

# My Hearing Journey

By Max Harpham



**On the 17th April 2005 I was born into this world, weighing in at 9 pounds and 10 ounces from birth,**

**I was a very big and happy baby.**

However, the world I was born into was missing something, I was born into a world void of sound. I was born profoundly deaf. The doctors had noticed an issue with my hearing ability after I went through the Newborn Hearing Screening. As a result, after only 18 days of being in this world, on the 5th May 2005, I was diagnosed with a profound hearing loss in both ears. The cause of my hearing loss was determined



Image Source: Supplied

to be the result of a recessive gene present in both of my parents known as 'connexin 26'. At 18 days old I was probably yet to form a single thought, so I can't say that I was too upset with this diagnosis at the time. My parents however, were understandably, very scared and unsure of what to do in the situation. Scared, uncertain and overwhelmed with many emotions, my parents reached out to a family within their social network that had a boy with a hearing loss. The family gave my parents their advice on what they did with their boy to ensure he got the support he needed. They explained how they attended The Shepherd Centre (TSC) which is a non-for-profit organisation that specialises in assisting deaf kids in learning to listen and speak from a very early age. And so at 6 weeks old, I joined TSC as a part of the early intervention program. Fast forward a few months to roughly around September/October 2005, I received my first cochlear implant in my right ear at a very young age of 5.5 months old making me among the youngest cochlear implant recipients at the time. To this day, I'm yet to meet anyone who has been implanted earlier than I was, although I'm sure there has been someone implanted earlier than me. I was then later implanted again in my left ear at 13 months old and within a short while I was able to hear out of both my ears. However, being able to hear out of both ears didn't mean everything was resolved, it didn't mean that my hearing loss was "cured" or "fixed", far from it. If anything, this was the start of my hearing journey and I started this journey with the Nucleus Freedom speech processors.

Growing up with a profound hearing loss was definitely not an easy task, it was a lot of work as there were many challenges that I faced over the course of my childhood and still face to this day. Hearing aids and cochlear implants open up our brains to the rich world of sound, but they don't teach us how to navigate it. Just because we have legs doesn't mean we know how to use them straight away, we learn how to use our legs and we learn how to hear, among many other things. More often than not throughout my childhood, I struggled to understand what people were saying, even though I could hear, it felt like the speech I was hearing was scrambled or encrypted and I didn't have the code to decrypt the message. I found it very challenging to decipher speech encrypted by everyday noise. As a result of this struggle, I had developed a habit of saying 'what' every time someone said something, even if I knew what they said I would just say it out of habit. My mouth just couldn't wait to say 'what'. I'd also find myself taking a while to process what people were saying and I wouldn't understand what they'd said until shortly after, or I'd understand what they said as they were repeating themselves. While that may not sound so

bad, it's important to factor in how quick and rapid conversations can be, especially when in groups and especially as kids in a playground or on a field running around. At times these challenges could be very discouraging and demotivating. I was struggling to keep up with group conversations as they're rapidly bouncing between people all while constantly changing topics. Trying to keep up with it all was exhausting, I often found myself zoning out and eventually withdrawing from the conversation and even the group. At times, it felt like I wasn't able to connect with my peers and this was quite a lonely feeling. Something they didn't tell me when they diagnosed me with a profound hearing loss at 18 days old was that it'd be quite a lonely journey, or maybe they did tell me, but I just didn't hear them.

However, if there is anything I've learnt, it's that there is always a work around to these challenges. Throughout my childhood, I was an excellent lip-reader, I could lip-read people on TV, people in the distance, I could lip-read almost anyone. Lip-reading relieved a lot of my struggles in understanding people, it restored a lot of my confidence too and not only that, it was an entirely sub-conscious process. More often than not, I wasn't aware that I was lip-reading, it became something that was as natural as breathing to me. However, over the years my lip-reading ability has declined and I can no longer lip-read as well as I used to. Lip-reading wasn't my only method of overcoming my communication challenges though, I'd also try to manipulate my surroundings by avoiding busy noise environments that would make it difficult to hear. Not only that, but I found it easier to follow along with conversations that I was guiding and over the years I've found it much more enjoyable and easier to have conversations with smaller numbers of people, particularly 1-on-1 conversations.

The challenges I faced weren't just about not being able to understand people though. When I had the Nucleus Freedom processors, they required a big battery pack to be accompanied with the processors at all times in order for them to work. This was quite a mildly infuriating thing to deal with, so my mother sewed together a battery pack holder which I would wear on my back underneath my clothes as a work around. Thankfully, I didn't have the Freedom processors for too long and in 2009 I upgraded to the Cochlear N5 processors which no longer required a big battery pack to go with them. I had the N5 processors until 2013 from which I upgraded to the N6. A major issue I had during my time with the N5 & N6 processors was when I would play sports. I used to be very competitive at soccer and basketball which I played for over a decade of my life. These sports tended to be quite physical involving a lot of rough contact making it very easy for my processors to come flying off. This is where I used double sided tape to stick the processors to my head, behind my ears as a work around. Doing this was very successful in stopping my processors from falling off.



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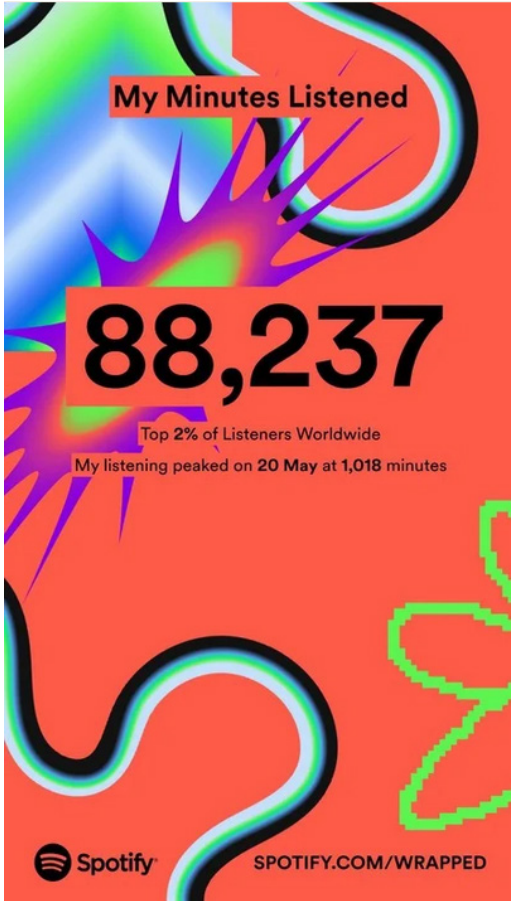


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A big part of me is my love for music, I am constantly listening to music. Last year in 2023, I listened to 88,237 minutes of music according to Spotify statistics. 88,237 minutes converts to 1,470 hours, 61 days or 2 months. That is 2 months straight of listening to music. This statistic placed me in the top 1% of people worldwide for time spent listening to music on the Spotify app. In 2021, I upgraded to the Cochlear N7 speech processors which have allowed me to stream music to my cochlear implants from my phone using the Nucleus Smart App. This feature has been amazing and it's definitely my favourite feature of the N7 or any of the speech processors. But whether or not I stream my music or listen to it live will usually depend on my mood and the type of music I'm listening to. If I'm in the car, I'll be listening to the music live through the car speakers usually on full volume. My car is my favourite place to listen to music. I often go on long drives listening to music live, but if I'm not in my car, I'll be streaming my music to my cochlear implants.

I attribute a lot of the success in developing my speaking and listening abilities to the professionals who supported me, but also those close to me who supported me during my journey. Throughout my childhood, I spent a lot of time at TSC and in intensive speech therapy developing my listening and speaking skills. Not only was I part of the early intervention program at

TSC, I was also involved in the School-Age Services program which contributed majorly to the success of my listening and speaking abilities today. I really admire the professionals who supported me along my journey. So much so that I've been inspired by these professionals to undertake a Bachelor of Speech and Hearing sciences and I'm currently in my 2nd year and I have a strong ambition to further pursue my studies in a Master of Clinical Audiology upon completing my Bachelor's degree. My goal is to be a paediatric audiologist specialising in cochlear implants.

I give back to the community who gave me so much by volunteering my time at Hear For You [Home - Hear For You](https://hearforyou.com.au/) (link: <https://hearforyou.com.au/>) as a mentor where I help facilitate and run programs primarily for kids of a high school age who have some sort of hearing loss. Hear For You shares the same goal as TSC, that is assisting children with hearing loss take control of their lives. I also volunteer my time with Hearing Matters Australia for their Hearing Aid Bank under the Samoa Program. I test and clean hearing aids which are then packed and sent to Samoa where they are fitted to those with a hearing loss. My Journey with TSC is very full-circle, I went from being an alumni to now being a part-time employee where I currently work for the clinical department.

My hearing journey started at 18 days old, and at the time of writing I'm just over 18 years into my hearing journey, I've come a long way. Growing up with a profound hearing loss has definitely shaped the person that I am today, and I still have so much more to learn in the years to come.

