

Never Knowing My First Diagnosis Of Muscular Dystrophy

When I was just a little older than a year and a half, my parents noticed that I wasn't meeting the normal milestones that other children were meeting at this age. I wasn't crawling or pulling up in an attempt to try to stand. My parents took me to a neurologist who, after examining me, told my parents that I had Muscular Dystrophy and that there was nothing they could do. Doctors told my parents to take me home and enjoy what little time I had left. I can only imagine the devastating feelings and the emotions that my parents were going through. While I was too young to understand the diagnosis and what this diagnosis meant, my parents never told me the about this diagnosis until I was around seven years old. My parents made sure that I had as normal of the childhood as possible, even living with the fear that my life may be cut short. Around the age of two, my overall strength grew, which contradicted the diagnosis of Muscular Dystrophy. When my parents took me back to the neurologist, they told them that I probably did not have Muscular Dystrophy, but they would have to wait until I was five years old so that they could take muscle biopsies to determine exactly what I had. While this was a relief to my parents, they were still left in the dark with regards to my condition.

When Did I Realize My Life Was Different Than The Children I Grew Up With?

I knew my life would be different at an early age. Outward appearances, (body size, physical attributes, body shape, etc..), were the same as my friends. Physical attributes, (strength, mobility, etc..), were apparent to me when I was around two years old. I knew that I was “different” but those differences were pretty much non issues because neither my friends or myself spoke about them. At an early age, children back in the late 60’s never made issues regarding any of these outward differences. Children that are raised around handicapped children, especially at an early age, haven’t learned the concept of teasing yet, so my early years were “normal” regarding acceptance among my early peers. Besides, all the parents back in this generation would not of tolerated any physical or verbal abuse. If something like this had occurred, one parent would’ve called the other parent and the guilty child and their parents would’ve had a “Come To Jesus” moment. BTW - Back in the late 60’s, a “Come To Jesus” moment would have guaranteed the guilty child the inability to sit down comfortably for the remainder of that particular day.

Being Around Other Handicapped Individuals

While my childhood was pretty much normal, one of the issues that I had to deal with at an early age was the feeling of being uncomfortable around other handicapped individuals. Even at an early age, I noticed that people would stereotype and label people who were handicap, and even though I was young, I didn't want this label being put on me. I learned at an early age that even though people accepted you for who you were, this label, or stigmatism, would be given to me. This awkward feeling of being uncomfortable around other handicapped individuals plagued me until I was in college. It wasn't until I was in college that I learned to accept these emotions that were causing me so much discomfort and it was also at this time that I learned how to deal with these emotions on a personal level. I will discuss these in further detail as we go through this presentation.

smajourney51

Walking With Braces And Crutches Until High School

From the age of two, all the way through junior high, I not only used my wheelchair to get around, I also used braces & crutches. My braces & crutches allowed me to get up and walk around for a few hours each day. Typically, while in school, I would get out of my wheelchair and walk from one class to the other. During the end of junior high, I realized that my classes in high school would be further apart from each other, and using my braces & crutches would be pointless because there would not be enough time for me to get from one class to the other. The summer before I began high school, my parents bought me my first electric wheelchair. Knowing that this would make my life easier, it also brought me a new sense of freedom because I could become more independent in the way that I lived my life. Both my parents and I understood that even though this may have been a step backwards, because I would no longer use my braces & crutches, we also knew that going into a wheelchair permanently would benefit me and make my life easier as I got older. Later in my life, my parents told me that this was probably the best decision that they ever made because they saw the amount of freedom and mobility that the electric wheelchair gave me. Looking back on this decision, I would have to agree.

The Freedom My Electric Wheelchair Brought To My Life

During the summer months before I began high school, I learned how to maneuver and drive my new electric wheelchair. While the doors and walls in my old house looked like a war zone from me running into them in my wheelchair, my parents never said a word to me. They knew that the learning curve from going from a manual wheelchair to an electric wheelchair would be a big step, and while I may have destroyed a few doors and done a little sheet rock damage to the walls, they understood that this was all part of that learning curve. The biggest sense of freedom that I gained from using my new electric wheelchair was the ability to go places by myself. I was able to go to the local shopping mall in my town, and I didn't have to have anyone go with me to push me from one store to the other. While this new sense of freedom may have been miniscule to some, this freedom, in my opinion, was the greatest thing that ever happened to me because I knew that I didn't have to rely on as many people as I used to.

smajourney51

Accepting God And My Lord And Savior Jesus Christ Into My Life

While my parents took my brother and I to church every Sunday while we were growing up, I never really knew the true meaning of what Christianity was until I was in high school. Even though I went to church and I prayed the prayers like everyone else, these were just words that I would repeat every Sunday. When I was younger, I would ask God to help me learn how to walk, and when these prayers went unanswered, it frustrated me and made me even question these beliefs that my parents were trying to instill in me. While sitting in church one Sunday morning when I was around fifteen years old, the priest that was administering the sermon, spoke about the importance of accepting God and our Lord and Savior Jesus Christ into our lives. It was around this point in my life, after opening my heart and soul and accepting Christ into my life, that my life began to change in so many positive ways. While the electric wheelchair may have brought me freedom, accepting Christ into my life brought me something much more powerful, it brought me a sense of relief.

smajourney51

High School – Learning How To Make And Keep Friends

When I started high school in the spring of 1980, I learned something very important. While I had friends around my neighborhood, I was not much of a social butterfly in grade school and junior high. The casual acquaintances that I had in grade school and junior high may have been what some called friends, but these were just people that I would pass in the hallway and wave to while going from one class to the other. The friends that I made in high school seem to be much different than those that I made earlier in my life. Many of the friends that I made in high school included me in all of their activities, including going to the weekly football games and making sure that I always had the best seat in the house. During the spring semester of my freshman year, I had back surgery for scoliosis and was out of school for nearly a month. When I returned to school, every class that I went to, threw a small welcome back party for me and made me feel that I was truly missed while not in school. The amount of get well cards that I received while I was at home recovering, touch me at a personal level. It was then that I realized that God was working something amazing in my life. He was working through others to help me realize not only how much I meant to other people, but how much I meant to him.

Learning To Accept The Reality Of My Life

While high school was a turning point in my life, it was during this time that I learned to accept my handicap. I noticed quite a few people who were handicapped like I was, and the majority of these individuals were dwelling in self-pity. As I watched from a distance, and over a course of a few years, I noticed that these individuals wanted everybody to do everything for them. It was like they had given up and that they were living their life vicariously through others. Seeing the amount of self-pity that these people were putting on themselves, made me realize just how lucky I truly was. While I may have asked for help doing some tasks in my life, I never found myself dwelling in self-pity and feeling sorry for myself. Much of this was due to my parents, because they never allowed me to use my wheelchair as an excuse for not doing something. They demanded just as much from me that they did from anybody, and they expected me to perform and make good grades no matter if I was in a wheelchair or not. This attitude that they instilled in me taught me that if I wanted something out of life, I would have to work just as hard as anybody else.

Going To College – Learning The Importance Of Handicaps That Others Deal With And Learning How To Be More Comfortable In My Own Skin (Slide 1 of 5)

After getting all of my freshman and sophomore classes out of the way, I went to the University of Texas at Dallas to finish my undergraduate degree. When I began UT Dallas, I joined a local co-ed business fraternity. After pledging the fraternity, I involved myself in some of the social activities that the fraternity required all the pledges to complete before becoming active members. During my senior year in college, I was elected president of the fraternity and I had to decide the social activities that the incoming pledges would have to complete to become active members. Earlier in the presentation, I stated that I was uncomfortable about being around other handicapped individuals. It was during my time as president of the fraternity, that I decided that I needed to address my uncomfortable feelings regarding this issue. We required all of our incoming pledges to perform forty hours of community service before becoming active members. The pledges were allowed to select thirty hours of community service of their choice, whether it be working in a soup kitchen or working in a homeless shelter. The last ten hours of their community service would be decided by the executive committee of our fraternity and myself.

Going To College – Learning The Importance Of Handicaps That Others Deal With And Learning How To Be More Comfortable In My Own Skin (Slide 2 of 5)

After examining the possible choices that my executive committee and I came up with, I decided to pick the one choice that would not only be beneficial for the incoming pledges, but it would also be beneficial to me. The Special Olympics were coming into town for their track and field events. I decided, as president, that all pledges and active members would participate and volunteer our services to the Special Olympics. When we arrived at the event, I assigned each active member and pledging student an athlete that they would have to be responsible for during the entire ten hour day. The executive committee, including myself, were also assigned an athlete that we would be responsible for, to make sure that they got to all of their events on time and to help them with all of their daily activities. After being paired up with the athlete that I was going to be responsible for, we had about one hour before his first event. We spent that hour getting to know each other. My athlete was an 18 year old who suffered from a moderate case of down syndrome. The one thing that I noticed first about my athlete, whose name was John, was his personality. He immediately extended his hand, and after we shook hands, it was like a cloud of fog had been lifted from the emotions that I was feeling.

Going To College – Learning The Importance Of Handicaps That Others Deal With And Learning How To Be More Comfortable In My Own Skin (Slide 3 of 5)

I tried to be as optimistic and positive as I could when I met John, but John's attitude and his excitement about meeting me far outweighed the positive vibes that I was presenting to him. I could tell from just the first few minutes of our meeting each other, that this was going to be a day that would forever change my life. During the next five hours of our day, I made sure that John got to all of his events on time, and I began losing my voice because I was screaming and cheering as he participated in all of his events. When it came time for lunch, I had planned on eating with my executive committee and my pledging students, but John asked me if I would like to eat lunch with him and his friends. Without hesitation, I accepted John's invitation. We went over to the group of athletes that John came with earlier that morning. It was a group of athletes who all lived together in one of the local group homes in the central region of Texas. One thing that surprised me was that I saw very few parents who were attending. Most of these kids with down syndrome were there by themselves and the only relationships that they had were those with their fellow athletes. I never asked John about his parents because I felt this was none of my business.

Going To College – Learning The Importance Of Handicaps That Others Deal With And Learning How To Be More Comfortable In My Own Skin (Slide 4 of 5)

As we approached John's group of friends that we were going to eat lunch with, the first thing that I saw was a group of athletes with down syndrome, and each one of them had a smile on their face that would make even the most staunch person smile. John began to introduce me to his friends and everyone of them came over to me and shook my hand. The smiles on their faces were electric and I immediately felt at ease. As they began to eat, I was having difficulty opening my soft drink can. Without having to ask, John stood up and opened the soft drink can for me and also removed my sandwich from the brown bag that all of the athletes and volunteers received for lunch. After opening my soft drink and getting my sandwich out of the bag, John sat down next to me and we began eating lunch. During lunch, I started questioning why I felt uncomfortable about being around other handicap people, and during the one hour that we took to eat lunch, my questions were answered. I saw a group of athletes with a disease that socially removed them from what most people would consider normal. They would never have the ability to hold full-time jobs making the kind of money that I would make, but their spirit for life would far outweigh any monetary value that I would make in my lifetime.

Going To College – Learning The Importance Of Handicaps That Others Deal With And Learning How To Be More Comfortable In My Own Skin (Slide 5 of 5)

I heard more laughter and felt more positive vibes during our one hour lunch than I had ever heard in my life. Many of the athletes were wearing their medals that they had won in their particular events. After lunch, John and I finished the remainder of his events. Throughout the day, John participated in six events, and he won a total of two medals. Even though he didn't medal in four of the events that he participated in, his attitude and spirit remained positive throughout the day. My responsibility for that day was to help John, but in reality, he helped me much more than I helped him. The lesson that I learned that day was that everyone deserves a chance to be themselves, without others stereotyping or labeling them as something other than a living breathing individual.

In Mathew 7:12, it states the following: "So in everything, do to others what you would have them do to you." The Mosaic law contains a parallel commandment: "Whatever is hurtful to you, do not do to any other person."

This was a lesson that I took to heart, and I use this lesson each and every day of my life.

Learning How To Treat Others By Watching Those Who Have Not Learned This Lesson

After graduating from college with my MBA, I worked for numerous companies throughout my working career. I had many good managers and bosses that taught me that managing one person, or a group of people, took a special skill that surprisingly, very few people have. While I learned quite a bit from them, the managers that taught me the most were those managers that did not know or understand how to treat others. One of my managers would make it their job, each and every day, to bring those that they managed down to their level of disgust. It felt as if their day was not complete until they were able to ridicule those who they were managing, and to make them feel as if they were not worthy to be working their jobs. As I moved up the corporate ladder during my working career, I always treated others with respect and dignity, because this is the way that I wanted them to treat me. Respect is a two-way street, and many of the managers that had poor management skills, acted as if they were the only car on the road. The lesson that I learned from Matthew 7:12, continues to be a life lesson that I use every day of my life.

Letting Go Of Your Fears

As I've gotten older, Spinal Muscular Atrophy has robbed me of many experiences that I would've enjoyed in life. While it would be easy to give up and let this disease take full control of my body, this would've contradicted all of the life lessons that I have learned. While this disease may have taken control over my body, I will never allow it to take control of my mind. I guess with age comes knowledge. This knowledge and understanding of never giving up is the definition of my life. Like everybody else, I too am nervous about the future. What's going to happen to me as I get older? Will there always be somebody there to help take care of those things that I am unable to do for myself? This, and a myriad of other questions could easily haunt me, but I will never allow this to happen. Many years ago, I gave all of my problems to my Lord and Savior Jesus Christ. I released all of these concerns and problems in my life over to him, and I asked Christ to handle these problems for me and I would accept whatever outcome he sought to give me. The peace that I feel is difficult to put into words, but being able to wake up each and every day without having to worry about what tomorrow will bring, allows me to live today. I've learned that each and every day is a gift, and while we are never guaranteed another day on this planet, I'm thankful that I've been given one more day to enjoy what God has given me.