

Powering Potential Podcast

Season 2, Episode 1: From Silence Into Sound

Peter:

I feel like what the world needs to know about hearing loss is that once you have hearing, like, when somebody who's deaf is gifted the gift of hearing, like, they're just like you. Like, they can hear all the ... Well, okay, we think we can hear the things the same [way]. We're not really sure. But like, we're just, we're just [like] a normal person. We have all the same dreams and aspirations and fears that you do. And, like, we think the same things that you do. So treat us like normal people.

Dr. Teresa Caraway:

That was Peter. He's one of thousands of teens and young adults with hearing loss who are part of a new generation. He's coming of age at a time when changes in technology, advances in research and Listening and Spoken Language, or LSL, have transformed the possibilities for individuals with hearing loss. Thanks to these advances, Peter has had the same opportunities to listen, speak, and excel as a child born with typical hearing does. His life looks pretty, well, normal. But while the journey to listening and speaking is full of joy and normalcy, it isn't without its challenges either.

Welcome to Season Two of *Powering Potential*, a podcast from Hearing First where we explore the unique joys and challenges of growing up with hearing loss. I'm Dr. Teresa Caraway, your host, a mother, and a speech-language pathologist specializing in Listening and Spoken Language. In Season Two we'll get to know six incredible teens and young

adults who are learning to navigate the hearing world as individuals with hearing loss.

Kane: My name is Kane, I'm 14, and I have severe-to-profound hearing loss.

Harper: Hi, I'm Harper. I'm 13, and I have profound hearing loss.

Jayden: I am Jayden. I am 15, and I have both ears hearing loss.

Peter: Hi, I'm Peter. I'm 19 years old. I have bilateral profound hearing loss.

Zach: My name is Zach, and I have severe-to-profound hearing loss.

Connor: My name is Connor Sullivan. I'm 27 years old. I have a profound hearing loss in my right ear. And I have a severe-to-profound mixed hearing loss in my left ear.

Dr. Caraway: Over the next six episodes, our brave, young friends describe what it means to have hearing loss today, getting the good, the bad, and the inspiring. When I began my career as a speech-language pathologist, well before Kane, Harper, Jayden, Peter, Zach, and Connor were born, so much of what they've accomplished wouldn't have been possible. The hearing healthcare landscape looked a lot different. Just over 20 years ago, most children born with severe-to-profound hearing loss did not achieve age-appropriate Listening and Spoken Language abilities.

Today, children are achieving on par with, and even surpassing, children born with typical hearing. I'm excited to share their stories with you this season and explore how we've

redefined the possibilities for a child born with hearing loss.

As they say, a journey of 1,000 miles begins with a single step. When it comes to learning to listen and speak, one of the first milestones is the day that a child receives their hearing technology. Today, we know that we hear with our brain, not our ears. Our ears are simply the doorway that lets sound into the brain. Hearing loss happens when that doorway is blocked, but hearing technology opens the doorway and lets sound pass through to the brain. Hearing aids and cochlear implants are the most common hearing technologies we use to provide access to sound.

For a child born with hearing loss, experiencing sound for the first time can be thrilling—and also, a little overwhelming. Let's hear from Kane who was diagnosed at age 4 years. [He's] an accomplished young man who plays traveling baseball and serves as student council president at his middle school.

And do you remember being diagnosed? Do you remember going into the booth and having your hearing tested?

Kane: I don't remember going into the booth and all that stuff, but I remember first puttin' 'em in and hearing the telephone ring for the fresh time, and screaming bloody murder. I'd never heard the telephone ring.

Dr. Caraway: Wow. It kind of startled you then because you didn't know what it was.

Kane: No, ma'am.

Dr. Caraway: Yeah. What else did you remember?

Kane: I remember hearin' rain for the first time. Rain didn't really scare me because it wasn't, like, a sharp sound. But then, like, of course when I started getting older, I heard more things around the environment and I just started getting used to it.

Oh well, when I first got these new ones [cochlear implants], it wasn't like ... But probably three or four years, when I heard the air conditioner for the first time. Well see, when I first got 'em, I got in the car, [and] I started hearing whistling noises. And I [had] heard it for about a week [when] finally, I asked my parents, I'm like, "What is this noise?"

They're like, "It's the air conditioner, like, how do you not hear that?"

I'm just like, "Well, I've never heard it before."

Dr. Caraway: Wow.

Kane: So, I've gotten used to that too.

Dr. Caraway: Connor received his first hearing aids at the age of 4. Though today, babies as young as 2 weeks old can wear hearing aids. As Connor grew up, his hearing loss became more profound, so at the age of 19, he received a cochlear implant. Connor was raised by parents who did everything they could to get him the best care possible.

He was so inspired by the pediatric audiologist who tested his hearing and fit his hearing devices that he decided to become a pediatric audiologist himself. Now he works with kids who are on the Listening and Spoken Language journey, just like he was.

Tell us what activation was like.

Connor:

Activation was very strange ... but it was awesome—one of the best days of my life. You just walk into a room just like the hearing aid programming room. They hook you up, and it really starts with a lot of listening for beeps, just like any other hearing test. What's different about this is that you're listening for beeps while there's about 15 people staring at you. So you're listening for beeps, and then once it comes time to turn it on, they start really, really, really quiet. And then they just start increasing that level up until you have some sort of sensation of something.

For me, that sensation was ... It almost felt like a physical sensation. It almost felt like a tapping on the side of my head. [It] didn't hurt or anything like that, but knowing what I know now, that was my brain interpreting the stimulus that it was getting. That tapping remained for a few minutes, and then I started noticing that I was getting the stimulation at the same time that my dad was chewing his gum. And so, I noticed that he kept chewing his gum and I was feeling something, and I was like, "Oh my gosh, I'm hearing my dad chewing his gum." And so, I said that out loud and everybody thought that was hilarious. But then I was like, "Oh, okay, so this is how this works. I experience something, I pair it with what I'm seeing, and then I kind of pair it together." And that's really how it works.

Dr. Caraway:

And so, do you remember when you first ... other sounds that you were first hearing that were kind of strange or that you might've been hearing for the first time?

Connor:

Oh yes. So, really, cochlear implants are so unusual when you first get them because you really have to learn to be able to even notice that something's happening. Whenever it first got turned on, it just so happened that a couple of doors down there was a baby crying at the same time. And my Listening and Spoken Language therapist, you, were in the room. And you noticed that and so you asked everybody to be quiet and you wanted me to try and hear if there was a baby crying.

Dr. Caraway:

Getting access to sound is the first step on the journey to Listening and Spoken Language. Learning to connect those sounds with meaning is the next step. Whether it's a baby crying, someone chewing gum, or your parents saying, "I love you," the sounds are essentially meaningless until someone helps a child understand them.

Let's get back to Peter. He's studying to become a CPA. He's also a devoted boyfriend, inspiring camp counselor, and avid soccer player. In an upcoming episode, we'll hear how he got his nickname, The Screaming Goalie. But in the meantime, let's hear how he responds to a common question about his cochlear implants.

So, do you remember the first time anyone asked you about your cochlear implants? Another kid?

Peter:

I don't remember the first time, that's for sure. I obviously remember many times telling people, like, what it's about and everything, but I don't remember the [first time].

Dr. Caraway:

Like, what are some of the questions they ask you or what [do] they think they are?

Peter:

Yeah, so, like, a lot of people, they say it's hearing aids, cause, that's their ... They're like, "What's up with your hearing aids?" And, like, that's a common thing I guess because most people view them as hearing aids not as cochlear implants, which is what I have. So, I politely explain to them that, like, it's cochlear—well if I care enough that day—I explain to them, "It's cochlear implants, not hearing aids. Hearing aids are, like, a step below cochlear implants. I have them because hearing aids didn't work for me and cochlear implants magnify the noise more than hearing aids did."

And then I do it, like, to kind of relate it to them so they can kind of understand what it's like, I say that, "If you put a gun next to my head and fire it, I won't be able to hear it." And that usually explains it to them pretty well.

Dr. Caraway:

Yeah.

Peter's exactly right. When hearing aids aren't powerful enough to provide a child with access to all the sounds of speech, a cochlear implant is often recommended. A cochlear implant is made up of two parts: an internal piece that is implanted under the skin behind the ear in a very low risk and painless surgical procedure, and the external part, which is worn on the ear like a hearing aid.

Cochlear implants were first approved for American children in 1990, and since then, thousands of babies have crossed from silence into the hearing world because of them.

Another one of those kids is Harper, an outgoing cheerleader with dreams of becoming a psychologist someday. The plastic ball she describes is actually a specially designed

bandage to reduce swelling of the incision site after surgery.

Harper:

Oh, this is a fun story. So, when I was going in, I remember I wore a button shirt so I could, like, take it off and do my surgery and stuff. And, I remember every time I got out of surgery, they put half of a plastic ball on my head and wrapped something around it, so I just had this huge plastic bump on my head. I remember that. And that was my first cochlear implant, and—

But I remember when, when we ... When they rolled me in, they gave me this little mask and it was connected to, like, a big tube and it had a balloon at the end, like a big metal tube with different ends and stuff. And they told me to blow up the balloon and I took one deep breath and then the next one was like half and then I don't remember anything after that.

And then when I woke up, I was just like ... And then I woke up in my hospital bed, I guess, like, recovering you know, with the big plastic orb over my head. And then they rolled, they ... My parents took me home. I remember I was really dizzy.

Dr. Caraway:

Uh-huh. Were you in pain?

Harper:

No. No pain.

Connor:

Did it hurt? The answer is no. It didn't hurt. No, it doesn't hurt. Does anything stick out of your head? No. Nothing sticks out of my head. Can I go through the airport? Yes. I can go through the airport. Much to the dismay of having to deal with TSA, yes, I can go through an airport.

Dr. Caraway:

While dealing with the Transportation Security Administration, or TSA, is rarely fun, traveling without the need for an interpreter or special accommodations for hearing loss makes the experience so much easier. Children who learn to listen and speak with the help of hearing technology and an LSL approach can truly lead independent lives in the hearing world, just like Connor and Harper.

Another one of our young friends, Jayden, took a long plane ride to a new life not too long ago. Jayden was born in China and brought to the United States by his adoptive parents 7 years ago. His mom suspected he had hearing loss when he didn't hear the alarm clock ring several days in a row.

Okay. So when you first got your hearing aids, what kind of sounds did you hear that you hadn't heard before?

Jayden:

So, when I first got [the hearing aids], I hear[d] these, like, scratchy noise[s] and things, and then I got used to it. And, now ... and then ... I [could] hear people talking, sounds.

Dr. Caraway:

Yeah. So, when you, when you first got your implants, it sounded kind of scratchy?

Jayden:

Yes.

Dr. Caraway:

Yeah. Was it kind of ... How did you feel? Were you scared? Were you happy? What were you thinking when they were first activated?

Jayden:

I was excited, but also a little ... a little afraid.

Dr. Caraway:

Yeah.

- Jayden: But, it has been helping me.
- Dr. Caraway: Good, good. Wow, so your English is excellent.
- Jayden: Thank you.
- Dr. Caraway: So you have only been in the States for seven years?
- Jayden: About.
- Dr. Caraway: Wow. So you came, and what was that like learning English?
- Jayden: It was challenging, but I got through it.
- Dr. Caraway: Learning English as a second language wouldn't be possible without hearing technology and LSL. For families where two or more languages are spoken at home, LSL helps keep their culture alive and family members connected in their native languages.
- Peter: Everybody asks, like, what does the sound sound like from your first ear or your second ear? To me they're the same. It's just sound, like I don't ... It doesn't differentiate it between the two. But like, how good I am hearing with that ear, yeah, I understand that. Like my first ear, I've had it since I was 13 months old. I'm very good at it.
- Connor: There are some good resources on how cochlear implants sound and work, and there are some very bad resources. I will say that the cochlear implant sounds different for everybody who hears one. Some people think it sounds mechanical, robotic, [or] Mickey Mousey, but that's really temporary. And by temporary [I mean] it could be a day, or it could be six months, but it will go away. For me, it

went away quite quickly. And so, you just have to give it time. But your brain is an amazing organ that can really adapt to almost anything.

Dr. Caraway: So your cochlear implant sounds normal to you.

Connor: Oh, absolutely. And people have a hard time believing that it sounds normal.

Dr. Caraway: I think Connor's point bears repeating: With hearing technology, life sounds normal. As we've heard in this episode, getting used to new sounds and their meanings can be exciting and scary at the same time. But once getting past those initial hurdles, the world can be a sweet, funny, and perfectly normal place for a child on the Listening and Spoken Language journey.

Check out episode two of *Powering Potential*, where we'll talk about the critical role a child's parent plays in teaching them to listen and speak.

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