

Transcription details:

Date: October 2017
Input sound file: *Conversations in Tinnitus* with Glenn Schweitzer

Transcription:

S1 00:00 Welcome to *Conversations in Tinnitus*, a podcast of the American Tinnitus Association. The American Tinnitus Association is a nonprofit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. *Conversations in Tinnitus* podcasts are an extension of ATA's magazine *Tinnitus Today*, the only publication dedicated to educating the public and practitioners about ongoing research, treatments, and management of the condition.

[silence]

S1 00:48 Welcome to *Conversations in Tinnitus*. I'm John Coverstone and again joining me is my co-host Dean Flyger. And we're speaking in this episode with a gentleman named Glenn Schweitzer, who is an entrepreneur and author of a book called *Mind Over Meniere's*, which is about living with Meniere's disease, and more recently a book called *Rewiring Tinnitus*, which is about his journey to find relief from troublesome tinnitus. He does volunteer work with the Vestibular Disorders Association and generally just looks for opportunities to spread his message of hope for people in need with these conditions. So, thank you for joining us today, Glenn. We are very excited to talk to you about your experiences with Meniere's and tinnitus from those patients' perspective.

S2 01:37 I'm glad to be here with you, John and Dean. Thank you for having me.

S1 01:41 You have a very compelling story, I think. And I can't think of a better way to start than just by having you tell your story about your journey through Meniere's, and when your tinnitus became worse and you had to deal with that, as well, which led you to the second book. But I'm just going to turn this over to you and let you start out by telling that story because I'd like to hear it again.

S2 02:06 Sure thing, yeah. So, it started back about seven years ago now. I was 24 years old and I started having these weird-- the very first symptom, I think, was probably dizziness, dizziness and tinnitus. I've had tinnitus my whole life. I guess I should start there. Ever since I was a little kid, I've had a very quiet ringing tone that I would hear when it was quiet. It was never bothersome. It was never troublesome. I didn't even know that it wasn't normal until my early teens probably, when I heard other people talking about it. It was just something I lived with. It was all I ever knew. And about seven years ago, all of the sudden it became

much louder. It would spike, and I would go through these periods where it would get much louder, and I would get very dizzy. And I didn't really know what was happening with me. At the time, I was in college taking courses at Florida Atlantic University. I was doing different business and IT courses. And so this dizziness and this tinnitus started happening and I was very much in denial. I'd just, "Whatever is wrong with me, it'll go away."

S2 03:22

And as time went on, it was progressing. My tinnitus was getting louder and louder. It was like sirens going off in my ears at times. And I started having vertigo, where the room would spin just sort of suddenly. It would come on, I'd feel this ramp up of pressure in my ear, and the tinnitus would just go from quiet to 100% volume in seconds, and the room would start to spin. And the very first time this happened was in class, and was in a computer class at college. And I remember sitting at the desk, I had just finished eating a big snack, working at the desk. It was a night class and, in hindsight, it was the high sodium content of the snacks I was eating that triggered that episode. But at the time, I had no idea of any of this. I didn't know what was wrong. I just knew that all of a sudden the room was spinning. I couldn't focus on the teacher or the words she was saying, and it was terrifying. And that was the very beginning. From there, over the following few months, I would get better for a little while and then I would get worse. But it was this steady progression, down, and down, and down.

S2 04:35

And it got to a point where I finally had a massive, massive vertigo attack that just completely shattered my denial. And I sort of broke down and realized I needed help. Lucky that when it happened, I was not standing over a staircase or driving my car. I had come home from class. As a college student, I didn't have a very good diet at the time. We had eaten some sort of fast food. My girlfriend, who's now my wife but at the time. And I remember I stood up and I just fell back to the couch, and everything was spinning, nausea washing over me, this intense vertigo, the loudest tinnitus. I didn't even know it could be that loud. And it was one of the most terrifying things I've ever been through. I mean, vertigo, it's scary even when you know what's happening. But when you're not sure what's going on or what's happening, it's absolutely frightening. You're just completely incapacitated. That attack lasted I think an hour or two hours, and the whole time you're just powerless. You can barely open your eyes. You're just holding onto the earth, to whatever you're sitting on, because you feel like you're going to fly off the chair. And when it's over, you're left just cognitively impaired. You feel exhausted. It just saps the energy from you.

S2 06:01

And after that, I finally went to a doctor and was diagnosed shortly after that. And from there, it was interesting. I had a bad experience with my first ENT, and he sort of put the fear of God into me about the whole condition. There's no cure for Meniere's disease or tinnitus, and

he painted a very dark picture of what my future was going to look like. And so I was very depressed and scared, and it was a very low point in my life. I fought against it for a few more days, and eventually I sort of realized I had to try to do something to get better. I didn't like this feeling of powerlessness. And so I started doing research and learning about some of the basic things, and with lifestyle management, and I realized I was eating a bad diet. I started eating healthier. I started exercising. Just anything I could think of to improve my health and lower my stress levels. And I was taking the medications, the ammonia diuretic and prednisone. And I think I was slowly improving, but I had no hope, and this is something that a lot of tinnitus and Meniere's patients go through. It's just I had no hope at all. I had no hope of a future that was going to be worth living, but I still wasn't ready to give up.

- S2 07:25 And I eventually saw another doctor, a neurotologist at The University of Miami, who changed everything and sort of painted a very different kind of picture of what my life could look like. He told me stories of patients that were doing well. He took time to answer my questions and really sat with me and tried to alleviate some of my fears. And I came out of that a changed person. I went home and just committed myself 100% to trying to improve. And just slowly but surely over time, I was able to just carefully track my lifestyle, figure out what was going wrong, what was triggering my symptoms, and I very slowly improved. And at some point, I realized that maybe my journey could help some other people along the way. Because I knew how much other people were struggling.
- S1 08:18 And you have a couple blogs in addition to writing the books. In fact, you just told me a few minutes [laughter]--
- S2 08:25 That's right, yeah.
- S1 08:25 --ago before we started, that you had the second one. I found you through the Mind Over Meniere's blog, which is mindovermenieres.com, and Menieres is M-E-N-I-E-R-E-S, in case any of the listeners want to check that out. But then you also now have a rewiringtinnitus.com address--
- S2 08:45 Yeah, that's correct.
- S1 08:45 --and a separate blog for people with tinnitus. And what caused you to start the second one? Because you already had this first blog. And then I'm also just curious how those have been received, and what kind of support people are finding? Because that's one of the things we really find and one of the missions of ATA is to help provide people with support and encouragement and hope through communication.
- S2 09:09 Absolutely, yeah. So, well, the Meniere's-- it started with the *Mind Over Meniere's*, that was my first blog. I had wanted to start some sort of writing project for a while. And as I was trying to think of what I might

be able to write about, I realized that I was living a pretty good life with Meniere's disease, and that I knew that a lot of people were still struggling. And I thought, "I know a lot about this. Maybe I can share some of these ideas." And I decided to take a very specific approach. With tinnitus and Meniere's disease, when you go online to research, which a lot of people do, they'll go to Google and start asking questions after a diagnosis or even before a diagnosis, and you're confronted with a lot of conflicting information and a lot of terrifying information, and not a lot of hope. And I thought back to my experience with the first doctor versus the second doctor, and how this idea of being even able to see that hope was possible just completely changed everything for me. So, I made a decision to sort of share what I had learned and infuse it with this idea of hope. And people took to it really well. I think there hadn't really been a voice. I mean, there had, but not in a big way doing anything like this, communicating this idea of hope and, "You can try these. Here's practical things you can try. And if this doesn't work, just try something else, just keep fighting." And people took to it really well.

S2 10:33

Now, the tinnitus stuff came about because as I improved my Meniere's symptoms, my tinnitus didn't improve. In fact, it had got a lot worse. It was the one thing that I didn't have control over. I've gone through phases since the Meniere's diagnosis where how bothersome and how troublesome the tinnitus was. And there would be times where it would just completely overtake my life, and it was very, very frustrating. It made it hard to focus. It made it hard to sleep. I was getting depressed again. And it was this progression and this one thing that I just never seemed to be able to make any headway with, as determined as I was to do it. And I sort of had at some point a few breakthroughs, and I started having a little bit of success, and it never went away but it became much less bothersome. And I realized that it was something that a lot more people deal with and deserved its own separate site. And so I started *Rewiring Tinnitus* as a new project to kind of share what I had learned along the way with tinnitus, and how I was able to habituate and find a little bit of relief from that. So that's how the second website came about.

S1 11:49

Sure. And you know, Dean, we should probably describe for the listeners what the heck Meniere's is because [laughter], a lot of people if they don't have Meniere's disease or they don't know someone who has Meniere's disease, they may not really know what this is. And so, briefly, Meniere's disease is a condition of the inner ear where the natural process of the fluid that helps make the inner ear work is replenished, except when you have Meniere's disease, the release of that fluid does not work properly. And so as it's replenished, the fluid builds up in the inner ear and builds up to the point where the pressure can cause all kinds of adverse effects. And the typical attack when you have it is extreme vertigo, generally tinnitus as well. Very often, you have some hearing loss during the attack until the attack subsides and

this feeling of pressure and fullness in your ear. And that's kind of the classic Meniere's symptoms. And that can last up to a number of days for people that have attacks. And very often as the condition progresses, the attacks will be more severe and prolonged over time. So that's what Meniere's is and that's what you were dealing with early on.

S2 13:10

Exactly.

S1 13:11

But one of the first things that really hit me when I was reading your book, because I've been encountering this more and more, is you mentioned that you-- and you mentioned a few minutes ago that you had tinnitus as a child. That you always had it. As far as you know, it's always been there. You've never really known what perfect, absolute quiet is like your whole entire life. And I myself, in practice, am starting, it seems like in recent years, to hear more about children with benign tinnitus. Meaning they don't have hearing loss. They don't have an underlying condition that's causing it. It's just there. And I think we really haven't done a lot of research into this. I have seen numbers that say that when children are questioned, it may be up to 34% of them that have this. And I don't know how reliable that number is, but I have seen a report from a source that seems fairly reliable that said that.

S2 14:07

I wonder if there is a hereditary component as well. Because a lot of members of my family have it, my father, my grandparents, my father's sisters. So, on my dad's side of the family, it's quite prevalent.

S1 14:19

Yeah, and I think there's a lot we don't know. And if you go online, this is what I've seen. And you research tinnitus in children you're going to find a lot of websites from a lot of major, well-known medical centers, pediatric hospitals and such that basically have a page that looks very much that if you took out the word children and put adults in there, it would be exactly the same advice that we give adults. We're not really treating this as a pediatric condition. We're just saying, "Ah, well, kids have it too." And so here's what you should do about it. And we're taking everything from adults to kids and I'm not sure that's appropriate. But that's a conversation for [laughter] another day. But that really struck me that you had that. And I would be curious to hear more about reflecting back on your experiences as a child with tinnitus, and what that was like for you. And what you're thinking in retrospect about that.

S2 15:09

It's interesting because I hadn't really thought about it very much until I was starting to formulate my ideas for the new book. And I was sort of going back in my head and thinking about my early experiences. I can remember just having this very quiet, high-pitched tone. The first memory I have of it being an actual thing where I felt like something was wrong was around the age of maybe 12 or 13. I think I had gone to a friend's bar mitzvah party and the very loud music, like a wedding. And I remember coming home and just having that temporary hearing

loss. And I remember feeling like my ears were stuffed with cotton. And my parents trying to explain to me, "Oh, when you listen to loud music, this is something that could happen and not really grasping anything at the time. But I remember distinctly not being able to sleep that night, just trying to do whatever I could to block it out. And most people with tinnitus know when you have tinnitus already and you are exposed to loud sound, it becomes much louder. I mean, anyone that is exposed to loud sound, they'll hear tinnitus and have mild hearing loss temporarily. But when you have tinnitus to begin with, it could become extraordinarily loud. So, this was a pattern that repeated throughout my life.

S2 16:31

As I got older and went to parties or concerts, every time I was around loud music or I'd listen to headphones with loud music, I had no idea I was doing damage. And it would be this loud music, mild hearing loss, extremely loud tinnitus, can't sleep, the next day slowly resolves itself. So, it was something that, I guess, I just-- I was a hyper kid. It was never enough to enter into my consciousness as some sort of major problem that I should be careful about or be worrying about. I wish I knew more when I was younger, because I certainly would have taken steps to protect my hearing. But, yeah, thinking back that pretty much sums it up. I mean, even today, now I never go out to any sort of loud environment without at least musicians earplugs at a bare minimum. So, yeah, thinking back, it was that same pattern over and over, music, tinnitus, hearing loss, sleep deprivation, repeat.

S3 17:38

Everybody has things like that when they're young [laughter]. Now, going back to some of those feelings that you had, and we've talked about this in other conversations, the symptoms of the Meniere's, the symptoms of the tinnitus can cause fear, anxiety, especially if you don't know exactly what's generating them, if you're experiencing them for the first time. You did a fantastic job of describing that. If you look at a person who is suffering from significant tinnitus, enough to affect their life, what do you in general recommend be their first resources that they seek? Is it a conversation in a blog like you do? Is it a specific area online? Do you think that they need to have an immediate medical referral to a neurotologist where you had your success? What are your thoughts as a person who's been through this and a patient who wants or a person who wants to give the best information to people for them to have a better quality of life?

S2 18:53

Good question. So, I think the answer is different for somebody with Meniere's disease, which like we covered, is a cause of tinnitus and someone who just has tinnitus from another cause. With Meniere's disease, in my experience and what I've seen from other people that I interact within the community, there is a big issue with a lack of experience on the part of a lot of General Physicians who won't have encountered it very often, even some ENTs may not have treated many cases or have a lot of experience past what they've learned in med

school, which may not be all that much. So, I think that one thing you hear people with tinnitus, a common story is you're told, "You just have to live with it, or it's in your head." They're not given very helpful advice. So, I think the first step is always-- the first thing I always will tell people for either is find a good doctor to coordinate your treatment. I am not a doctor. I am just a patient. And I have my own experiences and ideas to share, but I am not a medical professional. So, I always recommend finding a great doctor to coordinate your treatment, prescribe any necessary medications that might help in the case of tinnitus. Obviously, an audiology appointment is a must.

S2 20:13

I think as far as information, the first step is always going to be education, regardless of Meniere's or tinnitus, both are very scary. As you said, Dean, things that have happened to you. In the case of tinnitus, this onset of this loud noise that no one else can hear is terrifying. And then as time goes on, and it's not going away, this temporary problem is becoming this permanent thing and the fear starts to build. And then a lot of times, they'll go to the doctor and they'll say, "Oh, it's in your head," or, "There's nothing you can do. You just got to live with it." And that's not helpful advice. And so this fear response builds and I think that's very detrimental to the person, because it feeds into this-- I think a lot of the problem with tinnitus, at least from what I've experienced, is that it's not so much a question of how loud it is. It's a question of how much does it bother you, how intrusive is it in your life. I think that's the one aspect of the tinnitus that you can work on. And when this fear builds, it creates this negative conditioning that causes the tinnitus to get worse. And I think that's a terrible place for any patient to start.

S2 21:29

So finding a good doctor to coordinate the treatment is always going to be my first recommendation, and then finding a good source of information. And when I say good, just one that at least gives you hope. That's sort of the baseline. As long as you have a sense of, this is not something that is just a life sentence. This is not something that I'm stuck with and there's nothing that I can do. As long as you don't have that sense of powerlessness, I think is a good place to start. So resources like the American Tinnitus Association, or the Vestibular Disorders Association. These are all great resources of information. And then also, I try to put out a lot of information on my blogs, too. So I think that's always the first thing is finding a good doctor and education, whether that's from the doctor or from your own research. Educate yourself to a point where you feel there's a sense of hope.

S1 22:22

Yeah, and you wrote a bit in the book about your journey to coming to terms and getting on top of your tinnitus, so to speak. What were the triggers that you found that were significant for you? And you talked about a lot of different treatment approaches, but what did you find effective for yourself?

S2 22:46 Yeah. I should say that a lot of my triggers for me and what I've seen is everyone experiences this differently. No two people hear the exact same sound and everyone has a different set of triggers. Now there are a lot of common triggers. But for me personally, the things that trigger my Meniere's disease are what trigger my tinnitus to spike. So for me, it's things like stress, which I know is a big one for everybody. I think stress is--

S1 23:14 Always.

S2 23:15 --plays a very important role in managing tinnitus or Meniere's disease. But too much sodium in my diet for me seems to be a very big trigger. Too much caffeine is a big trigger for me. Sleep deprivation is a massive trigger for me. I'm useless. I break down very quickly without sleep. There's a lot of different things. And I think tracking it and identifying what is actually triggering you is a very important step with either condition. On either blog, I have a free tool that I've created that helps people track all the different aspects of their diet and lifestyle, and their symptoms, and their sleep, and the medications, and exercise, and stress, and all these different things. So the idea being, you can look back and try to find the patterns of what's triggering you. So I think keeping track is very important. For me, what worked with tinnitus, it was a very lucky accident. As my Meniere's symptoms improved, like I said before, my tinnitus didn't. And one of the things that helped me improve my Meniere's symptoms was meditation. I've always been a very anxious person. I had issues with panic and generalized anxiety when I was younger that I was taking anxiety medications for a while. And meditation was the thing that really changed the game for me. My anxiety levels went way down. My stress load went way down. It had this transformational effect on me. And it helped me cope with Meniere's disease for sure, early on. It kept me more grounded and more centered.

S2 24:55 But it was becoming very difficult to meditate and focus on my breathing or mantra with the tinnitus blaring in my ears. And this became a big problem. I did not know how to overcome this because I was getting so much out of it, but it was becoming very frustrating to meditate. And I sort of had an insight. An idea kind of hit me out of nowhere, that I was thinking about meditation and how meditation is the act of focusing your awareness on a single point, whether that's your breathing, or a part of your body, or like a mantra, which in transcendental meditation, which is like a mentally repeated word or phrase. And it sort of hit me. I was like, "Well, why couldn't I just focus on the sound of my tinnitus? I'm fighting so hard to ignore it. What would happen if I just focused on the sound as the focal point of my meditation?" And it seemed like this crazy idea in my head at the time, but it was interesting enough that I tried it. And the first thing that happened, the first sort of breakthrough I had happened almost immediately. When you meditate, your mind wanders. This happens to

everyone, especially people new to meditation. It doesn't mean you're doing it wrong. The meditation, I see it as sort of the exercise of catching your mind wandering, bringing it back. It's this sort of a brain exercise to be able to focus on a single point when you think about it.

S2 26:26

But when my mind wandered away in this meditation session, it wandered away from the sound of the tinnitus. So I was trying to focus on the ringing, and all of a sudden in my mind, and thinking, daydreaming about something. And it hit me that I wasn't noticing my tinnitus at all in that moment. I was blown away. Just in this moment, it was gone, gone from my awareness. Not objectively gone, but it wasn't in my consciousness at all. And so that was my first big sort of breakthrough moment, and I was like, "Whoa, this is interesting." And I maybe meditated for 20 more minutes to the sound of my tinnitus, and when I was done, it seemed quieter. Now I was kind of looking at it and paying attention, and it wasn't actually quieter. What I realized now is it just wasn't bothering me as much, so it didn't seem as loud. It wasn't in the forefront of my awareness. It was sort of in the back of my awareness a little bit, which is what people who have habituated will encounter. So this started me on this-- it took me in a whole new direction, and I had this moment where I realized maybe I have a little bit more control over this than I thought. And so over time, I kept practicing, and practicing, and practicing this tinnitus-focused meditation. And much to my surprise, I was able to habituate.

S2 27:50

And now, I should be clear that I still have tinnitus. It still spikes from time to time. It can still be bothersome occasionally, but it's never like it was anymore. A good way to explain habituation is just it's not in the front of your mind anymore. All of sudden, you realize days go by and you haven't noticed it at all. It's still there. It can still get loud. I know some people claim or some people have experienced a total remission, where they've habituated to a point where it disappears. I have not experienced that, but for me, it was transformational. My quality of life went up dramatically. And that's sort of what I try to tell people when I explain this approach is try to measure this with-- the way I measure success with me and the way I encourage other people to measure success with tinnitus is as an improvement in quality of life. You're going to have setbacks. You're going to have difficult days. But if the general trend, if your quality of life is getting better and it's bothering you less and less, then it's becoming less and less of a problem. So that's sort of the foundation of how I was able to do it.

S2 29:04

Now, I've found other things along the way, like with tinnitus retraining therapy, which is a very popular approach to tinnitus and one that actually works. And I find that it addresses the underlying issues that prevent habituation from happening, the way we react to the sound of our tinnitus, how it bothers us. One of the things I teach is the idea of sound masking. Just using sound masking, of course, if you have some of your hearing left, to lower the volume. But not just to make it less

bothersome or to try to ignore it, to lower the volume to a level where it's easier to meditate to. So I would use white noise or nature sounds, like a stream or whatever, and lower the perceived volume, maybe down like 50%, and that made it much easier to meditate to earlier on. I think for a lot of people who are hearing this, it's going to sound like a crazy idea to focus on the sound of their tinnitus. So having things like that, where you don't need to necessarily face it at full volume, especially if it's causing a lot of stress and problems in your life, I would not recommend just jumping into it head first, but using something like sound masking to make it a little bit easier. So I was able to discover a lot of things like that to make the practice a little bit more approachable and easier. And that's been what was the biggest change for me, and it really gave me my quality of life back.

S1 30:38

And just to remind everyone, this is Glenn Schweitzer. And he has authored a pair of books that you might want to check out, *Mind Over Meniere's* being the first one, and then more recently, a book called *Rewiring Tinnitus*. And he also has a pair of blogs that go with each book, with mindovermenieres.com, rewiringtinnitus.com. And so you may want to go onto those and see what he's saying beyond the books and connect with him that way. And I just want to thank you, Glenn, for joining us for this Conversation in Tinnitus. [music]

S4 31:26

The American Tinnitus Association is a nonprofit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. Gifts and donations to ATA are used to support research for a cure and other critical missions described on our website at: www.ata.org