

## Parent's stories: Spencer's story



I had suspected from around 12 months of age that something was wrong with Spencer's hearing, but every time I articulated my concerns, I was dismissed as overreacting. He had passed his maternal health nurse hearing test without any problems and seemed to hear the bell on our cat's collar, as well as my husband and my voices. When he was 12 months old I asked the carers at his crèche whether they had any concerns with his hearing, and was told that nothing was wrong, so ignored the warning bells in my head. When he still hadn't uttered a word at 14 months of age, I was told that 'late talking is in our family'. So I dismissed my concerns until the crèche carers realised that Spencer didn't appear to be responding to his name – he had developed exceptional skills in observation which had enabled him to get away undiagnosed for so long. Our local GP sent off a referral to the hospital, and was told that the waiting list could mean that we would wait for up to three months. Not being satisfied with that, I looked on the Internet for audiology testing, and after a number of calls, was able to get an appointment the following week at my local community health centre, to see a lovely audiologist who was able to advise immediately that Spencer has a moderate hearing loss in both ears.

She organised a referral to Australian Hearing, an appointment was made for the following week where they immediately made up moulds for his ears. Spencer was fitted with hearing aids within two weeks of his initial diagnosis and months before we were ever able to get in to see an ENT specialist. It all happened so quickly.

My initial reaction when I found out about Spencer's hearing loss was guilt that I hadn't acted on my concerns earlier, along with fears about his future. As I got used to the idea, I took comfort from the fact that he was able to hear some noises without hearing aids and thus could hear our voices. An audiologist very early on said that Spencer would be completely fine with hearing aids and that buoyed me through the initial weeks. My sister-in-law is a Vice Principal at a primary school in NSW and mentioned that she has three children at her school who wear hearing aids. I felt comfortable enough asking her questions about these children, and was assured that all three children are intelligent, have many friends and can speak clearly and were not disadvantaged scholastically with the aid of FM systems and special classes.



My fear was that Spencer would be teased at school for his hearing difficulties, and I was told that children can be teased for a variety of reasons, such as wearing glasses, being overweight, having eczema, wearing braces, or wearing hearing aids and that Spencer will need to have a strong self esteem in order to shrug off the teasing of his peers. Therefore, my aim is to provide Spencer with a healthy self-confidence and a tolerance of differences between people.

When I look at the range of possible disabilities, it feels ridiculous to complain that Spencer has a hearing loss. I have grown up with two of my sisters having juvenile diabetes and I am well aware that some people have added burdens to bear in life, and I would prefer to have a child with hearing difficulties rather than have to inject him four times a day with insulin, for example.

Spencer was 18 months of age when he was fitted with hearing aids and he accepted them from the beginning, only pulling them out when he was in the car for the first six or so weeks. I think that he knew that they made a huge difference, and his acceptance of the aids has made it considerably easier for us. His carers at the crèche advised that his 'frustrated' behaviour had abated once he was able to hear. It took my husband and I only a number of weeks before we were fully comfortable with the hearing aids, both inserting them into Spencer's ears and the cleaning process. When Spencer originally had the hearing aids fitted, we asked for both the hearing aids and the moulds to be coloured bright blue. This meant that they stood out, were able to be found easily in case they were pulled out, and the main benefit I found was that people (especially children) were quite forward in asking 'what are those?'. I discovered that the more I had to explain that Spencer has a hearing loss; the more comfortable I became with the fact myself. In fact, after only a short period of time, I discovered that Spencer looked 'not right' if he wasn't wearing his hearing aids.

Family and friends were naturally supportive on telling them the news, but slowly started to ask questions such as 'will his hearing get better?' 'how long will he have to wear hearing aids?' and 'why would he learn Auslan if he can hear whilst wearing hearing aids'. I have found that I have to be very clear about the fact that Spencer's hearing will not improve when I first tell people the news, otherwise they assume that it will just get better over time.

Overall, I have found that every single person who we have come into contact with since Spencer's diagnosis to be absolutely delightful; from the audiologists, to the staff at Australian Hearing and the early intervention program. We have been impressed with the high level of care that we have received. I have found the whole experience to be beneficial from a personal growth perspective; having to challenge myself on previously held beliefs about 'disabilities'; having to educate friends, family and the crèche community about what is going on with Spencer; having to speak to profoundly deaf people without knowing any Auslan; meeting parents of children with varying levels of hearing loss. This experience has taken me out of my 'comfort zone' more times than I can count, but this is good ultimately for my own development and for Spencer's future. I have been informed that Spencer will take his lead from his parents in how he views his 'disability', which is why our family intends to become fully involved in the deaf community and we embrace the opportunity wholeheartedly.