

[Music] [Narelle] Hello and welcome to I think it's episode 16 of The Digital Access Show. Today, I want to focus on the challenges that those with hearing impairment have. Because, obviously, I understand a lot about vision impairment. I have it myself. I don't know much about hearing impairment. I have a couple of sons that are autistic. So I can see from their experiences, what they've gone through. So today, I've been lucky enough to meet a lady called Alyce Carter-Edward. Alyce hails from Western Australia. And Alyce, I'll let Alyce tell her story. So Alyce, well thank you very much for coming on the show. [Alyce] Thanks, Narelle. [Narelle] Alyce, tell us about yourself. [Alyce] Yes, so I'm actually three generations confirmed. Most likely four generations hearing impaired on my mother's side the family. So, my mother and her father and most likely my grandfather's mother as well, were hearing impaired. So it's genetic for us. [Narelle] Yep. And, what level of hearing, I mean, do they talk about levels of hearing? They talk about level of vision? How does it work with hearing? [Alyce] So there's, I maybe a little bit wrong. But so there's moderate. And so mild to moderate, moderate to severe, severe to profound. And so you're profound hearing loss are those with no hearing loss. But also, if you have a cochlear device, you're also still considered to have a profound loss. Because they destroy the residual hearing if there is any, to put in the bionics. [Narelle] Now that's interesting, I didn't know that. Wow! [Alyce] So, Yeah, that brings into a whole host of other issues., So, my mother is considered profound. So she has a cochlear device. And that was her choice. My grandfather, he never opted to get one. And he just had hearing aids. And we did the deaf nod as we call it. Just smile and nod. No idea what's going on, smile and nod. [Narelle is laughing] [Alyce] So the thing, I am now considered, severe profound in my left, and severe, in my right. So it's progressive, which that is for all of us. And it just means that my hearing aid, that could be adjusted, and a different program put into them into them, and each time I get it, sometimes the programs and technology is updated to the point that I'll hear something new. Like the fridge beeping, and thinking there's something seriously wrong in this house. Looking for that sounds, and everyone's going, it's the fridge. And like the fridge make some noise? [Narelle] Wow! That's interesting to know. Because I can sort of relate, because for me, when I did first get glasses. I was excited, because I was at my grandparents and I saw an island for the first time. [Alyce] Oh, wow. [Narelle] Because they lived beside the beach. [Alyce] So, it it can get a little overwhelming at times, and then it's, like, my humour. I just laugh it off. But it can get very overwhelming, like hearing the keyboards clicking, and mouses, clocks ticking, and stuff like that. And it just becomes so overwhelming at times that um. And then sudden sounds. So like, if a trains brakes squeals really hard. That's like my head, is being ripped open. [Narelle] Oh, my God. [Alyce] So suddenly, because it's on such a high frequency, that there's just no way to prepare yourself for it. [Narelle] Wow, I wouldn't have thought of those things. But that's some really, that's that's some really good points. That must make it pretty tough for you at times. [Alyce] It does, yeah, because as a, overall, being hearing impaired, it's pretty much an invisible disability. Unless you're actively staring at someone's ears. And I mean, you know, we get told don't stare. So you don't notice the hearing aids. [Narelle] Okay, so, when, as a child growing up and going through school, how did you cope in school with it? What were. Was there much, I'm not sure of your age, obviously, was there much in the way of assistance for you? [Alyce] Oh, I'm 34. Um, Western Australia doesn't have a deaf school predominantly just for the deaf. We have deaf programs. [Narelle] Yes. [Alyce] And, uh, Shenton Park and Mosman Park Primary School, they have

classrooms for it. But they don't have just a school just for it. They used to be a long time ago in Cottesloe. Now, when I was going through school, we had Wade, which was the WA Institute for Deaf Education. And so someone would come to the school, I think it was like once a term, twice a term, to see how we hit. And I had a lovely woman named Pam Davies. She used to come as a, phenomenal lady. I'm fairly certain she's retired now. Or, if that, hope that she has. She deserves to be. Um, but she did make things a lot easier. But unfortunately, uh, I didn't really fit in the school at all. Um, you know, I got my first set of hearing aids at five. [Narelle] Yep. [Alyce] Um, I was so, very proud to have my hearing aids in school. That was a great adventure and everything. But I never fit into the hearing world. And I didn't fit into the deaf world. I mean, I had students at the school who were deaf. And they were, they signed. Um, they signed only. And then there was myself and a couple of others who, we wore hearing aids. And one was a young lad. He was supposed to wear hearing aids. He didn't want to wear hearing aids. He would rather not fit in because it was, you know, being a boy. But it did make it very complicated. Because teachers, I mean, you would remember all teachers though, yourself being blind would have been hard to see the whiteboard or chalkboard or whatever. Um, for myself, it was a case of the teachers would be writing on the whiteboard, talking to the board. So the sound is bouncing off. [Narelle] Oh, okay. [Alyce] So I wasn't getting any of what's been said. So unless it's given to me in a, you know, written down form, most of what was taught to me went for lack of a better term, in one ear and out the other. [Narelle] Amazing. So you never learnt AusLan or those, like that form of communication. [Alyce] No, it was, I did speech therapy. Um, I guess I don't hold, uh, resentments there cause I know that, you know, society would, uh, my parents were pretty much told, made me fit in. [Narelle] Yep. Yeah. [Alyce] And it's not their fault. That's how it was. [Narelle] It's how it was. [Alyce] Consequently, because I was made to fit in, it meant I never learnt to communicate, uh, sign language or anything like that. Uh, I mean, I know some signs. Like, Not here in Australians. Just American. Not very helpful. But yeah, it was in case of fit in. And so now I've fit in is so well that most people don't recognize I'm deaf. So when I get frustrated, I just look rude. [Narelle] But it, yeah, it's one of those things with communication, isn't it? The, you know, your parents wouldn't, you know, that's what they were told. And that's what they did. Cause I think you're only just a little bit older than my son. And yeah, it was all about the kids fitting in back then and being part of society because communities not going to change. You've got to change. [Alyce] Yeah. Very much so. [Narelle] Yeah, and, [Alyce] I mean, uh, relatives, uh, like distant relatives, they're not close relatives, uh, ask me why I don't just go and get fixed with a cochlear. Not understanding that. I actually don't want to fix much of anything. Um, it does help. Don't get me wrong. It does help from what I've learnt from my mum. But a lot of people don't realise that it's a very intensive operation. Like it's not just, uh, you know, like it's not like getting a pair of grommets inserted. It's three. There are a lot of, risk of complications, The older you are. You know, they're having to cut into your head, without getting into all the gory detail. That's also a chance it doesn't work. So they go through all that. And because essentially it's like an organ, you can reject it. [Narelle] Right. So you're using hearing aids now. [Alyce] Yeah. So I wear what's known as bilateral. So both hearing. Bilateral hearing aids. Which actually are, my hearing aids are not government funded ones. But I am entitled to government funded ones. But that's where the thing. Okay. So the government only allows you to have so much. For what you get out of the Centrelink. And they are really

cheap and nasty. [Narelle] Okay. Got it. Yeah. [Alyce] They only bring you up to a certain level of hearing. And it's not that the, it's actually how ever. Um, probably one of the funniest and best gifts I've ever received. [Narelle] It was a gift? Oh, wow. [Alyce] It was, okay, Um, my grandmother's partner. She, so after my grandfather passed away. She met a lovely man. And his name was Barry. And he was hearing impaired. But due to old age. And he had these hearing aids. And he, unfortunately, he passed away. And because they're very expensive, very beautiful hearing aids. Uh, my nan gifted them to me. And I took them to my hearing center. And I had them, um, calibrated for my hearing. Now, these are like, uh, like, top, top, top of the range type. It's opposed to what I had. So when I first got the put in, your left with sounds and noise I was hearing was overwhelming. But amazing as well. Because they have such a broad range of different hearings and stuff like that. That it was quite funny. So like, I heard my cats meow. [Narelle] Oh, my gosh. Yeah. [Alyce] So it was, um, very emotional and overwhelming for me. But, also through something extremely sad because he was a phenomenal friend. And he became my grandfather as well. Um, that, uh, I, I, I really cherish this gift because of the fact that, uh, I still get hearing fatigue and everything like that. But to be brought to a different level of sound. I mean, it is quite sad that, um, uh, here, getting hearing aids, it's considered a, uh, privilege. [Narelle] Yeah. And that's sad. [Alyce] Yeah. It is. I do find that Western Australia is quite lacking in that department. When it comes to support for hearing. I mean, we have, uh, to my knowledge, uh, quite a few different outreaches for the blind here. Lots for autistic. But the deaf are ignored. [Narelle] And that's really sad. Alyce, can you explain what hearing fatigue is about? I'm maybe on the right track, but I just want to confirm that I am thinking what it is. [Alyce] So, um, because I'm having to concentrate constantly. Everything's, even if you've just got my attention, I'm constantly having to use my brain. So I'm not just, so when people are like, oh, you can't multitask. It's like, I'm already doing two things at once. Aah, it's a case of, I can't just, you know, like, uh, text, listen, da da da. All that sort of stuff. It's constant process of information. Being aware of my surroundings and things like that. If you haven't gotten my attention, I've switched my brain off to get some quiet. And then people won't hear me. So, and it gets very frustrating. It's like, I'm tired. You know, it's like, yeah, run a marathon every day. [Narelle] Yeah. And that's like, for me, I have to really concentrate when I'm doing an assignment or whatever I'm doing. I have to really think, really hard because I've got to listen, analyze. And then I'm still at times trying to use my eyes. And it takes a lot of effort. It's a lot more effort than a person, or when I had full sight. Well, I never had full sight. But, you know, when I had glasses and with glasses, I had full sight. So, yeah, I get it. Now, yeah. What other challenges you've faced? [Alyce] So, going to the shops. There's just so many ambient noises and stuff like that, that people think I don't like them, when I say I don't want to go shopping with you. And it's much easier because most people when they go to the shop, you converse with each other, you walk, you talk. I can't do the whole walk and talk thing. I have to focus on what I'm doing. I have to focus on whether there's someone coming towards me, around me. Everything like that. Be aware of, you know, trolleys, banging into people. I'm not a small person either. So, I'm also mindful of that fact that, you know, like I'm big and deaf.. So, I sort of, you know, I have to be aware of what I'm doing. I can't, yeah, converse. If you, because we are a multicultural country, I have no issues with this at all. But it can sometimes get misconstrued that I don't like you, because you're from somewhere else. Or it's like, it's true, because, you know, softly spoken

accents, everything like that. I've not had time to listen to your accent for long enough to pick it up. To be able to recognize the different vocal tones. [Narelle] Oh, my gosh, I didn't think of that. [Alyce] I don't get what you say. So, I can process what you're saying. So, like, I actually don't always understand people from the bush. You know, when they use their slang. I can't pick it up all the time. Um, you know, pretty much the only accent I've okay with is a very thick Birmingham accent. Because that's where my family are from. So, I grew up for, you know, 30 years of hearing that accent. So, I can get that one very well. Father, I can keep, he's good. same with, you know, like for the Australian. He doesn't tend to use all those different slang words, thankfully. Um, but yeah, anytime we're in a group gathering. Not a chance. I just tend to just sit there. I hate it. I get anxiety. I worry that I'm going to miss something or I'm going to respond. And, in the totally wrong manner and embarrass myself. [Narelle] Oh, my gosh, Alyce. Oh, that's pretty full on. The things you've got to deal with. What about during COVID? How did you manage there? That must have been so difficult. [Alyce] Constant panic attacks. Constant. Because the government said, hey, you're deaf. You don't have to wear them. And my friends and I, who, we have here, and some of my friend have hearing issues. And my mum and I, we all laughed about that because it was just like, um, the mask, me not wearing masks. I don't need to see my own lips. I need to see yours. [Narelle] Yeah. [Alyce] So it was like, if everybody else could take their's off and I'll keep mine on sort of thing. Um, it was the nightmare. I had to go to hospital with COVID. And, um, I don't actually, okay, so it's kind of upsetting. But I had security called on me because I got really upset because the doctor would not, uh, stop and listen to the fact that I'm saying I'm hearing impaired. I can't understand you. I, I need help to understand you. What you're trying to tell me. And my husband had COVID. And we weren't allowed, so we both had COVID, were in separate rooms. So I didn't know what's going on with him. He didn't know what's going on with me. Um, I tried, I said, can we just text, you know what I mean to each other? No, no, no recording devices and it's like, I'm not trying to, I'm trying to communicate. And I go, [Narelle] Oh my God. [Alyce] It's upset. And the doctor went, "Madam, if you don't stop, you'll be told to leave." And got a security guard. And luckily the security guard, he had actually seen me a few times at the hospital before. He understood what I was trying to say because his doctor just wouldn't take 30 seconds to hear me say, I can't hear you. Could you slow down please? The mask makes it really hard to understand you. [Narelle] Oh my gosh. So you, you lip, you lip read as well. [Alyce] To a degree, yes. Not nearly as much as I used to. Because it does get hard if you've got long people. If you don't initiate, if you've got a lot of visual hair, that sort of stuff. People cover their mouth when they're talking. So it's doing that. [Narelle] Oh my gosh. So what about, you know, when you're at a restaurant, at a cafe, that wouldn't. You know, you must. [Alyce] We don't do it too often. It's just too overwhelming. There's like maybe a few places that we go. And I only ever take people who know what I'm like with my situation. So, yeah, it's very limited. There's actually one or two places that I know I can always go to. Like, so Dome Cafe Actually, generally pretty nice. I don't know how they've done it, but they're roof, because it goes like that. If we sit in the part of the roof, where it goes like that, the sound seems to stay with us. So, yeah. With my nan or my mum and we sit in there, the sound stays with us. So we can hear each other. [Narelle] So the actual, it's like the cafe's been built perfectly for you. [Alyce] It is. I don't know if they know the did it, but I love it. [Narelle] What about the staff? Are they really receptive as well? [Alyce] We never really have to say anything, but most

of them, they're pretty good with the fact that you just do. I actually find it's really easy to go it. Like a Chinese festival or whatever, because you don't know whatever they seem. If you just say, I just want a number 13 and a number 7 and then you just point to it. That's what you want. It's all good. But, anywhere that requires you to sit outside? No chance. Just the wind is in my hearing aids the whole time. And I've got no idea. [Narelle] Yeah, that's a good point. It's, you know, what in ten minutes that we've been talking. I have learnt so much. Tell me, what do you say to people about how can society, how can the community? Well, actually, let's go back and step. What about captions on Netflix and things like that? How do you go with those things? [Alyce] Um, okay. So, frequently, nowadays it's not so bad. But, like, my husband and my housemate and all that, and even friends. So, I've been like, how have you not seen this? It's like, did it come out with captions? Like, oh, yeah, no. It's like, because you can remember like, I grew up with VHS tapes and stuff like that. That's not a problem. But most of the stuff I watched was, or on Disney, the very, very first movie I ever had, or for me, with captions, is actually what I watch when I'm sick. And it was my mum who found it, and she noticed that it had it. And I loved musicals. And The King and I. [Narelle] Oh. That's a good one. [Alyce] That was my first DVD that had, um, subtitle. And I'd seen it on VHS years beforehand. And I never knew, "That you are very difficult". But this is what he was saying. And so reading it and that, that was just like, oh, so, you know, like, that's really good. But there are times where I can't even watch like, uh, so NCIS, um, the subtitles are like, almost three scenes behind or in front. So, it, again, can't hear it, can't understand it, get irritated, just play on my phone instead. [Narelle] So what about the ABC and like the public broadcast? [Alyce] I don't bother. [Narelle] You don't bother, it's that bad. [Alyce] It's absolutely rubbish. Watching the news, the news tends to have to be up at around 80. Um, and even then, that's just more a case of distorts because it's that loud. But yeah. The news captions are rubbish, most of the time. [Narelle] What can be done, what could be done to fix it? If they just seem pretty, like, most of the time, the news is prerecorded. So, it really only takes them just to slow it down. Make sure the words are correct. Like, you know, they're editing it regardless anyway. Why can't someone just edit it enough that it's, like, you know, slows it down a bit so it's the correct words or everything. I mean, sometimes we even get subtitled with captions that have suddenly got like symbols in the words. It's just like, that's not a word. [Narelle] AI generated in other words. [Alyce] Yeah. Nobody's actually bothering to think that there's actually somebody who wants to read this. Now, we're lucky when we're in major emergencies. They have people who are signing. Well. We don't all sign. So if there's not somebody hearing in the house with us to say, "Hey, they've just said, such and such. It's had a flooding situation. You know, we can't. We don't know what's going on. And like, sometimes like, I've got family in the UK. So, you know, signing in BSL, I don't sign that language, because that's a totally different language. But, and the captions are wrong. So I don't know whether I should be messaging family members and say, "Hey, is everybody okay?" Being, or not, because the subtitles are totally wrong. [Narelle] Yeah. What else do you think could be done? to make it [Alyce] Simply taking initiative to realise that, you know. Also, when you're releasing movies. A lot of the movies still get released on like Prime and that. No subtitles available. I don't understand why. That's an entire episode. I won't rent a movie when through Prime or anything, if there's no subtitle. It's just that simple. And, so I know friends, they're autistic. They like subtitles because they're normally farting about too much. And so, it allows them to still grasp what's

going on. [Narelle] Yeah. You make a good point there? [Alyce] Yeah. [Narelle] You make a really good point. Alyce, I always ask for three takeaways. What are three things that you really, that are the most important for you that you want to get across? [Alyce] I really wish people couldn't get annoyed when I'm, others don't respond straight away and then get, like, look, understand if you're with someone who's hearing impaired, just simply understanding fatigue. Or the fact that, you know, just because we didn't hear you straight away. Didn't mean, you get to say, "Oh, you're ignoring us?" We aren't. It takes us more to process. You know, we're on dial up and everybody else is on NBN. [Narelle] That's a really good analogy. That's a perfect analogy. Yeah. And so that's something I'd like. I'd like the media corporation to understand that you're missing a major target with the deaf people. Of not putting subtitles in and just putting them into it. Because that would really be greatly understood. And also, I've really wished people to understand that whatever you're saying on the tannoy and the shops. Regular people can't hear it. We've got no hope. You don't have to eat the microphone. [Narelle] Oh my god. Of course. [Alyce] That static feedback. Because all you hear is that. [Narelle] Yeah. [Alyce] Because our hearing aids are picking up all the ambient sound before the actual voice. So it says something, something, something, something. And then you're like, Oh, okay. And unless there's, like an actual alarm or whatever, like if it was trying to tell me my car lights are on. I don't even know you said anything about it. I just heard a bunch of noise come over the speaker. [Narelle] And people have to realize deaf people do drive. [Alyce] Yes, we do. I, personally, I don't anymore. Um, I get a lot of anxiety with that. Well, I am looking at getting it back, but it is quite overwhelming. Especially for driving instructors. So my left ear is my worst ear. [Narelle] Okay. Yep. [Alyce] So, receiving instructions from the passagener. I have to stop and listen. It's like, I can't turn to look at your lips. [Narelle] Yeah. Yeah. [Alyce] Yeah. It becomes a whole situation. [Narelle] [Alyce, [Alyce] It's my anxiety. [Narelle] You're amazing. And, seriously, in 10, 15 minutes, I've learnt more about the hearing impaired than I have for a while. [Alyce] A lot of us have anxiety and mental health issues from being hearing impaired as well. That is where I wish the health system would realize that we're not dangerous or aggressive. Because we need you to understand, we can't hear you. So just because you're against recording devices and stuff like that, you need to find a way to accommodate how to communicate with us. Because a lot of us don't seek medical attention. Because of the fact that so many of our doctors don't speak clearly enough. Never mind someone from a different country. It's not even that. The case of doctors are fly in, fly out. We have no idea what just got said. And unless you've got a nurse who has actually got a spare 30 seconds, which most of them don't, God bless them. They are working their butts off. I've seen them. It gets missed. You have no idea what you've been diagnosed with. You try to grab your medical file. They say you can't have that. And it's like, well, you've not told me anything. I've just said da, da, da, da. Again, you need to take 30 seconds. So you have to see a social worker and they think you're being a pain. It's like, I just want someone to tell me whether or not I'm going home tomorrow. Or, [Narelle] Because you're not getting the message. Because you can't hear clearly the way their assuming. [Alyce] And it's not just a patient. That's also the family member. My husband has a rare form of muscular dystrophy. And so in order for me to know how to care for him, I need to know what the doctor's instructions are. But if they don't bother to make sure we know what's going on, how can I effectively help my husband? [Narelle] Just incredible, isn't it? And if they just talk a couple of minutes and

listened. Maybe that's the thing the other take away again. And I know in previous podcasts we've said the same thing. Don't make assumptions. But again, that's what we're saying, isn't it? [Alyce] Yes. [Narelle] ]Don't make assumptions. [Alyce] Like, I'm not purposely kind of come across aggressive. Sometimes I have trouble adjusting my pitch because I get frustrated. So, you know, being hearing impaired, I don't stop to change my tonal pitch for my voice. So, I sound angry and things like that. But I actually can't hear my hearing. And I have friends who tell me, can you talk quieter? Can you talk louder? [Alyce laughs] It's not like we're trying to be difficult. Or anything like that. But it's a case of, we get I mean, so many different things. It's no different to when a child is excited. When we get excited our voice changes as well. Because we don't know if we pick up the pitch change. [Narelle] No, you wouldn't. You wouldn't. So, we can come across difficult. [Narelle] Alyce, how can people get in contact with you if they want to keep the conversation going? [Alyce] So, I'm on Facebook and I'm happy to chat with anyone via Facebook. [Narelle] Excellent. Thanks, Alyce. Alyce, look, seriously, thank you for your time. And, you know, as a vision impaired person myself, I have learned a lot. And, Alyce, the message that you're saying is an important one. And really, what we're saying is, everyone, take that extra minute to ensure that you are saying or getting the message across, that you want the person to get. It's as simple as that, isn't it? Thanks, Alyce. So, that is another episode of The Digital Access Show. Please like, subscribe, share, review, tell everyone about it. And, if you want to know more about digital accessibility, which we're going to have a show coming up soon when we talk a bit more about how to make things more accessible, documents, videos, your communication so that all of us can understand. Keep tuning in. I can't tell you exactly when it's coming, but it is. So, I'm Narelle and thanks very much. [Music]