



## **Transcript**

# Deafness Forum Australia 'Tinnitus Unveiled' Webinar (Via Microsoft Teams)

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### **About This Document**

This document contains a transcript only.

The transcript may also contain 'inaudibles' if there were occasions when audio quality was compromised during the event.



JANE LEE: It's Tinnitus Awareness Week and so we're doing a webinar on tinnitus. We are so overwhelmed with gratitude and so pleased for so much support.

The theme for Tinnitus Awareness Week is "T for Tinnitus: Unseen, Unheard, Ignored". We hope today is a step towards making tinnitus seen, heard and not ignored.

We've got a couple of interpreters - Kirk Barnett and Georgia Knight. If you're having trouble seeing them, let us know in the chat so we can help. We also have live captioning, we'll drop instructions in the chat so that you can set that up as well, and again, let us know if you have any difficulty in the chat.

So I'm Jane Lee. I'm the National Manager of Health Programs for Deafness Forum. I'll be the moderator. I'm joined by my colleague Hayley Stone, Director Disability and Advocacy, who's helping to manage and moderate. Our CEO, Steve Williamson, is here with us today.

Feel free to drop a hello and tell us who you are in the chat. Please use the chat to engage, make comments, observations, and so on. We welcome it. All specific questions for our speakers, please drop them into the Q&A. So we are here for Deafness Forum. We are the national independent citizen body for all Australians with hearing challenges and balance disorders. Our goal is to make hearing health a priority for all Australians.

And just very quickly, we are headquartered in Canberra. We would like to acknowledge the traditional owners of this land, the Ngunnawal and Ngambri peoples. We pay our respects to Elders past and present. We recognise that many of you are coming from other countries, so we pay our respects to all Elders and First Nations people across the country. Please feel free to let us know where you are coming from. And so with that --

So I'm really pleased, everyone, to welcome Myriam Westcott. She's an audiologist and the director of DWM Audiology, a leading tinnitus and hyperacusis clinic in Melbourne, Australia. Recognised internationally, DWM Audiology specialises in tinnitus, hyperacusis, acoustic shock, tensor tympani syndrome, or TTS, and misophonia.

Myriam is dedicated to developing innovative clinical treatments and works closely with health professionals in multidisciplinary settings. She has

conducted research on hyperacusis, acoustic shock and TTS and has published work in these areas. Myriam also provides medico-legal opinions and regularly presents lectures, writes articles and gives interviews on these topics. She is on the Advisory Committee for Tinnitus Australia, now Tinnitus Awareness, supports the Tinnitus Association of Victoria and serves on a scientific committee for the International Conference on Hyperacusis and Misophonia.

So with that amazing background intro, we're really happy to have Myriam speak for us.

MYRIAM WESTCOTT: Thank you. Thank you, Jane, and welcome, everybody, and welcome to Tinnitus Awareness Week. I'm going to give an overview on tinnitus and talk a little bit about what I might be doing during a consultation.

I'd like to, I suppose, start off with some facts about tinnitus. Tinnitus is a very common phenomenon. It's widespread. In most cases it's a subjective condition, a neurological phenomenon is probably the best way to describe it, and it is most commonly triggered by a change of hearing or the development of a hearing loss.

I like to make the point that it is a naturally occurring phenomenon. It doesn't mean there is anything wrong with the brain. The brain is designed to receive sound and I will talk a little bit about what that might mean in terms of our sense of hearing and the way our hearing, I suppose our peripheral hearing system, the ear, has evolved and the brain doesn't like being in the absence of sound and it will produce tinnitus in almost everybody in situations of abnormal silence and in fact in Microsoft in Washington there is such an abnormally silent room that nobody can bear to be in there for more than an hour because they develop such very loud tinnitus.

So I think the first thing is to acknowledge, however, that while most people will adapt to their tinnitus, for some people the experience of tinnitus is extremely distressing and they are the people that I see in my clinic and most people by the time they come to see me will have gone through some sort of audiological work-up, they may have seen an ENT specialist, and the idea is to try to make sure that there is no treatable cause, which there rarely is.

It is almost invariably a benign condition, but it is important for people to be investigated. So for people who have developed tinnitus, the first step, ideally,

is to see an audiologist and to have a hearing assessment. The audiologist will be able to provide guidance on the need for further investigation.

An ear, nose and throat specialist may be part of that picture, particularly if the tinnitus, say, is one sided or very strongly louder in one side. We might do some - or they might recommend some investigations. But almost invariably there is no actual treatment for the tinnitus and the ear specialist will tend to see their job done - you know, if there's no treatable cause here, there's not much that can be done.

So my first what I like to do with my patients is to take some time to acknowledge the distress. People are often blind-sided by the intensity of their reaction. Apart from being so distressed, they're bewildered. They generally know it's a benign condition. So I'd like to talk a little bit about why that intense reaction might occur and I think to start off with it might be worth saying or just considering a little bit our evolutionary history.

Our sense of hearing in humans and in animals as well evolved back in the mists of time as a sense to warn of danger in the environment, to warn of predators, to keep us safe, to keep us alive and if we actually look at the ear, and I might ask that that first slide of mine comes up at this point, please - I'm not seeing it. Jane, can I ask if my slide is coming up?

HAYLEY: Sorry, Myriam, just bear with me one moment as I bring it up, but I'm just doing that at the moment.

MYRIAM: Yes.

HAYLEY: I apologise.

MYRIAM: No, no, no worries. So I'll just talk around that while we're waiting for that to occur. You will all be aware how open a system the ear is. We have no ear equivalent of being able to close our eyes if we don't want to see something. Our hearing is always on. We need to - you know, the mother of a newborn baby needs to hear her baby while she's sleeping. It's extremely important from that evolutionary perspective and still now for us to be aware of sounds in the environment.

Our hearing is precious and we need to preserve it and I won't spend too long talking about that, but that is, of course, something that's very important to do

both to prevent tinnitus occurring, but also to make sure that we retain our connection with the environment and all the things that we do to use it. I mean, hearing in terms of communication and enjoyment of music, which we all consider or relate our hearing to, is a fairly recent human evolutionary development. Don't ever forget that hearing evolved to keep us safe and the way the brain responds to sound is very much based on that and that perhaps gives us a little bit of a clue why our reaction to tinnitus can be so intense.

Now, you can see on the screen the actual ear, the organ of hearing. Sound will enter the ear canal, reach the eardrum at the end of the ear canal, cause the eardrum to vibrate. That vibration will be passed along the middle ear bones, turned into a piston movement and that creates a wave in the fluid of the inner ear and the inner ear has hair cells that will pick up that fluid movement and the hair cells will convert that wave motion into a signal that gets sent up to the brain to be processed.

So there are many things that can go wrong in the ear that can create a hearing loss. So we can have problems with sound getting from the outside to the inner ear, we can have problems occurring in the inner ear itself. The inner ear can be vulnerable to things like ototoxic situations - that might be from medicines, that might be from viruses, et cetera - which can cause damage to the inner ear and all of that affects how sound will travel up to the brain and the brain is very smart and will recognise if there has been a glitch or a change in the amount of information, auditory information, being relayed up to the brain.

Now, before we have a look at what happens in the brain, I would like to make a few other points. For people with normal hearing, our hearing is extremely sensitive. I can remember being taught as an audiology student back in the day that people with normal hearing can almost hear atoms move our hearing is so sensitive. So you can imagine how much sound is barrelling through the normal hearing ear up to the brain all the time.

So the brain also evolved the ability to receive all that auditory information and fairly obviously, if we paid attention to everything we're capable of hearing, we would be overloaded. So the brain has developed the ability to weed out important from unimportant sounds which it does below our level of conscious awareness, and we'll have a look at that in a moment, and that's where a strong reaction to tinnitus can arise.

The other point to make is that - I can't actually point at this, but you can see that sort of about halfway up your screen towards the right side there's a little sort of pink line. That is actually a muscle called the tensor tympani muscle. It's cut - oh, yes, there, yes, thank you. And it actually - for the purpose of this diagram, it's been cut, but it attaches to a little tendon across the middle ear cavity, if somebody wants to point to that - yes, up a bit, just up slightly, yes, keep going, left, left, left, left, left, yes, left, left, left, okay, keep going, keep going, up, up, up, that little tendon that's got a broken end - down a bit, down, down, down, down - no, yes, that, that, it attaches to there. Now, that muscle attaches --

MYRIAM: So that little muscle is called the tensor tympani muscle and it ultimately ends up on the jaw and it has the potential to go into spasm.

Now, what we now know from tinnitus neuroscience research is that it is not only a hearing loss or damage to the inner ear that can kick off tinnitus. There has recently been a paper published that has shown that stress alone can cause tinnitus. And we'll come back to that, but we also know that muscular movements in the head, neck and jaw can aggravate tinnitus, and I'll show you in the next slide how that can occur, but can also - in my clinical experience, muscular tension held in the jaw can kick it off.

We all hold stress in our jaw. It's part of the human condition to clench our jaw, to grind our teeth when we're stressed and we never relax that, particularly not at night, and it's very common for me to see people who have woken up with sudden tinnitus and that muscular tension is not always held evenly on each side of the jaw and that can mean that the resultant tinnitus might be stronger on one side.

So in my opinion and in my experience, it's not an uncommon trigger for tinnitus to kick off or to be aggravated and people who struggle with tinnitus will know all about tinnitus spikes. So this is a way in which stress held in the body can actually both at a muscular and neurological level add to the tinnitus experience.

This is something that is now much more widely recognised in tinnitus neuroscience so we're looking more strongly at those aspects in the tinnitus experience and for me, when I'm seeing a patient, I want to explore for each of my patients at an individual level what their pathways might be that have either started the tinnitus or are contributing to adding to the tinnitus

experience because we can treat those, you know. So while we might not be able yet to switch off the tinnitus at the site of emergence in the brain, we can look at these aggravating factors and treat them and that can reduce the intensity of the tinnitus. So as far as I'm concerned, for all my patients I want to know and I spend quite some time exploring with them just exactly what their pathways might be and a diagram will show - we will come to a slide that will show that more clearly.

The other point I'll mention is that that particular tensor tympani muscle can go into spasm and that can create an additional layer to the tinnitus, often with a rhythmic quality or a vibrational quality. It can create other symptoms in the ear as well and the most common one being a sensation of blockage in the ear. So I always ask my patients, "Since you developed tinnitus, do your ears feel different?"

Now, this phenomenon of tensor tympani syndrome or spasming of that muscle is not going to cause harm, but it's not visible and the symptoms are subjective. So people will experience these symptoms, go to an ENT specialist or a doctor and the doctor doesn't see anything wrong, but they're very noticeable these symptoms and they cause a lot of anxiety. So one of the things that I like to do is to make sure that people understand, if I think they've got tensor tympani syndrome symptoms, that that is something that they do, you know, have a clear understanding of so that they don't get anxious that maybe there's something wrong that somebody hasn't been able to identify. So I see this quite commonly in my patients when I first came across this concept. I was in fact deeply shocked by how common this actually is.

So if we could move to the next slide, please. You should have now two heads on your screen. It's a very simple diagram, but it's one that I like to use to show my patients.

So on the left we have a head, you can see the ears down the bottom, and then in the middle of the head you can see a series of dots. Those dots represent the parts of the brain involved in processing sound. We only, however, become consciously aware of a sound when the sound gets to the end point, the cortex in the brain, but you can see there's a lot of work going on in the brain on the way up there.

Now, those little yellow dots down the bottom of the head are the parts of the brain where tinnitus is considered to emerge. That is the first step in the brain where the brain is starting to process sound. That is actually a very primitive part of the brain. If you look on the right, that purple shaded area is called the brainstem, that spot is in the brainstem, and that part of the brain is very smart at detecting if there has been a change of hearing or the development of a hearing loss.

Now, I should point out that for many people a hearing loss is a gradual and insidiously developing phenomenon, usually or commonly affecting the high frequencies only. Sorry, there was a message there that I missed. Okay. So it's very common for people being investigated for tinnitus

MYRIAM: Okay. So the point I wanted to make is that for a lot of people when they have an investigation for tinnitus, they might receive the - they might discover that they have a hearing loss that they were not aware of and that can cause a lot of concern and anxiety, but I would just like to reassure people that amongst audiologists we all see every day people coming into the clinic quite shocked at having a hearing loss identified. It is very common for hearing loss not to be noticed because it does develop so very gradually and it often just affects the high frequencies only. So please be aware of that, that there may be an underlying hearing loss that is causing the tinnitus and that may not necessarily be something that you have noticed.

So going back to those little yellow dots in the head, on the left head there on the screen, that is considered to be the site of emergence of the tinnitus. That also happens to be - and as I said before, that part of the brain is pretty smart at recognising if there has been a reduced amount of auditory information coming from the ears because a hearing loss has developed and that hearing loss may be temporary or permanent. So the brain there will neurologically compensate for that and that will stir up that naturally occurring phenomenon of tinnitus.

That also happens to be the part of the brain that will process head, neck and jaw muscle movements and as I was saying before, we now know that that can directly influence the emergence and/or the aggravation of tinnitus at that point. So that is why we're looking also much more closely at those muscular pathways and that is behind some of the bimodal treatment approaches trying to target that part of the brain.



So once the tinnitus has emerged there, the tinnitus is being processed along with every other external sound in those other spots in the brain. Now, those parts of the brain that are largely responsible for processing sounds, internal tinnitus and external sounds, have very strong links with the primitive parts of the brain that are processing our emotions, our anxieties, our sense of threat and we also know that the cerebellum, which is on the right marked as the reptilian brain, gets a look in as well and all that processing occurs below our level of conscious awareness and therefore conscious control. I could give examples about that, but in the interests of time, I'll move on now to the next slide.

Now, this is a slide taken from the Jastreboff neurophysiological model and tinnitus retraining therapy which I have expanded considerably to take into account perhaps a more psychological approach and also the pathways that I was mentioning. So let me take you through it because with every one of my patients I want them to know what exactly is going on for them as far as their tinnitus reaction is concerned.

So we've got sounds barrelling through the ear up to the brain. I showed you the spot where the tinnitus emerges and how that can be influenced by muscle tension in the jaw, which can also kick off tensor tympani syndrome and that is also being processed in the brain and can aggravate or cause tinnitus. The tinnitus is detected subconsciously and evaluated in terms of its importance to us. Only the important sounds will be sent to the conscious brain.

So this filtering process occurs below our level of awareness. We don't have control over that. Forget any rational thinking. What influences the decision about which sounds are important enough to send to the conscious brain is determined by the limbic system and cerebellum structures where we're processing our emotions. Those structures are dedicated to keeping us safe in the environment and managing our internal wellbeing. So if the tinnitus is judged as a disrupter to our wellbeing, a threat to our wellbeing, a threat to our coping ability, it's really important and the brain will highlight it in prominence, give it a bump up of volume and send it to the conscious brain.

Now, we only know consciously what's going on in that top box, but you've got all this stuff bubbling away underneath, and remember hearing is a survival sense, so the emotions that can be stirred up with a strong reaction to tinnitus can be very intense and this pathway, I think, or these pathways are really important for people to understand.

Now, we're not locked into this. We can retrain the brain. We can treat some of these pathways. When it comes to stress, it's a two-way process. Tinnitus causes stress, anxiety, depression. People who are already stressed or anxious or depressed will struggle more to cope with their tinnitus.

So it is a two-way process and I work with a team, I have a physiotherapist who absolutely gets the whole muscular side of things. I work with psychologists who understand this diagram and I will spend quite a bit of time evaluating my patients in terms of what sort of onward referrals I might need to make, but I do find I spend a lot of time evaluating my patients in terms of how this diagram applies to them and that is really reassuring and the actual strategies for management then make a lot more sense. What we're wanting to do is to make sure that people aren't scared of the emotions being thrown up by the subconscious brain but equally are not scaring the subconscious brain through having an incorrect understanding of just really what is going on.

So this to me has over my 30-odd years working with people become more and more pivotal in my consultations. Once people understand this, in my experience most people can self-manage a habituation process and habituation means that when the tinnitus is detected subconsciously, it is judged as a boring sound.

Now, even people who are really distressed by their tinnitus can quite often be aware that there might be moments when they didn't notice it. If they're very distracted, they're doing something they really like, the tinnitus may not be being sent up to the conscious brain. So the subconscious brain then knows it is safe not to always send the tinnitus up to the conscious brain and that is a really good starting point. We want those moments to become hours and all reputable tinnitus therapy is about how to promote that.

But the other point I should make too is that a sound that is judged as unimportant is accessible to us if we listen for it. We can pull it into the conscious brain and if we listen for it with a mindset of I hate that sound, we're telling the subconscious brain it's a really important sound. So it's really important, (a), not to be monitoring the tinnitus or actively listening for it, but to use distraction strategies, not to see that as avoidance behaviour but as management behaviour and to watch how the mindset might be influencing the subconscious brain's evaluation of the tinnitus.

I often say to my patients your subconscious brain is like another person in the room here. You can't tell it what to think. It will certainly tell you when it's scared. But equally, you can scare it through an incorrect understanding of what tinnitus actually is.

I'm noticing that people aren't always catching the slide. We can make it available to people after this appointment, these slides that I've used today.

So the other strategy is to use sound enrichment. So we use distraction strategies, stress management, making sure people have an accurate understanding, and we use sound. So we know that if people are in silence, as I was saying before, they're going to notice their tinnitus, so filling in the silence with a low-volume sound is really important. We're not aiming to mask the tinnitus, although if the tinnitus is covered up or masked by the sounds of the day, that's fine. That is a coping strategy. Masking doesn't assist habituation. What we want is to fill in the silence with a low-volume, neutral sound that takes the edge off the tinnitus and what that does, it's not really an auditory strategy so much. It helps the subconscious brain feel safer in the presence of tinnitus. It's all about threat, in my view.

I could talk about the management strategies in more detail, but I have actually talked quite a lot now. How about I stop for a bit and let somebody else have something to say.

JANE: Great. Thank you so much, Myriam, for everything, for your presentation. If you have any questions for Myriam, please drop them in the Q&A and we will talk about questions a little bit later.

So we have a surprise today. This speaker wasn't originally advertised, but at the last minute we're really happy to have him join us. So Ben Hoddinott is a highly experienced clinical audiologist with over 20 years of experience in complex hearing cases. After graduating from the University of Queensland's Masters of Audiology Studies, he's worked alongside some of the leading ear, nose, throat specialists and his effective career includes multiple roles in neurosensory, including regional manager, clinical services manager and after a stint away, he returned as Chief Operating Officer. During his time as CEO, he led the company to become the largest independent audiology provider in Australia.

His experience also includes working as a clinical specialist for Cochlear in Victoria, Tasmania and New Zealand. One of the highlights of Ben's career was working with the world-renowned Cochlear Implant Program at the Royal Victorian Eye and Ear Hospital, which further just solidifies his commitment to advancing hearing care.

In 2022, Ben and his wife, Jess, took a bold step. They opened their own independent clinic, The Little Hearing Co, in Brisbane, where they are raising the bar for hearing care and improved access to expert services in their local community. Ben is a proud father of two young boys. He enjoys playing music, cooking and sports like cricket and soccer. Please join me in welcoming Ben. We're really happy to have him here today. Thank you.

**BEN HODDINOTT:** Thank you, Jane. I look really red on the video. I assure you I'm not usually this red, or at least I hope I'm not that red because I might need to get my blood pressure checked.

Myriam's presentation was fantastic in terms of covering off on how tinnitus occurs and those underlying mechanisms and due to a little bit of confusion, that was what I was sort of going to cover off on. Fortunately, I do have another presentation handy, and I'll try to share my screen and hopefully we can get that working properly, which talks a little bit more through some cases of tinnitus and how we've managed those.

Are we about to change interpreter? Let me just get that one up. Okay. So can we see that screen there and I've tried to turn the captioning on on the presentation, but I've lost the video, so let me just confirm that that's all gone through okay. You can see that presentation when we've got that live? Alright. Let's kick that off. So this neurophysiological - oh, Cathy says, "No, we can't see the presentation."

**HAYLEY:** Yes, that's correct, we can't see it at the moment, Ben.

**MYRIAM:** No, I'm not seeing it either, Ben.

**BEN:** Okay, okay, let me just try that again.

**MYRIAM:** That's it.

BEN: Okay, so we can see it now. Let's see if we can get that going and we can see - the captions coming up at the top of the screen might be a bit small, but hopefully we can see that and the presentation.

So this was a simplified diagram of what Myriam was discussing with that neurophysiological model of tinnitus and basically there is often a change in what we're hearing. I noticed a comment in there about tinnitus arising following COVID vaccines and there may have been a change in your hearing through that period, but that highlights the role of stress and that hypervigilant state. If we're concerned about this vaccine giving us tinnitus because we've heard of other people having it, we will listen harder and we will hear that. Then we move to detecting it and perceiving it as a threat and so if we say that sound is potentially because of that vaccine, then we're inclined to focus on it, to monitor it to keep us safe and the more we listen for it, the more we hear it, so the worse we believe it's getting, so the more we listen for it and that is the cycle that often leads to quite disturbing tinnitus.

If we go to some of the different websites from hearing clinics, often they'll list loud noises, gunshots, things like that, as causes of tinnitus and while those things may cause a temporary shift in your hearing, or in rare cases a permanent shift in your hearing, it's the brain's awareness of a slight change in how much sound is coming in that then gets us to hear this internal noise and in the vast majority of cases it's a safe and completely normal reaction to noticing that little change.

So this is a case of a 59-year-old lady who came to see me and she had 20 years of hearing loss because of perforated eardrums and she hadn't been bothered by tinnitus for too long. She'd been fitted with some hearing aids and that helped for a while, but increasingly she'd been noticing more and more disturbing tinnitus over the last 12 months. She'd seen her hearing aid clinician and they'd adjusted it multiple times and she'd been back every few weeks, but the tinnitus just seemed to be getting worse and worse for her.

This is from a clinical presentation, but those were the big holes in her eardrum, so you can see there, and this is her hearing test. So for the people on the call who aren't familiar with this, we'll quickly run through. The red circles are the right ear, the blue crosses are the left and the further down the page we go, the more volume she needed in order to hear those different pitches. So her tinnitus was roughly matched to this big T in terms of its volume and its pitch and it was predominantly in that left ear where the

hearing was poorer. So she was hearing less outside sound and because of that, she was listening harder and she was noticing this noise.

At the same time, she was struggling with her hearing and she was stressed about the hearing difficulties she was having and so she associated the tinnitus with being a sign of those hearing difficulties that she was having socially and emotionally. It was impacting on her work and the more she wore her hearing aids, the more her ears got infected and discharged.

So for this particular lady, the hearing aids themselves were helping her to hear, but they weren't giving her enough sound and enough ease of listening and when we throw in the fact that if she wore the hearing aids for long term then her ears would block up and get infected and so there's two reasons there why she would be hypervigilant, on the lookout, what's going on with my ears? No one likes - she works as a massage therapist, so no one likes being close up to another person if their ear is leaking.

So we used a tool called the Tinnitus Functional Index and if you have disturbing tinnitus, there's a lot of good questionnaires out there that the clinicians should use some form of questionnaire to assess how this tinnitus is impacting upon you and this questionnaire breaks it down into different sorts of impacts. So for her the fact that she felt she had no control over the tinnitus was really upsetting her. She couldn't relax. Her quiet times of trying to relax were really impacted and the hearing impacts were quite significant as well.

Using this tool for other people, sometimes it will show that they have great sleep disturbance or big trouble in terms of their ability to think clearly and so by understanding that breakdown, we're able to target the therapies more specifically than just plonking some hearing aids on and crossing our fingers. So we were fortunate that we could use a specialist device called a bone conduction implant with this lady to give her back a good degree of hearing, not block her ears up so she was less concerned about the discharge with her ears, and reduce her overall listening effort.

So we'll skip through. We were able to just pop it on the headband like this and do a trial and over the trial she noticed a significant reduction in her listening effort, but also in her tinnitus disturbance. So for her it was all about trying to reduce that effortful listening and the distress she was feeling around being disconnected.

Her tinnitus results improved significantly one month after activation. She was reporting better hearing, no issues with comfort, she was playing pickle ball again, noticing more detail with her hearing and we saw that each of these measures - we've got the dark blue for her preoperative result and postop in the orange, in a lot of those higher bars it came down following the treatment. So for her - we've still got a way to go one month after, that relaxation, we need to work on how she's handling that, making sure she's still doing the things that relax her, but for her we found a great benefit by looking at how we were providing that auditory stimulation.

We'll just stick on her for a moment. This lady comes back in to see me from time to time and it's when her tinnitus is worse and we talk about it and I don't program her processor, deliberately I don't go straight for programming it, because as Myriam was alluding to, her understanding of how her body is reacting is key. So when she comes in, she says, "I've had such a stressful week, my tinnitus is really bad" and we talk about why the week was stressful and we talk about why the stress was making her tinnitus worse and I don't touch the settings. Then she goes away and she lets me know, "Okay, yeah, my tinnitus was back under control over this last week."

So she's still in that learning phase. She needs that hand holding to encourage her to think about the mechanisms, how stress is playing into her tinnitus awareness, but if I were to jump in and try to use the device to fix her tinnitus every time she came to the clinic, I'd be doing her a disservice because it's not just about auditory stimulation, it's about the reaction to that sound and that's what we're addressing in her case.

So we'll get out of that little presentation and I'll jump back into this one.

HAYLEY: Ben, just while you're paused, can I just check that people have the visual of Kirk, the interpreter. We've had a couple of people say that he's spotlighted, but there is no visual for him. Okay, we're having some people saying that there's no visual. I will look into how to do that. Okay, thank you, Ben.

BEN: No, that's alright. This is just a quick sort of run through of that same model that Myriam touched on and understanding that model is a really important step that we take and, you know, great to hear that we're on the same page with that education side. We see a lot of people, particularly



veterans, coming through the clinic where the stories they've heard about people with tinnitus are quite pervasive and nearly every veteran you speak to will have some tinnitus and they'll have a story about how bad it was for X, Y, Z.

So for those people, one of the first things we start with is trying to dispel some of the myths around what's going on. Often they will have a degree of hearing loss because of that noise exposure. You know, they might have been a firearms expert or an explosives expert and they've banged their ears up pretty badly. But when they understand that, first of all, there is a sound in everyone's auditory system and, you know, the room in Washington that Myriam spoke about or any really quiet room, if we go into those rooms and get people to listen to their ears, they will hear a noise. There's a very, very small percentage of people who won't. So our brain misses having sound and it listens harder and it hears this buzzing, which is our internal noise. It's a safe sound. But when we label it as being a threat, then we're inclined to focus upon it and uncertainty around what causes it increases that threat level.

If we think about a few generations back when we were living in caves and, you know, you'd go out with dad hunting and you'd hear a rustle in the bushes and that could be dinner and so that rustling sound in the bushes would be a positive sound. That's a sound that could mean food. So we listen for that in a positive way.

The next day there's a rustling sound in the bushes, a sabre tooth tiger jumps out and kills dad and all of a sudden that rustling sound has a completely different meaning. That rustling sound is now a threat. So when I go out the next day, or maybe a few days later after mourning the tragic loss of my father, I'm going to be on edge because that sound could be a threat to my existence and threats are right up the top of our hierarchy.

Another example of that is when you go to a friend's house and they live near a train line or a freeway and you say, "Jeez, it's noisy" and they say, "I don't really notice it." So when you go there, you label that sound as a bad sound, think how would I cope here? But when you live there and it just becomes part of your background noise, gradually your brain tells you it's not a threat and it starts to file that sound away into the background. If we can do that with the sound of the freeway and the sound of the train line or the fridge noise, then there's no reason we can't do that with someone's tinnitus, which is another constant sound that we can potentially turn into a meaningless



sound and we do that through education and we do that through providing a degree of control over the sound.

So I'm mindful of time and I might just pause there. Jane, did you want to hand over to Victoria at this point?

JANE: Yes. So I'm going to - thank you so much, Ben, for that. So right now I'm going to introduce Victoria. So she's last, but not least. I'm really pleased to introduce her. It's so lovely to have her here with us today.

Victoria has been living with tinnitus for 11 years. She's based in Melbourne. She's a proud mother of two adult sons. She has a background in acting and voiceover work. She enjoys staying active through swimming and hiking and recently began writing short stories and singing in a local choir.

As a passionate advocate, Victoria helped establish tinnitus awareness and has launched several campaigns to raise awareness (inaudible) by those living with tinnitus. So I'm really pleased to welcome Victoria to talk a little bit about her story with tinnitus. Thank you.

VICTORIA DIDENKO: Thank you so much, Jane, and thank you, Deafness Forum. It's been 11 years since I've had tinnitus and it's been one hell of a roller-coaster of a ride. I aim today to inspire some hope and positivity in those of us who struggle with this auditory torment.

Now, before I start, I think it's really important to say that not everybody who has hearing loss has tinnitus and not everybody with tinnitus suffers the trauma that goes along with tinnitus for some. Millions of people suffer ringing ears, but they seem to habituate really quickly and that's wonderful, but what I've found is that for people who struggle, like myself and millions of others, that's not the case and it impacted me so negatively and I really want to make a difference for myself and other people who are struggling to get the help they need.

So 11 years ago tinnitus landed in my brain, or my ears, and I really struggled. I don't know the cause of my tinnitus. I did have a fall whilst walking my dog. I'd arrived at middle age and I had attended some very noisy social gatherings. It could have been one of the above, all of the above or none of the above. So little is known about the tinnitus symptom. There's scant research being done. We need more funding for research.

The first days, weeks and months of my tinnitus onset were the darkest and most challenging times of my life. I don't take great pleasure in recounting publicly these intimate and traumatic experiences. I was at my most vulnerable and suffering great distress, yet I feel compelled to share my story with you today so that hopefully in the future no one has to go through the confusing, rocky road of a journey I travelled to eventually find the information, support and counselling required to get me back on track. I live a full life, the good, the bad, the ugly, the happy and the sad, with ringing ears.

Now, even though this is my unique and individual story, when I've listened and been privy to other people's stories about their tinnitus experiences, it's as if we've all been given the same script and this is usually how the story goes. All is well and then one day we notice a strange buzz or ringing in our heads. We hope it will go away. We wait and when it doesn't disappear, when it starts to get really annoying, we go to our GP.

Usually we're then advised to see an ear, nose and throat surgeon to have an MRI to rule out anything sinister causing the ringing, such as an acoustic neuroma or tumour. When a clear MRI is returned, we might then be directed to an audiologist to have our hearing checked. If there's hearing loss, we might be recommended to use a hearing device to address the hearing loss and to minimise the sounds of tinnitus.

Hearing aids work by amplifying the volume of ambient sounds, therefore making the tinnitus less noticeable. I love my hearing aids. They really helped a lot. I don't love how much money they cost me. That's another story for another time. So at this stage the tinnitus patient may be out of pocket from anywhere up to \$2,000 to \$15,000, depending on whether or not we purchased hearing aids and how much we paid for them.

This diagnostic process can take weeks and months, yet all the while the person in crisis with their tinnitus is walking a fine line. They're often being pushed to their very limits emotionally because the tinnitus continues to torment and remains unresolved. I was told to ignore the tinnitus, that it would get better over time and that I would eventually stop hearing it. What I wasn't told was how to do this. I was told I would cope. Other people do.

I didn't quite like the idea of having to cope with life. I wanted to live life, not just cope with it. I felt like I was the first person in the world ever to have

been struggling with tinnitus. I wasn't doing well. Now, I'm a robust person physically and emotionally and this new me, this falling apart me, was an unfamiliar and disappointing stranger.

Now, is there an elephant in the room here? Is there anyone? I think there is. "Get a grip, tinnitus patient who isn't coping. Put things into perspective. There are people worse off than you. Other people with tinnitus cope. Why can't you?" I wonder if anyone in the webinar who is a tinnitus sufferer has felt that. Doctors, friends, family, work colleagues and acquaintances might not necessarily say these exact words, but I get a strong feeling that it's what they're thinking sometimes. "Are you still banging on about your tinnitus, Victoria? Get over it. Other people do. It won't kill you. There are worse things you could be suffering."

My tinnitus sounds were closing in on me, wearing me down and I had nowhere to go to escape the sound because I was the sound. I was grieving the loss of me and the loss of silence. Tinnitus sufferers start to keep their tinnitus trauma to themselves because their doctors have told them not to talk about it, and I get that. The idea is that talking about our tinnitus draws our attention to it.

Now, the aim is not to focus on the tinnitus so it becomes something unimportant, like Rob and Myriam have said, and of little interest to us and our brain. It's boring, we're not listening to it anymore. Now, this should, in theory, stop us from hearing it, or at least minimise the tinnitus static so it becomes more like a background noise, but what if the tinnitus is so loud and all consuming that we're unable to switch off? What if we can't ignore it, what then?

And then there's the question is everybody's tinnitus the same? Are there louder and more chronic levels of tinnitus for some and not others? Do the people who habituate quickly and more easily to their tinnitus, do they have quieter, more mild head noise than those who suffer? We need objective measures to gauge exactly what it is people are hearing. There is so much work to be done. I know the Bionics Institute is doing a lot of research in this area of measuring tinnitus in the brain.

I think a lot of people also experience feelings of failure and shame for not being able to cope or manage with their tinnitus. For some reason, there's a huge stigma attached to hearing loss and tinnitus. There doesn't seem to be

the same stigma in having poor eyesight and putting big colourful or clear plastic glasses across our eyes, whereas having an invisible symptom, such as tinnitus or hearing loss, seems to go hand in hand with embarrassment. The stigma of the big brown Bakelite hearing contraption we used to use as a hearing aid of the past still lingers.

People are keeping their suffering to themselves. I understand it. We don't want to be seen as miserable or a burden on our families or the community. We want to be stoic, brave and be seen to be managing and isn't that what the doctor recommended in the first place to us, not to talk about it?

I can't think of any other medical conditioning where the advice from the medical profession, such as don't focus on the tinnitus and don't talk about it, has morphed into don't talk about the suffering you're experiencing due to your tinnitus. If you are suffering, then you need to go to a doctor and/or audiologist to get help. Talk and talk and talk constructively and with professional guidance until you find ways to manage your tinnitus and eliminate the suffering. Doctors want to help the tinnitus patient in crisis, but how can they if they're unable to write a prescription for a pill to take the tinnitus away?

If an ear, nose and throat surgeon can't operate the tinnitus away, what more can they do? If a dentist, physiotherapist, chiropractor, hypnotherapist, cranial sacral therapist dentist, naturopath can't help us, where does it leave us, and I've seen them all, believe you me. It leaves us with the internet and boy oh boy can you find lots of tinnitus cures on offer on the internet and usually for lots and lots of money too. Quackery is rife for people looking to relieve their tinnitus.

And who or what medical body is championing the call to the tinnitus sufferer? I'm sure all medical and allied health professionals throw their hands up in despair when someone walks into their surgery in crisis with tinnitus. We all want a remedy for the ringing, the medicals and the sufferers, but what's being done? What to do and where to go?

Now, has anyone heard the saying when the going gets tough the tough go shopping? Well, that's exactly what I did. I went shopping, shopping for a new GP. Yes, you can shop around for a doctor who is better suited to your personality, nature and health problem. A trusted and empathetic GP is worth their weight in gold, as is a trusted and person-centred caring audiologist.

I wasn't sleeping and I was feeling depressed, I was unable to relax because of the tinnitus. It was always with me. I couldn't escape it. There was nowhere for me to go. I was the noise. I felt like I'd become a vessel of noise and nothing else, that I'd lost myself to the tinnitus.

My first doctor gave me a script for antidepressants and sleeping tablets. So when I filled the script, a bit begrudgingly because I don't like taking drugs other than a Panadol occasionally, I read on the side of the packages that taking those medications could possibly trigger or heighten feelings of anxiety and depression. Goodness gracious, I thought. I already felt more anxious and depressed. I didn't want to risk feeling worse, so I didn't take them.

My new GP sat with me for more than 15 minutes, she asked questions and was genuinely engaged. She suggested I see a counsellor or a therapist. Well, what a task that was then - where to go, what therapist, where do I find this list of all these amazing people, where do I find Myriam?

So in my quest for a tinnitus counsellor, I realised that there does need to be more therapists trained specifically - oh, gosh, it's the tinnitus - specifically in tinnitus, trauma. Can you please clone yourself, Myriam?

Trolling the internet yet again, I did find one. She worked at Soundfair and she was wonderful. I was fitted with hearing aids. I was given time. I was introduced to sound therapy. I cut down on caffeine and alcohol. I drank more water. Whether or not that helps, psychologically I knew I was doing something constructive to make my tinnitus better and make me feel better with my tinnitus. I took up swimming, singing and hiking, and started feeling more mentally robust.

I became a member of Soundfair, a not-for-profit hearing association in Melbourne, and together we launched a successful tinnitus campaign, My Ear Rings for Peace, with a well-known Australian jewellery designer and this year we're doing a campaign See my T to help raise awareness of tinnitus the symptom and have more people see it because it's invisible.

Today I can now sit quietly in a room and read a book, I attend concerts and theatre, and I always carry earplugs with me. I'm sleeping better. I no longer use a sound machine, but when I did, my favourite sounds were, wait for it,

bird song with didgeridoo whilst there was water running and a violin playing - yes, all at the same time. I found it.

I do continue to find flying challenging. My tinnitus competes with the sounds of the internal aircraft cabin noise and can be particularly traumatic.

Hairdryers - hairdressers are so noisy, so when I'm having my hair cut and blown, I stuff cotton wool into my ears and it really helps. It helps me to protect my ears, so protection and prevention, protect to prevent hearing loss and tinnitus.

It hasn't been easy to stay solid, balanced and maintain robust mental health when one's ears are ringing, but I do have my ups and downs, so overall, I'm finding more joy in life than not. We have to make peace with our ringing, thumping, whooshing head noise. We have to lean into it, embrace it and see it as natural and as a new element of who we are. But if you are suffering, please don't feel you must suffer in silence, don't keep your suffering to yourself. Speak to a friend, go and see your GP, take your phone with you and share the tinnitus websites and educate your GP at the same time. That's what I did with mine and she was very appreciative. She learned a lot. I think they may only do half a day or one hour in medical training at medical school learning about the ear.

So thank you, Deafness Forum, today for giving me the opportunity to speak about my lived tinnitus experience. I hope it's helped someone out there in the webinar, in the audience, and it's time to make hearing health a national health priority in good heart, but with ringing ears. Thank you.

JANE: Thank you so much, Victoria. So I'm mindful of time, but we will go through some questions, so I'm looking at some of the questions.

MYRIAM: I've made a few notes from some of the questions that have come up. Thank you, Victoria. It's such an eloquent explanation and sharing your journey.

I would just like to dive straight in and say something about somebody asked a question about the different tinnitus sounds. Tinnitus can be a single sound. It can be a range of sounds. It can be tonal. It can be a hiss. It can be a rhythmic sound. It can have a vibrational quality. The pitch of it often matches the pitch of the hearing loss.

We do not know yet why some people will have a tonal tinnitus and some people will have a ring and some people will have a hiss. That's one of the things that neuroscience has yet to give us an answer for. But the collective word tinnitus means any sound that you can hear internally that is not present externally. So I hope I've answered the question of somebody who did raise that particular issue.

The other thing that came out is that people worry about why they might have developed a hearing loss. Of course we need to be careful to protect our hearing in very noisy situations, but the age-related hearing loss is very common. There is a word for it. It's called presbycusis. The way I explain it to my patients is to say that the inner ear is particularly vulnerable at the treble end, the high-frequency end, to wear and tear of life, but there's also a strong genetic aspect to this. So we are all vulnerable to losing some high-frequency hearing as we get older. How much we lose and the age at which we lose it often runs in families, but it does tend to stabilise at some point and it's not always obvious. So it may not be that obvious in one's parents or relatives, but there is a strong genetic aspect to an acquired hearing loss. My point is don't feel that you have caused your hearing loss and thereby may have caused your tinnitus.

The other thing is that people sometimes feel that their tinnitus is causing them to have hearing problems. That's not the case. If the hearing problems are there with the tinnitus, it's because there's a hearing loss. So if anything, the hearing loss causes the tinnitus rather than the tinnitus causing the hearing loss. So I hope that's answered a few questions.

JANE: Thanks. Myriam, there's a question - and Ben as well, there's a question about gut health and tension related to emotional response and tinnitus. Is there a link between the gut and the brain with tinnitus?

MYRIAM: Oh, well, there's never a short answer, is there, Ben?

BEN: I think - and there's a question posted by Hayley here as well about using apps to monitor the tinnitus. It's important that we rule out any medical causes underlying the tinnitus, but often patients and sufferers can go a bit too far in trying to analyse the tinnitus and remembering one of the keys to habituation is the relabelling of that sound as being unimportant. So if we go down every single little rabbit hole that comes up, we're going to be increasingly labelling that sound as being important.



So gut health - there may be a trigger. How about we get your gut as healthy as possible. That's positive for your general health. Whether it is a specific relation, we're not going to be able to show that and we have to accept that.

MYRIAM: There's of course the underlying common factor is stress. You know, I think it would be reasonable to say we hold stress in our body, we hold stress in our gut, we hold stress in our body musculature. A lot of psychological therapies and treatments are targeting the effect of stress in the musculature. Treatments for trauma, like EMDR and neural tapping, are looking into all of that. So I think that we have to consider and my view is as health professionals, we have to see our patients holistically and see the relationships there. You know, we can't just look at the ears. We have to go a bit broader.

JANE: Thank you. The question here, "My son sent me a link about using Propranolol for misophonia. I don't know there's been any studies yet, but there's a report of one person in Amsterdam using it to bring their misophonia scale down from 15 to 2, maybe a theory bringing down his baseline heart rate where his reaction to triggers stays lower. Does this sound like something worth trying for misophonia or maybe even tinnitus sufferers?"

MYRIAM: As a misophonia clinician as well, most definitely there is a stress association with misophonia, so what is underpinning misophonia, misophonia is an aversive reaction to very specific trigger sounds and you can almost see a parallel with misophonia and tinnitus. The trigger sounds in misophonia are external and often, but not necessarily made by other people, whereas the tinnitus trig is an internal trigger sound, but the reaction is the same.

What I suppose makes misophonia unique is that it is typified by an involuntary, and I say this entirely without judgment, but disproportionate immediate anger and because of that, it is put in a separate category of its own and at its most severe it is a disorder because it affects how people function in their auditory environment in terms of their vulnerability towards trigger sound exposure. But yes, there is definitely a stress link, but we need to look more deeply at those pathways and I have a version of the diagram I showed you which is specifically for my misophonia patients.

So there are parallels. Again, it's important to understand what might be the factors that cause misophonia to develop and misophonia needs to be



separated from hyperacusis. So misophonia is an aversive reaction - I hate that sound, I don't want it in my space, intruding into my space. Hyperacusis is more of a threat-based response - I'm frightened that sound will harm me in some way, will make my tinnitus worse, will affect my hearing, will damage my ears - and they are, in my view, quite separate conditions.

So it's not uncommon for people who have a strong reaction to tinnitus to actually become very anxious about anything that could make their tinnitus worse and as I think came up in your talk, Ben, the subconscious brain is very keen to look for associations in terms of what may have stirred up the tinnitus and that can very readily extend to external sounds and all sorts of other factors as well.

As I said, and as you said too, Ben, it is about threat and we're talking about primeval threat, you know, intense threat. So these are powerful emotions and we know that placebo is very common with tinnitus so-called treatments. If you believe something will work, well, it will have an effect, a beneficial effect, and the flip side of that is something called nocebo. If you believe something will harm you, well, it will aggravate your tinnitus. So the power of belief is huge.

When it comes to tinnitus treatments or interventions, then we need to be very careful with the research to make sure that we have eliminated the possibility of placebo bias in the analysis and a lot of treatment approaches - I mean, there's some absolute quackery out there, as somebody has rightly pointed out, but even the treatments that may offer some real benefit and the neuromodulation treatments, the bimodal stimulation, are looking to provide stimulation to that site of the tinnitus emergence in the brain and do offer some potential, but we need to make sure they are properly researched with double-blinded control studies and that's not always done. So I look at these things with a tooth comb before I would recommend them to my patients to make sure that the benefits that are promoted are not placebo.

JANE: Alright. Thank you. So I'm conscious that we're running short on time. I want to thank our speakers, all of you today, The Captioning Studio and Echo Interpreting. Please feel free to leave us feedback in the chat, the good, the bad and the ugly. We will try to do better, we promise. To all of the speakers, do each of you want to say one last final - what's one last final takeaway each of you would like to say, so Victoria first.

VICTORIA: More funding for tinnitus research and hearing health in Australia.

JANE: Thank you, and Ben?

BEN: On the spot, but I think it's that understanding what is going on and seeking education from experts in the field is such an important part of tinnitus, rather than a device or a pill that's going to help it. So find someone who knows what they're talking about and talk to them.

JANE: Thank you, and Myriam?

MYRIAM: Oh, have hope. Even if you are very distressed by your tinnitus and struggle to cope with it, you're not locked in there, and I agree with Ben that looking for a cure or a device is not ideal. I think we have to look at it much more holistically and I think that what Victoria has shown is that people do need to participate in an interactive way with their clinician, a trusted clinician, to achieve an outcome. I mean, it's relying on the neuroscientists to fix and cure a problem that to me reflects an outdated approach to medicine. We all have to participate in our recovery process. So have hope. You're not locked in. There is help out there and your suffering is heard. You are being heard and being seen.

JANE: Thank you, and thank you so much again for everyone. Thank you for taking time out of your day with us. We're sorry for the technical issues. Again, we will work through and be better. Please give us your feedback. We want to do more of these for everyone. So thank you all. Thank you so much.

MYRIAM: Bye bye.