

Parent Stories About Hearing Device Use

Many parents are unfamiliar with hearing devices and learning how to manage device use can be overwhelming. In this video, parents share stories about challenges they faced and strategies that helped them.

“After the technology is identified and the child is equipped with it and is programmed or tuned so that it is providing the maximum benefit, another challenge can be especially with young children, keeping the technology on. And by on, I mean literally on their ears. I remember that my son would frequently remove his hearing aid before he had cochlear implants, and he would enjoy holding it, looking at it and sucking on it, and then sometimes he would throw it, and it was a game for us. Well, every minute that is off his head is one minute, right, that he is not listening. And so, that’s a challenge. My mother who is an excellent seamstress made a modified version of some aviator hats. Perhaps, you have seen those. They have a covering that comes well over the ears and then she added a nice chin strap so that we could tie it, and my son wasn’t at that point dexterous enough to untie it and remove the hats and then get at the hearing aids or cochlear implants. We had him wear those for many months until he was familiar enough with the technology and enjoyed having the sound that prevent him from taking them off or from losing them.”

“We did the hearing aid and that one, we, we tried our best, he was ripping it off all the time. And they say, you know, you just keep putting it on and everything, but I will be honest, I really struggled that first like month and a half to get it on and to keep it on. The thing that has helped me the most to put the hearing equipment on and to keep it on and be diligent about it is knowing that these first three years of life and especially the first year is the time when like these neuro synapses are starting and everything and it’s just like the highest importance.”

“Initially becoming comfortable with the technology, I think at first when we got the hearing aid and then the cochlear implant, we weren’t too sure how to even work them. So, I think realizing that the technology is not as fragile as you think. And so, you do not have to be scared to touch it or play with it, sort of figure out how the technology works, and then also just that consistency with keeping it on with caps and toupee tape and little tethers and encouraging and praising your child when they keep it on so that they will do it and then, and then, yeah just lots of praise got us through.”

“Just like figured it out as we’ve gone along and talk to other parents. A lot of people use like the headbands, but our daughter does not like those, so we kind of just have to figure out what worked for her, so it was a lot of trial and error of using you know like the toupee tape, but she did not like that, so I said ok what am I going to do to keep this in, so I finally had just been scouring the internet and other, asking lots of parents what they were doing and I just came across these bows that happened to fit her cochlear perfectly and it’s a really snug fit so it never falls off of the bow, and we just clip that in and go with the mornings and she is set, and she doesn’t have to worry about it falling off or you know putting the magnet back on because it all stays in place.”

“A lot of our family didn’t believe us that my daughter was deaf and what that meant, and so like when she wouldn’t respond and things like that, like they were like well she has cochlear implants, why isn’t she



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answering me? And then like, well like you have to still like stand in certain way in front of her, you have to like get her attention and things like that, they thought that the technology would just fix everything, and it does help a lot, but it doesn't replace everything. The biggest struggle I think was going from like when she was sleeping to like the daytime and if she stayed with anybody else like making sure that they the put the hearing technology on her and starting her out in like a quiet environment, so that she wasn't overstimulated. That was really hard because everybody is like we are talking like, it is fine, we are not talking that loud. And it was just very overwhelming for her at first, and so just educating because nobody meant to like to come off rude or ignorant or anything like that, but they just didn't understand completely."

"Just keep trying and keep them on, I guess I think that was the hardest. It was really hard to get her to wear them, that we just keep trying, keep putting them back on, and it just got better with time and now she wears them really well. So, it took a long time, so just don't give up, just keep wearing them, keep pushing it."

"I think not completely understanding what he hears in noisy environments has been challenging. We'll notice a change in behavior, and we won't necessarily know what is causing it, and I think sometimes it's listening fatigue or too much input from the hearing aids, because they do not filter out all that background noise. I think that that's been challenging, just understanding where he is at, in what, if too much sound is too much for him. Yeah, the same as Kiera, it's just hard to envision what it's really like, I mean, like the closest he can do is just like pop in his hearing aid, so like when we conduct checks, if it's working, it's just a different experience, but on the other hand it's his typical experience, but relaying that to what's quote, unquote like a normal, a typical experience for regular hearing like person, it's just really hard to, like Kiera said like in, what does it really feel like in loud environments for him. Like everyone says, yeah, it's just background noise but what does this really mean or like it's, I think when he gets older, he is probably, hopefully going to explain a little bit better. I think just being aware of, you know, where we are going, if he might need listening breaks, giving him that time away from, you know, too much input like if we are at a crowded place just taking some space, that's helped. I think us modeling kind of if there is a loud environment, Wow! It's loud here! Or something that he kind of gets the feedback, yeah, this is not just loud for me, this is all in the environment so I think we have done this; a lot just pointing out sounds from the very beginning like there is a plane going over us right, there is a train going by us, wow this is loud, it is a loud noise, which I think as an adult you have already learned, basically you kind of blend it out if a train is going by, but I think especially for him with hearing aids, it's just overwhelming. It is just kind talking him through those experiences, I think it has been key, yeah. Just making sure we were, you know, he could see your face when we're talking, and we have attention and that we're, had his attention when we were talking to him and all of these things for good communication that are, it's good for everybody, we are really aware of that piece of it, and I think he surprised us as time went on because we were told he wouldn't be able to incidentally learn and he's shown us that he hears everything, he is always listening even it seems like he is just doing his own thing somewhere and like we are talking and he just pops out like a word we just mentioned so he is always listening."

Other parents and the professionals you work with can help you learn.

"When we were first finding out, I didn't know where to go, and so I called, we were in Nevada, so it was Nevada Early Intervention Services and I called them, they sent me to AGBell, and AGBell is a support group that taught me the different choices I had and they, and they just helped me understand what questions to ask even where to start."

"Learning you know the Ling sounds and learning to listen sounds because I really didn't know any of that beforehand and so just having those resources available to us and people willing to help us and wanting



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to help her and that they are so excited when she makes that progress, and they are just, you know, they back us up and they really love her and love to see her progress.”

“The parents helped me figure out simple things like, Oh! Her little Downs Syndrome ears are really floppy, they are not going to be great about holding the hearing aid on there. It’s just not strong enough, how do I keep the hearing aid on there. They told me oh, try doubles, you know toupee tape, it’s great! You know it’s double-sided tape, it sticks right to her head, and you won’t have to worry about them pulling off. Just little things like that were really helpful from professionals and other parents.”

If you are experiencing challenges with managing your child’s hearing device use or feel unsure about how to handle situations, contact your audiologist. There are also state and national parent support groups, see the resources section for more information.