Cambs Tinnitus Support Group

No. 173 NEWSLETTER November 2024

MEETING

&

Bring & Share Brunch

Saturday 16 November 2024

at

10.00 for 10.30 am

"Focusing on Tinnitus"

Speaker: **Alex Brookes -Thompson**

CEO Tinnitus UK

My background is in charity leadership having been a CEO in the voluntary sector for around 10 years now with 25 years in the charity sector in total. I have worked with charities of all shapes and sizes and most recently as the CEO of a social care organisation based on the south coast, where I live with my wife and two children.

Why this role? Well, first and foremost I see a charity with a few problems which I can address with my skills and experience, but I also have had tinnitus for 11 years.

I want to try to create and shape something which better reflects the scale of the problem and the significant opportunity to raise awareness, raise funding, research support, research treatments and deliver better support to people with tinnitus, the professionals and those conducting the research.

New Meadows Community Centre

299 Arbury Road, Cambridge, CB4 2JL

The car park is located off Arbury Road between the new Community Centre and the apartment block
(Parking is free for members attending a group meeting, but please be aware that available spaces can be limited)
NB: Other free parking is available in St Albans Road. Turn Right out of car park, St Albans Rd is next Right
The Centre is along the path across the green space

CONTENTS

EDITOR'S CHAT

In the last newsletter I kicked off by mentioning the 'curved balls' that Tinnitus UK had sent our way, and how the problem was not doing my tinnitus any good at all! However, as you know we moved the November self -help session forward, and despite several apologies for absence, we enjoyed a good session (read all about on page 3). We managed to straighten the other curved ball by getting the new CEO of the charity, Alex Brooks –Johnson, along as our speaker for our upcoming November meeting. I very much doubt this will be the first support group he will visit in his tenure, but for me it will still bring back memories of David Stockdale (new BTA CEO at the time) talking to us back in 2012, when we really were his first support group outing!

Alex is busy developing a new strategy and he wants this to be informed by the wider tinnitus community. He wants to meet people to gather their ideas, opinions and thoughts. Tinnitus UK want to know more about the support you need, the support you think others might need and how they can best engage with our various audiences and re-establish themselves as the global leaders in tinnitus.

This will be the theme behind his talk, so please think about these topics, and help contribute to the overall discussion at what should be an interesting meeting. And don't forget the Bring & Share Brunch!

Recently we had another contact with Tinnitus UK, in the shape of an invitation to join them at a British Acoustic Neuroma Association (BANA) Conference at Addenbrookes in October. As I write this, the conference is less than a week away, so I have been able to report how we got on in this newsletter (see page 5).

Chuckles

● A bricklayer, a carpenter and an electrician are arguing about which has the oldest profession. 'We built the Pyramids,' says the bricklayer. 'We must have been first. 'We built Noah's Ark before the Pyramids,' says the carpenter. 'We must have been first.' 'We were first.' The electrician says. 'You're both wrong. When God said, "Let there be light", it came on straight away. We must have been there to put in the wiring.'

● A 60 –year old millionaire has just married a 20 year-old model. 'You crafty old devil,' says his friend. 'How did you get a lovely young wife like that?' 'Easy,' replies the millionaire. 'I told her I was 95.'

MARTIN'S MISSIVE

I'm Deaf not Daft!

By now you've probably realised that photography is one of my main hobbies. The other is skiing. Recommending skiing to give relief from tinnitus is probably a big ask. However, using the medium of photography to illustrate to non - sufferers the affects of tinnitus and partial deafness may be an easier task. In the last newsletter, I tried to show how tinnitus confuses us by fragmenting sound, even when we recognise it as a picture. The photo below on the right represents a soundscape.

I took this picture walking around the Shambles in York. Street photography is a new venture for me. I stood opposite this shop front for ages, waiting for someone to look in the window or people exiting from the passage or both and mostly photos of people walking past the shop not doing anything interesting. Back at the photo club I asked what I should have been looking for in this place.

One of the members said "Look, there's a girl in the doorway, you can see the light on her thighs".

Our eyes are nearly always attracted to the highlights in a photo. It's also true with the soundscape. We focus in on the bright sounds and the next picture shows that point of focus.

Most confusingly the shaft of light is on her Doc Martens. Not wanting to make a fool of myself, I decided to keep quiet and quick as a flash, I'm out of the conversation. Sounds familiar? (No pun intended). Curiosity eventually got the better of me, and at the risk of making an idiot of myself, I asked…...Focus point in photo on the left.

"Look, there's a girl in the doorway, you can see the white of her eyes."

With Best wishes

Martin Middleton
CTSG Chair

Meeting Report - Self Help Session

As you know our self-help session is usually in November, but this year circumstances dictated that this was not to be. The unavailability at very short notice of the Tinnitus UK CEO speaker gave us a headache [*My tinnitus was through the roof* !- Ed]. However the problem was solved by bringing the self-help session forward (getting a speaker for November at very short notice was another matter!) Unfortunately this change was accompanied by several apologies for absence from some regular attendees, which meant that numbers were down on our usual November total. However this was not a handicap, because this year Rachel was keen to give the members more opportunity to ask questions and express their views, and this worked well with the reduced numbers. We also mixed up the format by asking members to write their question on a piece of paper, which were then drawn out of the 'hat' at intervals. I took the opportunity to draft some rough notes to give you readers a flavour of the topics and discourse.

● Member feeling 'unbalanced', especially in the morning, and having Meniere's disease does not help. This disease can be very disabling, leading to dizziness and vomiting, and can be very disabling. 'Emergency' tablets are available, but these don't always work. The local Meniere's group was mentioned, but the general opinion was it was not very organised, and therefore ineffective. The CTSG did invite the local group organiser to give a talk on the subject in September 2019. Rachel mentioned that the Meniere's clinic at Addenbrooke's was oversubscribed. Several others present mentioned their tinnitus can be a real problem in the morning, before settling down.

● Does anyone have musical tinnitus? Two people apparently, including a new person who was visiting us for the first time. The member who also has it finds it particularly distressing because it's not constant. Older people often have the musical variety because of reduced hearing, and it is more common with people who are musical. Rachel mentioned that the OTO app, which teaches cognitive behavioural therapy via the internet, can help by making the brain feel less distressed. One member uses audiobooks as a distraction.

● Another question raised was what the key elements and habits were to be able to achieve habituation, and each member had the opportunity to voice their opinion on the topic. "Don't let it get on top of you", "It depends on the size of the gorilla on your back" were some of the comments. Individual ways of relaxing are essential, whether walking in the countryside, gardening, gentle movements from Tai Chi or any other personal method. But with all methods the secret is to allow the benefits to come slowly.

● One member constantly wakes up around 5.00am with a headache and raging tinnitus. Takes tablets and after ~ 2 hrs, things get better. Possibly hyperacusis, or neuralgia? Rachel explained it could be due to tension in the muscles of the inner ear. Driving can also make one's tinnitus feel worse [*after a long period driving my 'noise' can be through the roof, may be down to concentration*? - Ed].

● The question of getting hearing aids repaired at Addenbrookes was discussed. If you phone the department you can get a slot booked to repair your aids on the spot. For replacement parts there is a website devoted to supplying bits [https://tinyurl.com/mfr5e9wf].

Rachel emphasised the importance of keeping your hearing aids in good condition, and being aware they will be need to be changed at some point.

● The use of hearing aids while listening to music was a popular topic. The use of ER 20 earplugs were discussed, and several members said they benefitted from them at concerts. They help reduce the number of decibels, as well as the singer's words gaining clarity. (The ER-20 earplugs use a proprietary tuned resonator and acoustic resistor to replicate the natural response of the ear canal. This technology allows sounds to be reproduced unchanged, just quieter, ensuring that most noise is reduced to safe levels while preserving the clarity and richness of speech and music).
[*Etymotic means "true to the ear", and is also the name of the company who produced these first noise-isolating high-fidelity in-ear plugs in 1991*— Ed].

Former RM Commando receives new treatment for tinnitus with the support of the RBL. (Edited from RBL website)

Commando Harris Tatakis was on tour in Afghanistan when his Land Rover drove over an Improvised Explosive Device (IED). The blast shattered his left leg, shin and ankle, broke his right foot, ruptured both his eardrums, and caused brain damage. His leg would heal over time, but the damage to his ear drums resulted in tinnitus.

"Having both a head injury and a physical injury to both ears is so complicated because if it's just hearing loss it's quite easy to rectify, but when you've got an audio-processing injury as well it's been hard"

"With hearing loss you can use hearing aids, but with tinnitus there is no cure and that's really frustrating. I got it to a level where I could live with it, but it never went away. Then after a medication mix-up after a knee operation I had a bad reaction, and my tinnitus just went through the roof. For about a year it really was ruining my life. I knew what was available on the NHS and I had tried it all before. People aren't aware of your tinnitus, so they don't understand why you can't tolerate them speaking to you, and that's the biggest frustration."

In 2017, with the help of the RBL (Royal British Legion), Harris became the first veteran in the UK to be treated with the revolutionary 'Levo' treatment that uses iPod technology to administer treatment while he sleeps.

"If I'm honest I didn't know a lot about what it could offer until I discovered that the charity funded hearing treatment. It's fair to say that the treatment – and indeed RBL – has given my life back to me."

The headphones that could ease tinnitus with a radical new treatment (From **Mail** Online)

Headphones that swap sounds from one ear to the other could be a radical new treatment for tinnitus. When a noise comes from the wearer's right-hand side, it is picked up by a microphone in the headphones and re-routed to the left ear. The opposite happens with sounds emanating from the left. Scientists think jumbling the direction of sound, with the eyes telling the brain it's coming from one place but the ears telling it the opposite, helps to 'rewire' the auditory nerve (which connects the ear to the brain), and this 'turns down' the tinnitus.

The results of a small trial suggest that using the headsets for two hours a day for three weeks significantly reduces their tinnitus. Many people put up with temporary tinnitus, but for around one in 100, the noises ringing is long term and is often combined with hearing loss.

When the ears are exposed to loud noise or infections, tiny hair cells that transmit sounds to the brain become stressed and emit excess quantities of a chemical called glutamate. This 'glutamate storm' overstimulates - and eventually kills - nerve cells in the inner ear, which send sound impulses to the auditory cortex, the part of the brain that processes noise.

This leaves cells in the auditory cortex switched on, so they constantly relay sound to the brain, causing people to 'hear' ringing, for instance. In some, the cells remain in this 'switched on' state. By this point, it is more difficult to treat. There are no drugs for it, and treatments include talking therapy, which helps patients live with the condition, or sound therapy, where background noise is used to distract them.

The idea for headphones treatment came from mirror therapy, which is used for phantom limb pain - where amputees still feel pain from the removed limb. By 'hiding' their affected limb behind a mirror which reflects the healthy limb, and focusing on this reflection, the brain is 'tricked' into thinking both limbs are intact. Studies suggest this leads to rewiring in the brain that reduces the perception of pain.

Scientists at Spaulding Rehabilitation Hospital in Massachusetts in the U.S., who developed the prototype headphones, think they work in a similar way, 'rewiring' connections between nerve cells so they no longer register tinnitus as a real external sound.

Results published in the Journal of the American Academy of Audiology in 2022 showed 18 volunteers experienced significant improvements in their symptoms. Now a trial is under way with 50 patients who will wear the headphones for three hours a day for three weeks, or a regular pair that play noise into the ear closest to the noise source. The results are expected later this year.

Commenting on the treatment, Dr Will Sedley, a lecturer in neurology at Newcastle University, said: "It's a neat idea, but we need the results of the trial before we can say it works. In the meantime, the one thing we know does work well for many people is talking therapy."

Engineering a solution for tinnitus (Update for Bionics Institute, Melbourne, Australia)

Building medical device prototypes is a way of life for Senior Research Engineer, Owen Burns. Over the past 13 years, his expertise in bio-mechanical engineering has been integral to the design of electrodes to treat Crohn's disease, epilepsy, blindness, and now tinnitus.

Owen and his team in the Bionics Institute Experimental Device Engineering Hub are working closely with lead researcher Dr Mehrnaz Shoushtarian to develop a new prototype to test tinnitus using a brain imaging technology that monitors oxygen levels in the brain called functional near infrared spectroscopy (fNIRS).

Dr Shoushtarian says: "We have developed an objective test of tinnitus using fNIRS and machine learning to detect tinnitus-related changes in the brain, which is an important step in developing reliable treatments". Using a general-purpose fNIRS system, Dr Shoushtarian and her research team have established a technique that detects tinnitus with 87% accuracy. However, to meet clinical usability requirements, a specialised prototype is under development. Supported by a generous donation from Hearts and Minds Investments the engineering team will produce five prototypes in 2024 for use in a multi-site clinical trial.

Dr Mehrnaz Shoushtarian and Owen Burns

CHUCKLES

● A man goes to a pet shop, where he sees a talking dog. After chatting to it for 10 minutes, he buys it. Later he goes to the pub and says, I bet everybody £5 this dog can talk. A number of people take the bet, but dog remains silent, and the man is forced to pay out. Puzzled, the man takes the dog home, where it starts chatting away again. Next time day the man returns to the pub and bets everyone £10 the dog can talk. To the man's astonishment, the dog clams up and won't say a word. After paying out on his bets, the man takes the dog outside and says, 'I'm taking you back to the shop. You are absolutely useless! 'Wise up,' says the dog. 'Think of the odds we will get tomorrow.'

● For months, a little boy has been pestering his father to take him to the zoo. Eventually dad gives in and off they go. When they get back, the boy's mother asked him if he had a good time. 'It was great,' replies the boy. 'And daddy had fun too, especially when one of the animals came home at thirty to one.'

● I have to exercise early in the morning - before my brain figures what I'm doing.

CTSG at the BANA Conference **(Notes from Alan Yeo)**

Tinnitus UK was invited to attend the British Acoustic Neuroma Association (BANA) Conference to be held at the Frank Lee Centre at Addenbrookes Hospital in October, and they in turn invited the CTSG as their local tinnitus support group in the area. Our companion for the day was Greg Hewitt, Fundraising and Events Administrator for Tinnitus UK.

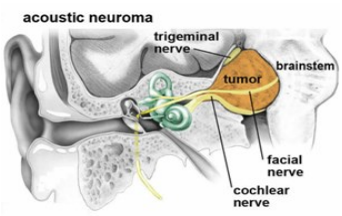
An Acoustic Neuroma (or Vestibular Schwannoma) is a benign skull-based tumour which develops gradually, and symptoms can include hearing loss (usually in one ear), tinnitus and possible vertigo. The condition can also compress the facial nerve, which can lead to temporary or permanent facial paralysis.

BANA was formed in 1992 by a patient-led group, and exist for mutual support, information exchange, listening and raising awareness for those with the condition. There are also two groups supporting patients: AMNET (The Acoustic Neuroma and Meningioma Network), and Facial Palsy UK. AMNET is based mainly in the East of England, with strong links to Addenbrookes, and two of their members act as 'patient representatives' in Clinic 10. [*It was founded in 1996 by consultant Davis Moffat, who was the first person I saw about my then recent tinnitus – Ed]*

Marian Day, our Facebook Coordinator, was my companion for the day, and committee member Pat Bowker, popped in to say hello. Everyone made us very welcome, and personally I felt there was a real 'family' atmosphere in the hall. This is maybe due to the fact acoustic neuromas are very rare, affecting only an estimated 0.001 % of the general population. Several attendees spoke to us about their tinnitus, but most seemed to be coping very well. We hoped to possibly 'sign up' some potential new members, but most seemed to have come from parts distant from Cambridge e.g. The Lake District etc.!

Several of the speakers were linked to Addenbrookes and all were excellent. We even had consultant ENT and Skull Base surgeon say he would be happy to come and talk to us!

A courageous lady told the story of the removal of her neuroma which was encroaching on her facial nerves, and her troublesome passage back to something like normality. Having to choose between an option which would definitely result in deafness but would be less likely to affect her facial nerves, or one that might not result in deafness, but would be more likely to result in facial palsy. Then the post-op effects of sickness and lack of balance etc., resulting in a long and difficult path back to walking properly. The support of her family was key in her journey.



Both Marian and myself found the day interesting and very worth while, and well worth the effort.

Could your waist size be affecting your tinnitus? (Summary from *Scientific Reports* by Nic Wray)

A recent research study has uncovered a potential link between tinnitus and body composition, particularly in men. So, what did the study explore, and what are the implications for people living with tinnitus?

The Korean study used data from the ninth Korea National Health and Nutritional Examination Survey, which included various physical, ear and hearing tests and bioelectrical impedance analysis (BIA) to assess body composition. Participants were categorised into two groups: those with tinnitus and those without. The tinnitus group was further divided into acute (lasting less than six months) and chronic (lasting six months or more) subgroups.

Study results

Higher body fat percentages: Men with tinnitus had significantly higher body fat percentages in the arms, legs, trunk, and overall body compared to men without tinnitus. This was true for both the acute and chronic tinnitus groups.

Increased waist circumference: Waist circumference, an indicator of central obesity, was also higher in men with tinnitus. This suggests a specific pattern of fat distribution linked to the condition.

Lower muscle and fluid percentages: Men with tinnitus had lower leg muscle percentages and reduced total body and intracellular fluid levels, indicating that muscle and fluid imbalances may also play a role in tinnitus.

Chronic tinnitus and body composition: Chronic tinnitus was associated with higher trunk fat percentages and greater waist circumference, alongside lower intracellular fluid percentages, highlighting a more pronounced body composition imbalance in those with long-term tinnitus.

Gender differences

Interestingly, the study found no significant differences in body composition between women with and without tinnitus. This suggests that the link between body composition and tinnitus may be more relevant to men, potentially due to differences in how men and women store fat and maintain muscle.

Implications

These findings suggest that body composition, particularly fat distribution and muscle mass, might influence or be influenced by tinnitus in men. Understanding this relationship could lead to better management strategies for tinnitus, such as lifestyle interventions focusing on reducing body fat and increasing muscle mass.

What does this mean for you?

If you are a man with tinnitus, it may be worthwhile to consider your body composition as part of your overall health strategy. Engaging in regular physical activity, maintaining a healthy diet, and managing your body fat and muscle mass could potentially help in managing tinnitus symptoms.

Tinnitus Definition and Cause by Tinnitus Specialists *(From Beyond Tinnitus website)*

In order to understand what causes tinnitus, and eventually how to cure the condition, we have to understand how the ear works. The ear is a fairly complex organ that converts soundwaves into brain signals by passing the waves through the ear canal, onto the ear drum and then through the ear bones into the cochlea (inner ear hearing organ), a small shell-like structure that picks up individual frequencies of sound. The cochlea works by transmitting different frequencies from the point where it receives the frequency to the corresponding point in the brain. The brain and cochlea are arranged exactly alike, with the frequencies (pitches) that are next to each other on the cochlea being exactly next to each other in the brain as well.

Tinnitus is caused when a particular frequency range in the cochlea is damaged and no longer sends information to the brain. This may seem strange at first as tinnitus is caused by the brain NOT receiving signals rather than receiving too much. To explain this, we need to understand one more piece of the puzzle of hearing: what do you hear when you hear nothing? Your brain is actually hearing a steady state of sounds, however soft, at every frequency simultaneously. Your brain tells you that you hear sounds only when it detects a pattern in the consistent noise it's receiving.

So, when you stop receiving signals from a particular frequency, it can no longer detect any patterns so you will at first hear nothing at that frequency. If you don't hear anything at a particular frequency at first, why do you eventually hear too much at that frequency?

Your brain is incredible and is very, very good at reusing space. For example, if you are blind your brain will often convert the areas traditionally used for image processing to instead process extra audio, smell, and taste sensations. In the case of tinnitus, your brain quickly recognizes that you no longer have a use for the space reserved for the frequencies that are damaged in your cochlea, so it reuses the space for other frequencies.

The frequencies near the damaged frequencies are given extra processing power. So they become better at detecting patterns and also tend to spontaneously fire more often. Unfortunately, that means they detect sounds much more regularly than other frequencies are detected, prompting the brain to create ringing or tinnitus. That extra spontaneous activity (firing of neurons) in the brain is interpreted by the rest of the brain as sound. So the conscious brain sees activity in the hearing part of the brain and interprets it as ringing, or other sounds.

Beware of tinnitus "cures" on social media. Many lack scientific backing and can be harmful. Always check with reliable sources. Use our treatment checker (https://tinnitus.org.uk/tinnitus-treatments) to check out the facts before trying any 'magic cures.' We provide verdicts on two aspects of each treatment:

Safety - whether the treatment will do you any harm:

3. Evidence of harm
2. Some potential for harm
1. Regarded as safe

Efficacy - whether the treatment works for tinnitus

3. Evidence that it is not effective
2. No or limited evidence that it is effective
2. Some evidence that it is effective
1 Evidence that it is effective

If you hear of a treatment that isn't listed, please call the Helpline 0800 018 0527 or send an email to: communications@tinnitus.org.uk

Please remember

This is your newsletter and all comments, letters, contributions or editorial copy relevant to tinnitus or CTSG, or anything you think maybe of interest to our members would be very welcome. Please send to:- Alan Yeo, c/o Newsletter Editor, 4 Claygate Road , Cherry Hinton, Cambridge CB1 9JZ (Tel. 01223 243570 alan.yeo622@outlook.com)

CONNECTIONS CTSG website: **www.cambstsg.com** Facebook: **Cambs Tinnitus Support Group** TINNITUS UK REGISTERED TINNITUS SUPPORT GROUP

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a Tinnitus UK-registered tinnitus support group. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting room, printing and postage of newsletters, replacement equipment and associated activities. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 15 February, where we are pleased to see Dr Eldre Beukes return as our speaker. Eldre will be telling us about some of her latest tinnitus research.