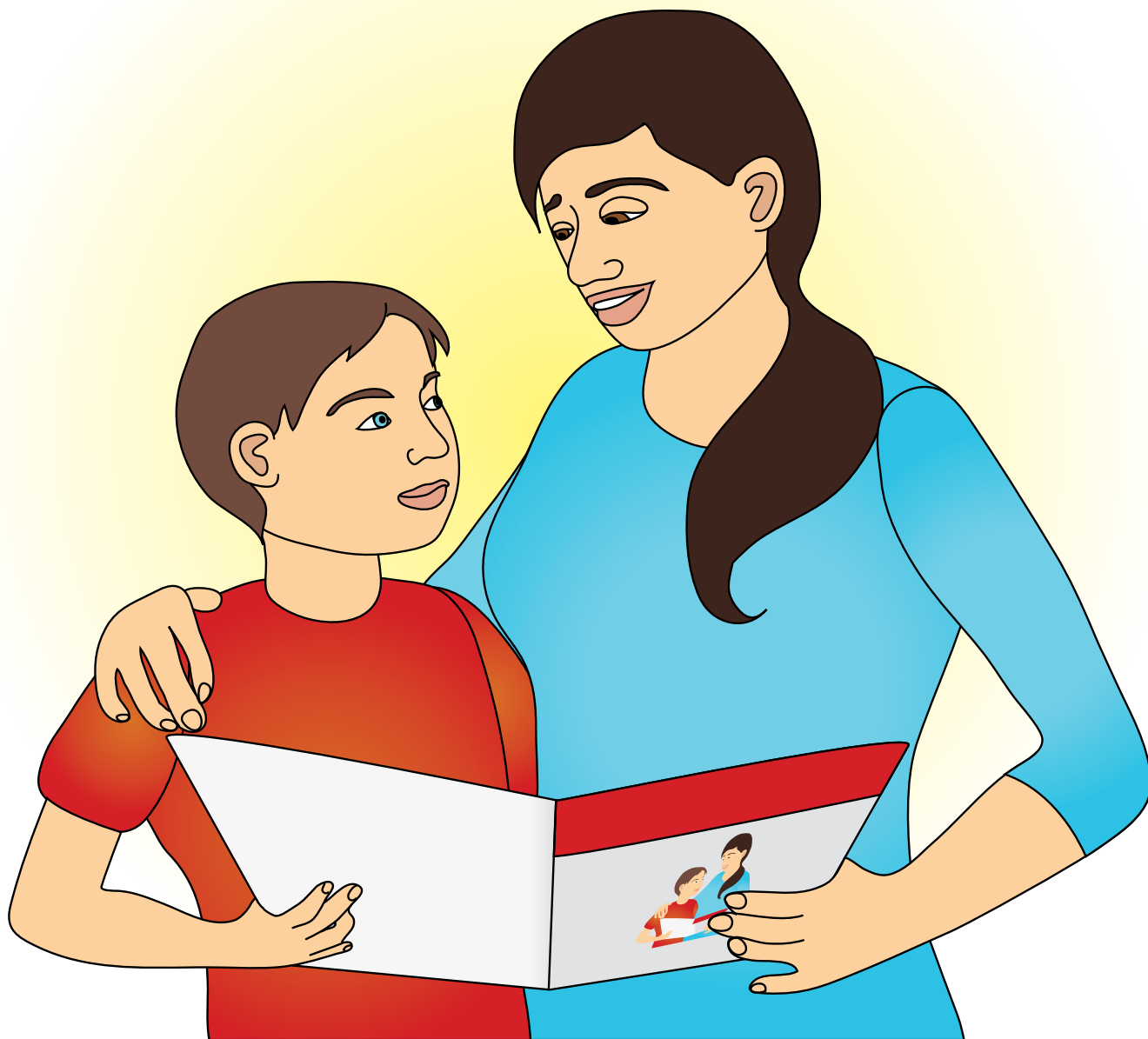


Home Enteral Feeding Guidebook

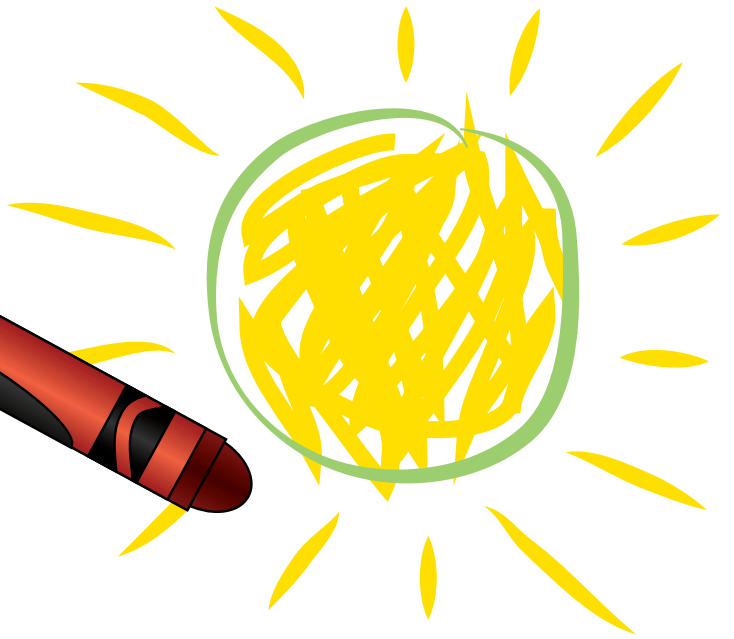
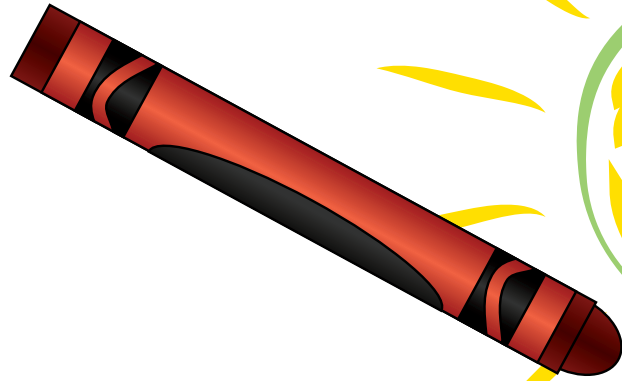
A Guide for Patients and their Families



Hôpital de Montréal
pour enfants
Centre universitaire
de santé McGill



Montreal Children's
Hospital
McGill University
Health Centre



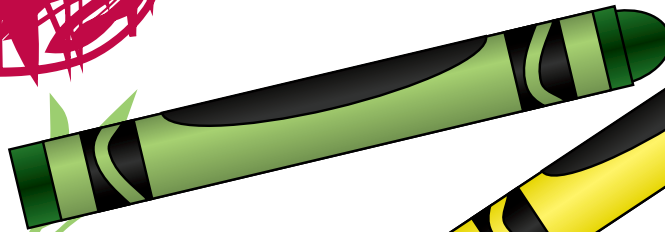
This personal guidebook belongs to:

Family Name: _____

Address: _____

Telephone #: _____

MCH #: _____



Acknowledgements

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Louise Colacci, BScN., HEF Nursing Coordinator.

It could not have been completed without the support and collaboration of the HEF Nursing team, of note:

Clelia Coccia, Nurse Clinician – Complex Care Service
Diane Martin & Patricia Grier, Nurse Clinicians - Neonatal Clinic
Hel  ne Pelletier, Nurse Clinician – Day Surgical Centre

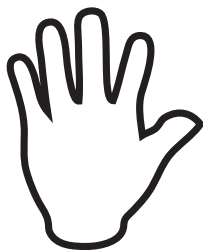
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IMPORTANT: PLEASE READ

Information provided by this booklet is for educational purposes. It is not intended to replace the advice or instruction of a professional healthcare practitioner, or to substitute medical care. Contact a qualified healthcare practitioner if you have any questions concerning your care.

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Introduction: a Family Guide

This Home Enteral Feeding (HEF) Guide has been designed to provide information and support for patients and their families and caregivers whose child is receiving nutritional assistance through a feeding tube.

What is the information in this guidebook about?

- **the goals of tube feeding**
- **how feeding tubes work**
- **how to insert a nasogastric tube safely and successfully**
- **gastrostomy tubes and buttons**
- **how to take care of feeding equipment**
- **troubleshooting problems you may encounter along the way**
- **ordering supplies and/or formula**
- **contact information of staff who can help you**
- **feedings, formulas and meeting your child's nutritional needs**

This guidebook can be used as a tool to remind you of things you were taught about tube feeding your child. Please review it and don't hesitate to contact your HEF team with any questions.

Why does my child need tube feeding?

Each child is unique. They come in many different shapes and sizes. The way they grow depends on many things:

- Genetics (they grow as their parents did)
- Nutrition or dietary needs (Without proper nutrition, they may not grow as much as they could or should.)

Some children don't grow as well as they should. Parents sometimes blame themselves for this, even though they have made every effort to encourage their children to eat the right foods and the right amount. However, these children often have health problems that burn a lot of their energy. This prevents them from growing as well as they could. Some may not be eating as much as they need and they may even not grow properly ("fail to thrive").

There are many health problems which affect a child's ability to eat and grow. One or more of these health problems can interfere with how food is eaten and/or absorbed in the body. Problems can include:

- difficulty with chewing or swallowing
- a chronic illness (or long-term health problem) that increases their calorie needs
- fatigue when eating (e.g. for very small birthweight infants)
- neurological problems
- problems related to sugar in the blood
- a need for the bowels to rest
- the need to "catch up" growth
- poor food absorption due to a digestive disease
- side effects from treatment and / or medication which affects appetite

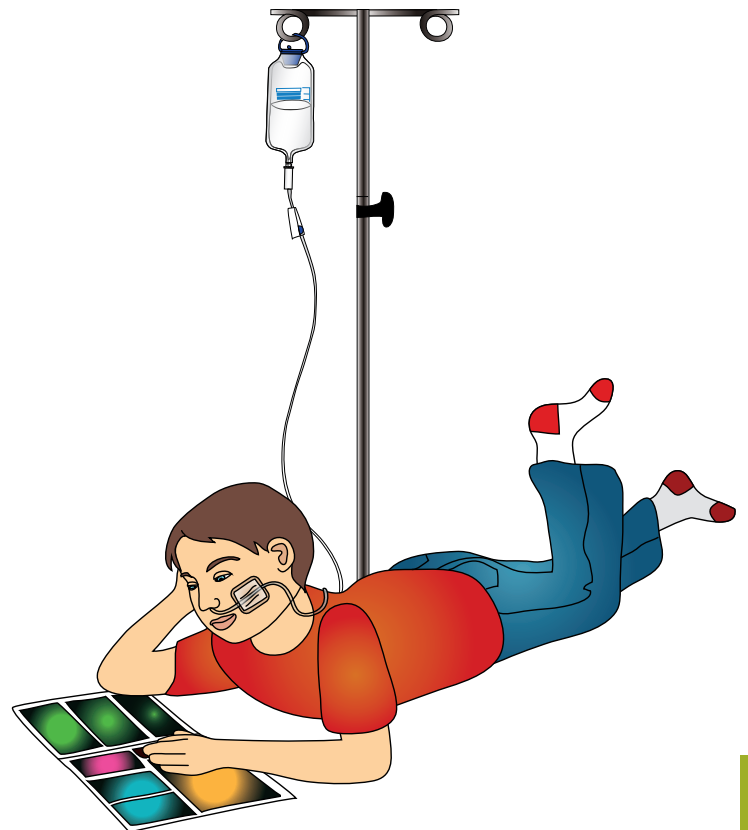


Your child may look smaller, younger or thinner than other children his/her age. In addition to the extra energy (calories) needed to meet his or her extra needs, even more may be needed to help him or her just catch-up.

Your doctor may suggest that you meet with a nutritionist who will work closely with you and your child to increase the calories in his/her daily diet. Sometimes even this modified diet is not enough to meet those important caloric needs and catch up is even more difficult. This is where tube feeding may become necessary.

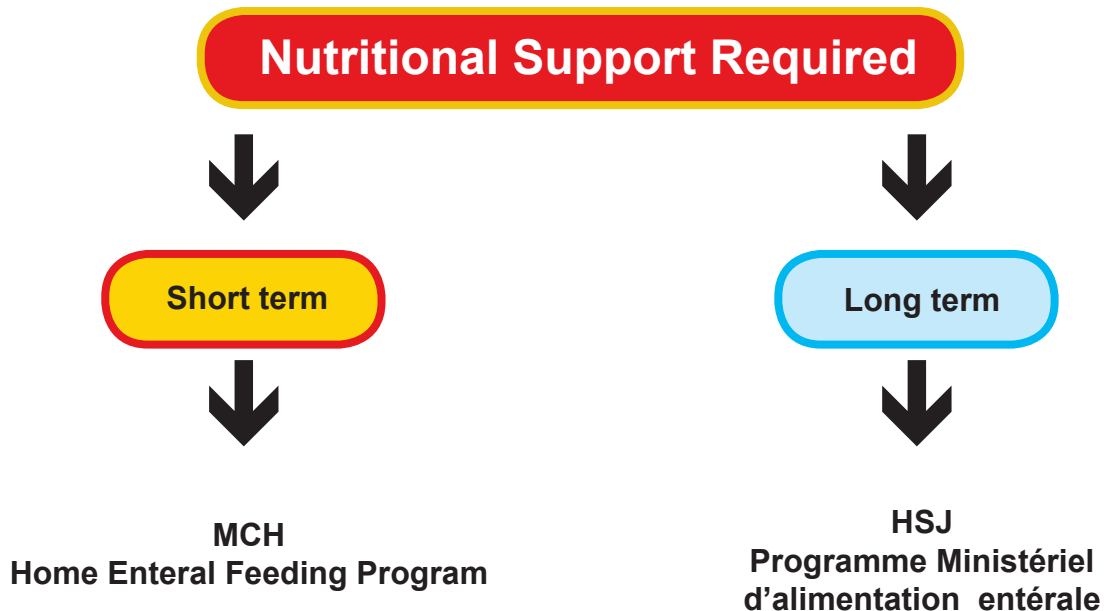
At first, it may be hard to imagine helping your child to feed this way. Maybe you find it hard to believe you'll ever get comfortable with it or you worry about the risks. Rest assured that the Home Enteral Feeding team at the Montreal Children's Hospital will be available to provide the appropriate information and will teach you the skills needed to safely provide your child with the nutritional support he/she needs. You will be encouraged to learn at your own pace and have plenty of opportunity to practice before your child is discharged from the hospital.

Finally, a Home Enteral Feeding nurse and nutritionist are just a phone call away in case you have questions or concerns. Your local CLSC or pediatrician may receive a referral from us requesting they provide the necessary support and follow your child's progress with regular weight checks. Both parents and healthcare providers must work together to ensure each child receives the necessary nutrition that will optimize his/her growth and development.



Nutritional Support at the MCH: how does it work?

The initial decision as to whether the needs will be short or long term will help determine where the feeding equipment resources will come from.



The Home Enteral Feeding Program (HEFP) is offered by The Montreal Children’s Hospital. The goal is to provide nutritional support for children who require “enteral” or tube feeding for a shorter period of time and for whom the return to oral feeds is likely. This short term program is funded by the Quebec Government and managed by the MCH.

The Quebec’s Programme Ministériel d’Alimentation entérale (PM) is offered to children who need tube feeding for a longer period of time (sometimes for their lifetime). CHU Sainte-Justine has been mandated by the Quebec Government to administer this program.

The primary specialty clinic at the MCH (neonatal, gastroenterology, complex care, nephrology, etc..) following your child has a HEF team to monitor and provide the nutritional support your child needs. This team is made up of a doctor, nurse and nutritionist.

For children requiring long term nutritional support, who do not have specialty clinic needs and who do not have adequate community support, a **Satellite Enteral Feeding Clinic (SEFC)** has been established to monitor proper nutrition and care. The team is made up of a paediatrician, nurse and nutritionist.

Your Child's Feeding Tube

Tube type and brand:	
Tube size:	
Health care provider who inserted the tube:	
Date the tube was inserted:	
Date when tube should be changed:	
Where to go to have it changed:	
Who can change it:	
Other details:	

Ordering Equipment

To order your child's feeding equipment:

1. Please place your order at least 3-5 working days before pick-up.
2. Resources are limited. Please order only what you need and for 1 month at a time. Exceptionally, orders for 3 months supply can be prepared for those families who live far from Montreal or who are travelling out of the country. In these special cases, please place your order at least 2 weeks prior to pick-up.
3. To order: call the Warehouse & Distribution Service (W&D) at 514-412-4400 ext. 24406 between 07:30 a.m. and 15:00 p.m.
4. During weekdays, you can pick up the supplies in the Home Enteral Feeding Cupboard located on the 1st floor C1.05.

Door Code: _____.

*Please see "Feeding Equipment & Formula Pick-Up" page for weekend and after 16:30 weekday pick-ups.

Please call the Warehouse & Distribution Service or leave a voicemail message if you are unable to pick up your order as arranged. Otherwise, another 3 days will be needed to prepare a new order.

Approved equipment	Quantity per month

If you wish to make any changes to the "Approved equipment", please contact your Home Enteral Feeding (HEF) Program nurse.

HEF Nurse _____ 514-412-4400 ext _____

Ordering Formula

Before your child is discharged home, you should receive a medical prescription for his or her formula. If it is a specialized formula covered by the government, a RAMQ form must be completed. Your nutritionist may guide you through this process. You may then have your prescription filled and receive the formula from the pharmacy. Specialized formulas covered by the Quebec government are free of charge. For those products that are not covered, you may submit a copy of the prescription and proof of payment from the pharmacy to your insurance company to determine if it is included in your policy. The HEFP budget does not cover these products in any way.

In special circumstances, you may be permitted to order your nutritional products from the HEFP.

To order your child's formula:

1. If you have been directed to order your child's formula through the Home Enteral Feeding Program, call 514-412-4400 local 23873.
2. Please place your order at least 1 week before pick-up. Orders placed between Friday evening and Sunday will not be ready before the following Thursday at the earliest.
3. Leave your message (order) on the answering machine including your child's name and hospital card number. You will not get a call back unless there is a problem with your order.
4. If you require more than 1 month's supply or if your child requires a special formula (not usually stocked), please allow 1 full week before pick-up. In these situations, it would be best to call before actual pick-up to make sure the product is ready and available.
5. You may pick up the formula in the Home Enteral Feeding Cupboard located on the 1st floor C1.05.

Door Code: _____

*Please see "Feeding Equipment & Formula Pick-Up" page for weekend and after 16:30 weekday pick-ups.

Approved products	Quantity per month

If you require any changes to your formula, please contact your child's nutritionist who may authorize the change.

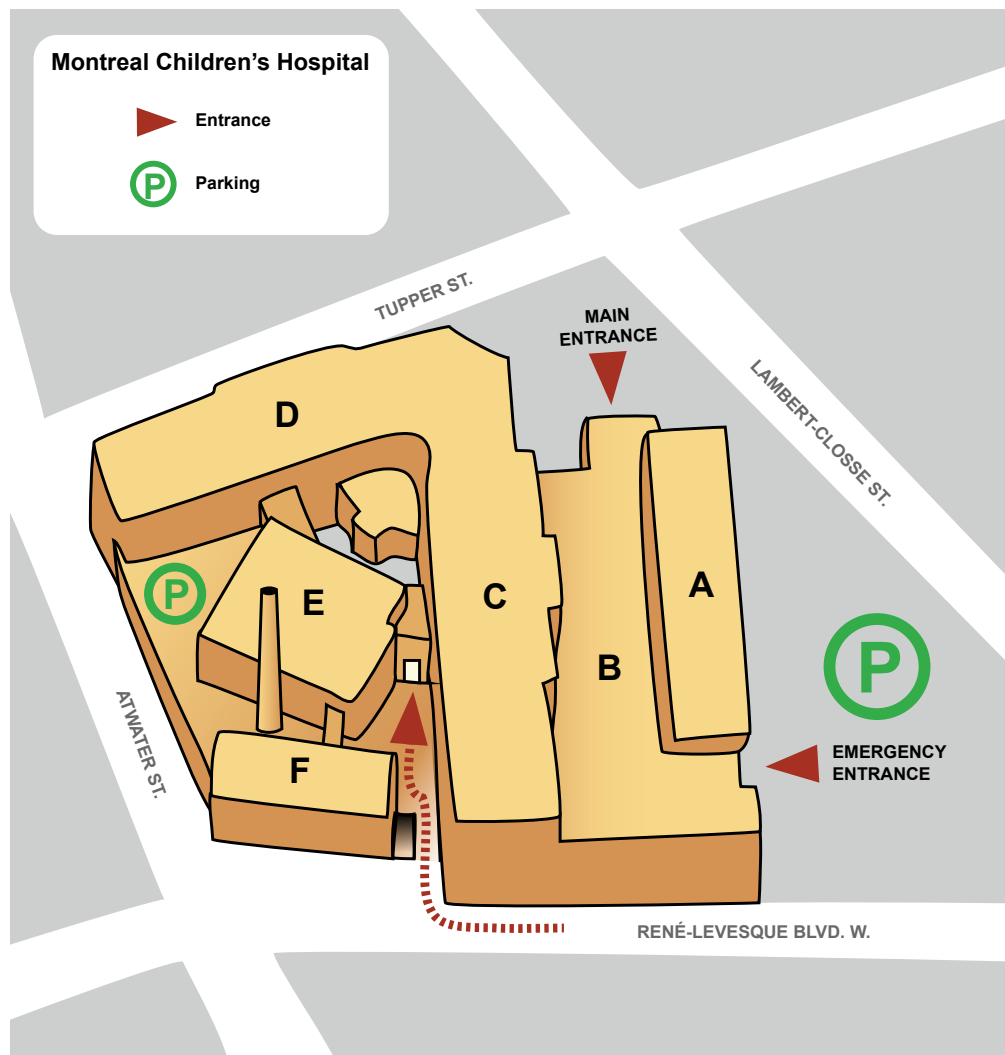
Nutritionist: _____ 514-412-4400 ext _____

Feeding Equipment and Formula Pick-Up

Weekdays, between 07:00 and 16:30, parents may pick up their child's enteral feeding supplies entering the hospital through the front entrance and proceeding to the home enteral feeding cupboard (C1.05) on the first floor (near Radiology Dept). However, on **weekends and after 16:30 weekdays**, parents may also access the cupboard by entering via the employee's locked entrance (up the ramp on René Lévesque Blvd).

Parents may park their car at the top of the ramp on the right hand side, for a few minutes while collecting their supplies using the employee's locked entrance. Press the button beside the door to buzz and ask for security to remotely unlock the door. Once the supplies are obtained from the cupboard, the inside buzzer beside the door must be pressed to request security to let them out from the same exit.

Please note that this access is not possible during the regular weekday hours due to the volume of traffic in the garage area. However, security would be pleased to assist the parents during the off hours.



Equipment Suppliers

Below are some suggested names of medical equipment suppliers for families who have private insurance and/or who wish to purchase additional supplies. Many pharmacies, ostomy centres and specialized supply centres also provide them. This list is a comprehensive list and is not sponsored in any way.

Caléa Ltée
4847 rue Lévy
Ville Saint Laurent, Qc
H4R 2P9

Tel : 514-335-3500 # 227
Fax : 514-335-3400
www.calea.ca

Dufort et Lavigne
1227 Rachel St. E.
Montréal, Qc
H2K 3T3

Tel : 514-527-9381
1-800-361-0655
Fax : 514-527-6883
www.dufortlavigne.com

Pharmacie Bergeron
Jutras, Ménard
145 St. Charles O.
Longueuil, Qc
J4H 1C7

Tel : 450-677-6366

Pharmacie Grondin Duval
250 rue King E.
Sherbrooke, Qc
J1G 2J1

Tel : 819-563-4401
Fax : 819-346-4855

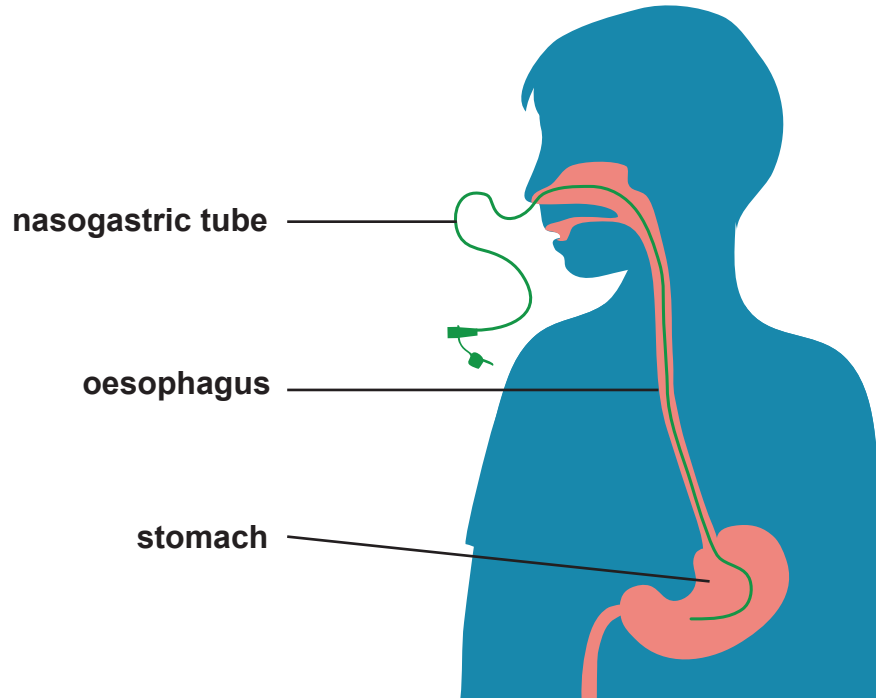
Médi Sélect Ltée
670 Bouvier, Suite 116
Québec, Qc
G2J 1A7

Tel : 418-623-3353
1-800-463-5166
Fax : 418-623-1211
1-866-323-1211
www.medi-select.ca

All About the Nasogastric Tube

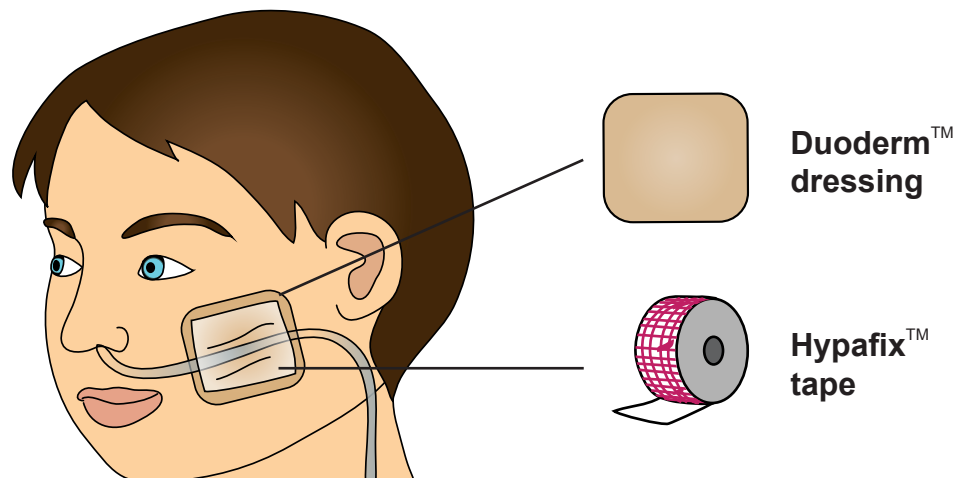
What is it?

A nasogastric (or NG) tube is a small tube that is passed into the nose, down the back of the throat, down the esophagus and into the stomach. It can be used for feeding your child or removing liquid from the stomach.



Parents can learn how to insert the NG tube and many older children learn to insert it themselves. The NG tube can feel uncomfortable at first. It's kind of like wearing a watch or a ring. With time, you become less aware of it being there. Having an NG tube in place should not hurt.

An NG tube is kept in place by taping it to the cheek. To avoid irritating the skin, a thin Duoderm™ dressing may be placed on the cheek first. Once the NG tube is inserted, it can be fixed in place over the Duoderm™ and finally covered with a small Hypafix™ tape. This way, the skin is protected and the tube should stay firmly in place.



Inserting the Nasogastric Tube in a Baby or Child

Steps	Technique
1. Wash hands	The insertion of a nasogastric tube requires a clean technique (not a sterile one). A clean technique means washing your hands carefully before you begin.
2. Gather the supplies	You will need the NG tube, water-soluble lubricant, a 10 ml syringe, the Duoderm™ and the Hypafix™ dressings.
3. Prepare the tube and the dressing	Measure and mark the NG tube. To figure out how much of the tube must go in: with the tip of the tube, measure from the tip of the nose to the earlobe. Continue down past the breastbone (sternum) stopping half way to the bellybutton (umbilicus). Mark this length with a permanent marker. (After inserting the tube, you should be able to see this marking at the edge of the nostril).
4. Prepare the child	Be sure the nostrils are clear of secretions. For a younger child, you can clear away any mucus with a tissue or gently, with a bulb syringe. Ask an older child to blow their nose.


Steps	Technique
<p>5. Insert the NG tube</p>	<p>Position: for an infant or young child, position on his/her right side or back, with head slightly raised. An older child may be more comfortable sitting up, standing or even inserting the tube themselves.</p> <p>You may need a second person to hold a young child or baby especially the first few times you are practicing putting the tube in. Your nurse can show you how to blanket cuddle a child if necessary.</p> <p>Insertion: Lubricate the tip of the tube with the water-soluble jelly or water. Close the cap on the other end of the NG tube. Insert the pre-measured, lubricated tip in a nostril using a slightly downward motion to the back of the nose (aiming the tip to the lower earlobe). Continue gently and smoothly until the marker reaches the edge of the nostril. Secure the tube to the cheek using tape. In cases where the tube is to be left in place, first apply a thin duoderm™ dressing on the cheek. Place the tube across the duoderm™ and cover with a hypafix™ dressing of the same size. This will help avoid irritation to the skin.</p> <p>For children using the polyvinyl (weekly) tube, we recommend changing sides each week when you are changing the tube. For those using the polyurethane (monthly) tube, it is important to alternate sides each month.</p> <p>Troubleshooting:</p> <p>(a) if the tube curls up in the mouth or it is difficult to move the tube forward, don't panic! Withdraw the tube and wait a moment for the child to calm down and then try again.</p> <p>Giving a pacifier to a baby or asking an older child to swallow some water through a straw while you are advancing the tube may help it pass more easily down the throat. As you're inserting the tube, gagging and coughing sometimes happens and is perfectly normal. However, once the tube is properly inserted, this should stop.</p> <p>(b) If you have great difficulty inserting the tube and/or the child turns blue (stops breathing), immediately pull the tube out as it may have gone down the wrong way. The baby/child should return to normal breathing right away. You should both relax for a few minutes and then try again.</p>


Steps	Technique
<p>6. Check tube placement</p>	<p>Each time you change/insert the NG tube and before each feed, you should check to see that the tube is in the stomach.</p> <p>How: Attach an empty 5 or 10 ml syringe to the end of the NG tube and pull back (aspirate) gently on the plunger. If you see a small amount of milk or stomach secretions, the tube is in the right place. If the stomach is empty, you may not get anything back in the syringe. You can try and move the tube a few centimeters further in or out and aspirate again.</p> <p>If you are still unable to see any stomach contents, push 5 ml of air quickly in the tube with your ear pressed against your child’s stomach. You should hear a “swoosh” of air as it enters the stomach. If you are still not certain that the tube is in the stomach, do not give the feed. It’s safer to remove and replace the tube and be sure of its position before starting the feed.</p>
<p>7. Start the feed</p>	<p>Remember, each time you use the tube for a feeding or to give medication, you must verify the position of the tube by:</p> <ol style="list-style-type: none"> 1) CHECKING that the marker is visible on the tube at the nostril. 2) WITHDRAWING a small amount of the stomach contents and/or 3) INJECTING 5 ml of air and listening for the “swoosh.” 4) OBSERVING your child for comfort as the feed begins. <p>Once you are sure the tube is in the stomach, always flush the tube with 2-5 ml of water before giving the feed.</p>
<p>8. End the feed</p>	<p>At the end of the feed, you may flush the tube with about 3 to 5 ml of water to make sure your child receives the total feed. Remember to close the cap at the end of the tube securely to avoid any spillage from a full tummy.</p>


Inserting the Nasogastric Tube (baby)

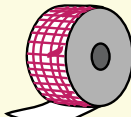
1.  **Wash your hands**

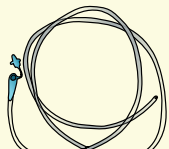
2. Gather your supplies

 10 ml syringe

 Water-soluble lubricant

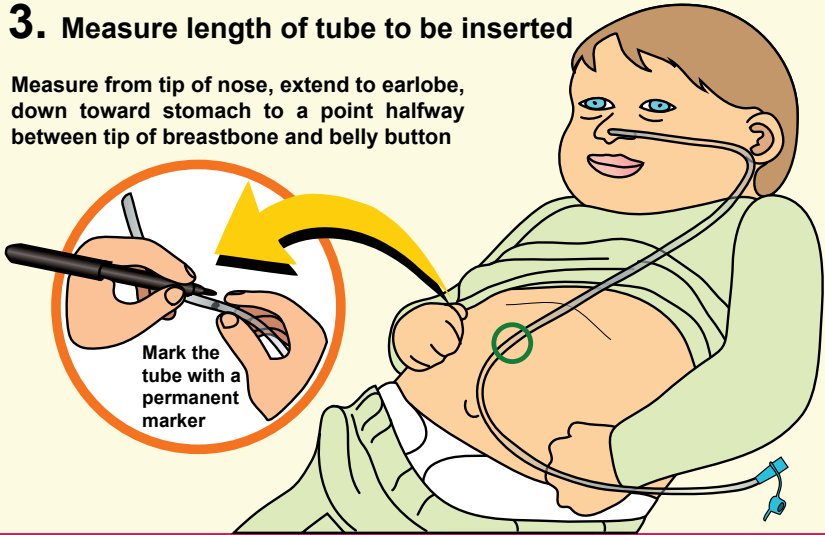
 Duoderm™ skin dressing

 Hypafix™ tape

 Nasogastric tube

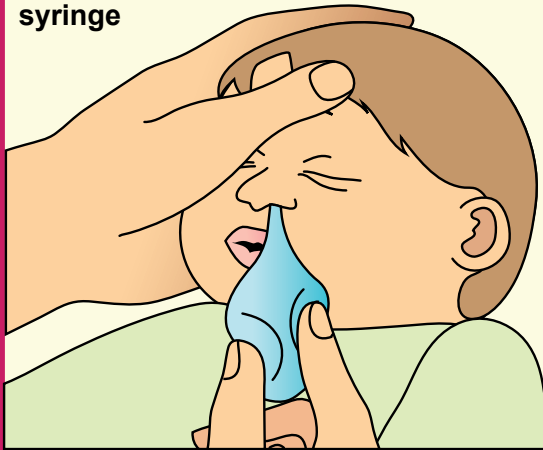
3. Measure length of tube to be inserted

Measure from tip of nose, extend to earlobe, down toward stomach to a point halfway between tip of breastbone and belly button

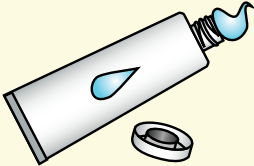


Mark the tube with a permanent marker

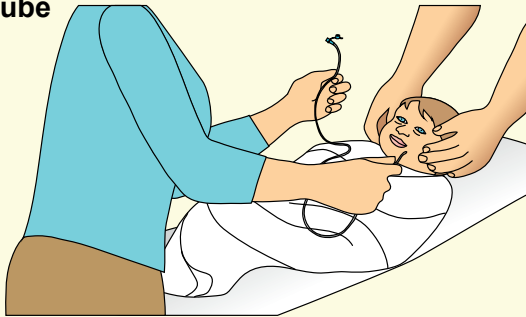
4. Clear nasal passage with tissue and and / or gentle aspiration with bulb syringe



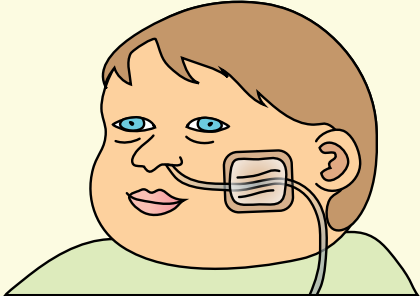
5. Insert the nasogastric tube



Dip the end of the tube in water-soluble lubricant



Swaddle the baby in a blanket. While gently but firmly holding the baby's head straight, thread tube through nostril. Stop when mark reaches the nostril



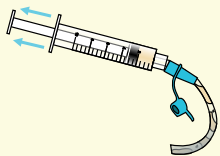
Use Duoderm™ skin dressing and Hypafix™ tape to secure tube to cheek. Alternate sides each week or month, depending on the type of tube being used

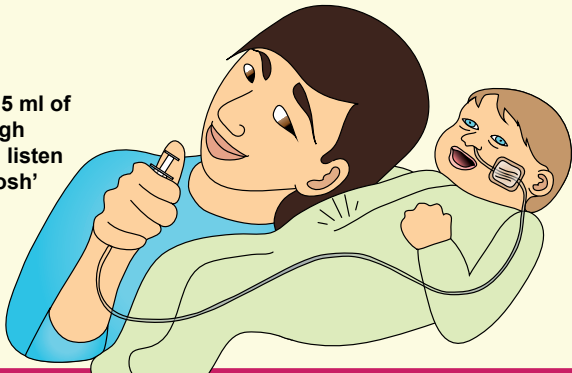
6. Check tube position by either:

a) trying to extract a small amount of stomach contents with a 10 ml syringe

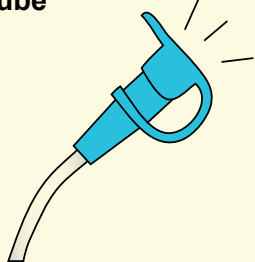
OR

b) pushing 5 ml of air through tube and listen for 'swoosh' sound






7. Close the cap at the end of the tube




Inserting the Nasogastric Tube (child)

1. Wash your hands



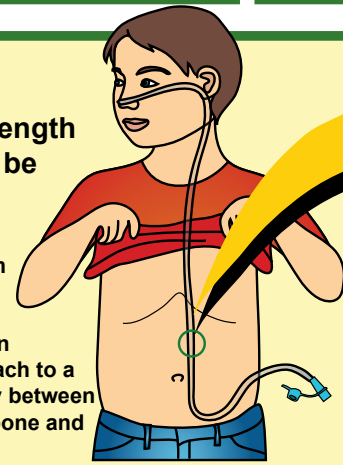
2. Gather your supplies




10 ml syringe Water-soluble lubricant Duoderm™ skin dressing Hypafix™ tape Nasogastric tube

3. Measure length of tube to be inserted


Measure from tip of nose, extend to earlobe, down toward stomach to a point halfway between tip of breastbone and belly button




Mark the tube with a permanent marker




4. Clear nasal passage



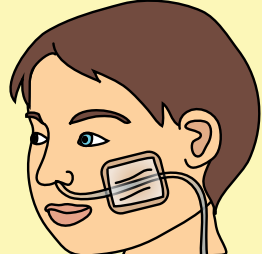
5. Insert the nasogastric tube



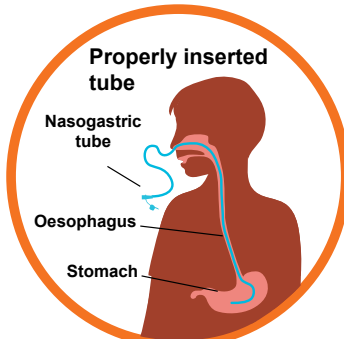
Dip the end of the tube in water-soluble lubricant



Gently thread tube through nostril. Stop when mark reaches the nostril



Use Duoderm™ skin dressing and Hypafix™ tape to secure tube to cheek. Alternate sides each week



Properly inserted tube

Nasogastric tube

Oesophagus

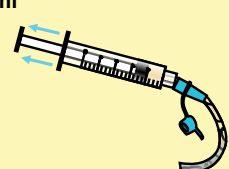
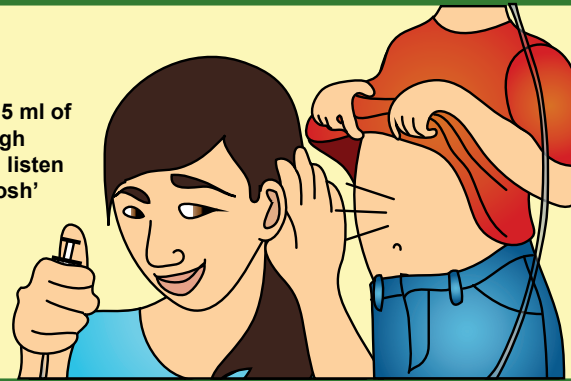
Stomach

6. Check tube position by either:

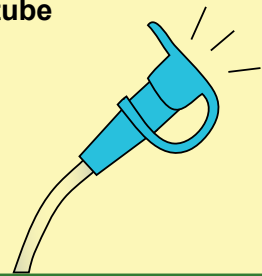
a) trying to extract a small amount of stomach contents with a 10 ml syringe

AND / OR

b) pushing 5 ml of air through tube and listen for 'swoosh' sound

7. Close the cap at the end of the tube



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Self Insertion of the NG Tube (older children and teenagers)

Some older children require NG feedings to get the extra calories they need to grow well. Others may need to give their bowel a rest for a few weeks or months and so they receive a special pre-digested formula. The NG route is used because sometimes the formula doesn't always taste good enough to drink or has to be taken in large amounts. Whatever the reason, many older kids prefer to take control and insert as well as care for their own tubes and feedings. Why not?

It begins with your HEF nurse and/or nutritionist working out the details with you about the changes in your daily routine. It's also time to express some of your feelings about it before getting down to the business of learning how to insert the NG tube.

If you're ready, let's get started!

Step 1	Gather all your equipment (nasogastric tube, water-soluble lubricant jelly, syringe, stethoscope - if you want one).
Step 2	Choose a comfortable place to do the insertion, standing or sitting.
Step 3	Ask a "coach" (if you have or want one) to come and encourage you, especially that first time! Or not. It's up to you!
Step 4	Using the NG tube itself, measure the distance from the bridge of your nose to the tip of your earlobe and continue down past the end of the sternum (breastbone) and continue halfway down to your bellybutton. Mark the spot on the NG tube with a permanent marker to remember how far you should insert the tube.
Step 5	Dip the tip of the NG tube in water-soluble jelly or tap water.
Step 6	Gently insert the tube into a nostril. When you feel it at the back of your nose, swallow as you continue to gently (but not too slowly) push it down. Keep swallowing if you can.
Step 7	If it tickles or makes you cough lightly, take some slow, deep breaths then continue pushing the tube in until the marking on the tube reaches your nose. Look in the mirror to know where you're at! If it feels too uncomfortable and makes you choke, take it out, take a few minutes to relax and try again.

Step 8	Once the tube is in place, tape it securely to your cheek. If you coughed during insertion, you should have stopped by now and, once in the proper place, the tube shouldn't hurt but it does take a little getting used to.
Step 9	Finally, you need to double check placement of the tube in your stomach. To do this, you can attach a syringe to the end of the tube and pull back on the plunger to withdraw some stomach juices. Another check is to draw about 5 ml of air into the syringe. Attach it to the end of the tube and push it quickly into the NG tube while listening/feeling for the "swoosh" with a stethoscope on your stomach or placing your hand on your stomach. If the room is quiet, you can probably hear it without the stethoscope or ask your "coach to rest his/her ear against your stomach and listen as you eject the air. If you hear it, you're in!
Step 10	And finally, always remember to recheck your tube's position before each feeding or after a lot of coughing. Also, before and after each use, flush the tube with about 5 - 10 ml of water to make sure it's not blocked.

BRAVO!! YOU DID IT!!

Fantastic!


Stupendous!

AMAZING

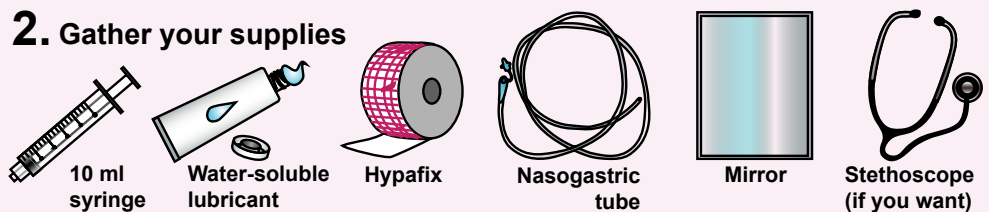
AWESOME!

PERFECT!

How can my child insert their tube on their own?

1.  Wash your hands

2. Gather your supplies



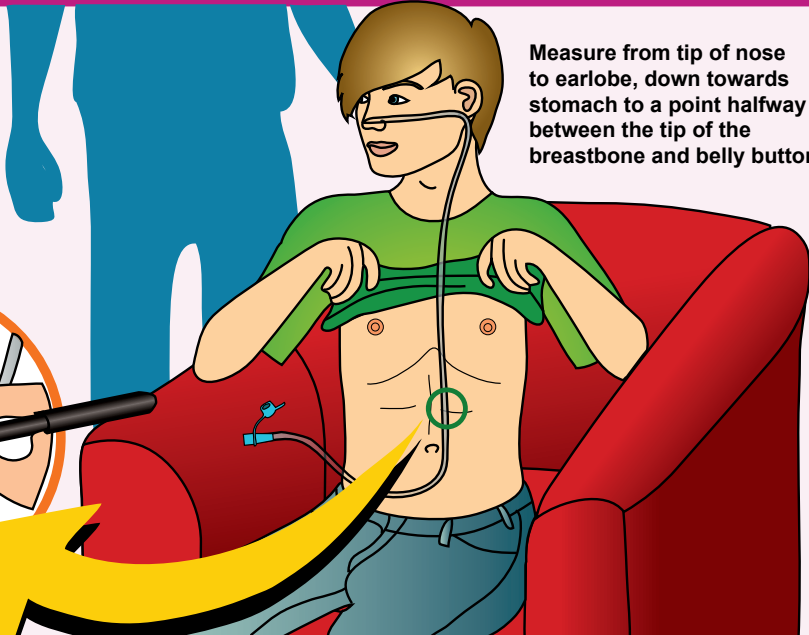
10 ml syringe Water-soluble lubricant Hypafix Nasogastric tube Mirror Stethoscope (if you want)

3. Choose a comfortable place to do the insertion (standing or sitting)

4. Consider asking someone to stand by for help or encouragement


5. Measure length of tube to be inserted

Measure from tip of nose to earlobe, down towards stomach to a point halfway between the tip of the breastbone and belly button




Mark the tube with a permanent marker


6. Dip end of tube in water-soluble lubricant or tap water




7. Insert tube into nostril




If you begin to choke, remove the tube and begin again in a few minutes



8. Tape tube to cheek

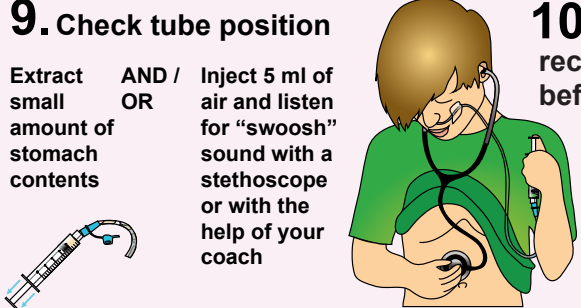


Look in the mirror and see how far you need to go. When you feel it at the back of your nose, swallow as you continue to push it down



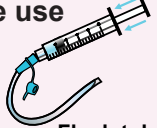
9. Check tube position

Extract small amount of stomach contents AND / OR Inject 5 ml of air and listen for "swoosh" sound with a stethoscope or with the help of your coach



10. Be sure to recheck position before use

Flush tube with 5 - 10 ml of water to make sure it is not blocked



Changing / Removing the Different Kinds of NG Tubes

If your child requires an NG tube, you can discuss with your HEF nurse as to whether it needs to remain in the stomach at all times and how often it needs to be changed.

1. The Polyvinyl Tube (most commonly used)

Depending on the age and needs of your child, this tube may be removed after each feeding or changed weekly only. For the adolescent whose nutritional needs include a daily bolus, the polyvinyl nasogastric tube can be inserted before a feed and removed once it's over. It can be washed and reused up to a week. For the baby or child who needs daily bolus feeds or continuous feeds at night, it would be more practical to simply secure the tube in place and change it once a week.

Always flush the tube with 5-10 ml water before and after feeding. Make sure the cap is closed and, before removing, pinch the tube firmly to avoid liquid dripping out of the tube during removal. The tube should be removed using a smooth, rapid motion.

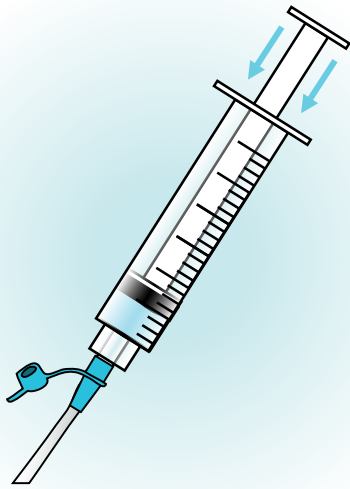
2. The Argyle Indwelling Feeding Tube

This polyurethane tube is used almost exclusively by the neonatal population and in special situations. It may be left in place for up to 1 month. As for all NG feeding tubes, the position in the stomach must be checked before each feed. Speak to your HEF nurse for more details.

3. The Corpak™ Feeding Tube

This tube is designed for insertion with a stylet (metal guidewire) and is usually inserted by medical personnel. Placement is done in hospital and verified by x-ray before discharge from hospital. It may be left in place for up to two months before changing. As usual, placement must always be verified before feeds or medication use. If accidentally dislodged, this tube should not be reinserted. Contact medical personnel for reinsertion.

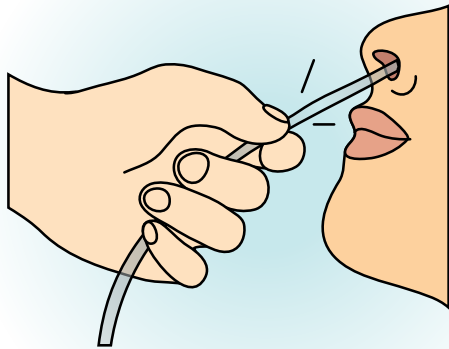
Removing the NG Tube



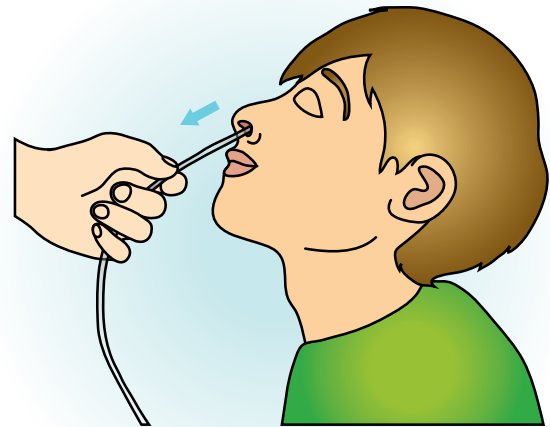
1. Flush the tube with 5-10 ml water after feeding.



2. Make sure the cap is closed.



3. Pinch the tube firmly to avoid liquid dripping out of the tube during removal.



4. Pull out the tube in one smooth, rapid motion.

Frequently Asked Questions About the Nasogastric Tube



Q. Does a nasogastric tube hurt once it's in place?

A. No. Inserting the tube can be uncomfortable but babies and children generally do not find the tube painful and get used to it fairly quick.

Q. Can I give my child a bath with the tube in place?

A. Yes, and remember, bath time could be a good place to begin the routine tube change. If it's not time for the daily ,weekly or monthly NG tube change, simply secure the tubing around the back of the neck with a piece of tape to prevent accidental dislodging of the tube during bathing. Take care not to wet the dressing on the cheek.

If it is time for the tube to be changed, wet the tape thoroughly and gently remove the tape over the tube. Making sure the tube is capped, gently but quickly, withdraw the tube. Once the tube is removed, peel back the Duoderm™ dressing from the child's cheek. When the bath is over, dry the skin well and prepare to re-insert a new one.

Q. What should I tell people about the tube?

A. Since the tube may be visible, people may curiously ask you what it's for. You can decide how much information you want to give them. The people who do need to know more about it may include family members, babysitters, teachers, classmates. The rest is up to you. **Remember, tube feeding is just a different way to feed your child.**

Q. Can I re-use syringes?

A. Yes, syringes may be re-used daily for up to a week and then discarded. Separate plunger from barrel to wash and allow to dry thoroughly before reassembly.

Q. Can I re-insert the tube in the same nostril each time?

A. Alternating the nostril side is generally more comfortable for the child and allows the cheek to heal if it's been irritated by the taping. If however, one nostril is blocked, or for some other reason, the alternate nostril is uncomfortable or unsuitable, there's no reason why the same nostril cannot be used.

Q. Does my child need any special mouth care?

A. If your child cannot take any food by mouth, his/her mouth may become dry, sticky and uncomfortable. A soft baby toothbrush or moist face cloth may be used to clean their gums, teeth and tongue. A gentle lip balm can soothe or prevent chapped or dry lips.



Q. Do I need to burp my baby after a tube feeding?

A. Babies can be burped after an NG feed. For older children or a baby who is difficult to burp, venting the tube (releasing the air by opening the tip) may help relieve gas or bloating.

Q. Can I replace some of the formula or add pureed food to my child's diet through the tube?

A. It is very important that any changes to your child's diet be discussed with the nutritionist. The quantity and quality of the formula is specifically adjusted to assure your child gets exactly what he/she needs for optimal growth and overall health. Also, no pureed foods should be given down the tube as it may block and damage the tube within the stomach.

Q. Do I need to use sterile water to flush the tube before and after feeds?

A. The digestive system is not sterile so it's not necessary to use sterile water. Using distilled or tap water is fine. However, if your child is 3 months of age or younger, sterile or boiled water is recommended.

Problem Solving for the Nasogastric Tube

Below are some of the more common problems encountered along with possible causes and solutions. If the problem is recurrent or severe and, if you have more questions, please contact your HEF nurse.

Problem	Possible cause	What to do
<p>Aspiration: difficulty in breathing with coughing and/or choking; may also have blueness or cyanosis.</p>	<ul style="list-style-type: none"> • Vomiting or reflux of stomach contents into the lungs • Food or saliva going down wrong tube (breathing tube or trachea) 	<ul style="list-style-type: none"> • Make sure head of bed is elevated and observe carefully before tube feeding. • If unsure of the placement of the NG tube, remove it immediately. • If symptoms persist, go to medical ER (to check for pneumonia) if this is unusual for your child or if the episode is more severe than usual.
<p>Blocked tube</p>	<ul style="list-style-type: none"> • Formula or stomach contents • Medication 	<ul style="list-style-type: none"> • Flush the tube with 5 -10 ml warm water before and after feeding or giving meds. • Do NOT give pureed foods through the tube. • Do not mix anything new into the formula without consulting the HEF nurse or nutritionist. • If blocked, flush the tube with 10 ml warm water and use a jet push motion to try and unblock the tube. • Use only liquid or finely crushed medicine dissolved in water.
<p>Constipation: infrequent hard stools that can be painful to push out.</p>	<ul style="list-style-type: none"> • Not enough fluids • Not enough fibre • Low activity level • Medication side effects 	<ul style="list-style-type: none"> • Increase fluid intake. • Increase fibre intake. • If possible, increase daily activity. • Consult HEF team.

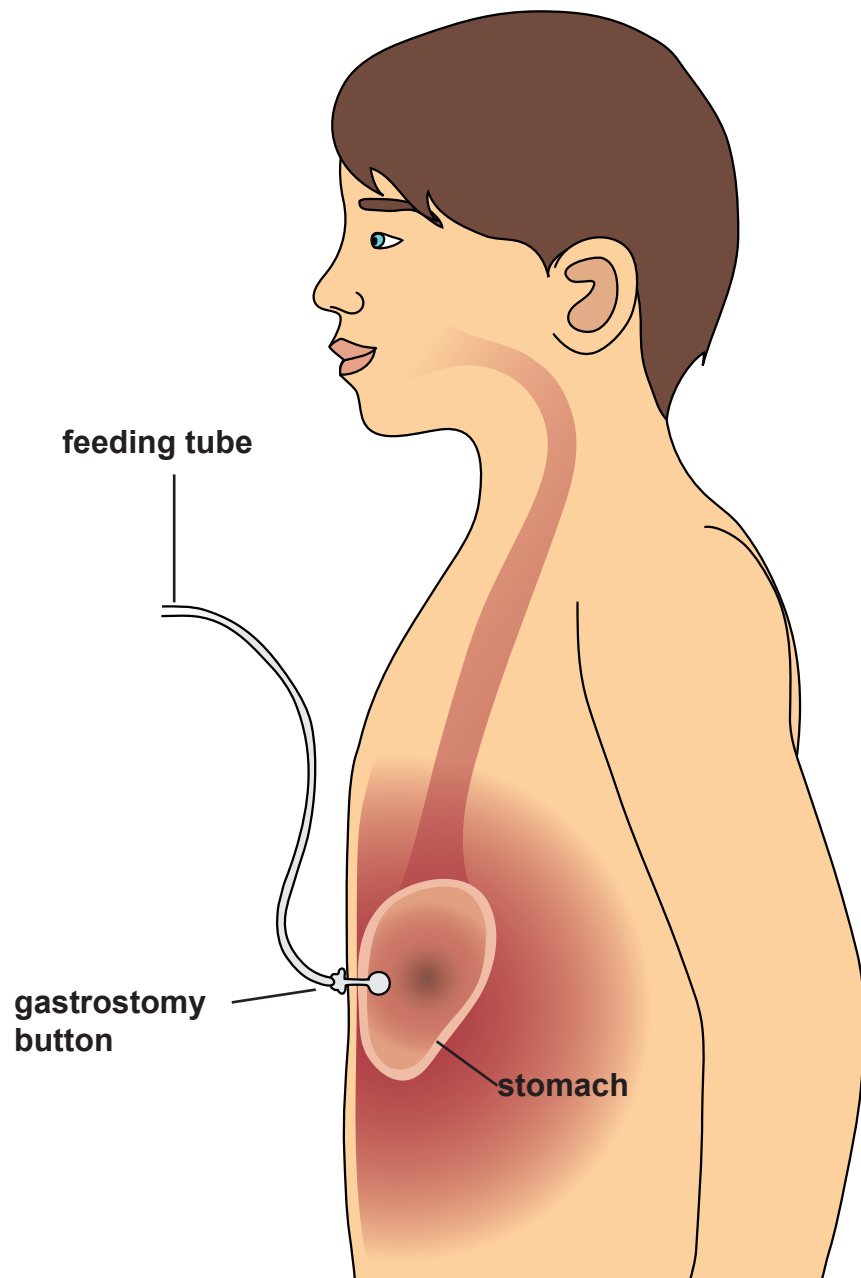
Problem	Possible cause	What to do
Diarrhea: frequent loose or watery stools	<ul style="list-style-type: none"> • Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis 	<ul style="list-style-type: none"> • Recheck and follow the directions to prepare formula correctly. • Check expiry date and throw out or return spoiled formula to pharmacy. • Review the guidelines for formula storage & “hang time”. • Decrease or adjust the feed rate after checking with HEF nutritionist. • Verify pump is functioning properly or readjust roller clamp for gravity feed. • Verify NG tube placement before each feed. Ensure gastrostomy tube or button is properly placed in stoma. • Speak to your HEF team. • Discuss an increase in fibre content with HEF nutritionist. • Speak to your HEF nutritionist. • Speak to your HEF team.
Dry mouth	<ul style="list-style-type: none"> • Underactive mouth 	<ul style="list-style-type: none"> • Brush the teeth and/or clean the mouth at least twice per day. • Apply lip balm or lubricant to lips.
Gas or bloating	<ul style="list-style-type: none"> • Air in stomach • Too much formula per feed. 	<ul style="list-style-type: none"> • Burp during the feed. • Ask you HEF nurse about decompressing the stomach or how to release the air/gas. • Make sure NG tube is properly closed when not being used. • Speak to your HEF nutritionist to adjust quantities per feed.

Problem	Possible cause	What to do
<p>NG tube pulled out by baby / child</p>	<ul style="list-style-type: none"> • Infants or children who cannot understand, may pull out the tube one or several times a day 	<ul style="list-style-type: none"> • Never leave a child alone during a feed as they can pull out the tube and choke. • Always check the position of the tube just before feeding. • Leave the loose end of the tube inside the clothing or taped to the clothing between feedings. • When taping the tube to the cheek, place the tape close to the nostril so the baby's fingers cannot slip behind the tube near his/her nose. • If frequently pulled out, try mittens/ socks to cover hands.
<p>Nausea and / or vomiting</p>	<ul style="list-style-type: none"> • Too short amount of time between feeds • Feeding too quickly • Slow digestion in the stomach • Other gastrointestinal problems 	<ul style="list-style-type: none"> • If feeding not tolerated, slow or stop the feed until the child is comfortable. If necessary, delay the next feed by 15-20 minutes and restart slowly. • Slow down feed, whether by gravity or pump. • Burp or decompress stomach during feed. Your HEF nurse can show you how to do this. • Feed child in sitting position or with head of bed raised to 45 degrees. • Speak to your HEF team.

All About the Gastrostomy Tube / Button

What is it?

A gastrostomy feeding tube is either a tube or a button (skin level device) that is surgically placed into the stomach through the abdominal wall. The purpose is to make sure your child receives the nutritional support necessary for optimal growth and development. There are a wide variety of tubes and skin level devices available. Your surgeon will choose the device which best meets your child's needs with the least invasive technique. It is mainly used for the long term administration of formulas, fluids, and medications. In particular health issues, it can also be used over the short term.



How is it inserted?

There are different surgical techniques for inserting a gastrostomy tube or button device and they are all inserted while the child is under general anaesthesia. Three of the more common techniques are:

1. Laparoscopic Gastrostomy

This method is minimally invasive and considered very safe as everything is done under direct vision. The surgeon will make about 2-3 small incisions in a patient's abdomen. A nozzle is placed into one of the slits and a gas inflates the abdomen. A laparoscope (flexible camera) is then inserted into another slit. This allows the surgeon to see clearly into the abdomen. A feeding tube or button device can then be safely placed into the stomach (gastrostomy) or small bowel (jejunostomy). The tube or button may be temporarily held in place with a few stitches. The gas is then released through the slits and these sites are closed. Once the stoma is healed, the stitches are removed, usually about a week or two after the surgery. The whole procedure takes approximately 30-45 minutes and the feeding port can usually be used within 24 hours. Your child will be given medication for any pain or discomfort experienced after the procedure.

2. Open Gastrostomy

An open gastrostomy is often done at the same time as other intestinal procedures or for patients who have had previous abdominal surgeries. In an open gastrostomy, a small opening is made in the abdominal wall (layer of muscle and soft tissue that covers the stomach). The surgeon brings the stomach up next to the abdominal wall on the inside and stitches it to the wall. An opening is then made into the stomach and the tube secured. A gastrostomy tube or button is brought through the skin on the left side of your child's abdomen just below the ribcage. The incision is then closed with stitches just like any other incision. Once awake, your child will be given medication for any pain or discomfort.

3. Percutaneous Endoscopic Gastrostomy (PEG)

The surgeon may decide to do a PEG in which a tube is inserted with the guidance of an endoscope. For this procedure, a camera (endoscope) is passed through the mouth and esophagus into the stomach in order to insert the tube through the abdominal wall. The procedure takes about 20 minutes. The tube is kept within the stomach either by a retention or mushroom-shaped dome which is wider than the opening or stoma. After approximately 2 months, the tube may be replaced with a button device.

How does it work?

The day after they are surgically inserted, the buttons are usually ready to go to work! The feedings are started using a special extension attached to the button. The formula bag is hung 45 cm (18 inches) above the pump, the feeding line is "primed" or filled with formula and finally attached to the extension for feeding. The rate is calculated with the assistance of your child's nutritionist and is adjusted based on how well your child tolerates it. The same can be done for a gravity feeding system.

Gastrostomy Tubes

G-tubes can be made from silicone such as a Malecot™ tube which has a mushroom-shaped end. The surgeon inserts this end into the stomach through the stoma and releases it. The mushroom opens and is gently pulled against the inner wall of the stomach. An adaptor is placed at the feeding end, against the skin, to prevent it from moving inward and to hold it snugly in place.

G-tubes can also be made from a polyurethane material such as a Corflo-Max™ which provides a larger inner lumen and a collapsible bumper making insertion and removal easier. It also has a disc or adaptor at the feeding end to ensure stability of the tube against the skin.

Gastrostomy Buttons

A gastrostomy tube can be replaced by a skin-level balloon button device either at time of surgery or once the original stoma has healed sufficiently. More and more commonly, gastrostomy buttons are the device of choice at time of surgical insertion. Buttons come in different shapes and sizes. Also, some are more “long term” than others.

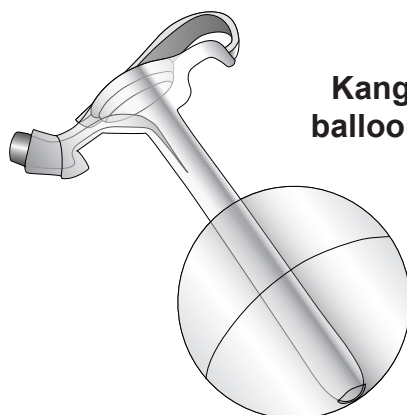
a) Skin-level balloon Button Devices

The balloon buttons have a side port/valve on the button and can be filled with 3-10 ml of tap water. The quantity of water depends on 1) the size of the button (e.g. 14 Fr = 4 to 8 ml water) and / or, 2) the “fit” of the button. For example, a button that is too loose may need more water in the balloon to prevent leakage around the stoma but never more than the maximum recommend amount. The balloon button also has an “anti-reflux” valve that prevents stomach contents from leaking out when the button cap is opened.

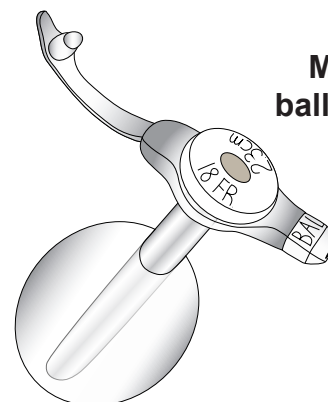
Emptying and refilling the balloon with a syringe every 1-2 weeks is an important safety measure to ensure there is no slow leak or defective balloon.

The Kangaroo™ balloon button is one such device and is made of a flexible silicone. It is held to the inside wall of the stomach by an inflatable balloon. A feature of this device is its size. It lies flatter on the skin than other similar devices. Visit www.kendallhealthcare.com for more information.

The Mic-Key™ button is similar to the Kangaroo, but is slightly rounder. This button is also 100% silicone and latex free. Visit www.mic-key.com for more information on the Mic-key balloon device.



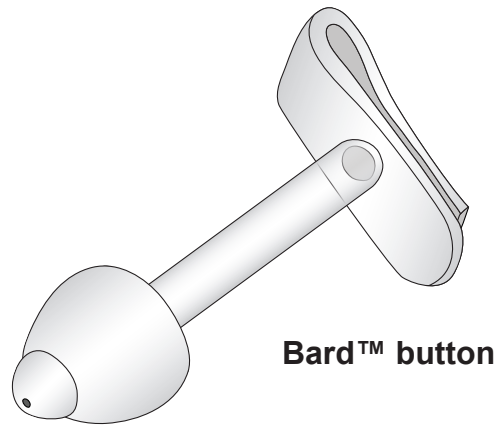
**Kangaroo™
balloon button**



**Mic-Key™
balloon button**

b) Dome-style Devices

Another option is the Bard™ button device. It is a skin-level button which does not require balloon inflation. It has a mushroom-shaped flexible silicone dome which can replace a G-tube or other button device.



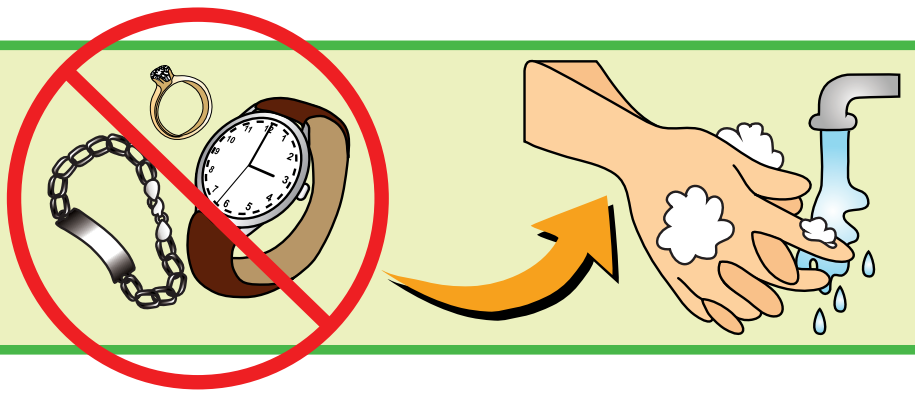
It cannot however be changed at home (as with balloon button devices) but must be replaced in the surgery clinic by a surgeon. The discomfort caused by the placement of a Bard button can be prevented with adequate medication just prior to the short procedure.

Advantages of this low profile button include durability, comfort and easy maintenance. This button can easily be left in place for 1-3 years or more depending on the growth of your child.

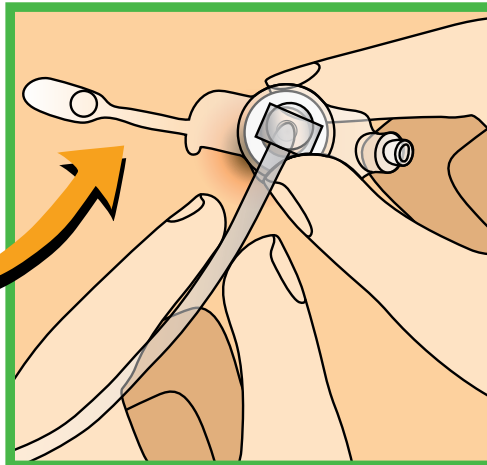
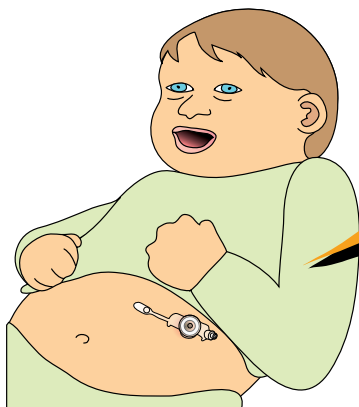
Disadvantages of this type of button include pain/discomfort at removal or change. Besides being more expensive than standard balloon devices, this button is only available starting in size 18 Fr and up. For further information, visit www.bardaccess.com.

How do I attach the extension tube to a Kangaroo™ button?

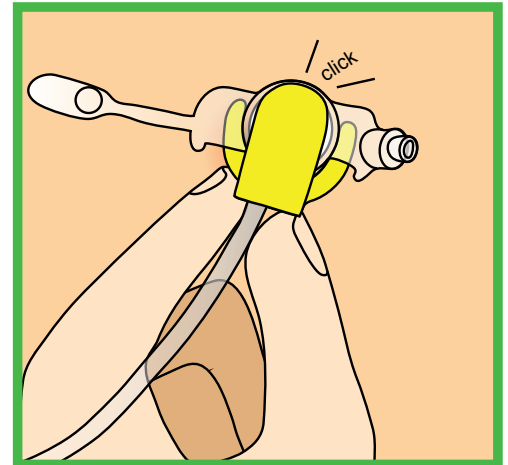
- 1. Remove all jewellery and wash your hands well**



- 2. Attach tube**

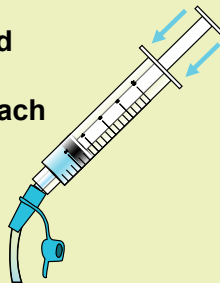


Place fingers on either side of the button, press the tip of the extension tube into to the main slot of the button

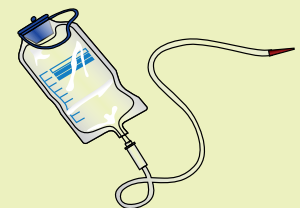


Then slide the clip over the tip of the extension tube until you hear a click

- 3. Attach a water-filled syringe and gently flush into the stomach**



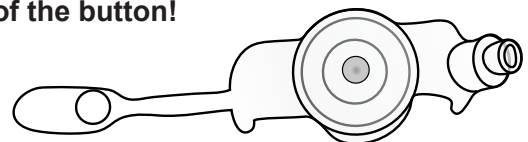
- 4. Once you can see that the flush went in easily and your child looks comfortable, you can connect the end of the feeding bag tubing to the extension and start the feed.**



Remember – if it's a new button or a replacement tube, you should flush the extension as above and then draw back on the syringe to check for stomach contents. If there's no return even after flushing with another 10-20 ml of water, do not use for feeding. Leave it in place and come to the MCH for placement verification.

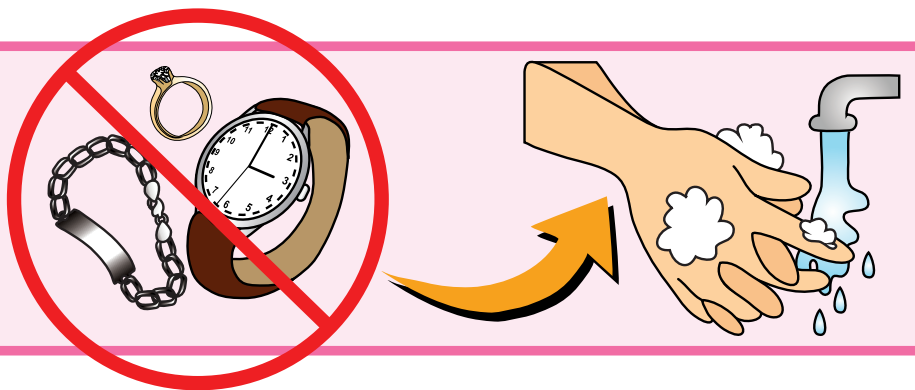


Also remember to remove the extension from the button device once you've flushed the tubing with water at the end of each feed. This will help prevent the valve inside the button from sticking and increase the life of the button!

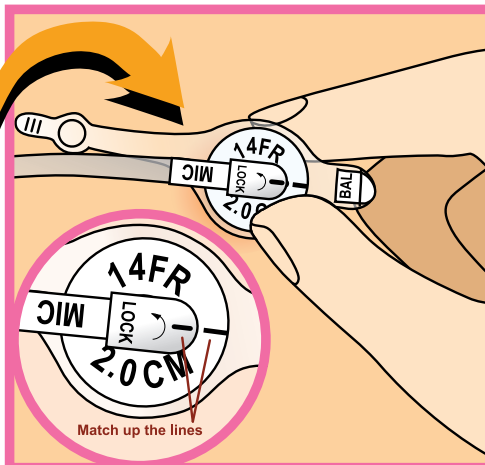
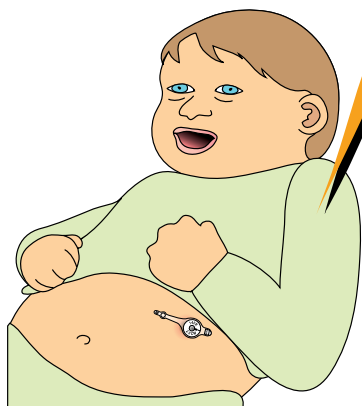


How do I attach the extension tube to a Mic-key™ button?

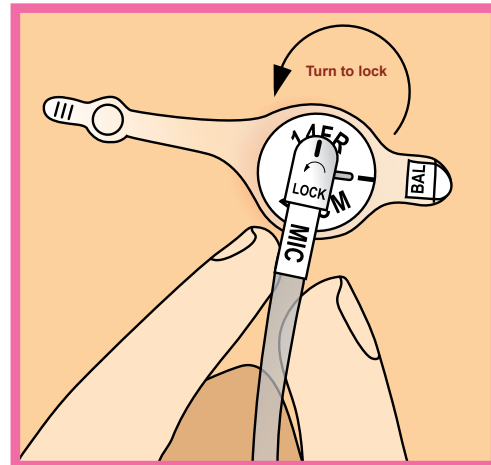
1. Remove all jewellery and wash your hands well



2. Attach tube

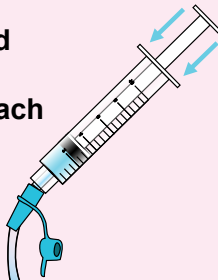


Place fingers on either side of the button, press the tip of the extension tube into to the main slot of the button by matching up the guide lines.

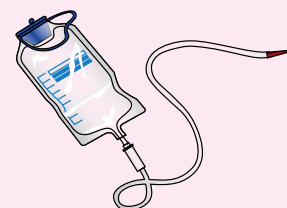


Then turn the extension tube to lock it in place.

3. Attach a water-filled syringe and gently flush into the stomach



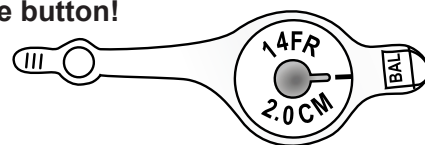
4. Once you can see that the flush went in easily and your child looks comfortable, you can connect the end of the feeding bag tubing to the extension and start the feed.



Remember – if it's a new button or a replacement tube, you should flush the extension as above and then draw back on the syringe to check for stomach contents. If there's no return even after flushing with another 10-20 ml of water, do not use for feeding. Leave it in place and come to the MCH for placement verification.



Also remember to remove the extension from the button device once you've flushed the tubing with water at the end of each feed. This will help prevent the valve inside the button from sticking and increase the life of the button!

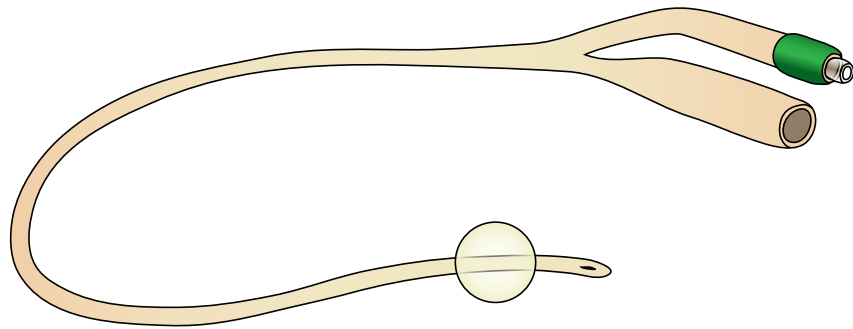


Temporary Replacements

Balloon button devices usually last an average of 6 – 12 months before requiring replacement. If the balloon or button device breaks and you have no replacement on hand, you may insert a Foley catheter as a temporary measure. The Foley has 2 ports - one for inflating the balloon with 5-10 ml of tap water and the other to feed your child. A catheter plug is available to prevent leakage from the end of the tube. The Foley catheter size should be the same size as the button, i.e. 14 Fr Foley to replace the 14 Fr balloon button devices. If it cannot be comfortably inserted, you may try inserting a smaller sized Foley catheter, in this case, a 12 Fr.

A gastrostomy stoma or opening can begin to close between 1-4 hours after removal so it is important to have a replacement catheter on hand for such emergencies. If you don't have one available or do not feel comfortable inserting it, please go immediately to the MCH Emergency Department for a replacement.

How do I insert the Foley catheter?

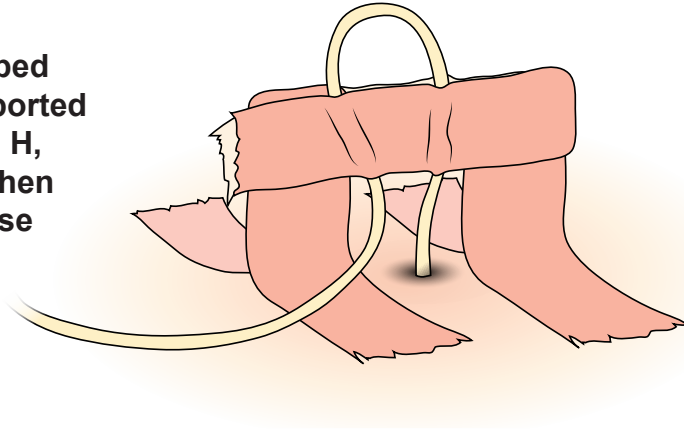


Once you have determined that the balloon device is broken and no longer usable, and you have a Foley catheter and plug on hand, you can immediately prepare to replace it.

- 1. Wash your hands with warm, soapy water and dry well.**
- 2. Lubricate the Foley catheter tip with water-soluble lubricant.**
- 3. With your child lying down, gently rotate the catheter into the stoma opening in a clockwise motion.**
- 4. If you are unable to insert the catheter, you may change sizes and try the smaller one.**
- 5. Once the catheter is in place, inflate the balloon with 5 – 10 ml tap water.**
- 6. Gently tug at the catheter until it feels snug against the stomach wall and tape the tube in place. (see taping illustration below)**

7. **A catheter plug should be placed at the opening of the Foley to prevent leakage of formula and/or stomach contents.**
8. **If you are unable to insert the smaller catheter, please take your child to the MCH Emergency Department as soon as possible for tube replacement.**

The Foley catheter should be taped to the skin. You can keep it supported by folding pieces of tape into an H, attaching it to the catheter and then taping the H to the skin, otherwise known as the “H” technique.



Also, to make sure the tube is not pushed further into the stomach, measure the length from the skin to the end of the catheter each day until it is replaced with the usual gastrostomy tube or button. If the tube is too short, reposition and re-tape it in place. Check its placement before each use by gently pulling on the tube to place the balloon snug against the stomach wall to prevent discomfort and/or leakage during feeding.

Remember, this catheter is only a temporary measure to ensure the integrity of the stoma for feeding your child. As soon as possible, it should be replaced with the appropriate-size tube or button device.

Once the new button or temporary Foley catheter is in place, it is important to:

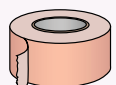

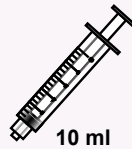
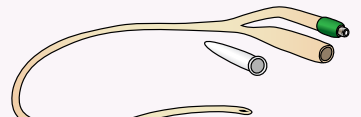
- **Flush 5-10 ml of water into the stomach and check for return of gastric content.**
- **!! If the return of gastric content cannot be confirmed even after an additional 10-20 ml of water has been flushed into the stomach, radiological confirmation is required before attempting to feed through the tube or button. Bring your child to the MCH Emergency Department.**
- **Feedings may only be started after confirmation of proper placement by either gastric return or radiology to confirm patency.**

This is especially true for the first button change but should be performed routinely after any tube change including the temporary Foley.


How do I insert the Foley catheter?

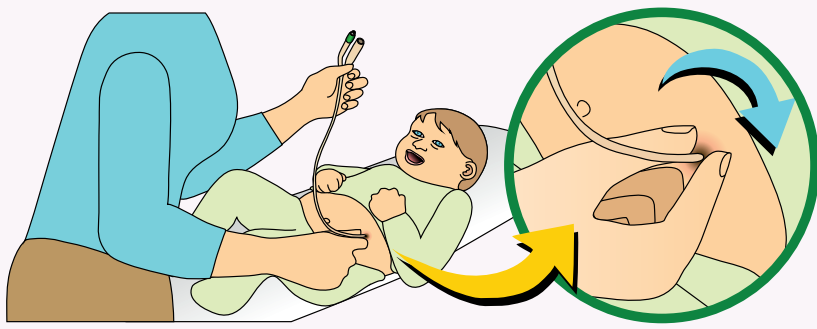
1.  **Wash your hands**

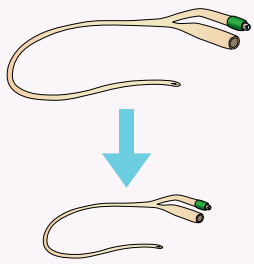
2. Gather your supplies

 **Medical adhesive tape**  **Water-soluble lubricant**  **10 ml syringe**  **Foley catheter**

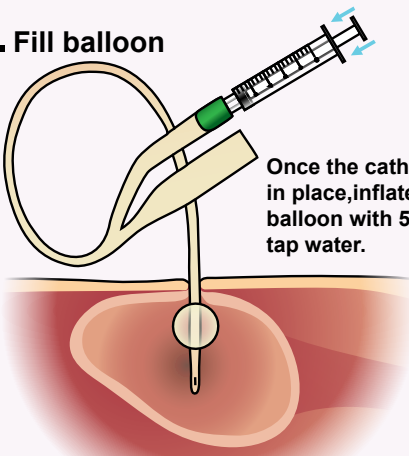
3. Insert catheter

 **Dip the end of the tube in water-soluble lubricant.**

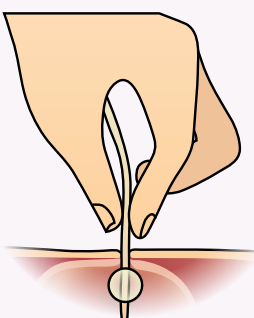
 **With your child lying down, gently rotate the catheter into the stoma opening in a clockwise motion.**

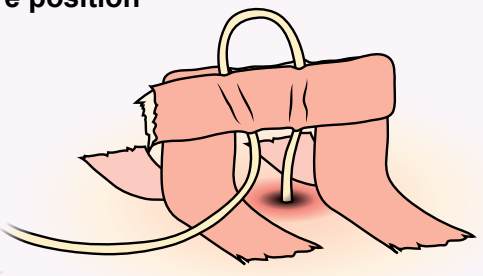
 **If you are unable to insert the catheter, you may change sizes and try the smaller one.**

4. Fill balloon

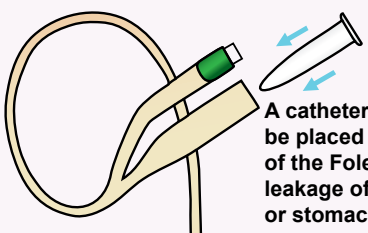
 **Once the catheter is in place, inflate the balloon with 5 – 10 ml tap water.**

5. Check and secure position

 **Gently tug at the catheter until it feels snug against the stomach wall and tape the tube in place using the "H" technique. →**

 **Fold pieces of tape into an H, attaching it to the catheter and then taping the H to the skin.**

6. Fill balloon

 **A catheter plug should be placed at the opening of the Foley to prevent leakage of formula and / or stomach contents.**

7. When to seek medical attention

If you are unable to insert the smaller catheter, please take your child to the MCH Emergency Department as soon as possible for tube replacement.



How do I take care of the stoma (opening)?

Regardless of whether a G-tube or button is in place, for the first two weeks after insertion, the skin under the button or disk must be cleansed daily with normal saline (which you can buy at the pharmacy or make at home) to remove any crusted secretions. After this period, the stoma area may be washed with mild soapy water and rinsed, once a day (in the bath or shower is fine).

Normal Saline: boil 1 cup of water and ½ teaspoon table salt for 15 minutes (covered). Cool to room temperature before using.

Do not cover the button or G-tube with gauze or any dressing unless specifically instructed to do so by the surgeon or HEF nurse. Leaving it open to air helps the stoma heal well and stay healthy. Also, unless prescribed, there is no need to apply ointments or barrier creams around the stoma site. Rotating the button or disc once a day during cleaning, may help prevent excessive tension or irritation to the stoma.

Once the healing process is complete, your child may resume his/her usual activities including swimming or other sports.

If the G-tube or button is not being used regularly, it should be rinsed or flushed with water once a day to prevent it from becoming blocked.

The water in the gastrostomy button device should be verified weekly for any signs of balloon leakage. Your HEF nurse will show you how to do this. **It is important to note that this weekly check should only be started 6 weeks after surgical insertion or as confirmed by your surgeon.**

Occasionally, especially during the first 3 weeks, an overgrowth of tissue also known as hypergranulation tissue, may appear around the stoma. For a better understanding of this growth and the appropriate treatment, please see the guide section entitled “**Hypergranulation tissue..... it can happen!**”

How do I change the gastrostomy button at home?

If you are comfortable changing a defective or broken gastrostomy button and have reviewed all the steps with the HEF nurse, you can do it at home.

Just a reminder of the steps to follow:

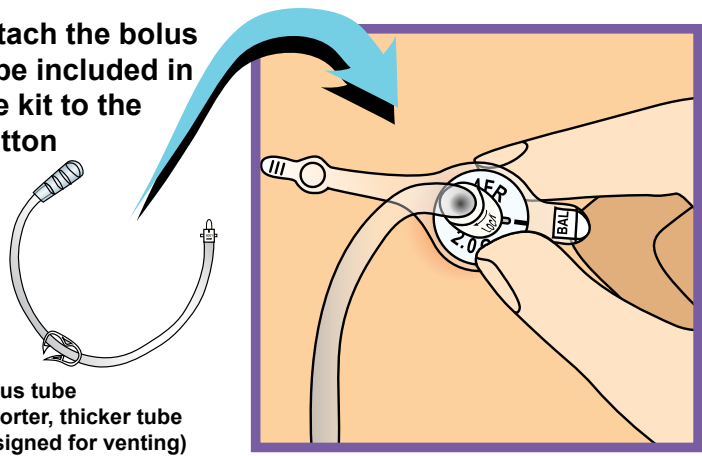
- 1. Wash your hands.**
- 2. Gather your supplies which include the new skin-level balloon button device kit.**
- 3. Test the new button by filling with the same amount of water you usually use to inflate the balloon. If the balloon is intact without any leakage, remove the water.**
- 4. Have your child lay down flat.**
- 5. Lubricate the shaft of the button with a water-soluble jelly or water and gently rotate clockwise into the stoma. DO NOT FORCE.**
- 6. Once inserted, inflate the balloon with water.**
- 7. You should be able to rotate the button comfortably on the surface of the skin.**
- 8. Test it by attaching a 5-10 ml water-filled syringe to the extension and flush into the stomach. Draw back on the plunger gently to check for stomach contents. If return cannot be confirmed even after an additional 10-20 ml of water is inserted, do not use. Leave it in place and come to the MCH for placement verification.**
- 9. If there are stomach contents or liquids, you may begin using your new button.**
- 10. Once you begin using your new button, call your HEF nurse and ask her for a replacement button...just in case!**

Remember to use sterile water if your child is 3 months of age or younger.

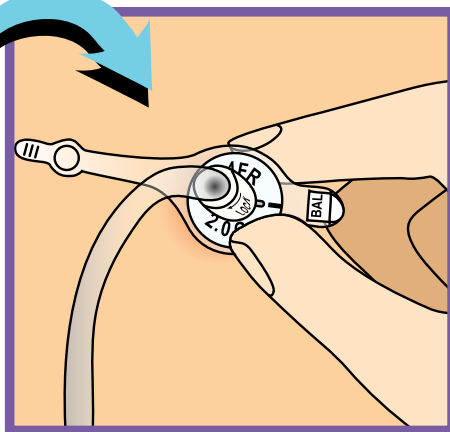
How do I vent the gastrostomy tube?

If abdominal distension or bloating occurs, the stomach can be decompressed or “vented”. This is simply releasing the air (burping) which has built up during a feed.

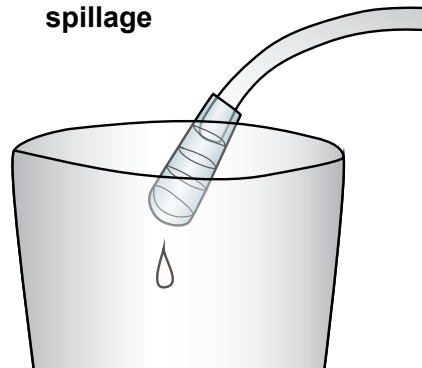
1. Attach the bolus tube included in the kit to the button

A diagram showing a shorter, thicker tube (the bolus tube) being attached to the button on the gastrostomy tube. A blue arrow points from the text to the attachment point. The bolus tube is labeled as being designed for venting.

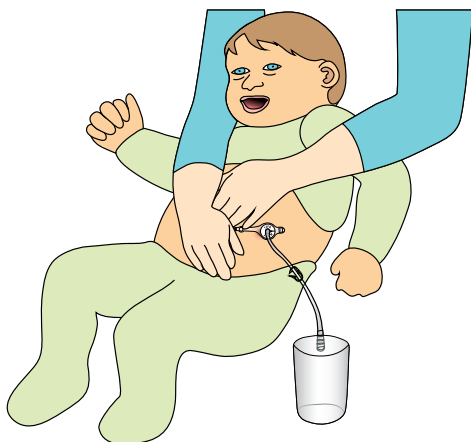
bolus tube
(shorter, thicker tube
designed for venting)



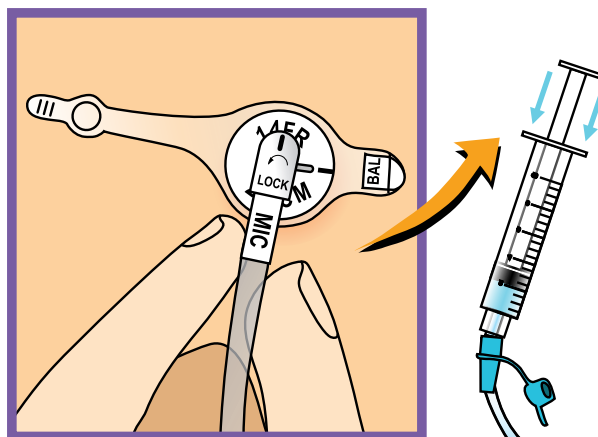
2. Place the tip of the tube into a container in case of spillage



3. Gently massage your child's abdomen to help release the air



4. After decompression, reattach the extension set and flush with 5-10 ml of water



Venting is particularly important if your child has had a fundoplication (anti-reflux operation).

Other options:

During a bolus feed, attach a 60 ml syringe, without the plunger, to the end of the feeding tube extension. Excess air can then escape upward and the gastric contents can flow back into the stomach.

During a continuous feed, a Y-tube is attached to the feeding tube, or the tube is “chimneyed” to release the excess air. To “chimney” a feed, attach a 60 ml syringe, without the plunger, to the end of the feeding tube extension. The syringe is filled with a small amount of formula and the tip of the feeding bag is laid into the syringe. Excess air is expressed from the syringe and the continuous feed is maintained from the infusion pump into the syringe.

Frequently Asked Questions About Gastrostomy Tube / Button



Q. Once the G-tube or button is in, does it hurt?

A. No, once it is in place and healed up, it should not be painful.

Q. When can my child resume bathing or swimming?

A. Once the gastrostomy site or stoma is healed, your child can bathe normally (usually after 7 days). Also, after the 2 week post-op visit, swimming and all usual physical activities will likely be allowed.

Q. Are special clothes needed?

A. No but you may want to avoid clothes with a tight waistband as it may rub against the stoma and/or pull on the G-tube or button. Parents may want to put a diaper shirt on their babies or toddlers to prevent the child from pulling on the tube or button.

Q. Is lying or positioning on the stomach okay?

A. Yes, unless it seems uncomfortable for your child.

Q. If people see the G-tube or button, what should I tell them?

A. Tell them whatever you're comfortable with. Educating people is always a good idea but not necessarily your job. If there are certain people who need to be informed such as the school nurse, babysitters, other family caretakers, ask your HEF nurse who will be happy to help you with this.

Q. What do I do if the tube or button falls out?

A. At this point, it is very important to keep the stoma from closing. If it is 6 weeks after surgery, you can use a spare Kangaroo™ or Mic-Key™ button if you have one on hand and have been taught how to insert it. If your child has a gastrostomy tube or if you are just not comfortable re-inserting the button, you may insert a blue Foley catheter which you have been given as part of your discharge equipment (see section on Temporary Replacements). And yes, the Foley catheter can be used to feed your child while waiting to have it replaced if you have been instructed to do so by your doctor or HEF nurse.

If you are unable or uneasy about reinserting the button or the Foley Catheter or if it is less than 6 weeks since the surgery, you must bring your child to the MCH Emergency Room to have the button or tube replaced as soon as possible. When you arrive with your child, please tell them that the gastrostomy button or tube is out and needs immediate attention to prevent closure of the opening (stoma).

Q. Does the button have to be changed and how often?

A. It all depends on what kind of button your child has. If it's a balloon-type like the Kangaroo™ or Mic-Key™, it can last anywhere from 3 months to a year. It only has to be changed if:

- 1) it is defective and/or the balloon breaks or you've noticed it's losing water gradually (a slow leak)
- 2) your child gains weight and the button begins to dig into the skin or,
- 3) your child experiences weight loss and leakage around the stoma develops
- 4) your child develops an "allergic" type of skin irritation/reaction to the material the button is made from but this is very rare.

If it's a different button like the mushroom dome-shaped Bard™, you cannot change it. You must call your HEF nurse or the MCH Day Surgical Centre at 514-412-4400 ext. 24489 to have it replaced by one of the doctors.

Q. Do I need to use sterile water to change the water in the balloon?

A. It is not necessary to use sterile water. You may use distilled or tap water at room temperature.

Q. Do I need to use sterile water when I'm flushing before and after using the tube?

A. The digestive system is not "sterile" so it's not necessary to use sterile water when flushing into the stomach. However, if your child is 3 months of age or younger, DO flush with sterile water.

Problem	Possible cause	What to do
<p>Constipation: infrequent hard stools that can be painful to push out</p>	<ul style="list-style-type: none"> • Not enough fluids • Not enough fibre • Low activity level • Medication side effects 	<ul style="list-style-type: none"> • Increase fluid intake. • Increase fibre intake. • Increase daily activity. • Consult HEF team.
<p>Diarrhea: frequent loose or watery stools</p>	<ul style="list-style-type: none"> • Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis 	<ul style="list-style-type: none"> • Recheck and follow the directions to prepare formula correctly. • Check expiry date and throw out or return spoiled formula to pharmacy. • Review the guidelines for formula storage & “hang time”. • Decrease or adjust the feed rate after checking with HEF nutritionist. • Verify pump is functioning properly or readjust roller clamp for gravity feed. • Verify NG tube placement before each feed. Ensure gastrostomy tube or button is properly placed in stoma. • Speak to your HEF team. • Discuss an increase in fibre content with HEF nutritionist. • Speak to your HEF nutritionist. • Speak to your HEF team.
<p>Gas or bloating</p>	<ul style="list-style-type: none"> • Excess air in stomach 	<ul style="list-style-type: none"> • Keep the G-tube closed between feedings. • Burp during the feed.

Problem	Possible cause	What to do
Gas or bloating (continued)	<ul style="list-style-type: none"> • Excess air in stomach • Too much formula per feed 	<ul style="list-style-type: none"> • Ask your HEF nurse about decompressing the stomach by “venting” the tube (see illustration on page 13). • Speak to your HEF nutritionist to adjust quantities per feed.
G-tube or button is out	<ul style="list-style-type: none"> • Balloon breakage • Accidentally pulled out 	<ul style="list-style-type: none"> • Replace balloon button if available or replace with Foley catheter on hand. If not possible, come immediately to ER (to prevent stoma from closing).
Nausea and / or vomiting of formula	<ul style="list-style-type: none"> • Excess air in stomach • Excessive feeding volume • Reflux of stomach contents into the esophagus • Delayed gastric emptying • Rapid feeding • Dumping Syndrome 	<ul style="list-style-type: none"> • See “Gas & Bloating”. • Consult HEF team concerning decreasing volume per feed. • Feed child in sitting position or with head of bed raised to 45 degrees. • Speak to your doctor about medical treatment. • Slow down the feed. • Speak to your HEF nutritionist for more information.
Pain/discomfort during feeding	<ul style="list-style-type: none"> • Excess air in stomach • Adhesions • Infection 	<ul style="list-style-type: none"> • Keep the G-tube closed between feedings. • Burp during the feed. • Ask you HEF nurse about decompression or venting the tube.

Problem	Possible cause	What to do
Vomiting of green-coloured bile	<ul style="list-style-type: none">• Tube migrated into intestine causing blockage	<ul style="list-style-type: none">• Gently pull tube outward to proper length.• If vomiting persists or tube cannot be pulled back, go to the hospital emergency department.

Be Prepared With a “Stoma Kit”

We suggest a permanent stoma “kit” be prepared and kept on hand in case of travel or unexpected emergencies. It should include:

- ✓ **Foley catheters (same diameter as button and one size smaller) and catheter plug**
- ✓ **10 ml syringes**
- ✓ **Pink (non-latex) adhesive tape**
- ✓ **Water-soluble lubricating jelly**
- ✓ **Container for tap water**
- ✓ **Replacement balloon button (optional)**
- ✓ **Type and size: _____ Fr _____ cm**
- ✓ **If travelling, medical letter explaining need for equipment**
- ✓ **Emergency phone numbers _____**

Do not try to replace a Bard™ or Entristar™ button, nor a jejunostomy tube or button. This must be done by a surgeon. However, if these type of buttons or tube becomes dislodged from the stoma, you can temporarily replace it with a Foley catheter until a new one can be properly reinserted.

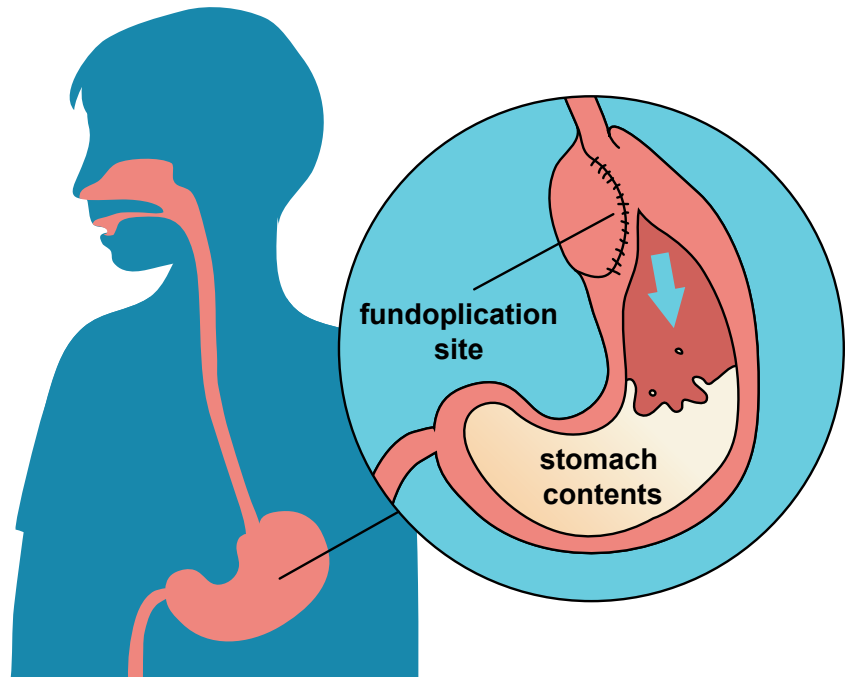
The gastrostomy balloon type device can be verified and, if it is intact (no sign of balloon rupture), it can be cleaned and reinserted with the help of a little lubricant jelly on the stem. Always check for gastric return before using the reinserted or new button. It must otherwise be replaced with a lubricated Foley catheter until a new device can be properly reinserted.

All About the Fundoplication

Some children have severe gastroesophageal reflux disease (GERD). This can lead to inflammation and possible narrowing of their esophagus (food tube), growth failure, asthma or asthma-like symptoms, recurrent pneumonias. Although many of these can be controlled by appropriate medication, sometimes the symptoms persist or lead to complications and a procedure called a fundoplication (fundo) may become necessary.

What is a fundo?

A fundo is a surgical procedure which is done to prevent the stomach contents from returning back up into the esophagus. It is done under general anaesthesia and involves wrapping the fundus (upper portion of the stomach) around the lower portion of the esophagus (food tube). This increases the pressure in the lower esophagus so that food and fluid that goes down the tube into the stomach cannot return back up to cause reflux symptoms.



The surgery is often done using a flexible camera (laparoscope). Four or five small incisions are made in the abdomen to complete the 1-2 hour long procedure. Recovery time is usually less than a week. A gastrostomy (feeding tube in the stomach) can be combined with a fundo if needed.

Will it hurt?

Your child may complain of a tight feeling in their chest. They may tell you that they can't burp and may occasionally feel as though the food is not passing through the wrap. It can take a few weeks for the swelling from the surgery to decrease and these feelings to go away.

What happens after the fundo is inserted?

Usually the reflux complications your child was experiencing before the surgery will improve. However, they may continue to require some reflux medications to control symptoms. Occasionally "retching" with feeds does seem to affect some children.

What can my child eat after fundoplication surgery?

If your child is able to take food by mouth, a full liquid or soft diet is usually recommended for a minimum of two weeks after surgery. Depending on the dietary habits of your child, the child's diet may then be slowly advanced to include more textured foods. The following dietary changes may help decrease discomfort in the first 2-4 weeks after surgery:

- **Encourage your child to have small frequent meals.**
- **Give liquids while your child is eating solid foods.**
- **Choose soft, smooth foods such as soups, soft-cooked pasta, applesauce, yogurt, ice cream.**
- **Avoid foods with sharp edges, clumpy or sticky.**
- **Avoid carbonated beverages.**

Problem Solving for the fundoplication

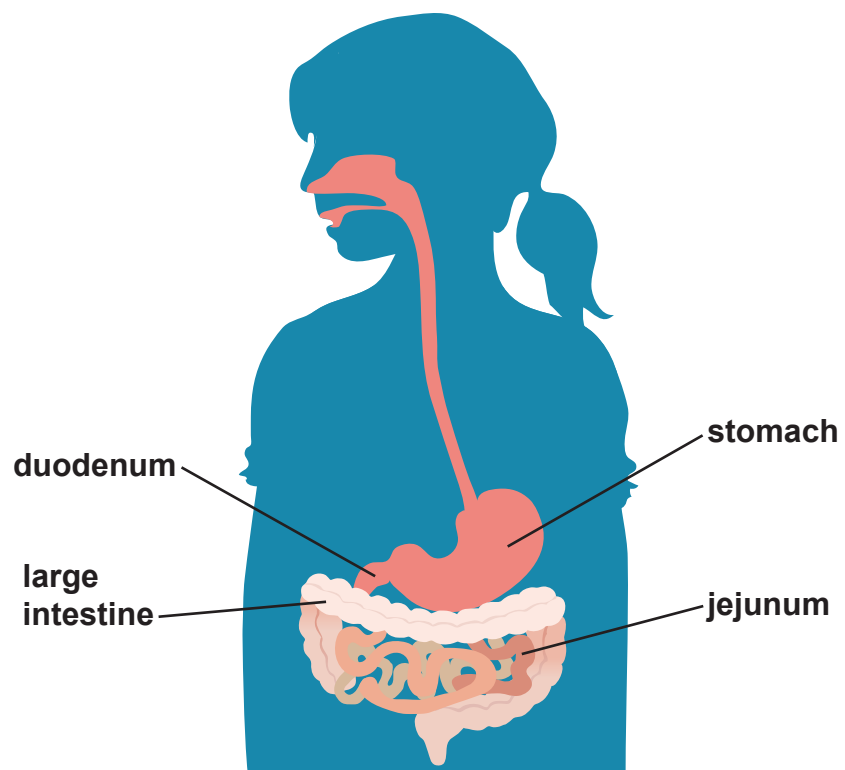
Problem	Possible cause	What to do
Bloating / can't vomit or burp	<ul style="list-style-type: none"> • Air / food cannot be vomited/burped because of fundoplication and can cause bloated feeling. 	<ul style="list-style-type: none"> • Vent the tube after feeding and/or if the child appears to have a very full or uncomfortable stomach.
Pain	<ul style="list-style-type: none"> • Post-op discomfort • Signs / symptoms of infection (fever, redness, swelling, discharge from incision) 	<ul style="list-style-type: none"> • Give pain med as prescribed. • Contact your HEF nurse or doctor
Gagging for more than 15 minutes, vomiting or difficulty swallowing	<ul style="list-style-type: none"> • Fundoplication may have partially failed. 	<ul style="list-style-type: none"> • Consult your HEF nurse or doctor as soon as possible. <p>*If vomiting is severe, prolonged, or bile-colored, go straight to the ER with your child.</p>

All About the Jejunostomy Tube / Button

What is it?

The jejunum is the second part of the small intestine. It is where digestion and absorption of liquid foods received from the stomach and duodenum (first part of the small intestine) takes place. A jejunostomy tube is a specially designed feeding tube that runs either directly into the jejunum or into the stomach and then on into the jejunum. There are 3 types:

- ❑ **NJ (naso-jejunal tube)**
- ❑ **JT (jejunostomy tube or button)**
- ❑ **GJ (gastro-jejunal tube or button)**



There are two main reasons why your child may need a jejunostomy:

1. If they suffer from severe gastro-oesophageal reflux or poor gastric motility.
2. Children who cannot have a gastrostomy tube inserted into the stomach for various reasons.

Types of Jejunal Tubes / Buttons

An NJ (nasogastric) tube allows formula to flow into the jejunum using a special tube which passes through the nostril, down the throat, through the stomach and duodenum and ends up in the jejunum. These tubes are often inserted with the assistance of the radiology department. This radiological visualization assures that the tip can be properly positioned into the jejunum and ready to use for feeding.

For patients requiring longer than 3 or 4 weeks of tube feeding or those who cannot be fed through their stomach, a JT (jejunostomy) or GJ (gastro-jejunal) tube or button may be an option. A small surgical procedure will be performed to create a “stoma” or opening in the skin. This is done to allow the tube to be inserted directly into the jejunum (JT). Another option, together with the GI endoscopist, would be to pass it through the stomach and then on into the jejunum (GJ).

How is it put in place?

Please refer to the section, “All about the gastrostomy tube/button” for an explanation on the surgical placement of tubes or buttons. The GJ tube or button has 2 ports: one for gastric decompression (removing air or excess liquid from the stomach) and one for enteral feeding directly into the jejunum.

How do I take care of the jejunostomy tube / button?

Initial care includes:

- Cleaning the skin under & around the button or tube daily with a saline solution to remove any crusted secretions. After a two week period and after you’ve had a post-op follow-up in our Surgery clinic, the stoma area may be washed with mild soapy water and rinsed daily (in a bath or shower is fine). Important: DO NOT rotate the jejunostomy button at any time.
- Occasionally, an overgrowth of tissue, also known as hypergranulation tissue, may appear around the stoma. For a better understanding of this growth and the appropriate treatment, please see the manual section entitled “Hypergranulation tissue.....it can happen!”
- Do not cover the button or GJ tube with gauze or any dressing unless specifically instructed to do so by the surgeon or HEF nurse. Leaving it open to air helps the stoma to heal well and stay healthy. Also, unless prescribed, there is no need to apply ointments or barrier creams around the stoma site.
- After the healing process is complete, your child may resume his/her usual activities including swimming or other sports.
- If the GJ tube is not being used, it should be rinsed or flushed with water at least twice a day to prevent it from becoming blocked. Remember to flush with sterile water if your child is 3 months of age or younger. Otherwise, distilled or tap water is fine.

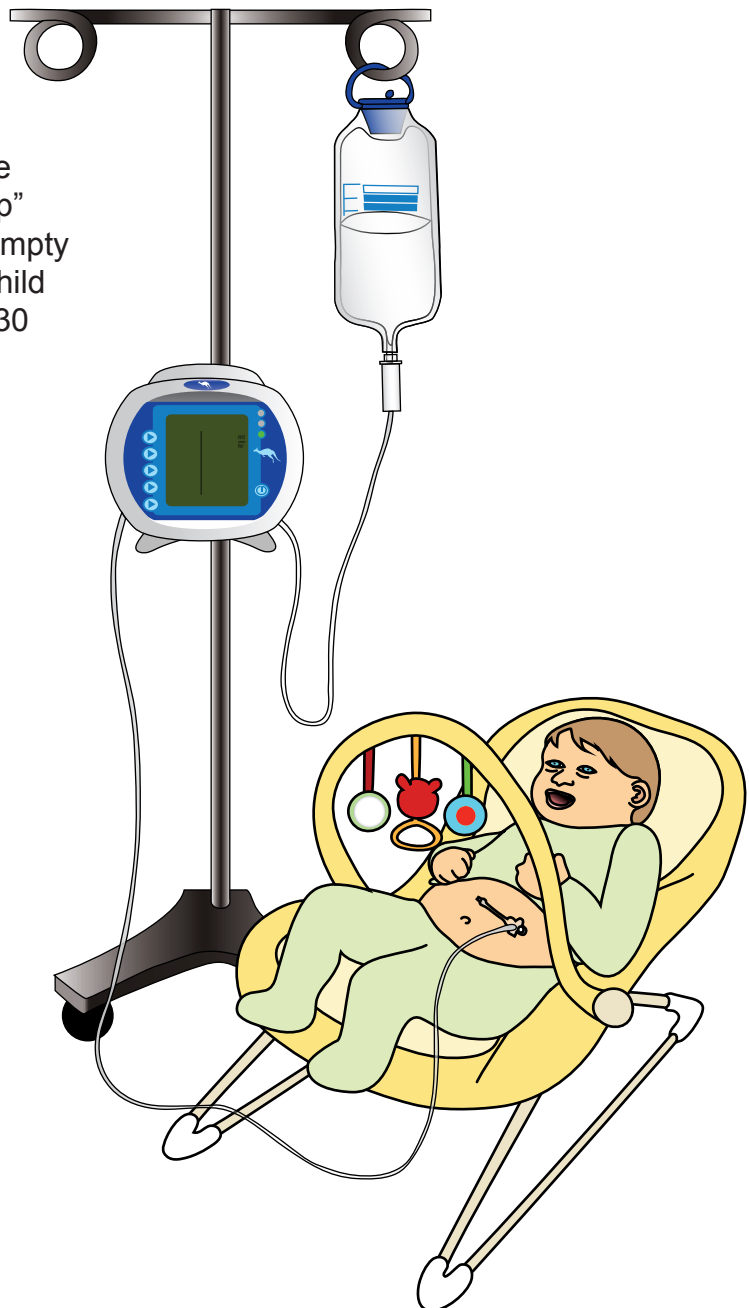
How do I feed my child with it?

Feeds to be given through these tubes are special formulations recommended by your child's nutritionist and doctor. Because the tube is lower in the digestive tract, it is not recommended to give large bolus feeds as they may cause diarrhea and abdominal pain. The feeds are usually continuous and are always delivered using a feeding pump.

It is important that the jejunostomy tube/button be flushed:

- **before and after feeds.**
- **before, between, and after any prescribed medication (only those meds which you have been told can be used through a jejunostomy).**
- **every 4 hours during a continuous feeding may help to prevent the tube from blocking.**

When feeding your baby or child, the best position is sitting or "propped up" because this helps the stomach to empty more quickly. Ideally, your baby or child is best left in this sitting position for 30 minutes after a feed.



Safety Checks:

- ✓ Check to ensure that the length of the tube from the exit site to the cap remains the same.
- ✓ Check to ensure that the tube flushes easily with water.
- ✓ Check with a test strip* (optional), any fluid which flows back in the tube for its acidity (pH should be alkaline - between 6 and 8). If it is acidic, it may have migrated to the stomach.
- ✓ Check to ensure that the tube is in place. If it has been pulled out, it is important it be replaced immediately. IF you have previously been shown what to do and feel comfortable, you can insert a Foley catheter into the stomach as a temporary measure. Bring your child to the hospital to have it reinserted as soon as noticed. If the stoma is not kept open, it will begin to close within only a few hours.

***As this temporary tube may not be directly in the jejunum, DO NOT USE TO FEED.**

Caring for a child with a jejunostomy will involve some extra work and may be quite stressful at first, until you get used to the routines involved. Try not to let feeding dominate your life. Accept what help you are offered from friends and family, and remember that the HEF team is there to answer questions and offer support whenever you may need it!

Frequently Asked Questions About Jejunostomy Tube / Button



- Q.** Once the GJ-tube/button is in, does it hurt?
- A.** No, once in place and healed up, it should not be painful.
- Q.** Do I need to use sterile water to change the water in the balloon?
- A.** It is not necessary to use sterile water. You may use distilled or tap water at room temperature.

Q. Do I need to use sterile water when I'm flushing before and after using the tube?

A. The digestive system is not "sterile" so it's not necessary to use sterile water when flushing into the stomach. However, if your child is 3 months of age or younger, DO flush with sterile water.

Q. What about bathing and swimming?

A. Once the gastro-jejunostomy site or stoma is healed, your child can bathe normally. As well, swimming and all usual physical activities are permitted. However, caution must be taken to avoid dislodging the tube as it is difficult to reinsert so some restriction of activities may be necessary. If unsure, please consult with your doctor or HEF nurse before allowing an activity.

Q. Are special clothes needed?

A. No, but you may want to avoid clothes with a tight waistband as it may rub against the stoma and/or pull on the GJ-tube or button. Parents may want to put a diaper shirt on their babies or toddlers to prevent the child from pulling on the tube or button.

Q. Is lying or positioning on the stomach okay?

A. Yes, unless it seems or feels uncomfortable. However, children often prefer lying on their side or backs to avoid pressure from the button.

Q. If people see the GJ-tube or button, what should I tell them?

A. Tell them whatever you're comfortable with. Educating people is always a good idea but not necessarily your job. If there are certain people who need to be informed such as the school nurse, babysitters, other family caretakers, your HEF nurse or CLSC can help with this.

Q. Should I rotate the tube/button daily during cleaning or bathing?

A. No, do not rotate jejunal tubes or buttons as they extend into the jejunum and rotating may cause them to torque and retract into the stomach.

Q. What do I do if the GJ tube or button falls out?

A. At this point, it is very important to keep the stoma from closing.

Do not try and reinsert a GJ button or tube. If your child has had his/her post-op visit and you have been taught how to use a blue Foley catheter as a temporary replacement, you may insert it into the stoma to prevent shrinking or closure of the opening.

Do not use the blue foley catheter to feed your child.

Once it is securely taped to the skin, please bring your child to the Montreal Children's Hospital emergency department for replacement of the GJ device.

Problem Solving for the Jejunostomy Tube / Button

Below are some of the more common problems encountered along with possible causes and solutions. If the problem is recurrent or severe and, if you have more questions, please contact your HEF nurse.

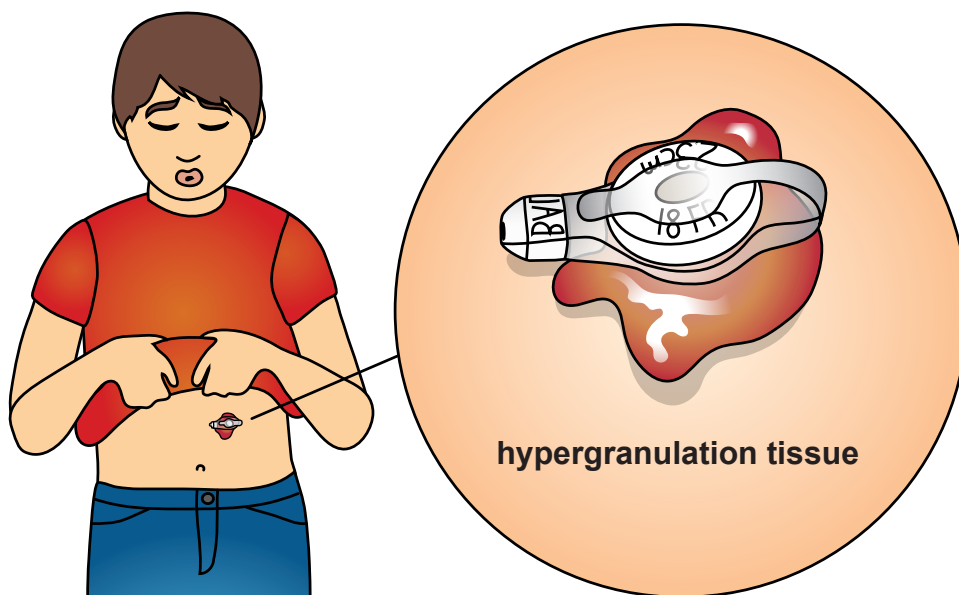
Problem	Possible cause	What to do
<p>Blocked tube or button</p>	<ul style="list-style-type: none"> • Formula or intestinal contents • Medication 	<ul style="list-style-type: none"> • Flush the tube with 10 - 20 ml warm water before and after feeding. • Do NOT give pureed foods through the tube. • Do not mix anything new into the formula without consulting the HEF nurse or nutritionist. • If blocked, flush the tube with 10 ml warm water and use a jet push motion to try and unblock the tube. • Use only liquid or finely crushed medicine dissolved in water. If unsure, check with your pharmacist.
<p>Infection: signs & symptoms</p>	<ul style="list-style-type: none"> • Pain at stoma site • Increasing area of redness around stoma • Pale yellow, mucous-like discharge • Fever • Decreased tolerance to feeds • Any or all of above 	<ul style="list-style-type: none"> • Increase fluid intake as tolerated. • Consult your HEF nurse, surgeon or family doctor for assessment and treatment. • Refer to section on Hypergranulation Tissue.
<p>Dry mouth</p>	<ul style="list-style-type: none"> • Lack of stimulation to mouth 	<ul style="list-style-type: none"> • Brush the teeth and/or clean the mouth at least twice per day. • Apply lip balm or lubricant to lips.

Problem	Possible cause	What to do
<p>Constipation: infrequent hard stools that can be painful to push out.</p>	<ul style="list-style-type: none"> • Not enough fluids • Not enough fibre • Low activity level • Medication side effects 	<ul style="list-style-type: none"> • Increase fluid intake. • Increase fibre intake. • Increase daily activity. • Consult HEF nurse or doctor.
<p>Diarrhea: frequent loose or watery stools</p>	<ul style="list-style-type: none"> • Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis 	<ul style="list-style-type: none"> • Recheck and follow the directions to prepare formula correctly. • Check expiry date and throw out or return spoiled formula to pharmacy. • Review the guidelines for formula storage & “hang time”. • Decrease or adjust the feed rate after checking with HEF nutritionist. • Verify pump is functioning properly or readjust roller clamp for gravity feed. • Verify NG tube placement before each feed. Ensure gastrostomy tube or button is properly placed in stoma. • Speak to your HEF team. • Discuss an increase in fibre content with HEF nutritionist. • Speak to your HEF nutritionist. • Speak to your HEF team.
<p>Gas or bloating:</p>	<ul style="list-style-type: none"> • Excess air in stomach • Swallowing air 	<ul style="list-style-type: none"> • Keep the J-tube closed between feedings. • Burp during the feed. • Ask your HEF nurse about decompressing the stomach by “venting” the tube (see illustration on p. 13).

Problem	Possible cause	What to do
GJ-tube or button is out	<ul style="list-style-type: none"> • Balloon breakage • Accidentally pulled out • dislodged tube or button 	<ul style="list-style-type: none"> • Do not attempt to reinsert the GJ tube or button on your own. • If possible, replace with Foley catheter on hand to prevent the stoma from closing. Do not use for feeding. • Call ahead and come to Surgery Clinic for replacement by doctor.
Nausea and / or vomiting of formula	<ul style="list-style-type: none"> • Excess air in stomach • Excessive feeding volume • Reflux of stomach contents into the esophagus • Delayed gastric emptying • Rapid feeding • Dumping syndrome 	<ul style="list-style-type: none"> • See “Gas & Bloating”. • Consult HEF nutritionist concerning decreasing volume per feed. • Feed child in sitting position or with head of bed raised to 45 degrees. • Speak to your doctor about medical treatment. • Slow down the feed. • Speak to your HEF nutritionist for more information.
Pain / discomfort during feeding	<ul style="list-style-type: none"> • Excess air in stomach • Adhesions • Infection 	<ul style="list-style-type: none"> • See “Gas & Bloating”. • Notify the HEF team.
Vomiting of green coloured bile	<ul style="list-style-type: none"> • Tube migrated into intestine causing obstruction 	<ul style="list-style-type: none"> • If ANY bilious vomiting occurs, bring your child immediately to the Emergency Room.

Hypergranulation Tissue... It Can Happen!

What is it?



After a stoma has been created, some patients have growth of “hypergranulation tissue”. It actually looks like thick red tissue that’s growing around and up the tube or button. It’s hard to say why this happens to some and not to others. It’s not uncommon in the first 3 weeks to 3 months and is believed to occur as a result of an extended inflammatory response. It may be the body’s reaction to the foreign body (tube or button), or possibly due to excessive moisture from drainage around the stoma, or from ointment use. It could also be due to bacterial overgrowth or a poorly fitting gastrostomy or gastro-jejunal button. Hypergranulation tissue can be the body’s way of healing and protecting itself from a foreign object (tube or button).

Hypergranulation tissue is new connective tissue with tiny blood vessels that form on the surface of a wound during the healing process giving it a bumpy or granular appearance.

It is usually:

- **not harmful**
- **red or dark pink in color**
- **soft to the touch and bleeds easily when rubbed**
- **moist, and may ooze a yellow, sticky discharge**
- **can affect how the tube or button fits in the stoma**
- **more common in the first 3 months**

What can I do about it?

When you first spot hypergranulation tissue, you may apply normal saline compresses (1/2 teaspoon salt dissolved in 1 cup boiled tap water and allowed to cool) for 10 minutes up to four times a day. The idea is to soften, dry out and flatten the tissue. You should never apply disinfectants or antibiotic ointments without seeking medical advice.

If the hypergranulation tissue continues to grow larger, your doctor or HEF nurse will show you how to “cauterize” it. You can be taught to do this at home if it is required on a regular basis. However, once the tissue heals, it does not usually reoccur unless there’s a lot of manipulation of the G-tube or button during replacement or trauma from pulling on it.

Cauterization is done with “silver nitrate” sticks. They resemble long matches with a dark gray tip. **Before** applying the stick, it’s important to apply a protective barrier such as Vaseline™ or a barrier cream (3M Cavilon™) on the skin around the overgrowth to prevent healthy tissue damage. The tip of the stick is then gently rolled over the moist, affected tissue. Following the treatment, the area is covered with a gauze dressing for a few hours (only) to prevent staining the child’s clothing with the silver nitrate product (will turn black). A Mepilex™ type dressing may also be placed, for a short period, over treated granulation tissue for a short time but should be changed daily until resolved. The silver nitrate is applied once or twice a week on moist hypergranulated tissue until it is dry and blackened. The tissue will gradually peel off and begin to heal. If however, after 2 – 3 applications, the affected tissue still appears red and/or continues to ooze, please contact your HEF nurse or doctor for reassessment. It’s very important to keep the stoma as clean and dry as possible to discourage further growth of granulation tissue.

The treatment itself is not usually painful but young children may become anxious when such a sensitive area is touched during treatment. The surrounding healthy tissue may or may not turn brownish but, not to worry, this discoloration also disappears over time.

Alternative Treatments

There are other possible treatments if the hypergranulation tissue keeps coming back. An antacid slurry (such as Maalox™ or Gaviscon™) applied to the tissue twice a day may help prevent any skin irritation caused by leakage. It may also help treat the existing granulation tissue. There are topical corticosteroid ointments (such as Triaderm 0.1%™) which some parents have found very helpful. Speak to your HEF nurse or doctor for their recommendations.

Changing the Tube or Button

A poorly fitting tube or button can be the cause for excess leakage and some hypergranulation tissue may form around the stoma. Some causes for this may be that your child is losing weight and the button gets loose or perhaps the button itself is defective. Contact your HEF nurse or doctor if you notice a change in the fit of the tube or button.

How do I feed my child with the tube?

Whether you're feeding your child through a nasogastric tube or a gastrostomy tube or button, there are different ways to deliver the feedings. A feeding method is chosen according to:

- the type of tube or button used
- the reason your child needs tube feeds
- how often your child needs tube feeds
- the length of each tube feed
- how your child manages tube feeds

The feeding method chosen for your child is meant to ensure that he/she gets the nutrients needed to be able to best grow. Your child will either be fed all the time (continuous), with breaks during the day (intermittent / bolus), or a mix of the two. The following section will cover these different feeding methods and the various types of feeding equipment. Your Home Enteral Feeding treatment team will speak with you about which one is best for you.

Intermittent (Bolus) feeding

Just as we have breaks between meals, intermittent or bolus feeds also allow for a time lapse between feedings. Bolus feeds can be used to supplement a child's oral intake or replace it entirely based on your child's nutritional treatment plan.

This type of feed is similar to how we eat meals or snacks, with breaks in between. It may be used:

- in addition to your child's regular diet (eating by mouth), OR
- to replace your child's regular diet completely through a personalized, nutritional treatment plan.

It can take anywhere from 15 to 45 minutes depending on how much needs to be fed and how your child manages with the tube feed.

Babies can be held during the feed and offered a pacifier to stimulate oral reflexes if appropriate. Older children who are eating and receiving a nutritional supplement can be encouraged to sit at the kitchen table while others are eating. Meal time is considered a social time for families and children fed by tube should be included.

Intermittent or bolus feeds can be given by:

- **Push Method**
- **Gravity Method**
- **Feeding Pump Method**

The Push Method

The Push Method means using a syringe to “push” the formula slowly into the tube.

Supplies include:

- 10 ml syringe for flushing
- 30-60 ml syringe with/without catheter tip to deliver the feed
- your child’s formula


To deliver the feed:

1. With the 10 ml syringe, verify the nasogastric tube’s proper placement in the stomach.
2. Once verified, flush the tube with a few ml of water. Remember to use sterile water IF your child is 3 months of age or younger.
3. For a gastrostomy tube feeding, attach the extension and flush with a few ml of water.
4. Fill the 60 ml long-tipped syringe with the measured amount of formula.
5. Connect the syringe to the tube or extension.
6. Slowly push the formula into the tube as tolerated, refilling the syringe until the entire amount of formula is given over a period of a minimum of 15-20 minutes.
7. Detach the syringe from the tube.
8. Flush the tube with 5-10 ml of water.
9. Close the cap at the end of the tube or remove the extension from the gastrostomy button.
10. Clean the supplies.

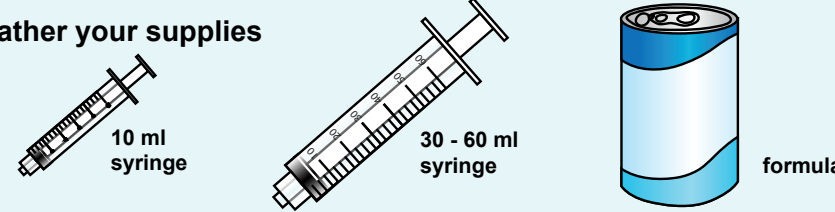
How to Use the Push Method

This type of feeding uses a syringe to “push” the formula slowly into the tube.

1. Wash your hands



2. Gather your supplies



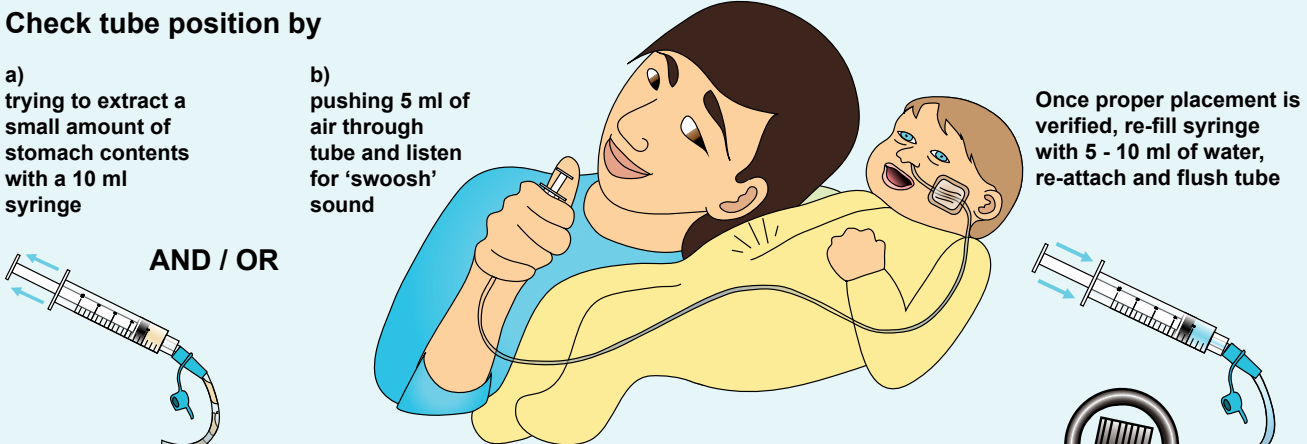
3. Check tube position by

a) trying to extract a small amount of stomach contents with a 10 ml syringe

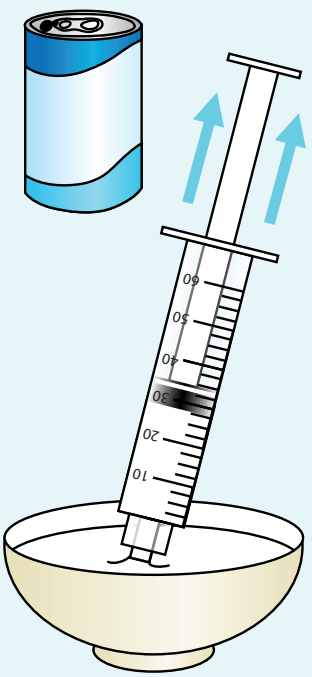
b) pushing 5 ml of air through tube and listen for ‘swoosh’ sound

Once proper placement is verified, re-fill syringe with 5 - 10 ml of water, re-attach and flush tube

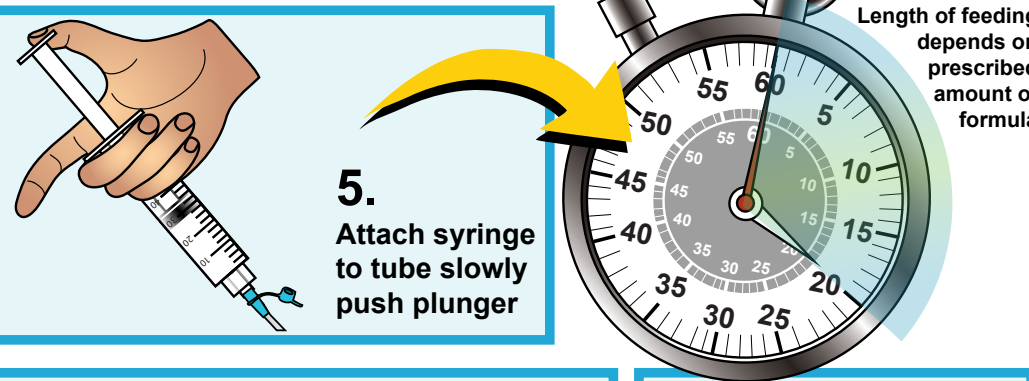
AND / OR



4. Fill 60 ml syringe with formula



5. Attach syringe to tube slowly push plunger

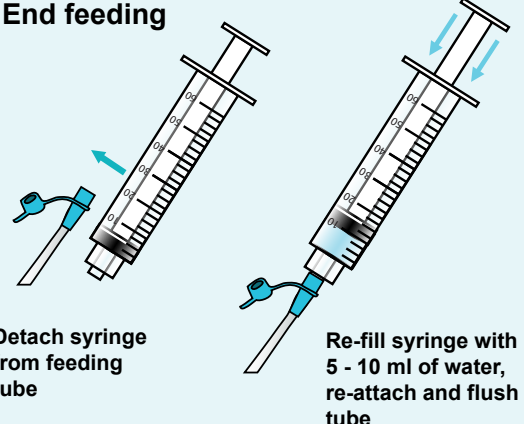


Length of feeding depends on prescribed amount of formula


6. End feeding

Detach syringe from feeding tube


Re-fill syringe with 5 - 10 ml of water, re-attach and flush tube



7. Remove syringe and close tube cap



8. Clean supplies



The Gravity Method

The Gravity Method means hanging a special formula-filled bag above your child and controlling the how it flows by adjusting a special roller clamp. Just as with the push method, it is used for what is called, “intermittent” or “bolus feeds”. This type of feed is similar to how we eat meals or snacks, with breaks in between. (This is different from continuous feeds, which are discussed later in this Guide.)

You may notice the drops slowing down over time. This is normal. This happens when your child’s stomach is full or almost full. If you notice this, pause the feed for a short period of time. This will give your child some time to digest. His or her stomach will then slowly empty again. You may then restart and complete the feeding.

Babies can be held during the feed and offered a pacifier to stimulate oral reflexes if appropriate. Older children who are eating and receiving a nutritional supplement can be encouraged to sit at the kitchen table while others are eating. Meal time is considered a social time for families and children fed by tube should be included.



Supplies include:

- **10 ml syringe for checking NG tube placement and flushing**
- **Gravity feeding set (bag and tubing)**
- **Hook or pole to hang feeding bag**
- **Your child’s formula**

To deliver the feed:

- 1. With the 10 ml syringe, verify the nasogastric tube's proper placement in the stomach or attach a feeding extension to the gastrostomy button.**
- 2. Once verified, flush the nasogastric tube or gastrostomy extension with 5-10 ml of water. Remember to use sterile water if your child is 3 months of age or younger.**
- 3. Fill the gravity bottle with the prescribed amount of formula and suspend about 46 cm (18") above your child. When possible, raise the head of the bed 45 degrees before starting the feed and for at least 30 minutes after the feed has finished.**
- 4. Clamp the feeding set closed and attach to the bottle.**
- 5. Turn downside and squeeze the drip chamber of the feeding set until half full.**
- 6. Slide the roller clamp up to allow the formula to fill the tubing (priming the tube).**
- 7. Close the clamp and attach the feeding set to the NG tube or gastrostomy extension.**
- 8. Slide the roller clamp up or down slowly until the desired drip rate is achieved. Watch the drip chamber and time the drips to run at:**

Drop rate	Feeding volume (or pump rate)
16 drops per minute	60 ml per hour
20 drops per minute	80 ml per hour
24 drops per minute	100 ml per hour
28 drops per minute	120 ml per hour
32 drops per minute	140 ml per hour

- 9. Allow a feeding to run in over 30 – 60 minutes as tolerated or, as instructed by the nutritionist or doctor.**
- 10. Once the feeding is delivered, close the clamp, flush the tube or extension with 5-10 ml of water and close the cap at the end of the tube. Remember to remove the gastrostomy feeding extension after each feeding.**

How to Use the Gravity Method

1. Wash your hands

2. Gather your supplies

10 ml syringe Formula IV stand, hook or pole Gravity feeding set

3. Check tube position by

a) trying to extract a small amount of stomach contents with a 10 ml syringe

b) pushing 5 ml of air through tube and listen for 'swoosh' sound

AND / OR

Once proper placement is verified, re-fill syringe with 5 - 10 ml of water, re-attach and flush tube

4. On gravity feeding set, verify that roller clamp is closed

Adjust to close

5. Fill bag with prescribed amount of formula

Suspend bag at least 18 inches above child's head

Child may be sitting or reclining at a 45° angle

6. Squeeze the drop chamber. When it is filled halfway, open roller clamp to fill tube with formula

Adjust to open

7. Connect gravity feeding set to tube or button

8. Start the feeding

Adjust roller clamp until required drip rate is achieved

Feeding Volume	Drop Rate
60 ml per hour	16 drops per minute
80 ml per hour	20 drops per minute
100 ml per hour	24 drops per minute
120 ml per hour	28 drops per minute
140 ml per hour	32 drops per minute

Once complete, you may add 10-20 ml of water to the bag to ensure child receives all of the formula.

Feedings usually last between 30 and 60 minutes or as directed by your treatment specialist

9. End the feed

Disconnect gravity feeding set, flush tube or button extension with 5 - 10 ml of water

Remember to close cap

How do I keep everything clean?

You may reuse your tubes, syringes and gravity feeding sets. The important thing is to clean everything properly. This will help to prevent your child from getting sick. Here are a few tips on how to make sure you are keeping everything clean.

After each feeding:

- Rinse all supplies with warm water. (Do not put them in the dishwasher)
- Place your supplies in the sink with warm water and a small amount of dish soap at least once a day. Let them soak for a few minutes.
- Push soapy water through tubes and small items using a syringe to make sure everything is thoroughly cleaned.
- Wash or rinse all connection pieces well.
- Gravity bags should be rinsed with warm water after each feed. They can be washed with a drop of dishsoap and warm water then rinsed thoroughly at the end of each day. Throw out after 3 days of use and replace with a new one.
- Syringe parts (barrel and plunger) should be washed and left to dry separately. If not, the black rubber tip on the plunger may swell and crack and the syringe will be unusable. Discard all syringes after 1 week.
- Check all supplies carefully before each feeding. If there is formula residue or if you notice a sour odor:
 1. Rewash your supplies with warm water
 2. Flush with a water and vinegar solution, and
 3. Rinse again with clear water.



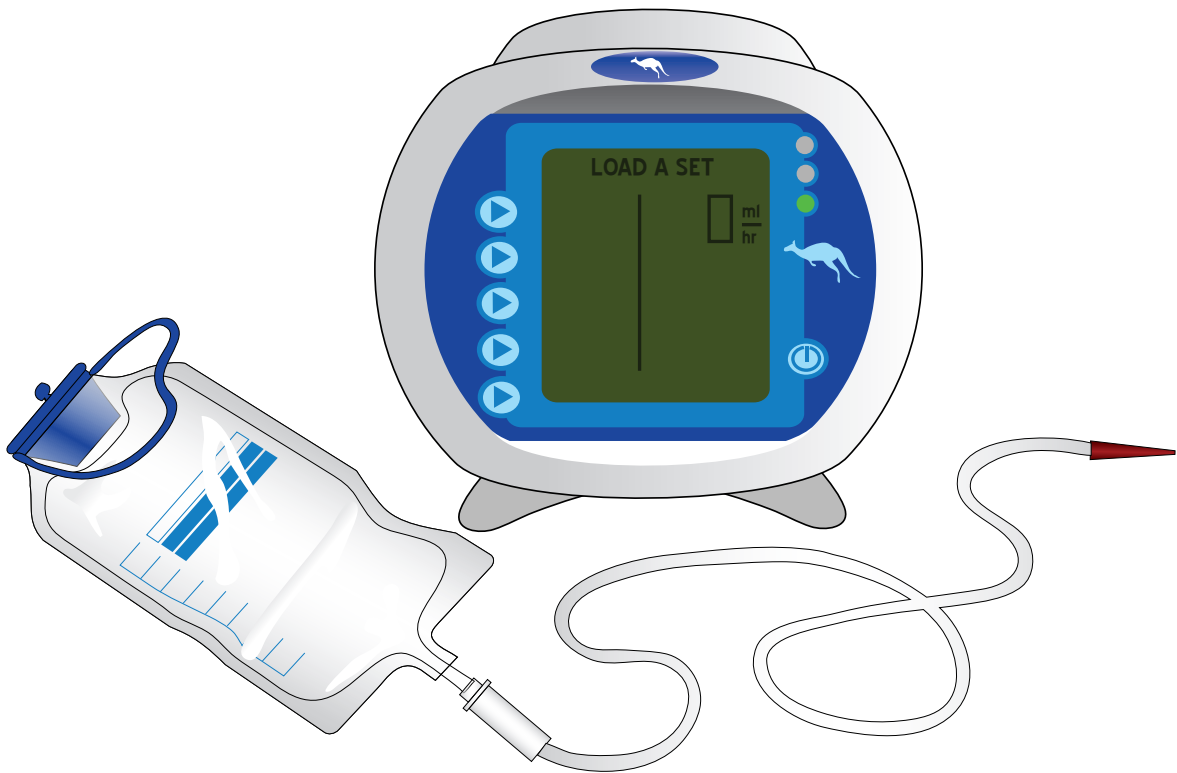
Your vinegar solution should measure 1 part white vinegar per 8 parts water.

Feeding Pump Method

This involves connecting the formula bag and tubing to an electronic pump (e-pump) and delivering the feed at a prescribed flow rate.

Supplies include:

- **Feeding bag with tubing (open system)**
- **10 ml syringes for flushing**
- **Enteral feeding pump**



More detailed instructions on the use and care of the pump are available in the sections following continuous feeding. Your child's unit nurse at the MCH or HEF nurse can also instruct you on the use and maintenance of the feeding pump before discharge.

Continuous Feeding

Your treatment team may suggest that your child be fed continuously. “Continuous feeds” means feeding over a longer period of time, with the help of a special feeding pump. It is recommended for children who:

- **Are having a difficult time managing gravity feeding**
- **Need a very specific amount of formula over a very specific period of time.**
- **Children with jejunostomies**

Continuous feeds must always be delivered using a feeding pump.

Continuous pump feeding may be offered in a few different ways:

- **using the feeding pump only at night, with no gravity or push method feeding during the day**
- **using the feeding pump only at night, with gravity or push method feedings during the day**
- **Around-the-clock feeding, night and day**



Continuous, around-the-clock feeding means using the feeding pump to deliver feeds to your child in a constant way throughout the night and day. How much feed your child will receive is specially prescribed by your treatment team. Around-the-clock feeding may be suggested if:

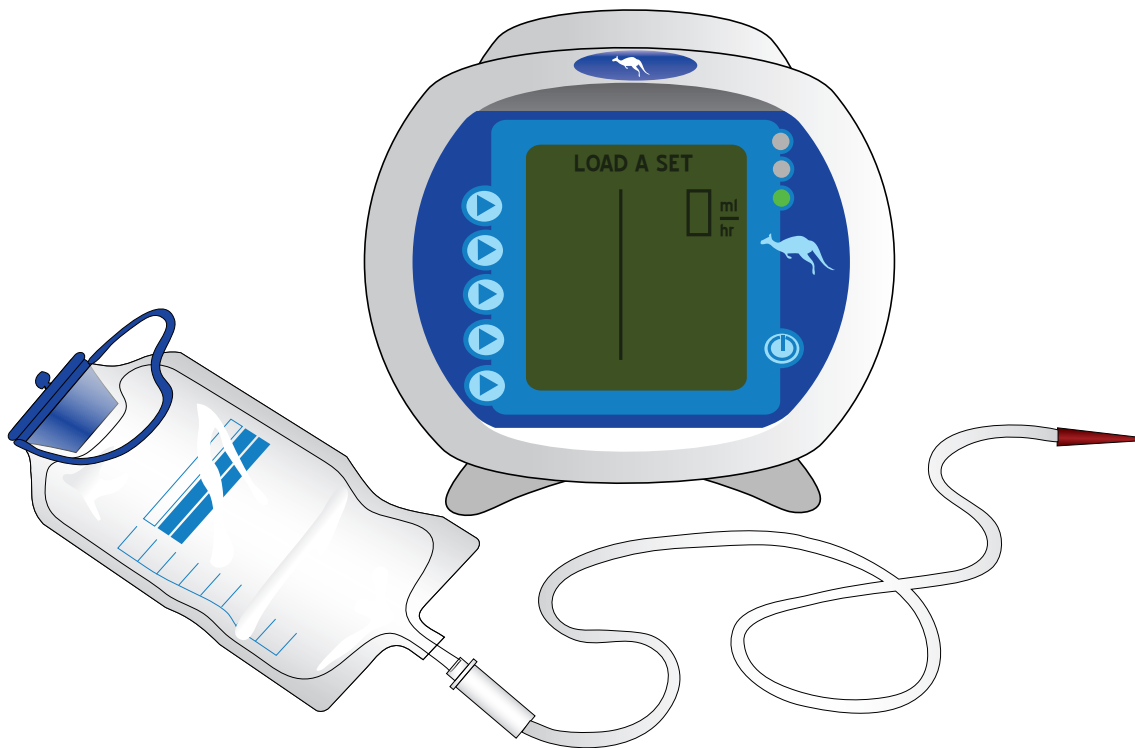
- your treatment team needs to take special measures to prevent formula going down the “wrong tube” (the breathing tube or larynx)
- your child has difficulty managing large amounts of formula all at once
- your child needs trans-pyloric feedings (feedings that by-pass the stomach and go directly into the small intestine)
- your child’s stomach is slow to empty during digestion

If your child will need pump feeding, you will be loaned a special feeding pump.

Before leaving the hospital, your nurse will teach you how to use it. You will have lots of time to practice and ask questions. Please consult the following pages for direction on how to use the Kangaroo ePump as well as hanging and loading instructions.

If your child’s feeding equipment comes from HSJ - Programme Ministériel, a Kangaroo™ Joey pump and equipment will be provided.

Experience has shown that flushing the feeding tube with water every 4 hours during a continuous feed will help prevent a tube from blocking. For babies who are 3 months of age or younger, flush the tube with sterile water.



How do I set up a pump at home?

When you arrive home with all your feeding pump equipment, you will need to set it up. This section of the booklet will cover how to hang it up and make sure that it is working properly.

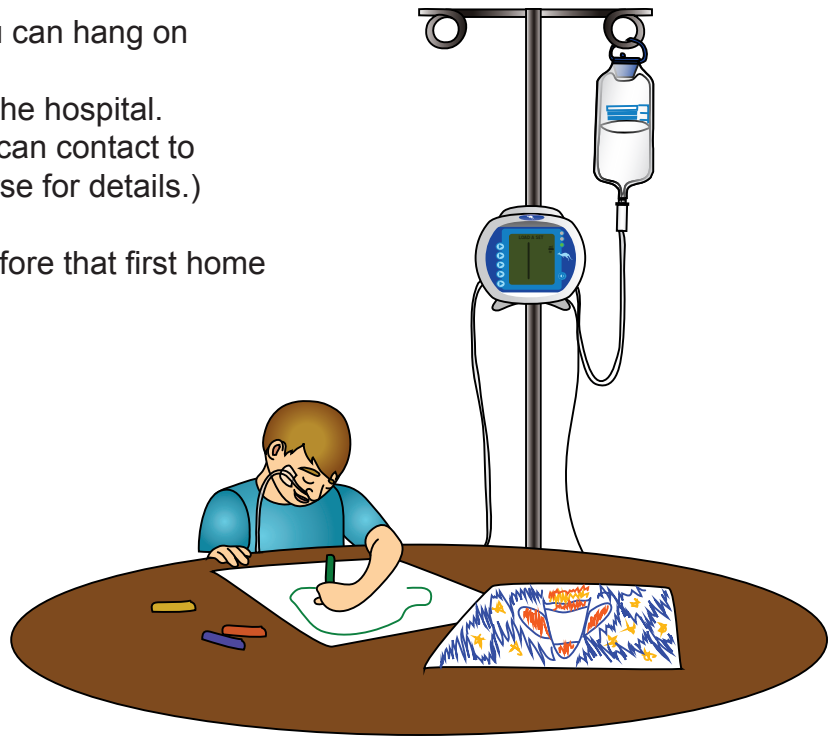
The following instructions apply for both the Kangaroo™ ePump (from the Montreal Children's Hospital's Home Enteral Feeding Program) and the Kangaroo Joey pump (loaned out from the Ministerial Program at Hôpital Ste-Justine).

To set up your pump:

1. Place your pump on a solid surface (e.g. a dresser, a night table or kitchen table)
2. Hang the bag and tubing 46 cm (18 inches) above the surface. You may use:

- A coat rack
- A hook on the hall
- An upside down hanger which you can hang on a small hook.
- An IV pole, as you see is used at the hospital.
(There are different suppliers you can contact to rent or buy one. Ask your HEF nurse for details.)

It's always a good idea to plan ahead, before that first home feeding!



How do I take care of the pump?

In order to ensure proper functioning of the ePump, it is important to care for and maintain the pump as per the manufacturer's guidelines.

For detailed cleaning instructions, the Kangaroo™ ePump Enteral Feeding Pump Operation and Service Manual is available, in many languages, at www.kangarooepump.com.

Care and Maintenance of the Feeding Pump

In order to ensure proper functioning of the ePump, it is important to care and maintain the pump as follows (based on manufacturer's guidelines):

CAUTION: "Disconnect pump from AC power source before cleaning.

After cleaning, do not connect to AC power source until pump and power cord is thoroughly dry."

- The outside of the pump, along with the tubing compartment inside the blue door, may be wiped down with mild, soapy water (never hot).
- The drop detector may be cleaned with a moistened q-tip only.

CAUTION: "Do not immerse pump or power cord in water or other cleaning solution. Failure to follow the cleaning procedures described could result in hazards to users. As with any AC powered electrical device, care must be taken to prevent liquid from entering the pump to avoid electrical shock hazard, fire hazard, or damage to electrical components."

Do not attempt to repair or alter the ePump in any way. Please return a damaged or non-operational pump to the Montreal Children's Hospital as soon as possible.

If any of the following events occur, **DO NOT USE** the pump until it has been properly cleaned and serviced by trained personnel at the MCH.

- Wetting of the pump's power cord or leakage into the pump interior during cleaning.
- Spillage of large amounts of formula onto the pump exterior or any spillage onto the power cord.

For detailed cleaning instructions, the Kangaroo™ ePump Enteral Feeding Pump Operation and Service Manual is available in many languages at www.kangarooepump.com.

It is the policy of the Montreal Children's Hospital that this pump must be periodically recertified to assure proper functioning and safety. The recommended service interval is every 6 months. Our home enteral feeding team will inform you when your pump checkdate is due. This recertification will be done by our Biomedical Engineering department. You need only bring your pump to our Warehouse & Distribution in the hospital's Sub-B level (C wing elevator).

E-Pump Maintenance Schedule:

Date to be checked	Date completed

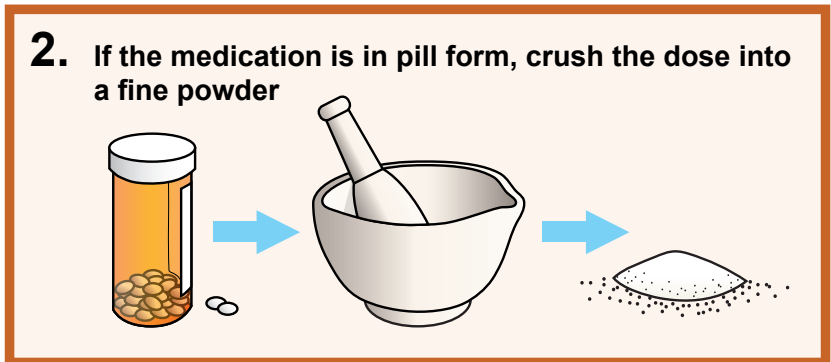
Medication Delivery through the feeding tube/button

Delivering medication through the feeding tube / button

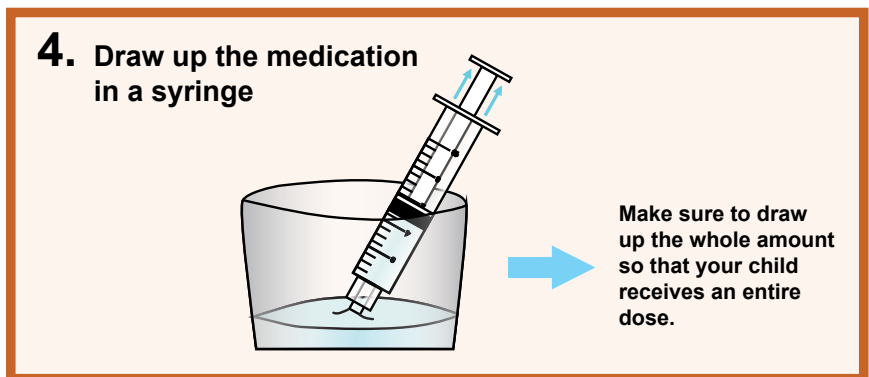
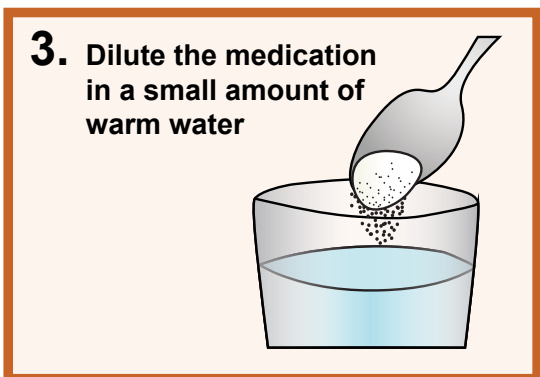
It is possible and often desirable to deliver medication using the nasogastric tube or the medication port of the gastrostomy feeding tube or button. With the proper information and a few tips, many medications can be safely delivered with convenient and easier ingestion. In order to ensure proper delivery to the stomach, here are a few tips to follow.

- Check with your doctor, nurse or pharmacist to ensure the medication can be delivered by the tube. There are a few kinds of medication that cannot be given in this manner. There are usually alternative methods of safe and effective delivery.
- When you order or pick up your child's medication, ask for the liquid or elixir form. If it is not available in liquid form, some pharmacists may be able to prepare a solution or suspension from the pill form.
- Remember to wash your hands first before handling medication or feeding equipment.
- Crush solid tablets into a fine powder and dilute in a small amount of warm water. However, please note that "enteric-coated" or "sustained release" tablets or capsules cannot be crushed. This process interferes with the protective effects of enteric coating and the timed absorption of sustained release pills or capsules.
- Prepare the medication and draw it up in the appropriate-sized syringe.
- Before giving your child the medication, always verify proper placement of the tube. Once the medication is slowly pushed into the tube, flush with a sufficient amount (5-10 ml) of water, regardless of whether the medication is a crushed pill diluted in water or a liquid form. This will help push the medication into the stomach and prevent blockage of the tube or button.
- Medication should never be added to the formula.
- Do not mix different medications in the same syringe.

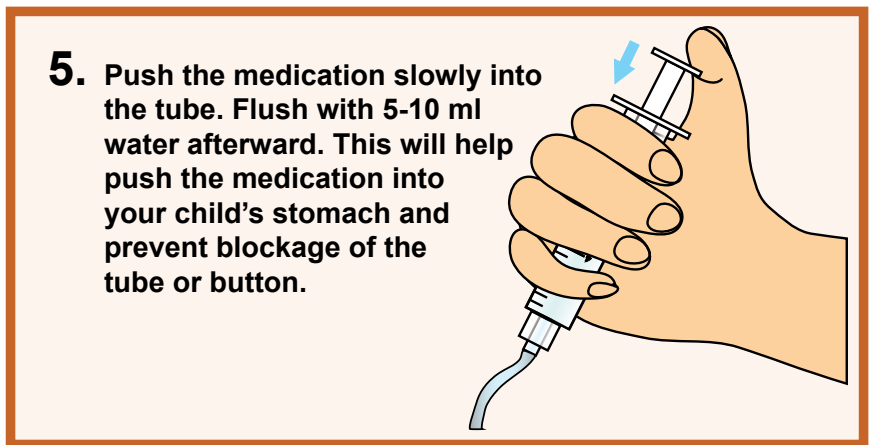
Delivering medication through the feeding tube / button



WARNING: please note that “enteric-coated” or “sustained release” tablets or capsules cannot be crushed. Crushing affects the enteric coating and the absorption of sustained release pills.



REMINDER: before giving your child the medication, always check the proper placement of the tube. If your child has a gastrostomy tube or button, flush a small amount of water into the extension to ensure it's working properly.



IMPORTANT:

Do not mix different medications together. Flush the syringe with at least 3-5 ml of water between medications.



Medication should never be added directly to the formula.



Types of Formulas

Depending on your child's nutritional needs, there are many commercial and/or specialized formulas available. The one that is right for your child may be based on his/ her age, diagnosis, health, etc. Formulas may differ in terms of the amount and type of protein, carbohydrate (sugars) and fat they contain. Your child's nutritionist and doctor will decide on the best formula for you by doing a careful dietary and health check of your child.

Formulas are usually available in 3 basic formats:

Ready to Feed

- no need to add anything unless directed by your nutritionist
- the most convenient and easy to use
- often the most expensive format

Liquid Concentrate

- is often used to make a calorie-rich feed
- dilute with water as directed by the nutritionist
- refrigerate when in concentrated form and opened for up to 48 hours
- once diluted with water, keep refrigerated and use within 24 hours

Powdered Formula

- more commonly available
- longer lasting and easy to store
- can be less expensive
- longer preparation time
- more chances of making mistakes when preparing a feed

Some specialty formulas are only available in powder form.

Once your team has decided on the best formula for your child, your nutritionist will:

- Give you careful instructions for formula preparation.
- Explain how much formula your child needs everyday.
- Help you work out the best feeding schedule for your child.

As your child's nutrition needs will change over time, you will need to make changes in the type and/or amount of formula that you use. Your treatment team will work with you to ensure your child gets what he or she needs to grow well and be healthy.



How to Prepare Formula

Young children, especially babies, can more easily get sick from germs that can grow or sit on food. They may have a hard time getting better because their immune systems are not yet fully developed, or are weak. Premature babies are particularly at risk.

You can help prevent your child from getting sick! Wash your hands with warm, soapy water before preparing formula and handling utensils.

1. Ready to Feed Formula

- requires no preparation. Remember to wipe the top of the can and the opener with a clean cloth before opening.

2. Liquid Concentrate Formula

- transfer this to a clean container. Add the exact amount of water indicated in the directions and mix well with the concentrate. Remember to refrigerate any unused formula once it's prepared.

Use boiled water when preparing formula for babies 3 months of age or younger.

3. Powdered Formula (requires a little more work)

- carefully measure out the required amount of powdered formula using the scoop (usually in the can), a spoon or a measuring cup. With certain formulas, a small scale may be useful when measuring out very precise amounts.
- If your child is 3 months old or younger, boil the water you will be using for a full 2 minutes. Cool the water to 70 degrees Celsius. This should take around 30 minutes at room temperature.

In some cases, special powdered formulas cannot be prepared with boiled water cooled to 70 degrees Celsius because of heat sensitive ingredients. Speak to your nutritionist before using these formulas.

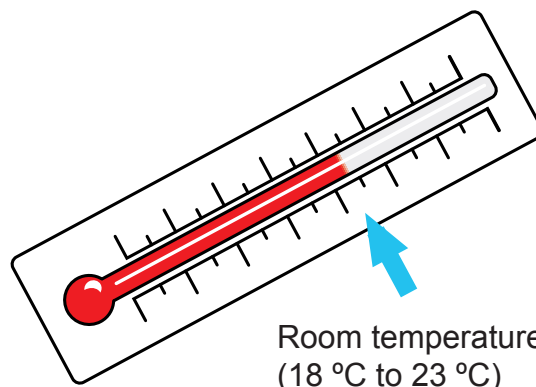
- For best results, mix a small amount of water with the required amount of powder to make a paste. Gradually add the rest of the water while continuing to mix.
- A blender may be useful when mixing this type of formula.
- If making a larger quantity, refrigerate immediately after preparation and check on the label to see how long it is good in the refrigerator.

Here are a few tips for all types of formulas:



- Check the expiry date stamped on the container and do not use formula after the expiry date.
- If you are adding any special oils (MTC oil), carbohydrates (polycose), micro lipids or any other, be sure to mix them well.
- You can use a blender for this.

- Re-heat formulas by placing the container in warm water for no more than 15 minutes until it reaches room temperature.
- A bottle warmer can also be used. Always verify the temperature of the warmed formula before giving it to your child.



Storage of Formula

Follow these guidelines to prevent your formula from going sour or growing germs.

- All types of formula will stay fresh in the refrigerator up to 24 hours if they are prepared in clean containers and well-covered.
- Unopened formula can be stored for use up until the expiry date.
- Well-covered liquid concentrate formula can be stored in the refrigerator once it is opened for up to 48 hours (2 days).
- Opened cans of powdered formula can be stored in the cupboard for up to 1 month when plastic covers are used.

Feeding your child formula through a feeding bag:

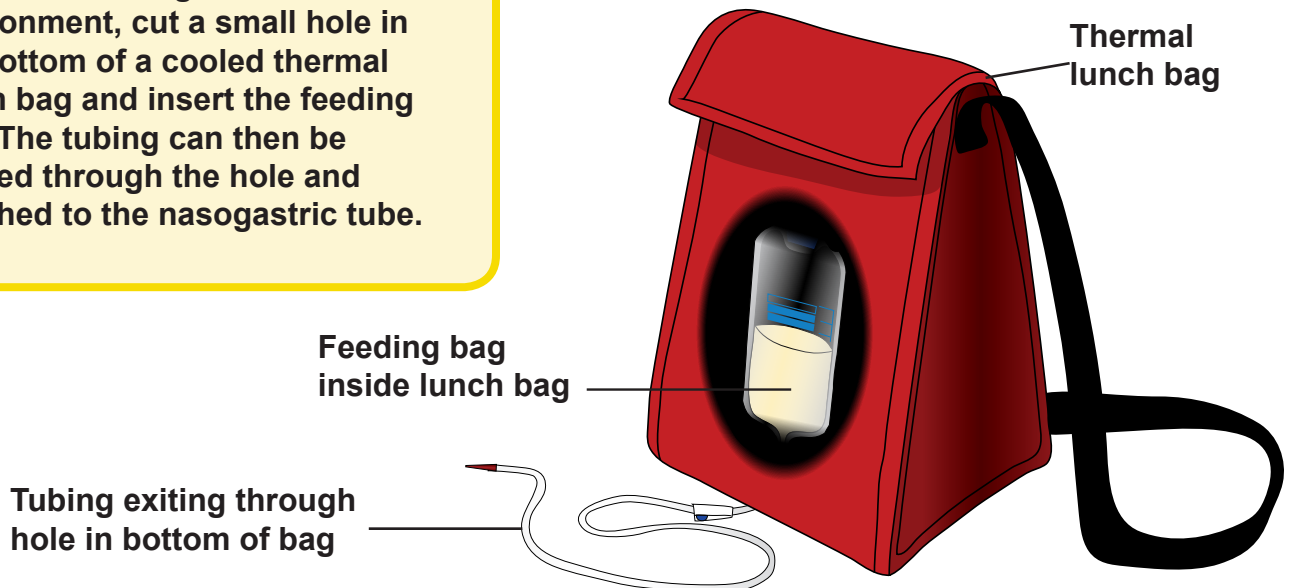
Formula that is poured into a feeding bag can stay out hanging at room temperature for:

- 4 hours (for infant formula)
- 8-12 hours (for Pediasure™ and adult formulas)

Remember:

- Formulas should be at room temperature before pouring into the feeding bag.
- Keep formula that is in a feeding bag away from direct sunlight or any heat source. If the child is being fed in a very warm room or outdoors, you may want to keep the formula cool.
- Do not add fresh formula to formula that is already hanging in the bag from a previous feed.

Tip: when feeding in a warm environment, cut a small hole in the bottom of a cooled thermal lunch bag and insert the feeding bag. The tubing can then be slipped through the hole and attached to the nasogastric tube.



Formula Hang Time

When it's time to hang your child's formula using either the gravity system or a feeding pump, it's important to know what to do in order to prevent bacterial growth in formula.

Different types of formulas may have different hang times.

Type of formula	Maximum hang time
Ready-to-feed liquid formula in a can	8 hours
Ready-to-feed liquid formula in a can with added water, oils, protein, carbohydrate, or electrolytes	4 hours
Powder or liquid concentrate formula with added water	4 hours
Breastmilk	4 hours (less is better)
Breastmilk with calorie booster	2 hours

Remember to add only enough formula to the feeding bag so that it does not hang longer than recommended hang times above.

To figure out how much formula you should add to your bag each time you refill, use the following calculation:

Rate x Maximum Hang Time = ml of formula to add to the bag

Example: If your pump or gravity rate is 40 ml per hour and you use powdered formula with water added (4 hours hang time):

$$40 \text{ ml per hour} \times 4 \text{ hours} = 160 \text{ ml}$$

That means that you could put up to 160 ml of formula to the bag each time.

Always rinse out the feeding bag and tubing with water before adding more formula.

How can I help my child eat by mouth?

Babies

Eating by mouth is a skill that is learned. For some babies, it is more difficult than for others. This can be due to a variety of reasons including physical or neurological ones. The following tips may help you teach your baby how to eat with his or her nasogastric tube. Your nutritionist, occupational therapist or Home Enteral Feeding Program nurse may also offer you other tips that are specific to your baby's needs.

Mealtimes should be something fun that your baby looks forward to. Here are a few suggestions to help you create a pleasant and calm atmosphere during feeding times. This can have a huge impact on the way your child views mealtimes for a long time to come:

- Try to prepare your food beforehand so your mealtime is uninterrupted.
- Keep the room quiet to help promote a calm and relaxed environment.
- Feed your baby on a regular schedule.
- Feed your baby in the same place everyday.
- Have only 1 person (the feeder) with your baby during mealtime. Try to have the same 1 or 2 people feeding the baby.
- Use the same type bottle and nipple each time you feed.
- Avoid tiring your baby with lots of activities right before mealtime.
- Don't confuse your baby. Avoid playing with toys during mealtime.

Try to follow these guidelines at least until the feeding pattern is well established.

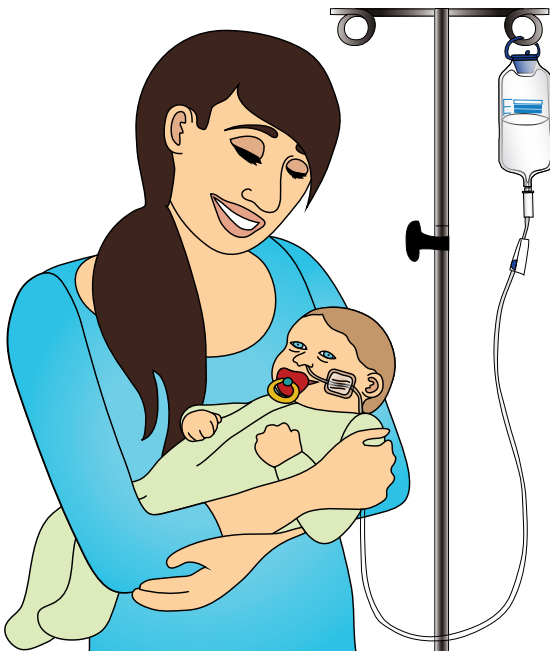
Patience and practice are the keys to success!

Your attitude and behavior during feeding times can make a big difference. Babies pick-up and respond to our feelings and mood. So, it's best to;

- Stay relaxed. Remember, you can always use the tube, if you need.
- Sit in a comfortable chair.
- Start the feeding while your infant is calm.
- Talk softly to the baby. Praising all the things he or she does that are positive (such as allowing the bottle to be placed in the mouth, sucking, smiling). Give lots of smiles.
- If your baby does something you don't like (such as refusing the bottle, crying, turning away), simply remove the bottle and try again in a few minutes.

Never force a baby to feed.

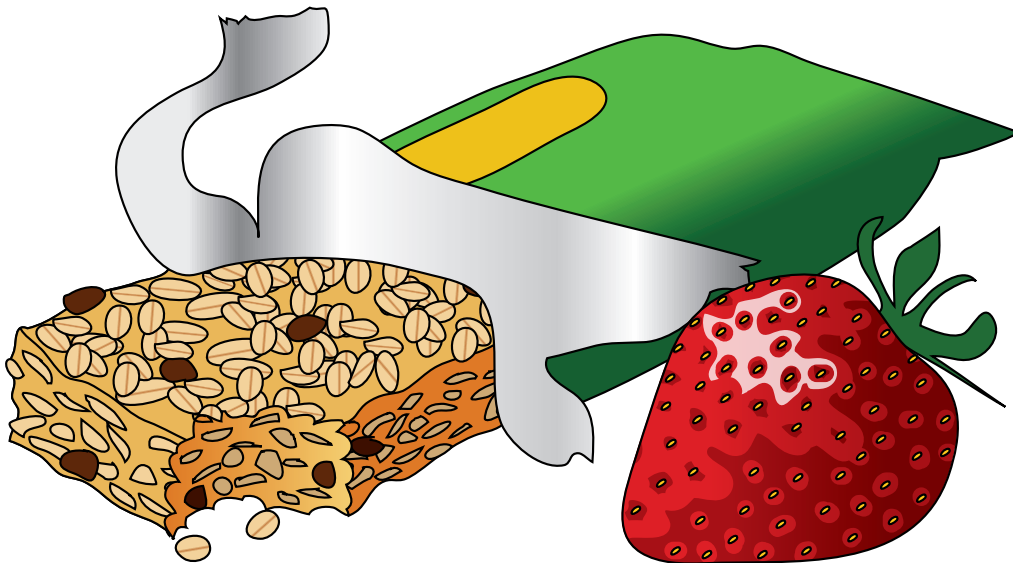
- Maintain a face-to-face position with eye contact during the feeding.
- Keep the feeding time to 30 minutes. After that, you'll both be tired.
- Don't put too much pressure on yourself or your baby. There will be good days and bad days for you both.



Even when tube feeding your infant, it's important to follow these guidelines. If possible, have your baby suck on a pacifier during the tube feedings so that he or she associates sucking with being fed. Even if your baby is never able to totally feed by mouth, he or she will learn to think of feeding time as a pleasant, social activity.

Kids and Teens

If you've been receiving a tube feed all night, chances are you may not feel too hungry first thing in the morning. That's okay, you don't have to force yourself to eat right away. You may start to get hungry a few hours after waking so having a snack close by is a good idea. Make sure it's something you really like!



Here are a few other tips for eating during the rest of the day:

- Avoid eating alone. If you can eat with your family or friends, you should. Meals are a sociable time as long as no one is pressuring you to eat!
- Don't get down on yourself if you have a day when your appetite is not as good as the day before. Remember, everyone has good days and bad days! Small, frequent meals maybe enough for that day and if you change your mind, you can always ask for a second portion.
- If the smell of food makes you feel nauseous, stay away from the kitchen while it's being prepared.
- Plan a menu with your parents and include your favourite foods!
- Try and keep a good sense of humour for the "tough" days.

Remember: even if you're taking in those extra calories by tube at night, you should still try and eat as much as your friends during the day. You can't get catch-up growth without those catch-up calories!

Be patient and your effort should pay off!



A Big Thank You!

To the following sponsors and donors for their generous gifts benefiting the families and children requiring nutritional support.

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To the kind and caring friends who attended and contributed toward the “Help the Kids Grow: HEF Fundraiser of August 3rd, 2013 – a wonderful evening was had by all!

To our amazing committee for their commitment, dedication and hard work in putting it all together for the Kids!

**John Colacci – Pasquale Di Pierro – Mario Di Rienzo
Joseph Farinacci – Salvatore Satangelo – Mario Tombari**

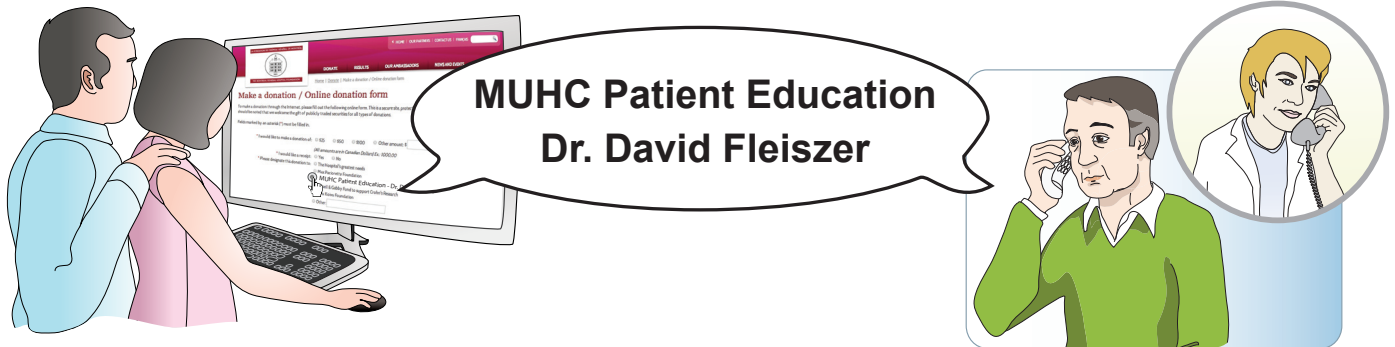
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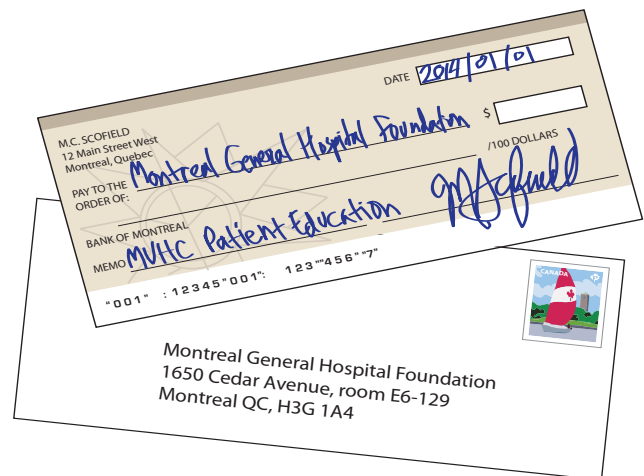
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D-590A
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