



# **Food, Fluid, and Formula: Navigating Nutrition in All Its Forms with ALS**

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# Objectives



1. Review the role of a registered dietitian (RD) in clinic and how to utilize this resource



2. Identify current guidelines in ALS nutrition and how to decipher diet and supplement claims



3. Apply ideas to maintain nutrition around challenges that may occur in ALS



4. Increase comfort around the topic of feeding tubes and discussing goals of care with family and medical team members

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# The Role of an RD in ALS Clinic



# Role of an RD in ALS Clinic

- Thorough nutrition assessment
- Education and counseling with evidence-based information
  - Adequate nutrition and hydration intake
  - Weight stability
  - GI upset
  - Supplements
  - Overcoming barriers (appetite, trouble swallowing, etc.) to making it practical
  - Tube feeding management
- Communication with other multidisciplinary team members



## Utilizing RD Resources

- Be open and honest
- Ask that question!
- Keep your RD updated
- Revisit handouts a few times per year
- Know who to contact. If you aren't sure, ask!



## Other Nutrition Resources

- Ask your doctor for a referral to an RD
  - *Usually billed through insurance. Ask when scheduling.*
  - Finding a local RD: <https://www.eatright.org/find-a-nutrition-expert>
- ALS Nutrition: <https://www.alsnutrition.org/patient-education>
- ALSA Resource guides: <https://www.als.org/navigating-als/resources/living-als-resource-guides>
- Your ALS Guide: <https://www.youralsguide.com/als-nutrition.html>



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# Diet and Supplement Claims



## Diets and ALS

- Currently, there are no specific diets with conclusive evidence behind their use in ALS.
  - Nutrient absorption and vitamin/mineral needs do not change in ALS.
- The goal of diet and ALS: weight stabilization, good nutrition.
  - This usually means increasing calorie and protein intake.
  - Also means: There are no specific foods or food groups that must be included or excluded **because of ALS itself.**
- Weight loss in ALS decreases quality of life<sup>1</sup> and length of survival.<sup>1,2,3</sup>



# Nutrition and ALS: Common Questions

- *Why do I eat more if I'm less active than usual? & Why do I have weight loss even if I don't have trouble swallowing (dysphagia)?*
  - Weight loss in ALS is not always associated with dysphagia<sup>1,2</sup>
  - Many people with ALS are “hypermetabolic” -> The body uses more energy than it did before diagnosis.<sup>4,5,6</sup> Potential factors:
    - Increased energy needed for everyday tasks
    - Muscle fasciculations
    - Increased work of breathing if not on breathing support (non-invasive ventilation)
    - Changes in metabolism itself?



# Nutrition and ALS: Common Questions

- *Will more protein in my diet bring back muscle?*
  - Unfortunately, no. With ALS, it is the loss of connection between the nerve and the muscle that causes the muscle to atrophy (decrease in size or waste).
  - It is known that people who do not eat enough protein can lose muscle mass.
  - Encouraging protein intake in ALS helps to ensure that undernutrition is not a cause of additional muscle mass loss.



# Nutrition and ALS: Common Questions

- *I thought sugar was bad for you?*
  - “Healthy” can change based on your medical needs!
  - With ALS, avoiding weight loss is important. Adding foods/drinks with sugar can be a tool in the toolkit to help.
  - It is still important to eat nutrient-dense foods too.
  - Talk with your ALS team if you have diabetes.
  - Recent research showed a high glycemic index diet is associated with slower functional decline and longer survival in ALS<sup>7</sup>



# Supplements and ALS

- Currently, there are also no supplements with conclusive evidence for use in ALS
- Existing deficiencies should be corrected
  - This is based on lab work and monitored by doctor
  - This is NOT related to ALS itself
- People who struggle to eat a variety of food groups may benefit from a standard multivitamin with minerals



# **Supplements and ALS: Is it worth a try?**

- Without a current cure, it is understandable to want to try
- Have open and honest discussions with your ALS team
- Weigh risks vs. potential benefits
  - Medication interactions
  - Medical contraindications
  - Safety of the supplement (regulation, side effects, etc.)
  - Budget
  - Appetite
  - Not avoiding what we do know to be effective



# Supplements and ALS: Reliable Information

- **ALSUntangled®:** <https://www.alsuntangled.com/>
  - ALS professionals scientifically review alternative and off-label treatments for ALS to assist PALS and caregivers to have informed discussions and decision making.
- **Northeast ALS Consortium (NEALS)**
  - Offers webinars for PALS and caregivers
  - Often will provide an update on evidence regarding alternative treatments for ALS. Last done in 6/2024 and can be found here: <https://neals.org/people-living-with-als/educational-webinars/promising-alternative-and-off-label-treatments-for-als>



03

# Food & Nutrition in ALS



# Loss of Appetite or Feeling Full Quickly

- Eat smaller, more frequent meals – **eat something every 2-3 hours** during the day.
  - Take usual 3 meals per day and split them in half to make 6 small meals.
  - Or, 3 smaller meals + 2-3 snacks/day (a nutrition shake counts as a snack).
- Adjust the texture of your foods throughout the day for energy conservation.
- Avoid diet or light foods without many calories.
- Avoid filling up on large amounts of liquid before you eat.
  - Taking sips of fluid between bites to avoid dry mouth and swallow safely is fine.
- Keep favorite foods around, as well as convenient or pre-made meals/snacks.
  - Home delivered meal services can be helpful
- External reminders to eat such as a schedule or alarms on a watch/phone



# Maximizing Nutrition per Bite/Sip

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Adding  
calories with  
fat

- Extra oil or butter (ex: add into oatmeal, soup or casseroles)
- Liberal use of sauces, gravies, and dips (sweet or savory)
- Switch to whole fat dairy products
- Use whole fat milk or cream in recipes that call for water
- Nuts and nut butters (can stir nut butters into soft foods)
- Avocado

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Adding  
calories with  
sugar

- Add sugar, syrup, jam or honey over fruit, toast, crackers, hot cereal, yogurt, pudding, etc.
- Add whipped cream
- Chocolate or caramel syrups

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Adding protein  
(and calories)

- Dry milk powder (in milk or add to milk-based recipes)
- Protein powder in recipes
- Sprinkle cheese over any desired dish
- Add extra beans or shredded/ground meats into casseroles and soups
- Cottage or ricotta cheese in eggs, waffles/pancakes, dips, etc.



## Example High Calorie Snack Ideas

- $\frac{3}{4}$  cup whole fat vanilla Greek yogurt +  $\frac{1}{2}$  banana + 2 tbsp PB + 1 tbsp honey (*485 calories, 23 gm protein*)
- Egg salad (2 eggs, 2 tbsp mayo) + 10 butter crackers (*488 calories, 14 gram protein*)
- $\frac{1}{2}$  cup chocolate pudding + 1 packet instant breakfast powder + whipped cream +  $\frac{1}{2}$  cup strawberries, mashed (*350 calories, 10 gram protein*)
- $\frac{1}{2}$  grilled cheese sandwich + cup of condensed tomato soup made with half and half (*300 calories, 10 gram protein*)



# Oral Nutrition Supplements (ONS)

- Convenient way to get calories/protein
  - 2013 study: ~60% of patients using high calorie ONS reported weight stabilization or regain<sup>1</sup>
- Versions high in protein AND calories are encouraged
  - Good rule of thumb: at least 250 calories and 15 grams protein  
*(talk with your team for specific recommendations)*
- Various forms: milkshake, juice-based, gelatin, ice cream
- Flavor adjustments: dilute with milk/plant-based “milk” if too sweet; add extracts, spices, syrups, decaf instant coffee
- Can be used in recipes
  - Protein powders are lower calorie but can also be used in recipes



# Dysphagia - Food Texture Adjustment

- Keep foods soft, moist, and cohesive
- Use sauces, gravies, and condiments liberally
- Dip or soak dry crumbly foods like cookies or toast in milk, juice, coffee, etc.
- Peel fruits and vegetables and remove tough seeds and cook to fork tender
- Use moist methods of cooking for meats (such as slow cookers)
- Cut meats into small pieces (about 1.5 cm or the tip of your pinky finger)



# Dysphagia

- Easier to chew/swallow foods:
  - Yogurt, pudding, hot cereal, mashed potatoes, short noodles with sauce, canned fruits, applesauce, banana, peeled and cooked vegetables, meatloaf w/ gravy, cottage or ricotta cheese, bean dips or soups, egg/tuna/chicken salad with extra mayo
- Foods that may cause more trouble:
  - Dry, crumbly solids (cookies)
  - Bread
  - Tough meats
  - Piecey foods (rice, corn)
  - Stringy foods (celery, pineapple, gristle)



# Dysphagia

- Some people with ALS find naturally thicker beverages easier to drink such as milk, yogurt drinks, fruit nectars, or milkshakes.
- You can talk with your SLP about thickened liquids.
  - Commercial thickeners (gel or powder)
  - Home thickeners
- Thicker is not always better.



# Hydration

- Muscle function
- Thinning oral secretions
- Constipation management/prevention
- Immune function
- Fatigue levels



# Hydration

- Goals vary, but good rule of thumb: 8 cup or 64 oz non-caffeinated, non-alcoholic fluid daily
- Tips for hydration:
  - Keep water with you during the day
  - Work with OT & SLP on water container that works for you
  - Set reminders on a phone/watch, use signs around the house, or change your phone lock screen
  - Foods with high water content (fruit, popsicles, soup, ice cream, gelatin)
  - Freeze juice or caffeine-free soda into a slushie or use crushed ice as a “snow cone” with juice or electrolyte powder sprinkled on top



# Hydration: Thick Saliva or Phlegm

- Good hydration helps thin saliva
- Milk products may worsen thick saliva.
  - Can try reducing intake of dairy or try plant-based dairy alternatives
  - Can try reducing dairy intake later in the day
- **Pineapple or papaya juices** are anecdotally helpful to thin mucus.
  - Enzymes in these juices may help break down some of the protein in the mucus.
  - The acidity in **lemonade, lemon water, and grape juice** may also help.



# Eating and Self-Feeding

- An occupational therapist suggest items that can make everyday activities like eating easier. Examples include:
  - Foam tubing for utensil handles
  - Rocker knives, pizza cutters, or pastry cutters
  - Using bowls or plates with raised edge
  - Placemats or tea towels to prevent plates from sliding on the table
  - Straws (large bore, long straws, one-way straws)
  - Jar openers



# Constipation

- Weakening of the abdominal muscles  
-> ?slowing movement of stool
- Reduced activity level
- Medication side effects
- Poor fluid intake
- Inadequate fiber in the diet.

In turn, constipation can cause discomfort and decrease appetite.



# Constipation

- Ensure adequate fluid intake (8 cups or 64 oz daily) to soften the stool.
- Talk with your dietitian or doctor about the fiber in your diet or a supplement.
  - Too much fiber may worsen constipation for people with less mobility or weakened abdominal muscles, but don't want to eliminate fiber.
- Don't skip breakfast
- Drink a warm beverage in the morning
- Try prune, pear, or apple juice. Start slow with  $\frac{1}{2}$  cup.
- Consider 5-6 prunes per day in the morning or 2 kiwi fruit per day
  - Constipation pudding: 1 cup applesauce + 1 cup oat bran, wheat bran, or ground flax +  $\frac{3}{4}$  to 1 cup prune juice. Start with 1-2 tbsp per day mixed in or followed by 8 oz water or fluid. Can increase to 4 tbsp daily. Can freeze in ice cube trays for easy storage. (<https://medicine.umich.edu/sites/default/files/content/downloads/constipation-recipe.pdf>).
- Include gentle movement after meals as much as tolerable/safely possible.
- Let your doctor know if you have constipation. They may consider medications.



## Quick Tips

- Proactive is better than reactive when possible.
- Eat regularly during the day. Do not skip meals.
  - If appetite is good and weight is stable, aim to eat something every 3-4 hours while awake.
  - If appetite is poor, meals are tiring, and/or weight is decreasing, aim to eat something every 2-3 hours while awake.
- If safely able, check weight 1x/week at the same day/time.
  - Fluctuations up and down of 1-2 lb are common. If you keep losing 1-2 pounds after a few weeks without an uptrend, call your ALS team.



## Quick Tips

- Still include foods from all 5 food groups as able.
  - Can start by eating protein food on the place first in case you get full.
  - Make fruits and veggies higher calorie with sauces, butter, cheese, dips, syrup, whipped cream, yogurt dips, or nut butters.
- Include protein at each meal and most snacks
- Use high calorie ingredients to maximize nutrition per bite
- Stay well hydrated. Aim for about 64 oz fluid/day and try to make at least half of this water.



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# Feeding Tubes & Decision Making



# Why might PALS consider a feeding tube (FT)?

- Reduce stress from worrying about eating enough to maintain weight
- Conserve energy for other daily tasks and activities
- Increase calorie intake to maintain weight and nutritional status
- Alternate route of nutrition if swallowing becomes too uncomfortable
- To help stay hydrated
- To take some medications more easily



# When might PALS consider a feeding tube (FT)?

- Getting tired from eating
- Unable to finish a normal meal or it takes too long to do so (feeling stuck at the table)
- Eating is not enjoyable; fear of eating
- Losing significant weight
- Eating less and losing appetite
- Worse trouble swallowing or feeling that eating / drinking is not safe or comfortable
- Trouble taking (swallowing) medications
- If the lungs are getting weaker and the ALS team suggests now is the time to consider feeding tube placement. The procedure becomes higher risk when breathing is worse.
  - Usually recommended that placement of a feeding tube occur before a measure of breathing function (the forced vital capacity or FVC) reaches 50%.



# What is a Feeding Tube (FT)?

- Feeding tube: a tube that is inserted into the stomach to be used for nutrition, hydration, and medications.
  - Often referred to as a “PEG tube”. This stands for percutaneous (*done through the skin*) endoscopic gastrostomy (*opening to the stomach*).
  - Sometimes called a “RIG tube” (radiologically inserted gastrostomy) or simply a “G-tube”
  - Some people have a “J-tube,” which is inserted into the jejunum (part of the small intestine). This is less common for PALS.

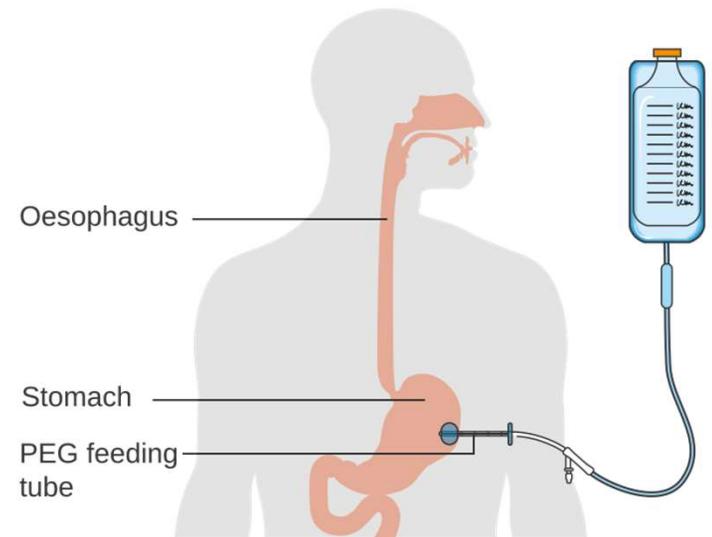


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# What is a Feeding Tube (FT)?

- How is it placed?
  - Endoscopically: Done by a gastroenterologist or surgeon. A physician puts a tube with a light and camera (the endoscope) down the esophagus into the stomach. The endoscope helps the doctor find the right spot to place the tube.
  - Radiologically: Done by Interventional Radiology. A small tube is placed through the nose and air is passed through the tube into the stomach so the stomach is visible on X-ray and the doctor know where to place the feeding tube.
- A bumper or a small water-filled balloon holds the tube in place inside the stomach.

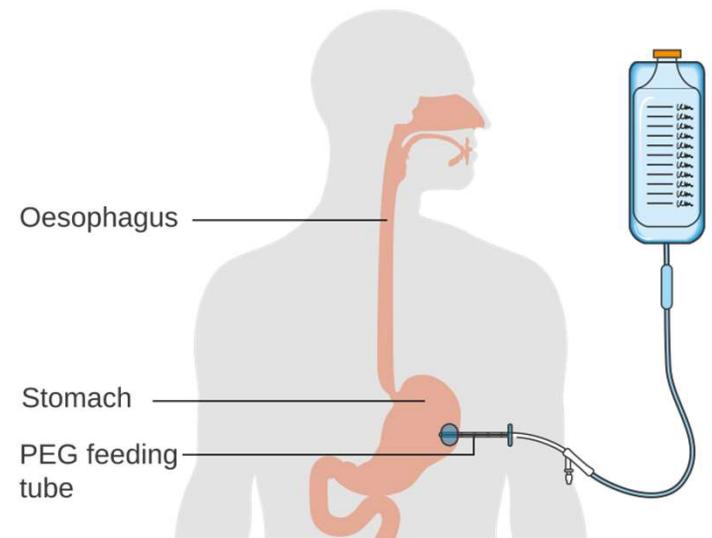


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# How does a Feeding Tube (FT) work?

- Tube feeding formula: liquid that provides the calories (from carbs, protein, and fats), vitamins, and minerals your body needs.
  - Prescribed by medical provider
- Most patients receive nutrition through the FT as a **bolus**
  - Bolus = a specific amount of formula given several times per day
  - Formula flows by gravity through a syringe to the FT.
  - Should take ~ 15-20 minutes, especially when first starting.
- Some patients need a **pump** that lets the formula go into the FT at a slower rate.



# How does a Feeding Tube (FT) work?

- A syringe is used to give water through the FT for hydration and keep the tubing clean and prevent clogs.
- Some medications can be given through a FT with a syringe
  - Not all medications can be safely crushed
    - Talk with your pharmacist/doctor
  - Always flush the FT with water before and after giving meds to avoid clogging.

**NEALS webinar if interested in learning more:** <https://neals.org/people-living-with-als/educational-webinars/feeding-tube-management-and-consideration-in-people-living-with-als>



# Feeding Tubes and Decision Making

- Your goals of care are your own!
  - Most important: you feel your decisions are fully informed.
- Feeding tubes (FT) and their use look different for each PALS, and can change over time. A person may choose to:
  - Use FT for 100% nutrition; nothing by mouth
  - Use FT for 100% nutrition; eat/drink for pleasure
  - Use FT for most nutrition/hydration; eat 1-2 meals/d
  - Use FT on low energy days; mostly eat by mouth
  - Use FT for hydration or meds only; eat by mouth
  - Have FT placed early but not yet use it
  - Not to get FT
- ALS Feeding Tube Decision Making Tool:  
<https://lesturnerals.org/nutrition/about-this-decision-tool/>



# Feeding Tube FAQs

- Does this mean I didn't try hard enough to eat enough?
  - Needing a feeding tube is **not** anything that you did wrong.
- Will I have a tube going down my nose/throat all the time? **NO.**
- Does it fit under my clothing? **YES.**
  - A standard PEG tube has a few inches of tubing that extends out from the body. It is usually secured from moving around with medical tape or devices made for this purpose.
  - Some people choose to have their tube exchanged for a low profile FT after they are healed from initial tube placement.
- What do I do if it falls out?
  - Don't panic, but do go to your local emergency department to have the tube replaced (*unless your team has provided you with other instructions*). The opening can close quickly, so it is important to get the tube replaced as soon as you can.



Standard feeding tube



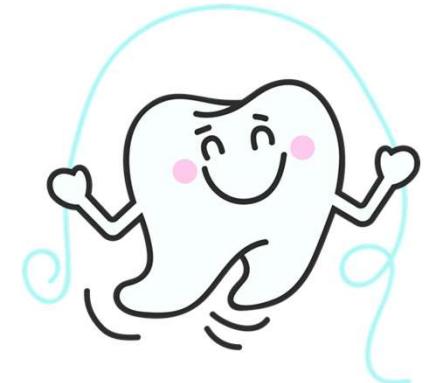
Low-profile feeding tube

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# Feeding Tube FAQs

- Can I still eat when I have a feeding tube? **YES.**
  - People who have a PEG tube are still able to eat by mouth as long as they are able to swallow safely.
  - **Whether or not you are eating by mouth after having a feeding tube placed, good oral hygiene is still important.**
- Can I put regular food in my feeding tube instead of formula?
  - Some patients choose to make their own formula with whole-food ingredients in a blender (blenderized tube feeding).
  - This requires extra time, food safety, and planning to ensure you are getting 100% nutritional needs and won't clog the tube. Talk with your dietitian if you are interested in blenderized tube feeding - do not start on your own.



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