

TINNITUS TALK

— PODCAST —

EPISODE 18



TINNITUS REALITIES

Steve and Sean

Steve: " And this is the struggle you have. You show—imagine you get an advert on prime time, you show somebody, you show the tinnitus, you show what happens; your next video is a child in a war-torn country, and then after that you've got a donkey. A person with tinnitus is long forgotten..."

00:18 Introducing our guests

Hazel: Welcome to The **Tinnitus Talk** podcast. I'm Hazel, and today we have something a little bit different for you. As our frequent listeners will know, usually we interview tinnitus researchers or experts in the field, but today we're just talking to people who have tinnitus—about their personal experiences. So I'm here with Steve and Sean, who both have had tinnitus for many years, and I would say have struggled with it from time to time—they will tell you to what extent that's the case, and we wanted to do an episode like this because we feel there's demand out there, and it's something you guys are interested in, just hearing personal stories. It also won't be much of an interview per se, more of a group discussion, because obviously I have tinnitus myself, so I'll also be throwing in my own personal notes here and there. So I'll ask... Well, first of all, welcome, Steve and Sean. I'll ask you both to introduce yourselves, and I think for our listeners, it might be nice to know a little bit about your background, so things like your age, where you're from, what you do, obviously feel free to tell as much or as little as you're comfortable with. Steve, can I ask you to go first?

Steve: Yes, well, I'm Steve Harrison. I've had tinnitus since, I think it's 2003, and that's a long time. See, you kind of lose track; it might be 2002. These things get sort of waylaid after many, many years. I got it originally from three separate causes. When it first turned up, I got it from flu, which blocked my ears, and I basically—I could barely hear anything. But then later on down the line, I realized that I had slight hearing loss in the ear I had the tinnitus, and then after that, I realized that I've got an issue with my jaw, I got hit with an RSJ, which is a rule steel joist, on a construction or demolition site, and that knocked my jaw out. Interestingly enough, I've realized within the last two months, because I've got a new pair of earphones for the gym, that I actually—the bone moves very differently on the left side, so if I sort of move my jaw when I'm lifting weights, I can feel on the left side it pushes the earphone out, so it's quite a weird thing, which I only just noticed that I've got this misalignment and this messed up bit of my jaw where I got hit, which plays a major part in the actual volume, so I am currently—I had my birthday a few weeks ago—47 years of age. And I live in the north of England, in Sheffield. And also, by way of minor earphone reduction for anybody who doesn't know, I did also call for tinnitus help, and I've been... Well, I was on the forum a lot many years ago, and I do music and sounds to help people with tinnitus through sort of YouTube, Spotify and what not, and also casually do bits of volunteering for tinnitus—not as much as I used to because life has a way of getting in the way sometimes.

Hazel: Right? We should get into many of these areas, for sure. Sean, do you want to briefly introduce yourself?

Sean: Yeah, sure. I'm Sean, I'm also known as Jack Straw on the forum. I've been there for a couple of years now. I'm 29 years old. I live in New York, New York State, Westchester in the US. I've had tinnitus for about... I wanna say since maybe around 1995. Really briefly, it started for me when I was a really young kid. I had the eustation tube dysfunction and had a lot of fluid behind my ears, so the doctors put in tubes and shortly after the surgery concluded, I have a distinct memory of walking into a room and hearing a sound and I was like, what is that... And I was kinda looking around, and then eventually—I was a young kid, like five years old, I realized, Oh no, that's coming from me! It didn't necessarily... And then over time, obviously, it got worse for me, part of my own error—I have not protected my ears as much as I should, but that's essentially when it started for me, is when I was very young.

Hazel: Wow. Yeah, you were so young... Yeah, and you still are very young, certainly compared to me and Steve, both in our 40s, so it's good to have that perspective as well of a younger person and getting tinnitus during childhood, which must be... It must be a different experience than getting it as an adult.

Sean: Well, yeah, to be honest, when you're kind of a child and, you know, I had it and I only really... When it first started, I would only hear it in a quiet room. If I had music playing or the TV going or whatever, I wouldn't notice it, so it very much habituated very easily to the point I never understood. And also, when you go to a doctor and the doctor says, Oh, don't worry about it, it'll go away, when you're a young kid, you think, oh, this... Doctors know everything. You know what I mean? So if the doctor is telling me it's gonna go away, I'm not gonna worry about it, so it kind of really easily fell into the back of my mind and didn't really come up again as an issue until more into my...say like my early 20s—until I was like 21-22-ish.

05:38 What do we mean with “tinnitus severity”?

Hazel: Alright, and well, I think our listeners can hear you're probably from the US or North America...

Sean: Right

Hazel: And I'm from the Netherlands; I'm mentioning this, because it can be relevant when we talk about certainly experiences with the healthcare system, which can be quite different from country to country, so... Alright, so thank you both for your introductions, and it's clear you've both had tinnitus for quite a long time. What would you each say in terms of the severity of your tinnitus... I know this is by itself a contentious term, right?—because we can get into a lot of debates about loudness versus distress, but however you want to define it, and certainly it probably is varied over time as well. How would you define the severity?

Steve: I would probably say that is for me, there's a split between the two, so the loudness versus the severity, and it can change depending on what time you ask that question. The minute I would say loudness is easily an 8 or a 9. It can go up and down; mine is very much muscular related, and mine is actually a bit higher at the minute because of self-induced—because I've been playing FIFA on the Playstation, and it's a highly intense game with the weekend league—for anybody who's listening and knows about it, it's incredibly frustrating at times when you feel like the AI is against you, so that gets my tinnitus is going up because I get tension through the neck, in the jaw and everything like that, so it often—mine, sort of, will probably sit around maybe a 6 or something like that, so it's very, very... I cannot know it's there, but I can hear it, so I'm a terrible person for concentrating, but in terms of severity and impact on life, I've kind of moved beyond that. I haven't, because I know, I think there's always a little thing in the back of your head that if I stopped and obsessed and thought about it, it could destroy us because the noise—having this permanently, constantly—it's just an unthinkable thing, but I've moved beyond the point where I fixate, and that has an impact. So

it's a difficult one, to ascertain the quality of life impact 2 or 3, so... But it varies because if it's very loud, for example, after I had the second COVID jab, I had two days of unbelievable, intense tinnitus. In the words of spinal tap, it was up to 11, it was *absolutely* ridiculous. And it was at a point where two days of that without a joke, I could imagine if I had a lifetime of that, I wouldn't be sitting here talking to you now, because it was *unreal*. It was just so loud. It was horrendous.

Hazel: And it went right back down after a couple of days, luckily. Okay, thank God. Sean, how about you?

Sean: Yeah, when I think about—I'm reading a lot about how people talk about it on the forums and stuff, like when I think of when someone says severity, I think it does go hand-in-hand with what Steve was saying. Loudness is one thing, and then when I think of severity, it's kind of like if it's severe or not as bad, or the different tiers of it. I think it's also an emotional response, like Steve was getting into... I remember when my tinnitus first was worsened significantly, I could easily say that the loudness was probably at an 8 or a 9, there's nothing that would get rid of it, you know what I mean? No sound, and that was very concerning in the sense that it would... If you can't escape it and it's always there, you can't mask it—I would say that would be on the severe level, but then over time, I know a lot of people may disagree and be upset with this term, but you habituate to it over time and it falls in the back of your head. Like I could be sitting at my desk doing work and be doing something, and all of a sudden I'll think about my tinnitus randomly, and it's like the bells start blaring, you know what I mean? And it's like, Oh wow, that's really loud, but it can definitely fade in and out even though it's constantly there and yeah, you kinda just have to... Steve was saying, just not think about it, keep busy and not focus on it, but yeah, I'd say my sound is like... I can hear it all the time when I'm driving, when I'm doing other tasks, so I'd say it's probably around like... Maybe like a seven or an eight. It definitely has... When it first got worse, it was definitely like an 8 or 9, but then I think it very slightly reduced in intensity, especially the pitch kind of rounded off and wasn't as piercing, but it was still just as loud. But severity wise, I think I'm more in the... Now that my emotional response to it has gotten better is definitely more in the middle range.

Steve: I think the emotional response thing's quite interesting because it's one of those things that you tell somebody who's new to tinnitus, and they can't process it. I couldn't when I had tinnitus at first; I couldn't process the fact—it's like loudness equals severity equals distress, and it doesn't necessarily. But you can't tell somebody about this when they first get tinnitus because they're in that horrendous state that you just can't process that information at all; all you are is in pain.

Hazel: Yeah, you literally cannot imagine ever being able to live with that sound. Certainly it's not like that for everyone who gets tinnitus; we know lots and lots of people have tinnitus, many of them, either it's very soft or they just don't care, but for those of us who get tinnitus and are truly distressed about it, which is still in absolute numbers, many, many people—you literally cannot imagine. I remember thinking this, there's no way I'm gonna be able to learn to live with this. And then it does happen over time.

Sean: And another thing is that I don't think—I know people talk about it, obviously when they are new to the forum, they're very emotional and intense about it. I think that initial onset of when someone's tinnitus gets worse and like if it happens to you, it's also something that I feel like you can't describe to someone who's never experienced it. It is so incredibly distressing and traumatizing, and I think that's kind of what makes a lot of us want to protect our ears and keep going, because going through an experience like that is so intense that I can't imagine having to relive that, you know what I mean? It's just insane.

Steve: And I think the funny thing is that my tinnitus was so quiet compared to what it is now, and yeah, if I had had the tinnitus I've got now, when I first got it, I couldn't imagine it. But that distress with a noise, which effectively I had to plug my ear to hear it, and if I was in a café, a bar or whatever, anywhere else, I wouldn't hear it, but because probably a lot of us who are bothered by tinnitus share a similar obsessive behavioral trait or whatever you would call it, I listened to it; I plugged my ears, I checked it. I was like, does this sound drown it out now? Yeah, that sound drowns it out. Oh, what am I gonna do if that sound stops drowning it out? And you have all these sort of weird thought patterns, but then when you get past that point when you're out and about and you're like, yep, I can hear it, there's nothing drowning this out, and you're actually okay with it. There's a kind of weird switch point, not for everybody, of course, but...

12:53 On habituation, or learning to live with it

Hazel: Yeah, that sounds familiar, yeah. For some people, it might be weeks or months or years, but for me it was like, I think maybe four months after onset when it started getting a little bit easier, and you notice that, oh, I can hear it now, and I'm sort of okay with it at least for this moment, it might be different in the next moment. And you think, well, if I can have one moment like this, right where I hear it and it doesn't hugely distress me, then maybe I can have more moments like this—when it starts catalyzing and things get easier.

Sean: It's funny you say that because I also thought about it in small victories like that, where it's like, Oh, I watched a 30-minute show and I didn't think about it once, and then from there, it increases in time to a couple of hours, you know what I mean, and it just kind of grows slowly.

Hazel: Yeah, yeah, yeah, I think for me, the biggest relief was realizing that... because at onset I had to stop working because I couldn't concentrate on anything, it's the only time in my life that I've had to stop work for more than a few days, it was a couple of months, but then after those few months to notice that I could do something, whether it's write a piece, an email or I don't know, just be focused on something that you're doing and for that period of time that you're focused on that, not consciously hearing it, obviously it's there, but then not consciously hearing it and then ending your task and you hear it again, but you realize I didn't hear it for the past 30 minutes because I was focused on writing this email or whatever it was, that was huge for me.

Steve: And I think that's a thing as well, being busy is actually one of the best things you can do when you get it, and when I've been ridiculously busy with work, I've got again, that dichotomy of really busy, so it's not featuring—but really busy, so I'm highly stressed and it makes it lower. So it's kind of when you're busy, you can just... You just go on and your brain goes into that mode of: I've got things to do, I've got to get on with it, and you don't have time to be distressed, which sounds a bit strange again, to anybody who's relatively new to it and in a distress state, but you just focus on the task at hand and get by.

Sean: Yeah, I think one of the hardest things for me after it got loud was reading... Just reading a book. I could still... TV shows were a little easier because you have a sound or whatever, but just sitting and reading a book was really intense because it was just you and the sound and the words on the page, and the sound always won for me. And then compared to a couple of years, maybe three years later—four years later at this point, and it's like the other day, I sat in my living room, laid down and my tinnitus was blaring and I could hear it and I just didn't...it was there and I just didn't give it any attention even though... You know what I mean? I can still hear it all the time, it's blaring in a quiet room, I didn't even try and mask it, and I can just get on and read now, which four years ago, it would have been impossible.

Steve: Yeah, it took me years to be able to read again, like properly read again and get immersed in a book, it took such a long time.

Hazel: Yeah, which is really a pity because it's such a rewarding experience to feel that immersion. Yeah, so we've sort of jumped ahead to the habituation stage that you've both reached, and we can talk more about what that means—habituation—and I always feel it's presented often by the experts in much too black and white a way. There's many shades of gray in between, I would say.

16:40 Hyperacusis and other struggles

Hazel: But before we get more into that, you've obviously each gone through a big struggle, can you talk more about what were actually—what were the most difficult times or moments for you. Let's start with Steve.

Steve: Yeah, I mean, when I first got it, it was that whole mental thing of going through it and not knowing what was gonna happen. Am I gonna go deaf? Am I gonna get worse? Is it gonna get to a point where I can't manage it? That was a huge thing to start off with, and that probably... I don't know how long it lasted now because it was so long ago, but then about a year or two in... was it about a year in and I got hyperacusis?... and then I struggled with that quite a lot, but it wasn't quite the same as the tinnitus, it was more that it really affected work and social... There's so many things I had to stop doing. I didn't wanna walk down the street, I lived in Brighton at the time, and the... Every single bus in Brighton, I swear, they didn't know what oil was, because they just made the horrendous screeching noise that went straight through... And it was just awful, so I almost felt like I couldn't go out because there are buses everywhere and you got that constantly and ambulances, police, just all the sirens and everything like that, and that was pretty difficult for about, I think three months— three to six months, I think it was... And that kind of made me go right inside myself, which was... It was quite difficult and then...

Hazel: Isolating, it sounds...

Steve: Yeah, it was really isolating, it was...

Steve: And then I got hyperacusis again. Oh, God, how many years ago? Seven, eight years ago. Again, I'm not keeping track. And that was really bad, that was through an ear infection, and it was a real pain response. Where the first time was more like a fear, the second time I got it was a real pain response and that was... that lasted about three months.

Hazel: So for those of the listeners who don't understand this, you were experiencing physical pain with certain types of noises?

Steve: Yeah, a lot of noises in one ear, so—the worst one was my other half talking next to us. I had to ask her to stop talking, which was quite a difficult conversation at the time; she's quite understanding, but I was like, can you stop talking? Because it's hurting my ears; that's not a nice thing to say to somebody.

Hazel: and it's not just right now, but for the foreseeable future (*laughing).

Steve: So that was a really difficult point in time, and that was very, very difficult. At that particular point in time, I handled it completely the wrong way because I used alcohol as a crutch, and as anybody who has done that knows, it's one of the worst things you can possibly do. It's ultimately a depressant, it creates jitters the next day, and you're just like, everything about it is bad. I know some people get relief from it, but in terms of psychologically and emotionally, it's not a good thing at all.

Hazel: I mean it... Temporary relief maybe, but...

Steve: yeah, you might get temporary relief, but you pay for it twice afterwards.

Hazel: Yeah, yeah.

Steve: So that was kind of... They're the main difficult points, I think when I first got it, it was the most—because it was new, because I didn't know what it was, it was really distressing at that point.

Hazel: Yeah, yeah, but the hyperacusis aspect, I count myself so lucky I haven't experienced this, but what I've noticed, when you look at the **Tinnitus Talk** forum, for instance, the people who are struggling the most, not all of them, but many, many of them have tinnitus and hyperacusis, and it's the combination that just is the worst. So, yeah... Sean, what were the most difficult times or moments for you?

Sean: When I look back, it definitely has to be... And I feel like we've kind of talked about this, so I won't get too into it, but it was basically the onset that was just so intense. It's honestly one of the things where it's... I try and describe it to people who don't have tinnitus or haven't really dealt with that, and it just kind of goes over their head. They'll shake their head and be like, oh wow, that sounds bad! But I'm like, Oh, you just don't really understand. That was definitely the hardest, having to do mental gymnastics, where essentially your life goes from, Oh, I'm gonna do X, Y, Z a couple of months/weeks from now to what am I going to do to get through today? How am I just going to get through today, go to work, get my work done and get back home and not kind of... and not break down essentially. It was intense and it was pretty scary. That was, I think, definitely the biggest challenging thing, and I think... I know we might talk about this later as well, but I'm also trying to get other people to not necessarily understand the worst thing of the onset, but understand the situation in general, kind of like how my lifestyle is now changing. You know, I can't do X, Y, Z, and having people understand that who knew you before is something very challenging because they just don't understand, you know what I mean? And

they're like, Oh well, this isn't that loud, and it's like, yeah, it's not that loud to you, but it is very loud, you know what I mean, and that was really hard to get people to understand and it was very frustrating too to, in my experience, have people kind of get on board to the point where they understand. Now it's a lot better that people close to me know the situation and everything like that, but in the beginning, it just made it a little harder because people just didn't really get it where it's like, Oh, let's go here, and it's like, Oh, I can't go there, it's too loud—or, oh, we're doing this, and it's like...Oh, I can't...You know what I mean? I think that was one of the biggest challenges, just getting everyone on board and to just understand and sympathize with what was happening.

Hazel: Yeah, yeah, we can delve a bit deeper into that actually. Did you feel the same, Steve?

Steve: Yeah, so I had to make basically overnight lifestyle changes. I just stopped going night clubbing. I went a little bit, but I went and then there was a mixture of paranoia and actual—paranoia that I'm making it worse than the actual of waking up to louder tinnitus the next day, but then you also have another peculiarity where if you've got a hearing loss with tinnitus—if you go to a loud place the recruitment of the neurons means that you hear things properly, so that your tinnitus can actually be a little bit quieter, it's a very peculiar thing.

Hazel: You mean while you're there?

Steve: In the day after. I've had that where I went on a stag do to Ibiza about eight years ago, seven years ago, I can't remember now—round about that time. I went to the clubs because it was just, I'm here, that's what I'm doing. And the next morning I was like, okay, the tinnitus is quieter. That's weird, but it is because the louder their music is, then you're able to actually hear the frequencies that you're struggling to hear when you've got a hearing loss, so that sort of recruitment can have that weird effect. So even though I'm battering my years, and probably damaging them, you have that strange sort of after effect.

Hazel: Yeah, that's a short-term effect, I'm sure. The longer-term effect is less beneficial.

Steve: The long-term effect is not worth it.

24:09 When others can't comprehend your experience

Hazel: Yeah, yeah. So anyway, you said you used to go to a lot of night clubs and then you mostly, although not entirely stopped, and was that difficult to explain to maybe the friends that you used to go clubbing with?

Steve: Oh yeah, definitely, definitely. At that point in time, I had just moved away from Newcastle, so I wasn't around people that often, but yeah, then you kind of meet new people where you go, but... And it was very difficult to explain—like, I can't be here, I'm just gonna go and sit at a table over there, and you kind of look like a bit of a weirdo. And I just had to do it, but there's a point. I am very much a person who will just say, I need to do that, so I'm doing it. I don't stand on ceremony for people, but it can be very difficult to say to people that I can't do this, and you kind of feel like you're causing a scene or whatever, but I'm just not—with people, I'm just like, this is why I've got, this is what happens, and this is why I'm not going there. So I stopped a lot of that.

Sean: I think a lot of people also struggle because a lot of people are people pleasers, and you don't want to put anyone out, you don't wanna be that guy that ruins the fun, but eventually you do learn to say... You just say, Oh, I can't do it. Because now when things like that come up, I don't feel bad about it. You gotta look out for yourself first, you know? And you just kinda gotta say, I can't do it—like, listen, I don't wanna be a party pooper where you guys go have fun. And it's fine with me. Don't worry about it. And that's just what you gotta do.

Hazel: Have either of you ever met sort of total incomprehension, like someone absolutely could not comprehend what the hell you were on about?

Steve: Yeah, I had a boss from hell. He's not likely to listen to this podcast. It was complete... Again, it's a language thing; I can't describe him whilst keeping the language clean, so...

Hazel: I don't really mind (*laughing).

Steve: I'm just thinking for your R rating or whatever you're going to follow. So, he was an idiot, and he kind of mocked it, and you know, you're going through an emotional time and you're trying to kind of manage it. When I first got it, and he just kind of mocked it all, and you're just like, yeah, that's not cool, but then that's your boss. What do you do? I don't think it would fly today in the workplace, because I think workplaces are much, much different, well, it will in some work places because there are some idiots around still, but they are few and far between these days fortunately. But yeah, so that was just—that was ridiculous. On the whole, people have been quite understanding, but I'm quite good at just explaining myself though, and I know a lot of people aren't, because a lot of people are just that I'm in distress and that they can't get across, but I'm quite like, this is what's happening. And the music connection as well, from an early time, I was able to synthesize. This is my tinnitus. This is what it sounds like, so anybody who wants to hear it, I play it and then they're like, whoa, that's not nice. So I've got that additional thing that I've been in the...

Hazel: Yeah, that helps. That helps, yeah. And that's an excellent way to get the point across, right, this is what it sounds like, put on these headphones and see how long you can take that...

Sean: That's kind of what I do as a last ditch effort. When someone's just not getting it, I say, you know what? Hold on a second. Take out my phone, you find a sound that sounds similar to it on YouTube, you turn it up to about how loud yours is and say, okay, you hear this? Now imagine hearing this and never being able to escape, you go to the bathroom. You do whatever. You gonna take a shower? It's always there. Then they kind of are like, okay, that would kind of suck. You know what I mean? Then it kind of all comes together a little bit...

Hazel: Yeah, yeah, exactly, yeah. Sean, have you had... What's your worst experience with someone not understanding?

Sean: Yeah, so I've had similar experiences to what Steve was describing, where some people just didn't get it and not necessarily mocked it, but was kind of like, kind of a jerk about it. One thing that kind of stands out to me is the people who somewhat, I think somewhat selfishly, think that, oh well, he can't do X, Y, Z anymore, this is now affecting me and my enjoyment of things, even though it's like... You know what I mean? There's people like that, and I remember sometimes people would say things like, oh, you really gotta go see a doctor, or you gotta really get that fixed, and it's one of those things where you're sitting there and it's like I spend every waking moment of my day thinking about the next step to resolve this, and I kind of had a unique situation where I joined the forum, I helped out with the podcast in the beginning, and I'd be interviewing people like Richard Tyler, CEOs of pharmaceutical company, other big players in size. I would, before interviews and after, I'd kinda throw in my own personal question in there, and so I literally took it as far as an individual can go to getting answers and to trying to get this resolved. And when someone would say something like that to you where they say, Oh, you really gotta go see a doctor, you got to this, it's like you don't understand the extent I have gone to try and resolve this problem. It just kind of felt like twisting a knife in my back where I already am dealing with this really badly, and then someone comes along and insinuates that I'm not trying to resolve this, and it's like if they only had any clue, you know?

Steve: When they say there's a quick fix mentality as well. Oh, there must be something. Google that on the Internet.

Hazel: People assume, don't they, that there must be a fix.

Sean: Yeah, why don't you go to the doctor and he'll give you a pill, and it'll go away. It's like, No, unfortunately, it's not how this works.

Hazel: Nope!

29:41 Tinnitus “cure” scams

Steve: Yeah, exactly. But the thing is, when you Google on the Internet as well, you would think there was a quick fix because there's so many scams out there.

Hazel: Oh, God, yeah. Yeah.

Steve: Yeah. I mean, the latest one, obviously, I've got the YouTube channel to turn the sounds on. I have it constantly on there with this Doctor Gabinga herbal remedy. I'm just getting spammed by fake accounts. Oh, my tinnitus is cured now, thanks to Doctor Gabinga. It's just like... honestly but it's a different one all the time, I just get... I'm constantly having... I report them to YouTube. The accounts don't seem to get banned because I get them constantly trying to post the same rubbish on video after video, but this is what you do. In so many Googles, it'll be like, oh, there's plenty of remedies—or this homeopathic—or this water and sugar.

Hazel: Let's not talk about homeopathy. Don't get me started.

Steve: Yeah, let's not go there.

Hazel: Yeah, yeah, it's so true. We were a while back working on the Google ads for our organization, and we were testing what happens when you type in certain keywords, tinnitus cure, et cetera. Ringing ears... you get seven ads out of which five or six are scams, like pure scams. So that's what people see when they Google.

Steve: Well, that's a slightly off topic as well, so that's another thing as well, where I don't get an awful lot of traffic compared to other sites, because I won't lie. So I go on, this YouTube video gets 1.2 million views in a year, because it says the most amazing tinnitus cure ever, because it lies... For the YouTube, I contacted YouTube recently about it and said, “Look, your algorithm is prioritizing scams,” but I'm here trying to... because I had a traffic drop recently, I forget what it was, by the way, YouTube make videos... ads mandatory since last November. So of course, to somebody who's got music on there specifically to help people with tinnius, people getting bombarded by video ads that I've got no control over knock my traffic down, which I was kinda trying to get the bottom of it, and then all of a sudden it was like... But if I lied, I would get loads of traffic, but because I'm honest and I tell the truth, I get a tiny

proportion of it, it's terrible, but it's the way the Internet works as well, which is one of the things which is most harmful to people with tinnitus. They'll go on there first thing and go, they want a cure, and what do they get? Scam after scam because nobody with any integrity would actually try and sell you a tinnitus cure.

Sean: And the worst thing about that though, is that some of those "cures" can very easily make someone's tinnitus significantly worse, like I saw one doctor, oh, you just gotta smack your ear around and it's like, Oh God, I am pretty sure that's not gonna work.

Hazel: That's bad. Yeah, the supplements are probably the least harmful ones, but supplements can be very expensive; people can spend up to like \$1000 a year on supplements that don't do anything well, hopefully they at least make you somewhat more healthy, but...

Steve: Yeah, at least you're getting something for your money though, it's questionable and very questionable what they actually do for tinnitus, but at least your supplement, your moment, you're getting actually a product for it, whereas these scam products are just a bit and often, and it's all ad, it's pure money-making schemes, and...

Hazel: Exactly, yeah, there was that one that cured your tinnitus through quantum mechanics or something. This was years ago, but the things are outrageous, we won't name them, but yeah.

Steve: No, no, no, no. I have had experience of legal action from questionable shady organizations in the past, so we'll steer clear of that one for the....

33:40 Seeking medical help

Hazel: Yeah, exactly, yeah. So we've drifted a slightly off topic, but we were sort of getting into the area of medical help or seeking help, treatment, et cetera, from the medical profession. I'd like to hear from both of you. What have you tried, like what doctors have you seen, have you tried specific treatments, was there anything that helped or was it in the end, any progress you've made is like 100% down to your own efforts?

Steve: We'll probably have quite different experiences based on a national health service and a private service, but my initial experience was very poor. I got the obligatory tests. I got the Marin test, which was kind of not very useful because I was in a glass booth and I could see the audiologist pushing the keys on a keyboard, so I got cues when listen, so I didn't really get a very good hearing, basically, cut... You're looking at a life-long gamer here! There is an advantage, you know, it's like, oh, I'm taking that... I actually don't get started on that, I don't

cheat at games and I never would, but there's a sort of like, Oh, okay, so it was a gamification actually, but then I got the MRI to check it wasn't acoustic neuroma. And then basically saw a consultant who just said you're gonna have to learn to live with it. Bye. And it was as cotton as that. It was very much, see you later. I got shot of spare the other side, and then I did try again a couple of times, I got some white noise— in-ear white noise generators, and then I got... It was like an information day, and it was pretty useless for me. I was about 30 years younger than anybody else on the information day, so it really wasn't geared towards me or... and other than that, I have not really had anything. All of my actual medical or interventions have been self-guided, because again, just from... I made my own music, made my own sounds, or did my own audio therapy, and then I've done other little bits and bobs, but nothing has actually helped me as much as what I've done myself.

Hazel: How about you, Sean?

Sean: I'm kind of conflicted because I feel like, especially my experience in the US, that kind of doctor's knowledge and what they learn in medical school about tinnitus is extremely poor. If you go to any general practitioner, they'll give you the two-second blurb that they learn when they were in school, which was... Oh, it'll go away. That's what they always say. But when I initially got it, I went to an ENT and I was very lucky; he was a very nice, compassionate man, and he didn't sugar coat it, but he was very understanding where he was just like, You know... You could ask like, is it gonna get better? Is it gonna go away? And he essentially was like, I can't tell you yes or no. He didn't try and make me feel that—give me a false hope, he was very straight forward, but he was also very sympathetic where he was like, listen, I'm really sorry, I know this is very distressing to you. I understand completely, I wish I could help you. I really do. And essentially, he said, the only kind of hope you have is to maybe check for getting an MRI and getting whatever, so I was sent to then a second doctor who was a neurologist/ENT... I forget what the exact terminology was, and essentially, this doctor was the opposite. You know, you go in and she gave me a hearing test with a sound threshold test, which I originally asked, imagine you just have your tinnitus get worse and your ears are really sensitive and you sit down in this audio, and I even said to the audiologist, I go please don't, please don't play any loud noise or anything; my ear is really sensitive. And in the test, she plays a loudness threshold test. It was brutal, I'm not gonna lie. And it temporarily made for two or three months after that, my tinnitus even worse than it was, and she was like, well, this is a safe level, like, this is a safe level. And I was like, Okay, maybe... The audiologist didn't get it, but then even when I saw the doctor afterward, it was a terrible experience because she essentially made it seem like tinnitus isn't that bad, it's not distressing, you're just making it worse than it is. I think you have a mental illness, that's the problem here, and I literally just kind of stood up and was like, thank you, and just left because...

Hazel: That's just astounding. Yeah, it's so disrespectful, isn't it? I mean, the one thing you want at the very minimum, even if they can't do anything for you, is to be taken seriously and not to be told you're delusional or something.

Sean: No, right, and that's unfortunately a good showing of the different levels of what doctors understand. Both doctors understood what tinnitus was—the ENT and then the neurologist—but the level of compassion was completely different, and I think that's one of the also another traumatizing experience that a lot of people have when you go to the doctor and they downplay it or make it seem like it's not a big deal, and it's like... They just don't get it. I understand that it's ignorance on their part, but a doctor should always be compassionate and sympathetic.

Hazel: Yeah, I agree. Compassion is the most important thing. I'm sorry, Steve, I know you wanted to say something else, but I want to also throw my own experience in here. I had some funny experiences with GPs, mainly, actually had pretty good experiences with... Well, there was one ENT and an audiologist that I went to—reasonably good experiences, but my first point of contact, of course—and this is how it works in the Netherlands and many countries—first point of contact is the GP. So I actually saw several GPs within the same practice, and I got some really weird responses, so one of them said, oh, it can't be that you have chronic tinnitus because you're too young. I was in my late 30s, mind you, and well, even if I had been in my teens, it doesn't matter, we know for a fact, it's less common, but we know for a fact you can get chronic tinnitus even in trials, so that was just false. And then there was another doctor, a GP, who asked... She literally asked me, Are you sure you have tinnitus, which again is like questioning my sanity or something like, Are you sure? And I literally told her, Well, gee, I don't know, I hear constant noise in my head, what do you think it is? I just, I couldn't believe it. And there was another GP who, Steve, you'll like this, she tried to prescribe me a homeopathic treatment for my anxiety. And I said, I don't believe in homeopathy, and she said, Well, you know, I'm a trained medical professional, so neither do I, but I still prescribe it. She said there's still the placebo effect. I said, well, I think you kind of ruined that one now, so I just had weird experiences with GPs. It's yeah, very strange.

Steve: Yeah, I think they're not really geared, and what I was gonna say was about the piece of research, I think came out many years ago, and I hated it because it was talking about tinnitus and neuroticism amongst people with it.

Hazel: I remember that one. Yeah.

Steve: I hate the terminology and I hate the words, but I understand the paper because I know that I would not describe myself as a neurotic, however, you talk about neurotic tendencies, but it's a horrendous word, and I don't wanna be badged with that word because...

Hazel: No one wants to be called neurotic, but I think I might have neurotic tendencies, I will admit...

Steve: Absolutely, yeah. And it's the obsession, it's the whole thing of it. And you can recognize the traits in there, But in neuroticism, it was just a horrendous choice of where it should have been something different.

Sean: So did they put that on a paper for you guys? If you have tinnitus and it bothers you, it's because you have this? Oh, wow!

Steve: It wasn't as quite... They didn't put it like that, but it was the title of the paper. I can't remember the full title, but it is said about tinnitus and neuroticism. Now, that is an awful title for a paper because you tell somebody who reads the title and abstract, oh, yeah, tinnitus patients are neurotic, which it's really unhelpful, and then what happens? An uneducated GP, quick Google—neuroticism. Yeah, well, so you've... you've gotta be really careful with those sorts of things. I think with research, especially, which will get taken out of context, you'll get a headline in a newspaper taking a whole paper over context and only using one tiny little sentence from it and expanding upon that for an article. But I do think we do share those characteristics and tendencies—certain ones of them anyway. Those of us who are bothered by tinnitus.

42:35 Intermezzo

Hazel: This is Hazel interrupting your broadcast.

Markku: And this is Markku joining in for a quick message!

Hazel: Markku, you started the Tinnitus Talk forum ten years ago, and now we have the podcast as well. You edit most of the episodes and are the guru behind the scenes, why is this important to you?

Markku: For me, it's all about connection. Struggling with my own tinnitus has made me want to help others.

Hazel: Yeah, I feel the same way. It's about turning something negative into something positive by reaching out to others.

Markku: We don't want anyone to feel like they're in this alone. We all know how lonely tinnitus can feel. So, we try to connect people but also help them learn about tinnitus by interviewing cutting edge researchers, biomedical companies, and the real-life experts, those with tinnitus.

Hazel: How do you think the podcast has evolved over the past two years?

Markku: I would like to think we've become more professional. But also, we try to be responsive to people's needs and interests.

Hazel: Yeah, I think this episode is a good example of that, responding to the need for more personal stories. So what can people do to support us?

Markku: You can leave a positive review on your podcast service, share on social media, volunteer your skills, or support us financially.

Hazel: If you choose to support the podcast, you will allow us to make more episodes and you'll get access to more Tinnitus Talk materials and other nice perks. Check it out on <https://www.moretinnitustalk.com> .

44:46 Tips & tricks for coping with tinnitus

Hazel: I'd like to get into maybe some tips and tricks and hear from each of you, what were the things ultimately that have helped you most... To cope with your tinnitus. Steve, do you want to start?

Steve: Yeah, so I am a not-practice-what-you-preach person. So for all the things that I've done with research and researchers and everything like that, I have not really done an awful lot to treat my own tinnitus other than just get on. With the exception of the music and the sounds that I do, that kind of is its own therapy, but outside of that, I would tell other people what to do, and so you need to find out this, find out that. I mean it took me about seven or eight years to realize the cause of the jaw and the influence of the neck. I didn't diagnose myself, I didn't do anything myself. So TLDR, I'm rubbish. But my tips are, you just have to kind of plough on and it will get better, sort of... It might not get better...

Hazel: It might get better.

Steve: It might; it might not... My kind of thing is, I think, as we know from the first research project we did with Tinnitus Hub, self-guided audio therapy was with one outlier, of course, the most helpful thing for people with tinnitus. They had the best results, and I think self-audio is the best thing you can do—is distraction and actually go on that, that I do have a tip, which is the distraction and stopping yourself from obsessing on it. It's not something I did, the obsession was something I did, but I wish that I'd use the audio in the early days to actually stop listening to it, so I wasn't constantly listening to see if it was there, if it was getting worse or anything like that, that would be the one thing I think is the most important thing, because for me, you should really be trying to stop it from ingrained in the brain, if you wanna create a stop and say, I'm not listening to the tinnitus, I'm not gonna make it a permanent fixture in the brain, so distract yourself and trying not to hear, which is easier said than done

Hazel: Obviously, yeah, yeah, and those obsessive tendencies can certainly make a distressing situation even worse. I will, by the way, ask you a bit more about the audio stuff, Steve, later and your views on sound therapy, et cetera, but I wanna hear first from Sean, what his tips and tricks are, or what has helped you personally most?

Sean: No, yeah, I do agree with what Steve is saying, and it sounds cold when you say it, but it's one of those things where you do just gotta get on with it. I'm not saying that's easy. That's not easy. That's really challenging, and I think a lot of us don't realize how strong we are. Looking back and me getting through it, getting on with it, I didn't think I would be able to do it, but looking back, I was like, wow, I was—I'm definitely impressed that us and a lot of other people, especially on **Tinnitus Talk** can just get on with it. I think my main tip would be to—you gotta somehow in that onset in that beginning is to especially reduce your stress level because your stress level is kind of like a cork screw that's digging it deeper into your brain and making it more apparent and making it worse. You gotta either stay distracted, do something that can try and help you relax, whatever it is, exercise is great, really exhaust yourself out, because if you're sitting and you're stressing about it, thinking about it and you're not distracting yourself, like Steve said, it's just gonna corkscrew in and just plant in there where you want to do the opposite, where you want to avoid it as much as possible. I know that's 100 times easier said than done, but realistically, that is what you have to do.

Hazel: Yeah, I would agree. I think stress management probably has been my main coping strategy, and that's both by the way, managing the stress directly resulting from tinnitus, but also just generally managing stress in your life because as we all know, all that other stress from work and life, et cetera, can exacerbate your tinnitus or cause you to suddenly pay more

attention to it and things like that, so... Yeah, I think for me, it started me on a whole journey of just stress management in general, and it got me into... I was already doing yoga, but got me deeper into yoga, I started meditation, which I still do from time to time, and just generally trying to take better care of myself, which is probably a good idea for any kind of health issues.

Sean: And I'd also say if someone, if you have a hobby that's like you're healthy, maybe playing rock and roll music isn't the best hobby after it gets worse or you get tinnitus—but if you have a hobby, I think you have to selfishly throw yourself into it and really distract yourself as much as possible in the beginning, so it doesn't... You don't just sit there and think about it all the time.

Steve: Yeah, I agree, and I think I'd be interested in actually hearing all about the time that you took off work. Was that beneficial or not? Because I would have thought that actually was potentially a bad thing in the long run.

Hazel: Yeah, that's a good question. I don't think there was... At the onset, I don't think it would have been possible to continue working. It's just the distress was so bad that... And again, it's the only time in my life that I've experienced that, because I have since and before experienced bad periods in my life, and certainly suffered from anxiety from time to time, and I seem to have this amazing trait as well, of where it can be... Well, I think it's amazing—many people with anxiety will relate to this, but I can be really... I can feel a lot of anxiety and then I have a work meeting and I'm like, okay, I just have to do this, so I'm just gonna go into the meeting and a second before I was like—maybe I was in tears or feeling I couldn't cope, and then I'm giving a presentation in a work meeting. I've been in that situation many times, but the onset of the tinnitus, I think it was kind of beyond that. It just wouldn't have been possible, like I just couldn't... But you're right, that getting back to work and not leaving that too long, that was a good thing. And I first got back to work part-time like, yeah, that was really important, and I can imagine if you don't do that and you leave it for a year or longer, it just becomes even more and more difficult, becomes more of a hurdle, and then the tinnitus will take such a central role in your life, right, because you don't have... Work has always been really important to me, and I'm sure for many people, and it was really important to go back and have something else take a big central role in your life again.

Steve: Right? Yeah, and I think it could become easy after some time to say, well, I can't do that because tinnitus stops me from doing this. Tinnitus means I can't do that. You can develop a very negative attitude toward it rather than, I'm gonna do this, and that's that.

Hazel: That's true. If you're always in can't-do mode, then you're never gonna try anything and it's just gonna get worse.

Sean: What's actually interesting is I kind of... So when you were talking about whether you think it was beneficial to stop or go back to work, I remember for the first time ever, my whole life, I looked forward to going to work and hated coming home at night and sitting up and being at home on the weekends, because when I'm at work, I was distracted, people would come talk to me. You know, it was a constant thing. My tinnitus was very easily in—more so in the background, whereas when you get home and you try and watch a TV show, it's easy for your mind to wander and think about it or whatever. You know what I mean? So I was happy that I was able to kind of, in that period, to throw myself into working because it was a good distraction for me.

Steve: I think the parallels have stress and anxiety as well. There's the—they say that you actually should not come away from work, you should carry—as long as the work isn't the cause of your stress and anxiety, of course—but you should carry on with it and carry on with normal things, because if you move away from it, it just intensifies everything.

53:34 When tinnitus gets worse

Hazel: Yeah, it's true. Yeah, yeah. Do you guys have any specific tips for people who experience a worsening in their tinnitus? Because I think you've both had that experience where you were coping with it quite well and then something somehow makes it worse. How do you deal with that?

Steve: Well, I think that would be the low point for me—where it's worsened several times. I did... After I went on a treatment trial, it worsened quite significantly, after I got an ear infection it worsened quite significantly. Those points, I... Do you know what, I don't have a tip for it because I just had to wait it out, I just had to just... I don't know. Just get on. And it wasn't easy. It was very, very difficult. I don't know. Well, for me anyway, I don't know if there is a way. I think it's just a case of you almost have to just wait it out until you habituate to it in some way, whether it's the noise going back down again, which has happened, or whether it's just the fact that you hit that psychological point of being able to go on all right again.

Hazel: Sean, how about you?

Sean: Yeah, to be honest with you, it's kind of, I guess the same type of thing we've been talking about where it's... You gotta treat it the same way as when you first got it, you just gotta push through it, and like I said, it's not something that's easy that you can just...It's easier said than done, but I guess there's no real alternative, you kinda just have to stick it out, tell yourself, I have been through this before; I can do it again. It'll hopefully go back down. Another thing that

people seem to talk about that's upsetting to them is when it does get worse, they blame themselves and they get really upset about it, and I used to have that kind of feeling of guilt as well, because I was pretty much when it got worse, I was probably the lowest point in my entire life. It was brutal. And then I realized that, you know what, based on what we know about tinnitus and how things work, it's gonna get you eventually, whether that one thing that you did happened or not... Unless it's like a massive acoustic trauma, if it was you just went to a concert or whatever, and this happened that happened, it's gonna get you eventually, so you can't feel too bad about it when it gets worse because it was gonna happen now, two years from now, three years from now, five years from now. It was gonna happen eventually. So don't beat yourself up about it essentially.

Hazel: Yeah, I would agree with that. Yeah, I think many people experienced that guilt, I've kind of forgotten about it, but I did have—did experience guilt in the beginning, and then just like you, I kind of came to the realization that if there's such a thing as being predisposed to tinnitus, which by then having done some research and read some academic papers, I do believe that probably is the case, then then it doesn't really matter whether it's this trigger today or another trigger a year from now, it's probably gonna get triggered, so...

Sean: It just maybe came out a little earlier, but it was coming anyway, so...

Steve: Yeah, I think you're right actually. I hadn't thought about that, but of course, remind originally, which the original thought was from not protecting my ears on the construction sites, and yeah, there was an element of guilt in that I just... I can't believe I've done that. Why did I not just reach for the ear defenders? Why did I not put them in?

56:57 Hearing protection versus overprotection

Hazel: Yeah, of course, and of course, that's no reason to... This rationale is not saying you shouldn't be protecting your ears. Obviously, I think we all agree, you should do whatever you can to protect your ears within reason and still being able to lead a somewhat normal life, but... Yeah, certainly not unnecessarily expose yourself to loud sounds... Yeah, I mean, I put hearing protection on when I vacuum, for instance. Vacuum cleaners are actually really, really loud, so I think that those kind of things just make sense, and I don't view that as being fearful of sound... I'm not any more fearful of sound at all, I never think when I walk down the street like, Oh my God, it's gonna—there's gonna be loud sound or I never... I don't avoid sort of normal, everyday experiences because of fear of sound, but I think it's only rational to when you know you're gonna be picking up the vacuum cleaner and it's gonna be making a loud noise that I've put on hearing protection.

Steve: Yeah, we used to have a Dyson—unbelievably loud. It's like a little jet engine. Those things are crazy. The one we've got now is relatively quiet, and again, we've got a deeper knowledge through all of the integration with researchers that we've done, and you know, there's that thing of... Now, do you understand the actual synaptic connection could be getting damaged—where the ears are getting damaged—the lower volumes could still be damaging for that, so we know these things, so we're cautious with good reasoning behind it.

Sean: Right, and I think that's the pitfalls when people first get tinnitus, they will overprotect, which we now know can make someone develop hyperacusis or make their tinnitus worse.

Steve: Well, that's how I got my hyperacusis.

Hazel: Can you expand on that? And how are you sure that was the case?

Steve: Well, I used to wear them all the time. I wore them in the car, I wore them anywhere that I possibly... because I'd have them on the loads.

Hazel: Earmuffs or?

Steve: In-ear plugs. So I just use them constantly because I was paranoid, and I thought that the car was loud because I had a diesel car, so you've got that diesel thrum of the engine that quite deep thrum, and I just had a paranoia about all these things, and after that—I didn't get hyperacusis at first, but it was after maybe two months, three months or something like that, that I got it, and that was with constant protection of the ears.

Hazel: Yeah, I think there was one study on animals that seemed to prove that over-protecting could actually induce hyperacusis. Yeah, it kind of seems logical. If you're training your whole auditory system to operate on these very, very low volumes, then the auditory system is gonna be yearning for that input and it's gonna turn up the volume even more and more.

Sean: What I think people could probably do— I've done this experiment where I've worn... Even like landscapers come in there right outside my window and I'm trying to get work done, and certain sounds also will make my tinnitus worse, so I just wanna avoid— like it'll temporarily make it like a certain pitch or something, so I'll wear headphones, and then when I take the headphones off, I noticed that my tinnitus is louder, and I think it's because my brain is lacking that audio input from wearing headphones, that even when I take them off my brain is still amping everything up, which is also the tinnitus.

Steve: Well, the brain thrives on input. It's a constant moving system, isn't it. It's not like it is happy when you're quiet; when you're quiet, it needs input, it needs all of these things going on. The whole body works on this input happening all the time. So, yeah, it just doesn't work very well if you deprive it... Well, it's like the anechoic chamber experiments. People, I think the vast majority, if not everybody will hear tinnitus in an anechoic chamber, and I think people—Is it something like half an hour? Because nobody can go longer than a half an hour in one?

Sean: Right, yeah, I've seen that video. Yeah.

Steve: Yeah, yeah, it's crazy. So that lack of input is just—we can't deal with it as human beings.

Hazel: Yeah, our brain has to then invent something, phantom sound or...yeah.

1:01:18 More on habituation

Hazel: I want to talk a little bit about the concept of habituation. Most of you out there, listeners, probably have heard of it, but for those of you that haven't it, it's a common term in neuroscience, and it basically means getting used to a repeated stimulus to the point where you no longer react to it. So the example that's often given is, you live next to the train tracks and the train goes by whatever, every five minutes, it makes a huge racket, and at some point, people who actually live next to the train tracks will say, oh, I actually don't hear it anymore, so it's something like that. Or another example that's often given is when you or put your pants on in the morning, you will consciously feel the feeling of the fabric on your skin, but you don't go through your day consciously feeling your pants on your legs, right?

Those kinds of examples are given and people who treat—experts who treat people with tinnitus, and there aren't many experts in this field, but they will explain this concept to people who are suffering, and it can be beneficial to understand that concept and understand that it's possible to achieve that state. The one, I don't know, that sort of annoys me in the way that it's presented by clinicians or experts, and I briefly mentioned this before, is that it's often presented as something very black and white, and I just don't feel that's the case. I would say I'm mostly habituated, and most of the time I'm not bothered by my tinnitus, but then something could happen, I get stressed, and then I suddenly hear it. And I'm like, oh my god, was that loud noise always there? Why is that noise there? So I have a problem with how it's sometimes presented, but I think it's an important concept, nevertheless, to understand. Where do you guys feel you are? Would you say you are habituated and how do you see the concept? Sean, do you wanna go first?

Sean: Yeah, I know habituation, like you said, is a controversial topic because I kind of view habituation as a spectrum because there's been scientific papers, a lot of... Actually, that I read, I made a post on the forum called "Habituation Linked to Sensory Memory," and in that forum post, I linked to a study where they proved that certain people have issues with their brain where they can't habituate. It's a—I don't know if you would call it a neurological disease or something, but some people just can't habituate and that's—it's a very unfortunate situation. That's not everyone, and I wouldn't suggest that someone just assume you have it, but sometimes habituation can happen to someone very quickly, not very quickly, but Hazel, you said it took you about four months. I remember it took me about two years to get to a point where I could say I was habituated. It is a long spectrum, and no one's gonna be able to tell you how long it will take you, but I would like everyone to give it a chance and to wait it out and never lose hope that it could happen to you. But yeah, I think it is controversial, because a lot of doctors will just assume that, oh, well, you'll habituate to it—in a couple of weeks from now, a couple of months, you're not even think about it, don't worry about it, and then when you return and it's still bothering and you haven't habituated, they kind of think, well, what's wrong with you? What are you doing? You know what I mean? And so it is something that takes a long time. It's different for everyone, and then there are those individuals who can't do it. But yeah, I think it's still a very interesting topic because there's still so much to learn about it.

Steve: I think there's a thing with habituation as well, because to a lot of people, and me when I first got tinnitus as well, that's kind of like a failure. So basically you can do nothing about it—so habituation is your fall-back point, and then equally, if you're not habituated, you're a failure. You're the one who is responsible for your tinnitus; why aren't you accepting it? It's a very emotive topic.

Hazel: It's a minefield in that sense, yeah, I don't think those—the types of clinicians that I mentioned, and they tend to be like the CBT (Cognitive Behavioral Therapy) practitioners, and they really mean well, and certainly many of them have helped a lot of people, but presenting it in that way, that, oh, anyone can habituate and you just have to reach the state of acceptance and work hard, and you'll be fine, that can be harmful to those people who really struggle.

Steve: Definitely. Absolutely. I think that's the worst thing you can do because you are effectively telling somebody they're a failure, and that's not how you deal with tinnitus. The way I would kind of... And I think you can almost say that we can all have our own interpretation of habituation. To me, it's getting to that point of accepting. I don't accept tinnitus because I want the cure and I wanna do what I can to help get a cure, but at some point you have to accept, I am a person with tinnitus—that I don't accept that I'm gonna have it for the rest of my life, because I'm gonna do what I can to get rid of it. But I have to accept that it's

there, and it's that sort of acceptance of having it, and then you're just like, right, now I need to move on. It's there, there is literally nothing that I can do about it. There might be things you can do about it once you've had your journey and find out what you can do, find out what makes it better, what makes it worse, and you've got to that sort of equilibrium, you have to accept it's there, and that's that. And you have to move on from that point. And I think whether you do that cognitively over there, or it's happening subconsciously, that is kind of a point with just acceptance where you move on.

Sean: And I think also getting to the point of habituation, the tools people will have to ultimately use to get there is different, like I know, Steve, you said sound therapy really helped you. For me, it was kind of the opposite where I would always try and mask it and it wasn't until, like you just said, I accepted that it's there and I'm gonna have to listen to it, and then I stopped going to bed with a sound machines and everything—it wasn't until that point where I really saw an increase in my habituation, so it's really something where you just have to test things and try different things and just learn as you go.

Hazel: I would agree, actually, one thing that helped me was I tried a couple of times to meditate to the sound of my tinnitus, so you're literally using the tinnitus sound as a focus of your meditation. So in meditation, you're always... You become like a passive observer of everything that you experience, right? So there's thoughts, there's emotions, there's sounds around you, and you just kind of without any judgment, try to experience whatever it is you're experiencing and noticing that you're experiencing that... I'm just trying to summarize meditation in like 30 seconds, so I use that technique to just listen to my tinnitus and purely just listen to it, nothing more, nothing less. And then if you do that for some time, inevitably you reach the state of its sound and it has no significance. And that helped me a lot, and I know some people will probably lambast me for saying, oh, it's too easy to say that it's a sound without significance. But it's not about saying that, it's just... It can be helpful to experience it that way, at least for a few moments. It doesn't mean you're always gonna be in that state of, oh, it's just a sound. Who cares?

1:09:37 What works for me may not work for you...

Steve: And I think it's kind of like we all have to find our own truth of tinnitus, because what works for me doesn't work for you, doesn't work for Sean... We all have our own thing that we have to find, and I think there's—obviously, we come across people in various states of distress who will rubbish something. It's like, yeah, you need to work out that that just doesn't work for you, and then you need to move on to what *does* work for you, and then again, people who will say that, this works, it's like, no, it doesn't. There is not one thing on the face of this planet that works for everybody. It works for some, doesn't work for others. Like with the audio, I'll have

people coming on, saying yeah, it's amazing, while somebody else is going this is rubbish, it's nothing—because it doesn't help everybody. It's impossible to find anything that does. You have to find your own methodology and your own things that work.

Hazel: I think that's such an important point, and this is where you see all kinds of online discussions going completely awry because a lot of people assume that their truth, their experience with tinnitus is the same as everyone else's, and it's just not.

Sean: Yeah, yeah, that's the one thing that really bothers me is when I see someone say, you guys just have to do this. That may sound hypocritical to some because this whole time we've been talking about a...

Hazel: Yeah, if you just run three hours per day and only drink celery juice your tinnitus will be cured or whatever.

Sean: It's very much an individual thing. And you really have to keep working and searching for what works for you ultimately.

Steve: But that's the—you can cut and paste this into the top tip section, because that really is it, you have to work on what works for you, you've got to find out your particular idiosyncratic behaviors of the tinnitus. And that takes a long time. It is not easy. It's like, you can't. And again, people will go into something with this hope that this is gonna work. It's like you actually can't do that either, because that damages... You've got to go in and say, I'm gonna do this and see what happens, and that speaks a lot to the psychological attitude that we've probably all been through early on. This is gonna work. I need it to work.

Hazel: Oh yeah, actually, that's a really important point, Steve, and I think, in a way, you're onto something when you say, I'm rubbish with managing my tinnitus or trying things, maybe that's not so rubbish because those people would keep trying, there's always the next thing that you've got to try, and there's always another treatment or another supplement or another, so you can really drive yourself crazy if you keep doing that. Yes, it's important to try things and find what works, but if you're constantly getting your hopes up and keep looking for the next thing that might help you, that's just gonna drive you crazy, isn't it?

Steve: Well, yeah, I mean, we've had it with various different clinical interventions across the years. This—I'm not gonna mention them by name because some of it... But this is gonna work, this is what I'm waiting for—the cure. I'm not doing anything until this happens, and then this...

This is gonna work. I'm not interested in anything else. This is the cure, and people—it's sort of self-destructive.

Sean: People kind of view it as like a baseball game where they're like, oh, this company is gonna do it! I know it! And then they start arguing about how this company is better than that company, and this drug. And it's okay, okay, everyone... I think everyone has to say, we're optimistic, but if you put all your eggs in one basket when you drop the basket and they all crack, it's gonna be just as devastating, you know what I mean? So you kinda have to say, I'm looking forward to all of these. I hope they all work out, but until it's in my case, FDA-approved in the US, and I can go to my doctor and get it, I'm not gonna jump for joy, you know what I mean?

1:13:26 Following developments in tinnitus research

Hazel: So yeah, so do you guys follow much the developments in tinnitus research and the development of new treatments, like for instance, the past few years, we've heard a lot about Lenire? Have you followed those things actively, or is it more like Sean just said, oh, I'll wait until something is actually proven to work and available?

Steve: Yeah, I mean, I did, and I don't particularly at the minute. I don't know. I've just kind of—you can follow it so much, and there's only so much that happens. You know, research is slow. So if you're obsessively following research, then you're not really gonna get much out of it, because you don't get tidbits here and tidbits there that are of any real use. You have to wait a long time for peer reviewed papers, you have to wait a long time for our CTs to complete, so I'll just kind of periodically update.

Sean: Yeah, same with me, I kinda just hop in and out and I'll look forward to things when I hear... I remember when I was first really looking for answers, I was reading it pretty much every day, reading everyone's updates, but yeah, it gets to a point, like Steve said, where you kinda just come back, graze a little bit to see what the general picture looks like, see where the status of things are, and then you kind of go back to focusing on yourself, which is ultimately what you have to do, because those things take years, and if you're gonna wait for that one thing and be miserable that whole time, you're not gonna have a good time, you really have to focus on yourself and hopefully those things come up as your journey goes.

Hazel: Yeah, I would say that's a healthy attitude, and I think it's good to have a healthy dose of skepticism about any new treatments coming to market, like we've seen with Lenire. When I read those clinical trial results, it was just so underwhelming to me. It's like, oh, you know, it kinda works for maybe two-thirds of people, they get “clinically significant improvement,” but

what is actually clinically significant? Some group of researchers has once decided that a decrease of x number of points on this survey that people fill out constitutes “clinically significant.” In reality, what it means is you go from being extremely bothered to still being quite bothered or something like that. To me, it doesn't really mean that much. It's not success, and you can probably achieve the same thing by doing nothing for—like you, Steve, your strategy again, I think it's not so bad. You could probably achieve the same thing by just letting time go by, literally.

Sean: I think that's what the main problem was with that study was that they got a lot of early onset people, and I don't know if they really took into account that naturally it gets better, you know?

Steve: Well, from a commercial perspective, I would say that probably did. It's a classic, classic—no, I wouldn't call it a trick because that's so unfair—but it's a classic way of testing a theory, bearing in mind you have to get a lot of money to get these things together. You have to get a lot of investors, so you wanna start with the easier wins in proof of concept, and to be fair to them as well, you do have a lot of data on early onset patients from the trials with no intervention and that sort of thing, so you can base things off it. But it is going for the easy win group is your best strategy because you wanna get next stage of investment, you wanna expand the product, and if you don't get the easy wins and you get a lot of difficult people, if you're really unlucky, and you get people who again, how on earth do you sub-divide the groups to make sure that you're not getting people who actually won't respond toward your therapy, so are probably not gonna respond to your treatment, you've got a real difficulty in segment, and so if you go for the easier section where you're more likely to show improvement, then you can move on to that next stage. I mean, I don't envy anybody getting into it because it is a horrendous thing to try and do any sort of trail on, and we've seen trials and companies go down the tubes in the past because it hasn't performed as they thought it was going to perform. So it's a really, really difficult thing. And I think in terms of the approach, I think it's a good approach. But I'm always—I'm a tinkerer. I like to fiddle with things, I like to play with things, I would like to say that device... Should I rephrase that? Should I start that again? I like to feel, think... Yeah, so it sounded a little bit sort of weird, so anyway, I say... So I'm a tinkerer. I like to actually take something to say, well, what more can I do with it? What else can we do with it? But once you've got your RCT done, your randomized control trial, and once you've got a protocol, you can't go outside of that protocol—you're going off-label, and if you do that, what happens if you have bad results? So you kind of cursed to constantly follow that one approach. I would love to get Lenire, and I would love to try lots of different sounds, so that I'd like to try different patterns. I'd like to say, what happens if we do this? What happens if we do that? because I do think there's a lot of mileage in bimodal stimulation, you know? The

more we know about neuroplasticity is the fact that with age, it doesn't seem decline, we can still carry on with people as they get older with the plasticity, so why can't we just try different things, but we can't because you've got investors, and you can't go off label because then you're risking the investor's money or you're risking what happens if one single person—you go off-label, you might help 100 people, but one person gets catastrophic tinnitus as a result by—byproduct. So it's horrendous that you can't experiment, but it goes with the territory.

Hazel: It sounds like you should try to hack Lenire, Steve, now.

Steve: Oh, I would. I totally would, honestly. I would be all over that. I'd love to try out different protocols, different things it would be... Because I think it's got a lot of promise, but it's ultimately just an acoustic neuro-modulation. What do you get? You get stuck with four noises. In my opinion, completely and utterly not correct, because you have to adapt your protocol to the individual. We are not all the same machine. Yes, I know that it's got a principle and it all works like that, but don't be a protocol. Change it for the next person if that's not working for you. I'll tell you what, we'll try this one and that's not working, and we'll try this. But they don't because they can't, because they are stuck to the protocol, which is in the published papers, which is with the one that's been trialed, and again, say like they go off label and then somebody gets bad and...

Sean: Yeah, I was just about to say that too, that I think with Lenire and a lot of stuff like that, and you can't have a one-size-fits-all because tinnitus is just so different for everyone. And when I think about an answer to that, I think about a forum member who was going to Susan Shore, and he had a very situation of mine where he had tinnitus his entire life since he was a young kid, had tubes put in his ear, eustachian tube dysfunction, all that—had it for like 26 years, went to Susan Shore for her bimodal stimulation device. And she, in their experiments and in their trials were changing it specifically for him, and the end result was that they were able to pinpoint, okay, this is what helps him, this is what doesn't. And he, as far as I know, since his last update, no longer has tinnitus, and it's very—it's very reassuring and it's very optimistic that something like that could happen, but they do have to take it to a point where they individualize it if they wanna get to it, and because it did happen with one of our own forum users, and you guys can look it up, but it has to be, in my opinion, like you were saying, it has to be on an individual level, or else it's just not gonna work.

Steve: Yeah, absolutely, because we've all got so many different causes, and it's not just the cause. Take two people who can pinpoint exact two causes and they'll respond differently, a different treatment, and then we all have noise, if we're using sound as one of the stimulation, we all have sound that we like and sound that we don't like; we've all got different taste in

music, and you have to listen to something which is at least pleasing to some degree. Some things you can't get to pleasant with, but you have to get to something which isn't horrible, so you can't just work with six sounds and then deliver; it doesn't work, you know, the human body doesn't work like that. You will get better results with individualization, and that's really interesting what you're saying, Sean, about Susan Shore, because—and I guess the difference there is it's an academic study rather than a corporate business study with investors. You've got the university sort of behind it, so it's really interesting that they've been able to do something like that, which—and I think that's got to be a way forward. Personalization is always gonna yield better results to me.

Sean: Right, and if anyone wants to read about what I was specifically talking about, I just pulled up his profiles, name is “kelpiemsp” on **Tinnitus Talk**. He has threads where he talks about his experience with bimodal stimulation and how they curated specifically to him and how he now has silence from tinnitus after—on his page, he says—31 years, so...it *is* possible.

1:23:02 Sound therapy: Tinnitus Works and TinnitusPlay

Hazel: That's amazing. So, Steve, I feel like we segued a little bit into your music and audio work, so do you wanna talk a little bit about that and what exactly is it that you do in terms of producing music/sounds that could help people with tinnitus?

Steve: Yeah, so I'll—well, you know, I'm gonna say it, because nobody else listening would... So I do it under the moniker **Tinnitus Works**. So I've got it on sort of YouTube and Spotify music and all that sort of thing. So I do... I started off... Actually, I actually started off from the forum when the acoustic neuromodulation device first came out. Before that I was making sounds for tinnitus, which were basic standard masking, you know, water sounds, birds, that sort of thing—a bit of experimentation, just seeing what sort of worked for me, what helped, and all that sort of thing. And then I started with the acoustic neuromodulation device, and was like, okay, so we reverse engineered the device with the number of people on the forum, and we all kind of got together and everybody did their little bit. And I started doing it with musical notes rather than with pure mathematical—well, music is mathematical division—but I started doing it with a musical scale because it was a logarithmic scale, just like the device, but of course our ears are tuned to harmony. So I started doing that and it seems to have helped a lot of people quiet the tinnitus. They say it does come back, but then I don't know if repeated use would help or... So that kind of got me started on a journey of looking at like, how can you—what else can you do with music? What else can you do with sound? So I end up—I do, I use acoustic neuromodulation techniques. I use amplitude modulation, which is basically sound going on and off very quickly, or the different speeds and things like just general sounds across the frequency spectrum, because what we get in a lot of the music and the sound we listen to,

there's not much in the high frequency range, so a lot of music actually does cut the high frequency. In modern years, they don't do that anymore. So for digital music, they've stopped doing this sort of what used to be called the loudness wars, where you had to sound louder than the next track on the radio, so to do that, they would boost the frequencies that we're sensitive to and cut the frequencies that were not, so a lot of that high frequency content was cut out of songs. So if you listen now to a modern—say, take a rock track—listen to a modern rock track, listen to a sort of '80s-'90s rock track, you'll hear a huge difference in the sharpness of the sound, because now they started putting those higher frequencies in, so I always had a little bit of a suspicion that for those of us who damaged hearing, it was damaging to us listening to music because we've got all that frequency content that's not there, because they stripped it out sort of.

Hazel: Oh, so you don't get—I never knew that! So you don't get that high frequency stimulation and you're saying we should be getting that?

Steve: Well, yeah, for me, I think that's one of the things that—because I have a reactive tinnitus, so the music that I produce, I don't—because I make sure that even if I do a rain track, I'll make sure that I've got a high frequency of the rain recording, and if it does not have high frequencies, I'll add another recording with just the high frequency sound just to pad it out. And then I find that that doesn't make my tinnitus worse. If I listen to something that doesn't have that high frequency, it reacts to it and makes it worse. So everything that I make and I produce, I make sure that I've got that high-end stuff in there, so that we're getting the stimulation across the frequency spectrum.

Hazel: that's interesting, because out in the real world, of course, rain probably does have the high frequency noise, but because these days were so much of the time getting our sound input from movies and music and all those kind of things, if they've cut out of the high frequency sounds from that we're not getting the stimulation you would normally get in the real world.

Steve: Yeah, so it's—with movies, it is a little bit different. They didn't do that with the movies, but it was more with the records. They did it with them and say it was for loudness, perceived loudness. So your ears are more sensitive to mid-range where vocals, where speech is, so that would boost those mid-ranges so that it was perceptibly louder, and also that's where we're most prone to take in damage, so anybody who's in to all the rock music is actually more damaging their ears because of the sensitivity on that level. That's great, coming from somebody who was very much into metal and rock.

Hazel: Where do you wanna take this next? Do you have more plans to do stuff with audio and help others with tinnitus?

Steve: Yeah, I mean I'm carrying on doing it, so I do... I release things, sort of periodically— other thing I've got about things out, I can't remember now about sort of albums of songs, the last two... I've done are a bit music-based things like that, but I use it in a lot of modulation, but I don't know it, I'm just doing it. I just do it because I get good feedback from people, so I just carry on doing it. I don't promote it, I don't advertise it, and I kind of look and think I really probably should, but then for what you make from streaming, you just don't make any money whatsoever, so for the 20 pound a month I make from streaming, I should probably put that into advertising. Bear in mind I get about 16,000 streams a month.

Hazel: Oh, that sounds good, I guess.

Steve: Well, it is, yeah, yeah. But it equates to about 20 odd quid a month.

Hazel: Okay, you're not gonna get rich off it. Okay.

Steve: No, no, no, it's never gonna be a career, so it's just something I do because I enjoy doing it and it's therapeutic for me.

Hazel: Okay, so people can check out your YouTube channel if they want, and then maybe worth mentioning, we also co-created an app called **Tinnitus Play**, for which you supplied all the sounds and which does allow for some degree of personalization. It's probably not perfect, but that was the intention, and it is free. Unfortunately, it's only on iOS, not Android, that's very unfortunate. We haven't gotten funding to do the Android version. But yeah, it's still out there and it's free.

Steve: I know, I think it's the best app that's out there as well, and of course, I would have a bias towards that, but I think, I cringe when I see people, I'll see somebody recommending one of the hearing aid company apps, and it's just a few nature sounds and I just think, God, why people not just going to Tinnitus Play? Just think, you've got this sort of wealth of customization and things that you can do and sounds that you can make and you can try out these therapeutic techniques that you would otherwise pay thousands for, for free. It's just like, why do they not know about this?

Hazel: There you go. Well, now maybe more people will listen.

1:30:02 Tinnitus portrayed in the media

Hazel: We've been talking quite a while, we've covered many topics; there is one topic that we, I think, briefly touched on, but I wanna get into it, which is how tinnitus is generally displayed or not displayed in the media, in the public sphere. Once in a while, you might come across a media article about tinnitus, I feel like it's—you hear about it a little bit more frequently than you used to. What's your, you guys' perception of that and the way that it's talked about, and is that kind of helpful or not?

Steve: I think that most media coverage for any health topic is bad in the sense of you have journalists who are very overworked and all they do is grab a few sound bites from here, there, and anywhere and put a lazy article together. So it really—it doesn't do anything for anybody usually, and it usually doesn't have very good quality information in it and, yeah, alright, there's a little bit of awareness to it, but I'd rather have good quality awareness from a high quality article, than 20 articles that are just cut and paste from another source.

Sean: I think we had recently, when the movie came out with Lady Gaga and Bradley Cooper, didn't they contact Markku about giving a quote, and he basically said that this article is kind of down playing it, it's very severe for some people, you know what I mean? And it kinda goes to show what Steve just said, that sometimes they just crank out, do a quick Google search, take the first link and just read what it says and then just put it out there without really getting into the weeds of it, which can be hurtful.

Hazel: Yeah, with that movie, I forgot the name of the movie. What was the name? Star? Superstar?

Sean: I'll Google it for you.

Hazel: But that was a real opportunity for some awareness raising, because you see Bradley Cooper's character struggling with the tinnitus.

Sean: It's from *A Star is Born*.

Hazel: *A Star is Born*. Yeah, *A Star is Born*, yeah. So it was a great opportunity, indeed there was one article, there were probably several, but there was an online outlet that published an article on this, and of course they only reached out to the American Tinnitus Association for comment, and the comment was something like, oh yes, most people get used to it and you'll be fine or something, and then Markku actually contacted the journalist and said, Hey, I also—

we're also another tinnitus patient organization, we would also like to give input and make clear that there is a group of severe sufferers out there for whom it's not that easy.

Sean: I feel like that was a big win. When I saw that published in the article, I felt somewhat validated when Markku did that. I was very happy when I saw that his comment was included in that article. But another thing that—outside of just journalism, I think that the way that tinnitus is also portrayed in media outside of just writing, let's say movies and video games and TV shows, is that when someone says tinnitus, they think of in a TV show where a bomb goes off or a gunshot in the movie, the character will experience a tinnitus, a fleeting tinnitus, where you hear that high pitch sound, but then after five seconds, it's gone. So a lot of people, I think have that misconception of, oh, so it's just kind of there and then it goes away after five seconds, you know what I mean? And they kind of learn that from movies, but it makes sense because you can't have a movie or a TV show with that sound.

Steve: That wouldn't be very good for anybody.

Hazel: Second half of the movie, you have the high pitch sound!

Steve: I know it's great recently, actually, there was a game... I can't remember what game it was, but it had an option to block the tinnitus.

Sean: Oh, God, I wish they had that in every game. It drives me crazy when I'm playing a game and that happens.

Steve: I was just like... I was like, whoa, I've never seen that before. That's really good. I wish I could remember what it was now. Yeah, because it does drive you crazy, well, you'll have the characters and it'll happen and you're just like, ahhh...

Sean: Yeah. It's funny, yeah, when I... Like my fiance, she loves to watch cop shows and stuff, so it happens kind of frequently... Whenever it happens, I'm just sitting there like, oh God, when is this gonna end?

1:34:21 Raising awareness for tinnitus

Hazel: How do you feel about how the tinnitus advocacy organizations—well, we are also one of those, of course, but—we know it's a struggle to raise awareness for this condition. How do you feel they're doing generally, and what's the right way to raise awareness if there is any?

Steve: I don't know, I've never been big on... Well, I was at first, but then I don't think with tinnitus raising awareness accomplishes much. I think you put in a lot of effort, but you don't get much return. I think the efforts should be focused on helping people, so the awareness side of it, you have always had this thing, analogy-wise, which obviously we did a video a little while back, a good while back about the donkey sanctuary and the tens of millions that they get every year. And this is the struggle you have. You show—imagine you get an advert on prime time, you show somebody, you show the tinnitus, you show what happens; your next video is a child in a war-torn country, and then after that you've got a donkey. A person with tinnitus is long forgotten. So the things, the other things that are out there are so emotive, tinnitus doesn't have a hope in hell. You just can't get with it. So I think you can't particularly get awareness out, but I think what you have to do is have high quality information and have support and services for people, in my personal opinion, anyway.

Hazel: Sean, would you agree?

Sean: Oh, yeah, I agree. Without giving any names, I've heard of people who have called some of those organizations and that we're supposed to help people, and they were not very helpful. So I think what Steve is saying is that, yeah, I think a lot of money in these bigger—in these big organizations who are for tinnitus—if you have a call line and someone calls—you should really care more about the person and helping them instead of just reading off a sheet and just giving them basic facts, you know what I mean? Or having some outreach program or something, because I do think that ultimately we're trying to,—they should be trying to help people, but ultimately they're more focusing on getting donations and then spending it however they want on random researchers and stuff like that. I'm obviously not talking about **Tinnitus Talk** right now. That's not what I'm talking about.

Hazel: That's a given, yeah.

Sean: I'm avoiding saying names of other organizations because I don't wanna cause any problems, but I do think some of the organizations need to step it up.

Hazel: Yeah, I think the messaging is to me often very confused, to the point where I'm not clear who the audience is.

Sean: Right, exactly. I think that's the main issue there, because if you're gonna be—if your aim is to raise general awareness among the general public, then you don't want to downplay the condition; if your aim is to reach people with tinnitus who are struggling, then I understand that you wanna say, oh look, for most people, it gets better, but that can be a helpful message, but

those two are often confused, to the point where I saw an ad from one of the main tinnitus organizations that started with seeing people in pain and suffering with—you were hearing tinnitus noises and seeing people like that. And then the screeching tinnitus noise is turned into beautiful music and people were encouraged to call the helpline, so it kind of started as a general awareness-raising message to make the public understand how bad tinnitus can be, and then it evolved into a message to people who are struggling that they should call the helpline and then everything will be okay. So it was so confusing. Like, what are you trying to accomplish here?

Steve: Yeah, it's such a double-edged sword of trying to do that sort of thing. How do you get the right message out there? Because no matter what you do, you will upset some people and it's so difficult, I mean, it was always something I struggled with, how much do you accentuate the severity because you don't wanna damage people and you don't wanna hurt people, but you also don't want to underplay it. It's just such a—it's a really, really difficult thing to do. And finding a balance is incredibly hard; you will get criticism from anybody, no matter what you do, so it's difficult.

Hazel: Well, yeah, no matter what you do. Of course, we know that. Yeah, with the **Tinnitus Talk** podcast, of course. It doesn't matter what kind of episode! If you do an episode on topic A, people will say, why didn't you talk about topic B? And it's like, well, that's a different podcast. Yeah, it's always—yeah, you can never do it quite right, of course, but we're trying. So guys, we've talked for quite some time, and I don't wanna take too much more of your time, but is there anything that you still wanna touch on?

Steve: I don't think so. We've gone through everything we had down there.

Sean: I'll probably remember something 20 minutes from now, but... (*laughing)

Steve: Yeah, yeah. That's always the way. Isn't it? I was gonna say, you know well enough about me and food, so it is nearly feeding time and so this is a good sort of break off point.

Hazel: Yeah. Okay, okay, well, we'll let you get some...

Steve: I can't think of anything else. I think we've pretty much—I think we've covered everything. Well, you say, I'll just wing things. I haven't got the list in front.

Sean: Yeah, I even think ultimately everyone, especially a lot of people in—you just gotta stay strong, keep moving forward and you're gonna get through this; you just gotta keep truckin'.

Hazel: Yeah, I think both of you are good examples of that, and I like the message here where it's like—we're not saying, oh, if you just put your mind to it and try hard enough, you'll be fine. No, we're acknowledging it can be really a struggle, and sometimes still is, it's not, now, I've reached the coveted habituation end point and everything's rainbows and unicorns, as Steve likes to say.

Steve: I was just about to say that. But yeah, it's absolutely right. The thing is that it's not easy. If it is easy, well done. That's awesome.

Hazel: That's great. Great for you!

Steve: You've got a win, but it isn't easy for the vast majority of us who do get it, and do have it in such a way it's not easy, and it doesn't continue to be easy. I would give—well, I don't know if I'd give my left arm, but I'd give something to get rid of the tinnitus. I'll be a bit bugged at the gym if I gave away my arm.

Hazel: Some people probably would give their left arm...

Steve: Yeah, yeah, you know, there's a lot I would give for it and, do you know what? If there was an opportunity to do something about it, generally for research, I'd be all over it. If there was a cure opportunity there, I'd be in it, but I would give a lot for silence; I would love to have silence back, but I can't obsess over it and I can't sit here, be mourning it. I can grieve the loss of silence in my own way, but I can't sit here and be downtrodden by it.

Sean: And I think, I hope everyone understands that even though we're talking, having a good time, joking around with each other, I'll maybe speak for myself, I do still have periods where it is hard. I'm not joking and I'm not smiling, you know what I mean? It's—even though I think I've pretty much habituated, there are times where it's rough and it's really hard, you know what I mean? But you gotta try and stay positive even when you feel you're habituated, you're still gonna have those bad, really bad days, you're still gonna have those times where you just wish you didn't have tinnitus, you know what I mean? But you know, you gotta just try and stay positive, which is what I think we're trying to do right now with each other.

Steve: Absolutely, those days when my other half will just sort of stop and go, is your tinnitus bad?—because I'm being grumpy and I'm not basically very nice to be around, and it's just like, yes, it is bad. And she's aware of that, and the relationship is really good in that respect, where

she understands it and will be kind of like a bit put out, but knows that I'm just not gonna be in a very good mood. And that's that.

Sean: Exactly.

Hazel: Yeah. So I think we struck a good balance here where we're taking it seriously, but also trying to give some hope or inspiration, although as you were saying just now, Sean, that we were joking around, I could already see the criticisms, like, these guys are just laughing with each other and not taking it seriously.

Sean: That's why I said that, because I know there are some people who are definitely going to see this and say, oh, how could they speak on it? They're not miserable like me. It's like, no, I was you. I was there, I still am there sometimes, but I'm not gonna let that dictate my entire life, every second of my day. You know what I mean?

Hazel: Yeah, quite honestly, I don't know how to make a podcast where we could all be literally crying and screaming and be in hysterics if we wanted to show the really bad moments, but that doesn't make for a particularly good podcast, so that's...

Sean: And that's the problem with an invisible illness, is that no one can see it, no one can see your struggle besides yourself when the cameras are off, when you're alone, when no one else is around.

Hazel: Yeah, exactly, yeah, yeah. On that note, guys, I wanna thank you so much. This was, I have to say, it was kind of a breath of fresh air for me because it felt like a chat with friends and I didn't have to study up on the topic and the person, so it's been good for me and I hope for you as well.

Sean: Oh, definitely.

Steve: No, it's been brilliant. Thank you very much. And of course, as you said, you are already an expert in the topic.

Hazel: Exactly.