

Tube Feeding At Home

A Guidebook for Patients,
Families and Caregivers

Tube Feeding at Home

This guidebook is for

Date:

Table of Contents

What is Tube Feeding?	5
Your Feeding Tube	6
Checking and Maintaining Your Feeding Tube’s Position	7
Replacing your Feeding Tube	8
Looking After Your Skin and Stoma at Home	9
Checking the Stoma	9
Cleaning the Stoma Daily.....	10
Taking a Bath or Shower with a Stoma.....	10
Mouth Care	11
Flushing Your Feeding Tube.....	11
Giving Medications through Your Feeding Tube	12
Blocked or Clogged Feeding Tube	13
Troubleshooting	14
Your Tube Feeding Plan	17
Who to Call	17
Where to Find Support at Home	17
Did You Know?	18

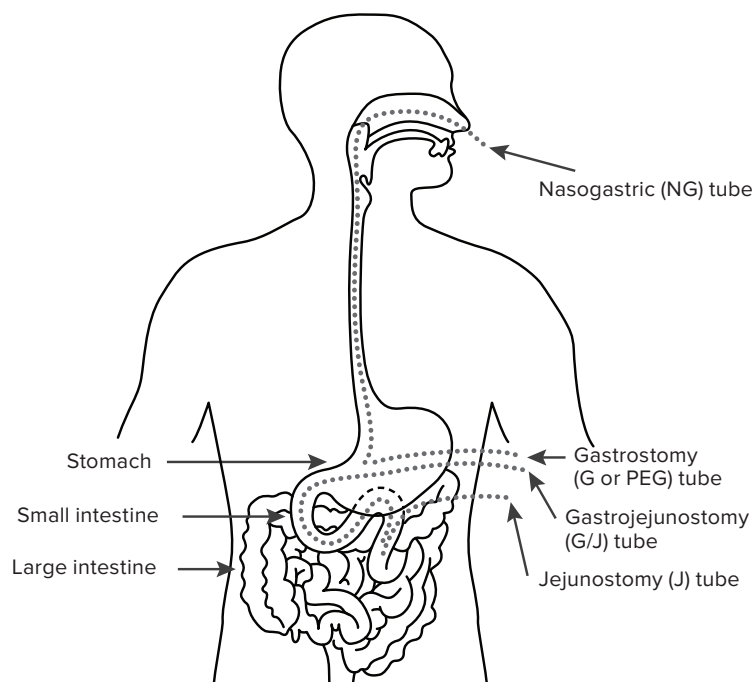
What is Tube Feeding?

Tube feeding is a way of giving liquid food (formula) or fluid directly into the stomach or small intestine.

Tube feeding provides nutrition and/or hydration for people who cannot eat at all, or extra nutrition and/or hydration for people who cannot eat enough food. The length of time any patient is kept on tube feeding will vary widely depending on the condition of the patient.

The information in this booklet, and the education and guidance provided by your health care team, will help you carry out tube feeding at home safely and effectively.

If you have problems with your feeding tube, please bring this booklet to your Health Care Provider.



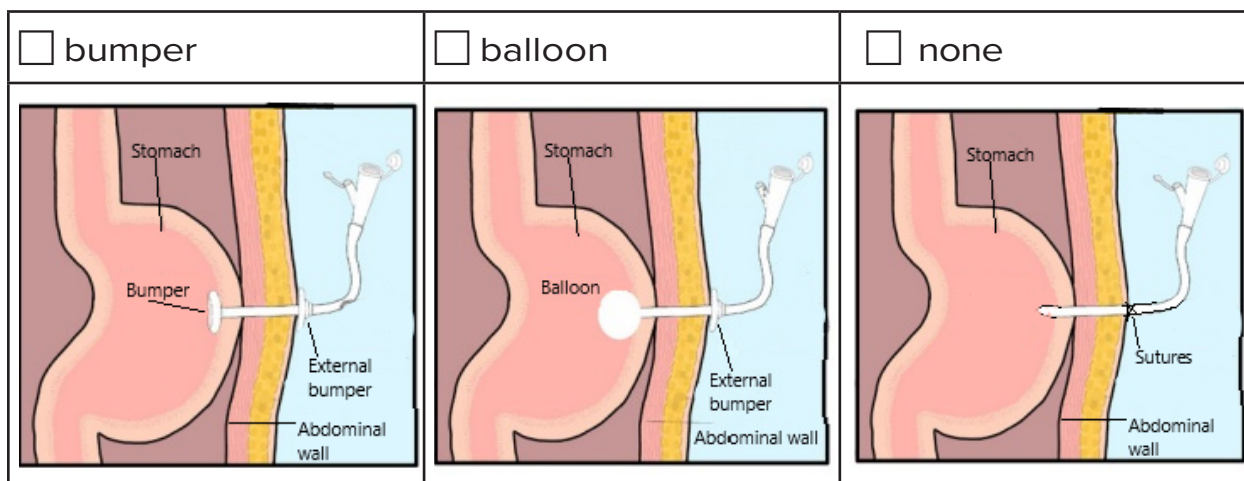
Your Feeding Tube

This diagram shows different types of feeding tubes. Your type of tube is highlighted.

- Gastrostomy (G-tube) - tube tip in stomach
- Gastrojejunostomy (GJ-tube) - tube tip in jejunum (small intestine) through the stomach
- Jejunostomy (J-tube) - tube tip directly in jejunum (small intestine)
- Other _____

Brand of tube: _____

Internal Retention Device:



You will have one of these three types of retention devices associated with your tube.

Tube size: _____

Service that placed tube: _____

Tube placement date: _____

Checking and Maintaining Your Feeding Tube's Position

Make a mark on the feeding tube where the tube exits your body. Use a permanent marker. Measure the length of the tube that remains outside your body.

- Write down this measurement here: _____

This measurement is the correct position of your feeding tube.

- Always check the position of your feeding tube before giving your tube feeding formula and/or medications
- The tube length should always be the same length
- If the feeding tube moves by more than 1 inch (2.5 cm), go to your nearest hospital to check tube placement
- Note: For surgically placed J tubes, the tube should not move at all

Balloon-style feeding tubes:

If you have a balloon-style feeding tube, this means that there is a balloon inside your stomach holding the tube in place. The balloon was filled with a specific amount of water when your feeding tube was inserted. Check the balloon inflation every month unless otherwise indicated, starting after 4 weeks.

To check the volume, use a Luer Lok or a Slip Tip Syringe. Attach the syringe to the balloon port of your feeding tube. Deflate and re-inflate the balloon by drawing up and pushing back. Ensure the original balloon volume is the same. Add additional water to the balloon as needed.

Your balloon volume is: _____

Replacing your Feeding Tube

Tubes **do not need** routine replacement. Frequency of tube replacement is directed by your Health Care Provider and based on manufacturer recommendations. All feeding tubes eventually need to be replaced, but the time for replacement varies with the type of tube.

You may need your feeding tube replaced if:

- The tube has a crack, or looks like it is breaking down
- There is a change in the amount, or look of the drainage from the opening where the tube enters the body
- The tube is blocked. You may be unable to flush or feed through the tube, or feeding takes longer than normal (see page 13)

If your tube is broken or needs replacement, call the service that placed your tube.

If your tube has come out, cover the site with a dressing and go to your nearest emergency department as URGENT REPLACEMENT IS REQUIRED (see page 14).

Contact Information for Tube Replacement

Monday to Friday, call the service that placed your previous tube.

- VGH Endoscopy Clinic: 604-875-4155
- VGH Radiology Clinic: 604-875-4770
- VGH Trauma Services Clinic: 604-875-5088
- Lions Gate Hospital patients: contact your family Doctor or the Doctor who placed the first tube.
- UBC Hospital Radiology - requires a physician requisition: 604-822-7267
- St. Paul's Radiology - requires a physician requisition: 604-806-8006
- St. Paul's GI Clinic - requires a physician requisition: 604-806-8080
- Other: _____

Nurse will Teach:

Looking After Your Skin and Stoma at Home

- The stoma is the opening on the skin where the feeding tube enters your body
- After insertion, there may be abdominal distension for the first 24–72 hours. Slight swelling at the site is to be expected. However, swelling causing discomfort or a pressure injury needs to be addressed
- After the first 24 hours: for long shaft tubes, the external bumper should sit approximately 1 to 2 mm above the skin. Evaluate when in sitting position

Checking the Stoma

Check your stoma daily for signs of skin irritation or infection. Notify your health care provider if you notice any of the following.

In the first 24 hours:

- Tenderness, discomfort or pain around the tube
- Discharge (leakage) from the stoma
- Active bleeding (a small amount of bleeding immediately after insertion is normal)
- Redness beyond the dressing border
- Swollen skin beyond the dressing border

Post 24 hours:

- Redness greater than 2 cm from the insertion site (stoma)
- Swollen skin at the insertion site (stoma) causing discomfort or pressure injury
- Leaking of stomach contents or wound drainage
- Hypergranulation (light red or dark pink flesh that can be smooth, bumpy or granular that forms on and around the insertion site)

Nurse will Teach: Cleaning the Stoma Daily

Keep the skin clean and dry to avoid skin irritation and breakdown. Follow these steps:

1. Wash your hands. If you have dressings, remove and discard them.
2. Note: Unless the stoma is draining, dressings are not usually needed, as they create a warm, moist environment for bacterial contamination.
3. For the first 7 days, use normal saline or sterile water for cleaning the stoma. After that, wet a soft clean cloth with warm soapy water. The use of hydrogen peroxide or antiseptics can be drying and harmful to the skin and should be avoided.
4. Gently wipe the skin around the feeding tube.
5. If you have an external bolster against your skin, be sure to clean all areas of the skin underneath. Use a moistened cotton swab to do this, and be careful not to pull hard on the tube. If possible, rotate your external bolster slightly.
6. If you have a G-tube, rotate your feeding tube by one full 360 degree turn plus a $\frac{1}{4}$ turn by gently gripping and turning it. Do not rotate any GJ-tubes or J-tubes, and/or tubes that are sutured in.
7. Clean the outside of the tube with mild soap and water.
8. Dry the area well with a soft, clean towel. Allow the site to air dry for a few minutes before covering with clothing.
9. If you have drainage around your stoma, replace dressings.
10. If you use tape to keep the tube in place, avoid taping over the same patch of skin each time, as this can irritate the skin. Use cloth, surgical, or transparent adhesive tape. Consider purchasing a feeding tube belt to avoid using tape at all.

Taking a Bath or Shower with a Stoma

Taking a Bath:

- Keep the stoma above water for the first two weeks
- Wait two weeks before submerging in a bathtub and one month before going swimming. The stoma should be completely healed before going into a pool

Taking a Shower:

- If your stoma is less than one week old, cover the site with a waterproof bandage or plastic wrap and tape to be sure it doesn't get wet. Remove the dressing immediately after showering and cleanse insertion site with normal saline
- If the stoma is more than one week old and completely healed, you do not need to cover it. You may clean around the stoma while showering

Nurse will Teach: Mouth Care

Effective daily mouth care reduces bacteria in the mouth which can decrease your risk of lung infections, if you aspirate. While brushing your teeth at least twice a day and flossing your teeth daily is usually recommended, you may have special instructions for keeping your mouth clean after leaving the hospital. You may be encouraged to use alcohol-free mouthwash or water-based gels to keep your mouth and lips moist.

Flushing Your Feeding Tube

Flushing your feeding tube with water will help keep the tube clean and prevent blockages.

To flush your tube:

- Fill a 50 to 60 mL syringe with the recommended amount of water. Volume of flushes may vary. Minimum flush is 25 mL
- Put the tip of the syringe into the feeding tube opening
- If you have a clamp or stopcock on your feeding tube, open it
- Push down on the syringe's plunger to deliver the flush
- Close the clamp or stopcock on your feeding tube, or pinch your tube
- Remove the syringe and close the cap on your tube

Nurse will Teach:

Giving Medications through Your Feeding Tube

If safe to do so, take medications by mouth. Check with your Health Care Provider if you can do this. If this is not possible, tell all of your Health Care Providers that you take medications through your tube.

Check with your pharmacist whether your medications can be given safely through a feeding tube, and if you should take medications on a full or empty stomach. This may depend on whether you have a tube in your stomach or in your small intestine.

Do not mix medications with other medications, formula, antacids or vitamin supplements containing iron, calcium and/or magnesium.

Check with your Health Care Provider before giving any herbal preparations, fibre supplements, or vitamin/mineral supplements through your feeding tube.

Liquid medications need to be diluted with water, or these may cause diarrhea.

Buy a pill crusher from your local pharmacy or medical supply store, or use a mortar and pestle to crush your medications.

Flush your tube before, between, and after giving medications to prevent the tube from getting clogged.

Follow these steps to give medications through your tube:

1. In a small cup, measure the prescribed amount of liquid medicine and add 15 mL of warm water, or crush pills and dissolve powder thoroughly in 15-30 mL of warm water.
2. Draw all of the medication/water mixture into one syringe and set aside.
3. Using a second syringe, flush your feeding tube with 15-30 mL of warm water.
4. Insert the medication syringe and push your medication/water mixture into your tube.
5. If you are taking more than one medication at a time, flush your tube with 5 mL of water in between each medication.
6. After the last medication is given, flush your tube with 30 mL of warm water.

There may be other ways to administer your medication that can be easier for you. Talk to your pharmacist about alternatives that may benefit your situation.

Blocked or Clogged Feeding Tube

Start by using a 30-60 mL syringe to gently administer 20 mL of warm tap water through the tube. If this does not unclog the tube, gently push and pull on the syringe's plunger while it is connected to the tube. Repeat this 3–4 times.

If this does not work, try baking soda and a pancreatic enzyme (e.g. Cotazym) to clear the blockage. This will require a prescription. Options for prescription are:

- If you are using Lancaster Medical for your pharmacy needs, your Health Care Provider must prescribe: "G-tube Maintenance Kit with COTAZYM". Follow the instruction in the G-tube Maintenance Kit. You may also need a pill crusher.
- If you are using another pharmacy, your Health Care Provider should prescribe pancreatic enzyme – for example "3 x COTAZYM 8 mg" with repeats as necessary.

In addition to this prescription, you will need:

- baking soda
- Two 30-60 mL syringes
- a household measuring cup

Instructions for unblocking your feeding tube:

1. Measure $\frac{1}{2}$ teaspoon (2 mL) of baking soda (sodium bicarbonate).
Note: if using a sodium bicarbonate tablet, it will need to be crushed prior to measuring it for use. Use a $\frac{1}{2}$ teaspoon (2 mL) size measure rather than a spoon used for eating. Level the $\frac{1}{2}$ teaspoon by using a knife to scrape off any overflow.

$\frac{1}{2}$ teaspoon (2 mL)



Levelling the $\frac{1}{2}$ teaspoon



2. Do not overfill. See picture above:
3. Open one pancreatic enzyme capsule (8 mg COTAZYM) and combine with the baking soda in a household measuring cup. Dissolve the combination in 15-30 mL warm (not hot) tap water.
4. Draw up baking soda and pancreatic enzyme solution into one syringe.
5. Attach an empty syringe to the feeding tube; then draw back on plunger of syringe to decompress all air and fluid from the feeding tube. Pinch off the tube with your fingers, and discard contents of the syringe.
6. Attach syringe with the baking soda and pancreatic enzyme mixture to feeding tube; push plunger in to add the mixture into feeding tube.
7. Clamp the tube (or leave syringe attached to the end of feeding tube); wait 30 minutes.
8. After 30 minutes, flush the tube with 30 mL of tap water.
9. Repeat steps 1 to 8 once if necessary.
10. If the blockage does not clear, and other causes of blockage (e.g. a kinked tube) have been ruled out, contact your Health Care Provider or go to the nearest emergency room to have the tube replaced.

Troubleshooting

This section explains how to prevent, recognize and treat the problems that sometimes happen to people on tube feeding:

Problem	What to Do
<p>Stomach fullness, gas, bloating, and/or cramping</p>	<ul style="list-style-type: none"> • Slow down the feeding rate* • Stop feeding for 1–2 hours and then restart feeding • Talk to your Health Care Provider about trying a different type of formula, making changes to your feeding schedule, or using your tube for decompression by “venting” (if possible) • If using opened formula from the refrigerator, remove formula for 30 minutes before feeding time
<p>Nausea, vomiting and/or reflux</p>	<ul style="list-style-type: none"> • Stop your tube feed. Wait 1–2 hours, and if your stomach feels better, restart the tube feed • Slow down the feeding rate • Sit upright or lie at least at a 45 degree angle • Call your Health Care Provider if: <ul style="list-style-type: none"> » Your nausea or vomiting continues for more than 24 hours » You cannot follow your tube feed schedule. This is especially important if tube feeding is your only source of fluid and you are unable to drink » You have signs of dehydration (refer to dehydration section below)
<p>Aspiration</p> <p>When formula or water enters the lungs. Signs of aspiration include:</p> <ul style="list-style-type: none"> • Coughing and/or choking • Wet, gurgly voice • Wheezing • Pale or bluish lips • Above symptoms with fever 	<ul style="list-style-type: none"> • Stop tube feeding immediately • Sit upright and make sure your airway is clear • If your condition does not improve right away, call your family doctor and go to the Hospital Emergency

<p>Diarrhea</p> <p>An abnormal increase in stool frequency and volume, or watery stool for at least 2 days</p>	<ul style="list-style-type: none"> • Slow down the feeding rate • Increase water flushes to prevent dehydration • Make sure you wash your hands well before handling the formula and equipment • Call your Health Care Provider if: <ul style="list-style-type: none"> » You have more than 5 watery stools in 24 hours » You have blood in your stool » You have severe abdominal pain » You have signs of dehydration (refer to dehydration section below)
<p>Constipation</p> <p>Decreased frequency of bowel movements that are hard and difficult to pass</p>	<ul style="list-style-type: none"> • Talk to your Health Care Provider about increasing your water flushes and fibre intake • Talk to your doctor or pharmacist about medications that may help • If possible, increase your physical activity • Call your Health Care Provider if: <ul style="list-style-type: none"> » You are vomiting or having severe abdominal discomfort
<p>Dehydration</p> <p>Signs of dehydration include:</p> <ul style="list-style-type: none"> • Small amounts of dark yellow urine • Increased thirst • Rapid weight loss • Dizziness when standing or sitting up 	<ul style="list-style-type: none"> • Increase water flushes before, after, and in between tube feedings • Call your Health Care Provider if signs of dehydration continues after increasing your water flushes

<p>Feeding tube falls out</p>	<ul style="list-style-type: none"> • Cover the site with a clean gauze pad • Call your Health Care Provider or go to the Hospital Emergency as your tube needs to be replaced right away so the opening on the skin does not close up. Do not try to replace the tube yourself
<p>Stoma leakage, irritation or infection</p>	<ul style="list-style-type: none"> • Follow the instructions for cleaning your stoma daily • If the skin around your tube is hot, red, swollen and painful with discharge that is thick and cloudy with a white or yellow-green colour you may have an infection. • Call your Health Care Provider if you think you have an infection at your tube site
<p>Feeding Pump Malfunction</p>	<ul style="list-style-type: none"> • Use a gravity or syringe administration method as backup until the pump can be repaired/replaced • Contact your Health Care Provider if you need instruction to adjust the tube feeding administration method

*** If you have slowed down your feeding rate, this may reduce the amount of nutrition that you are getting. Check with your Health Care Provider if you are not able to return to your original rate in 1–2 days and/or you are unable to get the amount of recommended formula and water indicated in Your Tube Feeding Plan.**

Your Tube Feeding Plan

Information on your tube feeding schedule, supplies, and how to give your tube feeding will be provided by your dietitian.

Who to Call

For questions about your nutrition, tube feeding supplies, feeding tube or skin around the tube, speak to your Health Care Provider.

If you have questions about your feeding pump, visit the pump company's website for support or contact your pump rental/supply store.

Your tube feed plan is NOT set in stone. If you would like to explore other options in regards to your schedule, tube type, formula type, or alternatives to formula, be in touch with your Health Care Provider.

You are your best advocate. Your tube feed plan should respect your lifestyle and best interest. We want you to be happy with your tube feeding arrangements at home.

Where to Find Support at Home

“It’s not just about the food *on the table* but the love of family and friends *around the table*.” D.R., tube fed individual

Oley Foundation educational website: oley.org

“Striving to enrich the lives of those living with home intravenous nutrition and tube feeding through education, advocacy, and networking”

Inspire – a patient community website: inspire.com

“Millions of patients and caregivers come to Inspire for information and support from others like them in our private, anonymous, and safe environment... get help in every step of your journey from diagnosis through deciding treatments, to coping, to managing your condition.”

Did you know?

- You may have options for other feeding methods
- There are different brands and sizes of syringes available
- There are tubes that don't have long tubing outside of the body
- You may be able to make your own formula with blended foods
- There may be products or accessories that can make your tube more comfortable
- There are devices to help you be more independent with your tube feeding
- There are over 450,000 tube fed people in North America. You are not alone!



Making better
decisions together
with patients
and families

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