OEI Podcast Episode #5 (Hosts: Alle)

(Guests: Betsy, Kassey & Lynda) The Affect of Hearing Loss on Your Relationships

Alle.... Hi everyone and welcome to "Have you Heard" a listening project. On this podcast we share tips, stories and practical advice to help people with hearing loss stay connected. My name is Alle and I'm so excited to be your host today to discuss really important personal stories about hearing loss. And today we have several of my lovely colleagues that are joining us which I'm really excited about. So we have Betsy (Betsy...hi) hi Betsy. We have Kassey (Kassey....hi everyone) hi Kassey and we have Lynda (Lynda...hi...happy to be here) hi Lynda we're so happy to have you all. Thank you for joining us and everyone today we're going to be focusing on relationships. So as we all know, relationships are key for all of us and we're each children, parents, teachers, siblings, spouses, friends and all of these relationships really are possible because we can communicate if you think about it like that. So for folks with hearing loss specifically when communication is impacted this can create unique challenges and opportunities in our relationships. Well, I know that I'm so excited about this topic and for our guests. So Betsy, Lynda and Kassey who are all work colleagues of mine and I'm so grateful to be able to say that. They are going to be able to offer their insights today about their hearing loss and their relationships. So let's just dive right into this topic but first let's make sure I remind you to stay until the end of the show as we will share some resources about how to be a more effective communicator that's really important. These tips will work with anyone but especially with your friends or your family members that have hearing loss. So let's get started. Kassey you have a really unique perspective on our team because I know that you have had hearing loss since you were a child. You are a parent as well as a "coda" that's a child of a deaf adults and you're a hearing loss advocate which is awesome. Can you tell us what it was like to raise kids? What did communication look like at home? Between you and your young children just tell us a little bit about yourself?

Kassey....(2:20) Well, I had a mild hearing loss which started in first grade and I never did anything or wanted to do anything about it until after my second child

was born. So when I was 24 years old - that's when she was born. Up until then I struggled and pretended I heard but in reality I missed so much. I finally decided to go and get a hearing test because my son, who was seven at the time, told me that the baby was crying and I needed to go get her and I said "really?" I don't hear her crying, yeah, this happened for a week or so but every time I went to go get her in the crib she either fell back to sleep because she was crying so hard or she was reading a book. So I was like no wonder why my kids started reading when they were 4 years old.

Alle....(3:19) Wow, that's really interesting. I bet that was really hard for you though when you realized that they really needed you and you had no idea.

Kassey....(3:27) Yeah, I felt like that I lost my independence because my son, who was seven at the time, was always coming to get me tell me when the doorbell was ringing and everything like that so my independence I though really yeah, low esteem. When I finally got my hearing checked they told me that I had lost all my word discrimination in my left ear and that I only had 30% hearing left in my left ear. So yeah, my right side was not any better but at least the word discrimination was better. So I ended up getting a powerful hearing aid and was called severe-to-profound hearing loss, so while I was really really shocked, when I tried on my first hearing aid I was like "wow!" (Alle....I bet) I couldn't believe how much I missed. I... yeah. I guess I used a lot of lip reading and sign language to get by. I also was feeling you know isolated and I ended up homeschooling my children.

Alle.... (4:36) Your story is so significant. So I guess we really do want to encourage people to get their hearing checked out. Is that what you would say? Do you agree?

Kassey.... (4:46) Absolutely. It's very important. I became completely deaf in 2010 and that's when I received my first cochlear implant. After receiving the cochlear implant, it took a while to you know get used to sounds again and voices and it was very difficult. But during that time I started using the CapTel captioning telephone which has been a blessing to me. Without CapTel I would have had to depend on others to help me call my doctor's office and other important calls and I would have not been able to talk to my friends either.

Alle... (5:27) Gosh and that's something I don't think any of us that any of us really think about until we have to. So how did the implant change life at home with you children? Can you tell us about that?

Kassey.... (5:38) Well, you know before the implant they kept on repeating themselves many times and saying you know "never mind, never mind" and that kind of made me upset because obviously they wanted to share something with me so I wanted them to hear. So I didn't like that that they kept on saying never mind. I finally was able to hear and understand them when they spoke to me from a different room so it was such a blessing when I got my cochlear implants they didn't have to repeat themselves as much as before.

Alle.... (6:14) Right. Oh, thank you so much for sharing that Kassey. I know that I personally find implants to be absolutely fascinating and your story just makes it that much more real for all of us. So thank you for being vulnerable and sharing that with us I really appreciate it. And I know that a lot of people can relate. Now Lynda your story is different from Kassey's because your hearing loss was progressive. So you two are a parent is that right? (Lynda....Yes I am!) So what was it like raising children? Did you encounter barriers with communicating with your children? Tell us a little bit about that if you would.

Lynda.... (6:51) Well since my hearing loss is due to hereditary, it really runs in my family. My grandfather had it, my father had it, so it just started happening gradually, not all at once. Hmmm probably should've done something before I did, you know I noticed a lot of times I just people would look at me and I would ask them "what? What?" So when I did finally, finally, have my baseline hearing test, the audiologist who I've known for several years since I've worked with him said that I faked it really well. (Alle....Oh wow). He just did not, I'm like okay. But I was getting by okay which I think a lot of us tend to do. Like I'm like "Nah, I don't have hearing loss! You know, I can do this." And he basically said that he did not think my hearing loss was not that bad. It really surprised him. And I'm like "Whoa. Okay. I guess I'm a great actress!" My biggest issue though with hearing loss has been understanding my friends I mean I remember being in a group of them and trying to understand conversations and trying to follow everybody and one of my friends is like "yeah you didn't hear anything I say did you?" I mean I nodded a lot "Sure all that sounds great! Okay!" But I think more

importantly than my friends was really understanding my children, who are now 21 especially my daughter she has a high pitch voice and it sounded like she was always mumbling so to be honest I'm sure I've agreed to many things I shouldn't have since I couldn't understand them. They're probably very happy about it (Alle....lucky girl) ha ha. I don't know, you know, you often wonder, what did I promise? But finally after waiting a few years, which again does happen. I finally made the best decision of my life and I got hearing aids. And really, why did I wait so long? I mean I will never forget the first time I came home with my hearing aids and my children were ecstatic that they were able to communicate with me without having to repeat themselves. I mean it just was like "oh my God mom you can hear us! We can have a conversation!" So it really didn't just affect me, it affected them as well.

Alle....(9:21) Wow what an interesting point that you make how it doesn't just affect you or the person with hearing loss but it really affects everyone that you're encountering. That's so important and thank you so much for sharing that. I really don't think that you're alone in waiting to get hearing aids because I actually read somewhere that people wait on an average of 10 years to get hearing aids, if you can believe that. So anyways, thank you for sharing your story Lynda. I think it's so important that everybody hears what you have to say. And Betsy, you are a wife, a parent and you're an actress (Betsy....yes I am) yes you are. And your hearing loss is more recent. So can you tell us a little bit about that and also how it affects your marriage?

Betsy....(10:04) OK, mmm. I've lost some of my hearing in the last couple of years. It's genetic, my mother struggled to hear as well. And it got more severe as she got older. I'll tell you I wish I could've had that CapTel caption phone that you were talking about Kassey before she died because it would've helped us communicate so much better on over long distance calls (Alle...right). Anyway, as for me I have specifically lost much of the higher frequencies that make it hard for me to hear consonants. Which means I often mishear words such as "fair, hair or there" so I thought my husband asked for a pear when all he said was "did you see that bear?" Ha ha ha, and so it goes, and sometimes people drop the last word in a sentence or throw it away and I have to ask them to repeat the last word. And my husband in particular does this which leads me to his story of hearing loss.

Alle....(11:03) Oh, I really can't wait to hear about that. So your husband has hearing loss as well? Tell us a little more about that.

Betsy....(11:09) Oh yeah, he had tongue cancer and had to be on chemo as well as radiation which thankfully saved his life (Alle...right), but the main damage came from the radiation treatment which is directed to his entire neck, mouth, nose and ear territory. And as a result his Eustachian tube shrunk leaving his ear too narrow to hear very well anymore (Alle....wow) thru it. It's become distinctly more noticeable to our family these past couple of years. He does have slight hearing loss in the other ear but oddly enough it's not as severe as mine, who knew (ha ha). But his mouth was traumatized and so his diction has been a challenge for him and for me. As I hear him make sounds but often not the exact words that he says. Which can be kind of crazy making you know (Alle....yes just a little bit). Yeah so so we're both we're both good contenders for hearing aids which we are in the process of exploring with our new audiologist, that's a given.

Alle.... (12:16) Well I appreciate you sharing that because I think it's important for people to realize that hearing loss can come from so many different factors so it can be genetic, it can come from an injury or an illness as you just mentioned, and I think it's important that we are aware of that. So let's change gears a little bit and let's talk about specific challenges and specific strategies. So Kassey you've mentioned that interacting in a virtual world has been challenging especially I can imagine this year. Can you tell us about that?

Kassey.... (12:48) The most challenging situations I have now is hearing on the computer and doing zoom calls. And people wearing masks and standing far away from me, I can't read their lips anymore which I am still depending on them and the sounds are muffled because of the mask. I ask them to speak out and I'm the best advocate for myself I'm always telling people to speak up, talk slowly. If you don't advocate for yourself you only have yourself to blame so I really strongly suggest advocate for yourself. Hearing loss is not visible for most people. Hearing aids are small, they're smaller nowadays and if you have long hair you can hide them so people will not know you have hearing loss unless you tell them.

Alle.... (13:44) Wow, I love that. I love that you are reminding us all to advocate for ourselves. I think that's something that people honestly forget to do and it's

extremely important. And so you're saying that hearing aids are really small these days, which I've noticed as well. And it's been challenging for so many people, the beauty of the size is that it's not so obvious. But I can imagine that the invisibility factor has created some new challenges. Lynda what about you?

Lynda.... (14:12) At home I started using closed captioning on the TV because even when I turned the volume up, I thought it would help to make it get louder, I still have a hard time understanding what people were saying. And my children would ask me to turn down the volume believe it or not it was too loud for their ears. Now when they come home from college to visit, they are used to watch TV with me with closed captions. So that's something I always have on at home now. And luckily there's peace in the house, they're not yelling at me to turn the volume down. So that's really the big bang. And since I no longer have a home phone and I only use my cellphone when I did get hearing aids I decided to get the ones with Bluetooth that would pair with my cellphone to make it much easier for me to hear. Although I personally have hearing aids with Bluetooth not everybody does and I do recognize that working with OEI that not everyone with hearing loss even wears hearing aids. And the biggest challenge that they really face is hearing on the phone. The CapTel phone has been so important for so many people because it not only amplifies by making it louder but it also shows the caption on the display screen just like I love the same idea of closed captioning on the TV.

Alle.... (15:36) Oh definitely that's so interesting because I find myself also using captions on TV and without them I'd be lost. So I definitely (Lynda....me too!) yeah it's a huge thing that I think we need to definitely recognize. And I think for also for so many people who don't want to wear their hearing aids all the time, I know a lot for people that don't want to, and especially in their own home they don't want to. Or for other people who are worrying about not being able to hear something like the middle of the night phone call that's important. I know that having a CapTel phone would solve those problems. Lynda, what other tools do you use to solve potential hearing issues?

Lynda.... (16:15) If I was attending a presentation, I would definitely try to sit up front so I could read the speakers lips if needed just in, you know just to have a backup. And honestly, no matter how big or small my purse might be that day or night, I always have paper and pen with me in case I am somewhere and I need

someone to write something down if I can't understand them. So anytime you open a purse, you'll see a pen and paper. So (Alle....that's so amazing) yeah I don't know about anybody else but being pulled over by the police is scary. But having hearing loss adds an extra layer of nervousness. "How am I going to be able to communicate with this officer?" They speak so fast oh my God I'm freaking out you know when you see the lights behind you. But one of the things is I have a visor card in my car that OEI created which helps police officers communicate with people that are hard of hearing during a traffic stop. So this card explains to them that I have a hearing loss as well as shows pictures of different traffic violations that they can point to that will show why they were stopped

Alle.... (17:25) That's incredible. That is incredible and I think to myself what would we do if we didn't have something like that. And I'm so grateful that you use that. So those are some really great solutions for anyone with hearing loss that they can use. I really appreciate you sharing those tips (Lynda....oh my pleasure). Betsy what about you? What strategies do you use at home with your husband?

Betsy.... (17:47) Oh okay what strategies do I use with my husband? That's a good question! (Alle....Hahaha) Well I am learning that losing my patience and accusing him of not listening to me or refusing to annunciate is not helpful. We made an agreement not to try talking to each other from another room. It is now totally impossible for either of us to hear what the heck the other person is saying form another room anyways. Again shouting "I can't hear you" is getting old and creates unnecessary stress (Alle....definitely). So yeah, so we are cooperating together in that that scenario. And we've both agreed to use closed captions on the TV. I couldn't understand what people are saying either especially if there's an accent it was insane. But I really need those captions on the TV. But even though, even though we do make a good team overall, we are getting tired of the dance of the hearing loss, you know. Now I didn't mention this earlier, you did. You said something about it. But I am an actress and I'm a singer professionally as well. And I'm losing confidence in my ability to hear a line read or even some of the accompaniment to a song when I was singing. And that scares me more than anything to be honest. My beloved husband knows that about me.

Alle.... (19:10) Oh Betsy I really I appreciate you sharing that with us because talk about being vulnerable. And I know you, I know you as a colleague and as a friend and I've actually never heard you say that before. So I appreciate you sharing that with everyone (Betsy....thanks). It is amazing how not being able to hear can really mess with your self-confidence and your relationships.

Betsy.... (19:32) Yeah. Thanks Alle. Anyway, we both have had our hearing checked so we are in the process of trying out hearing aids. And I am actually willing to consider that my difficulty understanding my husband's words could be improved if I actually advocated, like Kassey said for myself. Like you said Kassey, and get help because I need to do something about my own hearing loss (Alle....right). Yeah it's a big step, it's a big step but it is time to do a new dance now, right? (Alle....I think so) You know dancing with hearing aids (Alle....I love that!). Or wolves or something, but hearing aids actually or something like that.

Alle.... (20:14) Oh love it Betsy. Thank you for putting a positive spin on something that is really you know can be very troubling and hard to talk about. I just you know I so appreciate each of you taking the time to share your experiences and your personal experiences. I know I mentioned that we would share some resources on how to be a better communicator in your relationships. That's because we at OEI aim to support the ease of communication for people with hearing loss. There are a few things that will help especially in our current virtual world. So one for video calls, especially with multiple people, identify yourself when you start to talk. I know that that is a big one for me. Two, put yourself on mute when you're not talking to reduce possible background noise. I know that helps with my family zoom calls I always have to remind everybody to put themselves on mute. And three, keep your mouth uncovered to assist with speech reading. This may sound simple, but I think these are things that we often forget to do. And if you're out in your community, when you are speaking with people in person, make sure to maintain eye contact with someone. It's so important. As we know, our facemasks are creating our own barrier to communication and that can be really difficult to deal with. Also, limit distractions such as music or noise or anything like that in order to create a more ideal listening situation. Also, practice patience with your friends, your family members, or your colleagues, as conversations tend to require more focus (Betsy....or your husbands) Yes! Don't

forget about the husbands or your partners or whomever you're with, yes definitely. If you would like more tips and more information about living with hearing loss please visit our website at OEIUS.org again that's OEIUS.org. Our organization is so happy to share all of our resources with people who struggle with hearing loss and we would absolutely love to hear from you. So again that's OEIUS.org. And don't forget to join us next time for a very special Veteran's Day podcast featuring a very important guest that we're excited to share with you. Thank you so much for joining us today on the "Have You Heard" Podcast. And remember to stay safe, stay connected and please subscribe! Thanks everybody!! Bye!