



# Complex Child E-Magazine

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## Breathing Easy: A Trach at Home by Lisa Jennings

Very few things in an individual's life are as fundamental as breathing. In and out, over and over again. Unfortunately, it is just not that simple for everyone.

When my daughter Monica was born she was breathing just fine. Pretty soon the problem became apparent: she wasn't swallowing, not even her own secretions. I knew nothing about aspiration, wheezing, crackles, stridor, oxygen saturation, or apnea before this new life came into mine.



### **The Equipment Takes Over**

When the doctors recommended a tracheotomy, the only point of reference I had was the confusing image of an elderly customer at a bank I had worked at years earlier. He had a metal tube tied across his throat, and every time he spoke to me, he raised a gizmo to it

and spoke in a mechanical voice. It was as if I was hearing him through the drive-up speaker instead of right in front of me.

I could not reconcile that picture with my newborn daughter, who already had a feeding tube in her nose and monitors all around her. How could I possibly care for this child? Well, the answer did not come quickly, but eventually I got the hang of it.

By the time she was ready to come home from the hospital I had rearranged our entire house to accommodate all the equipment needed to sustain her. How quickly my home turned into a mini medical unit and my car into a portable one! A compressor, a tank of liquid oxygen, a portable companion tank, an emergency Ambu bag, and the feeding pump together took up more room than her crib. The dresser, decorated with a colorful lamp, photo frame and piggy bank, became crowded with an oximeter, suction machine, boxes of spare tracheotomy tubes, rows of medications and syringes. The adorable linens and blankets given to us at her baby shower were protected by towels and protective chux. Pushing aside the bright little dresses held on delicate padded hangers in her closet were stacks of medical supplies, including boxes of suction catheters, suction bulbs, humidivents, sponges, and normal saline ampules. The shelves held teetering coils of oxygen tubing (not to be confused with the corrugated tubing used for her compressor), boxes of gloves and binders full of medical reports and nursing forms.

### **Mothers as Advocates...and Nurses**

Eventually, I found the best nurses and doctors who helped me to understand all of the subtleties of caring for a child with extraordinary medical needs. Some were better than others. Some trained me, and others I needed to train, since caring for my child was beyond their usual nursing duties.

No matter how many professionals you have supporting you, parents are expected to become experts in all of these things and so much more. As a single, working mom I had little choice. So I learned to ask questions, even if they were unanswerable, such as, "When would she begin to swallow?" I asked questions to improve my understanding and knowledge of her condition, such as how to assess her breathing, evaluate the different signs and symptoms, and respond to her low oxygen saturations.

Few people could appreciate how to cut and size the trach ties in such a way that the pointy Velcro ends would easily fit through trach flange holes and not pinch the skin of her neck. I learned that proper positioning in bed or lowering instead of raising the oxygen delivered could actually improve her saturations. A few blunders along the way also clued me in to new, unconventional ways of doing things. For example, one time I brought the wrong tubing for her oxygen on a trip and found that when I used the nose (humidivent) while she slept instead of the compressor, trach mask, and oxygen, it provided just enough positive pressure that she didn't need the oxygen at all. Her sats were better than they had ever been before. Instead of inadvertent mistakes that caused panic and stress, I choose to remember them now as moments of incredible insight.

Learning how to push for answers and walk away from bad ideas (in other words, ones I didn't agree with) with poise while still maintaining a sense of your self worth is an acquired talent. When Monica was about ten years old, she went through a period when her chronic lung disease was not actually getting worse and she seemed to be thriving. Coincidentally, she'd had no surgeries or hospitalizations. Her pulmonologist seemed to be reaching for something to do and actually suggested we might want to consider removing the lower left lobe of her lung. I easily considered and dismissed it.

Another time, when we were having Monica evaluated for her swallowing problem at an out-of-state clinic, she was given the opportunity to participate in a research study. She really didn't like the MRI process and couldn't stay still. A pulmonologist on staff who was practiced in hypnotherapy eased her fears and also gave us a recommendation for using the pulmonary chest physiotherapy vest. Both were amazingly effective innovations that her own skilled team had never contemplated.



### **A Story of Success**

My story of caring for Monica is as complex as her needs, with many terrifying moments and even greater achievements. Through all of her medical challenges, Monica has attended regular public schools, made great friends, taken ballet and earned a brown belt in karate. The absolute best gift came September 10, 2008 when Monica was 14 years old and a freshman in high school. Monica likes to tell the story, including how the doctor didn't do anything. I removed the fashionable trach chain and Monica removed her own trach for the very last time. Dr. H looked at it and covered the stoma with a

piece of tape. Monica then proceeded to order all her favorites from the hospital menu. It took her over an hour, but she ate that entire meal of tomato soup, macaroni and cheese, winter squash, and mashed potatoes and washed it down with a bottle of root beer.

Monica, like many of us, will always have challenges. She has become a remarkable young lady with a unique self-assured attitude and an interest in doing everything from becoming a nurse or veterinarian, to an actress or director, and a whole lot in between. That's my girl!

I have become many different things in my life too, mostly because of her. As we celebrate Monica's sixteenth birthday this April, we also have the opportunity to celebrate the achievements of a young lifetime, and the community of people who have brought her to good health.



Lisa Jennings is a mom to Monica, and an educational advocate, parent consultant, and active leader in several nonprofits related to disabilities, special education, genetics and 22q11.2 Deletion Syndrome, also known as VeloCardioFacialSyndrome.

She can be reached at [lisamjenn@aol.com](mailto:lisamjenn@aol.com)