



Complex Child E-Magazine

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Caeley's Voice: Passy-Muir Valves for Kids with Trachs by Mary S.

When my daughter Caeley had her tracheostomy placed at 18 months old, my husband and I were concerned with whether she would be able to vocalize after the surgery. She was able to vocalize with her ventilator, but as we began weaning her off of the vent, we weren't able to hear her speak anymore. I asked her pulmonologist about options for a speaker valve, and we set up an appointment with a speech language pathologist for an evaluation.

The initial evaluation process was not difficult, and it went smoothly. We went in, talked to the therapist briefly, and she talked to Caeley a little about the valve, particularly that it might feel a little different. Then she hooked Caeley up to a portable pulse-ox machine, and put the speaker valve on. We used a Passy-Muir brand valve, but there are other brands that are all essentially the same. Caeley did very well with her oxygen saturations, although we noted that her work of breathing did increase somewhat.

She kept the valve on for about thirty minutes. The evaluation ended on a bad note because Caeley started coughing, and the sound of her coughing scared her. She got upset and didn't want to put the valve back on, so we ended the evaluation. We went home with the valve, and with instructions to start Caeley wearing it for ten minutes per day, increasing to thirty minutes per day in two weeks time.

The next day we put the speaker valve on Caeley, and she did wonderfully for about ten minutes. She had a coughing fit at the end, and once again became scared of the sound. The third day she refused to put it on at all, and became very agitated and upset at the sight of it. I worried that she was not tolerating the valve, but her speech therapist thought that it just felt different and the difference was scaring her. We kept trying for the next few months, and she refused to put it on at all. Eventually we gave up and began looking into alternate means of communication.

During this time, I did some research on speaker valves, and found that it is very common for children and even adults to get upset wearing the valve in the beginning. The basic design of the valve makes it feel very different while breathing, and it takes some time to adjust to the difference. A speaker valve for a trach is a one-way valve that fits over the end of the tracheostomy tube. The wearer inhales through the tracheostomy tube, and then the valve closes, forcing air up around the trach and out the mouth and nose upon exhalation. This allows for vocalization as air passes the vocal cords.

The way that a speaker valve functions means that it is not an option for everyone with a tracheostomy. Anyone with upper airway obstruction preventing exhalation out the mouth and nose would not be a candidate for a speaker valve. Also, caution is to be used with anyone who has tracheomalacia. Children with severe tracheomalacia may not be able to tolerate the valve because their airways collapse, either partially or completely, upon exhalation. There may not be enough airway space for them to exhale around the tracheostomy tube. When I came upon this information in my research, it caught my attention because severe tracheomalacia is one of my daughter's diagnoses. I wondered if this was causing her to become very resistant to using her speaker valve.

I spoke with her speech therapist about my research, but she felt it was more of a behavioral problem than a functional problem. Even so, we gave up actively pushing Caeley to use the valve. All of our various attempts, from forcing to bribing, got us nowhere. The therapist would get it out periodically, but Caeley was still very resistant to using it.

As Caeley got older, her respiratory status improved significantly, as did her airway. One day Caeley and her older brother were playing in her room, and found her speaker valve. He talked her into putting it on, and she wore it for about 30 minutes, screaming and shrieking while scooting around her room. Caeley had found a fascination with the sound of her own voice. She had an episode of coughing during that time, but she was willing to put it back on afterward, which was a huge improvement.

Since that time, she has been steadily improving in her ability to tolerate the valve. I am not sure why she was resistant to it initially, but I do believe that at least some of it was due to her airway. Even now, she works harder to breathe while wearing her speaker valve, and she cannot wear it at all when she is ill. If she exerts herself physically while wearing the valve, it decreases her ability to tolerate it.

However, I can see that there is an element of behavior to it as well. We have found that she is very picky about who is around when she is wearing her valve. She rarely wears it out of the house and it has been very difficult to get her to wear it at school.

The Passy-Muir valve is a wonderful device that restores voice to people unable to vocalize due to a tracheostomy. Most children are able to tolerate the valve very well, after adjusting to the difference in respiration. Sometimes, depending on the diagnosis, things are more difficult, and a child may not be able to rely on the valve as a primary means of communication. Right now, we will keep working with Caeley to help her tolerate her valve, but she also will use an augmentative communication device for when she cannot or will not wear her speaker valve.

Despite struggling through initial difficulties with the valve, there is no feeling in the world that compares to putting Caeley's Passy-Muir valve on her, and hearing her little voice say, "Hi Mama!"

For more information on Passy-Muir valves, visit their website at <http://www.passy-muir.com/>