

OEI Podcast Episode #4
(Hosts: Alle and Betsy)
Advocating for Yourself

Betsy.....Hello and welcome to “Have you Heard” a listening project. On this podcast we’re going to share tips, stories and practical advice to help people with hearing loss stay connected. I’m Betsy, today’s host, and I’m here with Alle (Alle... Hi) and in this episode we’re going to cover advocating for yourself with hearing loss as well as dealing with the emotions that come with along hearing loss. Now make sure you stay until the end of the episode to learn more about some great resources that can help you with advocacy and dealing with your emotions. You are your best hearing loss advocate. Talking to others about your hearing loss isn’t fun but advocating for yourself is essential (Alle....that’s true) yeah be honest with yourselves don’t’ be afraid to let others know that you have trouble hearing and let them know what they can do to make you understand them. Asking people to repeat themselves is so much better than responding to what you think you heard (Alle.....so true) and now with this pandemic going on it’s one of the most important times to advocate for yourself. With everyone wearing masks trying to understand what people are saying is more difficulty than it’s ever been since you are not able to read lips or read facial cues. As much as we wish that everyone was wearing clear masks most are not.

Alle....(1:27)

It’s so true Betsy thanks for bringing that up (Betsy...sure) well I would say also consider getting a pin which sounds maybe a little funky but it’s a great idea. So a pin or simply pinning a piece of paper to your shirt that says “please be patient and speak clearly I have hearing loss” I’ve actually done that before in meetings or thing like that it’s very helpful. You can also bring paper and pen or a white board with you if you go to the doctor or to a hospital especially places that are noisy so that you can communicate effectible with people. So just don’t be shy about telling other people what you need.

Betsy....(2:04) Exactly, well said or like in person ask people to get your attention

before they speak. If your back is turn when they start speaking you might miss important details (Alle...yes) This happens to me and my husband on a daily basis I'm afraid, ha ha (Alle....ha ha). We have been in a bit of denial about both of our hearing loss for a while now but it's becoming more clear that what we assume the other person is hearing is not always the reality and then we tend to get impatient with each other because there's no response until sometime later in the day he or she says "I just said that" you know that old saying "I can't hear you with the water running" it is the same concept (Alle...yes) If we really want to communicate we really do need to make sure we have the other person's attention. It can save a lot misunderstanding, irritation and sometimes your feelings. Ask people to look at you when they speak a lot of people with hearing loss rely on lip reading and facial cues. Well I can't facial cues or lip reading on a phone Alle as you well know.

Alle....(3:16) You know that's really true. I know I have so much trouble on the phone myself. So there's a lot of times my left ear is ringing with tinnitus. (Betsy... oh) So I can't hear people on the phone and it's really embarrassing. But I shouldn't be embarrassed, right? (Betsy....no) So I don't know yeah when you're speaking with someone on the phone, tell them that you have hearing loss. I have to deal with this on a daily basis. And ask them to please speak slowly and please speak clearly so that you can understand them. If you do have a captioned telephone which, mind you, are so amazing. Captioned telephones are fantastic (Betsy...unbelievable). Yes. Explain to them that you are reading what they're saying. So please, just be patient as you catch up. There's a really slight delay on those telephones. Again, extremely helpful though. When you record your greeting message for your answering machine, just ask them to speak slowly and clearly when they leave their number, and also to repeat their number twice. I think that's a great idea I know my grandfather does that. But also in the event that you have to make a dreaded phone call to customer service you know we all do that (Betsy....ahhh) yeah. Our phone company, our TV Company. The representative that answers the phone sometimes has an accent and just politely say that you love their accent, I usually do I love their accents but you do have hearing loss and it's hard to understand so can you please be put in touch with someone who maybe doesn't have an accent that really helps out. And you know

just saying it that way is understandable (Betsy....yeah that's a good good idea). I have to use it all the time! Also in the workplace, don't be afraid to ask your boss for accommodations, such as an amplifier or a CapTel phone, which will help you work more effectively because you won't have to guess what people are saying to you. We know a lot about captioned telephones here so please contact us if that's something that you think you need. We'd be more than happy to help you get one at no cost.

Betsy.... (5:14) Yeah it's a great thing. So when you're out and about, if you're going out to eat, call ahead if possible and let the person accepting reservations know that you are hard of hearing and would like a table with a quiet spot. With little or no noise from behind. A corner table or booth in the back is a good choice. Also having your back to the wall will make it easier for you to hear your companions and eliminate some of the background noise. The best time for the lower noise levels are before and after peak hours, just thought I'd let you know. That's a good point. My girlfriend does that she swears by that all the time (Alle....mmm). She's really hard of hearing.

Alle....(5:56) Yeah that makes a lot of sense (Betsy....yeah). Well I also think that at a lecture or a business meeting I found that letting the organizer of that lecture or meeting, just letting them know that you have a hearing loss and asking to be seated in the front of the room where you can actually see everyone's faces to lip read. That's very helpful, I've also done that. And if you have a hearing device, ask if the meeting room that you're in, or the museum, or the theatre, or the house of worship, if they have a loop system, those are so fantastic, so that you can sync your hearing device with the loop system and have the dialogue piped directly in your ear. And that's a special thing, if you guys have any questions about that please feel free to contact us as well. Do your homework is really what I'm trying to get at here because I know that I did to find out these things. Did you know that theatre productions actually have special performances for that, including captioning, which is so cool. And also, many live theaters offer headphones that tie directly to the sound system, making it easier to hear the show (Betsy....oh that makes a world of difference, yeah I love that). I just want to mention really quickly too that there are movie theaters that offer caption glasses. So what those are is some movie theaters will offer plastic glasses that provide captioning in them

(Betsy....Oh!) for the movie that you're watching (Betsy....you're kidding!) Yes and don't be afraid to ask about those. Yeah (Betsy....I didn't know about that. That's pretty cool). Yeah.

Betsy....(7:24) Okay so moving on, dealing with emotions of hearing loss. Now let's talk about that. Denial, anger, depression. The main thing is accept that you have hearing loss. Older people wait an average of 7 years to accept it and get treatment. This is like any other loss in your life, and you may move through a grieving process. So reach out to family and friends, support groups, or even a therapist for help. I finally took the plunge and got my hearing tested, humbling, but relieved to know the truth that I am not dumb. I just don't hear as well as I used to. I'm going to be trying out some of those hearing aids real soon I promise.

Alle....(8:13) Aww Betsy, (Betsy....yeah) you're definitely not dumb it's just so good that you admitted that though. I think that's definitely a feeling that people experience and so (Betsy....yeah) it's really important to know that it's not just you and that it is pretty common. Just like as is in anxiety. We all know that anxiety is provoked by hearing loss. And when you're losing your hearing, you may worry that your ability to communicate with everyone around you will go away, which is a scary feeling. But that's only true if you don't get help. So you can ease your anxiety and start to feel better by learning more about hearing loss. Plus, there are resources that can really make your life easier. So get the help of a licensed audiologist or an ear, nose, and throat doctor. And they can help you learn about all different things okay. So some of those things that they'll help you learn include, treatment options like hearing aids or cochlear implants which I think are amazing, support groups in your area, for meeting other people that are going through the same issues with hearing loss (Betsy....mmhmmm). Mhhmm. What you'll need in the way of medical checkups.

Betsy....(9:22) Yeah and the other system devices like the captioned telephone that you talked about that (Alle....right) we love so much (Alle....right). So there's also this thing, Alle, it's called embarrassment you know (Alle....mmm). Remember that this is a condition it's treatable. And life is too short to miss the laughter of kids or grandkids, and the sound of a bird or music. Take the leap and get back into the game. I just love all these, course I love and miss my grandbabies' voices every day. I was just thinking how much I need to hear the other sounds like the

sounds of a rushing river, or a frolicking creek on our hikes it's like music to me (Alle....oh yeah) and I don't want to lose that. The hills are alive with the sound of music, come to mind? Ha Ha (Alle....ha-ha) I actually do sing that when I sit on a rock when I'm looking at the creek, it's just something I do. Anyways

Alle....(10:20) You know what Betsy I wish I could hear you sing that I'm sure it's gorgeous, you have such a beautiful voice (Betsy....thank you). So yeah I I I agree. Don't avoid social interaction. Adults who end up needing hearing aids or cochlear implants actually need more social time so that they can learn to hear again through that device. Avoiding people will just not help. So ultimately, how can others help? Or how people with hearing loss can actually help those others who have hearing loss. Start by telling the person the subject of your message and follow up, maybe with a written note, for important points. Speak clearly and a little bit slower but in a normal tone of voice (Betsy....yeah no shouting). Don't chew or put your hands on your face when talking (Betsy....oh I find that so annoying. Good point! Hahaha). If the person doesn't understand something maybe try rephrasing, which can be more helpful than just repeating. Avoid talking from another room, oh gosh I do that all the time. Or ha ha ha or over avoidable background noise such as running water or a TV. Remember, I can't hear you when the water's running. (Betsy....there you go) Say their name or stomp your feet before approaching the person to get their attention. If the person is part of a large group of people, avoid cross talking. Talk one at a time so that the person can follow just one voice.

Betsy....(11:47) Really I I have trouble with group settings too and I start to panic a little because I'm losing parts of their stories so I can't fully participate. And it makes me feel like I'm not listening well enough and embarrassed that I missed something. Yeah, (Alle...I hate that) it's kind of weird, yeah.

Alle....(12:07) Aww. Well try to be understanding and empathetic of what the person might be going through. So for example, to illustrate, what if the words "make", "break", and "lake" all sounded the same to you I know they often sound the same to me (Betsy....oh completely to me! I'm right there) Right! And we have to laugh about it (Betsy....we do). Yeah. What if the only way that you could tell what was being said is by seeing the speaker actually pronounce the word? How

would you feel? Needless to say, there would be at least some frustration. I know we can both relate to that (Betsy....yeah). Respect that persons individual qualities, which are unimpaired except in the imagination of others.

Betsy (12:47) Right. HLAA, I'm just gonna jump in (Alle....yeah please) I wanna tell you about this certain association (yes please!) Hearing Loss Association of America provides assistance and resources for people of all ages with hearing loss to learn how to adjust to living with hearing loss. HLAA has chapters nationwide so you can find your local chapter and can meet others in your community going through the same thing as you are. Oh I'm telling you I love the HLAA chapter that I go to. I've got a couple of them that I like. And Alle, you've been involved with them from the very beginning.

Alle (13:24) Right. I absolutely love them I think they are such a great organization to help people learn how to advocate for themselves (Betsy....mhmm). So if you guys aren't familiar with HLAA like Betsy and I are, they are different chapters in different cities all over the nation and they usually meet at least I wanna say once a month (Betsy....yep) and they have different speakers that come but really it's a community of people that you can meet with to get support, to gain information, to share your own stories. I just, they're fabulous. And once a year we always do something called the "Walk for Hearing" to support and raise money for those families that have hearing loss or for others that have hearing loss.

Betsy (14:03) Yeah it's really a good worthy cause. Now there's another one, alda.org. It's called ALDA. This is association of late deafened adults and they support the empowerment of deafened people. Late deafened adults who have lost the ability to understand speech, with or without hearing aids. ALDA has local chapters nationwide. They're committed to providing a support network to share experiences

Alle (14:33) That's fabulous Betsy, thanks for bringing that up because I feel like a lot of the work that we do is of course is for everyone who suffers with a hearing loss or struggles with hearing loss but it's a lot of work with later deafened people (Betsy....yeah) so that's where the captioned telephone really seems to come as in handy well (Betsy....yeah) So really the most important thing is to remember that advocating for yourself will help you live your best life with hearing loss, as Betsy

and I talked about (Betsy...yep). And that's why it's vital that you find out what resources are in your area and actually take advantage of them to help you navigate your life and your emotions with hearing loss.

Betsy (15:09) Yeah. If you'd like a PDF copy of these resources we talked about on today's episode, please visit oeius.org that's oeius.org and click on content. And don't forget to join us next time when we will be joined by a couple of special guests who will discuss their own experiences navigating the world with hearing loss. In the meantime, don't forget to subscribe to this podcast so you don't miss out! (Alle....that sounds like fun) Yeah! I'm Betsy and I'm Alle and we want thank you for joining us today on the "Have You Heard" Podcast. And remember to stay safe and stay connected.