

# NOISY SILENCE

## Stereo Dreams



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Excerpt about  
CIICA's CI Advocacy  
in Action 2024  
conference



Oh Gaudi! Photo by Carl T. Bergstrom



I'm back in Dublin Airport again at crazy O'Clock for a two day trip to Brussels. It's strange to be going to a conference to represent myself, rather than my usual experience as a clinician or academic. My presentation is a bunch of pictures. The five of us smiling on Christmas Day 2021, not knowing what was coming the next day. Lots of steroid tablets. Me and Vincent Van Gough with matching bandaged ears. Successive screenshots of Noisy Silence blog posts that chronicle the journey. And the current result: working without any impediments, playing music, going to gigs and some of the positives from the process including writing, advocacy, a daily swimming habit and other surprise outputs.

I dreamt about being in a room with other CI recipients last week. It is rare that I get to meet people with CIs. I've met 3 in the past 18 months. Suddenly, I'm at Maison des Associations Internationales in Brussels and there are about 40 people in the room with a CI. People like me. I learn about the various experiences of the people in the room through lots of conversations and the conference presentations. Some born Deaf, some late deafened. Gradual hearing loss, sudden hearing loss. Recent recipients, and a lovely lady implanted over 40 years (with the original implant still going strong). Bilateral, unilateral and bimodal users (CI one side, hearing aid on the other). The conference attendees were an incredible bunch of people, there to share their advocacy experiences and to celebrate the positive change in their lives and those of their loved ones or patients.



There were lots of different stories, but we shared common experiences and a shared passion to advocate for better access to CIs and lifelong care. There were parents who had undertaken Herculean tasks to advocate for their children, setting up national CI programmes and raising public and political awareness of the need for CIs and ongoing rehabilitation, sometimes amid fierce opposition.

It was important to me that this wasn't an Astroturf or fake grassroots advocacy movement parroting medical device manufacturer's talking points. There is significant potential for power imbalance and perceived conflicts of interest with the medical device sector. However, I believe that the CI space is different to others as: there are significant barriers to accessing CIs and appropriate ongoing care- CIs are not being oversold; patients chose the manufacturer they want- this is left up to them and not the clinic; the public system funding model and public procurement processes also offer protections (in some countries); and the professional regulators have standards that the relevant professions need to comply with. [This article](#) contains a useful outline of how the hearing health sector is evolving.



The CIICA conference was very CI recipient driven. I learnt about the importance of telling stories from a CI recipient with an implant that is nearly as old as I am. Her story is a definite riposte that I will use in the future when I encounter tech dystopians, who think, because one company who did retinal implants folded, that all medical device technology is inherently flawed and shouldn't be used.

I learnt from achievements in other countries (e.g. tripling the number of funded CIs in the New Zealand health system) that advocacy works and ask myself, how can I be a more effective advocate? I need to think about my messaging in key areas such as:

- Awareness of sudden sensorineural hearing loss and the need for urgent treatment
- The experience of being Deaf/hard of hearing
- Living with severe tinnitus
- Being a cochlear implant recipient
- Cultural accessibility

I can share my experiences of the impact of sudden hearing loss on my life and how my story has changed since activation. I was fascinated by presentations that outlined lifetime cost estimates of hearing loss and how it impacts on people's careers, earning potential and the real effect on the government and the economy.

This is not to say that we are all economic units of production, but it does help with the argument around funding technology through the health technology assessment process where costs and benefits are weighed up in a systematic manner. Taking me as an example, I was heading for a shorter working week in a different role without access to a CI. The severe tinnitus and resultant auditory fatigue meant that all my energies went into my work and this unsustainable situation would not have lasted. Not being able

to access a CI would have had significant implications for me, my family, and my employer.

As I have been exceedingly lucky, I'm going to do what I can to support future CI recipients. The conference was really useful to learn the tools and techniques of advocacy. I learnt that narrative is essential to drive emotions, while at the same time the story teller needs to be less emotional in the telling of the story to be able to strategically control the message. There is very little perception out there in the world of what it means to live with a disability, until you or a loved one are directly affected, and we all get there eventually. For me it was that first realisation that I was now living in a different world. Those first days of my hearing loss for example, where everyone was laughing and I was missing the joke. The missed social and cultural events. The impact on my relationships, even those closest relationships, the impact of my children's voices on my tinnitus and my hyperacusis/extreme sound sensitivity. The missed conversations, and opportunities. The slowly building isolation from your old self and previous life. These stories need to be told as there are lots of decision makers out there shrugging and saying: "You have one good ear. You'll get by".

These stories can be used to steer the narrative. I learned in the conference that people have succeeded internationally in securing health system investments and changing peoples' lives. From my own perspective/microcosm, throughout my career, I have seen people using medications, sometimes on a lifelong basis, with significant costs because these medicines reduce the risk of adverse outcomes or enhance quality of life. Health systems fund these medicines on this basis, sometimes at exorbitant costs. We need to consider equitable access to binaural sound on the same terms. There are costs, but they are not as high as people are led to believe, and there are direct and indirect benefits to the recipient, the health system and society that far outweigh those costs. Anybody who needs and wants a cochlear implant should have the choice to receive one (or two, if required).

After the conference, I was winding down and sitting among a group of six people with cochlear implants. We shared our experiences and the highs and lows of the whole process. I sat on the bus to the airport contrasting this with the fact that I rarely meet people with CIs in the wild and resolve to organise an Irish meetup for adult CI recipients in Dublin within the next few months.

So what are my takeaway impressions sitting at the airport thinking about the conference?



Photo by Norman Best

I am very impressed. I didn't anticipate how meaningful it would be to meet people using cochlear implants, and to see the overlap in our stories and the similarities in our experiences. I found it really rewarding to talk to academics working in this context. I could relate to them as a patient/public member of the team, but also as an academic/researcher. I realised that I could do a lot more to advocate for people who need CIs, to advocate for a more accessible world for people with hearing loss occupationally, educationally, in the cultural space and more generally. For example, everybody, knowing some very basic sign language, at least being able to spell their name and understand signed letters, would make the world more accessible to the Deaf community, and finally, general awareness of hearing health and need to protect people's hearing from harm through music, occupational and other environmental exposures.