



## How to Approach Feeding Tube Conversations with Families

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For people living with neuromuscular diseases and their families, there are many difficult steps to take over the course of the disease. Getting a feeding tube may be looked at as one of these. For some, the idea is confusing or scary. For others, it can be mistakenly seen as a defeat. In fact, a feeding tube is a tool that can help make life easier for patients and families.

We talked with Umme Salma Vahanvaty, MS, RD, a clinical dietitian at the Neuromuscular Clinic at Children's Hospital Los Angeles, about talking with patients and families about this step.

### Start the conversation early

Patients and families often don't realize that there may be reasons to begin considering a feeding tube before it becomes necessary because of chewing and swallowing issues.

Recommending a feeding tube for a child with a neuromuscular disease depends on several criteria, such as whether the child can consume enough calories by mouth and whether they are growing adequately. “Muscle weakness might not even be the deciding factor,” Umme explains. “It could be difficulty with the textures of the food or if there are issues of aspiration when they can’t get fluids down.”

An often-overlooked factor is whether eating has become stressful for the patient and the family. “Sometimes it just isn’t worth it to go without a feeding tube even when it can be done,” Umme says. “There are moments when it’s such a struggle that you need to tell the family it’s okay to go to a feeding tube. It’s not a requirement to avoid it until the last moment. It doesn’t mean they’re not doing their job as a loving family member.”

She stresses patients and families are more comfortable when the idea of a feeding tube is introduced as something to consider in the future rather than a decision that must be made immediately out of necessity. Therefore, it’s best to mention feeding tubes and start educating patients and families about their potential benefits early, then guide them through the progression toward a feeding tube.

As a dietician, Umme’s role in this process is to look for feeding solutions that will help a patient before moving to a feeding tube.

“We usually start by optimizing their intake of foods and maybe introducing high-calorie supplements, such as Ensure or Boost, along with smoothies or shakes,” she says. “After that, we may introduce an appetite stimulant.”

Umme also notes that constipation can affect appetite, so it’s a good idea to rule that out.

“The bottom line is, usually, you can see the feeding tube will be needed for a while before that day comes,” she says.

## When it’s time for a feeding tube

How do you approach the patient and family when it’s time for a feeding tube?

- **Address any misconceptions.** A feeding tube is just another way to manage a patient’s diagnosis, and it’s important to try to destigmatize it. Umme advises asking questions and actively listening to the patient’s and family’s fears and concerns. Often, addressing their fears and providing your perspective will make it seem less daunting.
- **Use visuals or a class.** Give patients and families an educational handout or booklet about feeding tubes. (See “Feeding tube resources” for shareable materials.) “This can help reassure them and also give them something they can take with them and think about it when they have a chance,” Umme says. “In our hospital family center, we also have a class on feeding tubes that families can take.”

- **Make sure the care team is on the same page.** Umme says she makes sure she and the patient's other providers are talking with the family about feeding tubes. “Having a team approach makes families feel better that there has been that communication,” she says.

## Don't lose sight of what's most important

Even when the decision has been made to use a feeding tube, the family may still need some time to take that step — and usually, there is time.

“Often, you can give them a chance to get comfortable with the idea, even after they've agreed, and it really helps for them to be comfortable with the decision,” Umme says. “Remind them that it doesn't signify anything other than the patient needs a little more help getting the right nutrition. It shouldn't be a negative.”

In fact, in Umme's experience, many families that were unsure at first felt relieved after the feeding tube was placed because it eliminated a lot of stress around eating. “That allowed them to put their energies into other things — keeping the patient's spirits up is one of the biggest.”

## Feeding tube resources:

- Share this [Quest Media](#) article with patients and families: [What You Need to Know About Feeding Tubes and Nutrition](#).
- The [Oley Foundation](#) has resources and educational information appropriate for adults and children.
- Kids will enjoy the empowering [Super Tubie](#) children's books.