Welcome to raising a child with hearing loss with host Gretchen Fors. Gretchen is a mother of five children, three of whom are hard of hearing. Listen as adults, teens, parents, and providers share their own personal journey with hearing loss Plus hear the stories of moms who have walked this journey alongside their child. This podcast is intended for families to share their own personal journeys without judgment. Please respect and honor each family's choices. All information presented is educational and should not be Misconstrued as personal medical advice.

Eliza: [00:00:00] Hearing Mamas Tribe Host, Gretchen is a mother of five children, three of whom have hearing loss. Listen as Gretchen interviews, other Hearing mama's ,and maybe an occasional dad, or child too. Other guests will include people who have been instrumental in helping children who are deaf or hard of hearing thrive, including audiologists, speech therapists, teachers of the deaf ,doctors and other professionals. Due to the nature of this subject some of the names and identifying features have been changed to protect their identities, but the voices and the stories are their own.

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Gretchen: Hi, Alexis. I'm so excited to have you on today. So I'm really excited for you guys to all get to meet Alexis. I'm going to let her introduce herself in a second. But what I want to say is that Alexis was my kid's camp counselor at a camp called bear lake lions camp in Michigan a summer camp for kids who were deaf and hard of hearing.

And we participated [00:01:00] in family camp , and Gretta also participated in going as a camper herself, but because we were there as family campers, I got to spend time with Alexis too. And she was a light and joy then. And she was such an amazing example to me of what was possible. and as a parent that's what you want to see. So I'm thrilled and honored today that she said she would join me. So after that, Alexis, what do you want to say about yourself?

Alexis: I grew up in Michigan and, participated in the camp that you just talked about. And that is something that was also a huge part of my life, but I grew up and I have two Cochlear Implants my first one was at the age of two, but my second one wasn't until I was 17.

Now a graduate student at the UNC. Chapel hill audiology program and I'm in my third year. About to start my fourth year and we'll be doing my externship at the Durham veteran affairs medical center.

Gretchen: Oh, that's super exciting. Okay. So I want to go back to your childhood because I think a lot of people want to hear about your childhood being implanted.

Do you know what your hearing loss was [00:02:00] when you were born?

Alexis: We actually don't know the cause of my hearing loss or anything like that. So we actually didn't find out until I was close to six months. So my parents actually found out when we were at a parade and a fire truck was going by and the sirens went off and I was sleeping on my dad's shoulder and didn't wake up. So that was their Red flag sign right there that I possibly have hearing loss. They didn't really catch it before then, just

because I did respond to other things because of visual cues or just like vibration or breath by both, tactile cues and stuff like that. And so they would go shake something behind my back or do a vacuum and I would respond to because of.

Either catching it with my eye or feeling that. Vibration and that's why they couldn't think or suspect anything at the time. There were also new young parents at the time and just weren't educated

Gretchen: okay. And so at age two, you were implanted with a cochlear implant and then you wore a hearing aid in your other ear. And actually when I first met you and your teenage years, you were doing [00:03:00] the same, you were wearing a cochlear implant in one ear and a hearing aid in the other ear. And what would you say the biggest challenge of your education?

Do you remember any of those childhood challenges of being an elementary school or junior high? With, hearing loss.

Alexis: Yeah. I was very fortunate just with my school being very accommodating to where needing services or devices or anything like that. Honestly, Childhood memory is it's just growing up thinking that it was awesome that I had a magnet in my head and that I could stick.

Littlest pet shop, things that had magnets to my head and, Bobby pins. You name it. I thought it was awesome to be able to just hit that on my head and just have it right around. I thought it was awesome to also be the center of attention while I was young. People would really want to know what that was at my ear. And I always thought it was really cool for them to ask Hey, can I try it on?

But it was just something that was just for me. And so that was my positive experience growing up. My parents really fostered that and instilled that in my mind of like, be you [00:04:00] and. People will gravitate towards you. And so I think that is something that. I was fortunate enough to grow up with that mindset of, being who you are and your real friends will come around

So I think that's just, why my childhood was so positive is because my parents always are supportive. They always gave me a normal childhood. And so that was something I really appreciate. And they also taught me advocate for myself, which I think was a huge part of me becoming confident and.

Wanting to advocate for myself rather than them advocating for me.

Gretchen: I love it. And we were just talking about, how busy you were in high school. So tell people all the fun things you did in those teenage and high school years. Cause I know you did a lots of fun things.

Alexis: I was definitely enjoying a lot in my high school years. I took choir. I did volleyball. I did basketball.

I was involved in a lot of non. Organizational things like nonprofit charities, things that I would do. There was one called dream team where I was supporting kids. Who've had cancer and we were trying to raise money for them. So just little bits of things I was [00:05:00] involved, and that was something I always truly loved. I would define myself as an extrovert in high school.

And so trying to be busy and that was just something I really thrived on.

Gretchen: Yeah, and I weren't you in student council and maybe, Ms. Mattawan or something. You forgot about that. I still remember

Alexis: that's right. I was miss Mattawan 2015. That was an awesome experience as well. And so I did forget about that, but that is truly a great experience.

Gretchen: . And I remember as a parent looking at that and thinking, this is awesome, this girl doesn't let anything hold her back. So you were just such a joy . What made you want to become an audiologist?

Alexis: What made me want to become an audiologist. That's just my experience in being able to see behind the scenes, things that happen for both the family aspect and just my own experience as well. I think. Being someone who has gone through the experiences and. Knowing, oh, I wish I knew that, or I wish I had this and being able to take that feedback and information, meaning.

And not to [00:06:00] implement it for myself as a clinician, as something that I wanted to be able to connect with and be able to truly be able to provide that connection and empathy and understanding for parents and adults who have cochlear implants or hearing loss. And I think just through my experience of having hearing loss, it's really opens my eyes that as

An audiologist and even just as a person to be able to provide. Resources and tools for people to have communication. However, that looks for them, whether it's through ASL, Cued Speech speech or anything like that, it's their hearing aids or cochlear implants. I want to be able to have an abundance of resources and use my experience to be able to provide something for family and parents to become comfortable, and confident in like making their decisions.

Gretchen: What surprised you most about when you got into audiologist school? Is there anything that surprised you or you thought was different than maybe you expected it to be.

Alexis: What Surprised me the most was the [00:07:00] attention and focused on technology nowadays. I think that is something that. Because of the generation that we are in technology is the first and is the forefront of people's minds. And that was something that shocked me. And I think that my experience coming into school kind of was able to hold me back and be like, okay,

This is something that I want to be able to bring to the field because I don't see it. I don't see resources or abundance of resources for families who decide to use ASL or to decide to cued speech. And so I think that was something that shocked me was just peoples for individuals.

Resources first for hearing aids or cochlear implants. And that was something that I wanted to change. And to bring in and remember. That communication. Isn't only through hearing.

Gretchen: Yeah, I love that because you do bring such a unique perspective, and. That's why this podcast is called hearing mommas, right? Because we're [00:08:00] hearing moms and we don't always understand the whole situation.

So that was the thing that shocked you the most, but what was the thing that you just have loved and embraced the most about being an audiology school?

Alexis: Connections that I've made, but both families and mentors. I just really thrive on being able to connect to our parents, to be able to connect with others. And that's just something that, brings joy to my heart is being able to say for your raise connect, And to know that I fostered or started that connection and not to see them as lifelong friends or to same children

being able to see others that look just like them or the adults were in cochlear implants or have a sparkly ear molds or anything like that. And just to be able to see the joy as something that is just so rewarding for what I do.

Gretchen: I love it. And what advice would you give to a new parent? . What would you want to tell parents about what it was like and how they can help their child the best.

During this journey.

Alexis: During the journey and struck me overwhelming. And the beginning, you're getting an abundance of information. You can feel [00:09:00] overwhelmed. And my advice for you, it's just to follow your gut, take your time. There's no rush in anything to just truly look at all of your resources. Honestly, don't be afraid to get a second opinion. If you feel like something is.

So go ahead and get that second opinion. The more information for you is better and don't feel selfish for trying to think deeper or to see if there's more options. That would probably be my biggest advice is to truly just follow your gut. You know your child best, and your family best.

It's going to suit you all the best. And so that is something that I would advise you and to recommend, that you just truly. Follow what you guys want and what you guys need and your goals and family.

Gretchen: Maybe you can share some of the resources, the audiologist provide the parents because sometimes I think we get so segmented in our, how we provide care these days that you do.

This is the ENT, and this is the audiologist, and this is the speech therapist. So maybe share what, the things that an [00:10:00] audiologist can bring to the table when you take your child for these hearing tests and what their goal really is.

Alexis: So that's a very like broad question. And there's such a broad answer at that because each journey is very unique and each journey is your own journey. And that's something that a lot. Parents to be able to remember. Is that just because something works for someone else doesn't mean that it's going to be the best decision for your family as well?

There's so many factors to take in to consideration. But my biggest resource has truly been sharing other family's stories or sharing connections or just with the generation that we're in today. Facebook has gone such a long ways and just being able to see that you're not alone and so I think my first resource or audiologists, first resource is

is to really share that you're not alone to be able to share. But this is what we have worked with as well. Here's another family that's going through something somewhere to you. You can reach out to them. [00:11:00] Most.

Manufacturers or audiologists have the resource to be able to share forums such as Hearing Pears for Med EL islike the first one that comes up. There's.

A forum where families are able to talk through.

But other people who have cochlear implants are either people who have hearing aids. Some sort, just to share their experience. And that's one thing that I feel like audiologists do provide as a resource and as a tool for families to truly connect with others.

Gretchen: Okay. I love it. Okay. What is one thing that people get wrong about you when they meet you?

Do they make an assumption about, but they get wrong.

Alexis: That's a tricky one. I think a lot of it is if they don't know my back story and what I can bring to the table. They don't realize the connection and my resources that I can bring to the table. As someone with hearing loss. I feel like just being in the field that I'm at today, [00:12:00] sometimes people think why is she in a hearing career? Like why is she at a career that has to do with hearing. But doesn't she need hearing to be able to provide services. And that's not the truth. That's not. I feel like there's different resources and tools that I do use to be able to help myself as a clinician and as a provider.

A lot of people I think get that wrong is that. Just because I have hearing loss, doesn't mean that I'm not going to provide the top notch and best quality care that I can provide and that anyone can provide.

Gretchen: I love that there are no limits. I want you to share some of the different types of technology that you use to help yourself have access to sound.

Alexis: So there's a wide range of tools that I've used even just throughout my life and high school, I will start there start there. I used a Roger system, so my teacher wore a microphone and I had a boot that I put into my cochlear implant

And that was how I used things in high school. And high school. I also used the cart [00:13:00] system. That was where I had someone come into the class and be able to write notes. And if I felt like I needed that, I would look over it and look at the notes that I. Or look at the cart that was transcribed.

Throughout college. I also use those as well, and I thought it was really helpful having those services, even if I didn't use some consistently in high school, that was something that really. Guided me in college, having that backup to be able to show that, yes, I need this even. In college. And so sometimes having that backed up improved, but I used this in high school was something that helped make my experience and transition easier into college.

I also. Continue to use that even through grad school right now is a cart system and a roger system. I use that in the clinic as well. Oftentimes I'll hand my patient or Roger pen. And that is something that I use for being able to be in a different booths and all of that. In terms of zoom right now, I either use my audio link for my audio [00:14:00] stream for cochlear implants I personally love the audio stream because it allows me to be not how many wires, anything that I need connected to me or to the computer or anything like that. It just streams directly to my implant.

And I think that's something that's very helpful.

Gretchen: How hard was it to get some of these services for CART in high school and in college?

Alexis: So I was very fortunate to be able to have a easy and seamless transition to trying to get these accommodations for high school. My public high school was great in terms of providing it for me. I had a deaf and hard of hearing teacher that was just absolutely amazing. And being able to get the services that I needed and the help that I needed.

She was always on top of things. She was someone that as soon as something was wrong, she was on top of it and very proactive. And that was something that was really helpful. Like I said earlier because of that, having that backup and that proof that I used it in high school, even if I personally didn't use it every single [00:15:00] day, having that written information in my IEP was something that transitioned and guided me.

College to be able to bring this to the ARS or the resource service office and be like, Hey, this is what I need. This is what I had in high school. I'd like it for college too. So that was, I think what was the key? Importance for that transition from high school to college is having that in my IEP, all four years of high school to show this is what I need.

Gretchen: And that was what I think, like I said was the best thing that I could have done. I love that. So just a question. So do you, when you had these services where they all a person would come in or did you do AI technology, like where the teacher had a microphone someone remote transcribed or. Explain how your cause cart can be done multiple different ways. So how was it done at your university?

Alexis: Yeah. So it's definitely improved in high school and someone that came to class with me and typed right next to meon a word document. And that was how we [00:16:00] made it work at the time. And then in college has gotten better in being able to be more accessible. So right now in college, what we do is I give a microphone to my professors. I'll get them to actually one will be for my personal Roger pen that goes straight to my Cochlear Implant

and the other one is for the transcriber or the capture. and so she actually works in remote. And what we actually do is just get on a zoom call and we don't have any cameras on or anything like that. And she's able to hear. Through that microphone and able to transcribe. And what I do is I just call up.

Through internet explore our page that w e. Let me share with each other and she just types in everything. And I read it right at my computer as I take notes.

Gretchen: I love that. I think that what you're sharing is that sometimes you have to be your best advocate, there's a lot of good things out there, but if you don't explain.

To the school or to the university in a very. Precise and with a compelling. You know a story about why this is helpful. Sometimes it's hard for others to understand why those resources are so important to you. [00:17:00]

Alexis: And I think especially as a in in the clinical side of things and how audiologists and clinicians or deaf and hard of hearing teachers can really be able to guide that as well. By even just simply talking to the

university director or the high school director and whoever it is that you're talking to be able to truly explain this is why she needs it in the most simple layman terms of.

What about this? She is going to have difficulty or whatever. Is best.

Gretchen: Yeah. And I think that's a challenge with how invisible hearing loss is. Is there a disability, right? Like just like you, my daughter, she has very good speech. So people will say to me, she must hear fine because her speech is so good.

And so trying to make people realize that What and what you perceive are not always, what's actually behind the scenes. Yeah.

Alexis: Really, yeah. Hit the nail on the head with that. Especially with that, just being an invisible disability as a lot of people

call it is not being able to hear it in my speech or to [00:18:00] see it in my, good grades as something that we're really having to provide that proof of, because of these services, be successful or because of these tools and resources. That is why I'm where I'm at today. I think that's something that is hard to convey.

When you see me as a person, when you see. me talk when you see me. Have provide these good grades and stuff. That's it's because of the resources that I have.

Gretchen: I love that. And that you're working really hard. Hearing for you takes a lot of energy versus hearing for me and that there are things.

I know that with my daughter, I have to make sure she is looking at me sometimes. Like I'll yell something . And then she was like, mom, remember you have to look at me when you're talking to me. And so even as a parent can be hard to remember that, but that's, what's so great is you guys are doing so well, but then sometimes it also makes us not remember how hard you're actually working to get there and that we need to, make sure that we support.

All the good things you're doing.

Alexis: Yeah, I definitely remember guys like something that I did struggled with in high school. It [00:19:00] was just like my energy level was not as this extroverted person and really thrived on being able to do a million things. That was something that I had to remember because at the end of the day, I remember coming home and just like absent.

literally passing out and taking a nap because I was just so exhausted. Anytime I'm taking notes or anything like that. I'm looking at my professors, lips watching their lips move. And then I'm also looking at the board to see what notes they're writing on the board. Plus I'm also trying to take my own notes and looking down. And when I looked down, I'm not looking at the lips so I'm missing that context

so my brain is working at 110 miles per hour, trying to fill in those blanks that I missed before and looking at cues or anything like that. And so it is definitely exhausting. And listening fatigue is a thing. And that is

something that I did struggle with in high school. And that's something that I feel like I recognized more in college, was able to get myself a break of, okay, you listened really hard for.

This block of time, give yourself a 30 minute break and be able to just sit in silence or. Whatever it is that made me feel [00:20:00] more comfortable and able to take a break.

Gretchen: I really appreciate that perspective because I think that's the perspective. Most hearing people don't really get or understand.

And it's really important for the educators, for the parents, for people who interact with. Our kids to realize that. They're working really hard. And so I know that I'm guilty of that. My daughter likes to actually come home and watch TV and I am not really a fan of TV. But somehow TV is the way that she like to have some downtime.

That's what gives her a break. It's not what I enjoy when I have a break, but if that's what she needs, it's okay. And she still gets good grades and she works hard. And just having that patience, sometimes that life doesn't show up how you expect it to for sure.

Alexis: Yeah, definitely think it was hard for my mom to understand that.

I have come home as an extrovert. Extroverted child. And she, what kind of get confused because the first thing I would do is take off my implants and she would be trying to talk to me. And that would be frustrating on her end, but she didn't realize that soon as I took off my implants at the end of the end of the day. It's because I was exhausted. I was fatigued.

But that communication for [00:21:00] her was hard to be able to talk to me, to let me know what I needed to do, or if I needed any chores that I needed to do. Yeah, it was more frustrating on her end trying to get my attention but now as I've gotten older and being able to verbalize that and recognize that she realizes where that came from, but it was a frustration at the time for her and for me, because I would want that break. But for hers, she also was trying to tell me what I needed to know or.

Even ask me questions at the end of the day, just to see how my day was. And that was not something I wanted to do with the.

Gretchen: Okay, good. That makes me feel a little bit better that maybe my daughter just can't quite verbalize that yet, but she does also like to come home and take off her implants and I'll be talking to this. She's mom, I can't hear you. I don't have my implants on. And I'm like, oh, okay, I'll come back in a little bit and we can talk about this later. Or to, whatever she's trying to do.

Alexis: It would also be a thing that I would be guilty of. I would take them off. And then I would ask my mom a question and she'd be like, why are you asking me a question? Maybe.

Cause you just took off your implant. It was just a very confusing, but we look back on it now and we laugh, but [00:22:00] I would want be able to able to talk with her and let her know, because I missed her for the day, the same time I didn't want to hear, but I was wanting to know her questions.

Gretchen: Yeah, good to know that this is

Thanks Alexis for making me feel like it's normal. Okay. As we wrap this up, is there anything else that you'd really love to share with the listeners about, either your journey or encouragement for them on their journey?

Alexis: I know that they've heard it before, but it's just one of those things that your child can do anything. You're the best advocate for your child right now as they're young and you're their number one person in resource. So just like I said earlier, really follow your gut. So don't be afraid to get a second opinion.

You guys know your family best. And so finding a provider or a clintion that truly understands and takes your family and. And trust is someone that you want to connect with and be able to. Work through your hearing journey or your journey. However, that is. With someone that is going to provide the resources that fits best with your family.

Gretchen: Thanks. I love that. Thank you for sharing that. I just really appreciate you taking [00:23:00] time out of your busy schedule to join me today and for being the light that you are, because. It's just heartwarming to, and I think that this is the part that I want to give parents to is the hope that if your child can be whatever your child wants to be, and you have been a great example of that from when I met you, when you were 15 to wanting to be an audiologist there, to.

Being one year from graduating with your AuD audiology degree and in an amazing university on top of that. So I'm just really proud of you, Alexis, and thanks so much for joining us today.

Thank you so much for joining us for today's episode of the hearing mamas tribe podcast. I'm so appreciative for those who are willing to share their stories. And I hope as we share and listen to these stories that our hearts can be uplifted and we can find joy in this journey together. I welcome you into our tribe.

If you're a parent, a mom, a dad, or a professional who serves these children. And we'd love to share their story. Please check out the show notes for how to get in touch. Please like subscribe, [00:24:00] share this with your friends and leave us a review. That way more people will find this podcast. Thanks for being part of this journey.