

Transcription details:

Date: 16-Feb-2017
Input sound file: First_Podcast_David_Baguley_Ep.1

Transcription results:

S1 00:00 Welcome to *Conversations in Tinnitus*, a podcast of the American Tinnitus Association. The American Tinnitus Association is a nonprofit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. *Conversations in Tinnitus* podcasts are an extension of ATA's magazine, *Tinnitus Today*, the only publication dedicated to educating the public and practitioners about ongoing research, treatments, and management of the condition. [music]

S1 00:49 Welcome to the very first episode of *Conversations in Tinnitus*. I'm John Coverstone, an audiologist in Minnesota, along with my cohost Dean Flyger, an audiologist in Texas. And joining us today on this ATA podcast is Dr. David Baguley, who is a professor of hearing science at the University of Nottingham in the United Kingdom. Dr. Baguley has published extensively, we'll leave it at that, including a couple books which he has coauthored, *Tinnitus: A Multidisciplinary Approach*, and *Hyperacusis: Mechanism, Diagnosis, and Therapies*, as well as a self-help book entitled, *Living with Tinnitus and Hyperacusis*. And so welcome to *Conversations in Tinnitus*.

S2 01:40 Thank you, it's a real pleasure to be here.

S1 01:43 *Living with Tinnitus and Hyperacusis* - I have read some of your other materials but I'm really curious to hear the synopsis and the focus of this book, and how it's being received so far by readers.

S2 01:56 Thank you, John. A few years ago, myself and my coauthors realized that some people with tinnitus in the UK were getting a really bad deal. They were being told there was nothing that could be done, there were no services, essentially, that there was no hope. And I wanted to get something out there that said to people in a rather challenging situation, "Look, this is how you might get started." So together with the psychologist, Lawrence McKenna, and an ENT, Don McFerran, we wrote the book and tried to pour into it the wisdom that we had about how you get some traction on this situation, how do you reclaim your quality of life when you're struggling with tinnitus and hyperacusis. I've had some wonderful communications with people that have used the book, and it's been a lifeline for some of them. And that's a real humbling experience to have been part of that.

S2 02:58 In speaking of getting traction starting on this journey of living with tinnitus, to use that phrase, because it's a good one. I think many people find out very quickly that tinnitus is not something for which there's a cure. It's not something that is likely to completely go away, possibly ever. It does for some people, but living with tinnitus is certainly the focus. And I know that in my practice, and I believe Dean has found the same thing, that one of the first things you have to do is find a way for people to, for lack of a better term, come to terms with the tinnitus and get past that initial hurdle of being alarmed by it, having anxiety that comes along with that, and learning that in most cases, and hopefully in that individual patient's case, it is a benign condition and not something that is indicative of a serious medical condition. And of course, that's the first thing we want to investigate. What have you found to be most valuable in

helping people to initially come to terms with tinnitus and start learning to live with it?

S2 04:24

This is an area, John and Dean, where I'm really very interested, and I've been really listening to my patients over the years about what they tell me about the first few hours and days with troublesome tinnitus. Of course, in some of them it starts abruptly and suddenly. In other people, it's more of insidious, gradual, subtle building up. But once people realize they're in trouble, then they're in a very challenging situation. And most of the information that you can get in a hurry off the internet is really negative. So, I've been really interested in building up the idea of first aid for tinnitus, to talk to people about what they can do in those first few hours and days when they start to lose their sleep pattern, when their concentration starts to unravel, when they start to become frightened about what the future holds for them, and developing a set of tools for people to use with Sound Therapy, good advice, good relaxation to try and give people some early traction on that situation.

S3 05:41

I think it's important, and you're starting to help people and point people in a direction to give helpful, useful advice, which is very important. And, also I think you're creating a tool, or at least part of our tools, to tell the patients that in a society now at least here in our area where people are looking for something to quickly fix their symptom, what your book is giving tools for is the realization that these symptoms are to be mitigated but there is not one particular route to take down that path for relief. And it's interesting that you're creating this tool with help from many people and lots of knowledge, but to have a compendium for somebody to be drawn to both a patient that is suffering from these symptoms, and, from my perspective, providers who may not have comfort with much of the data with tinnitus or maybe they have not concentrated on that subject matter enough to be well versed. It sounds like this is useful for both groups.

S2 07:09

I think you're absolutely right, Dean, and I think there are two communities that we can usefully support. One is the patients, of course, and their families, of course. And then the second is the community of clinical colleagues who perhaps had a lecture or two on tinnitus in their audiology training but nothing more significant than that, and then find themselves in a room with a patient, who's in really deep trouble with their problems, and just does not feel able to deal with that situation. I have a real compassion for both of those groups, and I think the more we can help colleagues to deal with these things kindly, carefully, but effectively, then we would've done a really good thing. And I'm really pleased to hear you say that.

S1 08:04

The first step, I think, in most people's journey with tinnitus is, "I've developed this ringing sound in my ears." And of course, what do you do when something's going on with your body, your brain, and you don't know what it is, and you want to see someone to investigate that. You go to your physician, your primary care physician. And I think we all know the standard response that probably well over half the people that have tinnitus receive, and that is, "Well, it's a sound---doesn't appear to be anything wrong with you. You're just going to have to live with it." They probably then go on to find other information. That's what I've heard from patients. But what have you found is that initial journey, and what message could we take away? What do we need to do as professionals, and possibly, the American Tinnitus Association, as well as the British Tinnitus Association, which I've heard is an outstanding organization, to help people through that journey to raise awareness and make sure that people are getting the help that they need?

S2 09:14

Yeah, I think you're right. I think these early clinical conversations that people have with patients are really formative about how the patient manages, and I, like you and

Dean, see so many patients who can recite word for word what their physician told them. And it often sounds as though it was meant to be well-meaning, but really destructive and sometimes disastrous in terms of how the patient views themselves and their problem. Now, we could come to a view that these doctors are careless and not compassionate doctors, but I don't suppose for a moment that's the case. These are people trying to do their best. And I think those of us that have got knowledge, then, about tinnitus and hyperacusis have to share that with that community so that we can empower them to deal better with their patients and have some tools, themselves, that they can use. So, the British Tinnitus Association produces some material. I think it's called *Top Tips for General Practitioners*. We just revised it. And that gives 10 clear pieces of advice for family doctors about what to do with somebody who comes to see them with tinnitus [inaudible]. And, also, I've just been asked to write a piece for a magazine in the UK called *Pulse*. This is the magazine that's written by and for family doctors, and I'm really hopeful that by getting some material in their journal, it'll start to have some credibility and some accessibility for them. So, I think there's work to be done there. It's going to be slow and it's going to be interesting, but I think we really have to try our best.

S1 11:13

I've noticed that support groups seem to be on the rise here in the US and many people have found a lot of comfort and, well, support, from being able to talk with other people who have tinnitus hyperacusis and related problems. What have you found? Have you found that to be helpful? Do you refer your patients to local support groups?

S2 11:39

I do. And I think, at their best, they can be an invaluable system of support and care. I have a little bit of tinnitus but I don't have troublesome tinnitus, so I can be empathetic with my patients but I can't ever say to them, "I understand. I've been on that journey too." And I think it is really powerful for somebody to meet somebody who's been on a tinnitus journey and is living with it, is managing it. That can just be such an important source of mentoring and support and care. One other thing that tinnitus groups do in the UK is to get people feel they might have some options for tinnitus to come and speak to them as a group and say, "Well, maybe my relaxation therapy or my yoga or my aromatherapy might help some of you." And that's an empowering way that groups can say, "What do you have for us? Before I come and see you and spend my money, you come and talk to us and tell us what you have."

S1 12:49

We hear regularly from members and other individuals with tinnitus here in the US who don't have a support group in their area. I am wondering whether there may be a way that we could leverage technology to put together some of these individuals who have tinnitus, cannot access a support group in their area or would have to drive a long ways to access one, in order to get that same kind of support, or some kind of support from other people who have tinnitus. What do you think about that?

S2 13:26

I think that would be a real breakthrough for people because clearly what we have at the moment doesn't quite work. Because one thing I've noticed about tinnitus message boards across the world is that there are some people on there who are angry and some people who will be destructive and that can just be so negative for everybody else. I think that that particular format doesn't seem to work. So, some other form or technology would be good. It's not really my field but I think I'd encourage anybody listening who's got those gifts and skills to think, "Well, where would be the meeting place that people could actually positively share their experiences and be able to be open with each other about that."

S1 14:19

You also mentioned the international aspect. You, I think, are much, much better versed in what people are doing internationally than either Dean or I. What have you

seen that holds promise or is finding success that maybe we haven't seen before that perhaps you could bring to us and help us learn about?

S2 14:46

Well, thank you, yeah. Internationally as well people are really interested in tinnitus and what I've really noted is there is now rather than an atmosphere of competing with each other, there's now an atmosphere of cooperating with each other. In Europe, and Britain is still just part of Europe, we have a consortium of tinnitus specialists who are working together, and some are looking at [inaudible] and some are looking at subtyping, and some are looking at neuroimaging, and some are looking at outcome measures and questionnaires. But these groups are hyper-effective work groups cooperating and really producing some breakthrough information in terms of what we know about the situation. But also internationally, some of the drug programs that are going on are really interesting and people are really, reworking, revisiting the idea that maybe some form of therapy that would be truly effective at inhibiting the tinnitus signal. It might have to work in conjunction with sound and with counselling, but there are two or three drugs of interest being trialled at the moment that I think are exciting prospects. They may fail, but at least people are trying them.

S3 16:26

And again, it's important that you, Dr. Baguley, are a person who is communicating and publishing and speaking to the world and whoever wants to listen that people are developing drugs in trial and techniques to help that may or may not be successful. But the mere fact that we're working on it can be solace to many people suffering with tinnitus.

S2 17:01

Yeah, I think so. And I think in the middle of the night, when you're awake and you're stressed with your tinnitus and you're frightened, your mind has to go to, "Why has nobody fixed this? Why has nobody solved this?" And the idea that there are people right here, right now, working on this, understanding it, clinically focused projects really trying to change that situation, I really hope is of some comfort. Now, the privilege for me is that having been in this field for 30 years, I have learned how to use the vocabulary of the otologists, of audiologists, some of pharmacologists, certainly of psychologists. And I'm often used to kind of being a bridge-builder between those communities. That's a real privilege and I never lose the fact of being humbled by that.

S1 18:03

So, speaking of research, Dean and I follow research extensively. We talk about this a lot on our professional podcast for audiologists. What have you seen recently that you think is the most promising in research in the world of tinnitus?

S2 18:21

The paper that I have been most excited by recently is from a group in Newcastle in the UK, but in collaboration with neurosurgeons in Iowa. And they had a patient who had troublesome tinnitus, he was in his 50s, and he also had intractable epilepsy to the extent that the neurosurgeons performed a craniotomy. So, they opened up the skull and they recorded from the surface of his brain where the ignition focus of the epilepsy was, with the idea that they would try and ablate that. So, they try and remove that. It's a very last ditch procedure for epilepsy, but it is done. Now, this patient with tinnitus, had tinnitus that was very strongly suppressed by sound, and after the masking sound had finished, that suppression or inhibition would carry on for a few minutes. That's called residual inhibition. We used to study it a lot. It's not fashionable at the moment, but there's more to know there. So, while they were doing the surface of the brain recordings, they recorded this gentleman's brain activity with and without tinnitus. Now, you can do that with a scan, functional magnetic resonance scan or other types of scanning, but the resolution is poor, it's all very indistinct, and direct recording is very different. And the recordings they were able to make from the surface of the brain allowed them to interpret what was

happening deep inside the brain, a bit like an oceanographer can use ocean sonography to tell from the surface of the ocean what's happening on the floor of the ocean.

S2 20:29

So, you can look deep inside the brain with these direct recordings with and without tinnitus. And they found three different new brain networks that dealt with tinnitus. One was actually the signal itself being driven through the gentleman's brain, pushed forward through the gentleman's brain. One was an attentional network. There were parts of the brain then paying attention and monitoring that. And then there was a tinnitus memory network that was expecting it. Now, that last one is very interesting because I have a number of patients who say to me, "I don't have tinnitus when I wake, and then I listen and it comes back. It's as if my brain remembered it." And that's this memory network. Now, that's one patient and it's a proposal rather than a full theory, but it is a very important breakthrough, I think, in terms of our understanding of what is physically happening, physiologically happening, in a patient's brain when they have severe and troublesome tinnitus. The lead author on it is a young man called Will Sedley. He's a neurologist by training. He's extremely bright. I'm getting to know him well and sharing conversation with him, and it's just a good piece of work.

S1 22:02

I know in the research that Dean and I have watched over recent years and discussed, it seems like people are finding tinnitus in all kinds of areas around the brain. And, of course, that doesn't necessarily speak to the origination of tinnitus necessarily. I don't think we can say whether it's the cause or the effect. There may well be the effect of tinnitus in it showing up in different parts of the brain because of the way that it affects different people. Do you think that's what this research is showing us as we see people do studies of maybe like the ones that you mentioned? Some of them are fMRI studies, and so a little more of a gross measurement, but what are your inferences? I've wondered if that is the proper inference. Or do you take something different away from what we're seeing?

S2 22:57

Yeah. I think you're right to bring that up. So, my first response is to say, when I did my audiology training 30-something years ago, we were essentially taught that the auditory pathway in the brain was very simple, that it went from the inner ear, and then there was a very passive set of circuitry that would take sound up to the cortex, and that's where meaning and analysis occurred. Wrong. The system is [laughter]--

S1 23:32

I'm sorry. I had to laugh there. I just have this--

S3 23:35

An understatement of the morning.

S2 23:37

That's great. So, what do we know? Well, we know that the cochlea is really dynamic, and we know that the pathways in the brain are really complex and dynamic. There is a very fast five-lane highway that goes up from the cochlea. But there's also a back road, an old road that's not known so much about. It's called the extralemiscal pathway. Nobody's really sure what it's doing. It may have a role in tinnitus. And then, the simple fact is, that most of the time, there are three times as many nerve fibers coming down from the brain to the ear as there are going from the ear to the brain and, at one point, five times as many fibers. So, that's completely against the flow of traffic as the three of us were taught, and tells us that the brain is continuously monitoring, prioritizing, selectively attending to what's coming up from the cochlea. But, also that the auditory pathway, then, is linked into systems of emotion, and memory, and vigilance, and threat. And how could this not be? You listen to classical music with your eyes closed and it moves you, and warms you, and encourages you. That's your hearing system and your emotional system doing a dance together, working together to take you into that numinous space. Or a mother who wakes

when she hears her baby coughs in the night. Her hearing system is, of course, plugged directly into systems of vigilance and awareness and reaction. And then the farmer in a rural farmhouse who hears an intruder and reaches for his protection, his auditory system has alerted him to threat and he is immediately respondent. So, it's not surprising then that people with trouble with tinnitus when we studied them have all sorts of bits of the brain that are involved and connected and dynamic, and that's both interesting and complex. Now, we're not going to solve this without involvement from some of the really good brain scientists.

S1 26:09

Just to add to that, I have a conversation all the time with patients that we are, as a species even, the product, the descendants of people who developed the ability to tune in very closely to a new stimuli, auditory stimuli, such as that ancestor who was maybe in Africa and heard that rustling in the grass and either paid attention to it or ran away before the lion got to them or didn't, in which case they probably didn't survive to procreate. And we are the descendants of those people who developed that skill to take a new auditory stimulus and pay attention to it, and so our brain may very well and probably is hardwired for those kind of responses that you just described. And I think talking about that with patients and amongst ourselves gives us an idea of the very high hurdle that we are trying to help our patients overcome because we're essentially swimming against the current, so to speak, in trying to overcome something that we may be hardwired to experience.

S2 27:37

Yeah, I think that's very interesting and I think it does explain why patients with tinnitus will often say, "I'm really restless. I'm really jittery. I'm jumping out of my skin. This isn't like me." So, that deep sense of discomfort and arousal that they have, and that to me speaks of tinnitus actually being present at quite a low primitive level in the brain. I think the other indicator that we have of that is the language people use about tinnitus. You can have a patient who's a record producer or a symphony orchestra conductor and has got 50 different words to talk about the quality and timbre of sound. "What's your tinnitus like?" "It's a buzz." Or even about a third, maybe a quarter of people, when you say to them, "What's your tinnitus like?" They say, "I can't really tell you. I can't really describe it." So, that's happening deep and low inside the brain. And that tells me that we have to use bottom-up and top-down therapeutic approaches to try and get to grips with this. By top-down, I mean the approaches that change the meaning of the tinnitus. The *Living with Tinnitus (and Hyperacusis)* book is like that. It attempts, through information and encouragement, to change the framework of the tinnitus. But then bottom-up is using sound to try and bathe the auditory brain in sound to try and reduce the starkness of the tinnitus so that the person can start to get some traction on it. And using that in the daytime and at nighttime with the environmental sound generators, producing the rain and the ocean at night, to try and bathe the auditory system in sound. Now, this sounds a daunting prospect, but actually, audiologists are changing the auditory brain the whole time. When we fit a hearing aid to somebody who's had a deafness for 10 years, the auditory brain changes around that. When a child who's never heard is fitted with a cochlear implant, the brain plastically changes around that input. So, we're used to doing these big interventions. It's just in tinnitus, we need to think really carefully about what works and why.

S1 30:15

[music] We've been talking with Dr. David Baguley, who is a professor of hearing science at the University of Nottingham in the UK, also is co-author of the recent publication, *Living with Tinnitus and Hyperacusis*, as well as some other wonderful books. And I just want to thank you for joining us here today for this conversation in tinnitus.

S2 30:37

I've really enjoyed it, John and Dean. It's been a pleasure and it's just great that tinnitus allows us to reach out around the world, and have our common care for our patients really help there. So, that's been big fun. Thank you. [music]

S1 31:07

The American Tinnitus Association is a non-profit organization dedicated to research, advocacy, education, and support for people who live with tinnitus. Gifts and donations to ATA are used to support research for a cure and other critical missions described on our website at www.ATA.org.