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My Journey with Tinnitus

by Jack Curtin '24*

In the middle of March 2020, the COVID-19 pandemic forced most people to shelter in place at home. I am lying in bed frustrated, struggling to fall asleep. My ears are ringing. I suffer from tinnitus - ringing in the ears - which is usually caused by an underlying disease or overexposure to loud noise. In my case it is followed by prolonged, dull headaches which don't seem serious enough for medical attention but which affect my quality of life. In addition, my hearing is hypersensitive. I can barely listen to music and ask my family to avoid any loud, piercing noises. I think about playing my guitar, which has been sitting in its case under my bed for almost a month, waiting to be picked up. I'm growing angry; I just want the ringing to subside so I can get some sleep! Is this something I will deal with the rest of my life? I've lived with this for a few months now and it's gotten progressively worse. On the verge of tears, I think about better days when my hearing and health was normal and scream into my pillow. Most people have normal hearing at seventeen, but I am showing symptoms typical of a retired construction worker who has spent his whole life subject to loud noise.

By this point, I've seen my pediatrician, an ENT, an audiologist, and received an MRI on my brain. Still, no one has a diagnosis. I feel helpless. In the middle of a pandemic, the healthcare system has shifted its focus towards emergency care. My journey through the medical system is on hold. For now, I must live with the tinnitus, hyperacusis (hearing sensitivity), and headaches at home. Since I typically turn to music in times of stress - playing guitar or listening to the Grateful Dead and the Beatles - my inability to use music as an outlet to relieve my anger adds to my frustration. I feel like I'm trapped. I can' do the things I love with my condition. There's that ringing again....

My hearing issues began in early January 2020. , I remember being irritated by the music on my headphones while taking the bus home from school one afternoon. The volume was not abnormally loud, yet I was wincing at some of the high guitar notes I usually enjoyed. Confused, I put my headphones away and wondered what had just happened. A few nights later, I experienced ringing in my ears while trying to fall asleep. I'd felt this before, but only after a concert or on an airplane, which was normal. This time was different. I remembered that strange sensation on the bus from the piercing volume of my headphones. The ringing lasted for a few days before I began browsing the internet, searching for some information on what it was and what could be causing it. After some attempts to self-diagnose, I became worried with what I found online. I recall reading something along the lines of, "tinnitus can be a debilitating condition which is associated with hearing loss." Hearing loss? At seventeen years old? The more I read, the more troubled I became by my condition. I began

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*Note: Names have been changed to protect the privacy of patients and providers.

thinking of the worst case scenarios. This was not a broken ankle or a common cold. Hearing loss is often irreversible once the damage is done. This was enough to get me thinking: I need to see a doctor.

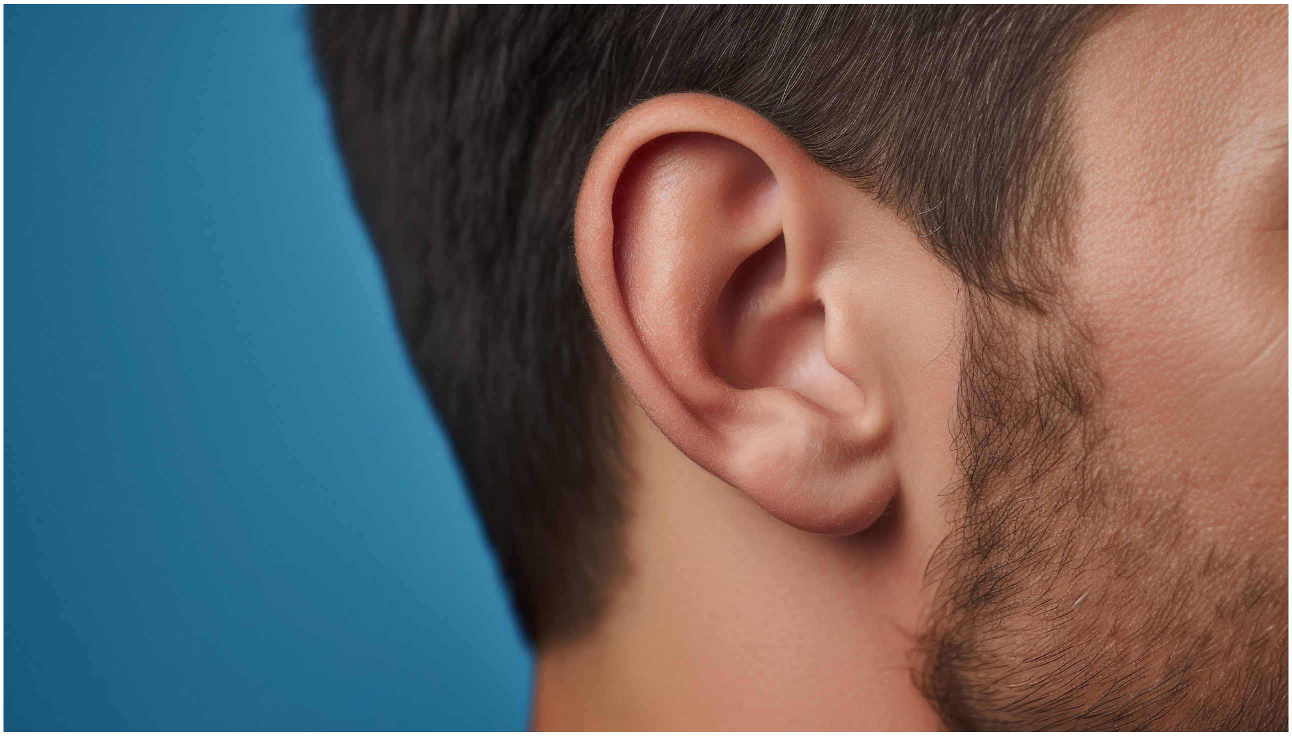
After frantically browsing the internet and talking with my parents, we all agreed I should see my pediatrician within the next few days. I did not expect much since this is a difficult condition to diagnose, and she referred me to an ear, nose, and throat (ENT) specialist. I had been seeing her since I was a baby, and I hadn't had an illness or injury she couldn't treat. I remember the expression on her face when I was describing my symptoms. Her inability to diagnose my condition was disheartening. How serious was this problem? I'd never seen another doctor before, and I was anxious about how I would feel in an office I'd never been to. The ringing persisted and with it brought along headaches and hearing sensitivity. I realized that I'd taken for granted my normal hearing.

A few weeks later, I found myself in the office of a crowded ENT on a winter afternoon with my dad. The place was packed. There was a mother holding her crying baby a few seats away from me in the waiting room. The wailing cries pierced my ears as I filled out my medical information on a tablet. I was anxious and felt a dull headache coming on from the crying baby nearby. I couldn't seem to figure out the outdated sign-in tablet. Why was it so hot in this room? Overwhelmed, I went to the men's room to escape the noise and felt helpless. The ENT was a younger doctor who seemed to be focused on something other than my condition during my visit. He conducted some basic hearing tests and examined my ears while asking procedural questions about my lifestyle. "I think you should see someone in our audiology department. The ladies at the front desk can find you a slot," he said. What? Aren't there more tests that can be done right now? My visit wasn't even fifteen minutes long! The ENT assured me the audiologist would perform in-depth tests to discover any damage to my hearing. At this point I was now 0 for 2 in my search for a diagnosis. I felt helpless, but I thought an audiologist must know what is causing my condition. I held on to hope that my next visit would yield some results.

By mid-February 2020, my hearing issues had not gotten worse, but they hadn't improved. I was optimistic about my appointment with the audiologist. I went into a small, soundproof room and put on a pair of high-tech headphones for the tests. My ears were hypersensitive on the day of my appointment, for I'd been exposed to some loud noise the day before. I sat down in the testing room while the doctor stood outside at a computer, looking like a pilot in a cockpit. The tests consisted of various humming and ringing noises at different volumes; the higher pitched ones really irritated me. After the tests concluded, the audiologist gave me some positive feedback: I did not have any substantial hearing loss. She gave me a list of possible causes which I had seen and heard before from other doctors or my own research, but nothing concrete. She suggested some remedies to relieve the ringing such as noise therapy, where I would be exposed to white noise to temporarily help with the ringing and pain. I felt helpless on the car ride home. I'd seen three doctors and hoped to schedule an MRI on my brain in the next few weeks. Could any doctor help me?

After the audiologist, I felt the lowest I had since I first started to experience the symptoms in January. I was losing hope. Doctors knew what my condition was, but no one could explain what caused it or provide a treatment. Thinking of my future health worried me. I was still experiencing ringing and sensitivity, and my head was aching for a larger part of every day. I often retreated to my room where I could find the closest thing to silence, but even then, I could still hear the ringing. Occasionally it felt as if my ears had water in them, pulsating like a heartbeat.

One day, I had an outburst when my sister was putting away dishes after dinner. The clinking of glass dishes she was placing in the cupboard pierced my ears; it is difficult to put this sensation into words. I screamed out, covering my ears,



and yelled at her to be quiet. My outburst was a wake-up call. The noise from the dishes was not loud to her or my parents, which reinforced my own hypersensitivity. I shouldn't have taken my anger and frustration out on her - she hadn't done anything wrong. During these months, my family had been extremely understanding and compassionate towards my condition, always altering daily tasks to make less noise when I was around, and for that I am grateful. We always had music playing in our kitchen, but since my ringing began, they would sacrifice listening if I was in the room.

The next stop on my journey was an MRI scan on my brain to rule out a tumor. The idea of this was enough to scare me. Could there really be something wrong with my brain? I thought the worst when I heard the suggestion to get the MRI. I entered an MRI machine for the first time in my life – a claustrophobic tube that produced all sorts of loud noises. The technician sternly advised me to remain still throughout the twenty-minute process. I reluctantly decided to wear headphones with music during the process to mask some of the noises from the machine, and I accepted I would get a headache from either the music or the machine. The machine was very loud, and I could hear the sounds over the music. As I exited the machine, my head throbbed. It would be two weeks before I would get the results from the MRI. But before that could happen, the pandemic turned the world upside down.

One night, I was reading *The Things They Carried*, a novel on the Vietnam War, when I became anxious due to my hearing sensitivity. A lamp in bedroom was producing a slight hissing noise which I couldn't bear. I felt as if the sound was penetrating my brain, leading me to clench my teeth in pain. I grabbed a pair of headphones just to mask out the buzzing. There I was, reading a book in a mostly quiet room wearing powered-off headphones. I couldn't even read a book in my quiet room without being irritated. Even such a simple task was almost unbearable. The worst part was, there was no way to escape this. As I turned off the light, I felt sorry for myself and wondered "why is this happening to me?" I had been suffering for more than two months, and no one could give me a diagnosis. What was the point?

During the early days of the pandemic, I couldn't see my friends. I rarely went outside. This included seeing my grandmother who lives a few blocks away from us. There hadn't been a week in my life when I hadn't seen and talked with her. We are very close, and her calm demeanor is always soothing in times of frustration when she would recite her poetry to me. I couldn't see her due to her vulnerability to the virus and her isolation. So, on one foggy afternoon I decided to take a walk down to the beach. The cool, humid air felt good on my face, and I recall the sounds of the waves breaking in the distance temporarily alleviating the sensitivity and headaches I had been experiencing. This relaxing moment with nature offered me some time to reflect on my state of mind. I was at peace, my ears weren't ringing, and I felt the power of the ocean in front of me. I remember reminding myself it could always be worse. I should be grateful for my family, friends, and all the things I have.

The tinnitus, hyperacusis, and headaches persisted throughout the rest of March and April as I tried to see another doctor. Through a mutual friend, I got an appointment with an otologist in New York City in May. The doctor was one of the more recognized otologists in New York. For this I was both grateful and optimistic that he could find something the previous doctors couldn't. My hearing issues hadn't gotten better, and I was still dealing with the dull headaches. I filled out a COVID-19 symptom information sheet before the appointment, and I felt restless in the nights before my visit. The drive into NYC was ominous. The usually bustling city was desolate in the midst of the pandemic. My dad and I entered the office wearing gloves and masks. We walked into the exam room and were greeted by the otologist, a kind man in his fifties with an Eastern European accent. After cleaning and examining my ears, he informed me that the ringing, sensitivity, and headaches were found together in many cases. He, like the three previous doctors I had visited, had no explanation for the tinnitus, but suggested it could have to do with a hormonal imbalance and could dissipate as my brain developed more. He instructed me to take vitamin B-12 supplements to help with the ringing.

This visit with the otologist was more satisfying than the previous three, but still left me with more questions than answers. Why couldn't anyone explain what was wrong with me? I felt helpless and let down by the doctors I'd seen. Up until this point, I thought any affliction or condition could be cured, or at least treated, through the power of medicine. Thankfully, my symptoms gradually dissipated over the summer - the ringing, sensitivity, and headaches persisted but became less severe. Maybe it was the vitamins, maybe it was spending more time outside, or maybe it was just my natural development. I'll never know. I still live with these symptoms every day. The frustration paired with the persistent, nagging pain I dealt with during these months was unlike anything else I've experienced. At its worst, I felt like my head could not register sound anymore; I just wanted to shut my ears off.

Living with tinnitus is difficult. It is never just about the ringing in the moment. Every time I experience ringing or sensitivity I think about my future. If my ears are ringing now, what will my hearing be like in five years? My journey with tinnitus, hyperacusis, and headaches in 2020 was frustrating and disheartening, but this experience gave me empathy for those who suffer, and especially for those who suffer while remaining positive and kind. We all suffer at points in our lives - some much more than others. It is how we deal with that suffering that defines us.