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Awareness  
Week®

[oley.org/tube](http://oley.org/tube)

# What You Need To Know

## A Family & Friend Guide to Tube Feeding



# FAMILY & FRIEND GUIDE TO TUBE FEEDING



## INTRODUCTION

It can be overwhelming to learn that you or 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.

# FAMILY & FRIEND GUIDE TO TUBE FEEDING



## Myths and 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 alternatives before deciding on tube feeding, which provides critical nutritional support. This decision is often based on the inability to eat enough or safely.

**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. If it's safe, oral eating is encouraged to maintain skills, but supplemental nutrition may still be necessary.

## THINGS TO KNOW...

- **Tube feeding may be a last resort** for some or an early intervention for others, depending on medical needs. It is essential for ensuring adequate nutrition and hydration when oral intake isn't safe or sufficient.
- **Support from loved ones is needed.** Many people with feeding tubes don't look sick, but their feeding tubes are critical for maintaining their health. Looking and feeling healthy can take a lot of work and may strain the entire family, feeling like a full-time job.
- **You can learn to help.** It's not as scary as it seems.
- **Be willing to learn and follow their lead.** Traumatic experiences may make accepting help difficult. Let them know you're there to support them in any way they need.



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**MYTH:** Tube feeding is forever.

**FACT:** Tube feeding can be temporary or lifelong, depending on the condition. Patients work with healthcare teams to transition if tube feeding becomes unnecessary.

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

**FACT:** There's often a learning curve. Tube feeding isn't one-size-fits-all, and adjustments are common.

**MYTH:** A person's physical activity will be limited by having a feeding tube.

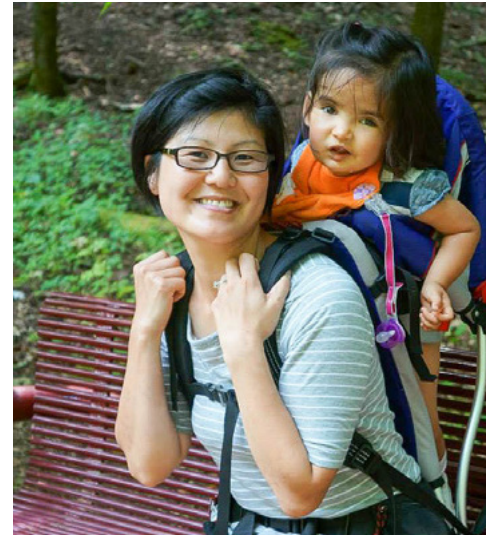
**FACT:** Tube feeding doesn't limit physical ability. People can still be active, including playing sports, traveling, and more.

**MYTH:** Tube feeding should be done by medical professionals.

**FACT:** Patients and caregivers can learn to use feeding tubes safely at home with proper training.

**MYTH:** You must only use formula for tube feeding.

**FACT:** Tube feeding diets can include breast milk, formula, or blended foods, depending on medical needs.



## Things to Consider About Tube Feeding

**Patients who are tube fed may not look "sick."**

There are countless conditions requiring tube feeding, many of which aren't visible. Underlying medical issues can increase risks from germs, even if someone appears healthy.

**Families may be emotionally drained.**

Seeing tubes daily can be a constant reminder of medical challenges. Stress from caregiving, testing, and other responsibilities can be significant.

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## **Families may be financially drained.**

Insurance may not cover all costs, such as specialty formulas or frequent doctor visits. Out-of-pocket expenses can add up quickly.

## **Challenging environments:**

- **Birthday parties and large gatherings:** These can be overstimulating or raise concerns about germs.
- **Holiday events:** Food-centered activities may be difficult for those with limited or no “safe” foods.

## **Pediatric Considerations**

- **Childcare:** Parents of children with feeding tubes often need specialized caregivers.
- **Safety:** Keep food out of reach and ask before offering anything to a child who is tube fed.
- **Social settings:** Navigating restaurants and public spaces can be challenging due to questions and assumptions.
- **Empathy:** Parents of tube-fed children may have a shifted perspective after extensive medical experiences.
- **Support services:** Families may rely on non-income-based programs for medical needs, which can be costly.



## What Is Helpful and What Isn't Helpful

- **Guilt trips:** Avoid comments like “just a little bite.”
- **Tube resentment:** Expressing dislike for the tube doesn't help.
- **Pity:** Empathy is good, but pity isn't productive.
- **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 parental permission.

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## Types of Feeding Tubes

TUBE TYPE	DESCRIPTION	TYPICAL USES	COMMON LIMITS
<b>Nasal Gastric (NG) Tube</b>	Inserted through the nose into the stomach.	Short-term feeding when the stomach can digest food.	Typically for a few weeks; can cause nose/throat discomfort.
<b>Nasal Jejunum (NJ) Tube</b>	Inserted through the nose into the jejunum.	Short-term feeding when the stomach cannot process food.	Requires X-ray placement; not typically for long-term use.
<b>Gastric (G) Tube</b>	Inserted directly into the stomach through the abdomen.	Long-term feeding when the stomach functions properly.	Requires care to prevent infection; unsuitable if the stomach cannot tolerate food.
<b>Gastric Jejunum (GJ) Tube</b>	Extends into both the stomach and small intestine.	Bypasses the stomach for feeding while relieving stomach pressure.	Complex placement.
<b>Jejunum (J) Tube</b>	Inserted directly into the small intestine through the abdomen.	Long-term feeding when the stomach must be completely bypassed.	Requires careful maintenance; might have a higher risk of clogging.

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## Questions to Ask

**The following is a list of questions for you to ask your loved one so that you can better understand their situation and provide support**

**How can I help you when you are tube feeding?**

**Are there aspects of tube feeding that you can teach me how to do?**

**Help me understand how I can make gatherings, visits, and outings easier for you.**

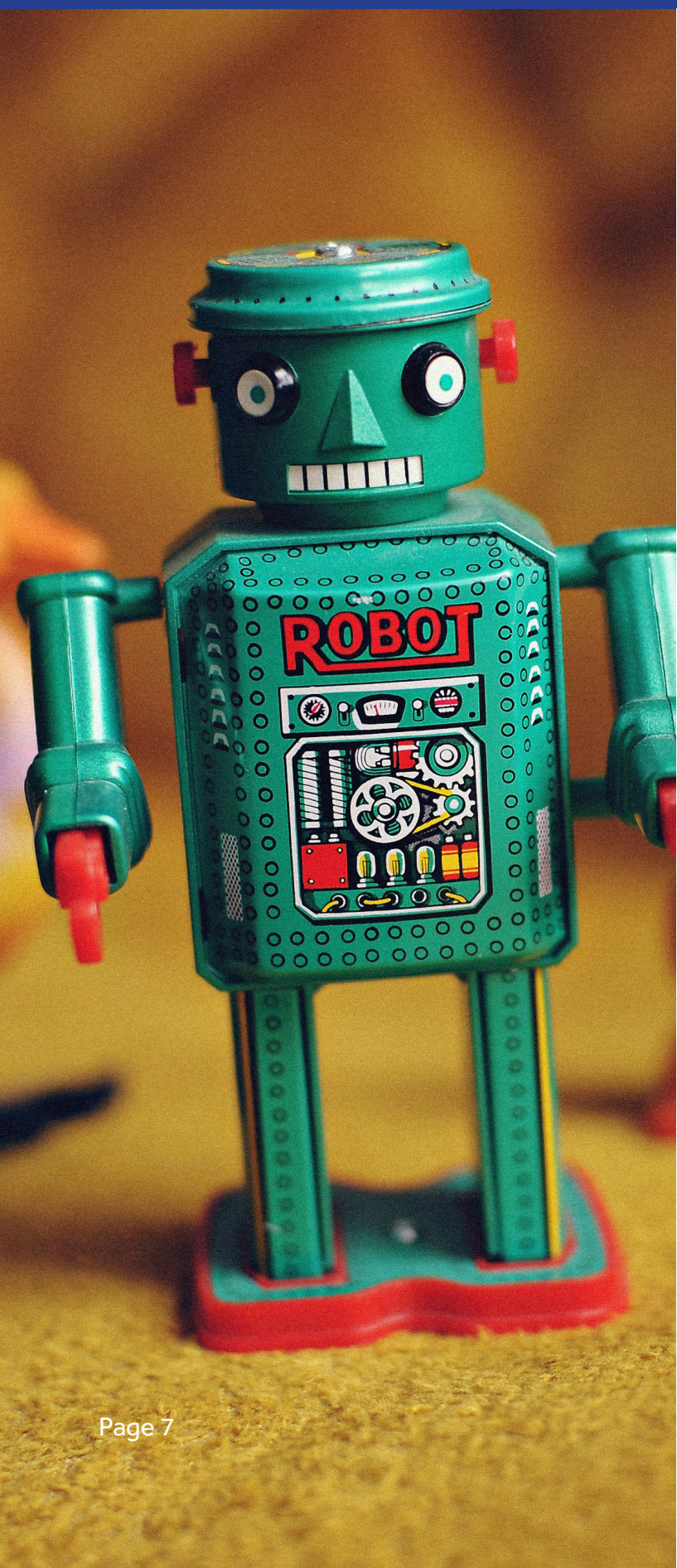
**What are some of the things I should/shouldn't do around you?**

**What else do you want me to know?**

Supporting a loved one with tube feeding can bring new challenges and opportunities for connection. By asking these thoughtful questions, 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/tube](https://www.oley.org/tube) or reach out to the **Oley Foundation** community. You are not alone on this journey—we're here to help.

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## **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 the Primed & Ready to Grow Conference or online, Kidz Klub provides a welcoming environment where kids can build friendships and have fun. Siblings are welcome too! Sign up for the Primed & Ready to Grow Conference, at <https://oley2025.vfairs.com/en/kidz-klub>.

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## Oley Foundation Acquired Feeding Tube Awareness Foundation

The Oley Foundation, a leading nonprofit dedicated to supporting individuals on home parenteral and enteral nutrition, is proud to announce the acquisition of the Feeding Tube Awareness Foundation and the FEEDING TUBE AWARENESS WEEK® registered trademark. This acquisition strengthens Oley's commitment to supporting the tube feeding community and raising global awareness.

The Feeding Tube Awareness Foundation has been a trusted source of education, advocacy, and support for families navigating tube feeding. Its signature event, FEEDING TUBE AWARENESS WEEK®, has played a key role in dispelling misconceptions and promoting awareness.

With this acquisition, Oley will expand the reach and impact of these initiatives, ensuring the continued success of FEEDING TUBE AWARENESS WEEK®, held annually during the first full week of February. Oley invites consumers, caregivers, clinicians, and advocates to join in this exciting transition and stay tuned for updates on upcoming initiatives at [oley.org/tube](https://www.oley.org/tube).

## About Oley

The Oley Foundation is a non-profit organization that advocates for and represents the home nutrition therapy community. Our vision is to create a world where those on IV nutrition and tube feeding are united, supported, and empowered to successfully manage and thrive on home nutrition support. We believe in inclusivity and value the collaboration of patients, caregivers, and healthcare professionals. Your participation and contributions help make Oley a unifying platform for sharing best practices and providing patient-centered care. To learn more about our initiatives and opportunities to get involved or to make a donation, visit [www.oley.org](http://www.oley.org).

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[For more information and support visit Oley.org](http://www.oley.org)

