



Coping and Planning

When your child was diagnosed with hearing loss, you may have found yourself being exposed to and learning new things, you might not have expected, experiencing what many parents call the “journey” of technological, educational, and even emotional ups and downs. This is normal, and you are not alone. Understanding common emotions and being able to plan for expected services, can help you plan your schedule, reduce anxiety, and can help you be a part of the process.

As a parent, your first concerns surround the needs of your child; however, many parents are unfamiliar with hearing loss and have feelings of uncertainty. You may have deeply pressing questions, such as: Will my child learn to talk? Does my child really need hearing aids? Will my child make friends? What will my child’s future be like? You should know, many children with hearing loss live the social and physical lives you expected before the diagnosis of hearing loss. They can and do make and sustain quality friendships with their peers and they often take part in extra-curricular activities.

We asked parents to talk about what they experienced when their child was diagnosed with hearing loss.

Parents go through a lot of different emotions, and different parents feel something different. Everyone’s experience is unique and individual to them when they find out their child has hearing loss. And even with two separate children both experiences were very different. All of it is just this big circle that we experience. So, we experience that loss and at times it’s hard, other times it’s motivating, and in the end, you really get to see this little child, you know, develop and the joy that the hearing world is for them when they get their cochlear implants or get their hearing aids.

When we found out about her hearing loss it wasn’t a huge deal for us because we already knew that there were hearing aids and cochlear implants, and different, speech therapy and things that we could do for her. So, our main goal was getting her tested, and getting her those hearing aids as soon as possible so that she would have access to sound.

Parents often experience a range of emotions when their child is diagnosed with hearing loss—just like when we receive other impactful news. Grief, confusion, denial, anger, self-blame, and even having no strong emotional reaction are all common reactions. Sometimes the emotions we experience may seem contradictory. We may feel sadness and anger at the same time. All of our emotional reactions are valid and do not need to make sense.

Caring for a child with hearing loss may present additional challenges to relationships. This can include your relationship with your partner, the relationship between you and your child, your



child and their siblings, you and your other children, as well as your child and extended family members. It is important to recognize all of these consequences are natural and can be helped with awareness and active intervention.

Parents often say they feel exhausted. This is not surprising given the emotional experience of the diagnosis and the intervention process. When hearing loss is diagnosed parents begin a journey into unfamiliar areas to learn how to manage their child's needs. This not only requires time, but also draws on emotional resources, and may leave you feeling spent at the end of the day, struggling to meet other demands in your life. When parents experience burn-out they will be less able to meet daily demands. Getting support is not only important but it is essential for your wellbeing and for your ability to help your child.

To manage your emotions, you need to first, notice the emotion without judgment, this allows you to be aware of the emotion without necessarily reacting to it. Noticing is similar to watching waves crashing on the shore without jumping into the water and being pushed around by the waves. Second, choose to be open to the emotion and make room for it. In other words, we can choose to create space for the emotion to be there instead of trying to make it go away—by distracting, ignoring, or any other method. Third, act intentionally based on your values or things that are meaningful to you. This could mean thinking about the kind of parent, partner, or person you would like to be. What would that person do in that moment? Use these values like a compass to guide action. For example, we can notice frustration toward our child and allow that feeling to be there while choosing to be patient with them because that is the kind of parent we want to be.

Raising a child is already difficult and raising a child with hearing loss can be complicated. Thankfully, you do not have to do this alone. Finding reliable sources of social support can go a long way toward building a sustainable lifestyle for you and your family. Your partner, other family members, friends, your audiologist, a therapist, in-person support groups, and online communities can serve as sources of support along this journey. Parents sometimes report simply knowing others are facing similar struggles can be incredibly validating. Furthermore, you can hear different perspectives from people who have gone through, are going through, or are about to go through what you are experiencing. Connecting with supportive others reminds us that we are not alone and reminds us that this journey is possible.

Your audiologist can help connect you with other families who have a child with hearing loss and provide lists of social media networks dedicated to parents caring for children with hearing loss, as well as area and national parent support organizations.

We asked parents what they would like other families to know.

Enjoy the process, recognize the feelings, you know, it's ok to be sad sometimes, when your child is struggling because they can't hear, but it really does make those victories and those successes so sweet when you get there. Because you know how hard they worked, and you



know, there is nothing wrong with any of that, to celebrate something that other families may, you know, take advantage of. But if you are in the grocery store and you hear your little one say apple for the first time, praise them enjoy it, make a big deal out of it, make a scene, it's ok, if you are walking around and you are labeling everything you see, and you are describing everything in sight because you are trying to give as much language, go with it, enjoy it, be silly, be fun.

I would go to the HearingFirst.com or .org, and also there is HearToLearn.org because you can watch all these really awesome webinars that have information from parents that have been through this, and they tell you what has been most important for them in their journeys like, I learned through that that having a good audiologist is like the highest importance to help you do your cochlear implant mapping but also to give you guidance on the best FM system for your hearing aids or anything. So, really just delve in and I know it's overwhelming but there is an incredible amount of resources and it's really inspiring.

Something I think would be helpful for another family is to take a deep breath and just feel confident in the fact that you are doing everything you can for your child. Make that you have done the research so that you feel comfortable sending them. Make sure that you have reached out and built a relationship with those preschool teachers. Go in and volunteer when you can, and I was never told I couldn't. I was always encouraged to come in and read stories. I would suggest that you start to empower your child now. Teach them to advocate for themselves and continue to build them up and strengthen those relationships, so that you can be a team rather than just the parent, because those preschool teachers and those services are going to be what help you to help your child be successful. I know, we started with one office and it was doing pretty well but then one of the audiologists left and so we tried a different office. And that's one thing, don't feel bad to get a second opinion or even a third opinion, if something is not working. It took us a couple of tries and then we finally found one, far away, but it works as long as you find an audiologist that is willing to work with your child and make sure everything is set properly, it makes all the difference.

As parents consider their options, they want to be careful. We want to make sure that we have done the right thing and sometimes being careful means taking time to do research to meet with people, to talk with families, to join professional societies for example AG Bell, to subscribe to magazines, to read online sites. But, in all of these we really do need to remember that there is urgency involved in making such a decision.

You know that's a hard one because I feel like when we first found out I was very skeptical to go the hearing aid route. It was not something I was comfortable with, it was not something I wanted to put my daughter through, it kind of comes across as a handicap sort of thing, and I did not want her to be labeled as that. But now that we are in it, she's had them for about a year and a half, it's amazing. I've never seen, she is just thriving, and she is so happy, and I know it's because she hears. She can play, she can run, she can do all the things that other kids are doing because she feels like she can participate easier, I guess.

I want them to educate themselves, as far as like on their individualized plan like a 504, IFSP. Get familiar with that, I would definitely just get educated on what your expectations are and kind of doing some role playing in a sense of knowing how to run that meeting.



I would say that it's not the end of the world, it's ok and there are some many resources and helps for you, and that you will just be engrossed in a great community of people who are willing to help you and want your baby to have that access to sound and speech and everything that comes along with hearing aids and cochlear implants. It's difficult, and it is but if you I think you just need to figure out on what it is going to be most important for you, and what their needs are going to be and it's really difficult and individual to each child, but for us figuring out what her most basic needs were, and then deciding what was our priority. That's what we did and so, you know, we can't fix her vision with glasses or anything, and so that was our next opportunity and we knew that we could help her with that, and so we went full force with that, and we knew hearing aids that was going to be our first step but if a cochlear was possible, that is what we wanted to do, and so that is what we have done.

If you find your child has a hearing loss don't go just trustingly with the first audiologist that you get sent to. I think it is really important to find the audiologist that specializes in pediatric care, that works with kids. I think that has made a huge difference with Marie, we started out with a different audiologist and we ended up going to a different one, and it has made a huge difference, I think for her.

Knowing what to expect and things to consider can help you take the next steps and move forward in helping your child.

Your child may have several appointments each month. Hearing will be monitored regularly and earmolds will be replaced as your child grows. Hearing aid programming needs to be checked so that that settings are appropriate for your child if your child's hearing changes and every time your child gets new earmolds. Speech and language therapy sessions will help you learn strategies you can use every day to increase your child's exposure to language and to help your child develop important communication skills. Some children may also have additional medical and intervention needs that require regular appointments.

It is important to monitor your child's progress and make informed decisions based on your individual child and family needs. It can be helpful to keep a binder for your child, so you have a place to keep test results, reports, and other intervention-related documents.

Partner with professional to talk about what you are experiencing, thinking and feeling, what is important to you, your concerns and worries, your goals, and the challenges you are facing. Ask for help as you build your skills. Explore your feelings and attitudes with your team. Many parents struggle with their feelings and this can show up in your behaviors. For example, do you talk about your child's hearing loss with others or do you try to hide their hearing aids? How parents feel and how they embrace the intervention process can influence how their child feels. Exploring your attitudes can put you in a better position to help your child learn how to be an advocate for him or herself. Together with your team you can find solutions to barriers that interfere with your child's development, monitor your child's progress, and celebrate the many successes along the way.



Young children are busy and curious, and it is common for them to remove their hearing aids. This can be frustrating for parents, and the professionals you are working with can help you learn how to manage your child's behaviors so that your child's development is not compromised.

Children with hearing loss often need accommodations at school. Your child may need an Individualized Education Plan, or a 504 Plan to access learning accommodations at school. For example, it is helpful for children to use a personal FM system so they can hear better in noise. Your audiologist and other intervention providers can help you determine what accommodations, if any, would benefit your child.

Taking care of your child's hearing needs is a team effort. When your child is young, everyone involved in your child's care needs to know how to check the hearing aids, put the hearing aids on your child, and how to use the language strategies you are currently working on. As your child gets older, you will also be teaching your child how to help meet their own needs, so they can become a good self-advocate.