



Complex Child E-Magazine

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Growing to Accept and Love the G-Tube

by Amy Eaton

To all the moms and dads out there who have been told their child needs a G-tube, I wanted to share our story with you. We lived a total of eight months in the PICU because of our son's heart condition. I have so many memories from it. Scary times, happy times, surgeries, first smiles and first hugs. I'm sure many of you can relate to that. Life was a roller coaster of events! But taking a step back, I want to share the experience of one of my son's very first surgeries: his G-tube surgery.



Issac was around two months old and having numerous problems. He was still on the ventilator most of the time and not doing well. When he was able to be fed, it was through an NG-tube. But because of severe reflux it was very difficult to feed him. It was during this time that I first heard the words G-tube and Fundo. I had no idea what that meant or what it was. After it was explained to us I did not like the sound of it! I knew he needed it to survive though. He was so thin and frail. I then started thinking of

how wonderful it would be to know that he didn't feel so hungry, and to watch him grow and put on weight. After thinking about it in this way, I felt ready.

After my son first came back from surgery I was a little scared to look at him. He had been through surgeries before, but this time was different. This time he was going to have his G-tube, and I wasn't sure what that would look like or if it would be something scary. I hated the thought of my child having something new and foreign on his body.

I had lots of questions when I first looked at it. How is he going to have tummy time? Isn't this going to stick out from under his clothes? Can he take a bath? What if he pulls it out? It seemed so big and awkward. Over the course of time I got used to seeing it, but was a little afraid to work with it. The nurses started letting me try to open and close it and hook him up to his feeding tube. I had trouble at first, but after a few tries it got easier.

Looking back at that time now, I laugh at myself. By the time we got home from the hospital we were so comfortable with his G-tube that we could easily give meds, feed, hook him up or disconnect him in the pitch black. After a little while you just get a feel for it and quickly become a pro!

You become so comfortable with it that it doesn't even faze you if it accidentally comes out. I remember one time we were taking our son out of his car seat and his tubing was wrapped around the edge of the seat. We didn't realize it, and before we knew it his button popped out. That might sound horrible but it's really not. Our son has a Mickey button, and if it pops out for any reason, we just pop it back in! The doctors are always willing to show you how to work with it.

As for it showing under his clothes, you can't even see it. As children grow their buttons become less and less noticeable. It might look huge on an infant, but give it a few months and it doesn't look big at all!

Another one of my fears was that people would look at him differently or be afraid to touch him. It is true that you will get some glances at the button or tubing. But it is more out of curiosity than fear. I actually enjoy it because it gives me a chance to spread awareness about children with special needs and make people feel more comfortable with feeding tubes.

I think the only real negative I've had is that it takes away the special moments of giving a bottle or breastfeeding. But, you find new ways of bonding and new special moments. It is also hard work to continue to give your child speech therapy and improve oral motor skills in hopes your child will someday learn to eat strictly by mouth. But being a parent is always hard work!

My son often plays with his tubing or twirls his button around with his little fingers. It is a part of him. I always tell him it is his second belly button. I really can't imagine him without it. He does all the normal things that any other child would do. He can take a

bath, do tummy time, or wear any type of clothing. His button does not limit him to what he can do. Really, it is very convenient. If your child becomes sick you can easily keep him or her hydrated. If he takes a lot of meds it is easy to give them. Plus you don't even have to wake them up for their feeding times, which means more time for mommy to relax!

All in all, I would say our son's G-tube has really been a blessing in our life! He is now 15 months old and eats nothing by mouth. Tube feeding is his only choice. It not only keeps him alive and growing, but thriving! I see now it is nothing to be scared of, but something you not only come to love but also to cherish.