

Season 4 Episode 1 Transcript

[Music]

00:00:10 **Dr. Karen Gordon**

Hi and welcome to the Hear Here podcast! This is season 4. We are a team at the Hospital for Sick Children in Toronto, Canada. We are hearing healthcare professionals, researchers and clinicians who are aiming to understand and possibly improve quality of life for people with hearing loss.

In season 4 of the Hear Here Podcast, I had the distinct pleasure of turning the microphone inward to our Hear Here podcast team to hear their very valuable insights and thoughts. So you're going to have the distinct pleasure of listening to Maryan Othman, May Wang, Nimrat Chani, Sofia Olaizola, Maria Khan and Annika Gasee. Enjoy.

[Music]

00:01:09 **Sofia Olaizola**

Thank you, Karen. My name is Sofia Olaizola and I am a cochlear implant user unilaterally on one side, and I was born with bilateral profound sensorineural hearing loss and actually had my entire pediatric audiological journey in Toronto, Canada with Karen, at the Sick Kids Hospital in Toronto.

So that is how I came to be a part of the lab. I am interested in a career in audiology and because of that I reached out to Karen because of the impact that the team at SickKids had on me in my life and I wanted to sort of spread awareness and spread knowledge about the research that's going on in the lab, and some common issues that come up with wearing hearing technologies, whether they be cochlear implants, hearing aids, or whatever else it is.

And I'm excited for this season because I'm excited to talk about some things that maybe the audience might have questions about, like hearing fatigue or what it's like to grow up with a cochlear implant, what it's like to... you know, I'm 23 years old, so I've had a cochlear implant now for 22 1/2 years. I would love to share about, uh, growing up for 22 years with the cochlear implant as the technology has evolved over the last couple of decades.

00:02:27 **Dr. Karen Gordon**

Okay, May let's hear all about you!

00:02:33 **May Wang**

Hi everyone, I'm a second year undergrad at the University of British Columbia with a major in nutritional sciences. I was born with single sided deafness. I was a 10 year patient at SickKids under the ENT department. So I joined this team with the hope to connect with others that shared similar personal journeys and also help raise awareness around hearing loss and hopefully have an impact on the children growing up now and make them feel connected.

00:03:09 Annika Gasee

Hi everyone super excited to be here! My name is Annika and I'm in my second year of studying Health Sciences at Wilfred Laurier University, and I joined the team because my oldest brother has a hearing aid in one ear and a cochlear implant in the other ear. So I was originally interested just in learning more and I knew there were some cochlear implant users on the team. So I was interested in hearing about their experience as well, in addition to my brother and seeing how like it differs from individual to individual.

00:03:43 Maryam Sattar Othman

Thank you for having me. So hello, my name is Maryam. My journey with this group is that I used to be a patient of Dr. Gordon's colleague and I just remember visiting the hospital and just learning about my condition and also sort of other people's journey as well. And as I grew up, I just always felt connected to SickKids Hospital and it was sort of the place that was magical to me as a child. And as an adult, I still wanted to maintain that connection. It's actually really sad to graduate from the program when I turned 18. And I did transition to the adult program, but I just never found that connection like I had with the pediatric program. So I ended up reaching out to Dr. Gordon and seeing if there was any way that I could get involved with her work with her research. And she indicated to me that this group was going on and it would be that adult connection to other people, who are Hard of Hearing or have family members and I would, I'm just really excited to be here.

Currently I just have the cochlear implant on my left ear, although I am bilaterally hearing impaired, I just never wore anything on my right side and a lot of the decision behind that was my sister is also hard of hearing, but she got the implant before I did it and she got it on both sides and my parents sort of witnessed how whenever she was sleeping, or in the shower when she didn't have her devices on, she was not aware of the world around her. And so when it came to me, their concern was, well, if the house alarm ever goes off, we want you to be able to wake up if there is something like beeping in the kitchen and you're upstairs in your room like we want you to at least have some awareness of that. As I've grown up, I've found it kind of hard to just rely on that one side. So now I'm looking into hearing the option for the right ear and a lot of that has to do with my position as a medical student. So

I'm currently in med school and I can't necessarily go and get a right implant because I need that ear for the stethoscope and so my only option at the moment is to just get a hearing aid and I'm hoping with integration and the technology that we have right now that the sound will be similar, but to be determined... I have yet to try it on.

00:06:10 **Dr. Karen Gordon**

Oh my goodness, such good points around. You know the what you need to do to adapt the devices to your needs and so forth. And I want to go from there to the topic that we discussed as a group. That was, we thought would be front and center around hearing fatigue. So you're all amazing users of this you know of your devices and your just amazing examples of of people who are overcoming, you know an extra challenge during childhood and how you're succeeding and thriving in life, but that does come with effort and I know you have all talked about that effort as fatigue and first of all, I want to understand that from your perspective. And you know with the view that people listening may not understand that it can be hard to listen sometimes. So I'm going to start with Sofia,

00:07:23 **Sofia Olaizola**

Maryam, May, me and many other people were kind of the test babies and test children because the technology is so new, it has only been involved evolving in our lifetimes. So really, I think hearing fatigue is relatively new as well. Because of its impact on me, I have done some research on it and I see that you know, the most recent research has come in the last within the last four years, so it's difficult to give a definition as well, but I'll speak on what maybe my definition is and if I'd be curious to hear what May and Maryam have as your definition, especially because we all have such different situations. I mean, I am fully deaf on both sides, personally have 0% hearing and I'd be curious to know if you know your level of fatigue is almost different than mine because you have a different sort of cognitive load going on in your brain when you're processing sound.

But for me, I the way I define hearing fatigue is that my brain it is taking on a significant cognitive load when I'm trying to have conversations with people. I mean, for me it presents not only in noisy environments. It's definitely worse than noisy environments, but it's also in quiet environments too. Even the smallest of sounds can irritate me. Growing up in school, I always had to take my CI off when I was writing tests because the cognitive overload of hearing other people writing with their pencils and the fan and just the different noises that happen in a regular room would be overstimulating from my brain, hearing fatigue is just sometimes it can manifest itself in headaches. I don't know if it's directly correlated, but I'm learning as I get older because I've always had this problem since I was a kid, it would be the number one source of conflict in my household. Was Sofia put your cochlear implant on and

that was, you know, I would wake up in the morning for school and everybody would be getting ready. We would have that half an hour before school, where we'd be doing breakfast and everything, and I would not want to put my cochlear implant on, I wouldn't put it on until it was time to go in the car and we're going to school. I would get ready for the morning with it off and I think that was my body, just not ready to take on the brain energy that's required for hearing. I just woke up I didn't want to immediately go to work so to speak. And then when I come home from school, it would go off again. So I would wear it all day at school and then I come home and it's off again. And then so that's kind of for me, hearing fatigue is the feeling of just needing to take it off in order to achieve the sense of relief from the auditory stimulus. Because when I take it off, it's almost as if my brain just stops doing a whole I I can actually physically feel my brain stopping and just kind of relaxing and do being able to focus on other things so I don't know if either of you can relate to that, but feel free to jump in at any point and I've seen it with other people too.

You know, when I meet other families at the hospital and parents are kind of struggling because obviously you want to be wearing it as often as possible in order to make it work, but at the same time there needs to be, I guess, a balance to sort of manage this hearing fatigue and it's not, it's hard because kids can't articulate, they don't understand why they want to take it off. They just know they want to take it off. And I think that was me. It was always why are you not wearing it? It's just, I don't know, it just I used to say it just feels better. It feels better off. And as I've gotten older, I've been able to actually articulate into words, "no, I just need some personal time". I call it like this is my quiet time. This is my me time. And you know, if you wanna talk to me during my me time, I will read your lips. But I'm not putting it on right now.

00:11:22 Annika Gasee

That's really interesting because so my brother, as I said, has a cochlear implant and a hearing aid and I notice, especially when we're at dinner, kind of like towards the end of the day. Oftentimes he doesn't wear his devices and we'll be having a conversation at the table or like my parents will call on him to like, say something. And he just doesn't hear. And then my parents will go. Are you wearing your hearing aid? Are you wearing your cochlear implant? And oftentimes he's not, and then my parents will kind of get mad at him. You know, we're at the dinner table. We should be talking. You know, it's our family time. But like, since I've joined this group, it's been really interesting to hear your guys's perspective because I don't really think my brother ever articulated hearing fatigue so much in my house. So when I came here, it was really interesting for me to hear about that because I immediately connected that with the dinner conversation. Or if we're in the car on the way to somewhere, you know he might not be wearing it, especially if it's like to a social event. So it's really and like right

away when we start talking about hearing fatigue here, I'm like, that's exactly what it is. And I'm not a user, but I had a completely new like understanding for my brother and what it's like, you know, by the end of the day to just be completely exhausted, like especially at dinner and just not want to wear his devices.

00:12:43 **May Wang**

I can actually totally relate, especially to what you know, Sofia mentioned about all the headaches and all that. It's it's completely true. I think for me, especially because you know I you never have any hearing device worn, so sometimes it's like hearing fatigue is less obvious in some sense to both myself and also my family, and I think it was only in the recent years when I started noticing that, you know, like every time after like a math test where I had to concentrate a lot that I started developing like this headache. Almost every time after you know some sort of hard tests and originally I didn't really like think too much. But later on as this pattern kind of develops, I started like picking up the hints and realizing like I felt really tired after and it was probably associated with, you know, like maybe not just like the busy environment, because it's quiet, but for some reason like, I feel like I just have to concentrate a lot more. Even if if the environment is, you know, really quiet and I think sometimes, especially at the beginning, I would think that maybe it's just my personality that, you know, my energy drains really quickly when I'm socializing or, you know, maybe I'm just like, a really introverted person that likes silence. But then I think as I grew up, I kind of realized that I think sometimes it's just like I need that time to kind of relax my brain. So you know if I have headaches or if I, like, realize that I'm experiencing some hearing fatigue, I think I just, like, have to stop everything and like make sure I get the opportunity to kind of like relax. If that's like, you know, doing nothing or like doing something that I enjoy. But I think I realized the importance of making sure that my brain could rest.

00:14:57 **Dr. Karen Gordon**

I think people will be surprised May that you have one normal hearing ear and that that's just not enough to combat this hearing fatigue completely that you know, we used to really disregard the impact of having hearing loss only in one year, so I really I want to thank you for for sharing that because this is an interesting perspective that you can't change it. You can't take a device off. I was going to ask that too is is there a difference between manipulating the environment versus taking off devices?

00:15:39 **Maryam Sattar Othman**

So Prior to joining this group, I didn't even know that there was a term associated with what I felt, which is hearing fatigue and in my case it would present as... I think back then the devices were like this...there were spikes on the outside of the device and so when you

would put it on, it would actually start to hurt the site of like where the magnet is a lot. And so as a child, any chance I got, I would take it off and that obviously did not help my development. I had to go through years of speech therapy because my speech was declining even though I was wearing a device as much as I could. At the same time, I was not and then as an adult I have noticed that I would just feel very tired when I come home from social events and then like May, I thought ohh is that just an introversion thing like am I? I used to be super extroverted, but maybe the pandemic changed me like I don't know what's going on and I think now that I'm reflecting on it in real time, during the pandemic, we weren't socializing as much so we had a lot of downtime and coming out of it, we were suddenly back in class back in school and having to deal with so much interaction very quickly too, that I think it just meant that I so I just need to go home and I need to relax and I don't want to be around anybody right now. And maybe it's not that, maybe it's not that I've become less extroverted, but I just need more down time to process that gap.

And there were a lot of great comments made about how you're straining to understand the conversation and stuff when speech is distorted or unclear because with hearing loss the brain has to work harder, greater cognitive resources are required for auditory processing at the expense of other brain functions like memory. The strain of this over many years they overwhelmed the brain, leaving one more susceptible to cognitive decline. So when I read that, I was like, I think this is like talking about me because I often find myself having to work a lot harder than other people to sort of understand what's going on in the conversation.

In terms of that, the environment make a difference as opposed to taking it off, see, I don't know because even when I go into the quiet study zone at school or at home, I still kind of take it off. And I think it just helps me focus more. I'm not really sure why, but it's because it's not like there's auditory stimulation around me, but I think it's just it's sort of like a unconscious thing that I have nothing around me. I'm able to focus more.

00:18:13 Sofia Olaizola

Just to say just so that they know, I consider myself to be a very extroverted person, and even me, if I'm at a restaurant with my family and my friends after the first hour, I'm absolutely exhausted. And like it gets to a point where I don't even try to understand what's happening in the conversation anymore. I'm just like what? Oh, you're talking to me. Ohh. What did you say? Like, I just get so tired. And then the second, we leave the restaurant, all of a sudden we're outside and it's like, whoa wow, that was actually intense.

00:18:47 May Wang

Yeah, it's just as as Sofia was talking. I started, like, wondering if like you guys also experience like this, I constantly have to like subconsciously I have to work harder to

concentrate and focus on my tasks. So even if under like quiet settings, I'm just like studying by myself like after maybe let's say an hour or two just like, you know, intensely trying to study and do my work. And then I sit back and then relax. I start realizing like I have a headache and I didn't realize that I worked so hard at that moment and it didn't seem like I had to work that hard. But sometimes it's like almost like the after taste like when I start to relax then I realize whoa, like I had to concentrate a lot and then I start experience like the effects of hearing fatigue. So like as you guys were, you know, meant describing your own experiences. I started wondering if you guys also experienced that as well or something similar.

00:19:56 **Sofia Olaizola**

I can completely relate to this when my device is on but I have the ability to take it off and you mentioned that you don't and I can't even imagine not being able to take it off at that point, because for me, when I take it off then I get that instant relief. Relief takes over because I just go from this work to being completely deaf. Whereas when you take the one off, you still have to continue this effort with the other ear. So I feel like it would totally make sense even when you're trying to. Cause for me, I don't, even if I'm trying to concentrate, I don't even try, it's off at work. I have a sign that goes on top of my desk that says my hearing aid is off, please tap me because I just keep it off all day and all of my coworkers know to just tap me instead, so I don't know what it would be like to not take it off.

I can absolutely imagine the load it would be because if I were to keep it on and try and be in study hall and you know, spend an hour just focusing on my work and you still have all that stimulus going on, I can completely understand why you would start getting headaches and why you would start to feel overloaded. Yeah. So I while I don't experience it, I can understand and relate to how you might be feeling? Because I can imagine it might be how I feel when I have it on and I'm trying to to do some work or to concentrate.

00:21:25 **May Wang**

This is really interesting because there's some I think there's like some lack of understanding of whether you know people with single sided deafness are more similar to like normal hearing individuals. Or are they more similar to you know like people with hearing loss in both ears and based on what I'm hearing and also from like some recent research articles that I read on my own time it seems like people with single sided deafness or unilateral hearing loss actually like their experiences are more similar to those with like bilateral hearing loss.

00:22:14 **Maryam Sattar Othman**

So May, I think I can kind of relate because although I do take the implant off, I still have the other ear to contend with, which is still like functioning, just impaired. And what I find helps is sort of manipulating the environment to your liking. So sometimes I'll play certain audio files on YouTube that are common and put me in a study mood, for example, so it will be something like you're walking in a forest playlist and it's just a bunch of like birds chirp or something and it's like an environment that you can control. So it's not that much cognitive load for you to take on. Whereas when you're in an environment that you can't control and it's very distracting, someone's talking next to you, chairs are being moved around. It's just a lot for you to deal with and it ends up taking away from your studying and your focus and I can imagine why you get a headache.

So I wonder if that could potentially help with the hearing fatigue that you're experiencing, because that helps me and it's helped me for a long time. I just thought that I like could relate to what you're going through and it's just it's just a matter of figuring out how you can manipulate the environment to work for you.

00:23:13 Dr. Karen Gordon

That is an amazing suggestion because I've been listening to you guys and thinking you know what would be the comparable like there's nothing comparable for somebody with normal hearing. I think Maryam, you've got something really important there around manipulating the environment where you may not need to interact with it as we do when we're communicating. It's a very hugely engaging experience and that part of listening is, is so active and that might be what you guys are saying around the fatigue, what do you think May?

00:23:54 May Wang

I think so, yeah. Like I use background music sometimes too, like some like classical Chinese music in the background, but I think perhaps it's because they don't have the opportunity to completely like shut off the background environment. So like even if I'm just like in complete silence on my own after an intensive period of studying, or like using my brain, some sort of cognitive activity. I still experience some sort of fatigue that I think is more than like normal. I don't know how like to exactly describe it. But yeah, I think the hearing fatigue is always kind of in the background and sometimes it's just like it's hard to identify if, like the fatigue I'm experiencing is just from, you know, a normal like for example exercise and I get tired or is it something additional that's being added because of my hearing loss?

00:24:58 Annika Gasee

Just to add something on, I'm not exactly sure if that's to do anything with hearing fatigue, but I know my brother is like a big, big music fan and with him he always has his music on

very loud like I know Maryam, you talked about kind of like a forest type of thing. My brother likes very like loud music, and we always I I always hear him like blasting the music. Sometimes I'll be like turn it down, turn it down! But I don't know if he's just like a big music lover, or if it has anything to do with his deafness, but I just. I just thought that was, like, interesting to bring up.

00:25:35 Maryam Sattar Othman

Yeah, I definitely have that as well. I I wonder if there's a correlation between hearing loss and an intense keenness for music or an appreciation for music. I don't know if it's a priming thing or if it just kind of helps you to maintain some normalcy. But definitely as I was a child growing up, music was my solace, and I always had headphones on, even if I couldn't hear like the headphones or whatever music was coming through.

I would get comments on like your headphones are so loud, like I can hear what you're playing, but because I couldn't hear and I had to jack up the sound all the way, but yeah, I'd be interested to know if there's a correlation, because I definitely experience it and I don't know what you do, Sofia.

00:26:19 Sofia Olaizola

So because I have a cochlear implant, like if only people knew how loud I was, listening to my music because my cochlear implant has always connected to my iPod, where now I have the Kanso 2, so that just wirelessly bluetooth connects to my phone. And when I'm listening to music, it's always at maximum volume and I almost think it's kind of like our superpower in a way, because people with normal hearing, I always say to my friends that they wish they could listen to music this loud, but it actually hurts them or actually so like I'll be driving and my friends will be in the car and I'll have the music up like all the way because it doesn't hurt me. But, you know, they'll tell me, Ohh, that hurts when you play it loud. It actually hurts my ears. Like, what do you mean it hurts your ears? Because I can't relate to that. And so I do listen to my music very, very loud.

I think that for me, a big part of it is, what's the point in listening to music if I can still hear other things? So, you know, if I'm walking and this isn't, I just want to say PSA, this isn't the safest thing, but if I'm walking on the sidewalk from, you know, the train station to go to work, I have it at full volume. I don't want to be hearing the other noises, like the cars or the people talking because then it distracts me from my music and I can't properly hear my music.

00:27:42 Dr. Karen Gordon

This is amazing. I've never heard this, so I think just from an audiology point of view, just to point out that you're right, your your device will limit how high the amplitude of the level of

the input can come. But what so it's it's safe as compared to somebody with normal hearing. Where you know it can go so loud that you're actually damaging your hearing and that's a problem. So.

00:28:10 **Sofia Olaizola**

I always tell people, I say I say all the hair cells in my cochlea don't work anyways so nothing's going to happen.

00:28:14 **Dr. Karen Gordon**

So you. Yeah. So you've got a built in safety mechanism there. But I love the idea that that you're sharing is that it's really masking everything else you want it loud because you don't want anything else coming in. And that's such a good strategy. Makes total sense. We either want nothing or you want it to only be one thing. So what kind of music do you guys like?

00:28:40 **Maryam Sattar Othman**

I actually prefer instrumental like classical like me just, uh, I think I'm open to any country's classical music. Sometimes I'll be listening to Italian classic. I don't even know what's going on, what instruments are being played but it just it sounds nice.

00:28:56 **Dr. Karen Gordon**

What about you, Sofia?

00:28:57 **Sofia Olaizola**

I'm not very genre specific. I listen to kind of just everything I do notice is that I have if I listen to a song, you know I might not. I might not. If I never heard the song before, I have no idea what they're saying, so I'll have to go and read the lyrics. And then after I read the lyrics once through then I go back and listen to the song, and now I know what they're saying.

So I don't know if that's just because I have a cochlear implant. I always assumed it was because I always notoriously got made fun of when I was younger, because I would always say the lyrics wrong and they would be like, that's not the song. But that's what I convinced myself the song was until I actually read the lyrics. So I see Maryam's nodding her head. So I feel that you can relate to this

00:29:40 **Maryam Sattar Othman**

Yeah. I was gonna say that. I don't know if you've noticed, but when I hear a song just like, not through Bluetooth or headphone, I'm actually able to decipher the lyrics and pick up, like, actual parts of it, a lot better compared to if it was being streamed to ears or headphones? And so the song is on the radio and I have the radio turned up. I can actually

like understand the human language that are coming from the singer. But if it's just connected to my ears, then I'm mainly focusing on the musical aspect. I don't know if that's just a device thing like like the Bluetooth technology has yet to catch up but.

00:30:22 **Dr. Karen Gordon**

Are you? Are you when you're listening? Like I know, Sofia says she's listening like stream to the device when you're listening, because you've got hearing in acoustic hearing in one ear. Are you wearing a headphone or is it through a speaker that you're listening? What? How are you listening?

00:30:42 **Maryam Sattar Othman**

I think I have the best quality of sound perception when I don't have anything on like headphones. Or when it's not being streamed to my ears when I'm just listening through speakers, or if it's actually happening in front of me.

00:30:56 **Sofia Olaizola**

Yeah. Interesting for me, it's the complete opposite. I can hear it better when it's directly streamed to me cause like it's going right to me, to be honest. Actually, I tell my family this all the time because sometimes when they play songs, let's say from their phone and it's coming out of their phone it bothers me like it actually makes me feel annoyed because I it just sounds like noise to me. It doesn't sound like music I don't understand that. You know, even if it's a little movie trailer or TV clip, it just it sounds not right to me. Yeah. So even when I'm laying in bed by myself at home, I'll still listen with streaming directly to my cochlear implant as opposed to just playing out that which I totally could because nobody else is in the room but I still I'll still stream it.

00:31:46 **Dr. Karen Gordon**

Some of this is about how the implant works with a little differently right than acoustic hearing. And so that, you know, Maryam's comment around wanting to take off the devices can make sense to me because it, it's can be hard to put the acoustic Sound of Music with what you get through a cochlear implant, which you don't have to contend with Sofia. So yours is your own experience of music that just...

00:32:17 **Sofia Olaizola**

Yeah, who knows what I'm listening to. That's what I tell people... To me, this is music. Maybe to you...

00:32:23 **Dr. Karen Gordon**

No, 100%, 100%. What? What were you gonna say Annika?

00:32:26 **Annika Gasee**

Yeah. So have you ever have you guys ever been to like concerts? Or like quinceaneras or sweet sixteens or like bar mitzvahs, where there's very like loud music. Like, I was just wondering if that's like an enjoyable event for you guys.

00:32:40 **Maryam Sattar Othman**

So I think a concert would be a nightmare for me personally. I think I'd get burnt out from the stimulation. I've also never been, so I don't know. I've been to like prom back in high school and I don't recall anything about the sound experience. I think I was just bored. I don't know why I went but yeah, I don't think I can. I well let's say you're outside, like if it's just super loud, like super noisy. I do find myself kind of struggling and experiencing more of that hearing fatigue.

00:33:19 **Sofia Olaizola**

I mean, I personally love concerts. I go to them all the time. I love musicals and concerts, and I think it's not the same as being at, like a restaurant, for example. And being in a conversation with people, because when I'm at a concert, I'm not having a conversation with anyone. I'm actually not using energy at all to converse, and it's predictable because I tend to go to concerts for bands that I know, so I know what the songs are, so it's not... There's no surprises because my brain knows what to expect. It knows OK, now it's playing this song, you know this song, you know the words to the song. So I don't have to think it's there's not a lot of thinking. I'm just singing along. I'm dancing and because...

I almost think that concerts are worse for people with normal hearing because the sounds hurts their ears, whereas for me the loudness of the sound does not bother me at all. But I think with concerts, there's a predictability to it and because of that, your brain isn't having to work so hard like you don't really have to think about it, you're not having to listen and then think about generating a response because you're not having a conversation with that person.

00:34:31 **Dr. Karen Gordon**

It sounds to me like you guys are using music the way that music is universally. It's an it's an experience, it's an emotion, and you don't necessarily have to have a response to it. So as opposed to communication, which is so active and has such a cognitive load because we're constantly receiving and then responding, receiving, responding and it like how many conversational turns do you think you have an hour? Those conversational turns, you know,

if we look in in the research, children who have, like, 3-4 hundred conversational turns are really, they're engaging and they actually do show on language measures, better language. So all that time and the engagement effort that's really worth it. But what you guys are telling us is that it does take that effort to keep going.

00:35:36 **Sofia Olaizola**

I think it has to do with like almost, you know, sustained cognitive effort like to have a conversation with somebody. You have to sustain a certain level of effort throughout, because if you drop the effort for even one second, all I I find myself doing that like sometimes I zone out for a second because maybe, maybe subconsciously, I just need a break. But then just for one second then I have to go. Sorry. What? I I didn't hear, like at all the last sentence that.

00:36:01 **Dr. Karen Gordon**

That you can get the information is going into the ear and it's actually even going up to the brain, but there's no registering like there's no further processing cause you're thinking about like, I don't know, lunch or whatever. The next thing is. So that's normal. It's just that the attention part it is active. It has to really be active and when you really have a a certain amount in your tank you know you're spending it more quickly when the input is harder to get. So what I wanted to ask you is about all of these you know once you do these you know, taking off the devices and being in a quiet space or listening to music to get a break. How you know how much time do you feel like you need and then can you reengage or is that like do you have a part in the day where you're just done for the day and you want to go to bed.

00:36:58 **Sofia Olaizola**

In the morning... I'll just say my routine, in the morning, I'll wake up and I don't have it on until I leave the house to go to work and then at work it's on and off throughout the day and I know I'm going to engage, reengage, engage, reengage so if I'm doing my quiet work time, it's off. If I'm, you know, in a meeting, it's on. If I'm talking to a coworker, it's on. I'd say a good 70/30 and then it's on until I get home and it'll stay on if I if I'm talking to my family. But then the second that I'm by myself, it's now off and it will stay off until the next morning, unless somebody wants to talk to me.

00:37:39 **Annika Gasee**

Again, so I I have a question for you, Sofia. So I think all of us sometimes on the weekend have like lazy days when we're just home the whole day, no leaving our house. So on days like that is your cochlear implant off the whole entire day or do you ever like, like, kind of

crave having it on or like? Is it kind of per? I guess it sounds like it's more preferred for you to have it off.

00:38:01 **Sofia Olaizola**

I've never had a day where I actually never, ever put it on, I don't think because...I don't think. I mean I probably have at some point in my life, but not that I can think of right now because I'm usually around friends and people and I wanna know what they're talking about. So I, you know, there will be a time where it'll be Sunday at 6:00 PM and I put it on and it's like, whoa qell, it feels weird. It's like I haven't worn this all day long, and now it's on. And now I hear things and it's a bit weird, but yeah, I do have lazy days for sure. You know, Maryam, what about you?

00:38:33 **Maryam Sattar Othman**

Yeah, I definitely. I think there's been a few days, where I don't put it on at all and maybe it's easier for me to do that because I can at least be aware of my surrounding with the acoustic hearing that's kind of left behind. And my sister, who's bilaterally hearing impaired and she wears the cochlear implant on both sides, we kind of like if we leave her to to her own devices and, you know, she doesn't have any plans, I think she'll also just keep hers off. She prefers it that way. But one of us is always coming up to her room to ask about something or I'll be like, hey, you want to go get a cup of tea? And then I'll make her. I'll be like put it on.

00:39:13 **Sofia Olaizola**

That's the beauty of the magnet, is that just as easily as it comes off, it can just come back on, you know, it's actually not, I don't think it's so difficult to reengage once you put it back on. You're just right back into it.

00:39:26 **Maryam Sattar Othman**

Yeah. Yeah. I think in terms of like, like how long do I need to recuperate. Like when I'm at school, I don't necessarily have the luxury of having like a long period of time off. I think if I just at least have a couple of minutes to myself when I'm I don't have to engage with anyone or anything, it's usually enough for me to bounce back to wherever I need to be. But if I get home and it's around like. 9:00 or 10:00 PM ohh, it just comes off like I don't even like plan to do it, but it's just a habit I've developed. Like at that time where I should be going to bed now. So just come up and then I'll put in the charger, but then I'll actually go to bed at like 12 or 1.

00:40:10 **Sofia Olaizola**

Do you have that issue, Maryam? I'm just curious because people have been bothering me about this lately of not being able to find it when you just take it off.

00:40:11 **Maryam Sattar Othman**

Yeah. Yeah. Yeah, that's happened to me a lot. And when we were kids, there was one time I thought I lost it somewhere. I knew it was at home, but I thought I lost it. I thought maybe I dropped it somewhere when I went outside or whatever, and I don't remember. And we requested like a replacement device and then we found the same device later rolled up in the bed sheets like a week later. So we had to ship the new one back because we're like, well, we don't need two of them right now. And technically it's not lost anymore. That's why I always have pockets on me, so if I do take it off, I slip it into my sweatpants or my hoodie pocket.

00:40:57 **Sofia Olaizola**

Be careful with that because last two weeks ago, I put it in the pocket of my bathrobe, forgot about it, decided to wash my towels, was like ohh, let me throw my bathrobe in there too, threw my bathrobe in there and it wasn't until two hours later that I was like, I had to go somewhere and I was like, where's my cochlear implant? And I'm looking. I'm looking, I'm looking. And then it hits me. No way. I go to the laundry machine. And I stopped the cycle. The cycle is full of detergent and water and because this thing is magnetic and the inside of my laundry machine is also magnetic, I just saw it. It was right there. The little brown Kanso was just magnetically attached to this, to the wall of the laundry. And it was so scary. But I ended up just taking it out of machine. And then I cleaned it, you know, dried it with the towel. I changed the microphone cover and. It's been 2 weeks and it works perfectly, so you know there's fingers crossed.

00:41:58 **Dr. Karen Gordon**

That's pretty good. This, this, this is real life. This is real life of having having devices, at least not durable. It's pretty amazing. I have learned so much from this conversation even after studying music and children using cochlear implants. Even after thinking about cognitive load and and looking at the differences between different children or on different measures like you guys have really provided so much more nuanced thinking and the sharing of information I think will be so important for people to hear.

00:42:13 **Annika Gasee**

Me too.

00:42:41 **Dr. Karen Gordon**

I really really want to thank you just being so open and and helping us understand what it's like.

00:42:53 **Sofia Olaizola**

Just wanted to say thank you, Karen, for giving us the space to talk about this. I think a lot of people listening can relate in some shape or form. You know whether they know somebody or they themselves are experiencing this, so thank you for giving us the space.

00:43:11 **Dr. Karen Gordon**

Oh, that's all you guys. Thanks.

[Music]

Dr. Karen Gordon

Thank you for listening to this episode of the Hear Here Podcast Season 4. I hope you enjoyed this conversation. I want to give a shout out again to the Hear Here podcast team.

Nimrat Chani, May Wang, Maryam Othman, Sofia Olaizola, Maria Kahn, Annika Gasee, as well as my colleagues that are involved Lora Carinci, an audiologist here at the Hospital for Sick Children. Dr Sharon Cushing and Dr Blake Papsin also. I hope you enjoy this music which was performed and composed by Dr. Blake Papsin. Thanks for listening.

[Music]