



PEG

When getting enough nutrition and fluids to meet your needs becomes difficult, PEG may be recommended to you. If PEG has been presented to you as a feeding option, you need information to help you decide whether to get one.

If you do decide to have a feeding tube, the recommendation is “the earlier the better – even before you need it.” The procedure is easier to tolerate and it gives you a chance to get comfortable with it before you actually have to use tube feeding.

What is a PEG?

PEG (sometimes referred to a stomach feeding tube) describes the what, where and how of the procedure:

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

Why get a PEG?

- significant problems eating food (chewing or swallowing) or drinking fluids
- progressive weight loss
- eating is no longer a pleasurable activity and is tiring
- intake is poor in spite of usual appetite
- respiratory function is decreasing and risk of aspiration pneumonia is increasing

Why not get a PEG?

- your breathing function is considered too poor to tolerate the procedure
- the idea of an incision or tube in the abdomen is unacceptable
- you are unable to manage the equipment and feeding yourself and there is no one to assist you
- the cost of the formula
- the risks of the procedure outweigh the benefits

The Procedure

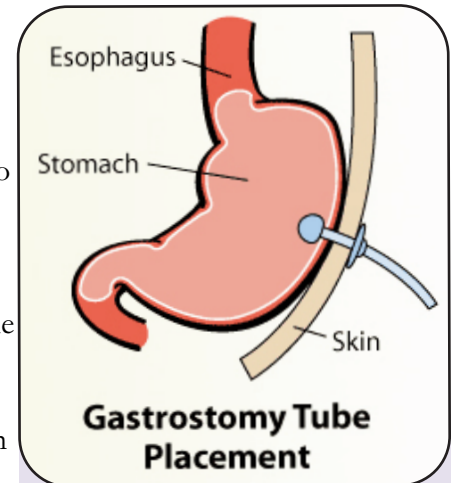
If you have made the decision to have a feeding tube, your doctor will refer you to a gastroenterologist, gastrointestinal surgeon or a general surgeon to perform the procedure.

PEG insertion is often an out-patient procedure requiring a local anesthetic and

mild sedation. An endoscopic tube is passed through the mouth and down the throat into the stomach. The ideal site is located when light can be seen on the outside of the abdomen. The feeding tube is slipped down and out 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. The risks associated with the procedure are rare but serious and should be discussed with the physician performing the procedure.

Timing of the Procedure

- loss of 5-10% of usual body weight
- dehydration from insufficient fluid intake
- eating or drinking leads to frequent choking
- it takes more than one hour to eat a meal
- respiratory function is decreasing and risk of aspiration pneumonia is increasing



Graphic: University of California, San Francisco



Benefits of the PEG

- avoidance of choking and swallowing problems from eating or drinking
- conservation of energy (energy is reserved for other activities)
- improved nutrition and weight management
- improved hydration
- improved general health
- many people experience a better quality of life

Risks of PEG include:

- pain at the insertion site
- infection at the insertion site
- leakage into the abdominal cavity
- clogged tube
- tube displacement

Managing the PEG 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

To Eat or Not to Eat?

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. Then there are those who switch from eating by mouth to total tube feeding. If you get a PEG when you are having a lot of problems chewing or swallowing, you may find it preferable to give up eating.

What to Put Through the Tube

Whether you take none or all of your nutritional requirements through the tube, you will have to flush it with water daily to keep it clear. If you are receiving some or all of your nutrition by formula, you will flush the tube with water before and after feeding. The amount depends on how much you are able to drink.

There are a number of products available on the market designed to provide all the nutrients (protein, carbohydrate, fat, vitamins and minerals) in amounts that meet your requirements. Some contain extra calories; some contain fibre. A dietitian will assess your calorie and fluid needs and will recommend a formula to meet your needs. You may have to try several to find one your digestive system tolerates well.

Financial coverage may be available through insurance or government drug program.

Feeding Schedule

Feeding schedules vary depending on personal preference, lifestyle and nutritional requirements. Since everyone is unique, a feeding/eating plan is developed on an individual basis and is adjusted as often as required due to changing circumstances.

Feeding can be continuous or intermittent:

Continuous feedings are given over 16 to 24 hours and require a pump to regulate the flow. It is administered slowly and can be given at night.

Intermittent feedings of one to two cans of formula are given, often at usual meal and snack times. These can be done with a syringe, pump or by gravity drip. Feedings by gravity or pump start slowly and the amount and speed increases gradually until the recommended amount and timing are achieved. Feedings by syringe can often be given more quickly but some people do not tolerate this method. You will be taught the proper technique associated with each of these methods.



Tips

Be sure to:

- 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)
- place a four-inch square of gauze between the skin and the external retention device to capture any excess moisture if noticing a little “oozing” around the tube (which is normal)
- 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)

The decision to have or not have a PEG is yours. If you choose to have a PEG, you decide when and how it will be used. You may also choose to stop using the PEG or even to have it removed. If you choose not to have a PEG, the ALS team will support your decision and will continue to assist you in finding foods and fluids that you can manage and with safe swallowing strategies.

You may find it helpful to speak to other people living with ALS or discuss it with a member of the ALS Team.