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# Tinnitus

## A patient's perspective

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I hung out my shingle as a solo general surgeon in 1982 (you could do that back then). By 1994, I had a phenomenally successful practice in North Atlanta, rewarding both emotionally and financially. I was in a call group with two senior surgeons and a younger fellow who loved operating at night, so I almost never had to go into the hospital after hours. I had married my sweetheart of many years. I had a beautiful home. I had two terrific kids. I was active in the community. I was trim and fit. And then one day my ears started to ring. . .and ring. . .and ring. . .and ring. . .and ring. . .and ring. . .and . . .

It began as a persistent hiss in both ears and rapidly became a constant, unrelenting, overwhelming sound like a cross between a screaming teakettle and a thunderous jet turbine. I would walk from room to room trying to “get quiet” to no avail. I would cover my ears not knowing what else to do, only to discover that covering my ears invariably made the sound louder. No way out. Fear. Frustration. Agony. Overwhelming despair. Picture the tortured face of the androgynous creature in Edvard Munch’s 1893 masterpiece, *The Scream*, which currently hangs in the Munch Museum in Oslo. *The Scream*—that terrifying image was my own living nightmare, every single minute of every single day.

The “tinnitus odyssey”—that is what I call it. I embarked on an odyssey, as do so many others who truly suffer from tinnitus. I started with an ENT friend of mine, then another, then an otologist, then another. I saw my internist. I saw a neurologist. Audiograms, immittance testing, MRIs. No improvement; no answers; and no relief from the piercing noise that was omnipresent. One ENT (meaning well, I am sure) hammered the first nail into my coffin of sorrow when he uttered the incantation familiar to most everybody with severe intrusive tinnitus: “There is nothing that can be done for you; you will just have to learn to live with it.” Those words are, of course,

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untrue. Those words are reprehensible. Those words are morally unacceptable. Those words are poison. Those words can take a treatable auditory phenomenon and turn it into a lifetime burden. Tinnitus patients should not be so sentenced. Tinnitus patients need not be so condemned. Please note that I refer to the concept of tinnitus being “treatable,” even though it might not be “curable.” There are many things that can be done to bring considerable relief to a tinnitus patient’s great satisfaction, even in the absence of an absolute cure. To shut that door with a “nothing can be done” is predictably devastating to a person who shows up at a doctor’s office because he or she truly is suffering.

I was indeed told that nothing could be done. At the age of 46 I broke down in tears in my wife’s arms as I left the ENT that day. But I refused to accept that I was facing a lifetime of incessant earsplitting noise; so on I went. I saw a psychiatrist with extensive experience in hypnotherapy—no relief. I did, however, find myself getting increasingly depressed. Depression is not uncommon in severe intrusive tinnitus, which after all represents to the tinnitus sufferer a very significant loss: the loss of silence, the loss of peace and quiet, the loss of an entity so near and dear to us that we do not know how much until it is lost.

The loss of silence was not my only loss. With my ears screaming to utter distraction, I lost my ability to function in the tense and demanding environment of the operating room. It did not happen all at once. I gradually began giving away the “tougher” cases and the emergencies. Eventually, the tinnitus and the depression feeding on each other, even the easier cases—the breast biopsies and the cholecystectomies—became next to impossible.

I had a freight train in my head, and I was carrying the gorilla of depression on my shoulders. The burden became unbearable; I ultimately had to stop operating entirely and close my office. Moreover, because my health insurance was tied to my business, I lost that as well, and I became uninsurable. (The laws in the State of Georgia have since changed.) I spent most days lying in bed, rolling from side to side holding my ears in agony and trying to sleep to escape from my amorphous tormentor. On a “good ear day” I might be able to accompany my wife grocery shopping or drive my kids to school in car pool. My son, then only four years of age, commented to me once that he wished he could reach into my ears with his little fingers and take out that bad sound so that I could smile again.

How could this be happening? I thought I might be going crazy. So I asked a psychiatrist if I was crazy. I told him all about myself and said that I was hearing sounds in my head. He asked me to describe the sounds, so I did in great detail: the pitch, the loudness, the timbre, the character, what exacerbated it, and so forth. It took about 20 minutes, all the while the psychiatrist looking at me and listening intently. At the end of my tinnitus monologue, I again asked him if I was crazy. Then he inquired, “Well what exactly is the sound saying to you?” Increasingly frustrated, I responded, “Haven’t you been listening to me? I told you, it’s a high-pitched endless

noise, like a cross between a teakettle and a jet turbine. It's not 'saying' anything!" At that point he looked into my eyes and said quietly, "Stephen, you are being tortured. You are miserable and justifiably depressed. But you are *not* crazy. If the sound starts *saying* something to you, *then* you're crazy."

I tried tinnitus maskers in the hands of a well-intentioned audiologist with little or no experience in tinnitus masking. She clearly had no idea of how to tailor masking sounds to my needs or how to convey effectively to me how to use the devices, and I had no idea what I should expect from them. Needless to say, my experience with tinnitus masking was decidedly suboptimal.

Under the watchful eye of my doctors I tried anxiolytics and antidepressants. I tried electrostimulation and biofeedback. I left no stone unturned.

Herbs—I could not believe it, but I found myself turning to herbs! Here I was, a surgeon with a decidedly conservative Western philosophy toward the practice of medicine trying to get relief through herbs: ginkgo, Kombuchion<sup>®</sup>, and herbs I could not even pronounce. I tried this potion; I tried that elixir. I tried eardrops that "guaranteed relief or you get your money back." I tried them even though I learned in freshman anatomy that the outer ear does not directly communicate with the cochlea. (And I also learned that even though you *can* get your money back for such medicaments, you very rarely ask for it.)

I heard that in another state a medical doctor with an extensive bibliography was offering tinnitus relief through a minimally invasive procedure. On the telephone he said to me, "We need to get you here right away. I'm sure I can help you." So off I went with my wife, full of hope. I recall sitting in the man's consultation room at his clinic on the day after the procedure, to my great dismay with tinnitus much worse than before we had started, a treatment failure. He looked at me from behind a large desk and told me that I was in need of psychiatric assistance. This was no great revelation. I was deeply depressed from my entire encounter with tinnitus, I had suicidal ideations, and I was already under the care of an excellent psychiatrist for that very reason!

I had read someplace that acupuncture could help. So I went to an oriental doctor who was a highly experienced acupuncture specialist. He told me that the reason my ears were ringing was that there was an imbalance between my liver and my kidneys, which he proposed to correct by sticking needles in my lower extremities. I know that may sound somewhat preposterous to the reader, but here is something even more preposterous: I actually believed him and underwent the treatment. How one's desperation and anguish can distort logic and basic common sense! I left the acupuncturist's office with many tiny holes in my feet—and with one larger hole in my wallet. My ears were screaming as loud on my way out as they were on my way in.

I joined the American Tinnitus Association (ATA) with the idea that not only would I be kept up to date through reading *Tinnitus Today*, ATA'S excellent quarterly journal, but also that I would be supporting educational

programs, tinnitus advocacy, and tinnitus research. I must say that I do consider those dollars to have been very well spent.

My odyssey went on, and yes, eventually I was able to find an appreciable degree of meaningful relief in the clinic of an individual whom I am sure has been asked to write an article in this issue. The who, the why, and the how are much less important than the fact that it can be done. Rather, the issue is: What particular approach to attaining significant relief is most appropriate for which person? After all, each person is different and each person's tinnitus is different.

As a physician, I have observed that people with tinnitus go to primary care doctors, ENTs, otologists, and other specialists with the chief complaint that their ears are ringing. But that is *not* why they make appointments to see us. They say it is, but they are mistaken. Most of us *think* it is, but *we* are mistaken. People with tinnitus come to us because their ears are ringing *and it makes them feel bad*. Sadly, more often than not after an appropriate evaluation to look for correctable causes or underlying pathology of concern, those same people are sent home and told in so many words that nothing can be done for them—that they will have to deal with it. The end result is that they still have their tinnitus *and they feel worse*.

When Mr. Jones's tinnitus evaluation is complete, I can tell him to go home and learn to live with it because there is no cure, or I can say the following [1]:

Mr. Jones, you have tinnitus. Although I see that your tinnitus does cause you considerable discomfort and distress, I am pleased to tell you and your wife after a thorough evaluation that it is not caused by something that is a threat to your health—you do not have a tumor or other underlying disease. I am sorry that in your case as in many others the tinnitus is not caused by something that we can cure with current technology, but there is legitimate hope for that in the future. Meantime, let's see what we can do to get you some effective relief—so you can set your tinnitus aside and get on with your life. Here are some things we might consider. . .[Or] let me put you in touch with someone who has a particular interest in this field. . .[Or] here's the website of the American Tinnitus Association ([www.ata.org](http://www.ata.org)) and the telephone numbers (503-248-9985, 800-634-8978). The ATA might be a good place to start your journey on the path to relief that best suits you. And be sure to stay in touch to let me know of your progress.

A tinnitus patient myself, I have learned firsthand the devastating impact of the quicker of the two previously mentioned options. It takes but five minutes to make the move from just being a doctor to being a healer. Five minutes.

## Reference

- [1] Nagler SM. First nail in the coffin. *Otology & Neurotology* 2001;22:457.