

## **CIICA Conversation: ADULTS WITH CI: WHAT SHOULD FUTURE CI USERS KNOW?**

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Facilitators: Kris English, Prof Audiology, USA,

Rikie Boevink: Implant + Hearing Aid , Blog: "Hearing is a Gift, Understanding is an Art", Arnhem, the Netherlands

Michelle Frisbie: Bilateral Implants, Treasurer, HLAA state & local chapters , Wisconsin, USA

Emma McAuley: CI user, Audiologist, Ireland.

21 Attendees from 8 countries: 15 users of CI; 3 audiologists (2 of whom also CI users), 2 waiting for CI, one with sudden hearing loss. Live captioning was provided. Participants were from Belgium, Canada, Finland, France, Ireland, Romania, UK and USA.

### **Introductions:**

Kris welcomed everyone, provided some Housekeeping notes and encouraged attendees to also introduce themselves and via the chat room.

### **Framing the Conversation**

Kris began by reminding attendees of the previous conversation: what do you wish you had known about CI? And then introduced the topic: What should future CI users know? This had been brought about by the previous discussion when people had commented that they didn't know what to ask.

- **A positive experience about "knowing" before implant (and how did you know/learn/find out?)**
- **OR: What should future CI users know? (and recommendations on how they know/learn/find out?)**

### **Conversation summary:**

Rikie began with sharing her story and then giving some advice as to what people should think about before CI when going to the clinic:

## **The importance of writing things down and taking to appointments – before and after surgery-**

*Please write down everything, whatever is on your mind, if it is fear, if it is another health question, if it is about your hobby - can I do this after my surgery? Please write it down and take all your questions with you to the team that is helping you to be able to hear again. .... In the normal process it takes three months to a year before you can start to hear and understand people again. But for me it took a lot longer because sound really had to be built slowly for my brain.*

She also advised writing down concerns throughout the process of rehabilitation; many people keep a diary which can be helpful both for the person and for the audiologist to help them adjust the programming. She advises starting this before CI to develop the team work:

*Please write down everything you feel you notice because you have to have a language to express yourself to the audiologist, to the person who is adjusting your cochlear implant processor to hearing again. You need many words to tell what you hear, what you feel, how a sound hears to you what you make out of it. Start with it now when you are not implanted because that can already help you afterwards and then the audiologist can help you. Take your notes with you and that-makes the team work, the team is not for you but working with you*

## **Making choices – understanding information**

Making your own decisions is important and having the information to do so; not only whether to have an implant, but which type of implant to have. In many centres you don't have a choice of brand but if you do it can be confusing:

*There'll be a lot of anxiety about which brand to go with. If you don't have the choice, there can be anxiety because you think the other brand may be a better fit for you, and you don't have that choice. So one thing my audiologist at my evaluation told me, I was studying all the different brands choices and it was overwhelming and confusing because we don't know what we're doing with it, what we're looking at. So I asked her which one should I go with? And she told me that it did not matter. She said that it's 90% your brain and your effort that you put into your rehabilitation and maybe 10% hardware they stick on your head that determines a good cochlear implant outcome. So, I just made my choice, went with it. I had brand anxiety, so weird at first. Then when it settled in and everything started normalising over a couple of months, I agree with her 100%. It is all about the effort you put into it and your brain adapting to it and not about the brand that we have stuck on our head.*

There was a discussion about talking to other users of CI and families about the decision you are making:

*Making sure that it is your own decision, so it's not the audiologist's decision. You have taken all the knowledge from your audiologist, from your surgeon, and then you make the decision yourself. So, for example, when I got my first implant in 2000, I was just two years old. So my parents were the ones making the decision and the audiologist told them that they should speak only English to me. They used to speak to me in Tamil before, but now they started to speak to me only in English and that affected both my sister's and my identity. We ended up not speaking in Tamil or Hindi. We only speak purely English, so taking that knowledge from your audiologist and critically think and do your own research on top of that. It's is very important rather than just blindly following what the audiologist and the surgeon are saying.*

**Note:** in 2000 the evidence wasn't available about whether children with CI would be able to learn 2 or 3 languages, and this advice was often given based on the knowledge at the time. Now we know that children implanted young can acquire more than one language through hearing. If they are implanted at a later age, that is more challenging.

*Make sure that you are making your own decisions and you are doing your own research and you talk to different people. My parents at the time talked to only to my audiologist. It will be beneficial to talk to everyone - cochlear implant recipients, and mentors as well.*

### **Remember that everyone's journey is different and not to compare**

It was considered important to realise that everyone's journey is different, with differing experiences: there are many influences on how well a person might do with CI, including length of deafness and what caused the deafness:

*Nobody is the same. You can't compare yourself to anybody else. Your rehabilitation period of time will be totally yours and you can't compare it to anybody else.*

*And the other point about expectations as well, we all have different journeys. Some of us have been deaf since birth. Others have gone deaf later in life. When you get your hearing back with a cochlear implant, it still doesn't make you a hearing person.*

### **Having realistic expectations is important; but be prepared, it can be a lengthy process**

*I really want to emphasise the importance of having realistic expectations. It is the difference between success and failure.... I didn't understand anything at activation, it took a while to understand anything. A lot of people could be very disheartened by that. They could easily say, oh, this is never going to work and put the device away. But if you are prepared and you know this can happen, and you've got the attitude that you are going to make this work, then you can make it work.*

There were 2 attendees who were both audiologists and CI users, and one commented that you are told many of the risks but not how hard it is to adjust to it, and how tired that makes you:

*You are told all of the possible side effects and things that may not work out with the CI, such as losing taste, facial paralysis, all of that. One of the key things I was not told and not aware of and still struggle with is that it takes so much time having a cochlear implant and that is something that I am finding really hard to adjust to. And I am always exhausted. I am hearing the best I have ever heard. I would definitely do it again. It is brilliant. But I wasn't aware that it would make me as tired as it does. And that's something that I find difficult.*

**Note:** *listening effort* was a focused topic in an earlier online conversation, summarized here:

<https://ciicanet.org/wp-content/uploads/2022/07/CIICA-Conversation-7-Adults-with-CI-Managing-Listening-and-Communication-Effort.pdf>

### **Others may not understand the change that has taken place for you and your relationships: the need to involve your family**

Another thing that people should know is that after implantation when hearing improves so much, others may not recognise the challenges that you have: mishearing and misunderstanding. Families should be told this too:

*The other thing I find difficult is a lot of people forget that I'm deaf. Because I cope and manage so well, they think I hear normally. Sometimes the family get frustrated when I don't always respond*

*because I'm doing something else, because they expect me to hear everything like a normal person. So it is getting the family to understand that, yes, the person with the cochlear implant will hear better, it will appear that they hear normally, but they still don't. And that's something I think will be useful to be portrayed to a family whenever they go along to the appointments as well.*

Michelle mentioned the value of the HLAA groups in the US, and how important it was to consider the impact on family and relationships. She reported that in the US more counselling and psychological assessments have been recommended during the CI journey.

*One of the things on our list is to get more professionals trained and find out about if there are professionals out there that can help with that journey. Listening fatigue is a very real thing that we experience. The benefits are far beyond the struggles and challenges but there are definitely challenges to be considered.*

There was agreement that you needed to work at it – and your brain was key:

*Your brain is the most important instrument in this process, and also the willing to keep going.*

People need also to ask about new technology:

*The nucleus app on my phone is great. I can check the volume, when it needs to be charged, and I think that is about it.*

### **Bilateral implantation for adults – and its funding – emerged as an issue people should think about**

The discussion turned to consideration of bilateral CI – and what happened if the second CI was long after the first, and the issue of which ear to implant if only one – the worst or the best?

Emma asked Michelle her experience of her second implant considerably long after the first. How had her brain adapted to it – how is the newly implanted ear hearing?

*Like someone previously said, it is all about your brain, truly. That it does most of the work. It was so long ago when I got my first implant, there was not very much discussion, way back then as far as getting a bilateral, both sides implanted. Since mine was hereditary I knew I would lose my hearing and most like I will be deaf in both ears. I was the first guinea pig in my family, my chapter and my state of HLAA people to take that jump and it was very successful. So my first one, we did elect to do my worst ear at that time.... in our country, most people were recommending get implanted in your worst side so you have the ability to hear in your other side. One thing I wish I would have done different is probably get that second side implanted sooner. I didn't really feel like I needed it for many years because the first one was so successful. That is why I didn't do it for so long. But then I got nervous when I would be out walking or hiking or biking if I wouldn't hear a car coming up. So for safety purposes that was really the main reason why I wanted to get the second one. Also one of my electrodes they told me was not functioning 100%. So I went for the second one. I will say, in my case, my own personal case and not everybody is the same, my second side has not been as successful as the first side, when you test them independently. I think personally, for me, part of that is because it was unaided. There's a lot of research and recommendations keeping that deaf side stimulated. I will admit I have not been as regimented with my aural rehabilitation and practising on the second side as I was with the first side. I need to do more rehabilitation, listening with just the second side.*

Another contributor had only recently had their second side implanted:

*I was quite a few years with just the one aided implant on the left and it is a challenge getting used to the new one. They were quite pleased, I was able to understand some speech straight away. Like*

*you, I still have to do practising, the listening and aural exercises, talking books and the radio, things like that. I only had slight dizziness for the first three, four days with the first side but this time dizziness and balance has been much worse. I need a cane to get around. I'm having to take time off work. That is one of the challenges. The audiologist thought there was some damage from the surgery. She thoroughly tested me again for dizziness and balance, so it's been over a month, about a month-and-a-half now since the surgery and anyway, still dealing that challenge.*

### **The value of peer group support**

Emma (an audiologist and a CI user) brought up the importance of peer group support. Although she knew a few people, she would have liked more:

*I didn't have access to peer support groups. I did know a few people through my work, or that I have come across in my years before as an audiologist, who have gone through the implant route and I was able to ask them a couple of questions in the run-up to the operation as to what to expect, what tips they would give me, et cetera. I have met quite a few CI users over the years. But I think for me the peer support groups are vital, both before and after. Listening to other people's stories, sometimes their stories will answer questions that you haven't even thought of, thinking, oh, OK, I never thought about that. It is an important factor.*

She also mentioned the technology and to think about it ahead of time:

*And then another tip that I would give people is, if you have a smartphone, and you know what implant you are getting, check the compatibility with that implant with the smartphones. The Bluetooth in the cochlear implant has really aided my rehab. I was now going around listening to the news bulletins and chat shows. I was able to go about my daily business, but constantly listening and my brain was picking it up. I think that has hugely helped my success of the implant.*

### **Developing an information tool**

An attendee who was a speech and language therapist and audiologist working in a university college in Belgium described the project she and her team are working on. This was really well received by attendees:

*it's in this topic of what future CI users should know. As a speech language therapist, I saw that lots of CI users who came to me for auditory rehab, that they still had lots of questions, and it seemed to me like the information that they received, pre-implantation, wasn't always quite clear to them. The fact we are doing these conversations -implies it as well, that the information is not so clear. So, after talking with a lot of colleague and CI users and other professionals, we want to create an information tool that professionals can use to inform CI candidates better about the whole CI process. It can also be used when the person already has CI, to go over things again like where are you now, what are the next steps, et cetera. We just rolled out a little survey for CI candidates in Belgium. We had the top three things that people really wanted to know about or that they feel like they don't have enough information pre-CI. Things they wished they knew before their CI. And now after our survey is done we will be organising some focus groups based on the topics that we saw in our survey and with that input of our CI users we want to develop a tool that can inform our CI candidates better. There are lots of brochures out there but I don't think that's the ideal medium any more. And in the future we will be happy to share all the results. Maybe later in this project we will inform you on what worked, what didn't work. So maybe this tool can also be implemented in other countries.*

*We're therapists, but we don't know what it is like to be hearing with a CI or going through the process. We know it is hard and a very intensive and difficult process. But we don't know what people want to know beforehand or during that whole CI process. We think we know, but actually we don't.*

Hopefully this project will be able to create this much needed tool: current information brochures are often too complex or don't cover what is needed.

### **Funding issues**

The issue of funding was raised which had been an issue for many in the CIICA adult research and many commented in the research that they hadn't been aware of this beforehand:

*Accessories and so on: they are all still self-funded and they are very, very expensive.*

Two people had inquired about paying for a second implant but it had proved costly and not clear:

*~~The implant centre~~ I asked about the benefits of having a second one and it must have been about the fourth time I asked the question - there was one audiologist who said to me, "What a lot of people don't realise is not the cost of having the surgery done, it is finding the extra £5,000 a year to maintain it if you get the second one done privately." That is the very first time that's been told to me. I thought you just had to pay for the surgery and that was the end of it. And she said, no, there is on-going costs.*

*Costs: It depends... for me it was very difficult to get clarity about costs, especially because my rehab did take so much time. They never charged me for that. But it was difficult to find out what the additional costs would be. Not everything was covered and you have an insurance policy for each year. They could not tell me if I was going to be charged the next year or not, or what I did have to pay. I did not know what to do for the next year and that has been worrying me in the beginning but now I can say it turned out well because there were not that many huge costs. I inquired as well about a the cost of second cochlear implant, because in the Netherlands it's not possible to get a second one unless you have to pay for it yourself. But even then you can't have the surgery done in the Netherlands because they have waiting lists. But then you have the costs afterwards.*

One attendee summarised the advice thus:

*Be patient. Do your listening exercises. It may be distorted and sound clacky at first. The sound is not perfect. Whoops! The healing takes time. There may be some pain but if you have pain, you see your doctor again. Ask about the financial stuff. Expect a big backpack of supplies when you get your new sound processor. And, yeah, like you were mentioning, write down your questions to ask your audiologist and your doctor. That is what they are there for.*

### **Summary :**

Kris summarised by saying *I am struggling to think of other conditions involved with healthcare that are this complicated over the course of a lifetime.*

### **Issues that people should know about/ask about beforehand, but remembering that everyone is different:**

- Be prepared that it may take a while to hear well and have realistic expectations
- Be prepared to do listening exercises and auditory training ~~and prepare for this~~
- Ask about ongoing funding
- Write your questions down

- Keep a diary describing what you can hear, your experiences, your journey, before and after
- Ask about which ear, about balance, about risks, about pain
- Ask about the future technology management, links with your phone
- Ask about speaking to others with implants
- Involve your family in the information and discussions

Attendees recommended the FB page: CI Experiences – with over 30,000 members there is a host of experience there and worth asking any questions, for example when the issue of single sided deafness came up.

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