

## **CIICA Conversation: Person Centred CI Services: What do you wish you had known before you had CI?**

**24 September 2024**

Facilitators: Kris English (USA), Rikie Boevink,(Netherlands), Michelle Frisbie (USA)  
Observer: Sue Archbold, Coordinator, CIICA

22 Attendees from 11 countries: 15 users of CI; 3 audiologists, 1 teacher of the deaf, 1 ENT surgeon and a public health specialist. Live captioning was provided. Participants were from Armenia, Belgium, Canada, Finland, France, Netherlands, Portugal, Romania, Slovenia, UK and USA.

### **Introductions:**

Facilitators: Kris is a retired professor of audiology specialising in Audiologic Counselling; Rikie use a CI + Hearing Aid and runs a Blog: "Hearing is a Gift, Understanding is an Art". She is from Arnhem in the Netherlands. Michelle uses Bilateral Implants and is Treasurer for HLAA (Hearing Loss Association of America) State & local chapters from Wisconsin, USA

Attendees also introduced themselves via the chat room.

### **Framing the Conversation ;**

Kris English began by referring to the number of previous conversations on the topics related to Person Centered Care. The summaries of these conversations can be found on the CIICA resources page. This topic had been stimulated by a question on the Talking Wall at our Advocacy Conference in Brussels, May 2024. This had asked: *What would you have liked to have known before you had your cochlear implant?* The topic had proved an interesting one with registration closed, in order to ensure real conversation.

Michelle began the conversation by sharing her own experiences and sharing what she wished she had known. She introduced the topic that CI is more likely to be successful the sooner implanted, and if the ear has been kept stimulated; the issue became important to her after her second implant:

### **Implanting the second side:**

*I am a bilateral cochlear implantee; got my first one in 2001 and then my second one in 2016. So quite a few years in between. The first one was amazing, life changing, highly successful. So I do very, very well and I did for quite some time with that one. Second side hasn't been quite as successful. So not sure exactly why, but I guess one of the things I wish I would have known to get that second side implanted maybe sooner because I didn't realise that typically cochlear implants*

*might not be as successful if you go unaided for a number of years. So I wish I would have gotten that stimulated or kept it stimulated even after I lost my hearing in that second ear.*

People were unaware about why implantation in the second side could be a challenge:

*And also when you hear with first implant better than with second one. Why? I didn't know*

When the period between implantation in the two ears is long, then implantation in the second side can be challenging, as the brain has to get used to a new signal, and that side hasn't been stimulated for a long time. Rehabilitation will be really important then:

*secondly, when I got my second implant it was much later. It was ten years after I got my first one. So we had therapy for the first three months but unfortunately I decided to stop because I didn't see any improvements .....The hearing on that side kind of deteriorated and I barely used it. So I wish I would have, you know, be patient and still work through the process. I actually started having therapy again after my re-implantation on my left side. So I used therapy on both sides, and then I noticed that this side has become much better again finally, which is really good. And it's actually better than when I first got it for the first few years, so that was amazing.*

This discussion led to others mentioning that they had delayed implantation and would not have done so if they had further information:

*the number one thing that I really wish I knew before getting the cochlear implant that probably delayed my getting the cochlear implant for at least five years, I would have gotten the courage maybe but I was 28 because I was afraid that getting the cochlear implant would make everything so much louder, but after getting my cochlear implant I realised that I could control the sound much better in those loud settings in the way that I could appreciate hearing the things that I wanted to hear and block out the other noise in the restaurants, sporting stadiums, etc.etc. So if I had known that earlier I would have done the cochlear implant at least five years earlier.*

*So what I would have loved to know is how great CI works. Itl was after this car accident I lost my hearing If I would have known how great the CI works I would have done the surgery far earlier and I was really afraid of getting dizziness attacks again with the surgery and nobody could guarantee me that there won't be any dizziness attacks .....I had no issues with the dizziness after the surgery,*

### **The value of music**

The other topic that Michelle wished she had known was about the value of music:

*something I wish I would have known or realised early on with the first one is the importance of music and I knew my hearing loss was hereditary, so I knew at a young age I would likely become late deafened. So I took the approach to make music not an important part of my life. I don't know why I did that when I was younger but that was my stance. I guess I thought that I won't miss something that's not important to me. So I thought it would be better or not traumatising to be able to hear music when I would eventually become deaf. But little did I know of all the amazing technology that would be available today, like cochlear implants and assistive devices so if I would have known that, I really would have I think taken more training to even learn how to read sheet music because I never even did that and I think with that knowledge I would have been able to better discern new songs and music over my life if I had known more about it earlier on.*

Music emerged as a really important topic that people hadn't realised would be such an important positive experience. Another participant:

*And because Michelle mentioned it, I would say that music is really, really important for re-hab. You don't need to be a good musician but just trying to play things allows you to see your own progress day by day, but to start with I couldn't tell any piano note from another and now I can enjoy the piano.*

*Also one more thing that it's still a little bit let's say uncertain even these days, it's music part. I actually play piano and I have participated in pretty many concerts all over the world, including in some dedicated especially to people with hearing loss and it's very good to see that it is more encouraged to play music, to play an instrument or even actually sing which is a great achievement, especially when you are born deaf or you have a hearing loss*

And another comment about singing as well as a musical instrument and not to underestimate the possibility of music:

*And the second thing is learning a musical instrument or learning how to sing at a younger age. My sister she's older and she's not deaf, but she went to a classical singing class but I did not because my parents think that my cochlear implant, my hearing loss would give me self-consciousness of my voice or even when I am playing the musical instrument and they think, Oh it's because of my implant I am not able to do this. I am not able to do that. But in reality as I was able to once I started doing musical therapy, and learning the musical instrument for the first time in grade 7, that's when I noticed how much of an impact it can have on us And so that's why I wish I would have learned it at a younger age, rather than older.*

### **Gaining enough information: knowing the risks**

The conversation went on to discuss the lack of information in general. It was recognised that for those implanted some time ago there had been very little information available and it had been very hard to get. It could be very difficult if you didn't know what to expect:

*There was not so many information here in Slovenia and I was just, able to read in English to find some information by ourselves, by myself. So, and my doctor explained me just a few things about the cochlear implant and of course because I was deaf in that time, I was so happy that there is one possibility that maybe I will be able to hear and I didn't know I remember that during the first mapping I didn't hear anything and that was so stressful for me. When my doctor said, Oh that is very common when, erm, when people got cochlear implants so late. I was completely down in that moment.*

Making one's own research was important and the CI Experiences FB page was recommended by several, where CI users could help each other.

*So after that I made a research then I found that that cochlear implant experience social group in Facebook and this helped me so much and I know that so many people lead m., I remember some man he was so patient with me and he helped me with all my questions. I also didn't know how careful I needed to be after the implantation, what to do; it was just a lack of information in fact. And because of that I decided to write down a brochure about everything. and then my audiologist checked everything and she said, OK, it's OK.*

There was a feeling that professionals often didn't feel the need to explain and assumed that information was understood or already known:

*I would loved to have known before the surgery, properly known, what the risks were; they were not properly explained to me. So for example the surgeon actually sacrificed one of my taste nerves deliberately in the operation to make a millimetre more room, something like that, and this was a known risk to him but it wasn't really a known risk to me and it came as a shock to me. OK, it was worth getting implanted but it was still something I wish I had known properly.*

*I think that doctors think that we are specialist in this and that we know a lot. But many times I think that users of cochlear implants are not good experts in cochlear implants.*

### **Being prepared for the hearing journey**

Many commented that losing hearing and having a CI was a journey and transition – and it seemed they were not well prepared for it:

*I would have liked to have been better prepared for the sort of incremental journey after getting cochlear implants because it was a really fast learning journey. I felt like I was learning every day, my hearing was getting better; it was rewarding but no one really described that path that you're on and how rewarding it is and how you can enjoy that path.*

However, the journey can be a long one and unpredictable: mapping (programming) sessions mean changes in hearing which may take adapting to:

*And I think that's so many times we don't have enough information about implantation, and also how long, how much time you need for this. I need to explain in my job how long I will be for mapping and after mapping I am usually taking 3 days from my job because I need to adapt myself on new voices on everything. It's not so simple and I think that other audiologists think it's so simple to change the programmes one programme to second programme, third programme, and then you just can change your brain.*

### **Practicalities in wearing CI processors:**

Other issues that may not be mentioned in the clinic which can be important in everyday life: for example, issues at work, wearing CI in bed or in sports. For example for one teacher:

*also life is very noisy with the cochlear implant, very noisy. Yes, I wish I had known how noisy it was going to be in an uncontrolled way ..... I am a teacher which is not the best job and I have rooms full of children but they very quickly learn that they have got to wait their turn and put their hand up, yes, and I can't have them all shouting because I can't hear and if they make too much noise I just unplug my implant until they sit quietly and then I plug it back in and carry on.*

*No one warned me about the fact that when I tried to wear cochlear implant processors in bed it is quite impossible. If I lay on a pillow to listen to an audio book or even read a book they just fall off. It's really irritating but there you are.*

### **Choosing your audiologist**

In many places choosing your sudiologist is not possible – but this person is a key figure:

*And then no one warns you that actually the audiologist that does your mapping is really, really important.*

*There are very big differences between your audiologist, so find the right one and be aware that there's big differences.*

### **The importance of therapy and of Bluetooth**

This was mentioned before in thinking about a second CI and about music:

*But I just wish I had more therapy when I first got it and then, lastly, it is before my re-implantation I did not have any Bluetooth, the first generation Advanced Bionics cochlear implant that I had and so at that time there was no Bluetooth, like, the processor did not have any Bluetooth, but they did have an audio jack, so but I never used that. After my re-implantation I am doing music therapy and now I have a greater appreciation for music, like, way more than before. And, yeah, so I am really happy with the changes I made now, but I wish I made those changes earlier than would have been more beneficial.*

### **Rikie's hearing journey:**

Following discussion, Rikie introduced herself and shared some specific issues:

*I am Rikie. I live in the Netherlands and I got my cochlear implant on my right-side ear in 2015, so nine years ago. But the story is that I gradually got deaf throughout my whole life, so it started at age of 18 that I did not hear the high tones. I have to say getting deaf that slowly it's it has been a real struggle because I didn't know I was getting deaf; and the struggle got even more heavy when there was so little hearing left that my tinnitus got worse but also I got hyperacusis or recruitment and that means that sound did really hurt me. I could not bear any sound, my brain was so overloaded that it was pain all over in my body. And that was when they said, well, hearing aids don't help you any more. Perhaps a cochlear implant will help. SO I had an Electro acoustic CI, which combines a hearing aid and CI.*

*So yes, I would have liked my cochlear implants before earlier but also I understand that our body and our brains are so clever. Only I know now how it has been this process and it took a lot of patience. Normally it takes about one year but now it took for me it took about 3 to 4 years to really get rehabilitated and to speak to you like this and to understand you*

Rikie's story led others to share their journeys of hearing loss and implantation:

### **The mental health hearing journey and value of a peer group**

*It's really, really important to meet other people with cochlear implants before you get the cochlear implants and I did that but I recommend it to everybody.*

There is rather more awareness now of the mental health hearing journey and several shared theirs, including one who is a qualified counsellor.

*I had mumps and it got gradually worse as I got older and I was quite let down by my hearing clinic; they didn't tell me it was possible to have a cochlear implant and then I had to go private to get it. But the main thing that I would like to share what I wish I would have known and this is coming from*

*somebody who is a mental health therapist and I am a counsellor, so I am somebody that's quite self-aware. After I had the implant surgery I really struggled with my mental health and I felt like I have this complete new sense of identity, like, I was kind of grieving part of the old me and I kept thinking to myself why are you feeling like that? And I had quite intrusive thoughts as well and just being very paranoid that I have this device in my head. Feeling quite emotional, very fatigued, especially after the surgery and I went into quite a dark place and I really wished that there would have been some therapeutic mental health support as part of my cochlear implant journey which would have, you know, I am in the process of writing a similar programme, and I strive to be a therapist that can support others on their cochlear implant journey, adults and children, by using what I kind of went through because it was very hard when I went for my activation to speak up about how I was feeling to the audiologist. I think a gentleman mentioned it earlier about getting the right audiologist to do your mapping and she was ... not very much empathy there. And when we are going through this we need that empathy, we need somebody to listen to us and our fears. I really could have done with that holistic therapeutic support, just somebody who understood maybe another person with a cochlear implant or a trained therapist who would guide somebody of, you know, the mental challenges that you might experience having a cochlear implant surgery.*

There was much agreement to these comments - with much nodding of heads:

*I totally get what you are saying because grieving is part of our process, of our journey because it's a new journey and it's adapting to a new kind of life and it's very important to have support, not only from your audiologist -- but also the mental part, the grieving part as well as the support part, because the uplifting words and to have that little hand in the back supporting in whatever way not only in the re-hab process but also in the outside world from family or special friends it's very necessary.*

*I have one cochlear implant with Advanced Bionics and I had it in 2016 and it's amazing. Up until 2015 I could hear perfectly. I woke up and I had had a complete vestibular failure and I couldn't hear or see, my sight came back, my hearing didn't. So a year later I was offered a cochlear implant and the one thing that I wish I had known that there were other people out there, because I had suddenly lost my hearing and I had no background in losing my hearing. I had nobody I knew who had lost their hearing and I had no idea what a cochlear implant was and it wasn't very well explained to me. I really just wish I had known more about it and that there were other people out there who I could talk to*

It was recognised that earlier there was no internet, no easy opportunity for discussion which are available now.

Most had been implanted as adults but three were young adults who were implanted as children:

*I was born deaf and I got my cochlear implant when I was really, really young. I was like one year and a half or three years and a half so I didn't quite know what happened back then. But I can say what I wish I knew later in life, for example, when I got the implant there was very little knowledge about this area and my parents didn't know, so they more likely listened to their instincts and also regarding this aspect things have improved now; there is a lot of information, there is a lot of counsellors and so on.*

For young adults with CI, as teenagers they become more awareness of their deafness in a different way and learn about limitations and how to be assertive. Rikie commented on this:

*Normally people get there slowly like me and they have to learn to cope, but teenagers realise at that age that they are different from normal hearing people because there are limitations, even with cochlear implants. And they have to learn to cope with all this kind of stuff and that's exactly what you are saying. And we have to be very assertive and stand up for ourselves to talk about it what we need, like, can you talk slowly? Can you talk clearly? Can I have your face in the light? So that I can see you. Can I ... and so on and so on, what is it that you need and in fact this list you always have to have with you in your mind or even a button or whatever, you want to explain it to them, because we need to do that over and over because even at young age people or any age I can say are so short of memory; you tell it to them and in the next hour or the next minute they already have forgotten about it and you need to repeat it and to repeat it and to repeat it and to repeat it for the rest of your life.*

### **Hearing aid and CI**

*and the second thing I would have loved to have known is looking to the future as that I am now being model when I got the surgery. I was just deaf on one ear and I chose AB Bluetooth capabilities and other reasons, but now I am so lucky and so happy because I have the matching hearing aid which I didn't forecast when I got the surgery. So I really can encourage everybody and to think about the day of today but also in the future and when you get older you might get deaf on the other ear as well and think about that*

### **Using more than one spoken language**

There was an interesting discussion about the possibilities of using more than one language:

*But I have been speaking different languages all my life, so I know it's in my heart and in my brain so it's available somewhere, but I really had to learn and hear and understand from scratch when I was totally deaf. First it's always the native language which is the easiest to get access to, which I was born in the Netherlands so it's Dutch is my native language and that's in the rehabilitation I got in Dutch. But after that I got back to English because English is in television, in movies and songs and so on, and I have English speaking friends and slowly it got back especially if you listen to the same voice for a longer time because then it makes it easier and after that I added German again, and that's got slowly back as well. So now I am capable of speaking 3 languages again and understanding French a little bit again. So don't let that -- that's the thing I want to say. Don't let anybody say to you that something is not possible, because I know now the brains are so clever and anything is possible, as long as you are passionate about it, and as long as you are loving the things you do anything is possible for you. So please carry on and do what you love.*

### **Finally – our families and friends**

*. It just occurred to me I would love to have known before getting cochlear implants the difference that my CI would make to the people around me. So it makes a massive difference to my wife, it makes a massive difference to my children, my friends and my colleagues and, you know, and I think the system doesn't prepare us for that at all. It's all about me and my hearing rather than what it's doing for others. So I would like to have known that, you know, it changes life for everybody.*

### **Summary**

The issues brought up in this wide ranging conversation were fascinating as usual and the major issues were:

- Several participants would have had their CI many years earlier with the right information
- The peer group is very important in providing information and support during the journey
- Participants wanted more information about the technology
- They recognised the importance of programming their devices and having a relationship with their audiologist
- They valued rehabilitation, including music, and advised “sticking with it”
- They wanted rehabilitation to include counselling support
- The impact of CI and the brain shouldn’t be underestimated.

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