

Learning to Dance in the Rain

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“Why do you walk like that?”

That single question haunted me for years. Young children would boldly demand an answer as they pointed at me. Adults would not dare to voice the question, but looked puzzled as they watched me walk. And I, I would ask myself that question daily as I struggled to understand why I had to be different from everyone else.



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When I was in elementary school, none of my classmates were familiar with polio. With the vaccine's development in the '50s, polio had become a disease that my friends had just heard about from their parents. Even in India, where I was born in 1964, the disease was almost eradicated although there were sporadic outbreaks since the vaccine was not given to infants less than 6 months old.

At 3 months of age, I contracted polio, but the inexperienced doctors assumed I had typhoid and gave me cortisone to lower my 105-degree fever. Twenty-four hours later, after the poliovirus had spread throughout my body because of my depressed immune system, they realized their mistake. But by then it was too late – I was almost a quadriplegic, with little movement in my arms or legs.

With limited medical options, my family quickly left India and moved to London, where I had my first surgery at age 2 by the renowned polio expert, Sir Herbert Seddon. Shortly afterwards, we moved to Canada where I went on to have 20 more surgeries, many at the Shriners Hospital in Montreal where I lived for months at a time throughout my childhood.

Most of my operations were muscle transfers which helped me to walk, though I always had a pronounced limp, visible evidence of my disability. Since my arms were very weak, crutches were out of the question, so I had to walk unaided or use

a wheelchair. The doctors recommended I try a special school for people with disabilities, but my parents were determined to keep me out of a wheelchair and in regular public school. I needed to learn to survive in the real world.

While hospital life was lonely, it was less painful than the constant mocking that I experienced in the “real” world. Through elementary and middle school, I buried the hurt of that teasing deep, yet it constantly whispered to me that I didn't count, that I didn't belong, that I'd always be an outsider. But at age 16, the acceptance of an unlikely friend broke through that pain, convincing me for the first time that I was worthwhile.

Finally feeling comfortable with myself, I chose to go away to the University of Virginia, to see if I could make it on my own. Virginia was not accessible, and I struggled to get into buildings with stairs without railings. Before one particular class every week, I had to find a friendly passerby to give me a hand up the countless steps.

Going to Virginia taught me to be independent; I discovered I could live on my own and survive if I had the courage to ask strangers for help. At first, it was humbling, but then it was liberating. If I didn't need to rely solely on people I knew, I could go anywhere and be okay.

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That revelation gave me the confidence to take a job in Boston after graduation, an unfamiliar city where I learned to manage on my own.

After four years in Boston, I moved to California to earn my MBA at Stanford. There I met my husband, and afterwards we settled down in North Carolina, near my parents. We had three children, two daughters and a son, who died at 2 months old. Although he was born with a heart problem, his death was the result of a doctor's mistake, which made the grieving even more difficult. I naively thought that after polio, I would not have to face more suffering; in my mind, everyone should endure only one major trauma, and I had already had mine. It only seemed fair. But as I buried my baby boy, Paul, I realized that none of us are or ever will be immune to tragedy.

About six months after Paul died, I was diagnosed with carpal tunnel syndrome. I was told that it could be a precursor to post-polio syndrome (PPS), but I was unconcerned. Surely that couldn't happen to me as well. And yet several years later, I learned that indeed I did have PPS after debilitating pain in my right arm led me to pursue treatment and an eventual diagnosis by Dr. Julie Silver at The Spaulding Clinic in Massachusetts.

Many of the changes suggested at Spaulding were helpful: electric gadgets, voice-activated computer software, assisted steering for my car, but other things were more difficult: giving up my hobbies, getting a wheelchair for community use and slowing down my pace of life. It seemed that all the things I'd worked for were crumbling before my eyes. At first, I was resistant to making any changes, but I soon realized that I needed to think long-term, if only for the sake of my daughters, who were ages 5 and 8 at the time.

I slowly made the necessary adjustments, trying to keep the activities that brought me the most pleasure. It was yet another grieving process as I said goodbye to my old way of life. Yet as with any loss, there is an opportunity for something

new to develop to fill the void created. My primary method of expression had always involved my hands, or specifically right hand, as I was an artist as a young woman and a scrapbooker as a young mother. Surprisingly, I found my new creative outlet in writing. I started writing poetry and just finished a memoir chronicling my childhood, detailing the unique yet universal struggles of growing up with a disability.

The last few years have been especially difficult, as I was recently divorced from my husband of 20 years. It has been a daunting task to raise two, now-teenaged, daughters on my own with PPS. Yet I know I can find joy as I face the next chapter in my life if I'm willing to look for it.

My faith is a big part of my life and has enabled me to weather the tempests without losing hope. I love the saying, "Life is not about waiting for the storms to pass, it is about learning to dance in the rain." I am truly grateful for my polio; it has taught me that I can overcome, that I am resilient, that I will endure.

So now, when I am asked the inevitable question, "Why do you walk like that?" I can answer, "Because I had to learn how to overcome adversity; I needed to know how to dance in the rain." ■



Vaneetha, age 2, with her mother.



Vaneetha, age 7.



Vaneetha and her daughters, Katie (left) and Kristi.