

Sibling Story

The sib way

I don't remember being told my brother had a disability, he just did.

I was five years old when my brother was born and all I remember is the excitement of getting ready to go and visit him. I have no memories of my parents finding out about his disabilities or of any grief around that time. I was a proud big sister and I didn't know any different.

In primary school I had a harder time. My brother often came to assembly, as other younger brothers and sisters did. He often made a lot of strange noises. I used to hear other kids talk about that 'spastic kid' over there. It really upset me but they weren't my friends so it didn't matter too much. Most of my friends in primary school just knew about him, I didn't really tell them nor did I feel a need to. I guess that's just how it works when you're little.

From early on, I did things in my own 'Sib' way without even realising it. In Grade 4 I remember choosing to do a speech on braille, probably because at that time my brother had difficulty with his eyesight. But not all of my writing as a Sib came out in such a positive light. In Grade 6 I wrote, 'Living with my brother is hard. I don't like to go shopping with him because people stare at him and I get embarrassed. Everyone else has normal brothers and sisters.'

For as long as I can remember, I have been able to explain my brother's disability, technical terms and all. He has agenesis of the corpus callosum, meaning that the fibres that connect the left and right sides of his brain are not there. This has meant that his is severely intellectually, and somewhat physically, disabled.

The difficulty of not knowing what to tell people about him increased as I got older. I began to realise that people felt uncomfortable because they just didn't understand or know how to react. Most people just don't want to offend me by asking questions. Once I tell someone about my brother, I can tell that they have a million questions in their head, and I just tell them to ask me.

In all, a sibling experience is quite different from that of parents and other family members but I think it's equally important. Being a Sib has changed my life in so many ways – some good and some not so good – and probably in ways I can't even recognise. At the same time though, it's the only life I have ever known and I wouldn't change it.

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