

Amyotrophic Lateral Sclerosis (ALS) Nutrition Tips

Good nutrition is important for people with ALS. Healthy nutrition can help you keep your energy and stay independent longer. There is no special diet for people with ALS. Try to eat balanced meals with a protein source every 3-4 hours. We do not know of any foods that need to be added or avoided.

Try to stay at a healthy weight.

- If you are at a healthy weight, try to stay at this weight.
- If you have lost weight without trying, ask to meet with one of the registered dietitians in the ALS clinic. The dietitian can help you meet your nutrition goals. Weight loss may make your weakness worse.
- If you are overweight, talk to your Neurologist about whether you should make any changes to your diet. A slow weight loss may help your mobility. Be sure to talk with the registered dietitian in clinic to make sure this is done in a healthy way.

Vitamins and minerals:

- Follow any instructions given by your healthcare team and take any vitamin and mineral supplements they have prescribed.
- If your doctor has not told you that you need to take a supplement, we do not have good studies to show that extra vitamins or minerals are helpful in ALS.
- There is a lot of information on the internet about nutrients and other products that are said to help prevent or treat ALS. If you have questions about any of these products talk to your physician or dietitian. You can also visit this website: <https://www.alsuntangled.com/>

Constipation:

- Constipation is a common problem for people with ALS. Some reasons are: less movement, not taking enough food or liquids, and medication side effects.
- Sometimes taking more liquids can help. The registered dietitian in clinic can help you know if you are getting enough fluid during the day.
- We do not recommend using fiber laxatives like Metamucil® or Citracel®. These may make the stool more difficult to pass. They may also make feelings of gas and bloating worse.

- If you have constipation, please let us know. Your doctor, nurse, or dietitian can help.
- Laxatives or other medicines may be needed.
 - Miralax® works by pulling water into the colon and helps with natural bowel movements.
 - The starting dose is usually 1 cap full, once a day, in 8 ounces (1 cup) of any liquid. The dose can be adjusted if needed.
 - It works best to take this on a regular schedule
 - Other medications may also be recommended by your team.

PEG Tube: Another Tool in the Toolbox

You may have heard that some people with ALS will need a feeding tube (often called a PEG tube). Over time, many people with ALS may have problems chewing and swallowing food, drinking fluids, and taking medicine. A PEG tube can be helpful and relieve some of the stress of these issues.

Reasons people decide to have a PEG tube:

1. To get more calories than they are able to eat from food.
2. Reduce the risk of choking on food and food going into the lungs.
3. Less stress at meal times. If nutrition and fluid needs are met by the PEG tube, less food is needed at meal time. Food can still be eaten for pleasure.
4. To help meet fluid needs.
5. To take medicine more easily.

When is it time to think about a PEG tube?

- You become tired from eating and drinking and cannot finish a normal meal. You may not feel full after a meal,
- It takes too long to eat a meal, or eating is not fun anymore.
- You are losing weight without trying.
- You are not getting enough fluid to stay hydrated.
- You are coughing and choking a lot when eating or drinking. You or your caregivers worry that eating and drinking may not be safe for you.
- You have trouble swallowing pills or taking your medicines. A PEG tube can be a safer, easier way to take medicine.
- You have trouble feeding yourself due to arm and/or hand weakness.
- Your lungs are getting weaker and your ALS team thinks now is the best time to place a PEG tube. It is possible to wait too long and that the procedure would no longer be possible. Placing the PEG earlier may also provide more benefit to you.

More Information:

You can read more about this and other nutrition topics with ALS at the following website: www.ginutrition.virginia.edu. See the Patient Education tab and look for the sections titled ALS and Feeding Tubes/PEG Tubes.