

## **Sam's Story**

Sam's mother told this story in an interview. This is the transcript

### **Acquiring disability**

Sam wasn't born with a disability; he had an acquired brain injury at the age of two. He was one of those extremely active children who never crawled - he walked at 10 or 11 months. He didn't walk for very long; he sort of got up, walked a couple of steps, ran everywhere and climbed everything.

We used to live on a property and when Sam was two years old, he climbed the farm gate, fell, and hit his head on a fence-post causing a small depressed fracture and bruising on the neck. Initially he was okay, he just had a very tiny cut, and then about half an hour later he started getting a bit groggy, so I took him to the local hospital.

The doctor sent us by ambulance to the Women and Children's Hospital, where a CT scan showed he had a very minor depressed fracture; no impact on the brain at all, and they put him in High Dependency that night. About 24 hours later, on Thursday evening, I told the nurses, "There's something not right, he's screaming a lot, and his left side isn't moving". They'd taken all the monitors off at this stage and the nurse on duty told me it was probably just some bruising or swelling. When I told the doctors the next morning, they immediately ordered another CT scan which showed Sam had experienced a stroke and would be left with Cerebral Palsy (Left Hemiparesis) as a result.

### **Family reaction**

I have this philosophy: An extreme challenge can either pull two people closer together or do the opposite. In our case, our marriage ended.

I had cancer when Sam was born and that took all of my energy. My family had very little to do with us. They didn't even know Sam. There was a huge level of aversive prejudice with the family believing and wanting the world to see they're egalitarian, but when it came to accepting there was a child with a disability in the family, their attitude was quite different. Some people didn't seem to want to have much to do with us. I think there was a level of fear. I think it was easier for them to stay away; to just pretend that it was someone else's problem.

Sam was all I had, and I was all he had.

### **Good friendships**

I know Sam's found it difficult that there has been no family support for him. I've been lucky enough to have some really good friends though. Through my work with horses, we've become really close to one family in particular. I taught their kids and helped them out with a difficult horse and they just embraced us as another member of the family, and still do. I think without them, and without some other close personal friends, it would have been even more difficult for Sam. They have always treated him like anybody else, and that was something new to us. We didn't see my siblings and their kids much at all, and if we did, there was always this sense of, "Oh,

he's different" with them looking down their noses at him. But I think that is as much their problem, their fear, their inability to accept other people.

### **Experiences of schooling**

I thought it was best to send Sam to a small church school. I'm not a religious person, but I was brought up in a Christian environment and believed that, "Yes, well you go to a small church school; they'll get more personalised attention, and more loving guidance." So he went to a local school. It wasn't easy finding the money to pay for it.

Sam had a great experience at kindergarten. They loved him and said what a great kid he was. There were no issues at all. When Sam started school, he had a lovely teacher and he started well. Then the teacher went on long-service leave at the end of that year and the relief teacher was very retributive in the way she worked.

Sam's concentration was all over the place (as is the case for many CP kids and like a lot of little boys anyway) and she did not manage this well. There were also a couple of kids in the class who struggled socially and were quite horrible to others, and Sam stood out as an appropriate target to be bullied. He was the weak link and he copped it.

He had been going really well with reading and then all of a sudden it was as though he decided, "No, I can't do this," and he wouldn't. He suddenly wasn't coping at all and at the end of the year, the Principal said "Sam's very immature; we think he should continue in reception for another year".

While I didn't really disagree with the benefits of having a full year of reception (Sam was a July baby, so started in the middle of the year), I wasn't sure and asked "Well, what about some remedial help?" His response was, "Oh, well, we don't give help to reception children." I knew at the time that wasn't quite right, especially as the school received funding because of Sam's disability, but I was struggling with depression, struggling to cope and make ends meet financially, so had little energy left to fight or even question.

In the end I thought, "Okay, well, getting away from these kids who have their own problems could be a good thing, perhaps he'd be better off out of that social group anyway". Sam stayed in reception, and the problems just continued and he became way behind in his work by the end of Grade 2.

I was fighting just to have him treated decently and all sorts of things went wrong. He had a nice teacher in grade 1, but no support until late in the year. The grade 2 teacher punished kids who were mucking around by putting them at the back of the room or in a spot where she couldn't see them, which of course makes them worse. By the end of Grade 2, I decided we would have to move, but knew the Grade 3 teacher was excellent and thought it better to get some tutoring to help and have the benefit of this teacher so that he could start at a new school with a more solid base. He was about three years behind in reading, but with tutoring, he caught up and was slightly ahead of where he should have been by the end of Grade 3.

Then we moved to another church school. For the first two years Sam had brilliant teachers but there were dreadful social situations. One boy made up a song about Sam that was going around, and I only heard it because there was this delightful boy who Sam became friends with, who told his mother. The teachers didn't tell me a thing; it was all very much, "Don't tell the parents anything." Fortunately, I was made aware of what was happening because of this wonderful parent. She told me what was going on, but the Principal was cross with her for doing so.

In grade 6, the year started badly with social problems. Sam had a very nice, but extremely weak teacher, who didn't seem to understand that by going with the majority, he was allowing the group mentality to dominate, and the bullies just got stronger. Sam's way of dealing with being bullied was to blow up, get very aggressive and upset. He was backed into the corner, and he'd fight his way out. Nothing was done and things got worse.

After a while, if someone hit him or pushed him, he would hit back. Nasty things were whispered to him, his lunch stolen, his books and other possessions thrown around the room, barriers put up to trip him or make it difficult for him to move around. Mean things were said and done so that teachers didn't see, then Sam's aggressive reaction would be very visual and he would be blamed.

He was continually under attack and none of the adults noticed or was prepared to take action. One child even told Sam that his SAPSASA Cross Country medal was only given to him because he was in the disabled class, and he seemed to make it his aim in life to ensure Sam was physically or emotionally challenged continually throughout the school day.

The school counselor verbally attacked him one day and as you can imagine, he was very upset. He told me, "Oh this woman told me I was the bully, and she was yelling at me, no-one will listen, and I just can't cope." After that I didn't send Sam to school. I asked this woman what was happening and she responded by telling me how wonderful she was, what a great job she was doing and how dreadful Sam was.

Home schooling became the solution after that. Sam was so traumatised that I didn't think it would be helpful trying to slot him into another school for a year and a half until high school. He needed some healing and confidence building, and needed to bring his schooling back to where it should be.

### **Support from professionals**

I think we were lucky in the early days. When Sam first had his accident we had a couple of Novita therapists who were really special people. His physiotherapist and occupational therapist for the first few years were awesome, and then in the last four years, he has had the most amazing psychologist. I think that's helped, and I think it's been important that neither he nor I have taken "no" for an answer. We've not accepted other people's attitudes, "Well, you can't do that." Those professionals have helped us to stay sane, and to follow a positive road forward.

During the last half of primary school, Sam was working with a wonderful tutor who gave him some invaluable support with social skills. When things went 'pear shaped'

at school, both he and the Novita Psychologist said, “Get him out of there” and with their support, I was able to successfully home-school Sam until he started at Heathfield High school. Our experience with Heathfield has been fabulous – teachers there have provided the appropriate support and encouragement needed to help Sam build some self-confidence and negotiate any problems which have arisen. Compared to primary school, it has been a breath of fresh air.

The biggest difficulty I have encountered has been an apparent inability for some teachers to look beyond what’s right in front of them and understand that with a little bit more time, encouragement and positive guidance, he will do well. Some people seem to assume that a disability implies stupidity and limited capacity to learn, rather than realizing that the processing might take longer, but the IQ, ability and scope are at least the equivalent of the average in the class.

Like many with acquired brain injuries, Sam has no problem understanding concepts, but there are issues with learning associated with speed of processing. Testing of Sam’s ability prior to starting high school, put him in the 85<sup>th</sup> percentile in maths, and while the Cerebral Palsy makes it difficult with handwriting etc., he’s quite capable, as long as he’s given time. If I had a dollar for the number of people who said to me in Primary School, “Well, he’s got a disability, what do you expect?” I would have done quite well financially.

### **A passion for sport**

Sam played a lot of sport from early on. He’s always been really, really active, even with Cerebral Palsy. His mind bounces off the walls, he is continually active both physically and mentally, and I needed to find an outlet for him. Initially, I struggled to find an activity where he was accepted. Little Athletics was brilliant! He was eight years old when he started in the under nines at Mount Barker Little athletics and they were great. He has also played cricket for a couple of seasons, as well as Football at the Echunga Football Club for four years. He’s always enjoyed running and continues to train regularly and compete in athletics. His dream is to represent the country in the Paralympics.

### **Sam’s personality**

Sam’s got the most incredible sense of hope. I think some people find him a bit infuriating because he’s always said, “I’m going to play AFL football. I’m going to be this and I’m going to do that.” He’s never seen his disability as preventing him from doing anything. I think this may come from me because I’ve always seen him as Sam, and I don’t like the ‘pity parade’. To me it’s not ‘dis-ability’ it’s ‘ability’. It’s what you CAN do that should be the focus.

People give Sam a hard time about not having many friends. I think he would prefer not to have to deal with the stress of peer pressure to have heaps of so-called ‘friends’. I have found over the years that young people with a disability just don’t get invited to things and it is more difficult for them to establish friendships. It’s just too hard, and it’s hard on other kids too because if they’re associated with somebody like Sam they’re seen to be out of the “in group” anyway.

No teenager and no kid want to be ostracised. They want to be accepted; they want to be treated with the same level of respect as anyone else, and I think Sam

desperately would like that. I think he'd desperately just like a little bit more warmth and love, and I know that he would certainly like some more love from family. They don't realise that by being the way they are has just made everything much more difficult for Sam. He doesn't want people to fuss over him or give him pity. Pity is a real problem. Let's celebrate people for who they are, not for what they are.

### **Resilience and determination**

My Dad always used to say, "You'll always succeed if you're prepared to work hard." He's a worker. I think that was a good grounding, but I think I'm just one of those people who believe you get back what you put in. Quite often you do what's considered the "right thing" and you still get kicked, but I don't think that should stop you trying to be the best and most compassionate person you can possibly be. I've just completed a degree in psychology, which I started because I needed to learn more about how to manage this and all the stuff that was going on around me to help Sam with his incredible challenges. From my perspective you have a choice; you either give in or you just keep going, one foot in front of the other. Giving in has never been a viable option for me.

I think over the years I've just got stronger and stronger, despite continual difficulties, Sam and I both have moments where we just get sick of it, and really want to go and curl up in a corner and tell the world to go away for a while. You might do that for half an hour, because I think sometimes you just need to give yourself permission, permission to acknowledge that things are tough, but then it's time to get on with it again.

### **Suggestions for others**

As a parent you do your best; don't be hard on yourself if you have days when you don't cope, because you will have them. People often think because someone looks different, talks a bit differently, or needs more time for something, that they must be stupid. No-one really knows about somebody's life unless they care enough to look beyond the surface. It's not what's on the surface, it's not about what car they own, what sort of job they do, how much money they have, and the type of clothes they wear; it's the person they are. The fact that somebody finds something difficult doesn't mean that they're not trying hard and achieving incredible things. We all need to look at the big picture, at all the contributing factors, and put things into perspective.

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