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My Cochlear Implant - a journal

Posted by [lizzy102](#) @lizzy102, Dec 9, 2019

I've been losing my hearing for around 25 years. It started after my first kidney transplant – or that's when it got bad enough to go see an audiologist to see why I was saying "What?" "Pardon?" "Could you restate that?" I would get home from work seeing clients and would be utterly exhausted, for no apparent reason. The audiologist I met with, Dr. Robert Sweetlow, advised a hearing aid for my right ear. I can't even tell you how many aids I've had since then – about enough to buy a nice new car I'd guess, since they run about \$2000 each.

I work and play for an RV Caravan tour company, we are wagon masters and tail gunners depending on the trip. We usually travel with 16 to 25 RVs and go all over North America, Europe, Africa and Australia. It's super fun! And it is super stressful for me with my hearing loss. I'm with groups of people in all kinds of challenging hearing/understanding situations. As a retired psychotherapist, you have to know that I love connecting with people and being in the middle of things. Challenging? Oh my, yes.

In 2015 my discrimination was at R-46, L-32. In 2017, Resound 3D Linx hearing aids offered a lot of help to my declining understanding. So, I struggled along for those years. Then this year (2019), after a particularly challenging caravan, I decided to make an appointment for another hearing test and adjustment. In Albuquerque, NM I met with Dr. Terry Sankovitz. I just wasn't understanding people and was cranky and exhausted all the time. After the exam, Dr. Terry showed me the audio gram... R- 14, L-12. Whaaat? Seeing it on paper my whole insides went cold and still, I was stunned. Barb, my best friend and wife, was just as shocked when Dr. Terry shared the test with her. The test measured how my ears understood speech without any visual cues. Dr. Terry said that there is no point adjusting my hearing aids further, louder wasn't working. She talked about my options, one of which is cochlear implant. I had to let that sink in...

With a cochlear implant, there is no going back. You're implanted period. But wait... with my 'discrim' I couldn't go back anyway. The other option would be to withdraw from the world. Understanding .4 in one ear and .1 in the other is deaf. I am highly functional because I speech read; read bodies, context and situations – in the right situation I do okay. In groups, in noise, in a car, in low light... well you know.

It just happened that Cochlear Americas was hosting a panel discussion the next day, for people interested in CI (cochlear implant) and for those with CIs. Did we jump on that opportunity!!! WOW. What an eye opening. The group moderator was a woman who had been deafened as a child and as an adult had chosen bilateral cochlear implants. She was dynamic and compassionate. Her mother was a member of the panel discussion that included a couple, sisters and a single person. Here's the best part. They hired a court XXX to transcribe speech to captions on a screen for all to see. I am not sure anyone in the room needed them as badly as did I. When I walked in the door, I felt afraid and when I left I felt elated. Arms full of booklets and information, Barb and I talked about the meeting and agreed that both of us felt a sense of hope, at last.

Posted by [lizzy102](#) @lizzy102, Dec 14, 2019

We were still traveling home when I found out I could get an appointment for a Cochlear Implant evaluation at University of South Alabama at the Speech and Hearing Clinic. The appointment was with Dr. Wilder Roberts. I knew we wouldn't be able to make the distance in time, so I flew home for the appointment.

Meeting with Dr. Roberts and her staff started off with lots of questions before the tests in THE BOOTH. Questions concerning situations that are hard for me to understand in, what about when I can't see someone? Crowds? Groups? Did I ever feel unsafe (all the time unless I have a hearing person nearby)? And more. Dr. Wilder explained the test I'd have in the booth. They would play three different voices speaking simple sentences at normal speaking speed. I would just repeat what I understood. Well, to me that sounded daunting – the word PLAY tipped me off that I wouldn't be speaking with someone. Into the booth I walked, hearing aids on and sat down in a chair placed a couple feet in front of a good sized stereo speaker – only it was mono.

The voices began. I repeated the occasional word but spent most of the time muttering to myself – 'if the speakers would slow down...if the one guy would speak more clearly...' I tried and tried to understand. The test went by quickly, I thought. Suffice it to say, I didn't do so well. I have .1% of understanding in one ear and .4% in the other.

Dr. Wilder got out the kit with processor colors and we looked over the equipment. I had already done tons of research and talked to other CI recipients and had decided that the Cochlear America equipment was for me (if anyone is curious, I'll be glad to share my research and reasoning). That over-the-ear-processor is sure big! I asked for the smaller processor, Kanso, as well – even though it doesn't have all the bells and whistles as the larger. We discussed accessories – the swimming covers for the OTE processor, a mic, a streamer for the Kanso. Then we discussed surgeons. Most everybody was booked for months ahead – I felt strongly about going to a surgeon who had done a LOT of implants.

Barb and I work for an RV Caravan company – we are scheduled to meet a new group in Maine to make a 59 day trip through Canada's Maritime provinces in July. I really need to have the surgery and activation as soon as possible so that I can be doing aural rehab for a while before being confronted with hugely challenging situations.

Dr. Wilder had worked with Dr. Blythe in Opelika, AL for some time and very much respects him. She sent the referral and we waited to 'hear' from the East Alabama Ear, Nose and Throat Clinic.

Posted by [lizzy102](#) @lizzy102, Dec 15, 2019

Hi Tony, I have three main reasons for choosing Cochlear America. The company has the longest track record, about 40 years since the original owner pioneered the implant procedure. They also provide a LOT of support: from the first contact – they offer mentors and meet-ups to the time you make your decision and go for the implant to activation and the enormous amount of support they offer for learning to hear and understand again. The other companies did not answer when I reached out. I really liked feeling like one of a community.

Also, I had spoken to a CI recipient who chose one of the other implants and was very unhappy. He had moved to a different state and there was no audiologist nearby that worked with that particular implant, he needed adjustment and was very unhappy. Because I travel so much, I need to be able to find providers easily.

Third, I use Resound HAs and am going for a Hybrid Hearing solution to my discrimination problems – Cochlear and Resound are partners so my remaining HA will work perfectly with the CI processors. I'm accustomed to using my iPhone and the Resound app to manage my HAs – the app for the CI isn't much different and will work seamlessly with my HAs.

I also appreciate the accessories that Cochlear offers. I'm getting the swim cover for my main processor, the second processor – the Kanso, the mic (I have one but it's been in near continuous

use since I got it), and the phone streamer for the Kanso and my audiologist ordered an extra battery – I'll have three.

I hope this answers your question, Tony.

Posted by [lizzy102](#) @lizzy102, Dec 21, 2019

After the appointment was set, I couldn't resist revisiting some of my research. I had made the decision to go for a Cochlear Inc. implant and for some reason I began second-guessing my decision.

So, back to the internet. One of my favorite sites: <https://www.fda.gov/medical-devices/cochlear-implants/benefits-and-risks-cochlear-implants> takes a hard look at CI and gives information about what to expect. I went back to risks and recognized that some of my decisions to choose Cochlear Inc. addressed the very risks listed. For example: won't be able to swim or shower – I chose a waterproof case for my processor as one of my accessories. I haven't trusted swimming for years, being so deaf I wouldn't have known that someone needed me out of the pool or ocean. Another concern, that the company may go out of business, by looking up the financial health of Cochlear Inc. that worry disappeared, this is a long running, healthy company. Dependence on batteries is another worry – well, right now I'm dependent on batteries for my HAs, I have them in all of our vehicles, in all of my backpacks and my purse, in the pockets of several outdoors jackets, in drawers in the front of the house and the back, it's pretty funny. Also the idea that I'll have to use processors for the rest of my life isn't disturbing because I wear not super helpful HAs now and there is no end in sight to that scenario, the only difference is that with the CI I have a chance of improved understanding and engagement with my world. I'm not worried about upgrades because the company does upgrade processors and the current implant is going to be effective for a long time yet – or so I have been assured. Another big concern for me was that at some point I may need an MRI – the implant I've chosen is one that is technologically capable of being in MRI.

Then came appointment day. We drove up to Opelika the day before (3 hour drive one way) so I could rest and be at my hearing best when I met with Dr. Blythe the next morning.

Let me tell you, the appointment was a big surprise to me! I went into the room and right away turned the exam chair around facing away from a very bright octagonal window, looked over the seating in the room and decided where I would sit. I don't mind telling folks how to speak with me – especially doctors, it's important I understand as much as possible (Barb helps with the rest).

Dr. Blythe came into the room, worked at turning the chair back around and proceeded to wash his hands (facing away from me) and talk. I immediately protested! Nope, that didn't work at all, he ignored me. He told me to sit in the exam chair. I explained I wouldn't understand him and he commanded me to sit! YIPES. So I sat, he looked in my ears and cleaned out the sebum while moving my head around roughly. I looked at Barb and mouthed "No WAY!" I did not like this guy. He had me sit down in the chair I'd chosen earlier and began to ask questions. I had to again ask that he slow his speech and speak more clearly. He replied that he was speaking at normal speed in a normal voice and that the problem wasn't what he was doing but that I do not hear. I thought "Wow that's a news flash!" I thought.

Suddenly, Dr. Blythe's brusque demeanor completely changed. He said that he can look at audiograms, "AC Bio" and "Hint" tests all day long and not get any sense of how an individual functions in the real world. The whole beginning of the session was a test of my functioning and how much Barb helps me. He changed the way he was speaking which helped me understand more and explained the surgery, risks and recovery process. By the end of the session, I had completely changed my mind! Though I'll only see Dr. Blythe twice, I know he's the surgeon for me. The office scheduled my surgery – January 16.

We went to lunch and drove back home to await surgery. I'm not sitting on my laurels here though. I received an invitation to a cochlear community meeting in a nearby city and sent an RSVP to attend both the meeting and an open house. I'll let you know what I learn at the meeting.

Posted by [lizzy102](#) @lizzy102, Dec 21, 2019

Btpanda, I was just sitting down to add to this journal when I read your post. Thank you for reading! I started my cochlear research a few years ago. I didn't know then about how much an implant could help me, I didn't even know I was eligible. I've been 'involved' with the medical community since I was diagnosed with Glomerulonephritis (from a strep infection I had as a child). After that diagnosis, I went to the nearest medical school library and dug through anything I could read about the disease. From that point I have become an extremely well informed 'patient'.

Initially, I wanted to know what people with CIs said about the experience. There are lots of online and YouTube stories told in the first person by CI recipients. I also talked to anyone who had a minute to share their story. Somewhere in that time, I stopped feeling that CIs are disfiguring. The stories folks told about learning to hear and how their brains somehow learned to translate the electrical stimulation in the cochlea into recognizable speech, it is inspiring to hear.

I also looked at the dangers of the surgery. A certain small number of implants are not successful and I wanted to make sure I was not one of them. Since I needed to have two kidney transplants and faced the risks of those surgeries, the CI risks paled in comparison. One thing I learned is that the surgeon is super important. They need to have performed many many CIs building an impressive skill level. I found it important that the surgeon take pains to see me as a person, to know what I hope the CI will do for me.

I also looked at each of the provider companies. First at their longevity in the business, their financial stability, reputation and customer reviews. I also assessed the support the companies offer. Since I travel so much, I looked for a company that would work with me no matter where I am, should one of my processors have a problem. It's important to me that if I need an adjustment, there will be a lot of audiologists around who have worked with my CI company and know the processors.

But now, I need to get my journal updated!

Best, Lizzy

Posted by [lizzy102](#) @lizzy102, Wed, Jan 15 1:59pm

In reply to @colleenyoung "[@lizzy102, anticipatory nerves for a CI implant is normal. You're right to...](#)"_+ (show)

I woke up this morning tingly, giggly and filled with joy. The wait for the first step toward understanding and hearing was so difficult for me! Per other CI recipient stories, I'm in for an even more excruciating wait in the next two weeks until my activation appointment. I am certain the decision I made is the correct one – the joy tells me so.

Last minute? What are the odds I'll have to stay overnight at the hospital?

Has anyone had a CI and NOT come out of it with balance problems and dizziness?

How do I best handle the days right after surgery?

Thank you, in advance, for any guidance.

Posted by [lizzy102](#) @lizzy102, Thu, Jan 16 7:34pm

In reply to @lizzy102 "[I woke up this morning tingly, giggly and filled with joy. The...](#)"_+ (show)

Surgery was today! It went just great! My surgeon was a peach and the staff very caring. I popped out of anesthesia with no dizziness or other issues. Pain is manageable. I do have a grapefruit sized bowl over my ear that has 4 x 4 dressings in it. Got a little bruising and my neck is sore from my head being turned on the side. I don't notice an increase in tinnitus at this time.

Thoughts about "How to get ready for your surgery".

Do neck stretches – looking over your shoulder with your shoulders down and back, for a couple

weeks before the dare.

Eat extra protein before surgery and bring some for the evening after. I did protein drinks and ate my usual healthy diet.

Bring socks.

Bring your positive attitude.

Bring Gatorade or a better electrolyte replacer for after surgery, hospital gave it to me and I had some in the hotel room.

Questions?

Thoughts?

Posted by [lizzy102](#) @lizzy102, Sat, Jan 18 1:12pm

In reply to @lizzy102 *"Surgery was today! It went just great! My surgeon was a peach..."* [_+ \(show\)](#)

Experienced some balance issues this morning but they have resolved. So far so good. I wear the protective gear for one more day then get to wash my hair – joy! Incision is not “little” it runs along the back of my whole ear. It is healing nicely and pain is still minimal, for me. Nobody mentioned that the muscles in my neck would be so sore! I’m using Bio-Freeze on it and Arnica Cream on the bruising. Will upload photos this afternoon.

Posted by [lizzy102](#) @lizzy102, Thu, Feb 6 3:25pm

In reply to @alice44 *"Yes, lots of readers like me who usually just lurk. You are..."* [_+ \(show\)](#)

Thank you, Alice44! I sure appreciate hearing that, pun intended!

Today, I was riding in the back seat of friends car going to lunch. I normally check out because hearing over the noise has been impossible for years. Today, I suddenly realized that I was understanding the conversation going from the front to the backseat! That was a delightful first. Also, over lunch I was part of a complex set of discussions in a restaurant that was very busy and loud. I didn't feel my shoulders climbing to my ears, I was able to understand and my body felt relaxed.

Another difference, I was easy to know when to interject or answer a question, I could understand!

Sound changes every day, it is still quite electronic. In the beginning, voices were monotonous.

Today, noticed I'm hearing differences in pitch and tone. Amazing.

This is a NOISY world we live in, I find myself glad to turn off sound at the end of the day. It's been a long time since I've heard keyboard clicks, water going down the drain, the dryer beeping...

Thanks again, alice44!

Posted by [lizzy102](#) @lizzy102, Thu, Feb 20 11:43am

In reply to @lizzy102 *"Thank you, Alice44! I sure appreciate hearing that, pun intended! Today, I..."* [_+ \(show\)](#)

Two week appointment was yesterday. My CA (cochlear audiologist) tested my hearing with my processor on, in the booth, using the ascending beep/noises. At first I couldn't figure out the noises, they seemed to vibrate or warble in my ears. Once I was able to identify the sounds, the test went very well. Dr. Roberts said that my hearing is already very close to target! She redid the test in my CI ear without my processor and my hearing clocked in at the very bottom of the chart – Yipes.

So, what have these two weeks been like? Stupendous. That's the word. Wonderous, that's another one that fits nicely. Let me give you some examples: doves wings slipping through the air as they

rise from the ground near where I kneeled, ethereal. How about a concert of lovely high ringing notes when ice hit the sides of the glass in a busy restaurant. How about FaceTime with my grandson and almost understanding every word while understanding my son, who I've not been able to understand for 20+ years? And NPR on the radio, understanding the discussion. And hearing while understanding my wife who spoke to me while my back wads turned, behind her face mask she wore while sanding some wood, amazing. Many tearful moments of hearing lost sounds. When I must remove my processor to sleep, I am bereft. As if I had taken off my right hand or a removed piece of my heart. In the booth without it, I could only feel that encompassing fear I used to feel when getting my hearing tested... fear of failing, looking stupid, being seen as incompetent. I've decided to name each of my processors – the black OTE and my blond Kanso. No names have come to me yet, but they will. My processors are now as important as family members or my cats. I don't want to take you on a 'Merry Sunshine' ride here, there have been difficulties, none concerning the function of my CI though. I have still got pain in my inner ear and itchyiness (a sign of low grade pain). The pain arrives in the late afternoon or evening nad persists into the night, so it is helping me to be more mindful about how tired I am – hearing fatigue hasn't disappeared (yet). On that note, usually I'm so much more relaxed than with my HAs – I don't have to work hard to understand now. IN fact, I'm writing this in Starbucks, surrounded by conversations and I am not at all bothered by the bangs of the machine or noisy laughter – my processor stops loudness in nanoseconds. MUCH better than my endearing HAs. Tinnitus is still a factor – louder than before the CI but quieter than just after the surgery, so that's good. Nuts and bolts. After the processor was turned on and mapped the first time, I was instructed to increase the volume (using my remote) from 6 to 10. Yesterday we re-mapped and I'm starting back at volume 6 again. It's about building tolerance to sounds I've not heard in years. This is such a complex process! Thank you, friends, for joining me on this magical journey. See you in a couple of weeks.

Posted by [lizzy102](#) @lizzy102, 1 day ago

In reply to [@lizzy102](#) "[Two week appointment was yesterday. My CA \(cochlear audiologist\) tested my hearing...](#) "_+ (show)

March! Gosh, It's been 6 weeks since my processors were activated. It would take hundreds of words to describe how much my life has changed. Things I could never do before – talk with my friends on the phone, talk with my grandkids on FaceTime – I now enjoy. A pine warbler was outside the RV window and the sound was so interesting, detailed and rich.

I am an immunosuppressed kidney transplant recipient – 20 years out – and this Covid-19 has me scared. I'm self-isolating to prevent exposure. I wasn't able to do a huge shopping trip because the number of people in grocery stores. I normally shop at odd hours to avoid the crowds. Barb shops and we use bleach to clean packages coming in to the RV. Oh, yes. We finished renovating our house and it gets listed today. Our goal before the virus was to sell the house and move closer to our grandchildren. Now, we're trying to decide what to do at all. Sticking in this lovely state park seems a good bet at least until the house sells. So not only have I been learning how to hear again, but the rest of my life is topsy-turvy.

The cochlear implant surgery didn't go as well as it could have, I'm still experiencing taste bud issues. A persistent metallic taste throughout my mouth and reactivity to salt and sugar that blow both flavors up to an intolerable level leave me not so hungry.

Aural rehabilitation has been a blast. I use Angel Sounds, listen to audiobooks, talk on the phone, and was talking to anyone who would stop a minute when I was out – not now with the virus, I'm home.

With hope you are all social distancing etc. I read a good thing, "Don't do social distancing because you could get the virus. Practice social distancing as you HAVE the virus and protect others in your community."

Posted by [lizzy102](#) @lizzy102, Fri, Mar 20 8:10am

In reply to @colleenyoung "*Hi @lizzy102, I didn't realize that you are a transplant recipient. You...*"_+ (show)

Here's an article about how taste issues develop post-CI surgery, Colleen.

<https://www.ncbi.nlm.nih.gov/pubmed/18033736>

I don't know why that didn't paste as a link. Please, copy and paste to your browser.

Thank you so much for the links. I am already reading and posting to the transplant group. I'm out 30 years on my two family members kidneys (one lasted 11 years and the other us 20 and counting!). I'll check out the others. Be well.

Posted by [lizzy102](#) @lizzy102, Fri, Mar 20 8:16am

In reply to @barbb "*Hi Lizzy, it's great all that you have accomplished with your CI!...*"_+ (show)

<https://www.ncbi.nlm.nih.gov/pubmed/18033736>

The above is a good link to why they happen. It is not a rare problem at all, it is just one that folks don't mention very often. My surgeon says it will get better with time. Could be as long as a year before they do, if they do. I'll get used to it I'm sure. Would I hesitate to have another implant? No, The implant has made my life so much richer and I am more present to my life now. Thank you for your comment. Your thoughts are much appreciated.

Posted by [lizzy102](#) @lizzy102, Tue, Mar 31 9:49am

Time for an update. I just changed the dry brick in my instrument dryer, so I know it's been about two months.

How things have changed! In this Covid-19 world, we are living in our 28' RV. We got the house on the market and it sold in four days – we're just waiting for closing now. We had planned to go west to the family and to find a new home. All of that is put on hold since RV travel is restricted by private and state campground closures. With my kidney transplant, I'm vulnerable and our ages put us in that category anyway!

I am SO GRATEFUL I had a cochlear implant! Beyond grateful. Without the incredible improvement in hearing, isolation would be torture for me. I talk on Zoom with family and friends, big groups of us. Barb and I have started the Mindfulness based meditation, MSBR, eight week class. I meditate with my eyes closed, listening to someone guide me through.

Barb complains that I talk so softly now she can't hear me! I am still doing aural rehabilitation – even though my university based cochlear audiologist is no longer working.

With hope, things will return to 'normal' in the next year or so. With hope, we will all be here to comment and connect. With hope you are finding good in your situation. Hang in there, y'all.

Posted by [lizzy102](#) @lizzy102, 2 days ago C.April 8, 2020

Thought I would add this note for those considering CI. When you first meet with your surgeon, take the hats you love to wear. Ask the surgeon to measure where to put the implant and assure you can wear your favorite hats. They may have different length implants which would allow them more leeway on where to situate the implant – and hence, where your processor will magnetically attach. I LOVE listening to birds. Without my processor on, I cannot hear them at all and it is utter joy to hear them and look for them. I am not so good at locating them yet, will need more aural rehab to do that I think.

Stay well, folks, and breathe.

Posted by [lizzy102](#) @lizzy102, Wed, Apr 8 3:40pm

In reply to @contentandwell "[@lizzy102 I was remiss in joining this conversation until now but I...](#)" [_+](#) (show)

Hi JK, First, thank you for your kind words, it means the world to me that my thoughts might help someone else in their hearing loss journey.

There are many drugs that transplant patients must take that are ototoxic. You can google your medications and see which ones are most toxic to your hearing, however... as a transplant patient, you likely must take these medications. To me, living with hearing loss is preferable to pushing up daisys!

Please, when this is over and it is safe, find a university or large speech and hearing program and ask them for an evaluation. Likely your audiologist isn't qualified to do the test or make the call. Cochlear recipients are entitled to 4 devices – from a large list – to help you live the richest life you wish. One of the devices I chose was a waterproof case for my implant. I can tether it to my hair and wear a headband to keep it in place while I swim or exercise in the water! You can buy other accessories but I am also a water person, so this was an important choice for me.

The last and most important thing I can say to you is do not be afraid to ask for what you need to help you hear in groups. Sheri Eberts has wonderful short articles on her blog of ways to ask, things to give folks so they understand more what life is like for you and tons of encouragement.

JK, You are going to move forward in your hearing journey. Be proactive and positive and breathe when things get so discouraging, depressing and frustrating.

Blessings,

Liz