



Information About Feeding Tubes

The digestive system prepares food for absorption by the body. This process changes all food into proteins, carbohydrates, fats, vitamins, mineral salts and water. The intestinal mucous then is able to absorb these products for transportation by the blood to their final destination.

The organs of the digestive system form a tube (gastrointestinal tract) that begins with the mouth and ends with the large intestine. These organs are the mouth, pharynx, esophagus, stomach, and intestines. The intestines are divided into three sections: the duodenum, the jejunum, and the ileum.

The issues that arise for persons with ALS are:

1. Should I have a feeding tube? Will it prolong my life?
2. If I choose to have one, when should it be done?
3. Can I still eat by mouth?
4. What's the difference between a nasogastric tube, esophagostomy tube, gastrostomy tube, jejunostomy tube, PEG tube and a Button or key tube?
5. What is involved in managing a feeding tube? Are there problems I should be concerned about?
6. What do I put down the tube, when and how?

1. Should I have a feeding tube? Will it prolong my life?

Many people with ALS choose to have a feeding tube. A few do refuse to have one and they have a right to refuse. If a decision is made not to have a feeding tube, weight loss and poorer health can be difficult for caregivers to manage. Physicians can make an opening in the abdomen and food can be transported through a feeding tube. The feeding tube ends in the stomach, or in the jejunum (part of the small intestine).

Some advantages to having a feeding tube:

- Feeding times are simpler and take 10-15 minutes.
- There are no choking, chewing and swallowing problems.
- Adequate nutrition helps to maintain weight, prevent deficiencies, improves general health and resistance to infection.
- Fluids can be given without choking.
- Life will probably be prolonged.
- Energy expended in the chore of eating may be saved for other activities.





The disadvantages may include:

- You may not want your life prolonged.
- The idea of a feeding tube may be intolerable.
- The insertion of a feeding tube is a surgical procedure requiring a hospital stay from one half to several days.
- Potential infections or discomfort with the opening for the tube.
- Cost of special food such as Ensure. Insurance may or may not pay for these products.

2. When should I get one?

If you wait until your respiratory system is compromised and you can no longer cough well, the risk of choking and pneumonia increases. Physicians recommend getting a tube early.

Do it now if you are spending more than an hour for your meals; if you have lost ten percent of your weight or more – you may be seriously undernourished; if eating by mouth means frequent choking; if you are dehydrated from lack of sufficient fluids; if your time and attention is consumed with getting adequate food and water.

3. Can I still eat by mouth?

Usually, by the time you get a tube, eating by mouth has become a lengthy, unpleasant chore and one that you are happy to give up. However, if you get one early, you may still enjoy eating by mouth for the taste, etc. The tube can be used to take in extra fluids and calories.

4. What are the Pros and Cons of the various types of feeding tubes?

Nasogastric Tube

The NG tube is used for temporary or short term use. The tube is inserted through the nose, down the esophagus, and into the stomach secured to the nose with tape. The nose and back of the throat can become irritated and even ulcerated from the pressure of the tube left in place for more than a few weeks. It is uncomfortable to remove and reinsert. There is also danger of the tube moving and going into the airway instead of the esophagus.





Esophageal Tube

The opening for this tube is in the side of the neck. A long catheter is inserted down through the esophagus into the stomach. After the opening is well-healed, the tube may be removed between feedings. This method is not used very often. One obvious disadvantage is that it is noticeably visible unless a scarf is worn to cover it. For persons with ALS that choose to use a ventilator, a second opening in the neck area may create problems. The advantage is no gastric juices can leak through the opening and cause irritations or problems.

PEG Tube

The percutaneous endoscopic gastrostomy (PEG) tube is currently used more often. The tube is approximately 10 inches long. A long endoscope (instrument) is passed through the mouth and down into the stomach. This feeding tube is threaded down and out through an opening in the abdominal wall. Some physicians use a simple method that doesn't involve an endoscopy. One of the strongest advantages of this method is that usually no general anesthesia is needed, only heavy sedation. With a skilled physician, this procedure can be done quickly with few problems. You may be able to come home the same day. Problems with initial feedings can be dealt with by experienced personnel while in the hospital. It is important that patients and caregivers feel knowledgeable and confident before going home. Arrangements can be made for visits by home care nurses until you feel confident.

Some of the problems with PEG tubes include aspiration pneumonia (fluid gets into the airway and lungs, causing infection). Gastric reflux and aspiration can be minimized by close adherence to elevating the head at least 45 degrees during and after feeding, for a period of 30 to 60 minutes. Liquid medications rather than crushed pills are preferred given through a PEG. Bulk-forming agents such as Metamucil should not be given through a PEG tube. Blenderized foods may be used if they are able to pass through the eyelets at the end of the tube. Have your doctor show you a tube before he inserts it. Careful routine flushing with water is a necessity to keep it from clogging.

Gastrostomy Tube

The term gastrostomy can simply mean a feeding tube; however, it usually refers to the placement of the tube via a more complicated surgical procedure to create an opening in the abdominal wall into the stomach. This procedure usually means a longer stay and may require the use of general anesthesia.





Jejunostomy Tube

The jejunostomy is a long thin tube placed via fluoroscopy through the stomach ending in the jejunum (in the small intestine). Proponents of this type of feeding tube believe that there is less problem from aspiration pneumonia due to reflux (the return of formula into the back of the throat). Critics say a J-tube should be used after all other methods of controlling reflux and aspiration into the lungs have failed. The J-tube has a greater incidence of diarrhea, clogging, and abdominal distention.

Another important disadvantage is that formula must be infused at a much slower rate than a gastrostomy tube, requiring the use and added expense of a pump. It also may interfere with the quality of life for many persons with ALS who want to remain active, and find so much time attached to a piece of machinery a hindrance. J-tubes also require a more expensive product for problem-free digestion. Lastly, placement of the J-tube is more expensive due to the need for fluoroscopy for proper placement. If aspiration pneumonia becomes an uncontrollable problem, a J-tube may be required.

Button Tube

The button tube is a short tube that lies even with the skin. An extension tube is attached for feedings. The advantage to this type of tube is that there is no tubing left hanging on the abdomen.

5. What is involved in managing a feeding tube? Are there problems?

Patency of Tube

The preferred tube requires pouring a liquid product “down” the tube about five times a day. This is followed by water. Home care nurses have a variety of things they do to “clean” the inside of the tube. The tube is always flushed with water usually at least one cup after a feeding. This may be followed with ¼ cup of “cleanser”. Some products used as cleansers are Coca-Cola, cranberry juice, meat tenderizer (one part tenderizer to 4 parts water) and vinegar water (one part vinegar to four parts water); Viokase, a commercially prepared product is available by prescription. Viokase is mixed with a small amount of water and used to unclog tubes or as a routine cleanser. After the insertion of the “cleanser”, the tube is plugged quickly and the solutions are allowed to set in the tubing and do their work for 15 minutes to an hour or more. Then these solutions are flushed with a cup of water.

Dumping





In the beginning, the liquid feeding should flow in over 15 to 20 minutes or more to prevent stomach cramps, regurgitation, diarrhea, etc. Sometimes skin flushing, perspirations, clamminess, or other unpleasant symptoms may follow feedings that flow too fast. This is referred to as “dumping syndrome”. Diarrhea is a common problem that requires care and attention. Abdominal distention may be severe enough to compromise respirations. Dumping syndrome may be lessened with diluted feedings, a different product, or slower infusion.

Insertion Site

The insertion site on the abdomen (around the feeding tube) should be cleaned with hydrogen peroxide. A cotton Q-tip can be used. Usually this is all that is required. Povidone-Iodine ointment or solution may be placed at the exit site until it is healed. The ointment/solution helps prevent an infection while the fistula or “tunnel” heals. A small dressing may be placed around the opening to absorb the small amounts of secretions that tend to ooze out of the skin. These may be acidic stomach secretions which can irritate the skin. A thin layer of liquid antacid can be spread around the tube insertion site and allowed to dry. This counteracts the acids.

Infection in the Tube “Tunnel”

On rare occasions, stomach juices will leak into the abdominal tissues and infection may result. You should press around the opening with your finger to check for any secretions that might look like pus. Any white/yellow pus-looking secretions require a physician for treatment.

Outer Tube

The feeding tube should not be too long. If it is too long, that length and weight will pull on the opening and be uncomfortable. Sometimes it is helpful to tape it to the abdomen with hypoallergenic tape. You may take a shower without concern. Immersing the opening in bathtub water could cause a problem from unclean water.

Replacement

The tube may need to be replaced if it stops working or the parts wear out. Some tubes can be replaced by a nurse or caregiver, but others must be reinserted in a hospital setting. Replacement routine depends on the physician. Most tubes are replaced every 6-12 months.

6. What do I put down the tube?

If your tube is the type that ends in the stomach, anything you can get down the tube is all right. That includes all drinks, blended thinned soups, crushed medicines (check with your pharmacist first; some medications cannot be crushed, some will harden when mixed with water and clog the





tube). A tuberculin syringe filled with water may provide enough pressure to unclog the tube. If the feeding tube ends in the jejunum (intestine) a predigested product may be preferable to lessen dumping symptoms such as abdominal distension, diarrhea, stomach cramps, etc. Normally a formula such as Jevity is tolerated.

Customarily, a registered dietician will give you exact directions as to the kind of and amount of feedings, beginning slowly and increasing the amount according to tolerance. You may take several days or even a week or so to tolerate the feedings without diarrhea, flushing, perspiration, etc. Occasional blood tests to evaluate your nutritional status is best for optimal care.

Ensure, Jevity, Pulmocare, or other such products are normally used. They come in easy-to-use cans or some come in powder form as the most economical way. These products may be purchased in pharmacies, through medical supply companies, and even in some grocery stores. Carnation Breakfast, with a small amount of oil added in, makes a fair substitute if you need one for a few feedings (note: Carnation Breakfast should not be used as a sole means of nutrition). These products should be used at room temperature to prevent gastric complications.

The stomach should be checked to see if the previous feeding has emptied into the intestine. This is done by aspirating with a syringe. If more than 100 cc's of fluid are obtained, the new feeding should be delayed or skipped. This is most important in the initial weeks. If it is not a problem, you may skip it.

There are several methods of nutrition through the feeding tube. I have tried to review the most often used.

Kangaroo Bag/Gravity Method

The Kangaroo Bag method uses a plastic bag connected to a long piece of extension tubing. This tubing is then attached to the feeding tube. The liquid then flows via gravity into the stomach. The bag can be hung on a hook, an IV pole, literally anything that is stable and approximately 18 inches higher than the stomach. After the supplement has been administered, one or two cups of water should follow for rinsing purposes. Although the manufacturer recommends daily replacement of the bag, I have found that it can be reused several times if strict attention is paid to abundant flushing and storage of the bag in the refrigerator. The bag should be changed more frequently when the weather is hot.

Kangaroo Bag/Pump Method

This method is essentially the same procedure as above, except that instead of letting the liquid infuse by gravity, it is infused by a pump at a rate you set. This method is always used with Jejunostomy tubes. J-tubes require a slower rate of infusion and are more problematic.





There is nothing wrong with using a simple funnel for introducing liquid down the tube – whatever works! Essentially what is happening is that the food is by-passing the mouth and esophagus.

The person receiving the feeding should remain in a semi-upright position for 30 to 60 minutes after each feeding. Those who are able to walk would benefit from a short, slow walk. This helps to prevent regurgitation and aspiration problems. Aspirating any of the feeding puts you at risk for pneumonia, a problem that can be avoided with a little care.

Bolus Method

While the fastest and simplest method, it can be the most dangerous method! The “bolus” method uses a large syringe which is attached to the feeding tube. (Syringes can be purchased from the pharmacy). The outer part of the syringe is the only part used. The plunger is not used! Liquid is poured into the syringe and allowed to flow in as fast as gravity will allow. **USE EXTREME CAUTION IF CHOOSING TO USE THE PLUNGER TO FORCE THE LIQUID INTO THE STOMACH!** Serious problems of respiratory depression, cramping, regurgitation aspiration and over-expansion of the stomach do occur more frequently with the bolus method. In the first few weeks, caution should be taken not to give too much formula too fast. Small frequent feedings is the best method. The bolus method is not the best method of administration to use in the first few weeks. Time for adjusting to a liquid diet should be allowed.

A person with ALS has the right to make their own decisions about feeding tubes. Experience has shown us that choosing a feeding tube does not lengthen the quantity of life as much as it improves the quality of life. If problems with swallowing come early in the disease, it seems to be a kindness to both the patient and the caregiver to have a tube placed. It is emotionally difficult for the caregivers to watch the process of losing ground in weight and health due to inadequate nutrition.

--Excerpt from an article by Betty Scharf, R.N., 05/96

-- Rev 9/09

This material is the property of The ALS Association and may not be edited or excerpted. To obtain original reprints call The ALS Association.



The ALS Association, 27001 Agoura Road, Suite 250, Calabasas Hills, CA 91301-5104,
Phone: (800) 782-4747 / alsinfo@alsa-national.org / www.alsa.org