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Christy: You are listening to the Love and Language podcast where we inspire hearing parents of deaf children and remind you that as long as you are giving your child love and language, you are doing a great job. Hi everybody. Welcome back to the Love and Language podcast where we aim to inspire, educate, encourage, and build community.

Christy: For hearing parents of deaf children, I'm Christy

Beth: And I'm Beth, today we're diving into the world of cochlear implants.

Beth: We'll talk about what they are, how they work, and some factors to consider when deciding whether they're the right choice for your. . Remember at Love and Language, we think as long as you're giving your child love and language, you're doing a great job.

Christy: Exactly. So when we get started diving into this topic, we just wanna make doubly sure you guys understand that.

Christy: But as cochlear implant parents, this was something for us that when if you don't know about cochlear implants, it's the very basics to find out what they are and how they work because they are a little tricky to understand. Even just making this podcast [00:01:00] episode today, Beth, I learned even more about what they are.

Christy: So let's just start with the basics. A cochlear implant is an electronic device that provides a sense of sound to people who are profoundly deaf or are severely hard of hearing. and they work different from hearing aids, which is what a lot of people initially think of when we talk about hearing support, hearing aids amplify sound, which is different from how cochlear implants work.

Beth: Yeah. With hearing aids, you have to have some level of hearing in order for it to be amplified. And the way that cochlear implants work is they bypass that damaged part of the ear and go directly to the auditory nerve. So if you think about it, kinda like a detour around a traffic jam where that traffic jam represents the damaged part of the ear.

Beth: They're just working around

Christy: Oh, I actually love that analogy because it does make a lot of sense but how exactly does that electronic component of it work?

Christy: And so we are going to use a resource from cochlear.com to explain this this has nothing to do with [00:02:00] brand preference at all. It just is the reference that I have in my favorites folder on my computer but a cochlear implant has two main parts.

Christy: There's the external component, so that is what actually hooks around the ear, or if you have one of the off the ear devices. There is a piece that can magnet directly onto the head, which we'll get into the magnet part of that. And then they have the internal component that is surgically implanted underneath the skin.

Christy: And when I say this, Beth, I bet you probably have a same similar feeling about this. I have to clear up a common misconception that getting a cochlear implant is having brain surgery.

Christy: I even thought that initially that this was a brain surgery it is not a brain surgery.

Beth: The way I like to explain it is that they make that incision behind the ear and they're literally just lifting that skin and muscle to place the other piece outside the skull. So in order to, get to the brain, you have to go through the skull, which is not [00:03:00] happening. And yeah, I think a lot of people when they have, hangups or issues with consent and cochlear implant surgery, they feel that it's brain surgery, which is not true.

Christy: I don't even think when we were scripting out this podcast today, what we wanted to go over that I talked about the incision, but when you brought that up, I did wanna share a little bit about our experience with that. Because the other misconception that I had when we found out that Charlie was deaf and we had decided on cochlear implant surgery, I thought that she was gonna have a scar all around her head.

Christy: Maybe at earlier first implantation surgeries. I don't know what those scars look like, but today in modern day and age, we're recording this In 2023, Charlotte had her cochlear implant surgery in 2018, in her incision it's maybe an inch and a half right in the crease of her ear. They do think of the aesthetics of it as [00:04:00] well. It's just something that has been kept in mind as they have

made this surgery more available and just more common.

Christy: But most of the incisions are in the little crease in the ear, so you can't even see it. I have pictures on my social media if you scroll through my highlights, somewhere of Charlotte's incision because you can't see it. It's not visible. Just wanted to clear that up because I was worried about it.

Christy: Yeah.

Beth: Yeah. I'll have to look at his again and see what they look like now, but that tells you how minimal it is. He has short hair and I don't even see it.

Christy: I imagined it as almost Frankenstein is what I thought

Beth: The other thing with incisions is that I think sometimes parents have the fear that it's gonna change, like the way that their kids' ears lay. And I've heard, parents that right after surgery, they feel like their child's ears may stick out a little bit more.

Beth: I think that has to do more with the swelling and the actual, surgery recovery than it does anything that's permanent. At least in my experience. So I just wanna mention that too.

Christy: You just unlocked [00:05:00] a memory of the early cochlear feeling days.

Christy: Cuz I remember worrying, I was like, oh my gosh, he's gonna have pokey out ears. Which in the grand scheme of things, whatever, it's not that big of a deal. But, we're raw and honest about the random stuff that crosses your mind that you think about and Google and spend time looking at and Wow.

Christy: Yeah. You just unlocked a memory there

Beth: So back to the kind of the way that cochlear implants function. So that external piece is \ made up of a microphone, a speech processor, and then a transmitter. So the microphone is what picks up the sounds from the environment.

Beth: The speech processor like selects, arranges those sounds, and then the transmitter is what sends those process sound signals to that inside piece.

Christy: So the internal part includes a receiver and an electrode array.

Christy: And I just remember electrode array sounding so. I don't know, complex, which I guess technically it is, but we're gonna try to work it down to you a little bit easier. But the receiver converts the sound signals into [00:06:00] electrical signals, so those electrical signal signals are sent to an electrode array, which is like thin, flexible wire that's inserted into the cochlea.

Christy: Your cochlea is a spiral shaped part of the ear, so that wire can go in and curve around through those curves in order to access the part of the ear that it needs to. I'll also put a little note here that some people don't have the same shape cochlea. Charlie has something called a Mondini malformation, so she

Christy: doesn't have one of the twists of the cochlea, which actually can make a difference in how this electrode array can efficiently get those electrical signals to the brain in order to be processed into sound. So we'll talk more about candidacy and everything for [00:07:00] cochlear implants, but I just think it's important to remember that not everybody's anatomy is the same and that cochlear implants might not always work exactly the same per every person.

Christy: The electrode array and this internal part is going to take the sound and convert it into an electrical signal. .

Beth: Yeah. And then those signals are what stimulate the auditory nerve. Which you probably, if you're in the hearing aid trial portion of things right now, have been told that hearing aids are still important, even if they're not necessarily helping your child here because they're stimulating that nerve.

Beth: So that auditory nerve is what sends that information to the brain. So sometimes I actually tell people Cooper literally hears with his brain, which is crazy if you think about it. \ he doesn't hear it with his ears. Because the brain is what interprets those signals as sound and then allows that person with the implant to essentially

Christy: hear.

Christy: Exactly. So I love that you put it that way that he hears with his brain. Because we should preface the episode and say, this is not a cure [00:08:00] for deafness. It's not a cure for not being able to hear, it's just a different mechanism to give access to sound.

Christy: Think of cochlear implants, like a special phone for our ears with a regular phone. When you're talking to a phone, it picks up the sound and it turns that sound into a signal, which travels through the air, through the telephone

poles and turns that signal into sound that you hear over the phone.

Christy: So a cochlear implant is the same way. You have the microphone that the sound that you and I, whoever are speaking to our children, they're in the external environment, goes through that microphone and then it travels through their little I guess telephone poles that are what this device is on the inside and then their brain is able to interpret those signals as sounds.

Christy: So just like how you would hear somebody talking on the phone, cochlear implants are how other people who have this device can make hearing and it's not always perfect but it is a way to help them hear better I think what's interesting that we [00:09:00] should talk about is how people hear with cochlear implants because. Beth and I don't have firsthand experience of this, and our children are still pretty young to be able to share with us exactly what that sounds like.

Christy: But we have also had a lot of opportunities to talk to adults and children who have cochlear implants who can explain that to us. Some of

Beth: the simulators out there are a little Scary sounding to us, very robotic and electronic. And then I've talked to adults who say that's not at all what it sounds like. So I think that's important too, is to note everybody's experience is different or their perception of what sound

Christy: is exactly.

Christy: Even with the terminology that surrounds cochlear implants and what they are and then of course the simulators that make it sound almost robotic.

Christy: The cochlear implant recipients that I have talked to describe it. I always think natural is a word that they say a lot. Even just listening to Charlie sing, her pitch and tone is really [00:10:00] nice and very accurate. Obviously everybody has different experiences and we cannot speak firsthand on that, but just wanted to give a little reassurance for parents who do have these myths and just different ideas about what it may sound like. It's amazing that technology is what it is and can bridge this gap in our ability to communicate. But let's just discuss the factors that you have to consider when deciding whether or not a cochlear implant is right for your.

Beth: .

Beth: So one of the main important factors is the child's age. Lots and lots of

research shows that children who receive cochlear implants at a young age often have better outcomes when it comes to language development. And then that's because, those brains are more adaptable. We talked about this a little bit and past episodes like a sponge that's just, soaking up.

Beth: And that the earlier the better when it comes to that.

Christy: Yeah. And. That's tying together what we were just talking about with how it sounds and age and how somebody who's late [00:11:00] Deafen might have a different experience. Did you watch Moonlight Sonata on H B O, the documentary? No. Beth, you have to watch it.

Christy: Oh, it's so good. Moonlight Sonata is a documentary and it's beautiful, first off, but the woman who made it, her parents are both deaf.

Christy: And were in. Seventies, eighties at the time of filming, and her son was also born deaf. She's hearing. her parents grew up using sign language, but also had the experience of being sent to schools and programs that tried to build speech, but without the same hearing technology that you have now.

Christy: So a very different experience to what our kids have and they decided to get implants later in life, like in their sixties. And then she has her son [00:12:00] who gets his cochlear implants when he's three years old it's really beautifully done because it's like deafness in three measures.

Christy: So it's supposed to be like Beethoven's Moonlight Sonata and the whole thing follows her son learning that piano piece for recital. The older adults, her parents in the documentary, talk about how the sound is for them.

Christy: Because the adaptability of their brains had 60 years of being deaf and interpreting visual language. Yeah. And then all of a sudden to have that electrical signals trying to be converted to sound with the cochlear implants was processed a lot differently.

Christy: So they talk about how it sounds for them, and then her son also shares how it sounds for him. You've gotta watch it. It's so good. It's very powerful.

Beth: We should do a whole episode on good, like media, like movies and

Christy: documentaries. Oh yeah. Oh yeah. Especially cuz I feel like there's been so many in the [00:13:00] last few years especially with representation,

Christy: Just speaking of that adaptability that Beth was talking about when we were talking about age being a factor, that's why I wanted to bring that up because you can see the difference between somebody getting it later versus getting it earlier.

Christy: Research just proves that age does make it a lot easier the earlier you can get it done. So another factor is the child's amount of hearing loss. So cochlear implants are typically recommended for children who have severe to profound hearing loss who wouldn't benefit from a hearing aid. It's a little bit different in recent years, but especially when Charlie got her surgery. the mechanism, how they put the implant in and how it works, it would take away all of your residual hearing. So if you had any hearing, you are basically consenting to losing that with the surgery, that would be a big risk.

Christy: If you have [00:14:00] significant to profound hearing loss, you're not able to access those sounds the same way, so you're not really losing that benefit. But yeah I guess I can't speak to a lot about the mild to moderate hearing loss

Christy: I think you mentioned something similar to it when you were talking about Cooper's journey, but it almost felt like a relief or the pressure was taking off. That Charlotte had profound hearing loss cuz it was not a wait and see. It was just , this is the option that's gonna give her sound because of how deaf she is.

Christy: So I could understand that it'd be a little bit more of a difficult decision and more to consider if you're not in that range of hearing loss like Charlotte was. So I would like to hear somebody's perspective on that out there.

Christy: But your audiologist can determine if you are a good option for that. We are definitely not the medical experts on that.

Beth: And another one of the factors is just the overall commitment that comes with the therapy and support after implantation. Children with cochlear [00:15:00] implants, they do need that ongoing therapy and support to help them develop their listening and spoken language skills.

Beth: It's a more intensive work than a normal hearing child, which you're still putting work in with a normal hearing child. You're just not really thinking of it. Cause it's that like natural. , communication, building with your child. But that's where I like to say it's just never ends.

Beth: Like Cooper doesn't do a lot of like traditional therapies right now just because his speech is so well developed at this point. But we do serve and return constantly, ever since he was little, just that constant feedback and replying to what he's doing and letting him reply and there's just a constant.

Beth: Verbal narration and conversation going on when we're in the car, when we're at home. Sometimes I catch myself and I'm like, why? Why are you talking right now beth? Just you, you miss silence sometimes. Let him just be in a silence. I think it just gets so ingrained into you if it's something that you really run with that it's hard to stop even.

Beth: And then I, like I said before, then I wonder why he talks so much. . .

Christy: Exactly. It's [00:16:00] important that you bring that up as one of the things to consider I remember being a little bit overwhelmed at first when they talked about the commitment that it takes, they never said to me, get a cochlear implant and it's going to cure your deaf child.

Christy: It was never presented to me in that way. It was presented as this is the amount of hearing loss that your child has. This is where they can reach sound. If you want speech and you wanna be able to benefit from hearing certain speech sounds, cochlear implants would be the option. Here's what you have to do to prepare for the cochlear implant.

Christy: Here's what you have to do afterwards. It sounds like a lot, and I love how you explained Beth, like over time it doesn't feel like a lot because it does just become natural and how you and your family communicate. But I imagine there might be situations where maybe they don't have the luxury to be home with their kid all the time and you have to worry about, [00:17:00] are the care providers doing these same sort of exercises with your children or are they developing speech in the same way?

Christy: Everybody has different experiences and different situations going on

Christy: did you ever have to deal with

Beth: that?

Beth: . Yeah, I've always worked since Coop was a baby, he started daycare pretty early and it's hard to hand off that responsibility to somebody else. That essentially that's why we left our first daycare.

Beth: Whenever I would pick him up, he never had his implants on they would just never try to put them back on throughout the day. Usually we, like I said, I've given him a ton of autonomy with that. But we'll try it again after 10 minutes, we'll try it again when it quiets down and they just weren't, and , our next daycare was a little bit better.

Beth: And then who he's with now, he's with a one-on-one provider, which is great. And she's also a special needs mom, and she had the welcome to Holland Poem on her table when I went and met with her and I, oh, written a story about her family years ago. So anyway where we are now is good.

Beth: She uses his Roger mic. She learns some signs. She takes him to preschool where his early intervention [00:18:00] team works with him. So it's really good. He's always been with Brandon's mom twice a week too

Beth: and they obviously were on board. It's their grandkid. But yeah, I think it's hard when you want to make sure that other people are following the same guidelines, and I should put this on our website actually. When he was in daycare centers, I made a cheat sheet for his implants.

Beth: And obviously this would only apply to probably cochlear, but just what the different lights mean and how to troubleshoot those and that kind of thing. So I highly recommend that if it's, you feel like it's something that they might not know how to deal with it if it's blinking orange rapidly or that kind of thing.

Beth: So I found that helpful and it's hard to delegate some of that when you want to make sure that you're doing everything you can.

Christy: It's hard enough just finding good childcare that are just compassionate and caring for your kid and disciplining them in a way, or, with that or with your values.

Christy: Then when you have to add in a whole nother element of the additional needs and communicating

Christy: it's a commitment and it's [00:19:00] not always the easy route, but then it just becomes very natural. We just touched on that because that's our experience going through it and it's important to just consider what your individual needs are, what your family's values are. All kids are unique, obviously even Beth and I have very different experiences with it, so it's never one size fits all.

Christy: But that's why it's just having open and honest conversations before you have this surgery. Be ruthless if you have a question before the surgery is the time to ask it, we should put together. And people please chime in with any questions that you think are good to ask an audiologist or the care team before getting a cochlear implant or things to consider that

Christy: maybe we wouldn't consider based on our lifestyle or different things we've been through. I think just having all these questions in mind when you go to all of your appointments and decide if a cochlear implant is going to be a good choice for you and your family when we were talking about being a candidate and it not being one size fits all I don't think we did touch on this. I hadn't [00:20:00] mentioned how Charlotte has an anatomical difference with her cochlea and it doesn't make her not a candidate for the surgery. Obviously she's has it and she gets almost a hundred percent benefit from it, but there are certain electrodes that we can tell when they're mapping aren't being processed as efficiently as maybe somebody who didn't have that difference with their cochlea.

Christy: as we've been saying, how the cochlear implant works, it's the nerve that is sending that signal to be processed from the brain. So if you do not have that nerve, the auditory nerve, then the cochlear implant is usually not a route for you and you might not be a candidate for cochlear implant surgery or your child might not be a candidate for cochlear implant surgery.

Christy: Those are just things to keep in mind. That's why they have you do the MRIs and the CT scans before surgery. So any anatomical [00:21:00] differences like what Charlie has or

Christy: not having a nerve. Sometimes it's just the nerve is smaller than an average size auditory nerve and that could also be one of those gray areas where it may or may not give you response. So when you are considering a cochlear implant, it's, there's far more to consider than just it being black and white.

Beth: Yes. Is the case to most of life. .

Christy: So hopefully that just breaks down a little bit easier what a cochlear implant is.

Christy: I was joking with Beth before we hit record because it seemed like such a cut and dry topic to talk about that we didn't think it'd be a long enough podcast episode, but I was like, you and I definitely always get off on a tangent on something about all of these topics because of our lived experiences and all

of the differences that we've had throughout the our journeys.

Christy: So thank you for listening to today's episode.

Christy: We will be doing a series soon that breaks down everything about the [00:22:00] cochlear implant surgery and. . I think that Beth and I are both hoping that's something we can pre-record and have an a bingeable episode.

Christy: So we will work on that. And yeah, until the next time, as long as you're giving your child love and language,

Beth: you're doing a great job. Thank you guys for listening.

Christy: Okay. Bye guys.