

MY STORY

IMAGINE BEING DEAF FOR A DAY!

You know how it is when someone presses the mute button on the TV – well - Would YOU be able to understand your favourite TV show?

Now instead I want you to think one step further. Imagine if they pressed it on your life. Imagine waking up and not hearing anything, not even your alarm clock, cane trains or being able to hear your grandchildren and loved ones talking to you.

Imagine being able to turn off your partner when they are telling you to do something, imagine even being able to switch off when the mower is mowing outside your door.

This is what life is like for me. Some people call it selective hearing at its best.

Being deaf is like living in only part of the world but I now have the choice not to live in only in that part of the world because I have cochlear implants which lets me hear.

I am a totally deaf person who is able to hear once again because of this wonderful Australian piece of technology – the Cochlear. I am a bi-lateral cochlear implant recipient which means I have two cochlear implants.

When you press the MUTE button on the TV – you are still able to hear other noises such as the phone – for me – when I take my two processors off I do not hear a thing – it is total silence.

You could now officially call me a bionic woman.

The cause of my deafness was Menieres disease.

My first attack was when I was 23 years of age – way back in 1981. Over the next few years these attacks became frequent until I was experiencing them, on average, at least 4 times a week.

My condition became chronic. Prior to an attack I noticed tinnitus (ringing in the ears) increased and I would experience quick eye movements or flickers. Meniere's attacks confined me to bed. They were characterized by intense vertigo, loss and distortion of hearing, dizziness, vomiting and severe sweats. All sense of orientation went and I became confused and unable to speak. Any movement of my head increased the vertigo, and therefore the nausea, so I always tried to keep very still. Each time these attacks lasted a few hours and sometimes longer and during an attack I was a VERY helpless person. After the initial vertigo and vomiting settled I would need to sleep before I could again speak, move my head or walk around.

In the early stages of the disease my hearing was affected but when the attack passed it returned to normal. However, as the attacks became more frequent my hearing worsened and permanent hearing loss was evident. Initially only my right side was affected, but later this became bilateral.

My disease was confirmed as Menieres by a test which required my ear drum to be pierced and hooked up to a machine which did 'whatever'. I was closely monitored by a specialist in Brisbane who at the time said I was the sickest person from this disease that he had ever seen, especially when he took into consideration my age.

Throughout 1992 and 1993 I had a series of operations in Brisbane with the ultimate goal of stopping the symptoms of Meniere's disease.

In December 1992 my specialist performed a right ear Endolymphatic Sac operation. Since the ultimate risk of this procedure is total deafness, he chose my right ear as it was already totally deaf. No damage could be done there! But alas, the operation was not successful – I remained sick.

In March 1993 he tried again – this time on my left ear. By now I was so sick I didn't care about the risk of losing my only hearing. I just wanted relief. But still no success.

In December 1993 a Cochleotomy was performed on my right ear. YES - At last success. This operation gave me back some quality of life, but I always knew these procedures were only killing the symptoms and the disease was now 'silently' aggressive within me. Down the track, I knew I was likely to be deaf for the rest of my life.

During this period I became a patient of Queensland Hearing (now called Attune) and subsequently was fitted with my first hearing aid. It was only viable for me to wear one in my left ear. Over the next 10 years or so I referred to my hearing aid as one of my most loyal friends. I was so dependent on it and it rarely let me down. Sadly, this companionship was not to last, faltering as my hearing deteriorated and it became evident it was no longer giving me any benefit.

As my hearing in my left ear slowly degenerated over many years it allowed me to adjust to hearing loss without realizing it.

In January 2006 at my regular check-up in Brisbane I had only, in layman's terms, 20% hearing left. I was really struggling in the hearing world by this stage and was advised it was time for me to change specialists. My audiologist recommended I go to someone else who dealt with Cochlear implants so I could be monitored for suitability. By March 2006, only two months later, it was obvious I needed to make this appointment urgently as my residual hearing was deteriorating rapidly.

By now I was desperate. There were many things I could no longer enjoy or do. Although I could hear when someone spoke it was merely an amplified, garbled sound. I was struggling to recognize a word here or a parts of a word there; continually lip-reading, and watching body language to try to understand speech.

I could no longer communicate on the phone or talk to anyone in the dark as I could not understand the spoken word without using my visual aids.

My responsibilities at work had to be changed. Work colleagues took my phone calls and wrote messages to me. Working in the classroom was difficult due to the noisy environment. Hearing at workplace meetings was difficult but my colleagues kept me informed of matters I needed to know about.

When shopping, I continually had to explain to people I had a hearing disability so that I didn't come across as a very rude, ignorant person.

At home I had to change my routines. I could not leave the bathroom when the taps were running in case I got side-tracked and forgot I had turned them on. There was no point setting an oven timer for I could not hear it when it buzzed. It was difficult to talk to loved ones because I could not follow group family conversations and be 'part' of the unit. Increasingly, I felt isolated and became very dependent on my husband. He filled me in on topics he knew I would be interested in. At the end of the day I was always extremely tired from struggling to concentrate; being on 'alert' mode all day. I came home from work absolutely exhausted. During this period I was silently grieving for my independence and feeling a huge burden on my family.

In May 2006 my hearing was once again tested prior to an appointment with my new ENT surgeon, one who specializes in Cochlear Implants. The results showed that since January my hearing had dropped a further 20dB. I could no longer hear consonants but could hear vowels and distinguish between short and long vowel sounds. I could also tell how many syllables there were in a given word. I was getting by with this little bit of hearing coupled with watching body language and gestures and very competent lip-reading.

When I arrived at my surgeon for the initial appointment I was greeted with a very cheery, "*You are deaf!*" as he had already examined my results from Attune. Upon confirmation that the results of my CT scan proved excellent for a Cochlear Implant, the ball quickly started rolling.

I underwent the other necessary assessments for a Cochlear Implant throughout June and July 2006 and it was confirmed I was a successful candidate. Despite the fact that a Cochlear Implant, back then, would destroy any residual hearing, we decided my better left ear should be implanted. Because my right ear had been profoundly deaf for over 20 years the Team believed implanting that ear could affect the outcome and their ultimate goal at that stage was to get me back into the hearing world as soon as possible.

I had the operation on 17th August 2006. The operation itself went very well and I was discharged from hospital the next day.

Living in a world of silence during this period was not a great burden for me. To pass the time I was spending many hours on the computer communicating to family and friends via email and MSN. To get my attention Ian kicked his right leg up in the air and then I used my lip-reading skills to understand. We had a real chuckle about this. No matter what obstacles, there was always a way to communicate if we persisted.

31st August 2006 was switch-on day. I was excited by the prospect of hearing again mixed with feelings of anxiousness and nervousness about what was ahead. After reading all the literature I didn't know if I was going to hear anything that you would classify as speech or just a heap of garbled sounds. Ian, our two

daughters and my parents came to support through this time. I was still in quite a bit of pain and was also secretly questioning whether I was ready for this next part of my journey.

Ian came in with me for the initial mapping. All of the 22 electrodes were mapped on day one and this was a whole new process to get accustomed to. Once the electrodes were mapped my parents and daughters joined us for 'switch-on'. Was I going to hear sounds like Mickey Mouse or Daffy Duck speaking to me?

Switch-on proved SO exciting. I will always remember. It is said, "Every day we live we are painting a new picture that is hung on the walls of our memory." This was certainly one of those days.

It was ABSOLUTELY AMAZING to hear voices again and to be able to understand speech. I could understand my audiologist speaking to me straight away and it sounded quite normal. But then I spoke myself. Surely I didn't sound that bad was all I could think.

Over the next couple of months I travelled to Brisbane for mapping sessions, initially on a weekly basis dropping off to fortnightly then monthly and so on. In between each visit I had to complete an Environment Sounds Checklist for my audiologist so that she could check what I was hearing in different environmental settings.

I will always have to go to Brisbane for mapping sessions, however, they are annual visits now.

Many changes were happening with my lifestyle and day to day living.

- I clearly remember the first time I went to the toilet in Brisbane after 'switch-on' and I came out to tell Ian: *"You know when a woman pees it makes a PSSSSSSS sound!"*
- I could now understand someone talking to me from behind without lipreading
- I was constantly asking people around me: *"What is that noise?"*
- After a few weeks I commenced rehabilitation with the phone and I started to use it with ease.
- Birds! I thought I was hearing ALL birds before the implant but I soon realised that I was only hearing certain pitched birds.
- When using the computer I now realized that the keyboard went tap, tap, tap when typing, and
- I also started enjoying some TV shows which was really wonderful.

Whilst I was enjoying all these wonderful sounds again there was one change within me that everybody was commenting about. I was now speaking with a much quieter volume. Because I wasn't getting any feedback when I was deaf I used to speak very loudly – something I was not personally aware of at the time.

This is one incident I will always remember. One evening I was working on the computer, while Ian watched TV about 5 metres away from me and he did a 'let off'. I immediately turned to him and said, *"Excuse you!"* He got the biggest shock exclaiming, *"Did you hear that?"* realizing he now had to be more careful of his p's and q's.

As my work environment is very noisy, and speech comes from all directions around me, my audiologist explained all the pros and cons of being a bi-lateral Cochlear Implant recipient. After consideration, and the required tests, I was approved for a bi-lateral implant. This was personally a difficult decision and I do admit I

had reservations. I knew that rehabilitation would probably be a long, windy road because this ear had been profoundly deaf for so many years. But I also hoped that eventually I would always have hearing if one processor malfunctioned. I also questioned: *“Was I being greedy wanting a second implant when I now had hearing again?”*

Decision final! I came to the conclusion I had the strength and support to handle this so on the 24th May 2007 I had my right ear implanted. With my head once again bandaged up I headed home.

June 7th 2007 was ‘switch-on’ day.

To my amazement, and that of the CI team, I was able to understand speech immediately. This was truly unbelievable and an outcome that myself or the CI Team expected so soon. This ear was no longer just a place to put earrings on, however, voices sounded very girlish and at a higher pitch than my first implant.

At the completion of my 3 months mapping my hearing stabilized. I had hearing tests to ascertain the success, firstly the new right implant by itself, and then bi-lateral. Within a VERY noisy testing environment I hear approximately 30% better by being bi-lateral.

Some noisy environments can still be difficult to hear in but my ability is far superior compared to only one implant. When I find that I am having difficulty now, other people around me are also having difficulty so I don’t feel out of it.

Now with my two external processors – it is just as well that I have a sense of humour. In the information given to me to read we were told to be aware of the umbrella trick. As there was no further explanation I always wondered what this was about. Because I am right handed and now that I had a processor on my right side I soon found out when Ian and I were walking in the rain up the farm during the February 2008 floods. The rain was pelting down and with the wind gusting around us so I was holding my umbrella very tightly against me so that I did not end up like Mary Poppins. Next thing the magnet on my external processor latched onto the umbrella and there was my processor hanging off the umbrella.

Having my two processors give me much better hearing ability. I never by choice wear only one processor. I find it very frustrating when only one is turned on as the sound is very dull and very different so I have no desire to go back to monaural hearing again. Sounds are all round and not one sided. They are clearer with more depth and more real – an improvement that is very noticeable. It is amazing to hear from all directions and to know where the sound is coming from. I hear people call me from quite a distance even if they are behind me PLUS a feature that was unexpected and truly welcomed was BACKGROUND NOISE was now under control. I do appreciate music once again although this is mostly songs and tunes I was familiar with before losing my hearing. Country and Western type music is the most enjoyable. To this day my second implant still sounds different to my first left implant if turned on separately – but when they are turned on together the quality of sound is balanced and exceptional.

When my batteries run out on one processor, I never go ‘off the air’ as I have a ‘back up’ with my second processor. This in itself gives me more confidence to venture out myself as I know I should always be able to hear and communicate.

In my case, bilateral cochlear implants have proved essential to manage in the hearing world. I definitely agree with the old saying, "Two ears are better than one."

Our bodies are designed to experience sound in stereo, using two ears to receive sound from the world around us. Just as we need two eyes to see the whole picture, we need two ears to hear the whole picture.

Life in general is wonderful at work, home and socially. I am an independent person once again, actively participating in life with very few challenges.

Ian says I am a new woman. He thoroughly enjoys being able to converse with me in all environments once again, particularly when we go out at night and driving in the car. For so many years we went places in silence as I could not lip-read in the dark. By nature I have probably what you would call an extrovert personality and love going out more so than Ian so he loves me having my sense of independence back again so that I no longer rely on him to come with me everywhere for 'hearing' assistance. Ian also enjoys not having to sit on my 'deaf' side anymore when we go out socially – something he did for many, many years.

When I go to bed at night I take my processors off so I cannot hear anything. No matter how loud a thunder storm or how much our dog barks at the dingoes, I always get a good night's sleep. Selective hearing again at its best!

Many people over the years, and still to this day, say: *'But you don't look deaf!'* This comment always amuses me. What does a deaf person look like? If they said, you don't sound like a deaf person I would understand it because I was post-lingually deafened and my speech is quite good.

There are so many people that I must give thanks to – my GP Dr John Mackintosh (Ambrose Medical Group); my surgeon Dr David Bell-Allen; my audiologist Karen Pedley and CI team with Attune; my family, friends and work colleagues just to name a few. Above all, I give thanks everyday to God who is in control of all things and last but not least my husband Ian. He has been the most patient, supportive and caring husband I could have wished for. For a few years I was so dependent on him. He got to really understand my polite, deaf smile – in other words my face was saying 'I have not got a clue what you are saying but I hope this smile is fitting for the situation.'

It's been said that when people lose their sight, their other senses become sharper, adapting to the loss of the one sense by expanding others. That's what has happened in my life. My hearing loss has helped me develop in ways I'm sure I wouldn't have and has forced me to stretch and strengthen 'muscles' I wouldn't necessarily have exercised. My lip-reading skills were very well developed (already this skill is declining now that I don't rely on it as much).

It is because of my life experiences that I was ecstatic to be invited to be part of the Cochlear Awareness Network. I look forward to the challenges and rewards that this venture generates as I spread the good news educating the wider community about Cochlear – in the hope of bringing hearing to more people than ever before.

I understand I still have certain limitations as I am still completely deaf when I am not wearing the processors although I am determined not to allow this to dictate to me what I can and can't do.

Deafness is often referred to as the silent disability and can be an unseen affliction but, let me assure you, its impact can be both seen and felt.

"I am what I am And I consider myself a very blessed person!"

"I am what I am..... And I will always be a deaf person!"