

This is How I Roll! - My Life with Cerebral Palsy

On August 1st 2009, I was born. Except something was wrong. I was born 12 weeks premature - 12 weeks earlier than I should have been. My official birth weight was 3lbs 1oz, and I was so small that I had to have heart monitor stickers put on my chest to monitor my heart rate & breathing pace. I was put in an incubator for 4 weeks. My proper birthdate - if it weren't for my prematurity - would've been around late October. When I was just a few days old, I was given a brain scan, and believe me when I say the news wasn't good at all. The scan showed damage in some areas of my brain, and the doctors could tell from where it was damaged exactly how it would affect me later on in life - that it would take me longer and more energy just to do simple, everyday physical movements. This condition is called Cerebral Palsy, with which I was officially diagnosed with at just 18 months old. Surprisingly, 15% of all babies born premature end up with disabilities - not just Cerebral Palsy, but other conditions such as blindness & deafness. Cerebral Palsy isn't a genetic condition, meaning it's not passed down through DNA. Therefore nobody else in my family has it or can relate to having this experience - which makes it unique and kind of cool in its own way.

Cerebral Palsy is just like having a stroke before you are born. There are four official types of Cerebral Palsy, but the type that I have is called Spastic Diplegia which mainly affects both my legs along with my core as well. People with Spastic Diplegia often have very tight leg muscles - so much so that it can sometimes cause deformities (which include flat feet, jutting bones, and even permanent spinal curvature.) These can cause need for surgery. In contrast, the core muscles are very floppy & weak, making it difficult to balance in some situations.

When I was 7 in 2017, I went to the United States of America to have a huge surgical procedure that would give me a chance to walk and change my life forever. It took over 20 hours of travel to get there. They call it Selective Dorsal Rhizotomy (SDR) and this surgery isn't available in New Zealand. Our family had to go ahead with over \$100,000 worth of fundraising to get there. The surgery was performed on my back. I also had another procedure over there which involved lengthening my calf and hamstring muscles. It put a lot of on me, and my family as well. It's funny how the things you remember most in life are the experiences that hurt badly, or were really scary, etc. For me, I remember feeling so terrified when I had to get up at 4:00am in the morning that I didn't even want breakfast! Of course it didn't make it any easier having a 6 month old baby (my brother) on a 22 hour flight to Missouri. It was emotionally terrifying as well - who knew what could go wrong?

Living with Cerebral Palsy has its challenges, and it hasn't always been very easy, but it's not all bad. For starters, during this mountain climb of a journey I've met lots and lots of amazing people who have helped me to gain confidence, make friendships and helped to change my life - people who, if I didn't end up in the situation that I'm in now, I wouldn't have otherwise known. Another great thing about living with Cerebral Palsy is that I get an awesome wheelchair! In my case, the wheelchair's purpose was to be there just in case my legs tired out or I needed to go long distances that my legs couldn't. But best of all was the fact that living the life that I was given meant I could have lots of super experiences that nobody else without a disability could have such as the Halberg Games, Disability Sports Annual Competition, and a few others.

The best thing that helps me stay motivated in my life is the fact that it isn't just me who struggles with the situation that I've ended up in. According to scientific research done by the CPSNZ (Cerebral Palsy Society of New Zealand) more than 17,000,000 people from around the world suffer from varying types of Cerebral Palsy.

Living with Cerebral Palsy has had a huge impact on the way I look at things that seem challenging in my life. There have sometimes been things that have simply been too much of a physical challenge for me to achieve - such as climbing trees or going on the slides at the park that have massive, tall ladders. But even though *some* things might be too difficult, that doesn't - for me - change the way I see things in life. I know that I can still have fun and enjoy my life just like any other kid can - even if I did have to make some adaptations and skip out on a few things that I would've liked to do. I don't think of myself as 'disabled', but rather 'differently abled', because the word 'dis' brings so much negativity into what you say, but negativity isn't needed in a life full of fun!

Not only has Cerebral Palsy impacted me, but my family has been majorly affected too - in both good ways and bad ways. My mum has probably been affected the most - she put her life on hold while she learnt how to take care of a child who's differently abled. She had to leave her job to take me to daily therapy sessions, and, on top of that, all the paediatrician, physiotherapy, and splint fitting appointments as well. My dad has also been impacted a considerable amount. He flew with me to Houston, did therapy with me, and lots of other things too.

Living with Cerebral Palsy has always been difficult, and I've always had to struggle a little to deal with it, but everyone faces struggles in their life, right? Like Sir Ernest Rutherford once said, 'you cannot call your life a life if you do not face struggles and hardship within it.'

Cerebral Palsy isn't who I am, it's just part of what I face in life. Because even though it'll never go away, I'll always find a way around it. Because I've had to make quite a few adaptations to make things easier in life, nothing will stop me having fun. It's not your physical needs that stop you, it's just how you look at your situation that stops you. My advice to other differently abled children like myself? Whatever you do, never stop believing in yourself - remember, there's always hope to believe in.

Bibliography

www.SickKidz.com

www.cps.org.nz

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