

Hear Me

Author's Note by Kerry O'Malley Cerra

At the age of sixteen, I was diagnosed with progressive sensorineural hearing loss. I'm not sure what prompted my parents to take me for testing, since I don't remember struggling to hear at the time. They say they just knew. I guess, in hindsight, I recall not being able to hear words to music very well, so I'd blast the radio or put my ear right up to the speaker to figure out the lyrics. But I didn't *feel* different back then. Honestly, I assumed TVs, radios, and movies weren't clear for anyone.

Things changed in college, when I knew for certain my hearing was declining. At that point, an audiologist recommended hearing aids. It's probably important to mention that as a kid—and truthfully, even now—I hated standing out. I hated being different. Growing up in the eighties, a time when disabilities were not widely accepted, kids laughingly tossed around the word “retarded” regarding anyone who was different. So I did all I could to deny my hearing loss. When I finally got my first hearing aids at age twenty, they felt gigantic! It felt like the whole world was staring at my ears, so I stopped wearing them after only a week.

As my hearing continued deteriorating over the years, I quit teaching, avoided most social situations, and eventually purchased the smallest hearing aids possible—upgrading to newer aids any time I could afford the \$5,000 price tags. The aids definitely amplified things, but never helped me decipher actual words. In essence, I could hear lots of things loudly but never clearly. And I felt stuck. Always! As a hearing-impaired person who doesn't sign, I knew I'd

never be accepted into the Deaf community, yet at the same time, I was legally deaf and trying to live in and navigate a hearing world that wasn't built to accommodate someone like me. My grey space didn't fit into a neat black and white world. My frustration, at times, turned to depression, and hiding from the world became my coping mechanism.

During those years, I'd become friends with my audiologist, and he often brought up the option of cochlear implants. He never pushed them on me, but he kept me informed and was fairly confident they would help me get my life back. Much like Rayne, I was terrified of the implants—terrified of surgery in general, terrified of how'd they'd look, terrified of how people would treat me, but mostly I was terrified of them not working. The majority of people who get cochlear implants lose their residual hearing. That meant, if the surgery didn't work—and it doesn't for some people—what natural hearing I had left would also be gone. I'd be completely deaf. For sure, a little hearing was better than no hearing at all, so I clung to hearing aids as long as I could.

Unlike Rayne, I had many years to come to terms with my loss. Mine was much slower than hers. I don't think there's a truer line in the book than when Mr. Lazar tells Rayne and her family that they deserve time to process and grieve the loss of Rayne's hearing just like someone would grieve the loss of a loved one or a pet. It took me years to grieve my loss, and while I wish it would have been a faster process for me to accept my disability, I'm so glad that, in the end, the choice to get an implant or not was my own.

I did much research over the years, and especially for this book. In doing so, I met a guy in a support group who had been bilaterally implanted (both ears). Surgery didn't work for him, so he had them explanted and reimplanted a few years later. Once again, the surgery was unsuccessful. This man was angry and bitter and voiced his opinion loudly. It scared me more than the thought of the actual surgery, but I appreciated his honesty too. I needed to contemplate the what-ifs. I knew, for certain, I'd never be able to have CI surgery until I got to a place where I could accept that if the surgery was unsuccessful for me, I wouldn't live my life angry and bitter, because honestly, what kind of life would that be?

More research for this book led me to a consultation with an amazing surgeon, Dr. Fred Telischi, at the University of Miami. I told myself I was only asking questions for Rayne's benefit. To make sure my story was accurate. It was a lie I believed, just like Rayne believed the lie that her hearing was fine. The truth of it, though, is that meeting Dr. Telischi changed everything for me. He answered my questions with fact-based science and essentially calmed my fears. By that time, the hearing in my left ear was only eight percent anyway, and after much soul-searching, I knew that losing eight percent versus the potential to gain hearing and clarity was worth the gamble. It was time to try a unilateral (one ear) implantation. That decision alone brought immense internal peace.

I'm grateful to have a supportive family and friend group who embraced my choice. They never pushed me to get or not get the surgery. They never saw me as broken, even though I saw

myself that way for far too long. And during my recovery, they were with me every step of the way.

My surgery was a huge success, but it wasn't perfect. In quiet situations, my hearing is now up to one hundred percent word recognition. In louder settings, it's around seventy-two percent. The clarity of words is incredible—something I've missed for the last thirty years. I still cannot decipher lyrics to songs well, and I still use captioning on my TV. Large groups and noisy places will forever be challenging environments for me. But for the most part, one-year post-surgery, I've gained back the independence I lost a long time ago, and that is exponentially freeing.

I swore I'd never write a book about a character whose entire story revolved around hearing loss. I never wanted that to be a focus. And yet, after a conversation with a wise, editor friend who felt I should write that very story, the entire first chapter came to me quite suddenly in the car the next day. Once I gave in to the idea, I ended up writing the first draft of the book in only four months. It not only allowed me to discover so much about my own hearing loss and the possible sources of it—it's likely that, as is the case with Rayne, my loss stems from an antibiotic that was used to treat my many ear infections as a child—but writing the book also provided much therapy for me. I wrote it before I had my CI surgery, but ironically, it sold just two weeks after surgery. Fate? Luck? Who knows? But I'm glad I'm able to share Rayne's story with the world.

For those of you who feel you don't fit in in either a hearing world or a D/deaf one, you are not alone. Reach out to support groups. Talk to people in similar situations. But remember, your journey is your own. No better; no worse; just different.