

RN I:D

WINTER 2023



Party on

Deaf DJ Troi Lee

ACTION

Hearing aid victory and wax services meltdown

PEOPLE

Are you escaping to the kitchen at parties?

EXPERTS

We answer most frequently asked tinnitus questions



Tony Keegan, who works for London Ambulance Service, was born with perforated eardrums which meant recurring ear infections in childhood. Surgery in his early 30s left him with profound hearing loss and he now wears implants. See p30 for our feature on recurrent ear infections in children

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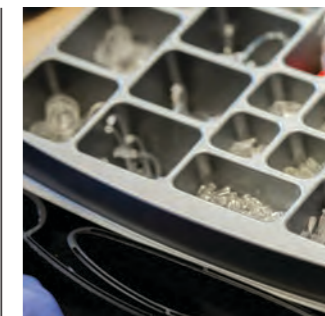
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Chase the winter blues away and cosy up with your latest issue packed full of expert information, inspiring people stories and our charity's ambitious plans for 2023 and beyond! Whether you're a new or long-term supporter, we're glad to have your company. Dawn Dimond, Editor

1 Hearing loss is a cause I'm strongly connected to. I'm a former musician who has tinnitus and chronic ear infections, and both impact my hearing. I want to contribute to research that could one day restore lost hearing but, until then, I want to be part of a movement that allows people to live full, inclusive lives and reduce isolation and loneliness.

2 Gifts in Wills fund many important areas of RNID's work, including our support services and our campaigning work. These gifts also fund a huge portion of our research spend – 70% in fact!

3 Leaving us a gift in your Will is pretty simple. Once you've decided what you'd like to leave, you just need our registered address and charity number. If you're looking to make, or update, your Will then we have two free Will-writing services partners – Farewill and the National Free Wills Network.

4 Every gift is unique and comes with a great story – because everyone who leaves a gift has the story of their own life. That said, there have been a couple of peculiar gifts – one was a gravel pit, and another was a set of Russian nesting dolls. Working out the going rate for a gravel pit was a bit of a challenge!

5 facts about DAVID LEADER

who talks about his work in the gifts in Wills team at RNID

5 We're a small team but it's important that supporters know about our work. We hold gifts in Wills events and send out mailings updating you on the latest news in biomedical and technological developments around deafness, hearing loss and tinnitus. You can also learn about our work online at rnid.org.uk

If you'd like more information about how to leave a gift, please get in touch with David at: giftsinwills@rnid.org.uk or give him a call on 0203 227 6034.

Action

CAMPAIGNS | SERVICES | INFORMATION

We report on a major breakthrough in our hard-fought campaign against hearing aid cuts



We're thrilled that after eight long years, our campaign against hearing aid restrictions in North Staffordshire has succeeded. NHS hearing aids will once again be available to everyone who needs them – regardless of their level of hearing loss

**HEARING AIDS
A HARD-FOUGHT
VICTORY**

The controversial restrictions that prevented some people in North Staffordshire from accessing hearing aids on the NHS have now been lifted, following a U-turn by Staffordshire and Stoke-on-Trent Integrated Care Board (ICB).

In 2015, North Staffordshire Clinical Commissioning Group (CCG) became the only part of England to restrict the provision of hearing aids, denying access to people with mild or moderate hearing loss. The decision to reverse this decision was made in the face of overwhelming evidence that hearing aids are clinically effective and, ultimately, cost-effective for the NHS.

A PRECEDENT

As well as affecting people in North Staffordshire, the unfair restrictions on hearing aids set a dangerous precedent for other areas across England. After 2015, several other areas across the

country proposed cuts to free hearing aids, potentially limiting access to thousands of people who could benefit. RNID, together with thousands of our supporters, local politicians and audiologists, campaigned vigorously against this and the proposals were dropped – except in North Staffordshire. Thanks to continued efforts by RNID and our communities, these restrictions were partially lifted in January 2021, but many people in the area were still left without access to hearing aids.

In September 2022, a statement from Staffordshire

“We celebrate this momentous change in policy, which will protect access to hearing aids for everyone who needs them.”

and Stoke-on-Trent ICB said the decision to remove the remaining restrictions had been made following a review of the latest clinical evidence and would deliver the best use of NHS resources.

UNAFFORDABLE

Crystal Rolfe, our Associate Director for Health, says: “Research shows that for people with mild hearing loss, hearing aids improve communication, relationships, self-confidence, social participation and overall health, as well as reducing the risk of



MY STORY

Linda Parton, from North Staffordshire, has supported RNID to campaign against hearing aid restrictions over the last eight years. She says:

“I decided to get my hearing sorted when it was becoming difficult to work, to follow the conversations of my grandchildren and to watch TV with other people. I've now been wearing my hearing aids for eight and a half years and they are my lifeline. When I was fitted with hearing aids, it was a miracle. There was an instant improvement. However, my local CCG (North Staffordshire) started talking about restricting the provision of hearing aids just a few months after I got mine. If I'd not been able to get hearing aids I would have been frightened, depressed, isolated, and not at all the person I am today. I'm delighted that the decision has been made to reverse these restrictions so that everyone who needs hearing aids can benefit from them.”

for Health and Care Excellence (NICE) guidelines.

“We're pleased that this decision removes the postcode lottery for hearing aids. It ensures that hearing aids are freely available for all who need them. A pair of private hearing aids can cost around £2,500, which is unaffordable for many people, especially during a cost-of-living crisis.

“We celebrate this momentous change in policy, which will protect access to hearing aids for everyone who needs them – not only in North Staffordshire but in the rest of the UK.”

Become a campaigner

It's thanks to our amazing community that we were able to keep NHS hearing aids safe across the UK. Join us, so we can continue making life inclusive together. rnid.org.uk/campaigns

Wax service meltdown

Our new report reveals the difficulties faced by people who need their ear wax professionally removed – and why we’re calling for urgent action



We surveyed more than 1,400 adults to find out about their experiences accessing ear wax removal on the NHS, what advice they were given, and what happened next.

Our report found:

- **73% of respondents** with ear wax build-up experienced hearing loss, and 37% experienced tinnitus. Half of respondents experienced earache or discomfort, and a quarter experienced dizziness.
- **More than a quarter** of those we surveyed could not afford to get their ear wax removed privately (which can cost between £50–£100). This was especially problematic for hearing aid wearers, who need ear wax removed more regularly.
- **Cost for private treatment** and long waits for ear wax removal at hospital led many respondents to attempt to remove ear wax themselves, although two-thirds did not feel confident doing this.
- **Many of the methods** people described to remove ear wax were dangerous, including hair clips, paper clips, toothpicks, cotton buds, and Hopi ear candles.
- After trying to remove ear wax themselves, only **20% of respondents** said their problems went away, whilst **55% noticed no change** in their condition. One in 10 said their symptoms got worse, or they caused themselves injury which required medical attention.

Ear wax is a normal substance that helps protect the outer ear. For most people, it moves out of the ear naturally over time but 2.3 million people a year in the UK require their ear wax to be removed by a professional. If left untreated, ear wax build-up can

“Ear wax removal services must be available on the NHS for everyone who needs them.”

Crystal Rolfe, Associate Director of Health at RNID

lead to temporary hearing loss, earache, a greater risk of infections, social isolation, and depression.

Historically, most people could access ear wax removal services on the NHS, often through a practice nurse. However, many are now being told to pay privately, or remove ear wax themselves. Some people told us they were quoted up to £400 for private removal.

We’re now calling for:

- **Ear wax removal** services to be brought back into primary care or community settings.
- The Department of Health and Social Care, NHS England and local health bodies to explore **new models for delivering ear wax removal services** to make sure people can access timely and appropriate treatment.
- The NHS to **publish clear information** on how people can manage ear wax build-up at home.

Crystal Rolfe, Associate Director for Health at RNID, says: “We are concerned that many people with ear wax build-up are at serious risk of permanently damaging their hearing now that they are unable to access ear wax removal services on the NHS.

We’ve heard of people living in pain and depressed at the lack of support they’ve received from health professionals. Someone with ear wax build-up used to be treated in a week at their surgery but now the service has been withdrawn, people who can’t afford private treatment are left with no options. This isn’t good enough. Ear wax removal services must be available on the NHS for everyone who needs them.”

Lizzie Jackson, 67, developed an ear infection in 2020 which caused a dramatic build-up of ear wax. She said: “The problem got worse until I couldn’t hear at all. The pressure in my ears caused some pain, discomfort, and a few balance problems. The only thing was to self-treat for wax build-up, so I put in special olive oil for softening ear wax, which I got from the pharmacy.

“The cotton wool that I placed at the entry to my ear canal to stop the olive oil dripping out got stuck deep in my ear. I had to go to hospital to get it removed. They eventually removed the ear wax, but I should have been able to access a practice nurse at my GP surgery and the problem could have been solved several weeks earlier.”

Paul Clarke, 51, lost his hearing through meningitis when he was a child. He used to get ear wax professionally removed at Belfast Royal Victoria Hospital, but the service was stopped during the pandemic. He said: “I lost my balance and fell. I contacted the GP who checked my ears; he gave me two options – to either go private or go on a waiting list with the health trust. I thought about going privately but it was too costly. I experienced a lot of discomfort and it had a severe effect on my communication with others. Eventually I got an appointment but it took over a year.”

Take action If you’ve been refused ear wax removal on the NHS, email your MP, MSP, MS, or MLA. Our online form makes it easy to ask them to ensure guidance on wax removal services is improved – and everyone who needs professional wax removal can get it. See: rnid.org.uk/ear-wax

Jackie White, RNID's Associate Director for Localities, explains how our local services have been redesigned to deliver the support you need where you need it



RNID has been through a major transformation over the past couple of years. We have ambitious plans about how we can help more people who are deaf, have hearing loss or tinnitus. We're concentrating on what we can deliver to large numbers of people, and where we can do most to influence improvements to inclusion, health, employment and research.

Alongside continuing to run local services across the UK, supporting around 3,000 people each month, we've been asking what people want from us – and re-working what we can best deliver. We've consulted with people who use our services, as well as our volunteers, our staff and the organisations we work with (such as the NHS and British Association of Audiologists, for instance).

We identified these core services as being the most valued:

- **Help with hearing aids** – maintenance, changing tubing and batteries and helping people handle and use them properly
- **Information and support** about hearing and assistive technology – drawing on our in-house knowledge and expertise
- **Encouraging people** to get their hearing checked and tested.



We know that our services have always been highly rated by the people using them – but we couldn't always reach everyone who might need us.

We wanted to design a new service that builds on what we do best and is of the same standard – wherever you live. We realised, too, that we needed to get better at making it clear that these are *free* services, provided by our specially-trained volunteers. Finally, we needed to make sure that people knew what to do next – whether that's making an appointment with their GP or audiologist, or being signposted to other support services available in their community.

Working with audiology

Everything we do will involve working in partnership. Our core partnership is, of course, with you. We need to make sure we understand the needs and priorities of our communities of people who are deaf, have hearing loss or tinnitus – and that you feel involved in all our activities. If we are to make society work better for you, we also need to build strong partnerships with employers, businesses, universities, funding bodies and health services.

We looked carefully across our local services to identify those that work most effectively alongside NHS audiology. What we found was that it's crucial we are really clear to potential referrers – including audiology teams – and to the people who use our services about what exactly we can do, and how this is designed to complement the role of NHS health professionals.

We partner with NHS audiology services in some parts of the UK to support people to get the most out of their NHS hearing aids

What you've said:

“ To visit people who understand my issues was so wonderful I was actually in tears at one point. They got my hearing aid working properly, took all my details to help me further, gave me advice about a doctor's referral and generally just made me feel that someone was really listening to me. It was such a positive experience.

“ This service is free, really helpful and much easier and quicker than booking a hospital audiology appointment. One of my hearing aids had been falling off my ear – I thought the tubing was too tight/short. They tried some different domes, then fitted my aid with the next tube size up, which is much better so far. They even gave me some extra batteries. They also let audiology know about any changes for you.

At their best, our services sort out straightforward issues around people's hearing aids and deal with simple enquiries on hearing health – leaving audiology and other health professionals to concentrate on more complex issues and questions.

Extending our services

The outcome of all this is RNID Near You; a service that will meet your needs and be delivered to the same high standards, right across the UK.

We already have 22 services across the country and we plan to expand this to 58 services by 2027. We can, of course, only deliver where we have funding to do so and we have a strategic plan to increase our reach. If we're not yet in your locality, we hope to be Near You, in the near future.

We're looking for volunteers at our Near You services. To find out more about volunteering, go to p16

Bev Oakley lost the hearing in one ear after surgery for acoustic neuroma two years ago. Following a **workplace assessment by RNID**, she's returned to work with new-found confidence



My acoustic neuroma was found purely by chance. I went to my GP as I was experiencing a strange smell of smoke over a few months, and I thought I should check it out. I was referred for an MRI which showed a tumour was growing off the balance and auditory nerves on my right-hand side. In hindsight, I realise I'd been experiencing some hearing loss but I put it down to needing to get my ears syringed.

Unfortunately, the neurosurgeon told me my tumour was large and impacting my brain stem, so the only option was to remove as much of it as possible surgically. This meant the nerves had to be severed to get to the tumour itself. One day I had hearing in my right ear – the next day, nothing. I was totally deaf except for all kinds of tinnitus.

I love music and find it hard not hearing in stereo. I've also been surprised by my inability to work out where sound comes from, as everything

now comes in at my left ear. It's challenging to walk down the road and not hear a car coming out of a driveway. And I spin round in circles if someone calls out my name!

Understood me completely

I also really struggle in environments like pubs and restaurants. I can't focus on a single voice anymore as it's hard to pick out from the background noise. I try to lipread while turning my head, so my good ear is pointing towards the person talking. It can affect my confidence as it's embarrassing to continually say sorry, excuse me, or please repeat that.

I work for a medical device and software company and my hearing loss hasn't had much impact on me when I'm working from home. I have a headphone/microphone set up for online Teams. We're now back in the office one day a week and this can be challenging when there are workshops across Teams and

there are people in the office.

When I was recovering from my operation, my line manager and HR department were so supportive. They asked if I would like a workplace assessment with RNID to make sure I had everything I needed to help me get back into work. My RNID assessor understood completely what I was feeling and the challenges ahead. In fact, I learned more from her about my hearing loss and how to manage it than from anyone else. She provided links to various hearing devices for me to look into and some tips for managing office meetings via video calls.

"My assessor understood completely what I was feeling and the challenges ahead."

We now have Transcriptions in Teams which help me read what's being said when I'm not using headphones.

I also use the Phonak Roger Select microphone system and a Roger II behind-the-ear receiver which looks like a hearing aid. It took me a while to get used to the settings, and what it could do, but it's a big help in face-to-face meetings with multiple people. I do still struggle with background noises but I alter my device and move to a better position to try and combat it.

RNID's help means I now have the tools and strategies to help me in office situations. I've also created my own personalised digital communication card. Most importantly, I'm not worried about telling people I'm partially deaf or wearing my hearing device; it's something that is now part of me.



We also offer remote courses to help businesses become more accessible. All our courses are delivered by people who are deaf or have hearing loss.

Deaf awareness training course

Gain skills and confidence when communicating with people who are deaf and those with hearing loss or tinnitus. Training is delivered via Zoom or Teams over two hours and is suitable for up to 16 people.

BSL taster course

Learn some basic signs to use with colleagues and customers whose first or preferred language is British Sign Language (BSL). Training is delivered via Zoom (for one hour) and is suitable for up to 10 people. Our Start to Sign training course is more in-depth and duration is three hours (one hour sessions over three days).

Online training - eLearning

We're working in partnership with Signature to provide an Introduction to BSL and Deaf Awareness courses, specifically aimed at organisations. Employees will benefit from flexible learning by using a range of informal clips, receptive practice, short quizzes and vocabulary.

For further information: email contact@rnid.org.uk or call 0808 808 0123 (full details on back cover)

Our latest research shows that 98% of people in the UK not diagnosed with hearing loss say their hearing is important to them - but only 6% took a hearing check in the past year

Many of you will recognise the scenario: struggling to hear what's been said at a social gathering and, instead of admitting it, smiling and nodding along – hoping that you laugh in the right places and make the appropriate response. Our new research, published last year, highlights the extent to which millions of people in the UK – despite believing themselves to have 'good' hearing – use coping mechanisms like this to deal with their potential hearing loss.

RNID's Associate Director for Health, Crystal Rolfe, says: "Sometimes people think that only older people need to look after their hearing but hearing loss can affect anyone of any age. As well as age-related damage, hearing loss can be caused by over-exposure to loud noise, certain medications, or genetic factors.

"Hearing loss can be slow to spot, but common signs include regularly turning the TV up too loud, struggling to hear in noisy environments or having to ask



people to repeat themselves. You might also feel that other people are mumbling, or find your partner regularly complains that you don't listen to them."

Our research found that despite 91% of these adults saying they rate their hearing as 'good':

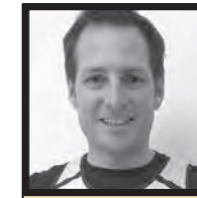
- **More than a third (34%) admit they've pretended** to follow conversations they've struggled to hear, for example by smiling and nodding along
- **The same amount (34%) found it difficult** to follow conversations in noisy surroundings like restaurants or parties
- **Almost a quarter (24%) have found themselves** asking people to repeat themselves
- **More than 1 in 10 (13%) say they have been told** by their partner they think they might have a problem with their hearing
- **However, despite these findings, 83% have never taken any action** in relation to their hearing, although **74% said they would be likely** to take an online hearing check that is free and takes three minutes.

* Research carried out by YouGov Plc in September and December 2022

Overall, 84% of people we surveyed said they recognise that early diagnosis of hearing loss is important for health and wellbeing. But with only 6% having a hearing check in the past year, it appears to be the 'poor relation' compared to how many respondents had a dental check (53%) and eye test (46%).

"Checking your hearing should feel as natural as having your eyesight or teeth checked," says Crystal. "We do know a lot of people simply don't know where to start. Less than a third of people we surveyed said they know how to access a free hearing check if they needed one."

In fact, checking your hearing is quick and easy to do yourself using our free, 3-minute online check which measures how well you can hear speech when there's background noise. More than 120,000 people have taken the check since its launch in 2021. This year, we're encouraging even more people to look after their hearing health in our 'New Year, New You' campaign.



CHARLES: "Just do it!"

The advice I would give anyone considering a hearing check is – just do it. It's not really clear how and when my hearing loss started but it became apparent that I was struggling with the phone and in social situations. I had a choice to continue to struggle or to improve my hearing situation; the latter was the driving force to overcome any anxiety and being overly self-conscious. The hearing aid I wear now is brilliant to have in work meetings and in social settings. It's great that I can get that extra clarity when I need it and, in those moments of wanting peace, I can achieve that as well.



DAVE: "What have you got to lose?"

A buzzing noise in my ears gradually became louder and began to take over my life. I had hearing tests in my local opticians but I was told there was no problem with my hearing. This went on for a number of years until I read about and decided to try RNID's online hearing check. I was surprised at the result and forwarded a copy of the report to my GP, who arranged a hearing test and then referred me to audiology. It was a shock to find out that I had hearing loss in both ears and tinnitus. I now wear hearing aids and I can hear quiet conversations and listen to the TV or radio at sensible levels. I would thoroughly recommend anybody who is having doubts about their hearing to give the RNID online check a go. What do you have to lose? Nothing – but all to gain to improve your life and wellbeing.

Do you know someone who could benefit from taking our hearing check? Simply go to: rnid.org.uk/check



RNID relies heavily on its army of dedicated volunteers to take our services out into the communities. There are lots of ways to get involved – join us and find out

MAKE A difference

Volunteering with us makes a real difference – to your life and to the lives of people who are deaf, have hearing loss or tinnitus. Here's why 90% of our volunteers, surveyed in 2020, recommend RNID as a good place to volunteer:

- Be part of a supportive community**
You can meet new people in your area. 87% of our volunteers have an increased sense of contributing to their local community.
- Gain new skills and experience**
Volunteering with RNID gives you the opportunity to develop and improve teamworking and communication skills, as well as gaining experience and knowledge supporting people with hearing loss.
- Do something you love**
You can choose a volunteer opportunity that suits your interests. Doing more things we enjoy can give us a better sense of purpose and help us feel more fulfilled and motivated.

- Try something new**
Volunteering is a great way to try something you've always wanted to but not had a chance.
- Build your confidence**
71% of our volunteers say that volunteering with us has increased their self-confidence.
- Stay active and healthy**
Volunteering can have a positive effect on our mental health: 76% of our volunteers feel that it improves their wellbeing.

Our volunteers say

"I really enjoy volunteering with RNID. My supervisor is very supportive, and it's lovely to see how grateful everyone is."
"Volunteering has given me the opportunity to discuss issues relevant to having hearing loss in a supportive, non-judgmental environment."
"Volunteering has given me more confidence in myself and has made my life more interesting."

Look out for more volunteer stories in our next issue. Apply to volunteer with us at: rnid.org.uk/volunteer

People

EXPERIENCE | INTERVIEW | OPINION

Lynne Kelliher knows she is good company. So why does she feel left out at social events? Read her story overleaf



do have a sense of humour, but I often don't hear the punchline. If I don't laugh at your amusing anecdotes or jokes, chances are I haven't heard them. I really am interested in what you have to say. But, to 'hear' you,

I have to lipread, watch your body language and facial expressions, listen to the tone of your voice, and process all this information in seconds to assess it. Even then, I can only hope I've got it right. Quite often I misunderstand what is being said – and I answer based on what I *think* you've said. This is irritating for you and frustrating, embarrassing and isolating for me. I often ask you to repeat what you've said but, if I still don't understand after the second or third go, I give a suitably neutral response and move on, none the wiser! I don't hear the beginnings and ends of words so, for instance, you might have said height, blight, night, tight, right or plight...

It's particularly mortifying when you confide in me, or tell me something sad, and I don't give an appropriately sympathetic response. I have had hearing loss since childhood, so I am fortunate in that I've learned to lipread well. Many people lose their hearing in later life when it can be harder to learn to lipread.

AN ACT OF CHOICE

Even so, I don't cope well in a noisy environment and I sometimes give up starting a conversation because I know I won't hear the response. This may make me seem aloof, disinterested and unfriendly; I'm not. Background noises such as music, chair scraping, television, traffic, feet on hard floors, the clatter of cutlery, crockery and machinery all make hearing almost impossible.

Subdued lighting makes it hard to lipread and observe visual clues. Parties or gatherings (especially in restaurants) are a nightmare. I want to be part of the fun and conversation but I usually feel on the outside looking in. If, sometimes, people give up trying to engage with me because I don't react in an appropriate way, who can blame them? So when I start collecting dirty cups or glasses at a party, it means I've given up on trying to be part of things. If I start washing-up, I've really zoned out.

Lynne Kelliher describes her experience of social situations – and hopes it gives friends, family and others a few ideas of how to make adjustments to include people like her

DON'T GIVE UP ON US

Facts about hearing loss that Lynne wants people to know

Approximately 12 million adults in the UK have some form of hearing loss.

The needs of people who are deaf or have hearing loss are often overlooked in day-to-day life.

Hearing loss is an invisible disability and those that live with it are more likely to suffer from mental health problems such as depression.

People with hearing loss are also more likely to experience loneliness and isolation.

Hearing aids only amplify what hearing the person has – not replace what is lost.



GOOD COMPANY

I often come away from these events feeling my self-esteem and personality disappearing. People with hearing loss are more prone to depression than people who can hear. I worry about what the future will look like for me; as my hearing deteriorates further, will I feel even more isolated, misunderstood and marginalised? The good news is, I'm great in a one-to-one environment. I'm witty, articulate, interesting, empathetic, engaging – and I react appropriately. Who wouldn't want to talk to me? I have lots of hobbies and interests that fascinate me. I'm curious about people and an active listener. Friends who know me well say I'm good company.

I emphasise that this is *my* experience in a friendly setting. I'm luckier than many people in my situation. Other people with hearing loss will have their own needs and ways of coping. Ask them how you can help make them feel more included – and *heard*.

What, dear reader, can you do?

- Be patient and understanding.
- Seek me out in a quiet corner and talk to me.
- In a group, make an effort to bring me into the conversation so I don't feel so isolated.
- Give me space to say something without interruption so I'm part of the conversation.
- Don't mumble, speak too quietly or with your hand over your mouth.
- Place me at the centre of the table so I can hear and lipread other diners. Or ask me where I would prefer to sit.
- Make sure you have good lighting and a quiet environment; to read lips, you need to be able to see them clearly (not as a silhouette).
- If I ask you to repeat something, do so calmly and without irritation.

Photograph: Peter Gloria



International DJ and Deaf Rave founder Troi Lee tells Margaret Rooke how music gives him everything he needs

Troi in party mode - with DJ Ceri Karma (left)

Make some noise!

TL I was born prematurely and profoundly deaf. I was born before my twin brother, Chun, but I had the umbilical cord round my neck, and I suffered a lack of oxygen; I always tell him I blame him!

But I'm a positive person; to me, it's a blessing that I survived the birth. Chun's the hearing one but I'm the loudest one. He's a computer analyst and I'm a DJ, so I make the noise.

My family is a quarter-Chinese, quarter-Vietnamese, and half-English. We grew up in Hackney, a musically and culturally diverse part of London with a lot of black music that played a strong influence in my life. I have a musical family: growing up, Chun was a rock drummer,



and my older cousins were DJs and MCs, and they all inspired me.

My early memories are of wearing box hearing aids from when I was around two, then later I wore analogue aids (which I still have).

I went to a mainstream primary school and, for an hour a day, they took the deaf children out of the class to be together in the Partially Hearing Unit; no signing, all speaking. This school was fantastic but secondary school was terrible; hardcore chaos. For the first three years, I didn't learn anything. There was me, one other deaf person, and no deaf awareness.

WITS AND SURVIVAL SKILLS

I witnessed a lot of bullying in those days but because I can talk back, and look after myself, I didn't experience it. I was a lively guy who could be friends with everyone. I had a great twin brother and great cousins, and I used my wits and survival skills. All of this meant I grew up confident, but a lot of deaf children don't have that path. I have faced racism when I was small. I don't think anyone should hold anything like this inside themselves – they should always talk to someone.

My mum fought to send me to a deaf boarding school, Ovingdean Hall in Brighton, when I was 14. We had six of us to a class and special support – it was a game-changer that opened my eyes to learning. I learnt sign language and got seven GCSEs. If I hadn't gone there, I wouldn't have achieved everything I have in my life.

Even in those days, everyone knew I loved music. I was into hip hop and had my Walkman on every day. When I was 17, I started going to the deaf pub once a month. That's when I really discovered this close-knit deaf community. There was a great bonding between people who travelled there from a lot of different deaf schools all over the country. >

My role is to give performers and DJs the platform and opportunity to show what they can do

This was the early 2000s and, by then, I knew I wanted to go to raves. But none of the others were interested, saying they were for hearing people. I started to buy record and vinyl decks and taught myself to DJ.

One night after the deaf pub, we went on to a club and a group of us, all sign language users, stood there for 10 minutes waiting to get in, with no one in front of us. I said to the bouncer "What's going on? Why haven't you let us inside?" and he said, "You lot aren't coming in. You're deaf". I guess the security people were scared they couldn't communicate with us, but this was the first time I'd experienced discrimination: I knew I had to do something about it.



Photographers: Becky Bailey, Adrian Joyner, Stephen Iliffe, Rajvi Vaya - Vayamedia

HEAVEN-SENT MOMENT

I set up Deaf Rave in 2003 and the friends I knew from the deaf pubs supported me. The first rave happened in central London and 700 people came to the party, including 200 from other countries. All the tickets were sold out. This event showed how tight the deaf community is. It was a glorious time, watching people who hadn't seen each other in weeks, months, or years, connecting again.

My name, Troï, means 'heaven' in Vietnamese and, to me, this moment was heaven-sent. I'd built up a line-up of deaf DJs and organised a mini-showcase in signed song and dance to inspire people and show they can get into dance and performance. That's my role – to give performers and DJs the platform and opportunity to show what they can do.

After that, there was pretty much an explosion of Deaf Rave. The people from other countries who'd come to the first one booked me to bring Deaf Rave to their countries. In everything I do, I work closely with MC Geezer, a sign-song rapper and music producer who's been with me for 19 years. We work as DJ and MC back-to-back and have been all over the world together; an incredible journey that hasn't stopped. In 2022, we went to the Birmingham International Dance Festival, the Edinburgh Fringe and a bunch of other mainstream festivals, so we're really on a high. We've also started running DJ workshops to teach the next generation. I'm 48 and old school now – some grey beard here! – so most of my ambitions now are for young people following our lead. Our next step is to produce music from young deaf people and give them a chance to perform. We're telling them if we can do it, so can you.

All of this is possible thanks to the analogue aid I wear in my best ear. I wear digital in the other, but it's computerized and robotic and adjusts automatically so I have no control.



Analogue is crystal clear for me. It gives me actual, precise sound. Being able to turn the T switch (loop settings), put the headphones on top of my ears and cut out all the background noise, the sound is more intense and direct – my brain gets magically tuned in. People tell us we are revolutionaries, but we have many barriers to overcome still – the music industry being one of them. Deaf musicians make up the smallest percent. We need to change that and expand, motivate, and inspire more performers.

You can be a DJ no matter what age you are. You'll need to work twice as hard as your hearing peers, you'll face barriers – but Deaf Rave has broken down a bunch of them. What you need is inner belief and confidence, knowledge, and passion. Then you will overcome these obstacles. Don't ever give up. ▀

For more information: deafrave.com



Mark playing in the Victoria and Albert museum restaurant

Pianist and composer **Mark Pampel**, who is deafblind, developed his musical talent after taking early retirement

MUSIC IS KEY

mark was diagnosed with Usher syndrome, a rare genetic disorder that affects both hearing and vision, at 16. He first noticed a change in his hearing aged eight, along with night blindness.

“As a teenager I was very active; I played table tennis, I went swimming, I played in a football team for a youth club,” he says.

When his parents took him to a private specialist at a London Harley Street clinic,

they were told that by the time Mark reached his 50s or 60s, he would be both deaf and blind. “I walked out of the clinic as though I’d been hit over the head with a hammer,” he recalls. “My eyesight deteriorated quicker than my hearing and I have no useful eyesight now. I have severe hearing loss and tinnitus and use two powerful BTE hearing aids. I also have Charles Bonnet syndrome, so I experience hallucinations.”

Despite the diagnosis,

Mark had a 20-year career as an administration officer in the civil service before taking early retirement once his condition became worse.

That is when he turned to music. “I enrolled in a number of piano courses which have taken me up to a professional standard,” he says.

“I use composing and improvising techniques to create new music. I hear a piece of music and re-play it by working out which notes I hear. I can then improvise

various parts to change the music and make arrangements of well-known classical and popular music. I compose my own pieces too.”

As pianist and composer of the LSO Create Orchestra, which runs music workshops for people with learning and physical disabilities, Mark has played at London’s Barbican Centre. He supports the orchestra (which includes some LSO professional musicians), as well as performing his own solo piano works at local concerts.

He also performs fortnightly at the Victoria and Albert Museum in London (pictured opposite) in a voluntary capacity.

“I play in the restaurant, which is very spacious, so people can sit any distance from the piano and hear as much or as little as they feel comfortable with. It’s ideal for people who wear hearing aids and those with hearing difficulties when there is music playing. They can find the right distance to sit in this exceptionally large space and still be able to communicate with others.”

Mark maintains his physical and mental wellbeing in other ways, too, including practicing Transcendental Meditation twice a day and swimming once a week.

“I also do Tai Chi exercise in the garden and feel the sun on my face,” he says. “But music is a key factor that gets me through; it’s so important

in giving me an amazing sense of wellbeing.”

Mark makes use of powerful modern hearing aids but wishes there were specialist devices for musicians to help him hear the piano sound natural again.

He can no longer use his earlier (2002) digital models as they are either broken or fading away. His long-awaited professional-quality acoustic piano sounds odd which is disappointing and upsetting. “These earlier digital hearing aids enabled me to hear the piano sound natural, which was a complete revelation and joy for me. I am deeply saddened that this feature is

no longer available as technology has moved on, and that the software is obsolete. I’ve even asked major hearing aid manufacturing companies just to listen to a small acoustic piano and to notice how the piano sounds so odd and unnatural but, to date, they have not listened or are uninterested in doing this. I just hope that in a few years time, and with the help of Hearing Aids for Music, something can be done to improve or bring back technology to make pianos sound natural again. It’s so important for me as I continue to struggle and work in my chosen field.

“The beautiful Steinway grand piano I play in supporting the LSO Create Orchestra also now sounds

odd and electric – which is very difficult for me to manage, especially as I’ve been able to retain my perfect pitch. The audiologist told me that most people want to hear speech far more than music. So, as I’m in a minority, the audiologists or hearing aid companies can’t currently offer any solutions to meet my needs.

“This is extremely disappointing and unfair as I desperately want to continue my work in entertaining people – and in supporting the LSO Create Orchestra to the best of my ability.”



Music listening with hearing aids

RNID says:

Many hearing aid wearers do struggle when it comes to listening to music. This is, in part, due to their design – hearing aids are primarily configured to improve the quality of speech (which is a relatively simple sound) whereas music is more complex. In fact, many of the features that make listening to speech easier – such as making loud sounds quieter and soft sounds louder – can make music sound distorted. This is especially so in an environment where you can’t control the volume of the noise, such as a live venue.

Some people find having a specific music setting, where most of these speech-enhancing features are switched off, improves the quality of music. It’s important to bear in mind that the maximum volume of the hearing aid won’t change so, in very loud environments, the sound may still be distorted.



Do you ever think that you might need an advocate about your hearing loss sometime in the future? This wasn't something that ever occurred to me until quite recently, writes **Vera Brearey**.

When family isn't the answer

THE MIND BOGGLES

Of course, it's not just those of us who have never had children who are potentially put in a difficult position by that assumption. There are also the people whose child pre-deceased them or where parents and offspring are estranged. Or indeed, people whose children are very loving but just live too far away for frequent visits; perhaps even on a different continent.

My worries are triggered in part by memories of my mother-in-law's care home experiences. She became very frail. She wore hearing aids. My husband would regularly discover some problem with them when he visited which had been ignored by the staff. They weren't in her ears; they weren't switched on; a battery was flat. One of them had been accidentally turned to loop setting. All manner of everyday issues that only seemed to get solved when her son turned up once a fortnight (we lived a four-and-a-half-hour round trip away). She also had dementia. If she looked confused when the care staff spoke to her, they assumed her dementia was

getting worse – when, in reality, it was often that she couldn't hear because her hearing aid batteries needed changing.

In my case, I have a cochlear implant. My mind boggles at the thought of an inexperienced care worker struggling to understand one of those! But I totally rely on it. Without it I am utterly, profoundly deaf – I hear nothing. Zilch.

THE ROLE OF ADVOCATE

What to do? I started researching. Some good news came straight away. The brilliant Cochlear Implant Centre said that they were getting used to implant recipients needing care – and would be willing to offer some training to staff in a care home, should it come to that. The local authority sensory needs team also responded rapidly and thoughtfully to my email queries, suggesting that I chose a care home carefully and put together, well in advance, a pack of information that staff could refer to. Good advice, but something was still missing. I then found material online about advocacy – maybe that was it! Someone who knows what they're talking about with regard to hearing issues, and could step in to fight

"There's a widespread assumption in society that older people have families to look after them, or at least to fight their corner."

battles on my behalf – as my husband fought battles for his mum.

The going got difficult then, though. Advocacy organisations exist, but don't seem to offer the sort of support I'd be looking for. One suggested I contact the Deaf Society in the nearest city – but their focus is on deaf people who sign, not people like me. Like the vast majority of deaf older people, I lost my hearing in adulthood and chose to stay in the hearing world.

Discouragement set in. Then, one day, a free magazine came through the letter box. I was leafing through it when I spotted an advert for a local care agency. Something made me fire off yet another email, explaining the issue and asking for their suggestions. Back came a very helpful reply, from someone who knew what she was talking about, had experience of hearing aids, and was used to providing a support service for people with hearing loss. They would be very happy to learn about cochlear implants if someone had one, she said, and to take on the role of advocate.

Perhaps that's the solution? I could employ someone. Expensive though (what if you can't afford it?). Shouldn't this be something that society provides, one way or another, for people who need it? Perhaps it could be a volunteering role? I'd happily volunteer to help do that, while I still can. But who will guarantee me there'll be someone there when I need them? When will we stop assuming that everyone has a family?

Read our feature on our local support service, RNID Near You, on pages 10-11



Rationing hearing

I thought I'd done everything to make sure I never come unstuck with my hearing aids (on which I rely). I have a great charger that powers up the batteries for over 24 hours. I have replacements for the wires that connect the receiver to the hearing aid, in case one should ever snap. I have extra domes that sit atop the wires, for when they tear. I have replaceable pieces that sit in the receiver so that it doesn't get blocked with ear wax. I carry all this kit around with me, just in case.

But recently my carefully-laid planning failed – due to human fallibility. I'd spent three fascinating days with a hearing research team in Nottingham, led by Helen Henshaw. But, when I arrived back home to London, my hearing aid charger was

nowhere to be found.

It must have fallen off my hotel bedside table, in the small gap between the table and the bed. I had to get it back urgently and, in the meantime, I had to ration the charge that was left in my hearing aids. I couldn't really go out as I wouldn't be able to interact with people. I used some of my remaining charge to phone the hotel, and the friendly receptionist said she'd phone me back. But if I kept wearing my hearing aids in the hope of getting the return call, I knew they could run out of charge beforehand. I then arranged a time for her to call, so that I'd know when to put in my hearing aids.

Then I started sourcing a replacement. The many online shops would take days to deliver – meaning days for me not to hear. I couldn't reach my audiologist to ask if she could source a replacement. My daughter, Annie, found a local hearing aid dispenser that had one at the ready. However, it cost £200.

I texted Helen, who offered to go to the hotel and try to track down the charger. Hurray! The staff found it easily and gave it to her. Helen offered to post it; reviews of the Post Office nearby said that it frequently lost items, so she drove out of town in order to post with confidence.

Although I was relieved that my charger was on its way, I realised I now had 24 hours without sound. I learned

that I can sort of manage.

Here and there, I could hear a bird (albeit a loud parakeet). I could hear myself chewing, the microwave beeping, water going into the bath. Soon I started to think: hey, do I *really* have moderate-to-severe hearing loss? I started to see how, if you don't have hearing aids and so have nothing to compare with, you might not think you actually have hearing loss.

I decided to use the remaining charge so I could hear the postman knock on my door when delivering the charger (the charge ran out just moments before he arrived but, luckily, I still heard the knocking).

Half an hour or so later, the charger was charged and so were the hearing aids!

I was reminded that, even with great equipment and however well-prepared we might be, human error can creep in – and there will be situations when hearing becomes dispensable.

And while it was unfortunate that I left my charger behind, I was lucky to have help and support to get it back again. I'm grateful to Helen for posting it, a willing hotel crew to track it down, for having the money to cover the cost of special delivery, an available (and non-striking) postal service. Without all of the above, I might still be without sound.

Jean Straus

Experts

BIOMEDICAL | AUDIOLOGY | TECHNOLOGY | INFORMATION

The technology used to provide traditional landline voice calls is changing. For what this means for you, see p34

If there's a topic you'd like Jean to cover, let us know! Email: dawn.dimond@rnid.org.uk

Middle ear inflammation (otitis media) is a common condition of childhood, and the most common cause of hearing loss in children.

"I'VE GOT AN EARACHE..."

Around 4 out of every 5 children will experience at least one bout of otitis media. Unfortunately, if it keeps recurring (usually due to an underlying infection), it's not always easy to treat. Antibiotics can be effective but may not fully clear the infection, allowing it to come back. Grommets can help to drain fluid from the middle ear – but they require surgery to fit them, they can fall out, and they can become a source of infection themselves.

Otitis media comes in a variety of forms:

- **Acute**

This is often linked to an ear infection, and usually resolves by itself. Fluid builds up in the middle ear behind the eardrum (called an 'effusion'), causing pain and fever. In some cases, the eardrum can burst.

- **Chronic with effusion ('glue ear')**

This may follow acute otitis media, where the fluid build-up behind the eardrum doesn't clear post-infection. The fluid in the middle ear reduces or prevents sound information from getting into the inner ear, causing a conductive hearing loss (the most common symptom). It may clear up by itself within a few months, but it can also be treated with antibiotics, or by surgically inserting a tiny tube, called a grommet, through the eardrum to allow the fluid to drain away. However, these treatments are not always fully effective.

- **Chronic suppurative**

This is a rare complication of acute otitis media, where the middle ear becomes chronically inflamed and there is persistent discharge through a burst eardrum. Like chronic otitis media with effusion, it can cause conductive hearing loss, and is often treated with antibiotics.

Photograph: Shutterstock

"We can proudly say that currently we have the largest donor-led hearing research programme in the world."

By discovering more about the processes involved in otitis media, and developing new approaches to treat it, we hope to reduce its impact on children's hearing and development.

We need better and more effective treatments for otitis media. Which is why, over more than 20 years of funding research, we've been supporting projects to tackle this problem:

We're funding Dr Peter Santa Maria at Stanford University in the USA through one of our Translational Research Grants. He's trying to develop a way to make antibiotics more effective against persistent middle ear infections by combining them with a formulation containing tiny particles (nanoparticles) of gold linked to a chemical called CPP. In mice with chronic suppurative otitis media, the combination of antibiotics and gold nanoparticle mixture was four times more effective at clearing the middle ear infection than antibiotics alone. The nanoparticle mixture enabled the antibiotics to kill bacterial cells known as 'persister cells'. Once antibiotic treatment stops, these cells are able to start a new infection, leading to further inflammation of the middle ear. But the gold nanoparticle mixture caused changes in the persister cells that made them more likely to be killed by antibiotics – making treatment more effective. Dr Santa Maria and his team are now working to develop their approach so it can be tested in people. They hope that it will provide a more effective way to treat chronic middle ear infections and reduce the hearing loss they cause.

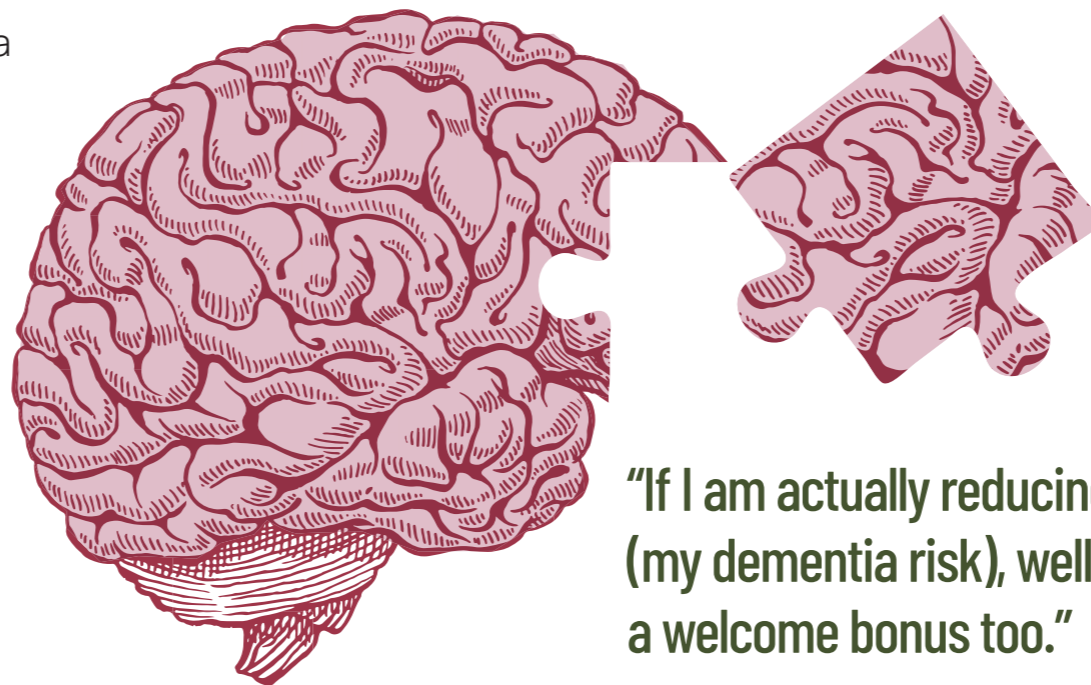
We funded research at King's College London investigating the role of a gene, *Eya1*, on middle ear development and the risk of developing chronic otitis media. The researchers showed that the middle ear space (the middle ear is an air-filled space encased in bone) was smaller in mice in which one copy of the *Eya1* gene was missing. These mice developed chronic otitis media with effusion from an early age, causing harmful changes in the cells of the middle ear. However, if these mice lived in a germ-free environment (free of bacteria and other infectious agents), they did not develop otitis media and their middle ear developed more normally. This suggests that otitis media in early life can cause permanent damage to the middle ear – and the importance of finding ways to prevent and treat it.

Our newest Fellow, Dr Juan Fons, also at King's College London, will investigate otitis media in the context of Down syndrome, focussing on a specific gene (*Dyrk1a*), and how it's involved. People with Down syndrome are at increased risk of developing chronic middle ear inflammation and conductive hearing loss. As part of his project, Dr Fons will also test a new treatment approach for otitis media using drugs that target the activity of the *Dyrk1a* gene.



Tom Dening, Professor of Dementia Research at the University of Nottingham, discusses his recent experience of getting hearing aids

A piece of the puzzle?



“If I am actually reducing (my dementia risk), well, that’s a welcome bonus too.”

My hearing’s going. How long? Impossible to say, as it is an insidious change. More than a year, probably. Subtle changes – for example, everyone else sets the TV volume at about 8 and I have it at 12, with the subtitles on for everything except the news. I complain about how actors mumble, especially American ones (actually, they do, that isn’t just hearing loss). Social conversations become hard work so I often give up trying. At work, remote meetings are fine because I can turn up the volume on Teams or Zoom. Face to face, though, is different because people are at different angles – and I can’t adjust their volume controls. I become aware that I often ask people to repeat themselves. I suspect my right ear is worse, as having conversations in a car when I’m a passenger is more difficult than when I’m driving. The subtlety of music in the car is lost beneath the rumbling of the wheels.

OFF TO THE AUDIOLOGIST

Hearing loss and dementia have a complicated relationship and the joint topic has been the subject of increasing research interest. There

are two main aspects: hearing loss as a risk factor for dementia and the challenges of hearing loss existing simultaneously with dementia.

Hearing loss from mid-life has been identified as probably the largest potentially modifiable risk factor for subsequent dementia (contributing nearly 10% of the population risk). This often gets translated into ‘hearing loss causes 9% of cases of dementia’ – but that’s not how it works; it’s the proportion of the risk that is due to hearing loss. Nonetheless, miraculously eradicating hearing loss would significantly reduce the number of cases of dementia by at least delaying its onset.

Second, dementia and hearing loss are both common conditions in older people. Having hearing loss on top of dementia compounds many of the problems that can arise and impacts on a person’s independence, well-being and social life.

Anyway, once I start to think that something needs doing, it really does. So, off I go to the audiologist (thank you Kirsty Davison!).

I spend some time in headphones, pressing a button whenever I think I hear beeps of varying frequency and decreasing volume. I’m aware that

I am doing badly, as there are long pauses of apparent silence. My concentration wavers. When Kirsty shows me my audiogram (which looks like someone falling off a cliff), she says: “You’re not hearing higher frequency sounds like S, F or Th, so your brain is having to work hard to fill the gaps. With this pattern, I would recommend hearing aids.”

A feeling of resignation and inevitability descends over me. Okay, let’s go for it. We discuss links between hearing loss and how treatment helps not only hearing but brain health. I don’t reveal immediately that this is an area of my research interest... Which is a moot point; just how good is the evidence that intervention for hearing loss (such as hearing aids) modifies the risk of subsequent dementia? Certainly, cohort studies show that people with established hearing loss have an increased risk of developing dementia – but the mechanisms of this are not clear. Theories

include: there may be a common pathology (cause and effect) underlying both conditions; or that social withdrawal following hearing loss, and a subsequent lack of stimulation, may cause accelerated cognitive decline. Trials are underway to assess whether hearing aids are effective in reducing dementia risk. The problem is that it’s not ethical to have a placebo group with dud devices, so you can’t do a randomised controlled trial of the necessary duration. There does seem to be better evidence, though, that hearing aid use is associated with improved mood and well-being, so these seem like useful outcomes anyway.

A LOOK AT THE EVIDENCE

After three weeks, I’m back to get my aids fitted. As they are switched on, I’m aware of higher frequency sounds; rustling paper, running water. I can now discern higher frequencies against background noise (so the car radio is once again pleasurable) and hear group conversations much more easily.

Am I cognitively sharper? My wife thinks so. She also thinks I’m smiling a lot and enjoying the new experience. Maybe I am less tired at the end of a working day but it’s hard to be sure. At my follow-up appointment, I rave about the hearing aids, much to the audiologist’s delight. She tells me that men take an average of two years from having an assessment to accepting wearing hearing aids, so I have been unusual in that respect.

Do I believe I am reducing my dementia risk? Not sure. Actually, I’m a bit fatalistic about whether I will get dementia or not. However, I will accept the current benefits in terms of improved hearing and being able to do my job properly. I am certainly not increasing my dementia risk and, if I am actually reducing it, well – that’s a welcome bonus.

RNID is co-funding several research projects with Alzheimer’s Research UK to investigate further the potential link between dementia and hearing loss. This is only made possible thanks to your ongoing support. Learn more at: rnid.org.uk/hearing-research

RINGING THE CHANGES



The technology used to provide traditional landline voice calls is changing. We asked Ofcom, the communications regulator, what this means for you

Will landlines be abolished?

No, but the technology that supports them is being upgraded over the next few years. Telephone providers are replacing the current analogue network for landline phones with newer digital or IP (Internet Protocol) networks. In future, voice telephone calls will be carried in the same way as data over a broadband connection.

The change is led by broadband and phone companies. The government and communications regulator, Ofcom, are working with industry to help ensure they deliver a smooth transition.

Over time, everyone who wants a landline will move over to the new system. Nearly everyone will be able to keep their current phone number and use their existing phone – but if your handset is very old, you might need to change it. You don't need to do anything yet – your phone company will get in touch with you.

Why is it happening? The UK's telephone network has reached the end of its life and cannot be maintained long-term. Telecoms providers have decided to deliver landline calls over new digital technology to make sure that phone services continue into the future. BT will retire its current network by December 2025. Other companies with their own networks (such as Virgin Media) plan to follow a similar timescale.

When is it happening? Some people have already migrated to

digital technology (if they decided to upgrade their landline and broadband package, for instance). Your phone company will contact you when it's time to migrate to your new telephone service.

What do I need to do? You don't need to do anything until your provider contacts you, or until you decide to change your telephone service. After migration, your phone will generally work in the same way it always has, but it will need to be plugged into a broadband router instead of into the phone socket on

Before you change to a digital landline, let your provider know if:

- you have a care alarm, health pendant or security alarm that uses the telephone line;
- you don't own a mobile phone, or you don't have enough signal at home to call the emergency services in a power cut; or
- you have a disability or any other needs that mean you need extra help with the installation.

your wall. If you need new equipment (for example, a router) or if you need broadband installed so your landline can work, your provider should arrange this.

Phone companies should assess customers' needs and provide help with migration as needed (such as help with installing a router).

What about textphones and amplified phones?

A range of these phones have been tested on digital phone networks and found to work. Text relay can also be accessed on any connected device

(computer, smartphone or tablet) using the Relay UK app. This has greater functionality than textphone calls: you can listen to the call as well as read the captions; speak your end of the call if you wish; and there's no need to say 'go ahead' after speaking. But if you want to continue to use text relay on a textphone, you should be able to. You'll need to plug it into a router

rather than a wall socket after migration. The same goes for regular voice and amplified phones.

This change will affect other devices that rely on a phone line, such as some telecare devices. You should mention those devices to your phone provider, and also check with your telecare provider if a device needs to be replaced or reconfigured to continue working.

Will my phone work in a power cut after migration?

A phone connected to a broadband router won't work in a power cut, as the router gets its power from the mains. If you rely on your landline (you don't have a mobile phone or a mobile signal at home, for instance), your provider must make sure you can contact emergency services for a minimum of one hour after a power cut. They may provide you with battery back-up, or with a mobile phone. If you have a textphone that uses mains power and doesn't have a battery compartment fitted with working batteries, it will not work in a power cut (this is also the case pre-migration).

If you do have a mobile phone, you can register for emergency SMS by texting 'register' to 999. BSL users can use 999BSL – go to www.999bsl.co.uk for details

To find out more, contact your landline or broadband provider. More information is also available at www.ofcom.org.uk or at www.futureofvoice.co.uk

Perfect partnership

AMPLIFIED PHONES



Key terms to consider when buying a telephone:

Amplified For many people who have hearing loss, an extra loud telephone will allow them to increase the volume to a comfortable level. All our telephones are amplified, to different levels.

Hearing Aid Compatible (HAC)

Most hearing aids have a 'loop' or 'T' programme. If a phone is HAC, it means that it will transmit sound directly from the handset to a hearing aid or cochlear implant on the loop programme (which normally gives the clearest sound).

Tone control Clarity of sound is just as important as high volume (if not more). Phones that have a tone control will allow you to boost the high or low pitches to suit your hearing loss.

Using the telephone can often be a difficult and frustrating experience for people with hearing loss. We've partnered with Connevans, a renowned provider of assistive hearing technology, who offer a wide range of special feature telephones

There are currently three main 'styles' of landline telephones

CORDLESS

The base station is plugged into the wall socket (or router) and there is a wireless handset which can be carried around during calls. The base station works as a charger for the handset. You can usually use more than one cordless telephone paired together to form a system, placed around your house.

Swissvoice Xtra 2355 Duo DECT Cordless Telephone - a HAC cordless telephone twin pack, with answering machine and memory buttons. Great for multi-user households.



Connevans Director, Laura, says: "A question we often ask people is: if someone stands at arm's length from you, can you hold a conversation without relying on lipreading? If not, we'd advise asking your audiologist to update your hearing aid programming to better match your hearing loss. Also, if your hearing aids have a loop or 'T' programme, this is the best way to listen to any of our phones, so ask your audiologist to set it up."

THE FUTURE IS HERE

The landline digital switchover is causing some confusion. You will be able to continue to use an existing amplified telephone (or any of the amplified telephones within the Connevans range) after the switchover. They are not digital, and you will need to connect them up differently, but it is possible for you to continue to use them.

The major telephone companies have set up a website to help explain how the switchover will affect people. As and when your lines are switched over, you will need to let your provider know that you need to continue to use your existing amplified telephones.

See page 34-35 for our feature on the digital switchover and what it means

CORDED

The handset has a curly cable to the telephone, which is plugged into the wall socket (or router, after digital switchover).

Amplicomms PowerTel 196 - a very loud corded telephone with sound amplification of up to 60dB as well as tone and volume control. A recommended bestseller.



COMBO

These have both a corded and cordless telephone (or several cordless telephones). They work together in a system and give the best of both worlds - the security of having a telephone that stays in one place, plus the freedom of a cordless that can be moved around.

Geemarc AmpliDECT 595 Big Button Telephone Combo with answering machine - great for multi-user households with a receiving volume of up to 50dB and hearing aid compatibility. Our most popular combo telephone last year.



For more details, go to our partnership website rnidconnevans.co.uk where 10% of sales is donated to RNID (VAT relief is available on all the amplified telephones.)

tinnitus A problem shared

With Tinnitus Week (6-12 February) just gone, we've picked out some of the most common queries we get about the condition. Contact us for practical and emotional support for tinnitus anytime

Why did I have tinnitus when my ears were blocked with wax?



Franki

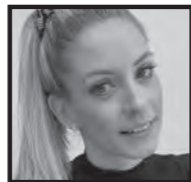
You're not alone; our recent survey showed that 37% of people with ear wax experienced tinnitus as a side effect (see page 8). Ear wax can cause temporary hearing loss and, as tinnitus and hearing loss are linked, this could also cause temporary tinnitus.

When we hear, sound waves travel through the ear into the cochlea, our hearing organ in the inner ear. The cochlea changes these sound waves into electrical signals which are sent to the hearing part of the brain. This then analyses them and recognises them as sound. When the ear is blocked by wax, sound waves don't travel as well to

the inner ear – and the number of electrical signals sent to the brain is reduced. Research has shown that the hearing part of the brain then 'fills in the gaps' of the sounds that are expected to come from the ear, which many people hear as tinnitus.

For most people with tinnitus caused by ear wax, the symptoms are temporary and go away when wax is removed.

Can I reduce the risk of getting tinnitus?



Rachel

You can't always prevent tinnitus, but there are lots of things you can do to reduce your risk of developing it or making it worse. One of the most important things you can do is protect your hearing from loud noise.

Loud noise is the second biggest cause of permanent hearing loss and tinnitus. Fortunately, it's entirely preventable.

Experts agree that noise damage can start at volumes of 85dB (decibels) and above. That's a problem when you consider that music at clubs and concerts is often around 110dB, and some headphones play music that's just as loud when the volume is turned right up.

What's more, the length of time you can listen to music safely dramatically reduces as volume increases. How long you're exposed is just as important as how loud it is.

The good news is, there are some simple steps you can take to reduce the risk:

Take regular breaks from loud noise – both when wearing headphones and when in a noisy

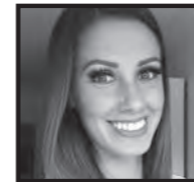
venue. Have five minutes off for every hour.

Carry earplugs with you – and use them! – on a night out. You can buy reusable ear plugs which block out harmful sounds without compromising sound quality.

Turn the volume down a notch – it'll make a big difference to how long you can listen safely for.

If you think you might have hearing loss, you can take our free online three-minute hearing check at rnid.org.uk/check

I have trouble sleeping with my tinnitus – how can I get a good night sleep?



Vicki

Many people are able to find ways to manage their tinnitus but, currently, there are no medical treatments. Some people with tinnitus have difficulty falling asleep or staying asleep. It may be that the shift from a relatively noisy daytime environment to the quietness of the bedroom makes tinnitus noises more noticeable.

If you do find that your sleep pattern has become disrupted, try to incorporate some of these techniques and see what works best for you.

Keep active during the day Staying active during the day can help you sleep better. However, try

to avoid exercise near bedtime – it may tire you out but can also disrupt the normal sleep cycle.

Try to clear your mind before bedtime If you have worries, set aside around half an hour earlier in the evening to jot down ideas or issues you might want to tackle tomorrow.

Practice relaxation exercises Have a warm bath, read, or meditate and try to avoid bright lights, including digital devices, before going to bed. Limit your amount of stimulants; tea, coffee, cola, energy drinks and nicotine are all stimulants and may help keep you awake. If you can't give them up completely, try to cut down.

Get up and go to another room If you're not asleep after 30 minutes, get up and do something relaxing like reading. Go back to bed when you feel sleepy again.

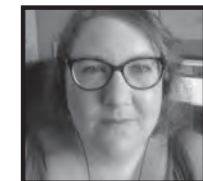
Get up at the same time each day – even at weekends. Try not to nap in the day or catch up on lost sleep, as this won't improve your sleeping pattern.

Introduce gentle sound into your environment – this can help you to relax and distract you from your tinnitus. People with tinnitus often find it more noticeable in a quiet environment but listening to a constant sound (known as 'sound therapy' or 'enrichment') can help

distract the brain from paying attention to tinnitus.

Options vary from simply increasing environmental sounds such as opening a window, having the radio on or listening to music, to using specific devices or apps that are designed for sound enrichment.

How close are we to finding treatments for tinnitus?



Rachel

Currently, there are no medical treatments for tinnitus – only strategies to help people manage it. There are two drugs being tested in clinical trials right now to treat tinnitus, and four more at an earlier stage of development. If these drugs are successful in reducing or silencing tinnitus, they could be available within a few years and make a real difference to the lives of people with tinnitus. There's lots more information about the research projects we're currently funding on our website at: rnid.org.uk/research



If you're concerned at all about your tinnitus, book to see your GP.

If you or someone close to you needs free, confidential and impartial information, contact RNID (see back cover for details)



best foot

forward



Andy Mundy, who experienced sudden hearing loss more than 25 years ago, turned to RNID for support. Since then, he's run not one but two marathons to fundraise for us – 11 years apart!



Andy (left) at Horse Guards Parade after his marathon finish

running for RNID seemed like a natural choice

We're so grateful to Andy for his double marathon – with a good rest in between! If Andy's story has inspired you to get your running shoes on, why not sign up to one of our forthcoming events?

I had an accident in 1996 and the head injury from it left me with partial sight loss in one eye and caused me to lose my hearing in both ears and my sense of smell. I didn't want to believe my hearing was damaged and, for months, I kept insisting that it would come back. It was a massive shock to me; only then did I understand that people don't realise how precious and valuable our hearing is. However, even after reluctantly wearing one hearing aid (my other ear had a damaged ear drum), I would carry a notepad and pen around with me and ask people to write things down.

After having 'normal' hearing for 20 years, it was quite an adjustment. I felt frustrated asking people to repeat things and I even felt as though I was being 'looked down on.' I then decided to take lipreading classes so I could

interact better with friends, family, and work colleagues. In 2011 my hearing deteriorated further, and I learned I was a suitable candidate for cochlear implants for both ears. It's changed my life so much; my hearing has improved greatly and I don't feel as restricted as I did previously.

For a few years, my hearing loss had really affected both my home and working life. Now I took the view I wouldn't let it hold me back and I decided, in 2011, to run the London Marathon for RNID. When I lost my hearing, I used the charity as a source of information and eventually signed up to become a member – so running for RNID seemed a natural choice. I enjoyed receiving the supporter magazine (and now I'm particularly delighted to feature in it!) and it gave me so much information on

various services that existed out there, like loop systems, bus passes and more.

Reading the magazine also helped me to realise I was not alone in having hearing loss. It helped break down my reluctance to admit it and probably helped a different belief grow inside me. I can't change my hearing loss, but I can carry on and enjoy my life as much as possible – well, try to anyway.

I was thrilled to run the London Marathon for RNID for a second time in 2022. You can tell from my smiley face how happy I was to see the RNID team just past Big Ben – their smiles and waves gave me some extra energy as I was on the home straight. If you're lucky enough to have a place in the 2023 London Marathon, or looking for one for 2024, I would really recommend running for Team RNID.

- Hampton Court Palace Half 26 March
- Birmingham Half Marathon 22 May
- Edinburgh Running Festival (5k, 10k, Half and Full Marathon) 27 and 28 May
- Royal Parks Half Marathon 8 October
- Amsterdam Marathon 14 October
- London Marathon April 2024

If running is not your thing but you'd like to raise valuable funds for RNID, please do get in touch. We have other challenges that might appeal or special events you might be interested in – you could even come up with your own idea! Visit rnid.org.uk/events

THE FIRST BRITISH SIGN LANGUAGE (BSL) TV channel globally has launched on ITVX. The new streaming platform will host a station that only has signed programmes – new and archive. RNID's Teri Devine says: "Building in accessibility from the start is important and should be the norm. We look forward to seeing ITV expanding its access services across the remaining platforms."

Helpline Awareness Day is 23 February and we'll be celebrating Contact RNID, and the fantastic work they do, across our social media channels. Join us there to share your messages of support for the team!



Each issue we hand-pick a selection of things that

...we love

LIVING WITH HEARING LOSS AND DEAFNESS
A guide to owning it and loving it.
Samantha Baines



RNID AMBASSADOR
Samantha Baines has written a book about losing her hearing at the age of 30: 'Living With Hearing Loss and Deafness'. The award-winning comedian, actor and broadcaster has previously written two children's books with deaf protagonists. Sam says: "This is the book I searched for when I discovered that I needed a hearing aid. It's been a pleasure to interview so many incredible people within the deaf community, share my own experiences and pull together information I've learnt so far on my deaf journey."

Photographs: Steve Best

The book, published by Headline Home, is available from April 27

POET'S CORNER

I am deaf now

I haven't changed
I'm just the same
I just didn't hear
When you called my name

It's not deliberate
And not a joke
I really didn't hear
When you spoke

I'm sometimes down
And feeling sad
Missing sounds
That I once had

With back ground noise
A daunting task
Is it just
Too much to ask

That you look me
In the eye
No lips to read
I can't get by

Karen Beasley



WOULD YOU LIKE TO GET OUT AND ABOUT MORE THIS YEAR

but feel anxious or stressed about going to a new venue? Now there's a way of alerting customer service teams at a range of venues nationwide about your communication preferences or any support needs in advance – with a free

service called WelcoMe. You create a simple profile, including any information about your access needs that will help venue staff to give you the best possible experience when you visit. You can use it to browse venues where WelcoMe is installed or to suggest places you would like to see start using it.

For more information, go to www.wel-co.me or set up your own profile at <https://my.wel-co.me/>



"XRAI Glass enables me to fully immerse myself in conversations and has completely changed my life."
XRAI Brand Ambassador
Jacqui Press

XRAI GLASS has pioneered revolutionary software, primarily designed for people who are deaf or have hearing loss, that allows you to 'see' conversations via phone-tethered augmented reality smart glasses. With recent software updates, new features include:

- **A personal assistant** for your eyes which enables users to ask questions with the answer instantly appearing as subtitles on the glasses.
- **Recall conversations** 'on demand', allowing users to playback a conversation that happened the other day.
- **Transcription and translation** in multiple languages both European and worldwide.

Over to you

Letter, email, social media - we want to hear from you



A SPECIAL SERVICE

Hilary Lewis and I have been volunteers with RNID for many years and we were privileged to be awarded MBEs in HM The Queen's Platinum Jubilee Birthday Honours last year. In September, we both received phone calls inviting us to attend the funeral service at Westminster Abbey. Our identification with the Queen and with Prince Philip, who was RNID's patron for more than 50 years, is a strong one so we were very honoured to accept.

We sat in the nave of the Abbey, totally immersed in such a truly poignant occasion. The beautifully designed service guide included a timetable of arrivals. With my social history interest, I was absorbed by the presence of so many global leaders.

The most riveting musical moments for me were provided externally by the Scots pipers and muffled drums as the Queen's coffin arrived at the Abbey. From a faint rhythm in the distance, this beautiful Scottish lament

increased in volume, gradually filling the atmosphere inside the Abbey. These moments were truly mystical and spiritual.

As the draped coffin passed us in the nave, eyes began to well with tears at the realisation that this really was the end of the Queen's diligent and illustrious reign of 70 years. Then her family processed with the undiluted grief of the loss showing in their faces. Everyone in the audience identified with this so much as human beings.

On a personal level, I was so gratified to pay my respects to her as a unique woman whom I've known all my 79 years. In my mind, I recalled her courageous visits to Dublin in 2011 and Belfast in 2012. She was such a reassuring presence when so many of us in the north and south of the island of Ireland were anxious about the survival of the Good Friday Agreement that had brought us peace.

And I know RNID, as well as many charities, were also thanking and paying their respects to her for her

unstinting support over the years.

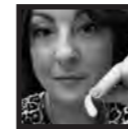
When the service ended, and the hearse was making its way to Windsor for the burial, I experienced an unexpected series of spontaneous conversations on my way to pick up my luggage en route to my flight back to Belfast.

Five people, totally unconnected and at different places, spotted the beautiful service guide tucked (I thought discreetly) under my arm, and asked if they could photograph the cover. They were also full of questions about how the service went, and some photographed the lists of music played. These were all people expressing a genuine love for the Queen as a person.



Dr Brian Caul has volunteered for RNID in Coleraine, Northern Ireland, for more than 20 years, running a weekly information stand at Causeway Hospital. He became a Trustee in 2017.

Popular posts from our social media channels:



"There is still so much people don't know or understand about hearing aids.

One day I want a Vivienne Westwood hearing aid - like you can get Burberry glasses!" RNID ambassador **Samantha Baines** wants to tackle misconceptions about hearing aids, educate others and show that hearing loss is not uncommon. See pp42-43 for news of Samantha's new book about living (and thriving) with hearing loss.

We know that the cost-of-living crisis is making life particularly difficult for deaf and disabled people. We've added our voice to a group of 50 organisations, all calling on the Prime Minister to **#FixThisCrisis**. We want to see financial help and support for our communities. For more information about the benefits you might be eligible for, go to: rnid.org.uk/benefits



"So, to all channels still subtitled less than 100%, please fix your problem and

to all broadcasters, please think about your audience". **Rose Ayling-Ellis** addressed the Edinburgh TV Festival recently on the importance of improving access and representation for deaf individuals on TV



Do you want to do something different in 2023 and make a positive impact to

the lives of deaf people and those with hearing loss or tinnitus? Last year, our volunteers gave more than 5,800 hours of their time to support people in their communities with practical information and support with hearing aids. Could you spare an hour or two this year? **Check out our volunteering opportunities today:** rnid.org.uk/volunteer

Answers to previous issue
Wordsearch and Crossword
How did you do? For this issue's puzzles, see page 46



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Get in touch

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Email: dawn.dimond@rnid.org.uk Social media: see back cover details

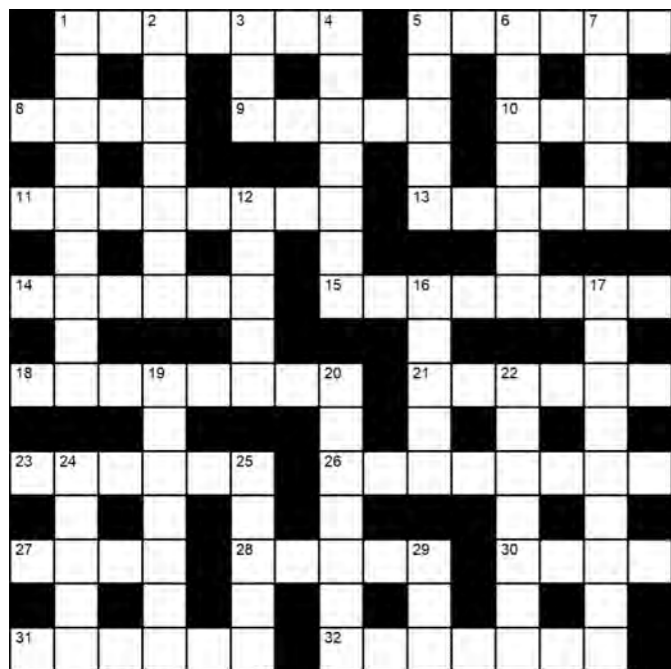


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Puzzles

Look out for anagrams in clues marked*



C A E K O H C I T R A T S
 A N E A L S G U L Y C E E
 U E A N M G O S A O I U P
 L P C H I C O R Y R O C U
 I G H F U R S I R T H M O
 F T O O R T E E B L C A L
 L N L E H O B G F U K U E
 O M O O C W E I N A A I T
 W T G M A L R O L A P C N
 E A N R E F R E S U T S A
 R M T N P L Y C H E E G C
 A S I A N G R I E C H E T
 E C P L S U G A R A P S A

20 fruit and vegetables

ARTICHOKE ASPARAGUS BEETROOT
 CANTELOUPE CAULIFLOWER CEP CHICORY
 FIG GOOSEBERRY KALE LEEK LEMON LIME
 LYCHEE MOOLI PAKCHOI PEA PEACH
 STRAWBERRIES TANGERINE

Across

1 *Modern electronic hearing aids are ____ – glad I moved with it (7)

5 Mother begins to speak indistinctly (6)

8 Cats and dogs used as sound effect for tinnitus relief? (4)

9 *Subject for discussion: “Optic distortion” (5)

10/23 *Charity improving Deaf people’s wellbeing – heal things, amazingly (10)

11 Provide text for film/TV dialogue (8)

13 e.g. hearing aid telecoil on/off device – swap? (6)

14 Financial part of tariff is calculated (6)

15 *Charity supporting D/deaf people across the NE – a feature initially in Kindle, perhaps (8)

18 *Ear membrane that vibrates – my man put out! (8)

21 *Uncommon thing – try air transport (6)

26 Sound accuracy of a hi-fi system (8)

27 Hearing device implanted in skull ... initially, boosts any high acoustic (4)

28 Lip-read ‘libel includes an impromptu remark’ (2-3)

30 Talks incessantly – of shaggy, Tibetan oxen? (4)

31 *Sounds from a pager makes Baby, initially, sleep badly! (6)

32 House of Commons officer’s audio equipment (7)

Down

1 *Charity empowering deaf people for success – a fine duty, anyway (4,5)

2 *Inherited, as deafness can be? Get nice operation (7)

3 Not much of a drink for a small child (3)

4 Cheek! Study and “hear” by observing (7)

5 Fluid contributing to

‘glue ear’ starts to mess up clarity, upsetting speaker (5)

6 *Accidentally call wrong number, spoiling slim aid (7)

7 Sound reasoning; from ship’s record book & integrated circuit (5)

12 Bird of prey’s claw turned up in Llandudno later (5)

16 *Did a broadcast of awful diatribe – bit removed (5)

17 *One who summarises on behalf of deaf person at meetings needs revised net rate, OK? (9)

19 Tinnitus noise may throb so – as heartbeats do (7)

20 Deadens sound (7)

22 *App helping you to communicate by phone – Luke and Ray excited (5,2)

24 *Electronic message moves a mile (5)

25 Perceives sound – as a trial judge does? (5)

29 Briefly, location of a type of hearing aid ... in subterfuge (3)

For the chance to win a £20 M&S voucher, send your Wordsearch and/or Crossword entries to: Magazine puzzles, RNID, Brightfield Business Centre, Bakewell Road, Orton Southgate, Peterborough PE2 6XU

RNID



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Plus, when you play the RNID Weekly Lottery, you’ll be automatically entered into our Superdraw for a chance to win a whopping £5,000


The money raised will go towards making life fully inclusive for deaf people and those with hearing loss and tinnitus.


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We are RNID, the charity working to make life fully inclusive for deaf people and those with hearing loss or tinnitus.

We campaign for an inclusive society, connect people to practical advice, and pioneer new treatments for hearing loss and tinnitus. We rely on donations to continue our vital work.

If you, or someone close to you, needs free, confidential and impartial information and support, contact RNID:

 0808 808 0123

 18001 then 0808 808 0123 (Relay UK)

 SMS/text 07360 268988

 contact@rnid.org.uk

 rnid.org.uk

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