

*Maintaining
good nutrition
with ALS*

**A guide for people with ALS,
families and friends**



The ALS Association is leading the fight to treat and cure ALS through global research and nationwide advocacy while also empowering people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

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families and friends**

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INTRODUCTION

This booklet was written to help people with ALS overcome eating obstacles. It discusses the importance of nutrition and makes suggestions for dealing with various chewing and swallowing issues. The booklet should be used as a guide to supplement the advice of a physician, nurse or dietitian.

ALS, commonly known as Lou Gehrig's Disease, is an abbreviation for amyotrophic lateral sclerosis. "Amyotrophic" means lack of nourishment to the motor neurons, therefore making muscles wither and become weak. "Lateral" refers to the area of the spinal cord that signals nerve cells and controls muscle movement. "Sclerosis" means hardening. When these nerves lose their function, they leave a hardened scarred area in the lateral columns of the brain stem and spinal cord. As a result of the disease process, the voluntary muscles weaken.

These weak muscles may make it difficult for people with ALS to eat enough to meet their nutritional needs. Swallowing may become difficult. They may have trouble preparing meals, feeding themselves, and experience fatigue, constipation, or a decreased appetite. The difficulties associated with ALS are different for each person. One person may have difficulty swallowing and someone else may have a decreased appetite or early satiety. However, approximately 30% of people with ALS will never have chewing or swallowing problems.

A WELL-BALANCED DIET

Good nutrition will give you more energy and a better sense of well-being. It will strengthen the immune system and help fight infection. A well-balanced diet is essential for maintaining muscle and supporting the respiratory system. If you do not eat enough food, your body will break down muscle and fat, causing weight loss and weakness.

Everyone needs a well-balanced diet with enough calories, protein, fluid, vitamins and minerals to meet nutritional requirements. Below is a chart of food groups with recommended daily servings and food examples. You should eat a variety of foods from each of these food groups. The chart is based on a daily guide for most people.

Food Groups	Daily Servings	Examples of servings
Meats and Alternatives	Three or more servings	<ul style="list-style-type: none">• 2 oz. beef, poultry, fish• 2 eggs (scrambled, pre-made omelet)• 2 oz. cheese• 1 cup cooked beans• 2 oz. hamburger
Milk	Two or more servings	<ul style="list-style-type: none">• 8 oz. milk• 1 cup of yogurt, or Greek yogurt (contains double the protein)
Fruit and Vegetables	Four to six servings	<ul style="list-style-type: none">• ½ cup canned fruit• 1 piece fresh fruit• ½ cup cooked vegetables• 1 cup fresh vegetables
Grains and Starches	Six to eleven servings	<ul style="list-style-type: none">• 1 slice of bread• 1 cup ready-to-eat cereal• ½ cup cooked cereal• ½ cup pasta, rice• ½ cup mashed potato
Fats	Four to seven servings	<ul style="list-style-type: none">• 1 tsp. butter, olive oil or 1 tbsp. cream cheese• 1/8 avocado• 1 tsp mayo or salad dressing
Dessert Items	One to two servings daily to maintain weight	<ul style="list-style-type: none">• Rice/bread pudding• Choc/vanilla pudding• Ice cream• Frozen yogurt• Smoothie/shakes

Note: A person with swallowing difficulties may need to modify food consistencies with the guidance of a Speech/Language Pathologist (SLP).

Reminder about protein

Remember to eat the recommended daily servings of beef, fish, poultry, milk, cheese, and eggs. Experiment with high protein plant based foods such as legumes, beans, and tofu. These foods are high in protein, which provides the building blocks for muscle. Here are some ways to add protein to the diet:

- Drink high protein beverages such as milk, hot chocolate, milkshakes, and smoothies.
- Add an instant breakfast mix to any milk-based beverage or food such as cocoa, custard, milkshakes and pudding.
- Add meat, poultry, fish, eggs, cheese, or milk to the following: soups, casseroles, and noodle and potato dishes. (To aid in swallowing, you may place dishes in a blender.)
- Mix dry milk powder into milk, soup, casseroles, mashed potatoes, cereals, and dishes such as custard and pudding.
- Add cottage cheese or ricotta to fruit or vegetable salads, pancake/waffle batters, egg dishes (scrambled eggs, quiche or soufflés), and as filling for pasta shells.
- Have meat salad (chicken, egg, ham or tuna with extra mayo or olive oil) or hummus with crackers or toasted bread.
- Stock your kitchen with snacks such as deviled eggs, yogurt, or pudding.

High Calorie and Protein Supplements

Name	Serving Size	Calories (gms)	Protein (gms)	Carbs (gms)	Fat (gms)
Boost®	8 oz.	240	10	41	4
Boost Plus®	8 oz.	360	14	45	14
Designer Whey®	1 scoop	90	15	2	18
Ensure®	8 oz.	250	9	40	6
Ensure Plus®	8 oz.	355	13	50	11
Fast food shake	Small serving size	330-610	8-12	109	14
Prosource Bars®	1 bar	330	30	30	12
Prosource Powder®	1 packet	32	7.9	0	0
Carnation instant breakfast®	1 packet mixed with 8 oz. whole milk	280	13	27	8.5
Prosure®	8 oz.	300	17	44	7
Proteinex®	6 tbs./2 tbsp.	60	15	0	0
Scandishakes®	1 envelope	440	6	54	21
Mixed with whole milk		600	14	66	29
Trader Joe's Protein Powder®	1 scoop	110	23	0	1.5
TwoCal HN®	8 oz.	475	20	52	22
Unjury Powder®	1 scoop	90	20	3	0

RECOMMENDED BODY WEIGHT

You should aim to maintain your usual weight and should **not** diet, even if you feel you are overweight. Frequently people with ALS feel they have gained weight, especially around the waist. This occurs from loss of muscle tone in the stomach muscles. In order to track weight, you are advised to weigh yourself weekly and keep a record. If you notice weight loss, you will need to add extra calories to your diet. If you continue to see weight loss, you will need to consult with a dietitian. However, it is not unusual for people with ALS to lose a certain amount of weight due to loss of muscle from ALS.

Ways to boost calories

You will need to eat enough calories to maintain your weight. Foods high in fat and sugar are good sources of calories, although you may be trying to avoid fats to lower your cholesterol level. The ultimate goal is to eat enough calories to maintain weight, and that will mean increasing the fat in your diet. If it becomes difficult to eat usual portions of food, choosing foods that are higher in calories can help maintain body weight. Butter, sour cream, cream cheese, half & half, whipped cream, gravies, and sauces can add calories to your diet. Heart healthy fats such as avocados, olive oil, canola oil, and olives can be used when cholesterol is a concern. Supplements with high calories and protein are listed in the back of this booklet. Try some of the following suggestions:

- Add one tablespoon of olive or canola oil or butter to soups, casseroles, pastas, vegetables, rice, potatoes, and toasted bread.
- Adding gravies and sauces to meat, chicken, or fish dishes will help moisten foods and also add extra calories.
- Spread one tablespoon of mayonnaise on toasted bread. Add extra mayonnaise to tuna, chicken, and egg salad.
- Add one to two tablespoons of sour cream, salad dressing, vegetable oil, or heavy cream to your meals.
- Drink high caloric beverages such as fruit smoothies, whole milk, eggnog, or milkshakes.
- Make milkshakes by mixing one cup of ice cream with four ounces of milk in a blender. For extra calories and flavoring add the following: fruit (canned, fresh, or frozen), syrup, and/or peanut butter.
- Add cheese to eggs, vegetables, rice, potatoes or soups. (Use caution when melting mozzarella cheese as it can stick together and pose a choking hazard).

Eating smaller more frequent meals is another good way you can get the calories you need. Consuming 5 to 6 smaller meals a day is sometimes easier than eating 2 to 3 larger meals a day. To prepare for smaller meals, you can stock your kitchen with healthy pre-made or easy to make snacks. You should limit your meal time to about 30 minutes. If eating a meal takes longer than 30 minutes, the meal may need to be prepared in a different way so the food consistency is easier to consume.

SUGGESTIONS FOR DEALING WITH:

Preparing meals and feeding yourself

Preparation and mealtime may become troublesome over time as simple tasks such as walking to the refrigerator, lifting cookware, and opening containers may become more difficult. Here are some suggestions:

- Ask a physical or occupational therapist to recommend special devices to make preparing meals easier.
- Purchase frozen and take-out foods.
- Ask friends to bring meals and freeze any extra portions.
- Have family members leave meals, snacks, and drinks within easy reach throughout the day. Put refrigerated liquids in a thermos.
- Arrange for meals-on-wheels or homemaker services through a social worker.

Mealtimes can be made easier by:

- Using specially designed silverware, plates, and mugs. A physical or occupational therapist will be able to provide more information. Disposable silverware is lighter and may make feeding easier.
- Substituting a nutritional supplement for part of a meal.

Swallowing difficulties

People with ALS may have swallowing difficulties. People with swallowing difficulties may grow tired when chewing, have trouble moving food with their tongue, cough or choke when eating or swallowing, or get food stuck in their throat. If you are suffering from these symptoms, you should request a swallowing evaluation promptly. A physician will refer you to a speech-language pathologist (SLP), a person trained in evaluating and diagnosing speech, language, cognitive-communication and swallowing disorders. To evaluate a person with ALS, the SLP will likely perform a video-fluoroscopy, a moving x-ray that assesses your ability to swallow. After this swallow study is performed, the SLP can work with you, to teach swallowing techniques, feeding strategies, and recommend the safest liquids and food consistencies to consume.

Eating and preparing meals will require more time, thought, and effort if you develop swallowing difficulties. By working closely with a dietitian, you can learn about preparation techniques, meal planning, and recipes to meet your specific diet needs.

The following sections provide suggestions for dealing with swallowing problems.

Tips for safer swallowing:

- A person with ALS should never eat alone. If there is any change in chewing or swallowing skills there may be a risk of food or drink going down the airway (aspiration) and having someone around to help if needed is important.
- For most people, if food or liquid has entered a person's airway they will start to cough and indicate that something is wrong. Some people do not cough so watch for other signs: increased chest congestion, temperatures or changes in breathing.
- If there is coughing when eating immediately swallow again before breathing in.
- If there is difficulty eating or swallowing, then it is recommended a speech-language pathologist evaluate swallowing function to provide feeding guidelines for the safest way to eat.
- Eat in a pleasant, relaxing environment with minimal distractions.
- Sit straight and upright, so gravity can assist food to go down. If there are eating or swallowing concerns, position the head slightly forward with the chin down to help prevent food from entering the throat before the person is ready to swallow.
- Eat slowly. Cut foods, take small bites (the size of a thumbnail) and chew food thoroughly. If chewing is taking a long time, cut food smaller or blend foods to puree.
- Concentrate on swallowing. Avoid distractions such as radio and television.
- Swallow all the food in the mouth before talking.
- Clean the mouth after eating as oral care is especially important. Brush teeth 2 times a day.
- Sit in an upright position for about 20-30 minutes after eating.
- If any choking has occurred, your family member(s) should be trained in the Heimlich maneuver.

Diet changes for easier and safer swallowing:

A speech-language pathologist may recommend changes in the diet to make eating and swallowing easier and safer. A recommendation for thickened liquids after a swallowing evaluation may occur if thin liquids are entering the airway (aspiration). Thickened liquids, a liquid consistency of nectar, honey, or pudding, can be easier to swallow than thin liquids such as water, coffee, tea, and soda. Thick liquids spread out less and travel slower through the throat than thin liquids, and therefore, have less of a tendency to go down the airway.

Here are some ways to prepare thickened liquids:

- Add a commercial thickening powder or gel to all liquids as recommended by the speech-language pathologist.
- Prepare milkshakes in a blender with four ounces of milk, one cup of ice cream, and about six tablespoons of an instant breakfast mix and a thickening powder to thicken to the recommended consistency.

- Mix soups in a blender with potatoes and vegetables. Blend into a smoothie consistency.
- Thicken soups with mashed potato flakes, flaked baby cereal, cornstarch, or arrowroot.
- Combine pureed fruit and fruit juice to the consistency of fruit nectar.
- Blend a banana into a milkshake, nutritional supplement, or juice.
- Add pudding, custard, or yogurt to milk and blend to proper thickness.

Choose soft, moist foods that are easier to chew and swallow. Add gravy and sauces to help moisten food. For example:

- Meat loaf with gravy
- Poached fish fillet (boneless)
- Omelet's, scrambled eggs and soufflés
- Chicken, tuna, and egg salad with extra mayonnaise
- Canned fruits, drained
- Ripe banana
- Baked apple without the skin
- Well cooked vegetables without the skin
- Mashed potatoes with butter, sour cream, or gravy
- Bread stuffing with gravy
- Macaroni and cheese, tuna noodle casserole, and baked pasta with extra sauce
- Pudding and custards

Foods to avoid with increased swallowing problems:

Avoid dry, hard, sticky, limp, fibrous foods, and those with skins and seeds. These foods are prone to getting stuck in the throat. The following are examples of foods to avoid:

- Raw fruits and vegetables
- Nuts
- Peanut butter
- Corn
- Strawberries, blueberries
- Crackers
- Soft Bread
- Lettuce
- Tough, stringy meat and poultry
- Popcorn
- Rice
- Coconut

Preparing food in a blender

A person may need to use a small blender or food processor to prepare meals if solid foods become too difficult to swallow. Foods prepared this way should be moist and form a smooth mass that will not separate in a person's mouth. A person should always try the first few bites cautiously. The following are some hints for preparing appetizing, nutritious meals:

- To blend foods, use liquids with flavor such as soup, broth, and milk. Also, try cream sauce, gravy, and salad dressing,
- If a blended preparation is too thin, add thickening agents such as a commercial thickening powder or gel, flaked baby cereal, or mashed potato flakes.
- Be sure to include foods high in protein such as pureed meats, ricotta, cottage cheese and soufflés.
- Add one or two tablespoons of fat such as mayonnaise, butter, olive oil, and sour cream to foods for calories.
- For fiber, eat fruit such as applesauce, banana, pears and peaches adjusted to the safest recommended consistency. Prepare cooked vegetables such as carrots, beet, peas, spinach and sweet potato.
- Add seasoning to flavor your food.

Managing saliva secretions

There are two problems with saliva secretions that may affect people with swallowing difficulties: accumulation and thickening. Normally, a person will swallow saliva unconsciously and automatically. With ALS, you must remember to swallow, or saliva will build up. You also may notice that your saliva is thicker and harder to swallow. Here are a few ways to handle these problems:

- Remember to swallow frequently, but slowly and carefully.
- Avoid very sweet and very sour foods that may stimulate salivary glands.
- Ask a physician if medication is needed to reduce saliva.
- You can increase your fluid intake to thin out the mouth saliva. The section on “Dehydration” suggests ways to do this.
- Avoid chocolate if it thickens the mouth saliva.
- Avoid lollipops and candies that will increase saliva production.
- Make sure to provide oral care several times per day to clear saliva and avoid increased bacteria build-up.

DEHYDRATION

Dehydration occurs gradually. Most people need about eight 8-ounce cups of liquid every day. If a person with ALS is experiencing difficulty swallowing thin liquids then he or she should try the following:

- Try to drink as many thick liquids as possible.
- Choose thicker liquids such as V8 and fruit nectars or add thickener to liquids.
- Try thickening fruit juice with commercial thickener.
- Eat foods with higher water content such as canned fruits, well-cooked vegetables, yogurt, custard, and pudding.
- You should avoid ice and sweetened gelatin desserts because they will melt in your mouth.

FATIGUE

Fatigue may happen, especially on busy days. Here are some ways to conserve energy:

- Take a nap before meals.
- Eat soft foods. Cut foods into small pieces.
- Substitute a nutritional supplement for part of a meal.
- Plan to eat six times a day. Try smaller portions at mealtimes and nutritious snacks between meals and in the evening.
- Have a main meal earlier in the day when energy levels are better.

CONSTIPATION

Due to the weakening of abdominal muscles, constipation is common. Inactivity, dehydration and a low fiber diet can make this worse. Constipation can cause fatigue and decreased appetite. Below are suggestions for controlling constipation:

- Walk as much as possible.
- Ask a physical therapist to teach you exercises that strengthen your abdominal muscles.
- Consume prune juice. Add a commercial thickening powder if too difficult to swallow.
- Drink eight to ten 8-ounce cups of fluid every day. Fluids include water, juice, and decaffeinated beverages. If drinking liquids is difficult, follow the recommendations in the section “Suggestions for Dealing with Swallowing Difficulties.”
- If swallowing is not difficult, eat eight servings of high fiber foods each day such as fruits, cooked vegetables, and toasted whole grain breads and cereals. If swallowing is difficult, eat mainly canned fruits, cooked cereals and vegetables to increase your fiber. Drink enough fluids as well.
- If drinking a nutritional supplement is recommended by a dietitian, drink one with fiber added.
- You should ask your physician about taking a bulk laxative or a stool softener.
- Your physician should be called if you are still experiencing constipation after three days.

DECREASED APPETITE

You may notice you have less of a desire to eat. To increase your appetite, try the following:

- Eat in a pleasant, relaxing environment.
- Make your food look attractive.
- Invite a friend to eat with you.
- Eat a variety of foods. Be sure to include your favorite ones.
- Season your food to your taste.
- Drink liquids between meals so you do not fill up on them at mealtimes.
- Avoid low calorie foods that may fill you up.
- Plan to eat smaller portions at mealtimes plus nutritious snacks between meals.
- Look for ways to relieve your stress.
- Remain involved in the activities of your family, friends, and community.

In review, swallowing problems usually follow a predictable pattern. First there is some pooling of saliva in the mouth and you are more aware of consciously swallowing. Thin liquids become harder to swallow than thicker liquids. Once you notice these swallowing problems, the following steps will be necessary: add thickener to thin liquids, avoid dry meats, crackers, or nuts, and supplement meals with nutritious (and thick) liquids.

When will a feeding tube be helpful?

Any combinations of the following are signals to discuss the need for a feeding tube:

- Loss of appetite
- Excessive weight loss
- Food going down the airway on a regular basis; choking and coughing with meals
- Dread of eating
- Fatigue with meals
- Meals taking a long time to eat (longer than 30 minutes)
- FVC-Breathing test less than 50%
- Treatment for respiratory infections

CHOOSING TO HAVE A FEEDING TUBE

Although you try your best, you may not be able to eat enough to maintain good nutrition. Receiving your nutrition through a feeding tube can stop weight loss and dehydration, and help you feel better. In addition, you may decrease the risk of choking on food and liquids. Placing the tube into your stomach is a minor outpatient procedure. An overnight stay may be needed if you are dehydrated and/or have lost a significant amount of weight. However, you and your physician must plan ahead so that you have the tube placed before you develop respiratory problems. If tube placement is delayed, it may become a major procedure.

Even with a feeding tube you will still be able to eat and you will not have to limit your daily activities such as bathing or leaving the house. The tube is soft and flexible, it tucks neatly under your clothes, out of sight, except during feeding times. Many families have found tube feeding easy to learn how to use. The liquid placed in the tube contains all the essential calories and nutrients you need. The excessive time and energy that may have been involved in chewing and swallowing can now be spent on more pleasurable activities.

VITAMINS

Many people ask questions about vitamins and nutritional supplements. At this time, there is no clear medical evidence that vitamins or supplements can help ALS. However, there is a growing school of thought that taking one or two vitamin E capsules daily may be beneficial. It is prudent for all people to take a generic (store brand) multivitamin daily. Some vitamins are available in chewable or liquid form for increased absorption. Most supplements can be taken safely for the purpose of enhancing general good health, if taken in the recommended amounts. There is active clinical interest in this issue but no clear recommendation yet. Refer to your physician, dietitian, or nurse for specific recommendations for your individual needs.

ACKNOWLEDGEMENTS

We gratefully acknowledge the important contributions made by Carol Asbeck, M.S., R.D., L.D.; Berri L. Burns, R.D., L.D., of the Cleveland Clinic Foundation; Hiroshi Mitsumoto, M.D., Eleanor and Lou Gehrig MDA/ALS Center; Martha-Sue Hoffman, M.S., CCC, the New England Medical Center and Fran Grabowsky, M.S., R.D., Hahnemann University.

The first printing was made possible through the generosity of the following companies: Sandoz Nutrition Corporation, Sandoz Pharmaceuticals Corporation, Warner-Lambert Pharmaceutical Research Division, and Arthur D. Little, Inc. We appreciate the generous support for the second printing from Sandoz Pharmaceuticals Corporation and Warner-Lambert Pharmaceutical Research Division, American Institutional Products (Lancaster, Pennsylvania 17606) and Milani Foods. The third printing was made possible through the generosity of the Goldberg and Solovy Foods—Martin Pine Memorial Nutrition Education Fund.

The Clinical Study Unit of the New England Medical Center is supported by the National Institutes of Health, General Clinical Research Center Grant MOI RR0054.

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Note: This booklet is intended for use under the supervision of a physician and dietitian.

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Revisions 1996, 1999, 2006, 2007



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