



Feeding Tubes: PEG (Percutaneous endoscopic gastrostomy)

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A feeding tube, also known as a PEG (percutaneous endoscopic gastrostomy), is a device that can be used to support the nutritional needs of a person living with amyotrophic lateral sclerosis (ALS). The feeding tube is placed through the skin directly into the stomach. When chewing and swallowing become difficult, a feeding tube can help supplement nutrition, calories, and hydration.

For people living with ALS, the decision to get a feeding tube is not always straightforward.

A feeding tube can help reduce weight loss and may prolong survival if placed early. Many people report a feeling of relief that they no longer have to work as hard to eat. They can continue to eat through the mouth for pleasure, but there is no pressure to eat a certain amount. Plus, many people find they have more spare time in the day to engage in meaningful activities after receiving a feeding tube.

However, a feeding tube can also represent the deterioration caused by ALS for some people, causing them to want to delay the procedure as long as possible. Some people fear losing the social connection they gain through mealtimes. It can also be uncomfortable or unpleasant to have a foreign device entering the body through the abdomen.

No matter how you see it, the decision of whether to get a feeding tube is yours. If you choose to have a feeding tube, you will get to decide when and how it will be used. You can also choose to stop using the tube, or even to have it removed. If you choose not to have a feeding tube, your ALS clinical care team will support your decision and will continue to assist you in finding foods and fluids that you can manage safely.

WHAT IS A PEG FEEDING TUBE?

PEG stands for percutaneous endoscopic gastrostomy, and it is also called a feeding tube.

P - percutaneous (through the skin)
E - endoscopic (using an endoscopic tube with a light)
G - gastrostomy (direct access to the stomach through a stoma or hole)

A feeding tube delivers liquid nutrition directly to the stomach, bypassing the mouth.

WHAT DOES THE FEEDING TUBE MEAN TO PEOPLE WITH ALS?

Researchers have found that the feeding tube has different meanings to people with ALS at different stages of the illness.

Frequently, people with ALS choose to delay the feeding tube procedure until it becomes a necessity, even though research shows that early insertion may increase survival. This is because, at first, the tube can represent a “symbol of deterioration”, much like a wheelchair or a respiration device.¹

But when people with ALS began to experience significant chewing and swallowing impairment, the feeding tube became an “eraser of complaints and concerns” and a welcome solution.²

WHAT ARE THE BENEFITS AND DRAWBACKS OF A FEEDING TUBE?

The following are some benefits and drawbacks to consider when deciding if a feeding tube is a good option for you.

BENEFITS

- Addresses problems with chewing, swallowing, choking.
- Allows the person to enjoy food for pleasure.
- Reduces weight loss and prolongs survival.
- Can improve quality of life by allowing a person to use their time for meaningful activities other than eating.
- As ALS progresses, respiratory functioning can decrease, and the risk of aspiration pneumonia increases.

DRAWBACKS

- Risk of complications -- usually infection.
- Must maintain the tube and ensure it is clean (flushing).
- Can be difficult to cope emotionally with having a foreign object in the body.
- May reduce the social aspect of mealtimes, unless a person also continues to eat normally.
- You will be unable to manage the equipment yourself, and will require assistance.
- It is important to consider the cost of feeding formula when making this decision.

Feeding tubes are recommended on an individual basis, though usually when a person is experiencing significant difficulties with swallowing, and/or if they have lost more than 10% of their initial body weight.¹

WHAT IS THE PEG PLACEMENT PROCEDURE LIKE?

The PEG placement procedure is typically performed by a gastroenterologist or a radiologist. The procedure can be performed on an outpatient basis, or may require a short admission if you are already having breathing difficulties.

During the procedure, an endoscopic tube is passed

through the mouth and down the throat into the stomach. The feeding tube is slipped down through a small opening in the abdominal wall. Retainers on the inside of the stomach and on the outside of the abdomen ensure that the tube stays in place. Water is then flushed through the tube to ensure the tube is in the right place and is clear.

While the procedure may be uncomfortable, people with ALS consistently report that the tube resolves their problems with eating and improves their quality of life.

One partner of a person living with ALS said, "Eating was very difficult, and it took a lot of time ... And now, with the feeding tube, she [has gained] lots of time and energy that does not go into eating and worrying about food."

CAN I KEEP EATING WHILE I HAVE A FEEDING TUBE INSERTED?

People with ALS can continue to eat normally while they have a feeding tube.

Because eating and tube feeding are not mutually exclusive, many people with ALS find a newfound enjoyment in eating for pleasure.

In their 2015 research paper, Jeannette Pols and Sarah Limburg concluded that "Once the pressure was lifted to obtain enough calories, eating – or rather tasting – could be organized in new, enjoyable ways, albeit in another form."²

Some people initially use the tube only for maintaining adequate fluid intake while their meals remain the same.

There are others who use tube feedings to supplement their daily intake either at the end of a meal or to replace one or two meals completely.

The pressure to satisfy all nutrient requirements completely by eating is reduced and they can really enjoy whatever they do eat.

Early insertion allows for a more gradual transition from oral to tube feeding which may be less stressful.

Some people may switch from eating by mouth to exclusively tube feeding. Those who are having a lot of problems chewing and swallowing may find it preferable

MANAGING AND MAINTAINING A PEG FEEDING TUBE

When you first start out with your feeding tube, you will be shown how to:

- Keep the insertion site clean
- Check for infection at the site
- Clean the tube
- Prevent and deal with blockages in the tube
- Clean and maintain other equipment required for feeding

Here are some general tips for maintaining your feeding tube.:

- Flush your tube twice a day to keep it clean.
- Have your caregivers and family members receive training regarding the tube-feeding system.
- Avoid lying down during and after feeding (at least for 45 minutes after feeding).
- Ensure you get enough water in addition to the formula (your dietitian will assess your fluid needs).
- Avoid putting ointment or a topical antibiotic on the skin around the tube as it will prevent the skin from “breathing”.
- Gently wash the skin around the tube with soap and water, occasionally using hydrogen peroxide.
- Replace your tube as required (if the tube is cloudy, hard to clean, stiff, etc.).
- If your tube accidentally comes out, go to a hospital Emergency Department as soon as possible for reinsertion; a feeding tube opening can narrow or close within hours of tube removal.
- Check with your physician if anything appears to be abnormal (excessive, large amounts of fluid leaking several weeks or months after the tube is inserted, discomfort, infection, difficulty in getting fluid into your stomach).

SUPPORT IS AVAILABLE

The ALS Society of Canada is here to help.

We can connect you to support groups, education, and other resources in your area.

It can help to join an ALS support group, where you can speak with others about the benefits and drawbacks of a feeding tube.

ADDITIONAL RESOURCES

- [Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis: Effect on survival.](#)
- [Frequency, timing and outcome of gastrostomy tubes for amyotrophic lateral sclerosis.](#)
- [Guide to PEG/RIG](#)
- [Living with ALS](#)

SUMMARY

- Many people with ALS find the feeding tube becomes a helpful part of their life, even if they initially feared it.
- People with ALS must weigh the pros and cons when making the decision of whether to get a feeding tube.
- This decision is yours, and you can opt not to have the procedure done if you wish.
- There is help and support available throughout the decision making process, as well as while you have a feeding tube inserted.

REFERENCES

- [1 Percutaneous endoscopic gastrostomy in amyotrophic lateral sclerosis: a prospective observational study](#)
- [2 A matter of taste? Quality of life in day-to-day living with ALS and a feeding tube](#)

KNOW THAT WE ARE HERE TO HELP I For people and families living with ALS in Ontario, ALS Canada can assist in connecting you to support services, equipment, and ALS clinics. Whether you are a person living with ALS, a family member or a caregiver, we will strive to support you along this journey. If you live outside of Ontario, please contact your provincial ALS Society for information on support available in your region. Learn more at www.als.ca.

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