. This method is bolus or gavage feeding. (See page 22 for instructions)
- By pump: A pump controls the flow of formula from the feeding bag through the feeding tube. The pump moves the formula down the tube and into the stomach/intestine at a set rate. (See page 27 for instructions)

Getting ready to feed your child

1. Wash your hands.
2. Measure the formula in a bottle or measuring cup.
3. If formula is in the refrigerator, take it out and allow it to sit at room temperature for 30 minutes. Or warm the formula by putting the container or bottle in a bowl or cup of warm water.
4. Pour a drop of the formula on the inside of your wrist to test the temperature. Be sure it is only warm and not hot – never warm formula in the microwave.
5. When you hold your infant during feedings, keep his head raised. You may place your child in an infant seat, but only if the child's head is raised and the child does not slump forward. If your child is older, place him in a chair or bed with the head of the bed raised 6 to 8 inches. To prevent choking, do not feed an infant or older child when he or she is lying down.

Feeding your child by gravity with a syringe (bolus)

Supplies you'll need:

- Feeding and Flushing Schedule (page 43)
- Formula at room temperature
- 60 ml syringe or a catheter-tip syringe for flushing
- Warm water for flushing

1. Flush before the feeding

- a. Remove the plunger from the syringe.
- b. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 21). If it has a clamp, open it after you insert the syringe (see Picture 22).



Picture 21. Preparing to flush the gastrostomy feeding tube without a clamp by pinching the tube prior to flushing.



Picture 22. Preparing to flush the low profile feeding tube with a clamp.

- c. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Hold the syringe upright. Slowly pour the warm water into the syringe.
- d. Raise the syringe above the child's stomach but no higher than the child's shoulders. As you pour, the water runs into your child's stomach and flushes the tube (see Picture 23 or 24).



Picture 23. Flushing the gastrostomy feeding tube.



Picture 24. Flushing the low profile feeding tube.

- e. Lower the syringe to the level where the feeding tube goes into the child's stomach. This stops the water.

2. Give the formula

- a. SLOWLY pour some of the formula into the syringe. As you raise the syringe above the child's stomach, the formula runs into your child's stomach (see Picture 25 or 26).



Picture 25. Pouring formula into the syringe for a gastrostomy feeding tube.



Picture 26. Pouring formula into the syringe for a low profile (MIC-KEY) feeding tube.

- b. Keep SLOWLY pouring formula into the syringe until you have given the required amount of formula.
- c. Lower the syringe to the level where the feeding tube goes into the child's stomach to stop the formula and prevent the syringe from emptying.

3. Flush after the feeding

- a. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. SLOWLY pour the warm water into the syringe to flush the tube (see Picture 27 or 28).



Picture 27. Flushing the gastrostomy feeding tube.



Picture 28. Flushing the low profile feeding tube.

- b. Clamp or pinch the feeding tube. Remove the syringe.
 - c. Close the feeding tube plug.
4. When the feeding is finished, keep your child's head higher than his or her stomach for about an hour.
 5. Wash and store equipment, following instructions on page 38.

Feeding your child by gravity with a feeding bag

Supplies you'll need:

- Feeding and Flushing Schedule (page 43)
- Formula at room temperature
- Feeding bag
- 60 ml syringe or a catheter-tip syringe for flushing
- Warm water for flushing
- IV pole or hook to hang feeding bag

1. Check the feeding tube and prepare the feeding equipment

- a. If the feeding tube does not have a securing device, check the position of the tube.
- b. Close the roller clamp on the extension tube by rolling it to the bottom until it feels tight.
- c. Wipe the top of the formula container with a clean cloth. Shake to mix the formula.
- d. Open the formula and pour the needed amount into the feeding bag. If your child is on continuous feedings, follow the feeding plan given by your child's medical team.
- e. Hang the feeding bag on the IV pole or hook. It must be higher than your child's head.
- f. Hold the tip of the feeding bag tubing over a container. Open the roller clamp. Do not fill the drip chamber more than half full. Let the formula run to the end of the tube, and then close the roller clamp. This pushes the air out of the tube so that it does not go into your child's stomach.

2. Flush before the feeding

- a. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Pull up the warm water into the syringe to flush the feeding tube.
- b. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube. If it has a clamp, open it after you insert the syringe.
- c. Slowly push the plunger of the syringe. Flush the water through the feeding tube.
- d. Pinch or clamp the feeding tube. Remove the syringe from the feeding tube.

3. Give the formula
 - a. Connect the tip of the feeding bag tubing to the feeding tube and unclamp the feeding tube. Open the roller clamp. This starts the flow of formula down the tube. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the tip of the feeding bag tubing to the feeding tube. If it has a clamp, open it after you insert the tip of the feeding bag tubing.
 - b. After the formula has run through, clamp or pinch the feeding tube. Remove the tip of the feeding bag tube.
4. Flush after feeding
 - a. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. You can pour the water into the feeding bag OR flush with the syringe in the same way as before the feeding.
 - b. After flushing through the feeding bag, close the roller clamp on the feeding bag tubing. Clamp or pinch the feeding tube. Remove the feeding bag tubing from the feeding tube.
 - c. Close the feeding tube plug.
5. When the feeding is finished, keep your child's head higher than his or her stomach for about an hour.
6. Wash and store equipment, following instructions on page 38.

Feeding your child by pump

A pump delivers a continuous amount of formula at a set rate. Check your pump manual on how to feed your child with the pump. If you have any questions, refer to the manual or call the home care company that provides your feeding supplies (listed on page 5).

Supplies you'll need:

- Feeding and Flushing Schedule (page 43)
- Formula at room temperature
- Feeding set (feeding bag and extension tube)
- 60 ml syringe or a catheter-tip syringe for flushing
- Feeding pump and IV pole
- Warm water for flushing



Pictures 29A and 29B. Not all feeding pumps need to be hung on an IV pole. This example shows a feeding pump in a bookbag.

1. Check the feeding tube and prepare the feeding equipment
 - a. If the feeding tube does not have a securing device, check the position of the tube.
 - b. Wipe the top of the formula container with a clean cloth. Shake to mix the formula.
 - c. Open the formula and pour into the feeding bag. Do not pour more than a 4 hour supply into the bag at one time, unless the dietitian has given you other instructions.
 - d. Follow your home care company's instructions on how to remove the air from the feeding bag tubing.
2. Flush before the feeding
 - a. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Pull up the warm water into the syringe to flush the feeding tube.
 - b. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 30). If it has a clamp, open it after you insert the syringe (see Picture 31).



Picture 30. Preparing to flush the gastrostomy feeding tube without a clamp by pinching the tube prior to flushing.



Picture 31. Preparing to flush the low profile feeding tube with a clamp.



Picture 32. Flushing the gastrostomy feeding tube using a syringe.



Picture 33. Flushing the low profile (MIC-KEY) feeding tube using a syringe.

- c. Slowly push the plunger of the syringe. Flush the water through the feeding tube (see Picture 32 or 33).
 - d. Pinch or clamp the feeding tube before removing the syringe from the feeding tube.
3. Give the formula
- The steps below apply to an Enteralite pump. If you have a different type of pump, please follow guidelines from your child's home health agency.*



Picture 34. Example of a feeding bag tube connected to a feeding tube.

- a. Connect the tip of the feeding bag tube to the feeding tube.
 - b. Press the power ON/OFF button.
 - c. Confirm the correct RATE on the pump and set DOSE to "INF."
 - d. Press the RUN/PAUSE button to start or pause the feeding.
 - e. When feeding is complete, the pump will stop, beep and read "NO FOOD" to alert you that the bag is empty. Press the RUN/PAUSE button to pause and then the power ON/OFF button to turn the pump off.
4. Flush after the feeding
- a. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Pull up the warm water into the syringe to flush the feeding tube.

- b. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 35). If it has a clamp, open it after you insert the syringe (see Picture 36).



Picture 35. Preparing to flush the gastrostomy feeding tube without a clamp by pinching the tube prior to flushing.



Picture 36. Preparing to flush the low profile feeding tube with a clamp.

- c. Slowly push the plunger of the syringe. Flush the water through the feeding tube (see Picture 37 or 38).



Picture 37. Flushing the gastrostomy feeding tube using a syringe.



Picture 38. Flushing the low profile feeding tube using a syringe.

- d. Pinch or clamp the feeding tube before removing the syringe from the feeding tube. Close the feeding tube plug.
5. When the feeding is finished, keep your child's head higher than his or her stomach for about an hour.
 6. Wash and store equipment, following instructions on page 38.
 7. Keep the pump plugged in when you are not using it. This keeps the battery fully charged.

How do I get ready for oral (by mouth) feedings?

Be ready for oral feeding even when your child is getting tube feedings. Eating by mouth, at regular mealtimes, allows your child to copy other family members. At the same time, your child is learning that oral feedings can satisfy hunger. It is important for your child to connect using his or her mouth with the feeling of the stomach getting full.

Reasons for oral feeding

- Tube feeding schedules can confuse the connection between hunger and eating by mouth.
- Children who are tube fed can miss out on the critical period of learning to use their mouths. Missing these critical times can make it harder to learn to eat by mouth later on.
- Many times, children who are tube-fed are not at the table to share family meal times.

Helping your child get ready for oral feedings

Use these ideas even if your child is not ready to eat by mouth at this time:

- Keep tube feeding equipment out of sight when you are giving a tube feeding. Hold babies while feeding. Tube feeding equipment should be behind the caregiver so the infant can watch the caregiver's face.
- Give infants a pacifier or a finger to suck on during tube feedings. This connects sucking with feeling full.
- Place something safe in their mouths of older children during tube feedings, for example an empty spoon or teething ring.
- Older infants, toddlers and children should sit with the family at the table during meals.
- If the doctor agrees, give your child foods to see, smell, taste and play with while receiving the tube feeding. A feeding therapist will give you other ways your child can use his or her mouth.

When to change to oral feedings

- Your child's doctor must first tell you that it is medically safe.
- Your child's doctor may work with a dietitian to decide if your child's weight is stable. It is normal for your child to have slight weight changes while his food intake adjusts.

- Your child’s doctor may also work with a feeding therapist to help decide on food that is right for your child.
- Your child should be showing signs of hunger or interest in food.
- Your child needs to have oral motor skills to begin eating food by mouth.
- Once your child is eating more by mouth, you can work with a feeding therapist to decide on foods that are right for your child’s age and stage of development.

How do I give my child medicines?

- Ask your doctor or nurse where the tip of the feeding tube is in your child’s body. The tip can stay in the stomach or past the stomach. Make sure that the medicine your child is taking is going to the right place. Each time you get medicines filled from the pharmacist, check with the pharmacist to be sure the medicine ordered should be going where the tip of your child’s feeding tube ends.

The tip of my child’s feeding tube ends in the: Stomach Past the stomach (Jejunum)

- There are some medicines you cannot mix with each other or feedings unless the doctor or pharmacist says it is okay. If you are giving several medicines, ask your doctor or pharmacist if you can give them in the feeding tube together or if you should flush with water after each medicine. Refer to the Feeding and Flushing Schedule on page 43 for how much water to use to flush between medicines.

I can give these medicines together	I should give these medicines alone and flush my child’s feeding tube before giving another medicine.

Preparing to give medicine

1. Wash your hands well. Use soap and water or an alcohol hand cleaner.
2. Gather all of your supplies:
 - A small cup or glass
 - A small catheter tip syringe
 - Medicine in liquid or powder form
 - Mortar and pestle or a pill crusher
 - Water
 - Spoon

Preparing liquid medicines

Mix the medicine with tap water. Check with your doctor about how much water to use.

I should mix the following liquid medicines in tap water:	
Medicine	Amount of tap water (mL) to mix with medicine

Preparing pills or tablets

Check with your doctor or pharmacist before crushing the pills or tablets. There are some medicines you should not crush. Crush the medicine into a powder and mix it with tap water. Ask your doctor how much water to use.

I should crush the following pills/tablets and mix them with tap water:	
Medicine	Amount of tap water (mL) to mix with medicine

Preparing capsules

Check with your doctor or pharmacist before dissolving capsules. There are some medicines you should not dissolve. Open the capsule and dissolve powder in tap water. Ask your doctor how much water to use.

I should mix the contents of the following capsules in tap water:	
Medicine	Amount of tap water (mL) to mix with medicine

Flush before giving the medicine

1. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Pull up the water into the syringe to flush the feeding tube.
2. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 39). If it has a clamp, open it after you insert the syringe (see Picture 40).



Picture 39. Preparing to flush the gastrostomy feeding tube without a clamp by pinching the tube prior to flushing.



Picture 40. Preparing to flush the low profile feeding tube with a clamp.

3. Slowly push the plunger of the syringe. Flush the water through the feeding tube (see Picture 41 or 42).



Picture 41. Flushing the gastrostomy feeding tube using a syringe.



Picture 42. Flushing the low profile feeding tube using a syringe.

4. Pinch or clamp the G-tube before removing the syringe from the feeding tube. Close the feeding tube plug.

Give the medicine

1. Draw up the first medicine into the syringe.
2. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 43). If it has a clamp, open it after you insert the syringe (see Picture 44).



Picture 43. Preparing to give medicine through the gastrostomy feeding tube without a clamp by pinching the tube prior to giving the medicine.



Picture 44. Preparing to give medicine through the low profile feeding tube with a clamp.

3. Slowly push the plunger of the syringe and push the medicine through the feeding tube (see Picture 45 or 46).



Picture 45. Giving medicine through the gastrostomy feeding tube.



Picture 46. Giving medicine through the low profile feeding tube.

4. Pinch or clamp the feeding tube before removing the syringe from the feeding tube. Close the feeding tube plug.

Flush after giving the medicine

1. Check the Feeding and Flushing Schedule (page 43) for the amount of water to use. Pull up the water into the syringe to flush the feeding tube.
2. If the feeding tube does not have a clamp, pinch the tube, open the plug and insert the end of the syringe into the feeding tube (see Picture 47). If it has a clamp, open it after you insert the syringe (see Picture 48).



Picture 47. Preparing to flush the gastrostomy feeding tube without a clamp by pinching the tube prior to flushing.



Picture 48. Preparing to flush the low profile feeding tube with a clamp.

3. Slowly push the plunger of the syringe and flush the water through the feeding tube. This makes sure that all the medicine is out of the tube (see picture 49 or 50).



Picture 49. Flushing the gastrostomy feeding tube using a syringe.



Picture 50. Flushing the low profile feeding tube using a syringe.

4. Pinch or clamp the feeding tube before removing the syringe from the feeding tube.
5. Close the plug or reattach the cap at the end of the feeding tube.
6. After giving the medicine(s), take the syringe apart. Wash all equipment with warm, soapy water. Rinse all equipment well.

How do I take care of the equipment?

It is important to keep all of your supplies and equipment clean.

- After each feeding rinse all supplies with water.
- Each day, wash the extension tubes and syringes with soap and water. Do not wash equipment in a dishwasher.
- You can reuse extension sets. Throw away Farrell® bags & feeding bags every 24 hours.
- After washing, rinse the extension tubes and syringes with diluted vinegar:
 - Mix 30 mL (1/8 cup) of vinegar with 125 mL (1/2 cup) of water
 - Rinse well with cool water, letting the water run through the tubing
- Once per week, soak the extension tubes and syringes in full strength vinegar for about 20 minutes to help remove dried formula or food. Rinse well with plain water before using again.
- Allow supplies to dry completely open to air on a paper towel/clean surface. Once dry, store your supplies in a plastic container or plastic bag.

How can I prevent and manage problems?

Follow these steps to prevent problems:

- Keep the site clean and dry.
- Secure the tube to the skin.
- Flush according to the Feeding and Flushing Schedule on page 43.

Here are some common problems and how to manage them at home. If you are unsure of what to do, please call your family doctor, listed on page 5.

Problem & Possible Reasons	What to do
Nausea <ul style="list-style-type: none">• The feeding is too fast.• Your child has an illness such as a virus.	<ul style="list-style-type: none">• Slow the rate of flow of the feeding, doubling the time it takes to feed.• If that does not work, try delaying the feeding for an hour and then give it slowly.• If your child still feels nauseated the next day, call your family doctor listed on page 5.

Problem & Possible Reasons	What to do
<p>Vomiting</p> <ul style="list-style-type: none"> • The tube is in the wrong position. • Your child has an illness such as a virus. • Your child has too much air in their stomach. 	<ul style="list-style-type: none"> • Vent your child’s stomach by opening the plug and attaching a 60 ml syringe to the feeding tube to let gas out of the stomach (see Picture 51). <div data-bbox="808 533 1049 873" data-label="Image"> </div> <p data-bbox="1089 659 1414 730"><i>Picture 51. Venting your child’s stomach.</i></p> <ul style="list-style-type: none"> • Call your family doctor if vomiting continues. • If your child vomits green bile, call your family doctor listed on page 5.
<p>Feeling thirsty</p> <ul style="list-style-type: none"> • Your child is not getting enough fluid (dehydration). 	<ul style="list-style-type: none"> • Be sure to follow the Feeding and Flushing Schedule on page 43.
<p>Dark yellow urine or passing urine less than 2 times a day</p> <ul style="list-style-type: none"> • Your child is not getting enough fluid (dehydration). 	<ul style="list-style-type: none"> • Call your family doctor listed on page 5.
<p>Diarrhea (More than 3 loose, watery bowel movements a day)</p> <ul style="list-style-type: none"> • Medicine may cause diarrhea. • The feeding is going in too fast. • The feeding tube may have moved out of place. • Your child may have an illness or infection. 	<ul style="list-style-type: none"> • Talk with the dietitian about changing the flow of formula. • Always wash your hands before cleaning the site or feeding your child. • Always use clean equipment (see page 35). • When your child has diarrhea, you need to replace fluids. Talk to the dietitian or nurse about how to do this. • If diarrhea lasts longer than 2 days, call your family doctor listed on page 5.

<p>Constipation (Hard bowel movements or no bowel movements for 3 days)</p> <ul style="list-style-type: none"> Your child is not getting enough fluids. Medicines may cause constipation. 	<ul style="list-style-type: none"> Ask your family doctor, pediatrician or pharmacist if your child's medicines may cause constipation. Talk to the dietitian or nurse about the amount of fluids and fiber your child is getting.
<p>Cramping</p> <ul style="list-style-type: none"> The formula is cold or not mixed properly, causing the bowels to contract. 	<ul style="list-style-type: none"> Make sure the formula is at room temperature before using. Be sure to use the right formula recipe. Formula may be infusing too fast. Slow down the flow of formula.
<p>Bloating</p> <ul style="list-style-type: none"> The formula may have gone in too quickly. Too much gas in the stomach. 	<ul style="list-style-type: none"> Delay the next feeding by 1 hour or slow the rate of feeding by half for 4 to 6 hours. Then slowly increase the rate back to the usual level. Open the plug and attach a 60 ml syringe to the feeding tube to let gas out of the stomach. If your child is able, exercise such as walking may relieve bloating and gas. If bloating lasts for more than 2 or 3 days, call your family doctor listed on page 5.
<p>Fever</p> <ul style="list-style-type: none"> There are many reasons for fever. 	<ul style="list-style-type: none"> If your child has a temperature over 100.4°F, call your family doctor listed on page 5.
<p>Coughing or trouble breathing during or right after a feeding</p> <ul style="list-style-type: none"> The formula may be coming back up into the throat from the stomach. 	<ul style="list-style-type: none"> Slow down the flow of formula. Talk with the person who handles problems with feeding (listed on page 5) about changing the flow of formula. Make sure your child is in a safe position for feeding (sitting or propped up). If the problem continues, call your family doctor listed on page 5.

<p>Skin around the opening is red, swollen, draining or sore</p> <ul style="list-style-type: none"> Leaking around the tube may irritate the skin and cause redness. Pain, swelling and redness are signs of infection. 	<ul style="list-style-type: none"> Do skin care more than once a day. Cover the site with a dressing to keep it dry. Change the dressing often. See ‘Leaking around the tube’ (page 41). If the problem continues, call the doctor listed on page 5 who takes care of the skin around your child’s tube.
<p>A build-up of skin around the opening that is pink-red, shiny, thick and bumpy</p> <ul style="list-style-type: none"> This is granulation tissue, a normal body reaction to the tube. 	<ul style="list-style-type: none"> Continue daily skin care. Secure the tube to the skin to prevent rubbing. If the tissue becomes irritated or bleeds easily, call the doctor listed on page 5 who takes care of the skin around your child’s tube. The doctor may treat this problem.
<p>Leaking around the tube</p> <ul style="list-style-type: none"> Leaking can irritate the skin and cause a burning feeling. Leaking may be due to: <ul style="list-style-type: none"> The tube is not secured properly. The tube does not fit the opening properly. A build-up of granulation tissue. 	<ul style="list-style-type: none"> Check that the feeding tube is secure in the correct position (not pulled). Continue skin care and try to keep the skin dry. If leaking continues, call the doctor listed on page 5 who takes care of problems with your child’s tube.
<p>Formula does not run through the feeding tube</p> <ul style="list-style-type: none"> Feeding tube is blocked. This can happen slowly over time, from a build-up of formula inside the tube. It can happen suddenly, for example, when crushed medicine blocks the tube. 	<ul style="list-style-type: none"> Draw up 2 to 3 mL of warm water. Attach the syringe to the feeding tube. Push the warm water in gently and pull the plunger back slowly. Repeat several times. If the problem continues, call the doctor listed on page 5 who takes care of problems with your child’s tube.

<p>Tube comes out</p> <ul style="list-style-type: none"> • Tube has come out by accident. 	<ul style="list-style-type: none"> • Put the feeding tube back in as soon as possible or the opening will close. • See page 14 - ‘What do I do if the feeding tube falls out or is pulled out accidentally.’
<p>Broken clamp</p> <ul style="list-style-type: none"> • Clamp is worn out. 	<ul style="list-style-type: none"> • Call the home care company that provides your feeding supplies (listed on page 5) for a replacement.
<p>Plug or cap breaks off tip of feeding tube</p> <ul style="list-style-type: none"> • Plug or cap is worn out. 	<ul style="list-style-type: none"> • Call the home care company that provides your feeding supplies (listed on page 5) for a replacement.
<p>Tip of feeding bag tubing keeps coming out of feeding tube</p> <ul style="list-style-type: none"> • Tube port is worn out. • Build-up of oils inside. 	<ul style="list-style-type: none"> • Call the home care company that provides your feeding supplies (listed on page 5) for a replacement. • Wet a cotton swab with water and clean the inside of the adapter and the tip of the feeding set.
<p>Pump not working</p> <ul style="list-style-type: none"> • There are many possible reasons. 	<ul style="list-style-type: none"> • Refer to the pump manual and call the home care company that provides your feeding supplies (listed on page 5) for help.

Feeding and Flushing Schedule

Name of Formula or Additives	Total Amount to give each day
1.	
2.	
3.	
4.	

I will feed my child by gravity:

How?	When?	How much?
<input type="checkbox"/> Feeding Bag <input type="checkbox"/> Large Syringe	<input type="checkbox"/> As needed <input type="checkbox"/> Every 3 hours <input type="checkbox"/> Every 4 hours <input type="checkbox"/> Every 6 hours Other schedule _____	

I will feed my child by pump:

When?	Rate	Dose
<input type="checkbox"/> Continuously <input type="checkbox"/> Bolus Times _____	_____ mL per hour	_____ mL

I will feed my child by mouth:

When?	How much?

I will flush my child's feeding tube:

When and how much?
<p><input type="checkbox"/> Before feedings: _____ mL/flush</p> <p><input type="checkbox"/> After feedings: _____ mL/flush</p> <p><input type="checkbox"/> Before giving medicine: _____ mL/flush</p> <p><input type="checkbox"/> Between medicine: _____ mL/flush</p> <p><input type="checkbox"/> After giving medicine: _____ mL/flush</p> <p><input type="checkbox"/> Other: _____</p>

Glossary

Aspiration pneumonia: inflammation/infection of the lungs due to inhaling food, fluids, saliva, or other foreign materials into the lungs

Bolus tube feeding: feeding method in which formula is inserted into the feeding tube with a syringe at regular times

Cap: a cover that is attached to the medicine or formula port of the feeding tube that, when inserted into the port, keeps stomach contents from leaking out. See also: plug

Clamp: a device that is attached to the feeding tube that can be used to pinch the feeding tube to keep stomach contents from leaking out

Constipation: bowel movements that do not happen very often or hard stools that are painful or difficult to pass

Continuous tube feeding: tube feeding where the formula is given via a pump at a constant rate for a specified time period

Decompression: removing air or fluid from the stomach

Dehydration: condition in which the body does not have enough water

Diarrhea: frequent loose, watery bowel movements

Dysphagia: Difficulty swallowing

Electrolyte: a nutrient (such as sodium, potassium, or chloride) that helps regulate cell and organ function

Enteral (enteric): a feeding given into the stomach or intestine by tube

Esophagus: muscular tube leading from the mouth to the stomach

External Bumper: a device that rests against the skin and prevents the feeding tube from slipping into the stomach; See also: plastic disk

Farrell® Bags: bag and tubing system that allows the release of gas from the stomach through a feeding tube

Feeding Bags: bag and tubing system that holds formula to be given through a feeding tube either by gravity or with a pump

Feeding tube: a tube into the stomach or small intestine through which formula is given

Formula: a liquid nutritional product that has the same nutrients as regular food

Foley: a type of feeding tube that goes into the stomach

Gastric: having to do with the stomach

Gastrostomy (G) tube: a feeding tube that goes into the stomach through a stoma, which may be placed surgically or endoscopically

GJ Tube: a type of feeding tube that goes into both the stomach and the small intestine

Gastrostomy site: the opening in the stomach where a feeding tube enters the body (also known as a stoma site).

Granulation tissue: extra tissue that grows around the stoma

Gravity drip feeding: feeding method in which formula enters a feeding tube from a container placed above the patient, providing nutrition without power, but by gravity

Jejunostomy (J) tube: a feeding tube that goes into the small intestine

Jejunum: the middle part of the small intestine located between the duodenum and ileum

Low profile feeding tube: examples of low profile feeding tubes: MIC-KEY Low-Profile Gastrostomy Feeding Tube; Bard Gastrostomy Button; Mini ONE Balloon Button

Nasogastric (NG) tube: a feeding tube that goes from the nose to the stomach

NPO: Nothing by mouth [Latin – non per os]

Nutrients: parts of food that nourish the body (protein, carbohydrate, fat, vitamins, minerals, and water)

PEG (percutaneous endoscopic gastrostomy): one of the methods of placement for a gastrostomy tube

PEJ (percutaneous endoscopic jejunostomy): one of the methods of placement for a jejunostomy tube

Plastic disk: a device that rests against the skin and prevents the feeding tube from slipping into the stomach; See also: external bumper

Plug: a cover that is attached to the medicine or formula port of the feeding tube that, when inserted into the port, keeps stomach contents from leaking out. See also: cap

Pump: a machine used to control the flow of the tube feeding formula

Regurgitation: the backflow of contents from the gastrointestinal tract

Residual: formula from the last feeding that is still in the stomach at the next feeding

Small intestine: the part of the digestive tract between the stomach and large intestine that digests and absorbs nutrients

Stoma: Opening in the abdominal wall through which a gastrostomy tube or jejunostomy tube enters the body (also known as a gastrostomy site)

Stomach: Organ between the esophagus and small intestine that holds food during the early part of digestion

Syringe: A hollow, plastic tube with a plunger used to draw fluid out of or inject fluid into a feeding tube

Units of measure:

- milliliter (ml) = cubic centimeter (cc)
- 1 ml = 1 cc
- 30 ml or cc = 1 ounce (oz.)
- 240 ml or cc = 8 oz. = 1 standard measuring cup
- 15 drops (in the plastic drip chamber connected to the tubing) = 1 ml = 1 cc



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