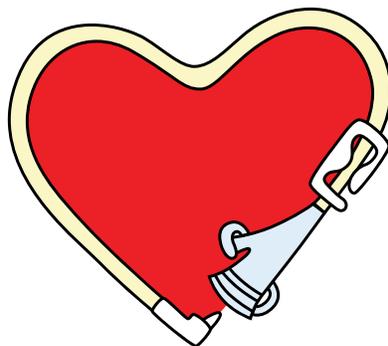




What We Want You To Know

A Family & Friend Guide to Tube Feeding



Feeding Tube Awareness Foundation®

Raising Awareness and Sharing Knowledge

Introduction

It can be overwhelming for a parent to learn his or her child needs a feeding tube. Therefore, one of the most important things that you can do to help is to offer them understanding and support. You are taking a wonderful first step by picking up this guide to learn more about tube feeding.

The first thing to understand is that tube feeding is often a last resort. For those with clear medical issues, it may be a first line to ensure that the child is receiving nutrition and hydration. However, for infants and children who have been struggling to eat, tube feeding is brought up after many things have been already been tried.

We need support from our loved ones.

It can be hard for some people to understand why our children are tube fed because many children with feeding tubes do not look sick. Their feeding tubes provide us with a way to keep them well nourished. It is important to remember that it may take a lot of work to keep our kids looking and feeling healthy. It can be a strain on our family, particularly if we have other children or if we are working parents.

You can learn to help. It isn't as scary as you think it will be.

Follow their lead. Remember that they may have had traumatic experiences that make accepting help difficult. Let them know that you are there to help however you can. Be willing to learn so that you are able to help.

Friends & Family Say It...

I love that tube. It has given my granddaughter life. In the beginning it seemed a little frightening, but you embrace what gives your grandchild life. I was determined to learn how to use it. It is just another way that I could get close to my granddaughter.

Melody, *Grandparent*

Yes I had my fears and was hoping that he would start taking his bottle and go right on. He didn't and that is okay. I KNOW I would not have him to love and share his sweet little ways.

Pat, *Grandparent*

When my baby sister first got her tube 4 years ago, she looked a little different but she was still really cute. When people wonder about her tube, I tell them about it and answer their questions. Most kids are nice about it, they've just never seen a feeding tube before so they're curious. I love her tube because it keeps her healthy!

Ashtyn, *Big Sister*

I wish that I had realized that having a tube placed did not make me a bad mom. We love our children dearly, but sometimes accepting that no matter what you try, your child needs a doctor's help can be very difficult. Those first few weeks after surgery were hard, but seeing her start to thrive, and laugh, I've realized that I made the best decision I could. Trust your instincts, keep your faith and remember that you're giving your child every tool possible to help them. A tube is no different. It's just another tool to help them eat, and it's my daughter's path to a happier and healthier life.

Jennifer, *Parent*

My cousin is cool. She eats right into her tummy. And sometimes I get to help!

Hazen, *Big Cousin*

I would like my friends and family to know how thankful I am for my child's tube. I wish they would let me educate them and show them that we know what we are doing. We don't want to talk about it being sad that they won't eat birthday cake...we want to focus on celebrating in ways that don't focus on food.

Amanda, *Parent*

Myths and Facts About Tube Feeding

In order to help you better understand what your loved one is experiencing as the parent of a tube fed child, here are some of the myths they may be dealing with. You can help them by knowing these facts.

Myth: *A parent didn't try hard enough to make their child eat.*

Fact: In our experience, parents try everything to get their children to eat. It is a natural instinct for a parent to feed his or her child. Some children require extra nutritional support to stay healthy. Tube feeding is a last resort. Tube feeding allows children to get the nutritional support they need to grow and develop, either when eating orally is not possible, or while exploring the medical reasons a child cannot eat and drink enough.

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

Fact: Some children benefit from tube feeding because they can't eat enough by mouth. Others need tubes because they can't eat some or all types of food safely. If a child can eat safely by mouth, oral eating should be encouraged as much as is possible to maintain and develop oral eating skills. However, just because a child can eat some, it doesn't mean that they no longer require supplemental nutrition through tube feeding. Moreover, forcing a child to eat will often make oral aversions worse and promote an unhealthy relationship with food. We highly recommend that interactions with food be positive.

Myth: *Tube feeding is forever.*

Fact: Some children have medical conditions that will require them to have feeding tubes their whole lives. But for many children, tube feeding is temporary. Children are able to wean off their feeding tubes once they are no longer medically necessary. It is often difficult to estimate how long a feeding tube will be needed, especially if the child's medical condition is not yet fully understood.

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

Fact: There can be a bit of trial and error in the beginning. Tube feeding isn't one size fits all. Learning what is best for a child is a step-by-step process, particularly with infants and children who are unable to tell us what they are feeling. It can take some time to figure out medical conditions and find appropriate treatments.

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

Fact: Tube feeding itself does not limit a child's ability to roll around, play, climb, run, swim or play sports. A child's physical ability will not be impacted by having a feeding tube. Even children who feed continuously can wear feeding pumps in backpacks and still be active.

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

Fact: It is easy for parents and caregivers to learn how to use the feeding tube safely at home. Very few parents have any medical background before they begin the feeding tube journey.

Myth: *You must use formula for tube feeding.*

Fact: You can tube feed breast milk, formula, or blended foods. The diet can vary based on a child's medical condition and tolerance.



Things to Consider About Tube Feeding

Children who are tube fed may not look “sick.”

There are hundreds of medical conditions that can require tube feeding and many aren't things you can see. You can't see how the body and different organs work. However, because they do have underlying medical issues, they may be at increased risk when exposed to germs. Please understand it may take a lot to keep our kids looking and feeling healthy.

Getting child care for a child who is tube fed may be difficult.

It is not an option to get a babysitter off the street. We are learning or have learned how to care for our children and their medical equipment. We would welcome your support, because we all need a break. Also note, that we may need to do some additional planning if we are leaving our child who is tube fed with a caregiver.

Some environments can be very challenging for children who are tube fed.

- Birthday parties and gatherings with lots of kids can be loud and boisterous. Children with feeding tubes are more likely to have sensory issues because of their medical history. Moreover, some parents may be concerned about exposing their kids to germs. A simple cold for a healthy child may land a child who is tube fed and has medical issues in the hospital.
- Holiday and family gatherings are focused on food. It can be difficult for a child who wants to eat but has limited “safe” foods. Please keep food out of reach and ask a parent in advance of serving food or drink to a child who is tube fed.
- Any child in a restaurant can be difficult, but a child who is tube fed typically can't be distracted by food. Moreover, other diners and wait staff may question why a child isn't eating, which can be uncomfortable for parents who are new to tube feeding.

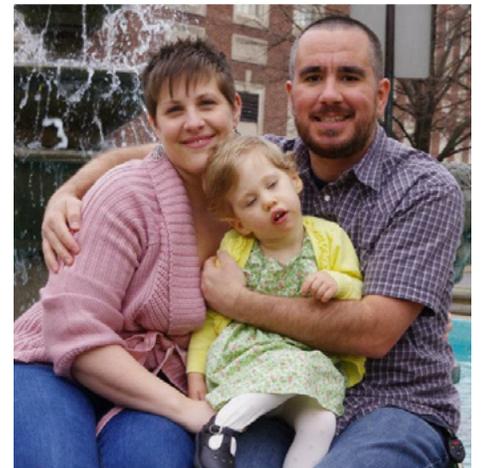


Parents may be emotionally drained.

It can be hard to see tubes coming out of your child day in and day out. It is a constant reminder they are not like other kids. Some children are undiagnosed and going through testing. Some children have developmental delays and other conditions where they need ongoing assistance with day-to-day activities. Family and friends may not realize the amount of stress parents are under.

Our level of empathy may have changed.

We understand that it is difficult for parents to have a kid who has an ear infection or an infant who needs shots. But, parents of children who are tube fed may not feel the same level of empathy as they did before. Children who are tube fed often have had numerous medical procedures, including surgery, and visits to hospitals. Children may be on various prescription medications and have been exposed to anesthetics, barium, and x-rays, often from very early ages.



Children who are tube fed may be entitled to certain services.

There are government programs designed for children with medical needs. Some of these programs are not income based. Parents shouldn't be judged for using programs that will help in the care of their child. It can be very costly to have a child with medical needs and specialized formulas can cost hundreds to thousands a month.

What Is Helpful and What Isn't Helpful

What is Helpful.

Listening. Parents who are just starting on this process have a lot on their mind. They have concerns and they may not know all the answers yet.

Helping by doing other chores. Cooking, straightening up, taking care of our other children.

Understanding that parents are the experts. This can be hard if you have raised your own children. Unless you are involved with conversations with doctors, specialists, nurses and are with the child day and night, you may not fully understand the situation.

Asking questions is fine. Just be mindful of our feelings. This is our child.

Talk directly to an older child. He or she may be able to answer questions.

Understanding that tube feeding isn't unpleasant. It is just another way to get in calories and hydration.

Learning more. Try to understand the child's medical conditions.



What isn't Helpful.

Saying you "hate" the feeding tube. Also, don't say you wish that the child would just eat normally. We also wish that there wasn't a need for a feeding tube, but we are very aware that tube feeding is making it possible for our children to get the nutrition and hydration they need to live, grow and thrive. If a child couldn't breathe well enough, you wouldn't hate the oxygen tank.

Feeling bad for us or our child. Empathy and acknowledging challenges is fine, but don't feel bad for our child if he or she is unable to eat certain foods. Help us find ways to make gatherings about more than food.

Telling us that it is just a matter of finding foods that our child will eat. If it was that simple, the feeding tube wouldn't exist. There are underlying medical issues that often can't be seen.

Comparing apples and oranges. Something may have helped your friend's cousin's child with reflux, but that doesn't mean it will help a child with a different medical history and conditions.

Telling us not to feed our child in public because it will make this person or that person uncomfortable. Children shouldn't have to be fed in a corner or a bathroom, or not fed at all because of social concerns.

Giving a child food without the permission of the parent some children have dietary restrictions or are unable to eat food safely by mouth.



Types of Feeding Tubes

Nasal Tubes (NG-, ND-, and NJ-tubes)

Nasal tubes are non-surgical and temporary. They enter the body through the nose and run down the esophagus into the stomach or into the small intestines.



Gastrostomy Tubes (G-tubes)

G-tubes are placed through the abdominal wall into the stomach. This sounds scarier than it is. G-tubes can be more comfortable than nasal tubes and are a safer option for longer-term tube feeding. There are two types of G-tubes including long tubes and skin-level buttons.

Gastrojejunal Tubes (GJ-tubes)

GJ-tubes are placed in the stomach just like G-tubes, but a thin, long tube is threaded into the jejunal (J) portion of the small intestine. Most often the J-port is used for feeding and the G-port is used for venting and sometimes for medications.



Jejunal Tubes (J-tubes)

It is sometimes necessary to place a separate J-tube that has a stoma directly to the intestine. This is not usually an initial feeding tube placement for a child.



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

What kind of feeding tube does your child have?

What is your child's condition or diagnosis?

How can I help you when you are feeding your child?

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 your child?

What else do you want me to know?

Feeding Tube Awareness Foundation®

The Feeding Tube Awareness Foundation was founded in 2010 by parents of children who are tube fed, who understand the emotional and practical challenges associated with raising a child who is complex.

The mission of the organization is to raise positive awareness of tube feeding, to increase the visibility and acceptance of tube feeding in our communities, and to help parents get the practical knowledge and support they need.

The Feeding Tube Awareness Foundation is a registered 501(c)(3) charitable organization that is run 100% by volunteers who have children who are tube fed .

www.feedingtubeawareness.org
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