OEI Podcast Episode #3 (Hosts: Audra & Mary Catherine) Advocating for Yourself

Audra.....Hello 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. Today we have myself, Audra, and my good friend Mary Catherine (Mary Catherine...Hi there) we're going to be your hosts and we just want to thank you very much for joining us. In this episode, we're going to discuss a little bit of a sensitive topic but it is a very important one. And it is, how do we bring up the conversation and address hearing loss with our older parents or our grandparents. I want to make sure that you guys stay till end of this episode because we're going to give you the three C's you need to keep in mind when you're talking to your parents or grandparents about hearing loss. So, why is this topic important and why can it be sensitive? Well, when we're talking to you know or talking about older parents and grandparents when it comes to hearing loss they're statically more likely to lose their hearing as they get older. So I have a couple of statistics for you guys here and this first one it's actually from the National Institute of Deafness and Other Communication Disorders and they say that nearly 25% of those 65 to 74 have a disabling hearing loss. And then once you're passed 75 it actually goes up to 50% of those who are 75 and older have a disabling hearing loss. And what that means is that it's not minor it is severe enough that it is impacting their quality of life. So the older they get the more chance they have of having a hearing loss it's really gonna start to impact them in a lot of ways.

Mary Catherine.... (1:39) For me personally, I saw this first hand with my father-in-law. He had untreated and unmanaged hearing loss for much of his life. I know when I met him back in 2012, I think he was in his early seventies at that point. It was very clear that he had a hearing loss and everyone in the family knew. It was just normal to talk loudly for him and at him and just kind cross our fingers and hope for the best. He like many others with untreated hearing loss knew how to manage the conversation on his terms. Which sometimes meant that he simply checked out. It was how he coped. He finally purchased hearing aids in maybe 2013 or 2014 I don't really recall. And I know he used them for a few weeks and I know that he recognized that he was hearing more but he also just really they bothered him. So he put them on his bed side drawer and that's where they stay indefinitely. It was unfortunate but he just wasn't interested in changing his ways. And honestly, the change was probably more than he could tolerate. That is why it is key to work with a qualified hearing healthcare provider. Who will work with your family member to get the best fit and also help them understand how to best utilize the hearing aids. In hindsight which is always 20/20 I wish I could have been there when he got his hearing tested and also got fit for his hearing aids. Perhaps, having somebody else there could have made a difference in terms of finding out different ways to modify in the environment in order to improve communication offer some coping strategies but also just

having another set of another person there listening in to what was being said so that information could have been shared with the family. In any case, I do think it's really important to know that a lot of people, I shouldn't say a lot of people. There's a misconception out there that if somebody gets hearing aids they will magically get their hearing back and that is simply not the case. It takes time for someone to adjust to the new hearing aids and to learn how to use them effectible.

Audra....(3:48) Exactly. Because when you lose your hearing it tends to be very gradual, right? So you don't lose it all at once. It's gonna happen over time so when you get hearing aids it take a while for your brain to reorient itself to hearing these sounds that it has gotten used to not hearing to hearing different pitches and decibels that it is just learned how to ahhmm work around because your brain is very adaptable and it has learned to adapt to not having those sounds so that when you get hearing aids it's not like Mary Catherine said a magical fix. You're going to have to take some time work with a professional to kind of step you up to where you need to be because it's a pretty steep learning curve when you get them. Which is why it's so important to get hearing aids sooner rather than later. So according to that same study I quoted earlier it said that among adults age 70 and older with a hearing loss and those who can benefit from hearing aids, fewer than 30% had ever used them so even though they would of benefited them even though it would have made a difference fewer than 30% actually got them. And here's the thing when we're talking about hearing loss it's not just the hearing loss that's the issue there are other dangerous that are going to hide inside of the hearing loss and I'm gonna share a couple of them with you. So, ahhmm, there was another study done by Johns Hopkins that said "that having a mild hearing loss doubled the risk of dementia" a moderate hearing loss "triples the risk of dementia" and people with a severe hearing loss "were five times more likely to develop dementia." And it's you know it goes beyond you know developing dementia, it's also going to kind of lead into other just mental wellness issues. And so a study done by the National Council on Aging found that suffering with untreated hearing loss ahhmm when people have that they have significantly higher rates of depression, anxiety and other disorders. But here is the good news, I know that was very gloomy, here is the good news. When these people were fit with hearing aids and were using them regularly they started to improve their symptoms started to go down because hearing aids they don't just improve the quality of your hearing but they can really improve the quality of your life.

Mary Catherine....(6:02) And Audra and I can attest to that in our work we meet so many people who are simply starved for conversation and sometimes they are isolated in their homes. And let's face it we've all been at home for the last, what? Five months now? (Audra....at least) And many of our customers are definitely feeling the isolation. And we see hearing aids and CapTel as resources that can support many seniors who have hearing loss do such basic things as pick up the phone to call a friend to schedule a day out or just to get the latest gossip from the senior center. This is how all of us develop and maintain our relationships, our friendships and we know that many of our customers are missing out on it because of their inability to communicate effectively. Sadly most of them don't understand the

downstream impact of this. Which of course is why we have this podcast and lots of resources for our seniors that are both fun and educational.

Audra....(7:01) I like that you use the phrase downstream because that's exactly what this is like it's not just one issue the hearing loss can kind of manifest and impact other areas of our lives so I think that that's a really good way to put it. But despite the you know the increase risk of depression and dementia and not to just mention like just the everyday frustration that comes with trying to communicate when you have a hearing loss like on top of all of those things studies show that people on average they wait about 10 years after their original diagnoses that tells them that they would benefit from hearing aids. They wait 10 years before they actually get them. And so they they're dealing with this for a lot longer than they really need to. And that's why it's so important as children and grandchildren that we are encouraging our parents and grandparents. That we're advocating on their behalf to help them prioritized their hearing health because it doesn't just impact one part of their lives it really does impact the quality of their lives overall.

Mary Catherine....(8:05) And you know one thing that really can mitigate a lot of this for all of us is simply starting to get our hearing tested at an earlier at an earlier age. And perhaps starting in your thirties or forties or if you or somebody who has hearing loss in the family or you're at risk for hearing loss because of some other condition, start getting your hearing tested early. And once you have that first exam, you can see what your baseline level is and you'll know if it's time for more support or not. I've personally have had my hearing tested multiple times over the last 15 years or so. The result always came back as hearing within normal range or limits. However, recently I attended a lecture about the use of microphones with hearing aids. The topic was interesting certainly relevant to the work that we do but I remember listening and having this moment where I thought maybe that's what I'm dealing with right now. Because what he said was that hearing loss and noise is a real thing and I realized that that is something that I really have an issue with. I began to notice maybe in the past year or so that I was really struggling with understanding conversations in noisy environments. It's a pretty common issue that may or may not mean that someone has a hearing loss but listening in a noisy environment it's simply not ideal. In any case, once I had this moment I rang at my husband's audiologist and scheduled an evaluation for myself. The test revealed that I had a moderate to severe loss in noise. As a result, I too am looking to get hearing aids soon. And I can't wait to see or hear the difference. Hopefully taking action now would result in less risk of developing dementia because of my hearing loss. Alright, back to the scheduled topic. Our final point I want to talk about is why people wait so long to get help for a hearing loss. Audra, can you talk more about that?

Audra..... (10:03) Absolutely, so hmmm I go to these "lunch and learn's" at an audiologists that I work with puts on once a month and I love them because they are almost like little focus groups where we get to hear some of the reasons why people have gotten their hearing tested or they don't get hearing aids and I love it when my real life experience matches up with the research

that I do so that's kind of how I came up with the little list I'm going to talk to you guys about now. As I researched it and in talking to people who are older and why they don't get hearing aids. One of the biggest reasons that people wait is because it's hard to admit that you have a hearing loss and you're getting older. A lot of its going to kind of come down to how people view themselves and how people see themselves. They don't want to feel old and getting hearing aids to them just feels like, man now there on display, everybody can see them. They can see that I am, you know, older, or xyz you know whatever negative connotation you may have around getting older or having hearing aids. And so it really just it keeps people from doing that because they are not ready to admit yet that they passed into a different phase of life where hearing aids would be beneficial. So that's one reason it's that they have a hard time coming to grips with the emotions that come along with a hearing loss as you get older. Another part of the stigma like I said is just that hearing aids tend to be very visible. For some people, they don't like the idea that they have to have something that's going to hook around their ear or two ears if you end up needing two. And they feel like it's just something that's going to make them stand out and that people are going to notice. And that's really a shame because there's not the same stigma around glasses. When you see somebody with glasses you don't think "Oh there's something wrong with you" like glasses are a fashion accessory at this point. And I feel like we can kind of come to a point in our lives where even hearing aids can be something of a little bit of an accessory to where we're not looking at that as somebody who has something wrong with them it's just something that improves the quality of life.

Mary Catherine.....(12:05) I think it's really important to note that hearing aids now are so small that often times (Audra....yes) they kind of look like our air pods or some other wireless (Audra... yes exactly) device that we put in our ear just for listening to our music or connecting with our phones. So, it's really not like it was 20 or 30 years ago when they were much bigger and much more obvious, they're pretty small now. So, there shouldn't be a fear of people seeing them because they really don't look much different in many cases than what we're already putting in our ears to connect with our phones so... just a note.

Audra.....(12:38) I love that you brought that up because she's absolutely right! And that's why we're creating this podcast for that because when we're at those lunch and learn's people say the same thing and then the audiologist are able to show them "look how tiny this is, look how small this is" Like you are... they're way cooler and way smaller than you think so that shouldn't prevent you because they can be nearly invisible. Another one of the things that stops people is just not feeling like they have the support from friends and family because they might be the first person in their circle or the only person in their circle to need hearing instruments and again it's that singled out feeling it's like "ugh, nobody else needs this, why is it just me, I don't want to admit that I'm going through this". So the reason that we're kind of bringing these things up when we can kind of talk about this we can help, especially children and grandchildren, understand some of the things that your parents and grandparents might be thinking when it comes to hearing loss. It gives you guys, just gives you the ability to come at it from a different way because you understand why they might be feeling reluctant.

Mary Catherine....(13:48) And I have to say that my father in law was a prime example of this. You know he didn't see hearing loss as a big deal, he just thought it was part of life, even though everyone else knew, they just made accommodation for him by speaking louder. And often times it lead to some pretty entertaining conversation. I can remember it now. Anyway, he is no longer with us and he, I miss him terribly. But one of the things that I really remember about him is that he loved to play card games and board games and he was from east Texas and he would just you know, he didn't necessarily follow what was going on while we were playing games but I remember I would ask him you know if he finished a play I'd say "are you done?" and he would go "I done" and he would move on. And that was his way of letting us know that he was he was done he was ready to check out for a bit. And he'd be back on when it was his turn. And one of the other things that I remember most about him was he loved to just sit out on the porch to just stay out of the fray cause he just sometime didn't want to engage and again part of his mechanism. So now that you know some of the facts and statistics around age related hearing loss, how can you start this conversation with your own family member? There are 3 C's that you need to know and keep in mind when talking to your family member. They're compassion, clear communication and consistency.

Audra.....(15:07) Those three things are going to help make the conversation a lot easier. Because it can be challenging. If your parent or grandparent are not ready to admit or deal with their hearing loss, it can feel like pulling teeth to have it. And that's where compassion is going to come in, because we have to put ourselves in their shoes. We have to feel what they're feeling so that we can come at this conversation from a place of not confrontation but from a place of compassion and love because we really just are looking out for them the way that they've been looking out for us you know our whole lives. So you want to make sure that you just start with the right card that you want to help and you want to support them and that that comes thru as you're talking to them so that's what we mean about being compassionate. The other part of that is clear communication. When you can start the conversation and have just some facts in your back pocket you know you don't have to have all the facts but just a couple, that's going to be really helpful because for some people until they see the data until they see that the hearing loss can impact them in so many other ways, they might just continue to brush it off. But the more they know and the more that you can educate them to some of the as Mary Catherine said, the downstream effects of untreated hearing loss. I think for a lot of people that might be the tipping point because they may say well you know I'm not really concerned about the hearing loss but I am a little nervous because I don't want to be at a higher risk of dementia or depression. So when we're talking about clear communication just have a little game plan for yourself and you can come equipped with brochures from an audiologist, the CapTel site has a lot of really great information where you can pull and use. So come prepared with facts so that you're ready to have a conversation. And the very last thing is just consistency. You might need to have this conversation more than once. You know, you don't want to stalk them you don't want to every time you talk to them bring it up. But if they brush it off, take it with a grain of

salt, bring it up in a couple of weeks, couple of months, whenever but don't stop advocating for them. Don't start or stop encouraging them to see their audiologist, to look into the different resources that are out there so that they can understand this is not about you wanting to not have to yell at them. This is really about their whole entire health and their quality of life. And I think that if we can be compassionate, if we can clearly communicate and we can stay consistent, we can really help them get the support that they need so that they're not living with an undiagnosed hearing loss.

Mary Catherine.... (17:39) That about wraps up this topic, Audra is there anything else we need to share before we finish up?

Audra....(17:45) No I think we're good. I think the biggest takeaway is just again how many issues can stem from an undiagnosed hearing loss. And how important it is to have these conversation with our parents and grandparents, even if the conversation is hard. So just keeping the 3 C's in mind (compassion, clear communication and consistency), those are gonna be really key to helping our loved ones feel valued and loved and remind them that we are here for them and that we're supporting them. So that's all the time that we have today, Mary Catherine thank you so much for joining us on this episode. I really love having you here

Mary Catherine......(18:20) I was thrilled to be here. I'm really enjoying this.

Audra.....(18:23) Wonderful. And I hope you guys are enjoying it too. So don't forget to join us next time because we are going to be covering "advocating for yourself if you have a hearing loss" as well as the emotions that go along with having a hearing loss. And that's a great episode for you all as well if you are dealing with aging parents or grandparents because this will give you even more insight to how they may be feeling so that you can have this conversation. So that's all that we have for you guys today, thank you so much for joining us on the "Have you Heard" podcast. And remember to stay safe and stay connected.

For more information about CapTel or other hearing health resources, please go to oeius.org and click on contact.