

Growing up with Fragile X

My parents didn't know James, my brother, had Fragile X until he was 5 years old. They had just thought he was just a 'slow developer', as he joined in with other children and copied what they were doing, (bar forming more than 1 word sentences) so never thought much further beyond that. Back in the early 80's, cognitive disabilities were taboo; they weren't as widely recognised as they are today, so when James' school teacher came to my parents to suggest that he attend a 'special school', it really took them aback. In their mind he appeared to behave as other children did and they felt that by putting him in a special setting, he would no longer be able to carry on making progress by copying children who were further along developmentally than he was.

James' diagnosis of severe Fragile X came at a time when there were only 1 or 2 confirmed cases in the entire country, so the University of Southampton took great interest and used my blonde haired, blue-eyed brother as their 'poster boy' for their conferences. I was born 3 years after my brother, so I personally don't remember any of this, but have asked my parents many a time to tell me the story. To give some information on how James' Fragile X presents: he is completely able bodied, he will flap his hands and bend his ears forward, he will close his eyes and rock and hum, he will not hold your gaze for longer than a few seconds and physical contact like hugging is kept very brief. He is classified as non-verbal, but can attempt some high frequency words such as 'Mummy' and 'duck', but mainly he uses what we as a family call, 'James-a-ton', which is essentially 'Makaton', but James creates his own sound effects and signs and often uses the same sign, or sound for more than one thing! It is quite hard to understand what he is trying to communicate to you when you are not in regular contact with him, or know the ins and outs of 'his World'.

My earlier childhood with James was spent crawling around our sofas at speed chasing each other, playing with dinosaurs pretending to be fossil hunters, riding our bikes around our driveway, making things from paper and watching Disney films, (Something James still loves to this day). Really, it was a usual childhood for a brother and sister, but I felt like I was always the eldest child as I always instigated and led the games and James would often be a spectator during making activities, because he did not have the motor skills to do as I was doing.

It wasn't always so peaceful between us however and I remember that there were physical incidents, tears and winding each other up. Just like any brother and sister I imagine, but for us, some of the physical incidents and tears came from frustrations – mainly from my side: I remember one time I wanted to play 'school' and James was one of the pupils in my class. I was trying to get him to write because I thought that he just wasn't writing or talking because he just wasn't taught properly. After much trying, I lost my patience and got cross and shouted at him because he wasn't doing what I wanted him to do. I remember us pinching and biting each other and James growling at me and my Mum having to separate us – again, I think that came from times where James' stimming was irritating me, so I would sometimes copy him and be nasty saying things like, "Why are you doing THIS?" and imitate him. Doing this would push him to the point where it would end up in us both pinching, or scratching each other.

As I got older, I became more self-conscious and began to dislike going out with my Mum and brother. I hated how people would stare because James flaps his hands when walking along and makes an array of sounds, which will naturally draw attention. Young people my age would laugh and point and make fun; that would make me so angry so I would shoot daggers, or shout 'What you looking at?' to anyone being unkind. Mum still recalls now how I used to start fights with boys older than me that used to stand on the opposite side of the road outside our house, when James and I were playing in the driveway. I never used to cross the road to their side, (I'm not sure I was allowed to, or was old enough to) but I would apparently give them hell for staring. It got to the point where I would sometimes really dread going out with my Mum and brother, as I just felt I was on the war path all the time. I almost became over-sensitive and paranoid that James was all anyone was looking at as they passed us when we went out – which probably wasn't the case at all! As much as I feel a terrible person to say it: I felt embarrassment. I didn't like the attention we were receiving. I was fairly popular at school and feeling like everyone was staring and laughing at my family didn't fall in with the image I thought I portrayed.

Because I used to spend a lot of time with James playing at home, I felt like I was his main protector and guardian because we would go out alone and ride our bikes away from the house and it was my job to look after him during those times. I remember lying awake at night worrying about his future and what would happen to him when we got older, or if my parents died. I remember one time speaking to my Dad about my fears and crying. My Dad just told me that it wasn't my worry to think about and that it would all be OK, but I remember questioning that and thinking that it wasn't a good enough answer.

Thankfully, growing up and being 21 years wiser has taught me that it is just human nature to stare at people, places and things that aren't typical and we do it out of curiosity and not out of the want to be cruel. It has also taught me that time can only tell what will happen and for James that has taken him to a shared house to live as much of an independent life as possible with other people who have disabilities. Even though he has full-time carers that live in the house with him, the worries about aspects of his day-to-day life and his future haven't fully gone away, but I think that's a natural part of caring about someone who is vulnerable. James enjoys an active week doing something each day, for example working at a gardening project, working at a furniture project and doing various jobs at the local day centre. On Friday and Saturday evenings he can be found pulling his carer up for a dance in his favourite bar, or watching a film in his bedroom. James and I have had some really special times as we have gotten older, in particular when he walked me down the aisle at my wedding and also seeing him laugh and bond with my 2 year old son.

It is very obvious that the last 30 years has brought about positive change in terms of disability awareness and support for families and individuals with disabilities. It was only since I had my son and started watching 'Something Special' on CBeebies with him that I realised how much Makaton James actually knew. It was then that it dawned on me that this whole time, my family and I had been expecting James to function and live in our World, but really, we should have been making more of an

effort to live in his World. I wondered why no-one had ever come to our house to teach us Makaton – as I would have been really receptive to learning it as a child, or telling us how better to deal with autism and understand James better. I don't know what supports and systems are in place now for families, but I hope that there is change in this area.

I hope that you have enjoyed reading my story and some of my thoughts, feelings and ideas have resonated with you.