Quiet

Volume 34 2023

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Tinnitus UK

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What’s inside:

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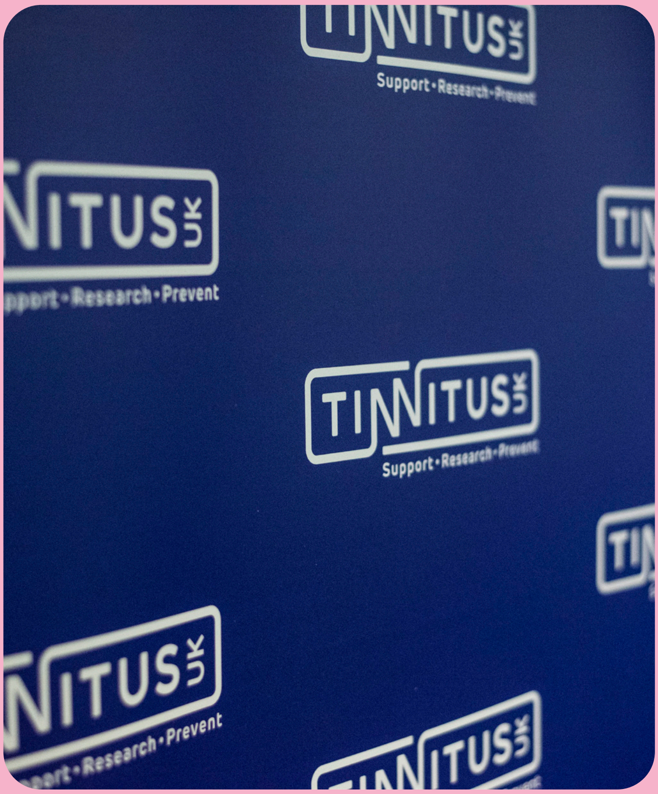
We are now Tinnitus UK!



You may have noticed some changes in this issue of Quiet!

We are now Tinnitus UK. This new name puts tinnitus first, because taking on tinnitus is the main reason we're here, and we want everyone to know that.

Becoming Tinnitus UK will help us reach more people with tinnitus, be more visible and raise more awareness of the condition.

We began life as the British Tinnitus Association in 1979, which reflected our roots as a network of tinnitus support groups. Then most people started to call us the BTA. And that really hid who we are and what we do.

Our new identity marks the start of a very exciting period for us as we build on our past successes and strive to reach even more people who may be struggling with tinnitus.

Our new name and identity deliberately coincided with our digital transformation. As a small charity with a very large potential audience, digital and online services are essential to reaching people and supporting them.

Thanks to grant funding, we were able to work with the tinnitus community to make our website easier to navigate, as well as introducing a chatbot to complement our live web chat.

We have changed our name, our brand identity and our website.

But our vision remains the same – creating a world where no one suffers from tinnitus – and people with tinnitus are always at the heart of what we do.

Our Communications Manager Nic Wray was asked to share details of how we approached the rebrand — scan the code or click here to read more.

Want to find out more about the chatbot? Turn to page 34 to read all about it!

Keep up to date with FOCUS

Each month we send our **FOCUS** newsletter to tens of thousands of people in the tinnitus community.

It couldn't be easier to sign up to receive your own FREE copy to read the latest tinnitus news, updates on tinnitus research, ways to manage your tinnitus, how to support us via fundraising and more. Register online at **tinnitus.org.uk/sign-up-to-our-newsletter** and you'll be the first to know about our exciting announcements!

Calling all businesses...

Did you know that 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-yourbusiness**

Welcome to our new CEO

We are delighted to announce that Caroline Savage has been appointed as our new Chief Executive Officer after a successful period as Interim CEO.

Caroline said: "The growing critical need for what Tinnitus UK does, combined with the drive, commitment and expertise of the team made my decision easy.

"Together with our award-winning support resources we have a strong foundation to build on for the years ahead. We will develop and deliver even better services and work even harder to increase investment in tinnitus research."

Caroline has 25 years of charity and voluntary sector experience, including working with health, arts and international development organisations.

Lynne Gillon, Chair of Tinnitus UK, said: "We look forward to Caroline's leadership, after her impressive tenure as our Interim CEO, in our continuous quest to support more people who are affected by tinnitus whilst searching for a cure."

"A cure for tinnitus would change my life"

Rebecca has had tinnitus for 23 years. As part of our Spring Appeal, she writes about the debilitating impact tinnitus has on her life and how things would be different if we could find a cure.

In 2000, I developed a serious infection in my inner ear which damaged all the little hairs of my cochlea. I was just eight years old at the time. The infection, that had started off so small, destroyed my balance and decimated my hearing in my right ear. It also gave me tinnitus.

I can't remember a day since then that I haven't heard it. My tinnitus is a noise like TV static, but someone's turned the volume up to 60. And it never goes away.

"I dread events like my little boy's birthday party."

I'm 31 now and I have two beautiful children with my husband, Dave, but, if I'm honest, my tinnitus makes relationships incredibly hard. I dread events like my little boy's birthday party because I can't bear the shame of having to ask people to repeat themselves over and over again. I'm constantly worried that people will think I'm rude and not listening to them but the truth is I can't hear them over my tinnitus.

Having tinnitus has made life exhausting. It's not just that I can't hear and I have to try and read lips or that I'm embarrassed about what other people must think of me but that after hours of straining to listen to everyone, of the social anxiety, I get horrible headaches that make my tinnitus even worse. Even louder. It's a vicious loop.

"I'm trapped in a bubble of noise."

Driving is where my tinnitus is at its worst. I was involved in a car crash last year while on my way to work. One of my tyres blew out on the motorway and my car flipped four times. I'm thankful every time I do that route now that it was the one day that week that I wasn't taking my little girl, Emily, to nursery.

Luckily, no one was hurt but driving on that road is a horrific experience for me now. I get incredibly scared when I feel uneven road beneath me. Then, because I'm getting stressed, my tinnitus starts screaming in my ear and I feel as though

I'm trapped inside a bubble of noise that's pressing in on me. My heart starts racing. I'm terrified because it's so loud. It's the only thing I can hear.

"I feel like the worst mum in the world."

Some days my tinnitus is so bad that I can't bear to face people. I pop the kids in front of Netflix and just curl up on the sofa and hide. I feel like the worst mum in the world.

My tinnitus affects me at work, too. It's hard to organise your thoughts between the constant noise in your head. I work as a biomedical scientist at my local hospital, and I have to be very thorough. If my tinnitus is making it hard to concentrate, I'm more likely to make a mistake, and that can throw off my work for the whole day.

The worry that this creates, that I'm falling behind and letting patients down, can start to spiral and my tinnitus will get louder and louder. I don't need to tell you how hard that is.

"Instantly my heart started to race."

Recently, one of the machines in the lab started making a new noise. It was a high-pitched beep that I'd never heard before and we couldn't turn it off. Instantly my heart started to race. I was so scared that I was hearing a new tinnitus sound.

I kept asking my colleagues over and over, "Can you hear that?" because I was desperate to make sure it wasn't just a noise in my head. Not many people will understand what that's like.

A cure for tinnitus

A good day with tinnitus is when I don't notice it as much. I'm chatty and bubbly. I sing silly songs or do little dances. I wish every day was like that, like I could be my true self.

After three years, I'm now finally on the waiting list for a bonebridge surgery. This little ear implant will send sounds, through vibrations in my skull, from my bad ear to my good ear, helping me hear better. And it should help with my tinnitus too! Right now, that's the best science can do for me.

I've found other ways to cope; at night I listen to a sound machine app on my phone that plays through a soft band I can wear around my head and I have in-ear hearing aids right now. But that's about as good as it gets for me. Maybe for you, too.

That's why I'm taking part in this appeal. A donation to Tinnitus UK is a gift of hope for people like me. With your support we could fund the next breakthrough in tinnitus research that could find new and better treatment options for even more people.

A cure for tinnitus would change lives. By donating to our Spring Appeal, you could help make a brighter future possible.

To make a donation, please complete the enclosed form and return it to FREEPOST TINNITUS. You can also give online at tinnitus.org.uk/gift-of-hope, by scanning the QR code or by calling 0114 250 9933. Thank you.

Tinnitus Week 2023

People across the country joined us in saying - when it’s loud, plug’em!

With the rate of tinnitus within the UK rising to 1 in 7 adults, we know something has to be done. One of the best ways to reduce your chance of tinnitus is to get some ear plugs and protect your ears.

Noise starts to become a risk to hearing at 80dB, and in a working environment, hearing protection should be provided at 85dB or above.

Although there is legislation in place to protect hearing in the workplace, there is no such legal status for noise outside of the working environment.

Studies have shown that the use of hearing protection in certain groups, such as musicians and young people, is quite low.

We wanted to know what a wider group of people experienced, so we asked our members and supporters - and you responded magnificently!

2.7 million adults have tinnitus from noise exposure

Our survey showed that:

- Over one third (35%) of people believed that their tinnitus was caused by loud noise exposure. This could mean that 2.7 million adults in the UK had their condition triggered by noise.
- Twice as many men (48%) as women (24%) claimed noise exposure as a reason for their tinnitus

- Shockingly, four out of ten (39%) respondents who were exposed to noise at work “never” used hearing protection and only a quarter (24%) “always” or “sometimes” used hearing protection.

- These numbers were even lower for the use of hearing protection for leisure activities, with numbers ranging from 8% to 29% for the most commonly undertaken pursuits (cinema, DIY and gardening).

Spread the Plug’em message

We’re asking people to remember these four simple steps - and to spread the Plug’em message so that the next generation doesn’t have to live with tinnitus.

- Always wear appropriate hearing protection when in a loud place, and working with loud equipment

- Avoid being exposed to excessive noise for long periods

- Replace hearing protection if it is worn or damaged

- Have your hearing checked regularly.

How to Plug’em

There are different types of hearing protection available. This will help you choose the best solution for you.

1. Disposable earplugs

These are widely available. They are usually made from foam, wax or silicone. They are cheap and fit everyone. They are reasonably comfortable and provide good protection if put in properly. There can be a loss of sound clarity.

2. Universal fit earplugs

These earplugs are better for listening to music, for example at a concert or nightclub. They decrease the decibel level but maintain the clarity of the sound. They are affordable and reusable. Some come in different sizes.

3. Custom moulded earplugs

If you regularly need to wear earplugs it might be worth having some made for you. They will be more comfortable and will have a perfect fit and seal to give the best possible protection.

4. Earmuffs

Earmuffs consist of two cups to cover the external part of the ears with comfortable padding on the inside. The cups are connected by a band which fits over or behind the head to hold the cups in place. They provide more consistent protection than earplugs and are easy to put on. They can be heavy and glasses wearers may not get a perfect seal.

For more detailed information about hearing protection, visit tinnitus.org.uk/plugem/earplugs

Learning to live in peace

Mark shares his experience of developing tinnitus through noise exposure.

In June, I will be 66 years old, and I feel that for certain I damaged my ears from my late teens and early adulthood.

I have played drums and percussion instruments from the age of 10 years old, and not knowing the dangers of hearing loss and tinnitus back in those times, I am sure I started the damage back then.

I also attended many loud rock gigs, the loudest being Grand Funk Railroad, at the then Wembley Empire Arena in 1975. I remember that gig well, as my ears were numb and ringing, and when I started the motor of my old Ford Anglia, I could not hear the engine!

No ear defenders were provided

When I was at university, to help pay my way, I also took a temporary job with Ready Mixed Concrete. The job was to repair the rusted conveyer belts by blasting the steel structure with impact drills.

No ear defenders were provided and I recall that after every two to three hours session, my ears would ring.

A cement truck exploded

During my forties I noticed that I had very mild tinnitus, a slight ringing in my left ear, but nothing to really bother me too much.

The problem truly arose 13 years ago when I was out walking in Beijing, when a close-by cement truck exploded. The noise was like a bomb going off and was so loud that I could not hear properly for a few days.

When my hearing recovered, I was left with loud ringing, especially in my left ear. Since then, I have truly suffered with tinnitus, with spikes when it is quite bad. This is made worse when I have periods suffering from eustachian tube dysfunction.

I have learnt over the years to cope

I have learnt over the years to cope with tinnitus, knowing that there is no cure. I have also learnt that my tinnitus becomes worse when experiencing stressful times and situations.

I always try to keep calm, peaceful and above all, fit and healthy, by eating the right foods and taking exercise. I find this helps considerably to ease my tinnitus.

I have never been a big alcohol drinker, but I found that when I did it, my tinnitus seemed to spike, so I cut out alcoholic drinks altogether and I feel better for this.

I always carry earplugs

I still play the drums, as this is a passion and love of mine, but I do so with care, wearing ear protection. I always carry ear plugs/protection with me.

If I travel on the London Underground, I will wear ear plugs, to cut out the screeching sound of the wheels on the track. When I use the vacuum cleaner or lawn mower at home, I will wear ear plugs.

Learning to live in peace with tinnitus is key, and I feel that I have managed to do this. I only wish that back in the 60s and 70s I knew about tinnitus and the dangers of not looking after your hearing.

Older adults reluctant to report hearing loss

A recent study published in the International Journal of Audiology has found that nearly 40% of older adults who recognised that they had hearing loss did not tell a medical professional about it.

Women, retirees, those with a non-UK education, lower education, smokers and heavy drinkers were all less likely to report their experiences.

The study's leader, Dr Dalia Tsimpida from the University of Liverpool said: "We cannot afford to ignore the impact of hearing loss on individuals and society. We need to raise awareness of the risks associated with hearing loss and take action to prevent, identify as early as possible, and manage it effectively."

For those who recognised and reported their hearing loss and were referred for hearing loss management, 8 out of 10 expressed a willingness to try to use hearing aids.

According to the authors, the findings of the study suggest the need for greater awareness of the importance of addressing hearing loss and access to treatment, particularly for those who may be less likely to report their hearing difficulties.

Research updates

Tinnitus UK are leading investors in tinnitus research. Here are updates on some current projects.

Understanding the origins of tinnitus

Dr Will Sedley, Newcastle University

‘Chronic’ tinnitus is a common condition, and just means tinnitus that has been there for a long period of time, typically six months or longer. Almost all research conducted with people with tinnitus has been on chronic tinnitus.

Yet, all chronic tinnitus has to start somewhere, and we believe that this initial period when tinnitus first begins may hold a lot of insight into the causes and mechanisms of the condition, which may become all but undetectable once the tinnitus has become chronic.

In this innovative research study, funded by Tinnitus UK and RNID, we are studying volunteers whose tinnitus began less than four weeks ago, and comparing the results obtained to matched groups of people without tinnitus at all, or with chronic tinnitus, and also to the same individuals after six months, once their tinnitus has become chronic.

This ability to study the same individuals at multiple time points of their tinnitus course is particularly powerful. We are taking a variety of measures, including tinnitus symptoms, perception of external sounds, resting-state brain activity, and brain responses to sounds at frequencies similar to, and different to, individuals’ tinnitus.

The first study is nearing completion, with all participants already studied for their first set of measurements, and the new-onset tinnitus group are mid-way through returning for their repeat testing after 6 months from tinnitus onset.

We will present preliminary findings at the Tinnitus Research Initiative conference in Dublin in June 2023, and aim to publish a first full set of findings before the end of the year. Further similar studies will follow, following on from the results of this first study.

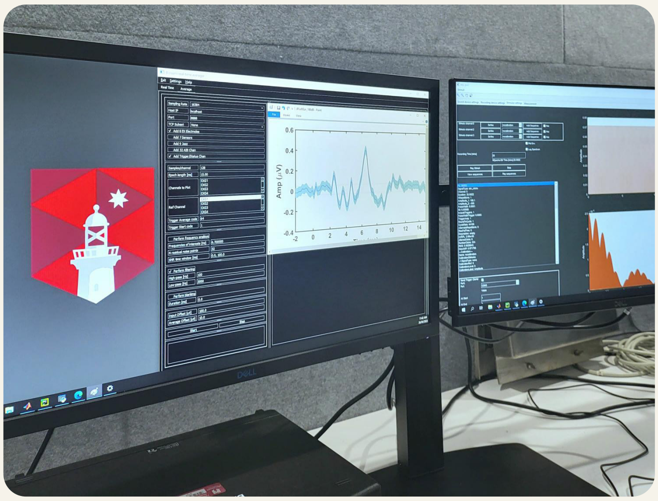
Developing a reliable objective measure of tinnitus

Dr Jason Mikiel-Hunter, Macquarie University

Finding an audiological test that can objectively identify an individual with tinnitus, without needing people's self-reports of their sounds, remains a key goal of many audiologists and auditory researchers.

The usefulness of an objective measure could extend well beyond its ability to diagnose tinnitus: from improving our understanding of how these auditory illusions are generated in brains to identifying individuals who may be susceptible to more debilitating tinnitus in the future.

Furthermore, any tool that allows researchers to describe quantitively how tinnitus is treated offers the prospect that novel therapies be introduced more quickly and effectively.



Our work has been focused on how tinnitus affects auditory neurons in the early stages of the auditory system. By presenting click trains to individuals, we record auditory brainstem responses (ABRs) using non-invasive electroencephalogram (EEG).

The aim of our project is to determine whether artificial intelligence (AI) software can determine which ABRs come from individuals who suffer from tinnitus. While our initial pilot study demonstrated that the AI software had a high success rate of identifying tinnitus sufferers, a larger, more inclusive dataset was required to train its machine-learning algorithm and validate its clinical merits.

Despite the impact of COVID, we have managed to acquire a large dataset for our test purposes, with the majority of our data coming from collaborators at Karolinska Institute who recorded ABRs from over 400 Swedish participants pre-COVID.

The dataset recorded at Macquarie University grows continually and after collecting data from the 25 participants all under the age of 35, we are now expanding our criteria to include older individuals with mild-to-moderate hearing loss and will be applying these data to test our AI diagnosis tool.

In addition to the EEG recordings, our participants have also undergone common audiological tests, whose targets have been previously proposed as other tinnitus biomarkers.

The results of the Acoustic Reflex testing have proven particularly interesting in our young participants, pointing to decreased acoustic reflex recruitment with sound level in individuals who suffer from tinnitus.

We hope to publish these results soon in a peer-reviewed journal.

Volunteering for research

According to the NHS, 1.3 million people take part in health research each year.

Tinnitus research is a growing field and there are researchers looking for participants to take part in studies all the time.

The type of research undertaken is very varied, ranging from answering a few questions online to in-person visits for testing or to trying new treatments.

So why should you take part in tinnitus research?

There are several reasons why you might want to take part in tinnitus research:

- **Improving tinnitus knowledge:** research helps us better understand how tinnitus is caused, how it develops, and how to prevent and treat it.
- **Access to new treatments:** Participating in clinical trials can give you access to new treatments that are not yet available to the public.
- **Contributing to the greater good:** By taking part in tinnitus research, you can make a significant contribution to society. Research often leads to medical breakthroughs that benefit everyone.
- **Personal benefit:** In some cases, participating in tinnitus research can have personal benefits, such as access to specialised care or closer monitoring of your tinnitus and hearing.
- **Empowerment:** Participating in tinnitus research can be empowering, giving you a sense of control over your tinnitus and your future. It can also help you develop a better understanding of your tinnitus and how to manage it.

If you are under the care of a health professional, you can ask them to consider any trials that you may be eligible for.

Inspired to take part in research?

Visit tinnitus.org.uk/taking-part-in-research to find open studies and centres that are recruiting for future research.

Tinnitus Biobank update

We're excited to be able to update you on our work towards a Tinnitus Biobank.

Researchers at the University of Manchester are reaching the end of the first stage of a feasibility study for the Biobank. They've been working with volunteers to consider the questions to ask and the tests to perform to make sure we get the best and most useful data possible.

The next stage is to take this 'test battery' and trial it in the field, using the University's mobile testing van.

This pilot testing will take place in Greater Manchester later this summer.

If you are over 40, live within Greater Manchester (the boroughs of Manchester, Stockport, Tameside, Oldham, Rochdale, Bury, Bolton, Wigan Trafford or Salford) we would like to invite you to take part in the pilot testing.

This will involve you completing a number of questionnaires, some of which you may do at home, and then visiting the mobile testing van at a location within your borough for further testing with the research team.

If you would like to sign up to register your interest in taking part (no obligation at this stage) please visit **www.tinnitus.org.uk/tinnitus-biobank**

Shapiro Prize awarded to genetics study

The 2022 Marie and Jack Shapiro Prize has been awarded to a study that looked at a possible genetic component to tinnitus.

The research, conducted by teams based at King's College London and the Ear Institute, University College London using data from the UK Biobank found a number of interesting candidate genes which may be linked to tinnitus, notably the RCOR1 locus.

Professor Frances Williams, King's College London said: "Understanding the genetic factors underpinning tinnitus is one of the approaches we can use to identify the biological pathways of importance, and from this to develop targeted therapies."

The study shows the potential benefits that a dedicated Tinnitus Biobank could bring, allowing us to understand the condition much better and answer many other questions.

Noisy neighbourhoods: do they cause tinnitus?

A new research paper published earlier this year shows there is a link between traffic noise and tinnitus.

In a new study with data from 3.5 million Danes, researchers from the University of Southern Denmark (SDU) found that the more traffic noise Danish residents are exposed to in their homes, the more they are at risk of developing tinnitus.

The researchers identified a vicious cycle: living near busy traffic increases stress levels, disrupts sleep and, as a result, leads to a higher risk of developing tinnitus.

This study is the first time researchers have found a link between residential traffic noise exposure and hearing-related outcomes. And for every 10dB rise in noise in people's homes the risk of developing tinnitus increases by 6%.

The study team also believe that noise at night time can be even worse for health, because of its impact on sleep.

To try to tackle sleep disturbance in people who live near busy roads, Germany has lower speed limits in some areas at night. Noise barriers and changing the road surface to one that dampens tyre noise can also help.

Other suggestions to reduce the impact of traffic noise include moving beds to the side of the house furthest from the road and installing double or triple glazing.

#Tinnitus23

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Tinnitus and menopause

Paul Harrison, audiologist and founder of Hearing Aid UK explores the connection between menopause and tinnitus. Can the menopause cause ringing in the ears?

There are several potential causes of tinnitus, including exposure to loud noises, ear infections and as side effects of certain medications. Tinnitus can also be a symptom of underlying conditions such as hearing loss, hypertension or temporomandibular joint disorder (TMJ).

However, it is recognised that hormonal changes may also play a role in developing tinnitus in women.

Menopause is a natural part of the ageing process in women, marked by the end of menstrual periods and fertility.

It typically occurs around the age of 50, but it can happen earlier or later. There is evidence to suggest that there may be a link between tinnitus and menopause but the relationship is not fully understood.

Low oestrogen and tinnitus – is it all down to hormones?

One possible link between tinnitus and menopause is hormonal changes. During menopause, levels of oestrogen and progesterone decline. This can affect the auditory system and potentially contribute to tinnitus.

Oestrogen has been shown to play a role in the development and maintenance of auditory pathways in the brain. A decline in oestrogen levels during menopause may contribute to tinnitus.

Additionally, some studies have found that women with tinnitus have lower levels of oestrogen compared to those without tinnitus. This suggests that oestrogen may play a protective role against the development of tinnitus.

Anxiety, lack of sleep and depression

Another possible link between tinnitus and menopause is the presence of other menopausal symptoms such as sleep disturbances, anxiety and depression.

These symptoms are often experienced by women during menopause and can worsen tinnitus. Sleep disturbances, in particular, can have a negative impact on tinnitus because they can interfere with the ability to cope with and therefore manage the condition.

There is also some evidence to suggest that the use of certain medications during menopause may contribute to tinnitus.

Hormone replacement therapy (HRT), which is often used to alleviate menopausal symptoms, has been linked to an increased risk of tinnitus in some studies.

Additionally, certain medications such as antidepressants and blood pressure medications used to treat menopausal symptoms may also increase the risk of tinnitus.

So, can tinnitus be linked to menopause?

The link between tinnitus and menopause is not fully understood. More research is needed to confirm any potential connections.

If you are experiencing tinnitus and are going through menopause, it is important to speak with your healthcare provider about your symptoms. They can then advise on any potential treatment options available. In some cases, tinnitus may be relieved with the use of sound therapy, cognitive behavioural therapy, or other treatments.

In some cases, medication may be used to treat underlying conditions that are contributing to tinnitus. The first point of call is to always speak with a healthcare provider. Finding the cause can help decide the most appropriate treatment.

Help and support

Our team of experienced and trusted advisers can give you clear information about this topic — and any other tinnitus related queries. No question is too big or too small for us to answer.

Helpline	**0800 018 0527**
Text/SMS	**07531 416841**
Email	**helpline@tinnitus.org.uk**
Webchat	**tinnitus.org.uk**

Monday to Friday, 9am-5pm
excluding bank holidays

Tinnitus and ear wax

Ear wax build-up can affect how well hearing aids work, and for some people can trigger tinnitus.

If ear wax build up is bothersome, it should be treated, but general advice is to leave it alone.

What is ear wax?

Ear wax is an important and natural secretion found in the ear. It keeps the ear canal lubricated and protects the ear against dust, dirt and bacteria, which helps to prevent infection.

How is ear wax linked to tinnitus?

Some people report they are more aware of their tinnitus when their ears are full of wax. This is because the wax build-up effectively blocks external sounds from reaching the ear drum, thereby making internal sounds more noticeable. When this wax is removed, most people find their perception of tinnitus decreases.

Very occasionally, people with tinnitus have reported ear wax removal made their tinnitus more bothersome. This could be because the procedure was uncomfortable. The effect is usually temporary. Considering that ear wax removal is a very common procedure, complications are few and far between.

How can I treat ear wax myself?

It is possible to treat your ear wax at home, provided you don’t have any of the following – in which case, you should see your GP:

- pain and/or discharge from your ears

- perforated ear drum
- current ear infection
- sudden hearing loss.

Consider ear wax softening drops or olive oil as the first option. Do not use cotton buds or other items to try to remove the wax.

Ear wax removal services

The National Institute for Health and Care Excellence (NICE) recommends that ear wax removal should be offered in the community. However, it is no longer one of the core services GP practices are obliged to provide.

Many people are now being advised to seek help from a private provider. The cost varies and some providers do not offer all the available methods. If you decide to have wax removed by a private provider, please ensure the clinician is suitably trained, qualified and follows appropriate professional guidelines.

However, it is important to see your GP in the first instance ifyou have a perforated ear drum, have had ear surgery or previously unsuccessful attempts at ear wax removal.

Risks of ear wax removal

Although problems following ear wax removal are very rare, these include:

- damage to the skin of the ear canal or ear drum
- infection of the ear canal or ear
- temporary reduction in hearing
- permanent reduction in hearing
- temporary dizziness
- possible sickness or fainting (rare)
- triggering of tinnitus or temporary increase in existing tinnitus
- temporary irritation to the throat.

For more information, visit **tinnitus.org.uk/tinnitus-and-ear-wax**

Ear wax removal

NICE currently advises two methods: electronic irrigation and microsuction. Some practitioners also use special tools to remove wax manually. It is recommended to use wax softening drops for up to five days before your appointment.

1. Electronic ear irrigation

In this method your ear is rinsed with warm water from an electronic irrigator to dislodge the wax and help its removal from the ear. The wax and water are collected in a metal cup-shaped dish which is held beneath your ear.

Ear irrigation does make some noise but it should not be excessive or uncomfortable.

2. Microsuction

During this procedure, the clinician looks in your ear using a high-powered microscope and gently suctions the wax out with a small instrument, without the use of any liquid.

This procedure is safe to use for most people, even for those with a perforated ear drum. However, some people may find the procedure to be noisy or slightly uncomfortable.

It usually takes between 15 and 30 minutes to clear both ears.

3. Manual removal

Ear wax may be removed by a clinician using a headlight and a handheld instrument.

Do not try to remove wax yourself in this way as this will likely push the wax further into the ear or cause injury.

June 5-6, BCEC Birmingham

British Society of Audiology

2023

Scientific Meeting

SHOWCASING THE BEST OF BSA

The BSA Scientific meeting continues to be the leading UK scientific forum to bring together clinicians and researchers who have an interest in hearing, tinnitus and balance.

REGISTRATION OPEN:

£190 for members
£230 for non members
£80 for Students

KEY SPEAKER:

Harvey Dillon - Separating the causes of listening difficulties in children

Register and find out more:

www.thebsa.org.uk

FULL PROGRAMME:

British Society of Audiology
Promoting excellence in hearing and balance

1 in 5 people in the UK have misophonia

New research shows the scale of the burden of negative reactions to everyday sounds.

Misophonia describes an intense dislike of or even repulsion to a particular sound, often one generated by other people, such as chewing.

These feelings can be very distressing, and people can feel powerful emotions, such as anger or panic, when they hear their trigger sounds.

Misophonia is a little-researched condition, and it was unknown how many people experience it, until this study from King's College London.

Study leader Dr Silia Vitoratou said: "Most people with misophonia think they are alone, but they are not".

Chewing or snoring

Participants in the study were asked about the sounds that they found triggering, such as chewing or snoring, and the impact of such sounds, as well as the type of emotional response participants felt to the sounds and the intensity of their emotions.

The results revealed that more than 80% of participants had no particular feelings towards sounds such as 'normal breathing' or 'yawning' but more than three-quarters were bothered by sounds including 'slurping', 'chewing gum'and 'sniffing'.

Emotional responses

However, Dr Vitoratou pointed out that not all those reporting a response had misophonia. "While there are a lot of sounds that irritate many people, people with misophonia express different emotional responses," she said.

Although there is no definitive diagnosis of clinical misphonia disorder, the study concluded that 18.4% of participants experienced misophonia to an extent that it was a significant burden on them.

Whilst previously it was thought misophonia was more prevalent in females, the team found no difference by sex.

The team is now carrying out further research into misophonia, including whether there are different types.

Fighting back against tinnitus

Here are some of our favourite #TeamTinnitus challenges and inspirational individuals from the last 12 months.

Teifion

Teifion raised more than £1,000 by taking part in Ironman Wales. The course consisted of an eye-watering 2.4-mile swim, a hilly 112-mile bike ride and a final 26.2-mile run along the Pembrokeshire coast.

> **"Tinnitus UK are a very important charity to me and my family. My wife, Melanie, as well as lacking sleep from my early morning training alarms, has to endure constant debilitating noise in her ears. I don't know how she does it, but Tinnitus UK have been there for her."**

Lara and Phill

Lara and Phill (pictured opposite) are currently trekking through the Californian desert as they raise money for Tinnitus UK. Together, they're walking a mammoth 2,650 miles from Mexico to Canada to help other people, like Phill, living with tinnitus.

The challenge will take an incredible six months to complete! They'll be wild camping for most of the walk and the couple are really looking forward to the relief the sounds of rain and wind on the tent provide from Phill's tinnitus.

> **"We hope by sharing our journey we can inspire others to follow their dreams, no matter what these might be. We also dream of a cure for tinnitus and if we can help, even a small part, by raising some awareness and fundraising then sharing our story and taking on this challenge is worth it."**

Phil

Last year, Phil completed a huge **eight** ultramarathons for Tinnitus UK and he's carrying on this year, too!

Phil took on these challenges to support people, like his mum, who live with the debilitating impact of tinnitus every day.

> **"My mum and my dad have been so supportive of my running that it's great to be able to give something back. My mum suffers terribly debilitating tinnitus [...] it makes life so difficult. It's hard to carry on regardless when you have constant ringing, drilling and banging noises in your head 24 hours a day. I'd like to help her and others that suffer from its effects."**

Want to join #TeamTinnitus? We'd love to support you with hints, tips and fundraising materials! Please get in touch on **0114 250 9933** or **fundraising@tinnitus.org.uk**.

Etta Mai

In March this year, nine year old Etta Mai raised an incredible £300 and achieved her Brownie Charity Badge with a bake sale for Tinnitus UK.

> **"You helped my dad a lot in lockdown when his tinnitus got really bad. He really liked the webinars and speaking to supportive people on the helpline. Thank you for your help."**

We are incredibly grateful to each and every one of our amazing fundraisers — thank you!

Tinnitus Adviser Training

Our Tinnitus Adviser Training course (TAT) is aimed at professionals working with people with tinnitus in a medical or social care setting.

The training is suitable for people who are new to tinnitus or those who have experience with it but would like to build their knowledge further.

100% of attendees have consistently said they felt that the training was worthwhile and that the presenters were highly knowledgeable and informative.

The training consists of input on basic counselling and listening skills coupled with how to respond appropriately to the many enquiries that are received around tinnitus.

There are also sessions on tinnitus as a medical condition and the audiological services available, so that you have knowledge to share with the people you support.

Our next TAT course is going to take place online on Thursday 22 and Friday 23 June. Another course will be held on 19-20 October 2023.

To book your place: **www.tinnitus.org.uk/tinnitus-adviser-training-june-2023**

Online tinnitus workshop

Our online tinnitus workshop is ideal for anyone who is looking for the opportunity to learn more about tinnitus and how to live with it better.

It is run in two parts with each lasting two hours and takes place over Zoom.

The workshop leader is Dr Lucy Handscomb. Lucy has over 25 years experience as a tinnitus therapist and is also involved in several research projects investigating the psychological aspects of tinnitus.

The workshop covers topics such as understanding what tinnitus is and how it relates to hearing problems, tinnitus facts and fiction, evidence-based techniques for tinnitus management and where to access further help.

The workshop is a great opportunity to discuss your experiences with others who are living with tinnitus.

Our next workshop is on Friday 30 June and Friday 7 July between 10am and 12pm. We will be running more workshops throughout the year so please look out for future dates.

The workshop costs £10 (plus Eventbrite fees) and is available to book at:

tinnitus.org.uk/online-tinnitus-workshop-july-2023

Our tinnitus webinars

We have a library of tinnitus-related webinars available to help you manage and live well with tinnitus.

Presented by leading experts in the field, our webinars range from 40 to 90 minutes long and cover everything from anxiety management and tinnitus to tinnitus and TMJ.

Webinars are pre-recorded and will be sent to you as a YouTube link, so you can watch them on any internet-enabled device, at any time.

Our free webinars

We have a selection of free webinars which are open to everyone, after signing up to our newsletter.

- Getting the most out of your GP consultation
- Assessment and management for tinnitus in adults
- Hearing protection and tinnitus prevention
- Hearing protection at work

Our webinar library

Each webinar costs £2.50 or you can purchase the entire webinar library for £25. If you become a Tinnitus UK member, you will be given access to two free webinars of your choice per year.

- An introduction to mindfulness
- Anxiety management for tinnitus
- Earwax: How does this impact tinnitus?
- Getting the most out of your ENT appointment
- Habituation: A patient’s experience
- NICE guidelines: What does this mean for me?
- Supporting an adult with tinnitus
- Supporting a young person with tinnitus
- Temporo-Mandibular Joint (TMJ) and tinnitus: What is the connection?
- Tinnitus and Cognitive Behavioural Therapy (CBT)
- Tinnitus – the basics
- Tinnitus and cochlear implants
- Tinnitus and hyperacusis
- Tinnitus and technology: What is available?
- Tinnitus and hearing aids: What do I need to know?
- Tinnitus and sleep: What can I do?
- Tinnitus during pregnancy
- Tinnitus treatments: What is available?

Access your webinar at **tinnitus.org.uk/tinnitus-webinars** scan the QR code.

Will you help create a world where tinnitus no longer exists?

Tinnitus UK was established in 1979 to create a world where no one suffers from tinnitus. And this goal is still true today.

Every week our free helpline receives thousands of calls from people at breaking point, people who can no longer imagine a future without their tinnitus, people for whom there is no hope.

A gift in your Will to Tinnitus UK will take on a remarkable power – the power to change lives. Thanks to you we could find the revolutionary medicine needed to stop tinnitus in its tracks; it could improve treatments and care for millions of people across the UK; and it could bring thousands back to their family and friends when tinnitus has left them feeling cut off and alone. **Your gift could change the future.**

If you'd like to write or update your Will, we can help.

Contact Daisy, our Regular Giving and Legacies Manager, on daisy@tinnitus.org.uk or call her on **0114 250 9933.**

Use our Free Will Offer, in partnership with Farewill, to write your Will online from the comfort of your own home. Visit farewill.com/tinnitus-uk and use the code TINNITUS-UK at checkout.

Living with RSHL: reverse slope hearing loss

Brenda Baxter wants to raise awareness that not all hearing loss is the same.

I was born in 1954 with a congenital sensorineural hearing loss. The ENT Consultant told my parents that I had inherited this from my father who was deaf in one ear and wore a hearing aid following service in Burma in the Second World War. I also experienced tinnitus from a young age. It wasn't until 2017 that I discovered that my condition was a rarer type of hearing loss and had a name — Reverse Slope Hearing Loss (RSHL).

Throughout my schooling I embraced learning, sport and making friends, however the noise and bustle of the classrooms and the playground meant that I missed out on a great deal. At primary school this became more noticeable as I fell behind with learning in certain subjects.

Although my hearing loss was first picked up when I was about six, my experience was it was a secret, a hidden disability since it was never mentioned by teachers or discussed with my friends. However, when I started secondary school I could no longer cover up my difficulties and I was issued with a single hearing aid. I will never forget what I had to endure — the many inquisitive questions, the touching, without protection from the teachers.

I refused to wear the hearing aid

After a few weeks I refused to wear the hearing aid because it was very visible, uncomfortable and because the frequencies increased certain sounds to unbearable levels. The special ear moulds blocked my ears and muffled sounds I could normally hear like telephones ringing, women's voices, birds singing and other high frequencies. Instead, I got by at school by lip reading and went to university to study History of Art and English, eventually establishing a career in social work.

By the time I was in my early 40s my hearing in both ears had deteriorated and two NHS digital aids were issued. Even though these were an improvement on the analogue aids, it became increasingly impossible to cope with conversations, attend meetings and manage complex cases.

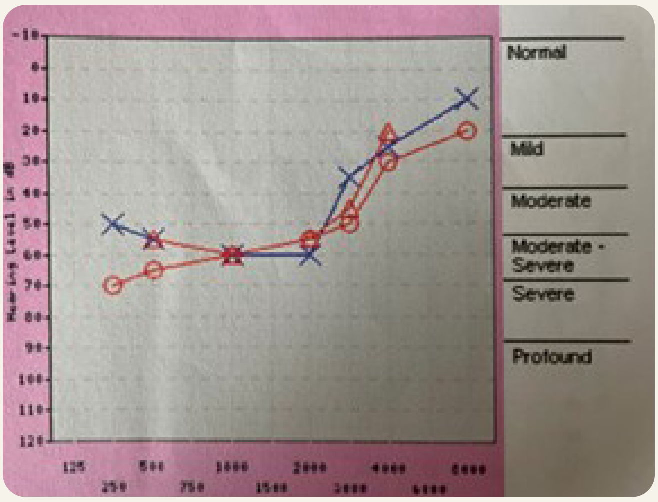
Ten years later I resigned from social work and since then have practised as a visual arts organiser, which has been less stressful.

RSHL is hereditary

RSHL is hereditary. Therefore, several members of my family including my youngest son have inherited RSHL and been issued with hearing aids.

The condition is different from age-related Ski Slope Hearing Loss (SSHL) or high frequency hearing loss. So if people can't hear low sounds in speech, bass sounds or thunder or struggle at the cinema, it's more likely to be RSHL. I have included my RSHL audiogram below — a SSHL audiogram will show the loss in the opposite direction.

Throughout my life it was impossible to find a hearing aid that suited my hearing loss since these were designed for the majority with common SSHL/high frequency hearing loss. Frustratingly I never encountered an NHS audiologist who could modify a hearing aid to help.



This experience was a breakthrough

I became so desperate that in 2017 I decided to purchase aids from a private company. This experience was a breakthrough — the audiologist listened, understood and identified the best aids I could afford. One of the first steps was to abandon the specially moulded earpieces which I had worn since I was 12. Instead, she fitted small cones which did not block out high frequency sounds. I still need to turn down the base to adjust the levels in noisy situations but for the past five years I've experienced a vast improvement in wearing aids that are comfortable and adaptable to different situations.

Be direct and explicit

My advice to others who have been diagnosed with RSHL is to be direct and explicit with GPs and NHS Audiology Services about how RSHL and their hearing loss affects them. It is important to find ways to become empowered, to be fully informed by research and to expect good enough support.

Meanwhile connecting on social media can help to share experiences, identify the best products as well as highlight the universal gaps in services. For instance, the RSHL UK Facebook group was an eye opener — the latest posts show parents struggling to access services for their children and demonstrate early identification and support is still needed to help children manage at school, at home and in various social situations.

Let's make this happen!

Campaigning for greater awareness and specialist research into RSHL is needed. When talking about hearing loss let's not forget that hearing worlds are different and we're not all the same — let's make this happen!

Chronic illness at playtime

Sarah Richardson talks about what it was like being diagnosed with tinnitus as a child.

About three years after I was first diagnosed with tinnitus, I joined a Facebook help group. The name of the group escapes me, but I remember it was primarily populated by tinnitus sufferers from the United States and their relatives. It was a place to share thoughts, feelings and information related to suffering, living and growing with tinnitus, and it gave people the means to seek reassurance from others in the same boat.

Unfortunately it quickly got swamped in junk articles and fake cures, so I didn't stay for very long.

Before the group became a dumping ground for spam, I was fairly active in it. Very early on in my membership, I decided to share that I'd made the decision to celebrate my tinnitus's birthday. I wrote a post about how I was planning on popping a bottle of champagne open with the family and getting in a very decent Victoria Sponge to mark the occasion in style.

Delicious. And why not? Positivity moves things along.

I also disclosed my age. At the time I was eighteen and a half years young.

During the week after I posted this message I didn't get a single negative response to my unorthodox birthday plans but I received many, many, many messages from complete strangers, from parents who had joined the group because their child had tinnitus, all wanting to know how.

How could I be so positive about having tinnitus while still also being so young?

What tricks and tips could I give them that could help their offspring?

Was the miracle cure for tinnitus found deep in the Amazon Rainforest as they'd always suspected?

Feeling failed by modern medicine

Suddenly I was drowning in caring — and in some cases overbearing — mothers and fathers who were at the end of their tethers trying to help their children, feeling failed by modern medicine, not knowing where to turn. I tried to help as best as I could — never before have I wished so much that I had some secret miracle cure to pass on — but it made me realise that tinnitus in children and young people is far more common and widespread than I could've ever imagined.

I don't think I'm wrong in saying that the leading cause for tinnitus is hearing loss, which in turn is associated with ageing. Almost every doctor I saw in the early days, be it at the General Practitioner level or specialised ENT, was surprised that I had tinnitus. "You're a bit young for that," they'd say in the same way someone might tell you you're a little young to be drinking or smoking. Naughty, naughty!

I've spoken on the radio about my tinnitus in the past and the conversation almost always revolved around my age. It's seen as an 'alternative' or 'fresh' perspective — about how it's unusual to hear from someone living with tinnitus who doesn't have the weight of fifty or sixty years of life behind them, from somebody who's just getting started at the grand old game of life.

I felt like my symptoms were taken less than seriously

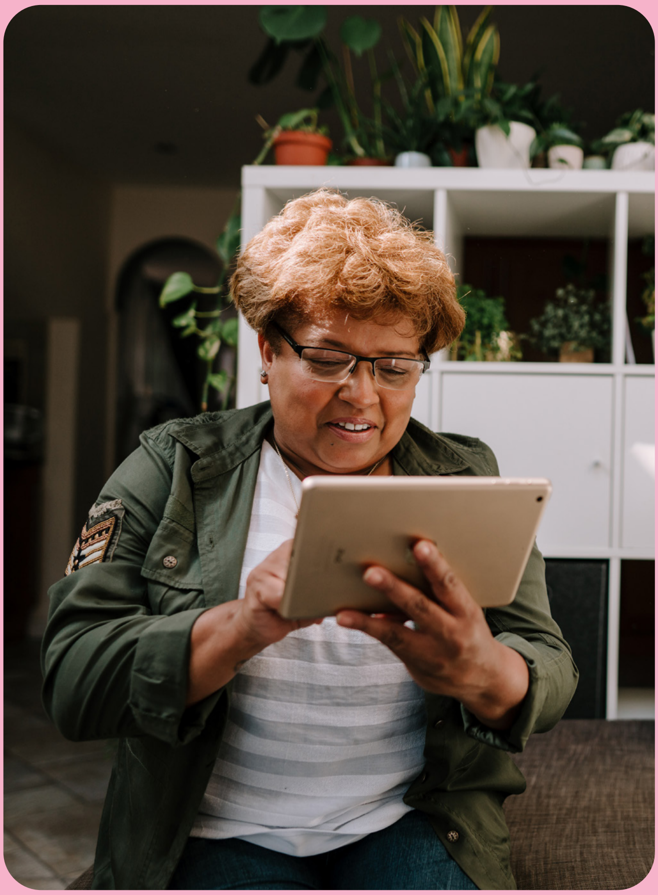
Because of my age, there were times when I felt like my symptoms were taken less than seriously in the doctor's office. Of course they didn't say so outright, but I knew certain individuals thought I was exaggerating. After all, according to their 'experience', tinnitus shouldn't happen when you're just bouncing out of school, it should happen in harmony with the bells of your judgement day. "Exam stress" they said, "hormones" they said, "normal symptoms of a cold" they said — as if I wasn't an intelligent young person who could tell the difference between the normal and the abnormal.

Who knows my body better than me?

Don't get me wrong, I encountered very few people on my tinnitus journey who had this poor attitude, but it's never in anyone's best interests to diminish the voice of children just because they're young. Invalidation is a form of violence, and it can have deadly consequences. I often wonder what would've become of me if Mum and Dad hadn't believed me from the start, hadn't fought to get me the healthcare I deserved. I'm definitely one of the lucky ones.

To young tinnitus sufferers I say this: you're valid, your opinions on your body are valid, and you deserve to be taken seriously.

Meet Axel* - the Tinnitus UK chatbot



Using technology to reach more people with tinnitus.

Demand for our services is greater than ever, and in order to make our limited resources reach as far as possible, we knew that improving our digital support would be the most effective way of helping the greatest number of people.

In 2021, we received a major digital grant and we used this to create a new website, an enhanced web chat service and a tinnitus chatbot.

What is a chatbot?

A chatbot is a computer program or app designed to simulate conversation with human users. Our chatbot – Axel – uses a text-based interface to communicate.

Axel is available 24/7 and guides users to relevant Tinnitus UK resources each time they visit. With our team and user group, we worked out the key questions and needs of potential users and created these journeys for Axel to guide people through. These were then thoroughly tested before launch.

Axel is able to learn based on how he is being used, which means that the chatbot will become even more effective over time.

With minimal promotion, more people are talking to Axel than anticipated, and this has reduced the numbers of human-led web chats, enabling more queries to be dealt with. Axel marks a significant step forward for Tinnitus UK in our aim to reach more people with tinnitus.

It is the only tinnitus chatbot that is free and available to everyone, and possibly the first charity support chatbot too. We are thrilled to be able to offer this new service and hope to expand it in the future.

Do you want to meet Axel? You can try the chatbot by visiting tinnitus.org.uk and clicking the speech bubble on the screen.

**Axel is the very cute puppy belonging to one of the Tinnitus UK team who worked on the project. Axel often joined in online meetings so when we needed a codename for the project, he was the obvious choice — and the name stuck!*

Tinnitus support groups

East Midlands

Chesterfield & N Derbyshire 🟨 ●

Derby ●

Northants ●

Nottingham ●

East of England

Cambs ●

Chelmsford ▲

King's Lynn and District 🟨 ●

NE Essex ▲

London *within M25*

Bexley ●

Boreham Wood 🟨 ●

Bromley ●

City of Westminster ●

Dulwich ●

Greenwich 🟨 ●

Hackney ▲

Kingston ▲

London (North) ●

Orpington ▲

Redbridge ▲

Online *Tinnitus UK*

Tinnitus ▲

Tinnitus & sound sensitivity ▲

NE England

Chester-le-Street ●

Darlington ●

NE Tinnitus Support Group ● ▲

Newcastle ●

Northern Ireland

Belfast ●

Newry and Mourne ●

Omagh ●

RNID Northern Ireland ▲

Western *(Londonderry)* ▲

NW England & Isle of Man

Aintree 🟨 ●

Bolton 🟨 ●

Cumbria *(Whitehaven)* ●

Cheshire East *(Macclesfield)* ● ⬢

Isle of Man ●

Lytham St Annes ●

Kendal ●

Manchester ●

Runcorn ●

St Helens ●

Widnes ●

Scotland

Edinburgh & SE Scotland ●

Forth Valley ●

Glasgow 🟨 ●

Highlands ▲

Perth & Kinross ▲ ⬢

SE England

Aldershot & District ●

Amersham ▲

Ashford *(Kent)* ▲

Basingstoke ●

Brighton ●

Canterbury ▲

Chinnor ●

Crowborough ▲

Dover ▲

Faversham ▲

Hi Kent ▲

Isle of Wight ●

Maidstone ▲

Marlow/Farnham Common 🟨

North Herts *(Hatfield)* ● ⬢

Pembury ▲

Rochester ▲

Salisbury ●

Southampton ●

Thanet ▲

SW England

Gloucester ●

SW England ▲

Torbay ● ⬢

Truro ●

Wales

Aberdare ●

Bridgend ●

Pontyclun ●

Pontypridd ●

Rhondda ●

Swansea ▲

Ystradgynlais ●

West Midlands

Birmingham & District 🟨 ▲

Newcastle-under-Lyme ●

Warwick 🟨 ●

Whitchurch ●

Yorkshire & Humber

Bradford ●

Brighouse ●

Earby ● ⬢

Keighley 🟨 ●

🟨 **Tinnitus UK Gold Standard Group**

● Meetings in person

▲ Meetings online

⬢ New group

To find details of a tinnitus support group or clinic in your area visit tinnitus.org.uk/service-finder or contact the Tinnitus Support Team on **0800 018 0527** or helpline@tinnitus.org.uk.

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.

Support • Research • Prevent

Find your silence

Helpline:

0800 018 0527

How we can help:

Tinnitus UK

Registered charity no: 1011145
Registered in England

Company limited by guarantee no: 2709302