

“How much longer are you going to need that tube?”

People would always ask me how much longer I was going to need the NG tube for my son, and the answer was always the same. I would reply, “He’s getting really close, I don’t think we’ll need it much longer.” He was born with a congenital heart defect and had surgery at 4 days of age, did very well, and came home with an NG tube mostly because he was too weak after the surgery to eat. Over the next three months, he continued to need the tube for supplemental feedings, but little by little he learn how to breastfeed. By the time he was three months old, he was taking all of his daytime feeds at the breast, and he would get one or two nighttime bolus tube feeds, just to help him gain more weight until his next upcoming heart surgery.

The next heart surgery was much different, however. Bobby spent 3 months in intensive care, and most of those days he was very critical. He was septic many times over, received almost daily blood transfusions, had 4 chest tubes draining fluid every day, was on and off the respirator so many times I honestly lost count, and I had almost lost hope that he would ever come home to us breathing on his own, if he came home at all. He lost all the weight I had worked so hard to put on him during all those months of breastfeeding and tube feeding. He developed reflux, and couldn’t handle more than 10 or 15cc over an hour time without throwing up. He had total kidney shutdown, clots breaking off from his legs and nearly going into his brain, yeast infections... the list can go on and on and on. My point in saying all of this, though it is gruesome to most, but familiar to some, is that those three months of watching my son being poked, hurt and abused in almost every way imaginable, was totally devastating for me as a mother.

When he left the hospital, he was on continuous feeds of 30cc/hr via NG tube, continuous oxygen, and his muscle tone resembled that of a wet dishrag. When I picked him up, his body would flop over my shoulder with absolutely no resistance. He would open his mouth to scream, and no noise would come out. He was afraid to be touched, even in a loving way, and would scream his silent scream if I even brushed against his feet with my body. He would sit in his car seat and rock his head back and forth until he would go to sleep, because he preferred doing that than to being held by his own mother.

I had various people over the next two years tell me that my son would probably be better off with a Gtube, but I wouldn't even entertain the thought. When I had to drive into the parking garage of the hospital just for follow up appointments, there were many times I felt like someone was choking off my airway as I got out of the car. It reminded me of the 80 days I had to get in and out of the car and leave my son in someone else's care.

There was no way I was going back in to that hospital for what I saw as an "elective surgery" for a Gtube. "What we had was doing what we needed it to do, which was feed my son", I told myself. "No more pokes, no more holes, no more

anesthesia. It took an act of God, literally, to get us out of the hospital alive, there was no way we were going back in there electively". So I kept that NG tube in him for 2 years. I taped and retaped, put it back down when he threw it up, taught him not to touch it, even managed to put solids down it without clogging it. And I deluded myself into thinking that I could do this forever if it would keep us out of the hospital.

Then one day, I couldn't do it one more minute. It was as if I wanted it gone yesterday, and the scheduled Gtube surgery for one month away seemed like an eternity. My son started throwing the tube up one or two times a day instead of once every two months. My husband and I couldn't stand to pin him down one more time. I hated tucking the tail into his clothes and being afraid I would somehow pull it, which I did once or twice when I was getting him out of the car seat. Instead of a lifeline, that tube became my worst enemy, and I couldn't wait to get him into the hospital for the surgery. For me, that's what it took.

Well, the good news is that despite a little irritation around the site when my son recently had a virus, I am 100% happier. I didn't notice until after I had the Gtube all the subtle things I was doing with the NG tube in place. I hold him differently now, in more of a normal toddler way, mostly because I don't have a tube dangling from his shirt or pants. He gets much more facial stimulation because I kiss him and play with him constantly on his "naked" face. I blow his nose, something I hardly ever did with the NG tube for fear of loosening it. He has in turn responded to my change by becoming more independent. I saw a definite change in his personality when the tube was gone. He was much more confident and more able to freely explore his environment.

And as if there couldn't be any more perks, his oral eating totally exploded after we got rid of the NG tube. He went from mouthing food and slobbering on things like teething biscuits, which was miraculous in itself, to biting and chewing, sucking, drinking from a straw, talking much more, and on and on. A whole new world opened itself to us in an oral sense.

I had thought I would beat the odds, keep the NG tube until he did all the eating on his own, and eventually I'd be more stubborn than this "oral aversion". But I am so glad I didn't try to wait because my stress has been cut in half since we got this Gtube. I feed him real food by bolus in the tube, he is healthier, and no one stares at us, which is a big thing when I'm trying to normalize the impact this has had on our whole family for the other three kids.

His hospital course for the Gtube placement was very smooth...he was in the hospital overnight, tolerated feeds right away, he was given a button from the beginning, and I was on my way with him 4 days post op across the country to AZ to work with a feeding specialist. His pain was minimal, and he was totally off Ibuprofen in about 5 days. This was much better than that awful NG tube.

Now I feel like the weight of the world has been lifted from my shoulders. I don't say things like "When he gets rid of this NG tube..." (as if my life would start when he didn't need it any more). Now I say, "Bobby is learning how to eat and this tube helps him until he can do it all on his own." He is happy and thriving. This tube is my ally, and together we were able to nourish my son until he was able to do it himself. But the decision to get a Gtube had to come internally; no one could tell me it was time to change, that the NG tube wasn't working anymore, and that it was actually hindering his progress. It had to come when we were ready to accept it, and it had to be our own choice. But looking back over those two years with the NG tube, I don't know how I ever did it!

Trish Whitehouse, Bobby's mom