



Complex Child E-Magazine

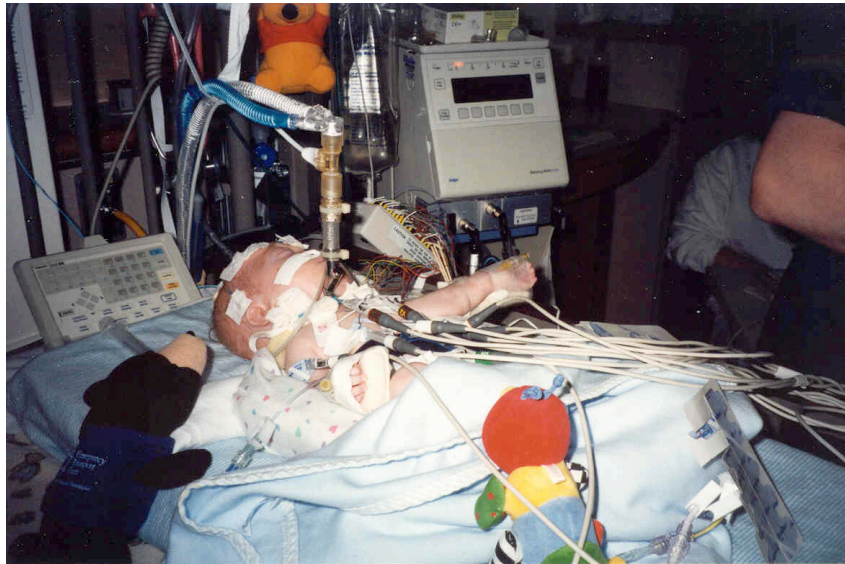
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Being a Kid: Thriving with a Trach and Vent

by Deb Millard

When I was pregnant, I was nervous about a lot of things. One of my recurring worries was whether or not my little guy would slip through my hands during bath time. I think those kinds of worries and fears are pretty normal for new moms. When Connor was born with a lot of challenges, I found my little worry was just that--a very little worry--and most certainly not something I couldn't manage. I was about to embark on the journey of my life, and the ups and downs of Connor's life would teach me some incredible things.

I could write volumes about all Connor's life has taught me, but right now I'd like to focus on how very typical a child's life can be, no matter what challenges he may face. It really is a matter of perspective.



More the Same Than Different

After a difficult pregnancy, a challenging eight weeks in the NICU, a crash and a code, Connor was given his emergency bedside tracheotomy, along with CPR, and emergency medications to literally give him another chance at life. He spent the next three weeks completely paralyzed and sedated as his body healed. Connor had sustained brain

damage; he was trached, oxygen and ventilator dependent. He struggled with seizures, severe GI problems, and many other serious health issues. We were told our son would be very low functioning, that he would never walk, never talk, that it would be best for him and for us to institutionalize him.

My husband and I had very different plans. We wanted to take our son home, share our lives and our love with him, provide him the best possible care, and be a family. One of the Physical Therapists at the hospital spoke with us during this difficult time. He offered us hope, and his words still resonate with both of us. He said, “Remember, Connor is more like other kids than he is different. Just treat him like a kid.” That is exactly what we did. It took time to get Connor home but we did it. We gave him everything we could, and he began to thrive in amazing ways!

Thriving with Medical Equipment

I think the key to living a full life with a child who has a trach, a ventilator, oxygen and other medical equipment is to remember that these items are there to help our kids develop, thrive, and enjoy a fuller, more meaningful life. They are not meant to hold our children back. It's easy to feel nervous around medical equipment, but instead of allowing it to intimidate us, we can master it, and use it help our children progress beyond what they ever could have on their own.



These are some things we did right from the beginning that really helped:

- Learning trach care by practicing on a trach doll until doing Connor's care was easy.
- Taking the time to learn the ins and outs of all Connor's equipment, including his ventilator, so WE became the "experts" on our son's care.
- Training several family members and friends to care for Connor's medical needs, so they felt comfortable around him, and we got much-needed breaks.
- Keeping an emergency bag packed and re-stocked after going out, with all his trach and other supplies.
- Keeping a journal of questions/concerns and issues to discuss with Connor's doctors during our weekly "check-in" phone conversation.
- Working hard to build positive relationships with medical personnel, therapists, educators and other resourceful individuals to provide Connor with the best possible collaborative services.
- Utilizing on-line support groups to develop and maintain relationships with other parents who had children with similar issues.
- Regularly updating an Emergency Information Form and having several copies available: <http://www.acep.org/patients.aspx?id=26276>



Just Being a Kid

Most importantly, we relaxed around our son and treated him just like any other kid as much as possible. He had to clean up his toys before snack time. He went to gymnastics with his friends, and we climbed through tunnels, oxygen, ventilator and all. We

expected a lot from our son, and he responded with more than we ever could have dreamed possible! He was very, very much like all of his friends, and enjoyed play dates, trips to Grandmas, times at the park, and so many other activities just like other kids.

Connor surprised everyone, most especially the doctors who had underestimated him. He learned to walk and to talk, to ride a bike, and so many other things. He charmed everyone he met with his amazingly sweet, spunky grin! He never could have done any of this without his trach, ventilator, oxygen and many other things that gave him his ability to breath, to have energy and to thrive.



Although it was not always easy, we know these “accessories” were what truly gave our son what he needed to enjoy a full and wonderful life, and we are incredibly thankful!

Deborah Tiel Millard worked full time caring for her son Connor, who struggled with significant medical and developmental challenges for over eight years before he passed away due to complications of mitochondrial disease and hemophagocytic lymphohistiocytosis (HLH). She now utilizes her experience as a Parent Liaison supporting parents of children with special needs at a private school in NJ. Deb also supports children and families through Connor's House, which she co-founded in September 2008. Connor's House is a non-profit organization in NJ that supports

children with complex health care needs, together with their families, by creating a community of support that helps them to embrace each day and live life to its fullest. To learn more about Connor's House please check out: <http://www.connorshouse.org>