JOIN ME ON
MY JOURNEY

Cochlear Story Archives:
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HearWell™ CENTER
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My Cochlear Implant Journey, Part 1: Join Me on My Journey

When I first meet a patient, I tell them I'm very hard of hearing. In fact, it's part of my welcome speech introducing them to HearWell Center. I explain that I need to lip-read to understand speech, that I might ask them to repeat themselves occasionally, and that I appreciate their patience. Because the patient is my primary concern — not my own hearing issues — I don't go into details.

Why do I do this? Over the years, as my hearing worsened, it became clear that those around me could tell I had communication difficulties. I could no longer ignore the clear sign that I was confusing those around me. So, when I opened HearWell Center, I decided to disclose my hearing loss to every patient that walked in my doors. I never want my hearing loss to be misunderstood as something else by my patients or their families. My worst fear is that I won't hear something, and my lack of response will come across as unkind.

Most people come to appreciate that my hearing loss puts me in a unique position to work with those who have hearing disorders. Some patients even tell me they're thankful I understand hearing loss firsthand.

Though I openly share that I have a hearing loss, many of my patients don't understand just how hard of hearing I am. Here, in this blog, I want to offer a more intimate look at my hearing loss because I am embarking on a journey: I hope to soon receive a cochlear implant. I want to share what I learn along the way because I think it will benefit my patients and others.

About My Hearing Loss

I have had severe hearing loss since childhood. I managed well for a long time by using hearing aids, FM systems, streaming devices, lip-reading, and captioning. In 2003, things changed dramatically for me: Overnight, I suffered the sudden loss of all remaining high-pitched hearing in my left ear. I haven't heard anything but bass sounds in that ear since.

At that time, I was not a candidate for a cochlear implant. The additional deafness was hard on me — I love music, but with the new loss it no longer sounded good — and I was crestfallen for a long time.

I learned to cope with the loss. I trained my brain to cope with not hearing a full spectrum of sound in my left ear. With hearing aids, for many years, I maintained nearly 90% understanding in most situations despite the significant and continued decline in hearing.

Now, things are not so easy. My loss continues to worsen. My last audiogram showed poor recognition skills in my left ear. My coping skills aren't as helpful as they used to be. Even with hearing aids, I drain more energy as I work hard to hear people all day long. The drain makes me less likely to socialize in person or on the phone — I fear I won't be able to participate fully. At this point, I have much to gain by getting the implant and very little to lose.

Although I'm an audiologist by trade, I'm still a woman living with deafness daily. It's not easy to connect at times, so text messages, online chats, and emails show me I do have a community. I'm very motivated to make this work. I'm inspired by so many of my patients that have implants. Friends, colleagues, and family from near and far are sharing in my excitement and showering me with well wishes. I couldn't ask for a better support network. I am bound to thrive with all these pillars of support!

My Cochlear Implant Journey, Part 2: Surgical Consultation

Surgical Consultation

The first step to determining if I can get a cochlear implant was to make an appointment at one of the centers in Pittsburgh with a neurotologist and cochlear implant surgeon. My insurance required that I go to Eye and Ear Institute, an old, familiar friend. I did my clinical rotations there as a student, I've been a patient there, and I've sent my patients there for services and cochlear implant evaluations. I felt very comfortable making my first appointment with the surgeon.

That first appointment was fast: I'd already completed the requisite paperwork, I had a recent audiogram, and I had a CT scan on file that the surgeon could review. We discussed whether to go forward with the testing to determine my candidacy, and I told him I was ready. He said if I met candidacy he would have no qualms going forward with the surgery. I was happy to hear this. Although I was pretty sure I was a candidate, I still had some doubts. Hearing the surgeon agree to take me as his patient added to my confidence and I started looking forward to having the final determination.

The implant audiologist had a busy schedule, so I had to wait six more weeks to be tested. It felt like time actually slowed down as I awaited this appointment. People kept asking me if I was excited or nervous. I was both. I knew the results could go either way. I've seen the disappointment of my patients after being denied an implant — the testing disqualified them even though all signs indicated they were a candidate. I guess I was wearing emotional armor while awaiting the test results.

Audiology Testing

I won't keep you waiting — my left ear qualifies for the implant! The testing went well! They definitely put me through my paces during the audiology testing — I had to perform four critical-listening tests for speech and one test for hearing beeps.

Each test was performed with my hearing aids, but only one ear at a time. For the first test, I repeated long, single-word lists (about 50 words per ear). That was difficult because there were no context or clues. For the second test, I repeated sentences that were read to me slowly. This was a good deal easier because I had some context. My better ear actually performed well! My left ear barely registered what I was hearing — I might as well have just guessed my responses. For the third test, I repeated sentences read more quickly with four different voices, two female and two male. That was so hard. It was weird that one of the more bass, low-pitched males was actually harder for me to hear. I thought it would be the other way around. The final critical-listening test was sentences in noise. That test was impossible; I don't think I heard more than a few words.

As I said, each test was performed on only one ear at a time. My brain doesn't like that! I much prefer to have both hearing aids in together. Before we wrapped up the test, the audiologist had me use both hearing aids together, just to see. I was thinking to myself, "This is going to be much easier." I was WRONG! Even having both hearing aids in, I only understood 16% of the speech-in-noise test.

By the time I saw the surgeon for the medical consult I was so wiped out I didn't think I would be able to follow. Thankfully my husband was there to lend his ears, and they put everything in writing, too.

Auditory Fatigue

Auditory fatigue is no joke. Every day I deal with fatigue from straining to hear. Testing took at least an hour, and then I had the consultation. I was with my audiologist from 8:30am until almost noon, and I was hyper-focused the entire time. I was practically dizzy from the effort.

I was still feeling the effects of the strain the next day. My eyes were tired from lip-reading, my brain was tired from piecing together a jumbled mess of sounds, and my ears were ringing. Since I didn't have patients scheduled, I decided to take the day off and rest up. A little rest did the trick. I was back to work the next day and holding up just fine.

This experience reminded me that when I finally got the implant surgery my listening skills were going to be pushed to the limits. I will only have my "good" ear for a few weeks while the surgical site heals. I am preparing for the challenge and making sure I have assistive devices in place to support my listening needs.

Thanks for visiting again and please feel free to comment. I may not be able to reply to everyone but I am thankful to have so much support. I'll be updating again soon!

My Cochlear Implant Journey, Part 3: Vaccinations

Vaccinations

To protect me from meningitis and other serious infections that can result from cochlear implant surgery, I'm getting two vaccinations. The vaccines occur about eight weeks apart. Their names are Prevnar 13® and Pneumovax®.

I got my first vaccine yesterday at RiteAid. It wasn't difficult — I just filled out an intake survey and waited for the pharmacist to prep the injection. That said, the event was still significant to me. Getting a needle pushed into the muscle of my arm somehow made things more real: It was like someone slapping me across the face and yelling, "THIS IS HAPPENING!"

It's weird how the mind works, but each step I take in preparation makes something I've only conceptualized in the past become more and more my reality.

Now my arm is sore, and I have eight weeks to forget about how much that hurt before they do it again. I guess I'm going to have to work on my pain tolerance — it's no small thing to have an implant. I hope I'm not too wimpy!

Learn more about vaccines for cochlear implant recipients: *https://www.cdc.gov/vaccines/vpd/mening/hcp/dis-cochlear-gen.html*

My Cochlear Implant Journey, Part 4: Choosing the Brand

I started the process of choosing a brand and model of cochlear implant, and I got a bit of a shock — the patient does most of the research on their own. I've been trained in implants, how they work, and what's available on the market, but not about how patients are counseled to decide on their brand and model. It turns out it's significantly different from hearing aids.

In my many years of using and dispensing hearing aids professionally, I've found it is rare that a patient will do the research on what they need. I've come across a few that are well versed in hearing loss, but by and large, they do not know enough to make the decision on their own. Why? The great complexity of the task. They're faced with understanding and factoring in so many aspects, from the types and degrees of hearing loss to the types and levels of device technologies.

Implant patients are different. For one, they're embarking on a lifelong commitment to something physically implanted in the ear. There's no return period or exchange option for the implanted electrode array. Secondly, they're choosing from three brands, and each brand only has one or two current models. The hearing aid patient, on the other hand, is faced with hundreds of hearing aid models and possibly thousands of setup configurations. Lastly, the implant patient is starting a journey that is unique to them — no one else knows what they can and will hear or how they will do.

Here I find myself in the shoes of the patient, and I haven't been here in a while. It's a bit unnerving to suddenly be tasked with choosing an implant. I imagine most people must feel a sense of loneliness at first, not knowing anyone else with implants. I am fortunate that I know many people with implants, so I didn't feel alone in this journey. I think social media is ideal for fostering these kinds of connections. I was able to join Facebook groups intended for implantees and quickly absorbed information about real-life experiences. I reached out to a network of audiology friends for support, and that was a tremendous help to me early in the process of choosing a brand. Some of my patients and close friends who have received implants shared their stories with me, and this was invaluable.

I contacted all three companies: Med-El, Cochlear Americas, and Advanced Bionics (AB). My audiologist provided me with information on each so I could start my research. I was fairly certain I wanted to get AB, but I needed some time to make up my mind. I spent roughly a month researching before I finalized my order.

Each company has its strengths. I admire that each company takes pride in their product, goes above and beyond to get information into the hands of the consumer, and even made face-to-face appointments to sit down with me.

I was excited to learn that Med-El was the first implant company, and that it has developed some unique features not found in the other brands, such as an MRI-safe magnet. I didn't, however, like Med-El's case design. I want onboard controls, which they don't offer; I'm not very good at carrying remote controls. I decided early in the process that I didn't want Med-El.

I focused my energy on comparing AB and Cochlear. Cochlear has attracted a great deal of attention with the direct-to-smartphone connectivity. This is certainly a great step in meeting a consumer need. I noted that the Cochlear product appeared a bit smaller and lighter in weight than AB, and it had a really nice Aqua-case for waterproofing. Cochlear also has a strong reputation for backwards compatibility, allowing newer technologies to work with older implant arrays. This certainly was a big plus. For me, however, the Cochlear product didn't quite fit the bill. Although it had many attractive features, I was still more interested in AB.

AB's strength is in options. I LOVE options. It has the onboard controls, many microphone configurations (including a really cool mic called a T-mic), and a large line of accessories. My favorite feature is that it pairs up with a hearing aid called Phonak Link. Since my right ear is not a candidate for the implant and looks to be holding strong for now, I wanted a hearing aid that would sync up with my implant. I liked the idea that the two would work in tandem.

It was difficult narrowing down to one company, but once I did, I could start to get excited about the features and accessories. I had a pretty fun time looking at all the battery accessories, waterproofing accessories, color options, microphone options, and more. Filling out my order form was a work in progress for several weeks, and I kept discovering options I needed to research more.

My Cochlear Implant Journey, Part 5: Preparedness and Hope

The date fast approaches.

With my surgical date just around the corner, I'm reminded of the need for not only physical preparedness but mental preparedness as well.

I went for my second vaccine. As you probably remember, I received the first one eight weeks before. The crazy thing about waiting eight weeks is that I almost forgot the implant was happening. I had to go back to my life and the things I normally do, and it was just easier to forget about it. Just like the first vaccine, there's something about getting jabbed with a needle to help wake you up to reality.

Thinking about the reality of surgery can be a bit scary, so I know I need to take my mind off my presurgical nerves. Writing out my hopes and dreams seems like a good place to start.

> **Hope for the best, but prepare for the worst.**

There's a magical quality to hope. When I found out I was getting an implant, a new sense of hope budded and gave me a little stir of confidence. I even started answering my caption phone without relying on my husband, Phil, to screen the call first. But I discovered the strangest thing: slowly over eight weeks, I started to lose sight of that budding hope and fell back on older habits. I resigned myself to my limitations instead of pushing myself to overcome. Deafness is trying for me; it causes extreme fatigue, so it only makes sense that my energies would putter out.

What I most look forward to with a cochlear implant is **renewed hope**. I look forward to the possibility of improvement and change for the better. I have aspirations and desires I am working toward with the implant. The first is to hear with ease in quiet situations when facing someone. This may seem like such a simple thing, like I'm setting the bar low, but for me it would be a game changer. Most of my interactions with people are face to face in proximity. What a wonder it would be to hear every word! I'd love to catch all the little side stories that people like to share. I'd really like to be able to hear jokes again and laugh along. Asking people to repeat jokes just doesn't work out well.

I don't enjoy my current coping mechanism, it's not really my style: I strong-arm the conversations and stick with the business at hand. I keep the conversation predictable. It's not fun for me, and my communication partners would probably like to be able to relax, too.

There are many things I dream of doing, but I don't want to get my hopes too high. Maybe after my implant activation I'll feel confident enough to dream higher. I just don't know if I can count on that, because so much about the process is unknown. Everyone has a different experience with implants.

I do know if I start to hope higher, I have a pretty long list…

I would love to answer the phone and not get all anxious about it. I'd like to talk to my friends when I need a friendly voice. I would love to relax. My current operating method is "high alert": I constantly scan for visual information to fill in what I don't hear, and I'm always checking in with other people for clarity and more information. Being on high alert all the time is draining. I dream of not depending on lip reading. It's a great skill to have, but when relied on heavily it leads to fatigue and a certain level of intensity. People who don't know me sometimes seem intimidated, and I think it's because of my nonstop lip reading.

I'd love to hear spontaneous discourse, random things people say in the elevator or the supermarket, the hellos and goodbyes of those I pass in the hall. I'd love to know what people say to each other, the local lingo, the newest slang. I'd like to know what my neighbor is yelling out her window. I'd like to hear some of the softer sounds my cat makes, not the loud meow I hear fine now, but the softer chirps and grunts.

It's hard for me to flex the optimism muscles, but if even a third of the things I listed were to improve, I'd be so happy. Even if the improvements were incremental and not complete, that would be alright, too. There's much to gain from and the implant, so I will practice hopefulness over the coming months, as it will motivate me to work hard to learn to use my implant and rehabilitate my mind to hear again.*

My Cochlear Implant Journey, Part 6: Surgery Day

PB&J On Standby

The Friday before surgery, I received my pre-op instructions and my scheduled time of arrival. I was to stop eating and drinking at midnight the night before and was instructed to shower with antibacterial soap the night before and the morning of surgery. I was told not to wear jewelry and to have loose-fitting clothing.

Dr. Yoder on surgery day

There was a flurry of activity all weekend prepping the house, the office, and me! I spent the weekend preparing easy-to-eat foods and stocking the fridge with beverages in case I didn't have an appetite. I cleaned the house top to bottom and did all the laundry. I knew if I didn't do those things, it would bother me when I returned home.

Thinking I may lose some of my sense of taste for a while, I made a pretty diverse meal plan. I figured I'd have some of my favorite easy comfort foods — eggs and buttered toast, oatmeal with berries, PB&J. These foods seemed not only easy to make but also easy to eat.

In preparation for the surgery, I washed my hair the night before. I knew that I would not be able to wash it again for a while, so I wanted to give myself a clean start. I set out some books, magazines, and a collection of DVDs to watch and made sure my Netflix streaming subscription was active. I felt prepared come Monday.

Nothing Left To Chance

I'm not sure when the sense of peace and calm came over me, but I really felt ready for the surgery by the time my date arrived. I felt very confident in my surgeon and felt I was in the best hands.

It likely helps that he had already performed the same surgery on many of my patients. Having referred patients to the implant center for the last 14 years, I was already familiar with the positive outcomes and had heard many patients relay their success stories to me.

The day of surgery, I arrived at the ambulatory surgery center around 5:15am for a 5:30am check-in. After a bit of waiting, I was sent back to the initial prep area where I was told to gown up. Although I was ready for the surgery, I was nervous about one thing: communication.

1. Dr. Yoder 48 hours after surgery
2. Dr. Yoder recuperating at home

I decided under no circumstances could I leave this up to chance. I spoke up to the nurse, letting her know she needed to face me and come closer to let me lip-read what she is saying. She was a champ, moving her entire computer system close to my bedside to do the intake.

Once I was gowned and my intake completed, and I had provided my consent, they let my husband, Phil, come back to see me before I rolled off to surgery. We had a short visit, and then I was rolled off to another floor for the surgery prep.

At this point, I still had my hearing aids and glasses on and was very protective of them; I needed both to hear and didn't want them removed until the last possible moment. I also wanted them back when I was in recovery so I would be able to hear the team when they woke me up.

The team decided my surgeon would be in charge of my hearing aids, including putting them back on when surgery was done. My glasses were sent down to Phil since I could see well enough if people leaned in closer. It made sense, but at the time I was nervous to part with my glasses. After surgery, I understood the glasses wouldn't fit on my head with the bandages anyway.

In surgery prep, I met the anesthesiologist and reviewed my history with him. The surgical nurse placed my IV, and the surgeon came in, marked the ear he was cutting, and reviewed the process with me again to make sure I didn't have any questions.

Dr. Yoder shows shaved area

I think there are few times in life when I have felt this ready. Maybe it had something to do with it being so early in the morning and that I hadn't had anything to eat or drink for a while, but my body and mind were very calm, and I didn't feel nervous. I just felt ready.

An Emotional Moment

After the IV was placed, they rolled me across the hall, and shortly thereafter I was breathing deeply into a mask. I don't remember anything from that point until I awoke in recovery. General anesthesia is so strange — one moment you're fully aware, and then you wake up as if nothing happened.

In recovery, I woke up and didn't feel bad but had some pain. The nurse decided to give me pain meds and said they might make me sleepy. Shortly after she injected meds into my IV, I was asleep again.

I can sleep long and soundly at home, so I suspect that with the sedating effects of the anesthesia and pain meds, I was very hard to wake. They told Phil I was taking a long time to wake up, so I stayed in recovery for a while.

I remember being moved back to the same prep area where I started but was pretty groggy for the ride there. The next thing I knew, Phil was walking toward me. I became overcome with emotion seeing him and started to cry.

To this day, I still do not understand those tears. Perhaps I was just happy to have survived a surgery. Perhaps it was the drugs. Perhaps I was relieved, and they were tears of joy.

I found one of my hearing aids was in my ear and one in a jar on my lap. I could not wear the left hearing aid, as this ear was under surgical bandages, but at least my right ear could help out.

Phil brought my glasses, and I put them on crooked due to the bandage. At least I could see and half hear what was going on. It was a relief to have some senses back but also a bit annoying to hear nothing from the left side.

I had a very tight bandage around my head with what I call an "ear cup" on my left ear. The bandage was so tight that I reported more pain from the bandage than from my ear. The nurse asked me to rate the pain on a 10-point scale. I said it was about a 4. She said she would prep pain medications I could take home and said the surgeon would come to look at the bandage before I was discharged.

A New Chapter

I had no concept of time while at the hospital. I knew we started the day at 5am and figured it was probably close to noon.

Turns out it was closer to 3pm by the time the surgeon saw and discharged me.

He was very reassuring, letting me know that the surgery went well and that my job was to just rest and heal and that he would see me in a week. He said I could adjust my bandage but that I needed to keep it on for at least 24 hours. The compression would help keep swelling at bay and aid in the healing process.

The nursed asked if I was up for walking out, and I said, "Yes." I amazed myself that I just had surgery on my head and yet was walking the hospital corridors to the exit with the nurse and my husband without difficulties. I didn't have any problems with my balance. I was beyond happy to know I would be able to walk and not be dizzy or off balance.

The nurse saw me off and wished me well, and Phil took me to the garage to our parked car. I was awake and in a great mood for the drive home and feeling as positive as could be. Phil took me home where he and I would spend a watchful 48 hours together, and I officially started my convalescence.

My Cochlear Implant Journey, Part 7: Convalescence

Thankful Homecoming

I made it home from surgery safe and happy. I suffered no adverse effects, had no dizziness, and walked fine. My taste remained normal — no metal taste — and there was no facial numbness, tingling, or facial paralysis. I can smile!

As per the plan, I spent a week on the couch and rested and healed as much as possible. I was on pain medications, and though I wondered if I needed them, I didn't want to skip one to find out.

I decided that the pain medications would support my healing process by allowing me to sleep more soundly, so I opted to stay on the prescribed schedule to maximize the effects. With my sticking to the plan, I had to avoid driving or making big decisions. I could do that for a week, no problem.

My husband, Phil, stayed home the first 48 hours to help me and keep an eye on me. Thankfully I was fully functional and able to walk and prepare my own foods and take my medications, but it was nice having him at my side.

Phil made some delicious meals for me while I was laid up. I was craving salty foods, and my favorite dish was eggs and salmon on buttered toast. I liked it so much I think I ate it every day. I'm happy to report I did not lose my appetite.

The pain from the surgical site was bad the first night due to the bandage I had to wear for 24 hours. I lost some sleep that night. The pain medications didn't seem to help enough. We tried loosening the bandage to relieve the pain, but my ear felt like it was tenderized by a meat mallet. No adjustments could provide relief.

Thankfully that bandage came off the next day. For many weeks following, I avoided touching that ear in any way.

Dr. Yoder's ear after the surgery bandages were removed

The Big Reveal

We got a good look at the surgical site once the bandage was off. The incision was bigger than I expected, extending all along the bone behind the ear in a curved fashion at least 4 inches.

The area was red and swollen, making it difficult to get a sense of the extent of the trauma. It would be two months before I'd see the depth of the drill points where bone was removed or drilled out.

The incision was covered with Steri-Strips to protect it and keep it clean, and I was instructed not to wash my hair until my surgical follow-up in 10 days. That's a long time, so I had to get pretty creative. Braiding my hair was my fix.

My time off was unremarkable, filled mostly with Netflix and Amazon Prime Video, emails, and social media. I gingerly moved around the house and did some light cleaning and organizing to stave off boredom.

I think in some ways I missed the office. Having time off after surgery just isn't much of a vacation. It felt like idle time. Going back to work the following Monday after surgery was a relief. I was really getting bored. With all the restrictions on activities, I wasn't feeling like I could accomplish anything.

No Crooked Smiles

I knew I'd be working two to three weeks without hearing anything in my left ear, so I gave myself a pep talk on the way back to work. I determined I could manage one way or the other and that my patients would be patient with me.

Still, it was scary to return with only one ear working. The right ear — my good ear — isn't that good. I give it a great deal more credit than I probably should. It has a severe-profound hearing loss that isn't much better than my left ear, but with my hearing aid I can maintain a decent speech score.

With context, lip-reading, and my hearing aid, the "good" ear can carry me. Even so, going from stereo to mono is jarring.

Around two weeks post-surgery, I felt completely free from pain. With no pain waking me up, I slept well and spent a couple weekends just catching up on sleep. I don't operate well without it, so this was a big help.

Dr. Yoder's ear two weeks after surgery

Around this same time, I had a post-op visit with my surgeon. His resident removed the Steri-Strips and checked the incision. Everything was healing as expected. They had me raise my eyebrows and smile to check for evenness. No crooked smiles here.

They looked in my ear, and my eardrum was looking great. I told the surgeon that my ear felt a bit clogged and that I suspected some fluid. He said that was normal and to give it more time to heal.

The doctor sent me home with instructions to apply triple antibiotic ointment twice daily and to go ahead and wash my hair but blot dry around the incision. He said he would be attending my activation appointment in two weeks.

A Turning Point

That medical visit was my first outing on my own since surgery. It was nice to be independently capable. I felt like I was getting back to normal.

I was also happy to have permission to wash my hair. I thought I would run home to do it, but when they took off the adhesive bandages, my incision became tender. I decided to wait another day, letting the inflammation subside before shampooing.

The next day, I felt much better and shampooed for the first time in ten days. What a relief! With my hair wet, I could feel some small new lumps from the implant and magnet under my skin. I expected that some of this was swelling, but it was still very strange to feel these new bumps.

With such a good report from the surgeon, I decided to put my hearing aid back in my left ear. Surprisingly during the first few weeks post-surgery, I still had usable residual hearing in my left ear, so I went back to wearing my hearing aid daily in the implant ear. It wasn't much but having a little bit of hearing helped me feel more balanced. Sadly, I later lost this residual hearing, but it was good to have it during those transition weeks between surgery and implant activation.

My second week back, I was still keeping up. Whew! I had feared the surgery would set me back more and force me to take sick leave. We did have to ask folks to schedule out farther because my follow-up visits with the implant center would take me out of the office. This would continue a couple more months as I went through rehab.

Thankfully we had some very thoughtful patients who were working around the scheduling challenges.

My Cochlear Implant Journey, Part 8: The Bubble

Not My Imagination

Nearly three weeks post-op I had a medical scare that was quickly resolved. The process of healing was going well, and I thought I was pretty prepared for what to expect along the way.

Still, I've come to realize that with cochlear implants there is much you can't predict. People's experiences can vary, and much of the process is discovered as you go along. My scare was no doubt fueled by reading stories about implant failures, so I think I'm partly to blame for how this went down.

I was just going about a normal day — had breakfast, went to work, attended a lunch meeting. On my way back from the meeting, however, I noticed swelling. While putting my hair up, I felt a distinct bubble and a large ridge behind my ear leading up to my magnet.

I thought I must be imagining things, but back at the office, I asked my husband, Phil, to take a look. He saw it, too. I had just come off the elevator and was feeling dizzy. To be fair, elevators have made me dizzy for a few years, but add in the swelling and bubble, and I started panicking with thoughts of an infection.

Detective Work

We called the surgeon's office, which had me come right down. I'm fairly certain the doctor was on his way home and was paged and turned around. I'm so thankful that everyone jumped to help me, for I was growing increasingly nervous thinking of every possible thing that could be wrong.

En route to the doctor's office, I took off my left hearing aid and glasses and just let the ear rest. By the time we arrived, Phil no longer saw swelling. I, too, thought the swelling had gone down, but it felt tight behind my ear, and I had an ache all over in the bone around my ear. It just didn't feel right.

At the office, the doctor looked me over. He said he saw no sign of infection and reported that all looked to be healing very well. He explained that the tissues are actively draining as they heal and, with gravity, will sometimes pool in a spot.

I had been wearing all my gear lately — glasses plus hearing aids — and the doctor determined that the combination caused a dam effect blocking the drainage from occurring, creating a temporary bubble. Once I removed my glasses and hearing aid from that ear, the bubble went away with the drainage reabsorbed.

The ridge I was feeling? It was my implant. The doctor demonstrated it on an implant model, explaining that I have thin skin and, with the swelling nearly gone, could feel the components.

Great Relief

I guess I underestimated how much of a bump I'd feel under my skin. I was so relieved, I admit I cried a bit. I thought I had hurt myself or had not been careful enough. We were so happy to learn that things were healing properly. The activation, set for the following week, was still on.

Activation couldn't come fast enough. I was feeling eager to have some sound again. The longer I waited, the more little doubts started to creep in. I suddenly felt I needed some results and some sign that this worked — that all this was leading to something worth the wait.

My Cochlear Implant Journey, Part 9: Activation

A Big Change

Twenty-two days after surgery, my cochlear implant was activated. I will be honest: I had some very mixed feelings on activation day. It was all so new to me that I needed time to process from a hearing standpoint and an emotional one.

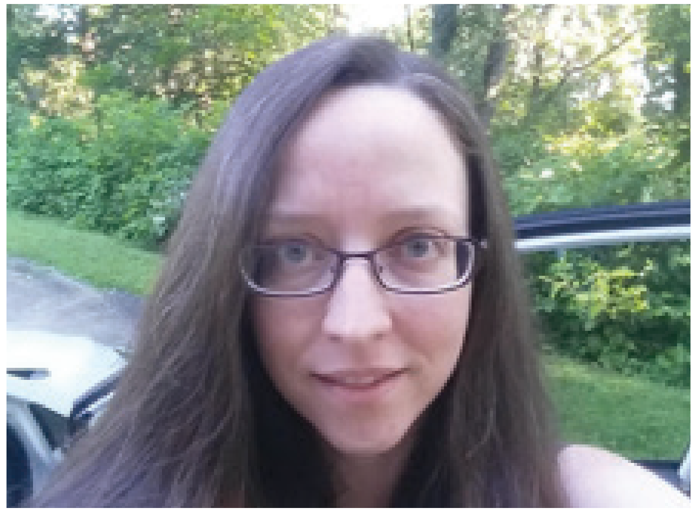
Of greatest importance, the implant did come on; there's always a risk that it won't. All but one electrode worked. With 16 electrodes, having 15 viable ones is still considered very good. I was not only hearing with the implant but also experiencing pitch and volume recognition. These were all positive results pointing in the right direction.

Emotionally, however, it was hard to appreciate the sound coming from the implant because of the strange quality. I was sad and scared that my hearing would always sound bad with the implant, and I had some fleeting thoughts of regret.

My audiologist tried to reassure me that it would get better, but the change was so extreme that it was difficult to believe her. Despite my emotions trying to get the better of me, I knew logically this was a process, so I dug deep and persisted. I would have to use the implant as much as possible — despite the sound quality — and return for further adjustments once I adapted to the electrical input.

An Epiphany

After activation, I was thankful to have some downtime. I reached out to many friends and colleagues, comparing notes with those that had been through this process. Many of my audiology friends warned me that I needed to set my expectations low, but I didn't know what they meant. Not really.



Dr. Yoder on activation day

There's just no vocabulary for describing electric hearing. There's really no way to prepare someone for this. My concept of hearing with an implant was that I would hear an enhancement of what I was used to hearing. This is not what happened for me. I was hearing in a completely new way. It wasn't good or bad, just very different.

I think it's only human and natural to face something this different and sort of panic a bit. Some moments of panic did take hold. Had I made a mistake?

My attitude started to adjust pretty fast. About eight hours after activation, I took off my implant to show it to a patient. Suddenly I fell back into my deaf, silent world on the left side. I was a bit surprised that in only eight hours the implant had supplied my brain with awareness, balance, and a sense of presence on that side.

I had volume. Maybe it wasn't the quality of sound I wanted, but it was sound, and I immediately wanted to put it back on! I felt this was my first step toward success. I wanted to wear my implant. Whew! I needed to give my brain and my implant more credit. Already, my brain was starting to like this.

Reconnection

I'm going to attempt to explain what I heard on activation day. It was Day 1, and things were expected to change rapidly every day and continue changing in the coming weeks and months. Keep in mind I was hearing sound electrically, not acoustically.

My best description is that speech sounded thin and lacking in body. Sounds were shrill and tinny. My voice came across like Minnie Mouse on helium, and my laugh sounded cartoonish. The fan on my air conditioner at home sounded like a wind tunnel. Some things sounded like a kazoo or the whiny sound of wind whipping against a house or across the roof of a car at high speed.

It was hard to even recognize speech at first. With each passing hour, I would understand more and more. During the hours I was being tested at activation, I knew speech was there, but I had to rely heavily on lip-reading to understand it. Later that day, I started to hear a few words without having to lip-read.

Some words came through clearer than others. The word "which," for instance, sounded pretty normal. While his head was turned, my husband, Phil, said, "I'm trying to figure out which one is which," and with my implant on I heard him! That was really something.

I was working hard to hear and figured that would be the case for some time. Speech would likely be a challenge for several months, but I expected to further improve each day.

Brainpower

I had an exciting discovery within the first week of activation: I could understand "S" sounds, which I hadn't heard for many years. My husband said my speech was already better, with less of a nasal quality. I was surprised he said this because I don't feel like I can hear my own voice well. I do hear myself — just differently.

To maximize the implant, I began online auditory training classes that helped exercise my listening skills. The exercises would appear easy but were actually quite difficult with an implant. For instance, I had to determine whether a sound represented clicking keys on a keyboard or a horse galloping. During the first few weeks, I could not tell.

I also tried to focus on speech sounds by listening to spoken words. I would hear a word — "pick," for example — and have to choose it from a group of words. This proved nearly impossible at first, but every day I worked on it and slowly but surely started to understand some of the words.

The brain is pretty amazing in its power to adapt, and I have surprised myself many times along this journey.

Dr. Yoder's cochlear implant

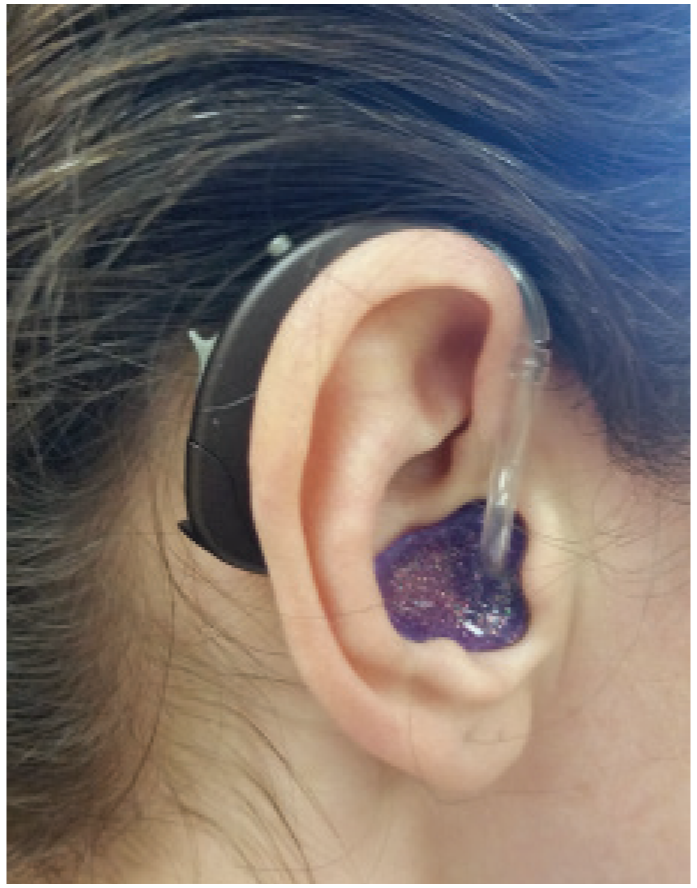
My Cochlear Implant Journey, Part 10: To Hell and Back

Where will I go with this map? My first trip was to hell and back.

Until I became a cochlear implant user, the term “mapping” was a pretty mysterious word. I understood that it basically meant that the implant was programmed and fine-tuned but I didn’t know how it was done or what was involved. I admit I was ignorant of the practice of mapping implants as I’d never seen one even in graduate school. My first experience was a personal one and it was terrifying.

Some may wonder if the YouTube videos with people hearing for the first time are accurate, and maybe for some they are, but in my case, my activation video was a sad and depressing watch. In fact, we deleted it — quickly. I received my first map on activation day — July 10, 2018. While I sat with my implant processor plugged into a pod attached to a computer, I started to feel more and more anxious. I was deaf to all around me, my hearing completed gone from a “natural hearing” standpoint in my left ear, my other ear unaided — during the mapping activity, my hearing aid was turned off — and my processor was not yet attuned to environmental noises. I was alone in my silence and my thoughts were not heading to a good place.

All I could do was wonder if this was normal, was I doing well, was I hearing, what do all these beeps mean? All I could hear were tiny electronic sounding beeps getting progressively louder. For a span of time that felt like an eternity, I sat and rated the loudness level of these tiny weird beeps. I was quickly feeling fatigued and almost lightheaded from the effort of focusing on these buzzy beeps. I started to fear that I was not doing well because it took so long. It seemed like everyone in the room was staring at me waiting for me to do something. I felt the weight of their stares. I started to just look straight down at the table and try to ignore that there were other people in the room. I was surrounded by people but felt alone. I thought I might cry and I almost did when the processor was finally turned on.



Dr. Yoder’s right ear

Finally, the mapping was completed, and the processor was turned on but all I could hear was a loud buzz and feedback. The buzzing overwhelmed me like a bright light. It was as if I exited a dark theater into the brightest summer sun, only I wasn’t adjusting, and it wasn’t getting any better. I felt a lump in my throat that got even bigger when my audiologist started talking.

To this day I don’t know why I didn’t break down and cry when I was activated. A rush of dread set in and I was falling farther into my regret by the minute. The audiologist sounded so far away, so thin and squeaky… her voice did not even seem human! Was she even talking in English? It was hard to know. I didn’t hear any speech sounds, only weird electric hisses, buzzes, and squeaks.

I hated it. I don’t think I’ve hated many things in life as much as I hated the sound of my implant.

Dr. Yoder’s fitting, side & back

I focused hard on her lips and realized she was trying to encourage me, trying to get through the haze of negative feelings that she probably read on my face like a book. She wanted me to know it was normal to not understand speech, that it takes time, and that it’ll get easier. I did not believe her because, I am sorry to say, I lost faith. I remained without faith as I walked out of the audiology office and got into the car to leave. I was numb, dumbfounded, angry, and feeling alone.

My husband was beside me the entire time, holding my hand, encouraging me, going with me to all my appointments and yet it felt as though I was alone. Why? I guess I felt that he can’t know, his hearing is normal, he won’t understand. It’s not really fair to him but it was a reality in my mind at that point. I wondered: *will anyone know what I feel?*

When faced with this type of challenge I figure there are two ways to go… panic and depression or persistence and faithfulness. I am ashamed to say when I left the office that day, I was in panic and depression mode. I felt pangs of regret. I recalled failure stories of people telling me it didn’t work, and people saying they never used it and wanted to explant. Thankfully, I jumped into action. I think I knew instinctively that my emotions were not serving me well and I started to reach out to others. I left messages with family, friends, audiologists, other implant users, consumer support groups, and my business networks. I posted my need for support on Facebook. My inbox flooded quickly with replies. Each reply helped me gain footing and climb out of the dreadful pit of despair I had dug for myself. The loneliness started to fade. I quickly bonded with others who felt the way I felt and experienced similar results with cochlear implants.

Admittedly, I can be willful, and I can put on emotional armor but I soften fast when others push. I received the push I needed. I am blessed to have a support system in many places. My husband and family, friends, audiology network, my patients, allied peers, and neighbors all rallied for me. They lifted me up. I had my ugly cry and after that, I turned a corner. I felt renewed faith. The side of me that knows all about hard work and persevering reclaimed my mental space. I decided to face this come what will.

How long did it take me to make this switch you might ask? It took 12 hours. That may seem like a short amount of time, but it’s a span of time that still lives vividly in my mind.

My Cochlear Implant Journey, Part 11: No Sugarcoating it — Adjusting Is Hard

After reading my previous chapter, you might wonder if I ever started to hear speech or anything other than buzzy weird sounds. The answer is yes! And quickly — I'm happy to report that within two weeks of activation I started to recognize big, positive changes in both my hearing and my general demeanor.

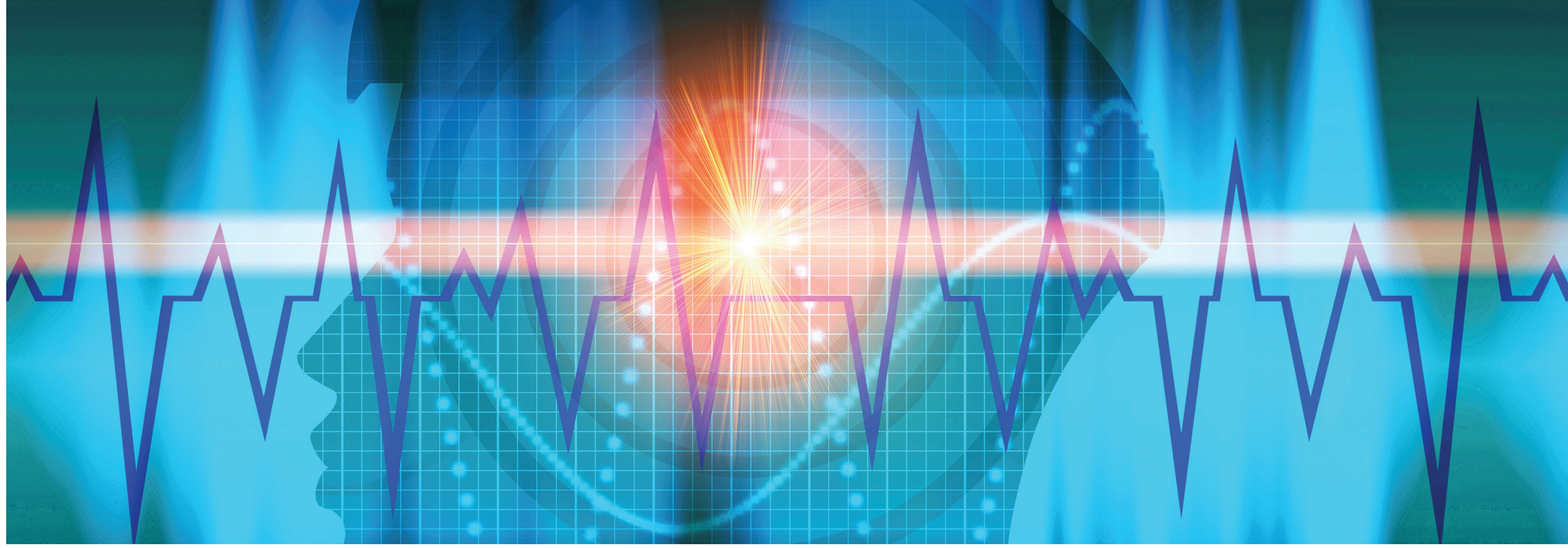
The implant has to be adjusted frequently in the beginning since there are changes happening both physiologically and cognitively. The trauma of inserting an electrode into the cochlea causes inflammation and, as that settles down, the implant will adjust and settle into a new home inside my ear. The healing occurring in my cochlea continued for many months. Also, the brain adjusted and what sounded weird and overwhelming on day one became quiet or even disappeared by day seven. This is due to my brain accepting electrical input as a new form of hearing and "relaxing" if you will. So, by the time I arrived a week later for map no. 2, I was in a much better position to undergo the procedure. I knew what mapping was, that buzzy, weird sounds were "normal" sounds, and I was familiar with how much can change in a matter of days.

Since I wore my implant every day, all day, I had adjusted to the sound so much I was turning the volume all the way up trying to hear more. My audiologist was visibly relieved and stated that this was a good sign and showed that I had accepted electrical input. We went through all the loudness levels again and added some progressive maps (maps I can use if I start maxing out the volume again) and reviewed my progress. We then set up my new right hearing aid and matched it up with my processor. Since I use an implant on the left and a hearing aid on the right, I'm considered bimodal. The new hearing aid was specially made to work with my implant and be its buddy. They are designed to share data and work in tandem to help optimize my hearing. We accomplished so much at this appointment that my audiologist stated that this was more like my real "activation" day and she expected things to be much more positive going forward.

After this appointment, I was hearing so much better that I experienced four days of elation. I experienced usable hearing. I was hearing speech! I wasn't constantly lipreading! I was able to hear in the car as a passenger! I was getting used to the sound quality and I was starting to like it. The endorphins were high. I began to experience renewed hope and I found myself more chatty and ready to take on the world. I was using my implant for long hours, doing auditory exercises an hour or more nightly, and just immersing myself in as much sound as possible.

I blogged in 2018 about renewed hope and how it can change a person and now here I am, hopeful. It's an amazing mindset. I found myself eager to skip ahead and impatient to reach the best outcome.

The excitement was palpable and even my husband could see that I was happier. I don't think I've ever before been so chatty in my life. Sadly, I wore myself out and did not pace myself. I became so tired so quickly I was forced to stop auditory training exercises for several weeks. I focused instead on getting through the workday and resting.



It is difficult to explain why the process is so tiring… you may wonder what I'm doing that is sapping my energy. Here's my best explanation. When it comes to hearing with the electricity, everyday sounds like dogs barking and traffic outside normalize quickly but speech and music do not. The brain is prioritizing sounds and everyday sounds are not "important" and therefore are not highly mapped in the brain, meaning the brain could easily replace those sounds with new sounds. It's an easy transition for my brain to learn a dog bark or a microwave beep since those sounds were never given much priority in my brain to begin with. Speech, however, is of the highest importance and possibly the most important sound the brain receives, and it has created a very large network of "maps" for speech. Furthermore, this neural network is intertwined with other parts of my brain giving speech "meaning." Speech and music are much more than mere collections of sounds — they provide sensations beyond hearing.

I imagine it takes a great deal of energy to do all this neural networking. I am actively forcing my brain to relearn everything about speech and music when I push myself to use the implant for long hours and to listen to my auditory exercises. My brain is working overtime and is not only relearning sound but destroying a lifetime of neural mappings and replacing them with new ones. No wonder I experienced fatigue and no wonder speech is so strange sounding. When I think about how the brain has literally been mapping speech since I was an infant and now I'm tearing that all down, it makes sense to me that it would and should be a long road to rehabilitation.

My Cochlear Implant Journey, Part 12: One-Year Anniversary

I hit the one-year mark on the left side feeling very positive and grateful for what I have accomplished. I'm continuing to perform well and have started to take for granted my hearing abilities to the point that I need to stop and remember how things used to be.

I know that with my implant just on the left side I have gained so much. As I reflect, here are some of the improvements:

I can hear in the car without having to lipread and I can hold entire conversations with my husband without facing him. The amazing part is that there is road noise in the car and normally, that would completely drown out everything, but with the cochlear implant, it's just not an issue.

I can hear a friend while walking side by side without lipreading. Again, the amazing part here is that I don't have to lipread and rarely have to ask for repeats. I make a point to have people on my "good" side (my implant side). I can remember when my other ear used to be my "good" ear. How things have changed!

I can have a conversation in a restaurant. The majority of the time when I sit in a restaurant with another person, I can hear the conversation. I do have to concentrate more and sometimes I need to lipread, but the effort is halved. I still struggle to hear the server and I can't make out the background music… so restaurant situations are still difficult, but not insurmountably so.

> { I can hold a conversation on the phone. }

I didn't think this would happen — I expected to always struggle on the phone. The amazing thing about the phone is that I can understand without captioning! Before the implant, I not only used captioning and amplification on the phone, but I asked people to speak slowly and I still didn't understand what they were saying. I missed so many subtle cues, emotional inflections, small talk, extension of niceties, and much more. I would apologize constantly for my ineffectual phone communication. I was often exhausted and embarrassed after calls and I had a real phone-phobia. That all changed. The phone is no longer the enemy. I still don't want to have long conversations but now I can function, and it is such a relief.

I can also hear random sounds in the environment. Just the other day while staying in a hotel I heard a machine running. I commented on it several times to my husband, and he said it was probably the wind outside. The following morning, he was standing closer to where I heard the noise and said that the fridge was running. I was hearing a machine after all and I heard it before he did, and his hearing is normal!

Being more aware of the environmental sounds has been very helpful for my awareness and has reduced how often I get startled. Hearing the world's noises keeps me grounded. I don't feel as though I'm on the sidelines all the time. It used to be that when people stopped to listen to anything, I would have to ask what they heard, never hearing it for myself… but now I am hearing many of the sounds, not always understanding what they are, but at least hearing them.

My Cochlear Implant Journey, Part 13: Deciding to Get a Second Cochlear Implant

There are several reasons I decided to take this journey again. I realize with all the positive outcomes of having just the left implant, it may seem unnecessary, so I'll try to explain.

For one thing, my right ear uses a hearing aid and ever since I was activated, the hearing aid doesn't seem to help. In fact, for many months, I could not even tell if the hearing aid was on or off.

Now that I've adjusted to hearing with electrical sound, when I take off the implant processor to hear with just my hearing aid, the acoustic sound is too weak to be useful. It would probably take months for me to re-learn how to hear and cope with only a hearing aid again. So, when in immediate need, I feel I cannot count on my right ear to help me. This means if my left implant is not working or I forget to change my processor battery, I would be without functional hearing. My coping skills are so unused at this point that hearing with only my hearing aid is very stressful. I have become wholly reliant on hearing with my cochlear implant. I want to be able to hear equally on both sides so that I have the security of at least one ear that can help at all times.

It's a small annoyance but having to always place people on my "good" side can be challenging. And sometimes I wish I could use either ear on the phone. I'd like to be able to switch ears when doing any listening-dependent activities.

Feeling more balanced and using both ears as the brain is designed to use them is important to me. I know that binaural hearing improves concentration and focus in noise, localization, and overall clarity of speech. I want to give my brain the best chance it has.

I'm not giving up much. At first, the idea of losing the remainder of my residual — natural — hearing was terrifying to me. If I'm being honest with myself, I don't have much functional hearing on my right side. The best I can hear without the hearing aid is a loud thunderclap, a dog barking 10 feet away, or maybe a very low-pitched machine running if it's close by. The only usable hearing in my right ear is the lowest pitches and even with a hearing aid, speech is muffled and reminiscent of Charlie Brown's teacher. To think that before I took this journey last year I used to understand this rumbling-mumbling with a percentage greater than 50% accuracy is just wild to me now.

Finally, I have hope that my right cochlear implant will work even better. The right ear, historically, was my critical listening ear.

Growing up, this was the ear I used on the phone and had the most residual hearing for the longest time. My right ear, being that it has not been as deaf as long, should, in theory, respond better to the implant. I hope that all 16 electrodes will work with this one and that I'll have even greater outcomes. My left cochlear implant, although it has performed well, does have some problems. On my left side, three of my 16 electrodes are compromised, and my hearing comprehension fluctuates, which means that I have good and bad listening days.

I'm very hopeful the right side will not experience problems; however, I'm prepared for all outcomes. I know there are no promises with surgery. It's possible that it won't work at all. I'm prepared that if it doesn't work at all, I'll need to rely on my left ear. If that happens, I will seek the help of the CROS device, use my FM system, and all the other accommodations I can make use of in order to continue to perform my best. I will hold to my optimism that it will work. I am prepared, even with a perfect implant, that activation may be difficult and that hearing with it will be harder before it is better. I expect it will take six months or more to adjust as it did with the first. I'm very excited and I feel ready!

My Cochlear Implant Journey, Part 14: Going Under the Knife, Take Two

I said goodbye to the last of my natural hearing on June 24, 2019, when I underwent surgery for my second cochlear implant, this time for my right ear. This second surgery was almost exactly a year after my first (June 18, 2018) but I remembered it so clearly that I felt nearly at home during the entire process.

The surgery was outpatient and lasted 4.5 hours. I also spent a long time in recovery. They gave me about three bags of fluids since I was a bit dehydrated. The nurses were very helpful and made sure I was feeling well enough before heading home since, apparently, I was a little pale and nauseated. Once the waves of nausea subsided and vitals were stable, I was sent home. I was in recovery for about four hours.

I briefly saw the surgeon but have no memory of what he said. Thankfully my family was there and took notes for me. The surgery was successful, and the implant was in place. There was difficulty getting the electrode to go in and the details are a bit unclear, but the surgeon reported he was confident, so I focused on that. The surgeon also hoped he was able to preserve some of my residual hearing since he used a steroid treatment this time. If I was lucky, some of my residual hearing would remain.

The healing process was easier this time. The earcup that I wore for 24 hours didn't cause as much discomfort compared to my previous surgery on the other side. Maybe I was just tougher this time around. When I took off the earcup, I had a brief bout of dizziness, but otherwise, I didn't experience issues with dizziness or vertigo. Initially, I reported that I didn't have numbness, but after 48 hours, I felt a mild numbness all throughout my body. I suspected it was a typical response to all the changes going on with the healing process and all the medications I was taking. I continued on my prescribed pain medication to ensure that I slept well, so I logged many hours of restful sleep.

I'm happy to report there was no tinnitus, which was a relief. I felt a bit of sloshing around in my right ear when I laid down indicating some fluid behind my eardrum (I anticipated this would happen since this happened last time too).

The pain from the surgery itself was very manageable. The worst pain was when I was still at the hospital. I reported pain at a 5 on the pain scale and it was enough to cause a few tears but once I was given pain medication, the pain was reduced quickly and stayed at a 2 or a 3 for the rest of the day. Forty-eight hours later, the pain was minimal and only peaked briefly around a 1 or 2 when the medication started to wear off.

Overall, the recovery went smoothly and seemed much easier than last time, though much of that ease may stem from being familiar with the process. It helped a great deal to have gone through this once before.

My Cochlear Implant Journey, Part 15: Activating My Second Cochlear Implant

Now that I have two cochlear implants, I'm done with hearing aids permanently. About a week after my surgery, I tried wearing my hearing aid but there was no sound. I realized I was completely deaf now. The attempt to save my residual hearing failed, but that was expected. After all, the surgery was lengthy and there were difficulties inserting the electrode. There are great improvements in technology and surgical techniques with cochlear implants and many people have residual hearing afterward. It just wasn't meant to be for me.

It's such a huge change for me to give up hearing aids. I've used hearing aids daily from the age of four and it was the most natural thing. I never thought I would ever be without hearing aids. They became a part of my identity. But due to slowly losing my hearing over the years and not being able to hear well even with hearing aids, identifying as hard of hearing was becoming demoralizing. It's sad to put away my hearing aids and close that chapter but, at the same time, it's been a relief to be free from the cycle. Cochlear implants have felt alien and unnatural from the start, but I've now come to love hearing with my implants and I'm embracing my new identity: I'm a deaf woman with cochlear implants in both ears.

July 24, 2019, was the activation day for the second implant. I'm happy to report that this activation was a pleasant experience for me, unlike with my first implant. I have experience, so I credit this with the majority of the differences. Looking back, when I was activated on my left side, it was very difficult from both a hearing standpoint and from an emotional standpoint. When I went home after activation, I was fatigued, and I didn't hear anything that seemed useful. I was near quitting.

Conversely, with my second activation I was mentally prepared for the worst.

I am happy to report that when the implant was turned on in my right ear, I was pleased with the sound. Clearly, my brain has made a huge transition in the past 12 months! Switching from the old familiar sound of the hearing aid to the electric sound of the implant felt right at home. As many of my readers know, the electric sound is unlike anything heard from hearing aids. Thankfully, since I adapted to this once before, my brain seemed to recognize the new implant as a friend instead of a foe and, instead of fighting it, my brain accepted it.

For the record, the sounds I heard on the right side were still strange and not normal by any means, but they were at least familiar. I heard the same squeaks and whirs that I heard with my first implant, but they weren't as intense and not as constant. I heard sounds I couldn't recognize at all but I also heard sounds I could. It was a good mix and this made the process way more enjoyable this time around. For example, upon activation, I immediately recognized the keyboard keys tapping, but the chair squeaking was just noise. I could hear a pen clicking but didn't recognize my husband's coughing.

My audiologist was so pleased that I was accepting more electrical input this time around. In fact, I did well enough that she decided to read sentences on my activation day. She started out having me read along and choose a sentence out of a list. That was pretty easy! Then she decided to read sentences without me reading along to see if I could repeat them back. Amazingly I was able to repeat most of the sentences without lipreading. Of course, they were easy and slow sentences like "How are you today?" and "How did you sleep last night?" I'm sure we will get to the harder sentences later, but it was a big deal to be able to do this on day one.

On the technical side of things, since my electrode arrays are not completed inserted, I do not have the use of electrodes 15 and 16. Unfortunately, 14 is also unusable. I only feel the electric input from 14 but there's no sound to go along with it. The other electrodes (1–13) are all working well. I guess 13 is my lucky number since my left ear also has only 13 electrodes that work (left electrodes are 1–5 and 7–14). I'm glad to report that I do not have any open electrodes this time and, so far, there isn't any facial stimulation.

In the first week post-activation, I still have a lot of work to do. I need to learn as many sounds as I can before my next appointment. I also have several accessories to try, including Roger Select (an FM System), Phone Dect (a special landline phone), and CI Connect (a Bluetooth streaming accessory). It will take some time to practice with all of them.

My Cochlear Implant Journey, Part 16: Bilateral Heaven

Deciding to get cochlear implants is one of the best decisions I've ever made. Having two implants has taken the experience to the next level — being able to hear in both ears is bilateral heaven. I have a greater sense of awareness of my surroundings and I'm able to have a conversation with ease. I need less visual information to communicate and I have a great deal more energy.

In comparison to my experience with my left ear, I've concluded that I am treating my right ear unfairly. I made a detailed log of my experience the first time around with the left ear. This time, each milestone is quickly noted but not cataloged. Each advancement gets a happy but swift celebratory nod. Since I'm doing so well, I'm not focused on the journey. I have to stop and think about my progress to remind myself that this should be a considerable undertaking and that it was a real struggle with my first implant. When I take a moment to consider my journey, I realize how amazingly well things are going and that this is the experience I wanted and hoped for!

Just six weeks post-activation, I started hearing speech with a high level of accuracy and with little noise. There was a slight kazoo effect that faded with each new map. With all the progress I've made, I've fallen into a normal routine both in my work and personal life, and much of what I do is easier because I can hear better.

Check out the new battery case I discovered — originally designed for hearing aids — that's waterproof and very tough! It's called the AidKeeper.

The AidKeeper is also great for batteries.

My Cochlear Implant Journey, Part 17: A Short Trip Away From Home

Taking My Ears on the Road

About a month after my second implant was activated and I was hearing from both ears, I decided to take a short venture away from home. It was not to test my hearing but rather to socialize again with good friends. I was concerned about the logistics of charging my batteries and remembering to carry spare parts more than I was worried about hearing.

The distraction of the trip was quickly broken as I was driving on the highway and suddenly realized, to my complete shock, that I was hearing the radio. I can't recall the last time I was able to do that! I missed some of the words, but I'd say I caught more than 80% of it — definitely enough to follow along. Music has been harder to enjoy with the implant but, as I traveled, I realized the music was becoming pleasant — not perfect, but not as bad as before. Talk radio came through with enough clarity that I didn't feel like I was straining.

For the first time in my life, I was able to just casually listen. The keyword being *casual*. Hearing has not been a casual thing for most of my life. Focus, concentration, fatigue were real issues that I battled daily. I never bothered to listen to talk radio since I couldn't hear it in any meaningful way. I used to blast music more for the beat than the lyrics. The only music I enjoyed in the car were songs of my childhood and better hearing days. As a child, I memorized the lyrics by reading the cassette covers and CD sleeves so I could sing along. This car ride was an unexpected joy. It was less tedious to travel having the radio for company instead of just noise.

After arriving at my destination, I realized that I was about to converse with a child for the first time since getting both implants. My best friend's daughter, a chatty and excitable eight-year-old, wanted to talk and talk we did. The fact that I could understand her was a big deal. Children have higher-pitched and softer voices that are often not as easy to understand. Over the years as she learned to talk, I would pick up more and more, but I would need to ask her to repeat herself 2-3 times until I either understood or I had to ask for help. Now, as an eight-year-old, she has more to share than ever before and it was nice to be able to keep up with her.

I did discover something very difficult for me, even with both implants. Time will tell if this continues to be the case. Hearing behind me is nearly impossible, so walking single file with my friend didn't work out. We have to be either side by side or I need to be the one to fall back in line. This is a situation where my accessories, like the Roger FM system, can help.

At the end of the day, we sat on a patio in the dark with a few candles and chatted. Only a year ago, my previous dependence on visual information would have limited my ability to communicate without a light source. I sat there in awe of the fact that I could hear without seeing, without lipreading, and without facial cues.

How many amazing things can happen to one person? I have lost count of the many ways that my hearing has returned to me.

My Cochlear Implant Journey, Part 18: More and Less Deaf

Self-perception has been on my mind lately. I've been thinking about how my cochlear implants changed how I see myself and my deafness. Before my implants, I was very tough on myself. I took full responsibility for communication and felt guilty when it would break down. I felt I should try harder to hear and socialize normally.

Truly, I had a twisted perception of my reality. Why did I think I could try harder to hear? I had profound hearing loss in both ears. Did I never fully accept my hearing loss? Had I not devoted my life to the treatment of hearing disorders, including counseling others on self-advocacy and overcoming limitations through communication strategies? After all, I tell patients all the time that hearing aids do not solve all hearing problems.

I think this knowledge and advice came too late after growing up hard of hearing. I was the only person in my school and the only child in my church or neighborhood that I knew to have hearing loss. I eventually befriended another child with hearing like mine later in my childhood. This was great for both of us, but one person is not a community. I was growing up primarily in a hearing world.

So, did I accept my hearing loss? I will say that I accepted it as a part of me, but I still believed it was something I had to completely overcome. I'm a perfectionist and I was very hard on myself in this regard.

Writing this, I'm feeling mixed emotions. On one hand, I think my refusal to excuse my hearing loss may have pushed me to be more successful. On the other hand, my chronic stress and guilt over failed social encounters likely imprinted on my personality in a not-great-kind-of way.

I struggled with many feelings, both as a child and as an adult, that I can now clearly label as *anxiety*. These feelings were with me for so long that it was as if anxiety is tightly woven into my life and I just assumed this was normal. How could I know I was carrying this anxiety if it was natural to me?

My parents always said I was never far away as a small child. I typically stayed glued to their side. Before seatbelts were well understood, I would sit in the center of the floor in the backseat with my head between the front seats, trying to hear everything my parents said. Was it childhood curiosity or anxiety? Maybe both. Certainly, later in life as my hearing worsened, my anxiety was amplified and undeniable.

Let me see if I can paint a picture of a typical day before my implants. For one thing, when I woke in the morning, I would insert my hearing aids immediately — not after sitting up in bed or after a trip to the bathroom. No, I had to be wearing them within moments of opening my eyes.

There were times I fell asleep with my hearing aids in and pulled them from my ears during the night. In the morning when I could not immediately find them, I'd frantically tear apart the bed and yell for help. My husband has saved many a morning by quickly locating the hearing aids in the covers or under the bed. Logically, I knew the hearing aids would be found but I would find myself near tears.

I lived in a state of constant alertness. Seeking out all the noises, often asking, “What was that?” for any sound, even the most mundane of noises. So anxious was I not to miss what was happening that I would drive myself and my husband crazy with inquiries. I didn’t hear well enough to recognize sounds from another room so I often would drop projects and seek out the sound. Looking back, it was a chronic issue. My husband would sneeze, cough, or drop something and I’d be in the doorway within seconds asking, “What happened? What did I miss?” After years of reporting mundane noises, impatience started to creep into his voice.

I remember feeling tired at the end of a workday and my husband would say, “Why not remove your hearing aids and relax?” I thought this was an insane idea. Why would silence be relaxing? I wanted to stay connected. I had to stay alert. I somehow convinced myself that it was my duty to be as aware as possible at all times. The only time I would release myself from this burden was when I took them off for bed at night.

As my hearing worsened, I developed the dreaded phone phobia. This anxiety was enough to cause some physical symptoms. The very sound of the phone ringing would cause my heart rate to increase. If I had to take a call, I felt so much apprehension, almost like stage fright. I was near nauseous. I didn’t find captions to be very helpful on the phone since they were so delayed, and I had less and less luck with phone modifications as my hearing declined. I prayed the other person would be kind. I would ask them to slow down, tell them about my captioning phone, and ask for an email or any written options so I could finish the call early. I would sometimes bow out in embarrassment saying, “I am so sorry, I simply can’t hear you, I’ll have to transfer you to someone else to get this information.” Even reminiscing about my phone anxiety now makes me anxious.

Another thing I experienced anxiety over is loss of awareness. As my hearing declined, I no longer heard softer or more distant environmental sounds. I didn’t hear approaching noises. I didn’t know people were in the room with me if I didn’t see them and I didn’t know how close they were. Often at home, my husband would speak loudly to get my attention. I proclaimed, “You scared me!” fairly often in our home. Outside the house, I would pick up on cues when people would stiffen up or look in another direction. When I didn’t hear anything, it would make me feel disconnected. This disconnection would just further fuel my anxiety. I can see why people have service animals — not just for safety but also for peace of mind.

I think about how that anxiety likely led to fatigue, depression, and social isolation — all of which I’ve experienced in waves throughout my life. As a child, I was admitted to the hospital twice due to severe fatigue. The medical staff could not deny the physical manifestation of it. Blood work and symptoms were first thought to be leukemia. Thankfully this and many other scary illnesses were ruled out. It took over a year of medical studies to reach the diagnosis by exclusion: Chronic fatigue syndrome. I now theorize this severe chronic fatigue was a result of adrenal burnout. It is still with me today but, as an adult, I’ve learned ways to manage it and I’ve built my life in a way that accommodates my needs.

Let’s circle back to self-perception. The reason I decided to write about this topic is that I’ve surprised myself with this seemingly contrary realization….

I am both more and less deaf, *and* I’m less anxious. I’ve started to recognize the lessening of anxiety over time. I ask myself, “How can this be, and does it even make sense?”

The device that allows my implant to work, the processor, comes off my head when I go to bed, take a shower, or just take a break from sound. Without the processor in place, I am completely deaf. Complete deafness is not something I have to fight. It just is. I can’t change it, and I can’t “try harder to hear.” When the processor is off, I’m deaf. I hear no sound. Somehow, it’s peaceful for me now.

When my processor is on, sounds of the world stream in and I am connected to everything at once. This connection far exceeds what hearing aids could achieve for me. It grounds me. It relaxes me. It is the sound I always craved but rarely achieved with hearing aids.

I won’t go so far as to say I don’t have anxiety around hearing anymore. I still have some. For example, I recognize that I still have social anxieties. However, I think they may stem more from a lack of experience than a fear of not hearing. I still struggle to hear in noise and get frustrated in situations that are challenging. Old phone anxieties creep in during a challenging phone situation because of a bad connection, rapid speech, or accents I’m not used to.

The anxiety of living with deafness is melting away day by day. I am more relaxed in silence *and* in sound.

About the author

Dr. Yoder is an audiologist and the owner of HearWell Center. She grew up hard of hearing and used hearing aids for more than 30 years. She slowly lost more of her hearing as an adult until her hearing loss was profound and she now considers herself to be deaf. She is a bilateral cochlear implant user (2018 left implant, 2019 right implant).

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