

Cambs Tinnitus Support Group

No. 140

NEWSLETTER

April 2018

MEETING

&

AGM

Saturday 21 April

10.00 for 10.30 am

“Another taste of T'ai Chi”

**Speaker: Faradena Afifi
Move2Health**

Faradena is a T'ai Chi Chuan teacher, community musician and massage therapist. She has been a musician her whole life and combines sessions of T'ai Chi Chuan and music for adults with complex disabilities as well as teaching mainstream T'ai Chi Chuan classes. Her aim is for the session to be a group interactive event; doing some exercises together and then inviting questions. The session will use gentle exercises to explore the following: stillness, awareness, whole body mindful movement, posture, balance and relaxation. T'ai Chi Chuan is more of a physical activity than something to be spoken about, so Faradena will probably be keeping talking to a minimum.

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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EDITOR'S CHAT

Thanks to your hard-working committee we have our own website, our own Facebook page and last year we celebrated our 30th Anniversary and successful Information Day. Which is an excellent lead into asking for at least one new person to join the committee. It really isn't onerous or time-consuming, and it can be good fun! No extra travelling is required as we combine our committee meeting with the ordinary meetings. If you would like to help please let me know.

Our AGM is in April and we need to consider a revision to the Constitution. Currently this lacks a confidentiality/data protection section, so with the General Data Protection Regs (GDPR) becoming law in May, it is an ideal opportunity to remedy this omission. The proposed new wording is included along with the other AGM papers, and we will ask members to vote on this proposal at the meeting. The GDPR requires members to give written permission for the CTSG to hold their details, so with membership renewals coming up an extra space for the signature will be added to the bottom of the renewal slip. A digital signature will also be acceptable, as several new members will not need to renew this time.

Just a reminder that at last year's AGM it was agreed the cost of membership would rise to £10 (our first rise in 30 years!), with the proviso that if the increase was too much, members could pay what they could afford.

New technology may supersede cochlear implants

A tiny electrode array placed directly in the auditory nerve could overcome the limitations of cochlear implants. Scientists at the University of Michigan Kresge Hearing Research Institute have shown that it's possible to implant a tiny, ultra-thin electrode array that can successfully transmit a wide range of sounds to the brain into the auditory nerve of animals.

If the idea is supported by further animal and human studies, profoundly and severely deaf people would have another option that could allow them to hear low-pitched sounds common in speech, talk in a noisy room, identify high and low voices, and appreciate music - areas where cochlear implants, though a benefit, have significant limitations.

"In nearly every measure, these work better than cochlear implants," says Professor John Middlebrooks, who led the study to re-evaluate the potential of auditory nerve implants. These implants would be suitable for the same

people who are candidates today for cochlear implants: the profoundly deaf, who can't hear at all, and the severely deaf, whose hearing ability is greatly reduced. Also, the animal studies suggest that implantation of the devices has little impact on normal hearing, offering the possibility of restoring sensitivity to high frequencies while preserving remaining low-frequency hearing.

Professor Middlebrooks says it's possible that the low power requirements of the auditory nerve implants might lead to development of totally implantable devices. That would be an improvement over the external speech processor and battery pack cochlear implant users currently need to wear and recharge daily.

[Professor John C. Middlebrooks, Ph.D. is a neuroscientist with interests in the brain mechanisms of hearing]

Jim's Piece

Apologies for not contributing anything in the last couple of newsletters.

We are all challenged with our tinnitus and hearing difficulties. We can choose to focus our lives on what we have



or what we desire, and it's quite hard to appreciate fully what you have until it's gone.

This reminded me of when our boiler broke for nearly a week while the 'Beast from the East' descended on us all - my house had never felt so cold. I was also concerned about the others in the house, along with the responsibility (and additional stress) of providing some kind of heating and getting the problem fixed. But my spirits were kept up by thinking how lucky we are to have heating at all, and I'm sure I coped much better with that attitude rather than one of complaining.

I remember being told I had hyperacusis and tinnitus, which were not curable. My reaction was that at least I still have my sight, rather than worrying about the sense that had just become impaired, and I'm sure that made me better able to cope with the adjustment.

Of course there are times when we feel low and we just have to be gentle on ourselves. Hopefully we are all lucky enough to have something that takes our mind off the difficult moments when our tinnitus gets us down. I leave you this very personal thought, and hope it helps.

Jim Infield
CTSG Chair

Your esteemed chair Jim Infield was seen pounding the streets during the Cambridge Half-Marathon to raise money towards an operation for a Bangladeshi colleague.

Speak Easy

As part of their Speak Easy campaign, in the summer of 2016 Action on Hearing Loss (AoHL) launched a comprehensive report calling on restaurants, cafés and pubs to reduce background noise. Based on a survey of over 1,400, the report found that background noise is by far the biggest problem faced by people when eating out, leaving many customers excluded from the conversations going on around them. The trend for hard surfaces, high ceilings, and background music make the problem worse.

Update: Speak Easy “hits the road”

(From Birmingham & District Tinnitus Group newsletter *Ears News*)

Across the country people have been speaking out about the barriers they face when dining out with friends, family and loved ones.

Public support for the Speak Easy campaign has been growing and as a result local dining groups are springing up to try and tackle the issue of background noise in restaurants, cafes and bars from the ground up. We now have two fully formed dining groups - in Brighton and London - and more in the making. These dining groups are making a real impact on a local level already. Getting local establishments to consider the needs of their customers with hearing loss can not only change the way that restaurant approaches noise but we hope it will also be fed up to more senior staff and go on to influence national policy.

Both the Speak Easy groups have an ‘anyone is welcome’ mantra - whether they have hearing loss or not. It’s about bringing together people who find the levels of background noise in restaurants, cafes and pubs a barrier to enjoying a meal or drink out with friends and loved ones, so that they can raise awareness of excessive noise levels.

The group meet ups have varied: some restaurants, such as Café Rouge, have been accommodating and



made sure they were accessible and others, such as Zizzis and Carluccios, have been so loud that no one could hear each other at all. But these bad experiences have only motivated our campaigners further and we’ve been supporting them every step of the way to make sure the restaurants listen to and take on board the group’s feedback. “What I think is so great about the Speak Easy Diners Club is that together we are raising awareness and also advising how little changes can make a big difference for all” - Megan Gibbs, Brighton Speak Easy Dining Group.

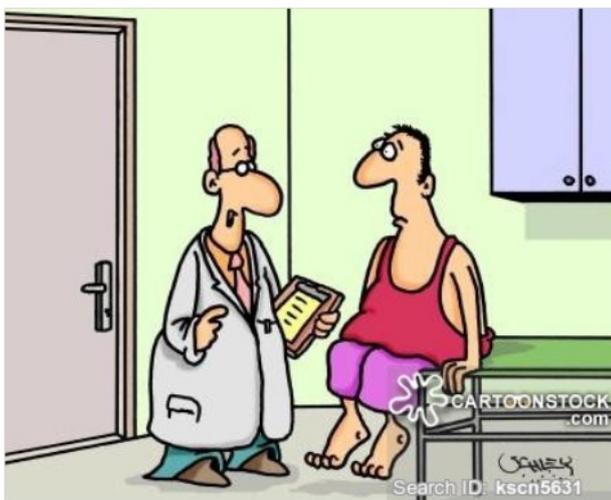
AoHL would love for more groups to start up; it’s a great way to start seeing change in your area as well as a chance to meet other people with hearing loss, deafness or tinnitus.

If you’re interested getting involved please contact maddy.boakes@hearingloss.org.uk.

They can help you to connect to others in your area and provide all the support you need to make your voice heard above the background din!

You can order your very own Speak Easy pack by contacting AoHL on 0808 808 0123 or their informationline@hearingloss.org.uk.

PS: I visited Jamie’s Italian kitchen in Cambridge for the first time shortly after this piece was finished. A magnificent setting, of course, being the former home of the Tourist information Centre in the Guildhall, and good food - but the real plus point for me was they had a quiet area, completely separate from the main dining area (with music, of course), and it just made such a difference to be able to converse normally without struggling to be heard or be understood. We shall return!



"YOU DON'T HAVE TINNITUS. YOU JUST NEED TO SWITCH OFF YOUR SMARTPHONE FROM TIME TO TIME."

(From Winter 2017 *Ears News* with thanks)

Tinnitus treatments through the ages

- from tree sap to technology

The Egyptians inserted a reed stalk in the external ear and tried infusing oil, frankincense, tree sap, herbs and soil through it as a treatment.

In Mesopotamia they chanted to get rid of whispering or singing in the ears.

The Greeks left miniature carved ears at the temples of Asclepius, the god of medicine, for divine intervention.

The Romans associated tinnitus with seizure.

In the Middle Ages, sufferers inserted objects into the ear, like a loaf of very hot bread.

In the Renaissance, it was believed that tinnitus was wind that was trapped in the ear so it was treated with surgery.

In the 21st Century, while there is still no cure for tinnitus, there are therapies and products available to help manage the symptoms, such as bedside noise generators, where a variety of sounds can be played through a pillow speaker.

(From AoHL Update leaflet via *Ears News*)

The cost of tinnitus revealed by BTA study

A study funded by the BTA into the healthcare cost of tinnitus management in the UK has calculated that the average cost of tinnitus treatment per patient per year is £717, equating to an NHS healthcare bill of £750 million per year.

The study — a collaborative effort between the British Tinnitus Association, Optimity Advisors and an advisory group comprising of tinnitus experts with backgrounds in audiology, ENT, research and general practice - calculated that over 1.05 million GP consultations for tinnitus take place each year and that the condition costs society £2.7 billion per year. The team mapped out the clinical pathways and treatment options used by people who seek help for their tinnitus. They generate an overall average NHS treatment cost and estimate cost-effectiveness, costs and probabilities of a patient receiving a particular treatment - and benefiting from it - were estimated using evidence from expert opinion, research literature, a patient survey, and national statistics.

With over 6 million people living with tinnitus in the United Kingdom, and the prevalence of bothersome tinnitus increasing, there was a pressing need to examine the costs of tinnitus care in the UK and to provide a benchmark for the economic evaluation of new therapies or modified pathways. Although over 6 million people in the UK have tinnitus, there is no standard treatment pathway for tinnitus patients within the NHS. Possible therapies include education and reassurance, cognitive behavioural therapies, sound enrichment, or

amplification of external sound via hearing aids. However, the effectiveness of most therapies is somewhat controversial. As health services come under increasing pressure to use limited resources more effectively, there is an increasing need to demonstrate the value at tinnitus therapies and how this value can be enhanced.

The objective of this project was to map out existing clinical practice, estimate the NHS costs associated with the approaches used, and to obtain initial estimates at cost-effectiveness. Our results show that NHS provisions for tinnitus are cost-effective against the National Institute for Health and Care Excellence [NICE] cost-effectiveness threshold.

The BTA is highlighting this study in the hope and expectation that healthcare purchasers in the UK will heed this work and improve provision of tinnitus services.

Authors: David Stockdale; Don McFerran, Peter Brazier, Clive Pritchard, Tony Kay, Christopher Dowrick and Derek J Hoare

("An economic evaluation of the healthcare cost of tinnitus management in the UK" can be downloaded from: <http://bit.ly/2ieWUDUV>)

Annoying telephone automated menus

This comes with a disclaimer that it is not an exact science, has not been tested and proven, and may not work every time! — to avoid queuing for ages or having to work your way through a very long menu to get to the section you want simply press * or # repeatedly. This will confuse the automated menu and you should find yourself transferred to a real person!!! Or swear long and loud and you will be assessed as being an awkward customer and put through to customer services! But remember to stop swearing at this point.....

(From *Ears News*, with thanks)

"Music as Therapy"

In February we welcomed back Peter Shearer with his particular brand of keyboard music which aims to bring a sense of well being, purpose and harmony to the listener. He emphasised that his music appeals to all sorts of people of any age, as shown by his improvised therapeutic CDs selling in over 40 countries. It is well known that music can improve our health and help boost our immune system. He believes relaxing music can have a positive effect on someone with tinnitus, and help them cope better with their condition — and that's what we all want.

Peter talked about music reaching the right side of the brain - the creative and emotional side — and we know the perception of our tinnitus tends to be dictated by our stress levels. He illustrated the power that music can have on behaviour with a video clip of an elderly guy who very unresponsive to normal stimuli, but when played a particular piece of music, almost literally came alive. He also showed us a clip of Bliss singing a particularly restful song called 'Come into the Light' [*It's well worth listening to it on YouTube*, — Ed].

Report on our September meeting with Peter Shearer Peter interspersed his talk with recorded clips of his "soaking" music as he describes it, while we sat back and listened. Did it help? The general consensus was his music was quite relaxing, and some of the audience definitely felt they had benefited.



We forgot to take any photos, so this is a pic of Peter actually playing at one of his earlier visits.

Certainly some of the CTSG loan CDs of Peter's music were taken home by members along with those purchased from him on the day. However, Peter himself admits. it's not for everyone, and personally I could relax just as well to many

other types of music.

But as we always say, if something helps even one of our members to relax and it helps manage their tinnitus, then bring it on!

Conspiring together: tinnitus and hearing loss (experiences of adults with different types of hearing loss)

In 2011 the British Tinnitus Association (BTA) initiated the James Lind Alliance Tinnitus Priority Setting Partnership in collaboration with NIHR Nottingham Hearing Biomedical Research Unit. One of the Top Ten questions identified through that process was, 'How can tinnitus be effectively managed in people who are Deaf or who have a profound hearing loss?'

The BTA commissioned The Ear Foundation* to investigate people's experiences with different degrees of hearing loss and tinnitus. (*The Ear Foundation bridges the gap between clinic-based services, where today's exciting hearing technologies, such as cochlear implants & bone conducting hearing implants are fitted, and home, school and work where they are used in daily life).

Launched in September 2015, the report presents the views of the 1432 participants on the treatment they have received, what helped, what didn't and their hopes for the future.

The report contains important messages for all those involved in supporting people with tinnitus and hearing loss - the medical and clinical communities, researchers and not least charities and support groups. We look forward to working with all of these in the future to better support this group often marginalised by both their tinnitus and hearing loss, conspiring together.

(From *Quiet* magazine: for report see [https:// tinyurl.com/y9qapfzg](https://tinyurl.com/y9qapfzg))

MORE WORDPLAY

- Cashtration (n.): The act of buying a house, which renders the subject financially impotent for an indefinite period of time.
- Arachnoleptic Fit (n.) The frantic dance performed just after you have accidentally disturbed a spider.

The latest in hearing aid technology

The way we communicate and connect to the world around us is changing rapidly. Technological advances often leave people with hearing loss behind, so it's great to see hearing aid manufacturers keeping up with the latest developments in mainstream consumer technology to ensure hearing aid wearers can benefit from all the latest technical advancements.

Bluetooth connectivity

For some time now, hearing aids have been able to connect wirelessly via Bluetooth to Apple products using 'Made For iPhone' technology. This allows the hearing aid user to hear all audio from their iPhone, iPad etc. directly into their hearing aid and adjust the sound to suit them. Conversations on your phone can be made much easier, listening to music and watching your favourite shows is improved.

Some hearing aid manufacturers have now also developed technology that allows Bluetooth connection to any mobile phone, smartphone or tablet. The user is able to adjust the sound of their HA themselves using a corresponding application, or app. This allows you to easily adjust the sound to different environments.

Internet connectivity

A hearing aid developed by Oticon called the OPN is also able to connect to the internet through a network known as the 'Internet of Things'. This is a system where individual devices connect and communicate to each other through the internet. British Gas developed the Hive system, which allows you to switch on your heating from an app. on your phone, and OPN uses a similar network called IFTTT (If This Then That), to connect to the internet.

So what are the advantages of having your hearing aid connected to the internet?

You can connect almost any device to the internet these days, and as a lot use sound to alert you, someone with hearing loss could quite easily miss them. Having your hearing aid connected to these devices means any alerts can be sent directly into the device, so you would always

be aware what is happening around you.

An obvious example is a doorbell sending an alert straight into your hearing aid when someone's at the door. Or your oven timer is telling you grub's up!

Tele-audiology

How we access healthcare is going to rapidly change over the next few years. With increasing pressure, technological innovation is key to ensuring that people still have access to healthcare as and when it's required.

The technology to update the settings of devices remotely (from a distance) has been around for a while; updating fitness trackers being an example.

The ReSound LiNX 3D hearing aid allows the person with the device to send their audiologist a real-time snapshot of any problems they are having through the hearing aid app. The audiologist can then remotely adjust the device, and the wearer can "sync" the

new settings to their hearing aid when it suits them. Not only is it more convenient, but the audiologist is seeing real-time information.

Hearing aid batteries

Making rechargeable batteries that last a whole day from an overnight charge without making them too large and bulky has been quite a big challenge for some time. Another obstacle associated with having the battery built into the hearing aid means any repair involves the whole device being sent back. However developments in rechargeable battery technology will significantly improve things for those people who struggle with the fiddly task of changing batteries.

(Amended from an Action on Hearing Loss *Soundbite*)



1. Hinchingsbrooke Hospital 5 – 7th February

As part of this year's Tinnitus Week, committee member Sue Peacock organised a CTSG stand at Hinchingsbrooke over 3 days. Sue was a stalwart, manning the stand for all three days, and helped by Alan on the first and last day. Typically, she had more 'customers' when on her own than the total for the other two days!

We listened to people talking about their (or a relative's) tinnitus, shared our experiences of the condition and gave out some advice as well as literature where appropriate. And as always we looked to attract



potential new members along to our next meeting. The three days were productive, with a good variety of people to chat to regarding sleeping patterns, hearing aids, stress levels and everything else that's associated with tinnitus.

Tinnitus was the result of excessive noise exposure for three people we talked to; a lady had attended a rock concert without ear protection, and two gentlemen had been in the armed forces. Hearing aids featured quite a lot; one guy spent a lot of money on an aid, but didn't get on with it, so went back at the hospital for an NHS one, which he found, suited him.

Interestingly, given this year's theme was 'Tinnitus in

Children', we had no child-related topics during our three days. In fact the youngest example that we dealt with was the twenty two year old grandson of a couple who visited us. He was having difficulty adjusting to his tinnitus as he had not had it for long. A pillow speaker was suggested to help him get to sleep, and to wear earplugs if he was going to attend future concerts.

On the third day we were joined by Graeme Johnston from Sensory Services Team in St Ives, who had been invited along to display his specialized equipment which help residents of the county with hearing and sight disabilities cope in their home.

Thanks go to Hinchingsbrooke Hospital who were very accommodating; giving us the space, supplying a table and putting up posters. Bring on 2019!



2. Addenbrookes Hospital 8th February

Unable to occupy our usual position by the Food Court this year, the CTSG presence was necessarily a modest affair: our roller banner, some literature, your Honorary Secretary and about half a day in total. Although the number of contacts was small, a lot of literature was taken and a couple of possible future new members emerged from our discussions. Reminder for 2019: must book earlier!

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 :-

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CONNECTIONS

CTSG is an independent voluntary organisation with a good supporting relationship with Addenbrookes' Audiology Department. We receive no financial support other than from membership subs, donations and sales. This pays for the hire of the meeting facilities and printing and postage of Newsletters. Reports and comments expressed in this newsletter do not necessarily reflect the views of CTSG.

Our next meeting is on Saturday 16 June at the Meadows Community Centre. Our speaker is Dr Kathryn Frackrell, from the National Institute for Health Research Nottingham Biomedical Research Centre, who will be talking about her hyperacusis project.

