Episode 4: Lacey...It's just fluid, or is it? Unilateral Loss

[00:00:00] Hi, my name is Gretchen, and proud mother of three beautiful girls who have hearing loss. If your child has received the same diagnosis you are in the right place. I welcome you into our tribe. You are not alone. Listen, as I interview other hearing mamas, maybe the occasional dad or child or teen or other guests who include people who have been instrumental in helping our children thrive.

As we share our stories to build community and connection, we will laugh together, cry together and find joy in the journey. While there are many communication choices for children who are deaf or hard of hearing this podcast specifically focuses on families who have chosen to use listening and spoken language.

Gretchen: Hi, Lacey, I'm so excited that you were willing to join me. I would like you to start to just introduce yourself a little bit and maybe your child.

Lacey: Okay. I am a mom of two kids. [00:01:00] I've got one that is in high school and I've got one. That's an elementary school. And my elementary school son is my son that has unilateral loss.

And he's always had his loss. It's never changed since birth. When he was a newborn, he came into the world with muconic I'm in his lungs. They told me at the newborn screening, they sit and he doesn't seem to be hearing anything and his left ear, but we think it's because of all the fluid that he's got in his lungs.

And maybe he's got that in his ears as well. And it just is, it's stuck in there and he can't hear. We just said, okay, that's fine. We let that go. Just assumed that was what it was. He was in the NICU for his first week with that infection in his lungs, from the meconium that he had and they gave him an antibiotic called gentamicin.

To treat that for his first week later in life, we learned that gentamicin has been known to cause hearing loss and newborns, [00:02:00] whether that is it or not. We're not sure

Gretchen: when they did his initial newborn screen. Did he refer to both years or did he just refer to one year? Do you know? Did they ever tell you?

Just one year. So it's always just been that one year and then he had the gentamycin and it's hard to know if that's what was the tipping point, cause it's auto time sometimes I'll take it back.

Lacey: I'm not sure if it was two years or one year. I'm not sure about that. Yeah. And

Gretchen: That's something I'm sure it's hard to know all the time we needed to know all these things and remember all these things, right?

Like you just take your kid to the NICU. You hope that he's going to live and you're just trying to survive. I don't wish the NICU on anybody. I spent way too many days in the NICU with my children too. It's very stressful. So I guess when you get out of there. Thriving. And, but now he still got referred to his hearing loss.

Did, when you left the NICU, did you know that, did they tell you when you left, they make you, you needed to follow up or

Lacey: Yes, they were great about that. Yeah. Like I said, I will go back on my word and say that I was just told he [00:03:00] didn't pass this hearing screen. Okay. So I'm not sure about that, but. He did have a follow-up.

We did another hearing screen. They said, let's give it whatever the amount of time was a number of weeks or something for that fluid strain out. We'll do another screening. Needless to say, we had several screenings after that, a few more. He didn't pass any of them and they kept coming out. At the age of seven months, we had to put in some ear tubes because he did have some fluid in one of his ears, or maybe both.

I can't remember the details, but it's been seven months. He went in with the ENT. They put in some ear tubes and he had an ear infection and they thought this is probably going to solve his hearing problem. So the fluid problem. I'm sure. He'll pass this hearing screen when this is done. He didn't pass that again.

And we kept going on with the fluid in the ear issue, the ear infections, and they kept coming up with all these different reasons of why this is probably why he can't hear. Okay. Now this is probably why you can't hear. And finally, at [00:04:00] age three, just right around his third birthday, the audiologist said he's had enough tests that have been.

Pretty much the same on the spectrum of where we think this is just a permanent hearing loss. And so we think he needs a hearing aid in that ear. And so that was at age three when he started wearing it, he had just turned three when he started wearing his hearing aid. And like I said, it's just in his left ear.

And it's funny because after being told all these different reasons for three years, I didn't think of it being permanent. I just thought they'll figure it out. I don't know what's going on, but when she said let's talk about hearing aids. I was shocked. I thought, oh, wow. Really? Okay. And so I would say it was a little.

Looking back on it now, it's not a big deal. He's living great. But at the time I felt it was a little traumatic. Yeah,

Gretchen: It is shocking. Yeah. And did he get offered any earlier intervention after he got his hearing aid or because he was [00:05:00] three because an infant toddler goes zero to three. So had he missed that boat or does he have any therapy or anything?

Lacey: We did a lot of speech there quite a bit. Yeah. In fact,

Gretchen: your insurance private pay, I mean your insurance covering or not any, or did you also have services from outside?

Lacey: We had a copay. It wasn't all covered by insurance, but insurance did definitely help. It was a good help, but yeah, we used to think it was so cute.

He called a helicopter. He called it. No, I'm sorry. The school bus was up. Oh, that's how he heard it. Apparently, because now at the time we, I still remember that word because we still say it as a joke because it was so cute. I was like, how cute is it that he's even, you'd see one going down the street and there's an alkali.

And now I'm feeling sad because. He couldn't hear what we were saying. And that was how he interpreted it. I'm trying to remember. He had a word for a helicopter to that. We just thought they were so cute, but I had no idea. Then the poor guy, that was the way he was hearing the [00:06:00] words. We get him into some speech therapy to this day.

He still calls a curb like a street curb calls it the curve with the V as he learned it. Thinking back on it, I'm a little bit frustrated with the system that we had to wait until he was three years old to get this figured out. I don't know if we just slipped through some cracks. I was not an advocate because I didn't totally understand the extent of what was going on.

You trust your doctors to tell you that, oh, this is happening because of the fluid in his ear. This is happening because of his recurrent ear infections. And you think, okay. I wasn't thinking back to how it would affect me. Long-term speech development and things like that. You don't

Gretchen: know what you don't know.

So I think sometimes as moms, we need to let go of that. And I think we all have that mom guilt a little bit, but I'd only known I would, would've done this differently, but you don't know what you don't know and you're right. The authority you trust the medical system and saying, oh, it's this it's [00:07:00] that? So there was no reason for you to think that it was anything other than that until it wasn't, luckily you could get him aided.

If, because I don't think your insurance covered the aide at the time. Did they? Or did they. Yeah. So you had to pay it out of pocket for a hearing aid. Then he ended up in speech for a long time, four

Lacey: years worth of speech. Okay. Yeah, I think he was probably a first grader when we stopped that and starting at three, we had an amazing speech therapist.

She did such a great job with him and she worked in the same office as our audiologists. They were a team and they did a great job with them. They talked to each other and helped me, gave me information on what I needed to know about what was going on. I still keep in touch with them and that's been a great experience.

So

Gretchen: getting aided at three, was it hard to get. Hearing aids on him. How did he accept the hearing aid? It's

Lacey: really truly been a miracle that he just, he never fussed about. You never tour, you never tug at it and pull it out of his ear. He was really [00:08:00] good about it. He did. After a couple of hours, he would say, I don't want to wear this, but actually putting in any, he never fought me on it.

Yeah, it was good. The funny thing was that the kids at school, he was in preschool at the time. There was one kid who was just, he had his favorite color was red. So we had a red hearing aid and this little boy in his class was just enthralled with what the heck was on. So this one little boy kept going up and he would pull it out in a year and my son would come home and say, he did it again.

I don't like it when he does that. And the boy would just pull it out and look at it and it would just hold it in his hand. And then they kept saying, okay, you can't answer yourself. You can't feel this.

Gretchen: I'm curious. Has he experienced any negative impacts since he's gotten to elementary school? Is he willing to wear it?

Has he been bullied about it. In fact, his interaction with kids is they, luckily one of those kids who just as embraced, moved off.

Lacey: He has done great with it. He has really embraced it. I guess one of my fears when he first got it, when he was young [00:09:00] was, oh my gosh, is he going to be made fun of when he gets a little bit older?

Is he going to be bullied? Is he going to be that kid? That everybody just be a different and grade school class. Some kids are just, they don't accept kids who are different sometimes. And I just worried about that, but it could not be further from the truth. He has owned it and it's been great. And it's funny because last night he actually told me a story when I was talking him into bed.

One of the kids on his basketball team. So funny, he said, mom, he keeps asking me, what were my, what did he say? Where my earbuds are, my headphones. He goes, and I didn't know what he was talking about. And he goes at one time at practice, he asked me, what song are you listening to? And he said, I just looked at him.

And I was like, that thing. Today. I figured out what he was talking about. He said today, he asked me because he said I wasn't wearing them because I actually forgot it. And he said that this kid came up to him and [00:10:00] said, where are your headphones? And he goes, what? And he goes, your blue headphones. Because his hearing is blue.

And he said my hearing aids and the kid just turned bright red and said, oh, I had, I didn't, I'm sorry. I didn't know. And he was like, he thought all this time that my son was rocking out when he was at basketball practice.

Gretchen: You know what a lucky kid, his mom lives somewhere, his air pots, the basketball practice.

That's two people walking right now with the things hanging in and out of their ears all the time. All the wireless. AirPods and earbuds, all of those you're right. That's super

Lacey: cute. And I had a mom tell me when he was probably in first or second grade, she said, my son wants a hearing urinate.

And I said, she sees your son with it. And he thinks it's really cool and it's red. And he just thinks it's cool. And he came home and said, mom, I need a hearing aid. Like my sons. Yeah. He thinks it's cool. He's

Gretchen: What am I going to get? And I think that is every mom's biggest fear. When you find this out, like how is this going to [00:11:00] affect my child?

Because they're different, something bad is going to happen to them. And you're always afraid of those things. So it's really great to hear that he's just thrived and doing so well. Would you just maybe share what have been some of your challenges? Him and school. And how has he faced that? And now becoming your child's champion and a little bit more,

Lacey: he's been at the same grade school.

He's in fifth grade now and since kindergarten and in kindergarten and first grade, he did fine with just his hearing aid. As far as I know, he did fine. He's the kind of kid who doesn't complain and he won't really say something unless it's really bad. So he has never complained about not being able to hear, but sometimes when I ask.

Can you hear in school? Okay. Sometimes he'll say it's hard, especially in gym class, when there's a lot of outside noise going on, he has a hard time hearing the gym teacher, the PE teacher. But anyway, by second grade, The principal came to me and said, have you talked to anybody about a 5 0 4? So I have no idea what a 5 0 4 is.

I don't know what you're [00:12:00] talking about. So she explained to me, yeah, this is something that we set up for him. And she explained what a 5 0 4 was and said, we could get him a speaker tower that we put in the classroom to help him here. Oh, okay. Nobody had mentioned that to me. I didn't know anything about it.

She was active in setting up a meeting for me. We got her all audiologists involved. We got some other people involved and got the 5 0 4 set up with them. And he now has an FM system, the speaker tower, where the teacher, a teacher where's the microphone. And usually they'll have him sit close to the speaker and he

says,

Lacey: As long as he's sitting close to that, it's awesome.

You can hear really well. I think he has a little bit of a hard time sometimes. Kids questions in the classroom. They're not sitting close to him and they don't have the speaker tower microphone on. Sometimes he can't hear it. And through second grade, he just let that go. In third grade, he said something to me about it.

And I spoke with his teacher about it and he worked out a hand signal with his teacher. He would try to give her a thumbs up from [00:13:00] wherever he was. And that meant I couldn't hear because he was too shy and felt a little insecure about raising a CNN. I can't hear you guys, or can you repeat that? And for a while, the math in particular is one where you need to know what's going on step.

She would be at the board explaining how to do something, and if he didn't hear it, he just let it go. And then he might ask me later to help him with it. Or he might dig into the math book himself and try to figure it out himself because he didn't want to say something.

Gretchen: It's usually at the board writing something.

So their back is to the students. I think our kids learn really quickly. Accommodations for themselves, right? Like lip reading, which is, he probably cannot even vocalize that to you. But it's different when the teacher turns around and talks at the board rather than when she's looking at them and talking.

Lacey: Yeah. And he can't quite figure it out. And, but he's getting better about that. But we are in fourth grade and now he's in fifth grade at the beginning of the school year. We just worked out a hand signal with the teacher. So that seems [00:14:00] to be working really well where he can say either Johnny across the room is asking a question, I can't hear him.

So if he can get the teacher's attention and give her a thumbs up, then she'll repeat the question. Let's say, oh, so are you asking me? Blah, blah, blah. So that has worked well. I do have a little bit of questions with him going into junior high. About how, what we'll do as far as an FM system or a speaker, or I know that you can do Bluetooth with a microphone directly to your hearing aid, but with him having a unilateral hearing loss with one hearing aid, it would only be going into one year.

I don't know if that would be a problem for him. So we'll have to figure it out.

Gretchen: What would your words of wisdom be to a mom who's just starting this journey,

Lacey: But yeah, I would say everybody's I hate this answer. Everybody's different. I hated hearing that from doctors when he was little, but that was what I got a lot.

I would ask lots of questions to your audiologist. What can I do to help [00:15:00] improve his or her understanding of. Do you think that we need to go to speech therapy? Because I guess in our situation, and it's not a huge problem, but in our situation, I feel like that from birth, not being able to hear those sounds that they have to form and understand at such a young age, he missed a lot of that.

I guess I would have told my former self that even something I could do at home with them, with helping to actually look at him when I'm talking and vocalize it. And a lot of times moms get so busy, I'll be in the kitchen like him as a little child. Maybe I'm in the kitchen doing a million things and I'm talking, but I'm not looking at it.

And he doesn't see my mouth and the way it forms words, or maybe it doesn't even understand it that well, because I'm not speaking to him. And even To this day, I have to remind myself, this has taught me patience, because I have to remind myself a lot of times that maybe he's sitting on the couch watching TV or something, and I'm in the kitchen and I'm saying your lunches are ready?

You need to come up to the table [00:16:00] or something. And then he doesn't realize. And then I'd say it the second time. And the third time I'm getting frustrated at this point saying, I haven't asked you three times, please get off the couch, turn the TV off and get up here. And then he'll turn around. He's just like what I had, what I didn't hear you.

And then I feel bad. Cause then I'm like, oh my gosh, you really hear me? I feel so bad. So it's taught me to be patient. And that's something that you probably know at a very early age. Honestly, I can't hear you sometimes. True.

Gretchen: That's true. My daughters she'll say, mom, you cannot yell at me from wherever I am yelling at her.

She says, I know you're talking, but I can't understand you. And luckily she's old enough to tell me that, but it's so easy to do, it's just so normal. Or as a mom, we're yelling at our kids to do things from different places, whether it's. Yeah. Okay. So this is another question about his unilateral loss.

Did anybody ever tell you? Oh, he'll be just fine because [00:17:00] he has one good ear. Yeah.

Lacey: I think, I feel like I've heard that. Not from anybody, not from the audiologist, not from the speech therapist. I get that sometimes. And it's almost like an implied thing. Like sometimes people will look at me like he has a good ear.

He can hear what's the big deal. Having your earplugs. It's like coming down from a mountain. And when you're in a car or an airplane, when your ears are plugged and maybe for one year. But the other one doesn't and just imagine how awkward that feels and you can't hear. And I have to sometimes say to people, he is just, because he has one good ear, he can't hear everything.

And especially if somebody is on his left side,

Gretchen: I know my daughter has one special say, if we're walking and talking, she said, mom, you got to stand on the other side of me or I can't hear you. I don't always remember that, but she's all. If you stand on this side, I'll hear you better. And I'm the mom.

It's still hard to remember that. So it was just like, we were talking about hearing loss as an invisible disability. So even those who live with us [00:18:00] every single day, forget. These are combinations that our kids need. It's really easy to do. Yeah. Yeah. Anything else you'd like to share with people?

Lacey: I think one thing I would like to share is that my son is very involved in sports poses, a whole new issue with the hearing aid you're sweaty.

So it gets wet. There was one time about a year ago. It was last summer. My son plays a lot of lacrosse and he played year round last year for the first. So he's playing in the summer. It's really hot outside and he's sweating like crazy. So the hearing aid got really wet and it stopped working. I ended up having to take it in to the audiologist to get a little bit of work done on it because it damaged it.

So we've gotten to some of his sports where he sweats a lot, he won't wear it. And it doesn't where it lacrosse is a little bit different and probably he doesn't play football, but it's probably the same thing with the helmet coming on and off, we have had an experience where he has lost the hearing aid because when he took his helmet off, it pulled it [00:19:00] out of his ear and he didn't notice it.

And when he got in the car to go home, he didn't have it. And I said, where's your hearing aid? Oh my gosh. So we had to go find it on the field. I can't remember this gentleman saying, but there is a football player who is no longer. The Seattle Seahawks, but he wrote a letter to this football player and this football player also wrote a book, which we got, and it was about how this football player guy had.

He has hearing loss in both ears and cannot hear hardly at all without his hearing aids. And my son really looked up to him, thought he was just the coolest, because he wore hearing aids, even got a Duracell commercial. Then they played on TV all the time because he had hearing aids with batteries.

And then. And so that really inspired my son to, just to be himself and not let the hearing loss or hearing aid hold him back from anything. And that was inspirational. One thing we've had with coaches has been [00:20:00] interesting. Coaches tend to be hard on players at times, depending on whichever sport it is and whatever they're doing.

I did notice that. Winter, he played club basketball and I, the coach, did know that he had this hearing last. A lot of times he doesn't wear his hearing aid when he plays basketball. Because he says it's too loud. He doesn't like the whistle of the referees.

Gretchen: The ball bouncing is even loud for me. Like I can't imagine that

Lacey: he will take it out and not wear it during games a lot.

I try to explain to him, you have to be able to hear what your teammates are saying. If they call. But he seems to have it figured out, but where I was going is that there are times when the coach would be yelling at no right. Go right. Or you're supposed to be over here or something. And I've seen it happen.

And then the coach gets so mad because he thinks he's being defiant and not doing what he's supposed to be doing or not listening to the coach. And he did the swim team for a while. We had the same thing with the swim team where you can't wear it when you're [00:21:00] swimming. And some team coach would be telling them to do something and he's not doing it.

Or his teammates are saying something to him and he can't hear it. That's been an interesting part of it because.

Gretchen: There's always things that come up, right? Like these things you don't think about that, like it works great in the classroom, but then you go to the swimming pool and all of a sudden they can't hear you.

So they just think, why is he not listening to me? Everybody wearing masks for the last two years has really given me a lot of empathy too. For the situations our kids find them in behind the plexiglass. We had the math. Sometimes I can't hear the cashier at the grocery store and it's frustrating to me.

And I think these are things my kids are just used to. That's been really eye-opening to me to realize that what would it be like if I couldn't always understand everything everybody was saying to me also gives me some empathy that sometimes they are listening because it's too hard to listen. It's just easier to tune you out, then try to figure out what is actually going on.

And that happens sometimes too. So

Lacey: trying to figure out the difference between listening and hearing. Those are two very different things.

Gretchen: Exactly. That is exactly true. And that is a great way [00:22:00] to end Lacey, thank you so much. I really appreciate you joining me today, and I'm really grateful for you to share your experience.

And I know you've shared some things that are going to help kids and moms and parents and families and everybody on this journey. So thank you so much for

Lacey: joining me today for letting me be a part of it.

Gretchen: Thank you so much for joining us for today's episode of the hearing mamas tribe podcast. I'm so appreciative of 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.

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