

The ONE Thing That I Wish I Knew Before Getting my Child Cochlear Implants

Alaine: [00:00:00] Welcome to the Midweek Minisode. This is an unscripted look at what I'm loving this week, what I'm thinking about this week, what we're trying in our home, and any other quick tips, encouragement, or useful information that I can pass on to you to get you through this week a little bit better. This may or may not have anything to do with hearing loss.

Alaine: You will hear things about health and wellness, personal growth, spiritual growth, parenting, and everything in between. It's kind of like a bag of Chex Mix. You never know what you're going to get with this midweek mini sode. I hold to the principle that variety is the spice of life for these episodes. If this sounds fun to you, then let's chat, new friend.

Alaine: Welcome to the Midweek Minisode. I just want to talk to you about, you know, something that's on my mind because a lot of people are coming into our Facebook group [00:01:00] who are considering getting cochlear implants for their kids and yay, I want to, you know, preface this with saying we got cochlear implants for two of our kids and I would 100 percent do it again.

Alaine: So, you know, I believe in the benefit of cochlear implants. I'm going to tell you to ultimately do what's right for your kids, what's right for your family what's right based on what your ENT, your audiologist, and your speech therapist have taught to you about. You have to make this ultimate decision for your kids.

Alaine: But after having gone through this whole process twice with two kids, I understand that this is a big decision. You're putting your child through major surgery. And you're kind of giving them something that is, like, somewhat life altering. And, you know, you're likely making this decision when your child is really young.

Alaine: For us, our kids were babies when we were making this decision. You know, so you're making decisions about this without knowing the future, [00:02:00] and that's a really hard position to be in. So, from one mom to another, I just wanted to sit here and talk to you today about, you know, if you're

considering cochlear implants for your child, the one thing that I wish I knew about cochlear implants before getting them for my kids.

Alaine: And the one thing that I wish I knew was that they are not a fix all for hearing. So let me explain that a little bit more. So when we found out that our first child had profound sensorineural, neural, I can never say that word, sensorineural hearing loss when he was about two months old you know, the audiologist was like, he can't hear, but good news, he's a candidate for cochlear implants and he will be able to be here.

Alaine: You know, I don't think really through anybody's fault, I think this has changed in the last eight years. About how cochlear [00:03:00] implants are maybe, like, presented to parents. I feel like cochlear implants were basically presented to us as a way to, like, completely fix hearing. And we were kind of told or led to believe that, you know, our child would get the cochlear implants, he would have some speech therapy, and then he would be fully talking on grade level by kindergarten.

Alaine: And, you know, maybe that happens with some kids, but that actually was not our experience with either of our kids. So what I wish I knew is that hearing and hearing loss is very nuanced. It's very individual for kids, and I would not go into cochlear implant surgery, expecting it to fix all of your problems of hearing loss and that you're not going to have to do anything else.

Alaine: But just in general, no matter what you do, hearing aids, cochlear implants, no [00:04:00] aiding, having a child with hearing loss, no matter your choice, is going to require some extra input from you for a long time. And it's going to require therapy sessions, potentially learning sign language you know, so many other things that we talk about on this podcast, how you.

Alaine: Communicate at home, you know, how you advocate for your kids, I mean, there's just so much that you are not even aware of when you get that first hearing loss diagnosis when your kids are really young, you figure it out along the way. Hopefully you have a community like ours that can support you, and if not, come on into our community, our Facebook community and we'll support you there.

Alaine: But yeah, I, I just wish that people had told me that it wasn't necessarily going to be a fix all, and that there were still going to be nuances in hearing with cochlear implants. So I'll just give [00:05:00] you information based on my two kids. So, my first child got the cochlear implants at around 11 months old and he has really good hearing.

Alaine: You know, it's been years of speech therapy, which I didn't realize at the time. I literally thought it was going to be like six months of speech therapy or something and he would just start talking because like that's what kids did and their brains are brains are primed for language at that age, which is true.

Alaine: But it's been like eight years of therapy instead of six months. So brace yourself for a lot more therapy in that six months. He was not completely on grade level with speaking. That could be due to like several things. He has a rare genetic condition. Him and my five year old. That caused a hearing loss, but also cause kind of like other difficulties as well.

Alaine: So there's a lot wrapped up for our kids and just the hearing loss. So he, he went to kindergarten and he went [00:06:00] to mainstream kindergarten. He has IEP, he's now going into third grade from summer. So he just finished second grade. And you know, he went to kindergarten, not necessarily on grade level of, you know, speaking but close and he's still not, I would say not as fluent in speaking as another eight year old his age.

Alaine: He's eight now. But he's definitely learning, but he definitely still has speech therapy. Now it's for like articulation and getting certain sounds out that he sees a speech therapist at school like five days a week. Well, yeah. So like every day. So, you know, he's still doing that. So, you know, that's something that I wish that I knew or had just been prepared for, I don't think it would have changed my mind.

Alaine: I think we still would have gone with the cochlear implants because he loves hearing you know, and loves talking and communicating with people. So I think we definitely was still made that decision. I just wish I had been a little more prepared for what [00:07:00] was going to like come up for us in the journey.

Alaine: And that maybe my child wasn't going to. Be on grade levels for speech in a way that like we had hoped or that it was kind of sold to us through cochlear implants. Now our experience with our five year old, we gave our five year old cochlear implants, but he was premature a little bit. He, he arrived on the scene at 34 weeks and he has a small cochlear nerve, which is of course is how the sound travels from the cochlear implant to the outside through the cochlear nerve.

Alaine: So he has a small cochlear nerve and We did know this before getting him cochlear implants, that the cochlear implants may or may not be giving him

full access to sound. So he may be missing certain parts of a sentence or certain parts of a word. It's still hard to tell because he doesn't [00:08:00] talk yet.

Alaine: He's five, he doesn't talk yet. It was always suggested to us from the beginning to use some type of visual system. We started with cued speech. He didn't love it. So we went to ASL signs and that's what we've been doing with him. And that has really worked. He uses ASL signs every day to communicate with us.

Alaine: And we're learning more and more. Also my eight year old does not use ASL. and can't sign for the life of him, he talks. So we have two different kids with cochlear implants who communicate two different ways. So I can guys honestly speak to both of those ways to you guys. You know, so cochlear implants, when you say, well, they fix hearing, well, they didn't really fix his hearing because there's still things even with his cochlear implants that he may not be able to hear.

Alaine: And he's definitely not very verbal. Probably impacted from what he can or cannot hear. He's definitely getting better, but, you know, he has a lot of services at school as well, and has a teacher of the deaf at [00:09:00] school. And, you know, the cochlear implants didn't fix his hearing. Knowing that, would I do it again for him?

Alaine: Yeah, because he does, he is getting some hearing. He wants to wear them. And it was worth it to me and my husband to give our kids access to hearing and hearing the world as much as possible. So I would still make the same decision today for both of my kids. I'm just telling you that I wish that I had known that it wasn't necessarily a fix all for hearing loss, like I was led to believe.

Alaine: All that is to say, if you're thinking about cochlear implants for your child, I'm happy to keep talking to you about it. Come into our Facebook group, ask the questions, email me at hello at raising deaf kids dot com. I'm happy to answer any questions that you have about getting cochlear implants from another parent point of view.

Alaine: I definitely recommend them if you feel like it's right. For your child, and there are so many benefits to cochlear implants and I would definitely do it again [00:10:00] with my kids. Given all that, I would do it again for my kids. All right, I hope this helped you at least start thinking about questions or concerns to take to your ENT or your audiologist.

Alaine: when you're thinking about having the conversation about cochlear implants. And once again, if you have any questions, email me at hello at raising deaf kids. com or come into the Facebook group and I'll answer your questions for you. All right. Have a good rest of your day.

Alaine: Did you know that I have a free community of women just like you, busy moms who want to help their kids learn language faster while still getting all of the things done in the house each day. In the community, we share strategies to help our kids learn language faster and lean on each other for encouragement and support in this up and down journey of hearing loss with your kids.

Alaine: If you haven't found your community yet, then welcome home, mama. Come join us at facebook. com slash group slash raising deaf kids.

Alaine: [00:11:00] Hey mama, I hope you enjoyed today's episode. If so, would you take 30 seconds and subscribe to this podcast? I never want you to miss an episode and to be without valuable information to help you and your family. Also, please leave a quick written review for the show on Apple Podcasts. It lights me up to know this podcast is helping you.

Alaine: Now go check off the rest of your to do so you can love on your family today. And I'll meet you here every Tuesday and Thursday for podcast episodes to support your whole family in language learning. Ciao mama.