

Patient and Family Resource Guide to ALS

Section 6 Nutritional Support

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Nutritional Support

Many factors can affect the nutritional status of a person with ALS. The goal of nutrition therapy in ALS is to maintain weight and muscle mass. Depending on individual symptoms, maintaining adequate nutrition may involve high calories and high protein foods, thickened liquids or pureed foods, or giving formula through a feeding tube. Your doctor and dietitian will be able to help recommend the best way for you to meet your nutritional needs.

Maintaining Weight

Severe weight loss equals muscle loss. Therefore, it is important that a person with ALS not become underweight. There are many reasons why people with ALS lose weight. Difficulty chewing and swallowing causes choking. Arm/hand weakness limits self-feeding. Other factors include decreased appetite, constipation, shortness of breath, fatigue due to the long and tiring process of eating, and increased metabolism with ALS.

Studies suggest survival significantly improved with early, aggressive nutritional management. While consuming adequate protein, vitamins and minerals is important for people with ALS, the most important dietary factor is the consumption of adequate calories. This prevents deterioration due to poor nutrition. The goal for people with ALS is to maintain weight and preserve muscle strength, endurance, and function.

Maintaining Calories

Studies have shown that ALS patients are hypermetabolic, meaning that they are burning more calories at rest, when compared to a healthy population¹. Contributors may include increased energy used in breathing, increased effort to move around, and muscle twitching.

This makes maintaining weight more difficult so ALS patients need to increase their calories to maintain weight. The challenge is to increase the amount of calories without significantly increasing the amount of food.

A few ways to increase calories would be to eat small, frequent meals during the day to provide more opportunities for calories (recommend to eat every 2-3 hours). Include high calorie or nutrient dense foods at meals/snacks (ie peanut butter, granola, dried fruit, muffins, pudding, nuts, and avocado). Avoid diet foods and choose the full-fat version for more calories. Add butter, honey, gravy, cream sauces, and mayonnaise to foods. Drizzle olive oil over foods such as vegetables, meat, and soup (1 tablespoon = 120 calories). Also, add high protein foods such as cheese, eggs, powdered milk to casseroles and soups to increase calories and protein.

Nutritional supplements are another way to increase calories and add extra vitamins, minerals, and protein. Commercial products include Boost Plus, Ensure Plus, Carnation Instant Breakfast, and Boost Breeze. There are also generic supplements available at most large retailers (Ex: Walgreens, Costco, Sam's Club and Walmart). Note that oral supplements with the word "plus" are better than the "high-protein" varieties as they contain more calories and protein.

Eating

Chewing and swallowing difficulties (dysphagia) make mealtimes exhausting for the person with ALS due to the need to concentrate and go slowly to keep from choking. Sometimes a person with ALS eats so slowly during a meal that their meal turns cold and everyone else is finished eating and the dishes are cleared up before the person is done – adding to a sense of isolation from the family.

Signs of swallowing difficulty include choking or coughing while eating, increased saliva or excessive drooling, sensation of food getting stuck in the throat or chest, needing more time to finish a meal, frustration during meals, avoiding certain foods, and loss of appetite.

If you notice any of these signs, try to determine what types of foods and liquids are the easiest to tolerate. If necessary, change the consistency of the foods taken in during the course of the day. A few strategies to make meals easier include cutting up food into tiny bites before eating, avoiding dry and crumbly foods, and using sauces and gravies to moisten foods and ease swallowing.

Drinking

Adequate fluid intake is essential for keeping saliva and mucus thin and avoiding constipation. Because drinking thin liquids can be difficult, and because drinking leads to urination, which can be time-consuming and require help, people with ALS sometimes don't drink enough fluids.

Ensure proper fluid intake with a goal of at least eight to ten 8-ounce cups a day. This will help prevent dehydration, which can lead to physical deterioration, constipation, weakness, headache, and thickened mucus that can cause choking. Also, avoid alcohol and caffeinated beverages, which can be dehydrating (although can be consumed with adequate hydration). Consider the use of a sports drink with electrolytes or other flavored beverages to increase fluid intake. Certain foods such as soup, Jello, sherbet, and fruit will also help to increase fluid intake.

Monitor for signs of dehydration:

- Dark colored urine
- Dry itchy skin
- Headache
- Confusion
- Dizziness/Lightheadedness
- Flushing/Fever
- Increased fatigue
- Decreased urine output

If thin liquids like water cause choking, serve thicker liquids such as milkshakes, smoothies, nectars, tomato juice, and pureed soups. Powders like Thick-It and Resource ThickenUp Clear add thickness to fluids without changing the taste. Other thickening options, which also increases calorie intake, include baby rice cereal, mashed potato flakes, and pureed baby foods.

Choking

As throat muscles weaken, in addition to weakness of the tongue and lips, the risk of food or liquids “going down the wrong way” increases and poses a real danger.

“The wrong way” means breathing food or liquid into the lungs (aspiration) instead of swallowing down the esophagus into the stomach. Aspiration can cause respiratory infections or a frightening choking spell, and is a leading cause of pneumonia, a life-threatening event in ALS.

You can reduce choking episodes in several ways:

- Do not try to talk while eating, as this and other distractions make choking more likely.
- Serve smaller but more frequent meals, avoiding dry, crumbly or large chunky foods.
- Take smaller bites and sips of liquids and swallow several times with each bite.
- Keep mucus and saliva thin by ensuring adequate fluid intake. You may also try papaya, pineapple, or lemon juice in water.

Feeding Tubes

If the person with ALS can't maintain his or her weight by eating or swallowing becomes too exhausting, time-consuming, or dangerous, a feeding tube should be considered. It is a much easier route to maintaining nutrition and hydration than trying to eat or drink everything by mouth. Feeding tubes can lessen the stress a person feels when they are unable to eat enough to maintain their weight.

A feeding tube allows the person to eat what they are able, then supplement with adequate calories through the tube. Vitamins and medications can also be easily taken through the tube. It is important to emphasize that having a feeding tube does not prevent oral intake, but offers a convenient method of nutrition, hydration, and medications.

Early studies suggest a correlation between feeding tube use and longer survival and better quality of life. People who use feeding tubes can save time and energy, which can allow time for more interesting things. It also gives control back to the person with ALS in terms of when to eat and how much. The feeding tube will severely lessen the likelihood of inhaling food or liquids into the lungs, which will prevent chances of aspiration pneumonia.

When to Get a Feeding Tube

As breathing becomes weaker, having a tube placed is more difficult because the person with ALS is at greater risk for complications. Ideally the tube should be placed before the FVC (forced vital capacity, a respiratory measurement) falls below 50 percent of normal, as the procedure is safer and recovery is easier. And having the tube placed while the person can still eat by mouth allows for a gradual transition to tube feedings. Even if the tube is placed and isn't used right away, it will be in place for when it is needed.

If the FVC is adequate, the tube is inserted directly into the stomach via a PEG (Percutaneous Endoscopic Gastrostomy) procedure. This is done under light anesthesia and will require hospitalization.

If the FVC has advanced beyond the safe level for a PEG, doctors may choose to perform a RIG (Radiologically Inserted Gastrostomy). Air is pumped into the stomach and the tube is inserted with guidance of a fluoroscope (an x-ray that projects images onto a screen) rather than an endoscope (a camera attached to a tube). The procedure has been shown effective and safe for those with moderate or severe respiratory impairment, although recovery may be more uncomfortable than with a PEG – another reason to get the tube early!

Maintenance of the Feeding Tube

For a few weeks after the insertion, the feeding 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. Commercial formulas are often recommended over homemade formulas because they are nutritionally complete, sterile and much easier and less time-consuming for caregivers than homemade formulas.

The feedings themselves are generally put into a special feeding bag and allowed to drip into the tube by gravity. 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 liquids and medications during the day. The dietitian, physician, and patient will determine the proper feeding schedule after discussion of needs and preferences.

Tips:

- Flush with room temperature water before and after putting anything through the tube. Gently squeeze the tube as the water is running through to dislodge anything sticking to the inside.
- Flush the tube with water prior to giving medication and follow by flushing again.
- Tube feedings sometimes cause heartburn or nausea because the stomach is being filled too full, especially after weeks of under eating. Solutions include having the feeding material at room temperature, sitting upright for a period of time after the tube feeding, feeding more slowly, giving smaller more frequent feedings, and checking with the doctor about heartburn medications.

Disclaimer: All care has been taken in preparing this document. This information is of a general nature and should be used as a guide only. Always consult your physician before starting any treatments.

References:

1. Bouteloup C, Desport JC, Clavelou P, et al. Hypermetabolism in ALS patients: an early and persistent phenomenon. *J Neurol.* 2009;256(8):1236-1242.

Adapted from the MDA ALS Caregiver's Guide, Chapter 5, Nutrition Issues. Published on <http://mda.org/print/book/export/html/37397>