

Member Spotlight: My Story by Carmen Zelenka (Shared first at the February 2009 NoLimits Support Evening)

When I was asked to be a guest speaker for tonight, I accepted without hesitation. I did that because of all of you here tonight, and for all the others who never got the opportunity to hear anything positive or inspiring about a future with Spina Bifida.



I wanted you to hear my story and leave tonight feeling refreshed about the endless possibilities you can have in life and love. When you leave here tonight look down the un-paved road with excitement, and wonder what good things are waiting for you. I hope my story does just that for everyone here tonight.

My story begins on October 18th, 1979. I arrived to two wonderful parents Darline and Rick. As any two parents should be they were both excited when I arrived until the doctor came in with the news that something wasn't right with there new baby girl. Spina Bifida and hydrocephalus is what I was diagnosed with. Now imagine in 1979 this was still a death sentence or a waiting game so to my mom and dad this was anything but good news. They both were scared and sad and for my mother she had a lot of blame. They placed a shunt in my head the next day due to swelling in my head. From there they waited to see what was in store for them and me.

10 days later and finally we were told I could go home. I have been told that a very special nurse grabbed my hand when I was intensive care and I grabbed her pinkie and held on with all the strength I had, she told my mom and grandma I was a fighter and she was positive I was going to over come all the odds against me. I would like to see that nurse now and show her how right she really was. When you have a disability I guess it's the doctor's obligation to the family to tell them the harsh realities that might happen, so when I began to walk at 2½ years old it must have been a blessed shock to see me do it as they were told I would probably never walk. From there my mom had to decide whether or not to put me into a regular public school or attend the school offered to me at the Glenrose. My mother decided it would be the best thing for me to go to public school, and here's why. The world is made up of all kinds of people, and if I only ever was around people who had my condition how would I get by in the real world.

For some people the choice goes the other way and that's alright too, that's the beauty of choices they are just that, and no one can tell you if its wrong or right, I just

know I am happy my mother decided to put me in with kids who were not like me, they taught me a lot and I know I had an impact on them as well.

In grade one I made myself show and tell. I took off my braces and passed them around and explained a bit about what I do on a day to day basis, and a bit about my birth till then. You know what I saw. Besides my teacher in tears I saw a bunch of kids in a room who were the same. Including me. No one had any differences no one was excluded from the circle, in fact I made more friends after that day then I ever thought I would. But that's the thing in order for people to not treat you like a wack-a-doo, you need to explain it sometimes, people can be so ignorant to what they don't understand, and I'm sure everyone in this room has his or her own story about being hurt or left out, believe me I do to, life wasn't always roses, I have went home many times in my later years crying because someone called me a name or imitated the way I walk.

I look at it this way those people have so much hurt in their life that the only way to make themselves feel better is by degrading someone else. So really its not you they're laughing at, its themselves. By the time I was in junior high I began to realize boys really didn't have cooties like I thought in fact they were starting to look pretty appealing to me. I remember my very first note I ever got from a boy, it read will you be my girlfriend circle yes or no. I felt on top of the world an attractive young man liked me. Of course we all know at that age a month seems soooo long which is probably how long it lasted, and with that came my first broken heart.

That was the first of many broken hearts for myself all through junior high and then came high school. I think it was probably by far the best time in my life socially, you are free to be who you are and no one says anything because they are doing the same thing as you are too. Love is different in the later years of school, by now I was looking into the future with the people I dated then. I was planning my weddings ,yes I said weddings, but by this time the men I dated were interested in a lot more then just a hug and a kiss. I wasn't ready for that because I knew I had secrets I knew I couldn't tell them.

I didn't meet the man I was able to tell my whole truth about myself to till May of 2002. He is the one I married and now have a beautiful healthy son with. Kenny is now 3 years old. The difference between the people you date and the person you marry is that he or she will love you even more once you finally open up and share the good the bad and the ugly with them. They will catch you when you fall emotionally, and they will hold your hand in public and stick out their tongue to anyone who gives you the second stare. I have been grateful to have found that, marriage is one of the toughest things to ever go through, there will be bumps, and patches that are smooth, it is kind of similar to spina bifida in a way, it can be hard to deal with some days, but giving up should never be a option. I hope that each and everyone here tonight, could relate a bit to my story, and even if you haven't yet, your futures are what you make of them and you are the one who holds your destiny in the end, so sing like no ones listening, dance like no ones watching, and love with all your heart.

By: Carmen Zelenka