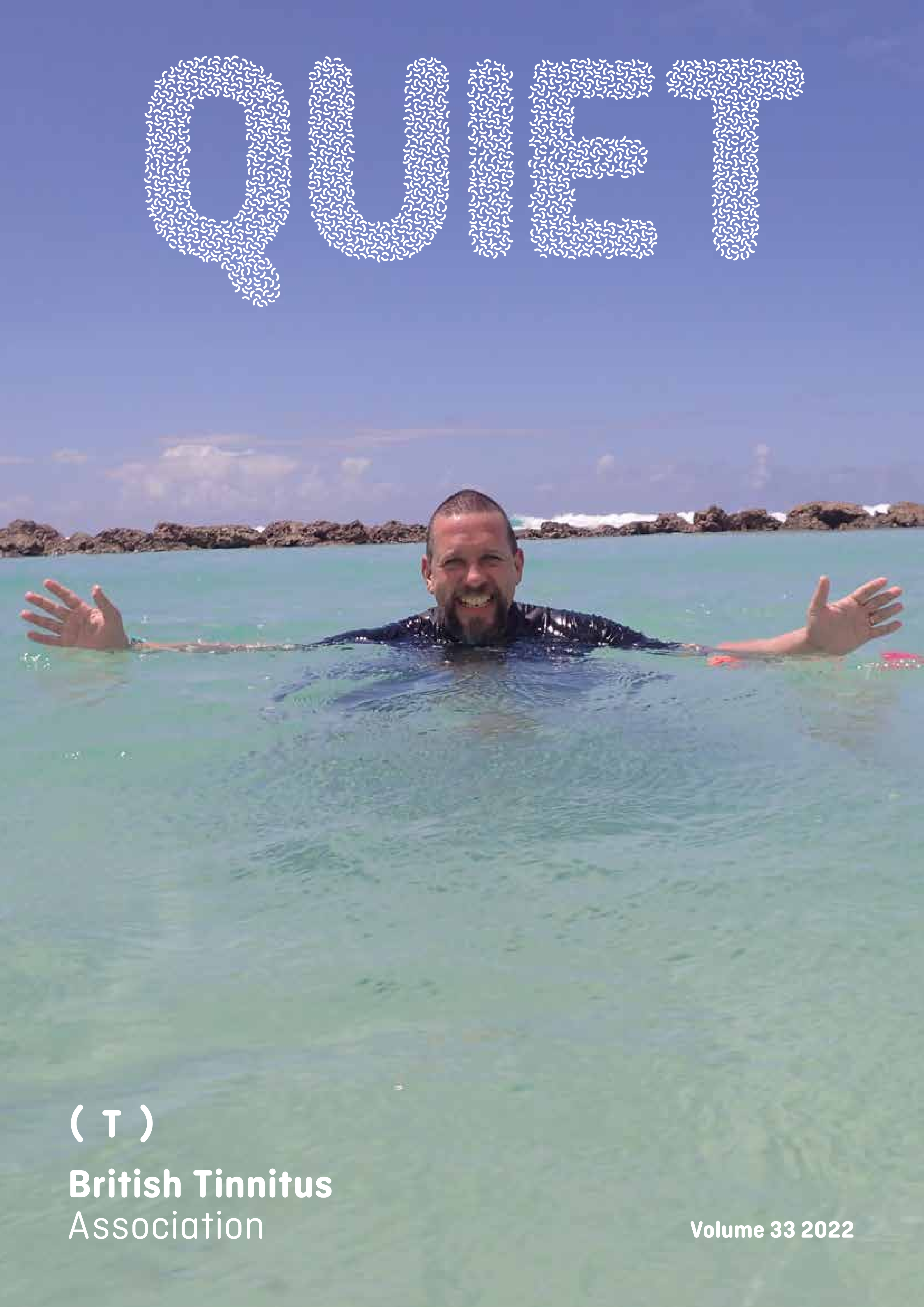
QUIET



(T)

British Tinnitus
Association

Volume 33 2022

Thank you to our Corporate Members for their Support

- AfterShokz
- Always Ear
- AngliEAR Hearing & Tinnitus Solutions
- Audiological Science
- Audiological Specialist Care Ltd
- Autifony Therapeutics Limited
- Better Hearing Clinic
- Bollington Hearing Centre
- British Academy of Audiology
- British Society of Audiology
- CAuRES Hearing Aid Solutions
- Chippendale Hearing
- Cubex Ltd
- Diane Hammond Independent Audiologist
- Duearity
- EarDial
- Geraint Davies Hearing Ltd
- Guymark UK Limited
- Halo Hearing Solutions
- Harbeth Audio Ltd
- Harley Street Hearing
- Hear Again Limited
- Hearbase
- Hearing Power
- Hearing Therapy Ltd
- Hear Pure and Wellbeing
- Hear We Care
- Help in Hearing Ltd
- Hidden Hearing
- HiKent
- Holland Doctors of Audiology
- I am Ear
- Isabella Fisher Independent Hearing Care
- Isle of Man Hearing Solutions
- Lakeland Hearing
- M C Hearing
- Neuromod Devices Ltd
- North East Hearing and Balance
- Nuheara
- Oticon
- Oto Health Ltd
- Peter Byrom Audiology Ltd
- Pinpoint
- Puretone Ltd
- Sivantos Ltd
- Smiths Hearing Care Ltd
- Snugs Earphones Ltd
- Sound Matters
- Specsavers
- Starkey Hearing Technologies
- The Hearing Coach
- The Invisible Hearing Clinic
- The Outside Clinic
- The Tinnitus and Hyperacusis Network
- Tinnitus E-Programme
- Widex UK Ltd

Hospital services

- Barnsley Hospital NHS Foundation Trust
- Chesterfield Royal Hospital NHS Foundation Trust
- East Kent University Hospitals NHS Foundation Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Nobles Hospital Isle of Man
- Royal Berkshire NHS Foundation Trust
- Royal Cornwall NHS Foundation Trust
- Royal Hallamshire Hospital (Sheffield Teaching Hospitals NHS Foundation Trust)
- Sandwell and West Birmingham Hospitals NHS Trust
- John Radcliffe Hospital (Oxford University Hospitals NHS Foundation Trust)
- University Hospitals Bristol and Weston NHS Foundation Trust
- Worcestershire Acute Hospitals NHS Trust
- York and Scarborough Teaching Hospitals NHS Trust

QUIET

Volume 33 ISSN: 0968-1264

Don't throw away the wrapper! The wrapper for your magazine is now compostable with your garden waste.

(T)
British Tinnitus
Association

Our Vision:
A world where no one suffers from tinnitus.

Our Mission:
We will drive progress towards a cure and deliver excellent support to help people living with tinnitus.

tinnitus.org.uk

Registered with FUNDRAISING REGULATOR

Contacts

Editor
Nic Wray
nic@tinnitus.org.uk

Address
British Tinnitus Association, Ground Floor, Unit 5, Acorn Business Park, Woodseats Close, Sheffield, S8 0TB
Registered charity no: 1011145. Registered in England.

Helplines Partnership Member

Helpline
0800 018 0527

THE SOUND OF SC

The urgent need for a Tinnitus Biobank

During Tinnitus Week 2022, we called for the establishment of a Tinnitus Biobank to deliver a step-change in the race to find tinnitus cures.

What is a biobank?

A biobank is a collection of biological data which helps to inform, develop and build a picture of a health condition.

Existing biobanks are of limited use as they have very little data about hearing loss and tinnitus.

A Tinnitus Biobank would be developed specifically for furthering research into the condition.

What do you want from the Tinnitus Biobank?

The Tinnitus Biobank would have several aims, including:

- finding a biomarker for tinnitus
- finding an objective measure for tinnitus
- categorising subtypes of tinnitus

Ultimately, we hope that these will help develop a pathway to finding a cure for tinnitus.

What is a biomarker?

A biomarker is a naturally occurring molecule, gene or characteristic by which a particular process in the body or disease can be identified.

Why do we need an objective measure?

The current questionnaires used to measure tinnitus have limitations. An objective measure of tinnitus would allow future treatments to be more accurately assessed, and would ultimately confirm a 'cure'.

And what is a subtype?

A subtype is a special type included in a more general type. So pulsatile tinnitus

IENCE

might be regarded as a subtype of tinnitus, for example. Researchers think there could be more of these.

Is the Tinnitus Biobank going to be expensive?

We believe the Tinnitus Biobank would cost about £4m to set up, which is 0.53% of the £750m that tinnitus costs the NHS each year.

As we picture it, the Tinnitus Biobank would be the largest single tinnitus research project outside of pharmaceutical research.

We are calling on the UK Government and research funders to fast-track their support for tinnitus research funding to establish a Tinnitus Biobank.

You can also donate to our Tinnitus Research Appeal online at **www.tinnitus.org.uk/donate** or over the phone on **0114 250 9933.**

How can I get involved?

You can sign up to be a potential Tinnitus Biobank participant or to be kept updated about our Tinnitus Biobank plans by visiting our website at **www.tinnitus.org.uk/biobank**

If you are interested in taking part in the biobank, you will need to be 18 or over and live in the UK.

Can people who don't have tinnitus take part?

Absolutely! We will be looking for people with and without tinnitus to take part in our Tinnitus Biobank.

Where can I find out more?

You can head to our website **www.tinnitus.org.uk/biobank** where you can:

- listen to our podcast
- watch our short animation
- download our White Paper
- read tinnitus stories and more.

Digital fatigue and tinnitus

Audiologist Paul Harrison explores how to pull back the feeling of fatigue and relieve tinnitus spikes.

Do you often feel a sense of exhaustion after a long day of digital meetings on Zoom? Experiencing head tension, eye ache and having spikes in your tinnitus? In short, it's your brain's way of telling you "Stop, it's time for a break!"

It is important to firstly normalise digital fatigue. It is a completely normal consequence of long periods of digital access. Unfortunately, people who have tinnitus struggle daily with managing their symptoms – then you throw digital fatigue into the mix! So how can we pull back that mental and physical feeling of exhaustion and relieve spikes in our tinnitus?

The effects of a digital generation

After the initial pandemic wave, organisations have either chosen to continue allowing staff to work remotely or have introduced a hybrid working structure. Both work methods are now a huge part of our lives, as this increasing digital generation evolves and shows no signs of stopping.

The result is a nation that is now struggling to cope with high levels of digital fatigue, as we continue to access digital tools to communicate with colleagues, family and friends. Most households are now living their lives in front of their screens.

Distorted viewing and strained listening are some of the many links to digital fatigue. Along with finding it harder to manage tinnitus symptoms, these additional strains can lead to a lack of sleep and higher levels of stress. Your body's way of reacting to these physical and mental complications, caused by digital fatigue, instigates a fight or flight mode that can often trigger spikes in your tinnitus.

Adapting to a new soundscape and new cases of tinnitus spikes

Those with tinnitus go through what is known as a habituation process quite regularly, and new organisation structures have forced them to adapt to new working environments at home, in the office or both quickly. The result? Most are finding it difficult to cope with the effects of long periods of digital meetings and tinnitus spikes and are left feeling debilitated and stretched to capacity.

Learning how to make changes to tinnitus relief methods that reflect this new soundscape is vital. So, you become less aware of the louder sounds of your tinnitus spikes and your attention eventually diverts elsewhere. But what at-home methods can we implement to cope with digital fatigue, whilst managing tinnitus?

6 simple tips

Finding a solution that's right for you requires some trial and error and seeing management from both sides - the digital fatigue and the tinnitus spikes. Here, I go through some brief tips that may help gain relief for both.

1. Focused meditation

Dedicate at least 20 minutes of your lunch break to meditate or practise yoga. Taking this time out consistently will help move the focus away from stress. Slowly you will become less aware of your spikes and tinnitus sounds. You will be able to habituate the sound.

2. Take note

Keeping notes of what triggers your spikes will encourage you to spend less time doing that activity, taking breaks from it or eliminating it altogether. Tinnitus spikes can be sporadic and it can be hard to pinpoint the cause. Retracing your steps and taking notes will help you to smooth out the ups and downs that come with tinnitus.

For example, it can go in some way to help you to adapt the way you work – like managing screen time more successfully and setting break times using your mobile's alarm.

3. Step away from your screen

After a long digital meeting, you could go for a short walk outside. Fresh air and movement will improve your lymph flow, connect your muscles, improve your posture, boost your mood and reduce stress levels.

4. Get your sleep back on track

As a tinnitus sufferer, you know how important it is to have a good night's sleep and recoup from the challenges of the day. It is the same for digital fatigue: you need to rest from the digital exposure and gain some control.

A strict bedtime and stopping using a screen an hour before you sleep will enable you to winddown.

5. Consider hearing aids

Because tinnitus and hearing loss are commonly linked, hearing aids might be considered. Hearing aids reduce background noise whilst offering tinnitus therapies and support to combat symptoms in realtime.

Being able to stream audio straight to your ears via these devices can also support you in your online meetings and reduce the risk of digital fatigue.

6. Switch your focus

To distract you from your tinnitus spikes, use tinnitus apps, white noise therapies and other audio to reduce the background noise of the loud sounds. Create your own playlist that can support you while you work as well as helping to increase your concentration levels.

Finding a relief strategy to suit you and your tinnitus symptoms will take time. Mixing meditation, limiting screen time, using the right tinnitus app and exercising more might be the combination for you. If you are disciplined and stick at it, you can get your life back on track and simply know how to cope better in the moment – with both digital fatigue and those unforgiving tinnitus spikes.

If you need to talk, we are here for you

- Call: 0800 018 0527
- Web chat: www.tinnitus.org.uk
- Email: helpline@tinnitus.org.uk
- Text/SMS: 07537 416841

Our Tinnitus Support Team are available Monday to Friday, 9am to 5pm.

Dispelling myths about HEARING LOSS

Nic Wray, BTA Communications Manager, separates fact from fiction

Hearing loss can be a sensitive topic, not least because it feels scary. But the more you know, the easier it is to live with it.

Here, I hope to look at some of the myths and misconceptions around hearing loss, and set the record straight.

MYTH: Only old people have hearing loss

One in five adults in the UK have hearing loss. Of these, more than 3 million are aged under 60, and there are 50,000 children with hearing loss.

MYTH: Hearing loss isn't a big problem Untreated hearing loss can also increase your risk of cognitive decline, dementia and Alzheimer's, social isolation and depression.

MYTH: Only very loud noises cause hearing loss

Prolonged exposure to even moderately loud noises can damage your hearing.

MYTH: I'd know if I had hearing loss

Hearing loss can develop so gradually, it may take you a long time to realise you are experiencing it.

MYTH: I don't need a hearing aid, I'll just turn up the volume

Turning up the volume - or asking people to speak up - often distorts sounds, making it even harder to hear correctly.

MYTH: Hearing aids will make my tinnitus louder

The opposite is in fact true: this is the most common - and one of the most effective - treatment for people who have tinnitus with hearing loss.

MYTH: Hearing loss is inevitable, especially with age

Hearing loss has many causes, including genetics, some medications, smoking, diabetes and exposure to loud noises. Noise exposure is the most preventable cause of hearing loss.

MYTH: Hearing aids won't help

Hearing aids work for almost everyone, but only if you use the right technology with the right settings. An audiologist will take the time to get these things correct.

MYTH: I don't need hearing aids yet, I can cope fine

It is easy to dismiss a mild hearing loss as unimportant, but it can still have an impact on your cognitive abilities, work, home and social life. The longer you wait, the harder your hearing loss will be to treat.

Signs of hearing loss

Audiologist - and BTA volunteer - Therese Goodwin describes how you might notice hearing loss and what you can do about it.

Imagine the scene. You're meeting a friend in your local café. You're enjoying her company, yet you notice you're missing parts of the conversation and you wonder why your friend is mumbling! It's becoming a strain to hear every word and instead of asking her to repeat, you nod your head, pretending to hear, trying to fill in the gaps. Not only are you feeling frustrated and a little embarrassed, but you're also exhausted! ***Does this sound familiar?***

According to the RNID, hearing loss affects 1 in 5 adults in the UK; however, it often creeps up on us, slowly and insidiously.

Like all change, it's something we'd rather not confront, preferring to blame external events for our difficulties: the noisy restaurant, friends and family not speaking clearly enough, etc.

Although rare, if you have lost hearing suddenly in one or both ears, you should contact your GP immediately.

Signs of an issue

We all have some difficulty hearing from time to time, but how do you know if you have a hearing loss? Here is a list of red flags that may indicate a problem within your auditory system.

- 🚩 You have trouble following a conversation, particularly amongst background noise
- 🚩 You regularly ask others to repeat what they have said
- 🚩 You notice a sound in your ear(s) that does not come from an external source (tinnitus)
- 🚩 You don't always hear environmental sounds such as birds or leaves
- 🚩 You turn the TV or radio volume up higher than others have it
- 🚩 You struggle to hear children's and women's voices
- 🚩 You have trouble hearing on the telephone.

What you can do

If you recognise more than one or two of these signs, it's a good idea to have your hearing tested. You'll need to make an appointment with your GP, who will examine your ears, check for any obvious explanations for your difficulties (such as a build-up of ear wax) and if suitable, refer you to your local audiology department.

Here, you'll have your hearing tested by an audiologist, who will explain your results and if appropriate, prescribe hearing aids, which you can either obtain from the NHS or you may choose to see a private hearing aid dispenser. Not only can hearing aids make listening easier, they can also be very effective in minimising the sounds of tinnitus that often accompany hearing loss.

Due to the pandemic, it may take some time before you receive your appointment with the audiologist. In the meantime, there are several helpful strategies to try.

For example:

- Let others know you have trouble hearing
- Try to face the speaker, if possible and ask them to speak a little more slowly
- Always have a small notebook and pen so you can write down important information
- The use of subtitles on the TV can be enormously helpful
- Consider joining a lipreading class either in person or online.

Above all, if you suspect you have a hearing impairment, don't delay. The sooner you seek help, the easier it will be to manage the problem, which will undoubtedly make listening much, much easier!

Resources

Whether you're new to hearing loss or have had it for many years there are resources available to help. Your audiologist can answer any questions, but these charities also offer support.

AbilityNet

AbilityNet supports anyone living with a disablity or impairment to use technology to achieve their goals at home, at work and in education.
W: **abilitynet.org.uk**
T: **0800 048 7642**

ATLA (Association of Teachers of Lipreading to Adults)

ATLA's aim is to create a world where lipreading classes are available to anyone who needs them.
W: **atlalipreading.org.uk**

Hearing Dogs for Deaf People

Hearing Dogs provide tailored help and support for people with all levels of hearing and their individual needs.
W: **hearingdogs.org.uk**

National Association of Deafened People (NADP)

A main objective of NADP is to increase awareness of the specific needs and requirements of deafened people.
W: **nadp.org.uk**
SMS: **07818 132961**

RNID (formerly Action on Hearing Loss)

RNID work to make life fully inclusive for deaf people and those with hearing loss or tinnitus.
W: **rnid.org.uk**
T: **0808 808 0123**

Living through a pandemic with hearing loss

Covid-19 has changed all our lives, but for people with hearing impairment, the ‘new normal’ has brought unique challenges.

Researchers at Hearing Sciences – Scottish Section in Glasgow (part of the University of Nottingham), ran a study which found face masks, social distancing and video calling can be difficult for people with hearing loss, and many of those who suffer from tinnitus said it was worse during the lockdown.

Four Patient and Public Involvement Representatives at Hearing Sciences – Scottish Section reflected on living through a pandemic with hearing loss:

"Lockdown has been a challenge in so many ways."

"During these times, it is difficult for most people, but for those with hearing difficulties it has added problems which most people do not realise."

"Keeping in touch with friends was absolutely essential during this period of restrictions."

"As a family, we use Zoom and Facetime a lot for wee get togethers but I find it very tiring and stressful if there are too many participants and when trying to listen in over lots of chatter and background noise. I have now had several job interviews over Zoom as well. A strange set up! Again, quite stressful trying to hear clearly."

"Once lockdown restrictions had eased, I cautiously ventured out again."

"Due to social distancing I am finding

it difficult to converse with people who are standing further away from me than normal. If they are wearing a mask this adds to the problem and for the most part I cannot hear what they are saying. Their voice is just a mumble of words that I do not hear. Masks also take away the opportunity to lip read. This has had an impact on my life and has taken away a lot of my confidence when I meet people outside my home."

"Then face masks became mandatory. Another trial if you wore hearing aids."

"I've ended up with packets of sugar, 'this week's special coffee' and extra milk at Costa because I've given up asking the barista to repeat what they just said, and so I just nod. When I finally get my tray and make may way to the table to meet my friend, it's with huge relief that I put down my tray and remove my face mask. What was that, pinging across the table and hitting her coffee mug? Oh, it was my hearing aid, once again dislodged by the mask."

"Light at the end of the tunnel."

"In general, people now seem delighted to say that there is light at the end of the tunnel and that things will be returning to normal in the not too distant future. Whilst that is indeed laudable, for those with acute loss the world around about them will not alter significantly with regard to their hearing. We need to understand this and take care of one another."

If you would like to read more about the study, you can read the discussion at **https://bit.ly/Q1Hearing**

Written by Fiona Mowat, Rita Rivero, Morag Sievwright, and Derek Macfadyen, Patient and Public Involvement representatives and Louise Burke, Research Assistant and Patient and Public Involvement Facilitator at Hearing Sciences – Scottish Section.

Myalgic Encephalomyelitis and tinnitus

People with tinnitus are often living with other health conditions, and wonder if they are connected. Here, we look at Myalgic Encephalomyelitus with Jayne Taylor, Communications and Engagement Officer from Action for M.E.

M.E. (Myalgic Encephalomyelitis) received a lot of bad press in the 1980s. The inaccurate – and offensive – phrase 'Yuppie Flu', used by many of the tabloids at the time, wasn't helping the thousands of people in the UK living with this debilitating illness. Forward more than 30 years and thankfully the tide has changed and research into the condition is gaining momentum.

What is M.E.?

M.E., also known as CFS (Chronic Fatigue Syndrome), is a long-term, fluctuating, neurological condition that causes symptoms affecting many body systems, more commonly the nervous and immune systems.

M.E. affects an estimated 250,000 people in the UK, and around 17 million people worldwide.

People with M.E. experience debilitating pain, fatigue and a range of other symptoms associated with post-exertional malaise, the body and brain's inability to recover after expending even small amounts of energy. Additional symptoms include cognitive difficulties (also known as 'brain fog'), digestive problems and hypersensitivity.

People with M.E. can vary enormously in their experience of the illness, and also how long their symptoms last.

Causes of M.E.

There is much debate about its underlying cause. Current theories about the cause of M.E. include autoimmune deficiencies, viral infections, autonomic/ sympathetic/ central nervous system dysfunction and genetic factors, amongst others.

Post-viral infection appears to be a common cause of M.E. The pandemic has highlighted the need for more research into post-viral infections, with an estimated 1.5 million people in the UK experiencing self-reported long Covid symptoms following Covid 19 infection.

According to the BMJ, patients with long Covid who have experienced chronic fatigue for six or more months, along with other mandatory symptoms, are likely to be diagnosed as having M.E.

Tinnitus and M.E.

There's very little information about living with M.E. and tinnitus, but a poll conducted on the *Science for ME* forum suggests that about 80% of people living with M.E./CFS have experienced tinnitus.

In a 2001 Belgian study of 2073 patients who met either the Fukuda or Holmes (CDC) criteria for a diagnosis of CFS found that 48.5% of patients meeting the Fukuda criteria and 52.1% of patients meeting the Holmes (CDC) criteria reported tinnitus. In the general population, this figure is around 30%.

A more recent study from the Netherlands, looking at over 167,000 people, has identified associations between tinnitus and a number of functional somatic syndromes, including fibromyalgia and CFS. People with CFS were 22% more likely to experience tinnitus than those without.

More research is needed to identify if tinnitus and these syndromes have underlying mechanisms in common.

Treatments

While there is no single medicine that cures M.E., there are a number of approaches that might help people manage their symptoms.

- **Pacing** is a methodical approach to balancing activity and rest, with the aim of bringing about more stability in symptoms.
- **Eating healthily** is important, and many people with M.E. opt for unprocessed foods and avoid (or reduce) sugar, caffeine and alcohol.
- **Sleep and pain management** can be achieved through a variety of ways including medication such as tablets or patches.
- **Complementary approaches** such as massage, reiki and acupuncture may be helpful. Good quality published evidence can vary considerably for each therapy.

Note: Strenuous exercise is **not recommended** for people with M.E. The NICE guideline for M.E. says people with M.E. should not be offered any therapy based on physical activity or exercise as a cure.

M.E. support

M.E. can leave many people housebound and feeling isolated.

Action for M.E. offers free UK-wide support, information, signposting and advocacy about any aspect of M.E. alongside doctor, physiotherapy, counselling and chaplaincy services (these are subject to a charge; bursaries are available).

Call: **0117 927 9551**
Email: **questions@actionforme.org.uk**
Website: **www.actionforme.org.uk**

LIVING WITH M.E.

Jules shares how she manages living with both M.E and tinnitus.

My first symptoms of M.E. appeared after I had glandular fever and whooping cough one after the other in 1982. I also suffered an extreme emotional trauma that year and I think my body just couldn't cope and was overwhelmed.

Relieved to finally have a label

In 1999, I had a knee operation that caused nerve damage and that was the real beginning of my more severe M.E. and I was finally diagnosed in 2014! I cried when the specialist gave me the diagnosis, not because I was unhappy, but because I was relieved to finally have a label.

I now have moderate to severe M.E. where even the simplest task can leave me bedbound for days.

A constant ringing

I honestly can't recall when I first noticed the tinnitus. I know I used to visit clubs and concerts in the 1980s and often had sporadic tinnitus but that was 'normal' back then. It only really became a problem in the last five years with a constant ringing/whistle. I have always suffered with ear infections and my hearing is now affected when I am in a busy location.

Seems worse in quiet places

I didn't really connect my M.E. and my tinnitus, they are both just something I live with but I haven't really related the two. My tinnitus is constant so I don't think it is triggered by anything anymore. I know it used to be loud environments and tiredness, and now it sometimes seems worse in quiet places when I am tired or stressed.

My M.E. is also worse when I am tired and stressed or when I have an accelerated heart rate. By that I mean every time I move, breathe, make a cup of tea or attempt a bath.


Jules

Life in general triggers my M.E.

Life in general triggers my M.E. and can leave me bedbound while I recover. I had to give up work as I just couldn't manage my symptoms while I was working.

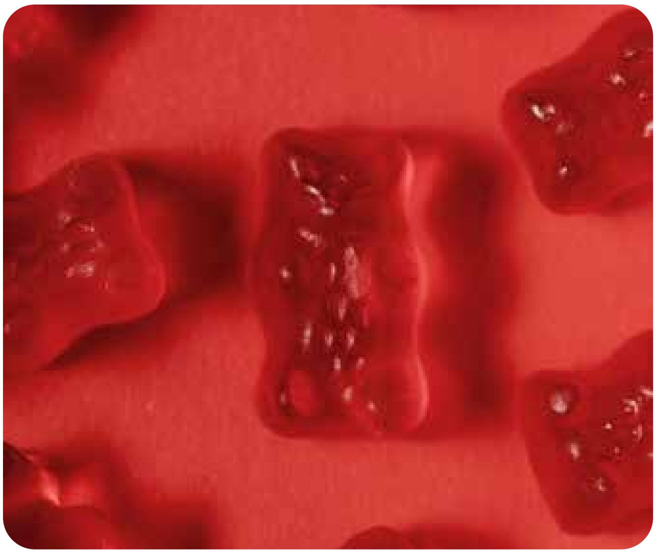
I have found Audible (an online audiobook service from Amazon) really helpful at night for tinnitus. Listening to anything really. I have 'sleep headphones' that allow me to fall asleep whilst listening. I can't fall asleep in silence as my brain is never silent.

Living my life as well as I can

During Covid-19 I thought my M.E. would improve. Being in lockdown and totally isolated, I figured my symptoms would ease. However, that wasn't the case and not having contact with friends and family made my mental health worse which in turn exacerbated my M.E. Now I try to limit stress and physical exertion but balance that with living my life as well as I can.

CBD gummies: a cautionary tale

We strongly suggest avoiding CBD gummies and their sellers. As well as there being no evidence for their effectiveness, we were aware that some people were paying more than they expected. Nic Wray spoke to one such person.



Retiree Rosemary had recently been diagnosed with tinnitus and it was causing her some distress. Looking on the internet for help, she saw a website in America which claimed it was supported by the 'dragons' from the TV programme Dragons' Den. She decided to purchase some CBD soft gels for £40.

After she'd entered her card details, a pop-up offered pain relief 'gummy bears' and Rosemary couldn't see a way of rejecting it. On the next screen, her order was instantly completed, and declared that not only had she ordered gummy bears for £38.99, but also the main order had been £198.78, not £40, meaning the order total was £237.77!

"I am a pensioner and there was no way that I would have wanted to spend that much money on a product I had not even tried!"

After immediately contacting her bank, Rosemary learned that the payment had already been taken.

She then contacted the vendor. They initially said they could not cancel the order as it had already been shipped but after insisting, the company reluctantly agreed to refund £38.99 and a further $70. If she returned the product on arrival, she would receive a refund in two instalments, less an administration fee of $70, and pay postage herself.

After talking to the vendor, Rosemary noticed three further charges to her card, and an email saying she had been enrolled in an e-book syndicate.

The Fraud Department of Rosemary's bank is now involved in the case and her debit card has been cancelled.

If you have fallen for a fake celebrity CBD brand scam, you must contact your bank or credit card company straight away. They will tell you if it is possible to claim your money back.

Rosemary says, "I feel such a fool. I am pleased to have found the BTA and your website and hope I can learn more which will help me in the future."

Dragons' Den and the celebrities from the programme are in no way involved in the manufacture and selling of CBD gummies.

The virtual London

The virtual London marathon is back for a third year!

We've secured 10 places for this year's event and if you're keen to get involved, we'd love you to be part of our team.

The 41st London Marathon on Sunday 3 October 2021 was the biggest marathon ever staged anywhere in the world: with 22,342 people from more than 101 countries taking on the 26.2 miles virtually and 35,871 participants back on the traditional central London course.

It was a celebration of everything the London Marathon stands for: fun, fundraising, fancy-dress and amazing community spirit, and a triumph of positivity and togetherness.

Our wonderful Team BTA 2021 raised over £16,000 and have some amazing memories from the event.

Are you interested in joining our 2022 marathon dream team?

By taking part in the 2022 event, you'll be one of 50,000 to complete the virtual marathon and one of 10 to do it for our charity and the tinnitus community. You'll have 24 hours to complete the 26.2 miles. You decide your route, start time and even if you walk or run!

Event details

Date: 2 October 2022
Distance: 26.2 miles
Location: Anywhere!
Entry fee: £28 (£35 overseas runners)
Suggested minimum sponsorship: £260 (£10 for every mile!)

L-R: Louise, Angela, Colette, Richard, Hugo, Helen, Jess, Chloe and Stephan, Neal, Jo and Christina

marathon is back!

What you will receive

- A BTA t-shirt/running vest
- Access to the Official London Marathon app to log your 26.2 miles
- Personalised fundraising support from a dedicated BTA fundraiser
- Lots of encouragement, help and advice
- An official London Marathon finishers medal and t-shirt
- An invite to our BTA London Marathon team celebration

To find out more and apply for one of our virtual London Marathon places, please email **fundraising@tinnitus.org.uk**

Already have a place?

If you were able to secure a place in the in-person or Virtual London Marathon, we'd love to help you fundraise for the BTA. As you have your own place, there is no minimum sponsorship AND you still receive personalised fundraising support.

Contact our team on **fundraising@tinnitus.org.uk**

Challenge events near you

From 5ks to marathons, we have charity places in a range of events across the UK and abroad.

Dedicating a personal challenge to support our work and the tinnitus community is a great way to raise awareness, and funds, amongst your friends, family and local community.

As in-person events start to resume you can find a local challenge event to take part in and use our booking system to secure your place.

Choose your event at **www.tinnitus.org.uk/local-challenge-events**

Our team will be with you every step of the way, supporting you throughout your challenge and fundraising.

Good luck!

Registered with FUNDRAISING REGULATOR

Phil's ultramarathon challenge - times five!


Phil Maull

Phil Maull (52) from Folkestone has challenged himself to complete five x 50km ultramarathons this year to raise awareness and funds for our work, as his mum lives with tinnitus.

Phil first started fundraising for the BTA back in 2018 when he completed his first ever marathon in Amsterdam.

He shared: “I want to help the tinnitus community because my mum suffers from it so badly. She doesn’t just get hissing but drumming sounds and drilling. I know she can find it debilitating but she just carries on so well which I really admire. She has always been there for me and now it’s my turn to give something back."

When asked “Why 5 x 50k ultramarathons?”, Phil replied, "Well why not? I have done some marathons previously and wanted a real challenge and this certainly is! I did my first Ultra last December and loved it. I completed it in 7 hours 15 minutes."

Phil completed his first of the five ultramarathons on 5 March and achieved a new personal best (PB) of just 5 hours 41 minutes –congratulations Phil!

Please support Phil and help him to reach his fundraising goal by donating at **justgiving.com/phil-maull** or by scanning the QR code.

SCAN ME

Want to take on a fundraising challenge? Email **fundraising@tinnitus.org.uk** and our team will help you.

Make your shopping count!

• You **Shop** • 6,000 Retailers **Donate** • For **Free**

Help us raise FREE funds

every time you shop online

easyfundraising feel good shopping | **£39M** Raised | Trustpilot ★★★★★

Support Us

We're registered with **easyfundraising**, which means you can raise FREE donations when online shopping with over 6,000 retailers, including John Lewis & Partners, Not On The High Street, Uswitch, eBay, Etsy, M&S and more!

So, whether you're buying a takeaway, presents, insurance or a holiday, you can help to raise extra funds to support our work, at no extra cost to you!

It couldn't be easier! Register online at **www.easyfundraising.org.uk/causes/britishtinnitusassociation** and start shopping. You can download the mobile app and install the web browser extension, so you never miss a donation.

It's such an easy way to support our work for the tinnitus community, for **FREE**.

CALLING ALL BUSINESSES! - you can support our work with your business purchases too! Retailers like Viking, Staples, Dell, thetrainline, Euroffice, Inkfactory, Booking.com, Apple, Travelodge and many more are all ready to donate (at no extra cost to your business) when you shop with easyfundraising. Go to **www.easyfundraising.org.uk/register-your-business**

Have a shot at our lottery!

> ***"I play this lottery as I want to support the work that [the BTA] do. I think it's very important and as a tinnitus sufferer myself, anything I can do to help research and avoid others getting this in the future I will do."***
>
> - Ben, BTA lottery player

The weekly draw costs £1 per entry and if your numbers match in the right order, you win £25,000!

The lottery results are calculated using the temperatures from selected destinations around Europe on a particular day each week.

Register at **www.tinnitus.org.uk/lottery**
Players must be 16 or over and must reside in Great Britain. Full Ts & Cs apply.

The Weather Lottery

MOVING FORWARD

John Cooper was sceptical that he would ever habituate and live well with his intrusive tinnitus. So how come he now co-faciliates an online support group?

I won't go into too much detail of the crisis days of my tinnitus. Suffice to say, my tinnitus started with an unexplained inner ear 'event'. As is common to a lot of us, the onset of tinnitus had a significant negative impact on my mental health.

Prior to the inner ear event, I would have considered myself a very physically and mentally healthy person who enjoyed playing sport, going to the theatre, going to festivals and generally feeling very happy and enjoying life.

Huge negative impact

I struggled for a long time with my tinnitus, and it had a huge negative impact on my whole life. I felt I had zero control: my nervous system was on alert 24/7 with the feeling of being constantly under attack from this noise I could not escape.

There have not been many positive things to come from Covid-19, but the BTA virtual online support groups which arose from lockdown were really my first big step in moving forward to living well with my tinnitus.

I was pretty sceptical

I have to be honest, I was sceptical of support groups and thought, "What could they offer me, a bunch of folks sitting around (virtually) talking about their tinnitus?"


John Cooper

After the first session, I was still not yet a 'believer'. In fact I was angry, as I heard several people talking about habituation and acceptance and I thought to myself, "You don't know how bad my tinnitus is, **YOU HAVE NO IDEA!**"

Techniques to help

However, after the second session I could see that I had been far too subjective and had allowed my emotions to overtake me. As the sessions went on, I realised not only was I learning about the condition, I was also learning techniques to help me live with my tinnitus.

I was also getting empathetic support from others in the tinnitus community. The sceptical me prior to my first group meeting wouldn't have believed that I was going to feel like this!

A sort of epiphany

Prior to attending the support group, I was doing a few distraction techniques to try and help me function day to day. After one of the group sessions I had a sort of epiphany and realised that I had to manage my tinnitus rather than it managing me. I had to take back control of my life, my nervous system, my mental health, everything.

Take its power away

Although the distraction techniques had been useful, I realised I had to put a complete plan in place that also included what I call behavioural techniques (cognitive tools, mental health tools, etc).

I realised distraction techniques were just that, a distraction from my tinnitus. What I needed to do was to stop my mind focusing on my tinnitus. I needed to take its power away, so I no longer thought about it as a threat and something to focus on.

The addition of the behavioural techniques into my management plan was the springboard to really taking significant steps forward in living well with my tinnitus.

Another epiphany

As the groups went on and I was working on my plan, I had another epiphany which was, "I have tinnitus, it's probably not going away, there is no cure **BUT** that's okay". I think this is what some would call acceptance. This phase was massive for me, as I realised all the things I had done in my plan were working. I no longer saw my tinnitus as a threat and ultimately my tinnitus was just part of my normal life. I had normalised it and it no longer had any power over me.

Try to help others

As I moved forward from this phase, I reflected on the suffering I had gone through prior to putting my plan in place. This was the catalyst for me wanting to give back to the BTA, not only thanking them for helping me but to also try to help others in the tinnitus community so that they didn't suffer as I had.

I began various volunteering activities for the BTA and was eventually asked to help co-facilitate one of the online support groups. It's an honour and a great responsibility to be a Support Group Leader and I hope I serve the tinnitus community well.

Tinnitus is all consuming

Music executive Jo Fry shares his experience of living with tinnitus

I've had constantly ringing, very high-pitched tinnitus in my left ear since around May 2020. I've had little episodes of it over the years, but we're talking about 10-15 seconds, which are forgotten about almost as soon as they start.

I was very concerned

ENT specialists have concluded that there's probably age-related hearing loss in that ear (although I'm only 46). I work in artist management in the music industry so my hearing is rather important, to say the least. Back in May 2020, the live music business was imploding due to the lockdown, and like everyone working in the arts, I was very concerned about the future. With two young mouths to feed and bills to pay, stress became a real issue, which is why I think my tinnitus has to be connected in some way with that stress. To add to that, I also have a (non-tinnitus) issue with my other ear that remains unresolved.

Ways of trying to mitigate it

There are times throughout the day when I sort of forget about it. Often that coincides with outside noise, or my attention being diverted in another way. But there are also times of the day when it's very prevalent such as last thing at night when I'm reading in bed or trying to fall asleep, so I've had to find ways of trying to mitigate it.


Jo Fry

At night, I tend to fall asleep listening to a podcast or whatever at a very low volume through an ear bud. I set a timer for 25 minutes, which is usually enough for me to fall asleep to, and the ear bud also drops out. It doesn't tend to stop me sleeping once I'm asleep, but it can very much delay me from falling asleep.

It's really hard

When I think about my tinnitus, and think how loud it is, it does make it louder. So, rather than do that and then end up talking to myself and looking a bit odd, I try to distract my brain from the tinnitus and try not to think about it too much. It's really hard, especially if you're not used to doing it, and it requires a lot of brainpower or concentration.

Try not to fight it

Another thing I try and do is to not to fight it, even to accept it. This ringing is not going away. It really does help so much if I don't work myself up about it: subconsciously, the tinnitus becomes less prominent. All this requires some kind of discipline that I'm not used to having, so I'm still learning on that one!

Playing sports and doing exercise is great because when your body is moving, what you're hearing is different. And I'm not focused on the ringing. It's been a great relief to me.

Brain trains itself not to notice

I found the medical approach has been at times very helpful and at times deeply frustrating. With tinnitus, which is all consuming, you would love for someone to say, “This is what you do”. The person I saw, I have huge respect for. He was very patient and very honest with me about the fact that there isn't a cure, but that how in many cases, the brain trains itself not to notice the sound, and that it may go away, but that it could take months or years. I've also had to understand that tinnitus is a symptom of something else, not a disease.

There's only so much I can say to my wife and two kids about this constant noise. And they can't help me necessarily. So that's been difficult because I haven't really been able to vent to anyone, especially at first whilst we were in lockdown. They've been really sympathetic at times, of course, but I don't expect them to understand what I'm going through because unless you have it yourself, it's very difficult, I think, to empathise.

Sometimes I worry about the future because I consider myself still 'youthful' at 46 and wasn't expecting my hearing to cause issues at this stage in my life. Rather worryingly, I am told that the ringing may never go away - which is also something hard to accept!

People can be desperate

While I'm open to trying anything, I like to think I wouldn't fall for one of the (very convincing) YouTube videos or internet adverts about new tinnitus cures, but I can understand that people can be desperate enough to try them. At one point the ENT specialist did put me on a no caffeine, low salt diet but I didn't notice a dramatic change.

Help each other out

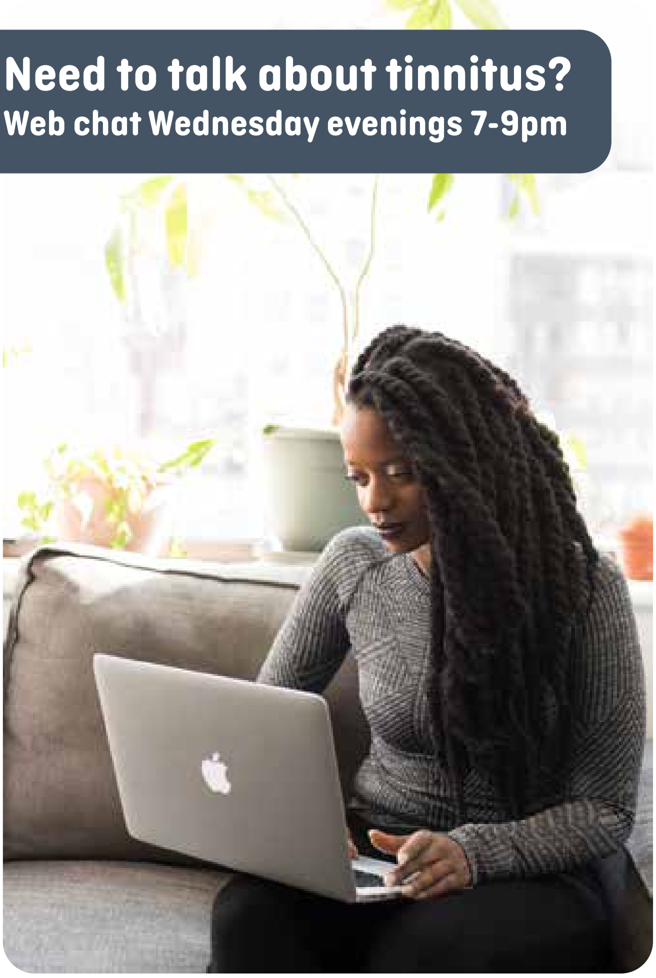
I wish I'd discovered the BTA a bit sooner. I always knew that tinnitus was quite prolific with many sufferers, but I used to wrongly assume that people suffer – excuse the pun - in silence. Having had this for nearly two years now, the time for suffering in silence is over.

I want to be able to talk to people and say, “You know what, I've got the same and isn't it tough? Let's see if we can help each other out; here's some things that have helped me.”

I think knowing there's a network of supportive people out there can be a source of great comfort. The BTA webinars and pages about potential treatments and cures are so helpful, especially with the clear and sensible traffic light system. I just wish there were a few more greens on there - maybe in time!

Need to talk about tinnitus?

Web chat Wednesday evenings 7-9pm



Chat with our volunteers

We know that sometimes people can't contact us during our main opening hours.

And sometimes, people want that extra understanding that comes from talking about tinnitus with someone else who experiences it themselves.

This is why, every Wednesday, our web chat service is open between 7 and 9pm and staffed by our wonderful volunteers, all of whom are living with tinnitus.

The service is confidential, and free of charge. To have a web chat with one of our trained advisers, visit **www.tinnitus.org.uk**, using computer, tablet or mobile, and click on the speech bubble icon at the bottom of the page - it's that easy!

Please note that we can't provide medical advice.

Membership changes

Like many organisations, we have found the last two years incredibly challenging.

The demand for our services has increased but unfortunately competition for funding and donations is fiercer than ever.

We receive no direct Government funding for our work. And like all of you, we are not immune to the effects of rising costs and inflation.

In order to support as many of the 7.1 million adults living with tinnitus in the UK, we are having to make changes to our services and member benefits. This has been a very hard decision to make.

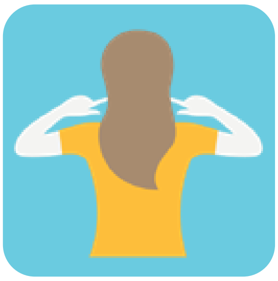
Going forward, members will receive *Quiet* in Spring each year and *Our Impact* in Autumn. Our *FOCUS*, *INSPIRE* and *EXPLORE* e-newsletters will be combined, and we will produce one e-newsletter each month.

We will continue to update our social media streams on a daily basis, so you need never miss out on news, information and support.

If you have any questions, please do not hesitate to contact us - details are on page 3.

SPECIALIST SUPPORT

Although everybody's tinnitus is different, people in our online groups find that they have much in common. But sometimes, a more specialist group might be more beneficial. Why not try one of these out? Find details at www.tinnitus.org.uk/online-support-groups



Tinnitus and hyperacusis

Meets on the third Wednesday of the month.

Hyperacusis describes when the sounds of everyday life are intrusively loud, uncomfortable and sometimes painful.

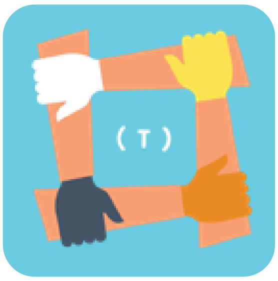
This support group is for those experiencing **both** tinnitus and hyperacusis.

Musicians

Meets on the second Wednesday of the month.

Following research conducted with Help Musicians, the BTA has recognised the need for a tinnitus support group for musicians.

This group is aimed at: anyone with tinnitus who has worked as a professional musician; musicians with tinnitus

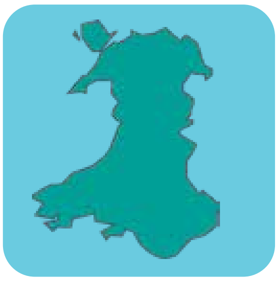


18-30s

Meets online on the fourth Monday of the month.

We have found that many people with tinnitus like to speak to others of a similar age or at a similar stage in life.

This group is aimed at 18-30 year olds with tinnitus, whether you're struggling or managing it well. Family members and/or friends of those attending are encouraged to join as well.



Cymraeg (Welsh speaking group)

Cyfarfod ar y pedwerydd dydd Mercher o bob mis

Gan y bydd y cyfarfodydd yn cael eu cyflwyno yn Gymraeg, bydd angen i gyfranogwyr allu siarad a deall Cymraeg.

Mae'r grŵp ar gyfer unrhyw un sy'n cael trafferth gyda'u tinitws; unrhyw un sy'n rheoli ei tinitws ac sydd am rannu awgrymiadau/cyngor ag eraill; anogir aelodau o'r teulu a/neu ffrindiau'r rhai sy'n mynychu i ymuno hefyd.

SUPPORT GROUPS

Scotland

- 🟥 **Edinburgh & SE Scotland**
- 🖥 **Forth Valley**
- ★ 🟥 **Glasgow**
- 🖥 **Highlands**

Northern Ireland

- 🟥 **Belfast**
- 🟥 **Craigavon**
- ⏸ **Enniskillen**
- 🟥 **Newry & Mourne**
- ⏸ **Omagh**
- 🖥 **RNID Northern Ireland**
- 🟥 **Western (Londonderry)**

North-West England & Isle of Man

- ★ 🟥 **Aintree**
- ⏸ **Blackpool**
- ★ 🟥 **Bolton**
- 🖥 **Cumbria**
- 🟥 **Isle of Man**
- ⏸ **Kendal**
- 🟥 **Manchester**
- 🟥 **Prestwich**
- 🟥 **St Helens**
- 🟥 **Stockport**
- 🟥 **Widnes/Runcorn**

Wales

- 🟥 **Aberdare**
- 🟥 **Bridgend**
- ⏸ **Cardigan**
- 🟥 **Dolgellau**
- 🟥 **Llanelli**
- 🟥 **Pontyclun**
- 🟥 **Pontypridd**
- 🟥 **Rhondda**
- 🟥 **Swansea**
- 🟥 **Ystradgynlais**

South-West England

- 🟥 **Bournemouth**
- ⏸ **Bristol**
- 🟥 **Gloucester**
- ⏸ **Kingsbridge &District**
- ⏸ **Mid-Somerset**
- 🖥 **South West England**
- ⏸ **Taunton**
- 🖥 **Truro**

South-East England

- 🟥 **Aldershot & District**
- 🖥 **Amersham**
- 🖥 **Ashford, Kent**
- 🖥 **Basingstoke**
- 🟥 **Brighton**
- 🖥 **Canterbury**
- 🖥 **Crowborough**
- 🖥 **Dover**
- 🖥 **Faversham**
- ⏸ **Harpenden**
- ⏸ **Hitchin**
- ⏸ **Isle of Wight**
- 🖥 **Maidstone**
- ★ 🟥 **Marlow/Farnham Common**
- ⏸ **Oxford**
- 🖥 **Pembury (West Kent)**
- 🖥 **Rochester**
- 🟥 **Salisbury**
- 🟥 **Southampton (on hold)**
- 🖥 **Thanet**

West Midlands

- ★ 🖥 **Birmingham & District**
- 🟥 **Newcastle under Lyme**
- ★ 🖥 **Shrewsbury**
- 🟥 **Stoke on Trent**
- ★ 🖥 **Telford**
- ★ 🟥 **Warwick**
- 🟥 **Whitchurch**

We have tried to ensure that this listing is as accurate as possible, but please check with the Group Facilitator before setting out to an in-person meeting.

Check the Support Groups Directory online at **bit.ly/TSGTT** or contact us on **0800 018 0527** or **helpline@tinnitus.org.uk.**

North-East England

- 🟥 **Chester-le-Street**
- 🟥 **Darlington**
- 🟥 **Newcastle**
- 🖥 **North Tyneside**
- 🟥 **Seaham**

Yorkshire & Humber

- 🟥 **Bradford**
- 🟥 **Brighouse**
- ★ 🖥 **Keighley**
- 🟥 **Rotherham**
- ⏸ **Rotherham Central**
- ★ ⏸ **Sheffield**
- 🟥 **York**

East Midlands

- ★ 🖥 **Chesterfield**
- 🟥 **Derby**
- ⏸ **Lincoln**
- 🟥 **Northampton**
- 🟥 **Nottingham** NEW!

East of England

- 🟥 **Bury St Edmunds**
- 🖥 **Cambs (Cambridgeshire)**
- 🟥 **Chelmsford**
- ⏸ **Ipswich**
- ★ 🟥 **King's Lynn**
- ⏸ **Lowestoft**
- 🖥 **North East Essex**
- 🖥 **Southend-on-Sea**

London (within M25)

- 🟥 **Bexley**
- 🟥 **Boreham Wood**
- 🖥 **Bromley**
- 🟥 **City of Westminster** NEW!
- ⏸ **Chiswick**
- ★ 🟥 **Greenwich**
- 🟥 **Hornchurch**
- ⏸ **Isleworth**
- 🖥 **Kingston**
- 🟥 **North London**
- 🟥 **Orpington**
- 🖥 **Redbridge & Hackney**

Key

- ★ **BTA Gold Standard group**
- 🖥 **Meetings online**
- 🟥 **Meetings in-person**
- ⏸ **Meetings on hold**