

Home Enteral Feeding Guidebook

A Guide for Patients and their Families



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de santé McGill



McGill University
Health Centre

Office d'éducation des patients
Patient Education Office

Cardinal Health is proud to partner with McGill University in providing you with this guidebook for enteral feeding at home. It was developed with a broad perspective of covering the needs of enterally fed people of all age, including infants. This guidebook will provide useful information whether you have been using a nutritional delivery system at home for some time, or are just now starting.

Very best,

The Cardinal Health Nutritional Delivery Team



CardinalHealth

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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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Table of Contents

Introduction

- 5 A Family Guide
- 6 Why does my child need tube feeding?
- 8 Feeding tube details

All About the Gastrostomy Tube / Button

- 9 What is it?
- 10 How is it inserted?
- 10 How does it work?
- 11 Gastrostomy Tubes
- 11 Gastrostomy Buttons
- 13 How do I attach the extension tube to the Kangaroo™ button?
- 14 How do I attach the extension tube to other types of buttons?
- 15 How do I take care of the stoma (opening)?
- 16 How do I change the gastrostomy button at home?
- 17 How do I vent the gastrostomy tube? – Illustration
- 18 Frequently Asked Questions About Gastrostomy Tube / Button
- 20 Problem Solving for Gastrostomies
- 24 Be Prepared With a “Stoma Kit”

All About the Nasogastric Tube

- 25 What is it?
- 26 Frequently Asked Questions About the NG tube
- 28 Problem Solving for NG tubes

All About the Jejunostomy Tube / Button

- 31 What is it?
- 32 Types of Jejunal Tubes / Buttons
- 32 How is it put in place?
- 32 How do I take care of the jejunostomy tube / button?
- 33 How do I feed my child with it?
- 34 Safety Checks
- 34 Frequently Asked Questions About Jejunostomy Tube / Button
- 36 Problem Solving for the Jejunostomy Tube / Button

Hypergranulation Tissue... It Can Happen!

- 39 What is it?
- 40 What can I do about it?

Feeding with a Tube - An Overview

- 41 Intermittent (Bolus) Feeding
- 42 The Push Method
- 43 How to Use the Push Method – illustration
- 44 The Gravity Method
- 46 How to Use the Gravity Method – illustration
- 47 How do I keep everything clean?
- 48 Feeding Pump Method
- 49 Continuous Feeding
- 51 How do I set up a pump at home?
- 51 How do I take care of the pump?
- 52 Care and Maintenance of the Feeding Pump

Medication Delivery through the Feeding Tube/Button

- 53 Delivering Medication Through the Feeding Tube / Button
- 54 Delivering Medication Through the Feeding Tube / Button - illustration

Enteral Nutrition

- 55 Types of Formulas
- 56 How to Prepare Formula
- 58 Storage of Formulas
- 59 Formula Hang Time

How can I help my child to eat by mouth?

- 60 Babies
- 62 Kids and Teens

Thank You

Notes

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
- gastrostomy tubes and buttons
- how to take care of feeding equipment
- troubleshooting problems you may encounter along the way
- 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. 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").

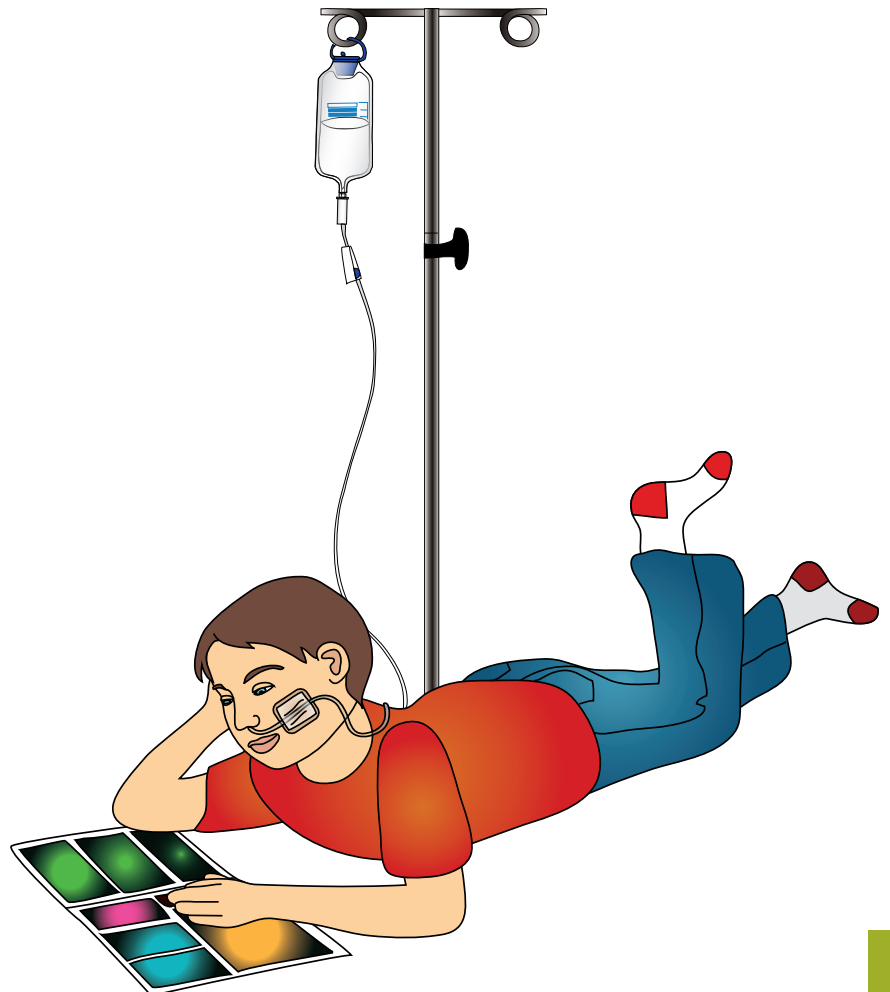
There are many health problems which affect a child's ability to eat and grow. One or more of these health problems can interfere with how food is eaten and/or absorbed in the body. Problems can include:

- 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.



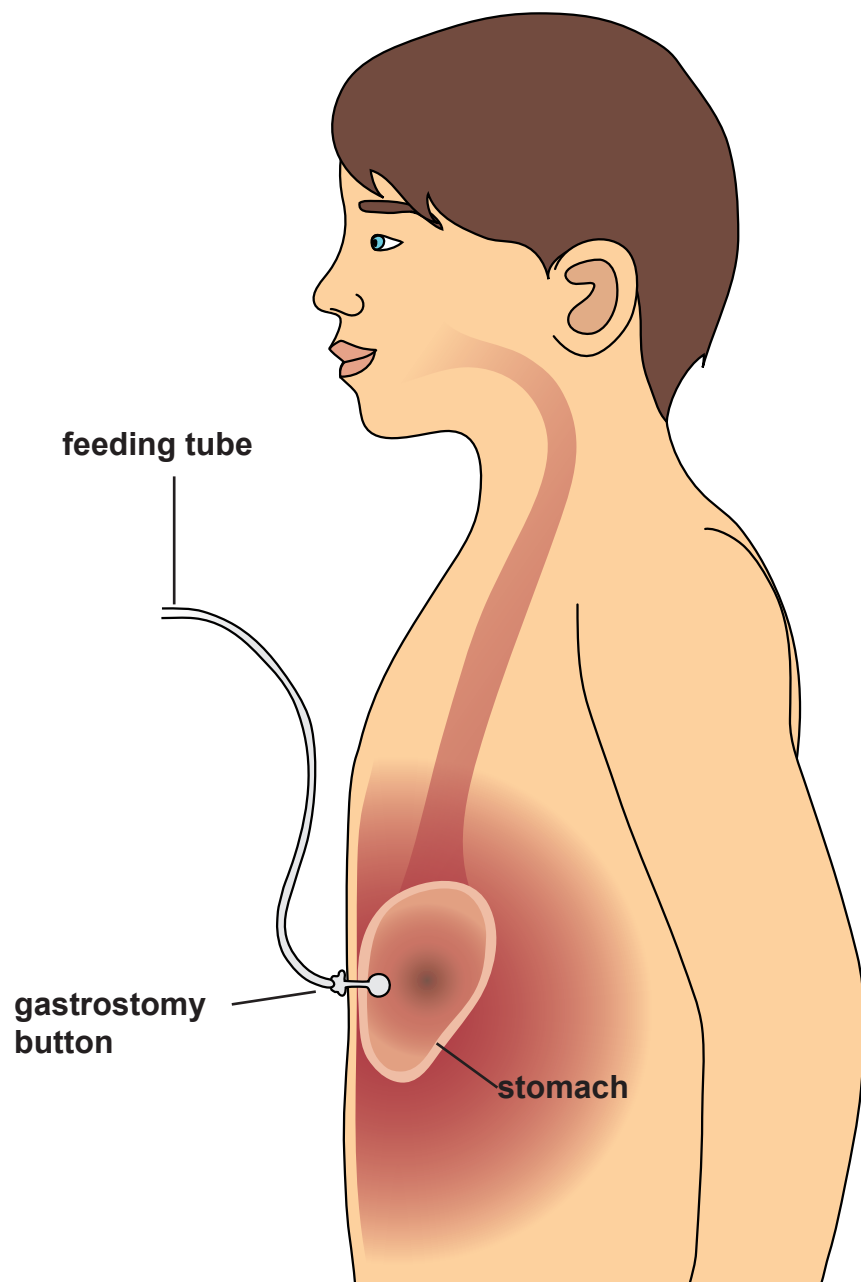
Feeding tube details

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:	

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 that the nutritional support necessary for optimal growth and development is received. There are a wide variety of tubes and skin level devices available. The surgeon will choose the device which best meets your or 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 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. Medication for any pain or discomfort experienced after the procedure will be provided.

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 the abdomen just below the ribcage. The incision is then closed with stitches just like any other incision. medication for any pain or discomfort will be provided.

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 a nutritionist and is adjusted based on how well it can be tolerated. The same can be done for a gravity feeding system.

Gastrostomy Tubes

G-tubes can be made from silicone, with 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 Kangaroo Gastrostomy Feeding Tube 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

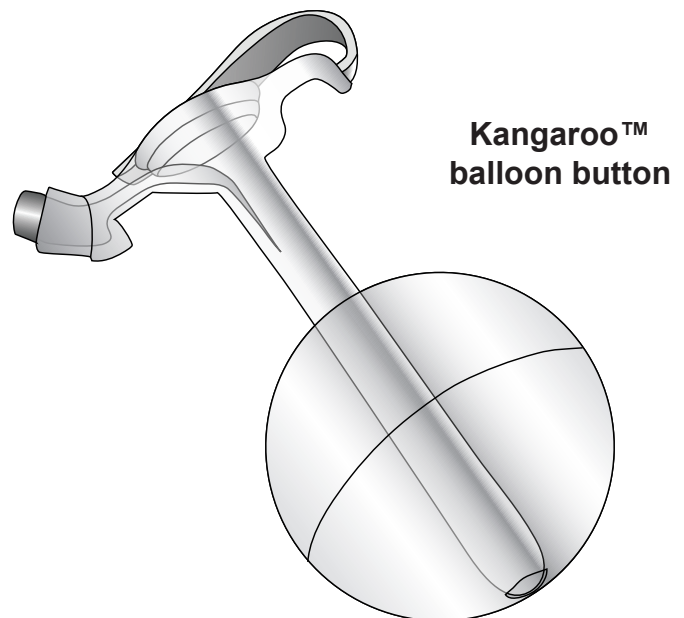
A gastrostomy tube can be replaced by a skin-level balloon button device either at time of surgery or once the original stoma has healed sufficiently. More and more commonly, gastrostomy buttons are the device of choice at time of surgical insertion. Buttons come in different shapes and sizes. Also,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

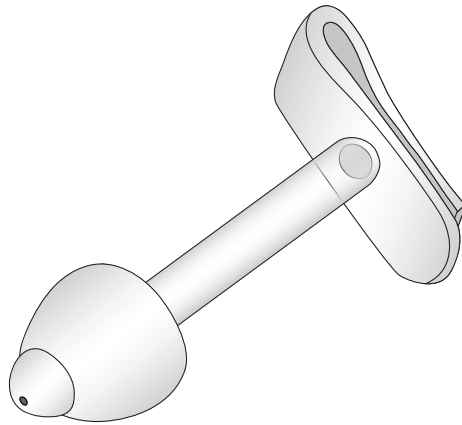
Emptying and refilling the balloon with a syringe every 1-2 weeks is an important safety measure to ensure there is no slow leak or defective balloon.

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.



b) Dome-style Devices

Another option is a dome-style 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.



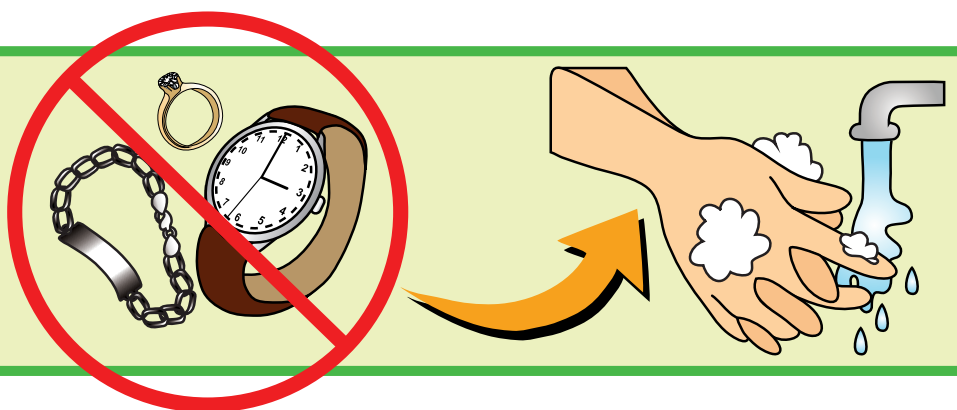
It cannot however be changed at home (as with balloon button devices) but must be replaced in the surgery clinic by a surgeon. The discomfort caused by the placement of this kind of button can be prevented with adequate medication just prior to the short procedure.

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

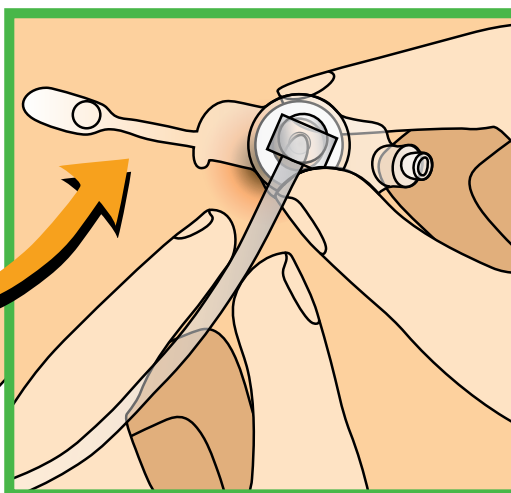
Disadvantages of this type of button include pain/discomfort at removal or change. Besides being more expensive than standard balloon devices, this button is only available starting in size 18 Fr and up.

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

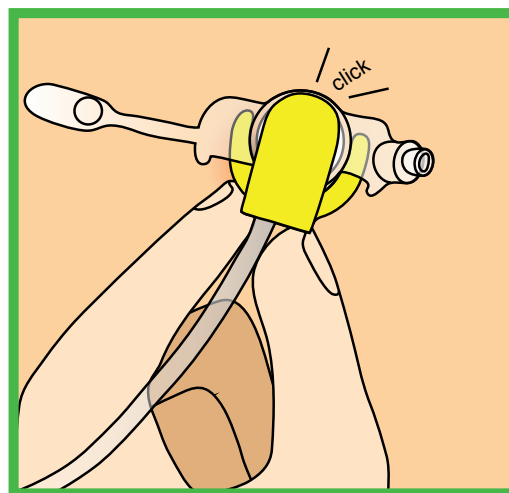
1. Remove all jewellery and wash your hands well



2. Attach tube

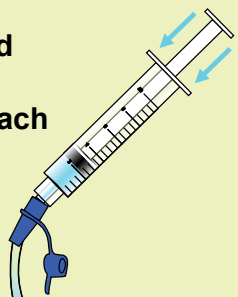


Place fingers on either side of the button, press the tip of the extension tube into to the main slot of the button



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



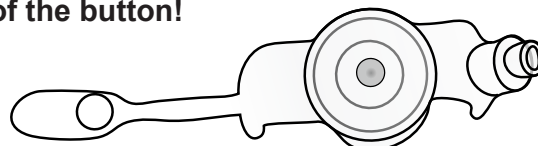
4. Once you can see that the flush went in easily and it feels comfortable, you can connect the end of the feeding bag tubing to the extension and start the feed.



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 go to the hospital for placement verification.

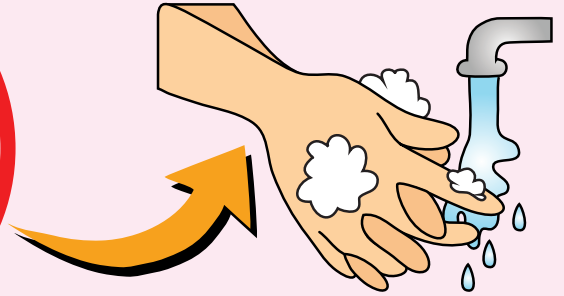


Also remember to remove the extension from the button device once you've flushed the tubing with water at the end of each feed. This will help prevent the valve inside the button from sticking and increase the life of the button!

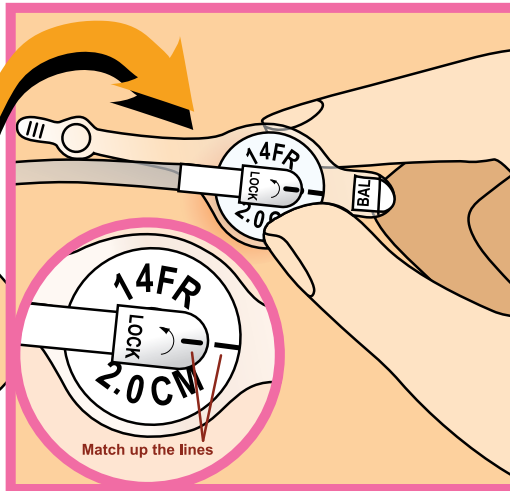


How do I attach the extension tube to other types of buttons?

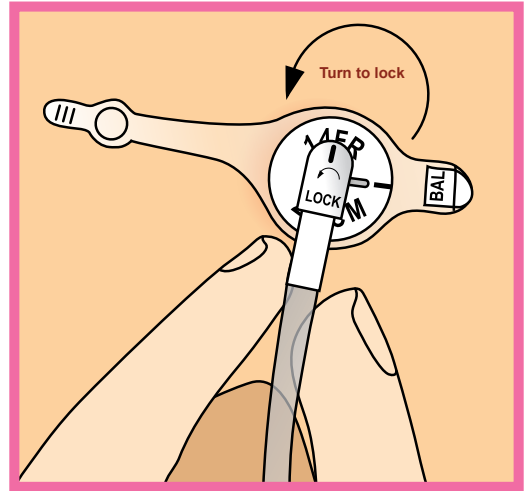
1. Remove all jewellery and wash your hands well



2. Attach tube

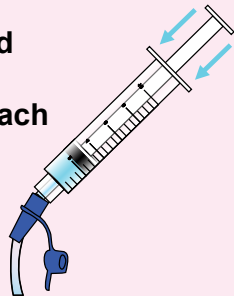


Place fingers on either side of the button, press the tip of the extension tube into to the main slot of the button by matching up the guide lines.

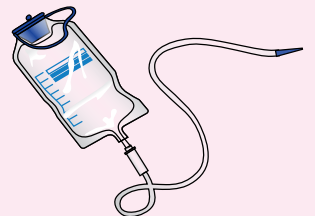


Then turn the extension tube to lock it in place.

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



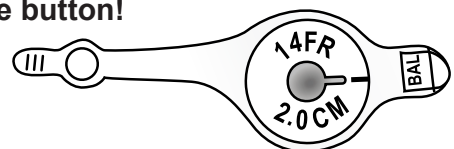
4. Once you can see that the flush went in easily and it feels comfortable, you can connect the end of the feeding bag tubing to the extension and start the feed.



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 go to the hospital 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 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, usual activities including swimming or other sports may be resumed.

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:

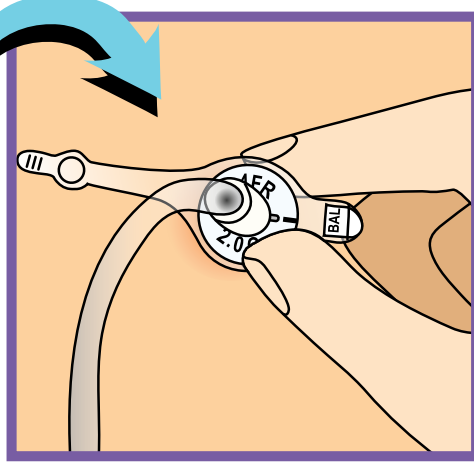
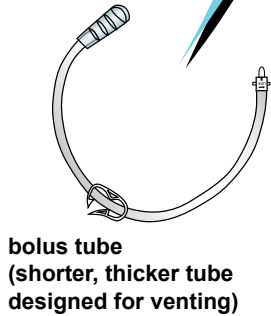
1. **Wash your hands.**
2. **Gather your supplies which include the new skin-level balloon button device kit.**
3. **Test the new button by filling with the same amount of water you usually use to inflate the balloon. If the balloon is intact without any leakage, remove the water.**
4. **If this is for your child, have him or her 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 go to the hospital 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.

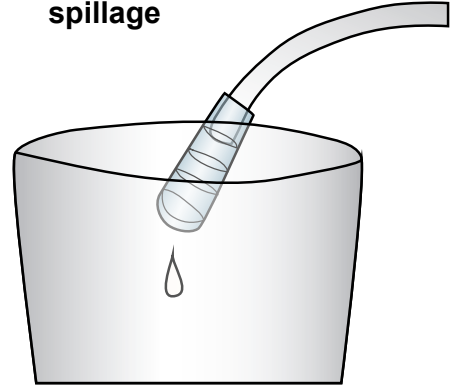
How do I vent the gastrostomy tube?

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.

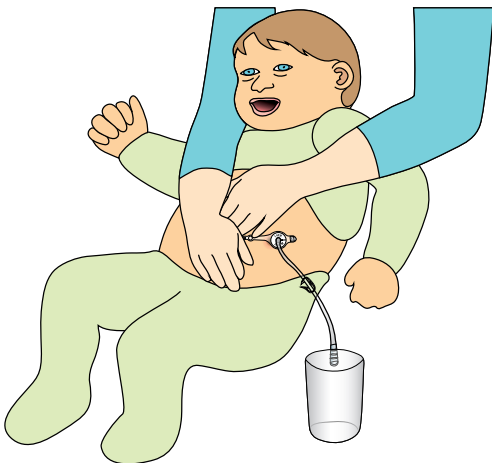
1. Attach the bolus tube included in the kit to the button



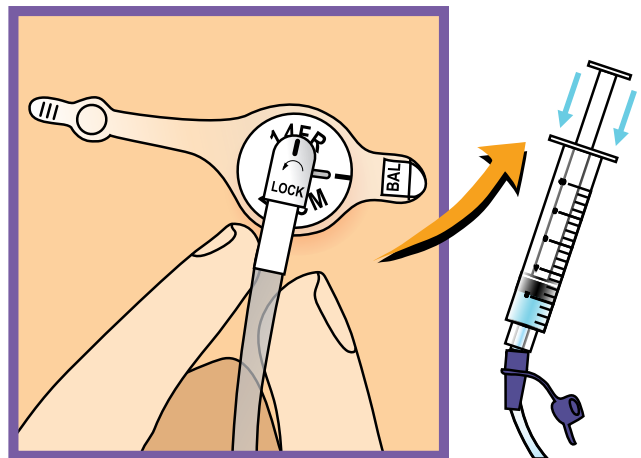
2. Place the tip of the tube into a container in case of spillage



3. Gently massage the 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 bathing or swimming be resumed?

A. Once the gastrostomy site or stoma is healed, you or 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™ 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 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 you or your child has. If it's a balloon-type like the Kangaroo™, 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) there is weight gain and the button begins to dig into the skin or,
- 3) there is weight loss and leakage around the stoma develops
- 4) you or 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, you cannot change it. You must have it replaced by a doctor.

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 Solving for the Gastrostomy 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
Blocked tube or button	• Formula or stomach contents • Medication	• Flush the tube with 5 - 10 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 nutritionist. • If blocked, flush the tube with 10 ml warm water and use a push-stop-push-stop motion to try and unblock the tube. • Use only liquid or finely crushed medicine dissolved in water. If unsure, check with your pharmacist.
Infection: signs & symptoms	• 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	• Increase fluid intake as tolerated. • Consult your HEF nurse, surgeon or family doctor for assessment and treatment. • Refer to section on Hypergranulation Tissue
Dry mouth	• Lack of stimulation to mouth	• 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
Constipation: infrequent hard stools that can be painful to push out	• Not enough fluids • Not enough fibre • Low activity level • Medication side effects	• Increase fluid intake. • Increase fibre intake. • Increase daily activity. • Consult HEF team.
Diarrhea: frequent loose or watery stools	• Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis	• 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.
Gas or bloating	• Excess air in stomach	• Keep the G-tube closed between feedings. • Burp during the feed.

Problem	Possible cause	What to do
Gas or bloating (continued)	• Excess air in stomach • Too much formula per feed	• 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	• Balloon breakage • Accidentally pulled out	• 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	• Excess air in stomach • Excessive feeding volume • Reflux of stomach contents into the esophagus • Delayed gastric emptying • Rapid feeding • Dumping Syndrome	• See “Gas & Bloating”. • Consult HEF team concerning decreasing volume per feed. • Feed 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	• Excess air in stomach • Adhesions • Infection	• 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	• Tube migrated into intestine causing blockage	• 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** _____

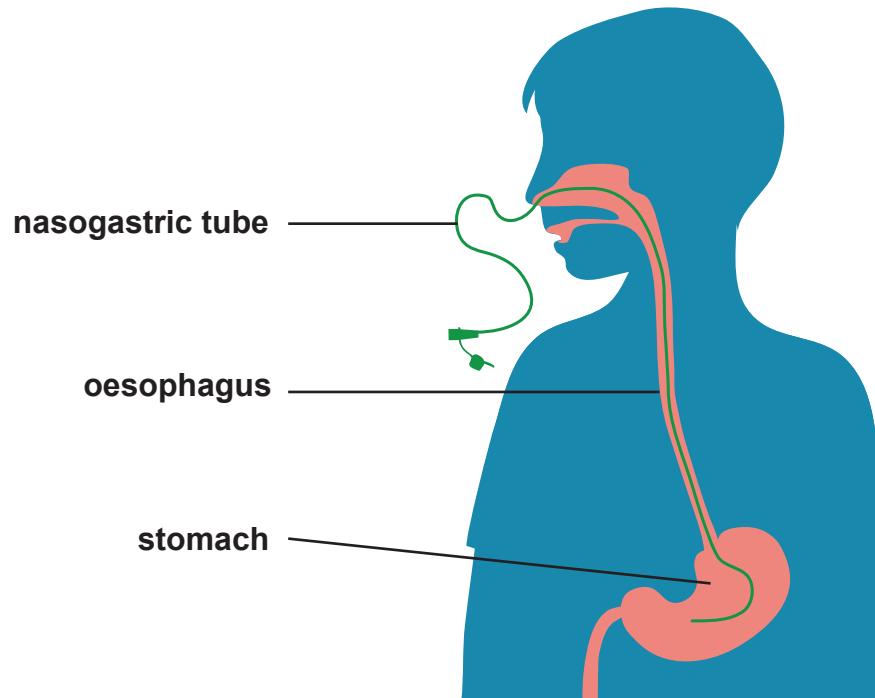
Do not try to replace a Entristar™ button, nor a jejunostomy tube or button. This must be done by a surgeon. However, if these type of buttons or tube becomes dislodged from the stoma, you can temporarily replace it with a Foley catheter until a new one can be properly reinserted.

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 Nasogastric Tube

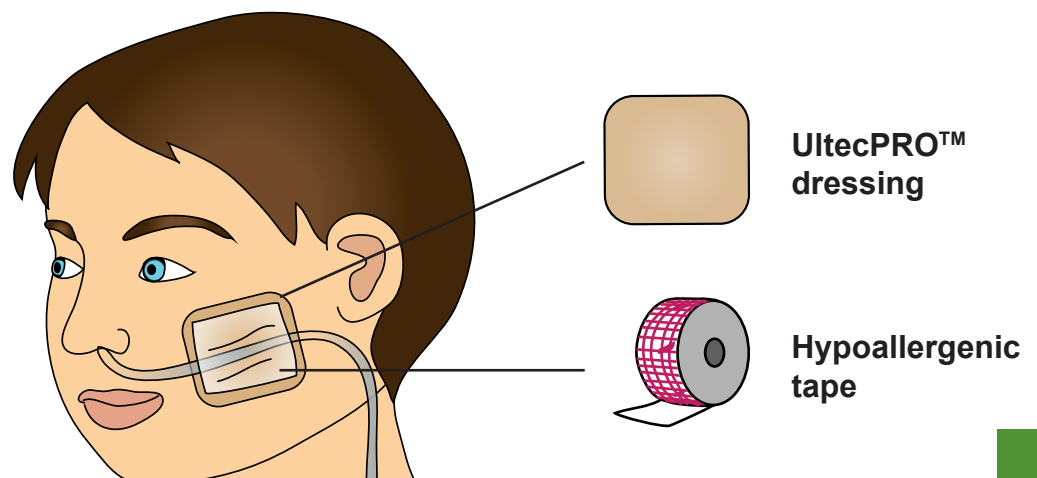
What is it?

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 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 UltecPRO™ dressing may be placed on the cheek first. Once the NG tube is inserted, it can be fixed in place over the UltecPRO™ and finally covered with Kandall™ hypoallergenic tape. This way, the skin is protected and the tube should stay firmly in place.



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 UltecPRO™ 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.**

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. 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
Aspiration: difficulty in breathing with coughing and/or choking; may also have blueness or cyanosis.	• Vomiting or reflux of stomach contents into the lungs • Food or saliva going down wrong tube (breathing tube or trachea)	• 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 or if the episode is more severe than usual.
Blocked tube	• Formula or stomach contents • Medication	• 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.
Constipation: infrequent hard stools that can be painful to push out.	• Not enough fluids • Not enough fibre • Low activity level • Medication side effects	• 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	• Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis	• 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	• Underactive mouth	• Brush the teeth and/or clean the mouth at least twice per day. • Apply lip balm or lubricant to lips.
Gas or bloating	• Air in stomach • Too much formula per feed.	• 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.

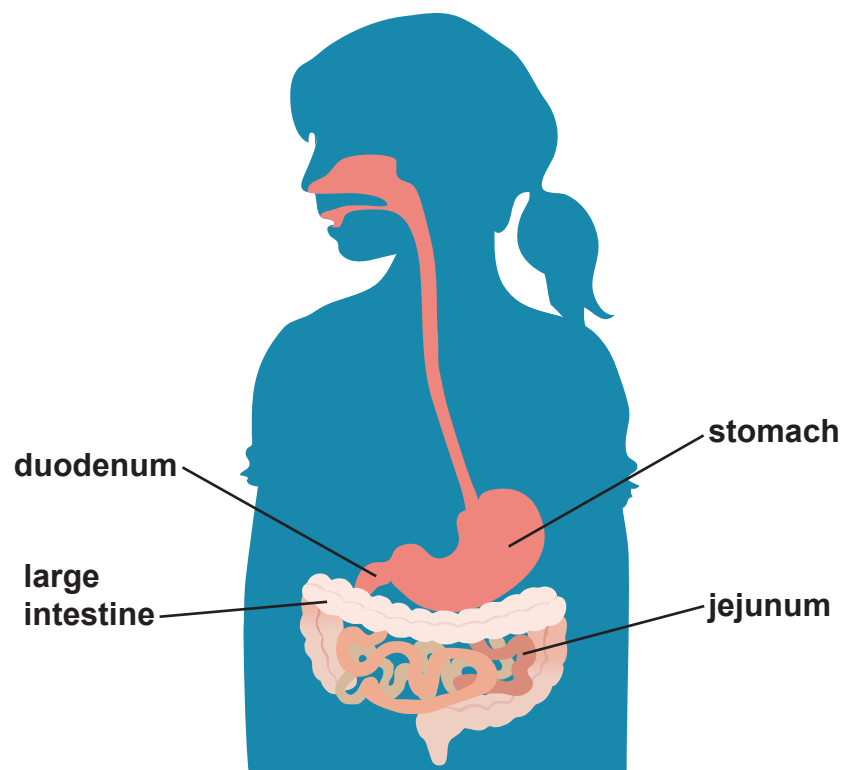
Problem	Possible cause	What to do
NG tube pulled out by baby / child	• Infants or children who cannot understand, may pull out the tube one or several times a day	• Never leave a child alone during a feed as they can pull out the tube and choke. • Always check the position of the tube just before feeding. • 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.
Nausea and / or vomiting	• Too short amount of time between feeds • Feeding too quickly • Slow digestion in the stomach • Other gastrointestinal problems	• 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 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 a jejunostomy may be required:

1. Severe gastro-oesophageal reflux or poor gastric motility.
2. A gastrostomy tube cannot be inserted into the stomach for various reasons.

Types of Jejunal Tubes / Buttons

An NJ (naso-jejunal) 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.

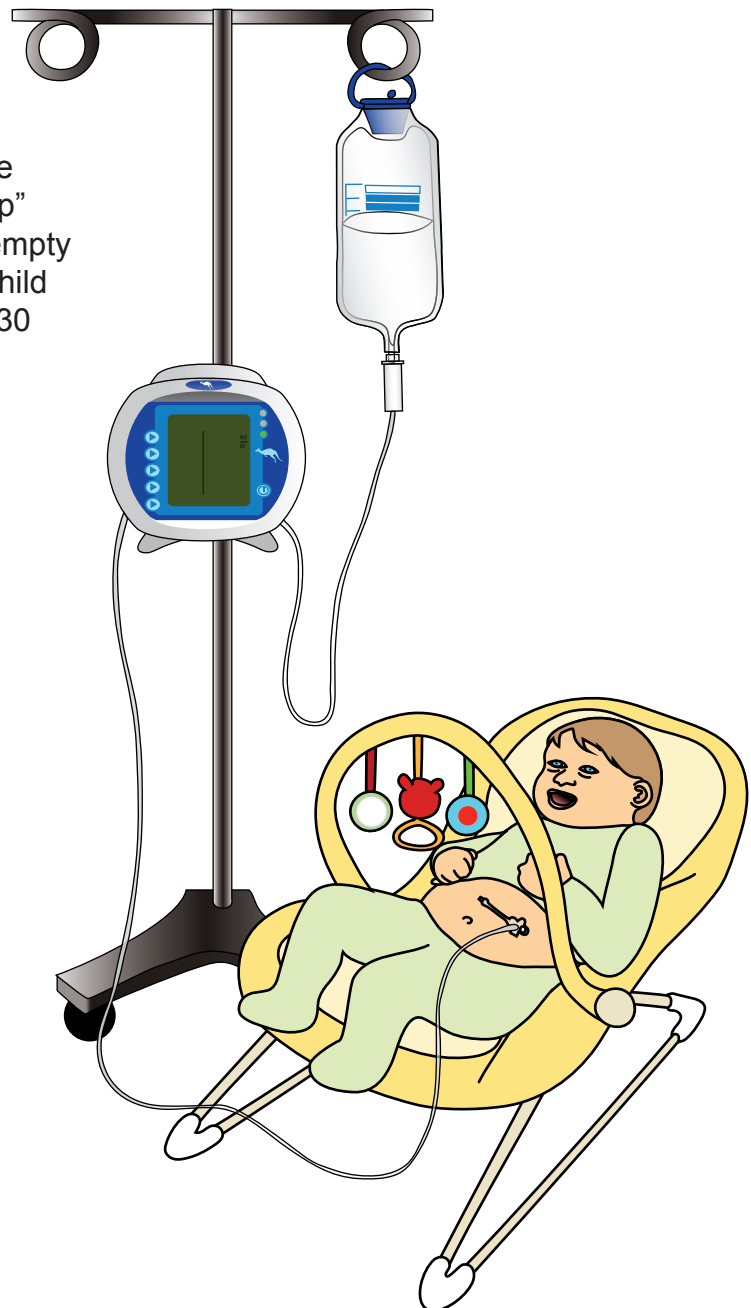
How do I feed my child with it?

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. Go 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, bathing is fine. 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 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 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.

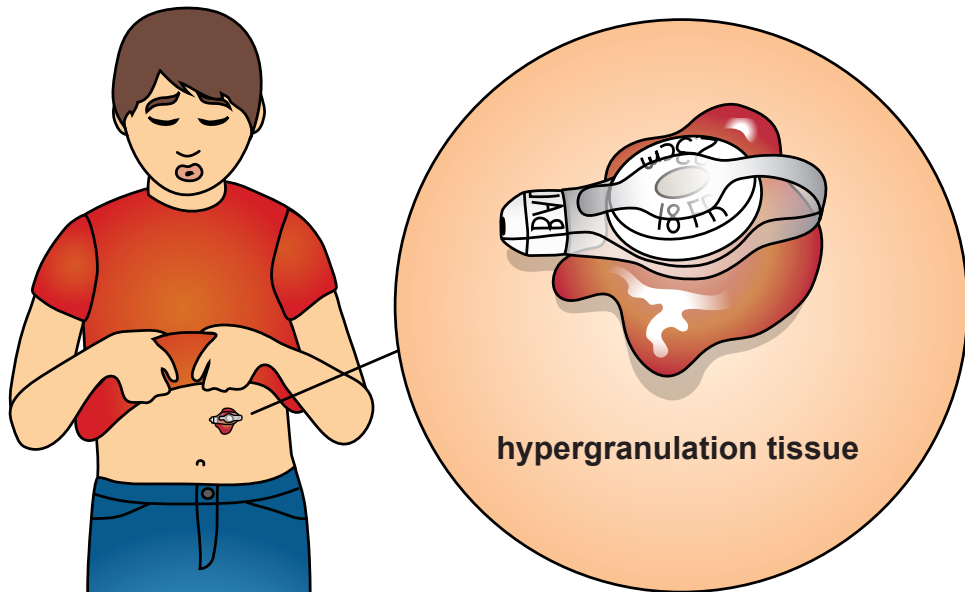
Problem	Possible cause	What to do
Blocked tube or button	• Formula or intestinal contents • Medication	• Flush the tube with 10 - 20 ml warm water before and after feeding. • Do NOT give pureed foods through the tube. • Do not mix anything new into the formula without consulting the HEF nurse or nutritionist. • 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.
Infection: signs & symptoms	• 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	• Increase fluid intake as tolerated. • Consult your HEF nurse, surgeon or family doctor for assessment and treatment. • Refer to section on Hypergranulation Tissue.
Dry mouth	• Lack of stimulation to mouth	• 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
Constipation: infrequent hard stools that can be painful to push out.	• Not enough fluids • Not enough fibre • Low activity level • Medication side effects	• Increase fluid intake. • Increase fibre intake. • Increase daily activity. • Consult HEF nurse or doctor.
Diarrhea: frequent loose or watery stools	• Formula incorrectly prepared • Formula soured • Feeding delivered too quickly • Displaced tube • Medication side effects • Not enough fibre • Feeding intolerance • Gastroenteritis	• 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.
Gas or bloating:	• Excess air in stomach • Swallowing air	• 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	• Balloon breakage • Accidentally pulled out • dislodged tube or button	• 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	• Excess air in stomach • Excessive feeding volume • Reflux of stomach contents into the esophagus • Delayed gastric emptying • Rapid feeding • Dumping syndrome	• 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	• Excess air in stomach • Adhesions • Infection	• See “Gas & Bloating”. • Notify the HEF team.
Vomiting of green coloured bile	• Tube migrated into intestine causing obstruction	• If ANY bilious vomiting occurs, bring your child immediately to the Emergency Room.

Hyper-granulation 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 foam 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 there is weight loss 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.

Feeding with a Tube - An Overview

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 oral intake or it is entirely based on the 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 the regular diet (eating by mouth), OR
- to replace the 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 well tube feeding is managed.

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
- the formula

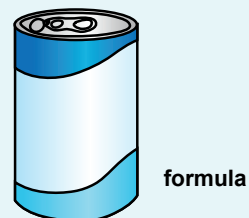
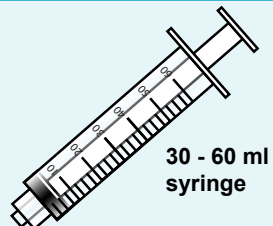
To deliver the feed:

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

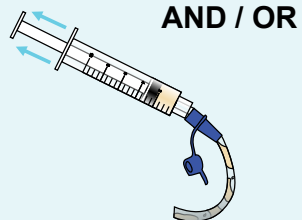


2. Gather your supplies

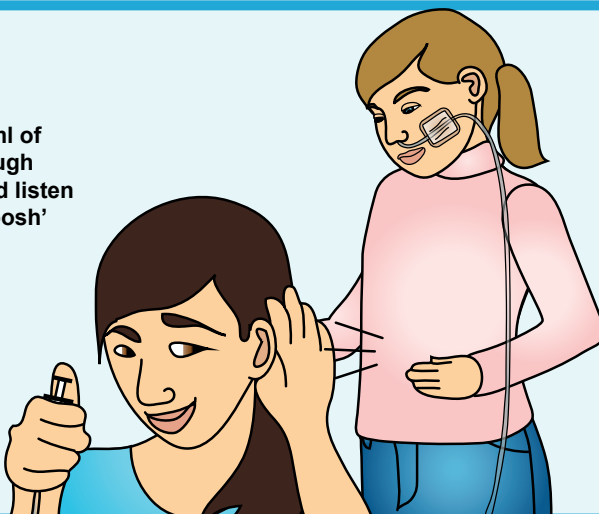


3. Check tube position by

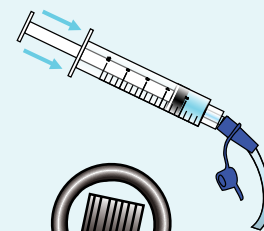
a) trying to extract a small amount of stomach contents with a 10 ml syringe



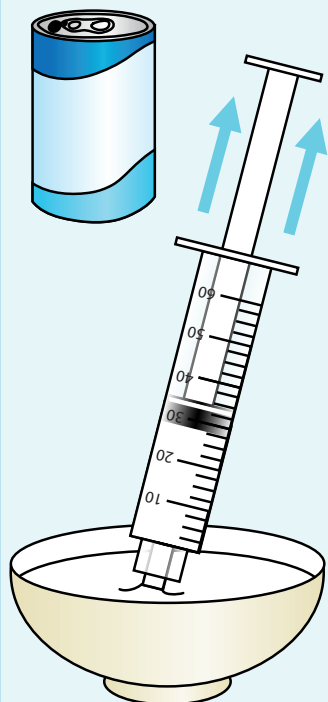
b) push 5ml of air through tube and listen for 'swoosh' sound



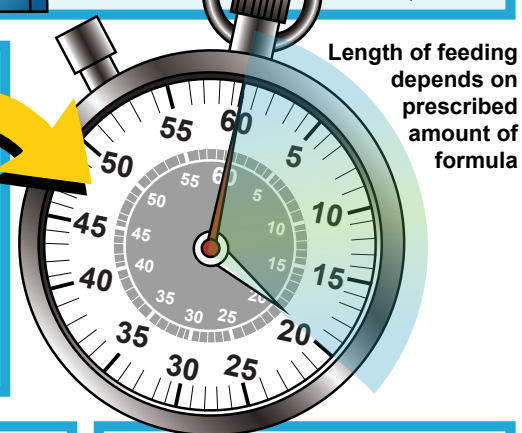
Once proper placement is verified, re-fill syringe with 5 - 10 ml of water, re-attach and flush tube



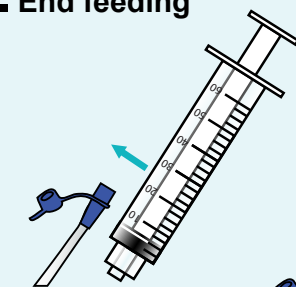
4. Fill 60 ml syringe with formula



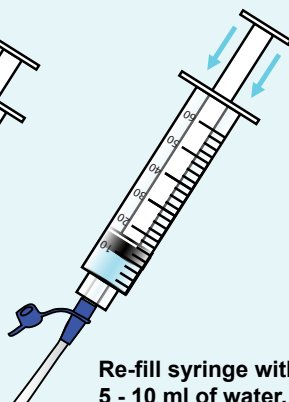
5. Attach syringe to tube slowly push plunger



6. End feeding



Detach syringe from feeding tube

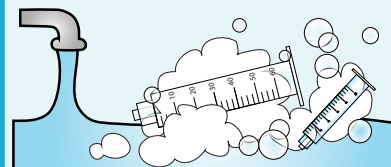


Re-fill syringe with 5 - 10 ml of water, re-attach and flush tube

7. Remove syringe and close tube cap



8. Clean supplies



The Gravity Method

The Gravity Method means hanging a special formula-filled bag above the person being enterally fed 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 the stomach is full or almost full. If you notice this, pause the feed for a short period of time. This will provide time for digestion. The 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
- the 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 the person being enterally fed. 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:**

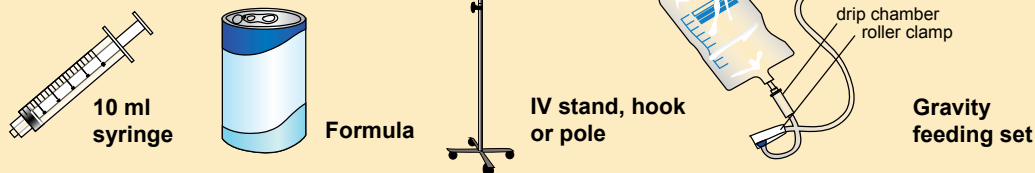
Drop rate	Feeding volume (or pump rate)
16 drops per minute	60 ml per hour
20 drops per minute	80 ml per hour
24 drops per minute	100 ml per hour
28 drops per minute	120 ml per hour
32 drops per minute	140 ml per hour

- 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



2. Gather your supplies

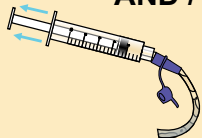


3. Check tube position by

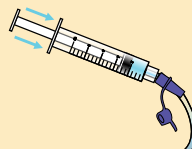
a) trying to extract a small amount of stomach contents with a 10 ml syringe

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

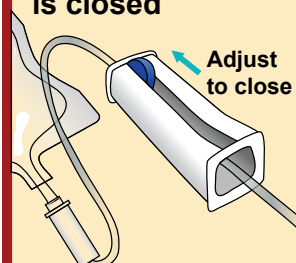
AND / OR



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

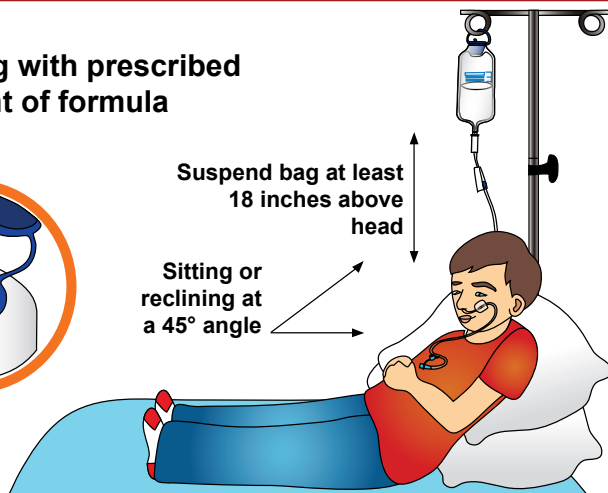


5. Fill bag with prescribed amount of formula

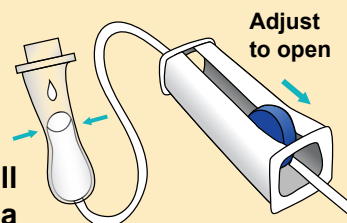


Suspend bag at least 18 inches above head

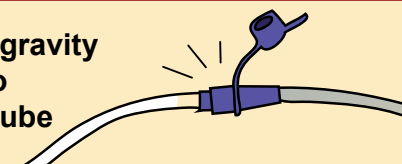
Sitting or reclining at a 45° angle



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



7. Connect gravity feeding set to nasogastric tube



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

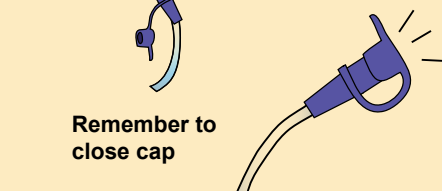
Once complete, you may add 10-20 ml of water to the bag to ensure child receives all of the formula.



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

9. End the feeding

Disconnect gravity feeding set, flush nasogastric tube with 5 - 10 ml of water



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.



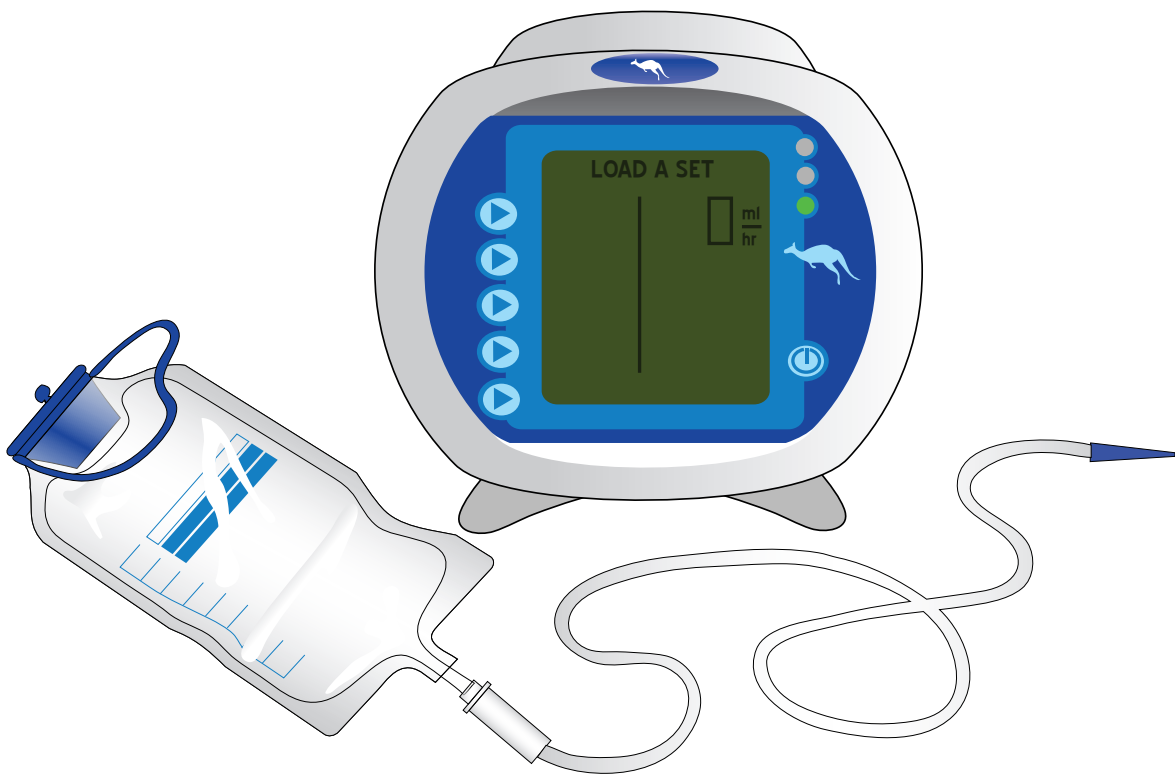
Your vinegar solution should measure 1 part white vinegar per 8 parts water.

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. The nurse can also instruct you on the use and maintenance of the feeding pump before discharge.

Continuous Feeding

The treatment team may suggest that feeding be continuous. “Continuous feeds” means feeding over a longer period of time, with the help of a special feeding pump. It is recommended for adults and 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**



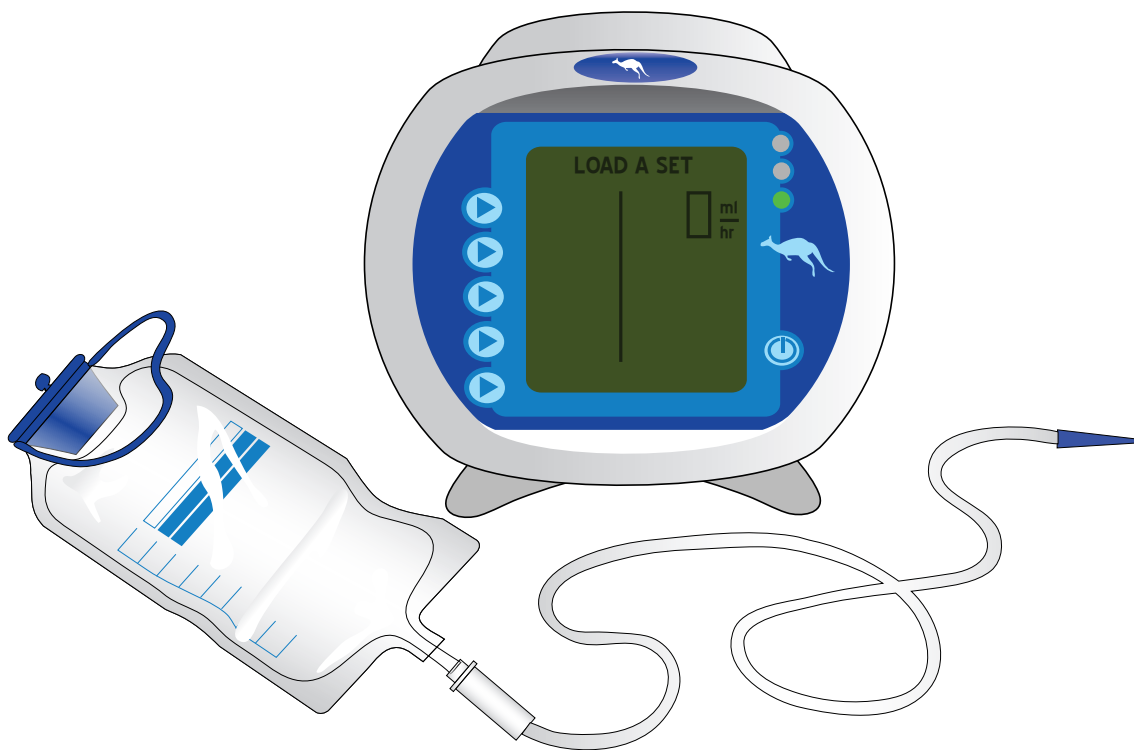
Continuous, around-the-clock feeding means using the feeding pump to deliver feeds in a constant way throughout the night and day. How much feed is to be provided is specially prescribed by your treatment team. Around-the-clock feeding may be suggested if:

- 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.

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.

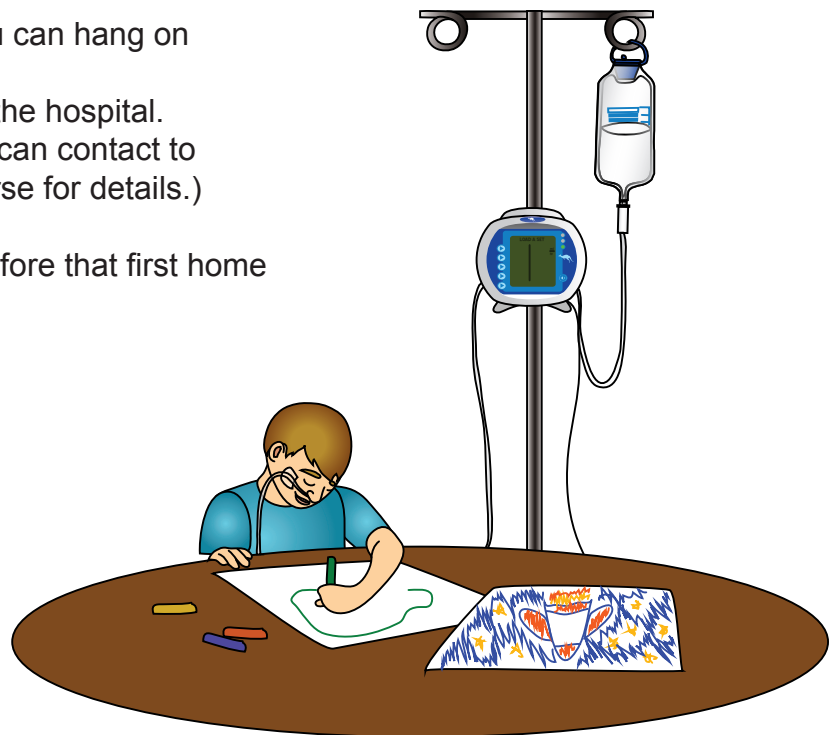
The following instructions apply for both the Kangaroo™ ePump and the Kangaroo Joey pump.

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 Covidien 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 Covidien.

- 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.

Medication Delivery through the feeding tube/button

Delivering medication through the feeding tube / button

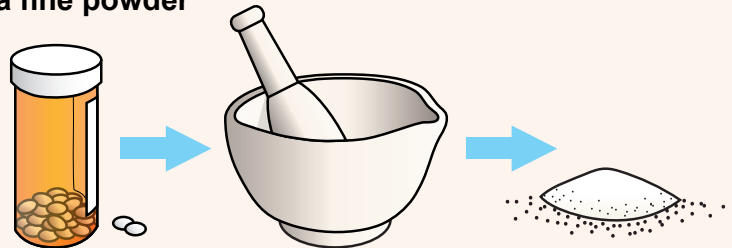
It is possible and often desirable to deliver medication using the nasogastric tube or the medication port of the gastrostomy feeding tube or button. With the proper information and a few tips, many medications can be safely delivered with convenient and easier ingestion. In order to ensure proper delivery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

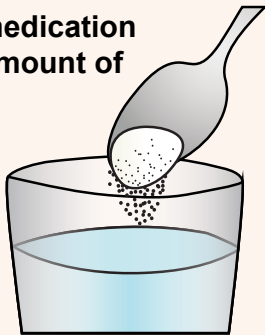


2. If the medication is in pill form, crush the dose into a fine powder

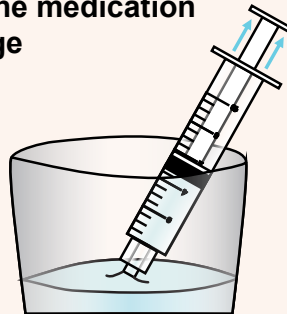


WARNING: please note that “enteric-coated” or “sustained release” tablets or capsules cannot be crushed. Crushing affects the enteric coating and the absorption of sustained release pills.

3. Dilute the medication in a small amount of warm water



4. Draw up the medication in a syringe



Make sure to draw up the whole amount so that your child receives an entire dose.

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.

5. Push the medication slowly into the tube. Flush with 5-10 ml water afterward. This will help push the medication into your child's stomach and prevent blockage of the tube or button.

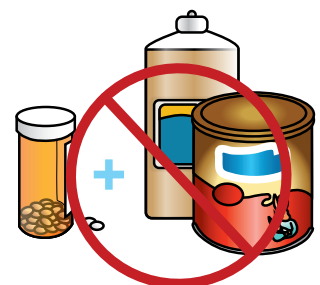


IMPORTANT:

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 nutritional needs, there are many commercial and/or specialized formulas available. The one that is right 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. The nutritionist and doctor will decide on the best formula by doing a careful dietary and health check.

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 changes 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, your nutritionist will:

- Give you careful instructions for formula preparation.
- Explain how much formula will be needed everyday.
- Help you work out the best feeding schedule.

As nutrition needs will change over time, you will need to make changes in the type and/or amount of formula that you use. If for your child, 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.

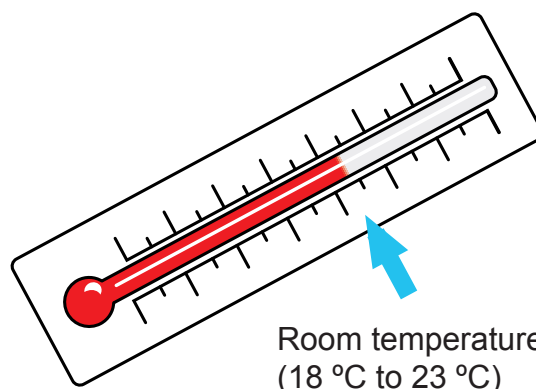
- For best results, mix a small amount of water with the required amount of powder to make a paste. Gradually add the rest of the water while continuing to mix.
- A blender may be useful when mixing this type of formula.
- If making a larger quantity, refrigerate immediately after preparation and check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

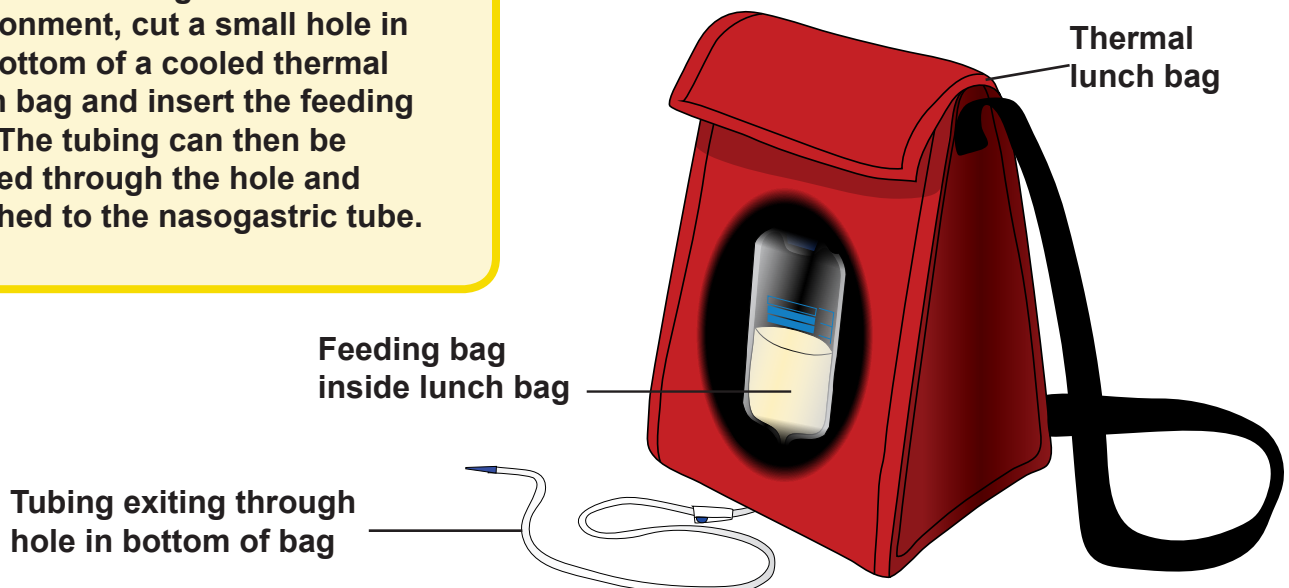
Formula that is poured into a feeding bag can stay out hanging at room temperature for:

- 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 the 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.

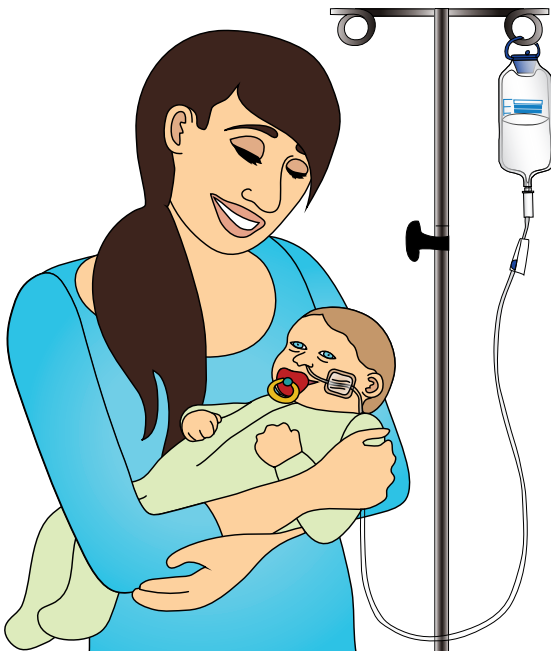
Patience and practice are the keys to success!

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.

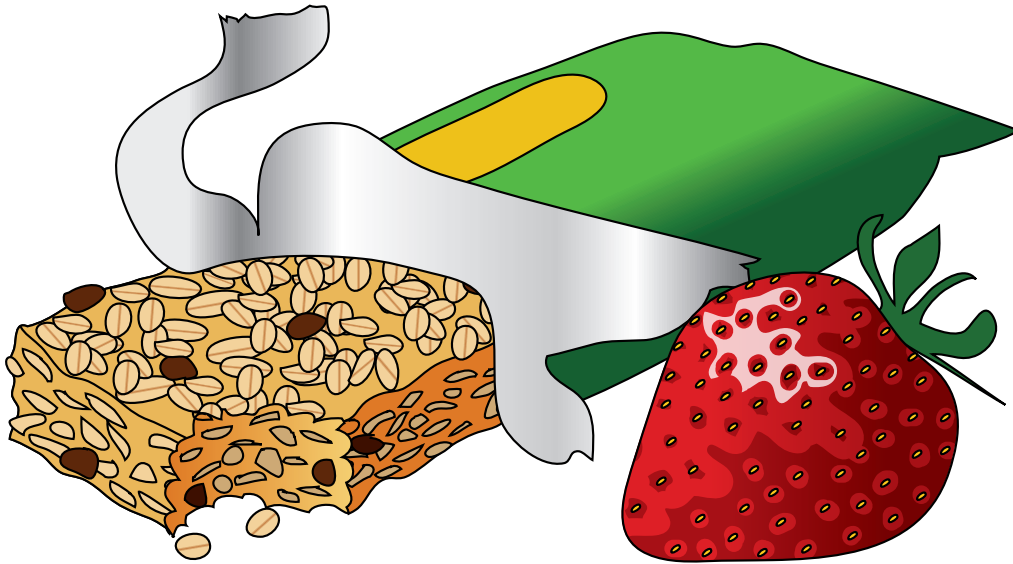
- Maintain a face-to-face position with eye contact during the feeding.
- Keep the feeding time to 30 minutes. After that, you'll both be tired.
- Don't put too much pressure on yourself or your baby. There will be good days and bad days for you both.



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!



Thank you

This material was originally developed by the Montreal Children's Hospital Home Enteral Feeding Program and the Patient Education Office of the McGill University Health Centre (MUHC). We extend a special thank you to the MUHC for this adapted version of the booklet.

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Office d'éducation des patients
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