

CIICA Conversation 7: Adults with CI, Managing Listening and Communication Effort

12 July 2022

Facilitators: Kris English (US), Lise Hamlin (US), Emma McAuley (Ireland). Observer: Sue Archbold, Coordinator, CIICA

Attendees: 14 users of CI from 9 countries (13 in real time and one offline). One additional attendee was awaiting implantation, and 2 were clinicians/educators, one of whom was a CI user. Live captioning was provided. Participants were from Canada, Finland, Germany, Ireland, Libya, Netherlands, South Africa, UK, USA.

Introductions:

Facilitators: Kris is a retired professor of audiology; Lise is the Director of Public Policy at Hearing Loss Association of America (HLAA), which has a national office near Washington DC and chapters all over the US. She is a CI user, as is Emma, who is an audiologist in Ireland at Chime, National Charity for Deafness and Hearing Loss.

Attendees also introduced themselves via the chat room.

Framing the Conversation

The inspiration for our Conversation topic, “Listening and Communication Effort,” came from the April 2022 CIICA Conversation event (“Reimaging Rehabilitation”). Using the familiar analogy of a phone battery to represent “effort energy,” Kris introduced the following three topics to frame the conversation regarding listening and communication demands:

1. What drains your “battery”?
2. How do you manage or recharge your battery?
3. Suggestions for next conversation?

Summaries

1. Demands: What drains your “battery”?

Attendees identified a wide range of demands on listening and communication efforts, a primary one being noise in social settings (restaurants, family dinners, birthday parties). An example was shared about a church service:

“If anybody is sitting behind me and I can't see it... a baby crying, a toddler talking, a diaper bag velcro opening, all felt like it was the same volume all at the same time and it was overwhelming.”

Family holiday dinners. Everybody sitting around the table and everybody shouting back and forward which I find difficult, to figure out who is talking and what they are saying

I got my cochlear implant in 2015, so that's 7 years now and I must say I know now how to manage it, but it's a lot about avoiding. I don't go to restaurants because it's not possible the surrounding sounds, when they are terrible they really create my bad way if you say it like that.

From the chat room:

unfortunately there are so few restaurants left with carpets and curtains 😊

Multi tasking... I totally agree. It's draining.

hearing / listening and reading took me a long time to get in my system during/after my rehab

Yes, Emma. I too have to take notes

Taking notes has taken me a long time too ... because I only could do one thing at a time.. it is still hard but getting easier because of practicing

Others commented that they enjoy going out - and don't avoid those opportunities:

I am happy to go to noisy places restaurants I am bilaterally implanted and I enjoy those situations but what drains my batteries is tinnitus, I have tinnitus all of the time but some days it's a lot worse than others. So it's unpredictable and that really tires me out and frustrates me and I don't know how to recover from it apart from coping with the next day better than the previous -but if I am invited to a party I go! I enjoy that

Others choose the situations they go to, and are confident about making their issues clear, to minimize their effort:

I wasn't deaf until I was 50 and then I developed tinnitus just like you, Robert, it became so loud I could not deal with it at all. I don't know what started it. ... I ran a Cochlear Implant Group and we would only meet in restaurants that had carpet and soft furnishings. That manages the sound but you can't always do that, so I tend to take myself

outside, and I will explain. I used to be embarrassed that I was suddenly not in the hearing world but I am so proud of my cochlear implant, I wear my hair up I make sure everybody sees it because that's the only way they will understand that I can't hear everything any more.

Others also contend with the impact of tinnitus and hyperacusis, to the point where these conditions are the primary cause of their fatigue:

I have tinnitus all of the time but some days it's a lot worse than others.

For me, it's very echoey hard surfaces like restaurants: they set the tinnitus off and it lasts for 2 weeks and I can't hear until it drops down again.

You have to know that it's hyperacusis as well. I have to take care very much about what drains my battery not to be in pain.

Interestingly:

What is interesting when I got my cochlear implant the tinnitus disappeared. Very interesting why that happened.

A contemporary complication has been the impact of the pandemic. Recovering from COVID is itself exhausting, and also affects the already-limited energy needed to listen. For example:

"Sound is terrible because [COVID] is in my system. I am too tired and I can't understand and hear well."

"If you are already sick you have little resources. The battery is half drained already and it takes its toll much faster. Even if you had a good night's sleep, it did not help a whole lot, you are run low already."

Whether personally recovering from illness or not, additional challenges included:

Listening to muffled speech when people wear masks, and lipreading when they are not.

Attending online meetings "where I am watching the captions, watching the faces and listening, and by the end of the day I am totally exhausted."

Several attendees reported that working full-time required excessive listening/communication effort, and they have scaled back:

"There is no way I could work a full week. It's too exhausting."

"I am the same, partially retired because of my hearing, because of my tinnitus."

"I work 3 days a week, it's probably the maximum I can do. And there's extra work to make sure everything is covered."

"The minute I started to go deaf that is when my exhaustion set in and I slowly retired"

"I am retired now, so I don't have a full day of listening, listening, listening ... do feel for people that have to listen all day long. When I was teaching it was hard work."

2. How do you manage or recharge your battery?

Several mentioned managing listening effort by being upfront about the challenges:

Lots of people talking is tough I always explain to EVERYONE that I may not hear everything

It was suggested that auditory skills training for adults can lessen listening effort but may not always be provided for adults; for example:

I would encourage you and anybody else is think about what is possible and to think about the particular auditory skills training available out there and if it's not available to you then find directly through the system to find out where else it might be (available) and to look how you can get that..... in terms of that listening effort things become easier

Attendees shared their strategies for recovery from listening effort, and found they had much in common, particularly about withdrawing from situations to take a break:

"My therapist taught me about those little slip aways: take out 4 or 5 minutes, ten minutes when you are in a room or in a conversation or wherever, and just say sorry I need a little break...I really had to learn that it's so helpful just go to the toilet or wherever and just breathe out, not being tense listening and relax for to ten minutes."

"I tend to take myself outside... remove myself outside for a minute and, as you say, recharge your battery."

The axiom "nature heals" was often alluded to:

"Just go outdoor in nature with my horse and have a ride."

"Working in my garden ... nature is so soft in sound ...really relaxing and yeah it's recharging my battery... I can take a nap but it's easier to just have a walk."

"Connecting to nature ...I live near a massive park that saved me during the lock down."

"Unplugging" from sound or concentration also provides a welcome break:

“Quite often I would go to the park and not even wear my hearing aid, so I was getting the rest audiologically... I notice things [visually that others] don't notice.

“Once a day, I will take my implant off and just go quiet and during that hour or maybe longer, I take the benefit of a beneficial glass or 2 of wine, read a book then I go back to normal evening time of watching TV. I seek programs that take me out of myself and I forget about the world and everything.”

“After a really hard day I will watch mindless TV. I don't have to think too hard. I like it better, that will recharge me.”

“I get home in the evening and I get my supper and I turn on mindless TV which does not need me to think...”

Another compensatory step included relying on the written word:

“I have problems communicating on the phone which I find hugely frustrating so I live in a world of e-mails which leads me to the point of writing things down rather than have people talk to me.”

“I take notes to have something to refer back to. I can't rely on my memory.”

“I scurry home and make notes of what people have said or I would dash to the loo and make a note of their names because I know I will not remember their names and I think it's because I try to remember so hard... you can't guess a name... compared to the life when I did hear.”

It was interesting to hear from one participant about reflecting on the accommodations she had developed over time with her implant (16 years) and had over time stopped noticing:

but what I find really interesting is the fact that I have had my implant longer than some of you and the longer you have your implant, the more you become accustomed to adapting the more you don't recognise those times you have (made) the additional effort. I was involved in a study not that long ago by a researcher that was looking into listening effort by cochlear implant users. She highlighted to me just how much of an additional effort it actually was, but I was not aware of it because I became accustomed and used to doing that. What I find difficult is to separate out what is the listening effort and what is caused by what am doing. ...That can be draining in itself, so I want to determine what makes the difference to do something about it, I think its actually quite challenging so those perhaps that have had their implants more recently will be more aware of those adaptations. I find it useful to listen to because people are bringing up situations that I don't think about as much anymore.

An unplanned theme developed throughout the hour, stressed by many attendees: We are all different, and on different stages of the journey. Our journeys will be different too, as summarized by one attendee:

its very different for everybody and that is really because of the nature of our hearing loss, the experiences we have had, how long we have been without certain sounds and that is something that is really important for everyone always to recognise in terms of what support is needed....people who have their implant the same time as I did, I am meeting with them in different groups along that journey, our experiences were so different, I often asked myself why that was, it was not until I understood the nature of how we hear and the impact it has with the time you have had been without certain sounds and what support can be put in place .

In closing:

“Very interesting, listening to the issues that people have and are currently dealing with. I have adults I work with, it’s encouraging to know that the problems they talk to me about are the things I am working with kids as well.”

“I just want to say thank you to everyone, it’s been enlightening listening to everyone’s stories. Having been an audiologist for many years on the NHS and then working for one of the companies, it’s just good for me to be reminded about what is important and to hear your perspectives.”

Sue closed with a mention about the “Living Guidelines” project (a literature review of research issues), noting that some of the issues brought up in tonight’s conversation do not appear in the research. “We have to make sure they are talked about and they are listened to.”

Notes: Two books were mentioned as being helpful:

On time management, I highly recommend the book Eat that Frog by Brian Tracy. Here's a fantastic book called LOST CONNECTIONS by Johann Hari, and one of the chapters is about reconnecting to nature!

With regard to the research on Listening Effort by Helen Willis, PhD, neuroscience researcher and CI user herself, Helen has produced two very useful resources based on her research – one for children and one for adults, Going for Gold: available from British Association of Teachers of the Deaf, BATOD, and available from [Go-for-Gold ADULTS.pdf \(batod.org.uk\)www.batod.org.uk/](http://www.batod.org.uk/Go-for-Gold_ADULTS.pdf)