

Cambs Tinnitus Support Group

No. 150

NEWSLETTER

February 2020

MEETING

Saturday 15 February

10.00 for 10.30 am

"Why haven't we cured tinnitus ?"

Speaker: Dr Don McFerran, FRCS,
Retired Consultant Otolaryngologist

Don has recently retired from working since 1999 as an ENT surgeon in Colchester, Essex where he had a general ENT practice with a special interest in tinnitus. After basic medical training at Queens' College Cambridge and the University Medical School, his postgraduate training was undertaken in London and East Anglia. He has co-authored two tinnitus books – a textbook for professionals and a self-help book for those with tinnitus and hyperacusis. Don is also a trustee of the BTA.

Tinnitus has no current curative treatment and people with tinnitus are dissatisfied with the available management options. Although supportive strategies are available, people would much prefer a pharmacological answer. There is relatively little tinnitus research compared to comparable health condition, yet the financial cost of tinnitus is high and a tinnitus drug would be financially worthwhile for a drug company. The reasons behind this seeming paradox will be discussed, together with some suggestions for improving the situation.

Meadows Community Centre

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

CONTENTS

2. Editors Chat ~ About Cambridge Lipreading ~ Can coloured lights really help with your tinnitus?
3. September Report: Tinnitus – Does how we think, react, sleep and relax, make a difference?
4. Report cont. ~ Pithy Quotes ~ Developing an objective test for tinnitus
5. Could reducing brain inflammation be a way to treat tinnitus?
6. BT revamps speech-to-text app for people who are deaf or have hearing loss ~ Chuckles

Refreshments and Raffle

EDITOR'S CHAT

I mentioned in the last newsletter the recently published paper "Why is there no cure for tinnitus?", authored by among others, Dr Davis Baguley, our past president, and Don McFerran, recently retired consultant Otolaryngologist. We are fortunate to have Mr McFerran as our speaker in February, so this really is one meeting you won't want to miss. Apparently the paper has already been downloaded over 25,000 times. If you want to read what the fuss is all about, then use the link: <https://tinyurl.com/y4rlq9nj>; on the other hand for a non-jargon presentation why not come along and hear about it from the man himself.

Recently the BTA hosted a tinnitus roundtable at the House of Commons, bringing together politicians, people with tinnitus, researchers, public health organisations and research providers. The outcomes from the discussions will be launched at the beginning of Tinnitus Week at the beginning of February.

While looking for some tidbits about tinnitus to interest you, Via LinkedIn I found a video by a PhD student from the Karolinska Institute near Stockholm reporting on some recent tinnitus research findings. Apparently while the existing evidence for a genetic influence on the tinnitus has been lacking, recent data suggest that specific forms of tinnitus have a strong genetic component. A short video can be found of the topic on the BTA website, and there is a link to the research paper at <https://tinyurl.com/tbqxqkb>.

Do you have difficulties hearing, even though you use a hearing aid?

Many people find hearing aids of limited use under certain conditions. For example, where there is background noise, possibly at social gatherings or in a noisy restaurant. *[It goes without saying that tinnitus can also make understanding speech difficult under challenging conditions – Ed]*

Softly-spoken people, and those with certain voices, can also be a challenge and in addition, there are a few who simply 'don't get on' with hearing aids.

If you have encountered similar problems, do consider learning some lip-reading, because it can get you over the threshold for understanding speech.

Cambridge Lip-Reading is an informal group of lip-readers of all ages; and most of us *BENEFIT* from hearing aids. We also really enjoy learning how to lip-read using light-hearted, well-organised and varied exercises. We also acquire other techniques to help

manage our communication problems.

Our Wednesday evenings are run by a fully qualified lip-reading teacher, helped by a few members of the group. Some attend to maintain their skills at lip-reading others are complete beginners. If your hearing is gradually worsening, it is better to start lip-reading sooner rather than later. We all benefit from being able to lip-read in a modest way.

Our programme involves 30 evenings per year (3 terms, each of 10 weeks), during school terms at Mayfield School off Histon Road, where there is free car parking. If you are interested you are welcome to join us one Wednesday evening, without charge, to see what we do and help you decide whether to 'sign on' by payment of a relatively modest subscription.

For further information please contact:

lipreading.cambridge@gmail.com

(Submitted by member Lynette Levitt)

While perusing the Tinnitus Australia website, your editor came across this charming little video put together by HEARsmart on preventing and coping with tinnitus, specifically for musicians: <https://tinyurl.com/vmvo8ga>

Can coloured lights really help with your tinnitus?

A lamp that gives out coloured light is being tested as a new treatment for tinnitus; researchers at the University of Leicester are using this approach following a serendipitous discovery from earlier research with migraine patients who also happened to have tinnitus. Using coloured lenses to treat their migraines also reduced their tinnitus. In a subsequent pilot study with patients who had only tinnitus, 40 per cent reported that their symptoms halved when they looked at coloured light from a special lamp.

The new approach is based on the theory that the light rays distract the sensory area of the brain, which then stops producing the signals that cause the tinnitus sounds in the ear. The light is also thought to distract the brain from the noises.

Now the researchers at University Hospitals of Leicester NHS Trust, are testing the treatment on a larger group of 32 patients, and instead of one bulb, the lamp has lots of tiny ones that emit red, blue or of green light. Three dials alter the intensity of

(Edited from an online daily newspaper article)

each colour, and the mix of tinted light projects down onto an A4-sized plate.

The patients will be asked to turn the colour dials to create different tints for ten minutes at a time to see which, if any, reduces their tinnitus. The specific colour combination they say helps the most will



be recorded on a computer connected to the lamp.

Commenting on the new therapy, Professor Jaydip Ray, an ENT consultant at Sheffield Teaching Hospitals, says: "This trial is based on the fact tinnitus can be modulated by sensory substitution such as distracting light, sound or tongue movements. If effective, it can be one of the self-help strategies that may help tinnitus patients."

[Although this article a couple of years old, this was new to me; I hope you will find it of interest - Ed]

Claire first spoke to us back in 2016, and your reporter noted then that we had never had so many members turn up for an AGM meeting. Her reputation had preceded her once again, as over 30 people turned up to hear her talk. Her role at the Norfolk & Norwich Hospital is Chief Hearing Therapist specialising in tinnitus and balance, and she also has a keen interest in how our thinking and behaviour have an impact on our well-being, and by implication our tinnitus, and this was the theme of her presentation.

The Basics

Our speaker, who has hearing loss and wears hearing aids (HAs) as well as having tinnitus, started by revisiting the probable history of our tinnitus. Starting with the physical examination in ENT through to the consultation with the tinnitus specialist (often with Rachel), including counselling and the passing on of information. Next may come a possible evaluation for the fitting of hearing aids, which can be a real benefit. Tinnitus is spontaneous neural activity anywhere along the hearing pathway, so the brain actively filters this information that it previously ignored, and decodes it as a threat. The ultimate goal from subsequent interventions is to help train our brain to ignore the threat, or to habituate, but Claire admitted this can be very difficult.

Tinnitus can be the result of noise exposure (which may also lead to hearing loss), inner ear infections, ototoxic drugs, acoustic neuroma, stress/trauma and other causes ; or in some cases there is no known cause at all.

Hearing

Hearing has always been essential to warn of predators and enemies; as an unexpected sound could be a threat! It was vital for our cavemen cousin, as it could give him early warning - probably flight, but possibly fight! This psychological level of hearing is very important as this 'threat', in this case tinnitus, can trigger an increase in activity of the sympathetic side of our Autonomic Nervous System resulting in higher adrenaline and cortisol levels and consequently increased levels of stress, anxiety etc.



Why we need to change our thinking

Unfortunately it's easy to have negative thoughts about our tinnitus, particularly if it is new experience: typically "I would do anything not to have tinnitus/I want a cure/If only I didn't have tinnitus/I wish it would go away". And these thoughts can promote fear, anger, sadness and even the need to apportion blame; but this reaction just encourages the brain to pay even more attention to the 'noise', and a vicious cycle can result.



We need to try and modify these unhelpful thoughts by being more accepting of the situation. Claire illustrated this with the example: one of the unwanted side effects of

chemotherapy might be tinnitus, which may make the patient angry, but the major plus side is it may well

has saved their life. She found an appropriate quote from Hamlet: "there is nothing either good or bad, but thinking makes it so.....since nothing is really good or bad in itself – it's all what a person thinks about it". Claire has second stage progressive MS, which is very hard for her to deal with; but her attitude is that it is what it is and she has to learn to get on with her life.

Changing the narrative can change our reaction

Why doesn't Claire hear the noisy heating system in her clinic room at her hospital? For the same reason she doesn't hear her tinnitus. It's unimportant in the scheme of things so her brain ignores it (i.e. it has habituated), as it does her tinnitus. We should try and modify the story we tell ourselves, and by identifying and avoiding negative thoughts and behaviours with regard our tinnitus, such as looking for cures and stopping socializing, etc., this will help us on the path to accepting the intrusive 'noise'.

Relaxation

Physical activities that you enjoy, such as walking, gardening and other hobbies etc. are beneficial, as is relaxation. Our speaker touched on mindfulness ('the art of thinking about the moment in a non-judgmental way'), and the audience remembered the excellent presentation of that discipline by Elinor Brown. A picture of a cut lemon then appeared on the screen, and we were asked to close our eyes and think about the lemon, and the juice; did we get a sensation of the mouth puckering - some members did! NICE (the National Institute for Clinical Excellence) recommends the use of mindfulness to help combat heart conditions, and recent research has shown that it is also beneficial for tinnitus. Lisa Unger once said: "The past is history, the future is a mystery, and today is a gift (which is why it's called the present)". Claire's version ends "and it's only in the now we truly live", in other words take time to appreciate the everyday things around you.



Sleeping

Claire also runs a sleep clinic, and she emphasised how important a good night sleep is to our general well-being. She urged us to try to cultivate rituals before bedtime – like taking a warm bath to encourage a relaxed state. Keep the room dark, as this helps triggers the pineal gland that releases the sleep hormone melatonin and which is also linked to your adrenal system and maintains our circadian rhythm. It's also important to have regular 'going to bed' and 'getting up' periods otherwise your biological clock can be disrupted. On average we wake 9 times a night, which we are usually not be aware of, and during these waking periods we may hear our tinnitus, and if we pay too much attention to it this can inhibit our ability to get back to sleep.



Cont. From page 3

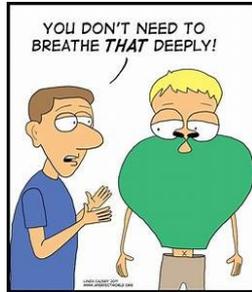
A little exercise to help you sleep:

- Taking a slow normal breath in through your nose and think '1' to yourself.
- Breathe in again and think "2"
- Continue up to 10.

When you reach 10 reverse the counting.

Breathing

Claire is very keen on exercises that help relaxation, and explained that relaxation begins through slow deep breathing. She described breathing meditation as being aware of your breathing without being aware of anything else. When we are under stress we have a tendency to breathe from our upper chest rather than from our diaphragm. Breathing from our chest causes us to have short shallow breaths. Learning to breathe more deeply makes us feel calm and relaxed, and making our out breath longer than our in breath makes us feel calmer.



Claire has provided us with 8 breathing exercises covering both mental and muscle relaxation, and these are attached to the e-mail. Those non-email members will be given the opportunity to receive hard copies.

Your editor likes sci-fi books, so was intrigued to find these quotes from 2 of the greatest sci-fi authors:

Yield to temptation. It may not pass your way again ~ Always listen to the experts. They'll tell you what can't be done and why. Then do it. Robert L. Heinlein

People who think they know everything are a great annoyance to those of us who do. Isaac Asimov

Developing an objective test for tinnitus

Several new PhD students supported by Action on Hearing Loss started their research projects last October, studying topics from a new way to measure tinnitus to improving cochlear implant surgery.

(Edited from the December AoHL Soundbite)

A top research priority for us and people with tinnitus is to find a treatment to eliminate or reduce tinnitus. Researchers around the world are working hard to achieve this goal. However, a major challenge slowing progress is that we do not have a reliable way to 'objectively' measure tinnitus. Researchers are largely limited to asking questions about how someone is perceiving their tinnitus. And this can of course be influenced by many factors including simply how someone is feeling at that moment in time.

One of their new PhD students at Newcastle University is attempting to develop a new way of measuring tinnitus to overcome these challenges. In theory, if a person has tinnitus, the tinnitus sound should influence how they hear real sounds in their environment. For instance, imagine a sequence of short sounds played one after the other with silent gaps in between. If a person was experiencing tinnitus the tinnitus sound would fill in the silent gaps so the actual sounds being played would no longer seem to have silent gaps in between. It is reasonable to assume that this would result in changes in the activity of parts of the brain that process sound. Could measuring this change in brain activity when listening to sequences of sound with silent gaps in between be superior to measuring tinnitus and the effectiveness of new treatments?

As before, Claire showed she is one of the most interesting speakers to have visited us, and my report can only provide a snapshot of the detail she covered. She is an experienced hearing professional, but the fact that she also has to cope with tinnitus, hearing loss and a serious debilitating condition lends added weight to her conviction that trying to relax more and modify one's behaviour towards tinnitus can really help us manage the condition.

After a lively Q & A session, our speaker was thanked in the usual manner.



Our members paying rapt attention to Claire!

The team will measure brain activity by placing small sensors on the scalp that can measure electrical activity in the brain. As there are many sensors it is possible to calculate what region of the brain is active. Using this technique they will investigate differences between people with and without tinnitus as they listen to sounds with silent gaps in between. They will optimise the test and examine its accuracy and reliability. Hopefully this research will prove pivotal in helping to develop treatments to for tinnitus.

Other new projects

At University of Sheffield another new student is studying how the connections between the brain and cochlea change with age and whether this has a detrimental effect on hearing.

And AoHL are also supporting a student at the University of Cambridge to better understand how cochlear implants can be designed to minimise damage to the delicate structures within the cochlea. The shape of the cochlea varies between people, but this isn't really taken into account when designing implants or selecting the type of implant to use. The student's research could help surgeons in the future select the optimal type of implant based on the particular shape of the person's cochlea.

Could reducing brain inflammation be a way to treat tinnitus?

(Edited from the AoHL Soundbite)

Scientists in the US have identified a link between inflammation in sound processing regions of the brain and tinnitus in mice. They have discovered that a molecule called TNF-alpha (TNF-A) is key to this link, and that blocking its activity reduced tinnitus in the mice. This research could be the first step towards developing an effective treatment for tinnitus.

Tinnitus is thought to be caused by damage to the inner ear, often following exposure to loud noise, and is also often linked to hearing loss. Hearing loss is known to cause inflammation in the inner ear and parts of the hearing brain. So researchers at the University of Arizona studied whether this inflammation is more widespread throughout the hearing brain, and if so, if it could be linked to tinnitus.

What is inflammation?

When someone has an infection, or is otherwise injured, cells of the immune system travel to the damage or infection to combat it. To do this, they produce proteins called 'cytokines' – some cytokines called pro-inflammatory cytokines, promote inflammation. Inflammation is a normal part of our body's response to damage or infection, and it's usually a good thing, helping our body to repair itself. But it can go wrong, if for instance when the immune system recognizes a normal part of the body as foreign and attacks it, which happens in autoimmune diseases like rheumatoid arthritis.

Inflammation and hearing loss

Inflammation caused by hearing loss is seen in two main ways; first, as an increase in activation of cells called microglia, special immune system cells found in the brain and spinal cord that can remove invaders (like bacteria) and help co-ordinate the response to more persistent infections or damage. They also produce a pro-inflammatory cytokine called TNF-A, the other sign of inflammation caused by hearing loss.

Microglia and TNF-A aren't just involved in inflammation, however. They're both important for the normal working of the brain and spinal cord, but they become chronically activated in hearing loss, so could they be involved in other hearing problems, like tinnitus?

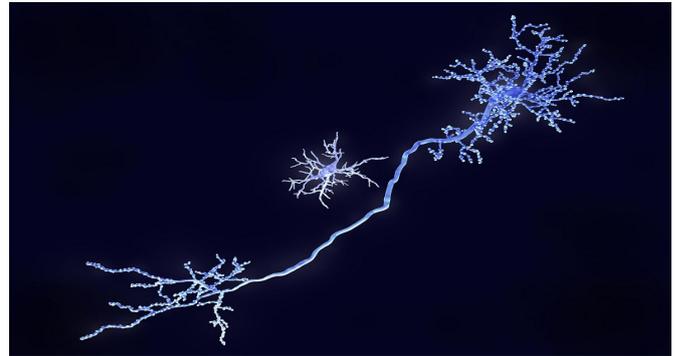
This is the question the researchers in Arizona wanted to answer. To find out, they exposed mice to loud noise to damage the inner ear, and then looked at TNF-A levels in the auditory cortex, which is responsible for perceiving sound. Levels of TNF-A increased, and the microglia in this part of the brain were also more activated. This suggested that loud noise causes inflammation, even in parts of the hearing brain furthest from the ear. Next, they went on to look at tinnitus in the mice, and how TNF-A might be involved.

But how do we know if a mouse has tinnitus?

Tinnitus is a subjective condition - and we obviously can't ask a mouse if it has tinnitus, or what it sounds like, or if it could rate it on a scale of 1 to 10!

So researchers have developed ways to assess if noise-exposed mice have tinnitus, usually based around 'gap detection', but it's controversial, and not all researchers working in the field believe it's an appropriate system to use.

Other ways have been developed to assess tinnitus in



Microglia - and - neuron

animals, usually involving training the animal to do something in response to a sound stimulus. These tests take longer and can be more difficult to use, but they may be better assessments of tinnitus. In this study, the researchers used both gap detection and a second method to assess tinnitus, which gave them more confidence that the effects they saw were real.

Testing the link between TNF-A and tinnitus in mice

Normal mice and mice that lacked the gene for TNF-A were both exposed to noise, and the researchers found those without TNF-A didn't show the same signs of activated microglia, or the same behavioural signs of tinnitus as the normal mice. Was the lack of TNF-A protecting the mice from developing tinnitus? Conversely, the researchers also showed that increasing levels of TNF-A in the auditory cortex induced tinnitus in both groups of mice in the absence of any noise exposure. This points to TNF-A having a role in tinnitus caused by exposure to loud noise.

So can blocking TNF-A also block tinnitus?

The researchers chose a drug, called dTT, that blocks TNF-A and reduces inflammation in the brain, and looked at what happened when mice, treated with dTT to block the TNF-A, were exposed to loud noise. In these mice, levels of TNF-A didn't increase, and there were no signs of tinnitus. These results were duplicated using the second tinnitus method, increasing their confidence that blocking TNF-A really can block tinnitus from developing – at least in mice!

So what does this mean for treatments?

These findings are potentially exciting, however this research was carried out in mice, and until further research is carried out to confirm these findings in people, we can't know if these treatments could be effective against tinnitus.

And even if this is the case, these treatments still need to be tested specifically as treatments for tinnitus before they can be used clinically – they might not be effective. In addition, TNF-A is part of our body's defence against infection and damage – so blocking it could have unintended side effects which also need to be tested for.

BT revamps speech-to-text app for deaf people

BT has launched a new service to help people with hearing and speech difficulties to communicate over the phone. Relay UK (pictured with keyboard blue 'swipe') is a smartphone app that connects you to a BT employee (called a Relay Assistant) who will translate text to speech and vice versa. It replaces the Next Generation Text Lite app, though this service will still be available on traditional landlines.

Before making a call, you have to select which option you need: Type & Read, Speak & Read, or Type 8: Hear. BT has also added some useful new tools to the app, such as the option of saving conversations and letting you look up vital information discussed during the call. You can also save commonly used phrases to quickly add into conversations. This will prove handy when companies ask for your name, address and date of birth.

The app was built on behalf of deaf groups including Action on Hearing Loss (AoHL), UK Council on



Deafness and National Deaf Children's Society. BT said only 5% of people who are deaf or have hearing loss can complete tasks over the phone. The figure comes from a survey it conducted with the UK Council on Deafness, which found that 70 % of respondents ask friends or family for help when making calls.

Jesal Vishnuram, AoHL's Technology Manager, said that using the phone is a 'big barrier' to communication for the 12 million people in the UK with hearing loss. She said Relay UK "can be pivotal in keeping people with hearing loss and deafness in employment, accessing healthcare including emergency services and other services as well as helping to keep them in touch with friends and family".

The app is free to install, though calls are charged at the standard rate. It's available for Android and iOS (<https://tinyurl.com/voybuhs>). A Windows version is coming in 2020.

CHUCKLES

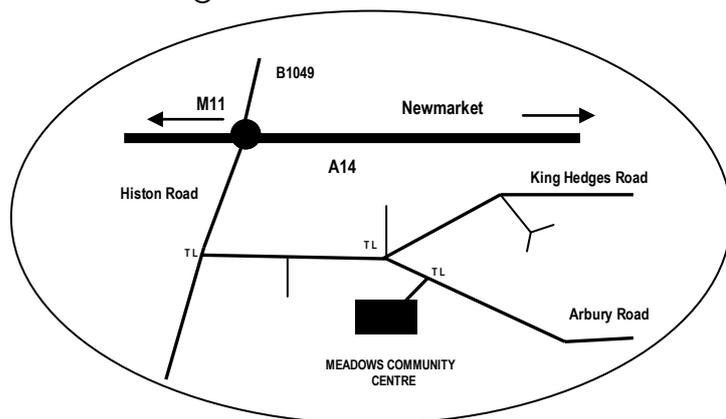
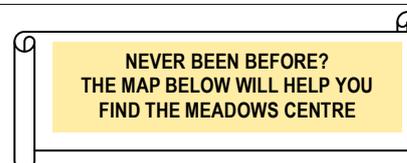
- What's a polygon? A dead parrot!
- Why do seagulls fly over the sea? Because if they flew over the bay they would be called bagels.
- Why do owls avoid being amorous in a storm? Because it's too wet to woo.
- Do you know why Turtle Wax is so expensive? Because turtles have really tiny ears.
- Driver to passenger: 'Lean out of the window and tell me if my indicator light is working.'
Passenger: Okay...Yes...No...Yes...No...Yes..No...'
- An economist is an expert who will know tomorrow why the things he predicted yesterday didn't happen today.
- What do you get if you cross an alligator, a gorilla, a lion and a parrot? I don't know but when it talks, you listen.

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
Facebook: [Cambstsg](https://www.facebook.com/Cambstsg)



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 18 April at the Meadows Centre where our speaker is Eldre Beukes, who is well known to many of you. The title of her talk is: "Insights into factors that aid coping with tinnitus". It is also our AGM, giving you the opportunity to have your say as to how the CTSG is run.