About Feeding Tubes

As ALS progresses, throat/muscle control over swallowing commonly becomes impaired. As it becomes increasingly difficult to swallow, meal times become longer and longer and choking episodes become more common. This can result in food or liquids entering into the lungs instead of the stomach (aspiration), thereby increasing the risk of pneumonia, and in inadequate intake of liquids and/or calories resulting in dehydration and weight loss. Additionally, although the patient’s appetite typically remains good, the effort involved with eating can consume a tremendous amount of energy from the patient and caregiver. For patients who tire from the efforts to chew and swallow food and/or caregivers who spend an excessive amount of time feeding the patient, tube feeding can result in a significantly improved quality of life. Not only does it give you more free time for enjoyable activities or to just relax with one another, it enables the patient to get the proper nutrition/fluids they could not consume.

From a medical standpoint, a feeding tube is recommended when the ALS patient is no longer able to ingest sufficient liquids to prevent dehydration and/or sufficient calories to maintain body weight. A feeding tube should be suggested by the physician after swallowing tests have determined the patient can no longer safely eat sufficiently to maintain their body. A swallowing study is typically performed by X-Ray technicians and commonly includes video taping the patient swallowing various consistencies of liquids/foods. If a feeding tube is recommended, it is then the patient/caregiver’s responsibility to make the determination whether or not they want to have this procedure done in order to maintain life.

The decision to get a feeding tube is a personal decision. It should be made by the patient (or their caregiver based on their knowledge of the patient’s wishes) in concert with their physician, and should be heavily influenced by the patient’s quality of life. If the patient no longer has a will to live, compounded by overwhelming physical deterioration, then the choice to die a peaceful death can be honored by not providing fluids or nutrients through a tube. A normal, healthy body will typically die within 14 days from the lack of liquids and food and someone with a serious illness can succumb sooner than that. Most medical professionals agree that it is a very painless choice in dying.

Like any decision though, deciding whether or not to get a feeding tube should be an informed decision. The ALS patient, their family and their caregivers should understand what is involved so they know all the pros and cons of deciding whether or not to proceed with getting a feeding tube. The following will, hopefully, provide some information on feeding tubes, which will help enable the ALS patient to make an informed decision.
G-Tube Types and Placement

What does a G-tube look like?
There are various different types. The two main ones are a PEG (Percutaneous Endoscopic Gastrostomy) and button. The PEG is a length of tubing with a valve at the end, which protrudes several inches from the incision area. Sometime this is put in first until the stoma site has healed well. It can then be replaced with a button. A button looks very much like the small valve that is used to inflate a child's beach ball. It is made of clear, soft plastic and sits right next to the skin and is flush to the body. A length of tubing is connected at feeding times.

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PEG Tube

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MIC-KEY Button Tube

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PEG Tube

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Bard
PEG Tube

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How do they put in a G-tube?

This depends on each individual. The medical team will decide the best way depending on how old the person is, how good their breathing is and what sort of tube they are going to have. The placement of a feeding tube is a relatively simple procedure. As with any surgery, patients are more likely to experience complications if they are smokers, obese, use alcohol heavily, or use illicit drugs. In addition, some prescription medications may increase risks associated with anesthesia.

The most common procedure for fitting the G-tube is called percutaneous endoscopic gastrostomy (PEG) tube placement. It is typically a short surgical operation that lasts about 20-30 minutes which is usually done with mild sedation given in the vein and a local anesthetic. The doctor will guide an endoscope through your mouth and into your stomach. An endoscope is a long, narrow tube with a camera and light on the end of it. It lets your doctor look into the inside of your stomach showing the surgeon where to make the hole. During the surgery, a hole (called the stoma) about the diameter of a small pencil is cut in the skin and into the stomach just below the lower ribs. The stomach is then gently attached to the abdominal wall. The G-tube is then fitted into the stoma. It is a special tube held in place by a disc or water filled balloon that has a valve inside allowing food to go in, but nothing to come out.

The patient is observed in a recovery area for about an hour, then moved to their hospital room. Depending on their level of health prior to having the PEG installed, their stay could be 1 to 2 days for observation of acceptance of the feedings. The stomach and abdomen will usually heal in 5 to 7 days.

Will it hurt?

There may be some discomfort from gas/air or adjusting to the liquid foods. There will be slight discomfort at the incision site after the operation but this can be dealt with using ordinary painkillers. Once it has healed you will hardly feel it is in there.

Will people know that I have a G-tube?

The tube is very small and is hidden by clothing, so nobody will notice it unless you show them. PEG tube holders are made by Dale Medical and NelMed and are available from CN Health (800-451-0015) and other suppliers.
Care and Maintenance

How much time will it take to care for the G-tube?
Usually G-tubes need very little maintenance. They need to be kept clean but a bath or shower does most of this for you.

What is the stoma?
The stoma is the surgical hole into which the G-tube is placed.

What does a “good” stoma look like?
Ideally, the site should be flat, dry and not tender or excessively red. If the site is red, oozing profusely or has a foul odor, you might have an infection. Consult your physician.

How should I clean my stoma?
The first week there is more care than afterwards since surgery has been performed. Sterile gloves, gauze etc., must be used to clean the area thoroughly around the wound. The nurses and doctor will instruct you in this procedure and will usually give you a booklet to take home with you. The incision will heal but of course remains open since the tube is through it. Afterwards the incision has healed, daily care of the G-Tube site is simple. The area around the stoma and under the tube flange should be cleaned daily with warm tap water and a tissue or gauze. A mild soap can be used to remove any small crusts. Allow it to dry completely. Some people carefully use a hair dryer to speed drying. There is no need to use saline (salt water) or sterile liquids - clean tap water is fine.

What sort of dressing should be used?
Ideally, none. The site thrives on fresh air and a daily shower or bath.

Will it leak?
Occasionally the tube may pull away from the abdominal wall resulting in leakage around the insertion site. Most G-tubes leak a small amount but this is easily taken care of with a little damp cotton. The fluid that leaks out from the stomach can irritate the skin around the tube so it is important to clean any leaks. If skin irritation is noticed apply a little protective cream or a prescription skin barrier for protection. Normally, the degree of leakage is very small and it will not be enough to mark or stain clothes. Leakage may also occur if the stoma site (incision) enlarges in the patient with poor nutrition A tube that leaks more than a little, probably needs replacing because the balloon is leaking or it is not the correct size.
What is proud flesh?
Occasionally the development of what is referred to as granulation tissue or “proud flesh” will occur. This is, basically, skin that grows around and sticks out from the stoma site. The use of hydrogen peroxide to clean the stoma site can lead to the growth of granulation tissue. Treatment is simple and painless. When it becomes bothersome, you can get rid of most of it by cauterizing the flesh with silver nitrate. This devitalizes or burns away the tissue and in a few days, it sloughs off. Your Gastroenterologist prescribes the silver nitrate in the form of a caustic pencil or applicator sticks that look like long matchsticks.

What other complications might there be?
Occasionally, the skin around the stoma can become sore or infected, or it can get a bit hardened. It is therefore important to look at the stoma when cleaning it and let your nurse/doctor look at it if you are concerned. Stomachache, bloating or diarrhea can also occur if too much food is put into the stomach too quickly. This may happen if the stomach is not used to large volumes. A feeding regime should be discussed with your doctor or a dietician so that tolerance can be gradually built up.

Does the feeding tube ever need to be replaced?
The feeding tube does not last a lifetime. They typically have a life span of about 6-12 months so it is important to understand they may have to have it pulled out and a new one inserted. If there is substantial drainage but flushing can be easily done, there is a good possibility a replacement tube is needed.

What happens if the tube comes out?
This is unlikely as the tube is secured either by a little water filled balloon or a small plastic disc. As the hole is only a fraction of this size, the tube cannot pull out until the balloon is deflated, which is only normally done to renew the tube. If the tube ever does come out - don’t panic. Place a clean dry towel over the stoma to absorb drainage. If there is an extra on hand, replacement of a button can often be done at home if the caregiver has received training. Otherwise calling a doctor or visiting the hospital emergency room is in order. In either case, it is a good idea to have an extra tube on hand. Remember though, the key to quick and easy replacement of a button of any variety is speed! It only takes a few short hours for the stoma to close up. If this happens, surgery may be required to reopen the stoma.

What if the tube becomes plugged?
This is most often caused by the build up of formula residual in the lumen (internal space or opening that exists within the gastrostomy tube). Tube blockage may be prevented with the routine practice of flushing the tube after each use. The tube should be flushed at least once daily. Although water is good, coke or other carbonated beverages are even better. If blockage occurs the tube should be irrigated using a large bulb syringe. Be careful to avoid excessive force while irrigating because the tube could rupture. Milking the tube may help dislodge the obstruction. Should these attempts to remove the obstruction fail, notify the physician immediately.

What about oral hygiene?
Good mouth care is imperative in preventing problems, especially with patients who are provided with total nutritional support through the PEG tube. Daily brushing of the patient’s teeth, gums and tongue
should be done. Mouthwash may be used with patients who retain a gag reflex. The patient’s lips should be moistened with water and, if necessary, lubricated with petroleum jelly to prevent cracking.

**Food and Medications**

**What kind of food is fed through the g-tube?**

**Commercial food:** It is usually recommended that a commercially available prepared (canned) formula and water for hydration be fed through the tube. This will provide a balanced diet including all the essential vitamins and minerals needed. Some of these formulas contain fiber so that regular bowel movement can be maintained even if you are unable to eat fruit, vegetables and other high fiber foods. It is important to understand that nutrition is a very critical to the continued well being of the ALS patient. Because of the need to make commercial brands of food supplements taste good to the public, they are high in fat and sugar content. Over a prolonged period of time excessive fat and sugar are not good for the human body. If the patient is getting the bulk or all of their nutrition from supplements, it is suggested that you work with a dietitian to find a high content formula. The best formula is likely one that is not commercially available through retail outlets. The formula comes commercially prepared or in powder form which requires dilution with water. Common brands, typically with or without fibers, include Ensure, Jevity, NuBasics, Boost, and Isocal among others. Most come in 8 oz. cans and contain 250 calories.

**Table Food:** Table foods may be blenderized according to instructions from the physician. Many people use homemade formulas prepared from cooked, blenderized foods but caution should be used to prevent clogging the tube in the stoma itself. Most tubes are roughly the size of a straw in diameter. Therefore food would have to be liquidized to prevent clogging the tube. Old foods left in tubing and other apparatus can lead to infection, therefore adequate cleaning is necessary. Specific advice, with respect to the type of food and the quantity required, should be provided by your doctor or a dietician.

**How much formula should be given?**

This is determined by your medical advisors and is dependent on many factors. The physician will advise the patient/family on the type of food, methods of feeding, frequency and rates.

**How do you take medications?**

Medications may be administered through the tube utilizing the bolus feeding method. The physician or pharmacist should be consulted. Ask for liquid medication where possible verses pills or capsules. If liquid medication isn’t possible, certain tablets and pills may be crushed dissolved in 30cc to 50ccs of water. A mortar and pestle (available at most kitchen stores) works well for crushing pills. Formula, juice or milk may be used if the medication does not dissolve in water. Gel caps can be cut open and the contents squeezed out. Highly viscous liquids (sticky, gummy, gelatinous liquid like CO-Q10) should be diluted with water prior to administration. Most gel caps can also be dissolved in very hot water, which can subsequently be cooled down with ice cubes. It is recommended that a physician or pharmacist be consulted for questions regarding medications and/or the administration of medications, as certain medications should NOT be crushed or dissolved and certain medications should not be mixed. Following the administration of any medication, the tube must be flushed with 30cc to 50cc of water. DO NOT give bulk laxatives through the tube without consulting with the physician first as some laxatives may obstruct the PEG tube.
Feeding

Will I use the g-tube at normal mealtimes?
The g-tube can be used at anytime that suits the individual. The feed can be given by attaching a syringe to the tube and pouring in the feed or by using an electric pump, so that feeds can be given without the person or helper needing to do anything during the meal. Some people choose to stick to regular mealtimes, while others use a pump and continuous feed to allow feeding to be done mainly at night. Some families find that it is nice to sit down to eat together even though one of them is getting their main meal through the g-tube. The person can sometimes be having a light snack at the same time or just a drink. Each person's routine is individual and is decided on with all their needs in mind.

Can I eat some normal food or drink by mouth?
It depends on why the tube was inserted. If it was because of slow mealtimes or poor weight gain only, it is OK to continue eating and drinking as usual. In this way your mealtimes can be as long or short as you wish as you know you can top up enough calories via the tube. Some people use the g-tube mainly as “insurance” so that the person can always be sure of getting food and drink even if they don't feel like eating by mouth.

However, if the reason for having the tube is that the person has swallowing problems and aspirates on food or drinks, it is important to have advice on what is safe to take by mouth. The team may recommend that only certain amounts or types of food or drink are safe by mouth. Sometimes it is the safest option to stop taking food by mouth altogether. This is not a forever decision and the swallowing will be monitored so alterations can be made as things change.

What if I am thirsty?
In some cases it is OK to drink normally. If the team has said that you cannot drink by mouth then fluids added via the g-tube will reduce thirst.

What will it feel like while I'm being fed?
Most people don't notice anything at all. If an attempt is made to feed a person too quickly they will soon complain of feeling sick, just as they would if they ate too much, too quickly. If this happens, then the rate of feeding is easily reduced or stopped.

Will I still feel hungry, and then full after a feed?
Yes. The stomach will still fill and empty in the normal way, giving the usual sensations of hunger and satisfaction.

How should food or formula be handled?
The caregiver should thoroughly wash their hands with soap and water before preparing formula/food and having contact with the patient. Formula should be given at room temperature (too hot or cold would make patient uncomfortable). Unused formula and blended foods should be refrigerated. Refrigerated formula and blended food should be warmed to room temperature over a 30 minute period before feeding. NEVER heat the solution as this could increase the growth of bacteria. In hotter climates, ice may be placed in the outside pocket of the full canister or bag for overnight feeding, but be conscious of the discomfort caused to the patient, as some people with buttons find cold fluid going into their stomach quite uncomfortable.
In what position should the patient be fed?
The patient should be fed in an upright position (at least 30 degrees) and remain in an upright position for 30 to 60 minutes following the feeding. This minimizes the possibility of aspiration (inhaling food into the lungs) and its inherent complications (pneumonia). Overdistention, where the abdomen becomes superinflated, should be avoided by careful attention to the rate of feeding flow and the development of abdominal bloating. The doctor will recommend the measurement of feeding and the flow to be used.

What is Bolous Feeding?
Bolous feeding is where the food is poured into the tube slowly verses by machine. Bolous feeding allows you more freedom in that you can give feedings anywhere, which is nice when you leave the house. Bolous feeding allows for rapid feeding of formula over a relatively short period of time. Formula may be instilled using a bulb or piston syringe or through the use of gravity flow. The feeding usually consists of no more than 250 cc’s to 500 cc’s per feeding and is given to the patient every 4 to 6 hours. Never FORCE fluids through the PEG tube. Infuse the formula slowly and carefully to prevent abdominal cramping, nausea and vomiting, gastric distension (inflated stomach) or diarrhea. If the formula is not infused (poured) slowly, the patient is placed at a high risk for aspiration (fluid into the lungs) and the complications of pneumonia.

What is Continuous Feeding?
This method is preferable for many patients because it allows for better regulation of the amount and rate of food. The feeding pump (a machine) is set up and the tubing connected to the PEG tube. The formula is infused over the prescribed period of time into the patient. Using a feeding pump to control the rate is normally better for digestion and causes less problems. Typically, the slower the rate of intake, the better the tolerance. The risk for aspiration is also decreased because less formula is given during the prolonged period of infusion.

What is the purpose of the alarm on the pump?
The alarm may sound to let you know the pump is running on the battery instead of the power point. It also warns of a blockage in the flow (check to make sure the clamp and roller brake are off), a kink in the tube (check under the patient, also the tube between the canister and where it enters the pump), and that the canister is empty of formula.

How do I clean the equipment?
After each feeding, flush the tubing with lukewarm water to clear the tubing and wash away any particles that might clog the tube. Remember, don’t flush the tubing with chilled water. If you use a canister type apparatus to hold the formula, scrub the inside with a brush and warm sudsy water. Plastic bags such as those for the Kangaroo pump (and similar pumps) are designed to be used for 24 hours then thrown away. Some people clean them thoroughly then use them for another 24 hours but caution must be exercised when doing this, as the threat of infection exists. Flushing the tubing with boiling water helps get rid of stubborn particles (after the tubing is removed from the patient!). Some people advocate the use of a carbonated drink such as Coca Cola to clean the tubing. Running a small amount through the tubing may help remove crusted formula.
What can be done about abdominal gas?
Trapping of gas in the stomach is sometimes a side effect of tube feeding. Massaging of the abdomen can sometimes help, as can bending the knees up to the chest. Also try rolling onto one side or other to allow the gas to be dispersed. Should the patient experience bloating prior to or following any feeding, the patient’s stomach and intestinal tract should be decompressed. Decompression is easily accomplished by removing the feeding adapter cap from the tube and allowing the PEG tube to be open to air. Encouraging the patient to cough will expedite the removal of excessive air. It is a good idea to put the bolus tube into the PEG before the patient cough’s or burps to prevent the contents from splattering out all over.

Summary
The care of the tube and the feeding sound like a lot of work, but it really isn’t. At first you swear you will never remember all of the steps necessary for each procedure!! It is a good idea to take notes and develop a checklist to use for the first week or so but you will find that you will quickly be able to do it from memory.