



# Complex Child E-Magazine

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## Our Tube-Weaning Roller Coaster

by Jinjue Serre

My son is 3 1/2 and has had some sort of feeding tube since he was three months old. We have tried continuous feeds (feeding him 24 hours a day), pump bolus (intermittent) feeds, gravity bolus feeds, and no feeds at all. It is such an up and down process that it gets incredibly frustrating. He has been off of his tube for a month at a time here and there, but always ends up losing weight and having to use it again. I am torn between being proud of him and sad. I'm proud because he can eat enough to be "off" the tube, but sad because it seems pointless to take him off since he always stops growing.

Jacob was born with a heart condition called Dilated Cardiomyopathy, but he was not diagnosed until he was three months old and in severe heart failure. Leading up to the heart failure, he would eat less and less and was steadily losing weight. By the time he was diagnosed, his body was too sick and weak to even drink a bottle. He started out with an NG tube and then switched to an NJ tube (because he was throwing up over 30 times a day) and finally a G tube. He took nothing by mouth until almost his first birthday. Between not eating orally and severe reflux, he developed poor oral motor skills and a very sensitive gag reflux.

I have recently come to realize that I have been jumping the gun on the whole weaning process. I have wanted him to be tube free so badly that I have rushed him, and that is why he always ends back on the tube. We are currently using the tube again after an almost one pound weight loss last month. His gastroenterologist was very specific **that we really needed to use the tube**. We have a very good doctor who knows that I use my best judgment when it comes to how much and when to use the tube, but he does on occasion have to remind me, "That's what it's there for!"

Another difficulty is that our urgency to get him off the tube as quickly as possible has affected him emotionally. We would always encourage oral eating by saying things such as, "eat like a big boy and we won't have to use your tube." Now when I do use his tube, he sadly asks, "Mom, did I not eat good?" It breaks my heart that he feels like he has done something wrong when we have to use the tube, but at the same time I do feel that he needs to understand that using the tube goes hand in hand with how much food he eats. I still don't think we have found that balance, and I am not sure if we ever will.

I don't know from day to day if he is not eating because he doesn't think he's hungry, if he's just being picky, or if he just plain feels sick and weak. So for now we encourage him to eat, and give him 50 percent of his nutrition through his tube, reminding him that

the tube portion is to help him get even bigger, and telling him that he did a great job eating, even if it is just three bites!

I have to remind myself that the number one goal is to have my son be healthy and growing, whether he gets his nutrition entirely through the tube, some by tube, or all of it orally. I have to focus on growth and development, and not the method of administration.

Some day I hope that he will weigh enough that he can afford to lose a bit, allowing us to again attempt to go one hundred percent oral and see what happens. In the mean time, I remind myself how happy he is when he has the proper nutrition by using his tube. And I love to see--slowly but surely--the ounces add to him.

*You can read more about Jacob at <http://www.caringbridge.org/visit/jacobserre>*