



I was being robbed of my ability to hear—as well as my meaningful connection with others—by a stealthy thief whom I could no longer ignore. I felt as though my world was shrinking, and I grew increasingly isolated. That’s when I decided to take action.

My Disappearing Hearing

Not long ago, I began to notice that familiar sounds were gradually fading away. I had to constantly ask people to repeat sentences and became totally inept at understanding peoples' speech in larger groups. Once upon a time, I could hear conversations without relying on watching people's lips, but now I can't discern who is speaking in a group conversation, much less what the person is saying. I find myself unable to communicate without lipreading.

I share humorous stories about this "new normal" with my friends, but in retrospect, they do not seem so funny. For example, one day, I was standing in line at a busy Starbucks, and anyone with a hearing loss who has entered one of these bistros knows what a nightmare this can be. The cacophony is maddening: people are driving up to the window, orders are being shouted all over the store, coffee machines are making obnoxious sounds, and conversations among the customers create a constant rumble of background noise.

On this occasion, I ordered my coffee, and the barista asked me if I wanted "wimp." I thought the coffee there was very strong and asked her to repeat the question three times. I was frustrated, the barista was harried, and the customers in the long line forming behind me were impatient.

I finally said, 'I am sorry, but I just can't understand you. I have a severe hearing loss, and that is why I have this service dog.' My wonderful hearing ear dog, Sita, was patiently standing beside me, and I fervently wished that she could talk and translate for me!

The barista relaxed and apologized. "I talk fast—I was asking if you wanted whipped cream!" If she had only said that in the first place, I thought to myself, the encounter would have been much easier. By the way, I challenge anyone to look in a mirror and try to speechread the difference between "whip" and "wimp." This exchange reminded me once again: I was being robbed of more and more of my hearing, as well as my meaningful connection with others, by a stealthy thief I could no longer ignore. My escalating hearing loss was

sneaking up on me so gradually that it took me years to realize what was happening.

But what was happening? Here's the backstory on my original hearing loss, which I had at birth. Experts surmised that it was caused by congenital cytomegalovirus; my mother had the flu when she was pregnant with me. The mother passes this virus to the fetus, whose ears are then affected. I had always been thankful that my hearing loss hadn't changed for more than 50 years. It hovered around 60-65 decibels, which professionals term as moderately severe.

I had always prided myself on being pretty well adjusted, for the most part. I didn't share the grief so many of my deaf friends and those with hearing loss had experienced when they lost their hearing later in life, since I never knew what it was like to hear normally. I was diagnosed at the age of six and began wearing a large, ugly body aid in the first grade. Over the course of more than 60 years, I progressed to behind-the-ear aids and then to digital aids.

I also had friends who were audiologists, and they kept me informed me about the latest technology. I used an amplified phone, as well as a transmitter for group conversations and TV. My Shake Awake alarm clock guaranteed that I would wake up on time, and my hearing ear dog, Sita, alerted me when people were at the door or approaching me from behind, so I felt safe.

I even learned sign language and made wonderful friends in the Deaf community. I was comfortable with both people who were deaf and those with hearing loss, and I have been a longtime member of the National Association of the Deaf (NAD) and the Hearing Loss Association of America (HLAA). I have written several articles for their magazine, *Hearing Life*, and I've also planned programs about hearing loss for my local HLAA Chapter for more than 30 years. I have even spoken at some of the HLAA Conventions.

I taught a course known as "Deaf Culture and Introduction to Interpreting" at a local community college for several years, and I worked as a counselor

for both people who are Deaf, those with hearing loss and other disabilities for 18 years. Obviously, anyone observing me would conclude that I knew a lot about hearing loss. What I didn't know a lot about was what it's like to lose more of my hearing later in life.

To my dismay, I was the one who had to figure out why. I had always advised my clients and students to be assertive, active consumers, because the professionals might not know everything. I respect and love my audiologist; however, I glanced at my audiogram on a routine visit and mentioned that my hearing loss was getting worse. She responded nonchalantly, "Well, if you don't lose any more hearing in the next 60 years, you will be fine." I asked her if she thought it was Presbycusis, which is hearing loss due to aging, and she replied, "Yes."

My previous audiologist had never mentioned a further loss in my hearing and just sold me hearing aids. I pondered what I might be missing. Something was just not right. I then remembered from my time teaching about hearing loss that chemotherapy drugs are often ototoxic, which means the drug can possibly destroy hair cells and cause temporary or permanent hearing loss. I began to connect the dots: I had been on Revlimid, an oral chemotherapy drug for myelodysplastic syndrome, or cancer of the bone marrow, for four years.

I had a copy of my old audiogram, which the previous audiologist had not sent to my new doctor, so I took it with me to my doctor's appointment and suggested what might be happening. She promptly conducted another audiogram, and we realized that my hearing loss had deteriorated from severe to profound, hovering now between 80-95 decibels. I asked my oncologist about ototoxic side effects of chemotherapy drugs like Revlimid. She acknowledged that she didn't know much but also reminded me that I had been on the oral chemotherapy longer than most people. I told her, "Well, I guess it is better to be deaf than dead!"

Here was the kicker: I am a former librarian, so I know how to conduct research. Yet nowhere in the several pages of side effects detailed in the literature about Revlimid was ototoxicity mentioned. I dug deeper, and an online article caught my eye. Thalidomide drugs are considered ototoxic, and Revlimid is a derivative of Thalidomide. Bingo!

Thus, the life-saving chemotherapy drug that had given me such a fine quality of life for the past several years had now turned on me. I was alive, but my world as I knew it was fading away. The only people who truly understand what I was enduring were friends who had also lost their hearing and were known as "late-deafened adults." I became very depressed.

Hearing is the essence of communication. We use it in almost every task we accomplish daily—from talking and using the phone to listening to the radio and watching television. Our ability to hear alerts us to sirens and smoke alarms; it signals someone's approach and even warns us of potential dangers. This critical ability was slipping away from me.

People grieve the loss of vision, hearing, mobility or a devastating disease the same way they do the loss of a loved one. We have funerals and memorial services when we lose someone close to us, but when we face the onset of a disabling condition or chronic illness, we are simply expected to soldier on.

As a rehabilitation counselor, I was intellectually familiar with all of the stages of grief, from depression and bargaining to acceptance, but now these stages had become real: I was living through them. I also felt somewhat betrayed that the change in my quality of hearing was dismissed so readily by so many.

My doctor placed me on another chemotherapy drug called Vidaza; I was to receive ten shots of Vidaza every month. One of my oncologists acknowledged that this dosage of the drug is ototoxic, although the literature does not mention this. I endured those chemotherapy injections for two years. If I suspected that I was losing any hearing during that time, I informed my audiologist, who duly performed an audiogram so that she could alert my oncologist immediately. Presently, I am not on any chemotherapy, but I do receive Procrit shots to elevate my red blood count. My cancer is in temporary remission, and I will need to begin a brand new chemotherapy regimen in a few months. We do not know what to expect in terms of side effects because the drug is so new.

The hardest part for me is that I can no longer hear conversations when in groups of people, which is depressing. Recently, I attended a retirement party in a noisy restaurant and bar, but I ended up leaving in tears. Every conversation was frustrating, because I could hear only three or four words at most. I miss all the announcements in church and have to read the weekly newsletter to know what's happening.

However, I also recognize that I am extremely fortunate. I have access to knowledge, thanks to my membership in HLAA. I also have the support of friends and relatives. I love and respect my oncologist and audiologists who have collaborated to help me. I have frequent audiograms now to track any further damage to my hearing. My feelings are mixed, but my depression lifts when I remember that, with the help of my team, I can overcome my challenges. I still have my vision—and rely on it more than ever before.

I used to both listen and read captioning when watching television. I am so exhausted when I come home and turn on the television that I prefer reading the captioning to any attempt to listen. If I am online and select a YouTube video that doesn't have captioning, I refuse to watch. Fortunately, HLAA is taking measures to change this by advocating for new laws.

I decided to get a captioned phone when I found out that it was free! I love it, but I get exasperated sometimes when the captioner types "inaudible." I talked to the installer about this problem, and his answer was simple: "Hang up and get another captioner!" I recently have installed InnoCaption+ with a caption assistant for my cellphone and love it.

Then along came COVID-19.

I believe in wearing masks and know the advantages. All of us cancer survivors are immune-compromised, and I feel it is important to protect myself and others. Even after seven years of speech therapy and 64 years of wearing hearing aids, I never realized how dependent I am on lipreading. When I went to the grocery store, tried to pick up carryout, and used a drive-through—not being able to lipread was challenging and I made many mistakes.

To add to the stress, I needed to go to the hospital every week for blood draws and the masks were a real problem. I would try to use every last ounce of my hearing. Since my blood draws determined whether I received one shot or two, it was vitally important I hear the instructions. Straining to hear is as fatiguing as cancer, so I was getting double whammy and coming home exhausted.

I fumed to myself how life is just not fair! I already have hearing loss and now I am deaf. I was diagnosed with cancer. And now a pandemic? I turned to my favorite social media—Facebook. I was tempted to rant on about "poor me," but refrained since this is not my personality. I simply explained how hard this whole mask-wearing was for all of us who are deaf or have hearing loss, and asked people to be kind and gentle with all of us.

The response was staggering. So many people flocked to help me. They sent website information on where to buy special masks with clear windows. These websites ran out of masks because the demand was so heavy. Friends from my church stepped in and developed their pattern to make some. I now have several and they are wonderful. I shared some with my deaf friends.

An audiologist sent me a post about phone apps that would transcribe live for me everything that was being said. An IT friend discovered a free app called Live Transcribe, which is incredibly accurate and much better than television captioning! I carried the phone to the nurses, who had not realized how much I was struggling with

“ I am no longer isolated from the rest of the world. ”



Jane Biehl
with Sita

communication. Seventy years of "fake it till you make it" had not allowed me to be honest and let them know. The nurses were incredibly understanding. Every professional has worked very hard to find the best solution for them and me. I still get frustrated when it doesn't always work, but that is the price to pay with any technology. I also have an app called Sign ASL that I use when I am with deaf people and there is a sign I don't know.

My new powerful hearing aids also stream from my cellphone and the television. I am afraid of losing the rest of my hearing and am still mourning my additional loss. I always will. But my eyes are replacing my ears. HLAA is a fantastic resource and I often contact them with questions about assistive listening devices. I can no longer be bashful about asking for help. If there is any time to be deaf, it is the present with all the technology and laws like the Americans with Disabilities Act to protect us.

Worrying about the future is a waste. Instead of being mournful, I can choose to be happy. I can read, follow captioning, use the telephone, watch television or movies, and communicate effectively one-on-one, so I am no longer isolated from the rest of the world. **HL**

Jane Biehl, Ph.D., has had several exciting careers as a librarian, counselor, college teacher and writer. She was born with a hearing loss and became profoundly deaf from chemo to treat her cancer. She has been a member of HLAA for more than 40 years and presented at several conventions. She has written many articles for various publications. She has written two books about her hearing ear service dog, a book about her cancer experiences, and a fourth one will be published in 2021 on her journey about growing up deaf. You can read her articles and contact her through her website janeandsita.com.