

Gastrostomy Tube Feeding Your Child: A Resource Booklet for Families

Dear Parents,

A group of dietitians, doctors, nurses, health caregivers and parents of children with gastrostomy tubes (G-tubes) wrote this booklet for you.

We hope that it helps you to:

- learn more about G-tube feeding.
- decide if G-tube feeding is the best choice for your family.
- give safe and correct care to your child with a G-tube.

As you read this booklet, write your questions in it and then ask your doctor or health caregiver to answer them.

Please note that some information may need to be changed to fit your child's own care. Be sure to write notes about your child's care in this booklet. These notes will remind you how to give this care at home.

We want you to feel at ease about G-tube feedings. The health caregivers involved with your child are happy to answer your questions.

- Your health caregivers





CAN I DO THIS?

This is a question you may ask yourself many times before you take your child home on G-tube feedings. Everything about this is new and most likely quite strange to you, and there is much to learn. With time, you will become the expert in tube feeding your child.

Please be assured that we will teach you what you need to know. Be sure to discuss your concerns and questions with your child's health caregivers. We recognize you will have many questions and encourage you to ask them all.

Before you take your child home you should be at ease with G-tube care. At home, it will take time to adjust to the tube feeding routines. When tube feeding becomes "second nature" for you and your family, your home life will slowly get back to "normal".

You can help yourself and your family to think in a positive way about tube feeding. Some families have found it helpful to focus on one day at a time, or to use humour. Some seek support from the rest of the family or from talking to other families who tube feed at home. Others cope by making sure that family members get some time for themselves. As time goes on, you will feel more at ease with tube feeding. Keep in mind that every family has its own pace. If, at any time, you and your family are finding it hard to cope, please contact your child's health caregivers. You are not alone. We can help you.

We have placed some contact numbers in the back of this booklet (page 35). Also, try our ideas for making the most of your clinic appointment (page 36). Please ask for help.

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

Feeling Overwhelmed?

Don't worry...

We will teach you what you need to know. You will also be able to practice your new skills *before* you go home.

This booklet is full of "need to know" information and "nice to know" helpful tips. Keep it handy to look at it again and again. Bring it with you to your child's clinic visits and feel free to write all over it.

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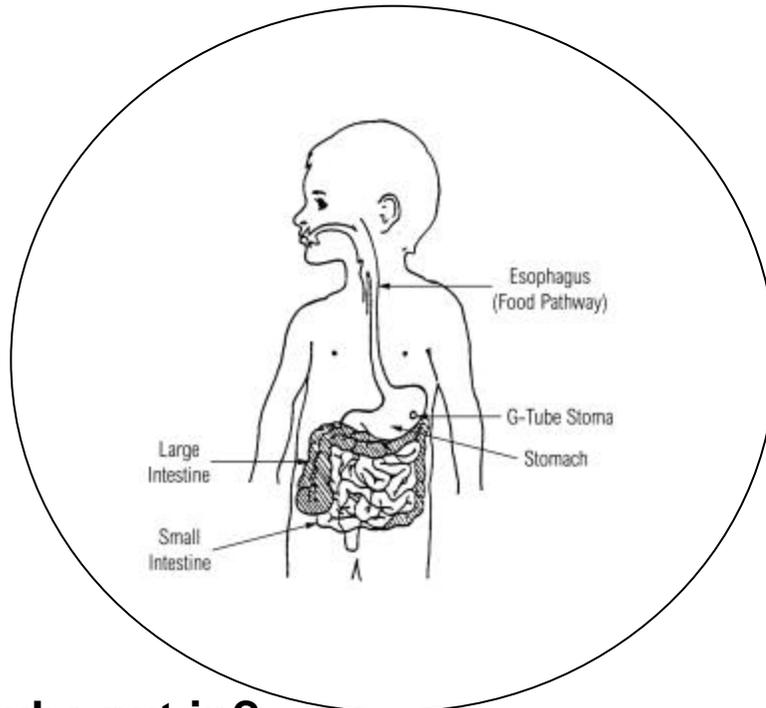
The G-tube will become your friend.

Over time, tube feeding at home can be a positive experience for you and your child.

Gastrostomy Tubes

What is a gastrostomy tube (G-tube)?

A gastrostomy tube (G-tube) is a thin, hollow tube that is put through the skin into the stomach through a small surgical opening (stoma). You can use this tube to give your child liquid food, fluids and some medicines.



How is a G-tube put in?

A G-tube may be put in using one of two different methods. Your doctor will decide which is best for your child:

1) Surgically placed G-tube

After your child receives an anesthetic, the doctor makes a small opening through the skin and muscles into the stomach. This opening is about halfway between the child's belly button and left nipple. The doctor then places the G-tube through this opening into the stomach and sometimes stitches the G-tube in place. This stitch may come out on its own or be removed by the doctor.

2) Percutaneous Endoscopic G-tube (PEG)

After your child receives an anesthetic, the doctor will put the tube down the throat and into the stomach. A small opening is made through the skin and muscles into the stomach. This is called a "stoma". The tube is then pulled through the opening.

Be sure to ask your doctor about your child's surgery.

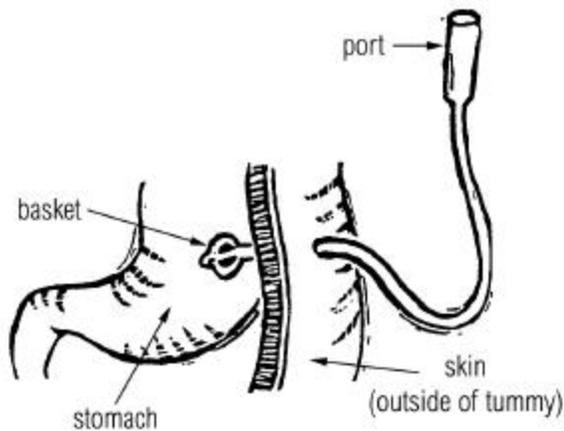
Which G-tube does my child need?

There are many types of G-tubes. Your doctor will explain which G-tube is best suited to your child's needs.

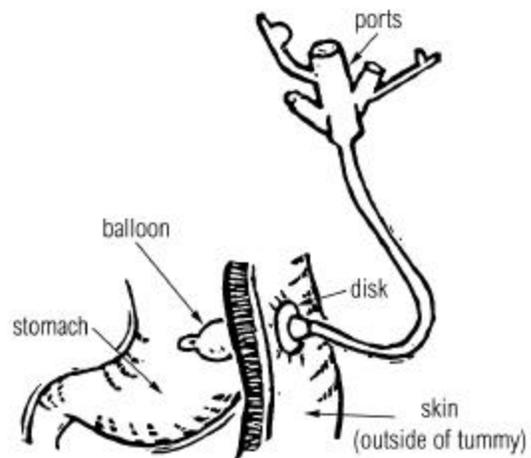
Malecot G-tube

This latex tube has a soft bulb that looks like a tiny, open-weave basket inside the stomach. This bulb helps hold the tube in place. The soft bulb and open weave allow thick fluids to move quickly and easily into the stomach. However, it may come out easily if pulled.

A Malecot tube is a *temporary* G-tube. About six weeks after surgery, the Malecot is removed and replaced by one of the other G-tubes.



Silicone Balloon Style G-tube



This silicone G-tube (MIC or Kangaroo) has a flat, flexible disc on the skin and a balloon filled with water inside the stomach to hold it in place.

**Children who are sensitive
(allergic) to latex
use silicone G-tubes.**

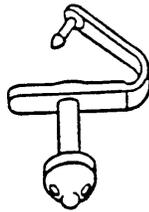
Skin Level G-tubes

Some G-tubes sit at skin level. They are made of silicone or polyurethane and have a small bulb, balloon or basket that holds the tube inside the stomach. A “one-way valve” prevents the tube from leaking when it is not being used for feeding.

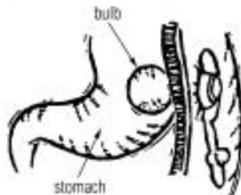
This G-tube is only placed in a stoma (opening) that is well healed.

Some common designs are **Bard Button**, **MIC-Key** or **Entristar**.

Bard



Mic-Key

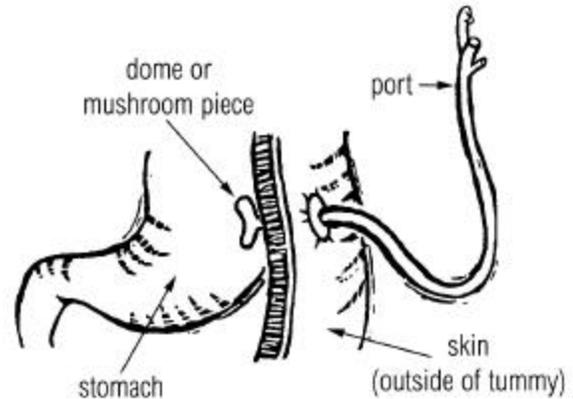


Entristar



PEG Tubes (Percutaneous Endoscopic Gastrostomy)

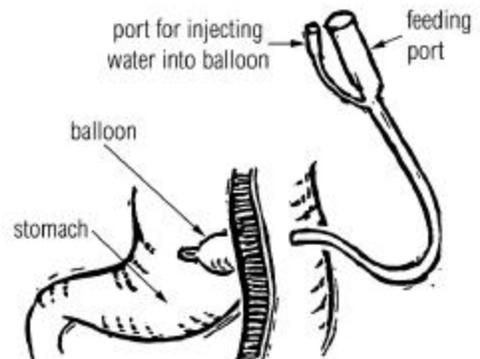
This soft silicone tube has a dome or mushroom inside the stomach and a bumper against the skin to hold the tube snugly in place. It is not easy to pull this tube out of place.



Foley Tube

This tube is made of latex rubber and has a small balloon on one end that goes inside the stomach. When this balloon is filled with water, it holds the tube in place.

This tube may be used for replacement to keep the stoma open if a child's G-tube falls out.



How will using a G-tube help my child?

Some babies and children cannot take in enough food when eating and drinking by mouth. A G-tube may help your child to:

- increase food, fluid and calorie intake when your child is not able to suck and swallow well, or has a chronic illness.
- make feeding less tiring for your child
- overcome health concerns that prevent feeding by mouth
- decrease choking and aspiration (aspiration is food or liquid going into the lungs. This can cause pneumonia and lung damage).

For children with these concerns, G-tube feedings are helpful for proper growth, healing and development.

Your doctor or health caregiver will discuss with you how G-tube feeding may help your child. At this time, please ask any questions you have about putting the G-tube in, the type of G-tube, follow up care and so on. All of your questions need to be answered so that you can be informed about your child's care.

G-tubes may be used for a short time or for a long time. It is hard to know how long a G-tube will be needed.

A family who is able to care for their child's tube feeding at home may be able to shorten the time spent in hospital and prevent other hospital stays.



What's it like to have a G-tube?

Read what other parents and children say about their life with gastrostomy tubes:

- *“There is no doubt in my mind that my baby would still be in hospital if it wasn't for the gastrostomy tube. Of course, home is the best place for him. He is gaining more weight and is happier at home. At first I felt overwhelmed with how to care for the tube, but he's only been home a week and I already feel confident that I can do this. I give him some formula by bottle and if he's too tired, the G-tube is there to give him the break he needs. I don't have to push him. I don't know whose idea it was to give him the G-tube, but thank you.”*
- *“After we got the G-tube, feeding our child became less of a battle and helped my husband and I enjoy our child more.”*
- *“No one has to know that I have the G-tube. At school, I eat like everyone else and at night I use the tube. It's my hidden secret.” (School age child)*
- *“Some families are quite open about their child's G-tube while others treat it as a strictly private matter. There is no correct attitude toward this, only the attitude that best works for your family.”*

If you would like to speak to a parent or child about G-tubes, please ask your health caregiver.

How will my child and family react to G-tube feedings?

A child's response to gastrostomy tube feedings varies with age, prior tube feeding, personality, and the way other family members react. Children and their parents may feel angry, sad, or even relieved and happy. It is also common for parents to feel upset about not being able to feed their child the “normal way”. There will be times when you or your family will feel stressed. All of these feelings are normal and will change from day to day and over time.

Your challenge as a parent is to help your child and family be as happy, healthy and active as possible. You need to feel at ease with tube feeding and work it into your family routines.

When they are ready, children and parents need to talk about their feelings. Do not hide your feelings. Your family and friends may offer support. The health caregivers involved with your child can be a “sounding board” to help you with your feelings. Other families with a G-tube fed child can give helpful advice and support.

Is it hard for parents to decide about a G-tube?

Yes, parents often find this hard. A G-tube is often suggested after you have spent much time and effort to get your child to eat. You may feel your success as a parent may be linked with your success in feeding your child.

Parents whose children have feeding problems often say that they feel like failures as parents. **You are not a failure.** We commend you for thinking about other ways to help your child develop and grow!

It is hard to know how your child will change over time and if feeding will get better or worse. Your health caregivers suggest a G-tube because they believe it will make feeding easier for you and your child. Feeding may take less time, be less stressful, and your child will receive the nutrients and energy needed for health and growth.

Please speak to your child's health caregivers. You will need information to decide what feels right for you and your child.

Feeding and Giving Medicine

How do I feed my child by tube?

There are four ways to feed a child by tube:

- A. "Top-up" feedings
- B. Bolus feedings
- C. Continuous feeding
- D. Combination feeding

Whichever method is needed, you will practice feeding your child many times with a health caregiver before doing it on your own.

A. "Top-up" feedings



These tube feedings are small volumes of formula (or breastmilk) and are often given after feeding the child by mouth. Children may need this type of tube feeding to be sure they get the full amount of nutrition needed to grow. "Top-up" tube feedings may be given by gravity, pump or syringe (see next page).

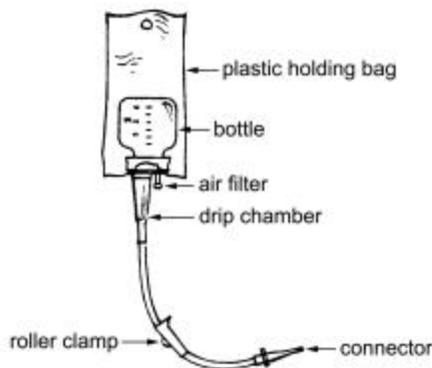


B. Bolus feedings

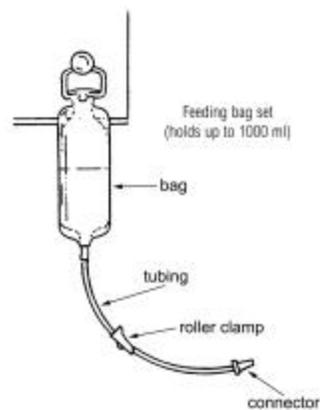
Your child may need an entire mealtime feeding to be given by G-tube. This is called a “bolus” feeding. The time it takes to give a bolus feeding depends on your child’s needs and tolerance. Bolus feedings are often given by gravity.

The formula is placed in the baby bottle or feeding set and hung above your child. These feeding sets may be hung from a pole, hook, or cupboard doorknob. Bolus feeds can also be given by pump or syringe.

Feeding Set
(Amounts under 250 ml or 1 cup)



Feeding Bag
(Amounts over 250 ml or 1 cup)



C. Continuous Feeding

This method of feeding is used to give fluids slowly over several hours or overnight. This is used when the child can only handle a small amount of formula at one time.

For continuous feeding, you will need a feeding set and pump. The pump is used to control how fast the formula is given.

D. Combination feeding

Your child’s feeding plan may use a combination of these feeding methods. For instance, your child may need top-up or bolus feedings at mealtimes and a continuous feeding during the night.

As all children grow, their nutrition needs and patterns change. Your child may progress from small, frequent feedings to meal size feedings. As oral intake increases, your child’s tube feed may decrease and may progress from continuous feedings to nighttime feedings only. Each child has different needs.

How do I vent the G-tube?

If your child is unable to burp or has difficulty burping, you may try venting.

"Venting" means letting air out of your child's stomach.

Open the G-tube and place the end of the G-tube into a cup OR attach to an empty syringe barrel or tubing. The tubing needs to vent for several minutes or longer. Some G-tubes have special tubes called "decompression tubes" which help to vent the tube.

Position the child on one side and then the other to help with venting. As the air vents, you may see bubbles come to the top. Some liquid may also come up with the air. Return this liquid back into the stomach as it contains important body fluids. Then flush the G-tube with water.

Helpful Hint:

Avoid letting air enter the stomach during the feeding. To prevent this, before you start, run the formula to the end of the tube. Then attach it to the G-tube.

How do I give my child medicine by G-tube?



1. Get the correct dose of medicine ready to put into the G-tube. For children who tend to spit up, give medicine at the beginning of the feeding. **Medicine should not be mixed with formula. Formula may react with the medicine and become lumpy and block the tube.**

Liquids Most liquid medicines may be given through a G-tube. Draw up the exact amount of medicine into a syringe.

Pills If your child needs to be given a pill, **first check with a pharmacist before crushing. Some pills should not be crushed.**

If crushing the pill is okay, then crush the pill between two spoons to a fine powder (or use a pill crusher).

Dissolve the powder in water.

Draw up **all** of the mixture into a syringe.

Capsules **Check with a pharmacist before opening.**
Cut or break one end of the capsule open.

Mix the capsule contents with water.

Do not crush any tiny, coated (sustained release) beads.

Draw up **all** of the mixture into a syringe.

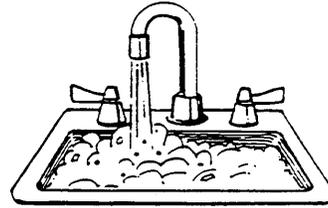
2. If your child is on a continuous feed, stop the feed.
3. Open the G-tube. Flush with the proper amount of water. Use the syringe to put the medicine into the G-tube.
4. Flush the G-tube with the proper amount of water to push the medicine into the stomach and clear the tube. Close the G-tube.
5. If your child is on a continuous feed, re-start the feeding.
6. Wash and dry the syringe and other supplies so they are ready to use again.

Points to Note:

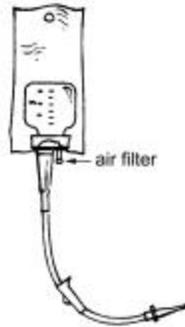
- Always give a medicine directly into the tube and not into the feeding bag.
- Try to avoid giving more than one medicine at once. This may cause the tube to plug. You may be able to space out your child's medicines over the day to avoid having to give more than one at a time. If you must give two or more medicines at the same time, flush well between each medicine.
- Check with your health caregiver about how much water to use for flushing.

Cleaning your supplies

How do I clean the G-tube feeding supplies at home?



You should be able to use the same supplies for several weeks. This makes it very important to **fully clean** G-tube feeding supplies right away after each use. **Supplies that are not fully cleaned may contaminate the formula and make your child sick.**



If your gravity feeding set has an air filter, pull it off so it doesn't get soapy. Rinse the filter under warm water and put the air filter back on before the next use.

Tubing that is used for continuous feedings (e.g. 24 hours a day) should be washed **at least** once a day. Use your second set while you are washing the first set.

After each feed:

1. Take the feeding set apart and rinse all of the supplies with cool water.
2. In a clean sink, fill supplies with **warm** water and a very tiny amount of liquid dish soap and let them soak for a few minutes.
3. Connect the tubing pieces to a syringe and push soapy water through them to clean the inside. Scrub bottles with a bottlebrush.
4. Don't forget to wash the outside and all the corners and connections.
5. Rinse with the **hottest** water you can handle. Rinse at least three times.
6. After rinsing, drain well. Store clean supplies in a clean ziplock bag or plastic container (e.g., Tupperware) in the fridge. Smell your supplies before using again. If any item has a sour or rotten smell, throw it out and use a new one for the next feeding.



TIPS FROM OTHER PARENTS

Add a couple of tablespoons of white vinegar to the first rinse water. It helps remove the soap!



Before using a syringe, cover the number markings on the outside of the syringe barrel with clear nail polish. This stops the markings from wearing off during frequent washings.

What do I feed my child?

Your child will be fed a liquid formula with all of the nutrients needed for proper growth and development. The dietitian will work with you to find a formula which best suits your child. It may be ready to use, or you may need to follow a recipe for mixing the formula.

If a recipe is needed, keep a copy of the current recipe and feeding schedule on the refrigerator.

Making the formula recipe - make enough for 24 hours only.

- If sterile water is needed, boil the water, place it in a clean container, cover and let it cool before using. Check with your local health unit about how long to boil your water.
- Wash hands with soap and water.
- Check the “best before” date on the bottom of the formula can.
- Rinse the can opener and top of the can with hot water. Open can.
- Measure the right amount of all the formula ingredients using measuring spoons or measuring cups.
- Place into a blender or a bowl for mixing.
- Blend or mix well.
- Cover container and store in the fridge.
- Throw out any unused formula within 48 hours after you have opened the can.
- Before feeding, warm formula to room temperature by putting in warm water.
- Put no more than 8 hours of formula in a feeding bag at one time.

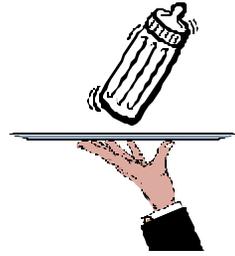
Ready to use formula

- Wash hands with soap and water.
- Check the “best before” date on the bottom of the formula can.
- Rinse the can opener and top of the can with hot water. Open can.
- If only part of a can is needed, cover the can with plastic wrap or put the leftover formula into a clean, covered container and put in the fridge right away.
- Throw out any unused formula within 48 hours after you have opened the can.
- Warm formula to room temperature by putting in warm water.
- Put no more than 8 hours of formula in a feeding bag at one time.



Write your child’s formula and recipe on the G-tube Feeding summary sheet (page 22).

Feeding routine



1. Prepare

- Wash hands. Unwashed hands are a major source of infection.
- Gather supplies and make the formula.

2. Check

- To be sure that tube placement is correct. See “checking tube placement” section.
- To be sure that the G-tube is not plugged by flushing with the proper amount of water. It should be easy to push water into the G-tube.
- To be sure that the G-tube and all supplies are clean and free of leaks or cracks.

3. Feeding

3A. Bolus or Top-up

- Position your child for feeding.
- Offer your child food by mouth, if this is allowed.
- Pour the formula into the bag or bottle, run the formula to the end of the tubing (to reduce the amount of air given to your child), connect the tubing to the G-tube, and start the tube feeding.
- Give the feeding slowly by moving the roller clamp and the height of the bottle (the higher the bottle, the faster the feeding). Feedings should last as long as it takes a baby or child to feed by mouth. This could take 15-30 minutes. Some children may need even slower feedings.
- For small feedings, it is possible to use a 60cc syringe and feed by gravity or by slowly pushing the syringe plunger.
- Burp your child if needed. If your child cannot burp, vent the tube (see section on venting tube).

3B. Continuous Feeding or Night Feeding

- Position your child for feeding (at a 30 degree angle if in bed).
- Pour the formula into the bag, run the formula to the end of the tubing (to reduce the amount of air given to your child).
- Run the tubing (that is attached to the feeding bag) through the pump. Then connect the tubing to the G-tube.
- Set the pump at the desired rate and begin feeding.

4. Finish

- Detach feeding bag from tube.
- Flush the G-tube with the proper amount of water.
- Clamp or plug the end of your child's G-tube between feedings.
- Allow quiet time after a feeding to help your child digest. Hold your child or lay your child on the right side or back with head slightly raised. If reflux is a concern for your child, ask your child's health caregivers for further advice.
- Clean all supplies.

Should mealtimes be changed for a child during tube feedings?

Try to make mealtimes as pleasant as you can to help your child digest food, gain weight, and enjoy feeding.

- Playing soft, soothing music may help you and your child relax.
- Do the same things with your baby during a G-tube feeding that you would do during an oral feeding. Make eye contact, coo, talk, hum, sing, or make sounds.
- Gently cuddle or rock your baby in a rocking chair.
- If your child accepts a soother, provide it during tube feeding to help your baby digest and to practice oral feeding.
- For older children, mealtimes may be more pleasant if the child is tube fed during a family meal or during family time. In this way, the child learns about oral feeding while watching others. Some children do need to be fed in a quiet place, free from extra noise or people.
- Let your child play with and explore food and utensils. Expect a mess.
- Give lots of praise and positive words of support.
- One mother says, *“For some kids, you’ll throw out food for a long time before they start eating it. Some just like to smell the food and touch it, but won’t put it in their mouths! All we can do is try.”*

How should I position my child during and after feedings?

All children need to feel at ease, safe, and secure during feeding time. Good positioning will help with sucking, swallowing and chewing.

Babies: A baby’s head should be higher than the stomach. The best position is to hold your baby firmly on your lap as if you were bottle-feeding. The baby’s hips and knees should be bent a little, the back slightly rounded, and the head straight (not tipped back).



At about four to six months, your baby may be fed in a baby seat or high chair.



Toddlers & Older Children:

Your toddler does not need as much support as a baby, but still needs to have good back support and enough foot support to allow hips and knees to bend a little. The child should not be able to slip or slide forward in the seat. A high chair with a tray and foot support is ideal for this age. Small children like to sit in a booster seat at the table or in 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.



"L" Position

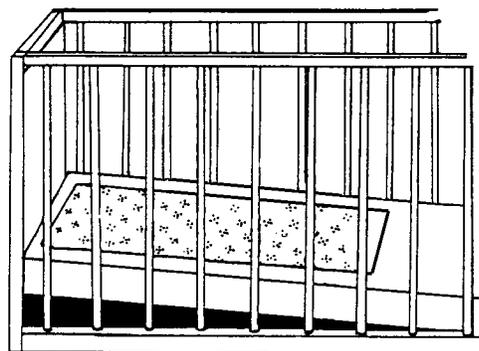
*Not
this*



"C" Position

If your child has poor motor control, check with your child's health caregiver for their advice about safe positioning for feeding.

Continuous feeding that is given at night should NEVER be done with your child lying flat. A 30-degree angle works best. Do NOT use extra pillows to raise your child's head. Instead, raise the mattress or the head of your child's bed.



30 ° angle

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

How do I know if my child is getting enough to eat and drink?

The best way to tell if your child is getting enough is to follow his or her growth. On a regular basis, your child will be weighed and measured. Measurements for height, weight and head size will be put onto a growth chart. The chart will show if your child's growth curve is staying the same or if it's getting better. As your child responds to G-tube feedings, other healthy changes may occur such as fewer colds and flus. Also, regular urination and bowel movements are signs that your child is getting enough fluid each day.

Can my child still eat and drink by mouth?

This depends on the child:

- Some children are tube fed only at night and can eat during the day.
- Some children are tube fed only after meals if they cannot eat enough food or formula by mouth at their meal.
- Some children are not able to eat by mouth because it is not safe for them to do so. If this applies to your child, your doctor will tell you.
- Some babies and children do not want to eat by mouth at all. *For these children, it is important to work on pre-feeding skills (see next section).*

**In most cases,
the goal is to increase the amount of food the child will eat by mouth
and to use the tube less and less.**

How can I prepare my child for eating by mouth?

Many children with feeding problems do not like to be touched on the face or inside the mouth. Daily care, known as “**oral stimulation**” can 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.

Pleasant mealtimes will help your child enjoy feeding and also develop “pre-feeding” skills for oral feeding. Learn to feed at your child's own pace. Don't force feed your child.

Babies

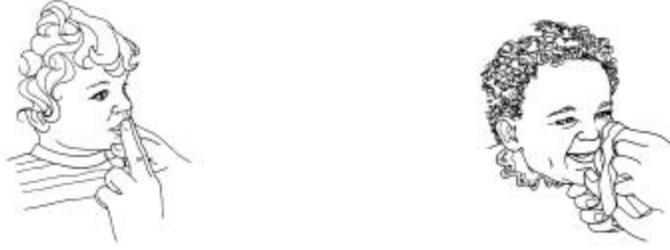


- Help your baby to practice sucking skills by urging her to suck her own hand or your finger, or a soother. It is very good for babies to practice sucking while being tube fed to teach them that sucking and the feeling of a full tummy go together.
- Hold your hand on your baby's face while you gently talk, sing or hum. Be aware that stroking the face can be too much for a very sensitive baby. Watch your baby's cues. Your child needs to learn to trust your touch.
- Urge your child to explore safe baby toys with his hands and mouth. This will teach your baby how to practice sucking, biting and moving the tongue or jaw. It is by mouthing toys that babies lower their sensitivity in their mouths. All babies are born with a very active gag reflex and this becomes less sensitive over time.
- Early on, work on mouth care by cleaning gums with a soft wash cloth, finger toothbrush and move on to a soft baby toothbrush. Brushing not only cleans the mouth and teeth, but also can lower sensitivity of the mouth. Your child's health caregiver can show you how to do this.

Older children:



- Try face play games, such as patting, kissing, and blowing. Take turns so your child can touch you as well.
- Routine regular tooth brushing is very important.
- You may have to work slowly to help your child accept being touched. Use puppets to stroke arms, hands, and face. Wipe the face with a firm dabbing motion rather than random wiping. Don't forget to watch your child's response. Trust is earned.



- Imitative food play – urge 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 textured play items, such as water, sand, or pudding. Ask your child to look for toys hidden in a bucket of lentils or rice.

Working on “pre-feeding” skills will help your child get ready for oral feeding. When oral feeding is started, it is common for children to have some problems with the feeling of food in their mouths, or with swallowing. A feeding therapist (for example, an occupational therapist or speech language pathologist) can help you and your child.



G-TUBE FEEDING SUMMARY

“PEACE”-FUL FEEDING WITH A G-TUBE

Prepare supplies & child

- Don't forget: clean hands, clean supplies, and clean working area
- Gather supplies and formula.
- Check that G-tube and supplies are clean and free of leaks and cracks.
- Run warm water through feeding bag and tubing and drain well (if supplies were just taken out of fridge)
- Position child and make meal times fun.

Ensure tube is in correct placement and check site

- Skin-level G-tubes should be snug.
- Other types of G-tubes: The length of your child's tube should be _____
The tube marking closest to the disc/stoma is _____

Always flush before and after giving medicines and flush before and after each feed

- Flush tube with _____ mL of water before giving a feed or medicine.

Commence feeding slowly

- Small feedings should last 15-20 minutes, larger feedings should last 20-30 minutes
- Adjust height of bottle/bag and/or adjust roller clamp to change rate of feed.

End feeding with flushing and burping or venting (if needed). Clean supplies.

- Flush tube with _____ mL of water after giving a feed or medicine

FORMULA PREPARATION

- Clean hands, clean supplies, clean working area
- Mix up 24 hour supply at a time and refrigerate formula in a covered container
- Discard any unused formula after 48 hours
- Warm formula to room temperature for feeding
- Put no more than 8 hours of formula in a feeding bag at one time

Formula Type _____

Recipe _____

Amount of formula per day _____ mL/day = _____ calories/day

FEEDING SCHEDULE:

DAILY ROUTINE

T=Top-up feeding B=Bolus feeding C=Continuous feeding

| | FEEDING By Mouth | FEEDING By G-tube | MEDICINE | OTHER |
|--------------------------|---------------------|----------------------|----------|-------|
| 1:00 a.m. | | | | |
| 2:00 a.m. | | | | |
| 3:00 a.m. | | | | |
| 4:00 a.m. | | | | |
| 5:00 a.m. | | | | |
| 6:00 a.m. | | | | |
| 7:00 a.m. | | | | |
| 8:00 a.m. | | | | |
| 9:00 a.m. | | | | |
| 10:00 a.m. | | | | |
| 11:00 a.m. | | | | |
| 12:00 p.m. (noon) | | | | |
| 1:00 p.m. | | | | |
| 2:00 p.m. | | | | |
| 3:00 p.m. | | | | |
| 4:00 p.m. | | | | |
| 5:00 p.m. | | | | |
| 6:00 p.m. | | | | |
| 7:00 p.m. | | | | |
| 8:00 p.m. | | | | |
| 9:00 p.m. | | | | |
| 10:00 p.m. | | | | |
| 11:00 p.m. | | | | |
| 12:00 a.m. (midnight) | | | | |

Don't Forget:

- **CLEAN SITE AT LEAST DAILY**
- **Clean mouth twice daily**
- **Give positive oral stimulation**
- **Check balloon as required**
Your child's G-tube balloon should have _____ mL of water.

Caring for Your Child with a G-tube

Washing Your Hands



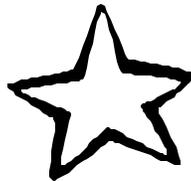
You can prevent the spread of illness to your child by one simple step.... **Wash your hands.**

Germs (bacteria and viruses) live on our skin and can be passed to each other by touch.

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

1. Remove your rings and watch. These can trap germs.
2. Use warm water and regular soap. Antibacterial soap is not needed.
3. Turn on water and leave it running. Don't touch the taps. They are not clean.
4. Lather up! Rub over all parts of your hands and wrists. Clean under nails. Friction is the best way to get rid of harmful germs. Wash for one minute.
5. Rinse well and dry with a clean towel.
6. Now that you have such clean hands, don't touch the taps! Turn off taps using the clean towel.

WELL DONE !!



Clean hands will help keep your child healthy!

How do I take care of the G-tube site?

Cleaning

- Keep the G-tube site clean and dry. Expect some leakage around the tube. Once a day, **gently** wash the G-tube site with mild soap and warm water. Rinse it and pat the skin dry. You may do this during your child's tub bath.
- If your child is unable to take a tub bath or more cleaning is needed, try the following:

Use cotton-tipped swabs to remove any leakage, crusts, oils or formula from around the stoma and tube. Also clean the tube opening, plug and any connections using a cotton-tipped swab.

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. Avoid covering with bandages. When possible, expose the G-tube site to the air when your child is napping, busy at play, or being held.
- Gently turn the G-tube device clockwise and counter clockwise daily when washing. All G-tubes should rotate fully in a stoma that is "mature" or has healed. **NEVER** feed through a G-tube that feels "stuck" in the tract. Contact your health caregivers to check that the tube is in the right place.

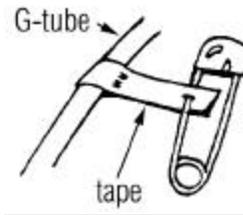
Scrubbing or cleaning the skin too often can dry and injure the skin. This causes skin breakdown.

CAUTION!

For safety, keep all tubing away from your child's neck by running the tube down the pant leg or sleeper. Also, place the feeding set at the foot of the bed.

Reduce Skin Irritation

- Secure the G-tube to prevent it from being pulled out. Tape or pin the tube to your child's shirt, pants or diaper. **Be very careful** to avoid putting the pin through the tube.



- Avoid any pulling or rubbing on the tape, G-tube or stoma. Make sure your child wears loose clothing that does not pull or press on the G-tube or site.
- If you use tape to secure the G-tube, find one that does not bother your child's skin.
- Common signs of skin breakdown are increased redness, discharge or crusting. If symptoms such as pus, blisters, rash or scrapes occur, they should be checked by a health caregiver.
- Check the G-tube site closely for signs of skin breakdown when:
 - you wash it each day
 - the G-tube, tape or stoma is pulled on hard or often
 - your child rubs, pulls at or protects the G-tube site more than usual
 - your child complains of pain, aching or itching at the G-tube site.
- To care for skin breakdown:
 - closely follow daily G-tube site care
 - expose the skin to the air more often
 - handle the irritated skin gently
 - keep skin clean and dry

If skin irritation stays the same or gets worse, ask your doctor or health caregiver for more help.

Some G-tubes need special care. Your health caregiver will teach you this.

Common care questions:

What can I put around the gastrostomy site?

The less we mess with creams and lotions the better! The skin around the stoma will usually stay healthy if it is kept clean and dry.

Can I bathe my child with the G-tube in place?

Yes! Once your doctor says the gastrostomy tube site is healed, your child can enjoy a bath. Be sure to dry the skin around the G-tube after the bath.



Can my child go swimming?



Yes! When your doctor says the skin around the G-tube is healed, your child can go swimming. Be sure the G-tube is clamped off tightly.

Does my child need special clothes?

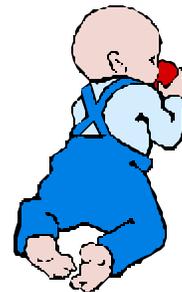
No! For infants, some parents prefer one-piece outfits with front button or snap closures for easy access to the G-tube.

For all ages, avoid clothing with a tight waistband that could pull or push on the tube.

Can I put my child on her/his tummy?

Yes! A G-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 to help them to 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. You could also attach some padding or a "donut" cushion around the tummy to protect the G-tube area. When your child is crawling, do not let the G-tube dangle.

Babies should sleep on their backs.



How can I keep little fingers away from the G-tube?

Children are curious. Their fingers could pull the G-tube out. Help to prevent this by:

- Tuck G-tube into clothing
- Dress in one-piece outfits, such as sleepers or overalls
- Secure G-tube to diaper using a tab of tape and a safety pin
- Put mittens or socks on infant's hands for short times
- Try to get older children to talk about the G-tube and explore the G-tube while you watch

How do I care for my child's mouth?



Mouth care will keep the mouth and gums clean and healthy. Clean the inside of your child's mouth at least twice a day.

- Make sure your child is in a comfortable, secure position (on your lap or in an infant seat).
- Wipe the inside of your baby's mouth with a moist, soft cloth.
- Brush your toddler's teeth and mouth with a soft toothbrush and toothpaste.
- Older children should brush their teeth and tongue with a soft toothbrush and a small, pea-size amount of toothpaste (if tolerated). Toothpaste should be spit out or drained from the mouth.
- Use petroleum jelly to keep the lips soft and to prevent cracking.
- Your child should see a dentist on a regular basis.

G-Tube Replacement

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

Over time, all G-tubes need to be changed.

Talk with your health caregiver and arrange to have your child's G-tube replaced when:

- the tube parts break and leak
- the tube tears and cannot be patched
- the tube comes out and cannot be put back in
- your child grows or loses a large amount of weight and the G-tube does not fit
- the tube blocks and cannot be cleared

What do I do if the G-tube comes out?

If the G-tube is pulled out, the stoma will start to close. **Some stomas can close in a few hours.** Your health caregiver will tell you in advance if you should replace the G-tube with the same G-tube, a new G-tube or a Foley catheter that will be used as a temporary G-tube until a new one can be put in.

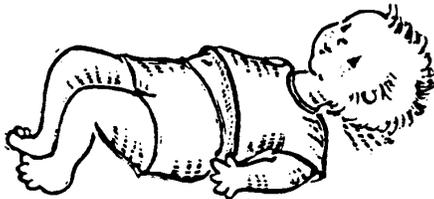
Always keep a G-tube replacement kit handy. This makes putting the tube back in easy and faster.

G-tube Replacement kit supplies:

- Foley Catheter Size _____
- 5 mL syringe
- a cup for water
- tape
- clamp or cap
- washcloth
- water based lubricant (e.g. Muko or KY jelly)
- waterproof marker
- emergency phone numbers
- money (change) for a phone call
- notes on replacing the G-tube

How do I put a Foley tube in?

1. Wash and dry your hands
2. Draw up 5 mL of water into a syringe (or the proper amount of water for your child's tube)
3. Lay your child on his/her back with knees bent or have someone hold your child. Calm your child using TV, music, tickling or massage. The tube will go in with more ease if your child is relaxed and not crying.



4. Use the syringe to fill the balloon on the Foley. Check the balloon for leaks. Then use the syringe to remove the water from the balloon. If your child's G-tube uses a disc, you may place it on the end of the Foley G-tube, or add the stent.



5. Put lubricant on the tip of the Foley.



6. Put the moist Foley tip into the stoma. Depending on the child's age and size, gently push and twist up to 2 to 4 inches (5

to 10 cm) of tube into the stoma. Hold the end of the Foley upright to stop leakage.



2 inches (5 cm)

7. Use the syringe to put 5 mL of water into the balloon port; then remove the syringe. If you feel resistance, don't use force. Remove the tube and try again.
8. Pull gently on the tube to ensure that it is snug against the stomach wall. (Close the tube and clean and dry the skin around it.)
9. Mark the tube at skin level with a waterproof marker.
10. If you are using a disc or stent, slide it until it is snug against the stomach or use tape to secure Foley G-tube in place. Your health caregiver will show you.

If you are not sure that the G-tube is in the right place, do NOT use the tube for feeding. Contact your doctor.



Refill your G-tube Kit right away.

Helpful Tips:

- All of the deflated balloon will disappear into the stoma
- Looking at the old tube that came out, check the distance from the tip to the skin disc. Use this distance to give you an idea how far to insert the new tube.
- Some tubes change colour when they are in the stomach. Use the part of the tube that changed colour to measure how much tube needs to go inside the stomach.
- It is easiest to put a tube in when your child's tummy muscles are relaxed. For example, when the child is not crying, or when the child breathes in. Some families suggest using music to relax everyone!
- Fill the balloon with the amount of sterile water you were told to use (usually 2 - 5 mL).
- Very gently pull on the tube until the balloon rests firm, (not tight) against the stomach wall.
- The skin disc on the outside of the tube should be the width of a dime away from the skin. Compare the measurement to the old tube that came out. If the disc is leaving a mark on the skin, it is too tight. It is easy to loosen with a little water.
- Tape the tube down to skin or clothing.
- NEVER give a feeding through the new G-tube unless it is in the correct place. You can check this by withdrawing stomach contents, listening for air or x-rays if required.

NEVER feed through a G-tube that seems “stuck” in the stoma.

TROUBLESHOOTING



Frequent Questions:

What do I do if my child has nausea, vomiting, gagging, cramping or diarrhea?

Nausea, vomiting, cramping or diarrhea may be caused by viral illness. Sometimes, tube feeding itself can cause problems. Follow the advice below. If your child still has any of these problems, then contact your doctor.

A G-tube that is not in the right place

- Check that your child's G-tube is in the right place. Gently pull on the tube to snug it against the stomach wall before each feeding and after cleaning or taping.

A formula* that is too cold

- Just before the feeding, warm your child's formula to room temperature. Shake bottle well before testing temperature of formula.

A formula that is too rich

- Ask your doctor or dietitian if you suspect this problem. They can help your child adjust to the formula.

A formula that is contaminated

- Store and prepare formula with care.
- Don't use formula if the can has dents or holes in it. Return it to the supplier.
- Do not use formula that is out of date.
- Keep opened formula covered and in the fridge for up to 48 hours only.
- Throw out any formula that has been open at room temperature for over 8 hours.

Certain medicines that upset the stomach

- Change the time or way you give medicines. Ask your doctor or pharmacist how to do this safely.

Air in your child's stomach or intestine

- Slow down the feeding. Halfway through the feeding, try giving your child a 5-minute break.
- Keep your child's head and shoulders raised higher than the stomach during and after the feeding.
- Venting or burping your child can be done before, during, and / or after the feeding.

Talk with your doctor if the problem continues or you have further concerns.

Feeding too quickly

- Give feeding more slowly.

*** Please Note: We use the word "formula" to mean expressed breastmilk, infant formula, or tube feed formula.**

What if my child is constipated?

Constipation is when bowel movements do not happen often and are hard or painful to pass. Constipation may be caused by low water intake, low fiber intake, low activity level or as a side effect of medicine. Check with your health caregiver about changing the amount of water or fiber in your child's diet.

- Increase water intake
- Increase fibre intake
- Increase activity level



The amount of water, fibre and activity will vary with each child. Check with your doctor or dietitian.

What if I see redness around the stoma?

Some redness and drainage is normal. If the redness continues, it may be due to:

- **skin not kept clean and dry**
You may need to clean more often (see section on cleaning). Avoid using tape. If the red area becomes bigger or tender, call your health caregiver.
- **drainage can cause skin breakdown**
Place a special adhesive wafer that protects the skin around the G-tube site to prevent further breakdown. Change this wafer every 2 days or when it no longer sticks to the skin around the stoma or when fluid is trapped under the wafer. Your health caregiver may suggest a barrier cream.
- **tube moving around too much**
Check tube placement (see section on checking tube placement). Ask your health caregivers how to tape the G-tube or if your child has the proper G-tube size.
- **infection**
If there is a foul smelling drainage or pus, call your health caregiver. A bad odor or foul smelling drainage around the tube may signal an infection. A fever or pain at the G-tube site may also indicate an infection. A red, pinpoint rash may indicate a yeast infection.
- **tape allergy**
If your child must have tape on the skin, contact your health caregiver to suggest types of tape to try. Place as little tape on the skin as you can to keep tube secure.

What if there is bleeding around tube or stoma?

During a tube change, you may see some bleeding. This bleeding should stop the same day. Other bleeding may be caused when:

- **the stoma becomes sore from movement of the tube in the stoma** (e.g., frequent coughing, lots of movement, loose G-tube).
Check the ring and tube placement (see sections on checking tube placement and skin care). Be sure tube is secure.
- **bleeding can signal a problem**
Call your doctor if a large amount of bleeding occurs.

What if there is formula leakage from the G-tube site?

A small amount of leakage is common.

- Try to keep the skin clean and dry.
- Make sure the balloon has the proper amount of water.
- Check that the G-tube is correctly placed.
- Use gauze dressing around the tube to absorb leakage. Change this dressing often to prevent skin breakdown.
- Small, more frequent feedings may help.
- Keep your child quiet for the first 30 minutes after feeding.
- Notify your health caregiver if leakage continues.

What can be done about skin tissue that builds up around the G-tube?

A small amount of tissue buildup (“proud flesh” or “granulation tissue”) is common. This is the body’s way to heal over an opening. This tissue can bleed easily, but is not painful.

- Keep up your efforts to clean the site well and keep it dry.
- If tissue build-up causes leakage, let your health caregiver know.
- Parents may be taught how to treat this. One method is to use silver nitrate sticks. Talk to your health caregiver about this.

What do I do if the G-tube blocks or plugs?

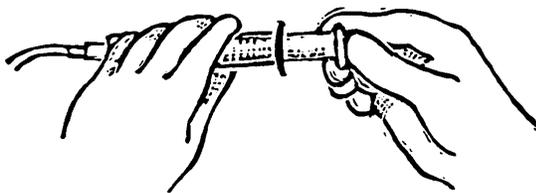
At times, the formula or medicine may block the G-tube. ***This does not happen very often.*** You can help prevent this by careful flushing.

When it does block, follow these simple steps:

1. Check that the tube is not clamped.
2. If the G-tube has tubing outside the body, use your fingers to massage the tube to break up the plug.



3. Use a syringe to gently push and pull air into the tube.



4. Use a syringe to fill the G-tube with warm water. Clamp the tube. Leave the water

in the tube for 30 minutes. Remove the clamp. Try to flush again.

5. If this does not work, contact your health caregiver for further help.

Be Careful:

- Never use too much force to unblock a G-tube. It could burst.
- Never probe the inside of a G-tube to try to clear a blockage. This will cause damage to the tube and it could hurt your child.
- Use warm water - NOT hot water - to avoid burning your child's stomach.

**Lessen the chance
of G-tube blockage
by flushing it with water before and
after *any* use.**

How do I prevent the tube from plugging?

The best way to avoid plugging is to flush the tube often. You should flush the G-tube:

- before and after every medicine (medicine and formula can form lumps and plug tube)
- before and after every feeding
- once a day if the tube is **not** being used for feeding.

The volume of water for flushing depends on the type and size of G-tube and your child.

Your child's G-tube should be flushed with _____ mL of water.

Use sterile water if your child is under 3 months of age and use tap water if your child is over 3 months of age.

APPENDIX

Where to get more Information

The health caregivers involved with your child welcome your questions and comments about G-tube feeding.

Northern Alberta Pediatric Home Nutrition Support Program: (780) 407-8503

Tip from the clinic:

- If you would like to speak with a certain health caregiver during your next clinic appointment, please be sure to call ahead.
- Be sure to ask if you want to speak to a parent or child about tube feeding.

Other important names and phone numbers

Dietitian _____
Nurse _____
Doctor _____
GI Specialist/
Surgeon _____
Stollery Children's Health Centre (780) 407-8822 Main Switchboard
Capital Health Link (780) 408-5465
Capital Health Authority Website www.cha.ab.ca
Other _____

When should I call my child's doctor?

Call the doctor when:

- you think the G-tube is not in the right place
- you cannot clear a blocked G-tube
- the G-tube may need replacing
- you see unusual redness, swelling or discharge at the G-tube site
- your child has nausea, vomiting, cramping, diarrhea or constipation
- your child chokes and coughs during feedings or seems to have a chronic cough
- you have any concerns or questions

If you are worried about your child's health, talk with your doctor.

Internet Information

Interesting information and trends may be posted on the Internet.

**Keep in mind that there is no way to be sure
if what you read is correct or safe.**

**Please bring any information you find
to discuss with your child's health caregiver.**

How can we make the best use of clinic/doctor appointments?

Giving you information and support are two of the best ways your health care team can help you. Here is some of our best advice for getting the most out of your child's clinic or doctor appointments:

Before your visit:

- Make a list of your questions and concerns.
- If you wish to meet with a certain person at the clinic/office, call ahead to arrange a time.
- Ask a family member or friend to come with you to take notes, offer support, or help care for your child while you focus on speaking with the health caregiver.

At the clinic/doctor's appointment:

- Ask your most important questions early in the appointment.
- Take notes to help you recall what was said.
- Share as much as you can with the health care team: thoughts about your child's health and response to tube feeding; what tube feeding is like at home; how your family is coping; and anything else that might help the team make good treatment plans for your child.
- Ask if you don't know medical words or want more information. Ask for a picture or sketch or written details to help you learn and recall.
- Repeat what you think your doctor said.

At home:

- Keep a journal of your questions and progress.
 - If you need to speak with someone before your next appointment, please contact your child's health caregiver by phone.
-

G-tube feeding supplies

The Northern Alberta Pediatric Home Nutrition Support Program will provide you with the feeding supplies you need such as feeding bag systems and syringes. These supplies are given at no cost to you.

To order supplies call (780) 407-1341 or submit order by fax @ (780) 407-8502.

Please let the clinic know as soon as you need supplies. We need **five working days** for equipment or supply refills. You may fax or phone in your supply order. If you “drop in” for supplies, we may not be free to help you, or may not have the supplies on hand. To be sure you get your supplies, please phone in your requests in advance.

The Home Nutrition Support Service provides tube-feed and specialized formulas. The cost of the formula will be a cost-share between yourself and “Services for Children with Special Needs” (formerly “Handicapped Children Services”) in your region. Children who receive assistance through Treaty status or Social Services (e.g., Medical Services Card) need to arrange their formula through those agencies.

For rural areas or to confirm these contact phone numbers, please call the Alberta Government province wide number at 310-0000 and ask for the phone number of the office in your area.

What G-tube feeding supplies do I need?

Each child will need a different set of supplies. These supplies may change over time.

- G-tube: type_____ size_____
- Gravity feeding set
- Pump feeding set
- Pump (if needed)
- Connectors
- Extension tubing (skin-level G-tubes)
- Syringes
- Temporary G-tube: type_____ size_____
- Water based lubricant
- Tape

The Home Nutrition Support nurse will review these supplies with you.

How long do these supplies last?

The gastrostomy tubes can last for several months or even years.

With proper cleaning and storage, most feeding bags and tubing may be reused for 7 days. Syringes can be reused until the numbers wear off or the rubber plungers get too sticky. Ask your health caregiver for guidelines.

What supplies should we take when we travel away from home?

There are times when you travel away from home: to come for a clinic visit, to the emergency room, to see your doctor, to have an x-ray, blood test, or during a holiday. You should be prepared for routine and non-routine care of your child's G-tube. Here's a list of items to pack:

- Formula
- Medications
- Water (for making up formula and for flushing)
- Syringes
- Feeding bags
- Connecting tubes
- Connectors
- Feeding pump, if needed
- Temporary G-tube & G-tube replacement kit
- Towels, wipes, cotton-tipped swabs, tape
- Gentle soap for skin care
- A way to hang feeding bag while away from home
- Plastic containers or bags to store feeding supplies
- Phone numbers for the health caregivers
- G-tube Feeding summary (see back of manual)
- This booklet

Tips: Powdered formula is easy to transport, as you do not need to use a fridge until it is made into formula. Ready to use formula is useful if clean water is not handy. Be sure to check with your dietitian about proper mixing and to be sure the powdered version of your usual formula is the same as the liquid version.

References

Please ask us if you would like a copy of the reference list used to create this booklet.

This booklet was designed to help you feel comfortable about the G-tube feeding process.

We welcome your feedback!

In order to improve this teaching booklet and our teaching process, please forward your comments to the Home Nutrition Support Service.