

## **“Our Journey from NG Tube to Ice Cream Cones”**

Trish Whitehouse, Bobby's Mom

The road of transitioning from tube feedings to oral feedings for my son was a complex series of twists and turns. It is not the same for every person, and this is only our journey. This journey progressed over the course of 3 years, and went from where my son would not even allow a drip of water in his mouth, to where he is eating totally orally without the support of the tube. A little background here might help you understand where the need for the tube came from and how we allowed our son to make the transition.

My son Bobby was born with a congenital heart defect requiring a series of surgeries. The first surgery at 4 days of age went well, and he came home in 10 days, requiring an NG tube for supplemental feedings. He was a bit of a preemie, (4 lbs) and weak from the surgery, so being an RN, I convinced the hospital staff to discharge him with a feeding tube so that feeding issues would not delay our discharge.

Over the course of the next three months, Bobby transitioned off the NG tube onto total breastfeeding. He went in for his second surgery when he was three months of age, but this time things did not go as smoothly, and he developed a complication which kept him in intensive care for the next three months. He had every intervention possible to keep him alive; numerous tubes down his throat so he could be hooked up to a breathing machine, chest tubes, IV and monitoring lines, suctioning down his throat on an hourly basis, tubes up his nose, on his face and every where there was an available patch of open skin.

When Bobby came home from the hospital that time, he wouldn't let anything in his mouth. I was told it was an aversion, or fear, because he had had so much inserted down his throat against his will. This caused him to be fearful that something else near his mouth or throat was just going to cause more pain. His muscle tone was atrocious; he looked like a limp dish rag, couldn't lift his head and his abdominal muscles were very weak. I was told that this aggravated his reflux and made him even more reluctant to eat. Also, because he had been intubated so many times, his gag reflex moved from the back of his throat to the front of his tongue, so whenever anything hit the front of his mouth, he'd just throw up. In retrospect, I think it is probably a combination of many things, and what worked to allow him to eat by himself was probably also a combination as well.

They said he had "oral aversion". I have always disliked the term "oral aversion" because it makes the kids seem like the bad guys and that they dislike everything that comes their way...that they are being stubborn and negative. I like the term "oral inexperience." in that when these kids were supposed to be doing all these oral things, learning how to suck, and eat, and swallow, they were

busy keeping themselves alive. So they don't have the experience that other healthy kids have, and they have to learn it all from the beginning. That always helped a lot when I was confronted with people telling me that he was just being stubborn, that it was all "behavioral", and that if I just starved him, he'd eat. He couldn't eat! Goodness knows I tried that;, went for two days without anything, but it did nothing but make me a nervous wreck and put tremendous pressure on him.

The very first few months after discharge the only thing he could do was mouth a metal measuring cup. It was very smooth, and I think he choose this because there was no chance of getting a frightening texture in his mouth. He would also only do this in the bath...something about the water helped calm him to a point where he could accept things orally that otherwise he wouldn't touch. I used a reclining tub because at 18 months he still could not sit up unassisted. We tried to put different tastes and flavors on that measuring cup, but he'd gag or throw up and toss the cup out of the tub on the floor. One day he'd accept something and the next day he totally refused it.. By following his lead, I learned what he liked, and he learned to trust that I would not push past where he was comfortable.

It was a very long process, but little by little, and I do mean little, he started to put things in his mouth. It was a cup here, a toy there, a toothbrush with a tooth paste he liked (but only that one flavor), and I tried food, but it was useless. At about 9 months of age, 6 months after he left the hospital, he took his first sip of anything. I had made a cup with a wedge cut out of it for his nose to fit in so he could breathe, and he would stick his tongue in the breastmilk and lap it up like a little kitten. I think having the control of putting his own tongue in the milk and not having it come at him helped him feel safe enough to continue trying. It had to be freshly pumped breastmilk, because if it was any other taste he would push it away. Most times I had to offer the cup to him only after he had his diuretic, because other times he wasn't motivated enough to touch it. But it was a starting point. I started to believe at this point, that because he had allowed 5 or 10 cc of breastmilk into his mouth (1 or 2 teaspoons) he would be able to drink all that he needed if only he had the motivation. I had no idea how long the whole process would take and how much more he needed to learn before that was possible.

At this point, Bobby was still on a continuous drip of breastmilk at 30cc/hr, day and night. In order for him to have a feeling of hunger and satiety, we needed to get him on a bolus schedule so that his stomach would stretch when it was full, signaling satiety, and when it was empty, it would trigger a feeling of hunger.

But getting him onto a bolus schedule from a continuous drip felt like which was pure torture because it was so slow. I could raise the drip only by about 5 cc every couple of days, and he'd throw up anyway, but most of the days were more better than they were bad, so we kept going. Our highest volume with the NG tube was about 5 ounces every three or four hours. After we had a Gtube, I

could go up to 8, 10, 12 ounces, though again in retrospect, I think they were a little too high and aggravated his reflux again. All along with the boluses, we were trying to give him food by mouth that only HE wanted, clearly asked for and invited. We never did the purees, because he would push the spoon away, and throw up. For some reason, purees were too threatening for him. He had to put the things in his mouth by himself, so it was a progression of handing him things that he would hold and lick; teething biscuits, crusts of pizza, anything where a piece of it would not break off. If a bit did break off accidentally, I bet you can guess what would follow next...he'd throw up. Looking back I don't know how I made it through with my sanity in tact. I would hold my breath with every bolus and every piece of food he mouthed and pray he wouldn't throw up. But a lot of times he did anyway.

Next, we moved to the high chair and tried to bolus him there while he was playing with food, so he could make the connection between high chair/eating/full, but he couldn't sit still long enough for me to finish the bolus. (He still can't) He'd throw up if he was playing with food and got some in his mouth while simultaneously getting a tube feeding. We always had to do the oral food play on an empty stomach. We played with crumbs on the highchair which was a big leap for us, because he'd get some on his hands and try to wipe it off (he had a tactile sensitivity as well) and eventually he'd get his hand to his mouth by mistake and get some in. At first he just tried to get the crumbs out, which put more in, but eventually it all helped to desensitize his mouth to food and textures. He liked to mouth Ritz crackers and pretzels, and they were less threatening because they would just melt in his mouth. He hated lollypops, Popsicles, anything that usually works, and I'm not sure why because he loves them now. At the time, I just listened to him, trusted his choices, and didn't push what was "supposed to" work if it didn't. But I kept handing him anything I had, asked my other kids eat in front of him constantly and had him join us at every meal at the table even though he wouldn't eat a thing, and we plodded along.

Then , with help from our team, we started the "appetite challenges". We would either delay a tube feeding by an hour, and see if that helped to increase his interest, or skip it all together and make it up on the night drip a little. We were on a meal, snack, meal, snack, meal schedule by tube, to set his body up for the way it was supposed to be whenever he would really eat. Some days were great, some days were awful and I couldn't get it all in him. But we eat different amounts every day as adults, and I had to learn that tubefed kids are no different. So I started to learn his cues for being too full, such as arching and fussiness, and stopped the bolus for a while to give him a break. That was a hard one for me, because I wanted to get a specific amount in his in order to feel like it was working...whatever "working" is. But we are so used to numbers and amounts with our tube fed kids that it is hard to see them as a person with feelings after a while.

Each time we did an appetite challenge, I'd see something. Maybe he'd start to take a food he hadn't before...and he'd get it on his hand, or maybe he'd even mouth it. Sometimes I'd see big changes, like he'd eat something and not choke. Sometimes I'd see him actually pick up a toy or a spoon and let something with a flavor get into his mouth. As we progressed with these challenges, I'd see him eat something I could actually count as volume and I'd have to cut back on the bolus I was supposed to be giving him afterwards. Sometimes I'd have a big smile plastered on my face because he'd do so well, and sometimes I'd be in tears because I was so discouraged. But we kept at it, getting support to do it this way. Higher pressured, behaviorally based feeding clinics enticed me but it always felt right for me to do it this way. Trust is a big issue for Bobby, and I worked very hard to regain his trust after he had, by necessity, been "abused" so many times in the hospital from medical interventions. I was not going to jeopardize that trust by forcing him to do what he clearly did not want to, or was not able to do at that time.

We always limited the appetite challenges...they would be for one meal, or for two days, or over a weekend...so that they didn't stress me out. That way I knew there was an end to it all and he wouldn't lose a huge amount of weight if we were skipping meals. So, after doing this for what seemed like an eternity, he finally started chewing. At first again, (nothing happened quickly with him) he would chew something and spit it out. Maybe some of it made it down his throat, who knows? Most of it wound up on his hands and face, but even that was an improvement from where we had started. But then over time the pieces started to disappear from a cracker and wouldn't be spit out, or I'd wonder where a bit of an apple had gone. (I actually looked under couch cushions and under the bed to make sure he really did eat a piece!) He started to insist on a carrot if my older child was eating one, and I'd make a face thinking "Sure, a carrot", but to my surprise he'd take a bite. The older kids were very important in this whole process because he just wanted to be like them and they included him in everything just as if he were an oral eater. They would hand him things I would never have thought he'd care about, and to my amazement, he'd at least take a lick.

But it was about 2 years into this whole thing, 2 long years, when he just started to swallow. I was shocked. Now we were seeing volume disappear...even difficult foods such as, nuts, whole carrots, pastas, cheese, apple slices...he would only like certain things and be wary of something new, but I kept putting something novel on his tray which he'd throw off most of the time. Maybe one day after seeing that item on his tray regularly for 6 months, I guess he got tired of throwing it off, and he'd try it. Now he eats a lot of foods. A lot! He'll try almost anything...salads, vegetables, sandwiches, pizza, he drinks from a straw, cup, he'll play with a bottle, though he skipped that suckle stage, he puts all kinds of things in his mouth with no gagging, and I can't remember the last time I saw him throw up.

The boluses I gave him were blended foods as soon as we got a Gtube. Before that I was really restricted with a 5 fr. NG tube. I think the blended foods helped get his gut prepared for oral foods, and helped his body develop a preference for the real thing, both in gut flora and in that he would burp up real food and taste it as it came up. I also think, personally, that we are all meant to eat real food, and that just because these kids are tube fed, it doesn't mean they should get any less than what we all get.

What has evolved over this journey is a happy, confident, trusting eater. He has an incredibly wonderful relationship with food. He loves it, screams for it, enjoys it, and feels like part of the family when it comes to eating. Last night we all got ice cream cones at the local place, (he doesn't like ice cream, it's too cold for him), but we all got one and he put out his hand to the window as if to say "Well, where is mine? You think everyone else is getting one and not me?" So I paid for another one, thinking that he'd never eat it, but he looked around at everyone else eating theirs, and licked that cone and ice cream for about 20 min. It's the things I never expect that keep me going and believing that this was the right way for us.

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