

The boy who never wore shorts.

Regardless of the high temperature and low comfort levels, our son never wore shorts. His condition rendered him with massive calves and chubby thighs, and he was extremely self-conscious. Despite our and his teacher's assurances, he would not be convinced that shorts were a good idea even when it was a typical hot and sticky Waikato summers day.

This was just one of the idiosyncrasies he developed as he transitioned from walking to relying on a power wheelchair. He resisted this as well, desperately wanting to be the same as everyone else, everyone else that was fully able bodied that is.

It's easy to say he had a lot to be thankful for. He had some great friends, a supportive and accommodating school, amazing teachers, and plenty of talent. During his intermediate years he became an imaginative and stylish writer. He developed a talent and passion for art, played the guitar and keyboards, was a key member of the school band, and won best keyboardist and best overall musician at Bandquest, which is Rockquest for Intermediate School kids. He became a bit of hero at school and we hoped this was enough to help him transition successfully to high school.

We as his parents made the conscious decision to not involve him in any events or organizations that supported those with his condition; Duchene Muscular Dystrophy. We didn't want him to see his future self and the probable health and life limiting outcomes that he would inevitably be exposed to. Looking back, this was more about us than him and was a massive mistake!

As his condition deteriorated and he became totally off his feet, his poor body image morphed into a total lack of enthusiasm for anything; school, music, art, even life in general. About this time, he moved to high school and he lost the ability to play guitar. He was devastated. A mental breakdown followed resulting in three months off school, counseling, antidepressants and a lot of family stress.

Sound familiar? Can you relate? Why am I telling you this? Where am I going with this?

Believe it or not, this is actually a good news story. While I wish there was a cure or at the very minimum the progress of his condition could be stopped, unfortunately there isn't. However, one life changing decision changed his life immeasurably; he discovered sport, team sport in particular.

His three older brothers all played sport to regional representative level. Number 4 loved watching his three older brothers play but neither he nor us ever envisioned he too would become a successful sportsman and would again be a happy, confident and future focused young man. Through the various people we met through this journey, we were introduced to wheelchair basketball. He struggled with self-propelling the manual wheelchair or passing the ball. He did however enjoy the support and camaraderie of others and being one of many who used wheelchairs. Parafed Waikato was at the time supporting the development of a local Powerchair Football club. We had previously been to Auckland to see this game, but our boy was unimpressed as he was still walking, just, and didn't like the whole "para" scene. In short, he wasn't ready. However, second time around, he fell in love with this exciting and developing new sport. Three years later, our young man who was so body conscious he wouldn't wear shorts, had no confidence, wouldn't say boo to a goose and hated being in the limelight, has become a member of the national powerchair football squad, been to Australia twice to play, is social, confident, fallen in love with art all over again, has achieved NCEA levels 1 and 2, and faces challenges with a can do attitude.

Sport has many benefits, not just physical. It teaches perseverance, goal setting, confidence and self-esteem and being part of a team with all the give, take and discipline that entails. It gives people a reason to get up in the morning and play less Xbox or PS4. All of these things translate to the rest of their lives and gives them an identity other than their physical self. Our son and his classmates from the Physical Assistance Centre at his school recently had the privilege to meet two Cabinet Ministers during a school trip to Wellington. When asked to introduce themselves, those that played sport or had clear goals, did not once mention their various conditions. Conversely, those that had none of those things only identified themselves in relation to their condition. That's tragic.

I'm no expert. I'm just a Dad who has seen his precious and fragile son develop into an amazing young man, simply due to being around others like him and being able to shine in an inclusive and safe environment, in his case sport. It's natural to want to wrap our kids in cotton wool and protect them from all the challenges and nasties life delivers. This is especially so for parents of kids who have additional challenges. But please, don't deny them the right to overcome challenges or find a community that can embrace them and their uniqueness, while also providing the tools to face all that life throws at them.

By the way, our son now hates wearing long pants.