



100 stories

Personal accounts of life with hearing loss

“Nothing ever becomes real 'til it is experienced.”

John Keats

This book contains 100 stories from the lives of the 1 in 6 Australians who are deaf, hard of hearing, have a chronic ear or balance disorder, or deafblind; and the experiences of their families, volunteers, and professionals.

These are the stories of our challenges, our moments of success, the times when we have made a difference, and the frustrations of having to navigate a fragmented pathway to be part of the community.

This is a public health issue of such scale in Australia, it is critical to raise the priority of hearing health care. Unaddressed hearing loss in Australia continues to have a high impact on individuals and also the economy. The level of communications access needs real work across all services. Ten years ago it was costing the national economy \$11billion each year. The latest statistics show the cost has blown out to \$15billion a year.

Half the incidence of hearing loss can be prevented or minimised through such measures as immunising against childhood diseases, preventing infections, avoiding the use of certain drugs, and reducing exposure to loud sounds. Unless action is taken, the numbers will continue to rise as populations age and young people continue to engage in harmful listening practices. It is urgent to take action.

Hearing is now a World Health Organisation priority. The World Health Assembly met in Geneva in May 2017 to vote on an international action plan to address hearing loss. It sets out a framework for a comprehensive public health response each country can implement.

We call on all Australian Governments to make Hearing Health and Wellbeing the next National Health Priority so we can work together in creating an integrated national action plan to avoid the growing national economic and social impacts of hearing loss.

David Brady
Chairperson
Deafness Forum of Australia

August 2017

Supporters



Name: **Haylee**

Age: **24**

Location: **Country, NSW**

I am an Early Childhood Educator, loving partner and mother to two amazing young boys aged 2 and 5 months.

I have just completed a diploma in Early Childhood Education and Care, with plans to head straight to university.

If you looked at me from afar, you wouldn't know I was deaf. But yes, I am. I have a severe hearing loss in both ears and I rely heavily on hearing aids to get me through. My hearing loss wasn't formally diagnosed until I was 18 months old. I was given hearing aids and had access to a hearing support teacher not long after. No one really knows if I was born deaf, or if it happened during my first years of life.

When I was around 8 years old, I started noticing I was different. I saw that my class mates were always pointing at my hearing aids, mouthing their words at me when they would speak. The bullying started not long after, I was called a freak. My friends started to join in. They didn't accept me. I started to feel ashamed, like a burden, different and believing what they were saying about me. I started to rebel. I had so much anger. I cut my first class at 10 years old, soon I was running from school, hiding from my teacher's aids and support teachers. I didn't want help, I didn't want to be different. I "lost" many hearing aids and FM systems. I hated the world, I blamed my parents, I hated myself. I was a deaf nobody. A freak.

Once I got to high school, I was excited. A fresh start. New friends. No more bullying... So I thought. It got worse. I was cutting class every day. I would pretend I was sick so I could stay home. I would pretend to get on the bus, and wait behind a tree until mum had left for work and run back home. I pushed everyone who had helped me away. I got braces, then reading glasses. Yep, I was a bigger "freak". Things would get better, then go back downhill again. I even tried to give up. That was a slap in the face. A wake up call. I left school, left the bullies. Went to TAFE. Life got better. I finally started to accept myself. Finally got to breathe.

Once I joined the work force, I would have customers and parents yell what they were saying to me because they thought I couldn't have a normal low key conversation and had to lip read. They thought that because I had hearing aids, that I could not hear or talk. This is how the world makes us out to be. We are not incapable of holding down a conversation whether we are oral or sign.

Fast forward to now, as a kid I would never have seen myself living this life. Two children, qualified childcare worker. Don't get me wrong, I am not perfect. I have my down days where I think "what if" and struggle with every day life and judgements, I struggle being deaf, but I am proud. I am NOT ashamed. I accept who I am, being deaf is not WHAT I am. And I will stand up for anyone with a hearing loss, and stand up for MORE. We need more awareness, more support and more access.

My name is Haylee, I am deaf but being deaf is NOT what I am. It is a part of who I am.



This real life story is brought to you by Haylee

Name: **Alex**

Age: **30s**

Location: **Adelaide, SA**

My story is more than what you see. When you look at me you will see a normal person going about his everyday life. You might catch a glimpse of my brown cochlear implant processor sitting on my left ear, cleverly camouflaged with my brown coloured hair. But you likely won't know the story behind it.

I was born profoundly deaf to two hearing parents and diagnosed at 15 months.



I was fitted with high-powered hearing aids, which didn't work as hearing aids only amply sound. As a result, I was only able to partially pronounce words. For example, for "shut the door" I would say "uh or". Fortunately, after much research and countless medical appointments, my parents were introduced to a relatively new cochlear implant system by an Ear Nose and Throat surgeon. At 3.5 years of age, my family and ENT travelled to Melbourne where I became the first young South Australian child to receive a cochlear implant.

I received weekly therapy to be taught to speak through hearing by an oral deaf service provider. My parents and brother also spent countless hours with me teaching me to speak through hearing. My language developed exponentially and I was ready to attend mainstream schooling by 5 years of age.

School was amazing and I loved it, well junior school that is. As for high school, it was a nightmare, awful, horrible and so on. No words could truly describe my experience. I felt like the whole world was against me. It is certainly not how a teenager should feel. Aside from my school work, I faced one challenge after another from being socially excluded by my peers to facing teachers who lacked sympathy and understanding for my hearing impairment. Teachers excluded me because they thought I was less capable than my hearing peers. My language was well below the average for my age and my academic performance was fast deteriorating.

I was on a fast track to becoming a school drop out. By God's grace, an internationally qualified auditory-verbal therapist (AVT) saw the situation I was in and voluntarily intervened. My parents worked with my AVT to put me in a new school and improve my language. My new school was very accommodating and I was included in a community.

Gradually, I improved academically and my language improved to the point that it was above average for my age. I managed to successfully finish high school and get into university. I completed a Bachelor of Economics and a Master of Commerce at the University of Adelaide.

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Messages to our elected leaders

I secured a job at a national accounting firm after university and still work in the same field over 7 years later.

My story is not just mine, it is also the story of my family, AVT, audiologists, doctors and so on. My successes are not my successes, but the combined efforts of everyone who helped me. But it doesn't stop there.

I still experience the stigma of being hearing impaired. It is a stigma that leads to people making assumptions about me that couldn't be further from the truth. People still assume that because I'm hearing impaired I'm less capable than my hearing peers.

I also have to continue to visit my audiologist and doctors to maintain my cochlear implant and hearing health. These appointments, which leave me with out of pocket costs, allow me to be included as an ordinary member of society and work in a job that allows me to earn an income and pay taxes.

We must raise awareness of deafness and hearing impairment in our nation. It is time for a national conversation to increase the country's understanding of deafness and hearing impairment. An increase in understanding will allow the country to move forward and appropriately address all issues relating to deafness and hearing impairment in order for deaf and hearing-impaired individuals to be equally included as ordinary citizens.

It is time to Break the Sound Barrier. It is time to make Hearing Health a National Health Priority. Let's not talk about it; let's make it happen. Let's make it happen today, not tomorrow.

There is nothing to lose and so much to gain.

This real life story is brought to you by

Name: **Elliot**

Location: **Sydney, NSW**

My first child was born December 2015, a beautiful little girl named Elliott who stole our hearts immediately.



Elliott had her first swish test at 2 days old, she passed in one ear and referred on the other. We were assured that this is normal and very common with caesarean babies. At this point we were not worried in the slightest. At 3 days old we repeated the test and she now referred in both, the technician tried one more time and again she referred. The technician assured us again that it could just be fluid but that we had to have a follow up in 4 weeks at Westmead children's hospital. Again, at this point we weren't worried.

Once we finally got home and the loudest of sounds wouldn't startle our tiny baby we began to worry, we would bang, crash, clap and make as much sound as we could while she slept and nothing. The appointment was still a few weeks away but as each day went on we knew there was something not quite right with her hearing. I remember worrying that she would never hear me say "I love you".

This real life story brought to you by Elliot and mum Kye

Messages to our elected leaders

Appointment day finally arrived, Elliott was 4 weeks old. We wrapped her up like a cute little baby burrito and handed her to the audiologist. We were given a pager and sent on our way for 3 hours while they did their tests.

We sat around worrying about the results and watching the clock. The time came to sit with the audiologist and receive the results. She took us into a room and we sat down, it was written all over her face but in such a caring and empathetic way. She said "the results show that there is a hearing loss" those words changed our lives forever. The audiologist then discussed our options regarding the technology available to us, funding, audio verbal therapy and organised an appointment with a paediatrician and Australian hearing. We left that day with a bright orange folder that said "hearing loss and your baby", I read that folder cover to cover as soon as I got home, I researched and researched the best way that we could support our daughter on her journey.

What followed was a whirlwind of appointments for us. Elliott had an ecg, blood tests, urine tests and a sedated MRI. We did genetic testing which confirmed that she inherited her hearing loss from my husband and I and that her future siblings have a 25% chance of inheriting hearing loss. She attended Australian hearing fortnightly for new moulds, attended weekly playgroup at the shepherd centre and weekly therapy with the department of ed. I have undergone Auslan classes to assist with her development and more recently have engaged a private tutor for home classes as a family.

Before Elliott we did not know much about hearing loss and the many people it affects. We are now apart of a lovely community who are always willing to help support us in guiding her along her journey.

She is now 18 months old and on par with her hearing peers, we still attend therapy and Australian hearing quite regularly but the appointments have definitely slowed down. We are very proud of her and her "ears" as we call them, we chose bright pink as a way of showing them off and to teach her to wear them proudly.

This real life story brought to you by Elliot and mum Kye

Name: **Michele**

Age: **53**

Location: **Melbourne, VIC**

I live with Mondini Syndrome and extreme Tinnitus.

My hearing impairment causes me embarrassment and anxiety every single day. A lot of my work colleagues still just don't understand they have to be facing me or get my attention before they speak to me. I've been told that people have often thought me rude because I've "ignored" them. I have a small sign on the counter in front of my desk which reads "Hello, I'm hearing impaired, please speak clearly". It's helpful sometimes but most people read it and stop talking all together.



It's also very hard to keep up an active, enjoyable social life when all you do is spend the majority of time with friends and family asking "what was that, what did he say"? Especially upsetting when everyone laughs and you have no idea what was funny.

I would like something done about not being able to go to the movies to see my choice of movie because only certain movies are supplied with closed captions. My daughter arranged for us to have a day out together but plans had to be changed due to what I believe is discriminatory as there were no closed captions supplied. I would like to see it be compulsory for all films.

Without my hearing aids I wouldn't be able to continue working. Mine are old and apparently obsolete. The thought of the expense of updating them is daunting. It would help enormously if they were tax deductible.

Therefore I am on board with "Break the Sound Barrier".

It's time for my political representatives to do the right thing!

This real life story is brought to you by Michele

Messages to our elected leaders

Name: **Jackson**

Age: **teenager**

Location: **Sydney NSW**

I been deaf/hearing impaired since I was born. I have an annoying twin sister. So far High School and life has been good to me.

But I've had to deal with situations all the time. Since I am literally the only deaf student in my school of about 600 students, so that makes me pretty unique. Many people cannot relate to being deaf, so they have no idea what it is like a situation. For example, when I go swimming, I can't hear.

I still have a hugely profound hearing loss. When hearing people found out, they didn't understand. But I gained a lot of confidence in being deaf, although I don't really talk about it. Being able to share with other deaf people my age is really important. Hear For You helped me get confidence and talk to these people, but not just a hearing people as well. The thing I like most about Hear For You was meeting other deaf people just like me.

It helped that I had fun as well, including the sessions, like the technology and apps. I tried out two of them to help with my communications access and they were really good.

The mentors are amazing, they are the backbone of Hear For You. They have told me so much. Before coming here, I couldn't really talk to people about being deaf. I didn't really know how the people felt. I can talk to people now who are deaf and my age. It is awesome. I am now more confident about hearing loss and being more open about telling people. It is great to have already done two programs already and meet other people are deaf and make new friends.

This real life story brought to you by

Name: **Christiane**

Location: **Sydney**

Age: **20s**

I was born hearing but at 14 years old I started to have trouble following conversations and hearing my friends.

One memory that sticks with me is using the phone. I had the receiver on my right ear and was hearing fine. I switched to my left ear and couldn't hear anything but muffled sounds. I quickly brushed it off and didn't make anything of it. However, as time went on my friends started noticing my hearing loss more and pointed it out to my mother. At the time I was experiencing really loud ringing sounds in my ears that drove me absolutely insane. I couldn't figure out why my ears were ringing and why no one else could hear it! I even tried pressing my ear against my mum's at one point thinking she might be able to hear and to confirm I wasn't going crazy.

I was diagnosed with Neurofibromatosis Type II (NF2) at 14 years old. NF2 is most commonly associated with tumours growing on the central nervous system, which can lead to complications such as deafness, spinal cord compression and facial nerve paralysis.

Diagnosis didn't come quickly for me. I underwent a series of inconclusive hearing tests before an MRI revealed two acoustic neuroma tumours – one on my left hearing nerve and the other on my right. I was told that once we surgically removed both tumours, this would result in complete deafness.

There were a lot of tears and there was a lot of confusion when I was first diagnosed. This stemmed from a lack of understanding about deaf culture and my illness (NF2) in general. I had never been sick a day in my life and then to one day be diagnosed with an incurable disease that would be with me for the rest of my life was just something I could not understand. At 14 losing my hearing was earth shattering. I kept asking 'Why is this happening?' I just couldn't make sense of it. I remember wanting to disappear.

I have had my teenage and adult years filled with surgeries, regular hearing tests, MRIs, balance tests, and a 2 and a half year Avastin trial to try and shrink and stabilise my tumours. At 18 years old, after an annual MRI, 12 tumours had appeared on my spine. I remember the day I was given this news so clearly. It seemed that after 4 years of dealing and trying to accept one thing, I was being hit with another.

Since my diagnosis, my biggest moments have been the times I've undergone three major surgeries - two to remove the acoustic neuroma tumours on my hearing nerve and one to debulk a tumour that was compressing on my spine. These have forever changed me. They've taken away my hearing, slight facial paralysis (invisible to anyone but me!), left me with no balance, regular vertigo, and leg muscle weakness that I will probably never regain full strength from.



This real life story is brought to you by Christiane

After 15 years of battling this incurable genetic condition, many find it hard to believe I am even dealing with this. When I meet new people and tell them about NF2 their initial reaction is always, 'You don't even look sick!'. When I meet people and tell them I'm deaf their reaction is always 'Are you actually deaf?! You don't look deaf! You speak so well for a deaf person!' without realising how ridiculous those statements are. What do they even mean?!

I have found that NF2 has made me stronger, more empathetic to the world around me, determined, and just a little bit stubborn. I try and make everything I go through as positive as possible. There's nothing my hearing loss has stopped me from achieving. I completed my Bachelor's Degree in Social Work from UNSW, Certificate III in Children's Services, and Diploma in Auslan. I was so inspired at a young age to make a change in the world, I now work with deaf and hard of hearing teenagers. It's an incredible rewarding job that I'm thankful to do every day.

It hasn't all been without challenges though. In losing my hearing there has been a lot of uncertainty. When I was first diagnosed, no one was able to give me a clear answer as to what my future looked like. I wasn't able to make future plans and lived on a day to day basis. Sometimes I still do.

However, I think one of the most incredible things to come from losing my hearing at such a young age was to be told by my Ear Nose and Throat (ENT) surgeon to learn Auslan straight away. He gave me such a gift when he suggested that. I've learned an amazing language, met so many wonderful people, found a career in the deaf community, and feel that this journey led me to meet a beautiful man who loves me to see past my hearing loss and have him learn Auslan for me.

A lot of people get very emotional when I tell them my story. To me it's nothing heroic or incredible. I just did what I had to do to get through it. It's a huge part of me, it's my story, and it's helped shape me to who I am today. I really wouldn't have made it without the support I get on a daily basis from those around me. I'm incredibly lucky.

This real life story is brought to you by Christiane

Name: **Maddison**

Location: **Townsville, QLD**

Age: **10**

Maddison had cochlear implants fitted to both her ears in 2013 after suffering a progressive hearing loss.

Maddison receives a range of support for her hearing loss including audiology services, listening, speech and language therapy sessions, inclusive educational setting visits and social skills support. She and her family have been supported and empowered by Hear and Say in her hearing loss journey since she was age six to learn to speak, listen and live a full and confident life. She attends school with her hearing peers and is a competitive horse rider.



Her mum, Natalie has had to become an advocate for her child and says this support was vital to the process and Maddison's outcomes. Natalie says Hear and Say are the experts in her daughter's hearing loss. By having Hear and Say so closely involved with Maddison's diagnosis, funding and services has been comforting and helpful in making sure she received the right services.

NDIS recently funded Maddison for her hearing technology needs, equipment upgrades, and listening, speech and language support, but they also broadened the funding to include social skills development and community support. The social skills program in particular has been fantastic for her confidence and development. Social skills development and meeting other children with hearing loss facing similar challenges has helped her to cope and understand that she's not alone.

This program was great for Maddison, as social skills development and meeting other children with hearing loss facing similar challenges has helped her to cope and understand that she's not alone.

Maddison received funding for social skills development through the NDIS and she was initially unsure as to how she would access programs with these funds. Maddison and her family were initially directed to disability support services, however this was a little confusing as she does not identify herself as being disabled. Many of the significant impacts of Maddison's hearing loss have been overcome by access to the right hearing technology, specialist therapy support, and now social skills development.

Her mother Natalie says the funding and process with NDIS is a bit "hit and miss". She hasn't been able to use some of the funding, but through the support of Hear and Say has better understood the process to support Maddison. Natalie was somewhat nervous during the process as she wasn't sure what she should be asking for and needed Hear and Say to guide her as the experts in hearing loss. This support from Hear and Say has meant she understands how to access funding for programs and services that are able to support Maddison to reach the outcomes and goals she desires.

One of her concerns about the NDIS funding is that it isn't always consistent or clear. Natalie wants to make sure no child, like Maddison is left behind due to a lack of funding.

Name: **Belinda**

Location: **Perth, WA**

Age: **31**

My hearing story started when I was about 7 years old. I was actually having surgery on my kidneys and had been given medication that didn't know I was allergic too. I had a very bad reaction to it that my body from head to toe was in rashes and had affected my hearing. I was then diagnosed with moderate hearing loss. This was in the early 90's so hearing aids were very expensive.

I had to repeat grade 3 because I was in and out of hospital for both my kidneys and hearing operations. I struggled through primary school and early years of high school. I was always saying what, please repeat that? It was so annoying.

When I was 16 years old I was finally fitted with hearing aids. I was both scared and relieved at the same time. I was scared because I thought people would just look at my ears and think she is disabled or something and I would get treated differently. No such case...I had such supportive friends and family and felt very normal.

Hearing helped me big time...now that I feel like I can hear like a normal person. Not annoying my friends and family with saying what or please repeat that every 5 minutes. I now use it as an excuse. If I need quiet or just don't to listen to someone I turn them off (hahahaha!)

I am now 31 years old, a photographer and loving life. I thought by now that Hearing awareness would be wide spread...people more educated...under Medicare scheme etc.

Hearing aids are still too expensive and not enough money is being put into Hearing research unlike cancer research.

Australian Government - please do more for us!!!

This real life story brought to you by Belinda

Name: **Andrew**

My hearing loss was not diagnosed until I was in Year 9 when I was fitted with hearing aids. I've been wearing them for 36 years.

I missed out on a lot of learning and classroom interactions, was ostracised and quiet. I know that my late diagnosis means I have been playing catch up. Even with hearing aids I know I operate at 90-95% capacity.

I would like to petition the government to have mandatory hearing tests for all Grade 5 students as part of NAPLAN - which tests students in grades 3 / 5 / 7 / 9 for their knowledge but doesn't measure learning ability or if any hearing issues are affecting learning ability.



Name: **Corey**

I've been blessed in that I am only partially deaf.

I've worn behind the ear hearing aids since primary school and recently in my mid 30's had to have a bone anchored hearing aid (BAHA) installed due to constant blockages in my middle ear.

I've felt the stigma growing up of having to wear hearing aids and have at many points throughout my life elected to go without easily hearing just so I don't have to wear them.

As a kid growing up Hearing Loss was something that happened to your grandparents. There was no information and little support for younger kids let alone adolescents with hearing loss.

Making hearing a national health priority will hopefully improve the outcomes for partially and fully deaf people like me!

Come on political leaders, we don't want to shout at you, but it's time you sat up and listened!



These real life stories are brought to you by Andrew and Corey

Name: **Alexandria**

Age: **8**

Location: **Melbourne, VIC**

Alexandria was born deaf and in November 2013, her family were devastated to learn she was also starting to lose her vision. Alexandria was diagnosed with Usher Syndrome, a rare genetic disorder which causes deafblindness. There is currently no cure and the doctors can't tell how long Alexandria will be able to see. She has already had an uphill battle all her life with her deafness, Asperger Syndrome and Attention Deficit Hyperactivity Disorder (ADHD).



Alexandria's mum Trina and dad Chris felt alone and overwhelmed. Thankfully, they came to Deaf Children Australia's Family Camp in June 2014 and realised they don't have to face this on their own. Since then, they have made so many changes in their lives and feel much better prepared to face what is looming for Alexandria.

Trina and Chris shared Alexandria's story:

"We got cochlear implants for Alexandria when she was tiny and until the camp, we didn't realise how much her hearing loss was continuing to impact her. Managing the behavioural issues from her Aspergers and ADHD had been so difficult and had actually taken our focus away from her hearing loss. We realised, particularly through the panel with the young deaf adults telling their stories, how much Alexandria's deafness is affecting her. It has helped us make some important decisions we had been struggling with.

When Alexandria was diagnosed with Usher Syndrome, we were told her struggle to see in low light will progressively worsen. Already, she is basically blind at twilight. At some stage, Alexandria will start to lose her colours and then her field of vision will gradually reduce to a narrowing, darkening tunnel. Her deafness will make her vision loss even more challenging, and her vision loss will make it harder to cope with her deafness. At the moment, she can read people's lips but she will lose that ability as her vision fades.

The impact from the camp was so huge for us. Meeting other families with deaf children made us realise we are not alone on the moon in dealing with these challenges. We realised we needed as much help and guidance as we could get to address both the deafness and blindness. We reached out to DCA for help – and things started to fall into place.

Our DCA Family Support Worker Emma has provided lots of support and we have been getting help to address Alexandria's vision loss as well. We no longer feel so overwhelmed and we are able to make decisions with a clearer focus. The camp even helped us decide on another school for Alexandria. She was attending a tiny country school with thirteen children. It was ideal for her

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behavioural issues when she began but provided limited opportunities for friendships.

On camp, Alexandria was able to cope with a large group of children she hadn't met before. She is very sociable but doesn't always know the social boundaries. Yet amongst that group, everyone was accepting. Alexandria made some great friends, Ashlee and Olivia, who are also deaf. It really showed us how important it is for Alexandria to have connections with other deaf children and DCA's School Holiday Program will be good for that. I hope we might be able to set up Skype conversations with Ashlee and Olivia so they can keep in touch too. Olivia started teaching Alexandria Auslan on camp and Alexandria was so keen, we thought we have to learn Auslan as a family. We received a CommuniCate kit from DCA to help us.

Now Alexandria is in a bigger school. She is extremely happy there and she is a lot more social now. DCA is providing deaf awareness training for the students and teachers. We have moved to a new town to be closer to family support. We are looking forward to getting a Pets as Therapy Dog after DCA referred us to Guide Dogs Victoria's program. Alexandria is so excited about having her own dog who will be able to assist her, and just always be there to keep her company.

Reaching out for help has opened up new opportunities and we now have a tremendous amount of support and resources. We feel a huge sense of relief. We were frozen by our grief before. It's almost like we are on a new journey now, it has been incredible. This condition means all these changes are looming for Alexandria – but the future is looking a lot brighter now.

Name: **Davie**

Age: **8**

Location: **Melbourne, VIC**



Like most new parents, Carol and her husband Henry were so proud when their first child Davie was born. They immediately fell in love with their gorgeous little boy yet their happiness was tinged with fear and anxiety over what lies ahead for Davie.

When he was just three days old, Davie was diagnosed with a genetic condition called Treacher Collins Syndrome. Henry's brother has the same condition so Henry understood the implications far better than Carol. She felt devastated with the diagnosis and overwhelmed with all the unknowns.

The Syndrome has prevented Davie's skull, cheek and jawbones from developing properly. Davie's ears aren't formed properly either so he is deaf. He also has small airways, which cause difficulties breathing. Since he was tiny, Davie has struggled to breathe at times. When he was just a baby, Davie was rushed to the Royal Children's Hospital, placed in Intensive Care and still they struggled to get enough oxygen into his tiny little lungs. None of the different oxygen masks they tried fitted properly because of Davie's lack of cheekbones.

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Carol and Henry anxiously watched every laboured breath he took. Davie spent a lot of his first year of life in hospital and on ventilators.

While Carol and Henry have done everything they could for Davie, this is not always the case for children with disabilities and complex needs. Recently, Carol, Henry and Davie met British activist Jono Lancaster from the BBC documentary 'Love Me, Love My Face' who travelled to Australia to support children who have Treacher Collins Syndrome like himself. Jono's parents looked at their tiny little son and gave him up for adoption two days after he was born. Supported by his wonderful adoptive mum, Jono began a long road of personal self-discovery to defy those who made fun of him and become the positive, confident young man he is today.

Carol and Henry are determined to make Davie's path through childhood easier.

Carol tells us that when they heard Davie has Treacher Collins, she started worrying about all the possibilities. "I was in such an emotional state. I felt like the future I had imagined for Davie had suddenly been swept away and replaced by something unknown. My mind was buzzing with questions and of course, one of my biggest worries was how he would cope with his deafness. I found Deaf Children Australia and to my relief, was connected up immediately with a parent mentor, Christina.

She was literally a beacon of light because she understood how I felt. Christina had been down this road before with her own son's deafness. She helped us firstly to accept the diagnosis and then guided us with how to interact with Davie. He doesn't have proper ear canals – one ear is just like a little peanut – so he couldn't hear us. Christina provided reassurance. I had all these questions and all these fears for my little newborn son: 'Is he going to be okay?' 'Will he be able to make friends?' I needed to hear another parent's advice. Deaf Children Australia's Mentoring Program gave me so much hope that with the right supports, Davie would be okay.

DCA provided lots of support, information and Australian specific resources. They understand children like Davie who have complex needs and they can navigate us through. I attended DCA's Better Start workshop over several days and got to know other parents and their children. Through DCA, I have met so many parents who have advised us of language choices, and techniques and strategies they use to support their deaf child. Knowing DCA is here and specifically providing expertise and support for children really gave me the confidence that we could make the right decisions – because the learning and language development is so critical.

Because he doesn't have formed ear canals, Davie wears a Bone Conductor Hearing Aid and when he is around five, he will have a Bone Anchored Hearing Aid (BAHA) inserted into his head with a screw. At 23 months, Davie is attending an Early Intervention Centre and has been learning to say a few words. He is a little behind so we will get extra assistance with audiology and speech therapy. We know he can't hear the soft consonants but speech therapy can help him learn how to make those sounds. We want Davie to have that second language and through signs, we can understand when he wants something. We have been learning baby signs and he is always signing 'Where is my Thomas?' because he loves Thomas the Tank Engine. It is very cute that when he signs thank you, he adds a kiss.

We know Davie has a lot of challenges ahead but DCA's ability to guide us in the right direction has

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been invaluable. We will keep accessing all the resources and in the future, Davie can join in recreation activities so he can get to know other children who are deaf.

Now, Davie is on the waiting list for his tonsils and adenoids to be removed. This surgery will open up his airways more but he will have to be in Intensive Care on the ventilator again because he won't be able to breathe naturally. The surgeons will do another cheek graft while he is under anaesthetic. Davie will need five more cheek grafts and when he is 15, he can have plastic inserts for cheekbones. He might have his lower ribs removed to build his ears up so he can wear glasses because Treacher Collins also commonly causes vision problems. But we would like Davie to decide how much surgery he has when he is older. I am in a much better space now to support Davie through all this and I want to thank Deaf Children Australia from the bottom of my heart for all the work you do."

This real life story brought to you by

Name: **Jane**

Location: **Australia**

Age: **Late 20s**



Just over a year ago I attended an indoor music concert, unaware that night would dramatically change my life forever.

My allocated ticket was front row. The music was loud. I didn't expect it. Not normally something I would go to. But it only takes one mistake. I didn't realise the damage that could be done from a 2 hour concert.

Next day I noticed a major hearing loss and shortly after the hell of permanent loud tinnitus set in. I now struggle to get any sleep without medication and each day is a battle coping with the 24/7 screaming of tinnitus. I've asked many friends if they would have known to use earplugs if they went to a concert and all of them said no!

I've since learned this type of preventable damage from concerts is very common. I have met others online from QLD to SA who have suffered the same fate - permanent tinnitus.

More needs to be done in prevention and to educate the public about the risk of hearing loss and especially tinnitus from loud music. There are health risk warnings on cigarettes. There should be mandatory warnings on music tickets and at the point of sale online before you can finalise purchase of tickets. There should be warning signs clearly displayed in venues that volume levels may exceed safe levels and hearing protection is advised. Why in this day of high awareness of OH&S and protection of workers in the workplace is it still considered ok to subject the public to sound levels in their leisure time that damage their health without even a warning?

I want my story and suffering to make a difference and to bring about change.

Name: **Alice**

Location: **Melbourne, VIC**

Age: **20s**



"I was diagnosed with a mild hearing loss at eighteen months of age and from that time, it kept on deteriorating. The genetic tests I have done can't identify any cause. I come from a hearing family and there is no one in my family background with a hearing loss. I also have balance problems which could have a relationship with my hearing loss but it is impossible to say.

"When I was around four, I was assessed for a cochlear implant. My hearing loss didn't meet the eligibility criteria they had at the time but at the age of ten, I got an implant. It made a huge difference in my life. There were sounds that I hadn't heard before that I was able to hear for the first time. My speech improved and it was a lot less frustrating having stable hearing. Before that, every time I had learned something or my speech progressed, my hearing would deteriorate and I would go backwards again.

Three years ago, I got another implant in my left ear. I don't have the same hearing in my left ear as I didn't hear anything from that ear for 11 years and my brain needs to get used to it but it is very helpful having the second implant. I feel I can hear more, especially when sounds are coming from my left side.

My family have always been fantastic at supporting me. I was the baby in the family and my brother and sister would help me a tremendous amount. On holidays at the beach, my sister would be my interpreter and always made sure I was involved. I never felt I was different. I had a lot of intervention when I was young too and my whole family helped to aid that. I went to Holy Trinity Primary School and was supported by St Mary's Teachers of the Deaf there. I was also supported by St Mary's at Aquinas College. So I was in mainstream schools but had a group of students who were also hearing impaired. I was never the only deaf person. I had teachers to confide in when I struggled and the support of friends with similar experiences. The teachers were great at doing presentations on hearing impairment. It made the students curious so they would come and ask questions.

It was a great conversation starter so it helped me to make friends. There are some situations now, like when I am swimming, when it's still difficult to communicate. But now I am quite confident to tell people what my limitations are so my needs can be met. It can be hard feeling confident enough to do that when you're younger. It was manageable in the classrooms because the teachers wore FM microphones and their voices would connect directly to our hearing devices. Most of the time, I received the help I needed but getting special consideration for VCE was really hard. My parents, my teachers and my school all fought for me to get special consideration. I did well at school so they said I didn't need any help. But I was doing well because I was getting the assistance I needed to reach my potential. Being hearing impaired, you have to work hard, you have to really focus on your

This real life story brought to you by

teachers' voices and you have to go back over everything more. I got special consideration for most subjects but I had to do two exams without any assistance.

I got into a Bachelor of Arts at Monash University and majored in Psychology, having had an interest after studying Psychology in Year 11 and 12. At Monash University, it was a lot easier to get help because I did advocate for myself. You have to be able to do that and you have to know the support you are entitled to receive – or you won't get any help at university. I had a note taker throughout my Bachelor of Arts and Honours year so I could focus solely on the lecturers. If I had been trying to take notes, I would have missed out on what the lecturers were saying.

After completing my Honours, I wasn't sure what direction I was going to take so I took a gap year and went backpacking through Europe for six months... which was an amazing experience. Working at DCA is great for me because I really want to focus my career in Psychology around preventative programs and I would like to develop programs myself. I aim to get my Masters in the future but I am really enjoying getting practical experience. Until I became a family support worker, I was a research assistant in La Trobe University's project focussing on the early language development of children with cochlear implants, and the factors which influence their outcomes. DCA is an industry partner in this research and the CommuniCate resource is an integral part of the research.

The knowledge gained from this national study will provide valuable information for parents and professionals all around the world about the language development outcomes for children with a cochlear implant. The study introduces some families to Auslan during the critical developmental early years and will compare language and communication competencies with those children who are not introduced to Auslan. As part of this research, I was doing observations of parent-child interactions and assessments of the infants' cognitive development.

The CommuniCate resource will really benefit infants and young children as their families will be able to teach them Auslan and learn how to communicate effectively with them from such a young age. There is already enough research to show the benefits of learning two languages early because our main language development occurs between the ages of 0 – 5.

I didn't begin to learn Auslan until I was 16 when I had a chance to study it during VCE and at Latrobe University. I managed without sign language but looking back, I can see how it would have filled in the gaps. In certain situations, no matter how many times something was said, I couldn't hear. I have friends who speak English well and they are fluent in both languages. I spent so much time in speech therapy so at the time that seemed best for me. But I would have liked that opportunity to become fluent in both languages when I was younger.

Alice joined Deaf Children Australia to help promote the Safe and CommuniCate resources and to build understanding of how these programs can assist infants, children and young people who are deaf or hard of hearing. Alice is a great role model for children and young people to show how you can fulfil your potential and realise your dreams.

Name: **Renae**

Location: **Newcastle, NSW**

I want to share with you my experience of being in a cafe/bar with very loud music in my home town earlier this year.

On arriving, I noticed that a fair number of patrons were 50+, including seeing that one lady sitting with two other friends had a hearing aid. On this occasion I'm here on my own, but if I had someone with me I would have to talk louder than usual to be heard even by someone with good hearing.

My mum wears hearing aids and I know that she would find it very hard to participate in conversations with me or any of her friends in this kind of environment.

I've been learning more about this issue and the challenges faced by Australians with a Hearing Loss from Deafness Forum and Break the Sound Barrier campaign and in my profession as a disability support worker.

At this time I asked the cafe waitresses what she thought about the music volume. The waitress replied, "You know, we were just having this conversation with our manager 5 minutes ago. We think that it's too loud for our clients, but the owners have said they want it kept loud. One of the owners was in this morning, and he turned it up. We have already turned it down a bit since he left, but there is a volume they do not want it to go below."

In a café where over 50% of the customers are over 50 years in age, it was strange to understand what the Café owners made of this? Especially as to what is the reason as to why the owners don't want the volume to go down? One wonders if this is a conscious decision to deter older people from coming here as well as excluding anyone hard of hearing?

When will Australia get the opportunity to be educated about hearing health and wellbeing?

Name: **Sam**

Age: **24**

Location: **Melbourne, VIC**

It wasn't until I was 6 months old that my mother knew that something was up. She was vacuuming my room and I didn't stir. Straight away she had me checked out and it turns out that I was profoundly deaf. Bang, straight away something was wrong with me. Alarm bells rang once they were told that I wouldn't be able to talk to my family and I wouldn't be able to communicate in today's society. The doctors did mention Australian Sign Language however being born to a hearing family they directed us to Australian Hearing for advice.



I got hearing aids but it was soon realised that these were not powerful enough and that I really needed a cochlear implant to access sound. I was implanted when I was 2 years old and underwent intensive speech therapy and through early intervention at the Shepherd Centre to ensure that I had age appropriate speech entering school.

School was an environment that was challenging. I couldn't hear what was being said at because of constant background noise. Society today really has no idea how hard it is to hear in a noisy environment.

Throughout my schooling years I have always had an itinerate teacher, a teacher of the Deaf and this is someone that really helped me on my journey through high school as the workload increased. I am forever thankful to her and me and my family formed a strong connection because of this. I became college co-captain and graduated from high school in 2011.

I haven't yet emphasised how much of an impact sport played. I would always be the sweatiest kid coming back into class because kicking goals, shooting hoops and beating my opponent at lunchtime was my way of being accepted and respected throughout school. I knew the school office ladies better than anyone because I'd be there so often after breaking my implant. Sometimes my mum would have to drive in with spare parts and I had to miss class.

I moved away from home with the support of my family and studied in Canberra for 3 years. The only true friends I had were the ones I met outside my course through sport.

I can say now that without the role that sport has played in my life, I would be a different person. Sport opened the doors for me because it was a platform where I could relate, communicate and share experiences with people who have no idea what it is like to grow up deaf or hard of hearing in a hearing world.

It makes sense that I found out about the Deaflympic Games through my itinerate teacher and all of a sudden I had something I wanted to strive towards. In early 2011 I got a chance to trial for the

This real life story is brought to you by

national Deaf Basketball Team 'the Goannas'.

I made the team and have ever since represented our country at 4 international tournaments. I can safely say that it is because of this team I found my Deaf identity. I learnt Auslan and I made countless friends from all over Australia.

I really want to raise the following points as they are the ones I hold dear to myself:

1. Raise awareness and educate the Australian community about Deaf and hard of hearing people – I am Deaf, yes I can drive, I can swim, it doesn't stop us from doing anything! We are physically able!
2. Accessibility to Auslan interpreters and captioning – since learning Auslan, it has become my second language and at times, my first when I struggle to hear. Australia is quite behind in terms of providing accessibility at major events (National Anthem for example) and especially for televised news events such as emergency broadcasts where the networks cut out the interpreter. A policy and standard needs to be set.
3. There is minimum funding allocated to Deaf Sports Australia, an organisation if I and countless others had been exposed to when young, would open us to an amazing community and fantastic opportunities and connect children and families with others.
4. There is no funding for national Deaf sporting teams – I and other members of the Australian Mens' Deaf Basketball Team 'the Goannas' have forked out over \$25,000 each player over the past 8 years to be involved with the program. Why do we stay? Because we have built a strong bond for the game that we love.
5. Make Auslan a recognised language – New Zealand Sign language is a recognised language, why can't Auslan be?

There are countless more things that need to take effect and these five are the ones that relate to me the most.

I really do hope that Australia can break through the sound barrier and recognise the actions that need to take place.

This real life story is brought to you by

Name: **Sandra**

Age: **77**

Location: **Tasmania**

I have been wearing a high powered aide in my left ear since 1974. I have zero hearing in my right ear. I rely on lip reading and have been told by audiologists that this is how I have got. How right they are? Turn away from me and I have no idea what you are saying. I have an appointment for a cochlear implant coming up. So that is something to look forward to.

Yesterday I had an appointment at a new state of the art hospital. The ceiling is 2 stories high, so there is a massive echo. When I went to speak to the person behind the thick pane of glass I couldn't hear her. She was sitting more than a metre away from the small hole in the glass AND not looking at me but at her computer asking me questions. Lucky my husband was with me to answer the questions. When I mentioned this to my audiologist she said she could hardly hear the girl so it would have been impossible for me.

There is a need to help people understand how to deal with hearing impaired people.

Name: **Andrew**

Age: **40 someting**

I learnt the NDIS won't include a hearing aid - only the processor for the cochlea implant. This discrimination forces deaf Australians to get cochlea implants without any choices or support. It doesn't improve or fix my situation.

I am not on a disability pension or a member of the Australian Defence Forces. I was born deaf, and lived it all my life. I've worn hearing aids to hear sounds and I am happy to live my life with it.

My partner is also deaf and relies on hearing aids, which means as a family we need to make the decision to upgrade to new advanced hearing aids - four hearing aids will total \$16,000. Imagine any family having to make this decision! We are a middle class family with financial hardship and we are raising three perfect hearing children. Our children's future is very important to us hence our decision about our own hearing support or our kids is a hard one.

Without NDIS, without hearing aids, we'd go mentally silent. We face barriers in our social, family and work environments every day.

Please don't create an Australia where we are deprived of choices especially if the cochlea implant is "free" and we cannot choose hearing aids.

We need a National plan that allows for real choices for all Australians.

These real life stories are brought to you by Sandra and Andrew

Name: **Anne**

Location: **Sydney, NSW**

I started to lose my hearing when I was about 20 years old. I wear a bone anchored hearing aid (BAHA), a behind-the-ear hearing aid and use a FM.

My hearing loss is hereditary, bilateral and progressive, and as far back as we can remember generations of females in my family have had hearing loss.

My mother was deaf and a very gregarious and gracious lady, but was at times excluded due to her inability to hear. My mother's experience affected me deeply and when I started to lose my hearing, I was determined that equity and access were vital lenses through which to view the world.

Hearing loss affects all aspects of a person's life: belonging, communication, education, and access to health services, information and technology.

School students need routine hearing testing before they start primary and high school.

Captioning needs to go mainstream, providing access to information for all, and for educational videos in school and tertiary studies. As people enter the workforce they need financial support, via tax deductions, for purchase and maintenance of hearing technology and /or Auslan interpreter services.

Hearing health and well-being needs to be a National Health Priority to ensure each individual's needs and choices for communication are respected, and the necessary services and financial supports made available.



This real life story is brought to you by Anne

Name: **Aarsi**

Age: **teenager**

Location: **Sydney NSW**

I wear a cochlear in my left ear and a hearing aid my right ear.

I am currently at Cheltenham Girls' High School in year 10. I am the only hard of hearing girl in my school and it is not easy for me. In the past, if I ever missed something in a conversation, all I heard from them was, "Never mind." I would usually join them a little while after. However, now I have a totally different approach, thanks to Hear For You. My confidence has increased and for example, I always insist that girls who said something I missed to repeat what they have said.

For me attending a Hear For You series of sessions has had a very positive impact on my personality and behavior. My mentor told me to advocate myself and never be afraid to speak up. Initially, it would have been daunting but I decided to give it a go when I was next at school.....it worked!

Now, I constantly ask my teachers questions whenever I am in doubt. Attending Hear For You has been an incredible experience for me. The sessions I attended included lots of activities that gradually improved my confidence. In particular, the second session provided activities and mentoring from the mentors about leadership and teamwork.

I also liked the fact that mentors gave us useful tips for job applications. Then in another session that I really liked was the communication and drama workshop. The mentors, Heather and John were very supportive in increasing my self-esteem and confidence. It has given me experiences of other hard of hearing mentors and mentees. I certainly developed a can-do attitude post Hear For You.

This program helps me successfully complete a one-week working experience at a place I wanted to try and work for. I also after finishing a series with Hear For You received very positive feedback from the principal who said that I was becoming way more self-reliant and is interacting well with teachers and students. I would like to thank my mentor for making my time at the workshops so interesting, enjoyable and insightful. I've made a lot of new friends from Hear For You and I will continue to learn and share acts experiences. Last but not least, I'd like to thank my Mother and Aunty, who strongly encouraged me to attend this program. Thank you Hear For You.

This real life story brought to you by

Name: **Dan**

Age: **15**

Location: **Adelaide, SA**



Dan before his operation; and today

Dan gained entry to a Special Interest Music Program through audition. Now in year 10, he plays Flute and Bass Guitar, he also enjoys extracurricular activities in the Boys Chamber Choir, iConcert Band and has joined the Tour Choir in preparation for the Tour later in the year to Sweden, Norway and Finland. Dan is thinking he will either go into music professionally, psychology or follow his other passion, Japanese. Dan enjoyed a language tour to Japan last year and he just can't wait to go back, he loves the Japanese culture and language.

Dan was diagnosed with Congenital Cholesteotoma just before his 7th birthday. He was in Grade 1 and all going well developmentally, he had passed his screening hearing test in pre-school. Dan had two three hour operations to remove the cholesteotoma, the longest 6 hours of my life! He lost his eardrum and incus bone, he has a graft ear drum made of muscle. He was left with a mild to moderate unilateral hearing loss - this effects Dan ability to hear in a classroom, limits directional hearing, and is intolerant of loud noises. If his hearing aid is not working he has to work extremely hard at school to hear and he often gets the wrong message.

Dan used an FM system for several years before being fitted with a hearing aid. There has been no looking back. Dan like many who have hearing loss experienced bullying in primary school, teachers who don't know how to work with children with hearing loss and tiredness because he needs to work harder to hear what is happening in the classroom. Dan's experiences have provided him with insight and empathy into operations, pain, hearing loss and how to cope with challenges in life.

We make every effort to support Dan in whatever he wants to achieve. His Mum chose to work part time and take positions that enable her to leave work to attend Dan's appointments and be there for him as he negotiates life. Diagnosis and managing medical conditions is challenging even though his Mum is an experienced paediatric nurse. Even with mild to moderate loss in one ear, she has witnessed the significant effects on learning, socialisation and family life.

For this reason I support making Hearing Health a National Health Priority and the Break the Sound Barrier Campaign.

This real life story brought to you by the Courts family

Name: **Shirley**

Location: **Brisbane, QLD**

It was first noticed that I may have a hearing problem when I was 4 years old. My mother recalls calling me when I was playing outside and she said that I ignored her and kept on playing. I told her that I didn't hear her, and so she tested me on this, and realised that I could have a hearing problem in my left ear.

A visit to the specialist said that he could find no reason why I could not hear in that ear, and said that as I heard very well in the right ear and could speak fluently, there was no need for a hearing aid. I went through school up to Year 10 without a hearing aid, excelling at English, writing and history. I always sat in the front row so that I could hear the teachers.

When I was about 12 it was noticed my hearing was getting worse, and I was fitted with my first hearing aid not long after. This served me very well in the coming years up to my marriage and it was only after the birth of my first child that my hearing worsened in that I could just hear on the phone and no more. A few months after the birth of my second child, my hearing went completely.

Specialists could not tell me why I had lost my hearing and only agreed that I should not have lost my hearing. I could not afford lip reading lessons, there was very little assistance for a person with a hearing disability in New Zealand at that time, and so I came up with memorising passages from newspapers and magazines, held a mirror in front of my mouth and mimed the memorised words. I taught my two children to slow their speech so that I could lipread them, and this worked very well.

Communicating with the general community was a different story, however. Many people just could not understand why I was speaking so well, yet couldn't hear or understand them. They gave the impression that I had mental problems, I just wasn't believed, and many just didn't have the patience to deal with a Deaf person who could talk, as many thought I should use sign language, and that I was born deaf. They just didn't want to know. About this time, I met my present husband whose father was Deaf and he very well understood the problems of someone with a hearing impairment. I had been working for a cosmetic company as an export clerk for a number of years.

Through all this time I continued to search for information on how I could get my hearing back and when I learnt that the cochlear implant was to be available in New Zealand, I applied through my ENT specialist to have the surgery. I was totally devastated to be informed some months later that I did not need an implant because I lipread too well, spoke too well and was well adjusted to being deaf, and that I did not need to improve my quality of life. A short time later my husband and I both lost our jobs through restructure and the children had left home.

We had always wanted to return to Australia, so we sold up and moved back in 1987. I had an occasion to visit my GP who was most interested to learn about my hearing impairment and suggested that I should consider a cochlear implant. I told him I was ineligible, and he replied "not from where I am sitting", and set me on the road to receiving my first implant. After the initial testing, I was deemed to be a suitable candidate and I had my first implant in 1989 in the left ear. I was switched on a few weeks later, but I could not hear as well as first thought that I would as the

This real life story is brought to you by

sound kept fading away. Tests revealed that the surgery was not the success at first thought, so a second implant took place, which also was not successful.

In 1992 I had a third implant in right ear, and this proved successful in that I could hear quite well with environmental sounds, but speech was a challenge. Over the years since then my hearing deteriorated to the extent in the left ear in that I could not understand or identify sounds as such, so in 2005 I was offered a second implant in the left ear, which was successful the first time. I found I could hear really well, and after a few weeks could identify where sounds were coming from, from that side and that I could understand speech without lip reading.

In 2008 I had the right ear re-implanted successfully. I remember my husband speaking behind me and I answered automatically, and I knew then that I had the full benefits of the implant in that I really could hear without lip reading. I found in my work situation that I could identify voices behind me as I became familiar with them, could hear people talking on the phone away from my work station, I found I could actually hear people who mumbled without lip reading, and rarely had to ask people to repeat themselves, that I could hear on the phone with a person with whose voice I was familiar, could identify sounds without looking from where it came, distinguish who had an accent, the difference between different makes of cars, all sorts of things.

The biggest challenge I now have is looking at people's eyes instead of lips – no easy feat after years of lip reading. Hearing with two implants is a bonus as I can hear all around me and not just on one side. I wouldn't be without it anywhere, and just can't imagine not hearing anything. It has improved my quality of life no end, given me much more confidence to go out and meet the world, listen to music once more and much independence.

Fast forward to 2014 – I now have upgraded to the latest speech processor N6 and it is challenging hearing with this new powerful technology. And so to end.....would I do it all again? Without a doubt. Life is for hearing! The long journey from 1989 to 2005 then 2008 was well worth it in more ways than I can say.

This real life story is brought to you by

Name: **Bethany**

Location: **Adelaide**

Age: **mid-20s**

I was 10 months old. My mum knew that due to my lack of response to her voice, there was something else going on. It took five months to get an answer, as I was a bright and happy baby. Doctors were convinced there was nothing wrong with me.



At 15 months of age, I was diagnosed as being profoundly deaf. The cause of my deafness is unknown as there is no family history and I had not had any major illnesses. With a family that was all hearing, it was hard for my parents to be told by a number of specialists that I was unlikely to develop any usable speech. They were told that I would have to learn to sign and go to school far away from home. I would become a part of a community they knew nothing about and one that they would never truly belong in.

My communication level would be better with my siblings than it ever would be with my parents. There would be an entire family I would never be able to truly communicate with. One day, the phone rang. A representative from the Cora Barclay Centre in Adelaide had gotten my parent's number and invited them to visit the centre. They went ahead and toured the centre with some hesitation. During the tour, the principal told my parents, "We believe we can teach Bethany how to speak." This was the first time since I had been diagnosed that my parents had heard something positive. My parents began to believe that there was a chance and went ahead with the centre's program.

I was fitted with hearing aids, and started intensive auditory verbal therapy, with my teacher, Kerry. But the lessons didn't stop there - there were listening games every day, in the morning, before bed, and during the day, when my mum would constantly talk to me about everything to fully immerse me in a world of sound. I was two years old when my hearing was re-tested and it was discovered the little hearing I had deteriorated even further. I was taken to my ENT, Dr John Rice, who told my parents that the time had come to seriously consider a cochlear implant.

It was early days of children receiving cochlear implants and only ever considered for the deafest of the deaf. It was a hard decision for my parents, who eventually decided it was the best option for me - I would lose nothing because I had no hearing, and if the implant failed, I could still learn to sign. But if I did not receive the implant, and soon, I would never develop normal speech.

More than a year later, I was implanted, and switched on at nearly four years old. To this day I still remember running outside and hearing things I had never heard before. The sprinkler was pointed out to me, the birds flew above, the clock was ticking and the pram with my younger brother in it was rolling along the path. There was still a lot of work to do. When it was time for me to leave

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kindergarten, and go to school, there was much debate as to whether I should be held back or not. This was because I was five years old and had the language age of a three year old.

I was allowed to enter Reception, with the idea that if I was behind, I could repeat. It was difficult to find a school that would accept me, because it was early days when children with implants were entering the school system. All the schools happily accepted my older sister, but would not promise a place for me. We were fortunate to find a school happy to take me on despite the unknown challenges. I ended the year, and went into year 1 the next year.

I started to excel in the classroom. By the time I was 10, I tested as speaking as an adult in some areas of my language skills. I went from two visits a week to once a term on a merely monitor service over the course of 7 years at school. At the age of 12, mum and I were flown out to Sydney to be trained as part of a new initiative by cochlear – called the Cochlear Awareness Network or CAN.

Mum and I were heavily involved for several years, speaking to over 60 service clubs and groups in the state about our experiences. In year 12, I entered a public speaking competition called 'Lion's Youth of the Year.' I was lucky enough to progress to the state finals - one of only two students from my high school to have done so. I finished High School in 2011, as top of my class in 4 of 5 of my final year subjects, meaning I achieved an ATAR in the 90's.

I started my Bachelor Degree in Media, with a major in journalism in 2012. I was lucky enough to meet Professor Graeme Clarke, a man I owe so much to in the same year. He is a humble man, who still works to improve the lives of the hearing impaired. In 2013, with generous support, I was able to study abroad for a semester. I went to California, USA. I studied at a liberal arts college about an hour away from Los Angeles called Pitzer College. I had the time of my life - I made many friends who I will keep for life, and saw many things I will never forget. When my semester at Pitzer ended, I travelled around the country for a bit. This included having my first ever white Christmas, and experiencing snowfall. I also went to many places I'd read about, or seen on a screen, such as the Lincoln memorial, and Route 66.

In 2014, I received a scholarship to travel to Japan and study media. I did not know a word of Japanese, but that did not stop me from having an incredible time. This trip was the first time my classmates were told I had a hearing impairment, and many were quite shocked. I finished my Bachelor's degree in 2014, juggling three part time jobs – working as a shop manager at a chocolate factory, as a promotions ambassador and working for University of Adelaide.

I completed internships at ABC, Radio Adelaide and Total Girl Magazine. I did cause dead air on Radio Adelaide for a few seconds because I could not hear that the sound was not coming through - I only wear a cochlear implant on my right side, and the audio came through the left side of the headphone.

I was 20 when I finished my bachelor's degree, and turned 21 not long after. In 2015 I was accepted into RMIT's media communication honours program, something I worked hard for. After a month long stint as an intern in Brisbane, I returned to Adelaide for two weeks before moving to Melbourne, where I have been since. I completed honours with first class honours, and immediately moved into work at Stockland. I am now a full time marketing assistant at Stockland, helping to market residential developments in Victoria. I have recently started marketing my own communities, and am on track to becoming a Community Marketing Manager soon.

Messages to our elected leaders

In 2016, I was offered both a scholarship and a bursary by the University of Melbourne to study Masters in Marketing Communications. Not one to let an opportunity pass me by, I am studying part-time while working at Stockland. But that's not all – I am continuing to pursue my love of travel, and take the opportunity to do so when possible.

In the past two years I have visited Vietnam, the United States and New Zealand, with many more trips on the horizon. Sometimes I travel alone, and manage just fine. In fact I noticed that because I can understand body language well, I found it easier to communicate with the locals who didn't speak English than my traveling partner did on our last trip!

The Cora Barclay Centre gave me the skills and the tools I needed to live an independent, satisfying life full of adventure.

Name: **Tanya**

Location: **Springwood, QLD**

Age: **55**

I am a mum of four. I suffer from Meniere's disease. I also have tinnitus and hearing loss. I had to retire from work in 2012 as a result of my condition.

I suffer from vertigo sometimes and this has affected my balance and hearing. I am affected every day of my life from Meniere's. I suffer from anxiety and often depression. I have seen a psychologist to help me cope with everyday life. I had to pay for my hearing aid myself, as I am not entitled to any government funding or help with my condition because of my husband's wages.

We had to sell our house as we couldn't afford it on a sole wage. I would like more public awareness raised about balance disorders so that the government could fund maybe workshops, therapy, and funding to help with hearing devices.

At present I have no support here in Springwood, Queensland. My only connection is with the Whirled Foundation and its Facebook support site. These are a wonderful help but I cannot physically go anywhere.

Thank you for your time in reading my story.

I hope I can help to make a difference.

Name: **Casper**

Location: **Wollongong, NSW**

Fiona shares the story of her six year old son Casper's experience of losing his hearing through the side effects of chemotherapy. "I would love it if our experience could help others coming off treatment with chemotherapy induced hearing loss to access treatment and not have to fight for it."



My son Casper has profound to severe high frequency hearing loss. His is due to chemotherapy he received as a baby. I believe it is widely misunderstood how impactful chemotherapy is on children. Because he has a lot of hearing in the other frequencies and can keep up with conversations in a one-to-one situation with perfect acoustics, people assume it is not an issue. He did not qualify for the early intervention funding for his hearing loss to get him support as his hearing loss was considered not bad enough but we eventually were able to arrange a lot of early intervention. He wears bilateral hearing aids. His classroom is fitted with a Roger FM unit that the teacher wears. He does get a visiting teacher of the deaf at his school once a week but I know he misses a lot at school still. He started prep/Foundation this year. Hearing loss has affected him in many ways. More and more children are suffering from this due to the platinum based chemotherapy used to treat cancer. The impact this has on children should be addressed and families should be supported. Surviving cancer is wonderful, but quality of life and "thriving" should be our ultimate goal! There seems to be a lot of research on the impact of this high frequency hearing loss and the impact it has on young children in the US and other parts of the world, but very little here!

It was very hard knowing that Casper needed the chemo to beat the cancer but also knowing just how devastating that could be on his poor little body should he survive. We always tried to be as positive as possible that Casper would make it through and we are so happy that he is still with us, but it has had a huge impact on the child that he is and has certainly left him with a number of challenges. At only six, he still does not fully understand the difficulty that his hearing loss causes him and the impact on his learning and education but is just starting to ask a lot of questions.

He says, "I can hear without my 'earin' aids" and whips them off to show people that he can hear, but the extra effort in listening and more importantly processing takes its toll. He gets very tired and very emotional. The effects of chemotherapy can continue to cause ongoing deterioration for up to 20 years on all sorts of areas, including hearing. The younger a child is at diagnosis, the higher the dosage of chemo and the types of chemo and/or radiation determine how likely the child is to have side effects and developmental delays. I would love it if some sort of study could be done here in Australia following children with chemotherapy related hearing loss and the struggles they have in the education system following this. It sometimes felt like he was "not deaf enough" to get support and I had to really push to get him help.

We were told Casper should have a hearing test prior to his treatment commencing and then one after every round of cisplatin chemotherapy. It was not till after his second round of cisplatin that I

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realised he had not had a baseline hearing test and had to push for it at the Royal Children's Hospital here in Melbourne. His hearing was perfect. Then after the next round of cisplatin, his hearing was starting to deteriorate. Once the deterioration started, we discovered that the antibiotics he was on were also ototoxic. Unfortunately he was having very high doses of these. We only discovered this through our own research.

We also discovered that high dose vitamin E was being studied in adults in Italy to reduce ototoxic effects of chemotherapy and that it was found to be having a profound impact in reducing the hearing loss side effect by preserving the hairs in the ears. My mother made contact with Professor Pace who was conducting the study but found that it was not being used or studied in children yet. We pushed to have Casper's antibiotics changed to those without ototoxic effects. We also asked if Casper could have alternative chemotherapy but it was considered that the one being administered was thought to be the best for treating his cancer, despite other protocols being used in other countries when treating his type of cancer.

We were stuck between a rock and a hard place, so to speak. We also asked if they would consider putting Casper on vitamin E but they were not interested in even looking at the research or contacting the researchers. I understand they wanted to win the fight against the cancer but with more and more children now surviving childhood cancer, there is going to be a large number of children struggling and requiring a massive support network to deal with the side effects to children's hearing of platinum based chemotherapy.



A recent photo of the three of us: Me, Casper and David

We were told that he did not need to wear hearing aids but it was up to us if we wanted him to. Therapists we were in contact with also said that we could wait until he finished treatment. It felt like it didn't matter because he might not survive anyway. In our minds, we could not think about if he did not survive. Even though the doubts were there we always wanted him to not only survive

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but to thrive.

The effects of the hearing loss became clear to me as he had started to say a few words eg; “mama, more, hi, bye”, but when hearing loss occurred he almost instantly stopped using his words. He also started to hate music therapy which he had always loved. He screamed if I took him and covered his ears. He hated it if I had the radio on in the car, or even if I sang to him. It was heartbreaking. He seemed to be confused by the change in his auditory world. The day he got his hearing aids fitted, it was obvious that he was hearing more. As we drove home from our local Hearing Australia office he smiled along the way at all sorts of “new” sounds.

Early intervention was not considered a priority for Casper. When we did contact the relevant therapists, they were very moved by Casper’s journey, but still did not see that he would need much support as his kind of hearing loss was, and is still largely considered “not that bad”. It makes it very hard because as soon as you are out of the oncology world you are left to your own devices with little guidance about how and where to access support.

We googled and found EEP – the Early Education Program for Deaf and Hearing Impaired Children in Brighton, who were close to us and they were wonderful. It took a lot of work from the team there to help him adjust to his new world and to wearing hearing aids. They worked closely with me and my husband to help us all through this tricky transition post treatment and we worked with a speech therapist to help him with his language quirks. As supportive as they were I had to work hard to get him the minimal support they were able to provide because even they could not access much funding for him.

It was wonderful to see the post from Cassandra about her son and how her son was able to articulate just how great the impact was for him. Just nice to know that we are not alone and others are struggling with the same issues and feeling somewhat misunderstood.

Chemo damage at such a young age has a massive impact on children as the effects are far greater on their developing bodies. The younger a child, the worse the side effects are and the more it affects their overall development. There are more and more children being diagnosed with hearing loss after cancer treatment. I think it seems more common now but that is most likely because children are actually surviving cancer at much better rates. Now therapy needs to move from concentrating solely on survival rates but also on how to help those that survive to thrive. Even since Casper’s treatment which was only five years ago, there is more vigilance with hearing testing. I sincerely hope that the deaf community can connect with the oncology community to help the children coming through. The thing I found hardest was accessing early intervention.

I think it would be great if oncology and the deafness communities could work together more to ensure these kids are getting support and that their needs are understood and not dismissed.

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Name: **Christine**

Location: **Adelaide, SA**

I am a middle age lady of 60 with a genetic progressive hearing loss which has progressively worsened over time.

I was not diagnosed with hearing loss till I was 19 years of age although I had been having difficulty at school. We lived on farms and I missed the regular hearing check-ups. I have quite good speech as my sensory neural hearing loss began in the high frequencies and I retained enough normal hearing for many years but over the years it has diminished to bilateral profound.

I have worn hearing aids in both ears since I was 19 but lately Australian Hearing Services have recommended Cochlear Implants.

On thoroughly researching what this involves I have decided not to go down that path as there is so much promotion of cochlear and it's success but nothing gets reported on the horrible surgery involved, the risk of infection, headaches, totally different way of hearing sound and the end of any residual hearing which gets replaced by an unnatural robotic like sound receiver.

My deafness is now a huge part of me and most times I manage as I lip read very well but am having increasing difficulty with independence when out and about. I have also developed a Vestibular Disorder related to the genetic loss which causes scary vertigo episodes.

It has got to the point that my social independence has dropped considerably. My daughter also grew up with the gene although she was supported and diagnosed from birth. She has got lots of previous support from Brighton Chic and CanDo For Kids and DeafSA. I have tried to learn Auslan but find classes extremely difficult in keeping up. My self-esteem has also diminished.

I would love to be taught some signs one on one if possible, just to enable me to shop or order a coffee by myself, as I tend to rely on my hearing partner or my daughter to aural interpret for me. I have developed a phobia with the phone since I cannot always hear or decipher incorrect captions. Also if there is an Internet Service outage I lose the captions. Most of my communication now is via text or email. I have a caption telephone but cannot always hear it ring unless I am alongside it.

I sought some help from GuideDogsSA Hearing Services but their services and knowledge of hearing impairment is somewhat limited due to funding resources. DeafSA and CanDo has significantly had to cut back on service provision due to cuts in funding.

Other disabilities get so much funding and sympathy because unfortunately hearing loss doesn't get seen or accepted as being very debilitating. This is a fallacy as hearing loss affects every aspect of day to day living.

I truly support more education and awareness of the impact of progressive deafness.

Hearing Impairment needs to be on level as other disabilities and with more awareness by all Australians.

This real life story is brought to you by Christine

Name: **Daniel**

Age: **20s**

Location: **Sydney**



My time at *Hear For You* as a mentee in 2009, when I was a Year 11 student, was a profound and formative cornerstone in my development as a teenager and into young adulthood. My experience in high school as one of the only Hard-of-Hearing students was a fairly miserable and challenging few years, whereby I threw myself into academia and chose to shun social interactions to a large degree due to a sense of shame and self-denial about being Hard-of-Hearing, and due also to my misplaced belief that I was a 'freak' and unworthy of attention.

This period in my life was eventually overcome in no small part by the influence of the *Hear For You* program and the time I spent with my fellow mentees and the older mentors. *Hear For You* provided me with the first real opportunity to interact with other people who were just like me and enabled me to see clearly that having a hearing loss is not a barrier towards a happy and full social life.

My involvement in *Hear For You's* first program helped me to realise that I shouldn't ever allow my hearing loss to negatively affect my decisions, and this provided me with the impetus to nominate myself as a candidate for my high school's Year 12 leadership positions, which were to be selected by the student body through popular vote. I was elected as a Captain's Prefects - a role which saw me involved in acting as a voice for the students and enabling the student body as a whole to have an influence in school decisions. This leadership role provided me with further public speaking experience and was a gratifying conclusion to my high school years.

Following the completion of high school I received an unexpectedly high ATAR score, an achievement which enabled me to pursue a Graphic Design bachelor's degree at UTS. My four years at UTS, including my honours year, was a period of self-discovery, and the self-confidence and self-esteem which I had lacked in high school increased considerably. My fond memories of *Hear For You* continued to influence my determination to always strive to achieve my goals and dreams.

Graduating from university with honours was a surreal milestone to reach! Following the conclusion of my studies, life post-degree has been a period of adjustment, including the realities of looking for work. Finding a full-time job has proved to be challenging and time consuming, however I have enjoyed doing internships and paid freelance design work in the interim.

I contacted *Hear For You* regarding the possibility of volunteering as a mentor because I wanted to give something back to the program that I fondly remembered. My time as a mentor has had me forging new connections with other mentors and mentees alike. It has also given me the opportunity to share my experiences and successful communication strategies with the mentees and this has been a richly rewarding experience.

While life has been full of challenges, this has made it all the more vibrant and meaningful. My experiences at *Hear For You* as both a mentee and mentor have prepared me well for the future and I can't wait to see what exciting challenges are still to come my way!

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Name: **Alexandria (Sandy)**

Location: **Canberra, ACT**

Between 2007 and 2012, I purchased about six different hearing aids and spent many thousands of dollars.

In 2012 I joined Better Hearing Australia in Canberra and discovered that, as my husband had a gold card, I was eligible for financial assistance with purchasing hearing aids through Australian Hearing Services.

I was in the process of trialling yet another type of hearing aid which was to personally cost me \$10,000. I had not been informed by the Practice Manager that I was eligible for assistance through Australian Hearing Services. The Manager very brusquely told me that it was not her job to inform clients as to their eligibility for anything!

After much discussion she agreed that she would honour \$1,000 of the \$1,500 allocation from Australian Hearing Services. When I asked her why, she said it was because there was not sufficient money included for the fitting of the more complicated, expensive aids. I argued that surely the \$10,000 included an amount for fitting as did the \$1500 from Australian Hearing Services but she insisted that the cost would be \$9000.

When the apparatus for testing the "T coil" function of the new Hearing Aid's did not work the Manager was very dismissive saying "It hasn't worked for months".

I returned the hearing aids and the manager refunded the \$9000 I had paid.

I then trialled hearing aids from Better Hearing Australia but the Canberra branch was very short staffed and I was informed that I would have to wait four months to get new moulds fitted. As the broken moulds were abrasive to my ear canal, in desperation I made an appointment with the Costco Hearing Services. The audiologist there was very helpful – and the COSTCO aids were very reasonably priced at around \$2,000. However, I still could not hear and after many comprehensive examinations and tests, the Costco Audiologist was the first audiologist to point out that hearing aids would be of no help to me and that I needed cochlear implants.

These I had in July 2013 and October 2013 – and then a replacement in December 2013.

I found the help and support received from BHA Canberra and the ACT Deafness Resource Centre invaluable especially at a time when I was vulnerable and having difficulty coming to terms with losing my ability to hear.

I was disappointed that the various audiologists denied me qualified and knowledgeable advice, as audiologists are the main contact, if not the only, that the hearing impaired person has with "professional experts".

But audiologists nowadays are business people, selling hearing aids.

Organisations such as BHA and Deafness Resource Centre offer a personal, caring, helpful environment, where deaf people can meet others suffering from this "invisible" disability and can learn a few strategic ploys to make life easier.

Name: **David**

Location: **Crows Nest, NSW**

Age: **40s**

I have a severe to profound hearing loss in both ears since birth, wear high powered hearing aids, and have the fortune of being able to speak well due to my parents consistency to teach me to communicate since 10 months old when I was diagnosed and fitted with hearing aids.

My first lessons were taken at the Armidale High School deaf unit, where I was exposed to both oral and sign language communications, from 1 years old. By the time I was 5 years old, I naturally gravitated towards the speak, lipread and hear path as I was the lucky ones with the right type of hearing aids.

To make a story short, I worked hard through school, became the first in my region to graduate University, and despite facing over 100 interview in a land of stigma against deaf Australians, secured a good job that gets me by. There are many stories like mine which covers these issues I faced in my life. However I want to touch on an area that is my and many deaf or hard of hearing Australians greatest fear, that is being unable to communicate in the hospital setting.

For most of my life, one of the biggest myths I am led to believe is that our doctors, nurses and allied health hospital staff have some form of understanding of deafness and hearing loss, and at least have an idea of how to compensate to a form of communication or understanding of the hearing aid or implant devices. Unfortunately, Australia's hospital staff of today, have no idea or any provision of understanding of hearing health at all.

My greatest fear, became real when I injured my eye in a water polo match in Canberra, I had to attend emergency to get it looked at. The situation was made worse when my hair being wet, damaged my hearing aids in both ears and made them ineffective. When I arrived at the emergency, I informed them I had an eye issue and needed help.

The first mistake was the fact I spoke well with only one half effective hearing aid, which led to the front desk staff not taking notice of my request that I am deaf and need the emergency nurse to write notes so I can understand. As my eye was injured, with only one healthy eye, I could only lip read to an ok level. The other challenge was the glass wall protecting the staff on the other side of the counter. This made it hard to hear and lip-read at the time so after asking if they have a hearing loop, to which they said "huh", I started getting frustrated with them. Then realising there is an issue with communications and understanding, I just nodded my head and sat to wait for my appointment.

After two hours of waiting, a nurse came to me and asked why I was waiting with ice on my eye? I nodded, said my name was "David, and I was waiting for admission to triage". The nurse then informed me that they called out for me two times during the past two hours with no response from anyone. I informed the nurse I was deaf and told the reception that I was, only to be informed I should have been paying attention with my hearing aid in. After trying to explain it was broken, all

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was forgiven and I had to wait for another 40 minutes before I was admitted, this time a nurse coming to get me.

The experience was made worse in triage when I had to explain I had a hearing loss and as they were poking lights into my eyes, I was unable to hear their messages. My mistake again was to speak. For the next hour I endured confusion, fear, and frustration which did no-one any good. Thinking it was a one off personal experience, I asked my deaf and hard of hearing friends of this, only to receive more responses of similar or worse experiences in our public and private hospitals and health care systems around Australia.

I thought we live in the 21st century? It is clear that one real needed purpose of Hearing Health and Wellbeing as a National Health Priority is to train our doctors, nurses, and health professionals on communications access, hearing devices, interpreters, and an understanding of the importance to respect us if we say "I have a hearing loss", they will work with us to ensure the right information is provided. After all, it is a matter of life or death for all parties involved.

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Name: **Hunter**

Location: **Melbourne, VIC**



Hunter lost his hearing as he started Prep. This is his story, told by his mum Amelia.

“Hunter was always a really happy, outgoing little boy. He just couldn’t wait to start Prep last year. He loved his first days and weeks. He would run into the classroom so enthusiastic. Hunter wanted to start reading... he wanted to learn everything there was to learn.

Then one day, Hunter lost hearing in his right ear. Only a matter of weeks after starting school, his world as he knew it crashed down around him. We found out Hunter could hear a drum beat and he could hear high pitched noises but he couldn’t hear voices through that ear at all. He struggled to hear the teacher. He struggled to hear his friends in the playground where there were so many voices, laughter and yelling. And he just withdrew into himself.

Hunter stopped playing with his toys and he stopped playing with his friends. He cried all the time and started sucking his thumb again. He shrieked like a hyena, testing his hearing. Hunter refused to go to school or even leave my side. He stopped eating and he completely disengaged from almost everything and everyone. At the age of five, he had experienced an emotional breakdown. At the beginning, we got a lot of support from the Royal Institute for Deaf and Blind Children and we spent two days on site at their Sydney facility working with their psychologists and paediatrician. We were told Hunter was experiencing a major depressive episode. As a parent, how do you deal with that – knowing that your child is so completely devastated by something that felt beyond our control?

We had to wait six months before we could get an MRI to rule out the possibility that his hearing loss was caused by a brain tumour. Thankfully, the MRI was clear but those six months while we grappled with Hunter’s hearing loss and depression were so hard.

I was desperate for guidance. I got on to Roz at Deaf Children Australia’s Helpline. She reassured me and encouraged me to be an advocate for Hunter – so we could access the services that he needed. She referred us to Deb at DCA who has provided brilliant ongoing support to Hunter and my husband Brenton and I. Deb advised us on how to manage meetings with health service providers and the school. When we told the principal that Hunter had developed a hearing loss, she replied, ‘We have never had a deaf child at our school in 90 years’. We told her, ‘You do now – so we need to figure out together how we can support Hunter.’ We have learnt together.

Children like Hunter tend to fall between the cracks in the school system because he is not bi-laterally deaf.

He wasn’t technically eligible for a Teacher of the Deaf and he had no additional funding to support him but we lobbied for a Visiting Teacher to attend once a term and she comes in now. It was Deb who was instrumental in teaching us how to navigate the system and how to advocate for Hunter. Deb has also met with the school and is going to deliver hearing awareness training. Hunter now has a hearing aid and in Grade 1, is really fortunate to have a teacher trained in special needs. He has a

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sound field system in the class and he is now the best at reading and writing. Hunter was starting to lose the ability to decipher some letters and blends and was hesitant to speak so we realise he needs a speech therapist. As his genetic hearing loss progresses, Hunter will lose all the hearing in his right ear and he might lose the hearing in his left ear as well. I have been told I could also go deaf... but that is the least of my concerns at the moment.

The emotional journey has been the toughest part of Hunter's hearing loss. We are trying to rebuild Hunter emotionally and that takes a long time.

The team at Deaf Children Australia have become our advocates, our sounding board, and our information providers. They have provided the camp and other recreational activities. But most importantly, they made us feel we weren't going to go mad on our own trying to deal with Hunter's hearing loss and breakdown. They were always there for us when times were really tough."

Name: **Lachlan**

Age: **8**

Location: **Melbourne, VIC**



Lachlan was diagnosed at 2 ½ years of age with bilateral moderate to severe sensorineural hearing loss. Someone suggested his speech wasn't clear so Lachlan was assessed at Australian Hearing. It was completely overwhelming for his family at the time of his diagnosis and they started on a rollercoaster of Early Intervention and other therapy.

Lachlan's hearing loss is related to genetic causes and it has been stable since diagnosis. But his mum Sandra said "we have come a long way in the last five years and Lachlan is now a very happy, busy little man. He participates in Chess Club, swimming and cricket. He recently started at Hebrew School and in three weeks, covered the entire Prep curriculum, recognising all the Hebrew letters."

The family tries hard to ensure Lachlan doesn't feel excluded and they're always checking whether he looks disengaged.

Sandra said, "We never play background music, we only have one conversation at a time at the dinner table with our three children and we always repeat anything that Lachlan has missed. We always have the captions on the television just in case Lachlan walks through the room and we sometimes use Auslan to support some of our conversations. Lachlan is thrilled that at school, his buddy has cochlear implants. It is a huge advantage for Lachlan that his teacher is well supported by Teachers of the Deaf."

"Lachlan wears hearing aids and just recently, a teacher was checking his FM system through a door. My Mum was there with Lachlan and he said, "Granny, can you hear that?" She shook her head. Lachlan responded, "I can hear it because I'm deaf and I have superpowers – I can hear through doors and walls. It's very good having a deaf person in your family because we get to go to family

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camps, Primary Deaf Sports Day and New Connections... and I can talk through windows with Auslan.”

“So we have gone from worrying so much about Lachlan’s future to our current situation where he has high self- esteem. And this comes from getting together with others who are deaf and hard of hearing, seeing others using their technology and knowing the potential. Lachlan doesn’t feel he is less than anyone else. I know New Connections is contributing to Lachlan’s self-esteem and if we can open up those opportunities for other children, that is fantastic.”

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Name: **Haydn**

Location: **Canberra ACT**

I met my wife, Sue, in 1975. She had always had a hearing loss which was picked up at the age of 7. Later she had two stapedectomies one of which was successful and this gave her reasonable hearing. Unfortunately her hearing has deteriorated and she wears two hearing aids but the right ear tends to be decorative rather than a help in hearing.



So I have been aware of the needs of the hearing impaired since meeting Sue. It is only by close contact with someone with a hearing loss that you get to understand the problems they have at work and in social situations in communicating. I admire any hearing impaired person, or Deaf person, who holds down a job and or maintains their social life as there seem to be difficulties at every turn. Of course technology has been a great help over recent years but nothing replaces your original hearing.

A hearing impaired person has to struggle to hear in most situations. Hearing requires concentration and various skills like lipreading and recognition of body language. Often not all the words are heard and the brain has to go into overdrive to fill in the gaps. It is no wonder that the hearing impaired person gets tired.

My wife has been extremely active in supporting the hearing impaired herself since training as an Aural Rehabilitation Teacher with Better Hearing Australia in 1994/5.

Now that I also have a hearing loss and wear aids myself I can understand better the challenges faced by those unfortunate to have a hearing loss. Although there is more understanding of hearing loss and deafness in the community there are still huge gaps. For example if you go to a lecture or presentation often the room is not looped. The lecturer may want to move back and forth across the stage and hence lipreading is difficult, they may want the light on them turned off so the audience can see the slides (and hence lipreading is made impossible) and so on. Music on TV while people are speaking is another problem not solved. Announcements at airports and railway stations are often not understood by those with reasonable hearing so you can imagine how those with hearing loss get on. Doctor's surgeries and hospitals with the TV blaring (rather than captions) make the hearing of one's name when called out very difficult.

Surviving in the hearing world that we are part of is tough but it is not all bad. There are pockets of success, the captioned plays offered by The Canberra Theatre Company since 2005, the wonderful hearing augmentation system in Llewellyn Hall are two positive examples.

Our story is dealing with all these problems and assisting others with the knowledge we have gained over the years. We are also committed to supporting the Deafness Forum in changing the political landscape to make Deafness and Hearing Loss better understood and technological and other assistance part of the normal process in everyday life so that we don't have to continually explain why we want the hearing loop to work or the sound quality to be good and so on.

Name: **Donna**

Life can be unpredictable. I had studied and worked hard for the last 5 years to get a level of attainment I was happy with, then overnight my life changed.

I wasn't born with an impairment but after waking one morning I woke with severe bilateral hearing loss and a whole range of other symptoms. I now have to adjust to the impact of hearing loss with communication, work, resources available, difficulty in early diagnosis, costs and wearing a hearing aid. I am in my mid 50's, my life changed in the space of a few hours - yours can too.



Name: **Peter**

Age: **77**

Location: **Tasmania**

I received my first cochlear implant in May 2000, and my second 6 months later after joining the Bilateral Research Program run by Hearing CRC in Melbourne.

That's when the exciting part started. Living in Tasmania, and having a love of flying I had numerous trips across Bass Strait, and continued to do this until late 2013. I have had the use of the Spear 3 Speech Processor which was the Primary unit for all the Research that we did, and continue to use it to this day.

But being aware that most of the hardware that I am using will be redundant in the near future, then I am looking forward to Upgrading to Cochlear's latest Speech Processors in the future and hopefully with some support from my Medical Insurance.

Much has been documented about the effect of a hearing loss without assistance causing social problems, and degenerative brain problems like Alzheimer's and Dementia. I'm sure that having my CI's when I did has contributed to my health and wellbeing both mentally and physically as I am quite fit at 77, and enjoy life.

I urge our leaders to make Hearing Health and Wellbeing a National Health Priority.

These real life stories are brought to you by Donna and Peter

Name: **Faye**

Age: **Retired**

I was born with a hereditary hearing loss. My parents, grandparents and brothers and sister were all hearing impaired too.

I grew up using two hearing aids and missed half of my schooling as I had difficulty in hearing the teachers even with my hearing aids. You get through life as best as you can but it can be extremely hard and isolating for those who live with a hearing loss.

We need to have Hearing Health as a National Health Priority in Australia. Hearing loss affects the lives of millions of people every day in so many different ways and unless you have experienced what it is like to live with a profound hearing loss you will never understand how hard it can be.

After growing up with hearing aids, I completely lost my hearing in my right ear at the age of 25 due to being hit in the head with a hard packed snowball. Then at the age of 46 I suffered another medical problem and as a result of taking some prescribed medication - it caused me to lose my hearing in my good left ear. I was now profoundly deaf in both ears. My whole world turned into total silence and I was devastated.

I then received Bilateral Cochlear Implants in 2005 and 2007 which I now can't live without. My Cochlear Processors have helped to give me my life back and have been amazing. However, I still live in two worlds. One is my world of my Cochlear Hearing, and the other is my world of reverting back to total silence when I take my Cochlear Processors off at night or when sleeping or in the shower etc. I am still Profoundly Deaf without my Cochlear Processors ON.

I also now have a Lions Hearing Dog (Assistance Dog) which alerts me to sounds when I can't hear and my hearing dog runs and touches me with her paws and takes me to the sound. For example, she alerts me to the telephone ringing, someone at the door, the alarm clock, a baby crying, the oven timer, the smoke alarm, security, and to Got Get another person during medical emergencies.

My hearing dog is more than just a hearing dog, she is a true little life saver and she alerts me in the middle of the night when a family member has a medical problem and when I can't hear. Just having my hearing dog by my side gives me the comfort to know that she will alert me in case of that important phone call, or medical emergency, not to mention the comfort, care and companionship that a hearing dog gives their owner with their unconditional love and devotion.

Along with hearing loss comes the costs. The ongoing costs of Hearing Aids, or upgrades to Cochlear Processors, the batteries, and Dry & Store equipment, wireless accessories, FM systems, TV Streamers, and Dry Briks to remove moisture from our Cochlear Processors, and maintenance costs and repairs if required too. Then there are Doctors and Specialists, Audiologists, Speech Pathologists, Speech Rehabilitation and all the other health services to do with hearing loss.

Also there is the cost of my Assistance Dog, (my Lions Hearing Dog), its vet costs, vaccinations, food and bedding, all of which I am out of pocket ongoing for the rest of my life.

Being a self funded retiree, I receive very little assistance for all of the expenses that relate to my Hearing Loss. Often people with hearing loss simply can't afford to buy a Hearing Aid or to seek help or get the assistive listening devices or help they need and deserve to give them a better quality of life. Let's make Hearing Health a Priority in Australia.

This real life story is brought to you by Faye

Name: **David**

Age: **29**

Location: **Wollongong, NSW**

I was born profoundly deaf in both ears and had a cochlear implant in my left ear around the age of 2. I have been dependent on my single sided hearing all my life. The journey has not been easy but was eased tremendously with the help from my parents as well as pre-school services from the Shepherd Centre and Sydney Cochlear Implant Centre (SCIC) in my early pre-teen life.



I have been fortunate enough to 'get by', although I strongly believe that the services and support provided to the deaf and hard of hearing has to be improved. It is already a challenge for me and for those others in less fortunate situations to keep up with society where 'hearing' is an absolute must as a communication tool. There is an increase in financial burden for those who are born into this life when compared to hearing individuals where there is always an upkeep of costs. This includes buying hearing aids or seeking private health insurance for assistance with cochlear implant technology update, purchases of accessories such as a phone clip, or audio cable to connect directly to a mobile phone and/or media devices and more importantly the batteries required to continuously power the devices to keep us listening. This upkeep of costs is only added on top of everyday living expenses so this alone is an enormous challenge for all those who are deaf or hard of hearing.

While I have had some support in my early childhood via SCIC and Australian Hearing, I definitely felt there was a gap in this support when it was discontinued as I transition to adult ages with the realisation that this support would not be available until I am a senior citizen. How much of my personal life would I have missed out on? Especially the quality of it? These are not easy questions to ask myself.

I will always be grateful for the Cochlear Implant technology and how it has enabled me to connect with the rest of the world at a certain level. It is even more wonderful with the new accessories that allow direct audio that combats against background noise, wind blowing and other interferences as these allow a higher quality of living. But more importantly how it allows me to personally connect with family, friends and peers much more easily and at the same time has made it easier for them to communicate with me which at the end of the day is all we really want. Just how we can make this a lesser financial burden for those who have been unfortunate to be deaf or hard of hearing?

This real life story brought to you by David

Name: **Gabriel**

“The transition from primary to secondary schooling was always going to be a big step for everyone, not just children like me with a hearing loss. I had already been in to see the staff while I had been in primary schooling to talk about how the school worked and how I could best start the year off and build it from there.

At the end of Grade 6, I had mixed emotions. I was sad to leave my school that I had been at for 7 years, while I was optimistic about moving to Secondary School with the lockers, the set timetables, the numerous amounts of teachers whose names you had to remember. It was all thrilling. I was transitioning from a school with a hearing unit to a school that didn't have a hearing unit and had never had a profoundly deaf student enrolled before.

I was asked to go to my new school to do some final checks on my equipment (Soundfield, RF etc.). While I was there, I gave my dazed teachers reassurance that everything that they were doing was exactly right, and they gave me reassurance that they were committed to give me the best (and the same as everyone else) learning opportunities they could.

After two more weeks, D-Day had arrived. As I walked in to my form room, my form teacher, whom I had not met yet, came up to me and introduced herself and asked me a couple of questions about the RF. One thing I noticed about my class throughout the first few weeks, they just accepted my hearing impairment and almost immediately I made new friends which boosted my confidence, and so the rest of the day went ship shape.

The next day, which was my first full day, it was photo day and our first whole school assembly. When we went into the hall for assembly I was asked if I wanted the RF on. Having sat in assemblies previously I knew exactly what would happen and also the acoustics of the hall wouldn't help the RF, so I declined. The point of that last little bit is to demonstrate how willing some people are to help people who have disadvantages.

The first week went as smooth as you could ask for. On the Friday, we had swimming trials in the afternoon and the teachers and I agreed that I wouldn't wear my waterproof covers and I was introduced to one of the swimming teachers (of whom is also hearing impaired) who agreed with me that when the whistle blew the marshaller would wave his hand so I knew the whistle had blown. As the days went by, and the weeks started flying I started making heaps of new friends and as always my teachers are doing a fantastic job at the FM and I really do appreciate the fact that they want to learn as much as they can about my hearing impairment to find ways to assist me.

I would like to say to any parent of a hearing impaired child that making the transition from primary to secondary schooling isn't that difficult and that I have well and truly settled into my new school and at the time of writing preparing for the end of the semester with tests, music concerts and sporting competitions.”

Name: **Eva**

Age: **15**

Location: **Adelaide, SA**



16 year old Eva was feeling lonely, troubled and uncertain about her future.

Her mum Shamiran told us, “Eva was born three months premature and only weighed 800 grams. She had to stay in hospital for two months and when we were finally able to bring her home, they told us to check her hearing as she didn’t seem to be responding to noises. We discovered our little baby’s cochleas had never developed and she was profoundly deaf. Eva was the first deaf member of our family so it was all completely unknown to us.”

At eighteen months, Eva had cochlear implants fitted which helped to some extent with her hearing and speech development. Yet as Shamiran explained, “Eva would ask ‘Why do I have this – and not my sisters?’ She felt there was something wrong with her. Eva has lacked confidence for a long time but this year, it’s been really bad. Before, she would talk with her sisters and her cousins but recently, she stopped opening up with them as much. She has some deaf friends at school but often, she feels left out with hearing friends.”

Eva’s school counsellor suggested Eva might want a youth support worker who could really understand what she was experiencing. Eva met Nicollette from Deaf Children Australia and the two immediately connected. As Eva explains: “Nicollette is someone that I have never had before.

When I need someone to talk to, she understands me well. Nicollette supports me so I can talk about my ideas and my worries.”

Nicollette is deaf herself and shared with Eva how she also struggled to accept her deafness and how she was bullied at school at times. This has encouraged Eva to open up with Nicollette.

Eva said, “When I was in primary school, sometimes I didn’t really care so much about being deaf. But then sometimes, I was teased and bullied and I did care. Now, I care a lot – mainly because I worry about the future, work options, and friends. With deaf friends, it’s much easier. If I miss something, I can ask them to repeat themselves. With hearing friends, they say, ‘never mind’. That makes me feel left out.”

This real life story is brought to you by

Name: **Gabriella**

Location: **Perth, WA**

Age: **20s**



Gabriella Gray, or ‘Gaby’ as she is more affectionately known to family and friends, was just 18 months old when her parents first realised something was wrong with their baby daughter’s development as she did not talk, but mumbled consistently instead.

“I had been to many appointments with paediatricians and other medical professionals without any of them suspecting a hearing loss, particularly when they found out I had glue ear as it was assumed that this was the cause of me not being able to hear.”

“Mum was determined that it wasn’t just glue ear so we were told to get a hearing test to put her mind at ease. That’s when it was discovered that I was profoundly deaf.”

Gaby received hearing aids at 22 months of age. At age nine, she received a cochlear implant in her left ear which she now wears along with a hearing aid in her right ear.

Gaby then joined Telethon Speech & Hearing after migrating from South Africa with her family in 2003. Mainly a part of the school support (Outpost) program at Newman College, she attended school from pre-primary to year six and also had regular audiology appointments at the Telethon Speech & Hearing clinic.

Some of these incredible achievements include being awarded the Year 11 English ATAR award from her school, John XXIII College in Perth and graduating with an ATAR score of 96.4.

“I think a hearing impaired child that got the best score in English at a well-regarded school is one of mum and dad’s proudest achievement. All thanks to the tools gained at Telethon and the continued support from my school.”

But while Gaby admits that achieving a high ATAR score is “definitely a significant achievement”, she cites her prouder moments come from working with horses.

Now studying a Bachelor of Science at the University of Western Australia and working as a horse riding instructor, Gaby is just like many other ambitious youths today with hopes to find full-time work after university and travel.

“I hope to be in a job that doesn’t feel like work because I am so passionate at what I’m doing and truly enjoy it,” said Gaby. “Whether it’s with horses or something to do with what I’m studying now, I am not too sure just yet.”



Name: **Gail**

Age: **70**

Location: **Brisbane, QLD**

I am a self-funded 70 year old retiree and do not receive any government handouts. I do not even receive a Health Care Card. I am also a deaf person, who uses Auslan for everyday communication.

I am bitterly disappointed regarding the Government's stance on not allowing the NDIS for people over 65 years of age. I am at a loss to understand the reasoning behind it. Being over 65 and retired does not mean I have stopped living or contributing to the economy. I'm not sitting at home doing nothing and waiting to die as the government would like to think.

I am still active and contributing my share to the thriving economy of Australia. It is a slap in the face, frustrating and very discriminating feeling for disabled/deaf people not to be allowed to have equal access to the NDIS that is granted to the under 65s disabled/deaf population. Most of us disabled/ deaf people have worked all their lives for a very tiny paltry wage, yet were expected to contribute equally to society and pay equal taxes. But when it comes to their old age there is no reward or extra support for us in our retirement.

Aged Care/ACAT is not applicable to everyone as the Government no doubt is aware; nor does it provide Auslan packages or the same benefits of the NDIS for people that use Auslan. I for one am not eligible as I do not fit in to the category of a sick older person who is in a nursing home. Fortunately for me I enjoy good health. Most disabled/deaf people have struggled all their lives, and always treated like second class citizens. It's amazing that in this age of a wealthy country like Australia they are still being treated the same.

For a perfect example of how Disabled/Deaf people are treated today, you just need to look at the different funding models that the Government has for the Olympics. The "abled hearing athletes" get much more funding than the "Disabled Olympics". Deaf/disabled people are often isolated because of access/communication issues which are not always addressed by the State and Federal governments. We are real people that the Governments of today still simply choose to ignore.

I suggest if the Government is still determined to not allow NDIS for over 65s then they should consider perhaps the following. Deaf/disabled people to be paid a monthly living/access allowance along the lines of the UK model. But to be equal in monetary payment to the same level of NDIS rules. OR Deaf/disabled paid a special DSP to match the equality of NDIS regardless of income. I urge this current government to re think the NDIS policy in terms of allowing all people to receive the NDIS equality regardless of AGE.

This real life story brought to you by



Name: **Karli**

Location: **Melbourne, VIC**

I am profoundly Deaf and never felt the need to have a cochlear implant or receive “hearing health” support.

I have signing people around me, my husband is Deaf and my three beautiful children are hearing but signs fluently with me. I have friends, deaf and hearing who can sign fluently. I love my yoga and meditation and I love my counselling work with Deaf adults and children. Meditation helps me to feel good with my Deaf identity, deaf culture.

I feel sorry for those who think they need to “hear” with cochlear and have to struggle with many years of speech therapy lessons and experience “painful” days wearing cochlear. I have had many years of speech therapy and I still do not speak clearly. What a waste. I struggled learning to write English. I read widely and that helped me a lot.

Early Language input is so important. It is best to introduce all deaf and hard of hearing kids to Auslan as the foundation language then learn English, the bilingual way, and if they can hear a bit they can learn how to speak English. Deaf people who struggle to learn to hear to communicate with hearing people often feel they are missing out...until they found the Deaf community and feel included. Their Mental health is affected.

I went overseas to study MA in mental health counselling at Gallaudet University in mid 1990s because there were no universities here that suits my “Deaf” focused psychology work. I am still the only Deaf Counsellor practicing in Australia!! why?! I studied with Deaf therapists and Deaf Supervisors overseas. I had Deaf professors who taught me the course Mental Health Counselling. I want the same here for Deaf people. there is more to life than to hear ... I have a favourite quote :

Coming to our senses

“The role of the senses, such as sight and hearing, in providing information to the mind has far-reaching effects. They are the doors of perception and we are often their slaves. But can we not examine what is even more powerful in us than our senses? Can we not make them sharper and at our disposal? By regular inquiry into the role of the senses we can reduce mental distortions”. Sutra 1.35, *The Heart of Yoga – Developing A Personal Practice*, T.K.V. Desikachar

This quote strikes me as something perfect and complete. I think about the essence of yoga that really emanates within myself and in others. I see myself with my purusha (soul, the perfect complete soul) choosing to live in a not-so-perfect body. But with yoga, if you let the purusha, with its clear perception, radiate through you to your imperfect body, you only feel joy, peace and love. Then your purusha will invade your imperfect body and mind and it becomes a holistic perfect body. The differences, the problems, become smaller and disappear. The purusha expands and spreads throughout your body and onto others. Life is like that. Life has a lot of hurdles. Everyone has them. But if we have faith in our wonderful, perfect inner selves, we can overcome anything in life.

This real life story is brought to you by Karli

Name: **Georgia**

Location: **Melbourne VIC**



Georgia and Stacey pose together (image: Geelong Advertiser)

This summer, seven year old Georgia hopes to hear the crickets chirp in her garden again. It's one of those lovely aspects of warm evenings that some of us take for granted. But for Georgia and her mum Stacey, it was really special when Georgia heard them for the first time last summer. She sat up in bed and asked, "What's that noise?" It brought tears to Stacey's eyes.

Georgia was diagnosed with hearing loss in both ears at 11 weeks of age. As her mum Stacey explains, the nerves that connect the cochlear to the brain don't work properly. Georgia has frequent painful ear infections, bleeding and fluid build-up, leaving her with more severe hearing loss a lot of the time. She has had hearing aids since she was diagnosed but she didn't want to look different and didn't want to admit she is hard of hearing so she has so often thrown them away – even down toilets. She has also resorted to burying them in sandpits.

Stacey wrote to Deaf Children Australia. "My daughter is deaf and is starting to get really upset that she is 'different' as she calls it. I was wanting to show her she isn't alone and is always loved. I've tried to show her it's okay, teaching her that there are plenty of disabilities in life and some you can't even see. I explained people with a guide dog have them to help them see, as her hearing aids help her to hear. I'm just at a loss as to what else to do at the moment."

"When we have seen other people who are deaf, Georgia has got so excited. She asks me, 'Mum, when are you going to get hearing aids too?' I tell her I will need them when I am older. I would give up my hearing to help her, but unfortunately I can't do that."

Stacey did the next best thing she felt she could do. She recently had a hearing aid, a butterfly and Georgia's name tattooed behind her ear. She wrote on Facebook: "I simply got my tattoo last month because my little girl Georgia has been having a hard time accepting her hearing aids again. I've done so many things in the past to try and get her to love who she is and the fact that hearing devices are a part of who she is. Three years ago I started making her charms to wear on her hearing aids and that worked until recently. So I decided I would tattoo her first hearing aid behind my ear along with her name and a butterfly. She loved it, I picked her up from school and showed her with a

This real life story brought to you by

few onlookers and her eyes were filled with joy. It made my day knowing I've managed to make her feel a little less 'different'. I'm happy to have the photo shared if it brings a smile to at least one other child who is deaf or hard of hearing."

When we shared the Facebook post, it reached many thousands of people around the world and obviously brought smiles to so many children and adults.

Stacey told the Geelong Advertiser afterwards, "I can't understand some of the things Georgia goes through sometimes, she has some pretty tough days and I don't blame her." Georgia had been hiding her hearing aids more recently but since Stacey got her tattoo, she has heard Georgia introduce herself to other children in the playground by saying, "My ears don't work. I wear hearing aids and my mum has a hearing aid".

Children and young people who are deaf or hard of hearing may wear hearing aids or they may have cochlear implants – or they and their family may choose neither. For some young people, the technology doesn't help them or doesn't suit them. Whether they are aided or unaided, children and young people who are deaf or hard of hearing will experience the world differently. They need support to feel that is okay. They need support to accept their deafness and their deaf identity – to feel comfortable with who they are.

Georgia started receiving services through the National Disability Insurance Scheme (NDIS) in 2014. Stacey says she felt overwhelmed trying to work out the options but the case worker has been fantastic in facilitating supports for Georgia. The NDIS pays for a psychologist, occupational therapist and speech therapist and covers two hours of respite each week. The NDIS paid for a second FM unit and Stacey is hoping they will cover waterproof hearing aids as Georgia found swimming lessons too distressing without aids.

By providing a young deaf mentor and positive role model for Georgia, Deaf Children Australia can offer her the guidance and acceptance she needs from someone who has shared similar life experiences. We can help Georgia build resilience and confidence. We can introduce her to more children who are deaf and hard of hearing on our fun recreation programs and we can link Stacey up with more parents who have walked a similar path. We can support Georgia and Stacey to continue to develop their Auslan skills. Georgia has been learning some Auslan at school and Stacey would like Georgia to have more opportunities to learn Auslan and for both of them to learn more Auslan together. Deaf Children Australia can also assist Stacey with advocating for the educational support Georgia needs to have equal opportunities to learn.

Georgia has additional learning challenges and was diagnosed with Attention Deficit Hyperactivity Disorder (ADHD) earlier this year. She has some difficulty understanding emotions and is about to be assessed for Asperger's Syndrome. Stacey tells us Georgia is an absolute ball of energy. She loves to dance like Elsa in Frozen and sing along with her karaoke machine.

Name: **Glenn**

Location: **Canberra ACT**

It's a late September weekend and I am at home looking after my son Peter, 3 years old and his sister Emma aged 1, while my wife visits her sister.

Peter had a restless night sleep the night before and was quite unwell in the morning. An hour later I am in emergency at Westmead Children's Hospital not knowing if Peter will make it through the day.

After 2 very stressful days we were informed that Peter had pneumococcal meningitis....he was lucky to be alive. Peter spent 10 days in hospital. By the time he came home we knew that all was not well.....Peter couldn't hear. He was diagnosed as severe to profoundly deaf in both ears.

Our world fell apart. We watched our beautiful, bubbly, talkative little boy change. The questions that used to come at a thousand miles an hour from him, stopped. His frustration grew at not being able to communicate.

Then we were introduced to the idea of cochlear implants. Was this the light at the end of our very dark tunnel?

As it turns out, yes. The cochlear implant was a bright beacon for us and our gorgeous boy. Peter was implanted 3 months later and 2 weeks after his switch on we were having conversations again. And guess what? The questions started again!

The cochlear implant proved to be a miracle for Peter and us. Peter now attends a mainstream school and does extremely well (thankfully he has his mother's brains!) and does all the things an 11 year old boy does - including talking back!

Even though Peter does very well, there is always work to do. We are forever advocating for him and teaching him how best to manage his hearing loss.

We need the government to understand the effect hearing loss has on individuals and their families and friends, not to mention on society as a whole.

Please make Hearing Health and Wellbeing the next National Health Priority

Name: **Lyn**

Location: **Littlehampton, SA**

Age: **retired**



For 55 years I had perfect hearing. Virtually overnight, I lost 100% of it.

In the first 55 years of my life, I'd rarely thought about my hearing, or balance. I'd seen people 'doing' sign language, and had even learnt the alphabet letters of signing at school, but I'd never even met a deaf person.

At age 55 I became the victim of a 'mysterious' illness, with doctors only being able to diagnose 'probably a virus'. This illness was extremely sudden, severe and a few days later, caused me to lose all hearing over a matter of hours.

I'd spent my entire adult life as a teacher and school Principal and loved every day of that time. With no hearing whatsoever left, I was no longer able to continue my profession, so had to resign from my much loved calling. So virtually overnight, I lost all hearing and much of my balance.

More crucially, I'd lost most of my ability to communicate with others, understand what they were saying to me and to those around me. I was unable to access huge amounts of information, particularly the day to day 'chit chat' that had kept me up to date with what was happening around me, and I had my options for entertainment severely limited. It was a dramatic and traumatic change of direction in my life, because I could no longer hear.

I was fortunate that, about that time, technology was beginning to open up some options. Emails and modified telephones helped greatly, as did the very slowly increasing amount of TV and cinema captioning.

Certainly, I have been able to find various ways to help circumvent my lack of hearing, but the sudden loss of it, certainly changed my life dramatically. Unfortunately, people like me, who've not grown up deaf or have been part of a Deaf community, find themselves almost totally isolated in terms of communication with the only real option being anything visual - mainly print, and attempts to read lips.

Unfortunately, deafness is an invisible disability - no, let's be realistic and call it a handicap, because it is, especially when it comes suddenly after 55 years!

In my case, a cochlear implant was not successful as my auditory nerves were destroyed. Services and options available to the Deaf community, whose first language is Auslan, are not realistic for the late deaf, who have very little access to captioning or other appropriate services.

The wider community has no comprehension whatsoever, of what total silence is like, and one can only wish that some of our politicians would accept the challenge to go without hearing just for one day (though they would be also missing out on the distressing and ever present curse of Tinnitus that some of us experience as well.)

So, let's spread the word to Break the Sound Barrier any way we can and that Hearing Health is a HUGE issue right across the community, and especially for those of us who do not, and can not, hear.

This real life story is brought to you by Lyn

Name: **Jennie**

Location: **Sydney, NSW**

I know that 1 in 6 Australians has a hearing impairment but after the age of 50, 1 in 4 Australians is SEVERELY or profoundly hearing impaired. And I am one of them.

As a teenager, I recall a night when I had girl friends to sleep over and one of them said your mother is calling. I wondered why she could hear this and not me. I mentioned this to my parents who in due course arranged for a hearing test.

It turned out that I had a moderate hearing loss. This was a big surprise because there were no relatives with hearing loss. And I needed a hearing aid. I managed to 'lose' that hearing aid...and the next one. (hearing aids were not cool).

At the age of 25 I was offered my first real job as lecturer in nutrition at the University of Sydney. I was over the moon but I knew I'd need a hearing aid if I were to hear students' questions. But the ENT specialist who I consulted told me that I should not have accepted the job. A little seed of doubt was planted that I was not good enough.

And slowly but surely, over the course of the two decades, I lost the hearing in both ears.

The decline in hearing was an emotionally painful process. I was embarrassed when I couldn't answer questions that were put to me. I dreaded being considered stupid in a world of intellectuals at the university. I learned to avoid difficult hearing situations. Any gathering of people, any meeting, any noisy environment, was stressful.

The telephone became a source of great torment. People's names escaped me and transcribing numbers, addresses and dates became impossible. I gradually lost the ability to enjoy television and movies. Public address announcements etc made travel difficult...I went to the wrong gate, I missed flights.

A little over 10 years ago, I was ready to resign and it felt like resigning from life. But a little miracle occurred and my life did a complete 'about face'. I was given something extremely precious...a gift that was unheard for any other previous generation... the gift of hearing...a cochlear implant or bionic ear...something only possible because of the recent achievements of another Australian - Professor Graeme Clark. It was 1998, almost 20 years ago, that I was given my first cochlear implant. It felt like *jump leads* to a car with a flat battery. Suddenly I had more confidence, more energy, more self-esteem and I was so proud of the cochlear implant and the fact that it was Australian technology.

Instead of being humiliated by my hearing loss, I was suddenly proud of it and I what I could do. I wanted to tell everybody about my bionic ear. And I did. So here I am now telling you.

Some of you may be aware that I have championed a new approach to nutrition and the management of blood sugar levels. The method is based on how foods are digested and absorbed into the blood stream rather than simply their nutrient composition. It's called the *glycemic index* or GI and the concept has led to better health outcomes for people with high blood sugar, especially people with diabetes.

This real life story brought to you by Jennie

Name: **Jess**

Age: **31**

Location: **Brisbane, QLD**

One day, you are likely to know what it's like not to hear. Even if only to some small degree. In one sense, you will join this club.

I'm 31, have green eyes, a warm (if serious and intense) personality. I am described as an achiever and learner. I hold a Bachelor's degree and have been working as a professional in the public sector for the last 10 years.

Since birth, I have severe-profound bilateral sensorineural hearing impairment. Fitted with my first pair of hearing aids before I was one, I started my education before I was two – learning both to speak and develop my balance at the Yeerongpilly Centre for Young Deaf Children.

I now communicate by lip-reading (aided by hearing aids) while speaking fluent English (perhaps a little fast!).

My integration into “mainstream” schooling is a consequence of the relentlessness, forthright effort (and sacrifice) by my parents. Mum and Dad worked hard to find and harness the right forms of tools and support that worked for me, my family, my teachers and my friends. Assistive technologies, speech therapy, awareness and education of hearing impairment ... not exactly the “usual” set of tools for school students.

Hats off to Australian Hearing and to the Queensland Department of Education's Advisory Visiting Teachers for Hearing Impaired Students. They provided vital help during this journey.

My tertiary education was supported with real-time captioning (converting speech to text) and peer note-taking services. Both were offered by the University of Queensland's Support Services team—to who I continue to be grateful.

My success is thanks to everyone who played their part in my journey. In equal measure, my success is also a direct result of my focus and sheer determination. I was fortunate, and consider myself lucky. But I still struggle with some everyday tasks, despite my success and integration into the ‘mainstream’. Following and engaging in meaningful conversations through to ordinary social banter with others—a fundamental component of being a connected human being—requires immense concentration and effort. This has flow on implications to expanding my vocabulary, which we naturally do by hearing new words.

Work is a particularly difficult environment; people of different values, interests and levels of understanding can be pulled together, required to work together when people just do not know how to adjust.

Is it curious that – during the largest portion of my life where my contribution to society and the economy is most valuable (i.e. being employed and spending) – the ability to source and harness services and support is generally left to the individual? It is the person who needs the help most that has to work hardest to navigate the myriad and layering of systems?

Is clear communication—to compliment speech and sounds with visual aids—too much to ask for?

This real life story is brought to you by Jess



Messages to our elected leaders

Hearing loss isn't a choice. Ironically, it is not something that can be switched on or off. Hearing loss is also not a 'one-size-fits-all' situation.

Do you recognise the stories of your grandparents, parents, siblings, children, spouses, partners, friends?

Hearing health and wellbeing matters for everyone. More must be done to realise the success of every individual, to *Break the Sound Barrier*.

Act now to stop your own future frustration, misunderstanding and social isolation.

Respect the courage of individuals with hearing loss who share their personal stories.

Recognise our call as we each to implore you to act.

And... thank you for listening.

This real life story is brought to you by Jess

Name: **John**

Location: **Sydney, NSW**



I was born profoundly deaf, diagnosed at 1, had hearing aids until 10 when I received a cochlear implant in my left ear.

I went to primary and high schools both here and overseas. I graduated from high school with an UAI (ATAR) in the 90s. I've graduated from university with a double degree of social science and law.

I've become a professional tennis coach with my own business, coaching people of all ages. I've travelled the world representing Australia in international deaf tennis. I've got a wife and a baby girl.

If I walked past you on the street, if I was served by you in a restaurant or a shop, chances are you'd have no idea I was deaf until I told you. I didn't consider myself as deaf because I didn't sign. I was deaf by biology, not culturally or identity-wise. I didn't want to know or meet any other deaf teenagers when I was growing up because their world wasn't the same as mine. I come from a hearing family, I have a hearing wife and daughter, I have many hearing friends, I went to a normal mainstream school, I did well academically and was active in sport.

Unless you have a family member or close friend with a hearing loss, you'd have no inkling of what it has taken for me to get to this point in life. I've worked so hard for so long to fit in but at what cost?

How much work I put in with my speech therapists for years, how many appointments I went to, how many times I was pulled out of class to do extra audio verbal therapy work when all I wanted to do was be part of the class and be with my friends,

How much work my mother put in to make sure I got the environment I needed at home and at school, chasing up teachers and administrators, when she had two other children to look after and a career of her own to build,

How much work it was to hang out with my hearing friends, to try understand group discussions with multiple speakers when I can only lipread one person at a time, to be consciously aware of how socially underdeveloped I was and constantly be in danger of being shunted out to the periphery of school friendships,

How much work it took my siblings to make sure I was always included, how many times they heard snide comments about me from bystanders behind my back, when they should have just been enjoying their time out with their own friends instead of worrying about me, how many times I kept asking them to explain what was being said in conversations, movies, tv shows when they could have been enjoying it.

How much work it still takes for me now as an adult member of society to make my way in life, how many times I have to ignore phone calls because I can't hear well on the phone and then ring them back through the National Relay Service, how many times I have to say "Excuse me" when someone is talking and I can't read their lips clearly, how many times I worry about meeting strangers and not be able to understand them.

In spite of it all, I am one of the lucky ones. I came from a well-off middle class family who were totally supportive of me, I had a mother who was an exceptional advocate, I had access to top speech

This real life story is brought to you by John

therapists and audiologists all over the world, I went to schools where teachers and principals were accommodating and helpful. Many others have not been so lucky.

Then again, how were you supposed to know all this? No-one told you. It's not your fault. I don't blame you. But with this national campaign to make Hearing Health and Wellbeing a priority, I hope you do now.

Name: **Kathy**

Location: **Perth, WA**

When my daughter was born they did a hearing test in hospital. We had this before with our 2 other sons and no problems. So when the lady said she passed with flying colours I thought great. Over the next year things weren't quite right.

She didn't seem to startle at loud noises or respond to her name. So when she was 1 we had her privately tested. The poor audiologist looked at me a bit miffed and upset. She can't hear anything she said.

We were quickly referred onto Australian Hearing, and they told me our daughter was profoundly deaf. I had no idea what profoundly deaf meant and assumed it was something an operation would fix or even hearing aids. So I remained cheery.

The day came to get her hearing aids. I was so happy, our girl would finally hear us. Anyway after some testing, they decided she wasn't going to hear speech through aids and the cochlear implant was our other option. I burst into tears that day. I just wanted her to hear my voice.

Flash forward to not long before her second birthday.

Our princess got her first cochlear and could finally hear us, hear music, hear laughter and hear everyone. We sadly had to wait a year for the second ear to be done as we didn't have private and the government only funded one cochlear per person here in WA. So after serving our year wait for private, Ella got her second ear done.

She is 8 now and hears well, she's even been known to flip her cochlears off if I'm nagging her or telling her off, cheeky girl. Cochlear implants changed our lives. More funding and research towards hearing services is so important.

This real life story is brought to you by John and Kathy

Name: **Jordanna**

Location: **Sutherland, NSW**

Being diagnosed as profoundly deaf at a year old, my parents then immediately placed me at a specialised preschool for the deaf and hard of hearing. From there, I had many opportunities provided for me, I was provided with access to sign language, speech, and even cued speech. My parents worked tirelessly to ensure I had no barriers and had access to communication at all times.

Today, because of my parent's efforts and those around me, I have grown up to identify myself as a proud Deaf woman and would not wish myself to be able to hear - you know the saying, you do not miss what you have never had, and in my case, it would be sounds. I communicate in what I am most comfortable with and that is sign language.

When my daughter, Callie, was born, at the hospital the nurse did the newborn hearing screening test (SWISH), and I could see the expression on the nurse's face that she had failed the test. It seemed like the nurse was afraid to give us the bad news, but my partner and I just laughed and said that we were deaf and that it didn't matter if our daughter was deaf. As a matter of fact, I thought this was a bonus for us, our daughter is just like us! My partner and I were ready for this. I actually predicted that Callie was deaf while pregnant with her, basically because she did not move when I made loud noises in the house.

Right after Callie was diagnosed deaf, I had to make the most difficult decision of my life, deciding if I wanted to give my daughter cochlear implants or not. As a proud Deaf woman, I would not get a cochlear implant because I do not want one, I do not even wear hearing aids. So call me a hypocrite but why would I give my daughter a cochlear implant when I won't get one myself? I struggled with making this decision for a while.

Eventually, my partner and I decided that we wanted to give Callie all the options available for her, including going ahead with the surgery for cochlear implants. I told the cochlear implant Doctor first thing, "just because my daughter will get cochlear implants, does not mean she will be excluded from sign language, she will still receive access to sign language." I did not want Callie to grow up and tell me that I was so selfish because of my proud Deaf identity that I denied her the opportunity to be able to hear. Eventually when Callie grows up, she can make her own decision and continue to wear her cochlear implants or not.

The pretty awesome part is when she hears an airplane and looks up and then signs airplane - that is access to all modes of communication and I knew right there I had made the right decision even though this may be controversial, but no regrets.

I'm still proud to be Deaf, and I am extremely proud to be my daughter's mother. I chose white cochlear implants because they stand out and I wanted the world to see that I'm proud that my daughter is Deaf as well as to teach her to be proud of herself.



This real life story is brought to you by Jordanna

Name: **Judi**

Location: **Geelong, VIC**

In 1970 at the age of 17 and in the first year of my nursing training, I developed tinnitus which turned out to be the beginning of a progressive sensory neural hearing loss. At the same time my mother was battling breast cancer which had spread to her bones, lungs and brain, my problem seemed insignificant in the face of her battle. I decided then that I would not let hearing loss interfere with my life nor let it define me as a person.

Sadly my mother died several years later and my increasing hearing loss began to cause real difficulties for me personally and professionally. I was fortunate to have a number of doctors and senior nurses who supported me and offered guidance. They encouraged me to continue with my nursing career. A hearing impaired patient who was a lawyer noticed that I did not hear well and he insisted that I try hearing aids. He explained how hearing aids helped him when he was almost ready to give up his law practice. So in 1975 I trialled and subsequently purchased my first set of hearing aids.

I cannot express how wonderful it was to once again hear the birds in our garden, to hear speech more easily and to enjoy music again. Hearing loss can occur insidiously and we are not always aware of how much we are missing. My hearing aids were my lifeline, if they failed I felt panic stricken. The cost of replacing them was a constant worry as by then I had young children to support and a home to pay off. I felt compelled to work so I could contribute financially to our family but also so I could afford new hearing aids when necessary, for without them I couldn't work.

During this time I received invaluable support from the Victorian Deaf Society and as a volunteer, I ran a self help group for young women with hearing loss in our town and also educated nurses and doctors about hearing loss and how to communicate well with their hearing impaired patients. I was fortunate to be given many wonderful opportunities during my nursing career but I always felt I needed to work twice as hard as anyone else to prove myself and to demonstrate that I could manage as well as or better than a hearing person.

Managing in a hearing world was often very stressful and tiring especially as I was given more senior roles and added responsibilities. Even though I relished the challenges and enjoyed the work it came at a cost. I was able to make difference in the lives of many patients, able to improve outcomes in our health system and develop new programs such as Hospital in the Home, but the satisfaction of doing so came at a personal cost. I was often very stressed and very tired.

If we are indeed to "Break the Sound Barrier" then hearing aids and rehabilitation for hearing impaired people need to be funded and accessible. Having to pay \$8000 to \$10000 for hearing aids so that you can continue to work is unaffordable for many people. The current government program which covers children and adults who qualify for Centrelink needs to be extended to include all people with hearing impairment. It has always irked me that those who are assessed as legally blind qualify for Centrelink support no matter what their income or assets yet the hearing impaired are denied this support unless they are unemployed or qualify for the age Pension. While I do not

begrudge those with low vision receiving that support I cannot understand why those with hearing impairment are not afforded the same level of care. It really seems discriminatory to me.

My hearing loss is now profound, yet with the help of Australian Hearing and the support of the government program I feel fortunate that I can manage fairly well with hearing aids and devices. I have hearing aids and a mini tech Bluetooth system which is wonderful for the TV and mobile phone.

It is like having my hearing restored, so good to enjoy TV programs and talking on the phone after years of struggle and stress to the point that I no longer wanted to watch TV or communicate by phone. Hearing in noise is still difficult but I can put up with that knowing I can enjoy TV, music and one on one conversation.

Eventually I will probably be forced to embrace the idea of a cochlear implant, or maybe two, but I am reluctant for a number of reasons. I figure the longer I can put it off the better the technology will be! Meanwhile I am grateful every day for the hearing aids and devices I have and for the care and attention given to me by Australian Hearing Geelong. Over the years I have been fortunate to meet so many caring professionals, their expertise made a huge difference when I was really struggling.

I hope in the future, programs can be developed to ensure all those struggling with hearing loss are able to more easily access professional help and devices, without a huge price tag. I was fortunate to have a supportive husband and a well paid job but others are not so lucky, therefore they often endure a life of isolation and loneliness as communication is so difficult and stressful for them and aids and devices that could set them free and open up the world to them are unaffordable.

Hearing Health and Wellbeing should be and must be the next National Health Priority in Australia.

Name: **Michael**

My hearing impairment is complicated by a mild form of Meniere's disease, and a major challenge is the rapid changing in hearing levels due to varying pressure in my head and ears.

In small groups or in meetings, or talking in a crowded room, what starts as a clear conversation may rapidly become like hearing a foreign language.

The sight of my hearing aids sometimes signals to those talking that additional clarity would be helpful, but it is not always a simple matter to signal that I have lost the drift. An accent will often complicate matters further.

If Australia was given the awareness to understand, then I believe my life and that of millions would be easier.



Name: **Julian**

Location: **Brisbane, QLD**

Julian was an unusual case as hearing impaired children go. It is thought that he experienced a late onset profound bilateral loss at around the age of three. He was a very clever and adept little kid, because he managed to keep his loss a secret from teachers, parents and himself until he was properly diagnosed at nine years.

While initially this felt like a big shock, he took to the news pretty well. During primary school years when the feelings of isolation were riding high, Julian sought refuge in books. Asking peers to repeat themselves can be awkward and tiresome, but the characters on the pages were always happy to oblige. At the time Julian felt that he was destined to remain a socially introvert. How wrong he was! Most of his friends today would describe him as charismatic, exuberant and successful individual who takes to every challenge with unfaltering enthusiasm.

High school is difficult for all teenagers, and for Julian, it was more difficult than for most. He buried himself deep in his studies and emerged 5 years later with one of the top final marks for his graduating year. Despite this academic achievement, at the time he still felt that his future employment prospects were dim.

Julian enrolled in engineering and had a fantastic and tumultuous time at university. When asked why it took him an extra 3 years to finish he will tell you: "that life kept getting in the way!" Before he graduated, he became a dad and a husband! His wife Roxanne has known Julian since the first day of high school, where they bonded over a love of...books!

In February 2012, Julian and his wife, Roxanne, made the decision to sell ALL their belongings, quit their jobs and set off to the tropical Philippines in search of an adventure. They purchased a tiny provincial rice plantation, established a homestead and learnt to live off the land with plenty of help from their neighbours. When the farm adventure wound to an end, they bought a motorbike and spent four months travelling over 3000kms to see all the sights that the Philippines had to offer. Looking back, Julian and Roxanne agree that the whole experience was definitely the craziest thing they have ever done!

Their son Myles is now 5 years old and they still have a fantastic time exploring the world together. Myles is well aware of his dad's hearing impairment, stopping to help dad lipread and vigorously shaking him in the mornings when it's time to wake up!

Julian has reconnected with the deaf community for the first time since he left high school. This has led to a period of self discovery and redefinition of what his hearing impairment means to him. Julian had, until recently, defined his success by his ability to 'fool' people about his impairment and carry on as if he had no disability at all. Now he carries a confident attitude, is happily transparent about his impairment and has a strong voice for self advocacy when needed. Without the help and camaraderie of the deaf community, Julian feels that he would still be quite challenged and frustrated when navigating the hearing world. He has never forgotten how uncertain the future had looked as a young hearing impaired teenager. With the Hear for You program, Julian endeavours to be the role model that he wishes he had.

This real life story brought to you by

Name: **Kate D-Q**

Location: **Melbourne, VIC**

Age: **20s**

I was born with a mild to moderate hearing loss, which is closer to a moderate loss these days. I was diagnosed when I was 3, yet it wasn't until I was 10 and given my first pair of hearing aids, that I really realised I had a "problem". I hated the idea that I had a "disability" and I simply denied it. I was coping fine at school, my marks were good, I had great friends, so I really didn't see the need to address this "problem" of mine.



I got through High School and University, talking very little about it, and rarely wearing the 4 pairs of hearing aids I was given over those 10 years. Rejecting my deafness and refusing to wear my hearing aids, is not something I am particularly proud of, but I have been trying to come to an understanding as to why I bottled it up and denied it for so long.

I had always considered myself to be a confident young person, comfortable in my own skin and without insecurities. That is until I realised there was this part of myself that I had been ignoring. Whenever I happened to tell someone "Oh I have a hearing problem.. Umm yeah actually I have hearing aids.. Oh but no I don't really wear them..." I would tense up, my voice would shake, I would go red. It was clearly a huge insecurity of mine. Yet I would brush it off, forget about it, move on.

It wasn't until a couple of years ago after I finished uni and began my career as a freelance photographer, that I realised that my hearing problem was affecting my professional life. If I didn't hear things in a social situation, it might have been slightly awkward or someone might think I'm rude, however in the professional world, I realized it could mean losing a job or missing out on future opportunities. Despite that I was becoming more aware of my hearing loss, it certainly wasn't a priority to deal with, I still didn't wear my hearing aids, it wasn't even an option for me. The thought of a client seeing them on me made me squirm with embarrassment, as though they would somehow think I was less capable, and I'll admit it, less "cool".

It wasn't until a bit over a year that all this changed. I was reading an article in a magazine and it was about a 27 year old woman who was deaf. She mentioned the awkwardness of missing punchlines, the embarrassment of being a teenager and telling boys she couldn't hear, and the satisfaction of watching a DVD with subtitles. She then went on to explain that visual imagery has always been a huge part of her life, and that it seemed to natural for her to pursue her passion as a photographer. I read it and I cried. I felt like I was reading about myself and for the first time in my life I felt an incredible sense of comfort that these insecurities I had were not something to be ashamed of and that ultimately I wasn't alone. For the first time in my life I actually realised that having a hearing loss WAS a part of who I am, part of my identity and that I should be accepting, if not proud about it. I suddenly had this urge to talk to people about, to share this part of myself that I had now realised was actually kind of fascinating.

This real life story is brought to you by Kate

For 26 years I had bottled up my experience as a hearing impaired, “partially deaf” person and suddenly thoughts and memories poured out that I didn’t even know existed. I began to think about my childhood, how I was apparently calm and quiet, yet I would dress myself in ridiculously colourful (always colour co-ordinated) outfits. I thought about how I felt when I first got my hearing aids and when I had to see a “special needs” teacher- that memory is particularly painful as it was when I got the idea in my head that I would never be as smart as my friends because I couldn’t hear everything. Despite the fact that I excelled at school, and got higher marks than a lot of my peers, I’m ashamed to admit I could never quite shake that thought, that I was never smart enough, and that my intellect was tied to my hearing loss.

But I’ve also thought about how my deafness has had a positive impact on my life. I am a patient, observant, resilient and reflective person and I like to think my hearing loss has contributed to that. I have been told that I am a good listener (ironic I know) because I give people my full attention and always look at them when they speak- a quality I strongly admire in others. And of course to have the skill of lipreading and sleeping through thunderstorms are two things I wouldn’t want to live without.

After I started to process these thoughts and memories I became excited to share them with people. I took photos of my hearing aids and I “came out” about my hearing loss. While this was in some way a liberating experience, above all else, I wanted to make others feel the way I now did. And so the idea for my ‘Right Hear, Right Now’ project was formed- a photography based project which tells the stories and experiences of deafness. From Deaf and hard-of-hearing children, teens and adults, to parents of Deaf children and children of Deaf adults.

‘Right Hear, Right Now’ is about empowering people to accept and embrace their differences, to raise awareness and to ultimately transform negative perspectives into ones of inspiration and understanding. Essentially I want to create something that I would have liked to have seen when I was 10, 16, 21 and 26. A project which could have inspired me to accept my hearing loss long before I actually did.

Over the past year I have met and talked to many people who have experienced deafness in some way or another. I have met adults, young and old, teenagers, children, parents and relatives. People with hearing aids, with cochlear implants, those who sign, and those who are bilingual. But I have also met those who choose not to wear hearing aids, not to get a cochlear implant, not to sign or not to speak. I have come to learn that there are so many experiences of deafness, so many different perspectives, attitudes and even debates. There is no right or wrong way, it is simply important just to know that there are many ways.

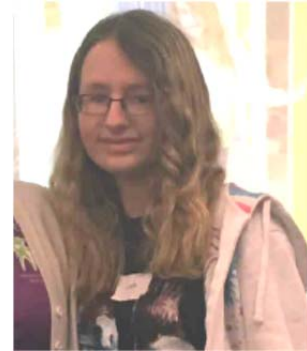
Despite all the differences, the most beautiful part of this project has been connecting with every single person I’ve spoken to. Even though there are many things I cannot relate to and I cannot entirely understand; and the fact that sometimes I feel that I’m perhaps not quite deaf enough, there is still always a common ground. Not only has my world opened up and I have learnt far more than I had ever anticipated, but I have also been able to provide others with that same comfort that I experienced when reading that first article. And to me, that’s really the core of this project. To educate people on what it means to be capital “D” Deaf, deaf, Hard-of-Hearing, hearing impaired or to have a hearing loss, and to provide people with a community where they know there is someone who understands.

This real life story is brought to you by Kate

Name: **Lara**

Age: **14**

Location: **Indooroopilly QLD**



I attend Indooroopilly State High School in Grade 9 in sunny Queensland.

I went deaf when I was eight years of age due to the CMV virus. This was a virus that I actually caught from my Mum when she was pregnant with me. This wasn't picked up until after I went deaf and they did some tests, including an MRI and looking at blood samples taken from when I was a baby (the heel prick tests that all new borns have). I don't recall too much about what my life was like prior to going deaf. I went deaf quite suddenly - my parents noticed a difference over a 2 week period. I was diagnosed as profoundly deaf in one ear and severely deaf in the other. This was just before Christmas and it was a few weeks before I could get fitted with a hearing aid in my severely deaf ear which still had some remaining hearing. My parents remember communicating with me via note writing over the Christmas period. They don't remember this as being a fun time. At least I could read and write with no worries.

On the 20th April the following year (it's an easy date to remember as it's a day after my Dads birthday), I went into hospital and was fitted with a Cochlear Implant. I'm really proud that this is an Australian invention and my parents would love to meet Professor Graeme Clarke one day and shake his hand. He is the next door neighbour of a friend of my grandparents so they may well do that one day!! I learnt how to hear again with my Cochlear Implant with the help of the Hear and Say Centre here in Brisbane. Their support was fantastic and they were surprised that I learnt so quickly. After 3 months I finished my therapy but I still attend the Hear and Say centre at least every 6 months for mappings and an annual review. For a long time I said to my Mum that I had a didgeridoo playing in my ear, but eventually that sound just went away.

My parents have asked me if I want an implant in my second ear as I actually hear better with my implanted ear, but I still like the fact that I can still hear a tiny little bit with one ear with no implants or hearing aids in, so I'll hang out for as long as I can. I get a little bit frustrated about being deaf sometimes as sometimes I'm not sure if I'm actually hearing the correct sounds. I love listening to music on my tablet.

We can choose electives in year 9 and not surprisingly 2 of my favourite subjects are my electives. I enjoy English, Art (called Visual Media Technology) and ITD (Industrial Technology and Design). Indooroopilly State High School is a great high school for someone like me since as well as lots of international students there are AUSLAN students as well. In classes where we have AUSLAN students there is a speaking teacher as well as a signing teacher, as well as a note taker, so for all my core subjects I am in classes with other AUSLAN kids and so we have lots of extra support. I know a little bit of AUSLAN now but have never really had to use it.

I have attended the Hear For You program each year for the last 3 years and it's great mixing with kids and Mentors with a similar hearing loss to mine. I really enjoy all the activities that we do and I appreciate the advice we get from the mentors about preparing for the future.

This real life story brought to you by



Name: **Leisa**

Age: **mid-40s**

It began when my twin boys were 6 months of age. I was at the point with a parent passing the year before starting IVF. Elderly parents-in-law, and no relationship with my sister due to a long history with her that caused me to not have her in my life. My father was too full of his own health issues and I never really had the support as a multiple birth Mother. The Benevolent Society was not helpful in the way I needed and I was stressed in all ways.

I started to have Tinnitus when my son was 6 months and it got so that I suffered severe depression and I would rely on the TV to assist my crying morning and night. I found out I had Scoliosis at 22 and during a pregnancy expo I saw someone there who said basically I was going to have a lot of issues as I got older. I got so depressed from the tinnitus and all that I was going through, but the Tinnitus was the worst.

By the time I had reached 39 I was diagnosed with Meniere's Disease with Migraine and my hearing was 1/4 to 1/3rd in my left ear. So now I face getting hearing aids at 43.

I am so sick of struggling to hear people behind me in the plaza eatery, or watching TV with other's talking and I can't hear the person speaking to me. Little sounds that my husband can hear from the other part of our house. In a small room while everyone is speaking and someone is speaking to me at a hushed tone. Hearing in general is no joy for me because I am always asking to have people repeat themselves. Or too embarrassed to say I can't hear them, could they speak up and admit I can't hear.

I have to pay for a hearing aid or two and when there is only one income with 2 Autistic son's, I can't do much but feed, clothe and send them to school.

So hearing aids that would be tax deductible would be a God Send.

Name: **Kate**

Location: **Sydney, NSW**

My hearing loss was first discovered during a routine primary school hearing test. My parents were shocked to discover I had a mild to moderate loss. I was 11. I was fitted with hearing aids through Australian Hearing but received no emotional counselling, so I didn't wear them.

I struggled through school and university, finally wearing them from the age of 18 years. My hearing dropped to profound levels, and I found I couldn't live without my hearing aids.

When Australian Hearing support stopped at age 21, I considered suicide because I didn't know how I would pay to be able to hear. Hearing aids cost \$4,500 each, and batteries were an ongoing costs, about \$1 per day. Eventually I took out a loan and paid them off over a year. The only reason I could do that was because an elderly Aunt passed away and left me money specifically for my hearing.

After a few years I got a cochlear implant, and it changed my life. They were fully covered by Medicare, but hearing aids are not. I hear better now, and I am not in financial strife, I'm a working professional, and I have a young family. I would never wish my hearing experience on anyone, so this is why I work so hard with the Deafness Forum and other groups to try to change the situation.

I want to Break the Sound Barrier for everyone.



This real life story is brought to you by Kate

Name: **Liz**

Age: **21**



I was born with a collapsed eardrum in my left ear. When I was 8, I was provided with my first hearing aid.

I was so excited to receive this magical little device that helped me hear things I didn't even know I had been missing (I was especially excited because I got to pick a purple one!).

When I brought my new toy to school, however, the excitement soon turned to embarrassment. All the other kids kept pointing and telling me I had something stuck in my ear. I no longer felt special, I felt like a freak.

All through primary school and high school I refused all the services offered to me. I refused to wear my hearing aid. I refused special provisions in tests. I refused to be part of social events for hearing impaired kids. I even refused to sit up the front of classes. I suffered for it. I missed a lot.

Now that I am 21 I have begun to wear two hearing aids out of necessity.

Even with my hearing aids, I miss a lot of things. Going out with a large group of friends to a restaurant or a bar is something any young person would love to do. I hate it. I sit there, surrounded by people I love, and I feel so isolated. I cannot hear them. I cannot be part of their conversation. I cannot communicate.

At work recently, a lady jokingly yelled into my face that I should 'turn up my hearing aids' when I couldn't understand her. I've never seen anyone tell a blind person to adjust their guides! She wasn't trying to be malicious. It was an awkward situation....it IS rather awkward when you're trying to communicate with someone who doesn't understand you. Her reaction was to lighten the situation by telling a joke. I didn't find it funny.

There are also jobs that I am too scared to apply for, even though I am perfectly capable of doing them, and doing them well. Who is going to hire a waiter who has trouble hearing the orders? Who is going to hire a receptionist who can't hear the phones?

I am at a disadvantage to a lot of my peers because I was born with an abnormality. I have fears and social anxieties that many of them do not have to deal with. The services available for young hard of hearing people such as myself are scarce. There are some services for the Deaf, and I was provided with hearing aids, but I honestly don't think this is enough. I feel like I am not deaf enough to be given any additional support. I think people assume because I am 'just' hard of hearing, I don't need any extra support. I don't think that is fair.

I have so much I can contribute to this world. My hearing impairment won't stop me. But the barrier created by lack of support services and public understanding, is definitely slowing me down.

This real life story is brought to you by Liz

Name: **Louise**

Location: **Sydney, NSW**

Audiology should be a registered profession in Australia.

I am an audiologist with more than 30 years of experience across academic, research, clinical and management aspects of audiology.

I received a letter from a colleague some years ago. The letter was written by someone who had been working in the hearing device industry. He said he would soon be setting up a new chain of clinics, but that the money to buy the clinics was not going to come from the hearing device manufacturer. That letter, sent to many audiologists, made my colleagues and I a little uncomfortable. If this was all above board, why send a letter? As it turned out, the money to buy clinics came from a parent company that now owns a clinic chain and several hearing device manufacturing companies.

Audiology practices that were previously independently owned have been bought by companies with links to manufacturer or clinic chains owned by medical specialists. Some audiologists, frightened that small practices would not be able to compete with large multinational companies that had the backing of device manufacturers or referring doctors, sold their practices. Some of those audiologists now work in those practices, under management of those with no clinical training. Companies with vast financial resources have bought out their competition. Vertical and horizontal integration is now a common practice model. Hearing clinics have popped up in every city suburb and in many towns. Where one clinic opens, another opens in competition.

I was employed in a university, as a professional responsible for a teaching clinic. The university decided that the clinic needed to become profitable. I tried to explain that high profits in audiology come about through very high hearing aid prices, through minimising contact time with patients, through meeting targets to fit top of the range expensive devices – none of which have any place in any audiology clinic, but least of all in a teaching. My position as a manager with professional qualifications was replaced with that of a business manager with no audiology qualifications. The audiologists in that university clinic now answer to a business manager, with no clinical training.

I subsequently worked for a group of clinics that was owned by Ear Nose and Throat specialists. As investors in the company, they benefitted from any profit that the company made. It turned out that most profits came from hearing aid sales. That company had an agreement with one hearing device company to provide them with hearing aids at a discounted price. Hearing aids fitted from that company were thus more profitable for the company and their medical specialist shareholders. I believe clinical advice should be independent, based on need and the best available option. I was presented with a complaint that I was not fitting hearing aids as per the company's preferred agreement. I left that position after just a few months.

Society expects healthcare advice to be independent, for business arrangements to be secondary to clinical practice, and for industry not to unduly influence professional advice. The Office of Hearing Services contract serves as a business licence to sell hearing aids to pensioners. Other aspects of audiology are self-regulated which, as admitted to by the professional bodies, does not extend to business arrangements.

This real life story is brought to you by



What happens in audiology is inconceivable in other healthcare fields. If your general practitioner offered you enticements or had a target to prescribe a certain drug – you would not trust that doctor. You would expect your doctor to be paid for their time (either by you or by the government) not to offer free services but charge high fees for drugs. Yet that model applies in audiology every day. It is no wonder that hearing devices are frequently abandoned and hearing loss is unmanaged in far too many cases.

Hearing devices have limitations that are seldom made clear to members of the public. Hearing aids do not improve hearing ability. Hearing aids modify sounds in the environment and deliver them to the ear and brain – which may still have difficulties with processing the sound, even if it can be heard. Many modern hearing aids are “open fit” which means that sound enters the ear canal normally – with nothing blocking it – so background noise, if loud enough to be heard, will not be affected by a hearing aid at all. Cochlear implants do not restore normal hearing, contrary to suggestive advertising.

Audiologists assess each person’s individual potential to benefit from hearing aids. Some people have a type of hearing loss that requires all sounds to be louder, and they do well with hearing aids – even ones that are described as “basic”. Other people experience distortion when sounds are made louder, so that hearing aids, even ones with very advanced features, may only help a little bit. Even with “advanced features”, most people with hearing loss will find listening to be tiring. So, audiologists counsel individuals as to what their optimal communication could be, and provide therapy programmes to build up listening skills. Audiologists may train partners or parents to communicate effectively. Audiologists may provide advice about room acoustics, or how to make use of alternative communication in public places.

Audiologists need a healthy and positive relationship with the hearing device industry. That relationship should be at arm’s length. Yet, now many audiologists are dependent on industry for employment.

The public needs to be able to trust the advice they receive. They need clear information about what hearing devices will and what they will not achieve for them. Fair and adequate payment for services and advice is necessary to separate hearing device prescription from advice about communication. Audiologists need to be recognised as healthcare practitioners with a role in medical and surgical teams.

Regulation of the relationship between the profession of audiology and the hearing device industry is necessary. Regulation of these relationship happens for other healthcare professions. Regulation of audiology happens in other countries. Audiology could be regulated in Australia under the Australian Health Practitioner Regulation Agency, according to a specifically designed code of conduct that effectively manages the relationships between industry and the profession.

Regulation of audiology will not solve all the challenges facing those with hearing loss in Australia, but would help Australia to meet its obligation to ensure hearing services are part of healthcare, as agreed to in the WHO resolution of 2017.

Name: **Lucy**

Location: **Alice Springs, NT**

The Hearing Health Program collaborated with the Indigenous Hip Hop Projects (IHHP) and Canteen Creek Community in May 2016, to develop an engaging ear health promotion music video.



The purpose of the music video is to raise awareness of ear and hearing issues in the Northern Territory and to encourage families to get their kids' ears checked regularly.

Students from Canteen Creek School and members of the community participated in developing this video. IHHP supported the community to write the song using key messages provided by the Hearing Health Program. IHHP also recorded the song and delivered dance workshops. This process enabled the Hearing Health Program to engage with many community members including children, young people, parents, Elders and the Traditional Owner to discuss issues that affect ear health.

Music and dance has played an important role in many Aboriginal cultures for generations to convey key messages on social issues, health and to keep culture strong. The Hearing Health Program hopes that this video will raise awareness of ear health not only in the Aboriginal population but in the whole of NT and Australia wide.

Child Health Checks show that from the 9,373 Aboriginal children who received health checks between July 2007 and June 2009, 30% had ear disease (AIHW 2015). Reducing this prevalence requires a collective input from relevant stakeholders. The Hearing Health Program would like to thank the Office of Aboriginal Health Policy and Engagement for the sponsorship that made this project possible.

Name: **Andrew**, *Translated from Auslan*

Location: **Australia**

Deaf all my life live with hearing aid. Also my wife is hard of hearing. We are Auslan and oral speech. We have outdated hearing aids. We are raising 3 children. No funding to get new hearing aids, we are hard working middle class.

Dealing with silence. We can't hear kids singing and play music, we cant hear DVD and music. I have to put it on very very loud to feel vibration and make the neighbours complain. We can't hear kids screaming when hurt or arguing. We can't hear in crowds. Now we are experiencing mental issues due to silence. We can't live with out sound!!

We are not one of those eligible for a Pensioner Concession Card, a Department of Veterans Affairs (DVA) Gold Repatriation Health Card (or a white card), or be in receipt of a sickness allowance. Nowhere can I get access. They tell me to find a hearing aid bank but none suit my needs.

We need four new hearing aids which we better off buy a new car to have better transport for the family. So we live mentally surrounded everyday by silence. We do not want cochlear implants. We just want to have hearing aids that are so much cheaper and save a lot of TAX and government funds??? We can't afford them as we invested for our children.

These real life stories are brought to you by Lucy and Andrew

Name: **Lucy**

Location: **Sydney, NSW**

I was diagnosed with a hearing loss at the age of two. I was fitted with the most powerful hearing aids; I did not get much benefit from them and I therefore received my first cochlear implant when I was 16 year old. During my hospital stay I observed the role of nursing staff which gave me an idea of my long term career to become a Registered Nurse. I have always been compassionate about caring for other people while growing up.



I enrolled in college. I achieved the grades I have wanted and met the entry requirements for university and fortunately I was lucky to obtain a place at university. During my three years course I have faced many challenges as a deaf student. For example, the loop system was never turned on and despite my effort communicating with the disability officer nothing was done about it which meant I missed out on a lot of information in classes. There was lack of support for a deaf person in place. I was informed that I was the first deaf person to attend that particular university which resulted in many issues due to lack of deaf awareness.

During my second year placement I was asked to wear a badge saying 'I am deaf'. What gives my mentor the right to request this? You wouldn't ask a person of different race to wear a badge saying, for example, 'I am black.' It is wrong. I obviously declined her request to wear the badge. She went on to explain that it would be very unsafe for me to practice without a badge, just because I was deaf. I had many health assessments completed prior to starting my course and passed these requirements.

I managed to complete my course and landed my first job as a nurse on a general mixed surgical and medical ward, and everything went well. I migrated to Australia in 2011 not knowing anyone except a family friend who I stayed with for a while. It took a while for me to become registered with the nursing board. I eventually did and had to find a job quickly. I landed one in an outpatient clinic where it did not involve much nursing skills.

I missed the work on the ward and having worked in a clinic for two years I decided to find a job on the ward. My manager at the time stated that I worked well and she didn't have any issues with me. I applied for two jobs in a hospital and obtained two interviews in two weeks. During my second interview I received shocking news - the interviewer considered giving me a job and he chased up with the references. However, the information I received was appalling - I was told that it was unsafe for me to work on the ward because I may not hear the emergency bells and would not be able to cope in an emergency situation. There was no evidence of me not being able to carry out this task, bearing in mind I did not do ward work and therefore this information was based on theory and not facts. Hence, I was in a very difficult situation as it was very hard for me to find a job.

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I decided to leave the clinic altogether and apply for a job through a nursing agency. I worked hard on many wards and received a positive feedback. Six months later, I decided to try again and I used the agency for a reference which resulted in me getting a job on the ward.

We must raise awareness and break the sound barrier together as a team. I would like to see people with hearing loss having the same rights as hearing people. My message to the public is that people with hearing loss are more than capable of working in a health setting whether you're considering to become a nurse, doctor, occupational therapy etc.

Fight for your right and show what you can do!

This real life story is brought to you by Lucy

Name: **Pauline**

I was born hearing, and lost hearing in my right ear at age 32 because of acoustic neuroma.

In my 40's the hearing in my left ear began declining due to another acoustic neuroma. By the time I got my cochlear implant I was profoundly deaf, the implant only providing a little sound to help with lip reading. I rely totally on lip reading for communicating.



The hearing in my right ear declined very quickly over a few short years. It was very upsetting and stressful for me and my family. Still is. But I can lip read better depending on the person.

We found there was no support for me or my family to help us go through this harrowing transition. The medical profession handed out my diagnosis and basically said ok off you go. They had no thought as to what us late deafened adults have to cope with. I felt totally alone and isolated. In group discussions with more than 2 people I am lost, I can't keep up. Most of the time people give up and talk a million miles an hour and leave me for dead.

I live and work in a hearing environment, I only know one other person with a hearing loss.

We are a minority I know, but I hope one day there would be more support out there for adults losing their hearing.

Captioning would be great at transport venues for us profoundly deaf adults. I live and dream of a hand held caption device that I can carry around with me, and use anywhere anytime.

Can our leaders make Hearing Health and Wellbeing a National Health Priority? Do they care? I hope they can find this in their hearts not for me but for millions of Australians.

Name: **Brett**

My wife has issues with hearing loss and tinnitus. As a partner that witnesses the problems on a daily basis it upsets me to see not only the effect on her, but how it then can affect the mood of the family who feel her frustration but cannot do anything tangible to help her.

Simple things like access to closed captions on all media, improved government financial assistance for hearing aids, greater community awareness campaigns and easily accessible specialist advice will all assist in creating a better quality of life for those affected and their family and friends.

My opinion is that because there is no obvious disability for the world to see, the whole issue is not given the attention and prioritisation it deserves. I applaud this initiative and those sharing their stories.

These real life stories are brought to you by Pauline and Brett

Name: **Marianne**

I was born with Sensinaural Nerve Damage which in my case is genetic on my Mother's side.

My Hearing Loss was picked up in my early twenties and I was wearing my first aid at 29. I gradually needed two hearing aids and my hearing continued to deteriorate over the years. In that time I worked in the swimming industry as a teacher and coach for 35 years, as well as raising a family.

It reached a stage where hearing aids were virtually ineffective as my hearing was dropping in big numbers in a short time frame. At one stage I lost 15 decibels of hearing in 18 months and continued to do this over the years.

At this time in my life, the discussion to have a cochlear implant was made as my role as a swim coach was being compromised and I was going to lose my profession.

My first Cochlear surgery was seven years ago under Prof Gibson and the second just recently as 3 month's ago.

The difference it has made in my life is fantastic. Clarity of speech is so important and I am starting to get back into my community and profession.

I have always been pro-active with my deafness but it's an ongoing battle to be accepted as a normal hearing person. I find the lack of education about hearing loss, especially in the service industry (retail in particular) is seriously lacking.

I could list all the examples of negativity by Australians against those with a hearing loss and about some of the things I have experienced over the years but have always stayed on top with a positive attitude as I think I've been lucky to work in an industry which is very motivational.

I'm also a very determined person and approached auditory training the same way as goal setting in swim coaching. It takes time and patience.

I hope this helps our politicians support the need to make Hearing Health a National Priority.

Name: **Mathew**

Location: **Brisbane QLD**

Age: **Early 20s**



I was born natural with hearing, but unfortunately lost it at 18 months old after the vaccination for Meningitis, which is a common factor in people becoming hard of hearing.

My life started communicating with Auslan because I was always around with many deaf people. I started to speak after age of 4 through speech therapy. I persisted this throughout my schooling years into mainstream high school. I had an interpreter/teach aide during high school. I graduated in 2008 with a nomination for a Teachers' Choice Award.

In 2009 I moved out of my home to start studying at university. I was connected with student support services where I get interpreters, note taker and transcript. I finished my Bachelor of Science degree in 2012 at James Cook University in Townsville.

I travelled to United States of America and Canada in 2012/2013 for my first time overseas. I became a more independent person in those years. I moved back home after this trip. I started to work on my career despite lack of employment acceptance due to employers' poor hearing awareness. I had qualifications and experience.

In 2015 I moved to Brisbane and decided to take a coursework and a Masters thesis in Sustainable Development at University of Queensland. In July 2016 I graduated with a Dean's Commendation Award for being a top 10% student of performance due to my high grade for my thesis paper.

Now I am starting to develop strong connections and networks with community organisations, and advocacy work in Sustainable Development and Diversity Inclusion. I have travelled places to take on research, attended conferences and community meetings to raise awareness.

Think of someone with a hearing loss. They should never give up their awareness because of something they want to do. I had lecturers and professors in early academic years told me I wouldn't excel in my courses. But I hold two degrees, 2 scholarships, Dean Commendation Award and a thesis paper.

This real life story is brought to you by Mathew

Name: **Natasha**

Age: **teenager**

Location: **Adelaide, SA**



Deaf teenager Natasha has always shown extraordinary potential from the time we met her two years ago.

She came to our first Communication Bridging Camp for deaf Aboriginal children and by the end of that special weekend, she had shown her leadership skills and opened up about her dreams. Natasha was inspiring in her determination to become a social worker but she needed to overcome so many challenges to enable her to pursue that goal – including significant educational and communication barriers.

“When I was little my aunty asked me what I wanted to do when I grew up. I answered her, ‘I want to help people like me’. She says she nearly cried. It’s something that I have always wanted to do for even longer than I can remember. I wanted to encourage the young ones because when I was little, my family taught me about my background being Aboriginal, but I didn’t have any role models to teach me about being deaf. I thought I could be a good role model for them.”

“I was the second eldest of 11 children and I have grown up looking after my little brothers and sisters. From the time I was around ten, I started making sure they were awake on time, taking them to school, preparing meals, making sure they were fed and not hurt, and washing their clothes.”

After the camp, Natasha had returned home to her regional community and at her school, the Head Teacher of Special Education Stuart Wood said he had seen a dramatic difference in Natasha after camp as her self-confidence started to grow. She had hardly been signing to anyone but after the camp, Natasha started signing in front of the whole school and sharing her ideas more. Stuart expressed his concern that Natasha needed the chance to strengthen her language skills and her sense of identity as a young deaf woman. He also advocated for Natasha to be able to access the educational opportunities she needs to become a social worker. As Natasha explains, “In hearing schools, I felt like there were a lot of barriers. I was just getting little fragments of information and wasn’t able to take it all in”.

Deaf Children Australia was able to provide long term support to Natasha – initially through the VidKids pilot program. Case manager Debra Swann and Youth Support Worker Paula Thornton became deaf mentors for Natasha and taught her Auslan skills and independent living skills through Skype. Debra explains, “We talked about life, Natasha’s problems and what she wanted to achieve. We spoke with the teachers about educational needs and advocated for her.” Natasha simply says, “They have helped me with anything and everything.”

When Natasha moved to live with her grandmother, Deaf Children Australia continued to support her through really tough times. Natasha fell ill with meningitis and lay in a coma for a week. Natasha explains, “When I woke up and found out I had almost died, it was a real shock to me. After that experience, I thought life is really too short. It really made me decide I wanted to move to Melbourne, do Year 12 at Victorian College for the Deaf (VCD) and go to university in Melbourne. I

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thought VCD would give me the best chance to get into university because all the teachers sign. So I really had some goals after the coma – something that I wanted to achieve. I wanted to do social work with deaf Aboriginal children and make an impact in the community.”

Debra talked with Natasha’s aunty in Melbourne about helping Natasha to move down here, and assisted Natasha with accommodation and school meetings. On the day Natasha arrived, Paula helped her with travel training and will continue to help with independent living skills.

Natasha says, “It is difficult of course being independent and away from most of my family but at the same time, it’s really good. I have some role models and older people guiding me. Like this morning, I got lost in the city on my way to school and Deb helped me find my way.”

Now, Natasha is well on her way to achieving her dream of helping other children like herself.

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Name: **Natalie**

My first child, and daughter Lila's hearing loss, came as a big surprise to us. We knew from when I was 12 weeks pregnant that there were going to be health complications with my daughter. At 27 weeks pregnant, a cardiologist diagnosed her with two heart conditions that would need to be repaired within the first 6 months of her life. We were obviously devastated and hoped that the diagnosis was wrong.



Soon after this, the doctors advised us that the heart conditions may be associated with a Syndrome, most probably 22q. We were given information on what this would mean, and researched it extensively. We tried to prepare ourselves with anything the syndrome would throw at us. When my daughter was born, blood was taken to test for 22q.

Lila had her first heart surgery at 19hrs old. Her recovery was hard and she remained in ICU for close to a month. Doctor after doctor came to us with news of something else that they found was wrong. I spent my days by her bed crying and trying to pick myself up from each new diagnosis I was given.

Lila was only a few days old when the technician came through to perform the SWISH test. She warned us that due to Lila's recent surgery the results of the test may not be accurate. Lila failed the test and the technician casually said to me 'if she is deaf, it's the best thing these days, as they can put something on her head and she can hear'. I was angry and not prepared to hear that she might have a hearing loss. This was not one of the things that people with 22q had, and I hadn't prepared myself for it.

I was so upset with the technician's bedside manner, and could not understand why she had even mentioned she might be deaf, after telling me the test may be inaccurate. I put a complaint into the hospital and asked for their technicians to get better training in how to approach parents if the SWISH test came back as a possible hearing loss.

A few weeks later the results from the blood test came back. No Syndrome was detected. The next day geneticist came to us, took us into a small room and told us that they had realised what my daughter had. They told me she had CHARGE Syndrome, and was probably deaf and blind.

Test after test was performed and Lila was diagnosed with bilateral severe to profound hearing loss, she has a Coloboma in her right eye, causing a blind spot and many other health issues. All I could think about was the technician saying 'they could put something on her head and she could hear'. I had no idea what it was or how it worked, but prayed that whatever it was, she would be able to hear.

We met with an amazing Cochlear Implant surgeon, who specialises in CHARGE Syndrome. She warned me that CHARGE kids often have absent auditory nerves and if they do have them, they are often too small to be able to successfully use a Cochlear Implant. I was devastated. She was right, Lila's nerves were small, and one appeared absent on the MRI. The doctors told us to be prepared for the Implants to only give her access to environmental sound and not speech. I did not know how

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to deal with this possibility and had no idea what it meant for Lila's future.

Years of speech therapy, appointment after appointment, and lots of hard work followed. Lila's cochlears are successful. She is hearing and speaking, despite all odds. The journey of my first child is nothing like I had imagined. She makes me so proud and honoured to be her mother. Her strength and determination have made me a better person. I have had to muster up strength of my own, that I didn't know I had in me to cope during the hard times and support her. There is nothing she can't do.

I no longer fear my daughter's hearing loss, but am excited by it. We have started to use Key Word Sign to help her communicate when she doesn't have her 'ears' on. She picks it up so easily, and it has allowed us to be able to help her understand and communicate her needs better.

Reflecting back on my reactions to Lila's diagnosis when she was first born, I wish I knew what I do now. I realise now that it was my ignorance and lack of knowledge to what hearing loss meant, that caused me to have so much fear around it.

We have been so lucky to be exposed to a community of the most wonderful people, helping us and caring for my daughter and showing us anything it possible. It's a world I never knew existed and I feel so privileged to be apart of.

It would be great to break the sound barrier, and help others to understand.

Name: **Lina**

Age: **66**

Using hearing aid from 1993 at the age of 42 1/2 with the gift of very active, friendly, person as I am, worked and achieved good result before and to use hearing-aid after that was so hurtful at the start but after 14yrs in childcare, and now 7yrs and still going on in Aged Care.

I have never looked back or had any hindrance to my achievement due to my hearing-aid.

I have now retired but still work part time and to crown all I am learning the violin at the age of 66 and am doing well.

Thanks to the persons who have improved on this miracle device, God sent device to make us privileged, to be in par with all other human beings. You can do what all the people do.

I strongly suggest more time and money spent to help all Australians with a hearing health challenge and raise awareness across our country.

Name: **Nicola**

Location: **Brisbane QLD**

Age: **Late teens**

Nicola, our daughter came fighting into this world on Anzac day 1999, born 26 weeks premature, weighing little more than a tub of butter only 674g.

Doctors and nurses told us her chances of survival would be less than 50%. Her first big battle was the first day I had to leave her alone in the hospital and go home. As we arrived home the phone was ringing and it was the hospital! Nicola had suffered a collapsed lung. As we arrived at the Neonatal, Nicola was in the middle of the room on a bed covered in blood. The nurses told us to keep talking to her and keep touching her as she would be able to hear us and know we were with her. Nicola's paediatrician told us that they were not expecting her to survive through the night. We spent the night watching and praying for her.

Nicola made it through the night. She again defied all the odds and conquered another two hurdles where they told us again there was no more hope. Through all this Nicola's hearing was destroyed as she was given the antibiotic "Gentamycin". Gentamycin destroys the hairs in the cochlear and this drug is used regularly on neonates to fight infection. This drug also caused some nerve damage as a result she developed mild cerebral palsy in her arms and legs. We have been uncertain what else was damaged during this time, as she was really not meant to have survived or even expected to have been able to walk.

Nicola was given the nickname of "The Little OZZIE battler". We are so grateful for Nicola and can't imagine how life would be without her. She has taught us so much in her short life.

Nicola had severe to profound hearing loss and had her first Cochlear implant at 18 months old in Sydney by Prof Gibson. Nicola had a big support system in Sydney through The Cochlear Centre. She also went to the preschool that was part of the Royal institute for the Deaf and Blind Society. After that Nicola went to St Gabriel's School (Catholic school for deaf children). Nicola communicated orally and with Auslan at St Gabriel's. We had to leave at the end of year 4 as we had to relocate to Brisbane due to work commitments. Nicola ended up going to Warrigal Road state primary school in Brisbane. Through all the support Nicola was getting, she was struggling to understand and keep up with her peers. It was a year after we arrived that Nicola ended up getting her second cochlear implant. It has been an on going battle with Nicola's language and no one has been able to guide us and let us know why she has been struggling in this way.

Nicola has a brother that is 7 years younger than her and yes! an 8 year old and a 16 year old ...well, just use your imagination.... the situations we get into and the arguments!

Nicola has always been a cheerful, happy child always embracing whatever challenges she has had to



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face. Nicola's was born with this stubborn streak and we know that it has saved her life a few times, but it does get in the way with many arguments in the home. As Nicola is in a very challenging time in her life and also due to her limited language, communication does lead to many misinterpretations. Nicola's Father also suffers from hearing loss and wears hearing aids. This becomes a challenge when the two of them keep misunderstanding each other.

Nicola does not have many friends and due to Nicola's age and language ability, she struggles to fit in. She spends most of her time reading, listening to her music and drawing. She also enjoys photography and enjoys been out in the Australian bush.

Nicola has taken part in a few of "The Hear for You" workshops since they started in Brisbane. She has always enjoyed them and fitted in well. Each experience & understanding of the experience has been different for Nicola and as she matures and develops the more relevant they have become for her. It helps Nicola to realise that she is not the only one with these challenges and there are other people her age with similar problems and many of the mentors have been in similar situations as Nicola, therefore can relate to her frustrations. The Mentor's have been amazing! The program is inclusive and very accepting. They communicate with Nicola from a teenage level and not from a parent or teacher. The mentors are an inspiration for Nicola, showing her that she has the right to be a valued part of our society just like everyone else and if she searches hard enough she will also have an exciting future to look forward to.

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Name: **Beverley**

Age: **70 something**

Location: **Sydney, NSW**

In June 2016 I was a recipient of a cochlear Implant. All my life I abhorred loud music concerts, blaring radio whether in the car or at home and TV that could be heard outside or far away. So I wondered why my hearing loss presented itself during my working days in 1998. Subsequently and after discussions with various audiologists it was ascertained that my job as Personal Assistant to a CEO of an importing company and his constant use of a Dictaphone which often caused me to switch to full volume, was probably the cause. So I proceeded on a long journey of being fitted with hearing aids. A costly exercise.

Family and friends commented that I was missing so much conversation; I discouraged people phoning me as I could not understand them; stopped going to the cinema; and my love of theatre also suffered.

Two separate audiologists suggested I consider cochlear implants as they could do no more. I was 83 years old and after having had eight major surgeries in my lifetime I always said "I would never willingly go under the knife". However, my son Michael said he would accompany me to investigate whether I really was a candidate. So Michael and I went to the War Memorial Hospital on Friday 6th May 2016 to decide my fate. Michael was able to understand the engineering/electronic side of the implant. I surprised myself when I did a complete reversal from negative 95% when we arrived and left feeling positive at 95% and keen to go ahead with the project.

Dr Kong fitted into the schedule by advising he could do it on 30th June at North Shore Private Hospital. The usual procedures of hospital gown, stockings + other leggings, and wheeled into theatre by a very smiling, bright man who "has a mother your age and her best friend is Beverley" – he lightened the trip.

Now with my first anniversary coming up soon I have to say I am very happy that I had this done. However, there are many people in the world who do not understand the problems with hearing loss. Actually, the younger generation are going to have major issues due to the headphones they constantly use now.

One goes to the cinema and the young attendants have no idea where there may be a telecoil loop or where the best seats are to receive this signal. Dining in restaurants is horrendous as most places have hard floors and ceilings, no table cloths or other means to soften the bedlam of everyone talking. Attending meetings and seminars difficult as it is not easy, or practical, to ask the speaker to wear a Minimic – and then there is the chance of losing it by way of the speaker leaving not aware he still has the Minimic attached. Ambient noise is a major problem and I consider more help and education to the world at large, should be available.

It is not just we older people who need the help. There are those deaf at birth, loss of hearing due to an influenza infection and many more such cases where the age group can be very young. And a long life ahead of them to cope.

Name: **Noah**

Location: **Sydney, NSW**

Age: **pre-school**

When Noah was diagnosed with hearing loss at birth, parents Michelle and Geoffrey reached out to RIDBC.

Noah was diagnosed with bilateral profound hearing loss at just two weeks old.

“It was a total shock to find out our little boy was deaf. Noah was our first baby and as first time parents we were already on an emotional rollercoaster,” said Noah’s mother, Michelle.

“I had heard great things about RIDBC through a friend who worked there and decided I would make an appointment with them. I found out as much information as I could so that I didn’t feel overwhelmed at the first meeting.”

When Noah was one month old he started receiving support from RIDBC Early Learning Program (Hearing Impairment).

“RIDBC has helped in so many ways. We’re supported by a range of professionals, including teachers of the deaf, audiologists, speech pathologists and occupational therapists. Whenever Noah was struggling in a particular area there was always an appointment booked with a specialist who could help him – it was so encouraging.”

At six months of age Noah was fitted with bilateral cochlear implants.

“Noah started to respond to sounds immediately after his implants were switched on and hasn’t looked back,” said Michelle. “RIDBC has supported us through every stage of his development and he continues to make progress with his speech and language every week.”

“Noah really enjoys preschool and is a typical little boy who loves playing with his superheroes and trucks,” said Michelle. “Noah’s teacher, Andrea, has really helped him become more confident with his expressive language and trying new words without being scared.”

Michelle and Geoffrey are optimistic for Noah’s future.

“Knowing that RIDBC is committed to making sure Noah has the best educational and specialist therapy support around him, I’m confident Noah will be able to attend his local mainstream school,” said Michelle.



Name: **Pat**

Location: **Berrima, NSW**

Concerns about Hearing Health for 1 in 6 Australians led to the development of my role as Hearing Coach in 2001. With my husband we bought a B&B in Berrima NSW in 1994.

Often on departure our guests commented how much they enjoyed conversation the evening before,” even though I used hearing aids”. This was a light bulb moment for me.



At that time, I reflected back 10 years to my own experience with my first hearing aid. I was advised to use my hearing aid for a few hours each day, increasing these periods. It wasn't until my nursing colleagues at meetings commented I wasn't keeping up with proceedings, that I was convinced I needed to use my hearing aid all the time.

It was in 2001 when we sold our B&B that I researched the Office of Hearing Services (OHS) website and viewed their own Client Survey revealing 30% did not use their prescribed hearing aids - known in the industry as “the bottom drawer syndrome”. It can be difficult to change the mind of many with this negative hearing aid outcome. Sadly from my experience over the past sixteen years this statistic still applies in both public and private sectors. It is likely to be a worldwide phenomenon.

An older client is humbled to receive a “FREE” hearing aid and feel they shouldn't grumble but should be thankful. Often these clients haven't used their prescribed hearing aid/s again as their problem goes in the ‘too hard basket’.

My Hearing Coach approach: “use hearing aids consistently all day, for the Brain to “get the message” and to modify the intrusion of background noise.

As a Hearing Coach I offer a personal “hands on” rehabilitation service to clients in their home. This can be quite an emotional experience for the client as they are reconnected again with their hearing aids, this could be after months or years struggling without their aids. I encourage clients and others to have a support person at appointments to ensure important information is not missed.

In 2008 the OHS commenced their Rehab Plus program for Hearing Service Providers to offer new hearing aid users two extra paid sessions to demonstrate this new hearing with their hearing aids. This initiative needs to be a compulsory element of the program.

I speak to community groups and clubs to raise awareness of the effect a hearing loss has on individuals, families, the workplace and socially - also to address the cause and effect of non-compliant use of hearing aids. This is a major issue for ageing couples and families as meaningful communication is compromised. Managing a hearing loss early will improve health outcomes and concerns for a person's safety and security when living alone.

I have a severe to profound hearing loss managed with a left cochlear implant and right hearing aid. Thank you Prof Gibson and Cochlear for bringing this technology into my life.

This real life story is brought to you by Pat

Name: **Rebekah**

Location: **Queensland**

Age: **working age Australian**

Growing up deaf back in the 70s and 80s, it was the Great Sound Barrier era but no one really understood deafness or people like me.

I was bullied at school for having a funny speech, not being able to 'hear' properly and for not being able to learn like other students in the classroom. I was seen as the dumb deaf girl, it was hard and very isolating. Many people thought if they touched me, they will pick up some kind of germ and become deaf. People used to tell me they'd rather be blind than be deaf because they were scared of losing their hearing. Because no one really talked much about hearing loss this is why it is very important to me that we make this campaign to make hearing a national priority successful.

My parents were told not to sign with me when I was 7 and raised me to be a 'hearing' person but I never was able to be 'hearing' because I was born profoundly deaf. I could never really understand speech and could not hear anything with my old analogue hearing aids. My family were very musical and it was a huge loss for them to have a child born profoundly deaf.

I used to spend hours every day at speech therapy and I hated it so much. It was so boring and always blowing a feather or paper. It was the same thing over and over even I was able to learn to 'speak' almost as good, I still hated it.

I would rather have a normal childhood, grow up with communication and be a kid without being ashamed of who I was. I grew up isolated and deprived, which turned me into a very angry person for a long time. My family didn't understand and couldn't help me then. My 'auditory' skill got worse over time, I developed full on 24/7 tinnitus and suffer from severe vertigo which can last up to six months at a time. I couldn't lip read anymore and became too tired to 'hear'.

I am glad I am as I am today, Deaf and Proud because life is much easier when I have my language, Auslan and my identity as a deaf person. I no longer feel resentment, angry and I no longer have to hide in shame.

Today I am a mother of 3 deaf children and 1 hearing child, I want to change the future for my children. I want my children to experience life in a positive and understanding perspective. To me, it is very important for everyone to see and to understand that hearing loss is not just an 'ear' and 'speak' issue. Hearing loss affect families, friends, employment, education, social and society. People with hearing losses experience many things such as isolation, deprivation, audism, surdophobia, mental health, identity and most of all, lack of access to services.

My youngest daughter is a bilateral cochlear implant child and people still expect her to hear and speak 100% but she cannot and she never will be able to hear like a hearing person. Cochlear implants are not a cure but a wonderful powerful technology and my daughter loves her implants. Yet she does gets frustrated when people assumed she can 'hear' everything.



This real life story is brought to you by Rebekah



Messages to our elected leaders

It impacts all of us whether we have a hearing loss or not and we need to be able to change that so we all, with a hearing loss matters. It is important for me to see diversity among all of us with hearing loss united for the future of our generation and people around us. I do not want my children to say “Why didn’t I matter? Is it because of my hearing loss?” I want them to feel included and to access life as everyone else. They matter, we, with hearing losses matters. Not one of us with a hearing loss are the same as the next person with a hearing loss.

This real life story is brought to you by Rebekah

Name: **Peter**

Age: **70 something**

Location: **Melbourne, VIC**

My hearing impairment was first noted in my mid 20's and became socially unacceptable in my mid 40's when it started to impinge on my working and social life.

Since then I have worn hearing aids which solve a lot of hearing issues but not the background noise one.



I am in my mid 70's now and find my hearing deficit contributes to a sense of isolation which I try to overcome by remaining actively involved in various interests. My prime interest in the hearing area is captioning and I am becoming increasingly frustrated with the TV and hospitality industries' tardiness in improving services for the hearing impaired.

Another issue not being addressed is the poor quality of public address systems in public places. I personally get zero benefit from such announcements.

All of which simply reflects the lack of attention given to hearing issues particularly for the elderly and emphasises the need to make hearing health a true national health priority.

Name: **Donna**

Life can be unpredictable. I had studied and worked hard for the last 5 years to get a level of attainment I was happy with, then overnight my life changed.

I wasn't born with an impairment but after waking one morning I woke with severe bilateral hearing loss and a whole range of other symptoms. I now have to adjust to the impact of hearing loss with communication, work, resources available, difficulty in early diagnosis, costs and wearing a hearing aid. I am in my mid 50's, my life changed in the space of a few hours - yours can too.

These real life stories are brought to you by Peter and Donna

Name: **Robyn**

I gradually lost hearing from about 45. I have a moderate bilateral hearing loss and have been wearing hearing aids for 15 years.

I was a public servant when I first noticed my hearing loss and would find it difficult talking on the telephone and hearing in meetings. This was often embarrassing and caused me anxiety and stress as I struggled to comprehend what was being said to me. The hearing aids made a world of difference.

As a mature age student I studied nursing and once again, despite having hearing aids, I found the noisy hospital environment often made hearing difficult. Trying to use a stethoscope was often impossible. So once again my hearing loss made my working life difficult and stressful.

I would like to recommend greater awareness of the impact of hearing impairment to encourage those with full hearing to adopt strategies that assist those with hearing impairment to hear; such as: looking at the person they are speaking to as this directs the voice to the hearer and allows them to supplement with lip reading; to speak clearly and with a reasonable volume; to pause to make sure the hearer has heard.

In regards to nursing, they need extra training to understand the needs of the hearing impaired. Hospitals can be frightening places and if patients don't hear all that they need to they can become stressed and anxious. I have seen many patients hearing impairment disregarded by nurses.

Raising awareness of the impact of hearing impairment is important because many in the community suffer from mild to severe hearing loss and it definitely impacts on their lives. The cost of hearing aids is another barrier for many people as it is necessary to replace them every 7 years at a cost of approximately \$5-6,000 a pair.

Name: **Pam**

Age: **67**

I was only around 50 years old when I awoke one morning to find I was deaf in one ear. No dizziness, just completely deaf.

After seeing my GP he referred me to ENT specialist, and was told there was nothing he could do. He did suggest I take steroids and try hyperbaric treatment. It helped and some hearing returned. But 12 years later the same thing happened and this time a different ENT said nothing would help and didn't treat me at all.

I am now completely deaf in that ear. I have tried a hearing aid but my hearing is so damaged that I only hear frightening noise so it was a big waste of money. I feel socially disadvantaged, depressed and have lost confidence. I am now 67 years old and my faith in our national and state leaders to support me and millions of Australians is almost zero.

Hearing Health as a National Priority would restore my faith.

These real life stories are brought to you by

Name: **Vanessa**

Location: **Riverwood, NSW**

I am an independent audiologist in Sydney.

Apparently only 10-15% of hearing clinics are independently owned by audiologists - the rest are owned by larger businesses and hearing aid manufacturers. It is difficult to survive as an independent practitioner, not least because the professions of audiology and audiometry are not licensed, and have never been subject to state or federal licensing, which I believe devalues these professions and makes it difficult for consumers to understand where to access high quality, ethical, professional hearing services.

Other health care professions are licensed and regulated, so why not these professions? I am also an experienced Optical Dispenser, and up until a few years ago, I needed a license that was renewed annually to practise this profession. It is ridiculous that audiologists and audiometrists do not have access to licensing. Audiologists require a minimum of 5 years university training in this country. An Optical Dispenser needs only to achieve a Certificate 4 TAFE education (via 2 years part time study), and on-the-job training in order to enter this profession, yet this profession was regulated and required a license, until recent years. A hearing professional usually requires several years of tertiary study, more years (or months) of intern training, and a vast amount of experience in order to competently assess hearing requirements, fit hearing devices, and develop rehabilitation programs for clients, yet the profession has been denied licensing.

The eye care and hearing industries have some parallel developments. The licensing laws for Optical Dispensers were scrapped around the time that a very large overseas business in the optical industry moved into Australia, and took a lot of business from both independent and established optical outlets; and it is suspected that pressure was put onto the optical industry to scrap licensing for Optical Dispensing, in order for the large business to staff their stores more effectively, often with unqualified and poorly trained staff who are allowed to call themselves Optical Dispensers, Opticians, or Frame Consultants, etc, or any name they choose. From my experience, the standards for optical care and optical goods has since diminished in this country, as a result of this development, and the Australian consumer is disadvantaged as a result.

Something similar could happen in the hearing aid industry, where businesses are being owned and run by large corporations and manufacturers, focussing on achieving sales targets and high profit margins, driving up the price of hearing aids, and bringing an unprofessional aspect to the industry of audiology. If licensing for hearing practitioners was brought in, it may prevent the problem that is happening in the optical industry, from occurring in the hearing industry. If the hearing professions remain unlicensed and unregulated, this could be a disaster for this industry, as large corporations continue to buy out and re-brand smaller hearing clinics, often at the expense of quality service and quality, ethically-based care for the Australian consumer.

This real life story is brought to you by Vanessa

Name: **Victoria**

Location: **Melbourne, VIC**

I am a board member of Better Hearing Australia (Vic). It is my pleasure and honour to share my tinnitus story with you. I congratulate you and your team at The Deafness Forum for the wonderful work you are doing.



I acquired tinnitus five years ago and have not experienced general well being since then. I also suffer mild hearing loss. My tinnitus journey has been fraught with trying to find AFFORDABLE and effective support, counselling and ways to learn to live with this auditory torment. My journey has been an emotional roller-coaster and an expensive one.

My experience with GP's and ENT specialists in Australia and overseas has been a very disappointing one in terms of getting help for my tinnitus. The ubiquitous response 'there is no hope, you will just have to cope' prognosis of tinnitus just doesn't cut it anymore. These words are often the source of the panic, the anxiety, the hopelessness experienced in the face of newly acquired tinnitus.

I have top cover medical insurance, yet many of the hearing services, and various other services which offer potential relief and management of the condition are not rebateable. These exercises have cost me well into the tens of thousands of dollars! Why bother with expensive health insurance when hearing in Australia isn't considered a 'health' issue. It truly beggars belief. How can anyone afford to have tinnitus or hearing loss in Australia? The non-existence of affordable support, care, services, hearing aids and tinnitus masking devices for the hearing loss and tinnitus community in Australia is a travesty.

I find it shocking and embarrassing that I live in a country that is NOT a third world country, and where hearing health is NOT one of the top National Health priorities.

In the five years since I first acquired tinnitus and other related hearing issues, I have dedicated my spare time to raise tinnitus awareness and help the two million Australians who struggle with tinnitus, learn to come to terms with it. I am now an active member on the Board of Better Hearing Australia (Vic), a not-for-profit organisation that has been supporting the hearing loss and tinnitus community in Victoria for over eighty years.

This year Better Hearing Australia (Vic) hosted Australia's first Tinnitus Awareness Week, and launched Tinnitus Australia, an alliance of various health bodies and individuals who are working hard to help those who suffer tinnitus. Better Hearing Australia partnered with the British and American Tinnitus Associations in the Tinnitus Awareness Week 2017. A 'Tinnitus Australia' website was created and launched during #TAW2017 campaign to support this important collaboration. www.tinnitusaustralia.org Hopefully this website will be used as a tool by the medical fraternity to allow proper diagnosis and prognosis of tinnitus, as well as house the latest information on tinnitus for the tinnitus client, their friends and family members.

We want more people to be aware that help IS available and how to find it easily.

There are many unscrupulous people particularly on the internet who profit from selling miracle

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tinnitus cures such as medications, sound therapies, books and tonics. This situation needs addressing.

Hearing health, hearing education, protection and tinnitus prevention in everyday life and in the workplace needs more emphasis in the community in general.

Tinnitus can be a traumatising auditory symptom that often causes depression, anxiety, and ruin lives! Tinnitus can trigger suicidal thoughts and worse!! There is no known remedy for tinnitus. Tinnitus affects One in Ten Australians. Tinnitus is non-discriminatory affecting equal numbers of men and women alike.

Tinnitus ignored, COSTS the country MORE MONEY than it would for the government to fund Tinnitus Support and Management Associations. Yet, the government, and the medical fraternity seem to be doing a very good job of turning a 'blind eye' to tinnitus and it's devastating consequences. Tinnitus must not get lost or forgotten under the general 'Hearing Loss' category.

Tinnitus needs addressing with a sense of urgency. Everyone has a right to peace. Australia spends billions of dollars on defence, fighting for peace and maintaining peace. And yet, tinnitus is the most common post traumatic stress disorder suffered by our returned service men and women.

Name: **Janice**

Tinnitus is hearing noises in your head that nobody else is hearing.

I am constantly in a room of noise my only relief is that I have a strong turn off switch and can sometimes cope but I have considered sticking a needle in my ear to release the pressure.

I have a radio on constantly which can ease the noise sometimes depends on my mood of the day. I long for quiet.

I've suffered 24/7 for over 40 years tried everything under the sun, but my screeching monster remains with me, the day I die will be my release from this curse.

I won't lie I have thought about it more than once.

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Name: **Christine**

Location: **Sydney, NSW**



I was diagnosed with a mild sensorineural hearing loss at age 5 following a bout of measles. My parents were told that nothing could be done to restore it. Throughout my schooling my hearing loss didn't really impact on me significantly but I compensated for the loss by sitting at the front of the classroom and I received some external coaching in English and Mathematics to fill in some of the gaps that were emerging in my learning. I left secondary school after achieving my HSC in the late 1960's with the aspiration of becoming a secondary school teacher. I gained a scholarship to Teacher's College and was the first member of my family to enter into tertiary education. At the end of the first year the College became aware of my reduced hearing and withdrew the scholarship as they considered I would be unable to manage classes. I was told I would be "a danger to children". There was no Disability Discrimination Act in place back then!

I proceeded to work for several years in office clerical roles that did not require much face to face interactive communication with my workmates or the public. Following my marriage and the birth of three children I was persuaded at age 30 by my mother-in-law to try a hearing aid. With just one aid I began to realise what I had been missing in terms of sounds. As examples, I was able to hear the phone ring, birds sing in trees and was better able to hear the activities of my young children. I decided to try again for a tertiary qualification and began a TAFE Certificate course which I completed and in which I excelled. This success gave me further confidence to enrol in a Bachelor of Education.

I subsequently completed 4 years of full time study and graduated with Distinction as top of my year. This would not have been possible without the confidence and increased communication ability gained from the use of just one hearing aid, the help of my classmates and the communication strategies I had acquired over the years.

By the time I graduated I found that my hearing was deteriorating and I consulted an audiologist who assessed that it had dropped to the moderate range of hearing loss. I was fitted with 2 hearing aids which helped me get a more balanced, all-round sound reception and which helped improve my ability to cope. I was able to gain employment as a teacher in both state and private schools, rising to Head of Department in a highly regarded Sydney private secondary school. I taught all levels of students in my subject area, including HSC, and during this time I was also able to complete a Master's degree in Education. I retired after 22 years as an educator.

In retrospect, without the initial assistance of just one hearing aid I would not have been able to contemplate undertaking tertiary studies. Also, as my hearing continued to deteriorate to a severe level, without the assistance of 2 hearing aids I would not have been able to work and contribute to the community as an effective educator for 22 years. This aspect is quite apart from these devices also providing me with improved interpersonal communication ability with family, friends and in everyday life situations. However, the hearing aids did not completely compensate for my hearing

This real life story brought to you by

loss as although they amplified sounds they didn't always improve the sound clarity. Also the background noise in the classroom situation was often problematic. I became very good at lip reading, and I utilised new technology as it became available, such as going from analogue to digital hearing aids and then incorporating features such as Bluetooth for television and mobile phone usage as it developed (which needed top of the line hearing aids to work!). I still had to actively manage the way I communicated in the classroom and in meetings. I found meetings particularly stressful as I needed to try and centralise my position so I could hear more easily and I often needed to enlist the help of others to fill in any gaps that I had missed. I was forever very conscious of perhaps giving an inappropriate answer in a group situation as I could not always see the speaker or understand what was being said if I could not lip read. No other assistive technology was offered in my workplace environment which added significantly to my stress levels.

Over that 22 year career and as technology improved I upgraded my hearing aids at least 3 times at 5 or 6 year intervals. During this time I spent over \$40,000 on my hearing aids and received less than one tenth back from my health fund. Overall for me, hearing aids were an essential tool of trade and although they were not the complete answer on their own, without their use my ambition would not have been realised and instead of being able to contribute meaningfully to society I could well have retreated into my own world and become an added burden to public health.

Again in retrospect, I wish that there had been (and still to this day) better public education regarding hearing loss and communication techniques, and more widespread communication help generally available for me and others with hearing loss. Because the condition is invisible it is not easily or immediately recognisable and the effects are often misinterpreted by others as ignorance or some sort of mental or processing deficiency. If hearing health was a health priority, like diabetes there would be management plans in place such as what is currently available for conditions such as heart disease and diabetes.

At present for hearing loss conditions, the pattern appears to follow that a hearing loss is diagnosed, and then assessed by an audiometrist or audiologist (often working on a sales commission basis) who prescribes hearing aids. These are fitted and there may be a series of 2 or 3 follow-up visits for adjustments and fine tuning. End of story: that is until you need another set which may be in 5 years' time as is often recommended by hearing professionals (and not when the aids actually wear out) and the cycle of hearing aid fitting is repeated. In the meantime, and because hearing aids don't fix the whole problem, with many users still experiencing poor sound clarity, difficulty in noisy environments, watching the TV or in social situations etc, there is a lot of wastage due to many users being frustrated and not wearing the aids consistently or perhaps only socially.

Volunteer consumer organisations such as SHHH (Self Help for Hard of Hearing People) and BHA (Better Hearing Australia) focus their efforts on providing reliable information and communication help to people with hearing loss, however their efforts are too often hampered due to lack of available resources and funding. If hearing loss were to become a health priority such organisations could become a valuable part of the hearing health management process which would also include more widespread and more readily available public education on hearing loss management. A national initiative where hearing health was a priority, managed by accredited and regulated hearing health professionals and supported by properly funded consumer organisations would have made my hearing journey and that of many others far easier.

This real life story brought to you by

Name: **David**

Location: **QLD**

Age: **50 something**

I'm somewhere in between. I'm not deaf. But then I'm not really hearing either.

I grew up the eldest child in a normal family. My parents were caring and encouraged me to do well at school as they worried about my future. Both were employed and worked hard in diverse jobs – dad was a rubbish collector for the council and mum was an actress. They loved each other, argued, fell out of love and divorced. All in all, my early experiences were those of living within a normal family – oh and yes, both my parents are deaf, but then being Deaf in my family was normal.



I've always found it strange how hearing people try to fit Deaf people into standard categories, making assumptions about them as a person with a disability, rather than seeing the Deaf person as someone who speaks a different language and belongs to a different culture.

Over the years, I've seen a shift in assumptions, attitudes and behaviours towards deaf people, but there is still a long way to go here in Australia. The biggest obstacle to achievement that many deaf people have to overcome is an external one; rather than the physical obstacle of deafness itself. The real 'limitations' are the perceptions that hearing people have about the deaf and hard of hearing.

I grew up being told by well-meaning hearing adults that it must be hard having deaf parents – as if I had any other point of reference to compare it to. The fact that I was bilingual was marvelled over, somehow dismissing that sign language was the only language used at home.

As a Child of Deaf Adults (CODA), I have experienced many unique and complex roles, straddling two cultures and moving between the deaf and hearing worlds my whole life. Therefore, I strongly believe that it is incumbent upon society and governments to provide choice for the deaf and hard of hearing. How do we achieve this – firstly by recognising Hearing Health as a National Health Priority, secondly, by challenging the limitations that hearing people place on the deaf by recognising that deafness is not a learning disability, and thirdly by providing a supportive barrier free environment with better community education.

In short, it is time to Break the Sound Barrier.

David Gibson is the Chairman of Deaf Services. He is formerly a Member of the Queensland Parliament, and has also worked as Newspaper Executive, Army Officer and strategist.

This real life story is brought to you by David

Name: **Isaac**

Age: **15**

Location: **Melbourne, VIC**

It was a warm bright Christmas Eve morning, music was playing softly in the background, a reminder of the family celebration of Christmas day only a matter of hours away and so important in our home.

Having my mum with me was such a comfort as we sat in the waiting room with my 7 month old son wriggling on my knee. We were ushered into a dark carpeted room with large boxes with ragged looking puppets in them. The puppets looked as if they were trapped, performing to a captured audience.

Both my mother and I were given industrial type head phones to protect our ears from the loudness of the beeps that accompanied these dancing puppets. Isaac was not.

Each beep seemed to be of no consequence to my little boy, I could hear them through the pressure of the head phones growing anxiety climbed from the tips of my toes to the very top of my head as the realisation that my little boy was indeed deaf.

I never knew what the word surreal really meant, I mean I had heard it thrown about on the news especially around the time of the World Trade Centre attacks on 9/11. I hadn't had a reason to understand that word deep inside. I sat there in a world of comparisons in my mind, playing video reel of my children's life, I sat between what I thought Isaac was only a matter of a few minutes before, to what he is now, being aware of this hearing loss made such a difference. My world had collapsed, my mind trying to reprogram the picture of his life that I had created in my imagination.

"Mrs. McMullen, your son is profoundly deaf, he will need hearing aids and most probably cochlear implants, merry Christmas" a calm monotone voice threw that at me from across that dark carpeted room. "What... no umm no...you can't just say that then dismiss yourself to celebrate Christmas with your staff" I thought, confused and overwhelmed. You have just changed my son's life forever. My mother, as they do, held herself together and when our eyes met that look reminded me that there is always hope in any circumstance. Such a mum thing to do, bless her she was and is my anchor.

As the silence swallowed up the room's oxygen, the audiologist passed me a card with Taralye's number on it and dismissed himself. Taralye seemed to be some sort of place for deaf children. I really had no idea of what I was calling and what I needed to say.

Christmas was more silent than usual as we as a family contemplated what the next year would bring for our little baby. Every present seemed to make a sound, a rattle, a song or a replica animal noise, all of these Isaac would have no hope of hearing. Each gift seemed to tear at my heart that little bit more. Everything has sound, we were surrounded by laughter, by carols, even the subtle sounds of ripping paper and gasps of excitement as presents were opened. Christmas, was all about the sounds Isaac had no chance of hearing.

This real life story brought to you by Isaac and his mum Mel

Messages to our elected leaders

After being fitted with hearing aids earlier the next year, Isaac's life was changed, even though it was minimal access to sound he was aware that there was such a thing as noise and that he actually had ears. Taralye became our home away from home and was our lifeline to choices and the options available to us.

We, as a family have chosen to go the oral path with Isaac, focussing on the auditory verbal approach. Having grown up with a great aunt who was a teacher of the deaf I learnt the impact of hearing loss from a young child. I was determined to have a child who had access to the same choices for life as his three older brothers.

At ten months old Isaac was fitted with his first pair of hearing aids. They were huge on his soft little ears. Many appointments and testing at Australian Hearing and we found a level that suited Isaac.

This was a huge learning stage, learning to read audiograms, understanding the terminologies that went with the diagnosis and really sinking in that this is a lifelong, a permanent issue. We as a family needed us to rise, to get strength and to fight for our son so he didn't have to fight for his rights as an adult.

Isaac wasn't progressing as well as we had hoped even with intensive therapy and playgroups with hearing aids alone. A cochlear implant was suggested to us, this was both exciting and a little terrifying a new language to learn and the only path possible to achieve oral independence that we had hoped for.

MRI, Blood tests, CAT scans, audiograms and many appointments at the Royal Eye and Ear Hospital Melbourne - we were told that Isaac was a border line child. That meant for us that he would not be a candidate for a cochlear implant. We learnt that to access to speech a child needed to be implanted by 2 years of age so as the neuromyths were placid enough to learn. So after much to do, and pushing down some doors our Isaac was the first to be implanted at the Royal children's hospital Melbourne.

I knew as my little boy was wheeled away in that huge hospital bed, through the large operating theatre doors that this would be the day that changed his life forever. This day would be the day he got to choose for himself the direction in life he'd like to take. What if he would be able to talk to his great grandmother and hopefully one day go to the same school as his three older brother's? That was our hope, would, could it be possible to make come true?

That little boy is now 15 and he has gone beyond any hopes we had for him. Yes, there were years of teaching Isaac to listen, hear and speak, but those years I'd have back again in a heartbeat. They were precious times of learning to discover a new world that I had taken for granted. I'd never really stopped to listen to my steps on the floor, to hear the late night song of the birds, the sound a spoon makes as you stir your coffee. Sounds that make up the music of life that I got to learn and be thankful for in a different way through Isaac's new ear.

Isaac and I learnt the colour of life after being in a black and white world.

Late last year Isaac had for himself chosen to have a bilateral implant after being unilateral for 13 years, and again to our surprise he has gained high 90's in word recognition in his new ear. This journey was exciting, we got to see and experience through Isaac's spoken language the journey of

This real life story brought to you by Isaac and his mum Mel

his cochlear Implant. He could express his joy, the awakening of that second ear and the pleasure of being able to distinguish where sounds came from. Isaac found out that in fact life was actually in stereo. It was like a new way of listening to music, going from a LP to a CD in a huge room set up for sound. Bird song actually surrounded us, totally filled the air space, the cars coming up the street had a clear direction of sound. Again a pleasure to experience and an incredible blessing to witness our boy discover life in sound.

Why is Isaac doing so well? Well he was equipped as we were in Taralye, an oral language centre, he was aided young and had access to the sounds of speech before he was two years of age. We never believed that he was restricted in life with his deafness in any way and told him to reach way beyond the stars because he could if he tried.

Isaac was mainstreamed in primary school, such a credit to the public system was Ringwood North Primary school. The Principal Michael Green saw our dream and he went above the norm to help us get there. Isaac was in the school productions, yes even with a speaking part. Oh, his speech? Well you cannot even tell he is deaf, even at times I cannot pick the difference between my four boys speaking. His grades? Well he has blitzed our expectations and we are so delighted he was given the opportunity to address Parliament at The Press Club that truly was a lifetime moment to behold as a mother.

Now in secondary school Isaac is again mainstreamed. He followed his brothers as he so desperately wanted to go to Donvale Christian College. He is the first profoundly deaf child they have had there, he is as happy and thriving as his brothers were. He continues to inspire me and all those around cannot help but be touched by his resilience and joy.

Ironically Professor Graeme Clark's wife used to teach at Donvale Christian College so we feel as if it's a full circle and a "sound one" at that.

University, most likely will be the next step for Isaac, probably something fancy and a little out of his mother's ability to help him with study wise, you see already Isaac had gone beyond his year level in some subjects and I know what ever he chooses to do he will be able to and will succeed. He believes in himself and we believe in him.

What we as a country can do for our kids is open up the assistance given to them, fund places like Taralye, give the parents the tools to make life choices and give these kids the ability to reach their full potential.

Choices are the key to success and fulfilment.

Isaac is happy, he lives in our community, and he can talk with whoever he chooses to, he can play on line on his PS4, something I never thought possible 15 years ago.

Education is the key to open the doors to living a full and chosen life.

We can turn these disabilities into an ability.

Isaac is deaf but he is not deaf Isaac.

This real life story brought to you by Isaac and his mum Mel

Name: **Brendan**

Location: **Lismore, NSW**

Age: **Early 20s**

I am a young adult who has been hard of hearing from birth. I grew up in a family where my grandfather was a returned services veteran with a hearing loss and I had parents who understood and worked with me to navigate the challenges that occurred on my hearing journey. For the first few years of my life, my hearing loss was simply something I learned to live with. Predominately this was because I knew nothing else and as a kid was more interested in achieving or participating in the same thing my class mates or my sister were doing.



In mid primary school, I went through what was and still is a typically difficult time for students with disability. The bullying that occurred to me was built on what was a fundamental lack of understanding on how to teach to the needs of a Deaf and Hard of Hearing student and also how to enable participation in everyday classroom activities. The severity of this bullying left me as a child with a low sense of worth, so much so that I didn't want to leave the house. With the care of attentive parents and teachers who were trained in working with students with disability, I returned to my education in a different school and began to move on with my life.

In Senior High School and as I moved on to University, I became involved in a number of leadership programs and activities. Through my participation I achieved the position of School Captain, State Youth Member for Lismore, ran for local government and spoke on behalf of Australian youth with Disability at the United Nations. Having almost completed my university degree in Media and Policy, I have maintained my civic and community engagement work to help reduce the likelihood of the barriers I faced occurring in the future.

As a hard of hearing person, I saw the issue of participation the same as a hearing person would consider how best they might play basketball. Where the difficulties were for me was in coming up against people, places and learning environments that didn't understand how simple it was to alter their work practices even slightly to enable my participation.

Hearing Health as a national priority to me is the difference between these barriers remaining and children and young people having the best possible start, both socially and from a health point of view.

This real life story is brought to you by Brendan

Name: **Jill**

Location: **Canberra, ACT**

Age: **78**

I have suffered from deafness for the past 16 years as a result of a viral infection.

I was examined by a professor and it was suggested to me to have a cochlear implant. I went ahead with the operation. However due to my profound loss even with a hearing aid for the other ear it still made my hearing situation too difficult to try for a job.

I have had to live on my earnings at low interest rates. There's no help from the Government for people like me.

This has isolated me greatly and denied me of any help through Government sources.

A lot needs to be done for people in this situation.

Surely Australia deserves a better Hearing Health plan for all Australians and not just for a few.

Name: **Geoffrey**

Location: **Perth, WA**

Translated from Auslan

I am profoundly deaf. My twin sister was her hearing. My parents lived a farm at Doodlakine, Western Australia.

At the age of 16 months old, the doctor tested me by clapping his hands near my ears. I couldn't hear.

I attended the Western Australia Deaf Children School at Cottesloe and Mosman Park. I have a Bachelor of Arts.

It is a very difficult life for profoundly deaf person.

Thank you.

These real life stories are brought to you by Jill and Geoffrey

Name: **withheld on request**

Age: **60 something**

Location: **Belmore, NSW**

In 1958 I started my working life in the metal trades as an apprentice in fitting, machining and spring making. In those days there was no WorkCover to oversee safety in the workplace. As my experience in my work increased, I was promoted to work on machines. After doing this for a while, I started complaining that my ears were hurting. I asked my employer if they had something to protect my ears. Their response was, what are you a sissy? After working for 30 years for different employers in the same industry, where the attitude was the same, I decided to have a hearing test done. The result of which was that the ear specialist recommended that I possibly could benefit from wearing hearing aids.

In those days the cost and even now it is prohibitive. So I carried on with my work. Slowly my hearing got worse and worse. The final result was that I withdrew into my own world as I failed to understand conversations. In family gatherings I sat in a corner, did not go out with my wife, until finally I started to fall into depression.

In 2000 I retired and in 2005 I started to receive a part age pension. I discovered that the Federal government had a Hearing program. In the end I received two subsidised hearing aids. They helped in the beginning but my hearing degraded even more.

In 2012 I attended a Probus Club meeting where a guest speaker made a speech about Cochlear implants. After her speech I approached her and as result of that I had an assessment done at SCIC Gladesville. From that assessment I received a cochlear implant in my left ear. What a revelation that was. 2 years later I received my implant in my right ear. I have become a completely different person. I join in conversations, became a member of the Cicada committee and also became involved with the Cochlear Company in research.

Loop systems to help people with hearing aids and Cochlear implants are rare. I believe that Council town planners and architects should pay a lot more attention to use sound proofing materials. The reason being that background noise and echoes are very difficult for us to cope with.

I believe a lot more should be done about public awareness regarding excessive noise. I strongly believe that an epidemic of deaf people will come in the next 25 years if nothing is done.

When I talk to people who ask me, what is that on your head and I explain to them the reasons how I got them they are amazed. As an example I get close to them and tell them to close their eyes. I then give a short sharp yell in their ear. Most of the time they say, hey that hurt then. So I say to them, multiply that by 50 times a day for 20 years. They say wow I did not realise that.

Governments, State and Federal, should investigate public awareness programs which have to be realistic by using people like me to show people what will happen if they do not look after their hearing.

Name: **Erica**

Location: **Barwon, VIC**

At the age of 32 I was told I needed hearing aids. As a young working mother the cost to our family was considerable. However the cost of not having them was even higher. It meant not hearing my own children's enthusiastic babbling, not being able to encourage them in their language acquisition, not hearing my husband's discussions and conversations, and not being able to work.



Finding the money for such an essential item was difficult and I seem to remember that it went into my husband's business overdraft (days before credit cards).

The aids were not that effective in my job as a teacher in a classroom of five and six year olds so I changed positions and became a specialist, teaching all primary year levels.

As my hearing got worse, more expensive hearing aids were needed and again the cost was almost prohibitive especially with household expenses, a growing family and my husband's business - to me, these were all higher priorities for our budget. I would get by. It will be ok, the old ones will do.

I changed jobs again so I had smaller quieter classes now in special education but eventually the high tech aids had to be bought. Other families upgrade the family run about, buy a new couch to replace the shabby kid-battered lounge or might go on a holiday. No, my family got hearing aids so their mum could talk to them, go on school council, be able to work and contribute to the family, be an almost normal mum.

The years have passed, now like many people who are hard of hearing I have had to adapt downwards in my career. I am no longer a teacher or special education teacher or advisor but work in the lesser paid community services sector and I'm thankful that I even have that. Now, like many other hard of hearing people, I live in a single person household. Like them, I don't socialise much out of work anymore as I am too exhausted at the end of the day to participate in the political and community groups that I once belonged to. Like others I am saving up for my next hearing aids that may take me through to when I retire, but with the uncertainty about funding and changes in NDIS eligibility, I fear I will not be able to afford them. Then where will I be? Old, deaf and isolated.

Hearing Health is a HUGE issue right across the community. It is under-diagnosed and the effects not acknowledged. It's time to Break the Sound Barrier.

This real life story brought to you by Erica

Name: **Hayley**

Location: **NSW**

Age: **37**

My name is Hayley. I have two cochlear implants and I still use sign language frequently and I can speak and hear well. I am a single mother of five children ranging from 5 to 16 years old.

I was born at 26 weeks. I survived. I'm lucky to have been introduced to sign language and wearing hearing aids before I was 1 years old. Growing up was challenging - I had to do a lot of learning. I'm often doing extra work, speech therapy, learning how to use a FM, learning how to use sign language, using an interpreter... fighting for our rights in an education field.

I'm currently a nursing student at a university. I struggle in my assignments due to language barriers, lack of understanding of our Auslan/Deaf language. I cannot have an Auslan interpreter or a dictionary while I sit for my exams, however I do have extra time. This is organised by my disability services.

The attitudes I experience in society, and from my clinical experiences in hospitals, have taught me that a lot of people don't understand the Deaf culture. People wonder how I can be a nurse!! While on clinical placement and in my job as an assistant in nursing I meet a lot of people. They can see that I can communicate very well in various areas.

There are still many people who don't understand that there different level of deafness and I'm always explaining the differences and our Deaf culture. I'm happy to work with everyone to share this awareness to the society. I believe this can be achieved by providing correct information (such a "blue book") to new parents who may have a child with a hearing loss. With information about sign language, hearing aids, services, and feedback from many deaf people about the achievements in their lives.

Sign language classes can be made mandatory in all schools (government and private) so everyone can be able to be part of our culture.

Placing a video or a blog or something like that on the internet where people search up and find those blogs would be beneficial.

Name: **Jack**

Age: **21**

Location: **Melbourne, VIC**

When Jack Dowling came to Taralye aged 2½ years in 1998, he never dreamed he'd be walking back through the door almost two decades later. Instead of playing with building blocks in the kindergarten rooms, Jack returned in 2016 as an intern and to lay foundations for a career in finance and business.

Half way through a Commerce & Economics degree at Monash University, Jack believes his early years at Taralye shaped him in terms of where he is currently, and where he's headed. In particular, he credits Taralye's early language and numeracy program, and the transition to school program, as helping set him up for life. Along with early intervention and school transition, Jack attended Taralye's playgroup, early learning program, and 3 and 4-year-old kindergartens. He describes Taralye's services as comprehensive.

"The staff really care about the children and go above and beyond to ensure their needs are met".

Apart from the focus on language acquisition, Jack remembers an emphasis on self-management of personal hearing devices. It's something for which he is grateful because of the independence it has brought him. Born with a profound bilateral hearing loss, cochlear implants are Jack's link to the world of sound. While Jack identifies as having a disability, it is neither defining nor limiting.

Like other university students, he works part-time and enjoys sport (soccer and skiing with Monash University's sporting clubs). As an alumni member, Jack has kept in touch with Taralye. He has given speeches to parents of hearing impaired children about living with a hearing impairment and transitioning to school, and about how he's been able to live life without being held back by his disability.

"It's important that parents share my belief that hearing impairment won't prevent their children from achieving happiness and success in life," he explains.

As Jack has grown and matured, so too has his appreciation of Taralye.

"I understand why Taralye was one of the factors that influenced my parents' decision to move to Melbourne when I was two".

His recent work as an intern has reinforced this.

"I was able to see that Taralye staff consider their work to be much more than just a career. Their passion and commitment to giving the very best early learning support to children was clearly evident and very heart-warming".



This real life story brought to you by

Name: **Isabelle**

Location: **Sydney, NSW**

Age: **Mid-20s**

I have a moderate to severe progressive loss in both of my ears. I first started wearing hearing aids when I was five years old and until recent years had only good things to say about Australian Hearing. I have had many positive experiences at Australian Hearing and have had some audiologists who were life changing to me in helping me achieve my goals of being able to hear and cope in the environments that I need to. A few years ago however I saw a new audiologist and the results left me struggling with anxiety over what used to be a simple appointment because I no longer trust that my audiologist will listen to my needs.

In August of 2015 I went to Australian Hearing to update my four year old hearing aids. It was my first time at the new centre in the hearing hub and having grown up going to Australian Hearing with some amazing audiologists I had high expectations for the new one that I was meeting that day. I went in and had my audiogram taken, feeling unsure at the lack of sound proof booth for the testing but went home with an unchanged hearing loss from the previous test 3 years ago despite many ear infections. My audiologist Sarah* had advised me that they no longer carried the brand of hearing aids that I had been wearing and would need to switch brands, always interested in trying out new technology I agreed to this switch and ordered my new pair.

One month later I returned eager to try out my new hearing aids. Aware that they would sound strange for the first three to four weeks I was not alarmed when they didn't sound like what I was used to. I knew from past experience that if you just stick it out your brain adjusts to this new normal and the new hearing aids will be back to just being my set of ears again. I discussed with Sarah about the settings that I wanted on the hearing aids so that I could get the best use out of them and was frustrated when she argued that my choices were wrong because having them on automatic switch to directional is "better" and that I should have my hearing aids linked so that I could not adjust the programs or volume on the hearing aids individually. I persisted and insisted that I have tried the settings she suggested however they simply didn't work for me. Reluctantly Sarah agreed to set them up in the way I had asked and I left slightly frustrated but excited to see what changes I might notice in the new pair ears.

My joy was short lived, I quickly noticed that outside of that quiet audiologist office I was being bombarded with painful environmental sounds; I also noticed that I was greatly relying on lip-reading to understand any speech at all, much more than I had struggled with any previous pair of hearing aids. Still I persisted, sure that if I simply gave these hearing aids a chance my brain would make it click that this was the new normal and once again I would be hearing clearly.

The next day I went to work at Woolworths at the checkout and found that I could not actually hear any of my customers but was relying solely on lip reading; meanwhile the simple sound of a trolley hitting a barrier or the beep of the register was hurting as if someone were scratching a chalkboard.

My tinnitus (ringing in the ear) was getting worse the more I wore the hearing aids and I started to develop near constant hyperacusis (hyper sensitivity to sound) meaning that whatever I could hear with the new hearing aids was extremely painful. After a day of wearing them I finally broke when I

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went to use the Tswitch on my hearing aids and found that despite my asking for the microphone to be turned off for the Tswitch it was turned on, which left me unable to hear what I was trying to listen to over all the background noise that I was hoping to cut out with this function. I burst into tears and found myself no longer wanting to leave the house because trying to communicate was too difficult, and often too painful due to my new sensitivity to all environmental sounds.

I went to my parents place to share all my frustration with my dad who I knew would understand how I felt. Then he suggested something that I hadn't thought of, I could go back to my old hearing aids. I had never given up on a set of hearing aids before but this time they just weren't working with the current programming. So after a week of emotional and physical exhaustion I put on my old pair of hearing aids. This switch meant that I could hear speech again but the hyperacousis and tinnitus didn't go away as I had expected it to. I was then left with a dilemma, I still needed new hearing aids as my old ones were out dated, but the idea of going back to see Sarah made me anxious and stressed to the point of tears again. She didn't listen to my pleas for the way I wanted my hearing aid settings and, despite telling me that she had set them up as I asked, had left the settings in ways that made the programs and features of the hearing aids completely unusable.

It was a few months before I was willing and emotionally prepared to go back and make a new appointment but this time with a different audiologist. Because I couldn't handle having another experience that left me unable to use my hearing aids for basic communication I insisted on seeing an old audiologist Angela* who I had seen in high school. Angela listened to what I had to say and altered the hearing aids accordingly however it seemed that some of the damage had already been done. The hyperacousis although not as bad as it initially had been in that first experience with those hearing aids, never quite went away, I found myself unable to enjoy music anymore as the high notes still hurt my ears. It also took me quite some time to adjust to the new levels of tinnitus that often prevented me from sleeping and noisy situations were now far more difficult and stressful to hear in. My left ear which was worst affected by those hearing aids became more decorative than useful. Either sound was so soft that I couldn't understand speech or the sounds were too loud and painful. I learnt to rely on my right ear and made adjustments to my life to accommodate my new hearing levels.

Another year passed and I returned to Australian Hearing for my annual hearing check, my hearing had always been the same between my ears and I knew that having a progressive loss I could expect a 5db loss in both ears as had been the pattern. To my surprise I had lost 15-20db in the high frequencies of my left ear, which is a far bigger drop then I had ever experienced. Angela adjusted my hearing aids accordingly and I found for the first time since I received that pair of hearing aids in August of 2015 I could understand speech with my left ear.

Unfortunately due to having a progressive loss I cannot prove that the drop was caused by that first audiologist, Sarah setting up those hearing aids, however having never had a difference between my ears in the past and only experiencing 5db drop per year I am certain that it wasn't a coincidence. I still struggle with hyperacousis and tinnitus in my left ear and the results of the loss are irreversible.

The simple thing of having an audiologist not listen to their client resulted in permanent damage to my hearing. The audiologist I see now is helpful and listens to what I ask for in my hearing aids and gives me the control to choose what settings and functions work best for me and how I use my hearing aids but that experience has not stopped me from feeling anxious at the thought of seeing any other audiologist just in case they too don't listen to my knowledge of my own hearing. Hearing

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Messages to our elected leaders

is an extremely personal thing and everyone uses their hearing aids differently to get the best experience out of them for themselves. Audiologists telling clients how their hearing aids should and have to be worn is not helpful, an audiologist appointment should be more of a trouble shooting session where together the audiologist and client talk through the needs and goals of the client and work out the best way to achieve those things for that person.

*Names have been altered

This real life story is brought to you by Isabelle

Name: **Janith**

Location: **Melbourne VIC**



“My goal is to be a doctor.”

When Deaf Children Australia first met twelve year old Janith his family was in crisis and Janith was suffering from trauma. The family were about to be evicted from their home. His teacher was very concerned about Janith’s emotional wellbeing and indeed, the whole family’s wellbeing after everything they had already been through.

When Janith was five years old, and his little brothers Pasindu and Ravindu were aged three and two, the family travelled from their Australian home to Sri Lanka for a supposed holiday. While in Sri Lanka, Janith developed pneumonia for the second time in his short life. His mum Thanuja was concerned that after he had recovered, Janith didn’t seem to be able to hear well from his left ear. Then every mother’s worst nightmare occurred.

With no warning, Thanuja’s husband disappeared with all three of their children. He hid out, refusing any contact. The three young boys were suddenly cut off from their mum, traumatising them – and Janith never got the medical care he needed.

Thanuja explains, “I was desperate to get my children back but I was powerless in Sri Lanka. I had to return to Australia as they are Australian born – and my only hope was a legal battle. The Attorney-General’s Department helped me through the Hague Convention on the Civil Aspects of International Child Abduction. Ours was the first case that the Australian and Sri Lankan Governments worked on together. We won our case in the High Court of Sri Lanka and after one and a half years of being forced apart, I finally had my children again.

“As soon as we were reunited, I realised Janith’s hearing was still damaged. I took him straight to the hospital and they told me he had permanent hearing loss.”

Janith’s hearing continued to deteriorate through primary school and when he was in Grade 6, his family were referred to Deaf Children Australia (DCA). We first needed to assist the family to avoid homelessness as the boys’ dad had stopped mortgage payments. They had no family in Australia and nowhere to go. Family Support Worker Keshanee advocated on their behalf, connected them up with other services and provided emotional support during the court case to split the family’s assets. They were then able to resettle in another home.

Keshanee has been working with the family over the past year and fortunately, has been able to communicate in their first language of Sinhalese as well as English. Thanuja expressed her concern to Keshanee about the impact of the past trauma on Janith, and the impacts of his deteriorating hearing. Keshanee linked in with other DCA Services to help Janith to strengthen his emotional wellbeing, and be able to self-regulate his emotions when he was feeling frustrated or upset. Keshanee has been helping Thanuja put successful strategies in place to help with Janith’s behavioural challenges, and encourage Janith to become more independent. Over the past year,

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these strategies have empowered Janith and Thanuja to build up a network of support, and access all available services.

When Janith was assessed at the Cochlear Implant Clinic, Keshanee was able to help Thanuja and Janith understand the complex medical information in terms of Janith's hearing loss. She supported Janith and Thanuja as they grappled with the decision on whether they should go ahead with a cochlear implant. Janith's hearing had been progressively deteriorating in both ears but as Thanuja explained, "They couldn't tell us how much hearing Janith would lose and how quickly he would lose it".

Janith and Thanuja had to weigh up whether to risk Janith's residual hearing for the benefits they could potentially achieve with the implants. Janith decided he wanted to get bi-lateral implants before starting secondary school. Keshanee provided support during some of the medical appointments and was at the hospital when Janith came out of surgery. Thankfully, the operation was a success but Janith is still adjusting to the different way of processing sounds through his cochlear implants. As he expressed, "Sometimes sounds are still too loud." Every child needs the right supports around them to make the best use of the technology.

Thanuja had many conversations with Keshanee about how to select the best secondary school to meet Janith's needs, and now Janith is settling well into Year 7. Due to Janith's academic excellence, he received a Hume City Council Education Scholarship to help with the extra costs of starting secondary school. Thanuja proudly told us, "Janith is a very smart boy and since getting the implants, his vocabulary and his work has improved. Janith loves sports and he is a beautiful dancer, performing at the Sri Lankan Language School concert. He also plays violin and keyboard. Janith is determined to move forward with his life and not let the challenges with his hearing hold him back."

Janith reinforced that, adding, "It's easier for me to learn at school now. My goal is to be a doctor when I grow up so I can help people. Maybe I can do operations too."

Name: **Kaitlyn**

Location: **Frankston VIC**

Sandi shares her story of her experiences with her first daughter Kaitlyn and why she has started the Parent Support Group 'Hear Together Mornington Peninsula' with support and encouragement from Deaf Children Australia.



When Kaitlyn was almost four, I was getting cross with her because she didn't seem to be listening to me. Then I thought, 'What if she can't hear me?' I felt like the worst parent. My dad and I have small ear canals so I thought maybe she has the same issue and her ears are blocked with wax. I

This real life story brought to you by

tried calling her from another room. "Kaitlyn, do you want a lolly?" I thought any child would respond to that – but she didn't come.

I took her to the GP and then the Ear, Nose and Throat (ENT) Specialist. Kaitlyn's hearing test showed she had a low level of hearing. She had been lip reading and we had gone for some time without knowing. She had fluctuating hearing with so many ear infections and she has permanent nerve damage. Kaitlyn was fitted with hearing aids and it was like a rollercoaster ride because we didn't know what to do next. Before the diagnosis, we enrolled Kaitlyn in a school, had done the transition program and had her excited about her new uniform. We soon found out that she was the first child at that school with a hearing impairment. I was concerned but she had help from a teacher's aid and had more grommets inserted.

Kaitlyn came through the first two years of school well and socially, she is great. She has very good speech and Kaitlyn has been learning sign language so we can use sign to communicate in noisy environments.

Our family and friends have been really supportive and we know older people with hearing aids who have been fantastic. But I wanted to start the Parent Support Group because at the time, I really wanted Kaitlyn to meet more children around her age who have shared similar experiences.

After twelve months of not knowing what to do, I had to learn to be very assertive for my child. I had to ask a lot of questions and demand what is in her best interests. When Kaitlyn was in Prep, I encouraged her school to apply for technology to help her in the classroom and assist future students with the same needs. At the end of Grade 1, we felt Kaitlyn would benefit from another school with a hearing unit. She moved there at the start of this year so she can be with other students with a hearing impairment and benefit from their specialist expertise. We have seen a remarkable improvement in Kaitlyn since the move and as a parent I have been overwhelmed by the support from the school.

As a Parent Support Group, we can support other parents dealing with the same issues and share our knowledge. Our group welcomes extended family members including children. It is a fun, relaxed environment and is open to all parents with a child that is deaf or has a hearing impairment of any kind.

I coordinate the local Toy Library so I thought we could run the Hear Together Parent Support Group from the Frankston Toy Library. My journey with Kaitlyn has made me more aware of the support needed for parents and I successfully applied for funding from the local Frankston City Council, Bendigo Bank and Lions Club to purchase educational toys and equipment for children who have a hearing or vision impairment, autism, down syndrome or other additional needs. I am so excited and proud to provide these programs for others.

Hear Together Mornington Peninsula Parent Support Group welcomes parents with children of all ages that have a hearing loss or deafness to their bi-monthly meetings at the Frankston Toy Library. The group is affiliated with and supported by Deaf Children Australia and the Frankston Toy Library.

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Name: **Joe**

Age: **69**

My journey from a hearing person to profound deafness has taken over 40 years; an ever encroaching process that now places me in a twilight zone, somewhere between the hearing and Deaf worlds. I wasn't always deaf, completing high school and technical college without any hearing issues. It was when I started part-time university, particularly in tutorial settings where there were soft spoken participants, that I realised I had trouble hearing.



Consulting my doctor led to a series of x-rays (no CAT Scans or MRI in those days) but no particular abnormalities were detected. I just need to get some hearing aids, rather bulky BTE ones, which I then wore as needed. It wasn't very hip for a young man to wear hearing aids back then. For the next thirty years I relied on ever increasingly powerful hearing aids and copped as well as I could in the hearing world. Many situations were difficult but with determination and reliance on assistive devices I did ok, both in relationships and employment.

During this period more medical advice was sought and the prognosis was that I suffered from otosclerosis. A stapedectomy proved useless and the medical consensus was that the disease had progressed, invading into the cochlear, causing both conductive and extensive sensorineural hearing loss. The continual use of hearing aids was my only option.

By age 50 acoustic hearing aids no longer provided sufficient stimulus, particularly in one ear; so the possibility of a cochlear implant was investigated. I was among the earliest cochlear implantees in NSW who still add some residual hearing. The result was very favourable and I could now hear better with friends and family commenting that even my spoken voice level had dropped.

While still experiencing many difficult hearing situations, the implant got me through to retirement age. Despite my continuation in the hearing world the ever continuing and insidious otosclerosis was still working away causing more havoc in my middle and inner ear. It prevented a bilateral implant with the surgeon unable to make a safe incision into the cochlear and, had compromised the initial success of the implant. There is not a lot of medical literature about cochlear otosclerosis but what there is describes its invasion into the otic capsule (bone area surrounding the cochlear), remodelling it causing sensorineural hearing loss.

Other research links otosclerosis to sensorial hearing loss due to the leakage of enzymes from bone into the inner ear, the degeneration of the outer wall and compartments of the cochlear ducts. Whatever the exact explanation is, otosclerosis has for me, resulted in profound deafness. What many people don't understand is that the post-lingual deafened can be deafer than the pre-lingual Deaf. I am now aged 69 and my ability to hear is severely restricted. The only conversations I can achieve are face-to-face with clearly spoken people in noise free situations; group conversations are impossible. I rely totally on captions to watch TV, utilise wireless microphones, use a Captel phone and have been experimenting with several voice-to text applications. Anticipating that it may be an

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eventual necessity I undertook the basic Auslan course and achieved some signing skills.

But, the dilemma in using Auslan is that I don't know any signers. I'm not part of the Deaf culture, I can't really decipher sign language at its normal speed and, for all of my life I've used spoken English, it's my culture, I don't want to abandon it.

Making the identified Hearing Health Strategies part of the nation's health priorities makes perfect sense to me.

I would, as an older deafened person, add "Improving and Extending Captioning Services" to the list of the identified priorities. I suggest this because anything that can improve the delivery of speech-to-text systems will diminish the isolation that deaf people experience and has real health benefits.

Name: **Alex**

Age: **70 something**

Location: **Sydney, NSW**

Mum and Dad came to this good country with their three little boys in 1951. I was the eldest at 11 years old.

My father passed away at 92 with perfect hearing. However, Mum wore two hearing aids for many years before she passed on at 75.

Unfortunately, all three boys inherited Mum's bad hearing and all of us had been wearing double hearing aids for many years until I was fitted with one cochlear implant three years ago.

My hearing life changed for the better almost overnight!

Directly and indirectly, the cochlear implant gave me a new lease on life socially, professionally and in every other way. The hearing aid in my other ear continued its good work but somehow the cochlear led the way and complemented the other in such small and large ways which gave me more confidence in social discourse as well as giving me a greater appreciation of music and dancing.

For this blessing I take this opportunity to thank people like Professor Bill Gibson, Mr Peter Anderson (former Minister for Health), Sue Walters (President of CICADA volunteer support group) for their multiple contributions to making thousands of Aussies like myself happier in the activities of our daily lives.

These real life stories are brought to you by

Name: **Kirsty**

Age: **45**

Location: **Armidale, NSW**

I have worn hearing aids for 50+ years. Four generations of my family live with varying degrees of hearing loss, so I continue to note the disadvantages over diverse age groups, of my siblings, nieces and nephews and grand-nieces and nephews. I offer my story as I am saddened that improvements in services for adults with hearing loss have been minimal during my lifetime.

I am fortunate in living a full active life though not without obstacles. The first in 1956 when my medical denied me access to Teachers College where mild hearing loss was first diagnosed (puberty onset). By the time my second child, a son was born in 1965 I noted further loss and purchased a hearing aid. I found out much later that pregnancy was likely to increase hearing loss. I progressed to two hearing aids fairly soon after and “coped” in a hearing world as a full time housewife and mother. My social life was family and church. Pressures of being responsible for the raising of my children (husband worked long hours) prompted a wish to find more stimulation in my life. Consequently, I took on mature age studies and did a full time degree at Sydney University. Without any assistance for my hearing loss. I graduated in 1980.

With my daughter age 18 and son 15 I started to think about re-entering the workforce. The 80’s were a time of high unemployment and all of many, many job applications were unsuccessful. So I did voluntary work in Adult Education and took on a Post Graduate diploma in Adult Education, receiving my Graduate Diploma in 1984. I had noticed with my studies that my hearing loss was a handicap. I did not attend tutorials as they were too stressful in following the ideas being discussed.

An advertisement in my church bulletin about an inaugural group of the Self Help for Hard of Hearing Organisation Inc (SHHH) prompted me to go along, and greater surprise, I volunteered to be its President!

I enjoyed a satisfying and rewarding career in the welfare community support sector - though underpaid given my formal qualifications - until my retirement in 2011 (age 71).

While continuing to live an active life in rural NSW I have noted awareness of access for hearing impairment is significantly lower in regional areas. The Town Hall, Bowling Club and Services Club of Armidale do not have loop facilities - so disappointing that I struggle with the limited acoustics when I attend functions at these public venues.

What disappoints even more though, is the observation that current services are inadequate for enabling younger members of my family to live an active lifestyle as a hearing impaired person in a hearing world. It is different to being deaf.

PS. I benefited too from Australian Hearing Services and the former Commonwealth Rehabilitation Service.

This real life story brought to you by Kirsty

Name: **Lewis**

Age: **21**

Location: **Sydney, NSW**



Lewis was born with severe to profound hearing loss.

‘When my parents first learnt I was deaf they were very upset,’ says Lewis. ‘They thought I would need to learn sign language and live a life communicating with only a small number of people.’

But this was not the case for Lewis whose parents brought him as a young baby to The Shepherd Centre – an early intervention provider for children who are deaf or have hearing loss. The Shepherd Centre is a learning hub for children with hearing loss and their families. Kids at the centre learn to hear, speak and develop social skills to their full potential. Their families are equipped to continue the child’s learning journey at home. Families go through this process surrounded by an encouraging team of expert staff in speech pathology, paediatric audiology, family counselling and a life-giving community of supportive peers.

‘My family and I are extremely lucky to have found The Shepherd Centre,’ continues Lewis. ‘When I started school I could listen and speak just like any other kid.’

Fast forward almost two decades and Lewis achieved a stunning 94.9 in his Higher School Certificate and is now in his third year of a chemical engineering degree at the University of Sydney.

‘I liked chemistry and maths at high school and I did pretty well in them. So I thought I’d combine the two and do chemical engineering.’

‘I have two Cochlear Implants and I hardly ever think about my deafness,’ continued Lewis. ‘I’m just like everyone else thanks to the wonderful team at The Shepherd Centre.’

Lewis is one of many examples of what can be achieved by children born with hearing loss with the right support. The impact of The Shepherd Centre’s work is remarkable. Over 90% of the students go to mainstream schools at the age of five.

Because of the right support Lewis has a great future ahead of him, but it wouldn’t have been possible without the philanthropic support that The Shepherd Centre received. Raising money from donations is becoming increasingly difficult with many worthy causes around. The Shepherd Centre calls on the government to support critical early intervention services with funding due to the obvious economic benefit to the Australian community.

‘I love to play cricket and also do a bit of surfing near my home in Sydney’s Northern Beaches. Being deaf doesn’t stop me doing any of the things I love!’

Without The Shepherd Centre Lewis says he wouldn’t have had anyone to help him with his hearing.

‘They taught me how to listen,’ says Lewis. ‘I’d be completely different without The Shepherd Centre.’

This real life story brought to you by the

Name: **Melinda**

Location: **Warrandyte, VIC**

Age: **50**

My story is about balance disorder, vestibular dysfunction and vestibular migraine.

We were a middle class family, a street full of children on their bikes, street cricket and playing outside until the street lights came on. I go back to that time in my mind when my world starts to spin, back to the times I could ride my bike, and nearly touch the sky on my swing. Nothing like this would be possible for me now. My life is like a constant merry go round. A constant theme park ride, a smooth lull then a big dipper drop unexpectedly removing all sense of space and moment. Fighting to keep myself upright and in a normal position preparing for the momentary calm before the next rise hits.

Me, well I'm the sort of person who sees the precious moments in life. I like to stop for a coffee and watch the "normal" people enjoy life without fear, trying not to find a touch of jealousy in what seems to be a simple request of life...to stop the movements in my head. Balance, its everywhere. It's in our steps, our hobbies in our planning and even now in our art work on our walls. It's a catch phase and unfortunately something we all take for granted.

Diagnoses for me took about 25 years. I knew I was not suffering from anxiety or a little virus. I knew this was not normal and could not be "me" after the years of previously never been ill as a child and young adult. I knew this was not normal and that indeed a diagnosis more than it might be Labarynthitis, was enough.

Months of being house bound, not understanding what was wrong with me, no doctor really talking notice of the hell I was living in my body. Trialling different medications and having terrible effects on my body, trying to be a mum to my four kids, one whom has extra needs and keeping them out of the fear of my ever moving world.

I went from doctor to doctor, specialist to specialist, MRI, CT scans, blood tests, medications, diets, relaxation ,numerous hideous testing from the Royal Eye and Ear hospital ,then a psychologist who deemed me quite normal which really confused the medical teams. This was indeed physical and not emotional. Although I was getting quite upset and frustrated by this time and that was beginning to take its toll on me.

Being relieved that I in fact didn't have MS, I settled to the final diagnosis of Pure Vestibular dysfunction and more recently Vestibular Migraine. Thankful that I had continued until I had found an answer and one that had finally made sense and fitted my symptoms.

It is a horrible diagnosis and the impact of that is devastating to my children, my family, my very beautiful and supportive husband and my friendship group.

I have found a way to forgive myself for all that I miss and destroy with my illness. I have a beautiful family and a wonderful husband who together we deal with this beast on a daily basis. I've lost friends, I have had comments made when I stumble in the shopping centres, I get that look from people when they see my DSP card I lose my words and cover it up by, lol that's just Mel. I take the

This real life story is brought to you by

long way around a shop to avoid escalators, I walk fast to keep my balance, I contemplate a walking stick now and then, but decide against it as my children have enough to endure. Those beautiful home shops, no never do I attempt to go in there, I stand at the window and peer in like a child at the Myer windows at Christmas.

I have tried to work, I try to volunteer in anyway can, but the reality is I can't really. I get it. I used to own my own business and I was a workable member in society, I cannot do that anymore. I wouldn't employ myself, I'm a risk and unreliable no matter how many skills I may have.

There is a huge gap in our medical teams, no follow up and no system to follow. I had to fight for myself to be believed and to find someone who would take me seriously. We need education and a system. Many years of trying and wondering and thinking maybe just maybe I've missed something would have been eased with a system and a doctor listening to me not a pre conceived idea of what is wrong.

I am disabled in every sense of the word, but I am able to try to make a better path forward and to be I that place where usual meet my normal.

I am still here, behind the veil of "normal" I am still here beyond the head fog, lost words, and diminished life. I am me.

Balance is a spinning issue and one that education and support would change the lives for so many. Trying to find a new balance in my life. Vestibular physiotherapy is really my last hope.

Name: **Sandra**

Age: **70**

I was born with a moderate hearing loss, and this was not known until I was 18 months old.

I was fitted with a hearing aid at the age of two and a half years. When I was 3 years old I had intensive speech therapy until I was 5 years old. Without my hearing aids I would be lost. I am glad my parents, grandparents, uncles and aunts persevered to continue to teach me to talk when I was young.

At 21 I then needed two behind the ear hearing aids and had these for several years until my hearing deteriorated. At the age of 56 I made my choice of having a cochlear implant which was an amazing success, and decided to have my second implant five years later. Going bilateral was the best thing ever as now I can hear.

The enjoyment of discovering new sounds each day is exciting and fun and continues to this day now. I am 70 years old and totally enjoying my life.

Name: **Louise**

Location: **Mildura, VIC**

Age: **27**

The main issue that I have is that I am exempt from any funding or support from the government as I have a full time job as a nurse (with thanks to my implants, otherwise I'd be on a disability pension).

I find this hugely frustrating as it's costly to maintain the implants and secondly there are people who are able to work who choose not to!

It's time for real change to help me and many Australians like me.

Name: **Elizabeth**

Location: **Perth, WA**

I have had loss of hearing now for around 30 years and it got worse over this period of time. I found that my hearing aids didn't pick up the high frequencies that I needed and they cost a few thousand dollars for the two devices.

Over the years I have had serious depression because of my hearing loss and found it hard in social situations and sometimes ended up in tears because when I asked what I missed, I was frequently told it didn't matter, but of course it mattered to me!

I went to see a specialist at Ear science in Perth a few years ago and after tests I was told that I would benefit from an implant. I have had my right ear implant for around 18 months now and I am waiting for the left ear to be operated on.

I have been very happy with the difference it has made and I would encourage anyone that was unsure to chat to someone about whether they could benefit from it.

For the 10 years I have lived in Australia I have found it very difficult to gain employment as I found employers were not helpful when I told them I couldn't answer the phone but I would be fine with other duties. I am still looking for regular employment now and I can hear better on the phone with my device, but I am never sure how to address employers to give me a chance of employment. I am not allowed any help from Centrelink, as my husband's wages won't let me do this, but all I want is work and help to find it.

I think hearing is very important and it affects families, friends, relationships and causes depression and anxiety to the sufferer.

Please take notice of people with hearing loss. We want to be part of Australia's future.

These real life stories are brought to you by Pat, Louise and Elizabeth

Name: **Pauline**

Location: **Sydney, NSW**

My name is Pauline and I'm a filmmaker. This is a photo of me on the set of my last short film, Blue Mist.



I've been working with the deaf community for the last four years through research for my novel, short films and feature film scripts at the Hearing Hub at Macquarie University.

The community couldn't be more supportive of my work. They believe that wider hearing community support, can only improve awareness of the deaf community.

I'm working closely with Hear For You to run '*Rock my World*' workshops for deaf teenagers. These workshops will teach teenagers filmmaking skills, so that they can tell their stories and reach the broader community. We will be showcasing these films through an inaugural film festival in August.

We only think of our hearing when we have a problem. The baby boomer generation is moving into the prime target range for aging hearing loss. We need to stimulate the conversation on hearing loss now.

I found the deaf community when I discovered that my hearing was decreasing in one ear, caused by a childhood virus. For now, it is okay... for others this can be the start of the rollercoaster ride for their hearing health.

Australia has nearly 4 million people who have some form hearing loss. They deserve to have their voice heard.

Please listen because one day it could be you, that can't hear their voice.

This real life story is brought to you by Pauline

Name: **Roslyn**

It starts with witnessing my grandmother and then my father becoming increasingly isolated from the world. My grandmother would sit in the corner at family gatherings and no one would talk to her. I now realise how difficult that would have been for her. I don't remember her wearing hearing aids. My father did wear hearing aids but he still found it difficult to hear when in a crowded room like a restaurant. He blamed his hearing loss on his war service.

In my mid 50s I became aware of my own deteriorating hearing. Initially in situations when I was chairing meetings and started to find it hard to hear what people were saying across the room. I needed to keep working and didn't want to become isolated from family and friends.

I made an appointment with the audiologist and discovered I had 50% hearing loss! I had learnt to lip read which worked to some degree when you are close and in front of people but not in meeting situations. My children also complained that the TV was loud. When they turned it down to a level of comfort I couldn't hear a thing. So I got my first hearing aid and was amazed to hear birds again!

My hearing aid has enabled me to continue working fulltime, which has provided me with the income to purchase a property that I now own. Last year I got my second hearing aid and have realised I do benefit by having two rather than one. Each of them cost \$3,600 with a mean rebate from my health insurer of \$300.

Having hearing aids never "cures" hearing loss but it goes a long way to making life more enjoyable and productive. I can enjoy going to concerts and listening to music, although I tend to favour orchestral music rather than singing as I can't hear all the words. I still misinterpret what people are saying at times, especially if they are behind me. I work in an open plan office which is not conducive to a pleasant work environment. I miss hearing the office chit-chat behind me so I just ignore it. I have subtitles on the TV to assist with my understanding of the dialogue.

I am concerned about how I will update my hearing aids when I retire in the next 12 months and will have to live on the pension.

Name: **Sam**

Location: **Melbourne, VIC**

Age: **late teens**

Carmel and Alan Greatorex suspected their baby boy had a hearing loss quite early but it wasn't until a routine test at seven months that professionals took notice of his unresponsiveness to sound.



Diagnosed with profound bilateral sensorineural hearing loss, Sam received his cochlear implant aged 14 months. Carmel remembers the sacrifices they made to give Sam the best possible start. "We were suddenly plunged into the unknown world of parenting a child who is deaf and the intense research began. We poured over information about what was on offer and it became obvious that we needed to move to Melbourne if we wanted optimum cochlear implant support and oral language early intervention."

"I've said many times that walking in to Taralye for the first time was like coming home. We were warmly greeted at the door and immediately made to feel like we belonged at this welcoming place. With the compassionate help of Taralye staff we were wonderfully supported and settled into the early intervention programs and then kindergarten where Sam grew into a very lively and full-on little boy with lots of friends".

At 18 months, Sam was enrolled into Taralye's early intervention program. He began one-to-one therapy to develop his listening, speech, and language skills. Within the caring environment of playgroup, his family formed supportive bonds with other families. The rich learning environments of Taralye's group programs and kindergarten, and the specialist skills of Taralye professionals, helped Sam gain self-confidence and social skills in readiness for school.



Supported by Taralye in the transition to mainstream schooling, Sam, now 17, has thrived. His deafness has been no barrier to reaching his dreams, one of which - representing Australia in the pool - was recently fulfilled. "I call myself a swimmer. It's what I do, it's who I am. It defines me even more than my deafness, although I do sometimes call myself a 'deaf swimmer' in instances, such as, when I represented Australia at the Deaf World Swimming Championships in Texas last year. If I wasn't deaf I would never have had that opportunity to compete overseas."

"My squad at Nunawading were all so excited for me and even a little jealous. I met people from all over the world and loved every minute of my time in Texas".

Sam now holds four Australian Open records and eight Australian age records in freestyle and backstroke. He was awarded Deaf Sports Australia's, Male Athlete of the Year in 2015.

Through hard work and steely determination Sam is well on his way to achieving his future aspirations of representing Australia at the 2017 Deaflympics in Turkey, and then at the Commonwealth or Olympic Games.

This real life story is brought to you by

Name: **Sandra**

Location: **Melbourne, VIC**

Sandra started the New Connections Parent Support Group in 2012 with the support of because, as she says, “I noticed a big lack of connections for families, particularly when they left Early Intervention services to move into school”.

“Our family had chosen a mainstream school nearby with no deaf facility for our son and when he started Prep, we noticed a big difference in him. He had some support from a Visiting Teacher but he was the only child with a hearing impairment at his school and he no longer had that fantastic boost to his self-esteem from being around other children with hearing aids. He missed the other children and I missed the support as a parent.

We have always gone to Deaf Children Australia (DCA) Family Camps so we were aware how important connections are. During the transition to Prep, I felt I had to find out a lot of information on my own and I thought that if some parents aren’t so good at accessing information, or if they have different linguistic backgrounds, they could be missing out on helpful resources.

So we started New Connections with the support of DCA to bring together families from across the Inner South East Region of Melbourne. We alternate between family events and parent discussions. Family activities have included rock climbing and a family picnic, and we have an African drumming workshop coming up. We had one child attend the rock climbing event who had never before seen another child with hearing aids. That opportunity was really special for him and it’s important for all of us families to share information in real life. The online forums are great but it means a lot for us to get together as entire families and build meaningful relationships. There are support services for siblings past eight but it’s important for younger siblings to share their experiences as well.

We decided to move Lachlan to another school that has a hearing support unit for the start of Grade One. It was lovely that when we visited the school, there were children waving to him and welcoming him in almost every classroom. He had met some of the children at our Support Group, some at DCA’s Camps and some at DCA’s Primary Deaf Sports Day. Now, my son sees children with hearing aids and implants every day. My pressing need to connect with other parents is being partly addressed in the schoolyard but it’s still really important for us to have a network to bring everyone together. Some kids feel like, ‘No one else looks like me at primary school and I feel alone in the world’. We have tried to avoid our son feeling like that.

As a support group, we can meet the distinct needs of parents, siblings and children with varying degrees of hearing loss just by getting together. When all the parents know how to use effective communication, we can have lots of fun. We can also access expert information through our parents’ workshops organised by DCA’s Community Development Coordinator Debra Gormley.”

Name: **Sue**

Location: **Sydney, NSW**

I lost my hearing completely and suddenly from meningococcal meningitis in 1984. I nearly died from the septicaemia. I lost the use of my legs, couldn't walk for several weeks and lost my balance completely.

I lost the use of one eye for a while too and everything looked blurry, which didn't help with the walking. One of the hardest things was hearing this roaring noise in my head, tinnitus, and nothing else, not even my own voice. I guess I was shouting at everyone. It's hard to believe that my "former" busy, social, ordinary life just came to a standstill like that. I couldn't work or pay my rent.

It took me some months to recover from all the effects of meningitis. Lots of hospital appointments to monitor all my health issues. My mother told me my voice was going flat, with no expression and tried to help me pay attention to this. I had to communicate mostly by written notes, if I wanted to understand properly what was happening.

Somewhere along the way I was sent to an appointment with Professor Bill Gibson who was starting a cochlear implant program at RPA Hospital. I wasn't that interested at first because I thought my hearing would come back. Several months later, my thoughts were more like "well, I've got nothing to lose by trying". I had the experience of being completely deaf for 5 months of my life and strongly remember how disconnected I felt from my usual world.

So there I was in August 1984 going into theatre for what was the first cochlear implant operation in Sydney. It was considered an experimental device and the outcomes were not certain. When I was "switched on" about 3 weeks later, the sound was not really what I expected, but it certainly helped me right from the start. There was something else to listen to besides the head noise and when I watched people talking, there was this recognition of something like my former hearing. The sound was fairly crude back then, compared with today and the improvements in technology have enabled a much more natural, clearer sound and smaller devices. The fact that I could hear again and even manage to use the phone to some degree within a few months was amazing. People also told me that my voice had gone back to what it was previously, whereas it had gone very monotone during the time I was totally deaf.

I had an implant in my second ear in 2005 and it was quite different to the first one, in that it sounded so much better right from the switch-on. So now I hear with 2 ears again and my hearing seems to be getting BETTER as I get older, rather than worse! Of course this still depends on whether I am paying attention. I still have to actively listen and interpret, especially in noisy or social activities, but I think I hear very well and effectively use the phone both at work and elsewhere.

I will be forever grateful to Professor Gibson, to Professor Graeme Clarke's team in Melbourne and the innovators at Cochlear Ltd (formerly Nucleus) for their perseverance in making this a reality. The growth of the Cochlear Implant program across Australia has involved the commitment of many dedicated professionals and profoundly deaf people from birth to their 90's and really changed their lives.

This real life story is brought to you by

I helped to start CICADA volunteer support group back in 1984 with Cathy Simon, who was also implanted on the same day as me as part of the experimental CI program at RPA. It was Cathy's idea to start a club and I was happy to be a part of this because I wanted to share the experience with everyone. After the success of our implants there was a lot of interest from both deaf people and professionals in the field and we wanted to be able to share our experiences of how it helped in our daily lives. Social situations with background noise are still a challenge for me, but after almost 33 years with a cochlear implant, I still think it is a miracle.

I work part time in Customer Service at the Sydney Cochlear Implant Centre, I can answer the phone at work and understand people well enough to answer queries and troubleshoot equipment over the phone. I also help with public relations and do presentations to groups about SCIC, the CI and how it works. I also assist my husband with his own plumbing business. I can participate socially quite well.

I understand how it might be for the signing deaf, that most people do not speak their language nor understand it. The Dept of Education has recently added AUSLAN to the National Curriculum, but are there enough teachers of AUSLAN to teach it in schools and/or the community? I would like to learn this as a second language so that I can communicate in AUSLAN and help others learn this language of sign.

I do find that there are situations where I miss out on some information, such as public announcements at the train station, meetings in public places or churches, where there is no audio-loop fitted, or trying to watch movies without captions. The newer Sydney trains now have visual displays inside the train carriage, advising which station is the next stop which is a great innovation. These could also be used for pertinent announcements. The electronic indicators at the stations are easy to read and up-to-the-minute, however they do not display the written equivalent of public announcements that are broadcast over the speaker system. I think it would be easy to do this, to alert deaf people to train delays, sudden changes in timetables or emergencies.

I would like to ask the large cinema chains to try, for 3 months, turning on the closed captions which are available on most new-release movies so that everyone can see them. The prevailing idea is that "most" people do not like to see captions on movies as it distracts them from the movie. However, it would be good to run this trial and see how many people actually object to seeing the captions on every movie. The captions can also help people who are speakers of other languages, to develop literacy by associating the spoken with the written word.

So there are things which could still be done to help hearing impaired people "hear/see" more in everyday life to participate more effectively in their communities.

Name: **Margaret**

Location: **Armidale, NSW**

I am 77 years of age and have worn hearing aids for 50+ years. How do I condense my experiences into a brief story?

Four generations of my family live with varying degrees of hearing loss, so I continue to note the disadvantages over diverse age groups, of my siblings, nieces and nephews and grand-nieces and nephews. I offer my story as I am saddened that improvements in services for adults with hearing loss have been minimal during my lifetime.

I am fortunate in living a full active life though not without obstacles:

- The first in 1956 when my medical denied me access to Teachers College where mild hearing loss was first diagnosed. (Puberty onset).
- By the time my second child, a son was born in 1965 I noted further loss and purchased a hearing aid. (Found out much later that pregnancy likely to increase hearing loss).
- Progressed to two hearing aids fairly soon after and “coped” in a hearing world as a full time housewife and mother. My social life being family and church. Pressures of being responsible for the raising of my children (husband worked long hours) prompted a wish to find more stimulation in my life.
- Consequently, I took on mature age studies and did a full time degree at Sydney University. Without any assistance for my hearing loss. I graduated in 1980.
- With my daughter age 18 and son 15 I started to think about re-entering the workforce. The 80's were a time of high unemployment and all of many, many job applications were unsuccessful.
- So I did voluntary work in Adult Education and took on a Post Graduate diploma in Adult Education, receiving my Graduate Diploma in 1984.
- I had noticed with my studies that my hearing loss was a handicap. I did not attend tutorials as they were too stressful in following the ideas being discussed.
- No real surprise that a little advertisement in my church bulletin about an inaugural group of the Self Help for Hard of Hearing Organisation Inc (SHHH) prompted me to go along, and greater surprise, I volunteered to be its President!
- Well. A huge learning curve. No thanks to any professionals up to this date. It was at (SHHH) meetings I first experienced the benefit of audio loops and was to continue using them regularly during my subsequent professional life.

Thanks to SHHH of which I became a member both of the group and its management committee I was set on a path of career opportunities. I finally found a job with a government funded pilot program for people with disabilities. This led to my personal experience of hearing loss playing a pivotal professional role in servicing the hearing support industry in the non-profit sector.

During my professional life I attended numerous workshops and conferences where I benefited from the Provision of audio loops.

This real life story brought to you by Margaret

Messages to our elected leaders

I attended two International Federation of Hard of Hearing Inc (IFHOH) conferences, at Graz, Austria in 1996 and Sydney, Australia in 2000.

As most of my jobs were strongly motivated by Equal Opportunity policies I was able to manage my phone work by being provided with an induction coil phone. (I wonder if the private sector would be so obliging?)

I enjoyed a satisfying and rewarding career in the welfare community support sector until my retirement in 2011 (age 71). (Though underpaid given my formal qualifications).

Most of my life was in Sydney, plus six years in Brisbane and four years in the United Kingdom before moving in 2005 to Armidale in rural NSW where I worked for six more years before retiring. While continuing to live an active life in rural NSW I have noted awareness of access for hearing impairment is significantly lower in regional areas. The Town Hall, Bowling Club and Services Club of Armidale do not have loop facilities, so disappointing that I struggle with the limited acoustics when I attend functions at these public venues.

What disappoints even more though, is the observation that current services are inadequate for enabling younger members of my family to live an active lifestyle as a hearing impaired person in a hearing world. It is different to being deaf.

This real life story brought to you by Margaret

Name: **John**

Location: **QLD**

Age: **66**



I was not diagnosed as being deaf until Grade 1 at Primary School. I have worn hearing aids all my life since then.

I attended an ordinary State Primary School and not a School for the Deaf. This was extremely difficult as it was not easy to comprehend what the teacher was saying to the class. My parents travelled each week into the city so I could see a speech therapist to improve my speech. I was never taught sign language so my communication was lip reading with some hearing aid device to assist my hearing.

At age 15 I commenced work in the caravan building industry but was told I was unable to do an apprenticeship due to my profound hearing loss. In 1981 my wife Caroline and I decided to start our own caravan building business. I had never been able to talk over the phone due to my severe hearing loss but Caroline handled the administration side of the business and was my trades assistant. We continued our business until 2008 when we retired.

Our two sons aged 17 and 15 were killed in a light plane crash on a joy flight in 1996. I received severe burns trying to get them from the wreckage. I had to close my business for two years because of my injuries. This tragedy has had a huge impact on our lives and at times my hearing loss was compounded because I felt isolated with not being able to communicate easily with people.

I was always involved with sport of some sort all my life. Last year I competed in the Queensland Multi Disability Lawn Bowls in the Hearing Impaired Men's Singles and won the Bronze Medal. I have just returned from playing in the Queensland Team for the National Deaf Lawn Bowls Championship in Western Australia. I was selected to compete in the International Lawn Bowl Championship to be held in New Zealand in 2019. I am over the moon.

The biggest positive in my life has been my cochlear Implant which was performed by Dr Chris Que Hee at the Mater Hospital Brisbane as a public patient in 2017.



This has been life changing for me to hear sounds and conversation that I have never ever heard in my whole 66 years of life. I cannot thank the doctors and my audiologist Barbara enough for all their commitment to the program and helping me to develop my hearing skills to where it has far exceeded my expectations. My only regret is that I never had it sooner. I wish that many more profoundly deaf people have the same opportunity that I have had, to benefit from this wonderful medical miracle. Thankyou Cochlear.

This real life story is brought to you by John

Please find on this page a USB consisting of videos of members of the Australian Deaf community sharing their message in AUSLAN, their national language.