Volume 35 2024

Quiet

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TINNITUS UK

We would like to thank our corporate partners for their vital support.

We are really grateful to the following corporate partners who have supported us financially over the last year. Their contributions are essential to Tinnitus UK's work. With their partnership, we can more effectively address the pressing needs of the tinnitus community, and make a real difference in the lives of those we help. Their commitment is truly appreciated.

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- United Lincolnshire Hospitals NHS Trust
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- University Hospitals of Morecambe Bay Trust
- Visualise Training and Consultancy
- Widex UK Ltd
- Worcestershire Acute Hospitals NHS Trust
- York Teaching Hospital

We work with corporate partners in many ways to help us raise funds for our vital services. Please email **fund@tinnitus.org.uk** or call **0114 250 9933** to find out more.

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Making the world aware

Our Communications Manager Nic Wray reports back on the most important week in Tinnitus UK's calendar.

February holds a special significance for me. It marks not only my birthday (with perhaps a few too many candles!) but also Tinnitus Week, the single most important week in our calendar at Tinnitus UK.

This year, our focus was on the impact tinnitus has on individuals, particularly its effects on mental health. The voices of the many who shared their experiences resonated deeply, shaping our report, 'Revealing the struggle for silence: Tinnitus UK highlights the alarming mental health crisis amid a void of support'.

We knew that the report would make an impact, but it exceeded our expectations and our goals. We've analysed the data, and we are thrilled to say that it reached a combined audience of over 100million people. Through social media, we've heard firsthand accounts of people living with tinnitus feeling acknowledged, with many saying that our report accurately reflects their reality.

The report garnered significant attention across broadcast media channels. Notably, it was featured on BBC Breakfast, where Dr. James Jackson and I discussed its findings. Subsequently, we were interviewed by BBC 5 Live – not the usual way I spend Sunday mornings!

On Monday 5 February there was a report on Five News featuring myself, Tinnitus Support Group leader Chris Nolan and audiologist Sue Falkingham. Good Morning Britain also mentioned the report when they covered Tinnitus Week on Wednesday 7 February.

The report was featured on television six times during the week. We also took over the radio airwaves with 36 radio interviews and three podcasts. The regional radio coverage spanned the length and breadth of the UK and included Welsh language programming. Additionally, I had the privilege of speaking at the International Tinnitus Relief Summit, connecting virtually with a global audience.

Our outreach extended beyond traditional media outlets, with podcasts such as Word on Health and Guardian Science Weekly offering platforms for further discussion. You can listen to the Word on health podcast here: www.wordonhealth.com and the Guardian Science Weekly podcast here: www.theguardian.com

Press coverage spanned a diverse range of publications, from regional newspapers and magazines such as *People's Friend* to specialised platforms like *Mixmag* (who featured eight online articles across the week) mixmag.net as well as *Medscape* www.medscape.co.uk

Building on the momentum of Tinnitus Week, our efforts continue. Recent features in publications like the *i*, *The Economist*, and contributions to the *Daily Mail* underscore our ongoing commitment to raising awareness and the interest that is out there in tinnitus.

Thank you to everyone who made Tinnitus Week 2024 a resounding success. None of this would have been possible without the invaluable contributions of the tinnitus community, and we hope that we did you all justice. The small but dedicated team at Tinnitus UK, and the community of researchers, audiologists, hearing therapists, and healthcare professionals were also fantastic before, during and after Tinnitus Week, giving support, and responding to my queries and media requests with professionalism and enthusiasm.

Now the planning starts for Tinnitus Week 2025. Your feedback and suggestions for future topics would be very welcome. Please feel free to reach out to me at **communications@tinnitus.org.uk** with your ideas.

Revealing the struggle for silence: the numbers behind the report

Tinnitus affects

1 in 7

adults in the UK, with severe impact on

1 in 6

of those living with the condition

The emotional impact of tinnitus is significant, with 68.4% of respondents reporting low self-esteem and 54.9% struggling to think rationally.

No known cure

exists, and dissatisfaction with current treatments is widespread.

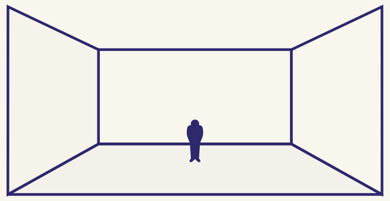
Over 1 in 5 of the people living with tinnitus surveyed had had thoughts of suicide or harming themselves in the last year.

There are over

1 million

tinnitus-related GP appointments annually, costing the NHS

£750 million

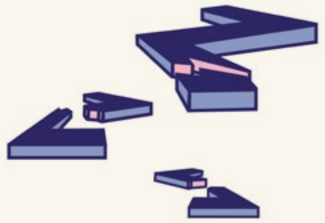


Tinnitus is linked to social isolation, impacting relationships and daily life.

An estimated

8 million people

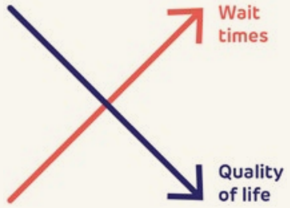
will be affected by tinnitus by 2025



Sleep disturbances affect 85.7% of respondents.

There is limited mental health support from GPs, with only 5% of the people surveyed offered Cognitive Behavioural Therapy (CBT) as recommended in the NICE guidelines.

More than 8 out of 10 respondents experienced low mood or anxiety in the last year, with 7 out of 10 feeling hopeless or helpless.



The increase in waiting times for audiology appointments impacted quality of life for two thirds of respondents.

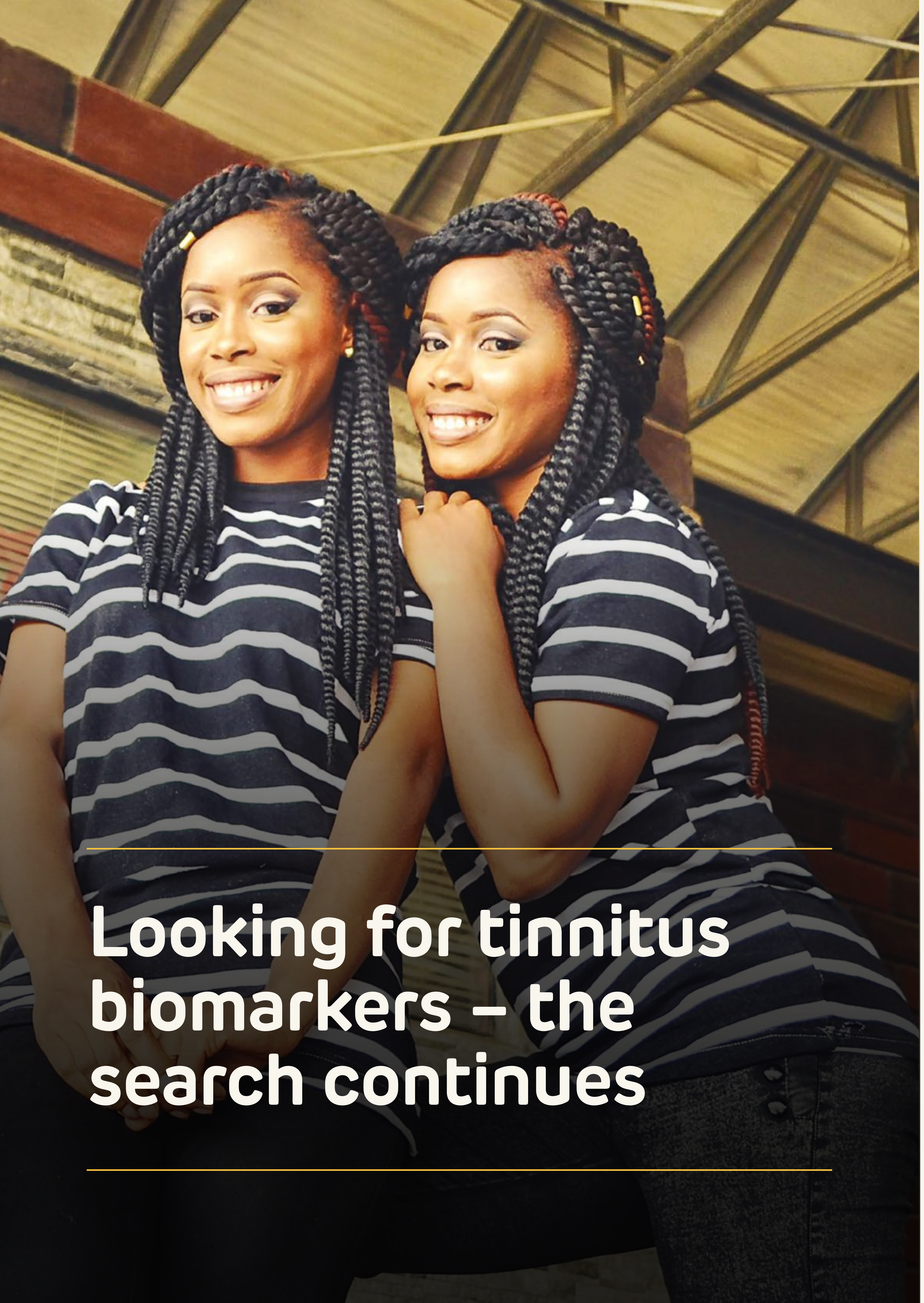
Teamwork makes the dream work!

Did you know that we work with local and national corporate partners to help us raise vital funds to pay for our services?

Companies work with us in all sorts of ways, by joining our membership scheme, by sponsoring our events, by offering discounts and percentages of product sales, through employee fundraising and charity of the year partnerships. We also help corporations by providing employee training, helping them to support people with tinnitus in the workplace and educating them about preventing hearing loss in loud environments.

With one in seven people in the UK living with tinnitus, that's a lot of affected people in the workplace. Successful corporate fundraising is all about building relationships and partnerships based on shared values and aligned business missions. As with most things in life, connections and networks are incredibly valuable and we are always looking for opportunities to expand our networks. A recent introduction from an employee at Nationwide led to an amazing gift of £10,000 for our helpline – teamwork really does make the dream work.

If you think your organisation would be interested in working with Tinnitus UK, or you would be happy to make an introduction for us, we'd be delighted to hear from you. Please email **fund@tinnitus.org.uk** to get in touch. Thank you for your support!



Looking for tinnitus biomarkers – the search continues

Professor Frances Williams’ chronic pain and hearing loss research group within TwinsUK at King’s College London has recently published another piece of the puzzle in the steps to understanding and treating tinnitus.

The large project – funded by Tinnitus UK as part of their Large Research Grants Programme - spanned Sweden and the UK, recruiting participants with tinnitus and matched controls firstly in over 1,000 participants in Sweden and then running a replication arm of the study in over 1,000 twins from Twins UK.

The aim of the research was to find a biomarker/s for tinnitus. A biomarker, or biological marker, is a measurable indicator of some biological state or condition – for example, blood pressure or cholesterol levels.

“It is difficult to establish biomarkers to detect or treat the disorder” says co-author Max Freydin “because tinnitus is heterogeneous”, meaning many different factors could determine whether a person gets tinnitus or not.

Perhaps surprisingly, tinnitus shares several signs and symptoms with chronic pain. Neuroimaging suggests there are similar disturbances in the prefrontal cortex of the brain which lead signals from sensory inputs such as sound being interpreted in a muddled way. A localised brain inflammatory response has been reported to occur with chronic pain and was detectable in the blood stream. Williams’ team investigated to see if inflammatory biomarkers could be found in people with tinnitus, hypothesising “that chronic and constant tinnitus may also be associated with neuroinflammation”.

Importantly, factors unrelated to hearing difficulties that affect inflammatory marker levels, such as age, sex and body mass index were accounted for. Tinnitus tends to be accompanied by stress, anxiety, and depression, hyper-sensitivity to sound, face pain and headache, however none of these conditions were related to inflammatory marker levels. While a weak association of five inflammatory proteins was seen in the Swedish cohort, the finding was not replicated in the UK cohort, leaving researchers to conclude “there is a lack of association between plasma biomarkers and constant tinnitus”. Other research has shown “biomarkers can be derived from electrophysiological measures, this does not appear to be the case for blood biomarkers”.

A biomarker, or biological marker, is a measurable indicator of some biological state or condition

Although the team didn’t find a tinnitus biomarker, negative results are progress and an important part of directing future research and treatment. Such steps forward are only made possible with the generous contribution of research investments made possible by Tinnitus UK, the participants belonging to the TwinsUK cohort and the generous support of individuals from both research institutions.

Reference:
Cederroth CR, Hong M-G, Freydin MB et al. Screening for Circulating Inflammatory Proteins Does Not Reveal Plasma Biomarkers of Constant Tinnitus. *Journal of the Association for Research in Otolaryngology* Vol 24 pp593-606 (2023). www.doi.org/10.1007/s10162-023-00920-3

This research was only possible because of kind donations from our supporters. If you would like to see tinnitus research continue, please consider making a donation today at **tinnitus.org.uk/donate** or call **0114 250 9933.** Thank you for your support.

Take part in tinnitus research

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

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

People's involvement in research has contributed important information to promote healthier and improved living conditions both now and in the future and drives medical advancements for better treatments, and diagnosis methods.

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 try new treatments.

So why should you take part in tinnitus health 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.

How do I find out about trials to take part in?

Tinnitus UK: Our website lists trials and studies seeking volunteers, ranging from short surveys to in-person visits for scans and tests.

www.tinnitus.org.uk

ClinicalTrials.gov: This registry and results database hosts clinical studies conducted worldwide, providing easy searchability and contact information for open trials.

www.clinicaltrials.gov

The International Clinicial Trials Registry Platform (ICTRP): Hosted by the World Health Organization, this database offers information on clinical trials.

www.trialsearch.who.int

The Auditory Cognition Group at Newcastle University: The group's website provides details of ongoing research and volunteering opportunities, along with updates on X (formerly Twitter) **@AuditoryGroup**.

www.newcastletinnitus.org

NIHR Nottingham BRC: This research centre conducts studies benefiting individuals with hearing loss, deafness, and tinnitus. Individuals can participate in studies or contribute to the development of research ideas by visiting their website or contacting Sandra Smith 0115 823 2600.

www.nottinghambrc.nihr.ac.uk/take-part

Biobank update

Thanks to your support, Tinnitus UK has successfully completed the next phase of the feasibility study for the Tinnitus Biobank.

To test the feasibility of collecting the necessary data for a Tinnitus Biobank, researchers from the University of Manchester embarked on a mobile testing initiative across Greater Manchester. Volunteers generously contributed their time to help refine the tests and questionnaires vital for the development of a comprehensive Tinnitus Biobank.

While the team continues to analyse the gathered data for future publication, they have already shared valuable insights and lessons learned. These include technical recommendations, such as the optimal type of earphones for accurate results, and practical considerations like ensuring questionnaires are completed before volunteer appointments. Additionally, the team has highlighted the importance of addressing environmental factors such as heatwaves and providing adequate facilities like toilets for volunteers and staff.

The final report will be submitted to our Trustees and the Research sub-committee for thorough consideration. Rest assured, we will keep you updated on our next steps and decisions. Thank you for your ongoing support!

Unlocking support: how trusts and foundations fuel Tinnitus UK's mission

Grants from trusts and foundations play a crucial part helping continue the work of Tinnitus UK. They are very important in sustaining our vital helpline, and they also help cover our operational expenses.

From small family trusts to nationwide grant-giving giants like the National Lottery, Tinnitus UK taps into a diverse range of funding sources. Some of the small trusts may meet quarterly to give grants of a few thousand pounds, whereas the National Lottery and other large funders may have dozens of staff to administer the process, and the grants they make may be very much larger. Every grant, large or small, plays a big role in advancing our mission to provide vital support for those affected by tinnitus.

Trusts and foundations form the backbone of our financial stability, particularly those funders who provide multi-year support, as this enables us to plan for the future.

Trusts and foundations tend to focus on specific causes, and each funder has its unique set of criteria and deadlines. What they have in common, however, is that they are looking to see that any grant will have an impact on the lives of those living with tinnitus and will be spent effectively and efficiently.

We have been fortunate to have been supported by the James Tudor Foundation for several years, and they have told us:

The James Tudor Foundation is keen to support positive patient outcomes and problem solving and, for that reason, it has been pleased to contribute to the work of Tinnitus UK over the last few years. We value the fact that the charity is uniquely and expertly placed to support those affected by the condition in a variety of ways and does so with very high best practice standards. Its work in providing training to healthcare professionals and investment in medical research rounds off the wrap around care that anyone affected by a condition so difficult to treat and manage would hope to receive.

The time taken to put together an application for funding can range from a couple of hours to several weeks, putting together the figures and a case for support, navigating through online forms or traditional postal submissions.

The current financial situation means that sometimes we are just one of hundreds of applications for a limited pot of money, so we are constantly researching potential donors and making sure that there is a stream of applications in the pipeline. If you are aware of any grant funders to whom we should apply, please contact **fund@tinnitus.org.uk**

Thank you!

We'd like to acknowledge the following trusts and foundations who have provided us with vital support to help us run our services:

The Drapers' Charitable Fund

The Frazer Trust

Garfield Weston

The Helen Roll Charity

The Hospital Saturday Fund

The James Tudor Foundation

The Maria Björnson Memorial Fund

The National Lottery Community Fund

The Woodroffe Benton Foundation

We would also like to extend our thanks to those trusts and foundations who have helped us, but who wish to remain anonymous.

Getting a good night's sleep

Sleep disturbances are common in people living with tinnitus. The transition from daytime noise to the quietness of bedtime can often amplify the perception of tinnitus sounds, making it challenging to fall asleep.

Understanding the sleep cycle reveals that it's a 24-hour process influenced by daytime activities. As we age, deep sleep diminishes, leading to lighter and more fragmented sleep patterns. Insomnia refers to severe and ongoing difficulty in falling and/or staying asleep. Generally, this means that the disturbance occurs at least three or four times a week and lasts for six months or more.

Contrary to assumptions, many people with tinnitus actually sleep well, finding solace in sleep from the sounds of tinnitus. However, worries about sleep duration, its impact, or tinnitus itself can exacerbate sleep quality more than the tinnitus noise itself. While tinnitus may not directly cause awakenings, heightened awareness during periods of wakefulness can prolong them.

The importance of sleep remains somewhat mysterious, with theories suggesting it conserves or restores energy. Studies on sleep deprivation reveal varied impacts on psychological functions, with cognitive tasks requiring creativity being notably affected. However, short periods of sleep can reverse these effects, akin to overcoming jet lag.

Chronic poor sleep often accompanies anxiety in individuals with tinnitus, creating a cycle of sleeplessness, worry, and heightened tinnitus awareness. Breaking this cycle requires addressing both sleep habits and stress management.

Top tips for getting a good night's sleep

Here are our tips for getting a restful night's sleep:

Establish a routine: Make sleep a habit by following a consistent bedtime routine. Poor sleep often stems from erratic routines, so aim for regularity in your sleep schedule.

Consult your doctor: If you struggle with insomnia, don't hesitate to seek medical advice. Insomnia may signal an underlying medical condition that requires attention.

Consider medication: If prescribed by your GP, consider short-term sleep medication under medical guidance. However, remember that medication isn't a long-term solution.

Avoid alcohol and stimulants: Steer clear of alcohol and caffeine before bedtime, as they can disrupt your natural sleep pattern and affect your ability to fall asleep and stay asleep.

Stay active: Take part in physical activity during the day to promote better sleep. However, avoid exercising close to bedtime, as it may interfere with your sleep cycle.

Unwind before bed: Dedicate at least an hour before bedtime to unwind. Relaxation techniques can help calm your mind and prepare you for sleep.

Address worries: Write down any worries before bedtime and consider potential solutions. This practice can alleviate anxiety and promote a more restful sleep.

Create a relaxing environment: Reserve your bedroom for sleep and relaxation only. Avoid stimulating activities like watching TV or working in bed.

Optimise your sleep environment: Dim the lights when you get into bed and avoid putting pressure on yourself to fall asleep immediately. Background noise, such as white noise or nature sounds, can help mask tinnitus and promote relaxation.

Adopt the 30-minute rule: If you're unable to fall asleep within 25 to 30 minutes, get up and engage in a relaxing activity until you feel sleepy again.

Maintain consistency: Stick to a regular wake-up time, even on weekends, to regulate your body clock. Avoid daytime naps to ensure better sleep at night.

Stay active after poor sleep: After a rough night, resist the temptation to take it easy. Engaging in activities can help combat fatigue and improve your mood.

By following these strategies, you will be better able to navigate the challenges of tinnitus-related sleep disturbances, fostering better sleep and overall well-being. Sweet dreams!

Tinnitus treatments on social media: helpful or harmful?

Living with tinnitus can be incredibly challenging. It's no wonder people search for relief anywhere they can, including social media.

However, a 2019 study in the *Hearing Journal* backed up what we at Tinnitus UK had long suspected: misinformation about tinnitus is rampant on platforms like Facebook, YouTube, and Twitter.

Fast forward to today, the era of TikTok, and the problem has only worsened. But what exactly are these supposed tinnitus "cures" circulating online?

Home remedies

Supplements, oils, and ear drops promising to "cure" tinnitus are widely promoted. Yet, many of these products lack scientific backing and may offer little more than a placebo effect. Some can actually be harmful – and not only to your bank account!

If you want to check the facts behind a treatment, call our knowledgeable Tinnitus Support Team on 0800 018 0527 or use the treatment checker on our website.

Dietary changes

From cutting out milk to following anti-inflammatory diets, social media is flooded with unconventional dietary advice. While certain foods, caffeine or alcohol might worsen tinnitus for some, there's no quick fix through diet alone.

You can read more about tinnitus, food and drink on our website at tinnitus.org.uk/food-and-drink

Physical interventions

TikTok and YouTube are rife with bizarre physical exercises, like tapping spoons under earlobes or pressing pressure points. The most popular exercise involves covering your ears and tapping your fingers several times on the back of your head. While some believe these actions relieve tension linked to tinnitus, their efficacy remains uncertain.

So what to do instead?

Tinnitus currently has no cure, which can make these social media remedies sound very alluring. How can we be in the 21st century and there's no cure for tinnitus? Tinnitus UK have even been accused (via social media, of course) that we're hiding a cure as we don't want to lose our jobs!

Whilst we aren't hiding news of a cure, what we do have are evidence-backed treatments that can significantly improve improve quality of life. Modern hearing aids, for example, can reduce tinnitus symptoms by addressing underlying hearing loss.

Sound therapy can also be used to train to brain to habituate to (learn to ignore) tinnitus sounds. Smartphone apps incorporating sound therapy, relaxation exercises and elements of CBT (cognitive behavioural therapy) also offer promising avenues for treatment.

While the allure of a quick fix is tempting, it's crucial to resist misinformation and rely on credible sources for guidance. By staying informed and seeking professional help, you can better manage your tinnitus symptoms and find genuine relief.

If you do find yourself tempted by treatments you see on the internet, you can download and print a PDF guide from our friends at PIF TICK to help you identify false health information **www.piftick.org.uk**

We can't do it without you!

Inspiring fundraising stories

Brandon's story

Cover star Brandon has struggled for silence for five years. His tinnitus has got progressively worse over the last twelve months. He has received some support from the NHS and learned about the support we provide at Tinnitus UK. He finds that walking is a happy place for him, so he decided to attempt the Pennine Way.

The Pennine Way is an epic 268-mile challenge and Brandon planned to walk the route over 14 days, setting off on Good Friday. He was mostly walking alone although he was joined by various people different points of his walk.

His challenge started well, and he covered over 26-miles in ten hours on his first day and 15 miles on the second day. On days three and four he covered over 44-miles and he was doing really well when he ran into problems on day five:

"I got over an hour into the walk, got my right foot stuck into a bog and fell over. I twisted my knee in the process. After a lot of effort, I managed to get to my feet. With no phone signal, walking into the cloud and being 8 hours from my next campsite and a lot more moorland to cross I made the decision to turn around and head back to the bunk house to try get some Wi-Fi to figure out a plan of action.

On my way down I met a lovely lady who ended up giving me a lift to Alston Hospital where I saw a doctor and got my leg checked. After a long wait in hospital the doctor strongly advised me not to carry on. Walking with my backpack (28kg) was really hurting. I was then lucky enough to meet someone who offered to drive me to Durham where I was able to get the train home."

Brandon is continuing to recover and hopes to attempt the Pennine Way another time, preferably when the weather is better! He smashed his fundraising target and raised over £1700 which will help to fund the training of a helpline volunteer.

Michael's story

Dr Michael Gach is an ENT doctor who has tinnitus. He says that this gives him a genuine insight into his patients' experience. He started running two and a half years ago at Parkrun and says that he has been bitten by the running bug, so he decided to take on the challenge of running a marathon.

The TCS London Marathon was Michael's first marathon, and he used the opportunity to help raise awareness of tinnitus and funds for us.

I am passionate about supporting Tinnitus UK and I hope I can help spread awareness of this important condition

Michael says:

"I wish for excellent tinnitus support to be provided to all of those who need it. I am also very keen that high-quality tinnitus research continues to be funded so that we can continue to find new ways to improve its management. I am passionate about supporting Tinnitus UK and I hope I can help spread awareness of this important condition."

He added: "I was delighted to finish the London Marathon in 3h39m. It was a truly incredible experience; the atmosphere created by the crowds was fantastic. I am thrilled to have raised over £2500 for Tinnitus UK and thank everyone who so generously donated towards this cause."

The money that Michael has raised will help us to pay for the telephone and IT equipment that our helpline advisers use when they take calls and online webchats.

We are grateful to Brandon and Micheal for the money they have both raised as this helps us to continue to help as many people as possible.

If you would like to take on a personal challenge to raise funds for Tinnitus UK please email us on info@tinnitus.org.uk.

“My tinnitus diagnosis has been devastating”

Annette was formally diagnosed with tinnitus on 5 January 2024. She spoke to Quiet about her journey so far.

“Looking back, I realise I’ve had tinnitus for about four years. I think that stress has caused it. For a long time, I assumed that the noise I could hear was an aircon unit on a nearby building. It wasn’t until I moved and could still hear the noise that my son suggested I should have a hearing test.

I had a hearing test at Specsavers and the audiologist asked me if I heard the noise in my left or right ear. When I couldn’t answer, he asked if I thought the noise might be in my head – his insight finally nailed it. I then visited my GP who thought that I had some fluid on my ear. I returned a month later for a follow up appointment and we concluded that there was no fluid so I was referred to audiology.

I didn’t receive any further advice from my GP but my appointment letter for audiology was accompanied by information. I chose not to look at that before receiving a formal diagnosis. I’ll never forget the date, 5 January 2024, because my tinnitus diagnosis has been devastating. I know that it will never go away and the constant drone drives me mad. I’ve taken this diagnosis worse than anything I’ve ever been told, and I’ve previously had a cancer diagnosis. There’s no cure for tinnitus so I feel hopeless at times.

For me the worst part of tinnitus is the sleep deprivation. I’ve experienced poor quality of sleep for the last ten years. Before, I would wake in the night but, crucially, I could always get to sleep. Now, the constant drone of my tinnitus makes getting to sleep a daily struggle and this makes everything feel worse.

For me the worst part of tinnitus is the sleep deprivation

I have typical hearing loss for a woman of my age but the drone of my tinnitus means that I struggle in noisy environments. I also can’t really hear conversations when I’m travelling in a car. I generally understand the gist of social conversations and have learned to lip read but I can miss a lot of detail.

I have a follow-up audiology appointment on the telephone soon. This is to see how I am doing and how I’ve got on reading all information they sent me. If I’m honest, it is all very overwhelming. I’ve been advised to try a white noise app, background noise as well as relaxation and breathing exercises. I was offered CBT. I’ve had this in the past and know the techniques so I just need to use the coping strategies I already have and to be more accepting of where I am now.”

“I can control the sound levels”

I’m Chris, and I’m 65 years old, and I’ve never known silence because of my lifelong battle with tinnitus. In 1976 I became an Engineering Cadet Officer in the Merchant Navy, where I spent hours in noisy engine rooms. But even before then, I suspect the ringing in my ears had already started. Growing up, stress was another constant companion and I just felt that the ringing in my ears was normal.

It wasn’t until the 1980s, after hearing others complain about similar symptoms, that I realised my condition might not be normal. When I visited the doctor, I was met with limited options and minimal care, and I can’t remember if I was even offered a proper hearing test. I was just told “there is nothing that can be done” and I had to “continue to just live with it” - a typical experience for tinnitus sufferers back then.

My tinnitus noise is very much in my head. Despite this, I do have very good hearing, except for a recent decline that might be age-related, or it might be the tinnitus is getting a little louder. I’d describe the tinnitus sound as a high-pitched tone similar to mic feedback. I’ve found that conventional hearing protection does little to block out this internal noise; if anything, it seems to amplify it. But as I now have an office job, I can control the sound levels.

The tinnitus is relentless. Keeping my mind occupied does lower the perception. However, my constant use of distractions such as games on my tablet or phone really annoys my partner! Sadly, watching TV isn’t enough to keep the tinnitus at bay.

One day when I was having a lot of trouble, I found Tinnitus UK (then the BTA). I joined their Readers Panel who help produce their resources, and my insight as someone with dyslexia was welcomed. I learned a lot from the information I read – including the best place to book a seat when flying! With their support, I sought further medical help and now have a hearing aid that helps with the tinnitus. I joined one of Tinnitus UK’s online support groups, and I now run an in-person group local to my home.

The biggest problem that we face is the lack of funding for tinnitus research

The biggest problem that we face is the lack of funding for tinnitus research, and the lack of profile the condition has. It’s so often misunderstood. It’s vital to recognise the impact this condition has and to stop the suffering. We mustn’t carry on suffering in silence. We must aim for silence for all of us.

“My life feels completely different”

I first noticed my tinnitus in the summer of 2012, when I was pregnant with my second child. For weeks I’d heard a high-pitched ringing in my ears, especially in quieter moments such as lying in bed. I tried to ignore it, but then I started experiencing headaches and dizziness too.

I’d struggled with my hearing in the past, had started using hearing aids years before, and wondered if the two were connected. For months, I hoped it would go away. Only, it just got worse.

My husband Greg encouraged me to see a doctor, and I finally did so in 2013. He confirmed that I had tinnitus. He explained the ringing or buzzing was often linked to hearing loss. There was no cure, and that I’d just have to learn to ignore it.

And for six years, I tried, but the constant noise made me irritable. I was still suffering from dizziness and headaches but now they were joined by shooting pains in my ears, making me emotional and scared a lot of the time.

If my children laughed too loudly or played too noisily, I’d snap at them. Even the sound of cups being put away was intolerable to me. I lost count of the number of times I went back to my GP. But each time, I was told the same thing. Just ignore it.

Soon, I dreaded going to bed, anxious at the thought of spending another night trying to ignore the noise. Before long, I only slept for three hours a night. Exhausting.

Greg did his best to support me, and although the children were very young, they tried their hardest to keep the noise down. But I just couldn’t carry on living like this. So in December 2018 I was referred to an ear, nose and throat team.

My specialist was really helpful and gave me lots of information about tinnitus. Adjusting my hearing aid, the team added a special white noise setting that helped me drown out the ringing. And they introduced me to Tinnitus UK. Their help and support proved invaluable, almost like an extra family. I met other sufferers, realised I wasn’t alone.

> **I thought the noise in my head would ruin my life**

It was suggested finding a new hobby could be helpful, and so I joined a yoga class, started walking and amazingly, it made a difference. The noise didn’t stop, but I found it easier to deal with. My mood improved and I had more patience with the family. And when the ringing spikes, becoming too loud, I just switch on the white noise on my hearing aid.

Now, my life feels completely different. Although I’ll never be rid of the incessant ringing in my ears, it definitely doesn’t affect me the way that it once did.

Tinnitus conference 2024: Save the date

sponsored by
LENIRE®
soothe tinnitus

23 – 27 September 2024

The five-day conference includes the latest information and research from world leaders at the very forefront of tinnitus and tinnitus support.

The conference is aimed at professionals and researchers supporting people with tinnitus; from audiologists, ENTs, GPs, mental health professionals, peer support leaders, educators and PhD students.

The conference will follow the below format:

Monday: **Psychology**
Tuesday: **Specialist**
Wednesday: **Practical**
Thursday: **Research**
Friday: **Research**

Across the five-day conference, our guest speakers will be delivering a total of 20 sessions, and all sessions will be subtitled, including the live Q & A.

Not available to make the live sessions? Catch up on all sessions on-demand until Monday 23 December 2024.

Tinnitus Conference 2023 highlights:

- Attendees registered from **35** countries, including Australia, South Africa, Canada, India, USA, Belgium and Tanzania.
- **53%** of attendees had not previously attended the Tinnitus Conference, which is an increase of 12% on 2022 attendees.
- **240** questions submitted by attendees across five days during our live elements.
- On average, sessions scored **4.9 out of 5** throughout the week.

Here’s what people said about last year’s conference…

> **“Thank you so much for such a fantastic conference! Really enjoyed the scope of topics and would like to thank you for such an easy format to watch all of the sessions.”**

> **“Best one yet.”**

> **“Thank you for a great week with lots of interesting and informative speakers. I am grateful to have had the opportunity to attend online and not miss this event.”**

The booking website is now live, scan the QR code for more information and to secure your place.

Creating a better tomorrow: leaving a legacy of hope

Imagine for a moment the ripple effect of your kindness extending far beyond your own lifetime. You might think that leaving a gift to charity in your will is only for the wealthy, but the truth is, it's an opportunity for everyone, regardless of financial status, to leave a lasting impact.

In fact, without the generosity of individuals like you, many of the charities we cherish today wouldn't even exist. Take Tinnitus UK, for example. Gifts left in people's wills helps us to maintain essential services like our helpline, information resources, professional training and support crucial research into managing and potentially curing tinnitus.

Despite the challenges to household finances many of us are facing, three quarters of people in the UK still support charities. And when surveyed, only a small fraction—just 9%—wouldn't consider leaving a gift to charity in their will after providing for loved ones.

Yet only a fifth of people have included a charitable legacy in their will. This is where you can truly make a difference. By leaving even a modest gift alongside provisions for your family and loved ones, you can help transform lives.

Your contribution to Tinnitus UK, no matter the size, offers hope for a better quality of life to thousands affected by tinnitus.

Our work, made possible by legacies like yours, aims to improve quality of life and offer newfound comfort to those struggling with this condition.

Whether you choose a residuary, pecuniary, or specific legacy, your support enables us to plan for the long term and continue our vital work. And if you already have a will, it's simple to update it to include a gift to Tinnitus UK through a codicil, with the guidance of a solicitor or professional will writer.

Moreover, leaving a gift to charity is not just a gesture of kindness—it's also a practical way to reduce the tax burden on your estate, ensuring that more of your assets go toward making a difference in the lives of others.

So, you see, you don't need fame or fortune to leave a legacy of compassion. By remembering Tinnitus UK in your will, you're already making a profound impact on the future.

For more information on how you can leave a gift to Tinnitus UK and make a difference for generations to come, please contact our fundraising team at **0114 250 9933**. Together, we can create a world where every act of generosity gives hope and healing.

New regional support groups

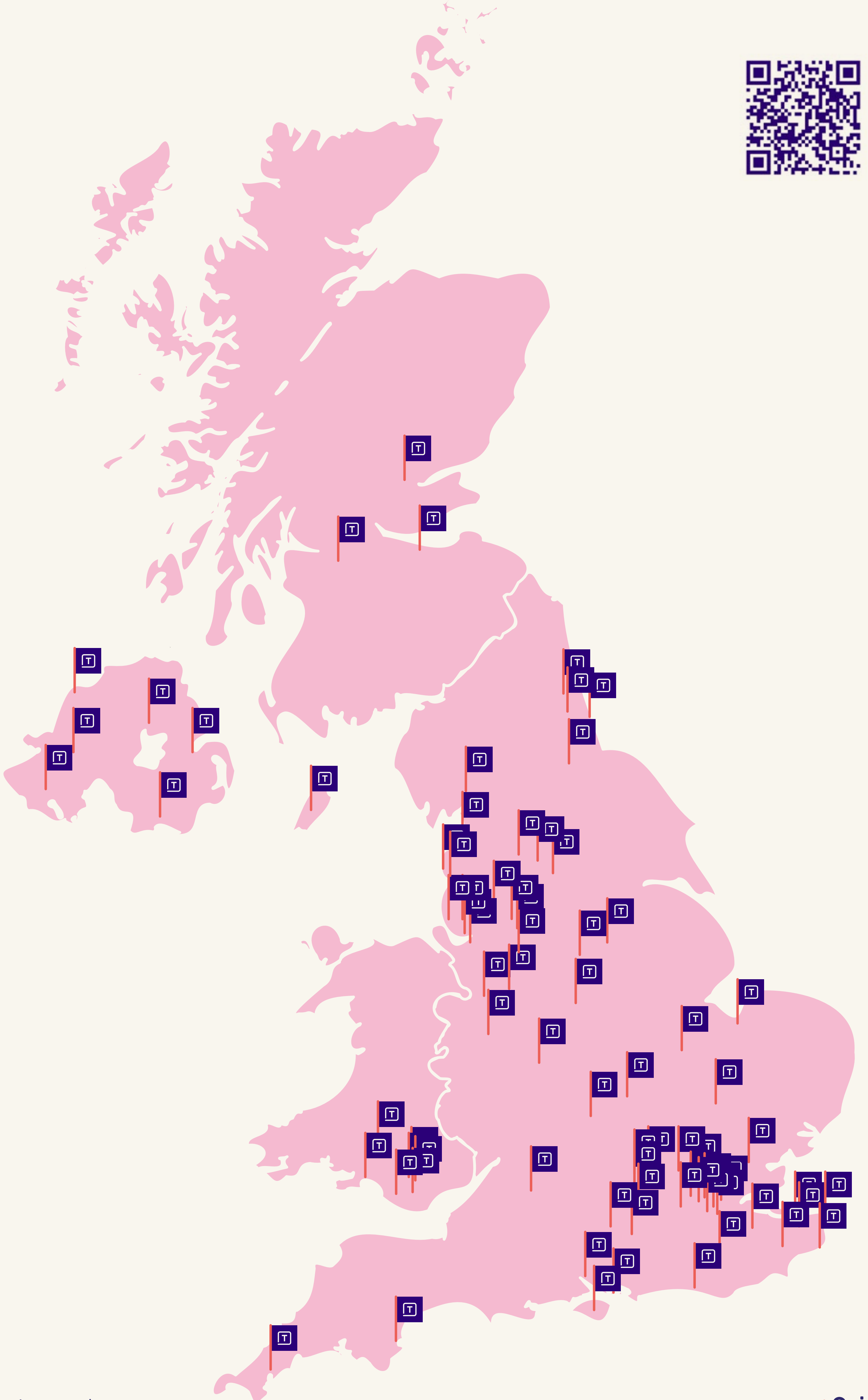
We are pleased to announce that we are increasing local support for people living with tinnitus. As we go to press, three new support groups have opened their doors to people living in Telford, Banbury and Coalville. Further groups are in development in Worksop/Bassetlaw, Lancashire, Peterborough and Lancaster/Morecambe.

We have more than 80 affiliated support groups across the UK and we facilitate five online support groups including a specialist group for people living with tinnitus and sound sensitivity.

Our report 'Revealing the struggle for silence', published in February, uncovered an urgent need for more support. Peer support connects people living with tinnitus to others who understand them. This helps reduce feelings of isolation and helps to increase an understanding of how others manage their condition.

We strongly feel that no-one should feel isolated because of their tinnitus diagnosis. We are working to increase the number of local support groups so that anyone living with tinnitus can connect with someone nearby.

We remain dedicated to providing a range of services backed up by the latest research to help people live well with tinnitus. In addition to support groups, We also offer a befriending service, telephone helpline, live webchat support, a chatbot named Axel as well as a wealth of information on our extensive website. We also facilitate a very active online patient forum.



Tinnitus support groups

East Midlands
Chesterfield & N Derbyshire 🟨
Derby
Northants
Worksop/Bassetlaw ●

East of England
Cambs
Chelmsford
King's Lynn and District 🟨
Peterborough ●

London
within M25
Bexley
Boreham Wood 🟨
Bromley
City of Westminster
Dulwich
Greenwich 🟨
Kingston
London (North)
London and South East ○
Orpington

NE England
Chester-le-Street
Darlington
Newcastle (Deaflink)
Seaham ○

Northern Ireland
Belfast
Enniskillen
Newry and Mourne
Omagh
RNID Northern Ireland
Western *(Londonderry)*

NW England & Isle of Man
Aintree 🟨
Blackpool & District ○
Bolton 🟨
Cheshire East *(Macclesfield)*
Isle of Man
Kendal (Age UK)
Lancashire ●
Lancaster / Morecambe ●
Lytham St Annes (Always Ear)
Manchester
Runcorn
St Helens
Stockport ○
Widnes

Scotland
Ayrshire ○
Edinburgh & SE Scotland
Glasgow 🟨
Perth & Kinross

SE England
Aldershot & District
Amersham
Ashford *(Kent)*
Banbury (Harrolds Opticians & Audiologists) ○
Basingstoke
Brighton
Canterbury
Chinnor
Crowborough
Dover
Isle of Wight
Maidstone
Marlow/Farnham Common 🟨
Southampton
Southsea
Thanet ○
Whitstable ○
Wokingham ○

SW England
Torbay
Truro
Wiltshire (SW England)

Wales
Aberdare
Bridgend
Pontyclun
Pontypridd
Rhondda
Swansea
Ystradgynlais

West Midlands
Birmingham & District 🟨
Newcastle-under-Lyme
Telford (DeafnAble) ○
Whitchurch

Yorkshire & Humber
Bradford
Earby
Keighley 🟨

Online
Tinnitus UK
Musician's tinnitus support group
Tinnitus - first Wednesday
Tinnitus - second Wednesday
Tinnitus - fourth Wednesday
Tinnitus & sound sensitivity

🟨 **Tinnitus UK Gold Standard Group**
○ New group
● In development

To find details of a tinnitus support group or clinic in your area, scan the QR code opposite, 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.

Find your silence

Helpline:

0800 018 0527

How we can help:

TINNITUS UK

Support • Research • Prevent

Tinnitus UK
Registered charity no: 1011145 Registered in England
Company limited by guarantee no: 2709302