



TUBE FEEDING: WHAT YOU NEED TO KNOW

A FAMILY & FRIENDS GUIDE TO TUBE FEEDING

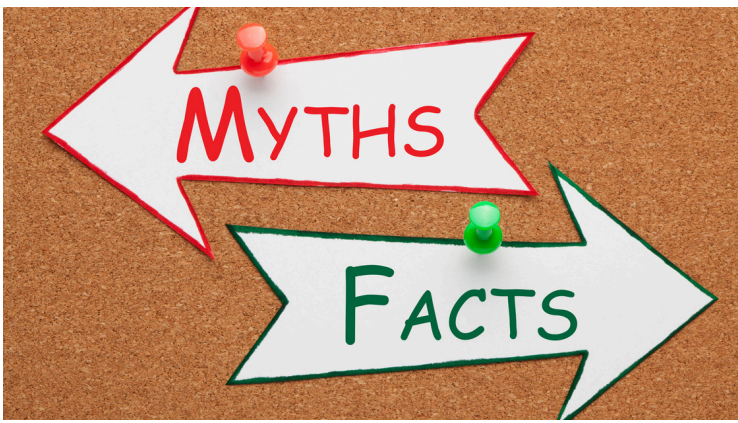
NEW TO TUBE FEEDING?

It can be overwhelming to learn that a loved one needs a feeding tube. One of the most important things you can do is offer understanding and support. Thank you for picking up this guide to learn more about tube feeding.



THINGS TO KNOW...

- **Tube feeding helps people get the nutrition and fluids they need** when they can't eat or drink safely or get enough of what they need orally. It may be a last resort for some people or an early intervention for others, depending on their medical needs.
- **It can be hard to understand** the need for a feeding tube when your loved one appears healthy. However, feeding tubes play a vital role in maintaining their health, much of which happens behind the scenes. Know that with time, things become less overwhelming. What may feel intimidating at first is simply part of daily life. Taking the time to learn shows understanding, care, and acceptance.
- **You can ask questions and offer help.** Be sensitive and follow their lead. Respect the boundaries they set. Memories of past traumatic events may make accepting help difficult. Some topics may be difficult or sensitive, or they may simply want to keep some things private. That is okay. Let them know you're there to support them in any way they need.
- **Tube feeding is simply another way of getting nutrition.** It does not define a person's identity, abilities, or personality.



MYTHS & FACTS ABOUT TUBE FEEDING

To better understand what your loved one is experiencing, here are some common myths and the facts behind them:

Myth: A person didn't try hard enough before moving to tube feeds.

Fact: Tube feeding is rarely the first option. Patients and healthcare teams typically explore many choices before deciding on tube feeding. Usually, tube feeding is chosen when someone cannot eat enough orally or cannot eat or drink safely. Tube feeding provides the nutrients needed to stay healthy. Some people feel deep loss, anxiety, grief, guilt, or failure when they or a loved one needs a feeding tube, especially after spending a lot of effort trying to eat.

Myth: Tube feeding should be done by medical professionals.

Fact: Patients, caregivers, and family can learn to use feeding tubes safely at home with proper training. No prior knowledge is needed.

Myth: If things aren't going well, the tube was a bad decision.

Fact: Adjusting to tube feeding takes time, and there is often a learning curve. Tube feeding isn't one-size-fits-all. It can take some time and trial to find the right treatments, methods, and products.

Myth: You can't eat by mouth when you have a feeding tube.

Fact: Some people benefit from tube feeding because they can't eat enough by mouth. Others need tubes because of foods that are unsafe for them to eat. If it's safe to eat by mouth, oral eating is often encouraged to maintain or develop skills, but a feeding tube may still be needed to get enough nutrition. While oral eating may offer benefits and be enjoyable for some people, pressuring someone to eat makes food feel unsafe, harms trust, and does not improve healthy eating skills.

Myth: Physical activity will be limited by having a feeding tube.

Fact: Tube feeding doesn't limit physical ability. People can still be active and enjoy their favorite activities, including sports, travel, and more. Lightweight feeding pumps can be carried in a backpack to allow freedom of movement, even during continuous feeds.

Myth: Tube feeding is forever.

Fact: Each person is different, and so are their needs. Some people need tube feeding long-term, while the need is temporary for others. It all depends on why each person needs nutrition support. Patients work with their healthcare teams to decide when and if a feeding tube is no longer necessary, and to make that transition when the time is right.

Myth: You must only use formula for tube feeding.

Fact: Tube feeding diets can include breast milk, formula, or blended foods. Patients work with their medical team to find the best diet for their medical needs and feeding tolerance.

THINGS TO CONSIDER ABOUT TUBE FEEDING



Life with tube feeding:

It is normal to feel sadness, anger, loss, grief, or confusion about a disability or illness. Feeding tubes can be a reminder of these feelings. Tubes can affect self-esteem and body image. They may decrease their sense of belonging. Stress from caregiving, seeking treatment, and other responsibilities can be significant. Insurance may not cover all costs, such as specialty formulas or frequent doctor visits. Illness and appointments can mean missed work and lost wages. Out-of-pocket expenses can add up quickly.

Tube-fed patients may not look “sick.”

There are countless reasons a person may need tube feeding, many of which aren't visible. The ideal outcome of tube feeding is that it provides nutrition that helps keep patients healthy. Feeding tubes and the reasons for them may be hidden, but they can have a real

impact on people's lives. You can show support by honoring your loved one's experience, withholding judgment, and offering needed accommodations. You don't need to know medical details to be supportive. Simply being flexible, patient, and willing to learn goes a long way.

Challenging environments:

- **Holidays and traditions:** Food-centered activities can be hard, lonely, or frustrating for those who can't eat or who have very limited diets.
- **Parties and large gatherings:** It may be hard to plan and attend large events, as space is still needed to prepare and connect tube feeding. Privacy may be limited. Crowds may be a challenge for those who have sensory needs or are at risk from germs.
- **Social settings:** Navigating restaurants and public spaces can be tricky for those who cannot eat or who eat little. They create awkward social moments that are hard to know how to respond to, both with friends and with strangers.

Pediatric Considerations

- **Childcare:** Parents of children with feeding tubes often require specialized caregivers who are trained in caring for feeding tubes. This may make finding respite care difficult.
- **Food safety:** Children may not understand diet restrictions. Keep food out of reach and ask before offering anything to a child who is tube-fed.
- **Friendships:** Parents may feel isolated or overwhelmed. Offering companionship, understanding, or help with non-medical tasks can make a meaningful difference.
- **Support services:** Some states offer non-income-based waivers to help families qualify for programs to pay for the high cost of medical care.
- **Perception:** Children with feeding tubes are also kids who want to play, learn, and connect just like any other child.

What Is Helpful? What Isn't Helpful?

What is Helpful :

- **Listening:** Be available to hear their concerns and questions.
- **Helping:** Offer practical support like errands or childcare.
- **Understanding:** Tube feeding is simply another way to get nutrition.
- **Learning:** Educate yourself about their medical needs.
- **Supporting:** Focus gatherings on non-food activities.
- **Empathizing:** Be mindful of feelings when asking questions.
- **Boundaries:** Allow people to choose which personal details to share.
- **Showing respect:** Acknowledge that patients and caregivers are the experts.
- **Engaging:** Address the person, not just their caregiver.
- **Normalizing:** Treat tube feeding as just one part of life rather than the focus of every interaction.
- **Flexibility:** Being open to changes in plans, timing, or environment can reduce stress for everyone.

What Isn't Helpful :

- **Guilt trips:** Recognize effort. Don't question choices or actions.
- **Correcting/coaching:** Avoid comments like "just a little bite."
- **Negative talk:** Expressing dislike for the tube doesn't help.
- **Comparing:** Every person with a feeding tube is an individual.
- **Pity:** Empathy is good, but pity isn't productive.
- **Hero worship:** Praise is kind, but too much praise creates a sense of "otherness."
- **Oversimplifications:** Don't assume solutions are easy.
- **Public shaming:** Support public tube feeding instead of suggesting privacy.
- **Unauthorized feeding:** Never give food to a child without their parents' permission.
- **Probing Questions:** Avoid asking detailed medical questions unless your loved one invites the conversation.
- **Wishful thinking:** Try not to ask, assume, or project hopes of recovery. Progress is personal.
- **Forced positivity:** Support includes all emotions. Make space for feelings of many kinds.

Great Questions To Ask

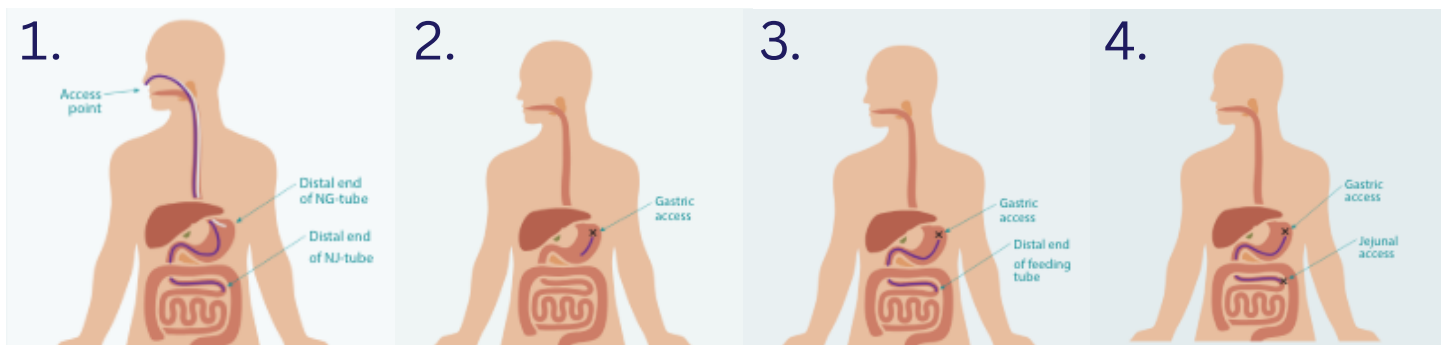
- Is there anything you wish I understood about your diagnosis?
- How can I help when you are tube feeding?
- Are there aspects of tube feeding that would be helpful for me to learn about?
- Would you like me to learn how to help with tube feeding?
- Are there any safety concerns I should know about?
- How can I make gatherings, visits, and outings easier for you?
- What are some of the things I should/shouldn't do around you?
- Is there anything that makes social situations easier or harder for you?
- How can I support you without overstepping?
- What else do you want me to know?

What Are The Types of Feeding Tubes?

You don't need to remember these details. This chart is simply to help you understand the general idea of where tubes go and why someone might have one.

Tube Type	Description	Typical Uses	Common Limits
1. Nasal Gastric (NG) Tube	Inserted through the nose into the stomach.	Short-term feeding when the stomach can digest food.	Can be uncomfortable in the nose or throat; harder to replace.
1. Nasal Jejunum (NJ) Tube	Inserted through the nose into the small intestine.	Short-term feeding when the stomach cannot process food..	Must be replaced in the hospital with imaging; not meant for long-term use.
2. Gastric (G) Tube	Placed directly into the stomach through the abdomen.	Long-term feeding when the stomach works properly.	Requires site care to prevent infection; stomach must tolerate feeding.
3. Gastric Jejunum (GJ) Tube	Placed through the abdomen, reaching both the stomach and small intestine.	Feeds into the intestine while allowing stomach drainage or pressure relief.	Hospital replacement with imaging; risk of shifting or clogging; routine site care needed.
4. Jejunum (J) Tube	Placed directly into the small intestine through the abdomen.	Long-term feeding when the stomach must be completely bypassed.	Requires regular care; higher risk of clogging and digestive discomfort.

Nasal –related to the nose | **Gastric** –related to the stomach | **Jejunum** –a portion of the small intestine



*Images created in partnership with Moog Medical



Kidz Klub at the Oley Conference & Virtual Kidz Klub

Kidz Klub at the Oley Conference is a fun and supportive program designed especially for children in the nutrition support community and their siblings. It offers a safe space where kids can connect, play, and participate in engaging activities while parents attend conference sessions.

Our Virtual Kidz Klub, facilitated by Oley's Youth Program Coordinator, Jade Lusk, brings the excitement online! Through interactive games, crafts, and social time, kids can connect with peers who share similar experiences, all from the comfort of home.

Whether in-person at our annual conference or online, Kidz Klub provides a welcoming environment where kids can build friendships and have fun.

Siblings are welcome too!
Sign your child up for Kidz Club at our annual conference here:

[KIDZ CLUB](#)





Supporting a loved one with tube feeding can bring new challenges and opportunities for connection. By staying kind and empathetic, you are taking an important step toward providing meaningful support and fostering open communication. Remember, your willingness to learn, listen, and adapt can make a significant difference in their comfort and well-being. Together, with understanding and compassion, you can create an environment where your loved one feels supported and empowered.



For more resources and support, please visit oley.org/patient_caregiver or reach out to the Oley Foundation community at info@oley.org. You are not alone on this journey; we're here to help.