

**M**y father had hearing loss but never discussed it. His mother had hearing loss but pretended she did not. I spent 10 years in denial about my own hearing loss, and then another 10 years hiding it. So how did I become a hearing health advocate, on the Board of Hearing Health Foundation (HHF) and the writer of a blog titled *Living With Hearing Loss*?

It has been quite a transformation, and one that convinces me that we must act now to break the stigma of hearing loss—not only because of the personal pain and denial that comes along with it, but also because of the medical dangers of untreated hearing loss. Here is my story.

I grew up the child of someone with hearing loss. I knew it in a peripheral way—my father wore hearing aids, but they were never seen—always hidden by sideburns grown long for that purpose. He never discussed his hearing loss and went out of his way to hide it. I remember social gatherings where he would disappear, only to be found sitting at a table in the corner by himself. I always wondered why, but now I know. He probably couldn't hear and was embarrassed, or exhausted and just couldn't bring himself to bother.

Looking back on it, I see that my family was not supportive of him. My mother would often whisper things to my sister and I behind his back saying, "Don't worry, he can't hear us." Even as a child, I knew that wasn't nice, but most of the time I was just unaware of the hardship he faced. I sensed his embarrassment and the taboo nature of the subject, but didn't dwell on it, being focused on myself, as most children are.

He never asked anyone to speak up or to face him when they spoke. He would never, as far as I could tell, position himself within the family group so that he could hear better. He never asked for a quiet seat at a

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restaurant or did anything to draw attention to his hearing loss. In fact, he would often fake it, pretending to hear what others said rather than admit that he couldn't. It makes me sad to think of it.

So when I first started having problems hearing in my mid-twenties at business school, I hid it, following the only example I knew—my dad's. And when I got my first pair of hearing aids, I refused to wear them, afraid someone might see them. I was embarrassed. I am not sure why. Was it a learned response from watching my father, or was it something larger—the stigma associated with hearing loss that I wanted to avoid? In any event, my mother's reaction was not encouraging. "Do you really need to wear them?" she asked me.

Eventually, the answer became yes, I really did need to wear them, but still, I avoided them as much as possible. I remember surreptitiously putting in my hearing aids on the way to work, wearing them all day hidden behind my long hair (easier for a woman) and whipping them out as soon as the elevator door closed behind me on my way out of the office. I would sneak them in and out right before and after important client meetings. I got pretty good at it, but always worried that the telltale whistle would give

me away. I hated my hearing aids and wore them only when I absolutely needed to, and never socially or with my family.

### **Leading By Example**

But then I had two children of my own, and this forced me to come to terms with my hearing loss. Since my loss was genetic, I worried that I might have passed it onto them. Given the adult-onset nature of my loss, we won't know for another 15 years or so, but I wasn't going to sit by idly and wait to see. And if they did have an issue, I didn't want them to feel embarrassed and ashamed of it the way my father had, and the way I was. I not only needed to admit my hearing loss to others, I also needed to accept it myself.

So I did. Around this time, I was lucky enough to become involved with HHF and found my way onto the Board of Directors. My work with the foundation has been a good excuse to be more vocal about my hearing loss. My friends asked me why I was devoting my time to HHF and I would give me the opportunity to tell them about my hearing loss. Most of them had no idea, and more importantly, none of them cared. And when I meet new people, they don't care either.

What had I been so worried about? In fact, most of the time I talk about my hearing loss, the person tells me about his or her own issue with hearing loss or tinnitus, or that someone in his or her family or a close friend has hearing loss. This isn't really that surprising given that there are nearly 50 million of us with hearing loss in the United States alone.

### **Growing Bolder**

As time goes on, I have grown bolder. I now regularly advocate for myself—asking for quiet tables at restaurants,

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By Shari Eberts

After wasting 10 years on not treating her hearing loss because of embarrassment and shame, the author grew bolder in her approach. Shari has genetic hearing loss and hopes that by sharing her story, it will help others to live more peacefully with their own hearing loss.

*Hearing Loss Doesn't Have to be a Showstopper*

# **Breaking the Stigma of Hearing Loss**

## Stigma of Hearing Loss

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using caption devices at the movies, and rearranging the seating at dinners with family and friends to make sure I can hear and participate. I even started writing a blog where I discuss the ups and downs of living with hearing loss and what I do to cope. It has been incredibly therapeutic and has helped me to feel a part of the broader hearing loss community.

Rather than hide my hearing loss from my family, I discuss it openly and brainstorm ways they can help me hear them better. My children are now quite practiced at making sure to face me and keep their mouths visible when they talk to me. This is not to say they always remember, but they do try. They are also much more aware and protective of their own hearing than I ever was, in part because they know they might have hearing loss one day. My children wear earplugs at loud school events and offer earplugs to their friends. We shall see if that continues in the teen years, but I hope so. They see me struggle with my hearing loss and I believe it helps them

to appreciate their own hearing and want to protect it.

This year, I joined the Hearing Loss Association of America (HLAA), began attending meetings of the New York City Chapter and went to my first HLAA Convention in St. Louis. What a pleasure it has been to know other people with hearing loss! We all make a point to speak clearly, face each other, and repeat ourselves with no sense of embarrassment or annoyance. It is just the norm. I feel proud to be a part of this community of incredibly diverse, intelligent, and fun-loving people, most of whom I would never have met if it were not for my hearing loss.

### Getting to Work on the Problem of Stigma

As I make progress in my own hearing loss story, I feel it is time to take more direct action to counteract the stigma that is associated with hearing loss. If it were not for the stigma, I believe my father would have been more open about his hearing loss and my family more accepting of it. I wasted 10 years trying to hide my hearing loss, for no real purpose other than to avoid the stigma. Plus,

as I learn more about hearing loss, I realize that embarrassment is only a small part of the danger of the stigma. New evidence links untreated hearing loss to numerous medical problems, including dementia. If stigma leads to a lack of treatment, the repercussions can be staggering.

I hope that by sharing my story, I can help chip away at the stigma of hearing loss, inspire others to deal openly with their hearing loss, and encourage people to seek treatment sooner rather than later. Only by accepting and treating our hearing loss can we take control of our health and happiness. And by spreading the word about the stigma of hearing loss, we are taking the first step in breaking it. **HLM**

*Shari Eberts is a new member of the HLAA Board of Trustees and is a hearing health advocate, writer and speaker. She blogs at [LivingWithHearingLoss.com](http://LivingWithHearingLoss.com) and serves on the board of Hearing Health Foundation, a nonprofit organization funding research into biological treatments and cures for hearing loss and tinnitus. She posts on [Facebook.com/LivingWithHearingLoss](https://www.facebook.com/LivingWithHearingLoss) and tweets at @sharieberts.*



Shari with her husband Ken, daughter is Aerin, and son Alden, at a wedding in Key West, Florida, this past spring.



Shari, who is active on Duke's Trinity Board of Advisors, tours a construction site at Duke University.



Shari loves Bikram yoga and hiking. Here she combines both in Mexico.



# Breaking the Stigma of Hearing Loss— The Who, What, Why and How

*By Shari Eberts*

**We must break the stigma that surrounds hearing loss. It is a matter of life and mind. Research shows that there is a relationship between hearing loss and cognitive decline. Hearing loss is also associated with higher incidence of heart disease, diabetes, and isolation and depression.**

## Who Has Hearing Loss?

Hearing loss is not an isolated incident. There are 48 million people in the United States with hearing loss today. This includes one in five teenagers, and 60 percent of our returning veterans from foreign wars. In fact, more people have hearing loss than have diabetes, Alzheimer's, autism and osteoporosis combined. Nevertheless, it does not seem to be a priority within the national health care dialogue. Maybe it is because hearing loss does not kill you. It is true that it is not fatal, but it can take away the quality of your life through isolation, depression and other health problems.

## What is the Stigma of Hearing Loss?

It is hard to figure out what the stigma of hearing loss is exactly. Are people with hearing loss old? Stupid? Ugly? Uncool? Not worth the extra time it takes to communicate with them? All of the above?

While the exact nature of the stigma is not clear, many of us with hearing loss feel it, nonetheless. Of course none of these stigmas are true. Those with hearing loss range in age from newborns to elderly folks, and with the increase in noise pollution so prevalent today, many new cases of hearing loss are in their teens.

I find the hearing loss stigma odd, since there is no detrimental view of wearing glasses, or using a wheelchair or other assistive devices. Perhaps it is because hearing loss is invisible, so that its presence is not obvious. This makes it easier for others to assume the person with hearing loss is stupid or rude when they respond inappropriately to a question, while the reality is that the person probably just didn't hear what was said.

## Why is it Important to Break the Stigma of Hearing Loss?

Due to the stigma, many people who could benefit from treating their hearing loss do not. The NIDCD (National Institute on Deafness and Other Communication Disorders, National Institutes of Health) states that among adults aged 70 and older with hearing loss who could benefit from hearing aids, fewer than one in three (30 percent) has ever used them. Even fewer adults aged 20 to 69 (approximately 16 percent) who could benefit from wearing hearing aids have ever used them. Given the serious health issues associated with untreated hearing loss, this needs to change.

Today's laws also contribute to the stigma of hearing loss. For example, glasses are covered by most health insurance providers in the United States but hearing aids are not. This prevents many people from seeking treatment. Until hearing loss is recognized as a serious health issue and appropriate accommodations for those with hearing loss are made, the stigma will not fade and people with hearing loss will not seek the help they need.

## How Can You Help Break the Stigma of Hearing Loss?

- Get your hearing tested as part of your annual medical screening and encourage your friends and family to do the same.
- If you have hearing loss, treat it. Visit an audiologist to learn about hearing aids today or talk to your general practitioner.
- If you have hearing aids, wear them. It takes time to perfect the settings, but hearing devices do help.
- Speak up about your hearing loss. Being vocal about your own loss will gradually lower the stigma for others.
- Show that hearing is something to be valued. Protect your hearing and help others protect their hearing by offering earplugs or turning down the volume.
- Appeal to your elected officials to make hearing loss an important part of the national health agenda. **HLM**

## Shari Eberts blogs at [LivingWithHearingLoss.com](http://LivingWithHearingLoss.com). Here are two of her most popular blog postings.

### Please Don't Tell Me Never Mind

It happens sometimes. A friend or colleague is telling me a funny story or explaining an event that happened, and at some point I will ask, "What did you say?" I got the beginning, but somewhere along the way I missed something and needed clarification of the last point. The speaker pauses, as if to think about the question, and replies "Never mind." Usually, this is accompanied by a dismissive wave of the hand or shake of the head or both. I hate that, don't you?

Never mind is a dismissal. It is an insult. It says that the listener is not important enough to the speaker to repeat what was said. This also applies to "forget it," "it's not important," and "don't worry about it." If I hear that from somebody enough times, I don't bother to interact with him or her any longer. It's not worth my time. I essentially say "never mind" to them—just not out loud!

Maybe I am being too sensitive. Sometimes the story is probably not important enough to repeat or there is not time to go through it again now. Even so, it still bothers me and it probably bothers others with hearing loss too.

More concerning is that this type of dismissal could lead to social withdrawal for people if it happens enough. "Why bother to interact with others if I am only to be scorned for not hearing everything perfectly," some might think. It becomes easier not to try, then to face the dismissal and shame. Thus begins a downward spiral.

So, how can we better handle this type of situation and nip bad feelings in the bud? I have two suggestions for the speaker, but more importantly, one very effective tool for the listener.

#### For the speaker:

- If someone doesn't hear you, rephrase the last thing you said. It really does not take that long.
- If there isn't time to do that now, say something like, "I want to finish telling you the story, but there isn't time right now. Remind me after the meeting and I will tell you." This is much more respectful than "Never mind."

#### For the listener:

- If someone tells you "Never mind," you should calmly reply, "Please, I really would like to hear what you have to say. Do you mind trying once more?" It is hard to say no to that, plus your assertiveness makes it clear that you will not take dismissal as an appropriate response.

### Do You Get Hearing Loss Exhaustion?

I sometimes do. Particularly on days where there is more listening than normal required—like at a conference or when there is a social gathering at the end of the day. Even family outings can be exhausting if everyone is talking at once and there is plenty of activity. One time there was such an exhausting activity, I just walked out in order to save my sanity. I now refer to it as the Circle of Hearing Hell. Here is what happened.

We were at a weekend retreat for my daughter's school and while the children were off working with the teachers on a project, the parents were expected to mingle and meet each other. Instead of a traditional cocktail party, the organizers tried a get-to-know-each-other game where the parents sat on chairs in two circles, one inside the other, so that each parent was sitting across from someone she didn't know. You were then asked to discuss a certain topic with this person, until the organizers announced, "Rotate!" at which point everyone in the inner circle shifted one chair to the left. Then you were to discuss a second topic with this new person. And so it went for several rotations.

You can only imagine the noise level in the room, with 150 parents chatting away simultaneously! When everyone was talking, I clocked the noise level at about 90 decibels on my handy iPhone decibel reader. I tried my best for two or three rotations, but honestly, I couldn't really follow what the person across from me was saying. I typically do better with female voices (I have better hearing in the high-pitch ranges, but in this context, it didn't seem to matter. Male or female, I could only speechread about half of what they were saying. At least I knew the topic we were supposed to be discussing, so that helped, but it was exhausting.

I rarely walk out of a situation because of my hearing loss. I am not a quitter and always search for a workaround, but in this case, it just wasn't happening. The overall background noise combined with a new voice to learn every five minutes was just too much. Between rotations, I excused myself to go to the ladies' room, and never returned. My husband stayed to carry the family torch and collect my daughter once she returned from her program.

My takeaway from this experience is that sometimes, you just have to protect yourself. I made an effort to meet as many parents as possible in other settings throughout the weekend, so no harm done. Plus, by leaving this situation, I preserved my energy for other interactions that would be more productive. Hey, life is a tradeoff, and I have no regrets about the tradeoff I made in this case. In fact, I encourage everyone to take the time they need for rest, so they can enjoy and thrive in the communication situations that are to come. **HLM**