S4E4 Transcript

Dr. Gordon

Hi and welcome to *The Hear Here Podcast*. This is season four. 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 four 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 are going to have the distinct pleasure of listening to Maryam Othman, May Wang, Nimrat Chani, Sophia Olaizola, Maria Khan, and Annika Gasee. Enjoy!

[Music]

Dr. Gordon

OK. I am delighted to welcome you back to another wonderful episode of *The Hear Here Podcast,* season four, and this season we have been chatting with our *Hear Here Podcast* team. They are with me now - at least some members, and so I will have them introduce themselves.

Annika

Hi everyone, my name is Annika. I'm in my second year studying Health Science at Laurier University. And my connection to hearing loss is my brother has hearing loss. He has a hearing aid in one ear and a cochlear implant in the other ear, and my interest in joining the team was to learn more about hearing loss and see how I can best support him.

Dr. Gordon

All right, Maryam.

Maryam

Hey, hello everyone. My name is Maryam. So honoured to be here, for yet another episode. I am actually a medical student at Western University. My connection to hearing loss is that I have bilateral hearing impairment and wear the implant on my left side. And part of my reason for joining this amazing team was to find the connections that I had as a child, but now as an adult, and explore my disability from another lens.

Dr. Gordon

Thank you. May?

May

Hi, everyone. My name is May. I'm a second-year undergrad at the University of British Columbia. I was born with single-sided deafness, and I was a 10-year patient at SickKids Hospital. I joined this team with the hope to connect with others that share similar experiences and help raise awareness around hearing loss.

Dr. Gordon

Awesome. Sophia?

Sofia

Hi, everyone. My name is Sofia. I am a Research Coordinator in Toronto at the Hospital for Sick Children. My connection to the team is that I have bilateral sensorineural hearing loss and wear a cochlear implant on my right side.

Dr. Gordon

Thank you, guys. And I know you are amazing representatives of our team. We have spent some really nice time together working on this podcast and also chatting for this season. We're expecting a couple of other members to join us today. But I want to think about where we've come through this podcast and particularly in this season, that you've all been so open, and shared so many experiences beginning from, you know, the earliest memories, sometimes that you had as young children. And then, you know, your entry into elementary school and the early stages of schooling. Then we talked about high school, and we talked about all sorts of different listening fatigues and some of the challenges that you're having in those situations. Some funny stories about what it was like at school. Some funny stories for me about, you know, what you guys like to do when you get home. So far, I've learned a ton, and I'm sure, absolutely sure, that people listening to this will just be fascinated by what you guys are telling us. As I've said to you, you're such an important group. You, having grown up with hearing loss and grown up with cochlear implants, you represent such an important group to help us understand the impacts of these devices and what it has meant to you.

Dr. Gordon

So, in this episode, I want to talk a little bit about life outside of school, outside the sound booth, outside of, you know, the hearing aid and cochlear implant fittings that you did with all the hearing and educational professionals.

Maryam

Yeah. So, it was grade one, we had picture day. It was I think in the fall, so the weather was quite nice, and my aunt actually walked my cousin and I to school. We were the same age, my cousin and I. So, we're walking to school, and this is in Toronto just to paint the picture. This is like Eglinton Ave. Honestly, I'm really bad with geography, so just bear with me. But it's a school somewhere in Toronto on Eglinton Ave. I'm just walking to school. It’s a beautiful day outside. I’m in my striped pink and white sweater that my mom got for me and I just got my hair cut too, so I had nice bangs and long hair. And along the way, I see a pink tulip on someone's lawn, and I just picked it up and I was like, “this is gonna match my outfit!” And then for some reason, keep holding on to this flower as it wilts and falls apart. And then I go into the photo booth session with the photographer and just take a picture with this with this poor flower that's like disintegrated by the end of the day.

Dr. Gordon

Laughs

Maryam

It's one of my fondest memories that I have, and I love that picture so much. Just the fact that I - it was like the earliest recognition of, hey like this flower matches my outfit. So let me just pick it up. Obviously, now I know you shouldn't be taking flowers from people’s lawns.

Dr. Gordon

Laughs

Maryam

But, I just, I couldn't resist.

Dr. Gordon

Oh, that is very cute. The picture days are always kind of fun. You wanna look your best, right? And it's gonna be a memory that you have forever. And in those kinds of situations, you know, I know that you had a kind of a longer journey to get to hearing in that time. Was that before you knew about your hearing loss or during that?

Maryam

I think the timeline would have been really close together. It may have been just after finding out or just before I knew. Since I got my hearing loss addressed when I was about seven or eight – and so the timeline corresponds.

Dr. Gordon

So, one of the things that this makes me think about is, you know, those kind of normal cues and kind of rules that we get as kids. That may not be told specifically. That you didn't know, that it’s not OK to necessarily go and pick a flower, but you might have missed it, because it wasn't exactly expressed, and it was something that wasn't obvious. It was gonna be, you know, a beautiful compliment to your outfit. Some of that does sound related to your hearing loss, do you agree?

Maryam

I mean, now that you've pointed it out, I can possibly see the correlation there, and it's possible. Yeah. I just, I didn't know, like in my mind, this wasn't a wrong thing to do until time had elapsed, and I realized that I shouldn't have done that.

Dr. Gordon

I know, it's that that interesting feeling of doing something that is not well understood. Or it's being accepted by the people around you differently than you expected, right? I think that's kind of a good segue to talk about what it's like when you don't always understand what's going on around you. I think it was a beautiful story and then just a nice segue. Do you have any-I'll just open the floor-can you remember any kind of feelings like that? That you think anybody (in the in the group), that you think might speak to your experiences with hearing and missing things?

May

I can remember playing hide and seek with my family. So, we used to live in a pretty small house. And then when we played hide and seek and I was the finder, it was really hard to find them. And the interesting thing was they would actually say, like, “I'm here! I'm here!” But, I still couldn't find them, so I didn't have any sense of direction, and even when someone in the house says like, “oh, I'm here!”, I wouldn't be able to really tell unless they literally state “I'm in the basement”, “I'm in the kitchen”, that kind of stuff. So that was kind of one of the earlier signs that something was a little off. And I remember that I think I was with my mom. Then my mom, one time, she whispered to my right ear, and she said, "Did you hear that?” And well, I was really small at that time, and I said, “I don't think so?” But at that time, because I was so young, I didn't understand that that was not normal. So, I think those are like some of the earlier cues along with, you know, being in school that my teacher noticed that kind of made us realize we probably should check. And then I was diagnosed with hearing loss I think around age 4. And then I went to SickKids later on. But speaking of games in early childhood memories, I remember in school we often play broken telephone with a big crowd and that was really challenging. I like the game itself. But it does make me have sometimes lots of anxiety when we're playing with a room full of, you know, classmates that I'm not all familiar with or comfortable, you know, showing that I had hearing loss. So, in those circumstances, I think there was a lot of occasions where I felt kind of stressed and a little nervous. So yeah, that's what I can remember.

Dr. Gordon

I remember you talking about that broken telephone thing, and that really is such a good example – and also hide and seek- cause in terms of the spatial hearing, that's hard for you. It's something that I think people may find surprising – that we understand that, OK, you have hearing loss, it might be hard to hear voices and sound, but the location of sound is also something hard to pick out, and that does affect how you do different things.

May

Yeah.

Dr. Gordon

So, hide and seek is a really good example 'cause you can see where anyone is.

May

Even if the person is just like on my deaf side, and there's no background noise, it's really obvious, like the difference is huge compared to when, you know, let's say my brother is walking on my left side compared to when he's walking on my right side. Even if there's no background noise. It makes a substantial difference, and that's why it helps a lot when I'm able to walk on someone else's side that I can hear better.

Dr. Gordon

Yeah. For sure. Any other comments about these kinds of situations?

Annika

Yeah. So, I've touched on this a bit in the other recordings, but something I've noticed about my brother is that- I don't know if it's necessarily a conscious thing, but he likes to do stuff out loud. So, for example, let's say we're both sitting on the sofa, I notice if he's like reading a book or just reading something off his phone, like a news article. He likes – it's not full on articulating every word, but he kind of reads out loud. I was kind of thinking if maybe there's a relation to his hearing loss? He also, when he listens to music, he likes to listen to it really, really loud. So yeah, I was wondering, you know, maybe there can be a correlation there.

Dr. Gordon

Yeah, that was one of the most interesting things you guys told me about, like wanting to listen to music super loud. I think that's really great. So, we did talk about that. I want to go back to some of these early memories. But a lot of these are about family, right? 'Cause when you're young, you're really with a lot of family. Does that speak to you? Sofia too? That, you know, there's a lot of family time when you're young and trying to interact with family members?

Sofia

Yeah, for sure. I have a sister who's five years older than me. So, when we were growing up, she was basically like my second mom. And so, when she, I don't know if this traumatized her or not, but when I was diagnosed deaf, which I would have been 11 months old, so my sister would have been six, really close to seven-because she's almost six years older than me. My mom sat her down and said like “you're going to have to take care of your sister in this world. You know she's going to need you. She won't hear things around her, and she needs you to guide her. You know, she’s just a baby, she can't hear anything, so just make sure you're looking out for her”. Anyway, my sister took that very literally. And to this day, she still has those words in her. So, basically, like when we were young, she was essentially my teacher. I credit a lot of my speaking abilities, a lot of my hearing abilities, and all of that to my family, because if it were not for them, I can't even, I would not be where I am today. I think especially because we were, all of us, born at a time where there wasn't a lot of research. People didn't really know what helps, what doesn't help. And so I think what helped me was the fact that my parents just-I've touched on this before, but just treated me as if I were the same as anybody else and didn't stop me from partaking in anything that maybe wasn't recommended by the doctors or with the information that was- they had at the time. When I first got my cochlear implant, like my sister used to get - so you know how you would get money for chores in some families, like my sister would get prizes – like candy and stuff for teaching me. So, she would sit me down and she would have, like, a chalkboard and every day for an hour she would do speaking lessons with me. She would, you know, teach me the vowels like the AH, EE, OO, like that kind of stuff. And whatever homework that my speech path gave to my parents, they would also obviously do it with me themselves too. They weren't putting it on her only, but she would also help 'cause she also loved it so much, too 'cause she was my older sister, and I was like her little doll. This was perfect for her 'cause she had this real-life doll that she could just sit and teach.

Sofia

And then going back to music, my dad comes from a Latin American country, so music was so integral to our family like there was always dancing and always Spanish music playing in the background of our house. So, when I first got my cochlear implant, they made sure to have music going 24/7. They didn't want there to be a moment of silence in our house. They wanted to make sure I was always hearing. My mom would have labels on every single thing in our house. So, there would be, you know, pictures on the fridge with like the noise that the fridge makes and the water and everything. So anytime anybody opened a drawer or opened a door or something, they would go “Sophia!”. And then they would open it, close it, and make sure that I'm looking. And they would want me to give them confirmation that I'm hearing it too with the, you know, motions that the speech pathologist taught us in terms of, like, pointing to your ear when you hear something. So, I really attribute so much of my hearing and speaking abilities to them. I realized growing up how cool it was that my hearing is able to decipher between accents as well, like, I know that accents can be really tricky for people with hearing loss because it's so difficult. Just because environment is everything and your implant is only gonna know what it recognizes. And so, because my dad is Hispanic, he has a really thick accent and so do all my aunts and my uncles. And then my mom's side of the family has really thick accents as well. I don't think there's anybody in my family who speaks English without an accent and that really helps me, as well. So, I do think, yeah, my family was so integral to everything growing. From the beginning of being diagnosed all the way up until I was at school age, their entire focus was all on like teaching me every possible sound and having me practice speaking 24/7. There wasn't a moment of silence in my house.

Dr. Gordon

That sounds super fun!

Sofia

Yeah, it was.

Dr. Gordon

I saw a lot of nods, a ton of nods. Maryam, I feel like you wanted to jump in there.

Maryam

Like I just, I love that you have such a great experience growing up. I think that's literally the audiologist ideal for a child to grow up in. And it really shows how much you love your family, so I wanted to comment on that. But when you were talking about your sister, so I was diagnosed when I was sevenish, but my brother and I are six years apart. So, when he was born, he was diagnosed from the get-go. And so, like literally the same rule your sister had, my parents had that same talk with me. “This is your baby brother, he doesn't hear. You need to guide him through the world.” And for that very small, brief, period of time in which, like my condition was undiagnosed and we were just focusing on him, it was like the most overprotective of anything I've ever been in my life. And even when I was diagnosed and the dynamic shifted a little and I no longer had to be, not necessarily the caretaker sibling, but in a way the guider, the mentor, to now being a patient. It still never left me - the responsibilities of an older sister - even when we were going through the same challenges. I was still so overly protective of my brother – I had to know where he was at all times. I was constantly paranoid that something would happen to him. And thankfully that was addressed in my teenagerhood because it was just not going to be a very healthy lifestyle for me to be constantly worried about someone else while I'm going through my own struggles as well. But it's just, it's so funny how this is almost like it's an innate response to jump in and want to protect the siblings when you're the eldest and there's so much that falls on your shoulders, but then also really interesting how that dynamic shifts, just a little, when you also have an issue that needs addressing and taking care of.

Dr. Gordon

Yeah, that must have been a lot for your parents. We spend a lot of time working with families, right, as you guys were talking about, and the need for this constant sound and exposure and engagement. There is a lot of pressure on caregivers and the whole family on doing this work, young children particularly. I mean it's so important as you guys can see, is when it works, it works! But it is a lot of pressure.

May

So, I'm the only one who has hearing loss in our family, and fun fact, my brother is 9 years older than me. So, I think for my situation it was kind of like, my family was also learning with me. So, because they've never really encountered this kind of condition, I think a lot of the times as I was growing up, they also learned how the hearing loss affected me. For example, maybe when I was younger, they weren't used to remembering to talk on my left side. And then it was perhaps a bit gradually where we realized, like, oh, I can't tell. I don't have a sense of direction. And oh, you know, like walking on my right side, even though there's no background noise, makes it a lot more difficult. So now, you know, when I walk with my parents, they just naturally go to my left side, or in other scenarios-it's like when I'm growing up, I learn about how this condition is affecting me, what's making other things challenging because of my hearing loss and I think at the same time that my family members were also learning about how to accommodate these conditions. And so, I'm really grateful for all their support and also how for the most time they really don't see me differently because of hearing loss. And I think my mom especially has encouraged me to pursue different hobbies and try different things throughout my childhood. I think the love and support that I received from everyone in my family, including my relatives, has had a really positive impact on my self-esteem and how I kind of deal with this disability.

Dr. Gordon

Well, you're getting a ton of nods - I can see everybody is thinking about their own families and their own support, and I think that's really wonderful to see. If the listeners could see your faces, right? What I wanted to talk a little bit more about is those ideas of feeling protective, in the family. I can totally understand that, because you know, things like just walking on the street, you're already protective of a young child who might run out into the street. But, you know, that feeling could be greater if you can't easily call to the child, or you can't-or there's a difficulty in localizing sound, or, you know, just a concern that the child might, you know, not hear traffic or something that is a warning. Do you have any comments about, you know the feeling of protection? I think you've explained it as being, you know, mostly positive. A feeling of support. Can you think of any time where it might’ve been a little too protective?

May

So, I remember when I was younger, my mom would tell me that like when you're in school, don’t just tell your friends or your classmates that you have hearing loss. And because I was really young, I didn't understand why. And my mom didn't, really explicitly tell me the reason. And so, for a long time I wondered if it was because of some sort of embarrassment, maybe? Or like, why couldn't I disclose my condition to other people? And then, yeah, for a long time, I had those feelings of doubt, and that lingering question in the back of my mind. But as I grew up, and I kind of became more mature, I also had really long talks with my mom. And then I began to see where she was coming from. And like Dr. Gordon said, I think it came from this sense of being overprotective and not wanting others to say things about me, and I later on found out after a discussion with my mom that she was concerned that children, as innocent that they can be, sometimes, they might say things directly without any thought. And so, although they don't mean anything bad intentionally, there is that possibility where they might say something directly from their mind and it might affect you. And so, I think my mom didn't want me to be exposed to, you know, potential rumors or other moments where your classmates are talking about you, or anything negative about that. And so, then I realized, it wasn't a sense of embarrassment or anything, but it was more of like, you know, that motherly protection and not wanting her child to be hurt in any way because of this condition or this difference compared to, you know, my peers. And so, with that understanding, I look back and I think that was a right decision? I think I was shielded by a lot of that potential negative experience. But yes, there were some moments where I think there was some doubt or misunderstanding.

Dr. Gordon

Yeah. Thank you. That’s a really deep thing to share. It is such a self-awareness that you can look back on that and see the change.

Sofia

I just wanted to touch on something that May had said earlier that really resonated with me that moves back to this. So basically, about being the only person in your family that has a hearing loss and how that can affect you. And so, I think that, you know, for me growing up, it did make me feel very insecure because nobody else had it -not insecure, maybe that's not the right word. Maybe it made me feel lonely a little bit, because while I praised so much how my family didn't treat me differently from anyone else, at the same time, it can also be a negative thing. Like while it's both positive, it can also be negative, in the sense that there was a lack of understanding about how the hearing loss might affect me in ways that are not obvious. So, you know, growing up, I was learning but as a kid, your frontal lobe is very much underdeveloped, and you're not able to express why certain things may be affecting you, and you can't really articulate it. And because nobody in my family has gone through hearing loss, they didn't see the signs. For example, like, you know, getting upset with me if I miss something, and then them not being able to connect that with my hearing loss. Or getting upset with me for not wearing it. Or even like little things - like not realizing, as May said, to walk on the right side of me. They still forget and that's not - I mean now what can I do? It’s been 23 years, but sometimes they still forget about it. So now I put myself in the right position. But when I was a kid, I don't know to put myself in the right position, I’m just frustrated because I can't hear properly. Or just little situations like that. And so, I think while treating somebody the same, it's still important to recognize that there are ways that they still need to be accommodated and there are hidden effects of hearing loss. You know, it might not be so obvious that somebody is going through those things. So yeah, I wanted to touch on that because of what May said earlier.

Maryam

Yeah. Thank you for sharing, Sophia. Just circling back to what May was saying, like I come from an immigrant family, so like my parents got here very late 90s and I think they already kind of felt a little “fish out of water” - they didn't really understand the system, especially as non-English speakers. On top of that to have not just one, but other children affected by a disability and then navigate the social system from that and the healthcare system, I think my parents just felt really unsure about how everything would pan out. There was a lot of anxiety and fear because of that, on top of, of course, like feeling isolated. My family, to this day, it's just us - my parents and my siblings. We don't have any other relatives here in Canada. And I think when I was officially diagnosed, coming from a protective place, I think my mom was just really focused on integration and making sure that I fit in as seamlessly as possible. So, I think a lot of kids often chose colorful colors for their ear molds and their devices, but I always got colors that blended in with my hair or my skin tone. And it was a sense of, like, secrecy in a way where my parents were just saying, you know, just try your best. You are like everyone else, you know, like you're not any different. But kids might give you a hard time if they see that you have devices that you have to go out of class and stuff. And I really do appreciate their efforts to maintain it and like, keep it a bit more closed off to the outside world. The reality is that it will always come out when you're playing the game of “Heads Up Seven Up” and you don't put your head up and everyone knows why - because you didn't hear. Or if you get in trouble at school, because your teacher thinks that you're not paying attention and your grades are falling, people start to pick up on signs. So, you know, I don't know. I think it's a very complicated thing because obviously my parents came from a really good place like May’s parents. I feel like if I were to have my own children now, and they had difficulty hearing, I think the best way possible is to just embrace it, be all out with it as much as you can, because it's not you that needs to adapt to the world, but sometimes the world needs to adapt to you.

Dr. Gordon

Oh, such a good way of putting it! The devices themselves that just kind of pull things out a little bit differently-that was a good point that you made, Maryam. You could choose just with your devices to put it out there just by showing them and their bright colors or you could choose to try to hide it. I think lots of adults as they age and need hearing aids will go through the same question - how can I make it super, super small? I think that the protectiveness, of course, for parents of how to navigate that for their child. It's gotta be double challenging, right? To know what is the right course in every situation. It may not be the same. Annika put in the chat something about driving and I can tell you that that is a tough thing as a parent to teach your kids to drive, or to allow them to drive at such a big milestone. So, I would say, you know, that's definitely - you can be protective about that one. What’s your story that goes along with that, Annika?

Annika

Yeah, so one of the cars we have has a screen with navigation, and then our other car doesn't. So, I was just thinking, and I only realized during this episode, but my brother likes to drive the car with the screen and I just put it together now, that probably-it's because he can't hear the GPS well, if he can't see the screen. Like the screen is an aid for him, and my parents also, like when it comes to driving the cars, like my parents will always kind of always make sure that he has that car to drive.

Dr. Gordon

But driving's a cool segue to independence and growing up. So, I don't know, do you guys all drive?

Sofia

Yes.

Dr. Gordon

I see a lot of nods. Do you remember anything about that process of learning to drive?

Sofia

I think for me it was pretty regular. I got lucky because I have my cochlear implant on my right side, so whoever is sitting next to me, I can hear. But if I didn't-if my right side was the one without the cochlear implant, then I think I would definitely struggle, but, I don't know, I think-

Dr. Gordon

Maybe you need to move to England. Then you could drive on the other side. [Laughs]

Sofia

Yeah, 'cause when I drive-so I think my learning to drive is pretty regular. My dad taught me how to drive because my mom and I would've bit each other's heads off, cause she still holds the safety thing when I'm driving with her. It's been many years, but yeah.

Dr. Gordon

[Laughs] Hand up near the window that – yes.

Sofia

Exactly. So, my dad taught me how to drive. He was very calm. Anyway, the one thing about driving deaf-not that I do drive deaf, I drive with my cochlear implant on. I wanted to try one day doing it without, but everyone tells me that that’s a bad idea, so I’m not gonna do that. But the one thing that I kind of just ignore when there’s a fire truck or like a police car or something, I have no idea where it's coming from, so I don't even hear it until it's like directly next to me. And then at that point, I’m like, “oh okay, I gotta move.” But I definitely don't move in the right legal time, and then that's the only thing, I guess. The other thing is that when I drive, I listen to the music really, really, really loud-again because it doesn't bother me in the way that it bothers regular hearing people. And so that the next person who goes in the car after I've been in it is always like texting me after and going, “what the heck are you doing? It’s so loud in here!” But, yeah, I think driving has been pretty regular other than the fact that I can't hear if somebody's honking at me, which doesn't bother me 'cause, I don't wanna know if they're honking at me-or if somebody is coming with a siren. [Laugh] I just stay in my own lane, do my own thing.

Maryam

So funny 'cause I feel like for me, like I got into the habit of regularly checking my mirrors, my side view my rear view because I'm so afraid of like a fire truck or an ambulance coming by. I just don't want to impede anyone's method of being saved. So always double check and triple check and like excessively checking too. So, driving, like the test was a breeze for me. Like the instructor was like, “you are always checking your mirrors" and I'm like, “I know.”

Sofia

That’s probably a better approach, Maryam, than just being ignorant.

Maryam

I promise if you're moving over your chill, but the other thing is the honking. And yeah, like sometimes it's kind of hard to figure out where it's coming from, and then my implant is on my left side, so I should move to England most likely.

Dr. Gordon

Yes. Yeah. No, we want to keep you here so-

Sofia

You can go to Scotland too. That works.

Maryam

True. I mean, if I'm on the passenger side, it's totally OK. But if I'm in the driver's seat, it is a little hard sometimes. But, what helps is I just don't have any music going so there's more room for a person next to me to raise their voice and everything. And also, the car you're driving actually does make a difference. If it's one of those newer electric cars-we don't have one-but I've been in one, and there's no engine, so there's no like underlying car noises. But if you're driving an older car, the muffler is blown. Then it's difficult to navigate that car.

Dr. Gordon

Yeah.

Maryam

I don't know if anyone has a different experience with driving.

Dr. Gordon

No, that's good. May you have any driving stories you want to tell us?

May

Well, about the honking and the sirens-so I can't tell where it's coming from, but I can hear it. So what I usually do is just look at what other drivers are doing and if the cars are like, if the cars in front of me in the same lane are like going to the right to, you know, stop, then I'll probably just do the same thing and then, you know, look for visual cues to identify if I see like a red truck or something.

Dr. Gordon

Yeah, totally makes sense. Yeah. I mean, it really speaks to how, you just have to get a little creative, a little adaptive, but that probably-that's pretty effortful. I don't know if you feel tired after you get out of the car. Not so much? So compared to conversations, cuz we talked about that at first. So, having these interactions and the language back and forth, particularly in noisy situations, is probably the hardest so, relative to that, I guess driving is not too bad?

Maryam

I think driving, because it's more of a skill thing that you get better at once you learn to drive, you're pretty much good to go, whereas conversations are an intellectual exchange and you have to be coming up with responses and taking in their response to generate more conversational points, and I think that ends up being a lot of fatigue on the brain. But then driving is more of a skill thing. You figure out your quirks and your tips and it helps you get through it.

Dr. Gordon

So, I think that is a good place to talk about peers, right. And your interactions with peers because as you guys said, your family knows and they're supportive and everyone kind of knows how to talk to their families, I guess until you become teenagers and nobody wants to talk to anybody anymore, but [laughs]-not your family for-and you'd rather talk to peers at that point. So how does this all change when you really would prefer to be spending time with peers?

May

I think when I'm with family, it's a lot easier for me to just say, “I can't hear you right now” and then I'll just make some sort of adjustment. But with other people, I think there's more opportunity for misunderstandings to take place, especially when, you know, I'm talking with someone who I'm not that familiar with or I just met, or a friend that doesn't know I have hearing loss. I think it can get a little awkward sometimes when there's no background noise and we're just having a conversation, but it's just like I didn't hear them and maybe I asked them to repeat once or twice. And I still didn't hear them. Then they’re also kind of, you know, questioning or confused why, you know, something's not clicking or you're not responding the ‘normal way’ I typically do. And so I think in those cases where you kind of sense like there's some sort of misinterpretation in the conversation and it sometimes makes me a little more nervous when I have to talk to new people or there's that inner stress that, you know, what's gonna happen if I'm going to this social event. What if this happens? I wanna talk to them, but I don't hear because of the background noise. A lot of these like thoughts in the back of my mind, sometimes kind of gives me that additional anxiety that I think originally I thought was maybe is just my personality and just like a really introverted person, but that I think a lot of it has to do with the kind of social aspects and social challenges that I have growing up with a condition that other people can't really recognize unless you disclose. I think there is a lot of, perhaps a little bit of emotional burden that I experienced as I grew up and I sometimes still continue to face, but I think I'm better with like handling it and just being less harsh on myself, thinking that, you know, I'm like, inconveniencing other people to make them repeat like three times. So yeah.

Sofia

I totally agree with May. With people that are not my family, even not just family, but specifically just my parents and my sister, I'm less likely to ask them to repeat or let them know if I'm not hearing them. And you know for me, everybody in my life knew that I was deaf growing up. There was no secrets. Like everybody at school knew, and even then I still wouldn't-so if I were to ask repeat, they would know why-I still wouldn't, I just never did. And I think that ties back to, you know, if people just treat-I think I just wanted everybody to treat me the same. And then that leads into the problem of if everybody just treats you the same then your needs will never get addressed. And so, because everybody just treated me the same, my needs were never addressed. Like to this day, my friends still will try and tell me something by whispering in my ear. I've known you for 20 years and I've never been able to hear you whisper. But I'll still just be like, “huh?” Like now I just go "huh?" And you know, I do have a pretty sad story, that you're all not gonna like. But when I was in high school, honestly, this was like a group of friends of mine and it wasn't even-I'm not friends with any of these people to this day, just so everybody knows. It wasn't even like, in their minds, they were just being silly teenagers and there was no harmful intent with this, it was just a really, really stupid joke, but essentially, I don't think anybody really understood what my hearing loss really was, because you can't really understand unless, you know, you're my family who grew up with me or you're me-or somebody else with hearing loss, and none of these people had hearing loss.

Sofia

I remember, we were at the beach, and it was nighttime, and we were just sitting and hanging out, and they thought it would be really funny to basically disable me. So basically, one person knocked off my cochlear implant and then another person flashed a flashlight in my face. Then a third person was like talking to me and they thought it would be so funny so see if I could figure out what they were saying and they were like mouthing nonsense to me, and I think that was the first time in my life-because these weren't the people that I grew up with or the people that I am friends with to this day or people that I've been friends with since kindergarten, for the most part. These were people who didn't really know me growing up, and so that was the first time I ever in my life experienced what I guess I would now-at the time, I totally did not advocate for myself at all. At the time, I just laughed it off, put my hearing back on and moved on, right? But now I'm able to like, look back at that and realize how messed up that was and that that was basically bullying, and I just didn't recognize it at the time. But, yeah, I guess that just goes back to like why parents feel the need to be overprotective around their kids, right? Because some kids are stupid and a lot of them are mean without meaning to be, and so, that was the first time I ever really experienced that feeling of being fully outcasted or targeted for my deafness specifically. That's thankfully the only bullying story I have. I mean other stuff is just again silly jokes, right? It's just teenagers being stupid. Like, I think a reason, a big reason why I would never ask people to repeat themselves is 'cause in the few times that I would, people would go, “Huh, huh. What? What?” And then they would just mimic me for saying, “what”, so I just stopped saying it all together.

Dr. Gordon

Yeah, that's probably hard to tell and definitely hard to hear. So, thanks for sharing that. We've talked about the best of people, but there are the worst that can come out too. You may think about what you would have done differently, but in the time, how do you react?

Sofia

Yeah, I think at the time it was just a shock. You’re in that moment and you’re thinking, “okay, I don’t even know how to react right now” so you’re just in a freeze mode, but obviously you can think about what you could've done and then there's nothing you could've done, at the end of the day. It did help me reflect a little bit and realize I should not be friends with these people.

Dr. Gordon

Yeah. I understand that.

Maryam

Sofia, so I just want to jump in really quick, maybe to end off the segment too, but I'm really sorry to hear that and I think a lot of us have had very, very similar experiences. It has come out in different ways, right? And transitioning into a conversation with peers and leaving the family environment, I've had to have multiple boundary talks with people and say, "you might think it's funny to make fun of me for my disability, but I'm not tolerating that. And I don't want to hear it around me, and you know, like, if you're not going to change, then we shouldn't be friends.” And ultimately, sometimes you will lose people, but most people are mature enough to recognize this is wrong, and I'm going to change and I don't want to lose this friendship. And it comes with time. It’s not something I was able to do as a child, it wasn’t something I did in high school or even, I don't know, transition into university, but it came with entering my 20s and then kind of progressing to mid 20s and then it comes with time. You become more sure and confident of yourself and you realize you know I don't accept this treatment, and I deserve better than this, and slowly but surely, like the people around you become much better at treating you well and treating you with dignity.

Dr. Gordon

Well that is the best message. And I do hope that when this goes out into the world that you know this will be heard by people and you guys will be the role models that you are for them. So, thank you guys so much for this. Is there anything else that you want to share before we close off today?

Maryam

Just, that is the support of people like you and everyone in this call that helps us get through every small, terrible moment, because the good just outweighs the bad. We just wanna say thank you so much for this platform. Thank you so much for the opportunity to meet other people who are in the same position, who have family members who are in the same position.

Dr. Gordon

I just love hanging out with you guys. It really, really helps me understand what it's been like through your lives. I have been there, we all have in this program to be there with you, but we never get time to just chat, and I have really valued these opportunities to just hang out. I've learned so much from you all. So, thank you. And we'll continue to learn. I continue to grow and learn and age and so do you guys, so there's gonna be lots more.

[Music]

Dr. Gordon

Thank you for listening to this episode of *The Hear Here Podcast*, season four. I hope you enjoyed this conversation. I want to give a shoutout again to *The Hear Hear Podcast* team; Nimrat Chani, May Wang, Maryam Othman, Sofia Olaizola, Maria Khan, Annika Gasee as well as my colleagues that are involved; Laura 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]
