



Episode #2: Jacqueline's Hearing Loss Story

This. My second hearing loss just happened. And so I feel more of a need now than ever to tell my story and to support other Hard of Hearing People because I don't know, there's just not, you can never get enough support.

It's a really, it's a disenfranchised group in society because it's like, Oh you look like you're hearing and you function as hearing, so we're going to treat you like you're hearing and you have needs that are not in alignment with the hearing, with what a hearing person needs.

📌 Welcome to the Hearing Wellness Journey Podcast, an exploration of determination, hope, self discovery, and triumph. We'll share the personal experiences of those that are living with hearing loss and provide a haven for their stories to show others that they are not alone in this journey. Your hosts, Dr. Dawn Heiman and Lindsay Dougherty.

📌 Okay. So I am Lindsay. I just want to welcome everybody to this episode of the Hearing Wellness Journey Podcast. And today our guest is Jacquelyn.

So welcome.

Thank you. Yes. Hi, my name is Jacquelyn. I live in Boston. I'm a New Yorker as living in Boston, and I've been living with hearing loss for 30, almost 34 years.

When I was two, I had bacterial meningitis and that was when I lost the majority of my hearing. And then I lost hearing later in life as well.

So it was actually a grandfather who noticed after I had meningitis that I wasn't localizing sound because ironically he was a hearing aid distributor. So it was on his radar that people with meningitis do have a hearing loss as an after effect. So a couple of months after I had meningitis I was in the hospital for two weeks.

I was very sick at the time. And then a couple of months later he noticed I wasn't localizing sound. So I got my hearing tested and I had a significant loss on my left in my left ear and my right ear also had hearing loss. Was severe to profound on my left and a moderate loss on my right.

So I immediately was enrolled in a preschool for the Deaf and Hard of Hearing.

Okay.

And so were you fit with hearing aids at that point in your life?



Yes, I got them when I was probably two and a half or three.

Okay. Do you remember anything about that when you were first fit with them?

Not when I was that young. I certainly in my later years, yes. Yes.

I don't really know how I adapted to my hearing aids, but I know there was one time that I went into the pool.

With them on, things like that, that a kid does my grandfather, because he worked in hearing aids. He knew some trick with orange juice to dry out the aids at the time. I don't remember exactly how he did it, but they were salvaged in the end. Thank you again, grandpa.

That is amazing. It's special grandpa magic. I'll have to Google that later. Can orange juice dry out your hearing aids?

I think that's what it was. Yeah. Yeah. If

not he made you think that, who knows what was going on in the background.

Get back to me on that.

That is so funny. Yes. I just it had to have been a different world, being a child and, you can't just run and jump in the pool or the sprinkler and

yeah, I think it did, it does make you a little bit more of a cautious child.

Because it's like, all right, are they on me? Did one fall off when I was running, there is that hypervigilance. I still have that sometimes.

I would say. It is not easy being in middle school and having behind the ear hearing aids. I also had an interpreter at the time until I was 13. Th that, and then I, there was a microphone that the teacher would have on their desks.

So I felt like there were a lot of things that made me stand out in a, not so great way at the time. And I really struggled with that. I didn't want people to know about my hearing loss. When I was in elementary school and middle school.

Did you receive any negative feedback from kids when you were in grade school?



Yeah, I think, it does make you more prone to bullying. So there was a little bit of that and yeah. It makes you stand out. Sure.

Yeah. And I think it really helps that some kids thought that the ASL was cool. And so they would be mesmerized by my interpreter. Meanwhile, I was like trying to not look at them. I don't know who this person is. But I think so there was some interest in learning sign language. And so I had some support around that.

And some friends that were really interested in learning sign language. I still talk about that with my friend. Actually, we recall like being in fourth grade and suddenly it was cool to learn a little bit of sign. So

That is excellent. I have to say it's it is amazing. My, my daughter, when she was in first grade was able to take sign language.

They had a sign language club after school. Yeah. So she started coming in. And that was not too long after I started working here. And some high schools offer it as a foreign language and there's such a big presence. And so I think that having your friends be interested in it and wanting to be a part of that and, to have your back and just kinda envelop you in that hug of yes, you are different, but we love it.

And we're going to embrace. This is awesome.

Absolutely. And I'm really happy to hear that it's being offered as a language option in more schools because it absolutely needs to be.

So when did you hop out of that rebellious period and finally come to terms like, yep.

This is just a tool I need.

I think when I was about 16, I was able to get an a CIC aid. So suddenly I could hide my hearing loss a little bit more. And I think I was able to become more simpatico with my hearing aids at that time, I was like, okay, all right, fine. I can do this. I can wear them more often.

And knowing that not everyone has to know.

Okay.

Yes. And there was a lot going on in my life at that time. I also lost the parent when I was 17.



So it was a really stressful time. So at least that was one thing, one less thing that I had to worry about.

Yes. Yeah. So I bet that was an exciting day when you got fit with that.

Yes, because I never thought that I would ever be able to, the technology evolved so quickly at a certain point that when I was younger, I was told all, no, you're never going to be able to wear the tiny one.

And then by the time I was 16, I was able to, so that was a huge deal for me.

Oh, wow. Did it, did the sounds change for you? Did you end up, obviously you were wearing the hearing aids more often and then, but did you also notice like the change in technology and.

I wouldn't say that it felt like more advanced technology at that time or anything. I think the quality was pretty similar. It was just being a kid you just want so badly to fit in or to not stand out in a bad way.

Quote unquote. So it was so important to me to have that discretion of the CIC's.

Although there were some instances where I just wouldn't wear them all together. Going out, I would rely on lipreading because in a loud environment, like at a party.

You just don't want that background noise and the technology wasn't super advanced at that time to be able to drown out the background noise and whatnot. So it was, but there I had behind the ear aids or CIC, it was just easier to not wear them in some settings. But I certainly embraced them more once they were more discreet.

Wonderful. They became your friends. Yeah. And then as you've gotten older and obviously have gotten new devices have you just researched them a lot and what, how has that progressed?

What steps did you take as you became the adult, as you became the handler of your solution your hearing aids?

I think it's a Testament to how much I dislike change. The fact that I'm still using essentially the same model of CIC that I first got 20 years ago.

My audiologist and I joke that I'm wearing like the flip phone version of hearing. Yeah, not a lot. I've tried different ones, but I tried the CIC's with Bluetooth streaming. I tried, I, ' I've done some



trial periods at some of the other ones, but I just kept, I ultimately returned them and went back to my trusty old ones.

I'm always hunting for them, I'm always asking my audiologist about what, anything on your radar that you think would be good for me?

And so on. And I do my research, but it hasn't felt like an urgent thing because the ones that I currently have are working for me.

Wonderful. So you've been with your audiologist for a long time now?

Yes. I've been with my audiologist since I was 13.

I'm almost 36 now. And I live in Boston and she's in New York, so I travel to New York to see her basically. But certainly if I have a more urgent matter I see people up in Boston at Mass Eye and Ear.

Okay. And who, if you don't mind me asking, who is your audiologist?

Lori Trentacoste.

Okay.

Wonderful. Yeah. So that's just so amazing that you've had the same audiologist knows you from being like a teenager into an adult and that longevity there.

Yeah. That relationship is so important. I feel comfortable with her. She knows me. She knows my ears. She knows My adaptability or lack thereof.

It just, it's so important to have that connection with someone, with your audiologist,

being able to be honest and open about what you want, what you like, what you don't like.

And she's just really been such a huge support of mine, especially, I'll get into it a little bit later, but in the last year I had more hearing loss and I was up in Boston dealing with all of that.

And yet we still stayed connected that whole time through phone and, other means of communication. Sure.

If you want to tell everybody about that, what's been going on. Yeah.



Yeah. So when I had meningitis, I lost some hearing and I lost some balance. And so fast forward to 2010 I'm 25. And I noticed that my balance. It was getting worse. I underwent a lot of testing. I did imaging, nothing was seen. I was basically told your meningitis symptoms simply got worse over time. As it turns out, I discovered last year, 10 years later that I had an acoustic neuroma.

So I had a benign brain tumor on my hearing balance and facial nerves. And I had a craniotomy last December, a couple of months ago to have it taken out. So in, in the process of that, I went completely deaf in my left ear. And then my right ear was knock on wood unaffected by that. But yeah, I I'm now deaf in one ear and hard of hearing than the other.

Oh,

wow. Yeah, that really has to have thrown you off.

Through a loop. It did I it made sense to me that I had a tumor in that area based on my symptoms. And so when it was diagnosed, I wanted it out ASAP.

Yes. Obviously you were being affected, you had symptoms related to that. It wasn't it may have been benign being there, but it wasn't benign to your life.

Correct? Yeah, it was affecting my ability to carry out daily activities like bending over to empty the dishwasher or scrub a tub. Do laundry. Those things were really difficult. So just walking across a room, honestly left me with such fatigue. So I'm glad that it's out. I don't feel as tired as usually which is great.

And I'm grateful that it was eventually caught, my, I was, so my, the vestibular system was so sensitive that I was feeling symptoms before they could see something on an MRI in a clear way. It was there, but it didn't really look like a tumor, so it wasn't caught when it should have been.

Oh, wow. And so what has that recovery been like now that you are completely deaf on the one side? How has that changed or how have you started getting back into things, getting back into the groove of the new normal.

I think I definitely had to take some time off to physically actually felt like I rebounded pretty quickly.

It was more, adjusting to the deafness and the way that the tinnitus kind of changed. Okay. There's, my there's like an echo that happens when I talk and when there's a lot of noise around me, so adjusting to that. Has it, I'm still adjusting to it. But every day it does get easier.



And but physically I'm back doing gymnastics six weeks after craniotomy, I was back doing gymnastics. So I do aerial acrobatics. At least it didn't take that away, right?

Yes. Oh my gosh. That's so amazing.

And I joke that. Aerial acrobatics, me spinning around in the air, was the perfect hobby for me because my feet didn't have to be on the ground.

That made me dizzy than spinning in the air.

Wow. Oh my gosh. Okay. So you're able to jump back into that. Yes. And then you're still working with your audiologist up in New York. To like what have you, I started doing, are there any rehabilitations you've been using to help with coping with that loss?

I know you said you're adjusting every day and it is getting easier every day. But coming to terms with that loss and you basically have to retrain the brain to just hear.

Yeah. Yeah. As far as like physical therapy, I was given some exercises, but I was told if you're doing gymnastics and that's child's play.

So don't worry about that. Searching for a new hearing aid. I'm putting that on a shelf. That's not a priority right now. I'm adjusted. I joined some support groups on superior canal dehiscence syndrome in case that's what's going on with the way that the tinnitus is changed. And my audiologist, Lori, put that on, in front of me, to look into that. But I haven't had imaging to rule that out completely or anything. Or at least I haven't had a cat scan, which is the gold standard for diagnosing that. Okay. It feels like that's something that I'll cross that bridge when I'm ready to go there, but for now I'm just coping with minimizing Symptoms, not that I'm minimizing how often I talk, but just a lot of them just getting used to how everything's sounds.

It's an adjustment period.

It is now. And realizing that, your brain is smart. It learns to hear what it wants to hear and should hear. And, also teaching it what what it doesn't need to pay attention to.

Yeah. I believe that over time it will learn to ignore this because when I first had surgery, I was like, please tell me this is swelling and that it's going to go away. You know, I didn't try to read into it or get too freaked out by it. But over time I realized this is a symptom that's here to stay. But I, my, I think my brain is getting better and better at ignoring it just a little bit every day.

That sounds. One step at a time, like baby steps.



Exactly.

I learned that if I put in an ear plug in the affected ear, then that minimizes some of the echoing. The tinnitus seems not so exacerbated by noise. So if I'm in a noisy environment that helps me.

Yeah. But it's really the face masks that have been the biggest obstacle. In the last couple of months, more than anything not being able to read lips has been really challenging. So it feels so hopeful that things are opening back up and I can see more faces.

Yes, most definitely. And do you find that you are around any ASL fluent people in your life now, or do you resort to signing with certain people or in certain circumstances?

So I'm a therapist and I have on my caseload at any one time, usually one, at least one client that is Deaf or hard of hearing. So I, in my work, I use ASL. In my personal life, not as often.

My, my mom knows a little bit and so we'll communicate that way if we're in like a noisy environment or something, but otherwise there's not, it's not a usual means of communicating for me with any one person outside of work.

So what do you want people to know from your experience?

As a member of the, as a proud member of the Hard of Hearing Community, I really feel like we need to join forces more and band together more. It feels like isolated. There's a person. There. The umbrella of hearing loss under that, here, some hearing loss or lots of hearing loss, but not Deaf, is so vast.

There are so many people living with some degree of hearing loss. And so I just feel like there needs to be more unity in the Hard of Hearing Community.

And I don't know how audiologists can enlist in that. Whether it's maybe being, you're not, this would involve violating HIPAA but if you had two patients who you thought would maybe be good buddies for each other, like connecting people, I know have the right answer for that, but I know that there needs to be a lot more unity, so that there's more support in that sense of community that the deaf community has, but the heart of peer who does not have.

Yes.

And so that, that is why Dr. Heiman and I wanted to pursue this podcast is so that there is community. There is conversation about it and hearing the stories that can resonate with other



people. Is huge, right? It's a comfort to know you're not the only one now of course, people listening, can't really directly connect with you at the moment.

But there is the Hearing Wellness Journey Facebook group that we like to have people come in and comment, and if there's questions and can be around for that and really having support of each other that is huge.

Yeah. Yeah, there's so many people...

When you have an IEP in school that doesn't translate to the workplace. There's no workplace IEP is for people who might have had like preferential seating, extended time on tests, another student taking notes. We need more support in workplaces as well. Fortunately, I work for myself, so I'm able to create and control my environment in that sense.

But when I did work for an agency, I did, there were times where it felt like things are happening, that I don't have control over, and this doesn't feel good. Because that change does not served me well so I don't know, just more awareness about how people and how to support people in work places as well.

There's a great need for that.

That is a great point.

And we should be able to go into a job interview and state our needs and for it to not be like eye opening or stigmatizing or what not, what have you.

HR. Maybe you needs more education on how to support staff? I don't know what kind of training they get around that, but sure. Probably whatever it is, it's not enough

oh my gosh. Gosh, I really enjoyed talking with you

and want to learn more about this aerial gymnastics, and how you keep doing this and how, you've not been affected and balance wise, and you're able to go in there. And I just I think that's fascinating.

You haven't let that ever get you down and lose that you lose that passion of yours to do that.

I think it's so important for adults to have hobbies too, to have passion projects and interests that just put a fire in their belly. And so I'm really lucky to have a couple of things that, that do that for me.



And, yeah, it's interesting. I, after I had meningitis, I, something happened with my vestibular system where I didn't get dizzy spinning around like some other people, like the average person. So I'm able to spin and not really feel that effected by it. Silver lining.

I was going to say the silver lining there, you always have to look for that silver lining, but that is that's amazing.

And it's now created this little outlet for you during, maybe harder times where you can say, I just, I need to go spin.

Yeah, absolutely. The creative outlet, the social outlet, it's a physical outlet, it checks a lot of boxes for me.

And yet, you're spinning around doing aerial gymnastics. Yes.

Usually not wearing them when I'm doing that. Oh, okay. Although right now I only wear one because I'm Deaf in the left ear, so I no longer need my second aid.

Okay. Oh, my gosh. Yes. That would be hard to make sure it doesn't fall out.

They're pretty like locked in, but just in case. Yeah. It's more the sweat that I worry about ruining them. So I have one of those hearing aid, dry boxes. Those are great.

Yeah. Yes. And there's all different kinds, where you can just screw a lid on there and then microwave the beads to dry them back out.

And then there's the electronic ones.

I have all of them.

You should have one in each place. So you're never

like without. Yeah, exactly. And it enables you to just have peace of mind so that you can live your life and be outside when it's hot out, break a sweat when you're walking with a friend and not feel panic.

Oh that's huge. And so you've been able to maintain that. Regular lifestyle of being young and fun.

I'm young? Yes! We're the same age. We



are a spring chickens. Yes, going out and living that life and not being, hesitant to do hesitate. Yeah.

That's that's great because you don't have to stop living life.

Because you have a hearing loss and have hearing

aids. Yeah. As adults, you're just so much more aware and vigilant and, as vigilant as I am as a person, there were still incidents as a kid when it would fall off. And I wouldn't be aware. So for parents who might be listening, who have kids that where hearing aids, I get it.

I would never do that now, if it fell out, I would immediately know, but as a kid, you're just not as tuned in. Things like that do happen, probably

they do. And it's hard not to, I think probably get a little irritated about it, but, Like you said kids probably aren't just as in tune to it, there.

Busy being stimulated and distressed by what's going on.

They might feel like, oh, suddenly I feel like I have a headache or I'm walking through a fog and not, oh, my hearing aid fell out. Like they know that something's different, but they're not really sure, but, so I see that as someone who is so tuned in and dialed in and aware, even I, as a kid still had my moment.

You were honing that that skill, that superpower of being able to tell. Oh, I'm I can no longer hear things or things are different and being able to respond super quickly instead of, not realizing it.

I liked the way that you put that.

This. My second hearing loss just happened. And so I feel more of a need now than ever to tell my story and to support other hard of hearing people. Because I don't know, there's just not, you can never get enough support.

It's a really, it's a disenfranchised group in society because it's like, Oh you look like you're hearing and you function as hearing, so we're going to treat you like you're hearing .And you have needs that are not in alignment with the hearing, with what a heard hearing person needs.

I need people, I need to be able to read lips and for people that face me when they're talking to me and. The list is endless. I have so many needs of the hard of hearing person. I am an



advocate and ally and I do, I love telling my story whenever I can. So thank you so much for having me on your podcast.

It's so wonderful. We are so happy that you volunteered to be a part of this, after meeting with Dr. Heiman and she, we were both compelled by your story that you shared on Clubhouse. So thank you. Thank you.

It's been an honor.

I really appreciate you having me here. Thanks.

Yes. And if you'd like to check in with us, let us know how things keep going for you, because right now you're, you're still at the start of your new journey.

Yeah. It hasn't even been six months technically, right? Yeah.

So it's a journey as we say, because it's, it is never ending and life is going to keep changing and you're going to keep finding ways to. Overcome obstacles and continue finding joy. And, yeah.

Thank you. And please let me know if there's any way that I can support you, your practice, your patients.

I like to feel helpful in that way, because like I keep saying, there's just, you can never get enough support as a Hard of Hearing person, especially as a Hard of Hearing working professional.

Thanks so much for having me.

Yes. Thank you. Take care.

Bye. You too. 📍

📍 Thank you for joining us on this episode of the Hearing Wellness Journey Podcast. For more information about what we do and the services we provide, please visit our website at hearingwellnessjourney.com/podcast, where you can find more resources based on today's discussion, as well as request to be a member of our Hearing Wellness Journey Community on Facebook. That's available for our listeners exclusively on [Hearing Wellness Journey.com/podcast](https://hearingwellnessjourney.com/podcast).