

Different

In many ways the most significant thing to happen in my life, occurred before I was even born. You see my brother was born before me, and by the time I appeared 16 months later it was clear he was different. If you were to ask me what my first memory is, I would not be able to give you a distinct event, instead I would tell you this, my earliest feeling was that I needed to look after my brother, that whatever happened he needed to be looked after.

As a kid, Scott was not really interested in playing with others. He was too much in his own world to be playing with his sister or anyone else. The exception to this was Star Wars. Star Wars was where we both connected and bonded. I wanted to be Princess Leia, to have hair that wrapped in big circular bundles on each side of my face and be fighting the evil galactic empire. In contrast, Scott loved Darth Vader, he had a black plastic mask, mum had made him a black velvet cloak and the pencil he loved to hold and twitch between his fingers became his lightsaber. Our back yard was space, the swing set was the Millennium Falcon and the trampoline was the Death Star.

By the time I was in primary school that meant walking Scott to school, down the end of the street and home again. I would drop him off at his classroom and pick him up at the end of the day. As we walked, he would continuously stop and pull his long socks back up to his knees after they once again dropped to his ankles. I was determined to get to school as quickly as possible, "Stop pulling up those damn socks and start walking." "Hurry up, what are you doing?" I may have been watching out for my brother but I was not making it easy on him.

Scott looked different, at that point of 5 years of age he had thick blonde hair, he liked to wear a white terry towel hat on his head and have a pencil in his hand, that he would flick continuously like a nervous tick. He spoke loudly and constantly; everything that appeared in his head was spoken aloud and repeated multiple times. His whole body would fidget. As we walked, Scott was jeered by older boys. I didn't know how to stop it. I just walked faster.

Eventually, the school found out, which for me made it even more difficult. A teacher I didn't know took me from one classroom to another in the older grades for me to pick out the boys that had been teasing. Looking at these older kids, twice my size they all just merged into each other. I didn't know who they were. I didn't want to know and yet somehow through that process the teasing stopped.

I was so used to walking Scott to and from school that one time I was walking home, while talking with a girlfriend and got half way home and realised Scott was not behind me. I walked back to school to collect him. He was still just sitting at his desk, waiting in his classroom for me. He knew the routine and knew I would eventually turn up.

Scott and I ended up in the same year level at primary school, he'd been kept down and completed two years at kindergarten and prep. By the time I got to prep it had been decided he would stay in my year level. I was so jealous, he always got the pick of the teachers, the one that would be the most patient, the kindest, the one that could help him. I always wanted that teacher.

My parents had to battle to keep Scott at our local primary school. Some at the school wanted him to attend a special school. That would have been a 40 minute bus ride and my parents were not keen on that. Scott could cope with the school at the end of the street, that was in his routine. Routine was very important for Scott. Everyday Scott would eat the same breakfast rice bubbles, for morning tea he would eat the same snack, two plain teddy bear biscuits and for lunch eat a peanut butter sandwich with a banana. He would snap the banana in two, as he did not have the dexterity in his hands to peel it down from the top. Dinner could change but dessert was always slices of canned peaches with a scoop of vanilla ice-cream.

The school gained an integration aide a few days a week to help Scott and some others at the school. Scott's aides were even more patient than the school room teacher, working one on one with Scott and explaining things again and again. They would cajole my brother. You see, although my brother is mentally disabled, Scott has his own personality and one of its features is that he is lazy. He may have cerebral palsy in his hands where he struggles with fine motor movement like doing up a button or a zip, but he can get out of any task he does not want to do. It might have taken him longer to learn how to speak, and some words may be challenging for him to pronounce but Scott has no trouble communicating what he wants and ignoring you when he wants to. No one can deny Scott, he's got that sweet look where you can't help but give him what he wants. I was his sister, I saw through this act.

There was one area where Scott was not lazy and that was with electronics. Scott's domain was our lounge room. He knew how to turn on the hi-fi audio system, the video player, the television and even record from the television onto a cassette tape, to play later on his walkman. He could operate all the multiple remotes, knew which knobs needed to be turned on, which not to touch, which setting you needed to change to get sound from the speakers, and how to switch from the TV to video and later to DVD. He likes nothing better than to sit and watch his shows, whether it be Star Wars, Dr Who, the AFL, the Muppet Show or a movie.

Along with his love for watching became his love of music, in particular, “The Three Tenors.” He would watch them over and over again, standing in front of the television conducting as they sang and then he would join in, singing off key at the top of his voice. My music stand was re-purposed and Mum hunted down a conductor’s baton.

We attend every musical we can. Our aim when buying our seats is always about trying to get the best seats where Scott can see the conductor. With the orchestra and the conductor usually in the pit this can be a challenging exercise. As we watch the show Scott sits upright and forward in his chair, he watches intently each movement of the conductor, as he watches the conductor his own hand flies up and down, matching to him.

By attending his local primary school, Scott was part of the community, he had a small and loyal group of friends. People knew him when he walked down the street and that continues to this day. I have long ago left my hometown but Scott and my parents still live there. Scott is still part of the community. When Scott walks down the street, he will always see someone he knows. When I visit, he’ll exclaim to them, “this is my sister, this is my sister, this is my sister.”

By the time Scott and I reached secondary school, it was clear Scott and I would need to move in different directions. It has been a vital part of his life to attend primary school but he would not be able to manage the big scale of secondary school and the more complicated system of moving classes and changing teachers for each subject. At that point, he started his 40 minute bus ride to from home to the special school. It was very strange for me not to be in the same school. He had been in the classroom next to me in the same year level for so long.

We had to move more in different directions. I was in school plays, I started dating, I learned to drive. At each point in these journeys Scott and I had to navigate through these moments. I remember when I started to drive and he was in the back seat talking to himself, “My sister is driving the car, my sister is driving, my sister is can drive a car, Scott is not driving, no, Scott is not driving, Scott is not driving.” Shortly after I got my drivers licence, I put Scott in the front seat next to me and we started driving down the highway. I could see him getting used to his sister as the driver versus the passenger and trying to work out whether this was a good thing. We drove into McDonalds and he knew it was a good thing.

There are pieces of my secondary school life that he later experienced for himself. After secondary school, each weekday he attended an adult development centre in our local town that offered activities and friendship with others like Scott. One of these is the annual play. After watching me in so many productions he was able to be on stage.

Scott has always been my yardstick, unbeknownst to him he is the perfect litmus test. At University I was moving out of college dormitories to live in a shared house with a girl friend when she raised my brother.

"I just wanted to mention, I'm not keen on your brother visiting the house when we move in together".

"What do you mean?" I asked.

"I don't think I'd be comfortable with him visiting."

"Why, wouldn't you be, he's my brother and if he was visiting it would be to see me. He's not violent or anything, he's just my brother."

"Well you know."

I knew at the moment I was not going to be living and sharing a house with that individual. I knew this person would no longer be my friend. It was so hard to hear her words, but at the same time I was so glad, as her words made it so easy for me.

When Scott met my current husband, he adored him. "My brother in-Law," he would utter over and over again.

From the very first moment he saw them, Scott adored my two children. As little babies they would be fast asleep in their cot and he would put his face as close as possible to their sleeping form. He just did not want them out of his sight and wanted to be as close as possible to them. He would just stand there, watching them sleeping. It took a lot of effort to convince him to not lean so close in, so as not to wake them.

When he visits, he follows them around, constantly commenting on everything that they do. They are now 10 and 15 years old and he still does it. He loves to hold their hand. "I'm their Uncle, their best Uncle" he utters over and over again. For his birthday just gone I had a windcheater printed with a photo of my children and him and the words, "Best Uncle".

Scott now lives in an assisted living house with four others. When he feels down I receive a call not to talk to me but to talk to my children.

Scott is very loyal and kind. Once he regards you as a friend he wants to know when your birthday is, how old you will be turning, what's your footy team, do you have pets, are you married, do you have children, what are their names, how old are they... Scott memorises all of this and will then continuously ask you about all these details. As part of this, birthdays are very important to Scott. He has a calendar in his room and tracks the day and dates. First off, he counts down to my Dad's birthday in February, followed by his own birthday in March, then it's our cousin in April, my eldest daughter in June and so forth. If I want to know how old I'll be turning I'll just ask Scott, it's quicker than having to try and think about it.

Scott is different, but he is not so different.