NUTRITION FOR PEOPLE LIVING WITH

AMYOTROPHIC LATERAL SCLEROSIS

openarms

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WHAT IS ALS?

Amyotrophic Lateral Sclerosis (ALS), also known as Lou Gehrig's Disease, is a nervous system disease that affects nerve cells in the brain and spinal cord. These nerves control the use of your muscles for chewing, walking, talking, and more. ALS is a progressive disease, meaning nerve damage and symptoms worsen over time. The symptoms of ALS may be limited to a single region of the body or spread more generally throughout the body. Symptoms include muscle twitches, cramps, weakness, slurred speech, difficulty chewing or swallowing, and loss of ability to use arms and legs.

There is no one food or diet that has been shown to help prevent, treat, or cure ALS. However, the food and drink choices you make can help you manage symptoms, promote swallowing safety, and prevent malnutrition. This guide will explain the general nutrition recommendations for those with ALS.

Please note that nutrition needs for ALS vary from person to person. Talk to your Registered Dietitian or other healthcare provider to learn what foods are best for you and your symptoms.

WHAT DO THESE TERMS MEAN?

A

AMYOTROPHIC

is a Greek word that tells us there is a loss of nerve signals to muscle cells

L

LATERAL

explains that the spinal cord is damaged on its sides where nerves from the brain pass through

S

SCLEROSIS

means scarring or hardening, which happens to the spinal cord as the disease progresses

NUTRITION FOR ALS

MALNUTRITION

Malnutrition occurs when the body does not get enough calories or nutrients to keep your body working and often comes with weight loss. When you do not eat enough calories to fuel your body, it starts to break down fat and muscle. Malnutrition and unwanted weight loss are very common in those with ALS. It is often caused by either difficulty eating or increased energy used to breathe and control movements. To slow down ALS symptoms and stay independent longer, it is important to eat a diet high in calories.

PROTEIN

People living with ALS need more protein than usual to maintain muscle. If you do not eat enough protein, your body may break down parts of your muscles and organs for energy. Aim to eat high-quality proteins like whole cuts of meat, poultry, fish, and eggs. Plant-based protein such as beans, lentils, and soy can also be great options and are sometimes easier to chew.

HYDRATION

Hydration is essential for good mental and physical function. Staying hydrated also helps you concentrate better when eating and makes swallowing easier. A healthcare provider or Registered Dietitian can help you figure out how much water you need. If drinking enough water is a challenge for you, there are foods that are rich in water that count toward your total fluid goals. Foods like canned or fresh fruit and vegetables, nectars, smoothies, cream soups, and drinkable yogurt are all great choices to increase your fluid intake.

TIP:
Pair fluid intake with fiber to help keep bowel movements regular!

CALORIES

It can be challenging for people with ALS to eat enough calories. Symptoms such as difficulty chewing and swallowing, decreased appetite, fatigue, constipation, depression, shaking, or weak grip can all make it hard to eat or eat enough.

The following tips may help increase your calorie intake and make mealtimes easier:

- Eat smaller but more frequent meals
- Eat soft foods to help mealtimes be less tiring
- Choose foods you are confident in eating
- Add fat with foods like avocado, guacamole, nut butters, oils, cream sauces, cheese, cream cheese, mayonnaise, and sour cream
- Avoid foods that are “diet” or “light”
- Add protein with foods like milk, cheese, eggs, beans, yogurt, quinoa, and moist meats
- Keep a variety of high calorie ready-to-eat snacks available
- Take medications with pudding or yogurt to aid swallowing and add calories
- Make sure mealtimes are comfortable and eat with other people

NUTRITION SUPPLEMENTS

Drinks like Boost, Ensure, or Thrive may help you increase your protein and calorie intake. These are a great option if you cannot eat full meals. You may also create your own shake or smoothie using your favorite fruits, vegetables, nut butter, protein powder, and more. If you need recipe ideas, talk to an Open Arms Registered Dietitian.

SWALLOWING SAFELY

One of the symptoms of ALS is weakness and loss of control of muscles in the mouth and throat. This causes difficulty speaking, chewing, and swallowing. Swallowing challenges are a safety concern as they can lead to choking, difficulty breathing, or pneumonia. If symptoms worsen, talk to your doctor about visiting with a Speech Language Pathologist (SLP) who can give you swallowing exercises and recommend safe foods for you.

Use the following tips to help make mealtimes safer:

- **Eat slowly** and **focus** your attention on the meal
- Take **small bites** of food and **small sips** of liquids
- **Swallow 2-3 times** to ensure all food is out of your throat
- Be careful with foods that are a mix of solids and liquids; **choose single-consistency foods** like oatmeal or thick cream soups instead of chunky soups or cereal with milk
- **Mash or blend** foods into softer textures
- **Choose thicker liquids** such as well-blended milkshakes and smoothies, as these may be easier to swallow
- **Avoid crumbly and sticky foods** that are harder to chew and swallow

OPEN ARMS IS HERE TO HELP

YOUR OPEN ARMS MENU

Clients with ALS may choose any Open Arms menu according to their health needs. While we do not have a menu planned specifically for ALS, each of our menus features important nutrients that you need to manage your health. If you have other health conditions or side effects, our nutrition team members can help you choose a menu that best fits your needs.

GET IN TOUCH WITH OPEN ARMS

Open Arms has a team of Registered Dietitians that provide free-of-cost nutrition education and counseling to Open Arms clients over the phone. If you have a question about your meals or want to schedule a one-on-one call, contact the Open Arms nutrition team!

Our Registered Dietitians can help:

- Recommend a menu based on your needs and preferences
- Answer your questions about food, nutrition, and health
- Provide nutrition coaching to support you in reaching your health goals
- Suggest additional food resources if you need them
- Give you meal and snack ideas according to your likes, dislikes, and medical needs
- Provide nutrition information about Open Arms meals, such as calorie, nutrient, and allergen information

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☎ **612-540-7760** Ask to speak with a registered dietitian

✉ **nutrition@openarmsmn.org**

ALS

Mental Health Support

- **ALS Association**
  - Phone Number: 612-672-0484
  - Email: InfoMN@als.org
  - Website: https://www.als.org/

- **I am ALS**
  - Phone Number: 866-942-6257
  - Email: gethelp@iamals.org
  - Website: https://www.iamals.org/

- **Everything ALS**
  - Email: info@everythingals.org
  - Website: https://www.everythingals.org/

- **Your ALS Guide**
  - Email: info@yourALSguide.com
  - Website: https://www.youralsguide.com/

- **Synapticure**
  - Phone Number: 855-255-5917
  - Website: https://www.synapticure.com/

Equipment Assistance

- **ALS Network**
  - Website: https://alsnetwork.org/

- **Team Gleason**
  - Website: https://teamgleason.org/

- **Compassionate Care ALS (CCALS)**
  - Phone Number: 508-444-6775
  - Email: info@ccals.org
  - Website: https://ccals.org/

Support Groups

- **Minneapolis/St. Paul Metro Area Caregivers, Families, Military Veterans, Patients**
  - Contact: anne.supplee@als.org or 612-672-0484

- **Adult Children Resource/Support Group**
  - Contact: Kristin.Ossenkop@als.org

- **Bereavement & Grief Support Group**
    - Contact: anne.suppee@als.org or 612-672-0484
- **Bulbar-Onset ALS Chat Group**
    - Contact: Kate.Nilson@als.org
- **Family Caregiver In-Person Support Group**
    - Contact: jennifer.myhre@als.org or 612-672-0484
- **Family Caregiver Virtual Support Group**
    - Contact: jennifer.myhre@als.org or 612-672-0484
- **Midwest Connect Support Group**
    - Contact: gloria.rentz@als.org
- **Nationwide Connect – Virtual Meeting for Men who are Caregivers**
    - Contact: tamara.witzigman@als.org
- **Nationwide Connect - Virtual Meeting for Women who are Caregivers**
    - Contact: tamara.witzigman@als.org
- **Nationwide Connect – Spanish Virtual Support group meeting**
    - Contact: tamara.witzigman@als.org

Financial Assistance

- **ALS Ride for Life**
    - Website: https://alsrideforlife.org/

Nutrition

- **University of Pittsburgh ALS Center**
    - Website: https://www.alsclinic.pitt.edu/patient-issues/nutrition-considerations-people-als
- **Les Turner ALS Foundation**
    - Website: https://lesturnerals.org/als-nutrition-guide/
- **Research on supplements and alternative treatments:**
    - Website: https://www.alsuntangled.com/