

What Price Hearing?

IN THE BEGINNING

During my last visit with my counsellor, she asked me a very astute question. 'What price do you pay to be in the hearing world?' This was something I had never considered before and it required considerable thought over the following weeks. The conclusion that I eventually came to was that I pay a very heavy price to communicate in the hearing world.

Like nearly everyone else, I was born with normal hearing. I got a bad case of measles when I was about 18 months old, which sowed the seeds of the ultimate destruction of my hearing.

Unfortunately, my developing hearing loss was not discovered until I was about 7 years of age, during a medical sweep at the local parish school.

I was born in 1946 and the understanding of hearing loss and its ramifications was not well understood then. To me, it is still shocking that here in the 21st century, there is still so much ignorance and fear around hearing loss. I was going to outline some of my own history about my hearing impairment and how it has affected me, but the vision of eyes glazing over as readers continued through my story, changed my mind. To understand the price I have and continue to pay because of my hearing impairment, some key issues are important.

One of the most significant aspects of hearing impairment is that it is invisible. This 'invisibility' is a major cause of why it is not recognised clearly and why its impact can be so profound. Let's face it; we live in a relentlessly hearing world. From the moment we are born we are bombarded by sound. Our ears are the receptacles that channel all the sound around us to the brain, which is where our 'hearing' takes place. These are some of the things that happened to me, as I was growing up and some that continued as an adult:

- I was constantly bullied as a child, even within my own family, where I was frequently told, "I could really hear if I wanted to". I was devastated and enraged by this comment, which in hindsight was incredibly cruel and ignorant.
- I was often treated as a simpleton. What I call the 'if you are deaf you must also be dumb' syndrome. Manifestly untrue of course, but still prevalent. Again, such attitudes made me very angry, since my natural intelligence was crucial to the development of the skills that allow me to communicate.
- I found my life as a child to often be intolerable. My solution was to run away, both physically and metaphorically. I was never very successful running away literally, so I began to retreat from a world that had become far too difficult and painful. Almost from the time

my hearing impairment was officially 'noticed', the separation of my emotional self from my physical reality began. I simply retreated in my mind. I found a place to hide in books.

- As I continued to explore books and reading, I discovered the world of fantasy, myths and legends, of which the local library had an extensive collection. These provided the ideal worlds for me to lose myself in
- My education suffered because of a complete lack of support during my school years, all the way to Year 12. As I engaged in further education in the ensuing years, I learned that whilst I was brilliant at course work, I was severely disadvantaged in pressure situations, such as examination settings. I simply was unable to cope, no matter how much study I had done or how well prepared I was. Consequently, my academic achievements were less than might have been possible without a hearing impairment. This also affected my employment prospects, particularly when I first started out. I still was using my Calaid - a body worn device - that looked and was clumsy, as well as obviously telling potential employers that I was hearing impaired.
- I did not grasp how much and how quickly my hearing deteriorated over the years. It was not as if I suddenly went deaf. My sensorineural hearing loss was gradual. Our brains have a terrific ability to adapt, which can often disguise our own recognition of increasing loss.
- I bought my first hearing aid at age twenty - a BTE (behind the ear) model - that was much more updated than my old body-worn aid that had been supplied to me in primary school. Before my mid-twenties, I was assessed as needing two hearing aids. The need to constantly upgrade my hearing aids every two to three years was a significant financial burden. Technology was expensive (it still is) and I did not have the resources or ability to simply purchase what I needed.

THE NEXT DECADES

To say that I resented my hearing impairment is a gross understatement. I too was woefully ignorant about the effects it was having on me. I was absolutely certain however, that my ability to communicate well would be fundamental to my very survival.

So where do I fit now? I always believed that I was part of the hearing world – the reality is that I am no longer part of it and haven't been for decades. Hearing impairment is basically invisible, unlike blindness for example. It leads to a sense of isolation. One apt description I heard years ago was that of *"being outside a window looking into a room full of people having a great time, but being unable to join in"*. This is such a common experience for those of us with hearing loss.

Over the years I have acquired a vast range of skills that help me communicate: lip or speech reading; tone analysis; body language; facial expression and so on. Sometimes the actual words heard are the least important part of the equation. My language skills and speaking ability are of a

very high order in relation to the degree of hearing loss I do have, which is profound. I was fitted with a cochlear implant in February 2014 and will be getting a second one late 2015 or early 2016.

My cochlear implant has opened up an incredible world of new sounds to me. An implant however, cannot replace natural hearing and certainly does not restore 'hearing' to what is considered normal for most people. It is a completely different type of sound, one that the brain has never experienced before. The brain has to learn to interpret what starts off simply as noise without meaning. Over time, the brain begins to make some sort of sense of the noise – rather like learning another language, except it is one that has never been spoken, written or read.

This is what it takes to communicate effectively with an implant and a hearing aid, or with just one or two implants: 100% concentration; close attention to the person speaking; using every other acquired hearing skill and ideal conditions for hearing well. My brain has to be switched on and operating at a high level of intensity for up to 16/18 hours a day. Every day, every month, every year for the rest of your life. This is just how it is if I want to participate in the hearing world.

Operating at this level is exhausting, particularly over time. I have been doing this for several decades with two hearing aids, at the high standard I set myself, simply because I wanted to do the very best I could with my innate ability to communicate well. At the beginning of this article I talk about the price I pay and that is a heavy price. How so?

For me, the high level of concentration and focus required, carried out for so many years has had significant impact on me at all levels – mental, emotional and physical. I feel as if I have been so drained that no amount of 'rest' will make any difference. The end result is that I am emotionally very fragile and that it is a now very fine balance for me to maintain my equilibrium under normal circumstances.

So what is the solution? For me, there really is none except to minimise my exposure to the things that trigger me or are essentially negative. I simply no longer have the energy or resources to spend on anything that does not enhance my well-being.

PROGRESS

It hasn't been all doom and gloom. Once I left school and ventured into the workforce in the middle 60s, things changed. I had no social skills whatsoever but did possess a creative and innovative mind. Over the years I realised that I often do my best work in the background. I have a particular facility with numbers, so moving into accounting at the start of my career was an obvious step. In 1972 I headed off overseas, like so many other young Australians. I stayed for more than three years, worked hard at a variety of accounting jobs and saved my money so I could continue my travels. I made three major overland trips during my time away. Kathmandu to London by bus (coach), all around Britain by motorbike and finally, visited every country in South America by truck, criss-crossing the Andes multiple times.

I have been passionate about photography ever since I was given my very first camera, an Agfa Clack, when I was about thirteen years old. For the next thirty years I spent all my spare resources on materials etc. On my return to Australia I put myself through a private photography school, studying for the next three years and which culminated in me being only one of three, out of a class of fifteen, to graduate with a Diploma of Illustrative Photography. I was totally thrilled!

During that time I worked in advertising as an accountant then as a photographer. I developed a reputation whilst at O&M as *'the Red Adair'* (Google it) of Finance, since I had a particular ability as a problem solver – able to unravel the knottiest problem. Eventually, a few years later, I went to work at La Trobe University at their Bundoora campus. This was quite simply, the best job I ever had! This was also where I discovered computers and the Internet in 1988 – from then on I decided that this was where I wanted to put my energies and learn as much as possible about these new technologies. At La Trobe I was able to move out of the Finance Division and into the Information Technology full time. I still am very involved with both since my retirement and even use my accounting skills.

It is also important to acknowledge the significant benefits I have received from professional counsellors. In my 40s and 50s I saw a fantastic psychiatrist for several years in each decade. Through this I was able to learn so much more about myself, learn additional skills and reach an acceptance of my situation. In other words I stopped fighting the reality of my hearing loss and got on with it. I still see a counsellor on a regular basis whenever I feel the need.

My life has continued to get better every day. I grew up lonely and was very isolated for many years. The real turning point for me came around 2011. I was still three years away from my implant and I was conscious of how much I was struggling just with my hearing aids. I actually make huge demands on myself, and the technology I use, always pushing to the limits. I was now getting out, becoming more social and making new friends. My friends, bless their hearts, have been fully engaged in my new hearing journey since my implant.

Having lived with hearing loss all my life and being totally conscious of how damaging and destructive it can be in what is a relentlessly hearing world, I feel an obligation to carry the message to my peers and those I have contact with in my community.

DOING SOMETHING ABOUT IT

Hearing loss in most people is well under way by age of thirty years of age. In a world where daily exposure to extreme levels of noise, our hearing is at even greater risk. Many people are still unaware or apathetic about damage to hearing through exposure to excessive or prolonged noise or that the damage is cumulative and permanent. Many people are not aware they have a hearing loss, even when it is more than a mild loss, especially when the onset is gradual and the person and their family/friends adapt to it often without realising they are adapting. Indifference to noise exposure and apathy are applicable to lots of people, with or without a hearing loss.

The average length of time before someone who is experiencing hearing loss takes steps to do something, is ten years. I personally find this fact appalling! There is so much new information now available on the long term impact of hearing loss, that it is even more imperative that the earlier the intervention, the greater possibility of reducing the level of permanent hearing loss. Ignoring any level of hearing loss can have the following consequences:

- Increased risk of early onset of Alzheimer's disease
- Loss of cognitive function
- Memory loss, especially of short term memory
- Breakdown in personal relationships - partners, family and friends
- Social isolation
- Increased mental and emotional stress

Our brain is such a wonderful organ that can continually make up for a deficiency in other senses. I mentioned previously that hearing loss is essentially invisible. With the ongoing adaptability of the brain, the loss itself can be masked for a long time. Facing up to a loss of ability in an area of our lives can be difficult, and hearing loss is no exception. There are many reasons why people won't deal with fading hearing. Some people, struggling to admit there is a problem, may not want to confront their advancing age, or are afraid of how they will manage or afford a hearing aid. Some genuinely don't realise there is an issue as their hearing is fading so gradually they haven't noticed it. In fact, in most cases it is someone else who notices the hearing loss, not the person with the impairment.

What can you do? If you find yourself in any of these situations:

- Turning the volume on the TV up
- Find it hard to hear a conversation in a restaurant or other noisy places
- People repeat themselves frequently
- Others start speaking to you loudly, then become irritated

Don't waste any more time. Get a referral from your GP and have a professional audiometry test done. By the way, your local GP is not an expert in hearing loss and frequently can give very poor advice in this regard. The only real way to establish any level of loss is to have the appropriate test done in the correct settings, usually a sound proof room. If you are fifty years or older, seriously consider getting hearing aids. The digital aids today are incredibly powerful and very small, no one will even notice if you wear any and you will really appreciate the benefits. The true key to

minimising hearing loss is early intervention, in the form of suitable hearing aids, which help provide essential brain stimulation.

I was extremely fortunate to benefit enormously from the services of one of the most highly skilled audiologists in the country. She looked after me for more than twenty years, always going above and beyond, for me and all her other clients. As a result of her deep and thorough knowledge of audiology, audiometry and speech pathology amongst other things, I was able to develop and expand my own communication abilities. What most people don't know is that hearing loss directly affects your speech. If you cannot hear it, you cannot say it. Despite my profound hearing loss, I have retained an excellent level of speech. This comes from the assistance and support I received from Marie-Louise, as well as my own self-education and brain training, over decades.

There is absolutely no need to put up with any of the stress and trauma that can result from being hearing impaired. I have put down part of my story to encourage everyone to look after their hearing better and to seek help when it is needed. The importance of taking steps early is that if delayed, any lost hearing can never be recovered. Let me rephrase that: without adequate stimulation to the parts of the brain responsible for our hearing, atrophy occurs (it dies, basically) and it can never be recovered.

I co-produced the manual "Hearing Loss and Hearing Solutions – A Guide" for Cicada Australia Inc. In it is a wealth of information about the causes, impacts and treatment for hearing loss. It is an invaluable resource available to everybody from the web site: www.cicada.org.au. It can be downloaded to a computer for easy reference and I recommend it to everyone.

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