

A Resource Booklet for Families

Tube Feeding Your Child by:

**Jejunostomy Tube
Or
Gastro-Jejunostomy Tube**



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Home Enteral Nutrition Team

HENT

- The Home Enteral Nutrition Team (**HENT**) at the Alberta Children's Hospital is a program designed to assist children who need tube feeding at home.
- We are a team of nurses, a physician and clerical staff working together to help you manage tube feeding at home.
- **HENT** provides teaching on tube feeding for home, as well as, provides supplies and assistance obtaining formula.
- You will be seen in our clinic for on-going support with your child's feeding and nutritional needs.
- This booklet gives you information about Jejunostomy tubes and Gastro-Jejunostomy tubes and feedings. If your questions are not answered here, please write them down and ask your doctor or **HENT** Support Team.
- Be sure to write notes about your child's care.

Remember:

- ◆ You Can Do this!
- ◆ Everything about tube-feeding may be new and strange to you.
- ◆ We will teach you what you need to know.
- ◆ You will practice your new skills before you go home.
- ◆ Be sure to tell us about any questions or concerns you have
- ◆ There are **NO** silly questions!
- ◆ We want tube feeding at home to be a positive experience for your child and family.

GJ Tube and J Tube

What is a Gastrostomy-Jejunostomy Tube (GJ Tube)?

- A Gastrostomy-Jejunostomy tube is a thin, hollow tube that is put through the skin into the stomach through a small surgical opening (stoma). The tube is then passed through the stomach into the small intestine. You can use this tube to give your child liquid food, fluids and medications.
- A GJ tube is secured with a small balloon that sits in your child's stomach and prevents the tube from moving from its desired location.

How is a J Tube different than a GJ Tube?

- The insertion and placement of a J tube is the same as a GJ tube. The big difference is that a J tube does not have a balloon to keep it in place. There is a loop in the J-tube that keeps this tube in the stomach. It is also recommended that the tube is secured to your child's skin. These tubes are used in smaller children.
- This tube does not have a separate gastric port so venting the stomach is not possible.

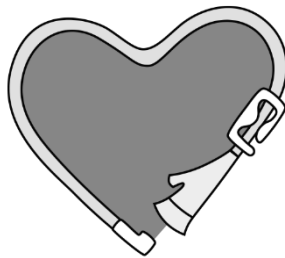
How are these tubes put in?

- Once your child receives an anesthetic, a small opening is made through the skin and muscles into the stomach, creating a stoma. The tube is then placed through the opening into the stomach, and passed into the small intestine.

Feeding - How do I give my child formula by tube?

Continuous Feeds:

- Your child will be getting his/her formula over several hours a day (generally 16-24 hours/day). Because their food is going into their small intestine, and not in their stomach, it is important that food is not to be given quickly (ie: bolus feed). Continuous feeds are given by a feeding pump to make sure the feed is running at a steady, slow rate. **Children with jejunal feeds should NEVER receive bolus feeds.**
- Your child may have a few hours a day that they do not get fed. The number of hours your child gets from formula, is decided by your doctor and dietician, to make sure that your child is getting enough nutrition and fluid to grow.
- It is important that you flush your child's tube with 10mL of water (other amounts may be prescribed by your health care team) every 4 hours to keep the tube working well.
- If you feel your child needs more or less food, please discuss with your health care team (pediatrician/dietician) prior to making any feeding changes.



Caring for Your Child's Feeding Equipment

****Clean feeding set, syringes and adapter after each use. Supplies that are not fully cleaned, may carry harmful bacteria. ****

After each feed:

1. Throw out any remaining formula in the bag
2. Rinse out the inside of the bag and tubing with warm water
3. Place the feeding bag in a container with lid or zippered plastic bag and store in the refrigerator until your next tube feed.
4. Feeding sets that are used for continuous feedings should be washed at least once in 24 hours.
5. Wash your syringes by pulling them apart. Wash both sections in warm, soapy water and rinse thoroughly with clean water. Do not refrigerate your syringes, do not clean them in a dishwasher or by boiling.
6. If your child uses a pump, wipe daily with a damp cloth. If there is formula spillage into the wheel and eye of the pump, clean with cotton swabs.

General Guidelines for Supply Usage:

- **Pump Bags:** should be replaced every day
- **Gravity Bags:** should be replaced every day
- **Syringes:** will need replacing every 3 days
- **G-Tube Adapters:** need to be replaced every week
- **Burn Net:** replaced every 6-12 months. (*Netting can be washed and dried several times*)

***** Please be mindful of these guidelines when placing your monthly tube feeding order*****

Giving Medicine by Feeding Tube:

How do I give my child medication by tube?

- Prepare the medication as directed by your pharmacist, making sure each medicine has its own syringe.
- Stop tube feed if running
- Attach extension set if tube not already in use.
- Flush the tube with 2-5 mL of water before giving the medication
- Push the medication slowly into the tube
- Flush the tube with 1-3 mL between each medication and flush with 5-10 mL after the last medication has been administered.
- If resistance is felt, stop immediately, and flush the tube with more water before continuing (thick syrups or powder medication may need to be mixed with more water, to prevent clogging of the tube).
- Restart the tube feeding or remove the feeding extension or close the cap.
- Wash and air dry the syringe and any other supplies so they are ready to use again.

Important Note:

- **DO NOT** mix medicine with breast milk or formula, because it may react or become lumpy, resulting in a blockage in the tube.
- **DO NOT** put medicine directly into the feeding bag. Only give medicine using the feeding extension tubing.
- **DO NOT mix different medicines in the same syringe.**
- Your pharmacist can help you decide the best times to give the medications.

Routine and Emergency Tube Replacement:

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

Over time, all tubes need to be changed

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

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

Routine GJ/J tube changes will be done every 6 months

J-tube and GJ-tube Changes:

Tube changes will be done only by an interventional radiologist. These appointments will be set up by the diagnostic imaging department at ACH.

Your DI Nurse will discuss with you any routine tube changes.

What do I do if the tube comes out?

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

If the tube is pulled out, the stoma will start to close. **(Some stomas may close in a few hours)**

Your health care provider will give you an emergency kit with instructions. This kit should accompany your child where ever they go.

If your child's tube is accidentally pulled out, insert the emergency tube found in your emergency kit, secure the tube, and contact the DI department for tube reinsertion. **DO NOT** feed through your emergency tube. If the tube comes out after regular hours of operation, please proceed to the ACH emergency department.

REMEMBER:

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

Stoma Care:

Cleaning:

- No tub bath for one week post-op
- Keep the site clean and dry. Expect some leakage around the tube. Once a day, gently wash the site with a wash cloth and warm water. Rinse it and pat the skin dry. You may do this during your child's tub bath.
- If your child is unable to take a tub bath, or more cleaning is needed, try to following:
 - Wipe down the outside of the tube.
 - Pat the skin and tube dry with a soft clean towel.
 - **NO** lotions, oil, cream to front upper torso
 - **NO** alcohol – **NO** peroxide to be used to clean the tube site.
- Allow air to get at the stoma and skin around it.
- Avoid covering with bandages (when possible, allow the exposed tube sit to the air when your child is napping, busy playing, or being held).
- Apply 2x2 gauze around the tube for the first week post-op.

Cleaning too often?

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

Stoma Care Continued...

Reduce Skin irritation:

- Secure the tube to prevent it from being pulled out. Tape or pin the tube to your child's shirt, pants or diaper. Be very careful to avoid putting the pin through the tube. Change the tape daily.
- Avoid any pulling or rubbing on the tape, tube or stoma.
- Make sure your child wears loose clothing that does not pull or press on the tube or site. See Frequently Asked Questions (Page 12) for appropriate clothing selection.
- If you use tape to secure the tube, find one that does not bother your child's skin.
- Check the tube site closely for signs of skin breakdown when:
 - You wash it daily.
 - The GJ-tube, tape or stoma is pulled on hard or often.
 - Your child rubs, pulls at or protects the tube site more than usual.
 - Your child complains of pain, aching or itching at the tube site.
- To care for Skin breakdown:
 - Closely follow daily tube site care
 - Expose the skin to the air more often
 - Handle the irritated skin gently
 - Keep skin clean and dry

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

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

The stoma may be infected

(See Appendix 1 for more information pages 15-20)

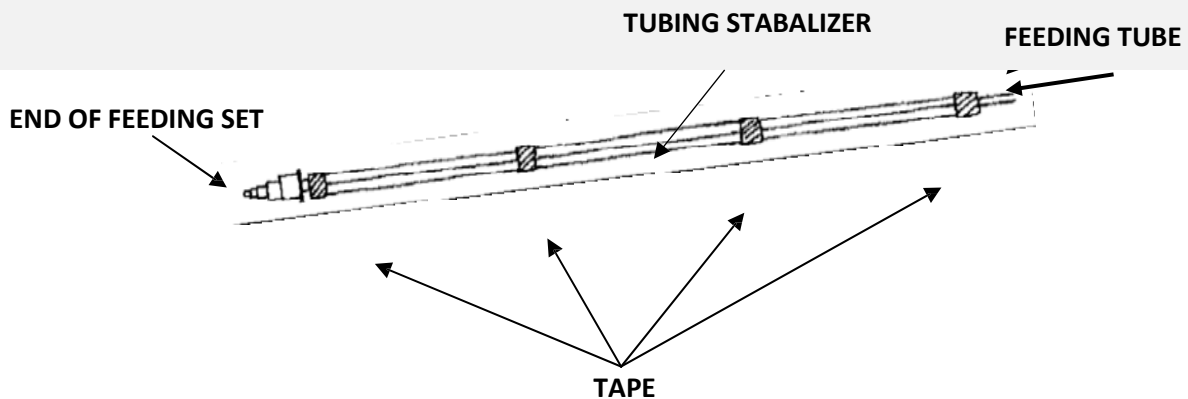
Tubing Stabilizers:

What is it?

A tubing stabilizer is a stiff, plastic channels, which can be placed on a feeding tube and the enteral bag tubing to prevent your child from getting tangled in the tube and to prevent choking. We encourage families to use the device for unsupervised feeds; for children between age three (3) months and thirty-six (36) months; for delayed children; oxygen tubing and for IV tubing.
Before you use it?

Setting up the tubing stabilizer:

1. Place the stabilizer on the tubing of the feeding set, as close to the end as possible. The tubing should be run parallel to your child. The pole should be at the foot of the bed.
2. Starting at the end of the feeding tube, press the tubing into the opening that runs along the length of the stabilizer. Continue pressing the tube into the opening along the entire length of the stabilizer.
3. Apply tape at each end and every 4 inches wrapping around the solid plastic areas.
4. Throw out the tubing stabilizer if you notice any kinking, damage or excessive wear anywhere on the stabilizer.



Frequently Asked Questions:

What can I put around the tube site?

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

Can I bath my child with the tube in place?

YES! If the tube site is healing and there are no signs of infection, you may bathe your child 7 days after the surgery. Be sure to dry the skin around the tube after the bath.

Can my child go swimming?

YES! If the tube site is healing and there are no signs of infection, your child can go swimming 1 month after surgery. Be sure the tube is clamped off tightly.

Does my child need special clothes?

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

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

- Tuck the tube into their clothing
- Secure the tube in place on abdomen, then secure through diaper tab.
- You may use burn netting to prevent tube from being pulled (HENT nurse will provide if required)
- Put mitten or socks on infant's hands for short lengths of time.

Can I put my child on her/his tummy?

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

When your child is crawling, do not let the tube dangle. Make sure the tube is secured under your child's clothing.

What position should my baby sleep in?

Babies should sleep on their backs, even when feeding.

Contacting the HENT Team:

The HENT Team should be contacted for any concerns about the stoma, skin care or supplies.

HENT Nurses: **403-955-7259**

If you have concerns about your child's tube feeding:

During program hours (*Monday-Friday, 8:00am to 4:00pm*) call one of your HENT team members.

For concerns that need **IMMEDIATE** attention, go to the nearest **Emergency Room**.

Tube Feeding Supplies:

The HENT clinic will provide you with the feeding supplies you need, such as tubes, feeding bag systems, syringes and feeding pump.

To order supplies, call, **(403) 955-7165** (*please leave a voicemail, with your child's health care card, spelling of last name, supplies you need, and where you would like to pick them up*) or you can FAX your orders to **(403) 955-2510** or by submitting an order by email to homenutrition.orders@ahs.ca

- Every month you will need to order enough supplies to last a month. Please refer to your template order form for maximum amount of supplies to order each month and order only what you need – additional supplies may be purchased at a Medical Supply Store.
- Clearly indicate your child's full name and a phone number where you can be reached.
- Please allow 1 week for delivery of supply refills. Local families will pick up supplies from ACH or the warehouse. For out of town families, supplies will be delivered by Canada Post.

If you are travelling with your child:

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

Solving GJ-Tube Feeding Problems

Appendix 1

Aspiration

What could this mean?

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

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

What to do:

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

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

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

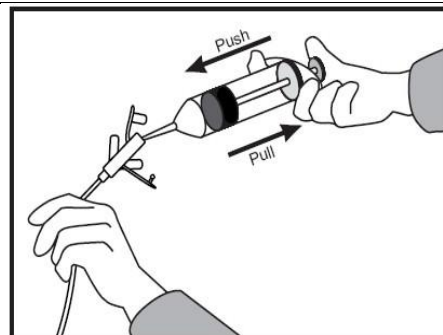
If your child settles and is breathing normally:

- ✓ Stop feed and contact DI department to have placement of tube confirmed

Tube blockage

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

1. Check that the feeding tube is not clamped or bent over.
2. Get a 30 mL syringe. Fill the syringe with 25 mL of warm water. Attach syringe to feeding tube. Gently push and pull on the syringe's plunger. **Do not force water into the tube.** When the tube is unblocked, flush tube with water.
3. Use de-clog kit as per instructions and attempt to unblock the tube
4. If your **GJ-tube or J-tube** will not unblock, **contact the DI department** or go to the ACH emergency department if after Hours/weekends. The tube may need to be removed and a new one put in.



Be Careful:

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

Nausea

What could this mean?	What to do:
Nausea can be caused by: <ul style="list-style-type: none">• Too much air in the stomach.• Changes in medications.	<ul style="list-style-type: none">• Keep head and shoulders raised at a 30-45 degree angle during and after feeding for 30 minutes.• For GJ-tubes, vent/burp your child before, during and after the feeding.• Minimize movement of child during feeds

Retching, Gagging and/or Vomiting

What could this mean?	What to do :
Retching, gagging and/or vomiting may be caused by: <ul style="list-style-type: none">• The first movement of formula or breast milk through the tube.• The feeding is given too quickly.• Air in the stomach.• Your child's tube has moved and is in the wrong place.	<ul style="list-style-type: none">✓ For J-tubes and GJ-tubes, if your child is vomiting formula or formula is draining out of the gastric port, stop feeding and go to your local health care facility as the tube is in the wrong place.✓ For GJ-tubes, vent/burp your child before, during and after the feeding. <p>Discuss changing the feeding schedule with the dietitian.</p>

Unable to Burp

What could this mean?	What to do:
Some children have trouble burping on their own	<p>For GJ tubes:</p> <p>Try “venting” the tube:</p> <ul style="list-style-type: none"> ✓ Open the end of the gastric port and attach to an empty 60 mL syringe barrel. Venting should only take a few minutes. ✓ Position your child on one side and then the other to help with venting. ✓ Return any liquid that drains from the feeding tube back to the stomach. ✓ Flush the tube with water. <p>There isn't a gastric port for J-tube so venting is not possible</p>

Diarrhea

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

Constipation

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

Redness around the tube site

What could this mean?	What to do:
<p>Some redness and drainage is normal. If the redness continues, it may be due to:</p> <ul style="list-style-type: none"> • Wet and unclean skin at tube site. • A lot of tube movement. • Infection: <ul style="list-style-type: none"> ✓ Foul smelling discharge or pus. ✓ Pain at the tube site. ✓ Increasing redness/swelling. ✓ Itchy pin point rash may be a yeast infection. 	<p>Wet and unclean skin :</p> <ul style="list-style-type: none"> ✓ If the skin is wet from stomach fluids clean the skin, clean with water using a face cloth ✓ apply calmoseptine as needed ✓ Make sure the bolster is snug against skin (if applicable) ✓ If the red area becomes bigger or tender, call your HENT nurse, Home Care nurse or local health care provider. <p>A lot of tube movement:</p> <ul style="list-style-type: none"> ✓ Contact HENT for suggestions of tube securement. ✓ Check that the tube is properly placed ✓ If your tube has a balloon, make sure it has the proper amount of water (check weekly) ✓ Ask your HENT nurse if your child has the proper tube size (especially if your child has gained or lost weight). If mickey GJ tube the DI department will need to assess for size <p>Infection:</p> <ul style="list-style-type: none"> ✓ If the site has signs of infection, call your doctor. ✓ Take your child's temperature. ✓ Antifungal ointment or antibiotics may be necessary (to be prescribed by your doctor).

Bleeding around tube site

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

Skin tissue build-up around the tube site

What could this mean?	What to do:
<p>A small amount of tissue buildup (“proud flesh” or “granulation tissue”) is common. This is the body’s way of healing an opening and it is one of the most commonly reported problems related to tube stoma. Granulation tissue will be pink-red in color, can be tender, bleeds easily and has a clear, pink or yellow sticky drainage.</p>	<ul style="list-style-type: none">✓ Keep up your efforts to clean the site well and keep it dry.✓ Secure tube to prevent pulling or movement.✓ Talk with your HENT nurse. It is not an emergency to treat the tissue but granulation tissue can affect the fit of the tube within the stoma. Treatment with silver nitrate done by HENT or Home Care nurse may be required. Following treatment, the granulation tissue turns gray or white and falls off. This treatment can be repeated every 3 days as required until the tissue is resolved.

Formula leakage from the tube site

What could this mean?	What to do :
<p>A small amount of leakage can be common. Some reasons for leakage are:</p> <ul style="list-style-type: none">• Illness• Constipation• Coughing• Decreased tube balloon volume (if your type of tube has a balloon)• GJ-tube is in the wrong place• If child sleeps on stomach• Bolster too loose <p>Frequent leakage may cause skin breakdown around the tube site.</p>	<ul style="list-style-type: none">✓ Stop the feed and contact ACH DI department for assessment of tube position.