TINNITUS TALK
PODCAST
EPISODE 4

TINNITUS MANAGEMENT: WHO CARES?

Richard Tyler, PhD

00:00 – Introducing Richard Tyler

Sean: Hello everyone, and welcome to the **Tinnitus Talk Podcast.** Today I have a very special guest with me, **Dr Richard Tyler,** from the **University of Iowa.** Thank you for joining us today, Richard.

Dr. Tyler: Glad to be here.

Sean: So, we have a lot of questions to get through. We have a lot of things to talk about but before we jump into that I want to get everyone to be on the same page as to who you are, and what you do and what goes on where you're working. So, could you give everyone a general background about yourself?

Dr Tyler: I was trained as an audiologist at **The University of Western Ontario** and then came to Iowa to do a **PhD in Psychoacoustics.** My first job was in the United Kingdom. I worked at **The Institute of Hearing Research** and eventually decided to come back to Iowa and joined **The Programme of Communication Sciences and Disorders and the Department of Otolaryngology** and I've been here for many years doing work on cochlear implants and on tinnitus and seeing tinnitus patients on a regular basis, and I'm enjoying myself.

Sean: So, it seems like you've pretty much been in this space your entire life, essentially, being an audiologist and making your way to the research side of it?

Dr Tyler: Yes, they were doing some research on tinnitus when I worked in England with **Ross Coles** and colleagues, and it sort of got me interested with my background in science and my ability to apply that to clinical issues and so I was very motivated.

Sean: Was there anything about tinnitus research or learning about tinnitus that kind of stood out to you that got you interested in it?

Dr Tyler: My training in **Psychoacoustics** really focussed on measuring things from a scientific perspective and, so, at the time, there was not much understood about measuring different tinnitus and different perspectives. So, I just took my basic psychoacoustics of measuring hearing and measuring hearing loss and applied that directly to measuring tinnitus.

Sean: Oh, wow, that is an interesting approach. A lot of people didn't really come to tinnitus from that perspective. That's pretty cool, in my opinion.

03:46 – 27th International Tinnitus and Hyperacusis Conference 2019

Another thing that I want to bring up to make everyone aware of is why don't we talk a little bit about the event that you host every year?

Dr Tyler: I am having the **27th Annual International Conference on the Management of Tinnitus and Hyperacusis** this June 13th and 14th in Iowa City, at the University and when I started this many, many years ago I just wanted to see if I could even attend a conference that was really focussed on the clinical management of tinnitus and there just weren't any. There were a few research conferences but at the time there was really nothing focussed on helping clinicians and so I decided to do it eventually and hosted a conference and, in the early days there would be 20 or 30 people and now there are well over a hundred people come from all around the world. It's focussed on **clinical perspectives** and managing tinnitus patients and helping them. We always have the latest in research but it's very organised. I create the entire programme. At most conferences people submit abstracts from the outside and it's mostly focussed on research and different topics, but this is very systematic, very organised. Every aspect, I hope, is covered that would lead clinicians to actually set up a practice and to know what the latest strategies are for helping tinnitus patients.

We also get researchers. We also get even investors trying to look and see what the latest things are but I control quite carefully the programme and we've been doing this for several years. And we always have, at the end, a square dance in a round barn just outside of Iowa City and that is always a big hit with the attendees as well.

Sean: So, from what I understand though, this isn't just for physicians or researchers. There are people such as students and regular people that can come to this event as well?

Dr Tyler: That certainly is true. It's focussed on clinicians to try and help them understand what is going on but, as I said, we also have researchers and, in fact, we enable patients to show up with their tinnitus and there are opportunities during the programme to let them share their experiences. For some of the clinicians attending the Conference it's very helpful for them to see patients there and hear what their perspectives are and what they've tried and what has worked and what they need and what has not worked. We have breakout sessions and we have lots of opportunities for people to interact and so I think it is very appropriate to help people, and to help clinicians get started in the field, and to learn what the latest approaches are to help tinnitus patients.

Sean: And when you say clinicians are you talking specifically about **ENT's** or **neurologists** or **general practitioners,** or pretty much anyone that's interested mainly comes, or is there a specific type of doctor that is coming?

Dr Tyler: Well, they are mostly **audiologists.** We have a few **otolaryngologists** but it's mostly **clinicians**, sometimes **psychologists**, sometimes **hearing instrument specialists**. There is quite a wide variety of people that show up. We have had **psychiatrists** and, as I said, it's just a wide group and the ability to interact and learn from each other is an important part of this as well.

Sean: Correct me if I'm wrong, but did you see a kind of dissociation between what patients were looking for from clinicians and what clinicians were providing and you wanted to bridge that gap and get everyone to be on the same page? I know that, for me and a lot of people who, when they got their tinnitus and they go to see their the doctor initially, the doctor initially, is very blunt and will say: 'learn to live with it, there's nothing we can do'. It wasn't very optimistic, that first meeting with the doctor. So, is that kind of what you wanted to do? You want to educate these doctors in better ways on how to approach tinnitus and how to help patients deal with it?

Dr Tyler: Broadly speaking, yes. I think part of the problem was that simply people did not know what to do. Clinicians weren't sure what the approaches were and, since there is no pill and no surgery in almost all cases, and some of the patients are very desperate. It just wasn't clear how to move forward for the clinicians. So, this was an attempt to develop the strategy so that the clinicians would have a plan and could be helpful.

Sean: With the Conference coming up can you tell us more about it as to what we can look forward to? What goes on?

Dr Tyler: So, the Conference again is at the **University of Iowa** June 13th and 14th of this year. We have a number of speakers coming from around the world. This year we are going to have a few talks on different physiological models of tinnitus by **Phillip Gander** and **Stephen Green**. We are going to focus on sleep therapy with a **sleep therapy specialist**, **Maggie Moore.** We are also going to focus on some medical evaluations with **Marlan Hansen** and with **Claudia Coelho** who has been helping tinnitus patients for a number of years.

We are also going to look at some new directions, including neuromodulation and somatosensory treatments. I'm sure you've heard of them and we're also going to emphasise a little more hyperacusis this year. So, we have **Anne Perreau** who is going to talk about the counselling of hyperacusis activities treatment. We are going to have **Sylvie Hebert** from Quebec talk about new directions and some research she's doing. **Ben Greenberg** is going to talk about some new questionnaires he developed to try and understand hyperacusis and **Brian Pollard** from the **Hyperacusis Group** is going to talk about some pain hyperacusis and the challenges that that has created for lots of people. So, we are going to emphasise that, and I am also pleased to say that, this year our guest of honour is going to be **Shelley Witt,** who I've been working with for over 20 years. Shelley sees tinnitus patients and hyperacusis patients on a regular basis and has been able to help so many patients from around the world. She just has so much experience; she cares so much. She has lots of individual stories to tell and she is going to be our **Guest of Honour** this year. I am proud to work with Shelley, who will share her experiences of people who are really troubled by their tinnitus and really troubled by their hyperacusis and how she has been able to help them.

Sean: Wow, sounds fantastic. Seems like you have a great line-up for people that would be interesting for people who have both tinnitus and hyperacusis kind of like a broad spectrum to get everyone.

Dr Tyler: In addition to the speakers we also have industry representation so a lot of the companies that are involved in using different sound therapies also have special demonstrations, also sound therapies and the strategies they use and they also have talks on Friday morning sharing what is new in the sound therapy fields that they have been able to provide from their different companies. So that is another regular event at our **Tinnitus and Hyperacusis Conference** that is giving the companies an opportunity to share what's new from their perspective as well.

12:36 – Sub-Typing of Tinnitus

Sean: We told everyone on our forum, on our community forum that we were going to be getting you on for an interview for the Podcast. Everyone was very excited. We had a bunch of people; we have threads already about you on there. We had people saying, 'can you ask him this, can you ask him that'. So, we have a bunch of questions that we want to ask you now.

So, on a recent Podcast we did with **Dr Rauschecker,** he highlighted the immense complexity on tinnitus, and so I understand that you were the first to emphasise the importance of sub-typing tinnitus. Can you tell us a little more about that?

Dr Tyler: Well, you can use a generic term for everybody but, in fact, there are all kinds of differences. I emphasised this in fact in an article back in 2008. I think it's unlikely that one particular cure is going to work for everybody, so we might need to explore different sub-types and that might be patients that have had tinnitus from different causes. For example, caused by noise exposure versus some pharmaceutical cause or the ageing cause. Or it might be that we can do different measurements of tinnitus that helps us sub-type and categorize tinnitus patients in different ways. By doing measurements like that and by sub-typing in general ways we are more likely to find a cure for a sub-type of tinnitus patient. So, I think that's what I was trying to emphasise many years ago.

Sean: Do you have a specific number of sub-types currently and is that ever-expanding?

Dr Tyler: One could get a little carried away I suppose because there are lots of different ways of measuring and quantifying tinnitus, but I think the first step is just to start off with some simple things and, again, that could easily be the logical cause. Causes like noise exposure versus ageing and there are some measurements that we have done looking at post-masking effects and pure tone masking effects. The quality that people report and the frequency region of the pitch match. So, there are lots of different strategies and I think that just picking on some of those, you know, is an important way to start. Just to highlight that these patients are quite different and, again, no one treatment is likely to work for everybody with tinnitus.

15:04 – Drugs to Potentially help with Tinnitus

Sean: So, this kind of ties into the next question I have. Do you know of any current or future drugs that may be able to short-circuit this tinnitus signal that's happening?

Dr Tyler: Unfortunately, I'm going to say, no, that I do not. Keep in mind, of course, that there are drugs that can help with anxiety and depression and there are drugs and dietary supplements that can help with sleep problems, but there are some interesting discussions going on about future drug treatments but at this point I really can't say 'drug 'X' is the way to go'. It's just not clear at all.

Sean: I'm happy you brought up medication to help deal with side effects of the tinnitus which would be things like anxiety and depression. I guess there's a lot of confusion about those drugs with many people worried that they are auto toxic or can negatively affect their tinnitus. Do you think that people who have tinnitus and they're struggling with it; do you think that it's better for them to seek help and use those alternative medications to treat those anxiety, depression and sleeping issues instead of avoiding them in case it makes their tinnitus worse? Do you think that risk is smaller than people really think it is?

Dr Tyler: I think the first step should be exploring counselling and sound therapy and hearing aid options. You know, that helps many, many people and does not include any medications that might make the tinnitus potentially worse. So, that's the first step but then, all I'm saying is that for somebody who has severe anxiety and depression resulting from their tinnitus, that does not preclude them from seeing a psychiatrist, for example, and getting some treatment - and it may be a temporary treatment - to help them get through that stage. But at this point at least since there is no drug for the tinnitus itself, the appropriate strategy is counselling and sound therapy and hearing aids.

17:25 – Other Potential New Treatments

Sean: Ok, and do you see any future cure or treatment in **electrical stimulation**?

Dr Tyler: Yes, so actually, I do. I have been exploring the use of electricity, at the eardrum, in the middle ear cavity and inside the cochlea with different electrodes for many, many years. We actually, back in 1989, published an article on using alternating current at the eardrum to try and do this, so we certainly know that lots of people who get cochlea implants for profound hearing loss say: 'Oh I can hear better, thank you very much. Even better than that my tinnitus is gone'. Now, it doesn't help everybody. There are some challenges, but a lot of people are helped, and I think there is some great potential here to use electrical stimulation in a variety of different approaches to try and help patients with tinnitus. It's also very interesting that, in some countries in Europe, somebody that has a unilateral hearing loss - a hearing loss in one ear, a profound hearing loss in one ear - many of them now also have tinnitus in one ear and many of these people are now getting cochlear implants in that ear and it usually helps their hearing but, even if it doesn't help their hearing substantially in many ways, it often helps their tinnitus. So, a lot of patients with unilateral deafness and tinnitus are getting cochlear implants because of their tinnitus, not their hearing loss. I think this is a great opportunity throughout the United States and the world to help patients with unilateral deafness and tinnitus. This is a win-win situation to provide cochlear implants in this population, so I think there needs to be more visibility and discussion in the United States and elsewhere to try and help these people with unilateral deafness and tinnitus. Great starting point for cochlear implants for tinnitus.

Sean: That sounds very promising.

Sean: And so, now to a big question because it's very relevant to a lot of us. What is your opinion on **bi-modal stimulation**?

Dr Tyler: It's been interesting because for several years we know that some patients that have tinnitus, when they touch their neck or touch their face their tinnitus can disappear while the stimulation is going on and for other patients touching the neck or the chin can make the tinnitus worse. So it has been known for many, many years that there is some ability of the sensory systems to interact in some clever way and there is some potential, and some preliminary studies I've seen in several situations where it may very well be that some of these neuromodulation strategies may help some tinnitus patients. So, again, I think we are at an early stage and I think we need some careful examination of results looking at individual patients, but I think there is at least some potential again to move forward to see how this neuromodulation might help some tinnitus patients.

21:01 – Does Tinnitus Volume Matter?

Sean: Alright Richard, so, the next question is, in your opinion, does tinnitus volume matter when dealing with patients and potentially how distressed they can be? Do you think that people with louder tinnitus suffer more, or do you think there is a much more complex equation going on in regard to how people are affected emotionally and how loud their tinnitus is?

Dr Tyler: **René Dauman** and I many years ago, in 1992, developed a psychological model of tinnitus that involves what I would refer to as the magnitude of tinnitus and that's different from the reactions that people have. So, your tinnitus has certain characteristics of loudness and pitch and quality, and the reactions you have result from that, but the reactions you have also depend on your individual psychological makeup. So some of us are used to dealing with a lot of stress in our lives. Some of us are equipped to deal with things. Some of us are quite sensitive to different things so we're all different so I think it is important to appreciate that you have the tinnitus and you have the reaction to the tinnitus. So the correlations between things like loudness and the tinnitus are not always high because there are individual psychological characteristics that contribute to that, but as I often say at meetings to tinnitus patients, because I have heard people say that the loudness is not that important, I always say, if you would prefer to have a louder tinnitus please raise your hand. Nobody does that because having the louder tinnitus is likely to be more disturbing for people. So, I do think it is important to keep a distinction between the characteristics of the tinnitus itself and the reactions that people have. Those are two separate aspects.

Sean: Ok, and as improvement happens with people and tinnitus and, when I say improvement, I mean better coping strategies. Do you think that when you talk and meet with patients it's not only a reduction in volume over time that's beneficial for them? It's also how they cope with it and how they deal with it?

Dr Tyler: Yes, absolutely, it's their reactions. So, the sound may not change. The sound isn't good or bad. It's a sound. So, the question is, from a Clinician point of view, how can I help you change your reactions to the tinnitus? It's a sound. It's not good or bad. We all have challenges in life, and this is a sound. You still have friends. You still have things you enjoy doing. You still have a job. You still have a partner. There are lots of different ways of thinking about this. But it's a sound. It's not a good sound or a bad sound. It's a sound.

24:06 – Tinnitus Retraining Therapy versus Tinnitus Activities Treatment

Sean: So, my next question. One of the treatments that is used for people with tinnitus. What is your opinion on **TRT**, **Tinnitus Retraining Therapy?**

Dr Tyler: When I was working in England this came about and there were already some strategies in place, including some publications we had made and it turns out that **Tinnitus Retraining Therapy** uses **directive counselling**, not **collaborative counselling,** which was against everything I ever learnt in a psychology class. You need to be collaborative and interactive with patients, so I thought that the counselling was not a good thing and the focus was on a mixing point which was just below the level that masked the tinnitus and that also concerned me. Because I think that a loud background sound has the potential to make tinnitus worse and also has the potential to make it more difficult to understand speech in the presence of a background sound. So, we argued early on that using a low-level background sound would likely be more beneficial for many people. Everybody's different, but we suggested at least starting off attempting just a low-level background sound, and I knew from my background in psychoacoustics, that even a normal hearing person hearing a pure tone you could reduce the loudness of that pure tone by presenting a low-level background noise. So we suggested using that low-level background sound; not using a mixing point and then we had developed and published some of our counselling strategies back in 1986, before **TRT** but that, sort of, was largely ignored and I didn't realise that we had to, sort of, promote this. We had several publications and several journals about it, and books on our counselling strategies, so eventually we gave it a name: **'Tinnitus Activities Treatment'**. It didn't have a name like that for years but I think that it can be very helpful for a lot of people but I think the focus on **TRT** of **directive counselling**, not **collaborative,** and the use of the mixing point was not a good contribution to the field.

Sean: Ok, you mentioned the aspect of counselling. What type of specific counselling are you referring to?

Dr Tyler: So, we, as I said, eventually gave our counselling a name: **'Tinnitus Activities Treatment',** and this focusses on what I considered the four common aspects that are affected by tinnitus potentially: thoughts and emotions; hearing; sleep and concentration. So, most of the patients we see have difficulties with thoughts and emotions and hearing and, sometimes, the hearing difficulties are hard to distinguish between the hearing difficulties due to the hearing loss and the hearing difficulties due to the tinnitus. Some people with tinnitus say that they have to hear 'through' the tinnitus or that they have to hear 'over it' or that their tinnitus is worse or it's more difficult to hear or the tinnitus masks some sounds. But most of the patients we see have difficulty with their thoughts and emotions and they have difficulty with hearing because of their tinnitus. In addition to that, a lot of patients come in with difficulties with sleep and a lot of patients - not all of them, but a lot of them - have difficulty in concentrating with reading something or focussing on a hobby and, so, our strategy therefore is to try and focus on the activities that go on in the individual results. So, we have picture-based strategies that have been available for years online on our University site that have been translated into several different languages and used around the world. So, it's interactive. They come into the Clinic. They go through and do some examples in the Clinic. They go through these picture-based strategies. We include things like **Cognitive Behavioural Therapy.** We include a patient focus treatment, so then they go home for a couple of weeks and come back, and they try some homework and they come back, and we go over what their homework was. We review things and go to the next step; hearing difficulties and how they can communicate better with their hearing loss and with their challenges of hearing caused by tinnitus. And if they have sleep problems, we go through some strategies that can help with sleep. That could include sound therapy strategies and if they have problems with concentration when they come back, we go through aspects having to do with concentration and focussing their attention. So there's lots of different strategies and that could include art therapy and music therapy and mindfulness and a lot of different strategies that could be incorporated depending upon the individual's perspective and the individual's needs so it has to be really individualised because we're all different, but it focusses on those four primary functions affected by tinnitus.

30:03 – Tinnitus and Understanding Speech

Sean: That's very interesting. I remember you mentioned, in also my previous questions, I just remembered this… you talked about how, when there's a lot of background noise – is it just people with tinnitus – or is it people with general hearing loss - sometimes they can have a hard time with hearing speech? Is there a specific reason for that, because a lot of people with tinnitus, when they have hearing loss, it's above the level of human speech? So, I do find it interesting that for some reason they would also have trouble, or some people would have trouble, with human speech range frequencies when there's background noise. Is there anything behind that that maybe you could shed some light on?

Dr Tyler: Well, everybody has more difficulty hearing speech in noise compared to speech in quiet. That's very common and we're all getting hearing loss. It's part of the natural ageing process and, when we have a hearing loss, that makes it more difficult in general to hear speech in noise and it's different for different people. But hearing speech in noise is quite complicated. Now, there are several aural rehabilitation strategies that can help with hearing speech in noise and we go through that in our hearing strategies and tinnitus activities treatments. That includes simple things: like making sure you can see the talker, and watch their face, and it's helpful if you know what the topic is, to move closer, to move away from the noise. And, of course, hearing aids are helpful to lots of patients with tinnitus. They don't always improve speech in noise, but they certainly improve speech in quiet. And can improve speech in noise in many, many situations. The hearing aids are much, much better now than they were even five or ten years ago. So hearing is really, really, important. We've done a terrible job, I think, emphasising how important hearing is. We can all feel very sad, appropriately, when we see somebody, for example, in a wheelchair but it's really hard to understand how important it is when somebody gets a hearing loss. It's not just about hearing. It's about communicating, interacting with people and socialising and having fun with your friends and looking forward to the future. Hearing and communication are really, really important. And then when you have tinnitus, again tinnitus can interfere with your hearing and how can we understand tinnitus unless we have it ourselves? What is it like to hear this tone, to hear this whistle, to hear this hum, that we have no control over? So, it's a real challenge for a lot of people and there's lots that can be done but it's just a mystery for a lot of patients and a lot of partners of patients and, unfortunately, a lot of professionals.

Sean: Right, it does make sense how important our hearing is and the lack of importance that it's emphasised on in our society. It's somewhat sad. I mean, I feel like a lot of the people in our community would agree that they had no idea what tinnitus was or how important hearing was until after they got tinnitus and they kind of realised: 'wow, this is a very big part of my life and it's very serious. I should have taken this a lot more seriously'.

33:35 – Can Tinnitus be Effectively Managed?

Sean: My next question for you has to do with, we kind of touch base a lot on this, the general question was, 'Can tinnitus be Effectively Managed?' which, I think we both can agree, it can be. When you look at the media though and some individuals that are in the media, some famous celebrities, sometimes they can report that tinnitus can be so effectively managed that it's a non-issue and that it's not something that really needs research or looking into. Obviously, we don't agree on this, but do you think they are damaging our ability to better spread awareness and to get more funding for research?

Dr Tyler: Wow, I've never actually heard anybody say statements like that. I think, again, it's very important to appreciate that we are all different and there are a lot of patients that are seriously disabled because of their tinnitus and that's a real challenge and, given that there is no pill or there is no surgery for people, it's very, very difficult to deal with. I recall a story; many, many years ago I had a small grant that was covered in the University newsletter that went out to alumni around the country. It was only one paragraph on this grant that I had going around the country to several thousand alumni from the University and a four or five page website and it was interesting for me because in the next six weeks I had about 200 emails from alumni all around the country and they all pretty much said the same thing. They said: 'I've had tinnitus for ten years and it does not bother me, but if you have found a cure, I will fly to Iowa City next week'. So, a lot of people really deal with this as best they can, but they really wish that it wasn't there.

Sean: So, they have a hard time with it, but they can deal with it. But, hey, if you can get rid of it, let's get rid of it, essentially?

Dr Tyler: Yes, I actually did a survey. I was in Australia many years ago and I did a survey of the **Australian Tinnitus Society** and published a work on the kinds of treatments people want and what most people want is a pill, but they will use wearable devices and many of them were prepared for a cochlear implant and some of them were prepared for a brain implant.

So, some people are very desperate given that they can't find help. So, things are changing. There are a lot more people willing to provide different counselling and sound therapy so that's a great thing, but at this point there's still no cure.

36:35 – Compensation and Payment for Treatments

Sean: So, Richard, another question I have has to do with compensation and how tinnitus treatments are paid for. So individual tinnitus management can require a large investment of a clinician's time. To the best of your knowledge has there been any effort made in the US to encourage insurance companies and the healthcare system to cover tinnitus therapies?

Dr Tyler: Well, not enough. There is a whole healthcare reimbursement field in general which is quite complex, so I think that this is becoming of greater interest to lots of professionals and lots of clinicians. I actually wrote an article last year on the challenges that people go through for compensation and, it turns out, and I was surprised to find, that you could be compensated for providing counselling for smoking cessation and for weight management, by a variety of different professions and it's not a **Cognitive Behaviour Therapy** for smoking cessation, it's just counselling for smoking cessation. So why can't we do that for tinnitus? Why can't we provide counselling reimbursement to help tinnitus patients? So, this is going to be a very challenging strategy in the healthcare system, and I think that some of the first steps are to become more open-minded about how the healthcare system works and how the reimbursement in the healthcare system works. I think we need to learn who gets compensated for what; what kind of training do they have? How much time does it take to provide these services? And I think that this, fortunately, is going to be a good thing to open up the whole reimbursement for healthcare systems and see what options there are for providing reimbursement and what training needs to have and I think there should be, again I think part of it is helping people appreciate how important hearing is, and how the system works for reimbursement of counselling for tinnitus. I think that we're going to go on the right direction but I think it's going to take a while and I think that it's going to take a very concerted effort of the healthcare professions in general, and the Government in general, to be more open about how the whole system works because I think, for the most part, people really don't understand how the healthcare system works and who gets reimbursed for what.

Sean: Right. And what is your opinion on compensation for tinnitus sufferers who get it due to work noise exposure or accidents?

Dr Tyler: Well, I think it's actually a wonderful thing that people can get compensated for having tinnitus. Not just for their hearing loss. I think this is becoming more and more widespread. I know it's happened in Iowa for a number of years, but the guidelines differ from State to State in the United States, but it's wonderful that now you can get compensated separately for hearing loss and for tinnitus. I think that **The American Medical Association** guidelines for compensation undervalue the distress caused by tinnitus. I think that now people that get in car accidents and people who work in noisy factories and people who are exposed to gunfire are now getting compensated, not just for their hearing loss but for their tinnitus and there are strategies and ways that I, and others, have developed to quantify the magnitude of the whole body impairment caused by tinnitus and I think it's a great thing that the Society is realising that tinnitus, indeed, is very serious and if you have tinnitus as a result of an airbag going off or as the result of working in a noisy factory for 25 years that you should be compensated for it. This is a great thing.

Sean: Yes, so, in the United States it seems, to the best of my knowledge, that you cannot get disability benefits for tinnitus specifically. Obviously, your research and what you are doing is helping show how significant and life-changing tinnitus can be. Is there any direction or any method that can be used to help make people or the Government aware? Or do you think it's more just spreading awareness about it as you're currently doing to bring it to the forefront?

Dr Tyler: Well, I think that you can get reimbursement for tinnitus.

Sean: For disability benefits?

Dr Tyler: I believe so, yes. I don't know how to make the distinction between… I think it's true both for the Military and in the Public Health you can get reimbursed.

Sean: Ok, I didn't know that.

Dr Tyler: So, what I do is I have developed formal Questionnaires that I use, and clients fill these out beforehand and discuss their problems associated with thoughts and emotions, hearing, sleep and concentration. They make ratings of how their tinnitus has been affected. Quite often, for example, when somebody starts work their hearing is measured. They are asked if they have tinnitus or not and then, after working for 25 years their hearing has been measured. They show that they have a noise-induced hearing loss. They've reported that they have tinnitus in the last few years and I come up with, after the interview and the questionnaires that the clients fill out, I come up with a whole-body impairment for tinnitus, not just for the hearing loss but for the tinnitus. Again, it goes State by State, but I am happy to say that you can be compensated independent of your hearing loss for your tinnitus.

Sean: Right, that's fantastic. I didn't know that the general population had that ability. I thought it was mainly for just, as I thought we were discussing mainly more Veterans and stuff but that's fantastic and it's great to hear that you're doing this work to help people get into programmes to get those benefits as well.

Dr Tyler: Yes, and of course it's often a starting place for using that compensation for getting hearing aids and getting tinnitus sound therapy devices and getting counselling procedures so it's appropriate that they receive this compensation and it enables them to go through and get help, so it's a great thing.

44:10 – Coping with Severe Tinnitus

Sean: So, there are some people in our community who have severe tinnitus and they think that they've done it all, they've tried it all. They don't necessarily know what their next step is, and they feel that they have done everything they could have done up to this point. Do you have any advice for those individuals?

Dr Tyler: Well, I think it's appropriate to keep in mind that there is no cure. No pill. No surgery. Everybody in life has challenges and, from the early work I did in the late 1980's it was obvious that the first six to nine months are the worst and that's normal. It's reasonable to be upset. It's reasonable to be angry. It's reasonable to say: 'why did this have to happen to me. It's not fair'. These are all reasonable responses. Eventually, and again, I'm going to say hearing aids, counselling and sound therapy can be very, very, helpful for a lot of people. Eventually, you would like people to be able to move on with their life. To realise that, ok, everybody has challenges. This is my sound and I'm going to move forward and do the best I can. And with the counselling hopefully people can move forward and put the tinnitus in the background.

Sean: When you said six to nine months, when we see a lot of people in our Community talking about 'oh, I've had it' and they're really struggling it usually is in that first six to nine months and then, eventually, for some people you do see that change of where: 'oh, I'm dealing with it a bit better, I'm coping better', but, yes, those first couple of months are pretty brutal. Do you meet with people who get it in those first couple of months and is your advice basically just like you've got to try and stick it out for a little bit? You'll adjust to it?

Dr Tyler: I do see people early on and, again, it's like you go in and you're diagnosed with cancer. It is quite reasonable to be upset. It's quite reasonable to say: 'This is not fair. Why does this happen to me?'. So, when you get the tinnitus, these responses, these initial responses are reasonable. So, then, the question is, ok, so it turns out there's no cure. This is a sound. It's not a good sound or a bad sound. It's a sound and so is there some way I can get used to this. Is there some way I can cope? Is there some counselling and sound therapy that can make this sound less important in my life? Is there something I can do to make this sound, this tinnitus sound less important? And, again, our **Tinnitus Activities Treatment**, the use of hearing aids, the use of sound therapy. For a lot of people, it helps them get to that point. It may take several months, but the strategy is to move forward and deal with this and own the tinnitus. It's not a good sound or a bad sound. It's a sound.

47:35 – Sleep and Impact on Tinnitus

Sean: So, coming up next, another question I have is: why do levels of sleep have such a huge impact on tinnitus? A lot of people report that when they get good night's sleep their tinnitus is very low. When they have a bad night's sleep or sleep that they keep waking up from, their tinnitus is very loud. Is there some type of connection here?

Dr Tyler: I recall giving a talk many years ago to a large group of people with tinnitus and, certainly, one of the things that I think is clear is that, again, sleep is one of the most common problems. Getting to sleep, and when patients wake up in the middle of the night and the room is quiet, they often hear their tinnitus outstanding and have difficulty getting back to sleep. Patients often say when they wake up in the morning their tinnitus is worse and, again, I'm going to say when you wake up in a quiet room, as background sound is often very helpful for tinnitus patients, when you wake up in a quiet room after sleeping all night long, for some patients this is very distressing. I remember, as I said, giving a talk to this tinnitus group and this patient said: 'oh no, for me, when I wake up it's really bad and even if I have a little nap during the day for five minutes my tinnitus is really, really, bothersome'. I thought about it for a minute and, in fact, when we are asleep our brain goes through different stages and different activities to sort of recycle itself and it may very well be that, when that brain is going through the different stages of neural activity, that for some patients that can trigger and affect their tinnitus in a way that makes it worse.

Sean: Interesting. It's interesting how sleep can affect different people's tinnitus. It's very much an individualised thing where everyone is different in that sense.

Dr Tyler: Yes, as it is for the mechanisms responsible for tinnitus. Very different in different people.

49:38 – Habituation, What Does it Really Mean?

Sean: So, when people talk to you or it's discussed, **'habituation'** – obviously people can hear their tinnitus if they look for it, but, in your opinion, is habituation not being to hear it and being able to go about your day or is habituation more of being accustomed to it and not getting an emotional response from hearing your tinnitus. Or do you think it's a kind of a combination of both?

Dr Tyler: I think this habituation has been over-emphasised a little bit and, it's not a bad thing, but the example that I give is that, you know, when we put our socks on in the morning, we can feel our socks on our feet for the first few seconds and then, eventually, we don't feel our socks on our feet any more. And that's what habituation is. It's not important, it's not catching our attention, and it's easy for our brain to habituate to it and people have used that as an analogy for helping to cope with tinnitus, for example, using sound therapy. And I guess that's ok, but part of the challenge is that some people don't seem to habituate to it easily and, so, have they failed? So, I have a Psychologist friend from Copenhagen, **Anne-Mette Mohr** who has been helping tinnitus patients for many, many years, and she's taught me quite a bit and so it's not necessarily about habituating. It doesn't have to be the goal here. The goal could be acceptance. The tinnitus isn't good or bad. It's a sound. She even made the point more recently that: <u>'it's my sound, I own this sound'.</u> So, it's not like you're fighting the tinnitus, or you need to deal with this. It's a sound. It's not a good sound or a bad sound and it's our role as clinicians to help the patient get to that stage where, and, again, with the use of counselling and background sound and hearing aids, how can we make the tinnitus less important in your life and, for some people, that has to do with accepting it. It's not good or bad, it's a sound and maybe even owning it. <u>'It's my sound. I own this sound'.</u>

Sean: So, it's more tackling it and <u>you</u> being in control instead of the tinnitus being in control?

Dr Tyler: Absolutely, yes**.**

Sean: And do you think how they perceive it, or the loudness of their tinnitus will affect their ability to 'habituate'?

Dr Tyler: So, clearly, the loudness is a factor. No question about that and again I will go back to the **Tyler-Dauman** model about separating the tinnitus from the reaction to the tinnitus but a louder tinnitus can certainly be more annoying for people and so what that means is that background sounds, sound therapy at low levels can actually make the tinnitus less prominent. So, I think the loudness is only one factor here.

Sean: Essentially, I think a common theme we that we have during this interview is that tinnitus is a very complex equation and it's not just one factor that is the end all part of the equation. That there are different aspects of it that can change and be adjusted to better deal and cope with it, essentially.

Dr Tyler: Absolutely.

53:28 – Random Acts of Tinnitus Relief – Share Your Stories!

Sean: As we get towards the end of our conversation here, I know that you wanted to talk a little bit about something you are putting together called **'Random Acts of Tinnitus Relief'.**

Dr Tyler: Yes, just recently I was reading a book called **'Random Acts of Kindness'** by Canary Press. As soon as I started reading this book, I was just very impressed about people who have had challenges in their life and written some wonderful stories about people that have been nice to them, or how they have been nice to other people or kind. Or have made things wonderful and, for all of us being kind to other people should be one of our main goals in life and so I was really touched by this book. As soon as I started reading it, I thought, gee, I wonder if we can somehow apply this to tinnitus and so what I thought is that I would actually like to collect stories and paragraphs and sentences that people have experienced; random acts of kindness or random acts of tinnitus relief and if they can share these stories with me then, and again, it could be just a paragraph or just a sentence, not too lengthy stories, but I would like to create something, perhaps on our University website, sharing these random acts of tinnitus relief. So, if you have something you'd like to share and you can do it anonymously or put your first name, and I'm not quite sure, but you might be able to use your whole name and I might be able to give you credit for that if that's appropriate, but if you can send me an email with these random acts of tinnitus relief I think it might be a good thing for the tinnitus population worldwide to be able to see how people have been helpful to them or what experiences you have had as a tinnitus sufferer that have made tinnitus not so problematic. Or have made it less of an issue for you. Or have had an experience where somebody has been really caring and that's really touched you in a very moving way. So if you have a story that you'd like to share about the random acts of tinnitus relief, you can email that to me at tinnitus2@healthcare.uiowa.edu. So, send me your story and I'd like to be able to share your random acts of kindness related to your tinnitus. That could be a wonderful thing.

Sean: Yes, I think that's a great idea and I think it's something a lot of people would enjoy reading and it will be informational for them as well.

Alright Richard, well I think that about wraps up everything we wanted to talk about. I do want to thank you for obviously taking your time on a Saturday to come and talk with us. We really do appreciate it. We do appreciate all the work you do and everything in regard to tinnitus. Obviously, us having tinnitus in our Community, we can't thank you enough for all the effort you put in trying to make this a thing of the past.

Dr Tyler: Well, I hope I can be helpful and, as I said, there are a lot of people out there that require help and there are a lot of professionals around the world that are making an effort to be helpful, so we're all going to work together and make this less of a problem.

Sean: That is the goal. Well, Richard, I just want to thank you again and I'm happy to have you join us today on today's podcast.