

A Life Less Ordinary

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I can state with confidence that if I had not started using a ventilator, I would not be writing this. Like many kids with SMA (spinal muscular atrophy), I was at the mercy of every virus or microbe that might decide to take up residence in my respiratory system. My parents made valiant efforts to keep me healthy, but I still managed to get several nasty colds each winter. Sometimes those colds would turn into pneumonia, followed by the inevitable hospital stay.

By my early teens, I had already made several trips to the University of Wisconsin Hospital in Madison, which was hundreds of miles from my home in Green Bay. My pediatrician began making pointed comments to me about a future life with a tracheostomy, but I didn’t want to hear it. I remembered the discomfort of a tube shoved down my throat, and the thought of having something like that as a permanent fixture of my body scared me.

It wasn’t long before I had to confront my fears. After yet another bout of pneumonia landed me in the hospital and on a ventilator, my doctors presented me with a stark choice. In order to go home without either a vent or a trach, I could spend the next several months in the hospital as I was slowly weaned from the vent or I could get a tracheostomy and go home with a portable vent.

My parents and I decided to go ahead with the tracheostomy. I was weak, and it would only be a matter of time before I would be back in the same situation. Better just to get it over with.

I won’t lie; the adjustment to life with a ventilator was far from easy. I deeply resented the loss of the little independence I had cultivated for myself before being admitted to the hospital. I had to get accustomed to the notion of having a nurse or family member with me at all times. My adolescent moodiness only amplified my anger. There was even some talk of placing me in a facility for kids

with intensive medical needs, but my parents quickly squashed that idea.

Little by little, things got better. My body (and the tubes coming out of it) didn’t feel quite as foreign to me as when I first came home from the hospital. The ventilator’s presence faded into the background clutter of my life as more of my attention shifted to school and other interests.

I had always had a fascination with computers, and a series of coincidences introduced me to assistive technology that allowed me to operate a computer with only slight head movements. Finding that device went a long way towards restoring my sense of independence.

I’m now on the verge of turning 35, and I’ve used a ventilator for more than two decades. In that time, I finished college and left Wisconsin to attend law school at the University of Minnesota. I became a licensed attorney and found work as a law clerk for a district court judge.

Siegel has used an LP10 for the last 10 years and before that the LP6. He gets around with an Invacare TDX3.

For the past six years, I've been employed at the Minnesota Department of Human Services where I work on policies to improve the lives of people with disabilities. I've done many of the things that most adults my age do: started a career, purchased a home in downtown Minneapolis, traveled to places around the country and points overseas such as Paris and Berlin.

In order to live independently, I depend on 24-hour private duty nursing funded by Minnesota's Medical Assistance program. After many years of using home care agencies and growing tired of their inability to retain good people, I discovered that I could hire nurses myself without using an agency.

Managing a staff of independent nurses has worked well for me, although it takes some effort to set up and maintain. It has also required me to become a more vigorous self-advocate. Nobody else knows my body and my needs as well as I do, and I've learned that I can't be shy about communicating that knowledge to my caregivers.

I still contend with the occasional frustrations that accompany life with a ventilator. My speech is sometimes slower than I'd like it to be. Privacy is scarce, and sometimes I can only find it in the glow of my computer screen. Ironically, I can also feel terribly alone on occasion.

And it's difficult to be spontaneous when I always have to consider things like battery charges and nursing shift changes. It's easy to become too focused on the daily minutiae of maintaining myself and my equipment. In the days leading up to my

trip to Europe, I remember being terrified that I would accidentally fry my ventilator by plugging it into the wrong outlet. But for the most part, things take care of themselves, and I don't give much thought to my ventilator use.

Despite the hassles and complications, I do not regret the decision to be trached and vented. I'm much healthier now than I ever was as a kid, and I don't get sick more than once or twice a year. My energy reserves are more than adequate to allow me to live a full life. With any luck, the ventilator will give me a few more decades to do the things I haven't gotten around to yet, like finishing that book and seeing a little more of the world.

I can't say that a trach/vent combo is right for everyone. It has worked well for me, but your circumstances and priorities may be different from mine. But I can say that life with a ventilator is not the bleak existence that many imagine.

In fact, I wish that my present self could somehow time travel back to 1987 to reassure my younger self that things would get better. That he can look forward to a future where he lives independently, has several close friends, and even the occasional girl takes a liking to him. I would tell him that it's a future worth living for. ▲



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