



Complex Child E-Magazine

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Feeding Tube or Not? Making A Hard Decision by Michelle Doty

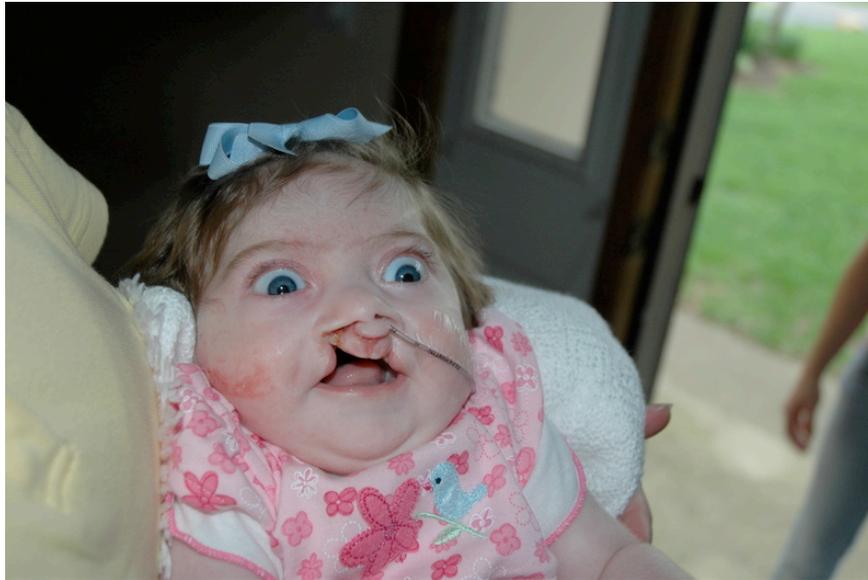
My husband and I were given the choice of whether or not to tube feed our daughter. Hers was not a clear-cut case of requiring a feeding tube for survival. However, feeding had been an issue since the moment she was born, and had become the central focus of our lives.

Campbell's Story

Our daughter was born with a bilateral cleft lip and palate that was not detected prior to her birth. Therefore, we were not prepared to address all of her needs. There was definitely a learning curve. We stayed in the hospital for five days consumed with learning how to feed her. She had a nasogastric, or NG-tube, to supplement calories that she was unable to take by mouth. There was always the possibility that she would go home with a feeding tube if she didn't take enough by mouth, but we were determined that she would eat independently. By day five she had gotten rid of the NG-tube and we were headed home with the special bottles that many children with cleft palates require.



We spent three weeks fixated on how many ounces she took with each feeding and how long it took. At that time, I think her intake equated to about two ounces over 30 to 45 minutes, which was not very efficient. She was burning the calories she was taking in because of the length of time it took her to eat. She lost weight the first two weeks, but started to gain some ground right before she was hospitalized for respiratory syncytial virus (RSV), which resulted in a sixteen-day hospital stay, including five days on a ventilator and a battle with aspiration pneumonia. She had a swallow study prior to being discharged that showed she was at risk for aspirating, so she went home with an NG-tube that she kept until she was seven months old.



Anyone who has had a child with an NG-tube knows that they are not the most comfortable or easiest form of tube feeding. Honestly, it was a nightmare. It was very easily pulled out and was highly visible. My daughter became a pro at pulling it out. It also was accidentally pulled out many times because it got caught on things, including my foot one time. I am thankful that one of my best friends is a nurse because I definitely called her in sheer panic the first time my daughter pulled out her NG-tube. By month seven, however, I could change the tube in my sleep, which I think I pretty much did one time when it came out at 3 am.

When my daughter passed her swallow test at seven months and the tube was removed, we were extremely happy to move forward into the world of oral feeding. Of course, it wasn't an overnight success, but within a few months she was taking a bottle and beginning some soft foods.

The Feeding Battle

I will admit it was never easy when it came to feeding her. As I reflect, the majority of my day was focused on what she had eaten, how much and when to feed her again. It still took a long time to feed her and she would often get tired and/or have reflux after a

meal. Beside her craniofacial abnormalities, she has hypotonia, global developmental delay and seizures that compound her feeding difficulties. Even after her cleft palate was repaired, she would get food in her nose due to a small space where she still had a cleft in her gum line. Soon after, ear infections followed, requiring ear tubes.



Whenever she had a surgery or was ill, feeding became the number one issue in her recovery. My constant worry was, “will she get dehydrated or have enough nutrition to heal and get stronger?” There were times when she had to be hospitalized for dehydration because she simply could not get enough fluids by mouth. One time she had strep throat and ended up spending four days in the hospital due to dehydration. Medication administration was also a critical component. When she was ill or was having seizures, her ability to take medications by mouth diminished greatly. This was the time when she needed her medication most, and getting her to take it was a hard job.

We worked with occupational therapists, speech therapists and nutritionists and I have a degree in occupational therapy as well. We all worked tirelessly to ensure that my daughter could eat by mouth. A feeding tube was never suggested at that point, but I knew from my background that that was the direction we were headed if things didn't improve. My daughter would frequently get sick and take a long time to recover. As soon as she gained some weight, she lost it with another illness. From her well child doctor visits at ages three to four, she did not gain any weight. It was time to do something.

Contemplating a Tube

I had researched tube feeding in children and had personal experience with tubes when I worked with the geriatric and adult populations as an occupational therapist. I also had grandparents who were faced with the “feeding tube decision” toward the end of their lives, and I was a huge proponent of not doing a tube just to prolong life.

I soon learned there was another whole side to feeding tubes apart from the perceived notion that tubes were just used to prolong a life that would not have any quality to it. I found that people of all ages from birth to adulthood live very fulfilling lives with a feeding tube. This included people who were healthy, other than needing a feeding tube, and those who had multiple medical issues but continued to thrive and enjoy life.



With my daughter, it wasn't a life or death issue. It was the opposite of what I had once perceived feeding tubes to be. While I had previously viewed them as an end-of-life decision that prolonged life, in my daughter's case it was all about improving her quality of life. Sure I could have avoided her having another surgery, adding another piece of medical equipment or even adding one more thing that is different about her--as some of the naysayers pointed out--but my husband and I decided a tube would improve her overall health. We decided to go with a gastrostomy tube (G-tube), which is a more

permanent type of tube versus the NG-tube. It is inserted through the abdomen and into the stomach for long-term enteral nutrition.

After a month or so, my husband and I could tell a huge difference in our daughter. She began to put on weight and had more energy. She did not get fatigued as easily. Now, when she does get sick, she recovers much quicker since we are able to keep her hydrated and nutritionally stable. Her cognitive abilities have improved as well. I still feed her food by mouth, but now it is for pleasure. I am comforted in knowing that she gets her required calories through the feeding tube. If she wants some yogurt or applesauce she can still have that. It has taken a lot of stress and worry out of both of our lives.

The Emotional Aspect

I often talk with other parents who are in the same place that my husband and I were when we were faced with the feeding tube decision for our daughter. They go through many of the same questions and feelings that we did. Of course, there is the stigma of having a feeding tube. It is something that sets your child apart from other children. There are the glances or stares and the questions.



I have found all of these worries have not been as bad as I once thought. People have been much more accepting than I anticipated. We are able to go out with our daughter as much as we did before. She has a cute backpack that holds her feeding bag that we have decorated. People still stare, but it often just leads to an educational experience explaining the benefits of feeding tubes.

Of course, there is the reality of another surgery and hospital stay when you get a feeding tube. Trust me, so-called “optional” surgeries are not viewed favorably at our house. Unfortunately, my daughter has required multiple surgeries, and if given the option, my gut instinct is a loud “NO WAY!” However, like all her other surgeries, she pulled through it OK and we eventually learned how to operate all of the new equipment. No, it was not a stress free time in our lives, but the benefits far outweighed the negatives.

Another factor is that parents, including myself, often feel like they are giving in or failing their child by allowing him or her to get a feeding tube. I know that I struggled with this a lot. I had spent four years trying so hard to avoid a feeding tube. A huge portion of my life was dedicated to ensuring that my daughter would be able to safely eat by mouth. Even the health care professionals that worked with us always hinted that it was not the optimal method of feeding.

What I have found is that this is not the case. Tube feeding is not a big deal and should not be seen as a bad or negative choice. It has been a good choice for my daughter and our family. She continues to thrive and improve daily. When I look back knowing what I know now, there really wasn't a choice. It has been one of the best decisions that my husband and I have made for our daughter's health. Her feeding tube really has been a lifesaver.

For more information, see the following sites:

- www.cleftadvocate.org
- www.feedingtubeawareness.com/index.html

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