

A Resource Booklet for Families

Tube Feeding Your Child by:

Gastrostomy Tube

or

Jejunostomy Tube

or

Gastro-Jejunostomy Tube

You Can Do This!

Everything about tube feeding may be new and strange to you.

We will teach you what you need to know.

You will practice your new skills *before* you go home.

Be sure to tell us about any questions or concerns you have.

There are no silly questions!

We want tube feeding at home to be a positive experience for your child and family.



Pediatric Home Nutrition Support Program

The Pediatric Home Nutrition Support Program (PHNSP) at the Stollery Children's Hospital is a program designed to assist children who need tube feeding at home.

We are a team of dietitians, nurses, social workers and feeding therapists (occupational therapists or speech language therapists) working together to help you manage tube feeding at home.



PHNSP provides teaching on tube feeding for home as well as provides supplies and assistance obtaining formula.

At home, you will receive follow up phone calls from a member of our team.

You will also be seen in our clinic for on-going support with your child's feeding and nutritional needs.

This booklet gives you information about gastrostomy tubes, jejunostomy tubes and gastro-jejunostomy tubes and feedings. If your questions are not answered here, please write them down and ask your doctor or Home Nutrition Support Team.

Be sure to write notes about your child's care.

Your Pediatric Home Nutrition Support Team

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About Tube Feeding

Who needs a feeding tube?

A feeding tube may be needed if your child:

- Cannot eat or drink by mouth safely.
- Cannot or will not take in enough calories by mouth.

Tube feedings are important for your child for proper growth, healing and development. You and your child's Home Nutrition Support Team will design a feeding program that is best for your child and for your family. Parents soon become experts at tube feeding.

What are the goals for tube feeding?

- To help families provide a safe way to feed their child at home that will promote health and growth.
- To help manage a disease or health problem.

For some children, the goal is to increase the amount of food the child will eat by mouth and to use the tube less and less.

How will my family react to tube feeding?

Many parents and family members experience a wide range of feelings about not feeding their child in a "normal" way. There may be times when you or your family feel overwhelmed and these feelings are **normal** and will change from day to day and over time.

Your Home Nutrition team is here to support you and your family. The social worker can be available to help you with your feelings, or you can talk to any member of your team. Your team members can also connect you with other families who have a child tube feeding at home.

Safety: Washing Your Hands

Stop the spread of germs with one simple step:

Wash your hands.



Good hand washing will help stop the spread of germs from your hands to your child or to your child's tube supplies or formula.

Follow these steps to wash your hands:

- a. Wet your hands with warm, running water.
- b. Use liquid soap or a clean bar of soap. You don't need antibacterial soap; regular soap is fine. Rub on soap. Lather well.
- c. Rub your hands together briskly for at least 20 seconds. Hint: Sing "Twinkle, Twinkle, Little Star", and 20 seconds will have passed.
- d. Scrub all over, including the backs of your hands, wrists, between your fingers, thumbs and under your fingernails.
- e. Rinse under running water for at least 10 seconds.
- f. Dry with a clean towel.

If you are in a public restroom, use a paper towel to turn off the faucet after you finish and to open the washroom door so you won't have to touch the taps or door handle.

Hand Sanitizer

Hand sanitizer can only be used if hands are not visibly dirty. Let your hands dry completely before touching tube feeding equipment.

Always start clean!

Clean hands, clean supplies and clean working area.

Safety: Positioning Your Child

How should I position my child during and after feeding?

A good feeding position helps will help your child feel more secure with feeding times. This will help them with sucking, swallowing and chewing.

Diagram 1



This is a good feeding position

Babies:

- Make sure you are sitting comfortably, with your arm well-supported by a pillow.
 - Hold your baby firmly on your lap as you would if you were bottle-feeding (refer to Diagram #1). Or, you can place your baby in an infant seat.
 - The baby's head should be higher than the stomach. Support head and neck.
 - Baby's back should be fairly straight with hips and knees slightly bent, with arms and hands in front of their body so that they can sit comfortably on your lap.
- **Do not lay your child down flat for 30 minutes after a tube feed.**
- If sitting, avoid the "C" body position (see Diagram 2) because it decreases the space for formula and digestion in your child's stomach.
- **Continuous Feedings:** Feeds are better tolerated if the child's head and shoulders are elevated. Elevate front legs of crib or bed to 30-45 degrees. Do NOT elevate only the mattress. Brace foot of crib or bed against a wall. Once child can roll over do not elevate crib or bed. Do **not** use extra pillows to raise your child's head.

Diagram 2



This is not a good feeding position

A good rule of thumb: Raise the BED, not the BABY.

Safety: Positioning Your Child (continued)

Toddlers & Older Children:



- As your child gets older, they still need to have good back and foot support.
- Your child should not be able to slip or slide forward in the seat.
- Small children can sit in a booster seat at the table or at a small child-size table and chair.
- Look at your child's position from the side. The body should be shaped like the letter "L" with the lower back fairly straight.
- Avoid the "C" body position because it does not give your child's stomach very much room for formula and digestion.

If your child has poor motor control, check with your Home Nutrition Support Team for advice about safe positioning for feeding.

Avoiding Tangled Tubing

Children with higher risk of getting tangled in tubing:

- 4 to 36 months of age.
- Active or restless.
- Cognitively or developmentally delayed and not able to untangle themselves.
- History of past tangling problems.
- Parents feel their child is at higher risk.
- Receive continuous tube feedings, especially at night when parents are sleeping.

How can I keep my child from getting tangled in the tubing?

- Place the feeding set at the foot of the bed while your child is sleeping.
- Run the tubing down inside the clothing, coming out at the ankle or bottom of the shirt.
- Use a tubing stabilizer. This stiffens the tubing to avoid tangling around the neck or limbs.

The best method depends on your child's condition and the way he or she is being fed.

Ask your Home Nutrition Support Team.

Tubing Stabilizers

What is it?

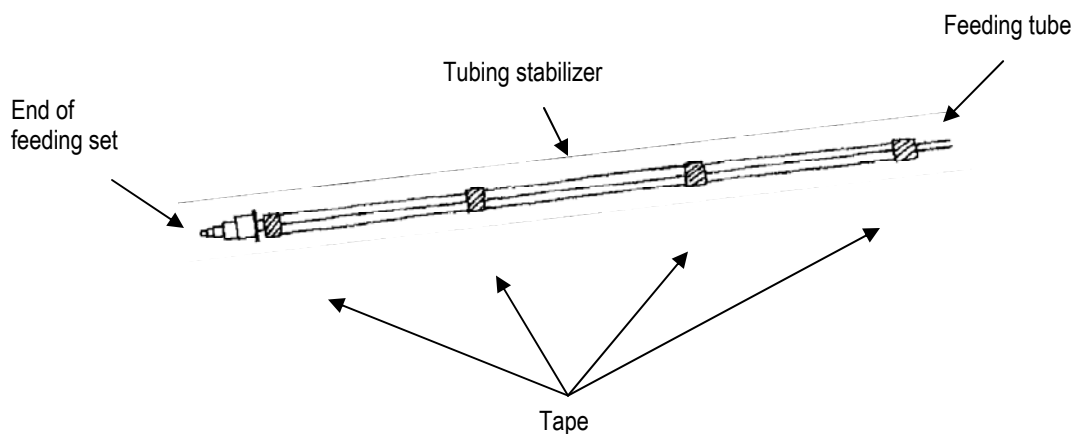
A tubing stabilizer is a stiff, plastic channel that looks like a tube. It can be placed around the tubing of the feeding set to prevent your child from getting tangled in the tube.

Before you use it

Check the tubing stabilizer for any kinking, damage or excessive wear. If there is any sign of damage throw it out and use a new one

How do you place it on the tubing of the feeding set?

- Have your child lie down. Place the pole at the foot of the bed. Ensure that the tubing of the feeding set is straight and lying beside your child.
- Find the end of the feeding set. You will want to place the stabilizer as close to the end of the feeding set as possible (see picture below).
- Starting at the end of the feeding set, begin pressing the tubing into the opening of the stabilizer using your thumb. Continue pressing the tube into the opening along the entire length of the stabilizer.
- Double-wrap adhesive tape around the stabilizer at each end (see #1 on the picture below).
- About 8 inches from each end, double-wrap adhesive tape around the stabilizer to keep the tube from coming out (see #2 on the picture below).



* Actual product name is the "IV/Medical Line Stabilizer" by IVY Devices Inc.

Teaching material adapted from:
<http://www.ivydevices.ca/stabilizer%20instruction.pdf>

Tube Feeding: Four Methods



You and your Home Nutrition Support Team will determine which type of feeding will be best for your child. There are four ways to give tube feedings. Your Home Nutrition Support team will discuss each of these methods with you.

1. "Top-up" feedings

"Top-up" tube feedings are small volumes often given after feeding your child by mouth. These feedings may be given by gravity or syringe.

2. Bolus feedings

Your child may need an entire meal to be given by G-tube. This is called a "bolus" feeding.

Bolus feedings are often given by gravity but may be given by syringe or pump as well. The time it takes to give a bolus feed is specific to your child.

3. Continuous feeding

This is when small amounts of formula are needed to be given slowly over several hours or overnight using a feeding pump.

4. Combination feeding

Your child may need a combination of feeding methods. For example, he or she may need "top-up" or "bolus" feedings at mealtimes and a continuous feeding during the night.

Every child changes as he or she grows. Your child may progress from small, frequent feedings to meal size feedings. As your child eats and drinks more by mouth, the amount of their tube feed will decrease.

The method used to tube feed your child may change over time.

Feeding Routine

1. Prepare:

- Wash hands (see page 4).
- Gather supplies:
- Formula (check expiry date).
- Pump (if needed).
- Feeding bag.
- Syringes (one empty for aspiration and one syringe with water for flushing).

2. Check to be sure:

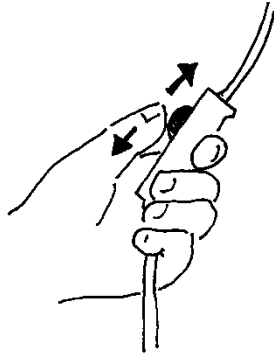
- Tube is the **feeding tube** and not another medical tube.
- Tube is in the right place (**see separate handout on your child's tube**).
- Tube is not plugged. Do this by flushing tube with at least 5-10 mLs of water.
- Tubing and supplies are clean and have no leaks, cracks or bad smell.
- Check to be sure that formula is at room temperature and shake well.

3. Feeding:

a. Bolus or “top up” feeding:

- Position your child for feeding (see pages 5-6).
- If your child is allowed to eat or drink orally, offer oral foods before tube feeds.
- Pour the feed into the container. Run the liquid to the end of the tubing to reduce the amount of air given to your child. Connect the tubing.
- Give the feed slowly using a gravity bag set. Adjust the speed of the feed by moving the roller clamp up or down and/or by adjusting the height of the feeding bag above your child's head. The higher the feeding bag, the faster the feed will go. A feed should last 15 to 30 minutes.
- For small feedings, a 60mL syringe can be used to feed by gravity or by slowly pushing the syringe plunger.
- Burp your child if needed. If your child cannot burp, vent the tube.
- If using a pump, see continuous feeding schedule below.

Feeding Routine (continued)



Roller clamp

Important Note:

- Use sterile water for water flushes if your baby is less than 4 months old.
- If the tube is not being used for feeding, flush with at least 5-10 mLs of water once a day.

b. Continuous Feeding or Night Feeding

- Position your child for feeding (see pages 5-6).
- Pour the formula into the bag and run it to the end of the tubing. This reduces the amount of air given to your child.
- Set the pump at the desired dose and rate.
- Run tubing through pajama pant leg and position pump at end of bed for night feeds.
- Attach tubing stabilizer and start feed.
- Flush G-tube with 5-10mls of water every 4 hours to prevent clogging.
- Formulas can be unrefrigerated for different amounts of time. Check with your dietitian for directions.

4. End of Feed:

- Flush the tube with 5-10mLs of water or as directed by your feeding plan
- Clamp or plug the end of your child's tube between feeds.
- Allow 20-30 min quiet time after a feed is completed. Have your child lay on their right side or back with head and shoulders elevated. If reflux is a concern, ask your child's health care provider for further advice.
- Clean your feeding equipment (see page 13).

Keeping Your Formula Safe at Room Temperature

When your child is tube fed, special care is needed to ensure your breast milk or formula stays safe when hanging at room temperatures. Formula or breast milk left at room temperature can grow harmful bacteria. Powdered formula is **not sterile** and should not be used in some circumstances. Speak to your dietitian about which formula is best for your child.

If you use breast milk alone, it can hang for up to 4 hours at room temperature.

If you add any powder (such as powdered infant formula) to the breast milk it is safe to hang at room temperature for 2 hours. (See tip below)

If you use a powdered formula, the formula can hang for up to 4 hours. If on a continuous feed put only 4 hours of feed into the feeding bag at a time.

Ready-to-use formula can hang at room temperature for up to 8 hours.

Tip: Use a freezer pack beside the feeding bag or in a back pack to help keep the formula cooler and safer

What kind of water should I use for tube feeding my child?

- **Treated tap water, and commercially bottled water** such as natural spring water with low mineral content are safe to use. **Well water** can be used if it has been tested for safety. (see Appendix 1, page 21 for more information)
- **Other bottled water** such as mineral water, vitamin water, flavored water, water with high mineral content, and softened water **should not be used**. Water from carbon filtered taps or pitchers and fridge filters should be used cautiously as bacteria can buildup in the filters if not changed regularly or as recommended by the manufacturer.
- Use of **sterile water** for flushing the g- tube, medication flushes and formula preparation is recommended for a baby **less than 4 months old**.

Important Notes:

- If you use water from a well, sterilizing it may not be enough. Ask your community health centre about having your water tested for safety.
- Distilled or bottled water is not sterilized water.

Giving Medicine by Feeding Tube

How do I give my child medicine by tube?

- Prepare the medicine as directed by your pharmacist making sure each medicine has its own syringe.
- Attach the feeding extension tubing if child not feeding or stop the tube feeding.
- Flush the tube with 5-10mL of water before giving the medication.
- Push the medication slowly into the tube.
- Flush the tube with 1mL between each medicine and flush with 5-10mLs after the last medicine. Flushing the tube with water pushes the medicine into the stomach and clears the tube.
- If resistance is felt stop immediately and flush the tube with more water before continuing (thick syrups or powder medication may need to be mixed with more water to prevent clogging of the tube).
- Restart the tube feeding or remove the feeding extension or close the cap of the g tube.
- Wash and air dry the syringe and other supplies so they are ready to use again.

Important notes:

- **Do not** mix medicine with breast milk or formula because it may react or become lumpy and block the tube.
- **Do not** put medicine directly into the feeding bag. Give medicine using the feeding extension tubing.
- For children who tend to spit up, try giving medicine at the beginning of the feed.
- Do not mix different medicines in same syringe.
- Your pharmacist can help you decide the best times to give medications.

Caring for Your Child's Feeding Equipment

Clean feeding set and syringes after each use. This will help keep your child healthy.

The Pediatric Home Nutrition Support Team will give you instructions about how to care for your child's feeding equipment.



After each feed:

- a. Throw out any remaining formula in the bag.
- b. Wash bags with a 5% vinegar and water solution once in 24 hours. Rinse with warm water between feeds. To make the solution, add 1 tablespoon (15 ml) vinegar to 1 cup (250 ml) of warm tap water. Run the 5% solution through the bag and line and then empty the water out of the line by running air through the line.
- c. Place the feeding bag in a container with lid or zippered plastic bag and store in the refrigerator until your next tube feed.
- d. **Feeding sets that are used for continuous feedings should be washed at least once in 24 hours**
- e. Wash your syringes by pulling them apart. Wash both sections in warm, soapy water and rinse thoroughly. Place them on a clean tea towel to air dry. Do not refrigerate your syringes or clean them in a dishwasher or boil them. Discard the syringe when the plunger becomes hard to move or unable to read numbers clearly.
- f. If your child uses a pump, wipe daily with damp cloth. Once a week or if there is formula spilled inside the pump, run water over the inside of pump and wipe dry. Running water is the only way to clean under the wheel of the pump.

Cleaning Your Child's Mouth

It is very important to clean your child's mouth **at least twice a day**, even if not eating food.

- Make sure your child is in a comfortable, secure position (on your lap or in an infant seat).
- Rub the inside of your baby's gums and tongue with an infant finger toothbrush. Wipe with a moist, soft cloth until the inside of the mouth is clean.
- Toddlers and older children should brush their teeth and tongue with a soft toothbrush and toothpaste. Toothpaste should be spit out or drained from the mouth.
- If your child is over 1 year old and their lips are dry or cracking, put a lip moisturizer on the lips to keep them moist.

Ask your feeding therapist for more detailed information as you need it.

Connecting with Your Child

Mealtimes for a child who gets tube feedings

- Do the same things with your baby during a tube feeding that you would do during an oral feed.
- Gently cuddle or rock your baby in a rocking chair.
- If your baby takes a soother, give it during tube feedings
- For **toddlers or older children**, running a tube feeding during a family meal helps the child be part of the family and learn about eating food.

Preparing Your Child to Eat by Mouth

How do I know if my child is ready to eat by mouth?

It is very important for children to be safe when they start oral feeding. Your child's feeding therapist will work with you to decide if your child is ready.

There are a few things to think about when deciding whether your child is ready:

1. **Is your child's medical condition stable?**
2. **Can your child eat and/or drink safely in a reasonable amount of time?**

Feeding by mouth may not be safe if your child:

- Cannot handle saliva or secretions in the mouth
 - Has breathing difficulties (sounds wet or noisy)
 - Must swallow more than once to clear food from the throat
 - Has many respiratory illnesses or chest infections
 - Coughs or chokes while eating or drinking
 - Stops breathing or turns blue while eating
3. **Nutrition**
 - Can your child tolerate bolus feeds?
 - Is your child at a healthy enough weight to tolerate a possible small weight loss while transitioning?
 4. **Readiness Cues**
 - Is your child comfortable around food?
 - Is your child showing signs of hunger?
 - Is your child showing interest in food?

How can I prepare my child to eat by mouth?

Many children who have not been eating need to start with pleasurable experiences in and around their mouth. These experiences are often called “oral stimulation”. You and your therapist can decide which experiences would be best for your child. These experiences may involve the touch of a familiar person or mouthing toys. They may include smelling and tasting food, if your child allows it and it is safe for your child.

Oral stimulation may help your child:

- learn to be more at ease with mouth care
- learn to enjoy touch around the mouth and face
- reduce gagging if this is a problem
- prepare for eating by mouth, **or**
- improve the way your child is eating by mouth

Babies

- Help your baby to suck on their hand, your finger or a soother while being tube fed. This teaches them that sucking and the feeling of a full tummy go together.
- Follow your child’s cues of readiness to eat. Make meals times enjoyable.
- Encourage your child to explore safe baby toys with his or her hands and mouth. This gives your baby practice sucking, biting and moving the tongue and jaw. Mouthing toys lowers sensitivity in your baby’s mouth.

Older Children

- Try playing face games such as patting, kissing and blowing. Take turns so your child can touch your face as well.
- Regular tooth brushing is very important.
- Some children’s faces are more sensitive and need time to accept being touched. Wipe the face with a firm dabbing motion rather than wiping. Don’t forget to watch your child’s response.
- Get your child to play with bowls, spoons and cups. Have them pretend to feed a puppet, a doll or you.
- Allow your child to explore play items with lots of texture. Some examples include:
 - a large container of water with cups and bowls
 - a bucket of sand
 - a bowl of uncooked lentils or rice with toys hidden in it
 - pudding with crumbs or pieces of cookie in it

Remember:

Learning to eat is a gradual process. Once your child is safe to begin eating by mouth, offer your child tastes when he or she is hungry or at family meal times. Begin feeding by mouth and follow with tube feeds. In this way your child receives good nutrition while developing their feeding skills.

It is important to move ahead with oral feeding at your child's own pace. Forcing your child to eat orally can be a negative experience for him or her. If you find yourself pushing your child to eat orally, talk to your feeding therapist for assistance.

Tube Replacement

Your PHNSP nurse will provide you with an information pamphlet for your child's specific feeding tube.

When does my child's tube need to be changed?

Over time, all tubes need to be changed.

Your child's tube may need to be replaced when:

- The tube parts break or leak (balloon or valve).
- Your child grows or has a big change in weight.
- The tube blocks and cannot be cleared.
- Another type of tube is better for your child.

G-tube changes:

Your child's **first** G-tube change will be done by the doctor who originally put the tube in. You will then be trained on how to do all future G-tube changes by a Pediatric Home Nutrition Support nurse.

J-tube and GJ-tube changes:

Tube changes will be done **only** by the doctor.

Your Pediatric Home Nutrition Support nurse will discuss with you routine tube changes.

What do I do if the tube comes out?

G-tube/J-tube/GJ-tube:

If the tube is pulled out, the stoma will start to close. **Some stomas may close in a few hours.** See your child's specific feeding tube pamphlet for instructions.

Your health care provider will give you a **Corflo Emergency Kit with instructions**. You must take this with you to your local emergency room along with the **discharge information sheet** and give it to a doctor or nurse.

Site Care

How do I take care of the stoma?

Daily care

- Keep the tube site clean and dry.
- Gently wash the tube site with a mild solution of soap and warm water. Rinse thoroughly and pat the skin dry. You may do this during your child's tub bath.
- When cleaning **G-tubes**, gently turn the G-tube device 360 degree + a quarter clockwise and counter clockwise. G-tubes should turn easily and not feel stuck.
- When cleaning **J-tubes** or **GJ-tubes** do **NOT** turn the tube.
- If your child is unable to take a tub bath or if more cleaning is needed, try the following:
 - Use a damp, soft cotton face cloth or cotton-tipped swab to gently remove any leakage, crusts, oils or formula from around the stoma and tube.
 - Also clean the tube opening, plug and any connections.
 - Wipe down the outside of the tube.
 - Pat the skin and tube dry with a soft, clean towel.
- Allow air to get at the stoma and skin around it. Do not cover skin with bandages. When possible, expose the tube site to the air when your child is napping, busy at play or being held.

Check the tube site when:

- You wash it each day.
- The tube and/or tape is pulled on hard or often.
- Your child rubs, pulls at or protects the tube site more than usual.
- Your child complains of pain, aching or itching at the tube site.

Remember:

If still unsure of placement, see your child's specific feeding tube pamphlet for instructions on how to check tube placement. If unsure of placement, call your home care provider or proceed to your local health care facility.

Cleaning too often? Scrubbing or cleaning the skin too often can dry and injure the skin. If skin irritation lasts for several days, ask your doctor or health care provider for help. Check with your PHNSP nurse before the use of lotions or ointments.

If your child's tube site has any of the following, contact your physician:

- Bad smelling drainage
- Pain
- Increased redness around the tube
- Swelling or cracked skin
- Itchy, pin point rash

The stoma may be infected.

See Appendix 3 for more information pages 27-32

Frequently asked Questions

What can I put around the tube site?

Skin around the stoma will stay healthy if it is kept clean, dry and with nothing covering the skin. If there is drainage or granulation tissue at the stoma, contact your PHNSP nurse.

Can I bath my child with the tube in place?

Yes! If the tube site is healing and there are no signs of infection you may bath your child 10 days after the surgery. Be sure to dry the skin around the tube after the bath.

Can my child go swimming?

Yes! If the tube site is healing and there are no signs of infection your child can go swimming 10 days after the surgery. Be sure the tube is clamped off tightly.

Does my child need special clothes?

No! Some parents prefer one-piece outfits or overalls with front button or snap closures for easy access to the tube.

For all ages, avoid clothing with a tight waistband that could pull or push on the tube. Children are curious. Their fingers could pull the tube out. Help to prevent this by doing the following:

- Tuck the tube into their clothing.
- Secure tube in place on abdomen then secure through diaper tab.
- Put mittens or socks on infant's hands for short lengths of time.

Can I put my child on her/his tummy?

Yes! A tube does not change your baby's basic growth and development needs. It is important for babies to have "tummy time" when they are awake. Tummy time helps them learn to raise their heads, and push up onto their hands and knees to crawl. If your child does not seem to like the tummy position, start with a short playtime on the tummy and slowly lengthen the time. When your child is crawling, do not let the tube dangle. Make sure the tube is secured under your child's clothing.

Babies should sleep on their backs. Follow the standard "back to sleep" recommendations for infants.

Appendix 1

Use of well water for enteral feeding

If you are using well water at home, please be aware of the following:

- **Well water** can be used to inflate the balloon of G- tubes as well as flush the G-tube **only after the water has been tested and found to be safe for human consumption.**
- A standard bacterial test should be done twice a year (spring and fall). If your well is less than 50 feet deep, it is suggested you have your well water tested four times per year. A water chemistry test should be done every two to five years.
- **Drinking water should be tested any time there is a change in the color, odor or taste.** Water should also be tested after long dry spells, heavy rains, if the well has not been used for more than one year, before a new baby arrives, when moving into a new home or if the water has not been tested in a year or more.
- Water testing kits are available from your Community Health Center or Health Unit or by calling (780) 407-8971 (Provincial Lab in Edmonton). Follow the instructions in the kit to collect water samples.
- Once the water has been tested and found to be safe for human consumption, you can “sterilize” that water by bringing the water to a rolling boil for 2 minutes. That “sterilized” water can be stored in the refrigerator for up to 72 hours (3 days) or at room temperature for 24 hours (1 day). For children less than 4 months of age use sterilized water.
- **Bottled water** maybe used for flushing G-tubes and inflating the balloon of G-tubes.

More information is available at:

“Working Well-Alberta Environment” (type this term in google search line)

www.albertahealthservices.ca (type well water testing in search bar)

Appendix 2

Preparing Breast Milk or Formula

What kind of water should I use for tube feeding my child?

- **Treated tap water, and commercially bottled** water such as natural spring water with low mineral content are safe to use. **Well water** can be used if it has been tested for safety. (see Appendix 1, page 21 for more information)
- **Other bottled water** such as mineral water, vitamin water, flavored water, water with high mineral content, and softened water **should not be used**. Water from carbon filtered taps or pitchers and fridge filters should be used cautiously as bacteria can buildup in the filters if not changed regularly or as recommended by the manufacturer.
- Use **sterile water** for flushing the NG tube, medication flushes and formula preparation is recommended for a baby **less than 4 months old**.

Important Notes:

- If you use water from a well, sterilizing it may not be enough. Ask your community health centre about having your water tested for safety.
- **Distilled or bottled water is not sterilized water.**

Babies under 4 months of age:

Use only boiled water:

- Run cold water tap until you feel the water getting colder. Then you know you are getting fresh water.
- Water should be brought to a rolling boil for at least two minutes.
- Cool to room temperature prior to mixing formula.

Storage of boiled water:

- Store boiled water in a covered container that has been cleaned well.
- Boiled water can be stored for up to 72 hours (3 days) in the fridge or at room temperature for 24 hours (1 day).
- This water can be used for flushing the tube or for preparing formula.

Sterilizing equipment:

- All mixing and storage equipment needs to be covered by cold water.
- Cover the pot with a lid and bring to a boil. Boil for two minutes.
- Let cool and remove the equipment and store in a clean place.

Preparing Breast Milk

Breast milk

- You can express breast milk for use in your child's tube feed.
- Wash your hands with soap and water before expressing (see page 4).
- For babies less than 4 months, sterilize expressing and storage equipment as above. Use a sterilized container, or storage and freezer bags specially designed for breast milk.
- Label bag or container with the date. Always use the oldest milk first.
- Chill expressed breast milk for one hour in a fridge or ice packed cooler before freezing.

Storage of freshly expressed breast milk:

| Room Temp | Refrigerator | Freezer (1-door fridge) | Separate Freezer | Deep Freeze |
|---------------|--------------|-------------------------|------------------|-----------------|
| up to 4 hours | up to 2 days | up to 2 weeks | 3 to 4 months | up to 12 months |

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- Thaw frozen breast milk in a bowl of warm water, or in the fridge. If milk has separated shake the container gently to mix.
- Refrigerate thawed breast milk and use within 24 hours

Important Notes:

- **For breast milk alone or breast milk mixed with non-powdered formula put only enough for 4 hours in the feeding bag at one time.**
- If powdered formula is added to breast milk, feed child immediately or within 2 hours.
- If you express breast milk away from home, it can be stored for up to 24 hours in a cooler with an ice pack.
- If on a continuous feeding, freshly expressed breast milk can hang up to 8 hours.

Tip for warm weather:

- On hot days you can help keep formula cool by putting a freezer pack beside the formula bag or in the backpack.

Preparing Formula

Formula:

- Wash hands with soap and water before mixing the formula.
- Clean all equipment that will be used for measuring and mixing. If baby is less than 4 months old (see page 13).
- Check the “best before” date on the bottom of the formula can.

| Three types of infant formula | How to prepare | How to store after opening | How long can you store open container | How long can you store prepared formula |
|-----------------------------------|--|-------------------------------|---------------------------------------|--|
| Powder (Is not sterile) | Follow directions on can for amount of sterilized water and number of scoops of powder | Covered in a cool, dark place | Less than 30 days | Follow the storage Instructions on the formula can |
| Concentrated Liquid | Mix with equal parts sterilized water | Covered in refrigerator | Less than 24 hours | Follow the storage Instructions on the formula can |
| Ready-to-use | No mixing required | Covered in refrigerator | Less than 24 hours | Follow the storage Instructions on the formula can |

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- **Put only enough formula for 4 hours in the feeding bag at one time.**
- Throw out any formula left in the feeding bag as soon as the feed is finished.

Storing prepared formula:

- **DO NOT leave prepared formula at room temperature.**
- Cover container and store in the fridge. Write date and time on the container.
- Throw out unused prepared formula after 24 hours.
- Store any unmixed liquid concentrate covered in the refrigerator for up to 24 hours. After 24 hours, throw it out.

Important notes:

- If a formula recipe is needed, keep a copy of the current recipe and feeding schedule on the refrigerator.
- Never add extra formula, water or cereal to prepared formula unless instructed to do so by your dietitian.

Preparing Formula (continued)

Formula from powder

Sterile liquid infant formula (ready to feed or concentrate) is a better choice for infants who are premature, have a low birth weight or weakened immune system. **Powdered formula is not sterile.** Some formulas are available only in powdered forms. Caregivers need to make sure that formula is prepared properly. Follow directions from your PHNSP team.

Tip:

- Add powdered formula to warm water just before giving a feed.
- Never keep milk warm in thermos or bottle heater.

If warming breast milk or prepared formula:

- Warmed formula is usually only needed for bolus or top-up feeds.
- Warm cold formula or breast milk to room temperature by putting the container in a bowl of warm water for no more than 15 minutes.
- **Shake the container well and then check the temperature of the formula on your wrist.**
- **Do not heat expressed breast milk or prepared formula in a microwave.** Microwaves heat unevenly and there can be “hot spots” that could burn your baby’s mouth.

Contacting the PHNSP Team

Stollery Children's Health Centre Main Switchboard: 780-407-8822

Alberta Health Services Website: www.albertahealthservices.ca

Northern Alberta Pediatric Home Nutrition Support Reception/Bookings:
780-407-1341. TOLL FREE Phone #: 1-855-497-1341

Other: _____

If you have concerns about your child's tube feeding:
During program hours (Monday to Friday, 8:00a.m. to 4:00p.m.) call one of your PHNSP team members.

After hours contact your Home Care Nurse or HEALTHLink Alberta:

- 780-408-LINK (5465) (in Edmonton)
- 1-866-408-LINK (5465) (toll free outside Edmonton)

For concerns that need immediate attention, talk with your doctor. After office hours, go to the nearest emergency room.

G-tube or GJ Tube Feeding Supplies

The Northern Alberta Pediatric Home Nutrition Support Program will provide you with the feeding supplies you need, such as tubes, feeding bag systems, syringes and feeding pump if necessary.

To order supplies call 780-407-7806 (toll-free 1-855-497-1341) or submit order by email to PedsHomeNutrition@albertahealthservices.ca.

Clearly indicate your child's full name and a phone number where you can be reached. Please order only what you need.

Please allow **10 working days** for delivery of supply refills. Supplies will be delivered by courier, Greyhound or Canada Post depending on your home location.

If you are travelling with your child:

- ensure you have a spare g-tube, supplies and formula as they can be difficult to find in case your travel gets unexpectedly extended.
- If you are travelling by air, ensure you have a **medical letter** to transport your formula and supplies. Also contact your airline for further instructions specific to that airline.

Solving G-tube Feeding Problems

Aspiration

What could this mean?

Aspiration occurs when liquid or food enters the lungs. This can occur if the tube is in the wrong place or if your child gags, refluxes or vomits.

Aspiration can be very serious and potentially life threatening, and can over time lead to lung problems.

What to do:

If your child chokes or coughs during feedings, stop the tube feeding.

- Watch your child closely. Is he or she breathing harder?

If your child has trouble breathing or turns blue, STOP the feeding and call 911 (or the emergency number where you live).

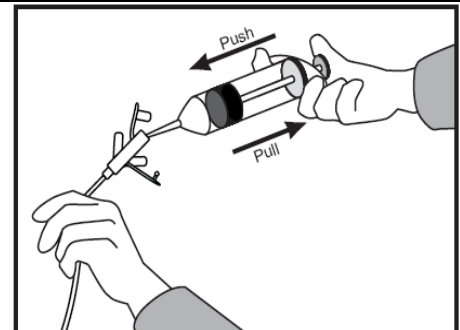
If your child settles and is breathing normally:

- ✓ Recheck tube placement.
- ✓ Try to burp your child.
- ✓ Make sure your child's head and shoulders are raised during feeding.
- ✓ Restart the tube feeding at a slower rate and watch your child closely.

Tube blockage

What to do for G-tube, J-tube, and GJ-tubes:

1. Check that the feeding tube is not clamped or bent over.
2. Get a large syringe (60 mL). Fill the syringe with 25 mL of warm water. Attach syringe to feeding tube. Gently push and pull on the syringe's plunger. **Do not force water into the tube.** When the tube is unblocked, flush tube with water.
3. If tube is still blocked, gently massage the tube using your fingers. This might help to break up the plug. Try to flush tube again using the large syringe. **Do not force water into the tube.**
4. If your **G-tube, GJ-tube or J-tube** will not unblock, **go to your local health facility.** The tube may need to be removed and a new one put in.



Be Careful:

- Never probe the inside of a tube to try to clear a blockage. This will cause damage to the tube and it could hurt your child.

| Nausea | |
|---|--|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes: |
| <p>Nausea can be caused by:</p> <ul style="list-style-type: none"> • Too much air in the stomach. • Feeding that is given too quickly. • Changes in medications. <p>Avoid letting air enter the stomach during the feeding. This can be prevented by running the feed to the end of the tubing before attaching the G-tube.</p> | <ul style="list-style-type: none"> • Give feeding more slowly. • Keep head and shoulders raised at a 30-45 degree angle during and after feeding for 30 minutes. • For G-tubes and GJ-tubes, vent/burp your child before, during and after the feeding. |

| Retching, Gagging and/or Vomiting | |
|--|---|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes: |
| <p>Retching, gagging and/or vomiting may be caused by:</p> <ul style="list-style-type: none"> • The first movement of formula or breast milk through the tube. • The stomach is too full. • The feeding is given too quickly. • During certain times of the day your child may be more likely to gag or vomit. Your child may gag or vomit with the first feed of the day because of mucous swallowed during the night. • Air in the stomach. • Your child's tube has moved and is in the wrong place. | <ul style="list-style-type: none"> ✓ For J-tubes and GJ-tubes, if your child is vomiting formula or formula is draining out of the gastric port, stop feeding and go to your local health care facility as the tube is in the wrong place. ✓ For G-tubes and GJ-tubes, vent/burp your child before, during and after the feeding. <p>For G-tubes:</p> <ul style="list-style-type: none"> ✓ Start feeding very slowly. After a few minutes, increase speed of feeding to desired rate. ✓ Allow a quiet time after feeds. ✓ When flushing the tube, do so slowly. ✓ If your child vomits, stop the feeding. If your child is lying down, turn head to the side or have child sit up. <p>Discuss changing the feeding schedule with the dietitian. For G-tubes, the dietitian may suggest:</p> <ul style="list-style-type: none"> • Giving smaller, more frequent feedings. • If your child gags and vomits at a certain time, make that feeding smaller. Divide the missed amount of formula and add to the next 2-3 feeds. |

| Unable to Burp | |
|---|---|
| What could this mean? | What to do for G-tube and GJ tubes: |
| Some children have trouble burping or are unable to burp because they have had a surgical procedure to prevent acid reflux from the stomach to the esophagus. | Try “venting” the tube: <ul style="list-style-type: none"> ✓ Open the end of the gastric port and attach to an empty 60 mL syringe barrel. Venting should only take a few minutes. ✓ Position your child on one side and then the other to help with venting. ✓ Return any liquid that drains from the feeding tube back to the stomach. ✓ Flush the tube with water. |

| Cramping (tummy ache) | |
|---|--|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes: |
| Cramping can be caused by: <ul style="list-style-type: none"> • Formula or breast milk that is too cold. • Too much air in the stomach. • A feeding that is given too quickly. • A side effect of medication. | <ul style="list-style-type: none"> ✓ Warm formula to room temperature. ✓ Check tube placement (see the separate handout on your child’s tube). ✓ For G-tube and GJ-tubes: vent tube or burp your child before, during and after the feeding. ✓ Give feeding more slowly. |

| Diarrhea | |
|---|--|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes: |
| Diarrhea is frequent, loose, liquid bowel movements and may be caused by: <ul style="list-style-type: none"> • Giving a feed too quickly. • Spoiled formula or dirty equipment. • A side effect of medication. • Your child’s tube has moved and is in the wrong place. | <ul style="list-style-type: none"> ✓ Check tube placement (see the separate handout on your child’s tube). ✓ It is ok to keep on your usual feeding schedule. ✓ Give feedings more slowly. ✓ Make and store formula as directed. ✓ Keep feeding supplies very clean. ✓ For J-tubes and GJ-tubes, if the diarrhea continues to get worse call your doctor or go to the nearest emergency room. The tube may be in the wrong place. ✓ If your child is younger than 6 months and has diarrhea, call your doctor. ✓ If your child has diarrhea and signs of illness (e.g. fever, crankiness, increased sleepiness or throwing up), call your doctor. ✓ Do not stop feeds unless directed to do so. |

| Constipation | |
|--|---|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes: |
| <p>Constipation is when stool is hard or painful to pass. Constipation may be caused by:</p> <ul style="list-style-type: none"> • Low fluid intake. • Low fibre intake. • Low activity level. • A side effect of medicine. • Slow movement of the intestines. | <ul style="list-style-type: none"> ✓ Increase fluid intake. ✓ Increase fibre intake. ✓ Increase activity level. <p>Ask your health care provider before changing the amount of fluid, fibre or activity as the amounts required will vary with each child.</p> |

| Redness around the tube site | |
|--|--|
| What could this mean? | What to do: |
| <p>Some redness and drainage is normal. If the redness continues, it may be due to:</p> <ul style="list-style-type: none"> • Wet and unclean skin at tube site. • A lot of tube movement. • Infection: <ul style="list-style-type: none"> ✓ Foul smelling discharge or pus. ✓ Pain at the tube site. ✓ Increasing redness/swelling. ✓ Itchy pin point rash may be a yeast infection. | <p>Wet and unclean skin :</p> <ul style="list-style-type: none"> ✓ If the skin is wet from stomach fluids clean the skin, use barrier wipe and foam dressing. ✓ Expose the skin to the air more often to keep it dry. ✓ If the red area becomes bigger or tender, call your PHNSP nurse, Home Care nurse or local health care provider. <p>A lot of tube movement:</p> <ul style="list-style-type: none"> ✓ See tube specific pamphlet on how to tape/secure your child's tube. ✓ Check that the tube is properly placed (see handout on your child's tube). ✓ If your tube has a balloon, make sure it has the proper amount of water in (this is explained in the handout on your child's tube). ✓ Ask your PHNSP nurse if your child has the proper tube size (especially if your child has gained or lost weight). <p>Infection:</p> <ul style="list-style-type: none"> ✓ If the site has signs of infection, call your doctor. ✓ Take your child's temperature. ✓ Antifungal ointment or antibiotics may be necessary (to be prescribed by your doctor). |

| Skin tissue build-up around the tube site | |
|--|--|
| What could this mean? | What to do: for G-tube, J-tube, and GJ-tubes |
| A small amount of tissue buildup (“proud flesh” or “granulation tissue”) is common. This is the body’s way of healing an opening and it is one of the most commonly reported problems related to G-tube stoma. Granulation tissue will be pink-red in color, can be tender, bleeds easily and has a clear, pink or yellow sticky drainage. | <ul style="list-style-type: none"> ✓ Keep up your efforts to clean the site well and keep it dry. ✓ Secure tube to prevent pulling or movement. ✓ Talk with your PHNSP nurse about using different treatment products. It is not an emergency to treat the tissue but granulation tissue can affect the fit of the tube within the stoma. Treatment with silver nitrate done by PHNSP or Home Care nurse may be required. Following treatment, the granulation tissue turns gray or white and falls off. This treatment can be repeated as required until the tissue is resolved. |

| Formula leakage from the tube site | |
|---|---|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes |
| <p>A small amount of leakage can be common. Some reasons for leakage are:</p> <ul style="list-style-type: none"> • Illness • Constipation • Coughing • Decreased tube balloon volume (if your type of tube has a balloon) • Poor fit of G-tube • GJ-tube is in the wrong place <p>Frequent leakage may cause skin breakdown around the tube site.</p> | <p>For J-tubes and GJ-tubes:</p> <ul style="list-style-type: none"> ✓ Stop the feed and check if tube is properly placed. Go to the nearest health care facility if placement is unknown. <p>For G-tube:</p> <ul style="list-style-type: none"> ✓ Keep the skin clean and dry. ✓ Check that the tube is properly placed. ✓ Make sure the balloon has the right amount of water. ✓ Avoid gauze dressings that keep moisture touching the skin. ✓ Use foam dressings to pull moisture off the skin. ✓ Small, more frequent feedings may help. ✓ Keep your child quiet and limit activity for the first 30 minutes after feeding. ✓ Set up a regular bowel routine. ✓ Call your PHNSP nurse or Home Care nurse if leakage continues. |

| Bleeding around tube site | |
|---|--|
| What could this mean? | What to do for G-tube, J-tube, and GJ-tubes |
| <p>You may see some bleeding:</p> <ul style="list-style-type: none"> • During or right after a tube change. • With too much movement of the tube in the stoma (for example during activity, lots of hard coughing or if the tube is too loose). • If your child's tube gets pulled on. | <ul style="list-style-type: none"> ✓ Check the bumper and tube placement. Be sure the tube is secure. ✓ There should only be a small amount of blood. If you are worried call your doctor, PHNSP nurse, Home Care nurse or Health Link at 1-866-408-5465. |