



Home Tube Feeding Guide for Patients with Amyotrophic Lateral Sclerosis Open Tube Feeding System

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1. INTRODUCTION

Good nutrition is important for overall health and well-being. For individuals with Amyotrophic Lateral Sclerosis (ALS), maintaining adequate nutrient and fluid intake is a constant struggle when faced with increasing swallowing difficulties, fatigue, weakness, breathing problems and lack of appetite.

Tube feeding thus provides a practical option for those individuals who are unable to meet their nutritional needs by mouth or unable to swallow safely. With a tube feeding, the source of food is in a liquid form. When given in the right amounts, tube feeding formulas provide all the nutrients found in a well-balanced diet.

There are many individuals with ALS who are at home with their tube feedings and who maintain their lifestyles such as travelling, shopping, and participating in family activities.

This booklet was prepared to help you manage your tube feeding at home. Your dietitian, nurse and doctor will assist you and your family in learning this feeding method. They will teach you how to prepare and administer your tube feeding, what equipment you need, infection control procedures, how to give your medications, how to prevent problems and what to do if problems should occur.

Your tube feeding guide has been designed to meet your nutritional needs and lifestyle. Keep it close at hand and check it regularly.

If you have any questions or would like more information, please contact your dietitian, nurse or doctor. The telephone numbers are on the front cover of this booklet.

2. TUBE FEEDING PRESCRIBED FOR YOU

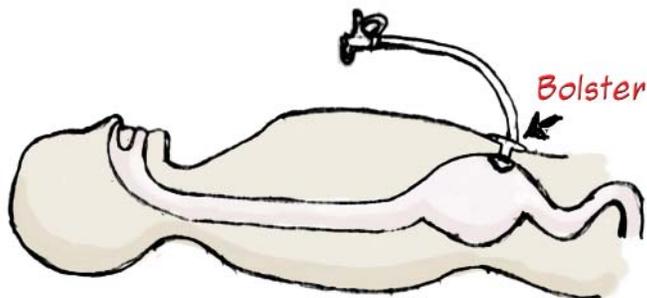
a) Type of Tube Feeding:

Your type of feeding is called a Percutaneous Endoscopic Gastrostomy or PEG tube feeding. This simply means that a feeding tube was placed directly into your stomach through the abdominal wall, to the outside of the body under the visual guidance of an endoscope (a lighted camera). Your tube extends _____cm from the skin with a cap on the end of it. To keep the tube in place, a bolster is placed near the skin surrounding your **stoma** (the opening to the stomach from the outside skin). Your nurse should mark your PEG tube exactly at the tube entry site with a non-toxic permanent marker. Any changes from this position will indicate that your PEG tube has moved. If so, do not start the feeding. Notify your nurse or doctor.

Brand Name _____

Size _____

Date Inserted _____



b) Type of Tube Feeding Formula:

Jevity 1-2/Isosource 1.5 _____

Nutren 2.0/Resource 2.0 _____

Glucerna/ Diabetic Resource from _____

Peptamen 1.2/Peptamen 1.5 _____

Other: _____ from _____

If you need to make a substitution, check with your dietitian first as formulas vary in nutrient content. The above formulas can be purchased from your local pharmacy. Contact your pharmacist to make arrangements or for home delivery services: Dufort & Lavigne: (514) 527-9381 or Calea: (514) 335-3500 or Stoma Medical (450) 786-0786.

c) Your Nutritional Requirements:

_____ calories per day.

_____ grams of protein per day.

_____ ml of water per day.

d) Method of Delivering Tube Feeding & Tube Feeding Protocol:

Intermittent:

You need to deliver _____ ml of formula within _____ minutes, _____ times per day.

Schedule: _____, _____, _____, _____, _____, _____.

You need to flush your feeding tube with _____ ml of water after each feeding to prevent it from plugging.

Continuous:

You need to deliver _____ ml per hour of formula from _____ to _____ for a total of _____ hours. You need to flush your feeding tube with _____ ml of water after each feeding to prevent it from plugging.

Pump: You need to set your pump at _____ ml per hour.

Gravity Drip: You need to deliver your formula by gravity.

Flush _____ ml of water per day or _____ ml 3 X per day.

e) Equipment needed:

pump to set rate of feeding.

pole or _____ for hanging tube feeding bag.

administration set (feeding bag and tubing)

syringe (60 ml or 2 oz catheter tip syringe)

If covered by OPHQ, all equipment needed will be provided free of charge. Otherwise, the above may be purchased or rented from Dufort & Lavigne or Caremark or Stoma Medical. Refer to Tube Feeding Formula section for telephone numbers.

Replacement of a PEG tube, cap or adapter can be obtained from GI department at the RVH.
Tel: (514) 843-1536

3. ADMINISTERING TUBE FEEDING

a) Position of Body:



You can walk, sit upright in a chair or sit propped up in a bed while receiving your tube feeding. If lying down, make sure your head is elevated at an angle of at least 45 degrees from the bed.



Stay in the above acceptable positions during and up to 30 to 60 minutes after your tube feeding is finished. **DO NOT LIE FLAT UNTIL THEN.**

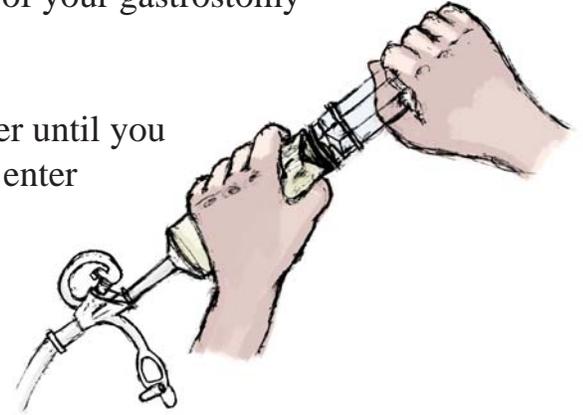
This will reduce the risk of **aspiration (accidental entry of formula into the lungs)**.

b) Verifying Gastric Residuals: (Only if asked for by the ALS Interdisciplinary team)

1. You will need to check the gastric residuals (presence of stomach contents) prior to each feeding. To do this, attach the syringe to the end of your gastrostomy tube (**not the tubing on your feeding bag**).

2. With the syringe in place, slowly pull back on the plunger until you meet resistance. This will cause the stomach contents to enter the syringe.

3. Note how much stomach contents or residuals can be withdrawn, then slowly push it back. Flush with 30 ml water.



➤ **Any or all gastric residuals must be returned to the stomach.**

➤ If the stomach is empty, nothing will be withdrawn.

➤ **If the amount of residuals is greater than _____ ml, wait 30 to 60 minutes.** Recheck every hour. If it continues to be high, do not attempt the feeding and report the problem to your doctor, nurse or dietitian.

N.B.: If you have just recently eaten by mouth, wait at least 30 minutes before checking for gastric residuals.

c) Starting Tube Feeding:

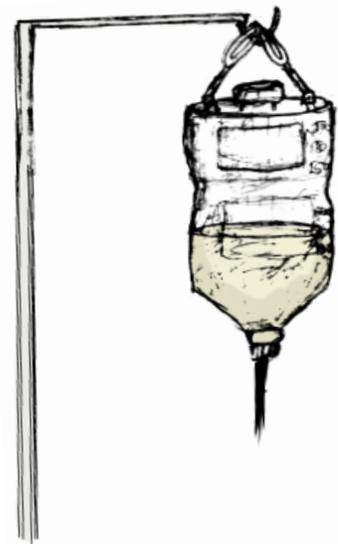
1. Close the clamp on your feeding tube.



2. Pour _____ ml of your formula into the feeding bag.



3. Hang the feeding bag on a pole or _____ that is higher than your head.

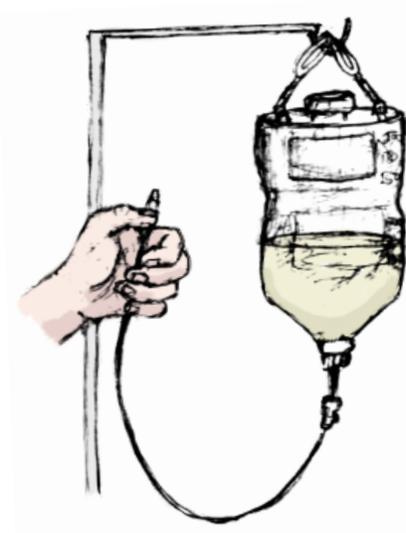


4. Hold the end of your feeding tube to prevent spills.

5. Open the clamp.



6. Allow the formula to reach the end of your feeding tube to get rid of any air in the tube.



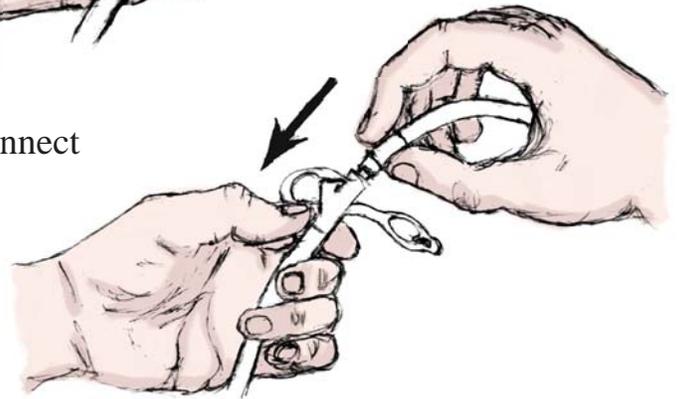
7. Close the clamp.
*If you are using a pump,
you now attach the feeding
tube to the built-in receptacle
on your pump.*



8. Clamp or kink (if clamp is not available)
your gastrostomy tube near the tip.



9. Open the cap on your gastrostomy tube and connect
to the end of the feeding tube.



10. If you are using a pump, set the pump at _____ ml per hour.

- Unclamp or unkink your gastrostomy tube and open the clamp of your feeding tube.
- Start the pump.

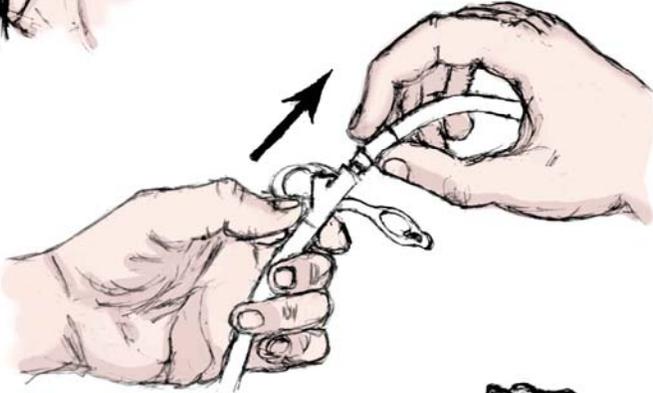
- If you are not using a pump, unclamp or unkink your gastrostomy tube and slowly open the clamp on the feeding tube.

- If the feeding is too slow, open the clamp of the feeding tube more.
- If the feeding is too fast, close the clamp more.

d) Stopping Tube Feeding:



1. When the formula in your feeding bag is finished, close the clamp of your feeding tube or stop the pump if applicable.



2. Disconnect the feeding tube from the gastrostomy tube.



3. Flush _____ ml of water into your gastrostomy tube with a syringe.

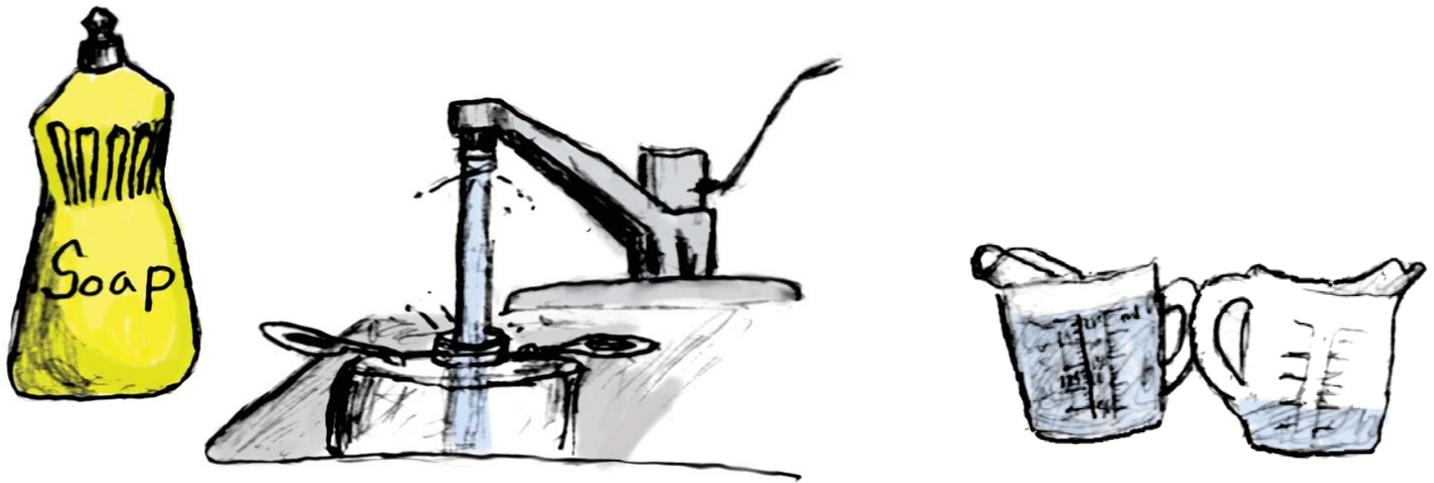
4. Put the cap back on your gastrostomy tube.

5. Refer to your Tube Feeding Protocol to see if extra water is needed.

6. If you are **refilling** the feeding bag for continuous tube feeding, flush the gastrostomy tube with _____ ml of water using a syringe. The feeding bag may be rinsed with warm water and then drained prior to refilling with the formula. See detailed instructions for cleaning under “Infection Control Considerations” section.

4. INFECTION CONTROL CONSIDERATIONS

- Before you prepare your tube feeding, wash your hands with soap and water to reduce risk of infection.
- Use only clean equipment and administration set (tubing with feeding bag). Follow the manufacturer's instructions on how often it needs to be changed. Usually every 24 hours.
- If reusing the feeding bag with tubing, rinse with warm water and dish soap 3 times a day. Use a clean bottle brush to scrub inside the bag. Rinse again with warm water.



Once a day, mix 60 ml (1/4 cup) of vinegar with 250 ml (1 cup) of water. Pour this vinegar and water mixture into the feeding bag and tubing. Sit the bag in the clean sink for 10 minutes. Empty bag out. Rinse the feeding bag and tubing again with cool water. Be sure to completely rinse it well. Keep your cleaned feeding bag and tubing in the refrigerator until used again. The syringe should be cleaned the same way.

- Discard the feeding bag with tubing if formula begins to adhere to the tubing and does not rinse clean or if any leaks should develop.
- Use only fresh formulas at every feeding time. Check the date of expiration prior to opening new formulas.
- For continuous tube feeding, hang fresh formula every 4 hours. Do not let formula hang longer than 4 hours at a time at room temperature especially during warm, humid weather as these are ideal conditions for bacteria to grow.
- Cover unused open formulas and refrigerate. Discard unused open formulas after 24 hours.
- PEG tube may need to be changed every 6 months to 1 year. Consult your doctor.

5. GIVING MEDICATIONS

Medications may be given through the gastrostomy tube if the doctor allows. Ask the doctor to order prescriptions in liquid form, if possible. You **cannot crush** just any medication. Consult your pharmacist about any possible interactions when taken in crushed form. **Do not** mix medications. Give separately.

1. If solid medication must be used, crush and dissolve the prescribed amount in 30-50ml of warm water in a small cup. If in liquid form, pour the prescribed amount of liquid into a small cup or dilute first with water if too viscous.
2. Open the cap of your gastrostomy tube. Flush with 30 ml of water.
3. Draw up the medication with a syringe.
4. Inject the medication into the gastrostomy tube.
5. Flush tube with 30-50 ml of **warm water** and replace the cap.
6. Stay upright or at an angle of at least 30 degree from the bed for 30 minutes after administering the medication.

If you are having trouble dissolving your medications, contact your nurse.

6. PERSONAL CARE TIPS

WEIGHT

Monitor your weight weekly, if possible. If you notice any weight change, please contact your clinical dietitian. Your tube feeding can be adjusted if needed.

MOUTH CARE

If possible, to keep your mouth clean, rinse 3 X a day. Use 5 ml (1 tsp) of baking soda in 500 ml (2 cups) of warm water to rinse. Clean your teeth carefully. An electric toothbrush, sponge-tipped toothettes and dental floss can be useful. You may also have your teeth cleaned by a dental hygienist.

SKIN CARE AROUND STOMA

Daily, using mild soap and warm water, gently clean and dry area around the gastrostomy tube as you bathe or shower. Always check for signs of redness, pain or soreness, or unusual leaking around the stoma. Report any signs of these symptoms to your nurse or doctor.

7. PROBLEM SOLVING

A) FEELING SICK (NAUSEA)

- Take your feeding more slowly. Adjust the clamp or reduce your tube feeding rate to _____ ml/hour.
- Sit up during your feeding. Do not lie down during and up to 60 minutes after your feeding is finished.
- Walk if you can after your feeding has finished.
- **Carefully** open the cap on your tube to let gas out of your stomach. Protect your clothing as stomach contents may come out as well.

B) DRY MOUTH OR FEELING THIRSTY

- Always follow your schedule for water.
- If you are still thirsty or have a dry mouth, call your dietitian to reevaluate your water requirement.
- For immediate relief, swab your mouth with moistened sponge-tipped toothettes.

C) CONSTIPATION

- Flush _____ml more water into your gastrostomy tube after feedings.
- Add _____ml of prune juice into your gastrostomy tube _____times a day. Rinse your tube well with 30 ml of water after the prune juice.
- Ask your dietitian for a formula containing fiber if you are not already on it.
- If the problem persists, you may need to ask your doctor to prescribe bulk-forming agents, stool softener or laxative.

D) DIARRHEA

- Always use formula that is at room temperature.
- Always use clean equipment.
- Take your feedings more slowly. Adjust the clamp or reduce your tube feeding rate to _____ ml/hour.
- Increase the amount of water taken to _____ ml with each feeding.
- Add 30 ml of liquid pectin into your gastrostomy tube _____ times per day: Mix pectin well in a small cup with 60-120 ml warm water. Draw up the pectin solution with a syringe and inject into the tube. Flush with at least 30 ml warm water.
- Check your temperature. If your temperature is above normal value, inform your nurse or doctor.

E) CLOGGED FEEDING TUBE

- If completely blocked: **DO NOT** attempt to unblock with liquids or insert any foreign object into tube. Contact your doctor.
- If partially clogged: Flush your feeding tube with 60 ml of warm water. Then aspirate by pulling back on the plunger. Repeat several times. If it continues to be partially blocked, contact your doctor or nurse. A pancreatic enzyme may be prescribed.
- To prevent a clogged feeding tube:
 - Do not mix your medications together. Take each one separately.
 - Do not mix medications with formula.
 - Rinse your feeding tube with at least 30 ml of warm water before and after your medications.
 - Make sure you always flush your feeding tube with the amount of water prescribed in your guide every 4 hours with continuous feedings and before and after intermittent feedings.
 - Flush feeding tube after checking residuals.
 - Flush feeding tube after any beverages taken

N.B.: If you are experiencing vomiting, unusual distention in the abdomen area, severe cramps, or significant weight change, contact your doctor.



**HOME TUBE
FEEDING**