

A feeding tube can assist you in reaching your nutrition and hydration goals, which may be difficult to achieve with swallowing difficulty (dysphagia) related to your ALS diagnosis. This handout will explain your tube options and help you determine if a feeding tube is something that may be right for you.

You might consider a feeding tube when

1. You are losing weight despite eating high calorie foods/drinks, a softer diet texture, etc
2. Meals are becoming more difficult due to chewing/swallowing issues
3. Meals are becoming stressful or taking a long time
4. You are unable to get adequate hydration with drinking
5. Your breathing is becoming more difficult (tubes are most safely placed when vital capacity, a breathing number, is >50% predicted value)

Methods for tube placement (depends on surgeon preference)

- PEG (Percutaneous Endoscopic Gastrostomy)- A feeding tube inserted into the stomach through the mouth by using an endoscope (camera) to identify the position and to secure the tube in place.
- RIG (Radiologically Inserted Gastrostomy)- A feeding tube inserted using x-rays to identify the position of the stomach and insert a tube through the stomach wall. These are inserted in the radiology department.

When deciding if a feeding tube is right for you, you should also consider if you are able to provide feedings yourself or if you have a support person who can assist you with feedings as needed.

Potential Benefits of Feeding Tubes

- Decreased stress with eating. You can eat as much or as little as you like. The tube can be used to get the nutrition and hydration you need
- Reduced risk of choking and aspiration pneumonia
- Can prevent losing weight
- Increased ability to achieve adequate hydration
- No need to swallow pills – can administer via the feeding tube
- Energy conservation for chewing/swallowing and speaking muscles
- Decreased meal times – tube fed meals typically take 5-30 minutes
- Can easily provide nutrition in different environments. You can bring formula with you if you are traveling or have MD appointments.

Resources to Help with Decision-Making

We realize it can be difficult deciding whether or not to get a feeding tube. The websites below can offer you help with making your decision.

- **myMND:** mytube.mymnd.org.uk
- **MND Association:** www.mnddecisiontools.com/public/1/decision_tool
- **Les Turner ALS Foundation:** <https://lesturnerals.org/nutrition/what-is-a-feeding-tube/>

Common Questions about Feeding Tubes

Can I still eat if I get a tube?

- YES! The tube can supplement your oral intake.

How can a feeding tube help my quality of life?

- You will be able to eat as much as you like and is comfortable for you. Many people start out eating by mouth and using the feeding tube as needed to meet their nutrition and hydration goals. A feeding tube is not considered an end of life intervention, but instead is a tool to help improve the quality of your day-to-day life when eating is becoming more difficult.

Are there any risks with placement?

- There is always risk for infection with any surgical procedure. If for any reason you develop an infection, your doctor will prescribe you antibiotics. In addition, a physician will talk to you about the typical risks of anesthesia.

When can I go home after placement and how long is the recovery?

- Most people can do a same-day surgery and go home that day. In some cases the doctor may recommend a short hospital stay. The feeding tube insertion site will heal over the next 4-6 weeks. There will be some soreness at first which gets better as you heal.

Will people be able to tell I have a feeding tube?

- Feeding tubes can be hidden under your clothing. There may also be an option to get a low-profile tube (MIC-KEY) once your tube site heals. This tube lies flush against your skin and comes with removable tubing.

What can go through a tube?

- Prescribed nutrition formulas, water, and medications. Technically, anything liquid can go through the tube. Some people choose to blend foods in a blender to put down the tube. This is safe as long as the consistency does not clog the tube.

How do I use the tube?

- There are 3 main ways to put feeds down the tube. Talk with your healthcare team to see which option is best for you.
 - Syringe bolus feeds (6-min video): <https://www.coramhc.com/patients/bolus-syringe-feeding>
 - Gravity feeds (6-min video): <https://www.coramhc.com/patients/gravity-feeding>
 - Container connector set (2-min video): <https://www.youtube.com/watch?v=674yBKFKOE8>

How do I clean my tube?

- You clean the outside of the tube and the skin around your tube site daily with soap and water. This can be done when bathing. Anything that goes in your tube will end up in your stomach, so we “clean” the inside of the tube with water flushes to prevent any clogging.

Can the tube fall out?

- Yes, the tube can fall out if it is pulled with some force. If this happens, you should immediately go to the emergency department to have the tube re-inserted. The tube opening (stoma) in your skin can close in <12 hours.

How often do I need to get the tube replaced?

- It is best to ask your surgeon. Initial tubes may have a silicone or rubber bumper inside your stomach. Silicone/rubber bumpers can last over a year. Other tubes have balloon bumpers which need to be replaced every 3-6 months. Your tube may also need to be replaced earlier if parts tear or break.

Will tube feeding change my stools?

- People generally have normal stools with tube feeding. In the beginning, stools may be slightly loose as your body adjusts to a mostly liquid diet. Fiber containing formulas or fiber supplements are available as needed to help bulk stool.

Are the feedings covered by insurance?

- Yes, typically insurances cover the cost of your tube feeding formula and supplies. Insurances will pay a durable medical equipment (DME) company to mail supplies to your house monthly. Some insurances won't cover supplies if you are able to safely eat enough food by mouth.

Will I gain weight?

- You may be able to gain some weight back that you had previously lost. The goal is to prevent further weight loss. Changes can be made to how much tube feeding you need to get to a stable weight.

Can I shower?

- Yes. Once your doctor tells you it is safe to get your tube wet.

Can I swim?

- Yes. You may need to wait for 4-6 weeks until your site is completely healed.

Can the tube be removed if I don't like it?

- Yes, the feeding tube can be removed by a healthcare provider at any time. The tube site would heal up over time.

Pictures of Gastrostomy (Stomach) Feeding Tubes




Type of tube	Description	Picture
Percutaneous endoscopic gastrostomy (PEG)	Has <u>silicone</u> internal (inside your stomach) bumper seen on the far right. Silicone or rubber bumpers can last over a year.	
Radiographically inserted gastrostomy (RIG) or replacement tube	Has <u>balloon</u> internal (inside your stomach) bumper seen on the far right. Balloon tubes need to be replaced every 3-6 months. This is also the type of tube used to replace RIG or PEG tubes.	
Low profile tube (MIC-KEY®) with extension	If this tube is desired, it is often not placed until 6 weeks after your first tube is placed. It also has a <u>balloon</u> internal bumper. Balloon tubes need to be replaced every 3-6 months. It requires an extension tube (on right) be connected to use the tube.	

Photo credit: Avanos

This is how the tube looks inside your stomach

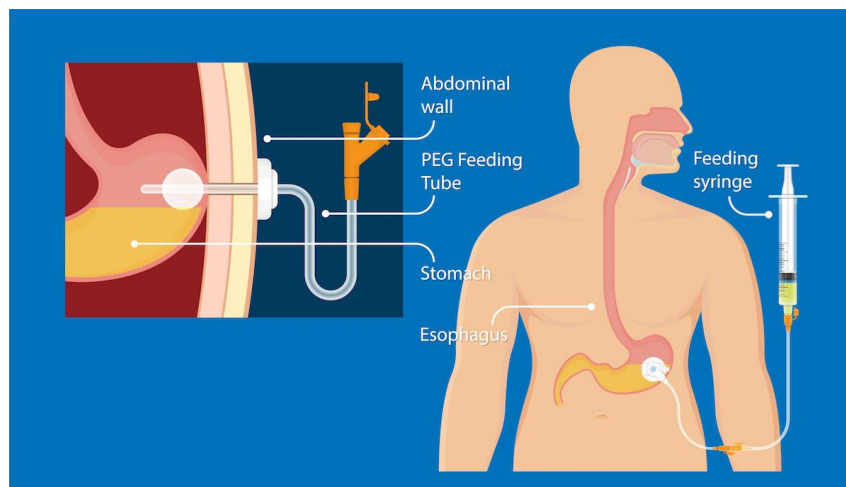


Photo credit: Roswell Park Comprehensive Cancer Center

This is how the tube looks from outside your stomach

1. PEG or RIG tube (“Standard Feeding Tube”) vs. Low-Profile Feeding Tube

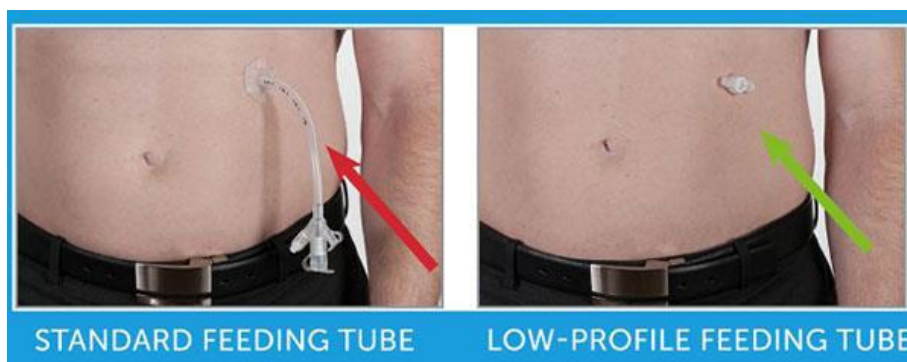


Photo credit: ALS Association

2. Low profile tube with extension tube

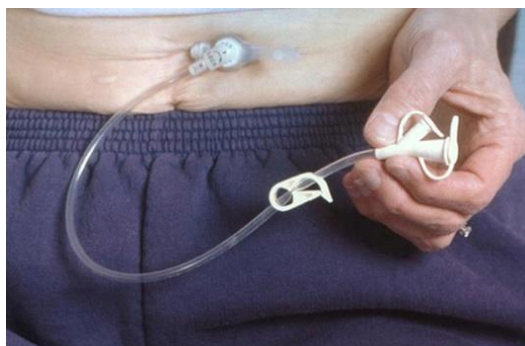


Photo credit: Farrag et al. *BMJ* (2019)