

## Observations and Reflections on a Teenagers Sequential CI Journey

### ppt slide - Title & presenters

#### **Decision to implant**

### ppt slide - Decision to implant

#### **Parent's perspective**

In December last year my daughter Jamie, who is presenting with me today, received a right CI at age 14. When she was 19 months old she had received a left CI. Our families decision for Jamie to receive a second CI lead us on a very challenging, emotional and at times exciting journey.

Jamie was born profoundly deaf. We received the diagnosis when she was 5 months old; this started our journey into a new world. One that lead us to a Total Communication program for early intervention, hearing aids, cochlear implants, the Deaf community, sign language and further study for me to become a teacher of the deaf.

The decision to implant Jamie when she was a baby required much soul searching but from the moment she was switched on my husband, Darren and I knew we had made the right decision. I have a little snippet of her original switch on video and a brief home movie 4 months post her first CI.

### ppt slides - Switch on video

### ppt slide - Bath home movie

### ppt slide - Photo movie

We had considered a second CI when Jamie was 8 years of age. But she was sure she didn't want it and Darren and I were happy not to go down that track.

One day towards the end of 2011 as Jamie and I were driving in the car, Jamie said to me out of the blue, I think I want the second implant. I want to be able to follow conversations in a group and not always miss the jokes.

The decision to implant was just as difficult the second time round. In many ways it was harder. In my eyes Jamie was functioning very well with one implant. Academically she was excelling, she had great friends at school and was achieving amazing things as an athlete, including travelling all around Australia. Her life appeared good and she was managing in a hearing world. We had also involved her with the Deaf community through sport and camps. My aim was for her to have the best of both worlds, access to the hearing world and involvement with the Deaf community. She only needed one implant to do that.

Professionally I was aware of the potential benefits of binaural hearing with bilateral CIs. The second implant could provide Jamie with the ability to localise sound and provide her with improved access to speech in background noise. This would probably help her follow group conversations better, her main goal. However, we were told that her speech perception with the second CI would probably never be as good as the left side.

As parents, Darren and I were very reluctant to take the risk, the benefits didn't seem enough. The main risks were facial nerve damage, taste nerve damage and her balance being affected. I was very concerned about facial nerve damage; I believed if the worst happened, it would be very difficult for a 14 year old girl to deal with. Jamie and Darren were probably most concerned about her balance, because Jamie is a very keen and accomplished sportsperson. Obviously if her balance was effected it could impact on her sporting ability. These risks were all very slim but still possibilities with this type of surgery. I also knew the MAPPING and habilitation would be very time consuming and this would be a challenge to fit into our busy family schedule. We also considered the ongoing expense for Jamie to maintain two cochlear implants as an adult. Probably I also remembered how physically and emotionally draining the first one was and didn't want to put myself through it again and more importantly this time around Jamie would be aware of everything that was happening. How would the process affect her emotionally? What if it didn't meet her expectations?

Again after much soul searching, Darren and I came to terms with the fact that we could never appreciate the world from Jamie's perspective, a deaf teenager, hearing through a cochlear implant in one ear, functioning in a predominately

hearing environment, mainstream school, hearing family. As we make decisions in life for our children we can usually put ourselves in their shoes to some degree, for this decision we could not. If this second implant makes her life a little easier, she doesn't have to work quite as hard to be part of conversations, can we deny her this? I have an insight into how hard Jamie works every day at school, on the sporting field and in the community to listen, because when she is at home she rarely wears her implant. I believe she works so hard that home is her 'safe place' where she can have some respite from having to listen. So we decided to let Jamie make the final decision after she had received all the information with regards risks and benefits from both her audiologist and surgeon.

Jamie found the inner strength to make a very difficult decision. Jamie was able to put the risks in perspective and make a very mature and rational decision knowing it was not the decision her parents would make. But she knew that we would support her 100% if she decided to go ahead.

I will let Jamie tell you about her decision making process.

### **Jamie's thoughts**

#### **ppt slide - Pros & Cons**

When I was 8 years old I was asked whether or not I would like to receive the second implant. I was very adamant that I did not want it. I thought I didn't need it. At the time, I was doing well at school and wasn't missing out on anything; however the idea never left my mind. During my second year of high school (grade 8) things started to change. I was growing up, becoming more social and the school work was getting harder. It was that year when I started to realise that the possibility of receiving the second implant may be a good idea. I thought about it for a very long time but no one knew that I was considering it. One day towards the end of grade 8 I eventually told Mum that I was seriously thinking about getting the second implant. I don't think she believed me at first but I was true to my word. After that I spent a lot of time thinking about it and going through all the risks and benefits. I was actually very quiet about it and when Mum would try to talk to me about my decision making I shook her off. I just didn't want to talk to my parents because I knew they wouldn't look at this decision objectively. That they would be parents and only worry about the risks, so Mum asked me if I wanted to talk to

someone like a psychologist. I didn't want to talk to someone who didn't know me well so I decided I would talk to the closest person to me who isn't family and that was my Advisory Visiting Teacher. I chose to talk to Glenys because she has known me since I was 9 months old and has given me the best support. She has helped me with so many things and understands exactly how I feel.

On the 20<sup>th</sup> of September 2012, I sat down with Glenys and had a really good long talk to her about the second implant. We discussed all the benefits of having surgery and not having surgery and also all the negatives of having the surgery and not having the surgery. The main reasons I wanted to receive the second CI was so that I could build my confidence, get more involved in group conversations and not miss out on things. I wanted to be able to localise sound and learn more in the classroom. If I didn't go ahead with the surgery, I wouldn't have to worry about the risks, I was already a high achiever and could still enjoy the things I enjoyed doing but I felt like I would lose a huge opportunity to be able to hear out of two ears. The biggest thing that worried me was that surgery may affect my balance. That it may affect my sport which is my life. Was I willing to take that risk? That was the biggest question. However, we also took into consideration that my surgeon had done the procedure many times and is an experienced ENT so the risks were very slim. Glenys and I noticed how I emphasised the positives rather than the negatives and I had made the comment that even though my brain was telling me the risks, my gut was telling me to have the implant. On the inside, I really wanted to receive the second Cochlear Implant. I really wanted the opportunity to experience switch on because I could not remember my first one and this time I was older and would be able to remember it. I honestly was not scared of surgery and was actually very excited to experience it.

When the day of surgery came I wasn't nervous or worried, I felt like I was doing the right thing and I was actually extremely excited! Everything went well and when I came out of anaesthetic I slept for about one hour, then was sitting up and eating. Mum and Dad went home for the night and I stayed in hospital overnight. The nurses were lovely and to be quite honest, I had a lot of fun going through the experience! The hardest part was having to stay home with a bandage wrapped around my head for a whole week. Eventually it got taken off and I was able to start athletics training again.

When switch on day came I was overwhelmed. I could not wait to switch on but it was very different to what I expected. I imagined that as soon as the implant was turned on, I would be able to understand speech or at least some sounds. I secretly believed it would be just like my left ear but obviously I was

wrong. All I could hear was noise but I wasn't sure if I was actually hearing anything because it was more like a feeling, like a vibration. I could hear sound but I did not have a clue what it was. Everything sounded the same.

### ppt slide - Switch on video 2012

We have been very fortunate to have had wonderful experiences at both Jamie's switch ons, as you can see from the videos.

Another exciting aspect of this process for me was having Jamie able to articulate her experiences. I work with babies and toddlers receiving unilateral and bilateral cochlear implants. To have an insight into what it is like to receive and learn to listen with a CI is invaluable for my practice as a teacher. I think I drove Jamie a bit crazy asking questions and taking notes.

I have used the auditory hierarchy to organise my observations and reflections.

### Detection

#### ppt slide - Detection

Jamie's ability to **localise sounds** was instant. The day of switch on we were waiting at the reception desk to sign paperwork after our appointment and a lady in heels came walking down the corridor on Jamie's right side. Jamie excitedly commented I heard that and knew where the sound was coming from. Obviously she had both implants on to do that, but still amazing it happened so quickly, especially when you consider that with just the new right implant she just heard noise with no ability to discriminate. In fact she didn't appear to have **spontaneous awareness of sound**. I could call her name, put music on, turn up the TV and Jamie was not aware of the sounds if she was just wearing the new implant. Probably because it was all just a noise, with no meaning, consciously or subconsciously she didn't bother to attend. However, if I **cued her to listen** then she was aware of the presence of sound. But it was just noise, no discrimination between voice, environmental sounds etc. Because of Jamie's prior listening experience with her original CI, I did attempt the Ling sounds very early, three days post switch on Jamie could detect 7 speech sounds if I gained her auditory attention.

### ppt slide - Seven Speech Sounds Test results from 21/12, 22/12, 28/12

As you can see on the slide Jamie couldn't identify or even discriminate them, although she made reasonable attempts based on her knowledge of speech sounds, but she could detect the speech sounds when I was about 1 metre behind her, if she was cued to listen and it was quiet.

It amazed me how easily Jamie adjusted to wearing both implants even though the signal she was receiving was very different.

### Discrimination & Identification

#### ppt slide - Discrimination & Identification

When children are first hearing with a CI I talk to parents about **environmental sounds**, cueing a child to listen to an environmental sound and then showing them what's making the sound, phone ringing, dog barking, toilet flushing. I realised from Jamie's experiences, discriminating between rain and a washing machine. Identifying a bird outside, that environmental sounds need to be revisited over time because how a person perceives a sound will change as the brain learns how to perceive sound meaningfully through an implant. This is important for discrimination and making connections for identification.

Jamie commented that **instruments and noisemakers** were a good way to help develop discrimination, for example just a couple of weeks after switch on Jamie could discriminate between a rattle, tambourine and cymbals. Jamie was unaware of what was making the sounds I was producing behind her. Jamie also started to identify the sounds, for example commenting *it's like a rattling*, for the rattle, *it's like bells* for the tambourine, Jamie suggested it was a *clapping action* for the cymbals. Jamie asked *Are these all like instrument type things?* Jamie probably used her prior listening knowledge with her original CI to work out what she was hearing with the new implant. But it is good to know these early discrimination and identification activities we use with young children new to listening are appropriate for developing their listening skills. I would suggest they are also a good way to develop confidence in older children new to listening. Jamie has excellent listening skills with her left CI but needed to learn to listen again with the right implant.

**Voices** all sound the same to Jamie with her new implant, including her own voice. Learning to discriminate voices to then be able to identify voices is an ongoing goal. I remember this skill took time to develop the first time round.

Jamie is very reliant on **suprasegmental and segmental cues** to discriminate and identify what she is hearing in terms of speech with the new implant alone. Highlighting prosodic cues, including duration, loudness, pitch, rhythm and intonation has been an important strategy used to develop Jamie's ability to identify speech sounds and words. In terms of segmental information, from very early post switch on Jamie used syllable information to help her identify single words and familiar phrases. It wasn't until May this year, Jamie started to pick up speech sounds in words to help with identification, for example /sh/ in *Shelley*.

Another strategy that Jamie has drawn my attention to is the importance of acoustically highlighting and contrasting sounds. The need to manipulate a speech signal in early listening tasks to develop skills and experience success is important for any new listener not just babies and toddlers. For example, a listening task I did with Jamie, about two months post switch on, was identifying a familiar food at the end of a sentence using a closed set; banana, ice cream, nuts, fruit.

At first I used the sentence *I am eating* then the target word. Jamie commented that she couldn't tell where the word *eating* finished and the target word began. We changed the sentence to *I like* then the target word and Jamie had some success identifying the word at the end of the sentence, even though she was still inconsistent and using prediction, it helped build her confidence.

## **Comprehension**

### **ppt slide - Comprehension**

Not there yet! I had expected Jamie to understand speech fairly quickly with the right CI because she did so well with the left. Just goes to show the impact of age, critical period of language development and auditory pathway deprivation. Also I think it highlights how complex the process is to train the brain to process sound and perceive speech through a CI. In 2013, Raeve, Archbold &

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Diller stated *the older the child at second implant, especially in the case of good performers with the first CI, the greater the need for individual second ear therapy*. This surprised me but my observations of Jamie's progress with both CIs would support this. This same article suggested there is little or no research concerning optimal rehabilitation after bilateral CIs. So hopefully some qualitative action research reflecting on personal experience is a good place to start to build our knowledge and experience for providing support to a rapidly growing number of sequential implantees of all ages.

So to finish here are some therapy tips from Jamie....

Six months down the track I am very happy that I had the implant. Being able to localise sound is great and having the two CIs is helping me heaps in the classroom. I currently attend fortnightly speech therapy at the Mater, this has been hard to fit in to my busy schedule and it is not something I enjoy but here are a few tips.

**ppt slide – Therapy Tips & Speech therapy photo**

### **Therapy Tips**

- Encourage natural conversations, including lip reading, with just the new implant.
- Don't cover your mouth with your hand or paper, it distorts the speech signal.
- Spending time at home with just the new CI is beneficial.
- Using content relevant to the individual makes listening tasks helpful, for example identifying friend's names or sports.
- Reading interesting books out loud with someone is an enjoyable and meaningful listening task.
- Remember that listening with an implant is really hard work and very tiring. Don't make therapy sessions too long and don't have unrealistic expectations about teenagers completing structured listening homework.
- Make it FUN. It's the only way to get the kids motivated.