

Cambs Tinnitus Support Group

No. 152

NEWSLETTER

June 2020

Like our April meeting, the dreaded Covid-19 virus has unfortunately prevented us from getting together this month to listen to our much-anticipated speaker, Julian Cowan Hill. However, although we cannot see him in person on the day, Julian has videoed part of the talk he was going to give us, and the link to the YouTube clip is: <https://tinyurl.com/y7pfo2sr>. And even better news is that Julian will be visiting us in 2021!

As with your last newsletter, the space created on page 1 has allowed me to vary the usual format a bit. There is another pictorial representation of tinnitus for you to look at, but it resides on the next page. It also very rare, in fact it maybe the first time, that I have given up my Editor's chat space on page 2, but this month your esteemed chair, Jim, has been given my slot – and well deserved.

So what to put on the front page? I thought a picture of us gathered together for one of our very popular self-help sessions (or is it the minced pies and mulled wine afterwards!) would help lessen your disappointment of missing our June meeting and give you something hopefully to look forward to later in the year.



CONTENTS

2. Jim's Piece ~ NICE guidelines for tinnitus published ~ Picture ~ A Description of Tinnitus
3. Tinnitus: Why it is still a mystery to science
4. Social distancing and managing tinnitus ~ Insults ~ Hearing aids may delay cognitive decline
5. Tinnitus throughout the Years ~ Well I Never! ~ Really bad jokes
6. BTA page ~ Working together 1 and 2 ~ Two new members of PAC

JIM'S PIECE

I hope this newsletter finds you safe and keeping your spirits up, in spite of the bad news that bombards us daily; in particular any of you that are living alone and may be feeling isolated. On the other hand it seems a number of people say they quite enjoy the complete slowdown and their own company without any social pressures. Perhaps better not to worry about tomorrow and all the uncertainties - rather focus on today and make the most of it. I am enjoying roads without noisy cars when I get exercise; as a lot more people seem to be doing now.

What have you been appreciating? Its so easy to take a great many things for granted - as the words of the Joni Mitchell song says: 'You don't know what you've got 'til it's gone'!

Who could have ever imagined anything on the scale of what has happened ? Let's hope some small goodness can come out of it all.

Stay well and safe

Jim Infield
CTSG Chair

NICE guidelines for tinnitus published

(With thanks to Nic Wray, BTA Communications Manager)

The National Institute of Health and Care Excellence (NICE) provides expert guidance for clinical practice, which is adopted by healthcare professionals. NICE are currently working on a set of guidelines for the treatment of tinnitus.

The BTA is a stakeholder in these guidelines, and we were invited to offer feedback. To do this, we wanted to ensure our views reflect the views of people with tinnitus - that means you!

We publicised the guidelines via *Quiet*, our magazine; *FOCUS*, our e-newsletter; stands at our Conference and Expo and via our social media channels, asking for your help.

And you didn't disappoint us!

Over 980 of you responded, which is a fantastic number, and really drove home to us how engaged the tinnitus community are in getting the best and most consistent care.

My colleagues Dave Carr (our Head of Development) and Dr Georgie Burns-O'Connell (our Research Officer) read **every single one** of the responses and categorised and tabulated them. I was then used as a fresh set of eyes to help make sure that captured the essence of what was said, and we then picked out the comments that we felt best summed up the responses. Georgie, Dave and I then discussed how we could summarise the survey responses, and how to word them, before Dave started the drafts, which included finding the evidence to back up some of our statements.

Once the internal team were happy, we offered the draft to our Professional Advisers' Committee, Trustees and President for comment, before finally submitting it.

You can read the draft guidelines (tinyurl.com/y9rgzs6o) and the response (tinyurl.com/ybdht5ab) we submitted.

Now it's going to be the turn of the Committee who produced the draft guidelines to sit and read feedback - and ours is not the only set they will have received. There are dozens of registered stakeholders who will all have their own feedback to offer.

Once the feedback has been considered, revised guidelines will be drawn up. The final version is expected to be published in March 2020.

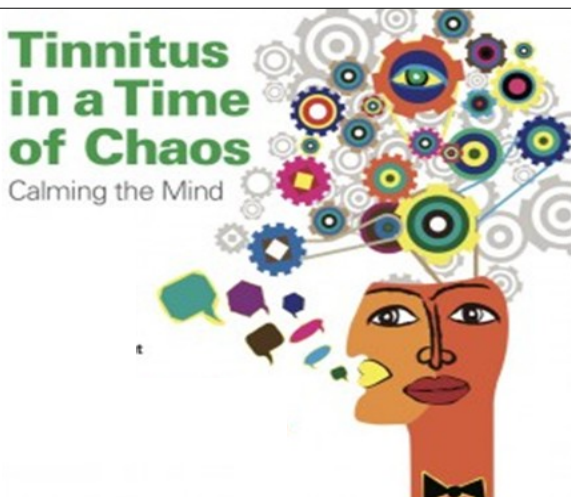
If you would like to see what the other stakeholders thought of the guidelines, NICE will be publishing those on their website in due course.

You will be able to access these, and find out more about the progress of the final guidelines by visiting (tinyurl.com/y982w8s9).



Nic Wray

The picture on page 1 of the April issue resonated with several people, so I decided to repeat the idea. Below is another representation of tinnitus, taken from the front page of the ATA newsletter.



A Description of Tinnitus?

"How's the folk? We've been over to Castle Boterel and what wi' running and stopping out in the storms, my pore head is beyond everything. Fizz fizz fizz"

"Tis frying o' fish from morning to night," said a cracked voice in the doorway at this instant.

"I am sorry to hear yer pore head is so bad still"

"Ay, I assure you that frying o' fish is going on for nights and days. And, you know, sometimes 'tisn't fish but Rashers of bacon and onions, Ay, I can hear the fat pop and fizz as nateral as life: Can't I Barbara?"

"Have you tried anything to cure yer noise, Master Worm?" inquired Martin Cannister.

"Oh ay: bless ye, I've tried everything....."

[Taken from Thomas Hardy's : 'A Pair of Blue Eyes', this must be one of the most unusual descriptions of tinnitus - Ed]

Tinnitus: why it's still such a mystery to science

(Edited from 2019 paper by Eldré Beukes)

Despite the many groundbreaking medical advances [<https://tinyurl.com/rhnwfy>] of the last century, there are still some conditions that continue to perplex scientists.

One such symptom is tinnitus, which people have reported experiencing as far back as 1600 BC. Tinnitus is characterised by hearing unwanted sounds, such as a ringing, buzzing or humming noise in your ears or head. For one in eight people these sounds never disappear. Although the condition is more common in older adults – possibly due to the natural ageing process – tinnitus can affect people of all ages, including young children. It's estimated that 30% of people worldwide will experience tinnitus at some point in their life, and this number is likely to rise as increases in life expectancy and exposure to loud music are both reasons people develop tinnitus. But while it's more important now than ever to find a cure for this condition which is likely to become more common, researchers still struggle to find one because of the complexity of tinnitus.

Why finding a cure is difficult

One reason that finding a cure for tinnitus is so difficult is because it's hard to quantify the condition. There's no reliable, objective way to directly measure the severity of a person's tinnitus, which means researchers have to rely solely on a patient's description of their symptoms. Because of this, it's very hard to establish a diagnosis and whether a treatment has worked.

Scientists also don't know why some people develop tinnitus and others don't. More than 200 conditions are associated with developing tinnitus, including anything from head or neck injuries, circulation problems, or a side-effect of some medications. Although hearing loss and loud noise exposure have been identified as the biggest risk factors in developing the condition, not everyone with hearing loss has tinnitus and not everyone with tinnitus has hearing loss. A further barrier to finding a cure is that tinnitus is also not fully understood. Although various theories exist, none can fully explain all aspects related to how the sound is produced, why only some become aware of these internally generated sounds, and why the sound may remain for years.

Current theories indicate that developing tinnitus involves multiple complex processes taking place in various parts of the brain. This makes it difficult for drug companies to know what area of the brain to target when developing a medical treatment. Although many drugs have shown promise in improving tinnitus during trials, none of these reported improvements were later produced safely and over a long-term period. In fact, during many of these trials people taking placebo drugs reported similar improvements to their tinnitus symptoms. There are many reasons for why these drugs might not have worked long-term – including being unable to ensure patients were taking

the correct dosage without triggering other side-effects, and uncertainty regarding which type of tinnitus the drug should target.

Another problem researchers face in finding a cure is related to the level of impact tinnitus has on a person's daily life. A majority of people with tinnitus don't find having the condition problematic, however, a small minority are unable to lead a normal life due to its severity.

When tinnitus is severe, it can make it difficult to hear, concentrate, relax, and focus. Those who are severely distressed by tinnitus even report an inability to work. Being aware of tinnitus may also make it difficult to sleep, which can affect daytime functioning. Being unable to escape or control tinnitus might also lead to feelings of frustration, anxiety and depression. These different individual reactions show how varied the tinnitus experience can be, and why the search for a cure is such a challenge.

How people with tinnitus can be helped

While it can be disappointing for tinnitus sufferers to learn there is no cure, there are still a number of things that people can do to help them manage the condition. In some instances, medical interventions may help when tinnitus is related to an underlying condition such as an ear infection, jaw problem or high blood pressure. Often, addressing any hearing loss greatly helps manage tinnitus. Using other strategies, such as [mindfulness](https://tinyurl.com/ycus8mwf) (tinyurl.com/ycus8mwf) and [relaxation](https://tinyurl.com/yd66nvv6) (tinyurl.com/yd66nvv6) techniques, or [sound therapy](https://tinyurl.com/y89agq9z) (tinyurl.com/y89agq9z) can also be beneficial in helping people manage their symptoms.



Currently, the approach with the most evidence of effectiveness in reducing distress and increasing quality of life is using cognitive behavioural therapy (CBT). CBT uses various techniques to

help change negative thoughts and responses to tinnitus. Strategies provided are aimed at helping people ensure having tinnitus does not restrict their lives. There are, however, very few specialists who deliver cognitive behavioural therapy for tinnitus specifically. Cost, and a lack of resources are further barriers for tinnitus treatment, but access to online therapy might be one way to address these issues.

More than ever before collaborations are encouraged between industry, academics and people with tinnitus to work together to tackle tinnitus. Although it remains an enigma, there is more research into tinnitus than ever before. There are clear indications of progress regarding our understanding of tinnitus and how to treat it. This should be embraced as it acts as stepping stones for further breakthroughs.

Social distancing and managing tinnitus

(Adapted from BTA website)

As coronavirus continues to impact people across the UK and globally, many people are having to stay at home, practice social distancing and substantially change their daily routine. What can you do to help manage tinnitus in these challenging times?

Manage stress

Many people find that their tinnitus increases during a time of stress and anxiety. It is understandable to be feel more upset or worried at this time, but being able to manage your stress will help your overall wellbeing, and manage your tinnitus.

Things you can do to support yourself

- Limit your viewing of news or social media – schedule times to check in to make sure you have the latest information, and then stop.
- Be mindful, and focus on controlling what you can control – washing your hands, keeping up with your tinnitus management techniques, and aspects of your daily routine.
- Understand that this too will pass, and you are not alone.
- Stay connected – phone calls, texts or video will help. If you are feeling overwhelmed with emotions like sadness, depression or anxiety, or feel like you want to harm yourself or others, contact your GP, NHS 111 or Samaritans on 116 123.

Acknowledge that there will be change

Our standard advice for people with tinnitus is to keep doing the things you love, and don't let tinnitus restrict you. This is going to be more challenging whilst the outbreak takes its course. Follow official advice about movements and socialising. Acknowledge that the

situation may change rapidly over the coming days and weeks. Retaining elements from your usual routine can be a comfort, but also be prepared for doing things in new ways.

Tinnitus management techniques (See also page 3)

Although we have advised our network of independent tinnitus support groups to cancel meetings up to the end of May, there are still many other things that you can do to help manage your tinnitus:

Wear your hearing aids – if you have hearing loss, hearing aids will help both your hearing and your tinnitus. Hearing aids don't work in a drawer!

Sound therapy – if the noises seem louder at night or quiet times, it may help to have some natural or gentle sound from an app, CD, sound generator or even a fan or ticking clock in the background.

Relaxation – learning to relax properly is probably one of the most useful things you can do. Check out some of our information, including ideas for relaxation without sound. If you have a smart phone, there are some excellent free relaxation apps available.

Take on Tinnitus – this is their free tinnitus management e-programme, which guides you through some facts about tinnitus and helps identify some simple strategies to keep it under control.

You can find it here: tinyurl.com/y88h2r8q

Wicked Insults (Anon)

- You must have a sixth sense, there is no sign of the other five.
- If your IQ was any lower, you would trip over it.
- May your sex life be as good as your credit.
- You are the sort of person who lights up a room by leaving it.
- I've heard better conversations in alphabet soup.
- Don't go away. I want to remember you exactly as you are.
- You couldn't count to twenty without taking your shoes off.
- What were you when you were alive?

Hearing aids may delay cognitive decline, research study finds

Wearing hearing aids may delay cognitive decline in older adults and improve brain function, according to promising new research published in the Journal of Clinical Medicine.

Improvement in cognitive function is something that is not usually seen in older adults said University of Melbourne Associate Professor and Chief Investigator of the study, Julia Sarant. 'Although there are successful treatments for hearing loss, there is currently no successful treatment for cognitive decline or dementia.'

Cognitive decline is associated with hearing loss, which affects about 32 per cent of people aged 55 years, and more than 70 per cent of people aged over 70 years. Hearing loss has been identified as a modifiable risk factor for dementia.

University of Melbourne researchers tested the use of hearing aids in almost 100 adults aged 62-82 years with hearing loss.

After having hearing aids fitted, participants were assessed before and after 18 months on their hearing, cognitive function, speech perception, quality of life, physical activity, loneliness, mood and medical health. Researchers found speech perception, self-reported listening disability and quality of life had significantly

improved for the participants.

Most notably, just over 97 % of participants in this study showed either clinically significant improvement or stability in executive function – their mental ability to plan, organise information and initiate tasks. Women, in particular, showed significant improvements in working memory – used for reasoning and decision-making – as well as most other cognitive functions assessed.

The study also found more frequent use of hearing aids was associated with greater improvements in cognitive function, and women were much more diligent at wearing the devices than men. [*Why are we not surprised!* – Ed]

Julia Sarant said 'This research is a positive step in investigating the treatment of hearing aids to delay cognitive decline. Further research is underway to compare cognitive outcomes from a larger sample size with those of a healthy aging comparison group of older Australians with typical hearing for their age.'

WELL I NEVER! FLYING CHICKENS (sometimes it DOES take a rocket scientist.....!)

Scientists at Rolls Royce designed and built a gun specifically to launch dead chickens at the airliners and military jets, all travelling at maximum velocity. The idea was to simulate the frequent incidents of collisions with airborne fowl to test the strength of the windscreens.

American engineers heard about the gun and were eager to test it on windshields of their high speed trains. Arrangements were made, and a gun was sent to the engineers in the USA. When the gun was fired, the engineers were shocked as the chicken hurled out of the barrel through the control console, snapped the Driver's back-rest in two and embedded itself in the back wall of the cabin, like an arrow from a bow.

The horrified Americans sent Rolls Royce the disastrous results of their experiment, along with the designs of the windshield and begged the British scientists for suggestions.

Rolls Royce responded with a one line memo: "Defrost the chicken."

Tinnitus Throughout the Years (With thanks to Chrissy Hughes; referenced in *Eldré's paper* - page 3)

Although tinnitus is considered to be increasing in these noisy modern times, it has actually been troubling people for a very long time. The first records of tinnitus date from the era of ancient Egypt. It has been documented and interpreted in different ways ever since. We thought it would be interesting to compile a post about how tinnitus was perceived and treated over the course of history.

1. Ancient Egypt

The oldest recordings of tinnitus date back to 1600 BC. It was written on the Ebers Papyrus. Ancient Egyptians believed that the people suffering from tinnitus were actually bewitched and were offered a cure for the "bewitched ear". Treatments included infusing a mixture of oil, frankincense, tree sap, herbs and soil into the external ear through a reed stalk.

2. Mesopotamia

Mesopotamians believed there were 3 kinds of tinnitus – the singing, the speaking and the whispering of the ear. They documented their treatments for tinnitus on clay tablets which were among the 600 clay tablets containing medical texts. The treatments varied from ingredients like opium, cannabis, belladonna to very original ones like chants dedicated to the god of water asking him for relief from the noises in the ear.

3. Classical China

The Chinese thought that tinnitus was caused by the imbalance of the Ying and the Yang. Ying represented support, structure, and constitution while Yang showed changing, adapting and moving.

4.) East India

The Annamite tribes of East India believed that human ears were inhabited by small animals. If they engaged in a fight with similar animals living in the ear or were upset by foreign bodies tinnitus would occur. The Annamites treated tinnitus with fumigation. It involved burning non-poisonous snakes and letting the fumes get into the ear to drive away the small tinnitus causing animals.

5. Ancient Rome

The term tinnitus was actually coined in the Roman Empire by an ancient Roman scholar, Pliny the Elder. The Romans divided their tinnitus treatments depending on the source of the noise. If tinnitus stemmed from the head, the treatment would include exercising, gargling and placing radish, cucumber juice, honey and vinegar in the ear.

On the other hand, if tinnitus stemmed from the ear then the patient should clear the ear and hold his breath until he laughed. Romans also recommended boiling earthworms in goose grease and putting them in the ear to solve all kinds of ear issues.

6.) 14th Century Medieval Welsh Medicine

The medieval methods were also quite interesting. One method included taking a freshly baked loaf of bread out of the oven, cutting it into 2 and applying it to both ears as hot as possible in order to produce perspiration. The patient then said the following prayer; Bind and thus produce perspiration, and by the help of God, you will be cured. This method resembled ear candling which is still used in alternative medicine.

7. Renaissance era

Renaissance doctors believed tinnitus was caused by the wind that got trapped in the ear and swirled around endlessly. So in order to liberate the wind, they would drill a hole into the bones around the ear using a silver tube which would suck the air out of the ear canal. This method was actually quite revolutionary as it introduced surgery as a treatment for tinnitus.

REALLY BAD JOKES

- So I was in Tesco's and I saw this man and woman wrapped in a barcode. I said "are you two an item?".
- So this bloke says to me, "Can I come in your house and talk about carpets?". I thought "that's all I need, a Je-hoover's witness".
- He said "you remind me of a pepper pot, I said "I'll take that as a condiment".
- One day a little girl was sitting and watching her mother do the dishes at the kitchen sink. She suddenly noticed that her mother had several strands of white hair sticking out in contrast on her brunette head. She inquisitively asked, "Why are some of your hairs white Mummy?" Her mother replied, "well, every time that you do something wrong and make me cry or unhappy, one of my hairs turns white". The little girl thought about this revelation for a while and then said, "Mummy, how come ALL of grandma's hairs are white?"

Working together Part 1

(Edited from article in *Quiet* magazine)

David Stockdale, BTA Chief Executive, reports on the first ever joint networking meeting held with our colleagues at the American Tinnitus Association (ATA).

The BTA and the ATA hosted our first ever joint networking event at the Annual Midwinter Meeting of the Association for Research in Otolaryngology [ARO] in San Jose, California, and the general feeling was that the meeting was a real success.

Just under 50 delegates attended, representing a really good cross-section of the field. These included industry in the form of pharma, biotechs as well as manufacturers. There were tinnitus researchers, of course, and within that group were both senior and new researchers to the speciality. Also present were other researchers from the wider otolaryngology arena, as well as some funders. There were some fruitful interactions and discussions in the networking section of the event, before our speakers took to the floor. The theme of the evening was 'Big Data' and we were very pleased to welcome:



L-R: Terry Brazell (ATA) and David Stockdale (BTA)

Christopher Cederroth (Karolinska Institute, Stockholm) who spoke on 'Tinnitus, Big Data and Genetics'

Will Sedley (Newcastle University) who discussed 'Tinnitus, Big Data and Objective Measures'

Gary Curhan (Harvard Medical School and Harvard School of Public Health), who looked at 'Tinnitus, Epidemiology and Big Data'

The talks went really well and were certainly well received. Some great engagement and discussion followed afterwards. The feedback from the event has been universally strong and everyone agreed that it offered the opportunity to showcase tinnitus research, the BTA and the ATA in a different light. We are hoping that we can do this again in future years, building and developing the event so that it becomes a notable diary date for the ARO Annual Midwinter Meetings going forward.

I would also like to thank Neuromod for sponsoring this inaugural event. I am looking forward to working to turn this meeting into something that's a more permanent fixture in the calendar.

New Advisors for the Professional Adviser's Committee



Dr Emma Benton is a GP with a particular interest in ENT matters. She is passionate about GPs being better informed about tinnitus and in new ways to help people with tinnitus to manage the condition.



Dr Chris Cederroth is a biologist with 11 years of professional research experience in academia. He is Associate Professor at the Karolinska Institute in Sweden, and creator of STOP, the Swedish Tinnitus Outreach Project.

Working together Part 2

The BTA are delighted to partner with Action on Hearing Loss (AoHL) to jointly provide necessary funding for an up-and-coming tinnitus researcher.

The scope to make an impact through research into tinnitus is huge, and there are significant opportunities for scientists to make a career in this field.

Our two organisations will provide funding to support a PhD student to work on the chosen project. This is an important step towards encouraging the best students to become involved in tinnitus research in the UK.

We are looking for universities to apply proposals for research which will:

Increase our understanding of the causes of tinnitus

Improve diagnosis

Advance the development of effective treatments.

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 mga978@hotmail.co.uk)

CONNECTIONS

CTSG website: www.cambstsg.com

Facebook: [Cambs 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 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 scheduled for Saturday 19 September at the Meadows Centre where our speaker is member John Williams talking about Relaxation Meditation. There is a high probability that this meeting will also be postponed; but let's keep our fingers crossed that it will happen!