

CIICA Conversation: Experiences of Tinnitus and Cochlear Implants

26 May 2026

Facilitators: Robert Mandara, CI User, Finland, Kelly Assouly, Researcher, Belgium , Charlotte Young, CI user with tinnitus, UK

Observer: Sue Archbold, CIICA

20 Participants include 8 users of CI; Researchers, Audiologists, advocacy leaders, industry
 Live captioning was provided. CIICA Conversations last for one hour and are not recorded.
 Participants were from 11 countries: Australia, Belgium, Czech Republic, Finland, France, India, Ireland, Netherlands, Sri Lanka, UK, USA.

Introductions:

Robert Mandara. Bilateral CI user and tinnitus sufferer
 Kelly Assouly, Researcher on the effect of CI on tinnitus - at UMC Utrecht (NL) and Cochlear (BE).
 Charlotte Young, tinnitus sufferer, CI user and Advocate
 Attendees also introduced themselves via the chat room and beforehand.

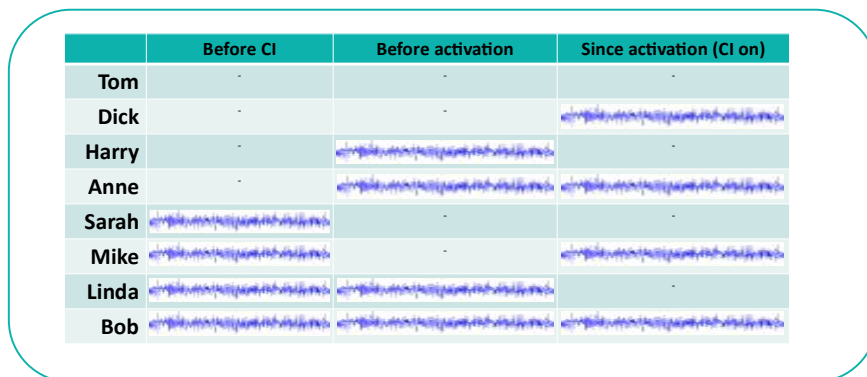
Framing the Conversation

The conversation aims to discuss the different journeys of tinnitus and cochlear implants. It's not just about tinnitus; it's related to the cochlear implant journey.

Robert showed the graph below to illustrate how many different types of tinnitus journeys there can be and introduced the conversation with a few questions:

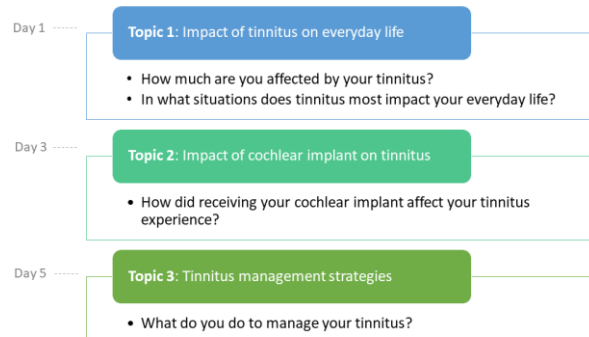
- Has your tinnitus changed for better or worse in either ear since cochlear implant?
- How about at night?
- How does tinnitus affect your daily life?

Simplified example CI tinnitus journeys



Summary of the verbatim live discussion and chat room comments:

Kelly Assouly presented a research study exploring the impact of tinnitus on CI users older than 18 years. Her PP is attached as a PDF. The study used a mixed-method approach, which consisted of an online forum discussion, followed by thematic analysis of the conversations, then the development of a survey which went out more widely. Please find below the questions asked in the forum and some words extracted from the forum:



Forum discussion

Tinnitus experience



"a friend"

"a music in the head"

"uncomfortable"

"unbearable"

"a problem"

"Since implantation on the left ear, almost more tinnitus on the right".

"No tinnitus when I have my implant, they are present just after I have unhinged when I go to bed"

"Decrease sharply when my implant is activated, always present when I remove my external processor".

Situations impact my tinnitus



"I feel a lot of tinnitus especially before going to bed and getting up in the morning"

"tinnitus occurs when fatigue occurs"

"The more focused you are on your tinnitus the louder the sound gets"

"When I jog, I remove my processors and the intense effort created tinnitus"

"tinnitus has developed mainly in a noisy atmosphere"

"In situations of silence, my tinnitus reappears despite the activated processors"

"I have to say that it is enormously strong every time I do hearing tests, specifically the one with the beep. Afterwards my head is buzzing, and I can almost only hear noises".



PLOS ONE

RESEARCH ARTICLE
The impact of tinnitus on adult cochlear implant recipients: A mixed-method approach
Kelly M. S. Assouly^{1,2,3,4}, Maryam Shalaby⁵, Ben van Donge⁶, David J. Hogg^{7,8}, Michael A. Atencio⁹, Robert J. Dobson¹⁰, Inge Stegeman¹¹, Adriana L. Smit¹²

136 people participated in the forums: these were the findings:

- Tinnitus experience can depend on the sound processor usage.
- Difficulties vary among CI recipients.
- Tinnitus management can differ between day and night.

414 people responded to the survey:

- Tinnitus seemed to increase when performing a hearing test or CI programming session, when being tired, stressed or sick.
- Difficulties are more frequent without sound processor.

- Fatigue, stress, concentration, hearing difficulties were the difficulties more reported.
- To manage their tinnitus, recipients reported turning on their sound processor and avoiding noisy environments.

Tinnitus impact can depend on the sound processor usage:

- 63% rated tinnitus as a small problem to not a problem with sound processor turned on.
- 70% rated tinnitus as a moderate to very big problem without sound processor (turned off).

Charlotte Young presented her cochlear implant journey and shared her tinnitus experience, which has changed since activation. See some of her slides below:

Why Every Journey Sounds Different

“The quietest room is often the loudest for me.”

My Tinnitus Story - Charlotte Young



Why Every Journey Sounds Different

Situation	My tinnitus experience
Before CI	Hissing, fizzling sound
Processor ON	Tinnitus feels like it has switched off
Processor OFF	Overwhelming hissing and fizzling initially then it reduces
Tired or stressed	Tinnitus is more prominent
When ill	Heightened



Reflections as a CI user...

- Tinnitus can change post CI and at different stages
- Discussion around this during the assessment process
- Ways to access support and guidance
- Not to listen or trust quick fixes you see online

There followed an open discussion on different tinnitus journeys:

Before CI

- *Reactive tinnitus*
"If I was in a loud environment hearing that with my normal good ear, it would make the tinnitus really loud."
- *Very loud tinnitus with severe hearing loss.*
"All I could hear was tinnitus." "The sound did not mean anything."
- *Severe tinnitus*
"Tinnitus can be terrifying. [] No one tells you what it is."
- Previous treatments have been tried such as cognitive behavioral therapy, hearing aids, transcutaneous vagus nerve stimulation (tvns) or bimodal stimulation (Lenire device).
"I accessed CBT through an electric tropic source that's provided through our health system, before I had a CI. You know, a few points reduction in the severity index, not a huge reduction. Some improvement, but compared to switching on a cochlear implant, insignificant, you know, like switching on the CI got rid of the tinnitus, CBT kind of helped you deal with it sometimes. So a huge difference in the magnitude of the effect."

After CI

- Tinnitus improved after implantation for some people.
"Even though the sound was very crude with that early implant, I could still hear something in relation to the outside world, and it just gave me something else to focus on outside of tinnitus. It really helped me to manage my tinnitus in the long run because the cochlear implant distracted me from the tinnitus. [] The tinnitus mostly fades into the background because I have something else to focus on because I can hear with my cochlear implants."

"The cochlear implant transformed it for me."

- In one person, pre-existing tinnitus in the non-implanted ear worsened after implantation.
“Since I've had my cochlear implant, I don't have tinnitus in my implanted ear but my tinnitus in my non-implanted ear has actually got worse.”

Someone noticed that the tinnitus might change in the coming months.

“I would say you are still on your hearing journey, you are still learning to hear with the implant and maybe your tinnitus will quieten down with time.”

- Tinnitus increases after implantation but decreases after activation.
“I knew straightaway from waking up from the anaesthetic, that my tinnitus was more prominent and I had fully expected that, I had been told that, and it was incredible that, as soon as I got activated, switched on and got my processor, my tinnitus completely vanished. And I couldn't believe it. I thought how incredible I've got this amazing technology, that's not only given me access to new sounds, and connection, but I've been able to silence my tinnitus which is phenomenal for me. [] having a cochlear implant has just been life-changing for me. I feel so, so lucky and blessed. And it's really enabled me to cope and manage with my tinnitus.”

Situations affecting tinnitus

- When you're tired or stressed, tinnitus gets louder.

“If you are very, very tired or fatigued, it does tend to get louder, and it still can be a bit overwhelming sometimes because it's not just in my head, it's like it's in my whole body. It's like my whole body vibrates with the sound.”

Management strategy

- Avoid being too tired or stressed to avoid tinnitus being too loud.

“The main thing is, you try to get not too fatigued and tired and the tinnitus, for me, seems to still be manageable.”

- Wear the sound processor

“So, as I said, mine was very much and is very much a loud hissing, fizzing, kind of sound and when I take my processor off, it's sort of overwhelming, it kind of almost consumed me, I would say, like reverberates around my whole body, it feels like initially. But as soon as I put my processor on, it's literally like a switch has been turned off.”

- Sleep with the processor on.

“However, since having my cochlear implant, and it's got louder and it's got worse, it's got to the point where I have to sleep with my cochlear implant processor in my ear, which is obviously not good from a maintenance perspective, because you are supposed to take the processor out and put it into the drying box most nights. And I tend to play the noise from the left ear which works quite well for me”

- White noise at night

- Change of program/fitting

“I went through and had new mappings done and recently I've had a change to my

programme, which again has resulted in that quieting down of the tinnitus and being able to cope day to day”

- Yoga / relax

“How I managed tinnitus. I am a fan of yoga, I do it regularly, it regulates my nervous system, it forces me to stop, slow down, because I am a busy person, so it forces me to take stock, focus on my breathing, calm everything down in my body. I really find that helps me a lot.”

Grace from TinnitusQuest also shared her journey as a person with tinnitus and with high-frequency hearing loss in one ear. She does not have a cochlear implant but asked questions to learn about cochlear implant experiences.

“I'm out of the loop for cochlear implants, I can't get one yet, but hopefully there will be something that can help me, not to restore hearing, but to help with my tinnitus. [] I'm interested to know if you think that it's just a distraction or if your cochlear implant is actually making your tinnitus quieter, because my experience is that there is some sort of sound input on my left ear that it actually makes my tinnitus quieter, rather than just less annoying. But I would just love to hear experiences from people who have cochlear implants about that.”

Main takeaways

- It is important to consider what can change in the contralateral ear too when you have a cochlear implant.
- Don't listen to or trust quick fixes you see online about tinnitus.
- It is very important to be counselled about what is tinnitus and its causes.
“The audiologists don't want to raise the subject of tinnitus because they don't want to put your mind on tinnitus, but I think it's really common at activation or after surgery for people to experience tinnitus for the first time and tinnitus can be terrifying. I experienced tinnitus as a child, had no idea what it was. I just thought I was going mad. No-one's telling you in the mainstream that, okay you might have tinnitus, so you don't know what everyone else is experiencing, but I think in a cochlear implant, it's really important to let people know if you do get tinnitus straight after surgery, or activation, it's not the end of the world. It's most likely temporary. Most likely to get better.”
- Totally implantable cochlear implant is under research and will soon be on the market.
“TICI you can choose a stop hearing with a lower sensitivity during the night”
“I have spoken to a lot of adult cochlear implant users who simply don't want totally implantable devices. We are very proud of the devices for our head, we are very happy for people to see them. Why shouldn't we be? So, certainly I am in no rush to get a fully implantable device, however attractive that might sound to the hearing person. But, yes, it's a complicated subject.”
- Interesting ongoing research on 1) cochlear implant technology to treat tinnitus in patients with less hearing loss and 2) bimodal stimulation using cochlear implants and Lenire devices.

Brian Cleary shared his fascinating blog on his CI and tinnitus journey: <https://noisysilence.ie/>

Sue closed the session by mentioning that there will be a session about tinnitus and cochlear implants at the next Cochlear Implant Advocacy and Action Conference in October.

“CIICA is all about where the science meets experience. We need the science, but we also need the experience and pulling them together. So hopefully several people who're on the call might be contributing to that.”

Thanks to all who joined us and Charlotte and Robert.

Kelly Assouly, May 2026.