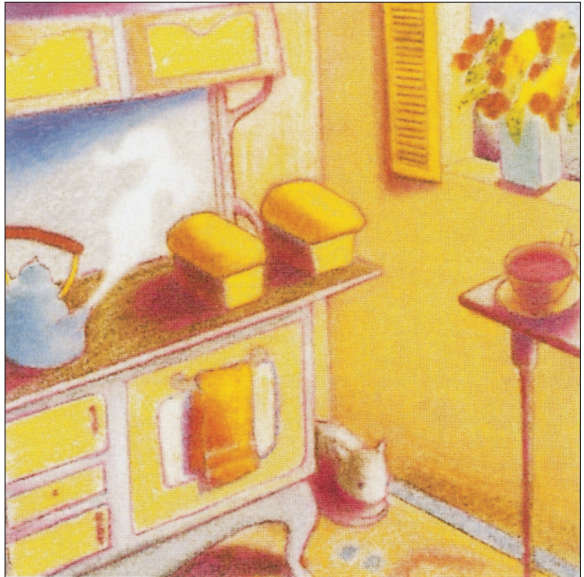


Maintaining good nutrition with ALS

**A guide for patients,
families and friends**





The ALS Association is the only national not-for-profit voluntary health organization whose sole mission is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower 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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good nutrition
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**A guide for patients,
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by

Barbara Tanenbaum, MA, RD
*Clinical Study Unit
New England Medical Center
Boston, Massachusetts*

James Taft, PAC
*Department of Neurology
New England Medical Center
Boston, Massachusetts*

Revised by

Dallas Forshew, R.N., B.S.N.
*Department of Neurology
University of Utah
Salt Lake City, Utah
1999*

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INTRODUCTION

This booklet was written to help people with ALS overcome the obstacles to eating well. It discusses the importance of nutrition to people with ALS and makes suggestions for dealing with various eating problems. Use it as a guide to supplement the personal care of your physician, nurse and dietician.

ALS, commonly known as Lou Gehrig's Disease, is an abbreviation for amyotrophic lateral sclerosis. "Amyotrophic" refers to the motor nerves that start the brain stem and spinal cord. These nerves control the strength of voluntary muscles. Amyotrophic means lack of muscle growth (the muscle withers and becomes weak when these nerves lose their function).

"Lateral" means side, and sclerosis means hardening. In ALS, the motor nerves that start in the brain will travel down the sides of the brain stem and spinal cord. 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. ALS patients may have trouble preparing meals or feeding themselves. They may experience fatigue, constipation, or a decreased appetite. ALS problems are different for each person. One person may have difficulty swallowing, another a decreased appetite. However, approximately 30% of ALS patients 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 your immune system, helping to prevent infection. A well-baanced diet is essential for maintaining body muscle and fat. If you do not eat enough food, our body will break down its own muscle and fat, causing you to lose weight and strength.

Everyone needs a well-balanced diet with enough calories, protein, vitamins and minerals to meet nutritional requirements. Below is a chart of the four basic food groups with recommended daily servings and examples of servings. Eat a variety of foods from each of these food groups. This is a daily guide for most people.*

<i>Food group</i>	<i>Daily servings</i>	<i>Examples of servings</i>
Meats and Alternatives	three or more	2 oz. beef, poultry, fish 2 eggs 2 oz. cheese 1/2 cup cottage cheese 1/2 cup soy bean curd 1 cup cooked beans
Milk	two or more	8 oz. milk 1 cup yogurt
Fruits and Vegetables	four or more	1/2 cup canned fruit 1 piece fresh fruit 1/2 cup cooked vegetables 1 cup fresh vegetables
Grains	four or more	1 slice bread 1 cup read-to-eat cereal 1/2 cup cooked cereal 1/2 cup rice, pasta

** People with swallowing difficulties will need special instruction in preparing their food.*

A reminder about protein

Remember to eat the recommended daily servings of beef, fish, poultry, milk, cheese, and eggs. They are high in protein, which provides the building blocks for muscle. Here are some ways to add protein to your diet:

- Add meat, poultry, fish, eggs, cheese, or milk to soups, noodles casseroles, and potato dishes.
- Mix dry milk powder into milk, soup, casseroles, cereal, and milk dishes such as custard and pudding.
- Add an instant breakfast mix to milk and milkshakes.

Ways to boost calories

You need to eat enough calories to maintain your weight and to prevent your body from breaking down its own muscle. Foods high in fat and sugar are good sources of calories. You may be trying to avoid fats to lower your cholesterol level. However, your goal is to eat enough calories, and that will mean increasing the fat in your diet. To boost calories:

- Add one tablespoon of margarine or butter to soups, casseroles, pasta, vegetables, rice, potatoes, and bread.
- Spread one tablespoon of mayonnaise on sandwich 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.
- Spread one tablespoon of jelly or honey on bread.
- Drinking eggnog.
- Make milkshakes by mixing one cup of ice cream with four ounces of milk in a blender. Add a banana, canned or fresh or frozen fruit, or syrup for calories and flavoring. Add an instant breakfast mix.
- Ask your dietician to give you brand names of nutritional supplements and to recommend an amount to drink. These supplements provide well-balanced nutrition. They come as a liquid in a can or as a powder. They are sold in drug stores and grocery stores. For variety, use a citrus-based supplement occasionally.

RECOMMENDED BODY WEIGHT

Aim to maintain your usual weight. Do not try to lose weight by dieting even if you feel you are currently overweight; eating may become more difficult later on.

Frequently ALS patients feel like they have gained weight, especially around the waist. This occurs from loss of muscle tone in the stomach muscles. Do not try to lose weight by dieting, even if your clothes are tight or you need a larger waist size.

Weigh yourself weekly and keep a record of your weight. If you are losing weight, try adding calories to your diet by following the suggestions in the previous section. If you still lose weight, work out a meal plan with your dietician. However, it is not unusual to lose a certain amount of weight due to loss of muscle from ALS.

SUGGESTIONS FOR DEALING WITH...

Swallowing difficulties

People with ALS may have swallowing difficulties. The first symptom is often choking on water. People with swallowing difficulties may grow tired when chewing, have trouble moving food with their tongue, or get food stuck in their throat. If you have any of these symptoms, request a swallowing evaluation promptly.

If you develop swallowing difficulties, eating and preparing meals will require some time, thought, and effort. Work closely with a dietitian, who can help you plan your meals, teach you food preparation techniques, and give you recipes specifically for your needs. A swallowing therapist, who is a specially trained speech pathologist or occupational therapist, will be able to teach you swallowing techniques and recommend the safest food consistency for you.

The following sections will show you typical ways of dealing with swallowing problems.

Tips for safer swallowing

- Eat in a pleasant, relaxing environment.
- Sit up straight, so food goes down by gravity. Position your head slightly forward with chin down to help prevent food from going down the airway.
- Do not breathe until you have completely swallowed.
- Eat slowly. Take small bites and chew your food thoroughly.
- Concentrate on swallowing. Avoid distractions such as radio and television.
- Swallow all the food in your mouth before talking.
- Cough when you need to in order to prevent food from going down the airway.
- Whenever you cough, swallow immediately before breathing again.
- Do not eat alone. Try to eat with a family member or friend who has learned the Heimlich maneuver.
- Clean your mouth after eating.
- Sit in an upright position for about 20 minutes after eating.

Diet changes for easier swallowing

Thick liquids, those about the consistency of fruit nectar, may be easier to swallow than thin liquids such as water, coffee, tea, and soda. Thick liquids spread out less in the throat than thin liquids, and therefore, have less of a tendency to go down the airway.

Here are some ways to prepare thick liquids:

- Add a commercial thickening powder to juices, soups, coffee, hot chocolate, milkshakes, and nutritional supplements to bring them to the consistency of fruit nectar. Your dietitian will be able to recommend one.
- Prepare milkshakes in a blender with four ounces of milk, one cup of ice cream, and about six tablespoons of an instant breakfast mix.
- Mix soups in a blender with potatoes and vegetables. Blend until smooth.
- Thicken soups with mashed potato flakes or flaked baby cereal.
- Combine pureed fruit and fruit juice to the consistency of fruit nectar.
- Mix fruit juice with sherbet.
- Blenderize a banana into a milkshake, nutritional supplement, or juice.
- Add pudding or custard to milk or yogurt and blenderize.

Soft, moist food is less tiring to chew and will slide down your throat.
For example:

- Meat loaf, very moist
- Poached fish fillet (boneless)
- Omelettes and soufflés
- Chicken, tuna, and egg salad with extra mayonnaise
- Canned fruit, drained
- Ripe banana
- Baked apple without the skin
- Well cooked vegetable without the skin
- Mashed potatoes with butter, margarine or gravy
- Bread stuffing with gravy
- Macaroni and cheese, tuna noodle casserole, and baked pasta with extra sauce
- Pudding and custards

Foods to Avoid

Avoid dry, hard, sticky, limp and fibrous foods, and those with skins and seeds. They may get stuck in your throat. Examples are:

- Raw fruits and vegetables
- Nuts
- Peanut butter
- Corn
- Strawberries, blueberries
- Crackers
- Bread
- Lettuce

Preparing food in a blender

If soft, solid food becomes too difficult to swallow, you may need to use a small blender or food processor to prepare your meals. The food you prepare should form a smooth mass that will not separate in your mouth and should be moist enough so that it slides down your throat. If necessary, strain the food before you eat it. Always try to the first few bites cautiously. Here are some hints for preparing appetizing, nutritious meals.

- To blenderize foods, use liquids with flavor such as soup, fruit juice and milk. Also, try cream sauce, gravy and salad dressing.
- If a blenderized preparation is too thin, add a thickening agent such as a commercial thickening powder, flaked baby cereal or mashed potato flakes.
- For tasty recipes, refer to the cookbooks listed at the end of this booklet.
- Learn to work with unflavored gelatin as another type of thickening agent.
- Choose to eat foods high in protein.
- Add one or two tablespoons of fat such as mayonnaise, margarine, butter, vegetable oil, and sour cream to foods for calories.
- For fiber, eat fruit such as applesauce, banana, pears and peaches adjusted to the safest consistency.
- For more fiber and to add color to a plate, prepare vegetables such as carrots, green beans, beet, peas and sweet potato.
- Add a protein, carbohydrate, or liquid vitamin supplement on the recommendation of your dietitian.
- Season your food with herbs and spices.
- For convenience, purchase pureed baby foods, which you may need to thicken with a thickening agent and season to taste.
- To make a plate look attractive, use garnishes. Prepare food made with gelatin in molds. Use a scoop to place food on the plate. Top entrees with a contrasting color sauce of the appropriate consistency.

Managing Saliva Secretions

There are two problems with saliva secretions that may affect people with swallowing difficulties: accumulation and thickening. Normally you swallow saliva unconsciously. With ALS you must remember to swallow, or saliva will build up. You may also 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. You can choke on saliva.
- Avoid very sweet and very sour foods that may stimulate salivary glands.
- Use a suction machine if medications aren't helpful.
- Increase the fluid in your diet to thin your saliva. The section on "Dehydration" suggests ways to do this.
- If you feel that milk thickens your saliva, try soy substitutes for milk, ice cream, and yogurt in drinks and cereal. You may be able to tolerate foods with "cooked" milk such as pudding, custard and yogurt.
- Avoid chocolate if it thickens your saliva

Dehydration

Dehydration occurs gradually. Most people need about eight 8-ounce cups of liquid every day.

- Try to drink as many thick liquids as possible.
- Eat foods with a higher water content such as canned fruits, well cooked vegetables, yogurt, custard and pudding.
- Avoid ices and sweetened gelatin desserts because they will melt in your mouth. Instead, prepare a gel of fruit juice with unflavored gelatin, using a quantity that will thicken the fruit juice to an appropriate consistency.

Preparing meals and feeding yourself

You may have some trouble preparing meals. Everyday 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 your meals easier.
- Purchase frozen and take-out foods.
- Ask friends to bring meals to you. 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.

Feeding yourself will be easier if you:

- Use specially designed silverware, plates, and mugs. A physical or occupational therapist will be able to advise you.
- Substitute a nutritional supplement for all or part of a meal. Ask your dietitian for brand names and how much to drink. If you are unable to purchase these products in a drug store, home care agencies may deliver them to you.

Fatigue

Fatigue is a common effect of ALS. Sometimes you may feel too tired to eat. Here are some ways to conserve your energy:

- Take a nap before meals.
- Eat soft foods. Cut your food into small pieces.
- Substitute a nutritional supplement for all or part of a meal. Your dietitian will be able to give you brand names and tell you how much to drink.
- See the section “A Well-Balanced Diet” for ways to add protein and calories to your food.
- Plan to eat six times a day. Try smaller portions at mealtimes and nutritious snacks between meals and in the evening.

Constipation

People with ALS are prone to constipation because of weak abdominal muscles. Inactivity, not drinking enough fluid, and not eating enough fiber 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.
- Drink prune juice. If you have swallowing difficulties, add a commercial thickening powder.
- Every day drink eight 8-ounce cups of fluid such as water, juice, and decaf feinated beverages. If you have trouble drinking liquids, follow the recommendations in the section “Suggestions for Dealing with Swallowing Difficulties.”
- If you do not have problems with swallowing, eat eight servings of high fiber foods each day such as fruits, vegetables, and whole grain breads and cereals. If you have swallowing difficulties, you will need to eat mainly fruits and vegetables to increase your fiber. Drink enough fluids as well.
- If you are drinking a nutritional supplement recommended by your dietitian, drink one with fiber added.
- Ask your physician about taking a bulk laxative or a stool softener.
- If you are still constipated after three days, call your physician.

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.
- Be involved however possible 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 must be more aware to swallow. Thin liquids may then become a problem so you would want to add a thickener. Next, you start to avoid some foods such as dry meats, crackers or nuts. Finally supplementing meals with nutritious liquids is helpful. 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

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 liquid. Placing the tube into the stomach is a minor outpatient surgical procedure. 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 whatever you can. 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 it easy to learn

how to use a feeding tube. Tube feedings are liquids that contain all the

essential calories and nutrients. 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 not clear medical evidence that vitamins or supplements can help ALS. However, it is prudent for all people to take a generic (store brand) multivitamin daily. There is growing thought that one or two vitamin E capsules daily may be beneficial. Some vitamins are available in liquid form. 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.

Suggested Reading

From the ALS Association, *Adjusting to Swallowing and Speaking Difficulties*, 1997; Revised 2007

This manual (number 5 in the six-manual series Living with ALS) discusses how your speech and swallowing can be affected by ALS. It covers specific techniques and devices available for improving communication. In addition, swallowing difficulties and how to maintain a balanced diet are covered.

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Telephone: ()

ALS Association Information and Referral: 800-782-4747

Note:

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

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The ALS Association

National Office

27001 Agoura road, Suite 150
Calabasas Hills, CA 91301-5104

Telephone: 818/880-9007

Patient Information and Referral: 800/782-4747

<http://www.alsa.org>

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