

My Polio Story by

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Over the years I've told my story many times. I've noticed that it changes slightly each time I write. I am never sure what I'll say, and I am always interested in seeing what will come up. I know that my current struggle is aging and that this idea of aging gracefully totally escapes me. I don't seem to be good at it at all.

I had polio at the age of two. I lived in a small south GA town with my parents, brother and a multitude of extended family. No one else in that little town had polio and the doctors refused to believe that I had it. I have several yellowing, crumpled pages written by my father, which describes my misdiagnosis, and his anguish as they finally determined that I did indeed have polio. For almost a week the MD's in that small town laughed at my mother and called her "hysterical" as she brought me in daily insisting that I had polio. As he writes, I was ill on Monday, August 12 with a cold and slight fever. By Friday, August 16 my temperature was 105 and I was unable to walk. Finally, I was rushed to Atlanta where a spinal tap confirmed my diagnosis.

Although I was only two years old, in severe pain and near death, I was ripped away from my parents and placed in an isolation ward. As I begged to see my parents and as they begged to see me, I was removed from everyone I knew and treated by frightening people who wore white,

starched uniforms and masks. Fortunately, I have very few conscious memories of this period. But, I grew up hearing my mother's lengthy descriptions of this four-month ordeal. Imagine four months of struggling to live while being abandoned by your parents, your brother and everyone else you knew. Mother later said that when they were finally able to come to the hospital to take me home, I was afraid of them and did not know who they were. This further added to their grief. I can't imagine what it did to the innocence and trust of that two-year-old.

Surprisingly, I did not have the remarkable recovery that most people that had polio experienced. In terms of paralysis, I am essentially as I was the day I left the hospital. My legs were paralyzed and I had some weakness in my back and trunk but no involvement of my lungs. To this day I feel cheated that I didn't have that amazing recovery that most people experienced. For years I wondered why God did not love me as much as he did others who had polio. Most people who had polio could stand and/or walk in one fashion or another. I never did. Being the good little Warm Springs "hero", I was able to stand with long leg braces locked at the knees and full-length crutches. But it was with great effort and difficulty and never a functional means of mobility. It became a useless endeavor that put me at constant risk of falls and injury.

After one particularly devastating fall in my late teens, I had a doctor question why I continued to try? It was a completely novel idea to me that I consider giving it up. He explained to me that I would never walk functionally and that I put myself at great risk of injury to my arms and shoulders to continue to try. He told me that if I gained psychological benefit I should continue, but otherwise he felt it was a detriment to my shoulders, elbows and wrists. That was the mid 1960's and although I do not even remember his name, I credit him with having uncommon wisdom for that period of time. As a result I threw away my braces and crutches and embraced the idea of life in a wheelchair. I now believe that this was a wise choice.

But, let's go back to that little, two-year-old girl trapped in a small south GA town facing life in a wheelchair. Like most of us, I faced incredible odds to become yet another remarkable polio hero. I went to first grade with my peers, excelled in everything I touched, became president of every club and organization I joined, and graduated from high school with more credits under my senior picture than anyone else in the whole yearbook. And by golly, I went to college, married, had two children and generally lived as if I did not have a disability. As all of your stories go, I refused to let having polio (being in a wheelchair) limit me in any way.

And, the glory does not end there...I continued to be president, chairperson, leader of everything I touched. I even became obsessed with wheelchair sports when the idea came to Atlanta in the mid 1970's. I was one of the founding members of the Dixie Wheelchair Athletic Assn. and competed in wheelchair basketball, swimming, track and road racing. I was among the first GA athletes to compete in national competitions. I held many national swimming records and was the first female wheelchair athlete to compete in the Peachtree Road Race. Nothing fed my ego more than competing in able-bodied road races, and I was off and running (pushing) at every foot race I could find.

My accomplishments go on and on...the ego was alive and well in those days. I am sure that part of the drive had to do with making up for lost time because I didn't have an opportunity to compete in sports as a child. Females weren't allowed in those days, much less a female in a wheelchair. The downside was that the training and competitions were burning up those nerve endings and causing irreparable harm to an upper body that was already into serious overuse.

Where were all the physicians to warn me about this overuse theory? Actually, they were just around the corner because by 1980 I heard the news, or suspicion, that people who had polio

where experiencing new weakness and fatigue. At first I refused to listen. After all I was still competing in all the sports that I loved. I had been denied the opportunity to compete in sports as a child, and no one was going to take away this one opportunity from me as an adult. Although I was in complete denial and refused to slow down, I could not overlook the fact that I did not recover after a hard workout as quickly as others did.

Reluctantly, I went to Warm Springs after having left it behind many moons ago. They had started up a new polio clinic and I was one of their first patients. I heard the doctors say things that I never expected to hear. I was in a state of shock. They told me that I should give up my manual chair and start using a motorized one. I was still competing some and had dreams of getting back to my sports competition fulltime. How could they expect me to start using a motorized chair!

Life began to get really difficult for me. I got weaker and weaker and training became more and more unrewarding. At the same time my living conditions were changing. We sold our home in the suburbs and moved out on some acreage. The plan was to raise horses and enjoy rural America.

What a poor choice for me! I went from a home that offered me the conveniences I needed, to an existence where everything was difficult; and most especially caring for my children. I couldn't keep up with them or anything else, including my husband. I will always believe that post polio problems were in part to blame for our divorce. Suddenly, I was alone to face raising our nine-year-old son and eleven-year-old daughter. And, for the first time in my life my disability loomed large.

It was another eight years before I began to believe the awful truth, a motorized wheelchair was an appropriate choice for me. During that time while I raised my children, I went back to college and got a degree in therapeutic recreation. I helped start the Atlanta Post Polio Association and am one of its founding members. I worked as a therapist both at Emory Rehab and the Shepherd Center.

When the Americans with Disabilities Act was signed, I became the Training Director for the southeastern ADA Regional Center. Later, I accepted the position as the State ADA Coordinator and worked under two governors towards ADA compliance in GA's state-owned facilities. I had a two/three hour commute back and forth to work each day, and I am sure those neurons continued to sizzle and burn. Unfortunately, I still wasn't taking post polio syndrome seriously. It was only after being diagnosed with cancer and having to undergo major surgery, that I resigned my position and retired.

Retiring was one of the hardest things I have ever had to do. I loved my job and believed so much in what we were doing. What has not been hard is adjusting to retirement. I love it almost as much as I loved my job. I had no idea how much strain I was putting on my body to work a full time job. I really think the colon cancer was my body's way of slowing me down. (Fortunately, I am working on year #7 without a recurrence.) I love not having a schedule, I love not having to face rush traffic every morning and I love using my time the way I want to use it. I have not missed the stress one minute.

I sold my home and live in an apartment near downtown Atlanta. I actually enjoy not having a house and living maintenance free. My wonderful children are now grown and live in the metro area about 40 minutes away. I use that motorized wheelchair prescribed back in the early 1980's and I appreciate all of the many things it does for me.

I have slowed down considerably. I am not "President" of anything, nor do I want to be. It has taken a lifetime for me to learn that the only things really important in this world are my relationships with my family members and friends.

And, I add to that my relationships with others who have had polio. We share a common bond and face common challenges that no one else can really understand. I have never met anyone who had polio that I didn't like and I am so looking forward to meeting you in Branson. Please ask me about going on a cruise. It is my new "most favorite" thing to do.

