

Section 6

NUTRITION SUPPORT

Patients with ALS will face many issues throughout the course of the disease, and nutrition should not be overlooked. Preventing nutritional deficiencies from the beginning will help improve the quality of life.

Initially, there may be a drop in appetite as an ALS patient's activity level decreases. Fatigue and choking can result from weakness in the muscles used for chewing and swallowing. As a result, the patient may not get enough food or liquids. Adequate fluids are needed to maintain proper hydration and to keep secretions from becoming too thick to cough out. Adequate nutrition is needed to maintain weight and energy levels, and to absorb the vitamins and minerals that enable the body's organs to function.

Some simple changes in habits can help improve a patient's appetite. Try to eat four to six small meals during the day, rather than two or three larger meals. This may reduce fatigue and provide adequate nutrition. Make meals enjoyable by taking as much time as necessary. Try to make mealtime appealing by having a variety of foods. Include the patient's favorite foods and provide a variety of bright colors. If you try these suggestions and the patient still does not get enough food and liquids, the problem may be difficulty in swallowing.

SWALLOWING PROBLEMS

Signs of Swallowing Difficulty

- choking or coughing while eating
- increased saliva production or excessive drooling
- sensation of food getting stuck in the throat or chest
- needing more and more time to finish a meal
- frustration during meals
- avoiding certain foods
- loss of appetite
- weight loss and/or decreased energy

If you notice any of these signs, try to determine what types of liquids and foods are the easiest to tolerate. If necessary, change the consistency of the foods and liquids taken in during the course of the day.

Suggestions for Dealing with Early Swallowing Problems

- Sit upright in a chair, as close to 90 degrees as possible.
- Remain sitting up for 15 to 20 minutes after meals.
- Chew food thoroughly with the mouth closed and swallow each bite.
- Swallow more than once, if necessary, to make sure the food has gone down. It may help to take a small sip of fluid after each bite.
- Take your time between swallows.
- Gently clear your throat or cough to clear any food residue.
- Do not try to talk while chewing and swallowing; wait until you are finished.
- Take smaller bites of food, and swallow smaller amounts of fluids.
- Cut food into smaller, more manageable pieces.
- Use a chin tuck position. As you swallow, lower your head so your chin is toward your chest. This will prevent food from being inhaled.
- Crush medications and mix them with applesauce or pudding. Switch to a liquid form of medication if possible.
- Avoid small particles of food such as nuts, seeds, plain rice, corn, popcorn, and peas.

Thin liquids are often the most difficult for ALS patients to swallow. It may help to try drinking thicker liquids such as nectar, tomato juice, or cream soup. Powdered thickeners can be added to liquids such as coffee, juices, and soups without changing much of the taste. Commercial thickeners such as Thick-it and Thicken Up are available at most drug stores without a prescription. Unflavored gelatin, which can be found in the baking goods section of the grocery store, can be sprinkled into food or fluids in small quantities as a thickener.

Please notify the Center if you are having difficulty swallowing or taking in adequate fluid and nutrition. A video swallow test, sometimes called a “cookie swallow test”, may be beneficial. This test is a special X-ray that can identify the problems with your chewing and swallowing. The test is reviewed by the Speech Pathologist, who can make recommendations on food consistency and provide tips on chewing and swallowing. If swallowing difficulty is caused by thick secretions, see Respiratory Care (Section 8).

Tips for Increasing Calorie Intake

- Eat small meals more often, preferably five or six meals daily.
- Add butter, margarine, cream, honey, and gravy to your foods.
- Add high protein foods such as milk, cheese, egg, powdered milk to your foods.
- Drink fluids between meals instead of with meals. Fluids with meals may make you feel full.
- Drink an oral supplement like Ensure Plus, Boost Plus, or Carnation.
- Use creamed soups instead of broth-based soups.
- Keep snacks handy to eat when you are hungry.

Try to add an extra serving of protein, such as meat, fish, eggs, cheese, or beans to a meal or as a snack. Some of these suggestions are not appropriate for patients with reflux disease. Those patients with gastrointestinal sensitivity may need to limit or eliminate citrus, tomato, dairy, and/or caffeine products.

Increasing Fiber

- Use whole grain bread and cereals when possible. Look for products that have at least 2 grams of fiber per serving.
- Choose more fresh fruits and vegetables.
- Add dried fruit, raisins, or nuts to your cereal or yogurt.
- Add cooked, dried peas and lentils to soup. Add soaked bran to meatloaf or casseroles.
- If on a mechanical soft diet, use prune juice or products such as Metamucil.
- Be sure that your intake of water is adequate when increasing the fiber content in your diet. (8-10 glasses per day)
- Fiber goal per day is 25-35 grams.

RESOURCES

Sources of Recipes and Menus

- *Meals for Easy Swallowing*, recipes, menus, and tips, available at no charge through the MDA. 800-572-1717
- *Non-chew Cookbook*, recipes, \$23.95, available from Wilson Publishing Company. 800-843-2409
- *Puree and Easy*, Thick-it recipes from Milani Foods, Melrose Park. 800-333-0003
- *Thick and Easy Recipe Book*, 800-866-7757
- *The Dysphagia Cookbook*, available from Cumberland House Publishing, Inc. 888-439-2665

Products that Can Help Swallowing

Helpful products include Novartis high calorie, high protein supplements, as well as Thicken-Up thickener and Resource thickened juice. Contact 800-828-9194 or www.resource-at-home.com, a website for prepared consistency modified foods. Most products are shipped frozen. The average cost per entree is \$2.90 for an order of 24 items, with shipping charges additional. The food is pureed and re-formed into patties, pasta shapes, etc. The resulting pureed foods are more appealing and can be heated in the microwave.

THE FEEDING TUBE

There will come a time when most patients will face the decision whether to place a feeding tube. The term *feeding tube* has a different meaning for every individual who is faced with the decision of whether to pursue this treatment. The gastrostomy tube that is discussed here is surgically inserted through the abdomen into the stomach. It is NOT inserted through the nose or throat. Medicines, liquids, and liquefied foods are placed directly into the tube, avoiding the need to swallow them.

There are many reasons to have a feeding tube placed, such as difficulty swallowing food or medications, weight loss, presence of inadequate oral intake, and diminished breathing ability. These are the problems that usually result in the issue being brought up during a Center visit. The most important reason for using a feeding tube is to avoid the likelihood of choking, inhaling food or liquid into the lungs, and possibly developing pneumonia. The tube is used to administer medication and to insure that you get enough food and liquids to avoid dehydration, preserve your energy level, and get enough calories to maintain weight.

The window of opportunity for placement of a feeding tube is related to respiratory function as well as other variables that the doctor will discuss. Sometimes a patient's breathing can decline to the point where the tube needs to be placed prior to when it is needed for nutritional purposes. In order to make an informed decision about whether to have this procedure, the patient and the family need to be aware of the many aspects of the placement and care related to this device. The questions and answers below will provide information to help you understand the situation.

What Is a Feeding Tube?

A feeding tube is a soft plastic tube that is inserted through the abdominal wall directly into the stomach. This tube puts fluids, medication, and nutrition directly into the stomach where they are absorbed by the body, rather than having to first pass through the mouth and esophagus (food pipe). The tube is called a **g-tube** or sometimes a **PEG** (percutaneous endoscopic gastrostomy), depending on how it is surgically inserted. About six inches of tubing extends from the opening in the abdomen, and can be anchored to the abdomen with tape or a special anchoring system so it is not noticed when it is not in use.

A newer device called a button is available, although it may not be appropriate for all patients. Not all physicians offer this option. It replaces the standard g-tube described above and can be placed in a well-healed standard g-tube site after about twelve weeks. The button lies flush with the skin and does not have the extension of tubing outside of the body. The advantages and disadvantages to the button should be discussed with the specialist who will insert the g-tube before the procedure is performed.

Who Needs a G-Tube?

Any patient who is having problems with swallowing may consider g-tube placement. Fluids and food are necessary to maintain overall health of many body systems. Fluids also help to decrease the thickness of secretions that are often a problem in ALS and to make them easier to cough or suction out. If a patient can no longer take in enough fluids or nutrition by mouth, the possibility of a g-tube insertion should be discussed with the ALS Center staff. Also, when medications can no longer be swallowed, a g-tube should be considered. Aspiration (taking fluid or food into the lungs) is often a problem when swallowing becomes affected. Inhaling fluid or food into the lungs can lead to infection and/or pneumonia. This can cause further problems with breathing that may already be compromised by the process of ALS.

Signs of Possible Need for G-Tube

- increased time needed to eat meals
- frequent choking or coughing during meals
- weight loss with decreased energy
- inability to take necessary medication
- one or more bouts of pneumonia caused by aspiration
- dehydration due to lack of sufficient fluids

What Does G-Tube Insertion Involve?

Before having the procedure, the patient needs to have a consultation with a gastroenterologist, or specialist in the digestive (GI) system. The staff at the Lois Insolia ALS Center can refer you to one of the GI specialists at Northwestern or we can contact your local doctor to have this consultation performed in your area. The gastroenterologist will evaluate and determine the best type of procedure for you. The g-tube insertion may be done as an outpatient or may involve a short hospital stay. This will depend on the type of insertion and the GI specialist's preference.

There are two ways to insert a g-tube: by surgical insertion or by endoscopy. After examining the patient, the GI specialist determines the manner in which the tube is inserted. Surgical insertion means that an incision is made to aid in the placement of the tube through the abdomen. Two small abdominal incisions are made, one to visualize the stomach and one to place the g-tube. Surgical insertion is done either under local or in some cases, general anesthesia. Endoscopic (or PEG) insertion means that the gastroenterologist places an endoscopy scope (a small flexible tube with a video camera) through the mouth into the stomach, and uses this to visualize placement of the g-tube. PEG insertion ends up with one small abdominal incision for the tube and it is done under sedation.

The Lois Insolia ALS Center recommends that the procedure be performed at Northwestern Memorial Hospital, which involves a one to two day hospital stay. At Northwestern, members of the Department of Neurology will be available to see the patient during the stay and to coordinate ALS care along with the GI care needed for the procedure. We prefer hospitalization rather than outpatient status because the digestive system often slows after this procedure. With a two to three day hospitalization, we can be certain that everything is back to normal before the patient goes home. This can prevent complications that could require the patient to go to a local emergency room or even into the hospital after an outpatient procedure. We will work with the patient and family to coordinate the procedure and hospitalization at Northwestern and to make the stay as easy as possible.

Will the Tube Show?

Even though the g-tube is inserted through the abdomen, it is not easily visible under clothing. When not in use for feedings, it is secured to the abdomen with tape or an anchoring device and does not interfere with normal activity. The button replacement device is even less noticeable.

How Much Care Is Needed with a G-Tube?

For a few weeks after insertion, the g-tube requires special attention to prevent infection (as with any post-surgical wound). After the site is healed, daily cleansing with soap and water is all that is necessary. Feedings through the tube are generally pre-mixed liquid formulas. The actual liquid used and the amount needed is determined by the dietitian and physician. The decision involves the patient's need for calories and other nutrients. The feedings themselves are generally put into the tube through a large syringe (no needle involved) or

allowed to drip into the tube from a special plastic feeding bag. Following each feeding, the tube is flushed with water to clear it. Most often, several feedings are given through the course of the day, just as with regular meals. Some patients receive tube feedings overnight using a special pump and take only medications and additional fluids during the day. The dietitian, physician, patient, and caregivers determine the actual feeding schedule after discussion of needs and preference.

Medications are generally given through the tube before or after the feeding. Liquid forms of medications or crushed tablets are mixed with a small amount of water, put into the tube using the syringe, and water is then given to flush the tubing.

The button device requires a few additional steps involving disposable equipment, but is not necessarily any more time-consuming than with a standard g-tube syringe feeding method. While the cost may be slightly higher due to the equipment involved, some patients feel that it is worth the expense as it often helps to improve the body image.

After a G-Tube Is Inserted, Can You Eat and Drink by Mouth?

As long as fluids or foods can be swallowed safely, a patient with a g-tube can still drink or eat by mouth. A patient may be able to swallow small amounts but not enough to maintain hydration and nutrition. The feeding tube can be used for the main daily intake of fluid and foods and other items can be taken by mouth for taste and pleasure.

Some doctors and patients decide to have the g-tube placed even though the patient can still take food and fluids by mouth. They are concerned about decreasing lung function and the possible inability to tolerate the insertion procedure at a later date. In these cases, the g-tube is flushed with water to keep it open, but is not used for nutrition or medications until absolutely necessary.

What about Mouth Care When There Is a Feeding Tube?

When a person is fed by a g-tube, oral care still remains important. Plaque (a film coating the teeth) and calculus deposits (mineralized plaque) can still occur if the teeth are not cleaned. A patient whose chewing and swallowing muscles are weakened may develop plaque. This can lead to tooth decay, gum inflammation and tooth loss. Teeth should be cleaned at least twice a day, whether or not the patient is taking food and fluids by mouth. A baking soda

and/or peroxide based toothpaste is particularly helpful when a patient has a problem with plaque. The teeth, gums, and tongue should be brushed with a medium to soft bristle toothbrush. An electric toothbrush or plaque remover with a rotary brush (such as Braun Collate) can be used more easily by the patient or caregiver.

If a patient cannot spit out the toothpaste, a Vacuum-Brush can be used. This is a toothbrush attached to a suction device. This equipment can be ordered from most durable medical equipment supply houses, and we can assist you in obtaining such devices. If the patient is able to spit out the toothpaste but cannot brush their own teeth, a caregiver can assist. The easiest way to brush someone else's teeth is to stand behind them. For patients without teeth, plain or lemon glycerin swab sticks can be obtained to cleanse the gums.

Does a G-Tube Prolong Life?

The g-tube itself will not alter the course of ALS or its ultimate outcome. However, it provides a means of delivering fluids, nutrition, and medications that will help to keep the patient with ALS more comfortable. It provides the opportunity for a patient to still enjoy whatever foods she/he can eat by mouth, while assuring that the nutrients, fluids and medications that are necessary can be taken in with much less effort and distress. This will also help to prevent associated complications of the disease process, such as pneumonia from aspiration or skin breakdown caused by weight loss and inadequate nutrition. In some retrospective studies, patients with a g-tube have had a longer survival than those without. The decision to have a feeding tube is a personal one, and there is no right or wrong answer. The decision should be made after discussion with the ALS Center physician, the GI specialist, and the family.

What Is the Experience of Those with a G-Tube?

As with the disease process itself, the use of a g-tube is a very individual experience. While some patients and families are intimidated by the prospect of something "medical" in the home, some patients have reported that they are delighted with the decision to have a g-tube. In addition to avoiding weight loss and the risk of pneumonia, it eliminates the aggravation of interminable meal times. While feeding, the patient can watch television, sleep, or converse with family and friends if able. Feedings away from home are easy to accomplish. Under the right circumstances, the g-tube may add significantly to one's quality of life.