

Cambs Tinnitus Support Group

No. 172

NEWSLETTER

June 2024

MEETING

Saturday 15 June 2024

at

10.00 for 10.30 am

"Unusual forms of Objective Tinnitus"

Speaker: Professor Manohar Bance
Professor of Otolaryngology and Skull Base Surgery,
Spire Healthcare

Professor Manohar Bance is one of the UK's leading otologists. Practising in Cambridge at Spire Cambridge Lea Hospital, he has been a subspecialist in diseases and surgery of the ear for 23 years, during which time he has performed thousands of major ear surgeries. Professor Bance's practice covers the management of all diseases of the ear. He also treats vertigo caused by a number of different diseases of the ear, such as Meniere's disease, vestibular migraine and BPPV. Professor Bance originally qualified from the University of Manchester before pursuing training in Canada. After a 21-year career in Canada, Professor Bance moved back to the UK where he became the inaugural Professor of Otolaryngology and Skull Base Surgery at the University of Cambridge and was Fellowship trained in Otolaryngology and Neurotology.



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)

NB: Other free parking is available in St Albans Road. Turn R out of car park, St Albans Rd is next R.
The Centre is along the path across the green space

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Refreshments and Raffle

EDITOR'S CHAT

Tinnitus UK has reported a very successful Tinnitus Week, with excellent coverage on both TV and Radio. The BBC Morning live session with James Jackson I mentioned last time and a further 5 TV pieces, including Good Morning Britain, plus 37 radio interviews and 3 podcasts clocked up a potential multi-million coverage.

In a similar vein, recently there was an interesting feature on BBC Morning Live session featuring tinnitus, which as usual, I managed to miss. However Marian who looks after our Facebook page managed to pick it up from iPlayer, and the link is <https://tinyurl.com/j9drp7j2> The video will play from about 8 minutes, 27 minutes in, and features research being conducted by Dr Will Smedley at Newcastle university. Gareth Malone (who featured in one of our recent newsletter pieces) is the link 'tinnitus' person for the feature. Gareth also spoke to Maria who was living with tinnitus., and when Gareth offered her a million pounds or a cure for her tinnitus, she chose the cure. What would you do?

I recently saw Tinnitus UK has announced that they have been selected as the third and final charity partner of TinniSoothe®. Apparently this is a new product invented by people with tinnitus for people with tinnitus(?). Certified as a Class 1 Medical Device, apparently TinniSoothe® is a small, wearable white noise device that brings the benefits of sound therapy to you, wherever you are, 24/7. Has anybody tried it? I've never heard of the device, and certainly haven't seen any trials featuring it. Tinnitus UK are promoting it, although it doesn't appear in the Tinnitus Treatments section on their website.

You will read in Jim's Piece below that he has decided to stand down from being chairman (chairperson?). However he will continue in his role as our Webmaster, and will attend meetings when he's not zipping off to the mountains or some other exciting location. As a result we will need to vote in a new chairman at the AGM on the 15th, and this item will appear on the agenda that will accompany this newsletter.

Your committee has started to think about our meeting programme for next year. Hopefully we already have one speaker pencilled in, as Dr Kathryn Fackrell was unable to come to us this April, we hope she will visit us in 2025. Also we hope our Bring & Share event in November will mean Rachel will support our self-help session. Next year I believe she intends to let the members lead the meeting! If you happen to know of someone who you think would be of interest to our members, then please let me know.

I'm definitely not having much luck with my new voice recorder; last September it stopped recording in the middle of Kim Bee's talk, and in April I managed to inadvertently erase the recording when downloading to my PC. See apology at the start of my report on p3. Memo to myself-must try harder!

A Pictorial Metaphor for Tinnitus

From Martin Middleton

Last year I joined my local photographic club. About once a month they hold a competition where entries are reviewed by an external judge.

Their comments were:- nice freezing of the fountain's water arcs and droplets; interesting ripples on the ground but not quite mesmerizing; there's no detail in the under exposed areas at the sides, difficult to see the man walking on the left side and the white areas at the top are completely over exposed. All valid comments. Some of the other members thought this was a bit harsh and asked me to explain what I had intended.

Stress sometimes produces creative, possibly



subliminal answers. I replied that when editing the image, I was thinking about my tinnitus.

Each of the fountain arcs being a representation of the different sounds we hear. The mesmerizing ripples the way tinnitus can mess with our heads. The dark spaces where we go looking for answers which we cannot find, when instead we should be seeking encouragement to raise our spirits, whether through CBT, mindfulness, meditation or other therapies. To lift our gaze and lookup for the light at the end of the imaginary tunnel.

I called the photo 'Arc Angle'.

JIM'S PIECE

My big news is I am taking the plunge and standing down from the chairmanship.

I have enjoyed being the chairman of our wonderful group for the last 8 years, and hope you feel I have done a good job, as well as a very committed and supportive team working behind the scenes to make our meetings successful. The group did well to keep going through the challenging Covid times, and it's good we are now back to our regular pre-Covid attendance levels. We eventually made the transition to our new premises, and although not everything is running smoothly, it's encouraging to see good attendances, both from old hands and newcomers.

With the freedom of retirement, I am making the most of travelling and hiking, while I am still fit enough to enjoy it. However I do not like to miss meetings, and therefore feel it's time to hand over the baton. The AGM will confirm who that will be. I still plan to come to our meetings when I am in the country as they are always such a positive and uplifting experience. May the group continue to flourish and provide the valuable service it has for so many years. I wish our new chairperson every success.

Jim Infield
CTSG Chair

April Report

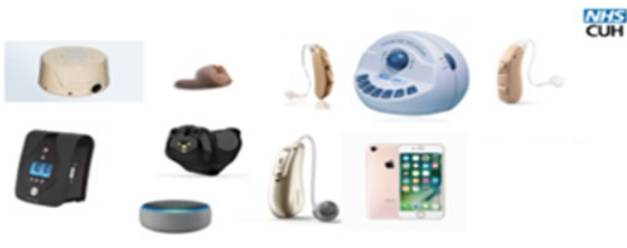
Just over twenty members attended our meeting on our usual sunny morning. Our planned speaker, Dr Kathryn Fackrell, unfortunately was not well, and we were fortunate that Rachel was able to step in at the last moment. The talk she gave us on sound therapy was based on a presentation she prepared for Otto app. developers.

At this juncture I must apologise that my report is not up to my usual, hopefully decent, standard. Unfortunately while down-loading the audio file, I managed to erase it, thus leaving only Rachel's slides and some odd notes with which to prepare the report.

Sound therapy is the use of an electronic device to produce sound for therapeutic use. This includes masking, using sound to make tinnitus less audible, sound enrichment, and the use of different sounds to make tinnitus less annoying/intrusive.

Benefits of the therapy include making the tinnitus less audible (masking), and providing relief as well as giving patients a break from their 'noise'. It can reduce the contrast between the external environment and the tinnitus, providing a distraction. It can also promote relaxation, as well as providing sound enrichment so the tinnitus is less intrusive and annoying. It has been shown to trigger neuro plastic changes within the brain, and can give a person back a sense of control over their noise.

Below is a selection of such devices from the last 20 years to illustrate how the technology has advanced:-



Devices, inc. Amazon's Alexa, can play up to 125 sounds, inc. City rain, Heavy rain, Rain on a tin roof, Distant thunder, Rain on a tent. Plus, Grandfather Clock, Cat Purring, Vacuum etc. A sample of noises/sounds were played, some via Alexa, with differing responses from the audience, mostly adverse.

Listening at Night

An external sound source can be particularly useful at night, when tinnitus can be at its most intrusive.



These sources can include pillow speakers, Sound Oasis unit or a virtual assistant device like Alexa.

Who else is using sound therapeutically? (besides those with tinnitus):

For young people there is an increasing trend thanks to influencers on TikTok, YouTube etc /People with Anxiety/Insomnia ADHD/Autism.

ASRM: Autonomous (spontaneous) Sensory (related

highest development)

Response - an experience triggered by something external or internal.

A term used to describe a tingling, static-like, or

goosebumps sensation in response to specific triggering audio or visual stimuli. It triggers a mildly euphoric, tingling sensation. Studies indicate it can help with anxiety/stress and also with sleep. It is the 3rd most popular search item on YouTube.

Binaural Beats

The brain perceives one sound which is equivalent to the difference between the two frequencies. Listening to two different tones in each ear, with slightly different frequencies, produces a third frequency tone. Potential Benefits include Lower stress/Increased focus-marketed for ADHD/Improved sleep/Relaxation /Boosts mood/Reduces pain/Fosters creativity.

Hearing Aids

What can hearing aids do for tinnitus?

When hearing aids are fitted to tinnitus patients, the clinician is trying to improve the audibility of one set of sounds while reducing the audibility of another (set of) sounds.

Before deciding what sort of device would be beneficial, the audiologist has several topics to initially consider, including:

- Motivation: hearing or tinnitus
- Life-style
- Dexterity
- Family Support
- Workplace
- Memory Issues
- Speech Discrimination
- One or both ears?
- Open fit?
- Comfort

How do hearing aids help?

- Improvement in hearing has psychological benefits
- Reduced listening effort that can be tiring
- Less attention paid to hearing and therefore tinnitus
- Helps understanding the impact of hearing loss
- Increased awareness of background noise, reduces awareness of tinnitus
- Opportunities for further counselling around hearing loss and tinnitus
- Internal circuit noise can help? (or combination sound generator noise)

[It's worth mentioning that several of our members in the past have had great success with their hearing aids – Ed]

Combination devices

Hearing aid with the option of a sound generator for those with milder hearing loss or not ready for amplification. Can be set as a separate programme, sound generator only or combined with the amplification.

Bluetooth

Enables the user to stream a far greater range of sounds and to create 'soundscapes.'

Rachel answered many questions during what was a very interesting session, and was given well deserved applause at the end.



Typical ASRM sounds

Humorous Quotes At 75, I sleep like a log. I never have to get up in the middle of the night to go to the bathroom. I go in the morning, like clockwork, at 7 am, I pee. Unfortunately I don't wake up until 8.00 am. *Harry Beckworth*

The distress caused by ear wax is rarely appreciated by those who have never experienced it

The National Institute for Health and Care Excellence (NICE), who provide guidance to health and care professionals, recommend that ear wax removal services should be provided by the NHS in local settings. Why then are people finding it so difficult to have ear wax removed locally by the NHS? Questions have been raised in Parliament about why people with ear wax are being referred to hospitals, resulting in long waiting times with expensive and inefficient use of specialist services. The alternative for individuals is often to pay a private clinic, essentially a 'tax on wax'. This applies to my own father, elderly and relying on hearing aids, as well as people on low incomes.

RNID is to be applauded for its ongoing campaign. Its investigations have revealed that less than half of Integrated Care Boards (ICB), who plan and deliver health and social care, are following NICE guidance on ear wax removal.

This new report is a clarion call. Remove the postcode lottery, follow NICE guidance, and improve the quality of life for two million people who need ear wax removed each and every year, and often on multiple occasions.

Kevin J Munro

Ewing Professor of Audiology at Manchester Centre for Audiology and Deafness,

CHUCKLES

Harry and Bob are out in their car. They park, get out, and shut the doors when Harry realises that they've locked themselves out. Bob says, 'We can get a coat hanger and try to unlock the door.' Harry says, 'Or perhaps we can prize the door open.' 'Well, whatever we do, we'd better hurry up,' say Bob. 'A storm's coming, and the top's still down.'

A man goes into a pub with a cat sitting on his head. The barman pulls him a pint and say, 'Look, I don't know if you know it but there's a cat sitting on your head.' 'What of it?' asks the man, I always wear a cat on my head on a Monday,' 'But today's Tuesday,' replies the barman. 'Oh God, is it?' says the man. 'I must look a right idiot.'

An Irish professor of linguistics is chatting with a Spanish counterpart when the latter asks him if there's an Irish equivalent of 'mañana.' The Irishman thinks for a moment and says, 'Yes, but it doesn't really convey the same sense of urgency.'

Why did the the escaped convict saw the legs off his bed? Because he wanted to lie low.



Another artist's impressions of tinnitus

Mass Eye and Ear study revives theory that tinnitus could have its origins in cochlear neural degeneration

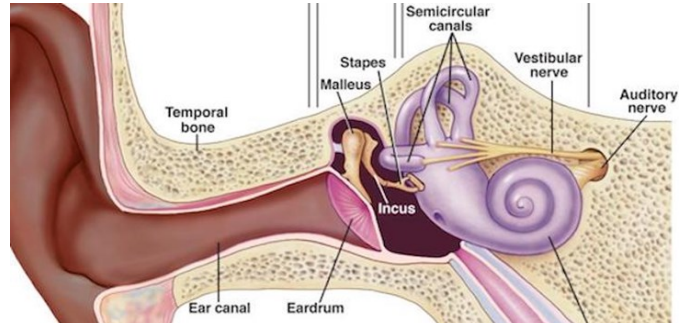
The goal of silencing tinnitus will not advance until there is understanding of the mechanisms underlying its genesis. This is the firm belief of Dr. Stéphane F. Maison, principal investigator at Massachusetts Eye and Ear Infirmary, and clinical director of the Mass Eye and Ear Tinnitus Clinic.

To advance this understanding, Dr. Maison - also a member of Mass General Brigham - and colleagues have authored a recently published study in Scientific Reports that takes the tinnitus cause investigation back to where it lost ground, showing that tinnitus may be triggered by a loss of auditory nerve, including in people with normal hearing. And the trail along this tinnitus-related investigative strand dovetails with work seeking a chemical cure to hearing loss itself.

Why was a neural degeneration tinnitus origin theory knocked back?

The buzzing, humming, ringing or roaring sounds that those with tinnitus experience have long been considered to arise as a result of a maladaptive plasticity of the brain. In other words, the brain tries to compensate for the loss of hearing by increasing its activity, resulting in the perception of a phantom sound, tinnitus. Until recently though, this idea was disputed as some with tinnitus have normal hearing tests.

But the discovery of cochlear synaptopathy back in 2009 by Mass Eye and Ear investigators revived this hypothesis when it was shown that patients with a normal hearing test can have a significant loss to the auditory nerve. In this latest study, Maison and his team sought to determine if such hidden damage could be



associated with the tinnitus symptoms experienced by a cohort of normal hearing participants. By measuring the response of their auditory nerve and brainstem, the researchers found that chronic tinnitus was not only associated with a loss of auditory nerve but that participants showed hyperactivity in the brainstem.

In the study, statistical analyses followed comprehensive testing using audiometric thresholds, auditory brainstem responses/electrocochleography, middle-ear muscle reflexes, and medial olivocochlear reflexes. Concluding, the authors say their study "clarifies the association between biomarkers of peripheral neural deficits with tinnitus and is consistent with the idea that cochlear neural degeneration may serve as a peripheral trigger for excess central gain.

"The idea that, one day, researchers might be able to bring back the missing sound to the brain and, perhaps, reduce its hyperactivity in conjunction with re-training, definitely brings the hope of a cure closer to reality", said Maison.

Working as a DJ in Liverpool, UK, a decade ago, James Rand would often leave work hearing strange sounds that he knew weren't real – a high-pitched whine or a low rumble. These symptoms of tinnitus always disappeared by the time he awoke until one day they didn't. A doctor confirmed that the sounds had probably been caused by Rand's exposure to loud music for hours at a time. There were no treatments, bar ways to help him get used to it. "I knew I was never going to hear silence again," he says. "It was incredibly depressing."

Tinnitus is one of the most common long-term medical conditions, affecting up to a quarter of older adults. The sounds can be intrusive and distracting, sometimes leading to depression, anxiety and difficulties sleeping. They can also interfere with hearing. Rand was worried it would affect his job as a music producer, his main career. "I work in music and I'd killed my ears," he says. "I spent a long time being angry at myself." When someone first seeks help for tinnitus, doctors usually try to rule out potentially treatable causes, such as a build-up of earwax or a reaction to medication. But most people end up being advised to find some way to live with it, using strategies such as talking therapies, hearing aids, or white noise to mask tinnitus sounds while going to sleep.

The link between tinnitus and hearing loss is paradoxical: the former is hearing things that aren't there, while the latter is being unable to fully hear. The leading explanation for this link is that the loss of input from the ears causes the brain to compensate by becoming more sensitive – sometimes called the central gain theory. As a result, the brain creates the illusory sounds of tinnitus in a similar way to how someone with an amputated limb may feel phantom sensations from the missing body part. But there is a problem with this hypothesis. There are some people, like Rand, who have tinnitus but have normal results on hearing tests.

An explanation for this has come from our growing understanding of how hearing can be damaged. Ordinarily, sound waves pass through the eardrum and reach fluid inside a spiral chamber within the inner ear called the cochlea. Cells with tiny hairs that are buffeted by this fluid turn sound waves into electrical impulses that travel along nerves to the brain. These hair cells gradually die off as we get older, especially the ones that register high-frequency sounds. For a long time, the assumption was that loud noise also damages hearing by killing hair cells.

Sharon Kujawa and Charles Liberman at Harvard Medical School showed that, under moderate noise overexposure the nerve fibres that carry signals from hair cells to the brain are more vulnerable to noise damage than hair cells.



Dr Charles Liberman

What's more, the damage doesn't affect all the fibres equally. While they look similar, there are at least three different types, letting us process sounds at different volumes: quiet, intermediate and loud. The ones that process loud sounds are most susceptible to damage.

The findings have several important implications. The first is that, if hearing loss that happens with ageing follows the same pattern, it explains why it's so common for older people to have difficulties understanding speech in noisy surroundings. Presumably the nerve fibres that respond to quiet sounds are fine but the nerves that respond to loud sounds have been damaged.

A second implication relates to the cause of tinnitus. People who have the condition but have good hearing, according to an audiogram, has long been a stumbling block for the central gain theory. However, if they had damage solely to their loud nerve fibres, this wouldn't show up as hearing loss in an audiogram, which only measures the quietest sounds that people can hear. This strengthens the case for the central gain theory. "It presented a new way to think about people whose audiograms are normal, but who have tinnitus," says Liberman.

Two years later, Roland Schaette and David McAlpine at University College London showed this could indeed be happening in people, as well as animals. They found that people with tinnitus but normal results in



Dr Roland Schaette

hearing tests had lower activity in the nerves leading from the ear to the brain, compared with those without tinnitus and normal hearing – supporting the idea that the brain is getting less input from the damaged "noisy nerves" and so responds by generating the phantom sounds of tinnitus.



Dr David McAlpine

The researchers also proposed that the condition of having hearing problems only in noisy environments be called hidden hearing loss.

The evidence that noise exposure can affect cochlear nerves to cause hidden hearing loss, even before it kills hair cells, is starting to be taken more seriously. But it is still unknown how common this form of hearing loss is, as it is such a recent discovery.

Rand says that his experience fits the description of hidden hearing loss. Standard tests indicate his hearing is fine, but he has difficulties understanding speech in noisy environments. "My hearing is quite bad if I'm walking with my son with the background sound of cars," he says. "I'm constantly having to stick my ear closer to him."



Dr Sharon Kujawa

Part 2 in next newsletter

Humorous Quotes

Like all ruins I look my best by moonlight. Give me a sprig of ivy and an owl under my arm and Tintern Abbey would not be in it with me. *W.S Gilbert* How foolish to think that one can ever slam the door in the face of age. Much wiser to be polite and ask him to lunch in advance. *Noel Coward*

Current perspectives of tinnitus and its management - Part 2

by Don McFerran, Marc Fagelson and Gerhard Andersson

Tinnitus - *the perception of sound in the absence of an external source - continues to intrigue, perplex, and infuriate clinicians, researchers and those with the condition. The authors here present an overview of the current approaches to tinnitus.*

(From ENT and audiology)

Psychological management

Psychological therapies remain the treatment options with the best scientific evidence of producing the desired result. efficacy. Cognitive behavioural therapy (CBT), mindfulness-based cognitive therapy (MBCT) and acceptance and commitment therapy (ACT) have all shown positive effects when investigated using randomised control trials. Unfortunately, there is a shortage of therapists who are both qualified to deliver these treatments and have the necessary tinnitus knowledge. Proof of concept studies have shown that CBT for tinnitus can be successfully delivered via the internet, and there are plans to introduce this into clinical practice in the UK as part of the Improving Access to Psychological Therapies (IAPT) programme. Psychological therapies continue to evolve, and it is likely that we will see other modalities (something likely, desirable, or permissible) used for tinnitus, particularly from the fourth wave of cognitive therapies.

Drug therapies

For many in the tinnitus world, development of a tinnitus drug is the ultimate goal. Although such compounds remain elusive, there have been some drug trials that got tantalisingly close to a solution.

Retigabine is a drug that was primarily developed for its anticonvulsant properties, and research on rodents suggested efficacy against tinnitus although this was never tested in a scientifically controlled trial. Unfortunately, retigabine had significant side effects and was withdrawn from clinical usage in 2017.

An epilepsy drug, selurampanel, was investigated for tinnitus efficacy in a double-blind placebo-controlled randomised controlled trial, and measures of both tinnitus impact and tinnitus loudness improved during treatment. Unfortunately animal tests resulted in benign and malignant tumours.

Bimodal neuromodulation

Bimodal neuromodulation combines sound therapy

with simultaneous stimulation of a non-auditory neural pathway. A commercial device is now available that combines sound stimulation with gentle electrical stimulation of the front of the tongue. Initial results are optimistic but independent and more rigorously controlled studies are required. [*This is the work being done by Dr Susan Shore and team at Michigan University – Ed*]

Transcranial electromagnetic stimulation

Various forms of electromagnetic stimulation have been explored for use in tinnitus, with treatments directed at both peripheral and central auditory systems and associated areas of the wider central nervous system. The two most rigorously investigated modalities are repetitive transcranial magnetic stimulation (rTMS) and transcranial direct current stimulation (tDCS). A strong varying magnetic field is applied over the scalp in rTMS to induce electric currents in the superficial layers of underlying brain tissue.

There is now a solid evidence base in support of rTMS in the management of treatment resistant depression.

Tinnitus trials with small numbers of participants have used different study designs. Several editorials have highlighted this issue surrounding tinnitus research and have suggested that a large multicentre study is required. In contrast to inducing electrical activity in the brain using magnetic fields, tDCS applies low power electrical stimulation directly to the scalp. Evidence regarding tDCS is still emergent, but it does seem helpful for some people with depression and schizophrenia. There is conflicting evidence regarding its efficacy for tinnitus, and further research in this area is needed.

Conclusions

Understanding tinnitus and developing effective treatments has never been easy but there is now a more structured and collaborative research network trying to solve the puzzle.

Humorous Quotes The older you get, the more important it is not to act your age. *Ashleigh Brilliant* My doctor says I have to have a hearing aid because there's a blockage in my Euston Station tube *Joe Hadley* The great thing about being 70 is, what can they do to you? What have you got to lose? It's just another word for freedom. *Clint Eastwood* Sometimes I wake up grumpy, other times I let him sleep. *Car bumper sticker*

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**



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 21 September we welcome back Nic Wray, Communications Manager, Tinnitus UK, for a talk on a topic yet to be revealed. Not a meeting to miss!