



# Parenting with Hearing Loss

BY EMILY TRUELL

An acoustic neuroma survivor and blogger with single-sided deafness shares her experience of raising two young daughters

I was 27 when I realized I couldn't understand phone calls if I used my left ear. I told my primary doctor, who scheduled a battery of tests. After hearing exams, audiology and otolaryngology appointments and an MRI, I was diagnosed with a 3cm acoustic neuroma (or vestibular schwannoma), a non-cancerous brain tumor. At that point, I'd already lost significant hearing in my left ear, and surgery to remove the brain tumor resulted in single-sided deafness.

Throughout all this, I had a two-year-old daughter at home.

As you can imagine, I worried that my brain tumor journey and hearing loss would have a negative impact on my child—and on my ability to be the parent I wanted to be. I imagined my single-sided deafness would mean I'd miss things, leading to frustration and miscommunication. While there have been many struggles and difficult days, I have been amazed at how well my family has accommodated the changes brought by my diagnosis.



## Adapting Together

While I struggled with the abrupt transition to a life with hearing loss, my two-year-old daughter was just developing her language and communication skills. She quickly learned the behaviors that we trained her on were necessary to be heard—facing me directly when she wanted to talk, waiting her turn to speak and never covering her mouth. I began to notice people complimenting her diction and clarity of speech, skills that I'm sure she unconsciously acquired to assist in our communication.

At the same time, she was also honing her sense of empathy. Keenly aware of the toll my recovery took, she developed an alertness to my condition, and did what she could to take care of me. Between my daughter and my husband, they managed to keep me from my natural inclination to push too hard and overdo it.

Together, we found strategies that worked for us, and in the end my daughter proved to be the most adaptable one of all. Of course, adaptation never really ends, and soon we were bracing for another big change.

## When the Kids Outnumber the Ears

A couple of years after my surgery, we decided to grow our family. I was very concerned about hearing my baby with my single-sided deafness; I'm a side sleeper, and when I'm sleeping on my hearing ear, the world is totally tuned out. (I've even slept through a fire alarm—thankfully a false one!) I had to be sure I wouldn't miss any times when my baby needed me.

We did some research and found a baby monitor that, in addition to transmitting sound, would use light and vibration to notify me when it detected noise. With the receiver under my pillow, I could sleep and still keep tabs on her.

By this time, I had elected to get a bone-anchored hearing aid (BAHA). It really improves communication by capturing missing sounds on my deaf side and sending them to my hearing ear. I also used my smartphone and smartwatch to help me monitor my environment—the Live Transcribe feature on my Android phone passively listens for baby cries, doorbells, fire alarms, etc., and alerts me through watch vibrations. This helps me feel more secure, especially when my husband is away from home.

When it was time to move the baby out of our room, we had both our daughters share a bedroom, so the big sister could come and get me for her little sister when needed. We trained the kids to always use touch to wake me. Although we delayed the move out of our bedroom, we changed from a crib to a toddler bed





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earlier—I felt much better knowing she could come and get me herself if necessary.

Two kids, it turns out, are exponentially louder than one. I found that the constant auditory input of parenting was a lot more tiring. Hearing fatigue wears me out quickly and makes it harder for me to follow their stories and be present the way I want to be. But in time, I developed strategies for managing. I take listening breaks—even a few minutes of quiet in my room can really help me reset. And I make liberal use of earplugs, especially in the car. (My youngest once told a nurse that Mom was done having children because there is no way she could handle any more noise in the car!) I prefer earplugs that reduce the sound to make it more comfortable, but don't block it out altogether.

### Audio Awareness

Over the years, the changes we worked on earlier simply became how we lived.

We keep a quiet home environment to make it easier for me to be able to hear. Our kids know to listen to music in their rooms or on headphones, rather than in the kitchen, when I'm cooking. They realize that there are times and places to be loud, and they work to be respectful of that. This consideration really becomes apparent when we have other children over. While adding more kids is bound to make the din exponentially worse, it's clear that other kids just don't have the same awareness of noise that our children do.

I make sure to stress the importance of good conversation "hygiene" with my kids. I ask them to start by making sure they have my attention, that we are looking at each other and that we are near each other before they launch into a story. Tuning out is a survival skill for me, so they need to make sure to notify me when it's time to listen. They mostly do a great job of this—although I do have to remind them that I can't hear when their heads are stuck in the fridge looking for snacks.

Because they need to get my attention, the conversations we have are more intentional and purposeful. This fosters a value of good communication and provides opportunities to practice communication strategies that will assist them wherever they end up in life. They're also learning to adapt to other's needs and not be too critical of their own bodies, because everyone has parts that don't work quite right.

### School Years Bring on New Challenges

In the kids' early years, we crafted a home environment that we could all succeed in. But both are now in school, an acoustic environment that I have no influence over.

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The standard script for school parents includes small talk and making connections with other parents during school drop-offs and pick-ups.

With all those kids talking over each other in the hallways, it's impossible for me to pick out the voice of just one person trying to invite my daughter for a sleepover. I find myself avoiding communication in those moments, walking quickly through with a smile and a nod.

Then there are sports activities. Competitions that take place indoors are incredibly loud, so I'm always prepared with earplugs; I want to be vigilant about protecting what hearing I still have. That's not without complication, because this is another space where school parents like to chat. I usually try to place my family on my deaf side. They're trained to let me know if I'm missing someone speaking to me, or to remind the folks next to me that I have hearing loss.

When school events and fundraisers are seeking volunteers, I take a different approach. I make sure to inform the organizer of my hearing loss limitations, that in a full gymnasium (the worst acoustics) I will have a really hard time hearing. I ask to be assigned physical tasks or contribute before or after the event. I find that, when I do a good job of describing my limitations and what I need to be successful, volunteer committees are all too happy to work with me.

But perhaps the most important adaptation I've made is giving myself permission not to attend every child-centric activity. I will drop my daughter off at that birthday party. I steer my kids' party plans toward settings I can enjoy—a pumpkin patch rather than an arcade, for example. Sometimes I drive myself to a field trip I am chaperoning and skip the loud bus ride. A stressed mom doesn't lend itself toward a fun time, and if I'm less overwhelmed, I can fully participate in the event.

In all these settings, the kids see me dealing with overstimulation and modeling strategies to cope. It's improved their own awareness of when they're feeling overstimulated. Through me, they're learning how to make appropriate choices that set them up for success and how to give themselves space when they get overwhelmed.

### Just Another Family Culture

Parenting with hearing loss has its challenges, but there are some fun moments, too. During those infant days, I absolutely benefited from sleeping through our baby's wake-ups, as the night shift would at times fall to my husband. I had a lot more staying power when I shifted that crying kid to my deaf side. These days, my younger daughter tells me she enjoys singing in the shower as loud as she wants, knowing I can't listen in. In our house, you can safely giggle during hide and seek, since I can't locate by sound. You can whisper a secret into my deaf ear and know it'll be kept forever.

These days, my kids will help me out in settings where I struggle to hear. My daughters will realize when someone is trying to communicate with me and happily intercede to smooth over any conversation I have missed. We've all learned lessons in grace and the importance of being adaptable and willing to change how we do things. For my kids, Mom having one working ear is normal and nothing to be worried or ashamed about.

And if my hearing fatigue makes me a little more tired at the end of the day—well, I hear parenting isn't typically a well-rested gig anyway. **HL**

*A hearing loss advocate with single-sided deafness, Emily Truell shares her experiences and reviews hearing technology in her “Lucky” Brain Tumor blog. She’s an HLAA member who also serves as a peer mentor and young adult support group leader for the Acoustic Neuroma Association. Emily was named a 2023 finalist for Oticon’s Hearing Loss Champion Award. She runs a tourism business and lives with her family in central Wisconsin.*

## One Mom's Quest to Help Her Son and Other Families

**N**aTyshca Pickett, M.Ed., and her husband were shocked and overwhelmed when their newborn son was diagnosed with hearing loss. “We weren’t sure how to navigate our new normal, and we had no family nearby to help,” she recalls.

At eight months old, Adrion was fitted with bone-anchored hearing aids, but his parents noticed little progress and questioned their doctor. It wasn’t until Adrion turned three that a new audiologist heard their concerns, retested and fit the boy with traditional hearing aids instead. It was the success they were looking for, and Adrion, who is now nine, has been thriving ever since!

NaTyshca credits crucial educational and support resources, like HLAA, that got her son on the right track. As a member of HLAA and Walk4Hearing volunteer in Arizona, she wants to make sure other parents don’t have the same struggles. NaTyshca spoke on the HLAA 2024 Convention parent-led panel in Phoenix to help provide them with support and guidance, and signed copies of her children’s book, *My Happy Ears*.

### Her tips for success for parents of children with hearing loss:

1. You are not alone in your journey! Joining groups like HLAA will build your community, knowledge and support system.
2. You are the best expert for your child. Trust your instincts and advocate for their needs.
3. Extend grace to yourself! Parenting is hard, and having a child with unique needs comes with its own set of challenges.
4. Remember that you’re doing your best, even if things don’t go perfectly!

