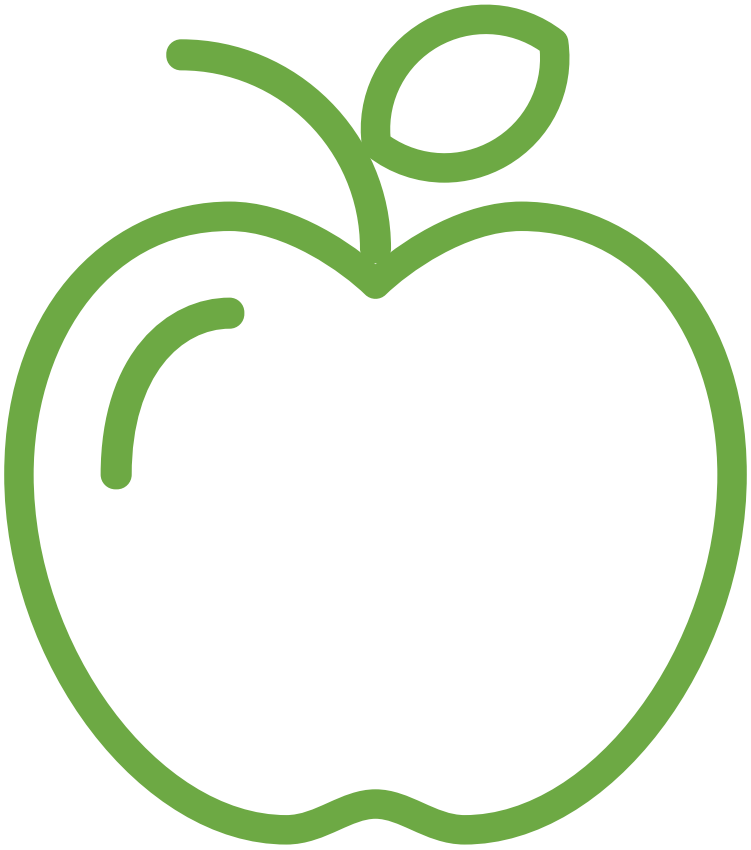


ALS & NUTRITION

A Les Turner ALS Foundation Guide for People Living with ALS

LES TURNER ALS FOUNDATION®

ALS & Nutrition

Learn how ALS can affect nutrition, weight, swallowing and hydration. Get practical tips for increasing calories, modifying foods, staying hydrated and understanding feeding tube options. In this guide you'll learn about:

Contents

How ALS affects nutrition 3

How to maintain weight with ALS 3

How to increase calories with ALS 4

Eating with ALS 5

Drinking and dehydration 6

Aids for eating and drinking 8

Choking 9

Feeding tubes 10

Learn more 14

Disclaimer Statement: The information in this guide is not medical advice. Talk to your ALS care team before making any decisions about your health or treatment. Together, you and your care team can find a treatment plan that works for you.

Last Reviewed: November 22, 2026 by the expert dietitians at the Lois Insolia ALS Clinic at the Les Turner ALS Center at Northwestern Medicine

LES TURNER ALS FOUNDATION®

©Les Turner ALS Foundation 2021
lesturnerals.org

How ALS affects nutrition

Good nutrition and hydration are very important for people living with ALS.

Some people living with ALS burn more calories because of the increased energy used in breathing, moving and muscle twitching. You may have challenges with low energy, maintaining weight and decreasing muscle mass. Proactively addressing your challenges can result in greater energy, strength and independence.

If you are having trouble eating, drinking, or taking medicine on your own, you may not be able to get all of the nutrition your body needs. This can lead to weight loss, infections, and other health problems down the road. This guide walks you and/or your caregivers through proactive strategies to maintain weight.

Early, nutritional management can improve your quality of life and help you live longer with ALS.

Your ALS Care Team can customize the best way for you to meet your nutritional and hydration needs based on your age, sex, weight and ALS symptoms.

Together, you and your ALS care team can find nutritional support that works for you.

How to maintain weight with ALS

You may benefit from a proactive nutritional approach to any of these symptoms:



Having difficulty chewing and swallowing
(coughing or choking)



Losing weight
without meaning to despite eating a "normal" amount of food



Eating less food
than you usually would or having a poor appetite



Taking longer
than expected to eat a meal (more than 45 min) because of arm or hand weakness or chewing and swallowing problems



Having problems from not getting enough water
Dehydration can lead to constipation or thick secretions

Even if you're not having these symptoms, it's never too early to be proactive with ensuring a healthy diet and adequate hydration.

If you ignore weight loss it may be hard to gain weight back. Severe weight loss contributes to muscle loss, decrease in independence and energy.

How to increase calories with ALS

You might be burning more calories at rest when compared to people who are not living with ALS

This makes maintaining weight more difficult, so people with ALS need to increase their calories to maintain weight.

A few ways to increase calories would be:



Eat small frequent meals during the day every 2 to 3 hours.



Fats provide more calories in fewer bites. Foods like nuts, nut butters, seeds, avocados, olives, and oils (olive or canola) are higher in calories.



Avoid diet foods and choose the full-fat version for more calories.



Add high protein foods such as cheese, eggs or powdered milk to casseroles and soups to increase calories and protein.



Add butter, honey, gravy, cream sauces and mayonnaise to foods.



Drizzle olive oil over foods such as vegetables, meat and soup.



Incorporate oral nutrition supplements into your day. These supplements can increase your calories and protein.

Talking with a registered dietitian or nutrition specialist can help guide you in selecting the right foods and supplements.

Eating with ALS

Chewing and swallowing difficulties (dysphagia) may make mealtimes more challenging or tiring for you. Concentrating and eating more slowly may cause a sense of isolation due to others having already finished eating. As a result, you may not finish your meal leading to a decrease in caloric intake. Some people listen to the radio or podcasts to lessen their isolation.

Dietary Supplements
ALSUntangled reviews alternative and off label treatments, with the goal of helping people with ALS make more informed decisions about them.

alsuntangled.com

Signs of swallowing difficulty include:



Choking or coughing while eating



Increased saliva or excessive drooling



Sensation of food getting stuck in your mouth, throat, or chest



Needing more time to finish a meal



Frustration during meals



Avoiding certain foods



Loss of appetite

LES TURNER ALS FOUNDATION

Try to determine what types of foods and liquids are the easiest to tolerate. You might want to consider a soft diet of foods that are easy to chew and swallow. A speech-language pathologist can help you figure out

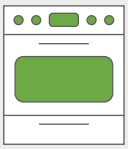
How to prepare soft foods?



Cut food into small pieces that are 1/2 inch or smaller because they are easier to swallow.



Use chicken broth, beef broth, vegetable broth, gravy or sauces to cook or moisten meats and vegetables.



Cook vegetables until they are soft enough to mash with a fork.



Use a food processor to grind or purée foods to make them easier to chew and swallow.

Drinking and dehydration in ALS

Adequate fluid intake is essential for avoiding health problems.

What are some of the signs of dehydration?



Dark colored urine



Dry itchy skin



Confusion



Dizziness or Lightheadedness



Headaches



Flushing/Fever



Increased fatigue



Decreased urine output



General guidelines recommend eight 8 fl oz cups of liquid a day. Work with your registered dietitian to determine a personalized fluid goal.



Alcohol and caffeinated beverages 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 Jello, sherbet, and fruit will also help to increase fluid intake.

Drinking thin liquids might be difficult causing you not to drink enough fluids. If thin liquids like water cause coughing, drink thicker liquids such as:



Milkshakes, smoothies, or drinkable yogurt



Puréed soups



Carbonated fluids



Thicker fruit juices with pulp, nectar fruit



Use thickening powders or gels, such as Resource Thicken Up Clear, Thick-It, or Simply Thick, to thicken fluids without altering the taste. Consult with a Speech Language Pathologist to see if thicken fluids are right for you.



Other thickening options for thin liquids, which also help increase calorie intake, include: baby rice cereal, mashed potato flakes, purèed baby foods

You might also be dehydrated because you want to avoid increased trips to the restroom, which can require assistance. Talk with your ALS care team about different bathroom aids and strategies.

LES TURNER ALS FOUNDATION

Aids for eating and drinking

See **ALS & Activates of Daily Living** for more information.



Built-up handles
Use foam tubing or wash-cloths on lightweight eating utensils for decreased grip



Universal cuff



Large handled cup for hot and cold liquids
This allows four fingers to fit through the handle to increase stability.



Offset spoon or fork that can be angled right or left



Clear plastic, clip-on plate-guard



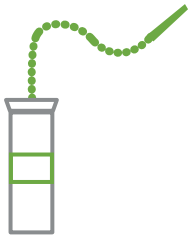
A non-slip disc; or Dycem,
a gel pad used to stabilize plates and cups on the table



Long rigid or flexible straws



Straw holder clip



Flexi-Mug and cupholder



Sports drink container with a straw



Nosey cup
The special cut out provides space for the nose, allowing you to tilt the cup for drinking without bending the neck or tilting the head

LES TURNER ALS FOUNDATION®

Choking

As face, throat and jaw muscles weaken, the risk of food and/or liquid **going down the wrong way** increases.

You can reduce choking episodes in several ways:



Limit talking and other distractions while eating.



Limit foods with different textures like chicken noodle soup or dry cereal with milk.



Serve smaller, but more frequent meals, avoiding dry, crumbly or large chunky foods.



Take smaller bites of food and little sips of liquid. Swallow several times to clear each bite.



Keep mucus and saliva thin by ensuring adequate fluid intake.
(Try papaya, pineapple or purple grape juice. These juices each contain enzymes which helps to breakdown protein in mucus. You can also add lemon juice to water.)



Ask to talk with a speech pathologist for specific strategies that might make swallowing easier for you. (Head in neutral position instead of head tilted back.)



Consider getting a feeding tube to reduce your risk of choking.



Food going down "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 potential life-threatening event for people living with ALS.

LES TURNER ALS FOUNDATION

Feeding tubes and ALS

How does a feeding tube work?

If you cannot maintain weight by eating, or swallowing becomes too exhausting, time-consuming or dangerous, a feeding tube may be considered. **A feeding tube is a type of medical device that can help you get the nutrition you need.** You will need to have a procedure for a doctor to place the tube inside your stomach. The other end will be on the outside of your skin but is easy to cover up under clothes.

Feeding tubes can lessen the stress you feel when you are unable to eat enough to maintain your weight. It may be a much better way to maintain nutrition and hydration than trying to eat or drink everything by mouth.

A feeding tube allows you to eat what you are able by mouth and supplement with adequate calories through the tube. Vitamins and medications can also be easily given through the tube when crushed.

What are the benefits of using a feeding tube?

Getting a feeding tube early can improve your quality of life and help meet your nutrition and hydration needs.

Using a feeding tube can help you:



Lower your risk of choking or pneumonia (a serious type of lung infection)



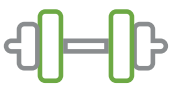
Have more energy throughout the day



Participate in activities you enjoy, like spending time with family and friends



Worry less about whether you're eating and drinking enough



Maintain your strength and keep you from losing weight



Make sure you're getting the adequate hydration your body needs



Considering a feeding tube

ALS is a progressive disease. This means your ALS symptoms will get worse over time.

If you choose not to use a feeding tube, it may become harder for you to swallow safely and you may be at an increased risk of choking.



Eating and drinking with a feeding tube

Some people can eat and drink in addition to using a feeding tube. Other people get all their nutrition through the feeding tube. This may also change over time as your ALS symptoms progress.

How will the doctor insert my feeding tube?

There are several different types of procedures that are used to place a feeding tube. Your ALS care team and consulting providers will provide you with more details about the procedure and review the options available to you.

Percutaneous Radiological Insertion of Gastrostomy (RIG): A special doctor called a radiologist will take an X-ray of your stomach. They carefully guide instruments through tiny incisions in the skin to make an opening in the stomach. You may have a Nasogastric Tube placed temporarily the day before the procedures. This is a flexible tube of rubber or plastic that is passed through the nose, down through the esophagus, and into the stomach to ensure accurate feeding tube placement.

Most ALS doctors recommend the RIG procedure. Talk with your ALS care team about which type of procedure is best for you. There are risks associated with the feeding tube procedure—like infections, breathing problems and reactions to medicines you get during surgery.

Your ALS care team can go over all the risks with you and provide you with more details about the procedure.

Percutaneous Endoscopic Gastrostomy (PEG): A gastroenterologist, or a doctor who specializes in the digestive tract, will use a camera called an endoscope to take pictures of your stomach. The doctor will place the endoscope down your throat so they can see inside your stomach.

LES TURNER ALS FOUNDATION® MY ALS™ DECISION TOOL

You can use My ALS Decision Tool™ to learn more about using a feeding tube. Then, talk with your ALS care team. Together, you and your care team can find a treatment plan that works for you.

ALSDecisions.org/Nutrition

LES TURNER ALS FOUNDATION®

Caring for your feeding tube



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 before and after giving medications. Your medications may need to be adjusted if they are going through a feeding tube. Work with a pharmacist or doctor to determine if any medication changes are needed.



Nutrition formulas, water, and medications can go through a feeding tube. Work with a registered dietitian to learn more information about nutrition formulas.



There are different ways to put nutrition formulas through a feeding tube including syringe bolus feeds, gravity feeds, and feeds through a pump. Work with a registered dietitian to determine which method is best for you.



Following each feeding, the tube is flushed with water to clear it, and prevent your feeding tube from clogging.



Feedings can be given throughout the course of the day along with regular meals. Work with your ALS care team to discuss your needs and preferences to determine the proper feeding schedule.

How do I care for a feeding tube?

Your healthcare team will show you how to take care of your feeding tube and provide instructions for when you go home following the procedure.

For a few weeks after the procedure the feeding tube requires special attention to prevent infection. After the site is healed, daily cleansing with soap and water is all that is necessary.

It is recommended that the feeding tube is exchanged every 6-9 months.

Don't worry—after the first procedure to place the tube in your stomach, it's much easier to replace with a new one. You will not need to stay overnight in the hospital.

LES TURNER ALS FOUNDATION®

Notes

Learn more

The Les Turner ALS Foundation exists to guide you to answers, support you and your loved ones and advance scientific research. To learn more about living with ALS visit, lesturnerals.org/resources.

My ALS Decision Tool™

If you have ALS, you will need to make some important decisions about your health care. As your disease progresses, your ALS care team may recommend different care options. You can use this tool to learn about some common ALS treatments, answer a few questions to help you think through what is most important to you and get ready to talk with your ALS care team about your options. To learn more, visit: alsdecisions.org.

MY ALS™ DECISION TOOL

ALS Learning Series

Our online ALS Learning Series aims to empower the ALS community through the latest information and insights. Educational webinars and interactive Q&A's covering a diverse array of topics, from nutrition to respiratory care, are offered monthly featuring members of the Foundation's Support Services team, our Lois Insolia ALS Clinic at Northwestern Medicine and other national ALS experts. To learn more about ALS care and research, visit: alslearningseries.org.

ALS LEARNING SERIES

My ALS Communication Passport to Quality Care

My ALS Communication Passport to Quality Care was created to make your life easier. You will be able to share health information and care preferences with caregivers. You have a lot of information to keep track of, and this tool will help you do that. To find out more, visit: lesturnerals.org/passport.

MY ALS COMMUNICATION PASSPORT TO QUALITY CARE

Support Groups

We facilitate support groups to provide people living with ALS and their caregivers and family the opportunity to share their experiences, give encouragement and help each other navigate their journey with ALS. To find out more, visit: lesturnerals.org/support-groups.



LES TURNER ALS FOUNDATION®