

Powering Potential Podcast

Season 2, Episode 4: Self-Champions

Dr. Teresa Caraway: So how would you describe yourself as a kid?

Kane: Like, whatever I want to do, I'm going to go after it. And if I don't get it, I'm still going to bounce back up. If adversity hits me, I mean, I'm not going to just let it knock me on the ground. I'm going to get back up and strive for greatness.

Dr. Caraway: Kane's resilience didn't happen by accident. He's fortunate to be growing up with role models who have taught him how to respond in the face of setbacks.

As we learned in the last season of *Powering Potential*, it takes a village to support a child on the Listening and Spoken Language journey. This village is made up of teachers, interventionists, parents, family, friends, and really anybody who stands up for the needs of a child on the journey. They're vital in helping a child not only learn to listen and speak, but [also helping a child] learn how to become a self-advocate and in Kane's eloquent words, "to strive for greatness."

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. In this episode, our young friends tell us about the practical and emotional aspects of self-advocacy, what it feels like to stand up for yourself as a child with hearing loss, and most important, they share their perspectives on the benefits of being a self-advocate.

Even for those of us with typical hearing, learning to be a self-advocate can be a lifelong journey. For children with hearing loss, the need to become one begins at an early age for very practical reasons.

I'll give you an example. If a child isn't able to ask for help with their hearing technology in school, they'll miss out on important lessons, developmental milestones, and childhood memories. So, what's one of the first steps in learning self-advocacy? It sounds simple, but it's when a child learns to take care of and manage their own hearing technology. Peter tells us about a turning point when his parents left him to his own devices, so to speak.

Peter: My parents did a very good job of that, instilling [in] me [the ability] to keep track of my own equipment. I would always have to carry my own, like, battery package thing, way back in the day.

Dr. Caraway: Do you remember what age you were when they expected you to start helping take care of your equipment?

Peter: I think it was, like, [age] 6 or 7. They trusted me very early on because I feel like I realized that, even at that young age, hey, this is very important stuff. I always realized, hey, that I'm different than everybody else. Nobody else had

cochlear implants or hearing aids on. So I always realized that I was different and that I'd have to behave and act differently than everybody else. And I just got used to it, and I kept up with my stuff, and I have a pretty good record. I'm not going to say perfect.

Dr. Caraway:

Knock on wood, right?

Peter:

Yeah.

Dr. Caraway:

As the saying goes, "Give someone a fish and they eat for a day. Teach someone to fish and they eat for a lifetime." Peter's parents were in the latter group. They taught him how to care for his own hearing devices, and in doing so, helped him become self-reliant. From the age of 6 or 7, he developed a habit that will last a lifetime.

One of the best habits a parent can teach a child with hearing loss is to be an active participant in a morning hearing check. We call it "Take Five" because it takes just five minutes to get your child's hearing technology ready for the day.

The first step is checking to make sure your child's devices are in working order and all the batteries are charged. Second, put the child's hearing devices on them as soon as they wake up. This is critical to developing Listening and Spoken Language. And finally, do a listening check to make sure that your child can hear all the sounds of speech.

Explaining and narrating the Take Five morning routine is a great place to start in helping your child become aware of their hearing technology and how to keep it in working order. Involving your child in the care

and upkeep of their own hearing technology is one way to create a sense of ownership.

Peter found another way of staying interested in his hearing loss journey that involves the “booth.” The booth is what we affectionately call the soundproof room where hearing evaluations take place.

So do you hate going in the boo— What do you think about going into the booth these days?

Peter: Oh, going into the booth is fun. I think it's fantastic 'cause, I don't know if they did this to me when I was a kid, but they now do sentences. I remember they did words, but now they do sentences and words [with] different background noise levels.

Dr. Caraway: Yeah.

Peter: And I love doing that 'cause I feel like it's a competition against myself.

Dr. Caraway: Ah.

Peter: And I have very good scores on them, so I'm always trying to get a perfect score. It's happened once, but most of the times I miss one word or something like that. And then I'm always disappointed, but I feel like it's a good [way to practice.] ... I like doing it.

Dr. Caraway: You rise to the challenge, huh?

Peter: I do.

Dr. Caraway: You think of it as a game.

Peter: I do.

Dr. Caraway:

Yeah.

Peter:

I'm a competitive person, so [I've] got to have fun with it.

Dr. Caraway:

Learning to rise to the challenge in the safety of the booth is a great practice for everyday life. As a child grows up, self-advocacy evolves from the very simple, like charging batteries and turning hearing evaluations into fun games, to the more interpersonal, like asking teachers to use remote microphone technology in school.

So did your teachers automatically put [the remote microphone technology] on, or did you ever have a time when you had to encourage the teacher or ask the teacher to put on the FM device, the microphone, for you?

Connor:

Sure. It was always ... I think it's kind of a hierarchy. You try and take it up with them yourself as the student. If that doesn't work a couple of times, then that's whenever, really, parents really help best. That's what's really going to make or break a kid's success is a parent intervening and helping with that conversation.

And I tell every one of my patients and friends: "If you have a hearing loss, whatever range it is, you really, really should apply for accommodation." Whether or not you had an IEP in high school, accommodations are a whole different ball game that I recommend that everybody applies for.

Dr. Caraway:

IEP stands for Individualized Education Program. It's a plan developed by the school team with the input of the parents to make sure a child receives the support they need to reach

their full academic potential. It's typically reviewed annually and includes notes on any accommodations a child might need.

When Connor was 19, he had to advocate for himself on a whole new level when he realized that his hearing loss had changed, and he needed more help. Let's hear his story.

Connor:

So, I was actually ... I never once was interested in being an audiologist. It never even occurred to me to be one. I was actually a theater major. I was really interested in doing lighting. Interestingly enough, sound design was something I was interested in.

I got accepted into a big college to go to a really nice school for theater. My second week of undergrad, I woke up one morning, I went to put my hearing aids in, and I could have sworn that those hearing aids were broken.

Dr. Caraway:

So that morning when you woke up, you thought your hearing aids were broken.

Connor:

Well, so I had the type of hearing loss that causes fluctuation. So some days it'll be really good; other days it'll be not so good. I thought maybe that could have been it. That also made me think sometimes my hearing aids weren't working very well. I thought, "Oh, I just need another programming, or I just need them to clean something out. I'm just going to swing on by [the audiologist's office], and he can look at it."

It really never occurred to me that I was going to need a cochlear implant because I was past the age that really the ENT [would say], "Okay, it's time to get a cochlear implant." So I texted my audiologist, and he got me in, and they

identified a hearing shift pretty quickly. And that's whenever I expressed to him that, you know, I was interested in pursuing a cochlear implant. We had had the conversation many times before.

Dr. Caraway:

Opting to get a cochlear implant is a big decision. Connor considered many factors when making it.

Connor:

Well, I mean I was already going through so many life changes. I had moved away from home. I had moved out of the town that I had known all of my life. In addition to that, I was becoming an adult. I had my own dorm [room]. I was taking on a lot of adult responsibilities financially, and I was getting concerned that, "How much is the cochlear implant going to cost?"

I was also anxious about, "What's a cochlear implant going to sound like?" And that's what led me, of course, to do what any millennial would do, [and that] is Google it. And that's what really led me to realize there [are] not a lot of good resources out there for a young person who becomes a candidate and needs a cochlear implant. And honestly, it scared me a lot to need to get that, and I was scared that my speech would go away. I was scared that I wasn't going to be able to stay in my program. I was scared about a lot of things.

Dr. Caraway:

How did you overcome that fear or being scared?

Connor:

I did what I do. I read. I prayed about it. I talked with my family, but I've always had a really strong support system. I talked with my audiologist about it. I talked with my Listening and Spoken Language therapist about it, and I

also had my family behind me. They were the strongest support system.

Dr. Caraway:

So that support system that got put in place back when you were four years old that you'd been relying on, you tapped back into them?

Connor:

Absolutely. They were always there.

Dr. Caraway:

Babies born with hearing loss may receive cochlear implants as early as 6 months old. For Connor, who lost more hearing as he got older, the decision to get a cochlear implant was ultimately his. And thanks to his support system, he was able to make that decision with a lot more confidence.

Harper's self-advocacy takes the form of a healthy self-confidence and perspective on her own abilities.

Harper:

I'd say, even though you're deaf, you still have the same abilities as other people physically. Not in hearing, but you could still be way better at [something than] someone else with regular hearing than ... You could be way better at running than them or kicking a soccer ball or acting or anything [like that]. And I [would] just tell [someone with hearing loss] to try new things and [ask a friend,] like, "Do you want to try this with me?" Because I know some people ... like, I never wanted to do anything unless my friends were doing it, like a camp or tennis, like, classes. I would be like, "Is Sutton doing it with me?"

Dr. Caraway:

Yeah, yeah.

Harper:

There's always things that I wish I'd done throughout my life that I thought I wasn't good enough for, like, competitions or just anything.

And I feel like I should have done it. You should always try, and you can't limit yourself, which means you can do so much more than you can imagine. You can't say, "Oh, yeah, I can't do that" and just [decide I'm] not going to do it.

Dr. Caraway:

Harper is absolutely right. With Listening and Spoken Language, hearing loss doesn't have to limit a child's participation in any activity that a child with typical hearing would enjoy. I think her positive attitude is one that we can all learn from.

Peter has a similar perspective on his hearing loss and the unique responsibility he carries out into the world.

Peter:

I ran into some people in college that had hearing aids, and they hid it with really long hair, which, that's your decision. I'm not going to judge you for that. But, for me, that's just not who I am. I want people to see it because people are going to find out eventually, no matter how well you try to hide it. That's just the day and age we live in today. So, I'm just going to be open and vocal about it like, "Hey, I have hearing loss. That's just who I am."

Dr. Caraway:

Well, you mentioned that you were one of the first.

Peter:

Yeah.

Dr. Caraway:

You've been a trailblazer.

Peter:

Yeah.

Dr. Caraway:

Okay. How does that make you feel to be a trailblazer? Why do you like being a trailblazer?

Peter: I love being a trailblazer. I think it's awesome because you get to drive the impression that people have of a massive group of people, and I feel like I at least try to do a very good job of putting out a positive image of [myself] and, by definition, everybody else that has hearing loss.

And so that makes me very proud to be a trailblazer, and I'm very proud to be a successful trailblazer. I feel like I've done a very good job throughout my life of doing things the way a normal kid would, even beyond what a normal kid would do. So I'm sure it's up there because that might be what I was put on this earth to do, but I don't know. I guess I'll find out.

I feel like even if it isn't [what I was put on this earth to do], it's still a part of my story to be a trailblazer and to open people's eyes to what deafness is and what people who are deaf can do. And even if that isn't my purpose, I'm passionate and happy to say that I've done a good job.

Dr. Caraway: You have. You're doing an excellent job.

Peter: Thank you. I appreciate that.

Dr. Caraway: And you'll have multiple purposes.

Peter: Yeah.

Dr. Caraway: But that's a pretty significant message that no matter ... because we all have things about us, right?

Peter: That is true.

Dr. Caraway:

And so, it's about being the best person a person can be and overcoming difficulties or overcoming challenges.

What moves me about these stories of self-advocacy, like Peter's, is the way that being an advocate for yourself so often naturally blossoms into becoming an advocate for others on the journey. As we raise children with hearing loss to stand up for themselves, to understand their unique challenges, and to embrace the joys along the journey, we're developing a whole generation of adults, like Connor and Peter, who have the ability to advocate for others too. To echo Kane's words from the beginning of this episode, I truly believe that our young friends are on their way to achieving greatness.

Check out episode five of *Powering Potential*, where we'll get to know what a typical day in the life of a young person with hearing loss really feels like. I'll give you a hint. It's profoundly normal.

Announcer:

This podcast is a production of Hearing First, an educational endeavor of the Oberkötter Foundation. Be sure to subscribe now on Apple, Spotify, Google Podcasts, or wherever you listen to hear the latest episodes. You can also find the *Powering Potential* podcast on our website, hearingfirst.org, along with additional resources and information about Listening and Spoken Language. Thanks for listening.