

## Addressing Feed Intolerance

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At the Feeding Tube Awareness Foundation, we hear from thousands of parents who are new to navigating tube feeding with their children. One of the early and more persistent issues that parents face is feed intolerance. So often when you start tube feeding a child, you aren't fully sure what is going on medically. Many children are labeled "failure to thrive" and are not eating or drinking enough when they first start tube feeding. They are often put on a feeding regimen that is a dramatic increase in volume and calories over what they were taking in orally.

The initial feeding regimen is a starting point, but most parents take it as written in stone. They usually aren't made aware of the fact that it can take some time and adjustment to work out what is best for the child.

When a child doesn't tolerate the feed schedule, parents can panic. I did. My son was two months old and we were instructed to bottle feed for 30 minutes, tube feed the rest over 30 minutes, and repeat eight times a day. Our total of 24 ounces over 24 hours was eight ounces higher than my son had ever taken in orally on his own. I was covered in vomit. We slowed the feeds down to where they were taking 60 – 90 minutes to infuse. I didn't sleep. I was exhausted and emotionally drained. I remember standing in my kitchen just crying and thinking why wasn't this working? In a nut shell, my son had pretty significant gastroparesis, but we didn't know that until many months later. Subsequently, we moved to continuous gastric feeding 24 hours a day and then to gastrojejunal feeds a few months later.

Over the years, we made dozens of changes, and I tracked every one to see how it improved his tolerance of feeds (or not.) My primary goal for several years was minimizing vomit.

Feed intolerance really does matter. The perception that many parents have is that no one cares if their child is vomiting, or retching, as long as the child is gaining weight. However, recurrent retching and vomiting takes a significant toll on both the child and the parents. It impacts oral aversions, oral eating, and quality of life for both the child and the rest of the family.

What would help parents navigate feed tolerance?

First, they need to **understand what feed intolerance looks like**. We have heard the full range from parents who accept numerous vomiting episodes a day, because they think that is what is typical of children who are tube fed, to those who panic over a once a week vomit or retching episode. You can help set the expectations, so that parents know what is in the range of "typical" and what is abnormal and should be addressed.

**Let parents know that changes to the feeding regimen are common** and that there are many things that can be changed or adjusted to make feeds more comfortable for their child. Few parents understand the myriad of variables that go into feed tolerance; they often just blame the formula and think the child can't tolerate it.

What can help with feed intolerance?

- **Venting.** We hear from so many parents who were never taught to vent gastric (G) and gastrojejunal (GJ) tubes. Infants often need to be vented frequently, as do children who have had fundoplication surgery or have motility issues. Older children may not need as much venting, but it is always best for parents to try venting to see if it is needed or not. Continuous venting using a Farrell Valve bag is a great option for kids who need more continuous

venting, particularly overnight while feeding. And, yes, the gastric (G) port on gastrojejunal tubes often does need venting, particularly right after transitioning to jejunal feeds.

- **Modifying the feed schedule.** Is the parent bolus feeding too quickly? Could using a pump make it easier for a parent to deliver a feed at a consistent rate or more slowly over a longer period of time? Would a child do better with a gravity feed over a syringe bolus? Does the child need to be on more continuous feeds either overnight, or both day and night?

Parents fear continuous feeds for two main reasons. They are afraid of their child tangling or choking themselves with the tubing overnight, or that the continuous feed will impact their child's ability to be mobile during the day. You can assure them that tens of thousands of children, including those who that are active, have managed well with continuous feeds. Also, when setting a feed schedule, please keep in mind the ability of the parent(s) to execute it over time. A round the clock bolus schedule might be fine with an infant, but it isn't sustainable over the long-term.

- **Evaluate the total volume/calories fed.** Is it just too much for the child given their medical condition or activity level? For example, kids who have very low muscle tone or are less active may not need as many calories as a child who is more active and mobile. Also, those who are on jejunal feeds may gain very quickly since it is such an efficient way to take in calories, and the child may no longer be vomiting their feeds. Or is the parent afraid of the child being failure to thrive and trying to add extra calories?
- **Caloric concentration.** There is a tendency to increase caloric concentration for children who have issues with volume or motility issues. However, these high calorie formulas can be really hard to tolerate. I always think of it in terms of the foods we eat and how caloric they are. There are few foods that are 45 calories per ounce, and we just don't eat them all day long every day. Moreover, calorie rich formulas have less free water so additional water has to be incorporated into the feed schedule or there can be issues with both constipation and dehydration. Also, consider the jump in calories when changing formulas. The move from 24 to 27 calories may be tolerated well, but the move from 20 to 30, or 30 to 45 may be more difficult. It is important to consider that every child may not be able to tolerate 1.0 and 1.5 formulas, however, you can teach parents formula recipes that will bring the caloric concentration to an appropriate level for their child.
- **Constipation.** So many children who are tube fed have issues with constipation, or bowels just not emptying as they should. Make sure parents understand free water and their child's hydration needs. Addressing the constipation or slower moving bowels can really improve their feed tolerance.
- **Type of formula or food.** Is it whole protein, peptide, amino-acid? Is it real food, or could it be? Is added fiber appropriate or not?

We find that parents do not understand the differences between whole protein formulas and ones that are partially or fully broken down. Nor do they understand how that can impact how a child tolerates their feeds.

Research has shown that a blended diet improves retching in children with fundoplication<sup>1</sup>, but experience has shown a broader range of children who experience less vomiting as the amount of real foods is increased in their diet. We hear consistent feedback from those who use blended diets that bowel function is normalized, which in turn, can improve motility.

- **Type of feeding tube.** Does the child need to progress from nasogastric to nasojejunal or from gastric to gastrojejunal feedings? If the child isn't tolerating continuous gastric feeds with an appropriate diet, then they will likely need to move to continuous jejunal feeding. However, encourage parents using bolus gastric feeds to try continuous gastric feeds before moving to jejunal feeds, as all jejunal feeds must be given continuously. Moreover, by switching from bolus to continuous gastric feeds some children may be able to avoid the more invasive procedure needed to place nasojejunal and more frequently, gastrojejunal feeding tubes.
- **Identifying the underlying medical conditions.** Has the child been tested for food allergies, eosinophilic disorders, motility issues, structural issues, etc.? Keep lower incidence conditions like visceral hyperalgesia and cyclic vomiting syndrome in the back of your mind. And, if a child has low muscle tone, they may have issues with motility, too.

Last but not least...

- **Modifying feeds when children are sick or have experienced trauma, such as surgery.** Parents would automatically change the diet of an oral eating child when there is illness, but they do not think of it with a "prescribed diet." Let parents know that when kids are ill, they will likely need to adjust feeds to focus more on hydration, than calories. Feeds may need to slow down. Also, that it can take a week or so (depending on the severity of the illness) to get back to the normal feed schedule. It can be tough for parents of children who are labeled "failure to thrive," but children will recover from the illness more easily if they are tolerating feeds and remaining hydrated.

Moreover, children who have had surgery may not tolerate the same feeding regimen they were on prior to the surgery. For example, a child who tolerated a particular feeding regimen may not tolerate the same feeding regimen after having the percutaneous endoscopic gastrostomy (PEG) surgery for a week or more, depending on the child's medical conditions.

It is really important to emphasize to parents that they only change one thing at a time. You can't determine what is and isn't working if you change more than one variable. It can be a lengthy process, but parents will give you more leeway, and be more patient with the process, if they feel you are working with them to achieve a better outcome for their child.

**Sample Feed Tolerance Tracker:**

Feeding Regimen:

Formula: \_\_\_\_\_ Calories/oz: \_\_\_\_\_

Total Volume: \_\_\_\_\_ Total Calories: \_\_\_\_\_

Bolus Feed:

Feed Amount: \_\_\_\_\_ Times Fed: \_\_\_\_\_

Feed duration: \_\_\_\_\_ Fed by: Pump Gravity Syringe

Continuous Feed:

Feed Schedule: \_\_\_\_\_

Pump Rate/hour: \_\_\_\_\_ Dose: \_\_\_\_\_

Oral Eating:

Amount of food: \_\_\_\_\_ Total Calories: \_\_\_\_\_

Amount of liquids \_\_\_\_\_ Total Calories: \_\_\_\_\_

Use the table to log all events. For vomits and retching, note correspondence to feeds, and note if they are tube feeds or oral feeds.

<b>Modify to what makes the most sense for the child.</b>	<b>Vomit</b>	<b>Retching/Gagging</b>	<b>Bowel Movements (note consistency)</b>	<b>Other, not related to illness: Hiccups, coughing, sneezing, hard swallowing</b>
<b>Day 1:</b> Morning Afternoon Evening Overnight				
<b>Day 2:</b> 9 am feed noon feed 3pm feed 7pm feed Overnight feed				
<b>Day 3:</b> Midnight – 6am 6am – noon Noon – 6pm 6pm – midnight				

Footnotes:

<sup>1</sup> Pureed by gastrostomy tube diet improves gagging and retching in children with fundoplication. *Journal of Parenteral and Enteral Nutrition*, May 2011 35(3):375-9. doi: 10.1177/0148607110377797. Pentiuik S., O'Flaherty T, Santoro K, Willging P, Kaul A.

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