

Cambs Tinnitus Support Group

No. 168

NEWSLETTER

September 2023

MEETING

Saturday 16 September

at

10.00 for 10.30 am

" Acupuncture for balance and health - discover the benefits of this as part of tinnitus management".

**Speaker: Kim Bee
Cambridge Acupuncture Clinic
16 Stanley Road
Cambridge**

Kim has been providing acupuncture treatments for more than 10 years. She trained at the College of Traditional Acupuncture near Leamington with a special focus on Five Element Acupuncture qualifying with a Licentiate in Acupuncture and BA (Hons) in Traditional Acupuncture (First-Class) from Oxford Brookes University. She regularly undertakes further training and development (e.g. Balance Method, supporting patients with cancer, for fertility, pain, cosmetic acupuncture etc.).

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
(Details of and vehicle barrier entry protocol required will sent out before the meeting)

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Refreshments and Raffle

EDITOR'S CHAT

You will remember from June's 'Chat' that last time we had some technical difficulties with unwanted ventilation noise along with a wayward loop system. We were in the adjoining room this time, and without actually measuring it, the duct noise seemed better, although not perfect. No progress with the loop system unfortunately, so we had to make do with the old 'wire round the room' (*which is a real pain setting up!*).

It had been four years since Dr James Jackson visited us, but it was well worth the wait. His talk featured some of his research on mindfulness that had been incorporated into the chatbot Tinnibot. James talked for nearly 100 minutes, and a thoroughly interesting and absorbing talk it turned out to be! With over 2000 words of rough notes, plus 57 slides to incorporate, I make no apology for my report having to run to 2 full pages! James has bilateral hearing loss and tinnitus, yet he is a brilliant speaker, and we were lucky he could spare the time to drive all the way down from Leeds to visit us.

Our new committee member, Martin Middleton, has sampled Tinnibot, and the newsletter has a few notes describing his recent experience. Martin joined the committee earlier this year, and replaced Pauline Brown, who had decided to stand down. We would like to thank Pauline for her input into our committee, and as regular attendee she will still be there to give us her thoughts.

At our September meeting we welcome Kim Bee, an acupuncturist, who runs Cambridge Acupuncture Clinic. Surprisingly, this is a topic we have not featured since 2007! I hope some of you aren't afraid of needles, because Kim had mentioned that she would like some volunteers for a practical demonstration.

PS: I have had my 'noise' for many years, and am fortunate that I have reasonably well habituated to it. I rarely travel on the London Underground, but when I do the 'train' noises don't normally bother me. Recently, however, as part of a journey across London, I used the Underground at St Pancras. The platform was quite wide and the station interior spacious, quite unlike tube below ground stations I had previously used. When the first train came through the station, I couldn't believe the horrendous screeching noise the wheels were making. It was moving so slowly that the noise seemed to go on forever. If I ever have to repeat that journey, I will definitely come prepared with my earplugs! I mentioned my experience because of a story in the latest *Quiet*, where the teller always wears his earplugs on the London Underground.

Noisy neighbourhoods – how they can cause tinnitus

(Edited from Tinnitus Week)

A research paper recently published shows there is a link between noise exposure to traffic and tinnitus.

In a new study with data from 3.5 million Danes, researchers from the University of Southern Denmark (SDU) found that the more traffic noise Danish residents are exposed to in their homes, the more they are at risk of developing tinnitus. The researchers identified a vicious cycle: living near busy traffic increases stress levels, disrupts sleep, and, as a result, leads to higher risk of developing tinnitus.

This study is the first time researchers have found a link between residential traffic noise exposure and hearing-related outcomes. And for every 10dB rise in

noise in people's homes the risk of developing tinnitus increases by 6%. The study team also believe that noise at night time can be even worse for health, because of its impact on sleep.

To try and tackle sleep disturbance in people who live near busy roads, Germany has lower speed limits in some areas at night. Noise barriers and changing the road surface to one that dampens tyre noise can also help. Other suggestions to reduce the impact of traffic noise include moving beds to the side of the house furthest from the road and installing double or triple glazing.

JIM'S PIECE

As I write I am looking out at blues skies and bright sunshine on the trees, the light fades in and out, but the temperature remains warm and pleasant. The changeable nature of the weather is something we just have to live with in this country. We often dream of summers abroad, yet if we go abroad to a country where the sky is constantly clear, and the light is fierce, we often find the temperatures unbearably hot.

Managing our tinnitus, as we all must, comes down to a state of mind and unfortunately for some this can be a real challenge. Think of it as putting up with weather we don't like, when the sky is grey and sad, or it's windy and raining. Remember there always be good days when the sun shines, and life is full of hope.

Take care, and apologies in advance for missing you all at the next meeting, I will be back scrambling around the Dolomite mountains as September is the best month. It's always a hard physical effort, but the views are so spectacular it's all worth it, even with the odd soaking, because when it rains there, it rains hard !

See you all in November. Enjoy the rest of the summer days.

Best wishes

Jim Infield
CTSG Chair

Introduction

Over twenty members and guests came to our June meeting at the new Meadows Community Centre, to hear Dr James Jackson from Leeds Trinity University give his return talk. James is a psychologist, and explained he has had poor hearing most of his life, contracting tinnitus at a young age, probably due to a bad case of measles. He remembers commenting to his Mum, "doesn't silence sound funny?" He spent most of his teenage years without realising all these noises – it sounded like a Hammer House of Horrors B movie – weren't normal, and were actually tinnitus. At university he suffered a bi-lateral, catastrophic hearing loss, waking up the next morning to a horrendous noise. Where before it has been a 'neutral' experience, tinnitus was now an invader. It hadn't got worse, he was just focusing on it more, and causing him huge distress. Our speaker says in the last 30 years his hearing has not got worse and likewise his tinnitus. When James had the chance of doing a PhD at university, his subject of choice was tinnitus. As a result of his studies he had better understanding of the condition, and this has helped him habituate to his tinnitus.

Help for those with Tinnitus

Trying to define tinnitus has always been a problem; James says it's 'The concept of a damaged brain sending signals to the ear, and the ear believing them.' An exact percentage of the UK tinnitus population isn't known; it averages between 7 and 8%, but in the retired population this could reach 15-18%.

James is very keen that people with tinnitus actively engage in activities to help themselves – like attending their local support group like ours – and not becoming a victim. In his case he likes real coffee, which can temporarily increase his 'noise', but he refuses to let this spoil his enjoyment, and let tinnitus run his life. As a psychologist, he says it's important that you don't let your tinnitus dictate to you.

James wrote a paper looking at 4 – 500 patients with tinnitus, of which 100 had only developed it after catching Covid. The reasoning is that the ear doesn't have its own blood supply (it leaches it from the local blood supply) and as Covid is linked to deoxygenation (in the lungs), this has resulted in the number of people with the condition increasing. A future associated paper indicates that those patients with more severe Covid symptoms also reported more severe tinnitus.

The first healthcare professional I saw...	Healthcare Satisfaction	Participant Response (n=358)					
		SD	D	N	A	SA	A+SA
...was honest but positive	3.1/5.0	45	48	127	100	38	38.5%
...really listened to me and understood my concerns	3.3/5.0	57	51	100	107	43	41.9%
...discussed tinnitus-related distress and helpful interventions/strategies	2.7/5.0	76	88	105	61	28	24.9%
...referred me to secondary diagnostic services (e.g. audiology) without me 'having to fight for it'	3.1/5.0	65	58	57	95	73	46.9%
...referred me to a therapeutic intervention (e.g. psychology) without me 'having to fight for it'	2.1/5.0	155	81	92	21	9	8.3%
...treated me as an individual – the referral felt relevant to me, rather than just standard practice	3.0/5.0	65	55	102	86	51	38.2%
...I was satisfied with my first healthcare professional interaction	3.0/5.0	64	60	100	88	47	37.7%



The previous slide relates to a paper where James looked at the level of dissatisfaction of patients when they visited their first healthcare professional about their condition. In a cohort of 500 tinnitus patients, only ~35% were referred to an audiologist, and 6% to a psychologist, which he thinks is not good enough. On average ~ 50% of patients with chronic tinnitus will have some psychological condition associated with it (i.e. anxiety, depression, insomnia etc.), which means it is a condition that needs to be taken seriously because it can have consequences. Only 8% of the patients accessed therapeutic intervention without 'having to fight for it'.

Therapeutic Help/Intervention - problems

Our speaker reminded us that with so many different causes responsible for our tinnitus, generating a cure will be very difficult. In our audience alone 20 different mechanisms may be responsible for our condition, which is why a different approach is needed if more people are to be helped. This is where therapeutic remedies such as cognitive behavioural therapy (CBT) and mindfulness can prove really beneficial, and why talking to a sympathetic professional can be rewarding. From the previous slide, the majority of patients may be unaware or unable to access this type of help. It could be simply a post code thing, or the cost in terms of time and/or money (CBT may involve a 1 hour session for 10 weeks minimum).

Use of the Internet

In response to lack of help, a lot of people turn to the internet, and providing the sources are evidence-based, then these can be effective at reducing anxiety and depression, and thereby helping their tinnitus. Unfortunately, our speaker reminds us there will be a lot of 'red herrings', and 'Guided' help is usually more effective than 'Self' help. However if someone, somewhere curates resources and puts them in a theoretically logical order for you to consume, then this tends to work better than 'random stabs in the dark'. Smartphone apps are not for everyone, but they can provide structure, education and practical tips etc. in a range of different ways.

Apps can play a part

Cards on the table; James is an unpaid scientific advisor to Hearing Power, producers of Tinnitbot. The app looks to see if an interactive chatbot can deliver suitable psychological information (CBT) that can help people with tinnitus. (Chatbots respond to Q & As without any notion of what they are saying, but research shows that people will respond more honestly, and be more open, then they would be with a human therapist). Tinnitbot even features a little character which is



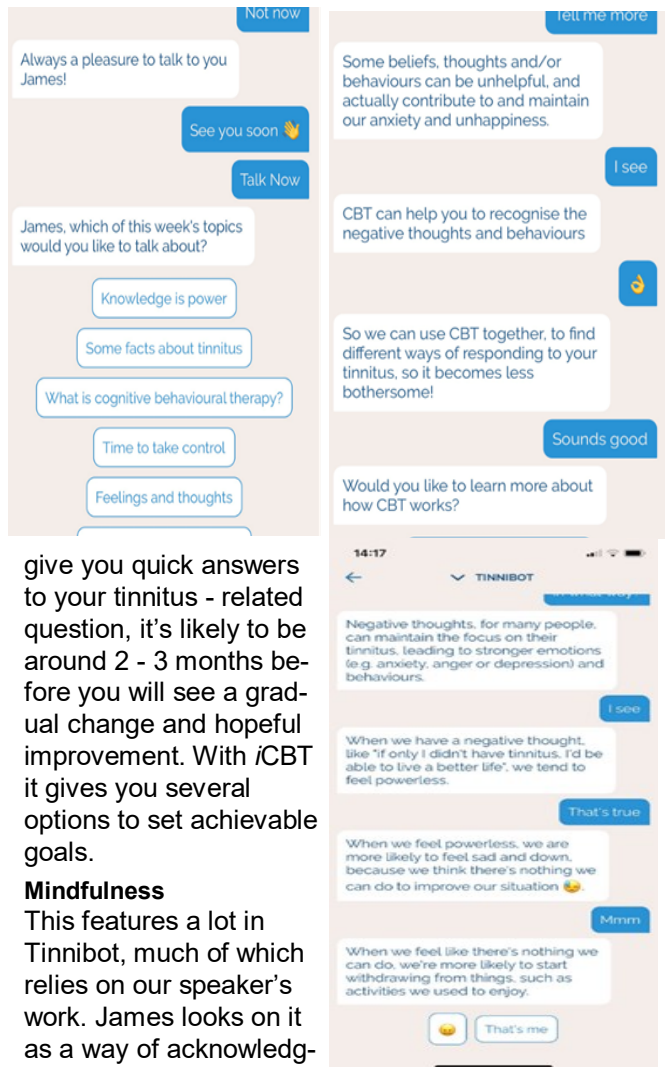
designed to be friendly. If chatbots are used long enough, then users may come up with their own ideas to help themselves. The app. is part-free and part-subscribable. Development was aided by a A\$50,000 grant from Australian Global

Connection. Conditions meant that an Australian

Cont. from page 3

company and a non-Australian university were to be involved. Because of some of their past research in this area, Leeds Trinity University were contacted, and as a result some of James's work has been incorporated into the app. Chatbots contain functions such as speech bubbles, which can be responded to, and conversation trees which lead to various exercises depending on how you feel. See sample screens :

The chatbot function won't



give you quick answers to your tinnitus - related question, it's likely to be around 2 - 3 months before you will see a gradual change and hopeful improvement. With iCBT it gives you several options to set achievable goals.

Mindfulness

This features a lot in Tinnibot, much of which relies on our speaker's work. James looks on it as a way of acknowledging something, dismissing it and then moving on. During lockdown he bought a dog, taking her on regular walks in the countryside, observing something, and then walking on to the next point of interest. By focusing on what was around him, he wasn't focusing on his tinnitus; however learning this discipline isn't easy, and it can be a slow process. The benefit of guided help is that it comes in progressive stages, building up as you go. You get 8 podcasts from James (using the voice of one of his students), and these are released weekly. Combined with visible imagery, and music in the background, this can work really well, but isn't for all.

The severity of tinnitus is measured by the Tinnitus Functional Index (TFI), used particularly for assessing the efficacy of any treatment. [score 24 or less = more or less habituated, 50 or over = very distressed]. If James knows your score, and intervenes, how much does he have to reduce it to be beneficial? [Advert: In

trial, tinnitus of 88% people reduced! The TFI score may have only gone from 60 to 59, which is meaningless]. The consensus now is you must reduce the score by at least 14.

Our speaker elaborated on a trial involving a control group, one using mindfulness, another Tinnibot and one using another chatbot called Woebot. (This was mentioned earlier as a possible free alternative to Tinnibot, but is no longer available outside the USA).

Intervention (n=sample)	TFI Change (8wks)	Not Clinically Significant	Clinically Significant (Fackrell et al., 2022) [-14.0]
Controls (n=48)	-0.58	48	-
Mindfulness v1 (n=54)	-9.52	38	16 (30%)
Woebot (n=38)	-8.08	32	6 (16%)
Tinnibot (n=41)	-14.68	28	13 (32%)
Mindfulness + Dance (n=30)	-13.66	24	8 (27%)

Results showed that after 8 weeks Tinnibot users had an average reduction in the TFI of ~14.7, which is clinically significant. The bottom figures are a bit of anomaly, since this group also included a dance session guided by one of James's post-doc students. Their results were also clinically significant. Apparently, if during these 8 week Tinnibot sessions, you include another activity, the results are encouraging. Those taking part in the trial were also asked to fill in a questionnaire commenting on:

Communication style (e.g. 'I found the language ... very good...light-hearted, just what you need...not being talked down to'),

Goal setting (e.g. 'I've gone back into some of those at times when I have seen one that particularly interests me, but I didn't know what I was supposed to achieve'),

Signposting (e.g. 'I find the interactive thing difficult for meI'm not a young person.....although I'm sort of reasonably computer literate, I found this app just a little bit needing to work through') and

Engagement insights (e.g. 'I use it more often at night...because that's when the tinnitus emerges'). James spent some time discussing these various factors that emerged from these questionnaires.

The speaker's concluded that the best interventions involve trying several things at once, and mindfulness is not for everyone. Regarding Tinnibot, more work is need on the user interface (UI); it maybe comes across as too friendly? But it will always be a work in progress.

James has several more related studies in the offing, including one using online mindfulness for between 6 months and a year to gauge if it actually takes. He will be looking for participants for that trial via Tinnitus UK, and who knows, some of our members may become involved.

After a lively Q & A session, James was warmly thanked for a thoroughly interesting and absorbing talk.

Is Tinnibot making a difference?

(Comment from Martin Middleton)

I downloaded the Tinnibot app some time ago and decided to wait until after Dr James Jackson's presentation before opening it. I was so pleased with what he had to say about the free introductory phase, and to see what topics are covered before subscribing, I opened the app.

It said something like "You have seven days free trial after activating your first topic search", so I decided to wait until I had seven days with few interruptions to make a serious evaluation. Unfortunately I misread the email; the seven days start after you download, open

and register the app. and now the 7 - day trial has expired and I've still not paid the subscription to open of the topics,

I have received several emails inviting me to join their free webinars. These freebies offering support and guidance are either very slick marketing or reflective of a genuine concern to help those with chronic tinnitus with the use of their app. I think it's the latter and when I'm free of this summer's holiday chaos I'll contact them to reset the 7 day free trial.

Watch this space for updates!

CHUCKLES

- Two 60-year olds are celebrating the 40th wedding anniversary. During the celebrations a fairy appears and says that, since they have been such a loving couple, she'll give them each a wish. The wife wishes to travel the world. The fairy waves her wand and poof! She has a handful of plane tickets. Next, it's her husband's turn. He pauses, then says, 'I'd like to have woman 30 years younger than me.' So the fairy pick ups her wand and poof! He's 90.
- A native American chief has three wives living in three wigwams, and one day he offers them new bed covers. The first asks for a buffalo-skin and this is duly delivered. The second wife asks for a bear-skin and, although this is more dangerous to catch, one is eventually brought to her. The third wife is the youngest and prettiest, and she asks for a hippopotamus-skin hide as a bed cover. This proves extremely difficult to find, but eventually she has her wish. Nine months later the first wife gives birth to a boy, the second gives birth to a girl, and the third wife has twins, a boy and a girl. Which goes to prove that the squaw on the hippotamus is equal the squaw on the other two hides.
- A man is marooned on a desert island for ten years. One day a beautiful woman is washed ashore and he tells her his story. 'You mean you've been on this island all that time?' 'Tell me, did you smoke before you were marooned?' 'Why, yes, I did', says the man. 'Here, have some of mine,' says the woman, pulling a packet out of her pocket. 'Say, were you a drinking man before you were shipwrecked?' 'Why, yes, I was,' says the man. The woman reaches into her pocket and produces a small flask. 'Help yourself,' she says. 'Say, since you've been alone all that time, I guess you haven't played around in ten years have you?' says the woman. 'Good Lord!' says the man, 'You don't happen to have a set of golf clubs in there as well?'
- A disgruntled man walks into a second -hand car showroom and approaches the salesman. 'Do you remember the car you sold me last week?' he asks. 'Yes, says the salesman. 'Could you go through your sales patter again,' asks the man. 'Only I'm starting to get discouraged.'

Chatbot success at BSA Scientific Meeting!

(Edited from *Focus*)

Members of the Tinnitus UK team attended a recent British Society of Audiology (BSA) Scientific Meeting. This is an opportunity for researchers and health professionals to get together to share and learn from the latest research and developments in professional practice. It was the first opportunity for our CEO Caroline Savage to meet some of the leading people in the tinnitus and audiology field, and she grabbed it with both hands, sitting in on every session.

The sessions at the Scientific Meeting covered a wide variety of topics, including listening difficulties in children, deaf awareness, accessibility and communication in the NHS, best practice for hearing aid fittings and the clinical application of otoacoustic emissions. Time was also given to discussing the links between hearing health, dementia and cognitive decline.

The presentation on the next steps in discovering the clinical needs and priorities in tinnitus and hyperacusis was particularly interesting, and in the post-talk discussions with the team behind the talk, we have offered our help to find out more about what people living with tinnitus and hyperacusis think – so there will be a chance for you to be involved in this

important research.

A highlight of the Scientific Meeting is the poster exhibition, where researchers and clinicians share a summary of their latest work. Tinnitus UK submitted three posters: 'A patient perspective on definitions for tinnitus and tinnitus disorder'; 'A lot to lose: noise exposure and tinnitus in a patient group' and 'The experience of Tinnitus UK and their development of Axel, a chatbot for tinnitus support'. We are delighted to say that the chatbot poster won the prize for 'Best Poster' and sparked many conversations between the team and attendees.



Becky Amery, Corporate Development Manager, Caroline Savage, Tinnitus UK CEO and Nic Wray, Communications Manager

Why are new treatments needed for hearing loss?

(Edited from the Bionics Institute e-newsletter)

Hearing loss is a very common disability affecting nearly half a billion people worldwide, but despite this there are currently no available treatment to halt the progression of hearing loss or to restore lost hearing function.

Hearing loss usually arises from damage to the delicate sensory cells within the inner ear due to ageing or exposure to noise. The only available options for people with impaired hearing are hearing aids and cochlear implants, but these devices do not treat the hearing loss.

World-first drug treatment for hearing loss

It is well-established that delivering growth factors into the inner ear can repair damage to the sensory nerves that occurs with hearing impairment. However, the lack of safe and effective technology to deliver these factors into the inner ear has limited its use in clinics.

Dr Niki Gunewardene and Dr Yingjie Hu, as part of a research team led by Associate Professor Andrew Wise, are working on a world-first treatment for hearing loss using nanotechnology. They are developing a ground breaking treatment for hearing loss using

nanotechnology to deliver a particular drug (called growth factors) into the inner ear. The drug is 'loaded' into small drug carrying particles created through nanoengineering. Once delivered into the inner ear, the drug can act to restore lost connections between the nerve fibres and sensory hair cells

Next steps for the Bionics Institute research team

"It's widely recognised that growth factors can repair damage to the sensory nerves in the inner ear. However, until now, there hasn't been a safe and effective way to get high payloads of drug into the inner ear, impeding clinical translation of previous research," said Dr Niki Gunewardene, Senior Research Fellow. "Our work paves the way for further research to develop this therapeutic technology and move towards a clinical trial to restore hearing in patients."

Gardeners - protect your ears!

(From Tinnitus UK website)

Now that peak gardening season is in full swing – weather permitting – we're calling for all you gardeners to protect your ears when mowing the lawn, trimming hedges or using power tools on your patch, as our research shows only a quarter (26%) "regularly" or "sometimes" use hearing protection. This means that over 4 million gardeners in the UK are putting themselves at risk of hearing loss and tinnitus, both of which can be permanent.

Noise becomes a risk to hearing health at levels of 80dB or above. Lawn mower sound levels vary, but they can be as high as 95dB for petrol driven models, and even higher for ride-on models.

Pressure washers – a popular way of cleaning paths - and patios – can reach 94dB. Hedge trimmers are

even more problematic as they can be as loud as 103dB. At this level, hearing damage can occur in under 8 minutes.

Noise exposure is the single biggest preventable cause of tinnitus, and it is clear from our research that people appear to be unaware of the risks. Even if you're only giving your hedge a quick trim or the patio a spruce up, use hearing protection. When it's loud... Plug'em is our very clear message.

We know gardening to be beneficial for people's physical and mental wellbeing, and we'd hate for people to put that at risk. People protect their cherished plants from frost and slugs – we want protecting your ears to be second nature too.

WIT OF A NATION

- My schooldays were the happiest of my life; which should give you an indication of the misery I have endured in the past 25 years. *Paul Merton*
- Growing old is compulsory, growing up is optional. *Bob Mortimer*
- Journalism is literature in a hurry. *Matthew Arnold*
- We make a living by what we get; but we make a life by what we give. *Winston Churchill*
- Money couldn't buy friends, but got you a better class of enemy. *Spike Milligan*
- We read to know that we are not alone. *CS Lewis*
- A pen is to me as a beak is to a hen. *J.R.R Tolkien*

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 alanyeo70@gmail)

CONNECTIONSCTSG 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 18 November at the Meadows Community Centre, and features our ever-popular Self-Help Session, facilitated by Rachel Knappett. We are also hoping to resurrect our Bring & Share Brunch that we last enjoyed before Covid and the lockdowns struck in November 2019. We will let you know.