

We Need to Share Our Tinnitus Journey to Build Acceptance



By John Capecci, PhD

Until recently, I had shared with only one person—my spouse—what living with chronic tinnitus is like.

For reasons I'll explain shortly, this is somewhat ironic. But first: here's my experience.

One sunny fall morning a dozen years ago, I woke and rose to get out of bed. Immediately, the room began spinning. I keeled to the right and collapsed onto the carpet. I closed my eyes, crawled to the bathroom and threw up.

Lying on the cold tile floor, I couldn't focus; my eyes rolled in their sockets, and my brain felt loose in my skull. I had intense vertigo and no idea why.

Then, out of nowhere, came a high-pitched tone. Electrical, vibrating. A single, sustained eeeeeeeeeeeeeeeeeeeee in my right ear or, strangely, somewhere behind it.

For the past 12 years, that screech hasn't stopped. Not for a single moment.

It's there while I'm driving, watching movies, and talking to clients. It's there when I close my eyes to sleep and if I open them in the middle of the night.

In the years leading up to that fall morning, I had gradually lost my ability to hear high-pitched sounds: birds, crickets, alarms. On that morning, my brain apparently decided I needed to hear these sounds and other high pitches after all, so it compensated by turning on the screech. It's as though half my head is a noisy electrical power plant that the other half must listen to 24/7.

Many of the 50 million Americans experiencing some form of tinnitus do not find it troubling and/or may experience it only briefly. But for roughly 20 million, me included, the condition is chronic and burdensome. For about 4 million, it's debilitating, resulting in insomnia, severe depression and anxiety, isolation, and even suicidal thoughts.

I've experienced some of the more common burdens: bouts of sleeplessness, depression, irritability, and intense, even painful, reactions to everyday sounds.

Though the screech I hear is constant, it doesn't prevent me from working or living a full life because I am able to ignore it much of the time. Occasionally, wearing hearing aids helps because they amplify external sounds that distract me from the screech; getting adequate sleep and managing stress also help reduce the sound's intensity.

This does not mean that I am able to "turn it off." The instant I think about the eeeeeeeeeeeeeeeeeeeee, it's there, sometimes dialed back in volume and sometimes—like right now, because I'm focusing on it to describe it—it's blaring.

Fortunately, my tinnitus is not debilitating. But listening to it nonstop for more than a decade, even in the background of my consciousness, is exhausting. I want the noise to stop. So do millions of others.

Choosing to Speak Out

Recently, I decided to share my experience of tinnitus publicly—first among family and friends, then more widely via social media and other platforms—and to become a vocal advocate for tinnitus awareness,

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research, support, and, ultimately, a cure.

But as I said at the start of this article, it's somewhat ironic that it has taken me 12 years to step into this advocacy role—especially given what I know about the power of personal stories to create change.

For more than two decades I have coached thousands of individuals on how to share their stories publicly to advocate for causes they care about—whether that means raising awareness or money, passing new legislation, or helping others change behaviors.

With a colleague, I even authored a how-to book on the subject and founded a communication training firm to support organizations and their advocates who want to share personal stories for maximum impact.

Why, then, had I not explored my own experience for its potential to make a difference?

People come to public advocacy via different paths and for different reasons. Making the decision to share our personal stories as advocates places us at the threshold between the private and the public, a space where we encounter feelings about what is and is not appropriate to share, what makes a “good” story, what we risk by speaking out, and more.

As I reflected on and explored my own path to advocacy, I learned that I was not alone in my hesitancy to speak out.

Those of us with tinnitus and other so-called invisible illnesses—such as arthritis, heart conditions, depression, mental illness, intestinal disorders, and many other conditions—often feel uncomfortable speaking about them because of the disconnect between

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how we look on the outside and what may be going on inside.

A recent survey of tinnitus patients revealed that the majority of us do not freely share how tinnitus impacts our lives, not even with the people closest to us.¹ Reasons include:

- Not wanting to burden others
- Fear that people may not see tinnitus as a life-impacting condition or instead think that it's all in our heads (actually, it is—in our brains)
- Not wanting to go through what I am at this moment: bringing the screech to the forefront of consciousness by discussing it

I've had these same thoughts myself—and they kept me from speaking up. In fact, when I shared early drafts of this article with three friends I've known for decades, I realized how rarely I spoke about my tinnitus. Their responses in all three instances were “John, I had no idea.”

Living with tinnitus significantly impacts quality of life for millions of Americans. And yet, we rarely talk about those impacts outside of our close relationships or the privacy of support groups. As a result, tinnitus is often dismissed as a common minor ailment, with research into finding a cure—and the funding for it—lagging far behind that for other illnesses and conditions.

This is precisely why we need to share our stories. Personal stories from lived experience have the power to move others from apathy to empathy to action. We can create real change by working together to raise awareness. Not simply raising awareness that tinnitus exists—most everyone knows about “ringing in the ears”—but by raising awareness of *how severely it impacts the quality of life* for millions. So:

If you, too, are living with tinnitus:

Consider whether you might talk more openly about the impact it has on your life, especially if you experience chronic tinnitus. I offer some tips for getting started in the sidebar.

If your tinnitus is not chronic,

and you have experienced it only temporarily or are not overly bothered by it, become an ally for others. Be sensitive to those who have chronic, troubling tinnitus. Rather than simply noting “I had tinnitus once, too” or “I have it, too, but it doesn't bother me,” offer support by letting them know you understand what they're struggling with. Help them convey to others how tinnitus impacts lives.

If you don't have tinnitus,

you probably know someone who does, so recognize that they may be experiencing much more than they let on: emotionally, psychologically, and physically. If they're open to talking

about their tinnitus—and if it’s not painful for them to do so—ask what it’s like and offer support. Let them know that you know that it’s not in their head. Share with others what you know and what you learn from those with tinnitus.

Finally: point people to www.ATA.org for information, resources, and the opportunity to directly impact research and shorten the path to a cure by

contributing. Together, we truly can make a difference. 



John Capecci, PhD, and his colleague Tim Cage are coauthors of *Living Proof: Telling Your Story to Make a Difference* (<https://www.livingproofadvocacy.com/new-book>) and cofounders

of *Living Proof Advocacy* (<https://www.livingproofadvocacy.com/>), a communication training firm that helps individuals and organizations tap the persuasive power of spoken personal stories to create change. Contact them at info@livingproofadvocacy.com

1 H. Goedhart, M. Vesala, & S. Harrison. (2018). How tinnitus can affect your relationships, employment, and social life. *Tinnitus Today*, Summer 2018, 56–61. Retrieved from <https://www.ata.org/sites/default/files/Summer2018-56.pdf>

Five Tips for Sharing Your Tinnitus Experience

1 Start by focusing on your message and goal. Rather than asking, “What should I tell?” or “How should I express my experience?” begin instead by asking, “What do I want people to know and do?” Having a clear focus helps you decide what and how much of your experience to share. It also helps move your audience—whether listeners or readers—from empathy (for you and your experience) to action (how they can help millions with tinnitus).

In sharing my story with you here, I focused on the importance of conveying the impact of tinnitus, with the goal of urging you to join me in doing so to advocate for more awareness.

2 Use language that is visual and specific. Take time to find words, phrases, or analogies that help your audience truly understand your experience. Draw upon your senses to describe what something feels like, looks like, or sounds like. Although you’re sharing real-life stories and want to be conversational and authentic,

they still require some crafting in order to engage others.

Try out your ideas on others; it’s the only way to know whether your language is having an impact. For my story, I was intent on describing exactly what the screeching tone sounds and feels like to me. My friends let me know that the “noisy electrical power plant” analogy helped them understand.

3 Use your fast-forward button. Rarely will you (nor should you) walk others through every detail of your experience. Instead, decide what important moments of your story are the “living proof” of your message and fast-forward to them.

Use transitions such as, “Three years later...” and “One evening...” as well as statements that summarize large chunks of time, as I did with “In the years leading up to that fall morning...”

4 Don’t expect your stories to do all the heavy lifting. Your lived experience is a powerful tool you can use to create empathy

and understanding in others. But stories aren’t magic. They need to be enveloped in facts and statistics. This is especially true if you’re trying to reach readers or listeners who have no experience or knowledge of what tinnitus is. You may need to first offer education in order to increase awareness.

In another draft of my story, one aimed at a more general audience than the readership of *Tinnitus Today*, I included much more information about how tinnitus isn’t something everyone can easily ignore, how it originates in the brain, the variety of ways people experience it, and the kinds of research that is being done.

5 Give clear calls to action. When you share your stories as an advocate, you do so because you want people to take action, which they are more likely to do if what you ask of them is clear, specific, and within their power.

“Help us find a cure” is less effective than a specific request to “Visit ata.org and click on ‘Donate,’” or “Please join me tomorrow.”