

ALS Nutrition

People living with ALS often struggle to consume enough calories to maintain their regular weight. Daily activities require more energy and calories than before, and when eating becomes more challenging, people living with ALS tend to consume fewer calories. The resulting weight loss can lead to accelerated muscle loss, weakness, low energy, and other issues.

If you notice that you are losing weight, taking longer to eat meals, getting more tired when chewing, avoiding certain foods, or coughing or choking on food or liquid, tell your ALS clinic or medical team. These may be signs that the muscles around your jaw, lips, throat, and tongue are getting weaker. If you ignore these signs and lose weight, it may be hard to gain the weight back. But if you are proactive and develop strategies to eat and drink well, you may have a better quality of life from having greater strength and more energy.



Increase Your Calories

Many people living with ALS do not get the calories they need on a daily basis. If you are having a hard time maintaining your weight, your dietitian will suggest ways to consume more calories without eating a significantly larger amount of food each day. This can be done by eating more healthy fats such as avocados, nut butters, and olive oil, drinking high-calorie protein drinks, and adding high-calorie foods like butter, sugar, cream, cheese, honey, and whole milk to your meals. Other ways to consume more calories include eating six smaller meals a day instead of three larger meals, eating more snacks between meals, and adding protein powders to foods.

Modify Your Food

Your speech language pathologist will make sure you are eating foods that are easy for you to chew and safe for you to swallow without choking. Your dietitian can give you tips on how to make softer foods, puree food, add sauces and gravies to help food go down, and avoid dry, crumbly foods that can get stuck in your mouth or throat.

Stay Hydrated

People living with ALS often struggle to drink the recommended 8-10 cups of liquid every day. Reasons may include choking when drinking and not wanting to take as many trips to the bathroom. But staying hydrated is important for staying healthy.

Dehydration can cause constipation, weakness, headaches, and thicker saliva, which can make swallowing harder. If you find yourself choking on “thin” liquids like water or juice, you can add thickeners to liquids, which will help you swallow liquids more easily. It may also be easier to drink thicker drinks like smoothies, milkshakes, nectars, and yogurt drinks.

Conserve Your Energy

As with other daily activities, try to find ways to conserve (or save) your energy while eating, drinking, and preparing food. Overexerting yourself will only burn more calories and increase the number of calories you need to eat or drink. If you spend 45 to 60 minutes eating one meal, you may be burning more calories than you consume. You may want to ask your caregiver to cook and cut your food into smaller pieces. Try to arrange things so you don't have to reach very far for each bite. Ask your occupational therapist about easy-grip utensils and other tools to make it easier to feed yourself. And when your arms feel weak, you can ask your caregiver to help feed you.

Consider a Feeding Tube

If these strategies are not helping you maintain your weight, you may want to consider getting a feeding tube so you can receive your nutrition, hydration, and medications safely through the feeding tube. Getting a feeding tube involves a short surgery that may require an overnight stay at the hospital. Before leaving the hospital, you and your caregiver will get training on how to use and clean the feeding tube.

A feeding tube can ensure that you get enough food and liquids and don't lose any more weight. If it has been determined to be safe, you can still enjoy tasting food by mouth, but your main source of nutrition will come from your feeding tube. This can help make your meals less stressful. Using a feeding tube can also reduce your risk of choking and having food, liquids, and medications go down the wrong pipe (into your lungs instead of your stomach). Your doctor and dietitian can discuss the pros and cons of feeding tubes with you and help you decide if a feeding tube is the right choice for you.

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Formerly ALS Golden West

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