

Are you considering a cochlear implant?

I would like to share the various stages of my cochlear implant journey which I am about to undertake.

Stage 1 - Will I, or won't I?

(this was written before the procedure)

As you all know Meniere's leads to various stages of hearing loss.

After 12 months of weighing up the pros and cons of getting a cochlear implant, not an easy decision, I decided to take the step!

Why?

You can say I am deaf in my MD ear. I now have trouble with hearing and clarity. Lip reading with masks, watching films, going out, constantly asking people "can you please repeat" plus some hearing loss in my good ear! Even with my hearing aid and cross aid I still have issues.

On 20 September I will be heading off to St Vincent's Hospital for an implant procedure and I have full confidence in my ENT. The procedure takes a couple of hours and I will be discharged the same day. Amazing! It's been recommended to rest up for two weeks before I am "switched on" which I will be doing at Healthy Hearing & Balance Clinic". I am so excited about this amazing technology, naturally anxious and curious at the same time.

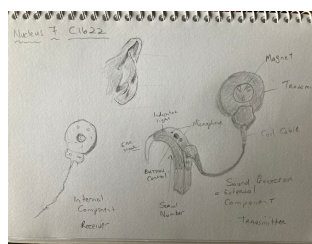
What I find interesting about this journey are the differences in feedback and recommendations I am hearing. The practitioners I see have been clear about the procedure, it's pros and cons, it's about my journey and I only I can make the final decision. I know the pros and cons and the cons are in my favour! I do know that us dizzies get good results. I also do know that I have a lot of work ahead of me.

As most of you know, Professor Gibson recently spoke to us on "Everything you wanted to know about Cochlear Implants" and Dr Celene McNeill followed it up with "Audiological aspect of cochlear implants" and the third and final was Belinda Kwok on "Cochlear implantation and its impact on balance function".

You can find these two informative videos on (highly recommended).

<https://sydneymenieressupportgroup.com/webinars-1>

Stage 2: The procedure, two weeks recovery and Switch-on day.



A sketch I did. It's not accurate but helped me understand after the procedure what had happened.

On the 20 September 2022 I checked into St Vincent's Hospital at 12noon. I was wheeled into theatre at around 1pm with pressure stockings, blue gown and bright red socks! As my emotions caught up with me, I just cried before they put me under then I woke up 5.15pm. The procedure took about two hours. When I woke there was a bandage wrapped around my head, they brought me in some food and water then I slept. At 1 am I was able to walk to the bathroom with no dizziness or balance issues.

The bandage was removed in the morning and Dr Flanagan checked up on me. All was good so gave me the all clear to go home armed with post-op info, a script of antibiotics, three steroid tablets to take over three days plus anti-nausea tablets if needed (which I have not needed). I had a moment of dizziness that morning, but after sitting for a while I was absolutely fine.

Over the next days your ear feels numb but as time goes on this gets less and less. You feel some blockage in the ear but that feeling disappeared for me after about 12 days. The pain is manageable with Panadol and which I took at night as needed. My worst moments were day 6 and 7, when I felt dizziness. It was not episodic but just that feeling many of us dizzies feel when walking around on bad days. On days 9 no dizziness and by day 12 no pain anywhere nor any feeling of a blocked ear.

Over that recovery period, I walked daily. It is encouraged to walk and get back to normal routine ASAP. Gentle mobilisation on same day is encouraged but vigorous exercise should be avoided for a period.

Although I knew my balance would be OK after the procedure, I do admit I was afraid it wouldn't be. But it's absolutely fine and no tinnitus!

The care I received during this period at the hospital and follow up care from Dr Sean Flanagan cannot be faulted.

I would like to thank all of you who sent me good wishes which I do appreciate. Support is so important as we all know. I would also like to thank Julieann Wallace who has been a constant support during this entire process.

Switch on – 4 October 2022 (14 days after the procedure)



It's difficult to put into words how excited, nervous and emotional I was feeling. The day dragged on as my appointment wasn't until at 3.30pm scheduled at Healthy Hearing and

Balance Care at Bondi Junction. What a wonderful team they are, led by Dr Celene McNeil. They explained what they were going to do, I was given a rundown on N7 Nucleus (Cochlear brand) which will be upgraded to the N8 when it's launched in a few weeks. Anyone who was been implanted with the N7 from August will get an automatic upgrade, so my timing was perfect.

Two hours later I walked out of the practice with a processor on my ear. I felt like I was the only person on the planet who had had this procedure and I still feel it. I wanted to show the world I have this amazing device and cannot wipe the smile off my face! And I am just one of millions who have lived through this exact moment.

What does it sound like for me?

I was hoping chipmunks (like some) but what I am hearing in the implanted ear is whooshing, swishing, static and some robotic sounds. Before I went to bed last night, I did 30 minutes of training from the apps that were recommended i.e. *AngelSound* and *Hearoes*. I was able to decipher some numbers and some words.

The challenge starts! And I up for it.

Today I wanted to test out how the world sounds. Having a processor on one side and a hearing aid on the other side, is something. So, I just walked and walked and walked, along busy main roads, went into the city, walked into shops and even dared to go to Westfield and survived, walked through some parks, had coffee in a café and just enjoyed listening.

Although I cannot decipher the sound coming from that side, having my hearing aid do the work in this situation works. I can have a conversation even though you hear the sounds coming from the other side. I actually heard voices behind me which is wonderful because I have been unable to locate sound direction for a long time. I could actually hear birds in the park and recognise the sound, as it was not robotic.

What's the Paul Kelly song? "*From little things, big things grow*"!

My day ended up with my appointment with Dr Sean Flanagan. Sean was following up and wanted to check the incision area, how I was after the procedure and over the last two weeks and answered all my questions and asked me a lot of questions.

Although I don't need to visit him again, he would very much like an update from me in three months' time which he will get.

I keep reminding myself how lucky us dizzies are to be surrounded and supported by a so many medical practitioners who understand the world we live in.

So, the next stage – *retraining this brain of mine* – I am very excited and motivated by this challenge. I will keep you posted.

Retraining the brain with a Cochlear Implant

The Procedure: 20th Sept 2022
Switch on: 4 October 2022
Follow up: 12 October, 19 October, 2 November, 17 November (to be continued)

Switch was five weeks ago and I am loving my CI.

Prior to the procedure, when watching the news, listening to music, radio etc I would have to turn up the volume, which was way too loud for my partner. At this stage of my journey, I turn the volume down and he has to turn it up which is too loud for me!

I see my audiologist regularly, as you can see above. Eventually the visits will decrease and one day become a yearly event. Celene checks my hearing and updates my program accordingly which involves a number of hearing tests. I am fortunate to be able to buy a hearing aid which is compatible with the processor. What this means for me is I am able to hear with both processor and hearing aid when on the phone! As my hearing aid ear is the dominant ear at this stage, I have no problem understanding. My personal challenge today was to talk to my sister on the phone in a noisy environment. As it was very windy, I took the opportunity to walk along a very busy main road, to test my hearing. And yes, I had a problem and that will take some time.

My daily training is via apps, e/books and podcasts (when time permits). The app I use is “iAngelSound”. What I like about this app is you can set it at different speeds, slow normal or fast. You can also choose a setting ie quiet environment, the phone or a restaurant. In the quiet environment I now get 95-100% word recognition. The phone exercises vary from 85% - 100%. The restaurant exercises on the app are challenging but I am working on this – it all sounds very static.

However, in a noisy café yesterday I understood what my friend was saying. Not sure if I was lip reading or not but I don't think I was. Prior to the implant just sitting in a noisy environment was a struggle. Now it doesn't seem to have the same impact on me as it used to?

Another challenge streaming music, but I am working on that too.

I will continue streaming my daily exercises and listen to podcasts when time permits.

No regrets!

Implant Progress – five months on (13 March 2023)

My last mapping was on 15 February 2023. My next will be in August.

How is life with an implant after five months?

Put simply, it's a life changer.

I can now stream **through both processor and my hearing aid** which is absolutely wonderful when I am on the phone or listening to music or podcasts.

When streaming **through the processor only**, depending on who is speaking, will depend on how much I can understand. In quiet environments I generally I understand most of the conversation when streaming. If I am walking and talking on the phone, I can have some issues due to surrounding environmental noise.

How does it sound when streaming through processor only?

I have come a long way from switch on day. It's no longer a flat robotic sound. I recognise if it is a male or female voice and can often recognise the voices of family and friends. There is now tone in the voices but it's 100% to how it should be. However, I know this is just a matter of time.

Noisy environments:

Restaurants, cafes, bars etc

I can now tolerate these environments. Wherever I am, I can actually hear the person who is sitting or standing opposite me with no issue! However, if someone is sitting to the left of me (on my processor side) it is a problem in this noisy environment, especially if I was not looking at them. I couple of times I did not realise someone was talking to me. I am sure in my next mapping session this can be sorted.

Music:

Streaming into the processor only:

Still not sounding good to be honest, but it's early days but a little better than five months ago. To be honest, I find quite difficult to do my streaming music exercises, but I will work on it. It will just take me some time.

Music is not an issue – if not streaming!

I can listen to music with no issues. My personal challenge was live music. So I decided to overdose on music at WOMAD world music festival. For three days and nights I watched and listened to musicians from all over the world. The venue a lot of stages and thousands of people attend daily. I had absolutely no problem at all, except if someone is talking while the music is playing. It was absolutely wonderful and I was a very happy dizzy.

Writers Fest:

They had a writers' fest in another venue with four stages set in a park. Again there were a lot of people. You have speakers on the stage, people walking around, lots of distraction happening at the same time. I had no issue generally only with two speakers (clarity). This could also have been because I was sitting in the back with crowds walking past.

Airport, supermarkets, shopping centres etc and other environments

I am finding although these places are noisy, with a lot going on visually and decorative, I can now tolerate. It's not that I like them, but I can be in them and handle the noise.

Summary:

Although not perfect yet, I cannot complain as the implant has opened up my old world again

My gosh, I just attended a three-day world music fest! Busy, loud and I had no problem at all – just a lot of fun.

October 2023 – 13 months since my procedure.

I would like to update you as it's been 13 months since I was implanted.

Water: Swimming/shower:

Honestly, I forget I am wearing a cochlear device. My only issue is “Will I remember to remove it if I go for a swim or have a shower?” I know there are waterproof covers available but I find they are quite large and not necessary for me as I still have hearing in my right ear. Gosh, the world is so quiet when you take it off.

The Magnet

I have had some funny experiences with the processor because of the magnet. For example, if I am using an umbrella, the magnet can attach to the umbrella! It's happened a number of times and ended up hanging on the umbrella rod or on the ground. I just have to remember to hold it on the right side. It happened to me in various places also e.g. in a pub one night. I leant back on the wall behind me which had metal. My processor ended up on the wall! I need to be mindful of metal objects near my ear!

Retraining the Brain Exercises

Oh, shame on me - I have slackened of. Life is my excuse for the moment.

I do know I have to do these exercises. For me it is so important, especially music training. Streaming music into my device only is not sounding as it should sound and this is what I need to work on. However, as I do have hearing in my right ear streaming generally is not an issue and music does sound as it should sound. **The issue is streaming into the implanted ear only.**

I have just tested it now and listened to couple of songs that I know really well. Interesting to say that they sound a little better than they did 12 months ago. But they don't sound like they should. I hear the voices which can sound tinny. The instruments for me are a problem. I repeat, it's my fault and I need to continue doing these exercises. So don't let me put you off.

Programming Visits

My programming visits to Celene are now at six months. I feel confident it will soon be annually.

I now have a choice of two programs. One is for general hearing which I call “surround sound”. The other is programmed for hearing people in front of you, say in a restaurant.

Volume

I hear what is around me from both sides. It's important for me as I feel safe when I am cycling, driving and walking. The world is louder than I remember. I hear the whistle of birds, rustling of leaves, footsteps, noise behind me, indicator in the car, small movements, the sound of a keyboard, the sound of water boiling, the fridge, cooking etc. I have now adjusted to this loudness. The volume on the TV, record player (yes I bought one last year), radio, computer etc have now been turned down – not up!

No regrets

Every day I am grateful and have absolutely no regrets. I have had fantastic support from both Dr Celene McNeill and Dr Sean Flanagan both of whom are experts in the field of hearing, Meniere's and cochlear implants.

If you are considering this pathway, you won't regret it.

There are a number of choices as to which device we would like. My choice "Cochlear™ Nucleus® 8 Sound Processor and Receiver" and I have no regrets.

If you have any questions, please feel free to contact me.

Dizzy Anne

There are a number of companies to choose from but my choice was:



Cochlear™ Nucleus® 8 Sound Processor and Receiver

If you have any questions, please contact me

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Dizzy Anne 🌻