

Cambs Tinnitus Support Group

No. 178

NEWSLETTER

November 2025

SELF-HELP SESSION

November sees us hosting our popular annual self help session, where everyone has the opportunity to share thoughts about tinnitus with others. As usual Rachel Knappett, will be our host, and as last year she will be expecting her audience to contribute to the session! This will be followed by our Bring & Share Brunch. Contributions are welcomed, but are not a requirement for attending! Our traditional minced pies and mulled wine will also be available.

Saturday 15 November

10.00 for 10.30 am

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.

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EDITOR'S CHAT

We have had Dr Kathryn Fackrell from Nottingham Biomedical Research Centre on our speaker wish list for some time but, unfortunately, the schedule coincided with a couple of periods of ill health so she wasn't able to come. However in September she finally made it, travelling all the way from Southampton as well! The wait was worth it as she gave us a fascinating talk about the effort involved in putting together a new digital programme for hyperacusis that patients could access easily and use for their benefit. It was quite an intense session (over 60 minutes/48 slides) and I just hope that my report does her effort justice. I'm sure our members who have hyperacusis will be looking forward to the launch of her project early in 2026.

Objective measurement of tinnitus would be a real step forward in helping gauge the effectiveness of possible tinnitus treatments. While browsing some recent tinnitus research headlines I noticed that researchers have identified biomarkers for tinnitus severity in subtle facial movements and pupil dilation that can be captured on video recordings. Until now, there has been no objective way to measure tinnitus severity and clinicians have had to rely on patient survey questionnaires. The researchers plan to use these biomarkers to develop and test new therapies that can reduce or eliminate tinnitus. A sign of progress hopefully.

I know we are very lucky to have our own 'in-house' meditator in John Williams, but I wondered if the following feature, taken from the Tinnitus UK website would be of interest to our members. Meditation is a really easy relaxing way to help soothe your tinnitus. Join Sandy, a qualified NHS hearing therapist, for this 15-minute introduction to guided meditation and find some peace in your day. The link is:

<https://soundcloud.com/sandy-g-408615340/guided-meditation-for-tinnitus-and-relaxation>

[Ignore the box asking you to fill your e-mail address etc., just tap the cross in the top right hand corner and it will disappear, leaving the recording to be accessed.]

Don't forget that November's meeting is about self-help and you the member. Rachel will be there to guide the session, but it is your opportunity to not only ask questions but also to offer opinions on a related topic. Afterwards we will have our ever popular Bring & Share Brunch, to which you are invited to participate (however it is not obligatory to bring an item!) Attached to the covering e-mail will be a list of the types of food members have brought in the past; if you intend to contribute please put your name against the appropriate food item, or add if it is something completely new) and e-mail the list back to me. I will keep a tally and send out the updated list at regular intervals.

MARTIN'S MISSIVE

Looking back at the September newsletter, where I talked about negative space to illustrate that place we seek to quieten our tinnitus, I realised I may need to show how difficult it is to find that place within a space.

When writing these pieces for the newsletter, my starting point has been to use a photograph that I've already taken. This time my mission was to take the photograph first, looking for that place within the space. Little did I realise how difficult this was going to be.

This summer holiday we went to Seahouses in Northumbria with the intension of walking more of the coastal path. Unfortunately, I had a recurrence of plantar fasciitis in my right heel. Not a problem, took the arch supports out of my ski boots, we decided to break up the walking into small stages of no more than five miles and use our bus passes where necessary. Another good decision was to walk on the wet sand near the water, which was soft underfoot but not as much hard work as walking on dry sand, or as painful as the hard paths. Actually we didn't have much choice in the matter as this was also our dog's preference.

Setting off from Waren Mill via Budle Bay to Bamburgh Castle one sunny morning, the coastal path started out over high ground and we couldn't find a route down to the sand. Then I remembered my mission as right in front of me was that huge landscape which represents our soundscape.



And in that soundscape, if you squint and look hard enough, is that calm, quiet and peaceful place I was seeking. A rare place, only accessible for a few hours a day when the tide is out and the sun is shining.



An example of there being a photo in every snapshot or a new memory in a space of that place we seek? This also poses me with a simultaneous dilemma and dichotomy: is this a place where tinnitus isn't a memory or a memory where tinnitus isn't?

With Best wishes

Martin Middleton
CTSG Chair

Cont. from page 2

all our work involving hyperacusis, everyone is saying there's no guidance or immediate support. We looked online and got rather scared by the inaccuracy of the available information. So we needed to change this situation, but in a systematic way so that the information we would provide would be accurate, up to date and good for people to use. This would involve designing a digital intervention that patients could access easily and use for their benefit. In order to design a digital intervention for hyperacusis that patients could access easily and use for their benefit, we needed to build a knowledge base (see example of the lived experience slide opposite) incorporating multiple tasks, including:

Noisy environment • Difficulty filtering out background noise • Unexpected sounds • Dependent mood, stress and sleep • Anticipation of sound • Support and understanding from others • Distractions - doing something else • Lack of recognition/awareness • Unexpected sounds • Focus thoughts through relaxation, mindfulness.

The project, generously funded by the National Institute for Health Research, is not yet complete. However it has reached the latter stages of testing and hopefully will be ready for release early in the new year.

The programme will be called **ishuh**, (**I**nternet **S**elf-help, **U**nderstanding and **S**upport for **H**yperacusis) and will be freely available on the website online.

Kathryn's talk was received with rapt attention by her audience, and for those who have hyperacusis, and we have several of our members who do, then I'm sure they cannot wait for her project to be launched. Well deserved enthusiastic applause followed before our speaker started her long journey all the way back to Southampton.

CHUCKLES

- A man finds an old bottle. He rubs it and is astonished to see a pixie emerge from the bottle's mouth. 'You look tense,' says the pixie. 'Would you like a back rub?' 'Well, I'd prefer a million pounds,' says the man. 'I can't give you any money,' says the pixie. 'But how about I rub your back?' 'Well how about a date with a beautiful girl?' asks the man. 'Sorry,' says the pixie. 'But why don't I work those shoulders of yours?' 'Can you make me taller?' asks the man. 'I'd prefer to be six foot six.' 'The pixie replies, 'Lie down and I'll get started on your clavicles.' 'Hang on a minute,' says the man. 'What's with the back rubs? I thought genies were meant to grant three wishes?' 'Who said I was a genie?' replies the pixie. 'I'm a massage in a bottle.'

- A man walks into a seafood restaurant and sees a sign saying, 'Lobster tails £1 each'. The man goes up to the waitress and says, 'Those must be very small tails if you're selling them so cheaply.' 'No,' replies the waitress. 'They are the normal size.' 'Then they must be pretty old,' says the man. 'No,' replies the waitress. 'They're fresh today.' 'There must be something wrong with them,' says the man. 'No,' replies the waitress. 'They're just our regular lobster tails.' 'OK,' says the man. 'I'll have one.' So the waitress takes the man's money sits him down and says, 'Once upon a time there was a big red lobster.....'

Build knowledge base: Lived experience

Another in our 'series' of tinnitus being displayed graphically, illustrating a web article on 'Understanding the causes of tinnitus.'

Prevention, Protection & Therapy – Safeguarding your Hearing for a Lifetime of Music.

The panel of 5 presenters included two rock band musicians, a drummer & base guitarist. They both had differing experiences of tinnitus, but they both now use ear protectors, especially when performing. They explained how the onset of tinnitus could be career ending for musicians and that even in the early stages it is stressful. Tinnitus UK were offering their rebranded ear plugs, that can reduce sound levels by 16db and are suitable for both performing and listening to music in loud venues. Martin bought a pair at the conference but has yet to test them.

One of the musicians explained quite a counter - intuitive method he uses to manage his tinnitus. He deliberately tries to increase the level of tinnitus and visualises it as a huge cardboard box that he can punch his way through. The outcome means he has found a way of reducing the effects of his tinnitus. The Tinnitus Coach on the panel explained that this isn't something that should be attempted without prior knowledge of the whole process but that it is helpful with correct guidance and supervision.

Meeting the unmet needs of people with tinnitus and the audiologists and other hearing health professionals treating them

This was a joint presentation by Dr Derek Hoare and PhD Student & Research Associate, Carol MacDonald. Derek has recently spoken to CTSG about an update referencing the "Tin Man Project", therefore I'm not covering his part of the presentation as at sometime in the future we may be able to arrange a return visit. Carol is based in Sterling, so it would be a big ask for her to commute all the way to Cambridge. Basically, the NICE guidelines, published in 2009, to evaluate the provision of CBT- based interventions for tinnitus delivered by trained healthcare professionals other than psychologists, is still missing after 16 years. Carol's research aims are to understand the 'elephant in the room':- 1) How self-harm & suicidal behaviours in

adults with tinnitus are addressed, 2) what are clinicians views on care practices, 3) Clinicians experiences in suicide prevention and needs in training and clinical supervision. (I'm not going to delve further but in a discussion with Carol at the interval; it seemed to me that we need to develop a vocabulary which distinguishes between "suicidal thoughts" and "thoughts on suicide" so that professionals and patients can converse freely.

Beyond Audiometry: Building Trust, Delivering Excellence and Working Together for the Future.

At the Tinnitus Week Research Launch event last February, an interesting finding was reported about Private Sector Hearing Aid Dispensers (HADs). Of those surveyed only 12% considered it essential to provide tinnitus care. If we assume that all of this 12% will be signed up to the above charter, then the size of the problem for the organisers promoting this charter to the other 88% of HADs becomes apparent. And we're only addressing the Private Sector (PS) here. Also reported in the Tinnitus UK Research were significant differences between the NHS and PS HAD's. So, whilst the NHS may already aspire to some aspects of this charter, the presenters claimed the bottom line for PS HAD's was that adopting the charter improved outcomes and increased trust by giving added value to the service they provide.

Exploring why sleep can make tinnitus vary in some patients.

Due to a very poor video link it was very difficult at times to hear the speaker clearly. Consequently his research into insomnia and sleep cycle patters and how it affected tinnitus, made interpreting his conclusions (other than more research is needed) difficult for me to follow. One of the aspects that intrigued me was how an afternoon nap can change the level of tinnitus. For better or worse? The video recording of his presentation is an equally difficult listen and hopefully I may get a copy of the PowerPoint so that I don't misinterpret his findings

Achieving a World Without Tinnitus: The Tinnitus Charter

	Our mission	Your commitment	How you might you demonstrate this?
1	Ensuring that people with tinnitus have immediate access to high-quality support.	"We are improving access to high-quality support for people with tinnitus."	<ul style="list-style-type: none"> Refer patients to Tinnitus UK's free-to-access services. Offer dedicated tinnitus care services. Run or regularly attend tinnitus support groups or other tinnitus community events. Provide free, subsidised or discounted services to those in need.
2	Working with the tinnitus research community to find a cure or cures, and better treatments for people with tinnitus	"Our practices are informed by the latest research, and we regularly learn about, implement or contribute to new discoveries."	<ul style="list-style-type: none"> Regularly attend research conferences and events. Fund, publish or partner on new research. Share new discoveries and participation opportunities with patients.
3	Providing high-quality training and information, advice and guidance on tinnitus	"Our standards of tinnitus training are exceptional, with a regular programme of CPD for staff, improving care at all stages of the tinnitus journey and preventing misinformation."	<ul style="list-style-type: none"> Attend training on the physical and psychological effects of tinnitus. Equip non-clinical, customer-facing staff with the tools to discuss tinnitus. Provide patients with up-to-date resources from trusted sources, including Tinnitus UK.
4	Ensuring that people with tinnitus have a voice in decisions and changes that affect them.	"We listen to people with tinnitus and ensure they have a voice in decisions about our services and their own care."	<ul style="list-style-type: none"> People with lived experience of tinnitus occupy decision-making roles in the organisation. Act on reviews, feedback and suggestions. Run or regularly attend tinnitus support groups or other community events.
5	Influencing and lobbying policymakers to ensure that tinnitus and people with tinnitus are given the priority they deserve.	"We are active in improving tinnitus care through leadership or participation in influencing efforts with government, healthcare and professional bodies."	<ul style="list-style-type: none"> Share evidence, data and expertise that strengthens Tinnitus UK's case when engaging with policymakers. Provide endorsements on policy campaigns from Tinnitus UK. Promote awareness through networks, communications, and industry platforms.
6	Raising awareness of the dangers and risk to help prevent people from getting tinnitus.	"We understand that prevention is better than cure, and offer appropriate information, care and protection to staff and patients to ensure tinnitus cases are reduced."	<ul style="list-style-type: none"> Provide guidance on hearing protection, stress management and other relevant topics. Offer high-quality, accessible hearing protection to staff and customers. A low staff to take regular hearing breaks if they are in high-risk work environments.
*	Tinnitus UK Values	"We will consistently demonstrate <i>respect</i> , act with <i>integrity</i> , provide <i>support</i> and embrace opportunities to <i>evolve</i> in line with the charity's core values."	
*	Professional standards	"Our staff have the appropriate registration for their role, and we understand that failure to maintain statutory standards may result in the termination of our membership."	<ul style="list-style-type: none"> Hearing Aid Dispensers (HADs) must be registered with HCPC.

The magic of stem cells folks.

The first-ever human trial exploring the use of stem cell therapy to reverse hearing loss is about to be under way, after getting the go-ahead from the UK's Medicines and Healthcare products Regulatory Agency. Conducted by researchers from the University of Sheffield who formed their own spin-out company, the treatment targets sensorineural hearing loss, which is caused by physical damage to the tiny structures of the inner ear. In a nutshell, the treatment, dubbed Rincell-1, is intended to regrow damaged nerves in the cochlea and allow them to start sending signals to the brain again. "Our research into Rincell-1 has consistently shown its ability to target and restore the delicate neural structures of the inner ear," Marcelo Rivolta from the University of Sheffield, CSO at the spin-out biotech company Rinri Therapeutics, said about the work." (<https://tinyurl.com/yyhpd53w>).

According to the WHO, more than a billion people worldwide are affected by some form of hearing loss. Existing treatments, like cochlear implants, don't fully restore a patient's hearing, and require that the cochlea - the centre piece of the inner ear that picks up sound and turns it into electrical signals - isn't significantly damaged to begin with. Key to the cochlea's function are the hair cells that line its surface, which are responsible for detecting sound. If these are severely damaged, it's game over: the hair cells are incapable of dividing to form new ones, meaning that they don't regenerate. This is called sensorineural hearing loss, and it's why your hearing inevitably worsens with age.

Attempts to regrow these receptors have long been the white whale of modern medical science, and the researchers hope they've found it in Rincell-1. The treatment uses embryonic stem cells designed to grow into auditory neuron cells, which form the wiring that connects the hair cells to the brain stem. These are administered into the cochlea during the surgery to emplace the cochlear implants. Once on site, the stem cells form auditory neurons that help reconnect the out-of-commission hair cells so they can send signals again. "We are taking the approach of transplanting in cells that can become functional mature cells and restore the cytoarchitecture of the inner ear, and therefore, restore hearing," said Simon Chandler, CEO of Rinri Therapeutics.

The randomized trial will be conducted in the UK and will involve 20 patients who will undergo cochlear implant surgery. Half of the patients will have severe-to-profound age-related hearing loss, known as presbycusis, and the remainder will have what's known as auditory neuropathy spectrum disorder (ANS), which is when the inner ear can detect sound but is unable to send the signals to the brain. Patients within each group will be randomly assigned to either receive a single dose of Rincell-1 or receive no dose and rely on the cochlear implant alone.

Chandler said that the Rincell-1 treatment can be used alongside cochlear implants, but didn't rule out the possibility that it would be used on its own, too. Needless to say, it'd be a game-changer if it turns out to be effective in either scenario.

JOKES

- A man walks into a bar near a concert hall with an octopus under his arm and says, 'I'll bet any of you that my octopus can play any instrument that you give him.' The first man hands over his French horn and the octopus starts to play. The second man hands over his tuba and sure enough the octopus starts to play it. The bartender then walks into the backroom and comes back with a set of bagpipes and bets all the money in the till that the octopus won't be able to play it. After about a minute of watching the octopus run its tentacles over the bagpipe, the owner of the octopus says, 'Come on now! Play it!' The octopus replies, 'What do you mean play it?! If I can figure out how to get the plaid pyjamas off it, I'm going to make love to it!'
- A small boy is struggling with his homework. 'Dad, can you help me with my maths?' asks the boy. 'I could,' replies his father. 'But it wouldn't be right, would it?' 'Probably not,' says the boy. 'But you can at least give it a try.'

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 February. We will e-mail you the details of the speaker later.