

# Cambs Tinnitus Support Group

No. 146

NEWSLETTER

April 2019

**MEETING**

&

**AGM**

**Saturday 13 April**

**10.00 for 10.30 am**

## "Tinnitus - The Anticipation Hypothesis"

**Speaker:** Dr James Jackson  
Associate Principle Lecturer  
Leeds Trinity University

James is a Chartered Psychologist and holds a BSc (Hons) degree in Psychology from the University of Sheffield as well as MSc and PhD degrees in Psychology from the University of Hull. His doctorate considered the effects of tinnitus on concentration and task performance. Research interests include how tinnitus affects individuals, how personality affects tinnitus distress, and whether objective measurement of tinnitus is possible. He is also interested in the concept of 'resilience' and how personality and environment moderate pain tolerance.

## Meadows Community Centre

1 St Catherine's Road, Cambridge, CB4 3XJ, off  
the junction between King's Hedges and Arbury Rds

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2. Editors Chat ~ Relaxation ~ Jim's Piece
3. Mobile Apps for the Management of Tinnitus
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5. February report continued
6. Tinnitus Week 2019 report ~ Jokes

Refreshments and Raffle

## EDITOR'S CHAT

Our speaker in April is Dr James Jackson, associate principle lecturer in psychology at Leeds Trinity University. James has had tinnitus since he was a child, and then experienced a sudden severe loss of hearing whilst studying at university. He led a pilot study, funded by the BTA, looking at the concentration of the stress hormone cortisol in tinnitus patients. His evidence suggests that people who report a high level of distress caused by their tinnitus also have a flat diurnal cortisol rhythm which could lead the way to developing more effective interventions. As a psychologist, he thinks that personality has a lot to do with how people react to their tinnitus; and may explain why certain therapies work for some people, but less well for others. Dr Jackson is one of the leading lights in tinnitus research, and this is a meeting not to be missed.

On a much less interesting, but nevertheless important note, April is the end of our financial year and therefore our AGM. We are looking for at least one new person to join the committee, please. We combine our committee meeting with the ordinary meetings so no extra travelling is required, it isn't onerous or time-consuming and we do have a laugh! If you would like to help the group then please let me know.

To assist you in the renewal process, the group has finally embraced technology and instead of a cheque you can also transfer straight into the CTSG account via a BACS number. See the e-mail/page for details.

Enjoy the Newsletter and we hope to see you in April!

*This is a really quick relaxation exercise that you can do anywhere.*

First of all is think of a word that make you feel relaxed, like: Sea.. Bed..Laughter.. River.. Beach..Beer....

- Lovely, you all have your word, now I want you to think of an image, a place, get a picture in your mind. Somewhere that perhaps makes you feel really calm, happy... Everybody got an image in their mind..... Fields...Beach...Trickling stream ..very nice... OK We have all got a nice image in our minds.
- Now I want you to do is focus for a minute on how you are breathing. Put one hand on your chest, and one on your diaphragm, and just breathe at your normal rate. I want you to tell me if you are breathing with your chest or diaphragm. Diaphragm is good; if you are just breathing through your chest you are not getting enough oxygen in to your body. You need to be breathing deeper and should be feeling your diaphragm moving up and down.
- Get comfortable for this bit. Uncross your legs, and just sit back in your chairs, a lovely sunny day... Hopefully after today, we can all go off, and feel lovely and calm and relaxed. Sit comfortably...
- Just do some deep breaths in and out making sure we are breathing with our diaphragm, in through your nose... Out through your mouth... Count of five breathe in... Out for a count of ten... Again in for five... and out for ten....
- And now, we are going to do the same thing but as you breathe out, in your mind say that word... That you came up with... So the word that makes you feel relaxed. So we breathe in... Now we breathe out... In again... And out...

*[Some of you will remember this little exercise that Rachel gave us at our 30th Anniversary & Information Day in June 2017. Personally, after a very stressful day, it was much appreciated!-Ed]*

### Speaking Scientifically

*Dr Rachael Richardson is a Senior Research Fellow at Melbourne's Bionics Institute. Action on Hearing Loss are funding Rachael to investigate if we can improve how cochlear implants work by using light instead of electric currents. She says:*

At the moment, cochlear implants (CIs) convey speech and sound by electrically stimulating auditory neurons. The cochlear implant has up to 22 electrodes positioned in the cochlea that separate sounds according to their pitch, compared to the thousands of sensory hair cells usually doing this job. So CI wearers find it harder to separate different sounds, making it difficult to follow conversation when there is background noise, or to listen to music.

By using electrodes that fire tiny beams of focused light at the auditory nerve rather than electric currents, we're hoping to stimulate the auditory neurons more precisely. The CIs deliver pitch information because the nerves in our ears are arranged much like piano

keys, unfortunately the electric current emitted from implant electrodes to activate the nerves or press the keys of the piano, ripple out just like dropping a stone in water. This 'spread' of activation means that a single electrode may activate a mix of low and high-pitch nerves at the same time. Imagine what listening to music would sound like when this happens!

I love the way cochlear implants have helped people with hearing loss to communicate, interact, work and learn. It would be exciting if we could go further to enable hearing in the presence of competing background noise, appreciation of music and other sounds

(Edited from AoHL *Soundbite*)

## Mobile apps for management of tinnitus

Dr Magdalena Sereda, Head of BTA Research, has recently published her paper ***Mobile Apps for Management of Tinnitus: Users' Survey, Quality Assessment, and Content Analysis*** after presenting her results at the BTA Conference in September 2018. This study is the first one to review mobile phone apps (iOS and Android) for tinnitus, and the first to assess the quality of these apps using the Mobile Apps Rating Scale (MARS).

### Background:

Sound therapy is a core component of many tinnitus management programs. Potential mechanisms of benefit include making tinnitus less noticeable, habituation, distracting attention from tinnitus, relaxation, and promoting neuroplastic changes within the brain. In recent years, there has been a substantial increase in the use of mobile technology. This provided an additional medium through which people with tinnitus can access different tinnitus management options, including sound therapy.

### Objective

The aim of this study was to:

- Generate the list of apps that people use for management of their tinnitus
- Explore reasons for app use and nonuse
- Perform quality assessment of the most cited apps
- Perform content analysis to explore and describe options and management techniques available in the most cited apps.



Dr Magdalena Sereda

### Methods

A Web-based survey consisting of 33 open and closed questions captured:

1. demographic information, information about tinnitus, and hearing loss and
2. mobile app-specific information about the motivation to use an app, the apps which respondents used for tinnitus, important factors when choosing an app, devices used to access apps, and reasons for not using apps.

The quality of the most cited apps was assessed using the Mobile Apps Rating Scale (MARS).

Content and features of the most cited apps were analyzed.

### Results

Of 643 respondents the majority (75%) had never used an app for the management of tinnitus, mainly (59%) because of lack of awareness. A total of 55 apps were available, including apps that were developed specifically for the management of tinnitus. However, the majority of cited apps were developed for other problems (e.g. sleep, depression or anxiety, and relaxation). Quality assessment of the 18 most popular apps using MARS resulted in a range of mean scores from 1.6 to 4.2 (out of 5). In line with the current model of tinnitus management, sound was the main focus of the majority of the apps. Other components included relaxation exercises, elements of cognitive behavioral therapy, information and education, and hypnosis.

### The benefits of the apps:

Content	Features	Apps	
<b>SOUND</b>	Variety of sounds	<i>White Noise</i>	<i>Oticon Tinnitus Sound</i>
	Mixing sounds	<i>myNoise</i>	<i>Sleep Bug</i>
	Random sound effects	<i>Sleep Pillow</i>	<i>Relax Melodies</i>
	Frequency adjustments	<i>Beltone Tinnitus Calmer</i>	<i>Soothing Sounds Lite</i>
	Download your own Personalization	<i>Nature sounds</i> <i>Rain Rain Sleep sounds</i>	<i>Relax Noise 3</i>
<b>RELAXATION</b>	Breathing exercises	<i>Oticon Tinnitus Sound</i>	
	Muscle relaxation	<i>Relax Melodies</i>	
<b>MEDITATION</b>	Guided Meditation	<i>Beltone Tinnitus Calmer</i>	
<b>INFORMATION</b>	Information about tinnitus	<i>Oticon Tinnitus Sound</i>	
	Information about sound therapy	<i>Relax Melodies</i>	
	Relaxation tips	<i>Beltone Tinnitus Calmer</i>	
<b>PSYCHOLOGICAL STRATEGIES</b>	Elements of mindfulness Elements of cognitive behaviour therapy	<i>Beltone Tinnitus Calmer</i>	

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## Conclusions

Dr Magdalena Sereda concluded that "As content of the apps varies in respect to sound options, information, and management strategies, it seems that the choice of the best management app should be guided by individual patient needs and preferences." This is something to consider when deciding if an app would be helpful in managing your own tinnitus.

Mobile apps are not a solution in themselves to managing tinnitus but they do provide another management option for people with tinnitus to try, and more choice is always a good thing.

(Edited from abstract from original paper *JMIR Mhealth Uhealth* 2019;7(1):e10353 and BTA website)

### CHUCKLES

- An A-road and a motorway walk into a pub. The motorway turns white with fear and starts shaking. 'What's wrong?' asks the A-road. 'Look at the crazy guy in the corner' replies the motorway. 'How do you know he's crazy?' asks the A-road. 'It's obvious' replies the motorway. 'He's a cycle path!'
- An attractive girl walks into a fabric shop to buy some material for a dress. 'How much does it cost?' 'Only one kiss per metre,' replies the male clerk. 'Fine,' replies the girl. 'In that case I'll take ten metres.' The clerk gives her the fabric and the girl points to the old man standing next to her, 'Thanks,' she says, 'Grandpa's paying the bill,'

### UNIVERSALLY CHALLENGED

- Host: Which famous racehorse was the word murder spelled backward? Contestant: Shergar.
- Host: Who was the first man on the moon? Contestant: Louis Armstrong
- Host: Name a kind of bank that doesn't deal in money? Contestant: Sperm.
- Host: Name a famous bridge? Contestant: Bridge over Troubled Waters.
- Host: Name a month of Spring? Contestant: Summer

## February Meeting Report on The Top 10 Tinnitus Uncertainties (the unanswered questions)

By Alan Yeo

On a sunny Saturday morning Nic Wray, BTA Communications Manager, came to talk to us about what progress has been made towards answering the final top ten clinical research questions arising from the James Lind Alliance Tinnitus Priority Setting Partnership (JLA Tinnitus PSP) which finished 5 years ago. [For a brief run down on the JLA Tinnitus PSP, see the Editor's Chat in February's newsletter – Ed]. These questions demonstrated the breadth of research required to develop a better understanding of tinnitus, the need for a cure as well as the requirement to better understand and determine the effectiveness of existing treatments. The questions were:

### 1. What management strategies are more effective than a usual model of audiological care in improving outcomes for people with tinnitus?

Alternatives that have been tried are tDCS (brain stimulation by direct current), which gave variable results and contradictory systematic reviews, and mindfulness that has been shown to be beneficial and gave longer lasting results, although few audiology units as yet offer this treatment. Although cochlear implants are not widely used, they have been shown to help those with tinnitus as well as severe hearing loss. A review on apps has recently been published [See pages 3,4 - Ed] that shows they can be beneficial although unfortunately they tend not to be used. Finally a review of self-help programmes couldn't be certain of their effectiveness. Several other treatments are undergoing trials and hopefully these will yield promising results.

### 2. Is Cognitive Behaviour Therapy (CBT), delivered by audiology professionals, effective for people with tinnitus?

CBT is a popular management strategy for tinnitus treatment, although despite a large number of studies on the subject very few of them have involved random controlled trials (RCTs), therefore the quality of evidence is poor.

A pilot RCT aimed to evaluate the feasibility of supporting audiologists with a CBT- derived guidance manual for tinnitus management compared with usual treatment is currently underway.

### 3. What management strategies are more effective for improving tinnitus-related insomnia than the usual care?

Sleep disturbance is a major factor affecting the quality of life of tinnitus patients. CBT can help, and CBT for insomnia (CBTi) forms part of the NICE guidelines for managing long term insomnia. Dr Laurence McKenna and Dr Liz Marks are investigating the effectiveness of CBTi as a treatment for tinnitus-related insomnia.

### 4. Do any of the various available complementary therapies provide improved outcome for people with tinnitus compared with a usual model of care?

The number of studies on this topic is generally small, of low quality and at risk of bias. Of those, 18 RCTs looked at the effect of acupuncture on tinnitus, but while half (from China) reported positive results, the rest did not. The effectiveness of acupuncture as a treatment is therefore unclear. Likewise trials of Ginkgo biloba as a potential benefit for tinnitus didn't demonstrate it was effective. The use of supplements have also been investigated, but with no evidence that they actually work.



Our speaker hard at work!

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### 5. What type of digital hearing aid or amplification strategy provides the most effective tinnitus relief?

Despite the fact that clinical experience shows that fitting hearing aids (HAs) can be effective for those with tinnitus and mild hearing loss, there has only been one previous trial on this topic. Dr Magdalena Sereda researched the clinical efficacy of NHS contracted sound therapy options for tinnitus including HAs and combination HAs. A review conducted prior to this work suggested a lack of consensus among clinicians on the topic. The recent concern about Clinical Commissioning Groups limiting the funds for supplying HAs under these circumstances has highlighted the lack of trial data about the benefits of this procedure. Trials involving a group fitted with HAs delivering notched sounds (missing certain frequencies) against ordinary HAs showed no statistically significant improvement.

### 6. What is the optimal set of guidelines for assessing children with tinnitus?

In response to the challenge posed by the JLA Tinnitus PSP, the Paediatric Audiology Interest Group (PAIG) of the British Society of Audiology (BSA) formed a working party of national specialists in paediatric tinnitus, and published the Tinnitus in Children: Practice Guidance document in 2015. A number of other resources for professionals working with children with tinnitus have subsequently been developed, including a training course, an award-winning information and activity booklets (with Nic's help) for children. A BTA-funded PhD student, Ms Harriet Smith, is also currently developing a questionnaire measure of tinnitus in children.

### 7. How can tinnitus be effectively managed in people who are Deaf or who have a profound hearing loss?

The BTA commissioned a report into people's experiences with tinnitus and profound hearing loss. They found 44% of those with severe/profound hearing loss thought tinnitus was a serious problem, they were less likely to receive help and more likely to be discharged. Also professional advice often concentrated on the hearing loss, and could be insensitive, e.g. like suggesting a sound masker as treatment. The use of cochlea implants often proved successful in decreasing people's tinnitus levels.

### 8. Are there different types of tinnitus and can they be explained by different mechanisms in the ear or brain?

As we know tinnitus is a diverse and individual condition, and this very diversity can be a barrier to developing effective treatment approaches. There is no agreed classification of the various types, and this needs to be addressed. New approaches include statistical analysis of large data bases, using the powerful computers that are available today. Another approach is being taken by Will Sedley, a neuro scientist at Newcastle University who researches the brain mechanisms for tinnitus, using human volunteers and various techniques including MRI and EEG. In particular he is interested in automatic predictions by the brain, and how these might contribute to developing tinnitus, or indeed to suppressing it. David Baguley says this model is at an early stage, but looks very promising, so this is one development to definitely watch!

### 9. What is the link between tinnitus and hyperacusis (over-sensitivity to sounds)?

Between 40 and 60% of patients with tinnitus report hyperacusis, a decreased tolerance to sound, although it has been estimated to be as high as 80%. The frequent appearance of both these conditions in the same individual is suggestive of a common mechanism. Researchers used the Tinnitus Research Initiative (TRI) database to compare clinical and demographic data of patients with and without tinnitus, leading the authors to conclude that there is an over-activation of some unspecified network in these patients, not dissimilar to the model that Will Sedley is proposing.

### 10. Which medications have proven to be effective in tinnitus management compared with placebo?

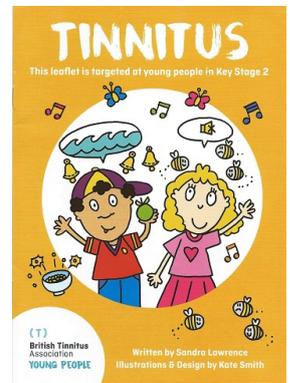
It is known that a third of people respond positively to placebos, so there is a high bar for medication to overcome to be deemed successful. One initially promising drug, Keysin (AM-101, see November 2017 Newsletter), failed the first of two Stage III trials and was withdrawn by the company, and there is no more encouraging news from other candidates such the benzodiazepine Clonazepam, the anti-convulsant drug Gabapentin, Trimetazidine, the steroid Dexamethazone and zinc supplements.

#### The Tinnitus road cure map

Whilst the research above is undoubtedly useful, for people with tinnitus the overwhelming need is for a cure, and this mirrors the BTA's vision. As a first step they have developed a mind map which illustrates the position of current tinnitus research. The mind map is a complex diagram, reflecting the diverse and heterogeneous nature of tinnitus, and the uncertainties that still exist about causes, mechanisms and management. [A version of the map can be seen at <https://tinyurl.com/yxbd2fcs> - Ed]. The map is continually being refined, with contributions being sought from the wider tinnitus community, including clinicians, patients and researchers.

#### Conclusion

Our speaker emphasised that more good quality tinnitus research needs to be carried out. Recent systematic reviews of this field shows that insufficient studies are of good enough quality for inclusion. However the trend over the last five years has been for increasing numbers of positive results from studies. This review has shown that there is much to be celebrated and much progress has been made since the publication of the Top Ten Unanswered Tinnitus questions. It will be interesting to see where the next five years takes us.



We then had a good Q & A session before Nic Wray received a very well deserved round of applause.

## Tinnitus Week 2019 - A brief report of CTSG activities by your Editor

Our contribution to this event involved manned displays at Hinchingsbrooke and Addenbrookes hospitals, and Monday 4th and Tuesday 5th February saw Sue Peacock and myself in the main reception area at Hinchingsbrooke. Unfortunately recent changes in layout meant we did not have as good a vantage point as last year, and this, plus a distinct lack of footfall during



Sue Peacock at Hinchingsbrooke

the two days, meant that the number of contacts were somewhat down on 2018.

However we enjoyed talking to people and giving out advice and literature; one particular gentleman made us chuckle when he mentioned that he had been given hearing aids for his hearing loss and tinnitus, and these had really helped him cope with his 'noise', the only downside being he could no longer ignore his wife!

The next stop for our roadshow was Addenbrookes on Thursday 7th, where Janette Byers and myself were kept very busy, particularly round lunchtime (we are just in front of the entrance to the Food Hall!). We

had around thirty contacts during the day, and gave out lots of literature and as much advice as we were able. Like tinnitus itself, everyone has an individual story but they often have a common theme. And we were really chuffed that during our day five staff from Clinic 10 (Audiology & ENT) came to say hello, including an ENT consultant.



Janette Byers at Addenbrookes

## CHUCKLES

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

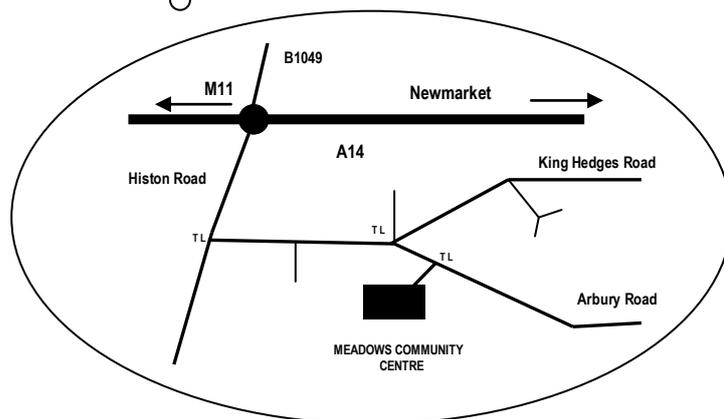
## Please remember

*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)  
(e-mail : mga978@hotmail.co.uk )

CTSG website: [www.cambstsg.com](http://www.cambstsg.com)  
Facebook: **Camb Tinnitus Support Group**

NEVER BEEN BEFORE?  
THE MAP BELOW WILL HELP YOU  
FIND THE MEADOWS CENTRE



## CONNECTIONS

CTSG is an independent voluntary organisation with a good supporting relationship with the Audiology Department at Addenbrookes Hospital. It is also a BTA 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.

Our next meeting is on Saturday 15th June at the Meadows Community Centre where we are pleased to welcome back Claire Gatenby, Chief Hearing Therapist, Norfolk and Norwich University Hospital who will talk about: "Tinnitus: Does how we think, react, sleep, and relax make a difference?"