

Parent Story- Sophie Ashley



I became an Aurora parent 2 years ago when my fourth child was diagnosed with bilateral mild to moderate hearing loss. I myself have bilateral severe to profound hearing loss. I was initially diagnosed with moderate hearing loss at 1 year old and by 4 years of age my hearing loss deteriorated to severe in one ear and profound in the other.

Recently one of the Aurora mums expressed her concerns after reading a statement somewhere that 'deaf children often feel isolated from their families' and asked me for my feedback.

Yes, this statement may be true for SOME deaf children and deaf adults. Not all, but some. It all depends on the attitudes towards deaf children by family members - parents, siblings and relatives, and perhaps the personalities of family members. Some parents take a long time to come to terms with their child's deafness. That's okay, there is no time frame, but the sooner the better. It can be a process that takes many years especially those with no family history of hearing loss. It also comes down to the deaf child's personality - some deaf children, especially in their teen years may struggle with their own hearing loss eg "it's not fair, WHY ME??" (I went through this). Sometimes it's harder when there is no clear answer to the cause of hearing loss. For some deaf children, it has happened for no reason - not illness like meningitis, not premature birth, mother didn't have rubella immunisation, etc. There is also the high expectation and misconception that the cochlear implant is the instant quick fix that turns the deaf child into a hearing person. So many factors and circumstances, no families of deaf children are alike. I can only share my thoughts and feelings of when I was growing up as the only deaf member of my family so others perhaps can learn from past experiences and not make the same mistakes.

I was born with sensorineural bilateral hearing loss but wasn't formally diagnosed until after 1 year of age. Growing up as a deaf child and as the only deaf member of a hearing family was exacerbated by my mother who has a personality disorder; she rarely fully accepted professional advice from anyone pertaining to my hearing loss (including audiologists, deaf educators, Aurora (it was called Monnington back then), visiting teachers of the deaf, etc.), otherwise if she did, she would lose her sense of 'superiority' which was one of the traits of her personality disorder. She had the idea that deaf people who used sign language were inferior and had little hope for the future. My mother is a nurse and my father an aircraft engineer, both academic people and had expectations for all their children to be as academic as them (I'm the firstborn of the family). My mother also wore the pants in the marriage; my father had no say and went

along with all of her decisions. One of the decisions was to not allow me to use sign language, even discouraged general visual gestures I used when I was a toddler trying to communicate with my parents, not allowed to start dinner until I passed speech therapy practice... imagine how difficult it was for a child with severe to profound hearing loss!! And back then hearing aids weren't as powerful as it is now! My first clear word was spoken at 4 years old. Playgroup was very small, consisting of a few children with much less severe hearing loss (mostly mild to moderate at worst), no sign language used so all the 'deaf' children were not "like me" as my mother used to tell me - they were capable of speaking and hearing almost like a hearing person, and I was still left out. I attended mainstream kindergarten for 2 years. I don't really have memories of kindergarten, it was all a blur for me. I only remember playing with toys, outside play, art etc. I don't recall playing with other children, I guess I was at the age I was focused on my own needs for stimulation which was play and art.

From Prep I was sent to a private mainstream school. During primary school years, I never had formal help in the classroom to understand instructions, the class teacher had to explain to me one-on-one each time. It affected the 'normal' dynamics of the class, even some parents of other children in my class were not happy their children were missing out on the student-teacher interaction because the teacher had to spend more time with me. I had a visiting teacher of the deaf come to my school twice week to help me "catch up" on the important things I missed out in the classroom. Literacy, maths, etc. The only good thing about that school was I had a really close friend, the only one friend I had, Rachel (hearing). And to this day, we are still close friends after almost 30 years.

Due to my parents no longer able to financially afford the school, I had to leave and go to a different private school when I started secondary education, it was sad leaving Rachel, but it turned out to be a wonderful school. After the first term of Year 7, I was falling too far behind in the classroom and the teaching staff were very concerned. They insisted that my parents allow them to get a note-taker to sit with me in some classes. A note-taker did help me understand what the class teacher was being said in the classroom however, it still did not enable me to participate and contribute to class discussions. I basically had no voice and I felt left out of discussions many times. But lunch times were great, I had a handful of good friends to hang out with.

Meanwhile, there was one other deaf girl at the school (only 2 deaf students at the whole school), her name was Susan, 3 years older than me and she came from a deaf family who used Auslan. When my mother learned of this, she made sure we didn't become friends because she didn't want me to learn signs and passed on her instructions to the school. One time, Susan and I ran into each other during lunch in the playground, we had to hide from teachers on yard duty. She taught me some signs. I still remember how exciting it was for me! I loved learning signs. Unfortunately, we were eventually caught after a few times, we got into trouble and she left the school (not for that reason only though). We did exchange our address and became pen pals but I didn't see her in person again for a long time though.

In year 10, the time came that I needed to choose what VCE subjects to study for Year

11 and 12. I had no idea what I wanted to do for my future! After all, my mother had always made the decisions for every aspect of my life that I had not learned to think for myself. She 'suggested' I could be a teacher for the 'oral' deaf so I was directed to select the VCE subjects I needed to do for university entry. Let me tell you, those two years of VCE were ATROCIOUS!!! To this day I still don't know how I passed. I just did, by the skin of my teeth. Note-takers did NOT cover every session of the school day. The school could only afford a note-taker for 3 days a week, my parents were not willing to cover the costs for the rest! At the end of each day, I was tired from the mammoth effort needed to concentrate in the classroom. I still had homework to do... AND speech therapy practice! I was a very unhappy child and teenager for so long. After graduating year 12, I really did not want to go to university. I needed a break from constant lipreading. I had already been to the university open day before, the lecture theatres were massive, the tutorials were too fast paced and required a lot of student discussion so I already had some idea what it was going to be like. My mother insisted that a cochlear implant would fix that and I'd be good to go straight into university after the summer break. She strongly advised me to not defer university. (My course was a double degree Bachelor of Teaching and Bachelor of Arts (Humanities)).

I had the cochlear implant surgery in early December just after I graduated from VCE at the end of November. Unfortunately, it did not go well. When I woke up from the anaesthetic, I was given an anti-nausea medication, it was the first time I had it and I had a very bad allergic reaction to it; I went into oculogyric crisis for 45 minutes before it was stopped by reversal drugs. I ended up with a very bad whiplash requiring a lot of chiropractic and physiotherapy sessions, which delayed the first CI switch on by 6 weeks. At the first switch on, I did not hear anything. Only just felt like live wires poking into my brain, it was quite painful. The CI audiologist decided to wait until I was fully recovered first. After 3 months, still no change with switch on results. All year whilst I was a first year university student, I went back and forth to Geelong - Melbourne for numerous scans, doctors suspected leaking fluid in my ears from the oculogyric crisis. When the fluid was cleared up, we tried again. After 1 year, they found there was a faulty wire in the internal component of the CI, possibly caused by the oculogyric crisis. So they decided to do another surgery - remove the CI and replace it with a new one (in the same ear). It was 13 months between the first and second CI surgery. Everything went well with the operation and recovery, I had different medication. I felt good the day after the operation, and went to the switch on 2 weeks later. But still the same results...didn't hear anything and felt like live wires in my brain. After that, the professors sat down with me and said sorry they don't know why the CI isn't working for me and don't know what else to look for to investigate but will let me know if they find more tests.

I actually took it quite well emotionally. After all, I had been deaf all my life and did not expect too much of myself, it wasn't like I had lost anything (ok well, just lost the use of a hearing aid in that ear but that was the worst ear, not much difference anyway). But my parents were devastated. I had the strong feeling it wasn't for me but for

themselves.

During first year of university, I had a very difficult time coping. My heart wasn't in it. I did field experience rounds teaching at Princess Elizabeth Junior school for the deaf in Burwood, they had only one class for oral deaf, and that was a pretty small class of only 7 students (grades prep to two). Even the class teacher was very difficult to understand! I found myself sympathising with the little kids who all seemed very inattentive. I noticed deaf children in the signing classes adjacent seemed a lot happier and attentive.

I found the whole year to be a drag - lectures, tutorials and field work. Didn't want to do teaching, it wasn't my passion but I felt pressured to keep going because of family expectations. But something good happened... there was one fellow student doing the same course as me, Chantelle and she was also profoundly deaf, and she had an Auslan interpreter with her most classes. I watched with envy as she was an equal contributor in the tutorials. I had only a note-taker so I couldn't be part of the discussions. I felt very inferior as a person. Though it was a good wake-up call for me, it still was a very low point of my life. I didn't want the rest of my life to be like that and it was up to me to do something about it.

Shortly after the second CI surgery, when I was told there was no answer as to why it wasn't working, something inside me clicked. That's it... I'm 19 years old, I'm in charge of my own life. Not my mother. I woke up one morning feeling adventurous, caught a bus to Vicdeaf's Geelong office and signed up for a beginner course in Auslan. I was so excited! My psychology major (for the Arts degree) classmate (hearing girl) was interested to learn Auslan too as she was studying to be a social worker, so we did this course together and practiced with each other over coffee and lunch at university. I kept it a secret from my family for a while though. I wrote to my pen pal friend Susan and told her that I was finally learning Auslan and I would love to catch up with her over the summer break (she had moved to Brisbane to study at university there, but often visited Victoria to catch up with her family).

When summer came around, she invited me to have lunch with her and her deaf parents and deaf brother at their house in Torquay. Perfect, more practice, bring on the challenge! I had so much fun hanging out with them, after lunch we walked to the beach and we were still signing as we walked. People were staring at us, but I didn't care and felt pretty proud of myself for the first time in my life. I ended up staying for dinner as well. I had a ball, it was a breath of fresh air and the best day of my life so far and it was looking to get better.

I frequently travelled to Melbourne almost every weekend through the year to meet with more deaf people and socialise at many different events. I learned Auslan amazingly fast - because it was what nature intended for a person with such severe hearing loss, like me. By halfway through my 2nd year of university, I was able to make use of the Auslan interpreters who were already attending the Bachelor of Teaching classes for the other deaf student Chantelle. I actually requested interpreters for my

Bachelor of Arts classes. That sure felt good just going to the disability students office to ask for an interpreter. That year was the first of the best years of my life. I actually began to LIKE going to university. Study was a lot more efficient; I had more energy at nights to work on my essays.

During the winter months, I played mixed netball for a deaf team in a social night league in Geelong. It was fun, but some nights we didn't have the sufficient numbers to make a team, so one day I sent an email to Susan's deaf brother Stephen in Torquay to ask if he was interested in joining the team, which he did. After each match we went out for drinks and chatted a lot. After a few weeks, we started dating. I wasn't going to hide my deaf boyfriend from my family so I brought him home for dinner one night.

My mother was quite unimpressed, long story cut short we had an explosive argument that night, ending at 3 o'clock in the morning. I WON when I stood my ground and made it clear to her that I'm now an adult capable of making right decisions for myself. Thank goodness for my strong personality, otherwise my life would still be a sad story. And thank goodness Stephen still stayed with me and wasn't scared of my mother!

That boyfriend eventually became my husband (and pen pal friend Susan became my sister in law!). Stephen and I have been married for 15 years, still happily in love and we have 5 children, ages 13, 11, 10, 2 and 4 months. In between our 3rd and 4th child, we lost 3 babies, each during pregnancy. The details of our loss are not relevant to this story here but I can just say that during our grief, my mother overstepped the fine line by trying to control our grief and that's when I decided to cut ties with her indefinitely to help myself better. I found myself in a bereavement support group. I learned a lot about grief, it's not just about the loss of a baby or loved one... I realised I was also grieving for never having a fully supportive family.

Finally, we welcomed the safe arrival of our fourth child. However he failed the newborn hearing screening and later formally diagnosed with mild to moderate hearing loss. This took me right back to my childhood memories and there was no way I wanted my mother back in my life to try to control things again!

So here I am now. I don't have a heap of advice to dish out as everyone is different but number one is just really nurture your children's needs, 100% accept your child's hearing loss and work your way up as you go along as you learn how to help your deaf child. I'm sure most of you parents already do this anyway. Remind yourselves often that it's a journey, not a destination. Keep them close to you but don't try to control too much of their destiny. Let them have best of both worlds if they want - deaf and hearing. Technology advances nowadays are closing the gap between hearing and deaf, so life will be a lot easier for them than it was for me. There were no emails, no facebook, no mobile phones back in my childhood. Social networking nowadays has broken down a lot of barriers which I am grateful for.

Meanwhile, the little tips might not mean much to you at the moment without realising it but will go a long way in helping your deaf child feel equal part of the family. Deaf

children don't have the maturity to speak up until early adulthood, by then sometimes it is too late.

1. At meal times, if there is a family conversation at the table, even just chit-chat banter etc... still always involve your deaf child. I was often excluded from family conversations, couldn't follow what they were saying. I asked what was going on, my siblings often rolled their eyes and my father often said "I'll tell you later". He did tell me AFTER the meal time was over. But I still wasn't an equal contributor during these meal times. Doesn't matter what level of hearing loss, even moderate with hearing aids, your deaf child still can miss out on some things.

2. If you watch TV at home, please turn on the subtitles (or captions as also called). Even if your deaf child is still a baby or toddler and won't be able to read for a while yet, still turn on the subtitles anyway and leave it on full time. Get used to it so it will become "second nature" for the whole family. My siblings used to roll their eyes and complain whenever I asked for subtitles to be turned on. They thought subtitles were annoying and got in the way of viewing pleasure. If this happens, deal with it as a family promptly. This was one thing that made me feel isolated from the family, things like that were not dealt with. It was like "don't worry about them". It might seem trivial to some people but it was a big thing for me. Also be aware the hearing siblings might be resentful if they feel their deaf sibling is getting 'special treatment'. Deal with this too.

3. Where applicable, if your child is using sign language and you don't understand some signs, it is important that you don't disregard them and don't pretend to understand. Work on finding out what the signs were, get involved. It's hard work sometimes yes, but you're still learning, so don't feel bad. Same goes for speech. It is very important to keep the line of communication open at all times and it is very very VERY important that your child feels that you will understand them. I wish I had that in my childhood, I craved it very much and that need wasn't met.

4. Let them have best of both worlds, hearing and deaf. Even a successful outcome with CI where your child can lead a life equivalent to a hearing person, remember, when the CI is switched off, battery flat, malfunctioning, broken, lost, stolen, etc, they are still deaf. When things like that happen and they have best of the deaf world, it's a lot less stressful and the whole family will cope better. Even if you don't need to be fluent in Auslan, basic skills will be handy as a back up. I have met deaf adults who grew up with CI and some have said the hearing world with CI is still artificial and that they find social life with deaf people more natural but still enjoy having both deaf and hearing friends.

5. Never assume either your child understands or not. Don't assume your child is understanding everything you say AND don't assume your child is not able to understand what you are saying. For example, if you're tempted to talk to someone about how challenging life is with a deaf child, don't do it with your child around. Just don't. Even if you mumble, whisper or turn your face away thinking your child can't hear

or see you talking about them, you're wrong. Even if your child doesn't hear word for word, they have the amazing ability to sense what you're saying. Deaf people, particularly the ones with more severe hearing loss, can read your body language in a way hearing people will never be able to comprehend. Loss of hearing as a sense will be compensated into other senses, particularly sight and touch. Like a blind person's sense of touch is heightened so they can feel Braille language, many sighted people will never understand. When the deaf child senses they are being talked about in a negative aspect, it can leave them feeling more inadequate.

6. Be sensitive about what you say to a young child about being deaf even if it's just banter and well intended as a joke. For example "lucky you're deaf, you can sleep through the thunderstorm!" or "lucky you, you don't get listen to this terrible music!". Or if someone else says it, stick up for your deaf child. Either way, it's not funny for a deaf child, nor it is seen as an advantage. It may be ok as a deaf adult, I can take jokes now, I'm mature enough to disregard them without it affecting me. Some people make comments like how lucky I am to not hear a baby crying and can switch off my hearing aid at my convenience. That is not true. I do not like to SEE a baby crying either, with my strong maternal instincts I will do anything to comfort them, pick them up, cuddle them etc. Crying is a baby's way of communicating and I know the feeling of not being able to communicate so I would never cut that line of communication and will never switch off my hearing aids. I personally believe with whatever hearing I have left, hearing a baby cry is actually a gift which many take for granted.