

# Cambs Tinnitus Support Group

No. 175

NEWSLETTER

April 2025

## MEETING

**Saturday 26 April 2025**

at

10.00 for 10.30 am

**"Update on clinical trials at Nottingham - addressing tinnitus research priorities"**

**Speaker: Dr Derek Hoare**  
Associate Professor in Hearing Sciences  
Research Lead in Tinnitus and Hyperacusis  
Nottingham Hearing Biomedical Research Unit, NIHR

Having trained as a nurse, Derek moved to The University of Manchester where he completed his BSc (Hons) Neuroscience, a Master of Research in Biological Sciences and finally his PhD in Sensory Neuroscience. His PhD work led to a particular interest in understanding the abnormal perception of 'phantom' sensations such as tinnitus, and how such sensations might be modulated by experience. He now leads a diverse portfolio of research in tinnitus, hyperacusis, and hearing loss at NIHR Nottingham Biomedical Research Centre. Derek is also currently Chair of the British Society of Audiology.



## 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 building (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. If necessary, parking might still be available in Daisy Close, as used for the February meeting. See details in e-mail.

### CONTENTS

2. Editors Chat ~ Martin's Missive
3. February meeting report: The effects of tinnitus on significant others (SOs)
4. New thinking about tinnitus ~ Chuckles ~ Positive developments in 2024
5. Tinnitus Week Research Launch Event Report by Martin Middleton
6. Flight Lieutenant George Webster's account of his tinnitus journey ~ Humorous quotes on appearance
7. Rachel Knappett's thoughts on the Tinnitus UK Research Report Day

**Refreshment & Raffle**

## EDITOR'S CHAT

The general public was certainly made aware of the topic of tinnitus during Tinnitus Week 2025, thanks initially to the brilliant performance of Dr James Jackson on the BBC Breakfast settee, and then by the publishing of Tinnitus UK's report, "Ringing the alarm: The tinnitus care crisis"

The charity is calling for better training for healthcare professionals. It says NHS patients face waits of up to three years for ENT appointments and more than 12 months for hearing aid assistance and psychological therapies - severely impacting patients' mental health and quality of life. Tinnitus UK CEO Alex Brooks-Johnson adds the charity is calling on the Department of Health and Social Care and the NHS to take a more consistent approach to training. He says: "We think we have an answer, which is that GPs are not potentially the best people to speak to. 1 in 7 people have it. It's a hugely prevalent condition but for most people they live well." "What we are hearing from people who have tinnitus is that the first conversation people are having isn't good enough and often they're being told there's no cure and nothing can be done, and they have to manage it themselves. That can make it worse because there's a direct correlation between stress and tinnitus."

Martin Middleton and Rachel Knappett travelled to Sheffield to attend the launch of the above report and you can read Martin's thoughts on page 5, and Rachel's impression of the proceedings on page 7.

In February it was brilliant to have Dr Eldré Beukes along as our speaker. She is a very busy lady and we were lucky she could spare us the time. Her talk, 'the effects of tinnitus on significant others', was a subject that I doubt many, if any, of her audience had ever seen as a research topic before, and this made the meeting all the more interesting!

Significant others (or SOs) seemed an slightly odd term, but it merely describes anyone; partner, parent, child, relative or child, who might have substantial close contact with anyone with tinnitus. Unsurprisingly, 87% of the those taking part in the study were partners, and it was therefore fitting that in our audience, by coincidence, there were also five couples. This helped make the discussions during the talk, and afterwards, really meaningful and useful.



Those of you who have been members for some time will be aware of the leaflets that the BTA used to produce, put together by a committee of experts, and updated when appropriate. Our leaflet folder was always on the display table at meetings for members to peruse leaflets and perhaps take a copy away. Well Tinnitus UK have updated some 14 leaflets to date, several of enlarged from the originals, and some in colour. Unlike previously, however, where the BTA use to supply the leaflets to the support groups for free, we now have to download them and pay for them to be printed professionally ourselves. The new leaflets are now available to peruse at the meetings, but if members think that they would like a copy they will have to download them themselves.



My apologies that the February meeting report on page 3 did not feature a picture of Dr Beukes giving her talk. We just ran out of space!

## MARTIN'S MISSIVE - 'Worlds Apart or Living in the Moment?'

Over the last four issues of the Newsletter, I've been attempting to show in picture form how Tinnitus can be explained to the 83% of the UK population who don't experience Tinnitus. This time I'm trying to show how your mood can be observed.



Consider the lady in the white coat. She's walking away from the fun. Like Jim with hyperacusis, telling us he just doesn't want to be in some noisy places, regardless of the fun.

I sometimes feel like the photographer, immersed in my own world and just ignore what's surrounding me, even when it makes fun of me.



Other times when we feel like joining in the fun, we end up like the boy in the blue coat, on the sidelines not knowing or daring enough to live in the moment, like the two children bursting the bubbles.



With Best wishes

Martin Middleton  
CTSG Chair

Eldré began her talk by reminding her audience that little is known regarding the impact of tinnitus on significant others (SOs), such as spouses or partners. This study was therefore aimed at identifying the effects of tinnitus on this group. This study was a follow on from the impacts of the COVID-19 pandemic on tinnitus, which among other factors impacted the relationship between tinnitus and emotions, including anxiety and depression. Some challenges also affect those they live with, as people severely affected by tinnitus may reduce socializing or household tasks they had previously participated in. There may also be a two-way health impact on those with tinnitus and their SOs, and this effect is known as "third-party disability".

The study group consisted of 156 SOs, with a mean age of 56 years and they completed three open-ended questions focusing on the effects of tinnitus. Individuals with tinnitus completed the Tinnitus Functional Index as a self-reported measure of tinnitus severity. 85% of the SOs reported that tinnitus impacted them.

#### Study: Impact on SOs

Possible lifestyle changes may include:



So could these changes impact others? Examples might include:

**Sound adjustments:** TV/Radio speech too quiet or too loud, constant adjustment.

**Activity limitations:** Social withdrawal (not going out as much), less music, sensitive to external change.

**Emotional impact:** Stressful, frustrated, feel hurt, more annoyed.

**Helplessness:** Worry, unable to support, difficulty understanding, sadness about the change.

**Demands:** Unable to support, difficulties understanding, sadness about change, worry.

#### Study: Impact on the relationships

When asked if tinnitus had any positive effects, 42% said their relationship had strengthened, bringing them closer together. They were also more open about their problems, resulting in a growing mutual respect.

A greater percentage of SOs (58%) had negative views on their relationship. Communication problems were high on their list, leading to misunderstandings, frustration and strained relationships. This often lead to negative mindsets and a feeling of growing apart.

#### Study: Severity of the impact on SOs

In order to assess the impact of tinnitus on significant others, Eldré explained they had developed a questionnaire using psychometric validation, entitled: Developed and validated the Consequences of Tinnitus on SOs Questionnaire (CTSOQ)

[Psychometric validation properties identify and define critical aspects of an assessment - Ed].

**Observations** regarding the person with tinnitus - how big is the impact? e.g. having difficulty sleeping?

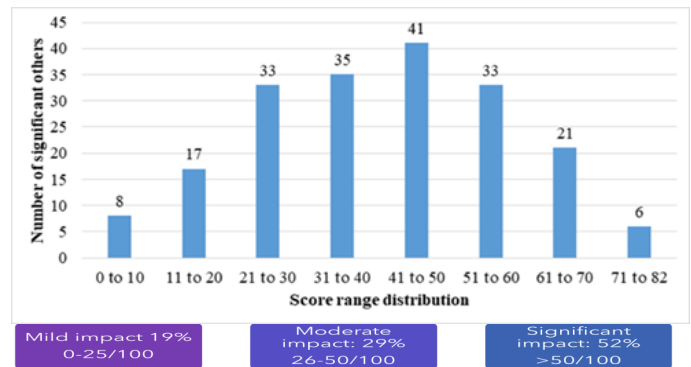
**Personal Impact** - e.g. there are more pressures on me due to the other persons tinnitus

**Relationship** - e.g. We do not socialize with other

people as much as before tinnitus

**Support** - Understanding the effect of tinnitus more

#### Severity



#### The most significant Predictors of greater impact on SOs

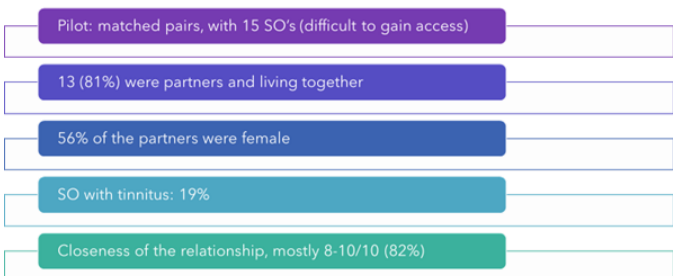


#### Study: Including significant others in interventions

Modules for SOs invited to continue



#### Effect of joint intervention



#### Study: Positive effects of tinnitus on SOs

**Positive lifestyle changes** – More relaxing activities/New pastimes/Slowing down

**Personal development** – Understanding/Empathy/Patience

**Health awareness** – Healthier lifestyle/Hearing loss awareness

**Changed outlook** – Grateful/Being proactive

There was no association between the level of tinnitus severity and SOs reporting that tinnitus had an impact on them individually, their relationships, or those reporting positive experiences. The study highlighted the third-party disability many SOs of individuals with tinnitus experience, and the results indicate that SOs may benefit from a shared intervention to help mitigate the negative effects through a better understanding of tinnitus.

Not knowing the topic of Eldré's talk it was a fortuitous that 5 couples attended the meeting, probably the most we have ever had. There was much discussion during and after the meeting concerning living with someone with tinnitus, and the potential effect it can have on one or other of the parties. Seeking positive experiences, as suggested in the conclusion to the study, may well help those concerned.

## New thinking about tinnitus

(Edited from Harvard Health Letter)

### Harvard Medical School scientists close in on a mysterious cause of ringing in the ears

Experts have long debated the most common cause of tinnitus, and some have maintained that it is triggered by hearing loss: with less sound coming in, the brain compensates by becoming hyperactive and generating a phantom noise. But that theory hasn't explained the problem for people with normal hearing tests who still have tinnitus. What causes tinnitus in those cases?

#### Mounting Evidence

Increasingly, scientists from Harvard Medical School have found evidence that some people have "hidden" hearing loss: damage to the auditory nerve - which carries sound signals from the ear to the brain - that isn't picked up by conventional tests.

Researchers first discovered the phenomenon in lab mice in 2009. "From there, it wasn't difficult to add two and two by suggesting that the loss of these nerve fibres in people with normal hearing tests could be associated with tinnitus," says Stéphane Maison, a tinnitus researcher and associate professor of Otolaryngology - Head and Neck Surgery at the School. Subsequent studies began making the connection, and the latest was published November, 2023. Maison and his colleagues at affiliated Massachusetts Eye and Ear recruited almost 300 people (ages 18 to 72) with normal hearing tests who had chronic tinnitus, no tinnitus, or intermittent tinnitus.

Scientists measured participants' auditory nerve responses and brainstem activity. Compared with not having tinnitus, having chronic tinnitus was associated with a loss of auditory nerve fibres as well as increased brain activity. "That fits with the idea that as a result

of hearing loss, the brain increases its activity, which is possibly why you perceive a tone or a sound that isn't there," Maison says.

#### What this means for treatment

For people with measurable hearing loss, getting hearing aids sometimes reduces the perception of tinnitus. But hearing aids aren't recommended for people with normal hearing test results - even if your doctor suspects hidden hearing loss - since we don't have tests outside of research labs to measure it.

Still, the new evidence linking hidden hearing loss and tinnitus offers hope for people with tinnitus. "When you have hidden hearing loss, only a portion of the auditory nerve has degenerated. Another portion remains alive for years or decades. And a number of experiments by others have found that it's possible to regenerate nerve fibres in animal models," Maison says. "If we can one day regenerate those fibres in humans, perhaps it might bring back missing information to the brain, reducing its hyperactivity and the perception of tinnitus."

#### What you can do

- Distract your brain. Listening to white noise or nature sounds might make tinnitus seem quieter. Use a white noise machine, sleep headphones, earbuds, or a wearable sound-masking device.
- Join a registered Support Group (Tick!)
- Reduce stress. Stress may increase both your perception of tinnitus and your reaction to it. Try yoga or tai chi to help manage stress; since you'll be concentrating on movement and breathing, you might not focus on the tinnitus as much.

#### Chuckles

• An art collector is walking down the road when he notices a mangy cat in a shop doorway lapping milk from a saucer. He realises that the saucer is extremely old and valuable, so walks into the store and offers to buy the cat for £2. The store owner replies, 'I'm sorry, but the cat isn't for sale'. The collector says, 'Please I need a cat around the house to catch mice. I'll pay you £20 for it.' The owner says 'OK, Sold.' And hands over the cat. The collector continues, 'Hey, for the £20 I wonder if you could throw in that old saucer. The cat's used to it and it would save me having to buy a dish.' The store owner says, 'Sorry, chum. That's my lucky saucer. So far this week I've sold 68 cats.'

## Positive Developments in 2024

(Edited from Tinnitus Talk Forum)

Some of you may already access the Tinnitus Talk Forum, or you may remember the odd article I have used in the past. It's run by a couple of Americans (Hazel & Markku) who recently posted a list of what they saw as giving them hope for 2025:

- Dr. Hamid Djalilian received a patent for his trans-stypanic electrical stimulation device, which showed complete tinnitus suppression in some patients (preliminary results).
- The Apple Hearing Study collected data on hearing and tinnitus from over 160,000 participants, bringing new energy to the field.
- The Rainwater Foundation launched a big consortium project to find an objective marker for tinnitus.
- Considerable advances in tinnitus research include new insights about tinnitus as an inflammatory response and the genetic basis for tinnitus.

- Tinnitus Hub organized a panel at the Tinnitus Research Initiative (TRI) conference, indicating that the research community takes patient voices more seriously.
- Tinnitus Quest is a new non-profit foundation co-founded by us and initiated by a German entrepreneur called Sven Köllmann. Frustrated with the lack of progress with tinnitus research, he has already donated significant sums directly to tinnitus research. But Tinnitus Quest will provide a much bigger platform to bring together many patients, donors, and researchers with the simple (but not easy) aim of silencing tinnitus.

For 2025, we expect that Tinnitus Quest's first research projects will take off, testing experimental treatment approaches. And we're confident that some of the above-mentioned developments will yield something valuable for the community.



To me it was very apparent that the target audience for this event was professionals in the provision of care, GP's, audiologists, ENT, therapists, counsellors and educationalists. The report title "Ringing the alarm: The tinnitus care crisis" is unlikely to inspire confidence in the provision of care to support group members. However, what was observed, both with the report and at the conference, was that whilst there's difficulty getting answers, the right questions are being asked.

The programme for the day: -

- *Introduction: by Alex Brooks-Johnson – CEO Tinnitus UK*
- *Report presentation: Sonja Jones – Lead report author*
- *Panel discussion*
- *Personal experience of Tinnitus: Flight Lieutenant George Webster, RAF*
- *What do patients want? Dr James Jackson - Report co-author*

Taking these in reverse order, I'm leaving Dr James Jackson's presentation for a separate write up. For me he's on a par with Prof Brian Cox: informative, entertaining and inspiring, and deserves the extra space. Same for Flt Lt George Webster's experience, which is very relatable, so I've given him separate airtime, and his presentation appears in this newsletter.

For me the panel discussion was confusing and disappointing. In the absence of a cure the best that can presently be done is through delivery of therapies; CBT, Mindfulness, Meditation etc... The lack of referring on by GP's and the delay in getting to a therapist is the dilemma. Do nothing or wait doing nothing. To solve the supply/demand problem much of the debate was on having the audiologist introducing a therapy, for which they're not qualified, or a therapist trying to help with tinnitus/hearing problems, where they have little experience.

Alex Brooks-Johnson in his introduction mentioned the Focus Groups, currently under way with support groups around the country (see November N/L), and I expect later this year we'll have another report from Tinnitus UK which is aimed specifically at our issues.

Sonja Jones opened her presentation with a sobering caveat to their survey:-

- *Only 5% of respondents offered CBT*
- *The number of people waiting for secondary care has tripled from 2019 to 2023 and 1 in 6 are waiting more than 12 months.*
- *More than 20% of respondents experienced thoughts of suicide or self harm in the last year.*

Those surveyed included: Universities, Private Sector

(PS) & NHS Hearing Health Practitioners (HHPs). Rather than list the questions, I'll skip straight to some of the salient points of the survey. But first another caveat from Helen Macdonald BABCP Senior Clinical Advisor:-

The current situation in the UK allows people to call themselves a psychotherapist or offer unregulated services to the public without being held to account."

Findings of the survey:-

- *There are significant variations from the NICE guidelines between the NHS and the Private Sector HHP's*
- *There are significant deviations in assessment and treatment options by both NHS & PS HHP's*
- *None of the Universities that responded provided clinical training, assessment of clinical competence, and tinnitus was treated as a secondary symptom*
- *Tinnitus Continuing Professional Development for NHS & PS HHPs was never reported above 50%*
- *In the PS 33% do not prioritise tinnitus care, only 12% consider it essential*
- *NHS has long waiting times:- up to 3 years for ENT; one year for hearing aids and psychotherapies*
- *In the PS 83% report the knock-on-effect of NHS delay but, per above, only give tinnitus a low priority*

Six IdEARS for change:-

- *Embed NICE guidelines fully*
- *Recognise and share best practices*
- *Foster cross-industry collaboration*
- *Standardise tinnitus education and CPD*
- *Align curricula with best practices*
- *Upskill the workforce*

My conclusion was that the report and conference was seeking the causes of the problem with regards to tinnitus treatment and the Focus groups will reveal many of the symptoms.

Ps. The importance of Tinnitus support groups didn't play much of a role in the report or conference but that's not to say that their importance was underestimated or undervalued.

The full report can be downloaded from the Tinnitus UK website or with the link below:-

<https://tinnitus.org.uk/wp-content/uploads/2025/01/TINNITUS-WEEK-2025-REPORT-FINAL.pdf>



Dr. James Jackson has been a member of the Tinnitus UK Scientific Advisory Board for almost 2 years. He is a reader in psychology at Leeds Trinity University. He is a chartered psychologist and an associate and fellow of The British Psychological Society.



Sonja Jones is a highly accomplished clinical audiology list and hearing aid dispenser with a wealth of experience across multiple sectors within the hearing healthcare industry.

## Flight Lieutenant George Webster's account of his tinnitus journey

(Supplied by Martin Middleton)

George Webster was a speaker at the Tinnitus UK Research Launch, Exhibition & Event during Tinnitus Week

This presentation explained his journey from the visceral attack of sudden Sound Sensitivity through a rational analysis process to achieve an understanding of how to manage his tinnitus.

I'm going to skip the gory details as all we need to know that as a helicopter pilot, he was working in conditions of extreme stress. The support and access to specialist help provided by the RAF and his own highly analytical thought processes is what is important to us. As a side note, the specialist help provided isn't exclusive to the RAF but, like any responsible employer, they will seek to protect expensive investments in assets and people.

At the first meeting with the councillor/therapist he was told that things will get better, although there was no guarantee of how or when. This wasn't what he wanted to hear at this stage of his career and could have escalated his depression. The diagram at the conclusion of this piece is his analysis of that journey. The nature of the consultations and therapies is of little relevance to us other than to say they were delivered with empathy and a good understanding of his path to recovery.

At the start George was sceptical of how improvements would occur but what he did experience is that after each session, "things" seemed to improve slightly. A major breakthrough was when the Sound Sensitivity dropped significantly leaving him with "just" Tinnitus. He anticipated a similar significant improvement with his tinnitus and when this didn't happen his analytical brain decided to record progress.

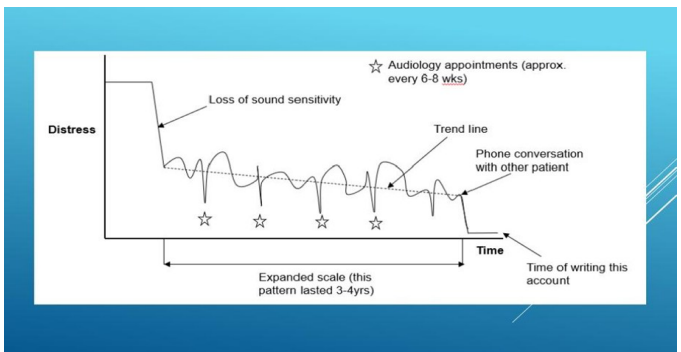
After each therapy session he noted that there was a significant improvement for a few days, then the tinnitus returned to a slightly lower level than before the session. Although a downward trend he couldn't figure out what was happening and decided to speak with another patient to see if this was their experience. Habituation was eluding him and during the conversation he realised that whilst the therapies will reduce the level of tinnitus it is for him to learn how to stop it going back up. It was down to him to change how he reacted / responded to tinnitus. This was the breakthrough he'd been looking for and why the therapist couldn't guarantee how or when.

George offered three takeaways:-

Everyone – Challenge the narrative

Professionals – Be careful (and humble)

Patients – Habituation is real – it's not the sound, it's the reaction



### Humorous quotes on appearance

- She has accomplished what according to builders is only possible to wood and stone of the very finest grain; she had *weathered*, as they call it, with beauty. *Ethel Smyth*
- I'm at an age when everything Mother nature gave me, Father Time is taking away *George Burns*
- Like all ruins, I look 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*
- As I rose from my bath, I caught site of myself in the mirror. I suddenly saw a great white sea monster emerging out of the water. This enormous sub-aquatic creature could not be me, could it? *Julian Fellows*
- Twenty-four years ago, Madam, I was incredibly handsome. The remains of it are still visible through the rift of time. I was so handsome that women became spellbound when I came in view. In San Francisco, in rainy seasons, I was frequently mistaken for a cloudless day. *Mark Twain*
- The paint and plaster may be peeling and cracking on the outside, but that doesn't matter if the rooms inside are warm and cozy.....*Anon*

### 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](http://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.

Saturday 21 June (the longest day!) is the date of our next meeting, when we welcome back Fara Afifi from Move2Health. The lovely lady teaches us all about the benefits of T'ai Chi Chuan, and helps us relax and de-stress.

### **Rachel's thoughts on the Tinnitus UK Day**

It was wonderful to finally have another face-to-face meeting organised by Tinnitus UK and it's good to see they have been energised by their new CEO- there seems to be some real momentum to start addressing some of the key issues for people with tinnitus in the UK.

The report they have published doesn't have any surprises (for me) We have been talking about the difficulties with UK practice guidance ever since it was first introduced. It tells us patients should be able to access CBT, and yet there's no accredited courses for Audiologists to be able to deliver this; and actually, the current evidence tells us that CBT is good when it's delivered by psychologists, but we don't know how effective it is if Audiologists provide it. Additionally, we would only ever be able to deliver CBT techniques and not full CBT, which has to be delivered by a registered psychologist or mental health practitioner.

We already knew that Audiologists lack confidence in using mental health questionnaires and screening for mental health, but it's good that their survey has drawn this out as well. It has also highlighted the lack of knowledge about tinnitus in the private sector.

At the event, Tinnitus UK held a private meeting with key stake holders including the British society of Audiology and British academy of Audiology- I am members of both and it's good that these different bodies are engaging with each other. Hopefully some joint working in the future can bring about positive change.

*[Apologies for the extra page, but it was the only way I could bring you Rachel's thoughts, as she has been unwell, and this arrived when newsletter was already complete - Ed]*