

## ***Conversation in Tinnitus***

With Markku Vesala and Hazel Goedhart of

Tinnitus Talk Support Forum ([www.tinnitustalk.com](http://www.tinnitustalk.com))

### Transcript:

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

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**S1:** Welcome to another episode of *Conversations in Tinnitus*. I am John Coverstone, along with my co-host Dean Flyger. And we are delighted this time to be joined by a couple of guests from Europe. We have with us Markku Vesala, who may want to correct my pronunciation of his name, but he is a co-founder of Tinnitus Talk, which is located at [tinnitustalk.com](http://tinnitustalk.com). And also content strategist with Tinnitus Talk, Hazel Goedhart, who is joining us. And you both have tinnitus yourselves. That's what drove you to, in Markku's case, develop Tinnitus Talk, and in Hazel's case, join Tinnitus Talk and start becoming active behind the scenes. But before we even get to some of the things you're doing on the forum and some of the things you've learned through that and what have you, I would like to just hear about your own experiences with tinnitus. Markku, I think you've had tinnitus for much longer than either Hazel or I have. And I'd be curious to hear your perspective having had it for many years.

**S2:** Yeah. So, hey, both John and Dean. And it's our pleasure to be on the podcast. I got tinnitus back in 2010. And it was so innocent. I thought I had blocked ears with wax, like many do, and you go to a doctor and you have them flushed or whatever. And I went to the doctor's office and I left with ringing in both ears. So, I think that water pressure of the syringing procedure actually caused my ringing. I could not think of anything else. It didn't seem loud, and I didn't have any noise exposure at the time. And after that, I have actually researched it quite a bit and there are other cases where people have gotten tinnitus from ear syringing. And there was even this study where I think about 2,000 people were monitored at the tinnitus clinic and asked how their tinnitus started, and there were a couple dozen from that group of patients whose tinnitus had started after a procedure to clear ear wax.

And so, of course, initial stages, I started monitoring it. Is it now louder, softer? How is it developing? And I Googled a lot. I thought for several weeks in the beginning that it would cease, it would go away. But at maybe one-month mark, I started thinking that, "Okay, this is probably going to stay." And I became part of the Action on Hearing Loss forum. Back then, they had a different brand name. It was Royal National something, I don't remember, unfortunately. But yeah, so I became involved with the tinnitus space online, and that was how I found my coping mechanism, basically, finding other patients to share and talk with. And yeah, that was my story, how it started.

Of course, with the years, it has, unfortunately, a couple of times become worse for no known reason, which makes it ever so more frustrating because I have been taking very good care of my

ears, avoiding loud sounds, making sure I don't take or avoid other toxic medications. And still, it's become more intrusive. And now, whereas in the beginning back in 2010, I could mask it with almost all daily-- well, not all daily noises, but a majority of daily noises, now, the shower is pretty much the only relief I get during a day. So it has become worse. And it's not easy to deal with. I have to say, I consider myself-- like I'm not suicidal to speak, like unfortunately some debilitated sufferers are, but it has a grip on my life and it does impact my concentration, sometimes harder to fall asleep. It has a big effect on my life for sure.

**S3:** And Hazel, how did you first experience your tinnitus?

**S4:** Yeah. So that was a bit over a year ago. I literally went to bed one evening and noticed it was there. It's very from one moment to the next. I didn't worry too much about it the first few days because I thought it would go away. People often get ringing for 24 hours or whatever. When I realized it didn't seem to be going away, I panicked quite a bit, as I think many people do. Not everyone, but yeah, a lot of people do panic about it. I did, certainly. I went to my GP. They didn't really know what to do with me. Again, this is quite a common story, I think. Doctors don't really know what to do with tinnitus patients. I had to push for an ENT referral, which I did get. But all they could-- well, they did two things. They sent me for a hearing test, which did show some hearing loss on one side, just on the right side, which is also where my tinnitus is loudest. It remains unclear where that hearing loss came from, so that's a bit of a mystery. And they did, as they do with many tinnitus patients, an MRI to rule out acoustic neuroma, which was ruled out.

And then that's the end of the line, right? That's pretty much what they can do. I did seek some psychological help myself, which did help somewhat. But for the most part, it was just-- well, as I mentioned earlier, I did have to take a few months sick leave from work because I was literally too anxious to work and I had a lot of trouble sleeping. But I did after a month or two I sort of make a conscious decision that I was going to do whatever I could to get better, to feel better. And so I just spent a lot of time and energy on finding whatever it was that could make me feel better. In my case, yoga helped a lot; certain breathing exercises, meditation. And yeah, I think I got to a place after three or four months or so where I pretty much accepted it and was able to pay less attention to it and function more or less normally again.

**S1:** And Hazel, your tinnitus kind of drove you to find Tinnitus Talk, correct? And then it also drove you to become more involved?

**S4:** Absolutely. Yeah. I mean these days for most people if you get any kind of health scare, the first thing you do, even before going to your doctor, is you go online, right? So, I think I found Tinnitus Talk within a few days. I was a member within a week of developing tinnitus and was reading avidly for the first few months. Specifically, reading the success stories section, which I think is a great section on the Tinnitus Talk forum because that really helped me so much. Because it's really hard to believe when you're in that early panic stage that you can get better, that you can get used to this, so just reading other people's stories and hearing them say, "I know it's hard to believe, but you can get better," and, "I was so bad in the beginning, but I'm much better now." And yeah, that gave me a lot more confidence that I could probably get better too, so that helped me a lot.

Excellent.

**S1:** Well, and Markku, your tinnitus, I'm assuming, drove you to create something, which ended up being Tinnitus Talk. How did that come about?

**S2:** Yeah. I'm asked this often. So, it's basically, back in the day – seven, eight years ago – there were one or two tinnitus forums in existence. But the other one I felt was very inactive. There wasn't really moderation or any good structure. And the other one also was a little bit back. And it

felt like there could be so much more to be offered – chats and private messaging and better categorization and all that stuff. So, I decided, because I had some background in [inaudible] development and I had been part of other communities in the past, yeah, so that gave me the inspiration to start with it.

And then in the initial days, we had a few members showing. Jim from San Francisco was one, and he was really encouraging. He was like, "This looks so good. You have done a great job. This will serve a lot of purpose in the coming years. Keep up with it." And we became good friends, and he became the first moderator of the forum. So, we got a really good group going at the beginning. There was this Karen from Atlanta, and she's still around after these years, although a little bit more inactive. Jim, on the other hand, has dropped off. That happens to so many volunteers over time where their tinnitus becomes less of an issue. And you don't really want to – I think most people don't want to associate themselves with tinnitus initiatives when they no longer are so bothered by it. So, you don't want to remind yourself.

But then there are exceptions, like Hazel and some others, like Steve, my co-founder, that they think they want to keep doing a difference and trying to shape the tinnitus field. So, [I'm] one of the few, and I still feel very motivated to keep going. And I think, actually, Tinnitus Talk has given me some sort of purpose during the tough times when I have been really low. I have also some other health issues, and I could say it's a constant struggle in that way. But the members, the volunteers, the community, the things we are involved with with researchers, other patient groups; it's really fulfilling. So, it's nice to wake up to another day. Yeah.

**S3:** That's very interesting how your condition and also your background kind of led you to create this Tinnitus Talk and the website, which is Tinnitus Hub. Is that correct?

**S2:** Yeah.

**S3:** Yeah. Going forward – you've done a very good job with the community, with the communication – what do you intend to do with your website to further help for people with the condition? Do you have any other plans at this time?

**S2:** Yeah. So, in the past few years, we have organized these tinnitus surveys. One of them got over 6,000 patients responding. The other one was over 5,000. So there have actually been a couple of research papers published where we are co-authors, and another one is coming in 2019. I think our future plans revolve around learning more about our patients, our members, and connecting them. Providing the support like we have been doing, but also then continuing the work where researchers can learn from our member base, which is quite unique. I don't think – well, many researchers have said that they don't actually know many resources or sources where they can get access to so many sufferers at once. And so surveys will be in the future.

Also, we want to expand the Tinnitus Hub website. So Tinnitus Talk will continue to be the forum, the community, but Tinnitus Hub will be the static content where we will want to, for example, improve the success stories, which I think 99% like most of our content because it's so encouraging to see other people's stories, how they overcame tinnitus, and what they did and how they are doing now. So, we want to create this static section where we have videos, maybe some audio, and pictures, and really go into detail with these people who want to share their stories. And then alongside with that, I think it's just creating more content and trying to do these awareness activities.

Last year, Tinnitus Week 2018-- or this year, sorry, change of year, so a little complicated. But 2018 Tinnitus Week, it was the first time ATA, BTA, and us, along with a few other organizations, came together and had their Tinnitus Awareness Week at the same time. Before that, I think ATA had its awareness week in May, and BTA had had its in February. So now we came together and

had this tinnitusweek.com website where we published all the initiatives the organizations were doing. And this coming Tinnitus Week 2019, the theme will be social isolation. And we are currently trying to gather stories of people, how tinnitus has affected them, how it has made them socially less capable. And we have already gotten a few, but we hope to get more. And BTA will have its own initiatives around the theme. And I think that's one of the exciting parts, to keep making the Tinnitus Week greater and greater, so I hope.

**S3:** Excellent. That's excellent.

**S1:** And you made a comment, Markku, a few moments ago that kind of struck me because I've heard this from other people in other environments, other organizations, and that is that people very often will get very involved, devote a lot of energy to a tinnitus forum or a tinnitus association and support groups and things like that, and then they tend to get benefit from that and their tinnitus gets better, and then they kind of go their way. They've gotten what they were seeking, and their tinnitus is better, and so you kind of lose their involvement. Do you both feel that there is a need amongst the patients in support groups who are mentoring others and such to stick around longer and fill that role for people with more recent onset of tinnitus so that we're not losing their experience and knowledge?

**S2:** Yeah. So absolutely, I think so. And we have this ambassador thing on Tinnitus Talk, which we give to members who stick around and who keep helping and sharing their wisdom. I would like to, for example, mention Billie48. But Billie48 is one of the members who has tinnitus, has had tinnitus for a long time, and he has it very severely but he's not too bothered by it. And he has been praised by so many members that when some members come back and they share their success stories, Billie48 is often mentioned and thanked. And there are a few others such as him. But we have kept thinking about that, how can we moderate, how can we encourage people who start to feel better that there's still a use, there's still a very fulfilling use for your time and experience, that you could be these experienced sharers where you help others who are afflicted by this, the newcomers? But I don't have a solution for that. We have thought about it so much. And Hazel, what do you think?

**S4:** Yeah. It remains hard. I think if you look at the forum members, you can divide them into different categories, right? There's the newcomers, who just got tinnitus and are scared, and a lot of them stick around for a few months and then leave when they get better. Then there's the long-time sufferers, the people who for whatever reason have never really been able to get better or learn to live with their tinnitus, for whatever reason are suffering severely, and stay on the forum for many years sometimes for that reason. Yeah. Then there's the group of people who suffered a recent setback. So maybe they've had tinnitus for a long time, but suddenly it got worse, so they come to the forum seeking help. And then there's this small group which, as Markku mentioned, really people we want to cherish who really have learned to cope very well with their tinnitus. They live a more or less normal, functional life, but they stick around to help others. And we have a few very notable members like that. Markku mentioned Billie48. He has a very inspirational success story because he struggled a lot, like really a lot, and finally managed to get better.

There's also – I think it's the most read success story in the success story section, if I'm not mistaken – is called Back to Silence. That's the title of the thread. It's by a member called I who loves music. I think that's his username. And he kind of devised his own method for learning to cope with his tinnitus after suffering for, I think it was 30 or 40 years, a long time. He was not able to habituate. And he came up with a sort of very simple psychological method, which just consists of writing down on a daily basis. And at any moment that you hear tinnitus or are bothered by it, you make a quick note of it. And for him, just the act of doing that, that was the one thing that finally changed his thought patterns and caused him to pay less attention. And he's

doing very well now. And this story has been so inspirational that this thread has been going on for years, and it's still active. And the user who posted this story still comes back periodically to answer questions from other members and is really helping a lot of people by doing that. So those are the kind of members you want to have stick around. There are others, like Ed209 in the UK, very active member who struggled a lot and is now doing well and is sticking around for others. I hesitate to mention people because you forget people. But those are really the members we want to cherish.

**S3:** As time has been going on and you're interacting with these people and you're watching people come and go, you're also looking at other sources of information as we are on the Internet. And information is getting more plentiful. How do you kind of safeguard against good advice and bad advice? Do you have any methods to filter what you're seeing since you both have experience, since you both have been active and involved with this cause and with this conversation that has gone on for many years? How do you safeguard against people getting poor advice or having poor expectation?

**S4:** It's tricky. It's something that's really at the forefront of our minds that we think about a lot. And we have a strategy for dealing with this, but it will take more time and effort to roll out that strategy. But yeah, there is a risk, right, as with any Internet forum. So, we're not unique in any sense of the word. But as with any Internet forum, it's a place where people can sprout their opinions. And we can't stop people from telling other people, "If you want to cure your tinnitus, you should take this supplement," even if there's no scientific evidence that this supplement does anything. And that's actually a quite harmless example because vitamin supplements are not harmful to your health unless you take them in large quantities. But people might actually give harmful advice to others. One example is overprotecting your ears can actually be a risk. Of course, we all have to be protective of our ears, and don't go to a concert without plugs and all of that. That's sound, good advice. But if you become overprotective, it has actually been proven that that's a risk for developing, for instance, hyperacusis. So, there is such a thing as harmful advice.

It's tricky how to deal with that because what we try to do is kind of put disclaimers around the forum in terms of, "These are people's personal experience, so distinguish between someone's personal experience and their opinion and the facts or what the science tells us." But to go further than that, I think what we need to do and what we are doing is provide more fixed content, as Markku mentioned. So, the fixed content will be a balance against the opinions on the forum. And the fixed content will be factual and evidence based. So, one of the projects I've been working on for quite some time but progress has been kind of painstakingly slow because it's all volunteer-based work, right, is called the Tinnitus Guide. So, we'll have chapters on treatment, on sleep, on causes of tinnitus, on just how to make your own plan for managing, things like that. And we want to make it evidence based. We want to be clear. What does the science tell us? What are the parts that we don't have evidence yet on? Because there's a lot that the science doesn't tell us yet. So to be clear on all of that and let people make up their own minds, but give them that objective information. That's really the aim.

**S2:** Because currently, it can be a little confusing for anyone who lands on the forum. It is the truth that there are groups of people who believe in different things. One group believes that you should protect your hearing at all costs, wear ear plugs outside all the time, you should never use headphones, even low volumes. And the other group is more relaxed about that. And then there's maybe something in the middle ground, like, "Use common sense." But yeah, I mean, as a new person with tinnitus, it is a struggle to know what is the right advice. And that's why the Tinnitus Guide and the fixed content will become really important. So members can actually refer to that content, that if they see someone saying something, they can maybe link to the guide and know

it's been stated here with scientific references objectively that, "This is the case. This is what has been found. Please look at this," so.

**S3:** It strikes me when John and I come from an audiologist perspective, from a clinical perspective, and we struggle all the time in many different areas of content to be very research based and do everything according to standards of care. And it's interesting to hear how, in your application, you can also struggle. You have to filter through the bad advice, the noise, the opinion, and actually get to the research and science-based answers. And I'm glad that you guys are able to present more of that. And I hope that in the future and now, the people that participate can feel the value and the value of having things that have a basis rooted in the knowledge base and the basis rooted in the cooperation amongst researchers. So, I'm very glad you're doing that.

**S4:** Yeah. I think educating patients, it's a part of our mission. So connecting patients is one thing, that's of course the main purpose of the Tinnitus Talk forum. But then for Tinnitus Hub, part of our mission is to educate patients. And the third element is connecting the patients and researchers, right? So getting that patient data to the researchers, representing the patients voice to the researchers. And I think Markku mentioned earlier, we're in a unique position to do that because academics, if they couldn't get access to our survey data, it could take them years to gather that volume of patient data. And we can do that for them in a matter of weeks. So that's really where we can help the research field to move along. And I think it's an area where we can contribute greatly and will continue to focus on that.

**S1:** As you both first developed tinnitus and were reaching out, what do you think some of the mistakes that you made were that maybe you would do over again if you had a chance?

**S2:** Mine for sure was the monitoring part. So, if I could go back, I would not make myself block my ears and listen all the time what's the status of my tinnitus. Because, yeah, that increased anxiety levels so much and made me worried. I think if I had been able to distract myself somehow, try to get more into the daily doing rather than monitoring my tinnitus, which was quite low at the time-- well, I don't know if it would have developed to become worse over time because of that, but yeah, that's probably one of the things, one of the major things, I would have done differently.

Also, I think that for some people what I've seen on Tinnitus Talk and other communities is that if you have a personality type that is very worrying, anxiety-driven, you might make yourself actually more bothered by the tinnitus by being on these communities because you see the worst stuff all the time. If we think about how common tinnitus is, but then also how few members and the people visiting these communities overall, like on Facebook and elsewhere, we are talking about tens of thousands of members in each of these communities at most. That's a very small percentage of the whole tinnitus population. And they are the cases that have felt bad enough that they had to look for information and have to become members. And if you are new to tinnitus and it might not even be that bad, barely audible in most situations, which we have had many members with that experience, then they become obsessed in the communities. And I've read these stories where people have over time said that if they had never joined or started reading about tinnitus online or become so involved, they think they would have been able to habituate much faster.

**S4:** Yeah. It's a conundrum, right? Because we want people to feel better from taking part in the forum, not to feel worse. But for some people, it might actually be better not to take part in an online forum. And so again, we want to sort of make members aware that the people you see on the forum are, well, first of all, not a representation of the total tinnitus population, as Markku mentioned. They are there because they're suffering, mostly. There are some exceptions, but-- So

they're not a representation of the average tinnitus patient. That's important to realize when you start taking part in the forum. And the second conundrum, like Markku mentioned, is there's so many different experiences out there. There are people who are fine with their tinnitus, from people who are suffering so much that they want to take their own lives. And we've seen examples, unfortunately, of that as well.

So, there's such a range of experiences that it's really hard to cater to all those different target groups. And that is something we constantly struggle with, both in terms of forum moderation, right? When do you decide, "Okay, this discussion is really becoming too negative," or, "We have to stop this. We have to intervene"? And in terms of the fixed content stuff when we talk about patient education, again, it's such different target groups, so how do you tune your messaging to those different target groups?

**S1:** I think that's a great place to end our conversation. I want to thank you both for joining us. We've been speaking with Markku Vesala and Hazel Goedhart, both involved with Tinnitus Talk, which can be accessed at [tinnitustalk.com](http://tinnitustalk.com). And Dean and I just want to thank you both very much for taking the time and speaking with us today.

**S4:** Thank you. It was our pleasure.

**S2:** Yeah. Thank you both.

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