



Complex Child E-Magazine

www.ComplexChild.com

My Irrational Fear of Feeding Pumps Explained by Rachel Nichols

I have an irrational fear of feeding pumps, which has perplexed many of my fellow tubie mommas. This fear is fueled by the horror stories I have heard from those very parents! While support groups such as Feeding Tube Awareness and Babies and Children with a Feeding Tube have given me unlimited support and advice, they have also filled my head with many possible, but highly exaggerated, scenarios in which the pump is the key culprit for disarray. Before I get into my illogical reasoning, let me tell you about my son Spencer.



Spencer is an amazing, hilarious, beautiful, and intelligent little boy. He has a huge fan base and is loved by nearly everyone who has met him. Spencer also has Pierre Robin Sequence with a submucous cleft palate, micrognathia, cranio-facial muscle weakness, bronchomalacia, laryngomalacia, tracheomalacia, hypothyroidism, bilateral club foot, moderate to severe hearing loss, ptosis, ASD, VSD, distal arthrogyriposis, hypotonia and developmental delays due to an unspecified genetic disorder. We knew about Spencer's foot before he was born, but the rest was a complete surprise. We have also found out that Spencer has a wicked case of reflux, fueled by volume issues and lactose and soy intolerance.

Copyright 2011 by Complex Child E-Magazine. All Rights Reserved. This document may be distributed for educational use only with proper citation.

Spencer had an NG-tube placed when he was one day old. After a couple of weeks of getting nowhere with a special feeding device, we decided that a G-tube would be the best option for him. This was the best medical decision we have ever made, as Spencer is still tube fed at 15 months old. He has little interest in eating by mouth, but that doesn't stop him from chewing on every non-food related item in his path!

At two months old, Spencer had a supraglottoplasty and was hooked up to a feeding pump continuously for a few days after surgery. It was a miserable experience for all of us. He was already hooked up to all these electrodes and the pulse ox, and the pump was another connection reminding us that we couldn't take our child more than three feet from his bed. His site didn't handle the pump well and he had a lot of drainage, his reflux was awful, and the feeds were time consuming. I vowed to myself that I would do everything in my power to keep the feeding pump out of our lives.

Spencer "graduated" from the neonatal intensive care unit when he was 83 days old. We were offered a feeding pump when he left the hospital, but we politely declined. Instead, we give him bolus feeds by gravity using a syringe.

My main objection to the feeding pump is that I fear he will eventually be put on continuous feeds. What is interesting about Spencer's reflux is that we'll try a new formula, it will work for a while, and then he will turn into a puke machine again. His doctor has actually encouraged me to put him on the pump because of his inability to take more than six ounces of formula a feed. It is my belief that she would rather find a quick fix for his reflux than a long-term solution, which involves finding a diet that works for him. I believe that because of his reflux, his feed rates would be slowed down until Spencer was on the pump continuously.

We are currently transiting Spencer to a blenderized diet, which his nutritionist and I think is the best option for him. We suspect that even the smallest amount of milk in his food will set off his reflux. The blenderized diet has been working great so far and his reflux has nearly gone away. If this diet wouldn't have worked, the next option would have been the feeding pump.

Another irrational fear is that night feeds would end in utter disaster! Spencer moves around a lot in his sleep. I have a fear that he will somehow wrap his tubing around his neck and choke himself. I also picture Spencer wiggling around until he pops his button out and his site closes before morning. I can also see him unhooking himself all the time and feeding the bed often.

If Spencer was hooked up to a feeding pump all the time, the tube would become a new "toy" to play with! This would involve Spencer tugging on his tubing and either pulling out his tube or keeping his site constantly irritated. He leaks profusely if his site gets the least bit irritated, so it would involve a lot of frustration and changed outfits.

On the plus side, our life without a feeding pump is great! It's one less thing I have to worry about. We already have so much medical equipment in our lives, so it is one less

annoying machine to deal with. I am grateful that feeding pumps exist because many of our tubie friends depend on it to survive, but I'm also grateful that it isn't a part of our everyday lives.

Rachel Nichols is a stay at home mom to her 15-month-old son, Spencer. Rachel holds a degree in English Education from Northern Kentucky University and enjoys reading, art, and music. Spencer is currently working on figuring out how to crawl and enjoys painting, terrorizing kitties, playing piano, and sticking things in his mouth. They reside near Cincinnati, Ohio. You can follow their journey via their blogs:

- ***Adventures in Tubieland: One Boy's Transition to a Blenderized Diet***
<http://adventureswithfeedingtubes.blogspot.com>
- ***Joining the Club Foot Club***
<http://talipesbaby.blogspot.com>