TINNITUS TALK
PODCAST
EPISODE 10

CORONAVIRUS SPECIAL
Tinnitus in Times of Quarantine

Ed: I get irritated seeing people saying, ‘it’s just the flu’. It’s not the flu. It’s literally that people are dying, and you need to take it seriously!

Hazel: Welcome to **Tinnitus Talk**. That was **Ed** whom you heard just now, one of the contributors to this special episode on Corona and tinnitus. Ed actually got infected with the Coronavirus and you will hear more from him about that later in this episode, including how it has affected his tinnitus.

00:31 Reflections on Coronavirus and Tinnitus

Hazel: These are crazy times that we are living in. The Coronavirus has impacted pretty much everything, including this podcast. We’ve had to postpone some of the interviews that we had planned because our guests got too side-tracked dealing with this new situation, or because they couldn’t get access to proper recording equipment because of working from home, so it has been a bit of a setback for us. But we are moving ahead nonetheless and we decided to create this special episode for anyone out there suffering from tinnitus to hear about experiences from others on how this crisis has impacted their lives and also their tinnitus, and we will also be looking a bit at how Tinnitus research has been affected as well as clinical care. We have been a bit worried to be honest about all of you out there whose tinnitus has, perhaps, got worse because of the stress of this crisis. It can be a very stressful situation being stuck at home. Social isolation is generally not good for mental health and then there is the fact that many people’s livelihoods have been affected. People are worried about their own health, their elderly relatives and other loved ones. So, all of that can cause a lot of stress, and stress, as we know is not good for our tinnitus. It can make it go worse. It can make it spike so if that is the case our thoughts are with you. Please try to reach out for help. We’re there if you need us at the **Tinnitus Talk Forum.** Just reach out for support if you need it and I am also thinking, in particular, of those people who are just now developing tinnitus for the first time during this crisis. As with many of you out there I remember how awful that initial period can be and it must be even more awful during these times, so if you’re one of those people, hang in there, you are not alone. Please reach out for support and we hope you get through this ok.

We’ve interviewed a good many people for this episode. Many of them are members of the **Tinnitus Talk Forum**, also one researcher and one clinician. It’s actually the first time we have done an episode in this format where we have interviewed a number of people in shorter segments and then we're trying to sort of cobble it all together into one coherent episode, which is a bit of a puzzle and, to be honest, I think it is a more challenging way of putting together an episode than just doing one, long, in-depth interview with someone. But, hopefully, it's interesting and valuable. Before we continue, I do want to thank two of our newest Patreon supporters, that's Mike Bakker and Jefferson Nunn. I wanted to mention them both by name because they came in at the highest tier that we've set for our Patreon support, so they are supporting us with a very generous amount and we're obviously very grateful for that. It will actually help us a lot during these times because now that we are forced to interview many of our guests from their homes we will likely have to send them good microphones so that we get good audio quality and that will cost money. So that is one of the ways that this support helps. But, of course, we are grateful for all of our Patreon supporters and if you don't have much money to spend and you can only afford to support us with, let's say $2 per month, we're also very, very grateful for that.

So, let's start with a few impressions from the **Tinnitus Talk Forum.** I was looking today through the thread that we have on there about Corona, COVID-19. It's a very active thread at the moment. I was looking through it together with Markku and we were sharing our observations and one of the things we noticed is that at the start of the thread, I think it was back in about early February or something, the general sentiment was, 'oh, don't panic, this is not too bad' and, of course, it has completely shifted since then to 'this is actually really bad'. There are concerns over the mental health impact of this crisis and how it could impact tinnitus, concerns over how research is affected and clinical trials coming to a halt. Some people have expressed concerns over 'what if I get sick and I need to be treated with ototoxic medications' - so, medications that could be harmful to the ear – 'because I really can't have my hearing or tinnitus go even worse?'

05:40 Tinnitus Talk Members' Experiences with Tinnitus during Quarantine

Now, let's hear directly from a few members of the **Tinnitus Talk** community on how they've been affected.

We spoke first of all to **Liz** who lives in the UK, in Glastonbury. Incidentally, she is also the person who transcribes all of our podcast episodes which is an immense amount of work so we're very grateful to her. And, here's what she had to say about how the current situation has impacted her tinnitus. I should pre-empt this segment by apologising for the very poor audio quality and I promise the other segments will be of better quality.

06:22 Liz in Glastonbury, UK

I think it has impacted it although I try not to dwell on it too much, because the way I deal with it is I have lots of distractions, one of which is I like to exercise a lot. I go to the gym several times a week and that's one of the only places where it's not at the forefront of my mind. It's not a noisy gym and I think the combination of being out and being very active is very good for me personally. So not being able to do that, I'm doing as much as I can at home. I have a rebounder which I've had for many, many years but it's never had so much use as it's been getting in the last two weeks. So, that takes up quite a lot of time. I do a bit of yoga, anything physical, but I'm not really that tired. I'm not doing as much as I would normally, sort of going out and about so I'm not sleeping very well because I'm physically not tired enough. There's not enough to do to fill my days and there's only so much Netflixing that you can do. I've just invented that verb. Probably I haven't, but anyway… Yes, you can get a bit bored, but I've made lots of soup. I try and eat healthily. Just all the things probably most people are doing because it would be easy to come out of this and feel really horrible in addition to the tinnitus. You know, to feel really lacking in energy or you've been eating rubbish or whatever, so I think take a broader view really. Try and make it more of a positive thing.

Hazel: So, you haven't really noticed a change in your tinnitus per se, apart from just finding it a bit more difficult to get the distraction?

Liz: On occasions it does feel a lot louder but, again, I think that is, apart from talking to myself, I don't have conversations, well, I don't talk to myself generally, but unless I were talking to myself I'm not having probably the same amount of conversations so all that I've got for company is my tinnitus in many ways. It's just another level. It's not going to go on forever. It will go back to what it was. I look forward to that, really. I also have an incredibly clean apartment now because it's been cleaned within an inch of its life so that's another positive to come out of it.

08:52 Steve in Sheffield, UK

We also spoke to **Steve** who is also a long-term member of **Tinnitus Talk** and also our former Director before I took over. The impact for him has been mainly with regard to work. He is, I guess you could say, a tinnitus veteran of nearly two decades and he says his tinnitus is always very loud but that hasn't changed significantly because of the current situation. He spoke with us from his home in Sheffield, UK.

Steve: In terms of work we were incredibly busy, and kind of work just dropped off a cliff edge and that's the same for a lot of companies I think, not just in the UK but around the world. Because of course I do a lot of work around construction about things, pre-planning on the environmental side as well. Everybody's just stopped. So, the whole industry has just completely stopped dead, in the sectors that I work in anyway.

Hazel: So, apart from work how has your life been affected?

Steve: I mean, it's pretty huge. You know, you can't go out, well you're not supposed to anyway. But we haven't been going out, well maybe once or twice a week we'll have a walk around, keep local. But I go to the gym quite a lot so that shut down, is it two and a half weeks ago now? So, I managed to, from your native country, purchase a TRX from the Netherlands that took about a week to arrive. I think I actually managed to get the last one they had at the time because they went out of stock just after I bought it.

Hazel: I don't even know what it is Steve!

Steve: Right, well, it's a suspension trainer so, basically, because I live in an older building, I've got an exposed roof beam so I can wrap the suspension trainer around and do a lot of bodyweight exercises. It helps me to keep fit during all of this. Also, I'm big into my gaming so I've got a Playstation VR, so I've been downloading quite a lot of active games, playing a lot of Beat Sabre, a lot of boxing and things like that.

Hazel: So, you actually have more time for fun activities? Doesn't sound bad!

Steve: It's not too bad actually. You know, you've got to look at the best side of things, haven't you, rather than the dark side. It's been good to sit down and actually look and say, do you know what, I've got time to play those games that I didn't have time to play or I've got time to do certain things. One thing which Markku will empathise with is I've been for a long time wanting to learn a bit more about Wordpress and **gravity forms?** and a bit about coding. So, I'm going to be enjoying doing a bit of that whilst there's nothing else to do.

11.33 Sean – somewhere on the East Coast of the US

Hazel: Finally, we spoke to **Sean** who is actually the former host of this podcast and who spoke with us from his home somewhere in the east coast of the US. I don't remember the exact location, sorry Sean! He shared with us his thoughts on the pros and cons of being stuck at home all the time with tinnitus.

Sean: In regard to my tinnitus, it was kind of a good thing because you know, when I'm at home and you're working from home you can have music playing in the background as loud as you want. You can have your white noise machine going if need be. You have a lot more soundscape distractions that you can have going that I don't really have the ability to do at my job. So in the sense of tinnitus it's kind of great where I'm at home and I can use as much sound as I want to help distract my tinnitus and it's made my days a lot easier and I guess it's a lot more enjoyable being able to use those sound distractions, more so than I could previously. But in regard to everything else it kind of obviously sucks, you know. You're stuck at home. There are these other distractions that I like to do for my tinnitus such as go exercise, go ride my bike, maybe go to a restaurant, go to the store, maybe look at things, pick up things, that's not really an option right now. So, the social aspect of distraction when it comes to tinnitus is kind of not really there anymore, where it was previously. The only kind of distractions I have from my tinnitus necessarily now are these soundscapes and distractions and whatnot.

Hazel: Yes, that's a really interesting side effect of the Corona crisis that you speak of which is that working from home is probably, in many ways, better suited for someone who suffers from tinnitus and, certainly I imagine, hyperacusis although I don't think you have that, but I think someone who suffers badly from hyperacusis would be much more comfortable working from home than in an office environment where they can't control the soundscape.

Sean: Exactly, I think that you just have a lot more control over your environment which is also reassuring for people who are very concerned about noises and their tinnitus. Being at home is a lot more comfortable for those people because they know the sounds they are going to be exposed to at their home, versus at the office, walking down the street, whatever.

Hazel: Exactly, but you did mention also the flip side of social isolation in and of itself, is, for many people, certainly in the long term maybe it's ok for a few days, but when the days turn into weeks or months, it's actually not very good for your mental health. I think a lot of studies have also shown this and that could potentially affect your tinnitus as well, I imagine.

Sean: I definitely agree with that. I think that something that the tinnitus community I guess it's big on. I don't know if a lot of people think about it or talk about it, but talking about it with a couple of people is that the social distraction, like, I know that when I have tinnitus and I'm with other people and I'm talking and engaging with other people face-to-face in an environment, it's another layer of distraction on top of sound and it helps me focus my brain and tries to help me tune out that tinnitus tone. It's never completely gone but it helps put it in the background a little more and not having that difference between sound and social face-to-face distraction, I was thinking about it today before we got on this, but it is definitely something real. I would like to know how the other people with tinnitus in our community are also dealing with this isolation aspect socially as well.

15:54 Overall Impressions of Dealing with Tinnitus

Hazel: My impression from talking from Sean and Liz and Steve is that they are all coping quite well, luckily, but then again you have to remember these are all people who have had tinnitus for a very long time and in spite of describing their tinnitus as quite loud and intrusive and still struggling with it from time to time, I mean Liz, for instance, has tried out the Lenire device which you wouldn't do if you were completely ok with your tinnitus, right? But nonetheless these are people who have had tinnitus for many, many years and have had a lot of time to develop their own coping mechanisms and I think that's maybe the reason they don't seem too phased by the current situation, at least not when it comes to their tinnitus. I found it interesting though that all of them said, or alluded to the fact that, isolation is kind of a mixed bag when it comes to coping with tinnitus. So on the one hand when you are stuck at home you have complete control over your environment, including your soundscape, which can actually be a good thing when it comes to tinnitus. But, on the other hand, you have to go without many of the normal activities that you use to divert your attention away from your tinnitus so, whether that's going to the gym, or going for a walk, or meeting up with friends, we don't have any of those activities any more, and that can mean it's harder to distract yourself from your tinnitus. I actually just came across a good example of this on our forum. Someone started a new thread titled, 'I've always had tinnitus but the COVID-19 quarantine just made it real for me' in which the person basically describes how they've had tinnitus for many, many years but didn't really get bothered by it until they were stuck at home where it's quiet and you've got lots of time to think, so that definitely seems to be a potentially negative side effect of this situation that we're all in, unfortunately.

I should also note that we didn't actually interview anyone with hyperacusis, so I'm curious to know how those folks have been affected. If you do suffer from hyperacusis maybe you can let us know in response to this episode.

18:18 Tinnitus Talk Member Ed209 Discusses his COVID-19 Infection

Hazel: Alright, now let's now hear from a **Tinnitus Talk** member who has actually had the Coronavirus. So, he came down with the disease, COVID-19, along with all of his immediate relatives. His name is Eddie, otherwise known as **'Ed209'** on the forum. His tale is really quite harrowing, I would say, and it describes what it's like when you get sick in a country where, well, like many other countries right now, the healthcare system is completely overwhelmed beyond capacity.

Ed: We've all had it, my wife has had it, my daughter has had it, I've had it and now my mother also has it. She's still in hospital with it right now at the moment.

Hazel: That's very sad to hear. I really hope she'll be ok. How's she doing at the moment?

Ed: We don't actually know. She's due to have a scan today and an X-ray to check what her lungs look like compared to the last X-ray, which was about two weeks ago. All I know is that they've said that her lungs still sound 'squeaky' is what she told me, whatever that means, so there's obviously some fluid there or something that's being picked up.

Hazel: Alright, I can imagine that's very concerning. What is the situation like in the hospital in terms of capacity, resources?

Ed: As far as I know the hospital that she's in is one of the worst affected in the country, in all of the UK. It's the hotspot. It's as bad as it gets, I think.

Hazel: That's an extra reason for concern then, I suppose.

Ed: Absolutely, yes. As far as I know I think, but I can't clarify this because the data changes every day, but the hospital that she's in had the highest death rate in the country, so it's not very comforting.

Hazel: Not at all, not at all. And the rest of the family, you said everyone has had it. How are you guys now?

Ed: I've still got the cough a little bit, not much. It took me about two weeks and three or four days, something like that for the symptoms to fully go away. Well I say fully, I've still got the cough, so it still hasn't completely gone, but I had a temperature for over two weeks. My temperature was between 38 and 39 and it wouldn't go any lower than that, so that took a while. My symptoms started with a sore throat. It was more like a tickly cough that developed into a proper cough and then my breath became a little bit shorter. I remember the first night I went to bed when I developed those symptoms and I had like a fever building up and I just became quite ill the next day. I felt like I had the flu. I had body aches all over and it was quite peculiar because I was sort of hot and cold at the same time and that's how it started, for me at least.

Hazel: Right, and was it confirmed that you guys all caught the Coronavirus?

Ed: No, I was about to bring this up. I've got a lot of students who work at the hospital in question who I teach, and they've been checking up on us pretty much every other day to see how we're getting on and when my mother went into the hospital and was confirmed as a definite case, he basically told us that he was absolutely confident, without any doubt, that we've all had it in this house, based on clinical symptoms. He said he would have no doubt, without a test, that we've definitely had it because it's clear that we passed it onto her, and she picked it up from work. She works in a school.

Hazel: Yes, that does seem very logical and we know it's so easily transmitted that you guys must have all caught it from each other if she is confirmed to have the virus indeed. Have you noticed any impact to your tinnitus or how you experience your tinnitus?

Ed: That's a good question. I usually get worse tinnitus with a cold anyway. So, I usually get quite bunged up if I get a cold and once my eustachian tubes block up my tinnitus always gets louder, and this was no different. It did get louder, but it wasn't the virus. It was the symptoms of the virus that made it louder, so it blocked me up and my tinnitus literally hits the stratosphere when it gets like that. But there's nothing you can do, it's just one of those things you know. It was really loud but after about a week it started to go back to its normal level, which is loud, still loud but not like absolutely, ragingly, insanely loud.

Hazel: Oh wow, that must have been scary although I imagine you said it happens every time you have a cold?

Ed: It happens every time, so I wasn't really freaking out to be honest with you. I expected it because I've got hay fever, I've got allergies and I'm always getting bunged up so this happens frequently, it's sort of par for the course. I didn't immediately think the 'virus is attacking my ears and making my tinnitus worse' though. I wasn't freaking out.

Hazel: Ok. And what's the situation now? Has your tinnitus gone back down?

Ed: My tinnitus is back to the way it's always been, it's not behaving any differently. It's exactly the same. So, in my case, I can't say this will be exactly the same for absolutely everybody out there, but in my case it did nothing to my tinnitus.

24:05 Raj Shekhawat (UCL) – Impact on Tinnitus Research

Hazel: Now, let's shift gears a bit away from people's personal experience, to the bigger picture of what the Coronavirus means for tinnitus research and tinnitus care. Many of you have expressed concern about this. For instance, will there still be funding for tinnitus research? We spoke to **Dr Raj Shekhawat,** who is a tinnitus researcher. His background is in audiology and he is currently focussed on optimising non-invasive brain stimulation for tinnitus relief. We talked to him a bit about how the Corona crisis has impacted his research very directly and how he is now trying to come up with innovative ways to keep the research moving in spite of the fact that his clinical trials are on hold. Raj is also the Public Relations Manager for the **Tinnitus Research Initiative,** which means that he has a pretty good overview of the tinnitus research field as a whole, so we also asked him about his outlook for tinnitus research in times of Corona and beyond.

25:14 Dr Raj Shekhawat’s Experiences

Dr Raj: Well, as you know, Hazel, the whole world is encountering this pandemic and it is also having a massive impact on UK as well, just like rest of the world, so if you look at the tertiary educations most of the universities are sort of trying to make their teaching and learning online – most of the labs are shut down for obvious reasons, and also people are practicing social distancing, so we are practicing exactly the same thing in UK as well.

Hazel: All right, and you’re working from home permanently, or are you still able to go to the university?

Dr Raj: For past few weeks I'm working from home because these are the guidelines for us. Those people who are not in the front line and who are not essential workers and who can work from home, they should be working from home, so from past two weeks I'm working from home.

Hazel: All right, and how has this affected your work?

Dr Raj: It is affecting things in a very different way because a lot of us who are involved in doing teaching and research of course now because we don't have the physical space of the class and that physical encounter with the students and the learners – all of that is shifting to an online environment which is, in a way, a good approach if you look at the future. We want to make education as accessible as possible, so I think if we look at one positive thing that has come out of COVID-19, I would say that the push it has given to the online pedagogy is really really amazing. On the other side, of course, there are the things which you must be doing in person. For example, a Ph.D. student was supposed to do her data collection, which was supposed to be in person, and of course we can’t do that now, so our lab is shut down for a couple of weeks and the government is monitoring the situation, and as things will unfold, we will decide what to do.

27:17 Impacts on Tinnitus Research

Hazel: And how if you look at tinnitus research overall – I know you’re in touch with a lot of other researchers who are focusing on tinnitus, you’re also one of the staff members of the Tinnitus Research Initiative so you have a good overview – what is happening right now in the field and how has the corona crisis impacted tinnitus research?

Dr Raj: I think it’s important for all of us to acknowledge that COVID-19 has had an impact on education, economy, social life, and it is touching millions of spheres of people's life. To give you an example, we were supposed to have our annual tinnitus research initiative conference in Vancouver in May this year and there were people who were planning this for almost a year’s time and they invested heavily into it in terms of their time, energy. We had a fabulous program all lined up, but now of course considering the health and safety of the participants and the travel restrictions around the world, we decided to postpone that conference, so something like that has happened globally in terms of tinnitus community. Also, a lot of labs around the world who are doing clinical research as well as basic research for that matter, those things are definitely delayed as well. I would also like to give you an example of… as I was talking about my Ph.D. student who was really excited to roll the data collection of her study, now we have decided that because we can’t do that, so instead of sitting idly at home we have decided to sort of add in an extra component to our research and we are trying to plan an online study now so as we speak my student is in the process of getting in touch with the ethics committee to see if we could do an online study and I think that's how we all need to be – being very agile and being willing to look at the best in the situation and figure out what is the best thing going forward for all of us.

29:25 High Definition tDCS Study

Hazel: Yes, so you're saying a crisis can also make you more inventive and find innovative new ways to do research.

Dr Raj: I absolutely believe that crisis and chaos can result into creativity and you all should be open to that.

Hazel: Absolutely, and as you know at **Tinnitus Talk** we are very much in favor of online studies, or, you know, we strongly believe in the power of online communities, so I hope you will be able to succeed in that way. What is the study about, by the way?

Dr Raj: So this original study, this Ph.D. project is about use of non-invasive neuromodulation, **high-definition tDCS for tinnitus management**, and what we are also planning to do in the study is now we are adding, because we know that for the next couple of months, we can't do some lab-based work and clinic-based work in here in UK, so we have decided to do this online survey of tinnitus participants about their expectations about tinnitus management and also what are their views about tinnitus management and the research direction. So I think it's extremely important to involve patients and the public right at the inception of study. Rather than just telling them ‘Okay this is what we do, these are the findings,’ I think it's important to involve them right at the beginning and that's what now we are going to be doing with this online study.

Hazel: Ah, right, so the topic of the study will still be neuromodulation, but rather than diving straight into the trials or whatever it is you were going to do, you're now taking more time to discuss with the patients - with the participants - on how the study should be set up and what the goals should be and things like that.

Dr Raj: Absolutely, and what are their expectations in terms of the benefit and what exactly is they consider a real benefit is. So I think this will give us directly the voices of tinnitus patients directly, and that will definitely help us in terms of not only shaping the study, which we’ll be doing in near future, but also creating more opportunities to involve real patients. I am very grateful for Tinnitus Hub for opening up these avenues for basically bridging the gap between research community and patients, which is extremely important. So well done, Hazel and Tinnitus Hub, for doing this.

31:58 Follow-Up on Raj’s Study by Tinnitus Hub

Hazel: That was Raj, and we recorded this segment with him a few weeks ago and we've been in touch with him and his PhD student a couple of times since and agreed that we will help them out with their online survey for their study. it's for a transcranial direct current stimulation study. I think I said something else during the interview I may have said neuromodulation but it's transcranial direct-current stimulation, which is a non-invasive brain stimulation technique. So we'll be helping out with an online survey to gauge how patients feel about such a study and what kind of expectations they would have from it, so if you're interested in that, keep an eye out. On the forum, we will be launching that survey very soon. We've also wondered how tinnitus care is impacted because of Corona. Now, of course, the level of care for tinnitus patients is already very limited in some countries, even non-existent, but we wondered is it now even more difficult to get help. Well, it turns out that's true to some extent, but we also see a shift in providing care online where possible. We spoke to Alan Hopkirk about this. He's an audiologist with a specialization in tinnitus who operates out of Glasgow, Scotland. His clinic there is now closed, but he told us how different types of technology are enabling them to carry on in spite of not having a physical location anymore, from where they can treat patients.

33:43 Alan Hopkirk

Alan: Well, I think we were very lucky for the patients that I have that are in early-stage support - that we got everything in place before the full force of this crisis had happened, so they were comfortable - they felt they knew they had that support. So I'm really pleased that they’re all coping very well.

Hazel: Well, that's good to hear because I think it's, as you say, we often hear stories - and I don't know how much research there's actually been done on it, but - that people's tinnitus either starts during or gets worse during a period of great stress and turmoil. You know, so even if it might be caused by hearing loss or some other physical issue but the trigger is often, you know, that emotional stress, so I can imagine that that's happening a lot right now.

Alan: Well, I think it will be, and I think these are people who feel isolated, and that's one of the problems. If you're sitting there isolated, you're sitting dwelling on things, catastrophizing what’s going to happen, feeling there’s no point in reaching out to people because, you know, it almost seems like any help line, you’re just on hold for an hour. But there are facilities available. I know that the British Tinnitus Association has a virtual support group. We did a kind of Facebook broadcast earlier in the week, as well, which we were beset with a couple of technical problems to begin with, but you know we had thirty-five people that joined at some point. So I think it's very important that we offer support lines to people particularly when there's a crisis like this. Emotional support can go a long way.

35:52 Treating Patient Remotely

Hazel: Yeah, no absolutely and it's good to hear that you are developing these new mechanisms tools, you know, online tools - whatever is needed to still stay in touch with your patients, but have you found that that also changes the way in which you interact with them, the way in which you can support them?

Alan: So, now that we're doing this, we're finding actually it's very successful. People like it because you don't have that stress of making sure they get to the appointment on time: Is the traffic going to be busy? Is the train going to be canceled? Yeah, there are still some technical issues with the internet, which, you know, but even with that, people are prepared for it. We accept it might take longer to make a connection, signals might drop out, but I think it's probably going to be with us. The best way of helping patients, I think, is having a step forward. I don't think it will replace a face-to-face fully, and I wouldn't want it to, but I think it means that we can give more concentrated support in smaller bites. And I think that could be quite beneficial.

Hazel: Absolutely, yeah, at least we have these modern ways of connecting with each other, thank God. You did mention -

Alan: Can I just say that it's not just, sorry Hazel, it's not just having a conversation, we can physically make adjustments to equipment that they have, so my patients have hearing devices, sound generators – I can access how often they're using them, what settings, I can make adjustments. So we can actually very much interact. It's not just saying 'How are you doing?' although that's important, too.

Hazel: All right, so you can remotely control some of the tools they're using to manage their tinnitus, you mean?

Alan: Yes. Yeah.

38:20 Coping in the Midst of Crisis

Hazel: What would you say to someone who right now in the midst of the Corona crisis and while the whole world is in turmoil and they're sitting at home alone, they suddenly develop tinnitus or an existing tinnitus suddenly gets worse, and they're not in any in contact with any clinician or in any kind of treatment program, and they really don't know where to go?

Alan: Well, it's easier said than done, but my first words of advice would be: Don't panic. Take a deep breath. If you feel this noise suddenly popped into your head, or it had been fine and it came back, then don't panic. That's the number one thing because that's when you'll exacerbate it. So the second thing is that it's a good thing to get some input from somebody else. So there's a variety of different resources. Our next support group is in May and it's not likely that's going to happen face-to-face, but I think we'll put in place a virtual support group and we might even do one earlier than that because in some ways we can actually - what we'll have a go at it - it's an hour of my time, perhaps, rather than an evening. I have, you know, so we can, perhaps, do you more support groups, and they will be more accessible because, you know, you don't have to live half an hour or an hour away or whatever.

39:41 Hazel's Reflections on the Role of Forums

Hazel: As you probably know we run an online forum under the same name as this podcast, **Tinnitus Talk**, so this whole situation has made us reflect a lot on the role that online communities can and should play in times of crisis. Now I've personally always believed very strongly in the power of online communities – I mean that's why we do this work, right? And we just heard Alan talk about how online help doesn't have to be inferior to face-to-face help. I guess it depends on personal preference, but, yeah, we'd like to think that **Tinnitus Talk** could play an important role in providing everyone who needs it with support especially during these times. I am aware that Healthcare professionals will sometimes, maybe even often, tell their patients with tinnitus to stay away from forums, online forums, because of negativity whether real or perceived negativity. Personally, I'm not denying that there's some of that, but I think there are ways around that, and ways to make the online experience a positive one - or at least if not always a positive one, then at least a helpful one, right? Because we can't expect everyone to always be positive when they're struggling a lot with their tinnitus. But anyway, let's first hear what Alan, the audiologist we heard from before, has to say on this topic.

Alan: So, the internet's wonderful, but of course, it's got many pitfalls, and that's the challenge. You know, you got vulnerable people and you can end up down a path where the fear is amplified. And another thing I'm going to say - going back to what to say to somebody that suddenly is afflicted by tinnitus - is be positive. There is help around; you're not alone, so, you know, peer support is so important in making people understand that. And I do think that, you know, we run six support group meetings a year which are face-to-face, but I do think that if we nail (and we will!) doing virtual support groups, we'll probably do more. So we will extend that support mechanism, which is great.

Hazel: I think Alan makes a fair point about the internet being a potentially scary place for certain vulnerable groups, but I do also think there are ways around that by focusing on the information that is helpful to you. On our forum, for instance, we have sections where people can come just to vent if they want to be heard, but we also have a section on success stories where you can come for inspiration on how other people got better, and we have a general chat section where you can just connect with others on any topic, so I would say focus on whatever helps you. We also have a very active section on tinnitus research on the forum, and this is, I think, where we can play a big role in actually influencing the course of research because we host this community of many people with a deep interest and a stake in tinnitus research, and we can use that community as a resource to engage with researchers and have the patient voice be heard. We talked a bit about that potential for online patient engagement with Raj.

Dr Raj: I think eventually anyone who is working in the area of tinnitus research, be it basic signs or clinical work, the end goal is to find strategies which will help real life patients and people. So I think people are in the heart of everything. The patients are the heart of every effort which we are doing here at the UCL and at other universities – and at other research centers around the world. So I think it's only fair to involve them right from the start and also listen to what their expectations are and listen to what they have to say because sometimes they can come with creative ways which can be really, really beneficial.

44:12 The Importance of Connecting with Each Other

Hazel: The **Tinnitus Talk** members we interviewed for this episode, I think, all agreed that online communities can play an even more important role in coping with tinnitus during this crisis. Liz, for instance, advised people, especially people who are new to tinnitus, to reach out online and connect with others.

Liz: I can’t imagine doing that situation. It would be pretty difficult. You haven’t got your mechanisms that you evolve over years to deal with it. They’re not in place because it’s new and you have that extra level of anxiety that probably goes with it. I think that’s another level of difficulty, but they’ve got to hang in there. And there is **Tinnitus Talk** and people - and people thinking about them, if that helps them a bit.

Hazel: Steve said something along the lines of what I was trying to say earlier, which is that there's a lot of good information online and, you know, you should use your common sense in filtering out the helpful information and the reliable information from the unhelpful or harmful information.

Steve: Yeah, I think that’s the thing. I think it’s always about your own personal space, and I think we can all – all of us who’ve have had it for a good while – can all relate to the fact of going online and you might find somewhere that’s got 99% positive content, but if you're in that wrong space of mind, you will find the 1% of negative and latch on to it, and it's all about how you process the information. You have to kind of check your own responses, which is very easy for me to say after, however long, 17 years, I don’t know - God, that’s a long time, isn’t it? But you know, it would not be so easy to say to somebody in year 1 at all. I know what I was like and I just didn't, I couldn't.

Hazel: And Ed in particular stressed the need to vent online - to vent about your frustrations or desperation or whatever it may be as actually a very important part of coping.

Ed: Well, they’ll probably become more pivotal because they will be the backbone of support. There's no real life supposed at the moment, so it’s a great resource that you can just log on to **Tinnitus Talk** or any other sort of health website and talk to all the sufferers. Don’t hold back. Just unleash your feelings and tell all the people what you’re feeling like, and it can help; it can help a lot. Don’t bottle anything up. Don't be too brave. I think a lot of people - they try to be too brave or too macho. They don't want to show weakness. Showing weakness is, I think it's the opposite. I think it's actually bolder and braver. It shows more character. Just talk to people. Especially talk to the people around you if you’re in isolation with your parents or people close to you, just talk to those; get support from them as well.

Hazel: So that was Ed, and Sean stressed how important social contacts are for mental health in general, which I think a lot of research has already pointed out and specifically mental health when dealing with tinnitus, so he actually advises people to find the social aspects that we are now lacking in our day-to-day lives in our day-to-day interactions, many which are just gone but to replace those with online communities like **Tinnitus Talk**.

Sean: I'd encourage everyone to not necessarily lose out on that aspect of socialization and in reaching out to people. You can still call your friends; you can still call your parents or family whoever it may be and you can still talk with them about whatever, but you just, I guess you're going to miss out on that face-to-face aspect of it for a little while now. I think that **Tinnitus Talk** is probably a good outlet for everybody, you know what I mean? I think especially at a time like this when everyone's stuck at home, you know, you're working from home or whatever, you don't have that face-to-face interaction but I feel like - Markku could probably tell us, but - I feel like the traffic towards **Tinnitus Talk** and the amount of postings and messaging people are doing has probably gone up significantly because, you know, you're either at home or there's not a lot to do and you can socialize as some type of media outlet where you can talk with other people on **Tinnitus Talk** and you can see how everyone else is doing, you can have more daily conversations versus more long-term discussing treatments and stuff; you can have a daily 'Oh how you doing? How is everything going?' I bet the general section is probably exploding right now.

49:14 A Few More Words of Advice and Encouragement

Hazel: Okay, guys, before we wrap up, here are a few more words of advice and encouragement from several of our interviewees. Steve, for instance, talked about the benefits of distraction and finding the right kind of distraction for you when you're struggling with your tinnitus.

Steve: I think when you're feeling like that, what you really need is to escape in some way and you have to find which way of escaping works for you, whether it's masking it with sounds, whether it's getting out and about as much as you can, escape using video games or something like that, but I think being stuck indoors, using that to do as much research as you can into yourself and your tinnitus - to actually sitting down and figuring it out 'You know what? I think this makes me worse. I need to try and knock that out." Or 'I think this helps. Maybe I should try and do a bit more of that.' So I think the research time is invaluable with tinnitus to understand yourself.

Hazel: And Raj stressed the importance of kindness and taking care of each other, which I think is a lovely message.

Raj: I would definitely like to tell the wider community, whoever is listening to this podcast, please look out for your mental health and physical health. Try and get out of the house if you can. Go for some walks if you can. Try and reach out to people, too. We have technology at our disposal. Use WhatsApp, FaceTime, Skype calls, the **Tinnitus Talk** forum to reach out to community to check on people - how they're doing. And please be kind to others. And if you are struggling, please do not hesitate to reach out because we all are struggling; we all are having difficult days.

Hazel: Well, that brings us to the end of this episode. I hope you found it useful or interesting, and I really hope we were able to inspire a sense of connection so that you don't feel that you are all alone with your tinnitus in these rather dark days. I also hope that you all stay safe from Corona or if you have been impacted, I hope things will turn out okay for you. It's been said a bunch of times in this episode, but please reach out for help if you're feeling desperate.

If you don't know where to turn, please reach out to us directly. You can post your story on **Tinnitus Talk**, or if you don't feel comfortable doing that and just want some one-on-one support, feel free to send me and Markku a private message on **Tinnitus Talk** and we will do what we can for you. I want to remind everyone that you can support this podcast directly on Patreon, and I assure you even small amounts are very much appreciated, so thanks again for your support. Stay safe, stay well, and please tune in again next time.