



## Ask Me Anything ALS - Feeding Tubes/Nutrition

As ALS progresses, eating and drinking can become difficult, which can often lead to discussions about feeding tubes. The decision to get a feeding tube is a personal one. There are advantages and disadvantages that must be taken into account when considering a feeding tube. It can be helpful to hear from those who have been through this process. Like with all decisions, it's incredibly important to consider your personal values when navigating the healthcare system.

This resource was created as a result of conversations had and resources shared during the [I AM ALS Ask Me Anything ALS series](#) on feeding tubes and nutrition. Use this resource to learn more about how and why community members decided to get a feeding tube, the advantages and disadvantages, how they maintain their feeding tube and more.

### Resources

- [FYI: Information About Feeding Tubes](#) - ALS Association
  - Description: Written by professionals from the ALS Association and Stony Brook ALS Clinic, this factsheet offers easy-to-follow bulleted information about feeding tubes for ALS.
- [Is a Low-Profile Feeding Tube Right for You?](#) - ALS Association
  - Description: As the name suggests, low-profile feeding tubes sit at skin level, which can make them easier to conceal for some people.
- [The G-Tube Talk](#) - Massachusetts General Hospital
  - Description: In this YouTube video, nurses from the Healey Center for ALS at Massachusetts General Hospital present information and options about gastrostomy tubes.
- [Coram CVS G-Tube Guide](#) - Coram CVS Speciality Infusion Services
  - Description: Coram, the CVS Specialty Infusion Services Team, provides ongoing education, care and support to help people with nutrition therapy. This guide offers how-to information about tube feeding.
- [My ALS Decision Tool - Nutrition support](#) - Les Turner ALS Foundation
  - Description: This interactive tool from the Les Turner ALS Foundation offers educational information about using a feeding tube with ALS, and is designed to help you decide if a feeding tube is right for you.
- [ALS & Nutrition](#) - Les Turner ALS Foundation
  - Description: This companion guide walks you through proactive strategies to maintain weight as a person living with ALS. Information on calories, eating, choking, drinking/hydration, and aids for eating and drinking are included in this resource.



- **[My Experience Getting a Feeding Tube, and Care](#)** - ALS 411
  - **Description:** This discussion shares why Todd, a person living with ALS, decided to get a PEG tube, even though it was not yet needed for nutrition. Todd, along with his wife Kristin, share about the procedure, recovery, and usefulness, along with how to care for the feeding tube and useful tips.
- **[Frequently Asked Questions](#)** - I AM ALS
  - **Description:** These frequently asked questions about ALS have been collected and answered by professionals and members of the ALS community. This resource addresses questions regarding feeding tubes, nutrition, and swallowing, in addition to many other ALS-related topics.
- **[Questions to Ask About PEG Feeding Tubes](#)** - I AM ALS
  - **Description:** This checklist offers questions to consider asking your ALS care team about PEG feeding tubes.
- **[Oley Foundation](#)**
  - **Description:** The Oley Foundation strives to enrich the lives of those with home intravenous nutrition and enteral tube feeding through advocacy, education, community, and innovation. [This Oley newsletter](#) offers information about swimming with feeding tubes.
- **[Get Prepared for Emergency Medical Situations](#)** – I AM ALS
  - **Description:** The information on this page includes advice from patients, caregivers, ALS physicians and The ALS Association about preparing for emergency medical situations with ALS.
- **[Managing Saliva Problems](#)** – The Motor Neurone Disease Association provides information about managing thin, watery saliva, as well as thick saliva, mucus and phlegm
- **[Transportation Security Administration Passenger Support](#)** – when traveling with a disability and medical equipment, call ahead to request support.
  
- **[Feeding Tube Supplies](#)** (**disclaimer:** I AM ALS has no affiliation with the product manufacturers below – these are non-exhaustive lists meant to offer examples of products available.) Your ALS care team can help arrange for you to receive all of the necessary supplies to use and care for your feeding tube.
  - **G-Tube Holders** - Various Medical Supply Companies, Amazon, Etsy
    - **Description:** A G-tube holder/belt can help with securing PEG tubes in place and can be purchased on [Amazon](#), [Walmart](#) and other locations.



- **Site Pads** - Various Medical Supply Companies, Amazon, Etsy
  - **Description:** Use G-tube, GJ Tube, Mic-key button pads with snap closures to soak up any leakage from the feeding tube site. Pads can be reusable or disposable, as well as simple or decorative.
    - Washable plain button pads can be purchased on [Amazon](#), [Etsy](#) and other locations.
    - [Drainage Split Gauze Sponge](#) is a disposable tube site dressing to help prevent pooling fluids.
    - A [waterproof dressing](#) can be used when swimming to cover the feeding tube site on the abdomen.
- **Pill Crushers** - Various Online Stores, Pharmacies
  - **Description:** Pill Crushers can crush or grind tablets into powder, which can then be administered through a person's feeding tube. **Note:** not all tablets can be crushed, so be sure to ask your care provider about how to effectively take your medications.
    - Pill crushers like the [Pill Grinder](#), [Silent Knight pill crusher](#), the [CVS Health Pill Crusher Plus Storage](#), or the [Equate Easy Grip Pill Crusher](#) may be helpful.

### Relevant ALS Facebook Groups

*The information posted in Facebook groups does not represent the views of I AM ALS and has not been verified by us. Please discuss questions and decisions related to your diagnosis and medical care with your health care team.*

- **[Feeding Tube Families](#)**
  - **Description:** This Facebook group is for caregivers of children and adults with feeding tubes. Members can be parents, grandparents, aunts, uncles, and other family members/loved ones that are directly involved in the care of a person with a feeding tube.
- **[Feeding Tube Support and Friends](#)**
  - **Description:** This is a Facebook group for Feeding Tube users and their caregivers. Members join to share about their trials & tribulations, ask questions, and offer advice and support to others navigating feeding tubes. The group works to provide a safe place where people can share the good, the bad, and the ugly of feeding tubes.
- **[PEG Tube User Group](#)**
  - **Description:** This Facebook group was established by Keith Yaxley for PEG tube users, their families, friends, and caregivers to share experiences, information, and concerns. The page's goal is for people to use the experiences of others and what is discussed as a conversation starter with their medical provider(s).



- **[Adults with Feeding Tubes Support Group](#)**
  - Description: This Facebook group is for adults living with conditions that require enteral or parenteral nutrition. The page exists to provide a supportive forum for adults with feeding tubes to ask questions, share stories, and reduce feelings of isolation.

### **Additional Learning Opportunities**

- **[Ask Me Anything ALS - Feeding Tubes/Nutrition Event Recordings](#)** - I AM ALS
  - Description: The Ask Me Anything ALS - Feeding Tubes/Nutrition events focused on how and why panelists decided to get a feeding tube, the benefits, how they maintain their feeding tube, and more.
  - [Part 1 Event Recording](#)
  - [Part 2 Event Recording](#)