

NASOGASTRIC TUBE FEEDING YOUR CHILD: A RESOURCE BOOKLET FOR FAMILIES



Alberta **Children's** Hospital



Alberta Health
Services

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Nasogastric Tube Feeding Your Child: A Resource Booklet for Families

Parents:

Does your child need Nasogastric (NG) tube feedings?

Like other families, you have many questions and concerns about tube feeding your child:

- What is tube feeding?
- Can I learn to put the tube in?
- Can my child insert the tube?
- What about costs?
- Who do I call to ask questions?
- Will we have to change our family meal times?

A group of dietitians, doctors, nurses and parents of children with nasogastric tubes wrote this for you.

This booklet was designed to inform you and to answer your questions about nasogastric tubes and feedings. If your questions are not covered here, please write them down and ask your doctor or health caregiver.

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 own care. These notes will remind you how to give this care at home.

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

CAN I DO THIS?

This is a question you may ask yourself many times before you take your child home on 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. Don't forget there are no silly questions but the ones you don't ask.

Before you take your child home you should be at ease with NG-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. A referral to Home Care will be made. The Home Care Nurse will assist you with your NG in-services, but it is your responsibility to insert the NG Tube.

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

We want tube feeding at home to be successful 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 and we encourage you to do so.

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.

Nasogastric (NG) Tubes

What is a nasogastric (NG) tube?

A nasogastric (NG) tube is a hollow, thin, soft tube that is passed through the nose, down the throat, and into your child's stomach. The tube is used to feed your child and may also be used to give other fluids and some medicines. For some children, this tube may be passed through the mouth, rather than the nose.

You and your child's caregivers will work with each other to make the best choices about feeding your child with the nasogastric tube.



Who needs an NG tube?

A number of health concerns can affect how well a baby or child is able to eat. An NG tube may be needed if a baby or child is not able to eat enough food to get all the nutrients needed. This can result when he or she :

- does not feel hungry, such as the child with cancer or liver disease
- is not able to eat or drink by mouth, such as the child with a broken jaw
- tires when feeding or eating, such as a premature baby
- is not able to chew and swallow well
- has a high need for calories, such as the child with cystic fibrosis, heart disease, or lung disease
- is not able or not willing to take in enough calories by mouth to support proper growth, such as "oral aversion"

For these reasons, some babies and children cannot take in enough food by eating and drinking by mouth. For these children, nasogastric tube feedings become very helpful for proper growth, healing, and development.

What are the goals for NG tube feeding?

- To provide nutrition in a way that the child and family can accept
- To achieve and/or maintain ideal growth
- To provide the right amount of nutrients
- To provide the right amount of water
- To help control a disease or health problem

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 an NG tube?

If you would like to speak to a parent or child about NG feeding, please talk to your health caregiver.

Here are a few comments from parents about life with nasogastric tubes:

- ❖ *“Without the tube, my baby would have had to stay in hospital for a long time. It was a hard choice at first. Tube feedings seemed scary to me. But I was tired of going to the hospital. My family was suffering because I was away from home for so long. Bringing my son home now meant coming home **with the tube** and the responsibility was ours. But we got used to it quickly and now **we wished we had considered it sooner.**”*
- ❖ *“It is important to me to breastfeed my baby and I don't want to push her with bottle feedings. The nurses told me that my daughter would eventually be strong enough to breastfeed, but for now she needed a “top up” by a nasogastric tube after breastfeeding. After she nurses and falls asleep, I can let her sleep while I add a bit more milk into her stomach. Less pressure for her to do the feeding all by herself!”*
- ❖ *“When they first told me that I should try putting my own tube in, I thought ‘no way!’. But then I realized that if I knew how to reinsert the tube, **I could take the tube out when it was not being used.**”*
- ❖ *“Other people may look at you when you are walking in the mall with tubes held high in the air, but you will be surprised how many other parents will stop and say that they had to do that for their children, too. Forget about those who stare - sometimes a simple explanation is all that's needed for understanding.”*

How will my child and family react to NG tube feedings?

A child's response to nasogastric tube feedings varies with age, prior NG tube use, 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 they can. You need to feel at ease with tube feeding and to work it into your family's 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 an NG tube fed child can also provide helpful advice and support.

How is an NG tube put in?

Inserting an NG tube may frighten you at first, but it is not hard to learn how to do it! In fact, many older children prefer to put in their own tube. Your child may gag at first, but this often stops quickly.

a) Always start clean – wash hands with soap and water and clean your working area.

b) Gather needed supplies:

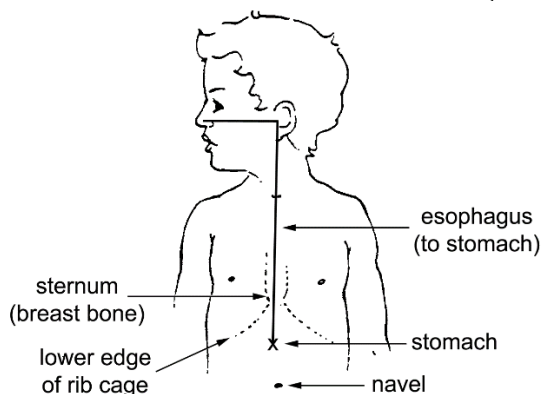
- NG tube
- syringe
- tape & adhesive wafer (if needed)
- glass of water or soother, depending on your child's age
- tissue to clean nostril
- water-soluble lubricant
- straw (for older children; optional)
- green or red permanent marker
- a blanket to wrap baby

c) Comfeel / Tegaderm

- Do not put oil, cream or lotion on face.
- Cut Comfeel in a tear drop shape and apply on cheek close to nostril.
- Cut Tegaderm (2) lengthwise (used to secure the NG tube).
 - * Ensure tube is well secured at all times: may require taping throughout the week.

d) Measuring

- Before measuring, landmark on child / infant abdomen between sternum / breast bone (xyphoid process) and the belly button, (your nurse will show you how). Place a dot with your permanent marker "x".
 - Now you are ready to measure:
 - Head must be midline
 - From tip of nose to earlobe, to permanent marker dot, that you placed on step 1, apply a mark with your permanent marker
 - Measure the tube twice:
 - Put NG tube to tip of the nose across to the ear lobe.
 - From the ear lobe, draw the tube to midpoint between end of sternum / breast bone (xyphoid process) and the belly button, then mark with a permanent marker, your nurse will show you.
- TIP:** We recommend that you put a dot on baby / Child abdomen between the sternum / breast bone (xyphoid process) and belly button before measuring.
- If the measurement difference between the two measurements is half an inch or more, re-measure a third time.
 - You need to have two measurements that are the same.
- *Please measure each time, as children can grow quickly.**



e) **Bundle the baby / child.**

f) **Remove old tube:** Peel the comfeel / tube / tegaderm slowly from the ear towards the nose. Gently grasp NG-Tube close to nostril and pull straight down in a smooth quick motion.

g) **Cover the tip of the feeding tube** with water-soluble lubricant.

h) **Insert the tube:**

- You may find it easier to insert the tube if your child / baby lie on their back with their upper bodies and heads propped at a 30-degree angle. It is helpful to have someone else hold your child while you insert the tube.
- Your nurse will tell you how often to change the NG-Tube. We recommend to use the alternate nostril with each change.
- Hold the NG-Tube close to the end, between the index and the thumb. Baby approx 1cm, older child: 2.5 cm.
- Insert the NG tube along the middle of the nose, and once that tip can no longer be seen, lift your elbow. Your tube will be in a vertical position, then push with 2 hands, until your measurement mark is at the child's nostril. Then secure with tegaderm.
- After NG-Tube inserted, remove excess lubricant and apply 1 tegaderm, to hold the tube in place.

TIP: The person holding your child can:

- 1) Put one hand on the top of the head, to immobilize the child's head.
- 2) The other hand places under the child's chin to maintain the mouth closed.

TIP: If the tube curls up in your child's mouth, do not be alarmed, just pull the tube out and reinsert.

TIP: If your child has a little cough, while inserting the NG-Tube, continue insertion.

TIP: If child is holding their breath stop the insertion, do not remove the tube, wait until your child takes a breath then resume insertion.

TIP: In older children swallowing helps move the tube down to the stomach. Advance the tube when your child swallow. Giving a soother to suck may help your baby swallow. If oral fluids are allowed, older children may take sips of water through a straw to help the tube to pass.

TIP: It is common for children to gag, cough or choke as the tube passes down the back of the throat. If your child is very upset (crying, coughing), pause. For instance, a baby may suck on a soother, or an older child could try slow breathing. Once the child is calmer, continue to gently insert the tube.

TIP: If you are not able to forward the tube, **do not force**. Pull back slightly and try to insert the tube again. Next time, you may want to add more lubrication to the tube prior to insertion.

If your child has any trouble breathing or turns "blue",

Remove the tube right away as it may have entered the airway or lungs.

TIP: Sometimes there will be a small amount of blood in the tube after tube insertion. The inside of the nose is very sensitive and may bleed a bit.

i) After you obtain stomach contents, give the stomach contents back to your child and then flush with 2-3mls tap water (for PVC) or 5mls (for Silicone tube).

* **Please do not use well water into NG-Tubes.**

j) Coil the tube and tape to child's back to prevent strangulation.

h) Cuddle baby / praise child.

Checking NG tube placement

Why check tube placement?

- to be sure that the tube is in the stomach and not in child's lungs
- the tube may move due to activity, play, or by "curious fingers"
- the normal motion of the stomach may move the NG tube out of place

How to check tube placement:

- **Withdraw fluid from the stomach by attaching a 10ml syringe to the end of the NG tube**, and pull FAST. **For **corflo tubes** use a 30ml syringe.

If you withdraw stomach contents, it means the tube is in the stomach. Normal stomach contents may appear grassy green, tan to off-white (mixed with formula), brown, clear and colourless, or mixed with mucous. It is common to see small flecks of blood, too.

- After checking the colour of the fluid you have withdrawn, gently inject the stomach contents back into the tube. These stomach contents contain important body fluids your child needs! Flush with 3-5 mls of water to clear the tube.

After checking the tube placement:

- Flush tube with 2-3mls water (PVC), 5mls (Corflo).
- Coil Tube and secure to child's back with two pieces of tape
- Cuddle/praise child.

TIP: You must see stomach contents in the syringe, before giving any fluids to the child (meds/Formula) by NG Tube.

- **DO NOT GIVE A FEEDING if you are not able to obtain stomach contents first.**
- **DO NOT GIVE A FEEDING if your child has problems breathing or speaking or complains of pain. Remove the tube quickly.**
- **CONTACT YOUR HEALTH CAREGIVER OR A HOME ENTERAL NUTRITION NURSE.**

Keeping the NG Tube in place

Firmly taping your child's tube in place will help to:

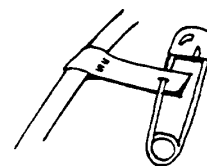
- Prevent the tube from moving out of the stomach and perhaps causing "aspiration" (fluid going into the lungs).
- Prevent the tube from wrapping around your child's neck.
- Your tube must always be securely taped.

Here are some Suggestions to help keep the tube in place:

- Be sure your child's skin is clean and dry before applying Comfeel/Tape, DO NOT use creams or oil on face.
- Place a piece of comfeel in the shape of a teardrop on your child's cheek as close as possible to the nostril onto which you are putting the tube. Try to avoid handling the narrow part of the Comfeel.



- After you insert the tube, place the tube over the pre-placed Comfeel. Hold the tube in place with a piece of Tegaderm. Keep your tube well secured at all times and re-tape as necessary.
- Have your tapes cut and ready before putting your NG in. This makes taping much easier.
- You may choose to use the pink waterproof tape to secure your tube, if your child has a cold or runny nose.
- When not using your NG Tube ensure you coil the tube and secure it to the back of the child's clothing using 2 pieces of tape in a criss-cross (x) or place a piece of tape with tabbed ends further down the NG tube. Pin the tape to your child's clothing to prevent the tube from being pulled out or wrapped around neck. You may also want to tape over the pin to prevent it from opening by mistake.



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

A. "Top-up" feedings

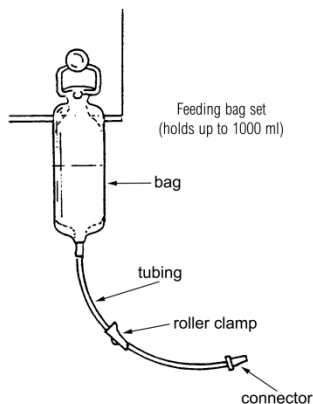
These tube feedings are small volumes of formula (or breast milk) and are often given after feeding the child by mouth. Children may need this type of tube feeding to be sure they get the full amount of nutrition needed to grow. "Top-up" tube feedings may be given by gravity or syringe.



B. Bolus feedings (Must always be supervised)

Your child may need an entire mealtime feeding to be given by NG 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 feeding set and hung above your child. These feeding sets may be hung from a hook, or even a cupboard doorknob. Bolus feeds can also be given by pump or syringe.



C. Continuous Feeding (Must be given by pump)

This method of feeding is used to give fluids slowly over several hours or overnight. It 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 a feeding pump. The pump is used to control how fast the formula is given.

Combination feeding

Your child's feeding plan may have a combination of 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. Every child has different needs. Your dietitian will guide you.

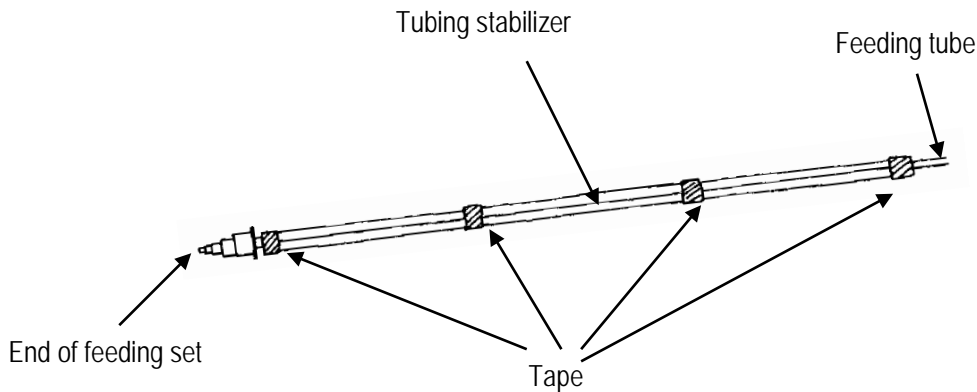
- You may hang your bag from a metal hook in the wall or coat hanger.
- Your feeding set must be 14 inches higher than your child's stomach.

TUBING STABILIZER

A Tubing Stabilizer is a stiff plastic device which can be placed on top of a feeding tube and the enteral bag tubing to prevent your child from getting tangled in the tube and to prevent strangulation. We encourage families to use the device for **unsupervised feeds**; for children between three (3) months and thirty-six (36) months; for children with developmental delay who require oxygen tubing, IV tubing and for night feeding. If your child is restless and very active, we suggest for you to use this device..

Setting up the tubing stabilizer:

1. Press the feeding set tubing into the stabilizer as close to the end as possible.
2. Apply tape at each end and every 4 inches wrapping around the solid plastic areas.
3. Throw out the tubing stabilizer if you notice any kinking, damage or excessive wear anywhere on the stabilizer.





How do I give my child medicine by NG tube?

Before giving a medication, check placement.

- Have the correct dose of medicine ready to put into the NG tube.
- For children who tend to spit up, give medicine at the beginning of the feeding.
- Do not put your child's meds in a feeding bag.

Liquids

- Most liquid medicines may be given through a NG 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.** Check if your pill can be available in a liquid form.
- If crushing the pill is okay, then crush the pill to a fine powder by using a pill crusher.
- Dissolve the powder in water.
- Draw up **all** of the mixture into a syringe.

Capsules

- **CHECK WITH A PHARMACIST BEFORE OPENING CAPSULES.**
- 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.
- Open the NG tube. Flush with the proper amount of water. Use the syringe to put the medicine into the NG tube.
- Flush the NG tube with the proper amount of water to push the medicine into the stomach and clear the tube. Close the NG tube.
- If your child is on a continuous feed, re-start the feeding.

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 Supplies

Feeding Bags:

- a) Once a day you must clean your bag using the following 4 steps:
1. Soapy Water: Put warm water and a couple of drops of dish soap in your bag and run through your tubing.
 2. Rinse your bag and tubing thoroughly with warm water.
 3. Rinse your bag and tubing using warm water and 1/2 teaspoon vinegar.
 4. Rinse bag and tubing with warm water. Place bag in closed container and put in fridge.
- b) Rinse bag after each feed with cool water. Place in a closed container and keep it in the fridge between uses.

Syringes:

Remove plunger from syringe. Wash both sections in warm, soapy water, rinse and place on paper towel and let dry. Do not scrub rubber plunger or place in the dishwasher.

Preparing Formula

*** PLEASE NOTE: We use the word, “formula” to mean expressed breast milk, infant formula or tube feed formula.**

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.

General Preparation for all types of Formula or Formula Recipes

- Wash hands with soap and water.
- Make sure all equipment that will be used is clean.
- Check the “best before” date on the bottom of the formula can.
- Formula is best given at room temperature this can be done by putting the container of the cold formula in a bowl of warm water for no longer than 15 minutes.
- Put no more than 8 hours of room temperature formula in a feeding bag at one time.
- Store unused formula covered in the fridge.
- Throw out any unused mixed formula or opened can 24 hours after you have opened the can.

Making the formula from a 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.
- Measure the right amount of all the formula ingredients using measuring spoons or measuring cups.
- Place into a blender or bowl for mixing, mix well.
- Keep a copy of the Formula Recipe and feeding schedule on the refrigerator.

Feeding routine

1. Prepare:

- Wash hands with soap and water.
- Gather supplies and make the formula.

2. Check:

- Check placement of your tube.
- To be sure that tubing and supplies are clean and have no leaks or cracks.

3. Feeding

Bolus or Top up

- Offer your child food by mouth, if this is allowed. If your child receives part of a feeding by breast, bottle, or cup, and part of feeding by nasogastric tube, *insert the nasogastric tube before giving any fluids by mouth*. This will reduce the chance that your child will gag or vomit during the feeding.
- 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), connect the tubing, and start the tube feeding once tube placement is confirmed.
- Give the feeding slowly by moving the roller clamp and the height of the bag (the higher the bag, the faster the feeding). Feedings should last as long as it takes a baby or child to feed by mouth. This could take 15 to 30 minutes. Some children may need even slower feedings.
- 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.

Continuous Feeding or Continuous Night Feeding

- This must be done with a pump only.
- Pour the formula into the bag and run the formula to the end of the tubing (to reduce the amount of air given to your child).
- Load tubing cassette into the pump.
- Program pump.
- Check for placement of your tube.
- Connect feeding tube to end of your NG once placement is confirmed.
- Start your feed.

4. When Feeding is Completed

- Turn off pump.
- Disconnect feeding tube from NG.
- Flush the NG tube with the proper amount of water.
- Allow quiet time after a feeding to help your child digest.

♦Clean all supplies immediately after feeding your child.

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 tube feeding that you would do during an oral feeding.
- 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.
- Give lots of praise and words of support.

How should I position my child during and after feedings?

Your physician will direct you on how to position your baby / child while feeding in bed. All children need to feel at ease, safe, and secure during feeding time. Good positioning will help with sucking, swallowing and chewing.

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



"C" Position

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

How to set up for a Continuous Feed

- Run child's NG Tube down Child's back and tape in place.
- Place feeding bag at the foot of the bed/outside the crib.
- Connect feed to NG tube and tape.
- Use medical stabilizer.

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 NG feedings, other healthy changes will occur such as fewer colds and flu. 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 not able to eat by mouth because it is not safe for them to do so, or they need to rest their stomachs. If this applies to your child, your doctor will tell you.
- 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 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).*
- If unsure, check with your doctor.

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.
- Improve the way your child is eating by mouth.
- Never restrain or force feed your child.
- Have your child to sit at meal times with the family.

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.

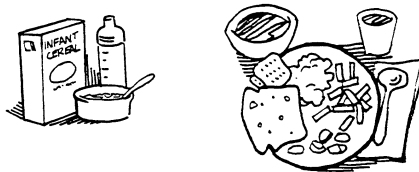
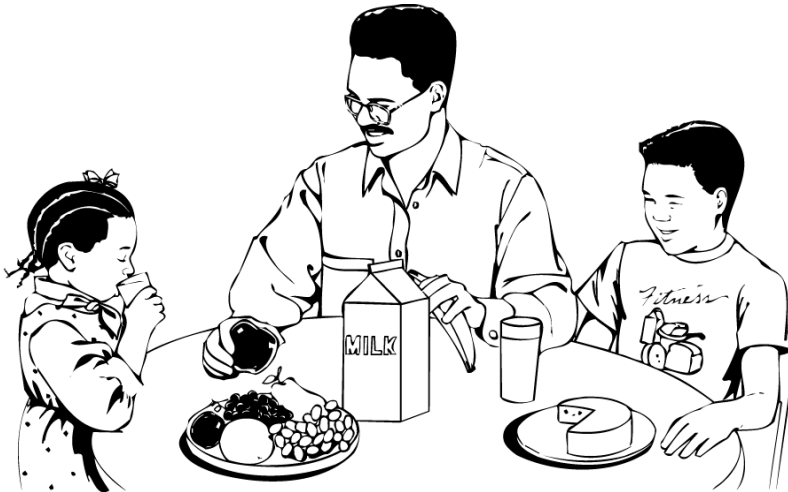
Babies



- 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 that babies 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, 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.
- Your dietician will help you with introducing finger foods.

Points to Remember:

- Routine regular tooth brushing is very important.
- 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. Be patient with them as this is new to them.
- A feeding therapist (for example; an occupational therapist or speech language pathologist) can help you and your child.



Ordering supplies

- 1) When you are discharged from hospital your Home Enteral Nutrition Nurse will give you some supplies.
- 2) Your Home Enteral Nutrition Nurse will tell you how and when to place your first order for supplies and Formula.
- 3) Order supplies once a month as instructed by your Home Enteral Nutrition Nurse. An order sheet with amounts and what to order will be given to you. Speak clearly and slowly when phoning in your order.
- 4) You can order by phone fax or email.
 - Phone: (403) 955-7165 (You will be speaking to an answering machine).
 - FAX (403) 955-2510
 - E-mail: homenutrition.orders@albertahealthservices.ca
- 5) No one will call you to confirm your order.
- 6) It will take seven days for your supplies to be available for pickup or eight days if there is a statutory holiday.
- 7) You need to tell us your child's name, address, phone #, where you plan to pick up your supplies and the date you will pick them up. Ensure it's at least seven days from when you place your order.
- 8) You will be provided with a Hospital or Warehouse map of where to pick up your supplies.
- 9) If ordering formula from us you must place the order at the same time as your supplies.
- 10) You will be sent a bill at home for formula (if it applies).
- 11) Remember you must order once/month only.
- 12) When you pick up your supplies make sure you take only supplies labeled with your child's name.
- 13) If unable to pick up your supplies within a week or your child is in hospital please notify the supply office (403) 955-7165.
- 14) When no longer feeding via NG:
 - a) If you have a feeding pump – return pump, charger, clamp, backpack (if provided), manual and DVD as soon as possible.
 - b) We are unable to accept unused formula and/or supplies (as per AHS Infection Prevention & Control Guidelines).
 - c) You will no longer be able to order formula or supplies through the Home Enteral Nutrition Therapy (HENT) Program.**
 - d) A Social Worker can assist you with formula costs if needed.

Pick-up Locations:

Orders can be picked-up from either location:

East Lake Centre Warehouse South Calgary – 9:00am – 11:00pm

ACH (Alberta Children's Hospital) North West Calgary - 9:00am – 7:00pm

For Warehouse Order Pick-up:

- Turn onto 106th Ave from Barlow Trail
- Take the first right turn. Drive along the back side of the warehouse along the loading docks.
- Park at the step of **Loading Dock Number 1**.
- Ring the doorbell at the top of the stairs and someone will meet you. Tell them the name of the child's order you are picking up and they will assist you with loading it into your vehicle.

If you are picking up after 5:30pm from the Warehouse, you must call the **After Hours Customer Service Line at 403-955-9800** prior to arrival to ensure somebody will be available to assist you.

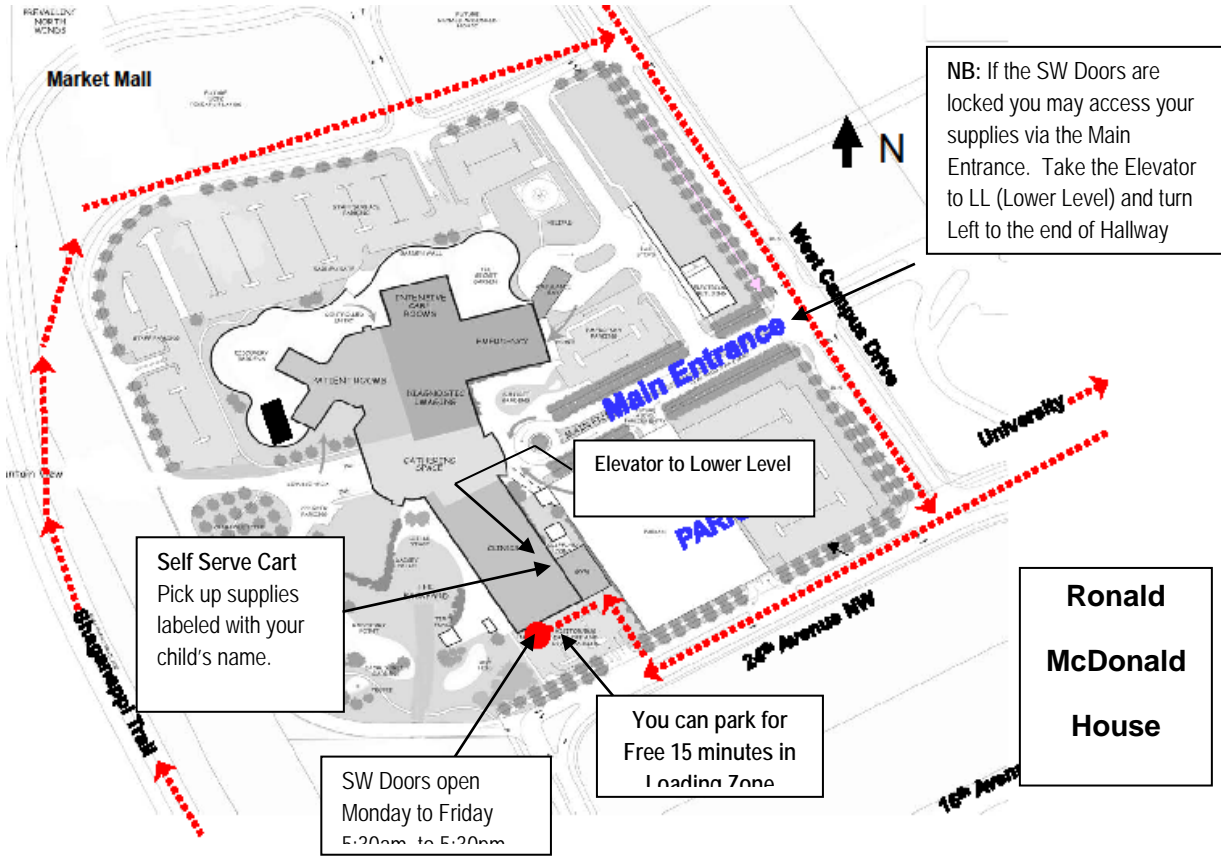
For any questions regarding your order, please call the **Order Line** at 403-955-7165.

Remember to place all orders 1 week in Advance.

East Lake Centre Warehouse



ACH (Alberta Children's Hospital)



The HOME NUTRITION Pick-up area is located at the 'REHABILITATION' entrance off of 24th Ave.

NB: Questions re Supplies call 403-955-7165

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.				

Trouble Shooting

Frequent Questions:

What do I do if my child feels nauseated?

Too much air in the stomach sometimes causes nausea. It can also be caused by a feeding that is given too quickly.

- Check tube placement
- Give feeding more slowly
- Keep head raised at a 30 degree angle during and after feeding
- Burp your child before, during and/or after the feeding

What do I do if my child has cramping (tummy ache)?

Cramping can be caused by formula* that is too cold, a tube that is not in the correct place, too much air in the stomach, or a feeding that is given too quickly.

- Warm formula to room temperature
- Check tube placement
- Give feeding more slowly
- Burp your child before, during and/or after the feeding

What do I do if my child gags (retches) or vomits?

Many things can cause a child to gag or vomit. Sometimes the first movement of formula through the tube can cause gagging. Other reasons are the stomach is too full, the tube is in the wrong place, or feeding is given too quickly. There may be certain times of the day when your child is more likely to vomit. For instance, your child may gag or vomit with the first feed of the day because of mucous swallowed during the night.

- Check tube placement
- Start feeding very slowly. After a few minutes, slowly increase speed of feeding to desired rate
- Allow a quiet time after feeds
- Vent tube or burp your child before, during and/or after the feeding
- When flushing the tube, do so slowly
- Give smaller, more frequent feedings
- If your child gags and vomits at a certain time, make that feeding smaller. Add the missed amount of feeding to the next few meals.
- If your child vomits, DON'T PANIC. Stop the feeding for 15 minutes. If your child is lying down, turn head to side or have child sit up.
- If your child constantly vomits phone your dietitian.

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 fibre intake, low activity level, or as a side effect of medicine. Discuss with your doctor.

What if my child has diarrhea?

Diarrhea is frequent, loose, liquid bowel movements. Sometimes, diarrhea may be caused by giving a feeding too quickly, spoiled formula, a side effect of medication or your child has a stomach flu.

- Check tube placement
- Give feedings more slowly
- Make and store formula as directed
- Keep feeding set clean
- 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, cranky, sleepy throwing up), **call your doctor**.

What is aspiration?

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

*** Remember to check placement of your tube before each feed***

If your child has trouble breathing or turns blue, STOP the feeding, remove tube quickly and call 911 (or the emergency number where you live). If you have other concerns, CALL YOUR DOCTOR.

How can I prevent the tube from blocking?

The tube may become blocked if it is not flushed well, or from some medicines that are thick, lumpy, or have not been fully crushed or mixed with water. Some medicines will clump when mixed with formula.

- Be sure the NG tube is not kinked
- Flush NG tube after each feeding
- Flush tube after checking tube placement
- Use liquid medicine or dissolve very finely crushed tablets in water
- Flush tube after giving medicine
- Do not mix any new things with the formula without checking with a health caregiver
- Do not use home blend / pureed foods into NG Tube.

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

Always book an appointment.

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.
- **Arrive 15 minutes before your appointment.** If you arrive late to an appointment there is a risk of having to reschedule to another day, it will depend on the clinic bookings of that particular day.
- 24 hours is needed to cancel or reschedule an appointment.

At the clinic/doctor's appointment:

- Call your Nurse with questions / concerns.
- 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 insertion and feeding; what tube feeding is like at home; how your family is coping; and anything else that might help the team to 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.

NOTE:

- If you have any questions / concerns re: your NG Tube; call the Nurse.
- If your child is vomiting / or unable to tolerate feeds, having questions re: Formula, Call the dietitian.
- If you have questions re: Supplies call the supply order desk.



“Tips from Teens with Tubes”

Hi! My name is Meghan. I'm 15 years old and I have Crohn's Disease. This disease requires that I sometimes use a feeding tube to ensure that I am receiving all of my daily requirements of calories, vitamins, minerals, etc. The tube is inserted through the nose and throat into the stomach. It takes a little while to get used to, but once you do, you barely even notice it. It's not uncomfortable at all if you know some tricks to help it go down. Some of my own personal tricks include:

Warming the tube in HOT water before insertion

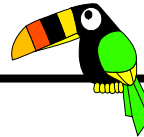
Once you reach the gag reflex, have a glass of water ready and take SLOW deep swallows.

As you swallow, push the tube really fast and don't pause

Personally, while I'm inserting my tube I like to concentrate on wiggling my toes...

Also, ask your doctor if they know anyone willing to show you how they put their tube in. Sometimes it really helps to see someone do it first. It takes away that little bit of fear!

-Meghan



Some words of advice from Amanda & Sarah:

When the NG tube is in place, you will feel it mostly in your nose, a bit in the throat and not at all in your stomach.

When you are on a tube feed, you can eat anything you want. You may have trouble with some chewy foods like toffee that may stick to the tube at the back of your throat, which is very uncomfortable. When you swallow food, it will pull down on the tube, but the tube does not move during tube feeding. If you cough hard, the tube might come out.

You will probably get people asking what the tube is for. You can tell them you get “nutritious milk” at night to help you gain weight.

If you are on total tube feeding and cannot eat, when your family sits down to supper, you can go to a different room and keep your mind busy by doing something else.

NG tube feeding supplies

Please talk to your dietitian about what formula your child needs and where to get it from.

If you have concerns about the cost of formula contact your Social Worker.

You can contact Family Support for Children with Disabilities (FSCD) about getting help to pay for formula.

Calgary (403) 297-6022

Lethbridge (403) 381-5500

Red Deer (403) 340-5478

If you live in another area of the province, please call the Alberta Government province wide number at (403)310-0000 and ask for the phone number of the office in your area.

Which NG supplies will I need for my child?

Your Nurse will provide you with a list of supplies.

Each child will need a different set of supplies. These supplies may change over time as your child changes and grows.

- | <input type="checkbox"/> NG Tube (SIZE _____) | Type | Order number |
|---|------|--------------|
| <input type="checkbox"/> Feeding bag set | | |
| <input type="checkbox"/> Pump and feeding bag | | |
| <input type="checkbox"/> Syringes | | |
| <input type="checkbox"/> Lubricating Jelly | | |
| <input type="checkbox"/> Tapes | | |

The Pediatric Home Enteral Nutrition nurses will review these supplies with you. An order form will be given to you.

***You must purchase a permanent marker in red or green.**

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

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

- Formula
- Medications
- Water (for making up formula and for flushing)
- Syringes
- Feeding bags
- Connecting tubes
- Feeding pump, if needed
- Towels, wipes, cotton-tipped swabs, tape
- A way to hang feeding bag while away from home
- Plastic containers or bags to store feeding supplies
- Phone numbers for the health caregivers
- NG Tube Feeding Summary (see back of manual)
- This booklet

Tips: Powdered formula is easy to transport, as it does not need refrigeration 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.

If travelling by plane: you will need a letter (RN will provide).

This booklet was designed to help you feel good about the NG feeding process.

We welcome your feedback!

**In order to improve this teaching booklet and our teaching process,
please forward your comments to the Home Enteral Nutrition (HENT) Team.**