

Powering Potential Podcast

Episode 1: The Diagnosis

- Dr. Teresa Caraway: Mercedes and her husband looked forward to having a baby for years: dreaming, planning, taking note of other parents' advice. So when she found out she was pregnant with her son, they were thrilled.
- Mercedes: After eight years with my husband, we [wanted] to have a kid, and everybody said, "O.K., motivate your kid. Put [on] music and talk to him." So I really enjoyed that part in my pregnancy. I actually enjoyed my pregnancy.
- Dr. Caraway: Her baby Kevin was everything Mercedes had hoped he would be. Shortly after his birth, and while they were still in the hospital, he received a routine newborn hearing screening.
- Mercedes: I saw that red part on the crib, but I didn't know what it means. I didn't know what it means. I asked, "What does this mean?" And they said, "Oh, it's because we did the hearing test, and he didn't pass the test." He failed.
- Dr. Caraway: The red dot meant that Kevin had failed the screening test. Mercedes and her husband quickly took action. They brought Kevin to a qualified pediatric audiologist for a comprehensive diagnostic evaluation. There they learned that Kevin, the long-awaited baby Mercedes had such big plans for, was deaf.
- Welcome to *Powering Potential*, a podcast from Hearing First, where we explore the unique joys and challenges of raising children who have hearing loss. I'm Dr. Teresa Caraway, your host, a mother, and a speech-

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language pathologist specializing in Listening and Spoken Language.

For so many parents, a diagnosis of hearing loss comes as a complete surprise. It can feel like the end of your hopes and dreams for your child, but it's actually the beginning of an incredible journey— a journey full of hope, joy, and opportunities. I'm here to share the stories of families who are teaching their children, who are deaf or hard of hearing, to listen and speak.

We'll get to know Mercedes and her children Keily and Kevin, Phin and Daily and their son Roark, Ketty and her daughter Nura, and Matthew and Sarah and their daughter Fiona.

In this episode, we'll chat about the experience of receiving the diagnosis that their child has a hearing loss. Hearing loss is a more common health condition than you might expect. It occurs in about three in every 1,000 babies born, and it can happen for a variety of reasons. Many times, we never really know why the child is deaf or hard of hearing.

Let's meet Matthew and Sarah. Their 3-year-old daughter Fiona is about to be an older sister any day now.

Can you take me back to when you first found out you were expecting, and what your thoughts were, and what your thinking was?

Sarah:

Yeah. We were just really excited. I'm the oldest in my family, so she was the first grandchild on my side and the second on Matt's side. So everybody was really excited waiting for her to come.

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- Matthew: Yeah. We were just super excited, like any other parents. It was a very exciting time. It allowed us to really think about our family. It was such a hopeful time for us both. It was really great.
- Sarah: And we had no idea what was coming. I mean, just in terms of becoming parents. First-time parents, you just, you think you know, and you wanna go out and buy all this stuff to prepare yourselves, but there's no real way to be prepared.
- Dr. Caraway: Yeah, it's one thing to just be prepared to be new parents, right?
- Sarah: Yeah.
- Matthew: Mm-hmm (affirmative).
- Dr. Caraway: And then, so Fiona's born, and then tell me what happens after she's born.
- Sarah: So we were in the hospital, and they come in and do a bunch of different screening things, for their heart, and they did do the newborn hearing screening. I think you're supposed to say, "She referred," not that she failed. Basically, it means the same thing. She referred for another test.
- It was kind of ambiguous, I would say. You know, not a great feeling as a new parent to have your child fail some kind of test. But still, we had no resolution. We didn't really know if anything was wrong or not.
- Dr. Caraway: All babies should receive a newborn hearing screening in the first few days of life. It's a routine yet critical part of care in most birthing facilities. If a baby fails the screening, they are

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referred to a pediatric audiologist for a comprehensive hearing evaluation or diagnostic testing. This usually includes other tests such as an ABR, an Auditory Brainstem Response. The ABR test tells us how the inner ear, called the cochlea, and the brain pathways for hearing are working. Or the diagnostic testing for the baby might include an OAE, otoacoustic emissions test, to measure how the baby responds to sound waves. The diagnostic evaluation is a complete hearing test. If a baby has a hearing loss, this complete testing can diagnose the type of hearing loss, the severity, and possible treatment options.

Fiona was referred to have an ABR a few days later.

Matthew: So the first time that Fiona didn't pass this screening, it was just Sarah and I. So we woke up, Sarah was sort of—

Sarah: I don't know if I woke up; I was still awake.

Matthew: Sarah was half out of it. I had slept on a chair, basically. They came for the ... a little while later to follow up. I remember my sister was with us for the second time she failed. And we all kind of looked at each other, and it was this sort of uneasy feeling. The hospital staff is very much trying to get their job done, whereas we're like, this is our brand new child, and every little thing matters to us. So we were not on the same page. Sarah and I were very worried, and the hospital staff was very much like, "O.K., well, probably it's nothing." It felt very much like we had different levels of concern about the whole thing.

Sarah: Yeah, and I think we asked them to come back a few times, **and do [the test] a few times.** So

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she referred a few times. And then they told us, "O.K., in a month come back to an appointment," basically, "and we'll do it again." So we kind of just existed with not knowing if anything was wrong.

You know, meanwhile, we had a newborn. I would say she wasn't the easiest of newborns. She didn't really sleep that well. I was trying to learn how to breastfeed, and it wasn't going well. I had to have a lactation consultant come help me. She lost 10 percent of her body weight, and we were like, "Oh, should we give her formula? Should we not?" There was a lot of stuff going on also in the interim, plus that extra worry on top of it.

Dr. Caraway:

So wrestling with all the new parent things, adjusting to having this new little one enter your lives that you've been excited about, but it dramatically changes things.

Sarah:

Yes, absolutely.

Dr. Caraway:

Things that you thought you were prepared for, and things you had not prepared for at all. Yeah. So you're dealing with all that, and you kind of have this thing about the hearing screening hanging over you. So where were you with that at this point?

Matthew:

You know, one of the things that we did a lot was we tried to see if she could hear us, which I think was really funny because I think most newborns are not really responsive to hearing anyway, but we were very focused on trying those little things, and seeing if she could hear us.

Sarah:

You know, I remember there was one day where I was taking a walk with my sisters, and

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I had Fiona. She was like 2 weeks old. She was in the carriage. We were walking down the street, and a fire truck came by. It was so loud, it had all its sirens on. She was sleeping in the bassinet of the stroller, and she didn't even twitch. I kind of was like, oh. I think that was when I was pretty sure, and some of my hopes that it was a false positive were a little deflated.

Matthew:

I think that first month when we weren't sure, we still were in fixing mode. We were in "trying to find [a] solution" mode. We were researching. I think we were anticipating that in a month we would find out that this was a possibility. We did a lot of research. We went on the internet. We looked at a lot of videos, and we really used that time to kind of prepare ourselves for that possibility.

Dr. Caraway:

Sarah and Matthew aren't alone in their frustration. So many families encounter providers who downplay the possibility that their child might have hearing loss. But insisting on getting a diagnosis as soon as possible is crucial. Hearing loss is considered a developmental emergency. The critical window for language development is between birth and 3 years old. In order to grow neural pathways for listening and speaking, a baby's brain needs access to sound right away. Delaying a diagnosis, by even a week, makes a big impact.

Daily and Phin found themselves in a similar situation as Matthew and Sarah. Today their son Roark is a vivacious 4-year-old with a love for reading and superheroes. He was born at eight pounds and 11 ounces, after what his mother Daily says was a pretty uneventful pregnancy.

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Daily: He seemed perfect and healthy. He is perfect and healthy. At 24 hours, they do a newborn hearing screen, and he didn't pass. They told us, "Oh, lots of babies fail. Don't worry about it. You just need to get retested." And they retested us, and we left. We kept doing it at the pediatrician's office.

Phin: Nobody ever seemed concerned, though, that he wasn't gonna eventually pass.

Dr. Caraway: Yeah. And so what was your thinking during that time, when he first failed newborn hearing screening, and then the second one, and people were telling you, "Don't worry"?

Phin: I was sure it would work out fine.

Daily: I sobbed after every test.

Phin: Daily was sure, and she said she just knew. And, you know, I didn't just know.

Daily: The other thing is he had trouble regaining his birth weight a little bit. And he had jaundice.

Phin: He had jaundice.

Daily: So were putting him in the sun. We were at the doctor every other day just for the jaundice test; I don't even remember what that is now. Plus, I was having to pump, and I was having breastfeeding consultants in. So it was a chaotic time anyway. We just had a lot going on, and each time we went to the doctor for one of these other reasons, they would redo a hearing screen, and he would fail.

Being an aggressive mother, I called a million places to get... We had a follow-up appointment with some kind of audiologist or

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ENT who did an initial test. He failed there, too. And then they referred us to a sort of audiologist at one of the local hospitals that did an ABR, which is the more definitive test for hearing loss. And that happened at three weeks.

Dr. Caraway:

I mean, having a new baby is juggling enough, right? And how dramatically it changes everything, and all the things that you thought you were prepared for, but you're not. Tell me about what was that like going to the ABR, and what happened during the testing?

Daily:

I mean, we were in a conference room. We weren't even in a sort of traditional testing [room], but that's where they did it at that... just anywhere that's quiet. I feel like he nursed or slept through most of it. I mean, he's so little at that point. It's a really long test. I feel like it took forever.

I think my husband and I were trying to sort of read her facial expressions to see if she's sort of giving us a thumbs up or any look one way or the other. She was kind of stone-faced, which probably in retrospect was because she knew pretty quickly she didn't have good news. At the end of the, I don't know, hour-and-a-half, maybe, that the test took, she told us that it was permanent, severe, or at that—

Phin:

Moderate to severe.

Daily:

... point it was moderate to severe sloping sensorineural hearing loss, which I was like, all I heard was like, "Blah, blah, blah, blah, blah, hearing loss."

Phin:

Permanent.

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Daily: Permanent hearing loss, right. Those are the words that you register. I mean, honestly, we had to go back, I think, a few days later, because I didn't absorb anything else that she said, any of the other information about hearing aids. It was just a blur.

Dr. Caraway: Those first few moments after a hearing loss diagnosis are full of emotion. Since 95 percent of babies with hearing loss are born to parents with typical hearing, most families aren't prepared for the news. It comes as a surprise and is shocking. But even for parents who are aware of the possibility, getting to a diagnosis isn't always easy.

Ketty: I became a mother very late in life. I was almost 36 when I had my daughter, one month shy from 36, and I was pretty stressed. And then I'm like, I need to relax. It's my baby, and no matter what comes, it's my baby. I'm gonna love her. I'm excited. So the pregnancy in that sense was a little bit stressful. I used to get sick a lot.

So when the doctors kept saying, "Something might be wrong. You know, she looks small. You're older, so you have to be ready for anything." My answer always was, "Well, my job will be to open paths, so whatever her abilities, whoever she is, she will become." And then that's how I approached it. But most of my thoughts were about, oh my gosh, I know I'm gonna be almost 36. I'm almost 40 having this baby, but am I sure I know how to keep her alive?

Dr. Caraway: There's so many unknowns when you're waiting, and when you're expecting. It's such mixed emotions. Like you say, "Can I even

keep a little one alive? Do I know how to care for someone?" Yeah.

Ketty: I think everybody thinks that way, but I'm like, yeah, I just want to keep her alive. And also [give her] the gift of confidence. I always said, "Just sort of, like, smooth the path, so she can walk it." The greatest gift I can give my daughter is the gift of confidence. If I can manage for her to believe in herself, no matter what the circumstance, I'll be pretty satisfied with the job.

Dr. Caraway: Yeah. So that's how you're entering into her birth and her arrival.

Ketty: Yes.

Dr. Caraway: So she enters this world, and you finally have her in your arms.

Ketty: Well, the first question after looking at her in awe, and understanding for the first time what truly being in love was... I thought I knew, but at that moment I said, "Oh, no. You know nothing." I look at her physically. She was just [a] perfect, beautiful, young thing. I started asking out loud, "What is her score? Did you do the hearing screening?" I was so focused on that.

Dr. Caraway: Ketty works in early intervention. She helps parents find the services they need for reaching developmental milestones. When her daughter Nura was born, her mind went through the checklist for healthy babies.

Ketty: I mean, I've been working in early intervention for so long that I think you have an inclination even with your own children to ask all the right questions when you shouldn't really, so you're

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not more stressed at that moment. But I did ask, and everything went very, very well. She was born incredibly healthy. She passed the hearing screening as well. I was sort of, like, immediately at peace for a moment and just went home.

Dr. Caraway:

So you were going down your checklist because [of] your background. You've worked in early intervention and supported parents along the journey as they sought services for their children of all kinds of challenges. So you're going through your checklist.

Ketty:

I was.

Dr. Caraway:

She passed her hearing screening, so you leave the hospital and go home.

Ketty:

Yes.

Dr. Caraway:

And tell me about life after arriving at home.

Ketty:

Well, at first it was great, except she had acid reflux, which happens to a lot of babies. So that was [the] first true experience about having a screaming baby for hours and hours. I'm like, "What is going on?" But we took care of that. But she was very healthy, growing really, really fast.

It was not until she was, I would say, 5 to 6 months that, in my mind, in my eyes, I insisted that there was something off with Nura's connection with me. Then I started thinking maybe there is, sometimes there's no good initial bonding with mother and child, even though I'm with her constantly and very interactive.

- Dr. Caraway: So what was it that was off to you? What were some of those things that caused your gut to say, "Wait a minute," to kind of be concerned a little bit?
- Ketty: Yes. You know when you're looking at someone but looking and not reacting?
- Dr. Caraway: Mm-hmm (affirmative).
- Ketty: Even though she was so young, I would expect more consistently that there would be sort of like a social-emotional reaction to me, a more frequent smile. Or if I'm talking to her, to at least see a change in expression on her face. Something that shows me that she's listening to me, that she's perceiving something from my tone, and what I'm trying to convey. And that wasn't always there. She wasn't really reacting to me, or the environment, the way I would expect her to always do that.
- Dr. Caraway: Babies like to zero in on your eyes and your face. And you know that they're engaged, and they're connected with you. You know that they may stop and start their little arms and legs kicking when you start singing or stop singing. Yeah, so you—
- Ketty: And she would sort of—
- Dr. Caraway: [crosstalk] Yeah.
- Ketty: ... do that, but it was not as intense and consistent.
- Dr. Caraway: O.K.
- Ketty: So I started talking to a few friends, being that I was in the field, and some clinicians. I asked the pediatrician, of course. Everybody said,

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"It's fine. She's great. She's reaching all her milestones. It's all in your head because you work in this field, and you're too concerned about development."

By the time she was close to 9, 10 months, I insisted, "She's not developing well." Nura doesn't imitate many sounds. Still, I feel like the connection when you spoke to her was absent because although I knew she was seeing me, we were not together in that connection.

Dr. Caraway:

In the search for answers, Ketty took Nura to see another early intervention specialist— this time, her boss.

Ketty:

As soon I walk into the room, and she says, "Hi, Nura. How are you?" And she looks at her and smiles. She says, "Your daughter is deaf." I'm like, "What?" I was very shocked, in a not very nice way, because I'm like ... I thought she was very abrupt, and she was. "What do you mean she's deaf? This cannot be true. She can hear me."

And she looks at me, and she says, "You know, let me rephrase. Yes, she responds. She cannot hear you the way you wanna hear each other. I think Nura needs a hearing test." And I'm like, "But she passed a newborn screening." And she said, "She needs a hearing test." And then she suggested, "I have a really good speech therapist. I want her to evaluate her because the responses for a 9, 10-month-old are not that great. And she also understands children with hearing loss. I want her to see her."

I remember that was the first time I couldn't go with her to an evaluation in her life. The first and only. Her father took her. I was present via

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phone. As soon as she walks in, the speech therapist introduces herself. She's talking, and the first thing out of her mouth is, "I have to tell you, I'm confident your daughter doesn't hear me well. The way she's responding to my sounds, she's not hearing in a normal, typical way. She needs a hearing assessment at this time."

Dr. Caraway:

Ketty was referred to an otolaryngologist. This doctor had a particular focus on the ear.

Ketty:

Effectively, not only did she have hearing loss, it was not just a mild, little thing. She has indifferent frequencies, and according to the ear, anywhere from mild to moderate, to moderate to severe, hearing loss. So it was quite significant, and it was bilaterally.

Dr. Caraway:

Ketty's persistence in getting a diagnosis for Nura paid off. Today, Nura is a happy and bright 12-year-old who wears hearing aids in both ears. She goes to a mainstream school with her hearing friends and plays chess competitively. In fact, she's nationally ranked and has big dreams for her future.

Through the experiences of these families, we've heard that the road to a hearing loss diagnosis can be bumpy and full of emotions. But what's most important is that these parents were persistent and insistent on taking action for their babies. Today, all of them are thriving and reaching developmental milestones, just like their hearing friends.

I want to end with Ketty because I think her story offers an important lesson: Our children may start the journey to listening and speaking at different points in time, but that doesn't mean a family will not get there.

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Check out episode two of *Powering Potential*, where we'll learn what to expect during early intervention.

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Thanks for listening.