



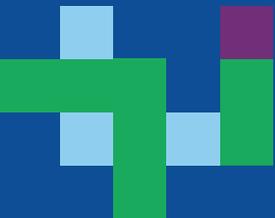
Cochlear Implant Patient and Parent Stories

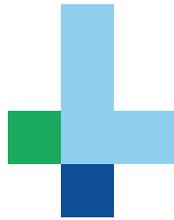


the royal victorian
eye and ear
hospital

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Introduction

Dear Reader

The stories within this booklet have been written by Cochlear Implant recipients and parents. It has been developed to provide you with a personal insight on the journey you are about to embark on.

We would like to thank Daniela, Michael, Joanne, Ahida and Jodie for sharing their stories with us.

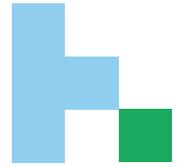
Kind regards

**The Cochlear Implant Clinic Team at
The Royal Victorian Eye and Ear Hospital**





Jodie's Story



“I feel that the implants didn’t just restore my hearing but my confidence and happiness too”

There wasn’t an exact moment when I realised I was deaf. I think my family picked it up before I knew. It was only when they made comments about me not hearing them that I knew I didn’t hear as well as they did. I was also only thirteen years old and didn’t want to acknowledge the fact that I had a hearing loss. Tests confirmed I had a mild hearing loss and I was given hearing aids and sent on my way. They didn’t seem to help and I didn’t want to wear them either. I managed to make my way through my VCE with only a couple of my friends knowing my secret. My hearing remained stable through my teens and I managed to get by with lip reading and the small part of good hearing I still had. I avoided situations where I knew I would struggle such as loud restaurants. I did confide in my good friends eventually who were and remain very supportive.

When I was 19 I met my wonderful husband Steve. I was surprised to find out that his mum and other members of his family had hearing loss, I didn’t know many people with a hearing loss like me. I was lucky enough to get a great job at the Victorian Deaf Society and felt so accepted there working with other people who understood.

In 2006 we had our beautiful daughter Bethany. I was so happy until one night when Bethany was a baby I was watching a movie when I got tinnitus for the first time. I was familiar with tinnitus and knew that this affected a lot of people with hearing loss and that it was hard to live with. That night I discovered why. The ringing in my ear was so loud and impossible to ignore. This led me to the first appointment I had with an ENT in years. This was also the start of my journey to receive a cochlear implant. I had lost quite a lot of hearing and was extremely distressed and emotional. I had always had a deep fear of losing more hearing, however my fears were replaced with hope at my first appointment with my audiologist Michelle at the Cochlear Implant Clinic.

Throughout my life I had so many hearing tests and always came out of each appointment feeling sad but this time Michelle made me feel positive and hopeful. I had so many tests and read many stories about other people’s experiences. I knew I was making the right decision and remained as positive as I could.



My right ear was implanted in September 2009, all went well with the surgery and the 'switch-on' day arrived. I had no idea what to expect. Everything I read said it would sound robotic but when Michelle switched it on and said "ok so how does that sound?" I just thought, wow, her voice is so much clearer, a little bit like she was speaking through a microphone, but not robotic at all. One of the first things I noticed was that I was hearing an 's' sound a lot. I went home happy and rediscovered so many sounds I remembered hearing when I was a child such as train bells ringing, the microwave beeping and birds chirping. It was a wonderful feeling. One of the moments that stands out was hearing the 60 Minutes clock ticking. I remembered hearing this clearly as a child and then not being able to hear it, so I looked up in surprise when it came on being able to suddenly hear it again!

My experience continued to improve and I just loved it. I slowly gained more and more confidence in social situations and though I still couldn't hear as well as others it was still so much better than before. I embraced any opportunity to hear better in lots of different situations. I looked forward to each mapping session with Michelle and I no longer hated the tests, because I loved the results!

A year or so later I noticed my hearing was worse in my left ear. When tests confirmed I had lost more hearing I made the decision to have my second implant, I was booked for surgery.

It was easier this time because I knew what to expect. The operation went well and even though I did find the recovery a bit harder this time round with a very sore head, I knew it was worth it. 'Switch-on' day arrived and I was extremely excited. When it was switched on and Michelle spoke to me I couldn't understand what she was saying and I felt very disappointed, but not for long. As Michelle made some adjustments and spoke again I began to understand her better. At first it sounded like lots of beeps and I knew the beeps were words because of the pauses between the beeps. I was worried that I wouldn't be able to hear as well with the first implant but I knew that I needed time to adjust. As Michelle kept talking to me I started to understand the words being spoken and felt so much relief I got a bit teary! Over the next few weeks I practiced listening using my newly implanted ear as much as possible. I started hearing the beeps again but the longer I listened, the more the beeps became words. This took a few weeks but I felt so much relief that I now had two successful implants!

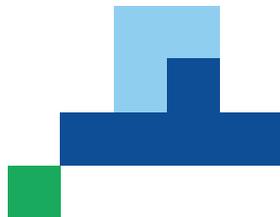
When I use my second implant alone my daughter sounds a little different, a bit like she is speaking through a microphone but still very cute. When I listen with both implants, her voice is just natural, the two together gives me so much more volume, clarity, direction and awareness. It is especially good in a noisy setting like a kids party. At times I do struggle to hear and probably have too high expectations from my implants and have to remind myself that I do still have a hearing loss. It's interesting that I have finally accepted the fact that I have and will always have a hearing loss after so many years of resistance and denial. I accepted the fact that I had such a profound hearing loss that I needed to reach out for help. Throughout my whole life I had ignored any advice and became anxious when any mention was made about my hearing loss.

I feel very lucky, especially that I am able to talk on the phone again. It has definitely been one of the highlights for me. I can now use my mobile phone which makes my life so much easier.

My future now feels so much brighter, travel, study, new business and extending our family are all plans within my near future. I feel that the implants didn't just restore my hearing but my confidence and happiness too. I would encourage anyone considering an implant to remain hopeful and positive. It is an amazing journey and extremely rewarding. If my story helps others make the decision to go ahead with an implant then that would be wonderful.

I am extremely grateful.

Jodie Boyd





Muhammad's Story

“We cried tears of happiness, his speech progressed every day”

My husband always wanted a son. We have two beautiful girls and are very grateful to have children. Every father wishes to have a son with whom he can play sport, football and do boy things. In 2004, I gave birth to a beautiful four and a half kilo baby boy. We were the happiest parents when our son Muhammad came into this world. It was a wish come true.

When Muhammad was three months old, I had a suspicion that he wasn't responding to his name or to loud bangs, everyone thought I was crazy. I took him to the maternal child nurse, who told me “he was probably used to all the environmental sounds in our home.” At four months, Muhammad became sick. He was rushed to the Royal Children's Hospital because our local doctor thought he could have meningococcal. Luckily it wasn't. It was some sort of viral infection. This is when I told the doctors at the hospital that I was concerned about Muhammad's hearing.

It was the last week in Ramadan, just before the Eid celebration when Muhammad had his hearing test at the Royal Children's Hospital. And to our huge shock the audiologist told us that our son had a profound hearing loss, we

had no idea what that meant. “So does that mean our son can't hear?” I asked the audiologist over and over again. How could this be? My husband and I came from healthy hearing families and our daughters had normal hearing too. This was an indescribable feeling, we left the hospital crying and speechless, our Eid celebration wasn't enjoyable. How could we celebrate when we've just found out Muhammad had hearing loss. We had many appointments to attend at Australian Hearing, I'd walk in crying, I'd leave crying. Everyone would tell me it was going to be alright. How could it be alright?

Muhammad was fitted with the most powerful hearing aids at six months, only they were of no use to him, he'd hate anything in his ear, putting them in his mouth and they'd always be whistling. For the next year I was a total wreck. My world was black. I was depressed and constantly yelled at the girls and my husband even when they hadn't done anything wrong. I gained weight, hated socialising and just wanted to keep to myself.

We attended our first appointment at the Cochlear Implant Clinic, I remember seeing other children with aids and



implants and I'd burst into tears. Often other parents would say to me "we've been through exactly the same and we're feeling just like you".

We met other families whose children had cochlear implants to help us make a decision, we were very confused. This was one of the hardest decisions we ever had to make. Finally we decided to go ahead and implant him because the younger he was the less he would be behind in his hearing development. I remember my husband saying "I can't wait for the day my son calls me daddy."

When Muhammad's surgery date came he had an ear infection and it was delayed, he was given another surgery date but once again his ears were infected. Was this a sign for us not to go ahead with the operation? In July 2005, Muhammad had his first cochlear implant. This was a terrifying day. The operation went for three hours and when the surgeons came out and told me it was successful I sighed with relief. Two weeks later Muhammad was switched on. His facial reaction to noise was amazing, he was turning and smiling when he heard noise.

Life after the implant was hectic. There were many mapping appointments and therapy sessions. Eight months after the operation Muhammad said "mummy and daddy". This time we cried tears of happiness, his speech progressed every day.

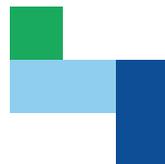
A year later Muhammad's ENT specialist suggested we think about giving Muhammad a second implant. Oh no! This was another huge decision we had to make. We didn't think it was necessary because he was doing so well with his first implant, but we were finally convinced after five months it is better to hear with two ears than one.

When Muhammad had his second implant I was more relaxed and aware of what to expect this time round. When he was switched on he adapted straight away to wearing it and was hearing with his second implant just as well as his first implant.

Muhammad is now three and half years old. He wears both his implants all day and is making wonderful progress. He attends weekly therapy sessions at Taralye and will be going to a normal kindergarten next year. We are very happy with our decisions and feel like all our hard work has paid off.

Earlier this year, I nominated and entered my husband for all his hard work in a father of the year competition in our community. He won this recognition and became Hobson's Bay Father of the Year. Omar was honored to have won and was very proud to have a wife and children who appreciate him.

Ahida El Souki



Michael's Story

“I joined in making comments back and forwards, it really was a wonderful feeling”

I have had my cochlear implant for nearly 12 months; it has been an amazing journey, which has seen me bound from the depths of despair, to a new and vibrant lifestyle. I was diagnosed with mild to moderate nerve deafness at the age of 5, and with the use of hearing aids was able to get through school without major drama. By the time I reached my mid twenties my hearing began to deteriorate,



first in one ear and then the other, so that by the time I was 40 my speech discrimination levels were so low that using a telephone was out of the question, watching television could only be done with teletext, listening to the radio for those important football and cricket scores could not be done, and listening to music was just not the same as I remembered it.

I had been following the breakthroughs and success stories of the cochlear implant program for quite sometime, in fact I had first hand knowledge of how good they were. My neighbour had an implant and raved about the success he was having, a colleague at work had an implant and was doing so well he was using the phone. I was also aware of another colleague interstate who was also doing wonderfully well with his two implants.

Taking inspiration from these people, I made an appointment with the clinic, had all the tests and was accepted into the program. I was to be implanted in November 2004.

The actual surgery went very well, so well in fact that I was immediately sitting up and very alert, it was almost as if nothing had happened, (apart from the big bandage on the head). I was out of hospital within 24 hrs feeling great and with little pain.

‘Switch-on’ was two weeks post surgery, the process was relatively simple and involved listening to a series of beeps, for the softest sounds (called the t levels) and then listening to the most comfortable sound level on each electrode (c levels). Once this process was completed (mapping) the processor was turned on. Wow what a lot of noise in this small room! I could hear EVERYTHING, the fan of the air conditioning, fan from the computers, the shuffling of feet, probably even the dust falling. An interesting observation was that the noises I could hear and identify were out of sync (like a bad sound track on a movie) and speech sounded not like the Donald Duck I was expecting but rather Darth Vader.

The first map drove me to distraction, so many sounds, refrigerator motor, the birds, and the unintelligible noise of the television from any room in the house, running water, the electric fan on the computer. However I had the house to myself during the day, and while sitting in a quiet room I could listen contently to individual sounds as they came to the processor. The bang of the hammer and the whirring of a circular saw from a nearby building site and other noises that, taken on an individual basis, were quite pleasant.



The second map a week later increased the dynamic range to such an extent that a fair proportion of the distracting noise disappeared to be replaced by sounds that were more identifiable. The third map was a revelation, I suspected I could understand speech in the clinic, but there were visual clues. It was not until driving home with two children in the back bickering at one another, for a while I just listened hearing every word, eventually I joined in making comments back and forwards, it really was a wonderful feeling. As an added bonus I was able to listen and follow the radio both talkback and music, I was able to identify songs that I had not heard for many years.

I still had some difficulty on the phone particularly in recognising voices, or the gender of the person speaking to me. It was somewhat embarrassing listening to other peoples conversations, I couldn't help it, I had an insatiable thirst to hear and understand the spoken word. I managed to improve my hearing on the telephone, through practice. Finding willing subjects is always hard but I took advantage of those pesky telemarketers, who would often ring our house I would let them waffle on making sure that I understood what

they were selling, asking questions to clarify their offer, and then, thanking them for their time in helping my rehabilitation and then decline the offer. I'm sure we have had less calls from them lately.

With practice and time, my speech scores have improved in background noise and single word scores are also up. What a huge difference it has made to my life, my confidence in dealing with people has returned, people are more comfortable in speaking to me. The word 'what' has almost been eliminated from my vocabulary. The phone has become my friend instead of something to be avoided.

I feel extremely lucky to have had so much success with the implant, it has exceeded my expectations many times, although I must stress that it has at times been hard work and there were some frustrations along the way, however persistence and determination are always the keys to success.

Michael O'Connell



Daniela's Story

“I take such pleasure in sounds, I go out of my way to create them, even amplify them”

Five months ago I was a completely different person, I'd lost my sense of identity, lost my place in this world. At a social event I'd be hiding in the corner, silently hoping that nobody would approach me. I'd look at the floor, never meet anybody's eyes in case it sparked a conversation. If I had to take part in a discussion, I'd mimic the face expressions of the other people in the group and hope it was the right reaction to whatever was being said. I could never make new friends. It took all my energy to simply keep my current friends. To be honest, I would have been too afraid to come to a social event in the first place, I doubt you'd have met me at all, five months ago.

I lost my hearing quite suddenly in 2007, at the age of 27. I'd been fighting an ear infection at the time. It turns out my immune system fought off the infection and then kept going. The autoimmune hearing loss was often able to be reversed or stabilised with medication, but every time I stopped the medication it would suddenly disappear again. When the medication caused some other serious health issues, I decided to stop taking it and just say good bye to my hearing instead.

Every time the dizziness would start, my world would spin, when it stopped I'd be stranded somewhere a little quieter than before, where everybody was speaking a foreign language. In this place I felt like I was observing the world, never living in it. I felt like the condition had destroyed my hearing and destroyed my sense of belonging; my home.

In March 2010, I received two cochlear implants simultaneously, in April 2010, they were switched on. That day everybody talking to me seemed to have swallowed a large dose of helium—I loved it! I could understand words again. I walked through the park and listened to the birds in the trees, with a huge smile on my face. I couldn't wait to get home to test out the piano – I dragged my husband into the nearest music store so I could hear for myself. Afterwards, I said to him, “there was music in the store, wasn't there? Coming from a speaker somewhere?” He frowned and shook his head. I said, “but I heard it – it was a piano. Somebody was playing the most beautiful song.” He then looked at me, horrified - “you can't mean the pianos being tuned out the back?”

Yep, it turns out I did. We still laugh about that today.

With a little luck, quite a bit of sound rehabilitation, and a lot of optimism, the sounds started stabilizing, now I am living a very different life. I don't hide in the corners of rooms anymore; I seek people out. I don't look at the floor anymore; I make eye contact. I'm not afraid to pick up the phone when it rings. I can talk effortlessly with my family and friends again. Hear my husband tell me he loves me. (Even if I have to force it out of him sometimes!) I take piano lessons every Tuesday night. Fill the silences with my favourite songs again, if there's nobody around to talk to. I've changed my wardrobe purely to match the processor covers that I swap around each day.

I've reasserted my place in this world with a vengeance, driving my family mad by repeating the things they say, just because I can. I take such pleasure in sounds, I go out of my way to create them, even amplify them. I make my

hiccup as loud as possible, and my teeth chatter as loudly as possible. I've been known to make our cuckoo clock chime when it's not quite supposed to. My friends describe me as a 'listening junkie'. My husband describes me as a 'noise machine'.

I remember too well what it's like to not be able to do any of these things, and I take nothing for granted now. I'm so grateful I can hear again, that I feel like I'm on top of the world every day.

Please visit Daniela's blog:
<http://www.daniela-andrews.com>

Daniela Andrews



Joanne's Story

“One of my best experiences has been teaching in the classroom”

When I was nine months old, I was diagnosed with a severe/profound hearing loss and started wearing a hearing aid. When I was about 11 years old, I started wearing two behind the ear aids until I was 15 when I decided to not wear my right hearing aid because I felt it was not very helpful. I grew up orally, until I swam for the Victorian Deaf Swimming team when I was 16 years old. It was then I learnt to use sign language because it helped me to explore new language and to improve my communication through using signing interpreters in the hearing environment.



I had become aware that I could not understand the speakers at various professional development workshops and having a sign language interpreter helped me to understand what the speakers were talking about. My hearing level has been stable over time, but I had a lot of difficulties understanding the speakers at meetings. I also had trouble understanding my daughters when they would try to tell me something and even though my daughters can sign, I would prefer my daughters to speak with me.

Before the implant, I wore my hearing aid on my left ear and no hearing aid on my right ear. I always relied on wearing my aid as I have residual hearing and am able to hear different sounds. I still identify myself as a Deaf person and proud to be what I am.

I am a Leading Teacher in a Deaf Unit, working with mainstream teachers and teaching deaf/hearing impaired students and hearing students at a secondary college. I first thought about having an implant when I observed the improvement of students and a couple of my friends after receiving a cochlear implant.

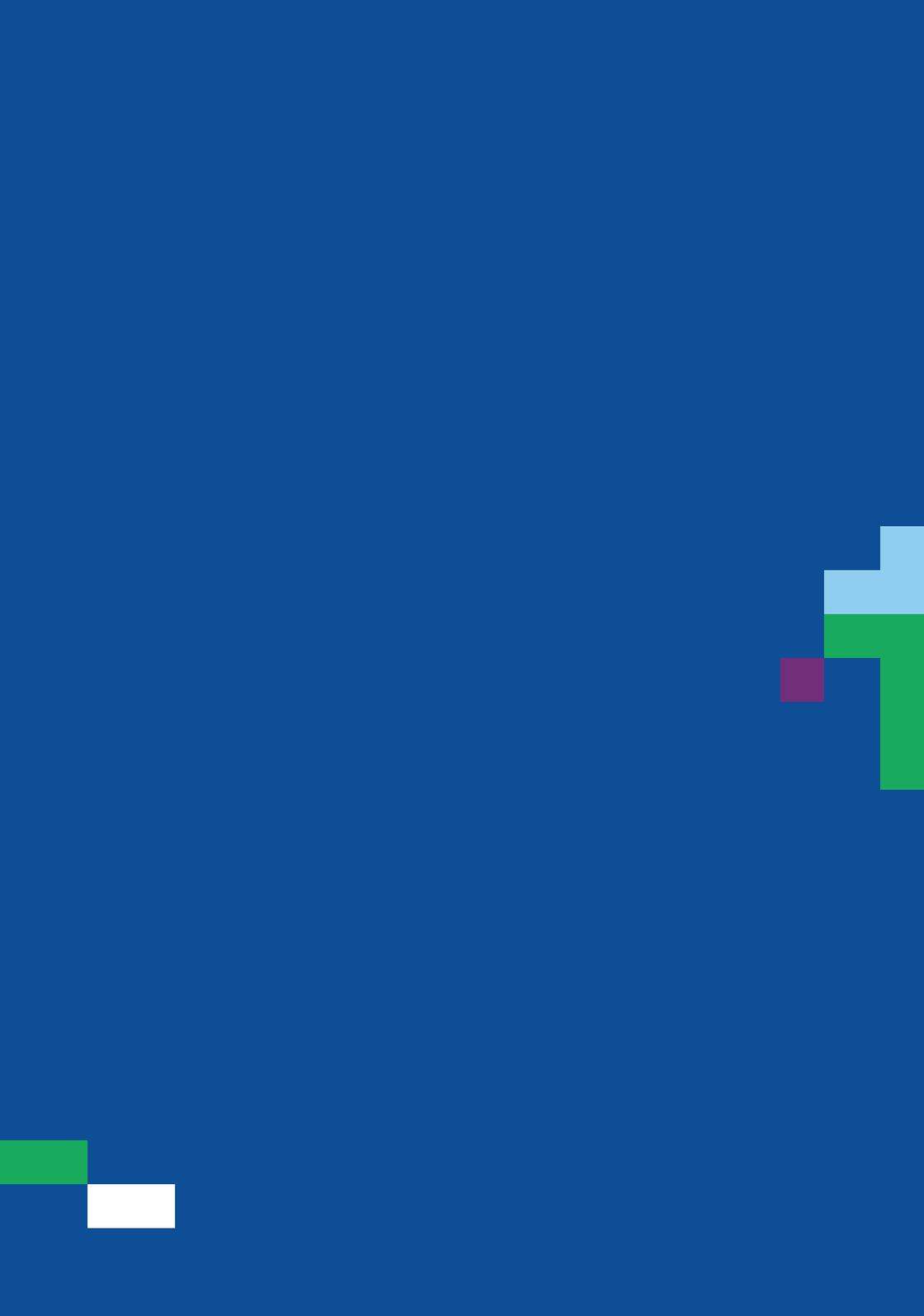
It took me two years to decide to go and see a clinician at the Cochlear Implant Clinic.

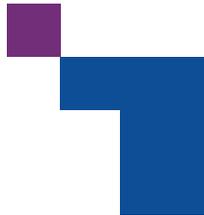
After taking part in assessments and counseling, I decided to go ahead, knowing that the result may not be what I expected; I was prepared to take the risk. On the day of 'switch-on', I was quite

nervous not knowing what to expect, but to my surprise I heard different sounds to what I had normally heard with my hearing aids in my teens. I wasn't disappointed but excited to experience strange sound stimulations.

One of my best experiences has been teaching in the classroom. During a class I was writing on the board, changing the whiteboard marker from red to blue, I noticed a different sound every time I changed the markers. I looked at my students also writing and changing pen colours and I realised that when the students dropped their pens on the table it made a 'clanking' noise. So I really heard that 'clanking' sound for the first time! At the end of the class, I heard a strange sound coming from the loud speaker and it sounded like a voice. My students were about to leave the room and I asked them not to leave the room. With their 'surprised' facial expression, I told them that the sound wasn't the school bell. One of the students told me it was a voice announcement and they were so thrilled that I could tell the difference between the announcement and school bell sound. I could not tell the difference before. Now my students know that they can no longer get away with leaving the class early because I can hear the difference between the bell and an announcement!

Joanne Davis





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