Spring 2020

ACTION ON HEARING LOSS

A national charity since 1911

magazine

Sophie Woolley: why she calls herself a

deaf cyborg

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This issue, we bring you exciting news about a new initiative to help GPs understand hearing loss and tinnitus better (p11). Tinnitus Week was in February and on p21 we look at why the condition, first documented 3,000 years ago, remains an enigma today – and what can help in managing it. We have some fascinating technology updates (pp26/34) and a plea for better maintenance of good old loop systems (p30).

Editor

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At the front

In the middle

At the back

Over to you

As many Members will be aware, Trustees conducted a governance review during 2019. It is good practice for charities to review how they are governed on a regular basis and this should be done at least every three years. The review sought to modernise the way the Board makes decisions and bring Action on Hearing Loss more in line with best practice and the Charity Governance Code.

There were some quite significant changes that Trustees felt were needed to make sure our decision-making is fit for the future.

Trustees agreed a number of changes including reducing the size of the Board, how Trustees are appointed and removing the need for us to hold an Annual General Meeting. Some of the more significant changes needed to be approved by you as members. The approval of the membership is required when charities like Action on Hearing Loss want to change their constitution.

This is why many of you will have received information in the autumn of 2019 ahead of the Annual General Meeting (AGM) which took place in December. We wanted to make sure you were fully informed of the changes and had an opportunity to feedback on them before we asked you to vote for them. Following the consultation and the Board's consideration of feedback, we asked Members to approve the final changes to the constitution.

We are pleased to say that all changes were approved by an overwhelming majority. This was confirmation that the membership supported the Trustees' recommendations and agreed with the need for change and modernisation. We would like to thank members for this support, especially those who provided feedback through the consultation and who came to the AGM to take part.

The next step in the governance review will involve recruiting a number of new trustees. We can't provide details of the recruitment process yet but if you are interested in hearing more or becoming a Trustee, please contact us at governance@hearingloss.org.uk.

Members will be asked to take part in a new Trustee election process later in the year. All Trustees will now be put forward for election by you as Members.

News

Sign to make a change

For Tinnitus Week in February we teamed up with the British Tinnitus Association (BTA), supporting their petition to urge the government to invest in more tinnitus research and work towards finding a cure.

One in eight people in the UK live with tinnitus but investigation into the causes of the condition – and potential treatments – currently receives 40 times less funding than other comparable conditions. Studies have also found that people with tinnitus are much more likely to suffer from low self-esteem, anxiety, depression, and overall poor mental health.

Many people agree that it's time to demand change and, to date, more than 110,000 have signed the petition. For more details, go to tinnitus.org.uk

The right support

We launched our first webinar for GPs and health professionals in Northern Ireland in March, to share best practice for managing patients with tinnitus in primary care. The webinar was delivered by Dr Emma Dickson, a GP Adviser on the current NICE guidelines, and introduced by our Northern Ireland Director, Claire Lavery.

During our webinar, we highlighted the importance of signposting tinnitus patients in Northern Ireland to the right support, and giving them a positive message upon diagnosis.

Our syndicate

Action on Hearing Loss has launched the Hearing Medicines Discovery Syndicate, a group of organisations dedicated to finding treatments for all levels of hearing loss and tinnitus. Our Executive Director of Research, Ralph Holme, says: "Our initiative will help bring life-changing treatments to people with hearing loss and tinnitus faster."

Let's get quizzical!

In February, we hosted our first-ever fundraising quiz night in London, raising an incredible £50,000 for our charity! Our Vice President, Sir Rocco Forte, hosted the star-studded night for over 50 guests, including major donors, celebrities and other VIPs who came along to quiz and raise money for our charity. The quiz master was none other than political commentator, Andrew Marr, with expertise from special guests, the UK's Brain of Britain, David Stainer, and Paul Sinha from ITV's The Chase.

Campaign

Five years ago, an unwelcome precedent was set in a cost-saving exercise which has ongoing repercussions for thousands of NHS patients with hearing loss.

Hands off our hearing aids

In 2015, North Staffordshire became the first part of England to restrict the provision of free NHS hearing aids, denying access to patients in the local area who have a mild or moderate hearing loss. The decision by North Staffs Clinical Commissioning Group (CCG – the NHS body responsible for the planning and commissioning of health care services for its local area) was made in the face of overwhelming evidence that hearing aids for mild to moderate loss are clinically effective and, ultimately, cost-effective. We've campaigned against this unfair restriction in the five years since – but, despite your support, and our best efforts, North Staffordshire CCG will not budge.

So what's been happening recently? There are five other CCGs in Staffordshire and Stoke which provide hearing aids on the basis of need and without restrictions, following all medical evidence and national guidance. However, in 2019, all six CCGs in the area announced they wanted to end the postcode lottery, and ensure everyone has equal access to NHS treatments.

Fantastic turnout

Our concern is that the restrictions could spread across the county, meaning more people could be unjustifiably denied access to life-changing hearing aids.

The CCGs have now engaged with local residents about the provision of five treatments and services, including hearing aids, to get a better understanding of their experiences. This took place over an 8-week period from January to March. People could share their thoughts via a survey and directly to the CCG at a series of events.

During this period, we shared the survey with our supporters and encouraged as many as possible to respond. We also held a public ▸

We held a public meeting to allow people with hearing loss to put their concerns directly to the CCG.

An excellent opportunity for people to share their experiences of their hearing aids and, crucially, how they wouldn't want to be without them!

meeting to allow people with hearing loss to put their concerns directly to the CCG.

This meeting was an excellent opportunity for people to share their experiences of their hearing aids and, crucially, how they wouldn't want to be without them! The turnout was fantastic and we would like to thank each and every one who took the time to attend. Local councillor, Charlotte Atkins, gave a particularly impassioned speech about how the CCGs should be levelling up their services – not levelling down.

First line of defence

The CCGs are now studying the responses to the consultation and will compile them into a publicly available report, as well as deciding on which service changes they want to take to a full, formal public consultation. We're not expecting them to make a substantive announcement on their next steps until late summer – or to increase restrictions on hearing aid provision without further engagement with the public.

You can be sure Action on Hearing Loss will continue to engage with the CCGs during this process and, of course, fight against any formal proposal to further restrict the provision of NHS hearing aids.

As the people most likely to be affected by CCG rationing of hearing aids, you are our first, last, and everything in-between, line of defence. If we're to stop this erosion of the only viable treatment for adult-onset hearing loss, your help is crucial. Please join the fight to defend NHS hearing aids, and sign up to our Campaigns Network online at actiononhearinglos.org.uk

What you told us:

"As soon as I put my hearing aids in, it was brilliant. My life changed."

"I was told I needed hearing aids and had to pay for them – it took me ages to save for them. I live on my own, I'm a pensioner. If something goes wrong in my house, I have to divert that money. This was over two years ago – I still don't have the money. I'm struggling with hearing but there's not a lot I can do."

"Hearing aids have brought my wife's social life back, reduced her isolation, and she is able to go out and do things. For the people of North Staffordshire, the policy has isolated people."

"The isolation you feel without hearing aids is very similar to how people with dementia become isolated."

"Before I had my hearing aids I used to avoid certain situations – even a family meal – because I felt I couldn't join in. Now, I not only enjoy family get-togethers, I also volunteer, help at living well with dementia groups, and run a tea dance on a Friday afternoon – none of that would exist for me if I didn't have my hearing aids."

"Our relationship has improved since my wife has been able to hear."

"I'm a quite keen bird watcher and photographer. The first time I wore my hearing aids, I walked through town and heard birds singing for the first time in years – which I didn't know I couldn't hear."

"I dread to think where I would be in terms of mental health if I didn't have my hearing aids."

Campaign

PHYSICIAN heal thyself

If doctors had the right information, training and resources, it could mean a healthier outcome for 12 million people in the UK living with hearing loss

People who are deaf or have hearing loss often struggle to use GP services – from difficulty in booking appointments to not fully understanding their diagnosis or the health advice given. We know from our previous research (*Good Practice?* report, 2018) that there's a lot of work to do to make sure that all practices meet accessible information standards, and that GPs can identify the signs of hearing loss and refer people appropriately.

In fact, only around 40% of people who could benefit from hearing aids actually have them. Shockingly, the stage at which most people fall between the cracks is when they contact their GP – between 30-45% of adults who report hearing problems to their doctor are not referred on to NHS hearing aid services. ▶

As the professional membership body for more than 50,000 GPs nationwide, the Royal College for General Practitioners (RCGP), has a crucial role to play in improving GPs' understanding of hearing loss. Each year, the body focuses on under-represented clinical areas with its 'Spotlight' projects – and we're delighted to have secured funding for one such project to raise awareness of hearing loss among GPs.

Dr Devina Maru (see opposite page) has been appointed as the new Clinical Champion for deafness and hearing loss. She is leading on producing materials (such as videos, podcasts and training sessions) to educate GPs on how to correctly identify hearing loss and make appropriate referrals, as well as improving how surgeries in general cater to people with hearing loss.

We're also delighted with the RCGP's publication of the new GP curriculum which now stresses the importance of early intervention, effective communication and improved access for people who are deaf or have hearing loss (see below).

Some extracts from the updated GP curriculum guide:

Early intervention

- Promote the benefits of early intervention to ensure people who need hearing aids get the most out of them
- The impact of hearing loss on quality of life, the relationship between hearing loss and other long-term conditions (such as dementia) and community and cultural attitudes to deafness
- High levels of undiagnosed hearing loss; many more people could benefit from having hearing aids

Accessibility

- Ensure that a patient's hearing loss does not prejudice the information communicated – or your attitude as a doctor towards the patient – and be able to communicate effectively
- Ensure patients can contact and access GP services and communicate effectively in waiting areas and consultation rooms.

What some of our supporters have told us:

"I once told a GP that I was deaf and then she started shouting at me, which left my ears ringing slightly when I left. She was looking everywhere except my face. I felt a bit bewildered as to why she didn't just look at me so I'd be able to lipread her better."

"[You] have to phone the surgery the morning you want an appointment – otherwise, you have to make it online, six weeks in advance. So a hearing person doesn't need to know if they will be ill six weeks in advance – but a deaf person does...?"

"If I have to go to the doctor's surgery, it's worrying enough – but it's always more stressful for me because I know I'm going to have difficulty hearing what's said. Sometimes I can hear the doctor reasonably well; other times, it's really difficult. It's a lottery."

"The interpreter didn't show up for my GP appointment so the doctor made me write everything down – even though I find this difficult. I hope I understood all the information correctly."

Action on Hearing Loss Director of Policy and Campaigns, Dr Roger Wicks, says: "As well as raising awareness, the toolkit that Dr Maru is producing will provide GPs with easy access to high-quality resources that support them to bring their practice in line with national clinical guidelines and accessibility standards. This could make a real difference for the 12 million people living with hearing loss.

"We're delighted to be working with Dr Maru and the RCGP on this project. We're also attending the RCGP annual conference in Glasgow in October – it is the largest gathering of UK GPs so we can make sure information about the project reaches as many doctors as possible."

60%

of people who could benefit from hearing aids don't have them.

You can access the webpage for further information at: rcgp.org.uk/hearingloss

Meet Dr Devina Maru, the new Clinical Champion for deafness and hearing loss:

"I've had an interest in audiology from a young age, when I used to accompany my mother to the Royal National Throat Nose and Ear hospital. I found ears, hearing aids, cochlear implants, people using sign language and so on fascinating and I would go visit and explore the library and hearing aid museum on the top floors of the hospital. Another link is that my grandma wears hearing aids.

I want to empower people with hearing loss – to enable them to fully participate in their health care from initial consultation to ongoing treatment. I am passionate about raising awareness and educating GPs and trainees, to help reduce current variations in accessibility to GP practices.

My role as a Clinical Champion is to develop and create educational resources for GPs around deafness and hearing loss. One of these is a 'toolkit' information resource package for GPs which they can access easily online. It covers things like signs of hearing loss, the psychological and social effects, referral guidelines, practical tips and communication tips for GP surgeries and information and support for patients. For the first time, the RCGP has accredited a Deaf Awareness Online Course for Doctors. I collaborated with the UCL Deafness Cognition and Language Research Centre and RCGP to get this accredited.

I've recorded two podcasts on deafness and hearing loss, which include interviews with a patient with hearing loss, an audiologist, GP, and ENT surgeon and a video raising awareness about making GP practices hearing-friendly. In fact I'm developing a 'hearing-friendly practice charter' that GP surgeries can sign up to. It's a great way to make some simple but impactful changes both in the practice and during consultations. Those who achieve this will gain a certificate and be part of a growing movement of healthcare professionals and practices who are promoting these adjustments rather than making them on a responsive basis.

We're holding an event for GPs soon, teaching them about deafness and hearing loss in primary care (Action on Hearing Loss will be speaking at the event, too).

Augmented

Sophie Woolley is a writer and performer from London. She writes scripts for stage plays, is a company director of Augmented Productions, and sits on the board for The New Wolsey theatre.

"So what is a deaf cyborg? A cyborg is defined as 'a being with biological and mechanical parts'. I call myself a deaf cyborg because I have a cochlear implant – and when I take off my external processor, I hear nothing at all. When I put it on, I can hear in ways hearing people cannot.

I was implanted in 2013 after going deaf for 20 years. The implant allows me to hear and understand speech. It enables me to stream music direct to my brain via bluetooth.

When someone phones me on my mobile phone, it 'tells' my brain that "Thomas (or whoever) is calling". I can hear on the phone now where before I couldn't. I can use my mobile phone in the old-fashioned way, like a hearing person, holding it to my ear, or with a Compilot, which bluetooths the sound direct.

The implant, when I got it, suddenly made my life easier in thousands of ways, and in every moment. For example, regaining 'incidental hearing' allowed me to relax more. This gave me a sense of identity vertigo: it made me look back on my life before my implant, and reflect on how high the barriers were for me before.

Being a deaf cyborg is not the most interesting thing about me – but when I tell people that I am one, they often laugh or don't believe I'm being serious. And I think that's interesting; why do we laugh? I feel really proud of being a deaf cyborg. I'm keen to raise awareness about this identity, in order to establish that it's no longer science fiction and it's not a menacing threat to humanity. It is my joyful, everyday reality – and, one day, it will be more common.

Knowing that I hear with a cochlear implant makes me feel like I'm from the future and that hearing people live in the past. So when I say I'm a deaf cyborg and people laugh, I think to myself: I'm from the actual future, and you're laughing at that? I know it's strange and funny – and, when I think about it, it does feel remarkable for me to be able to play in the role of a hearing person when, actually, I'm totally deaf.

I wasn't always a deaf cyborg. I've been adapting to new ways of hearing, and being deaf, and communicating, my whole life. I know how it feels to be totally hearing; also how it feels to be hard of hearing, partially hearing, severely deaf, profoundly deaf and totally deaf. My deafness is genetic and my mum, my sister, grandad, ancestors, we all went deaf from our teenage years. If we marry hearing people, our deaf gene remains strong. It's made many brilliant deaf people down the ages.

My mum was first to start using British Sign Language (BSL) and Sign Supported English (SSE). I was first in my family to get a cochlear implant. Each generation has found a different way to be in the world. So I've been hearing, deaf and now cyborg. My sister got a cochlear implant shortly after me and, although she was deaf for longer, she's had the same miraculous results as me.

Sometimes I see negative comments on social media about cochlear implants and I understand where they're coming from. It's hard to believe that implants work, or what they do, unless you have one yourself. They're seen as a threat to Deaf culture because parents have been given the advice that using BSL will prevent or slow the acquisition of speech.

Recent austerity cuts are affecting deaf education. Some children get cochlear implants as babies and young children but they don't learn to sign, as most of them have hearing parents who aren't encouraged to sign, or who can't afford lessons. These children don't have the best of both worlds, like I did and still do.

As an adult, I have a cochlear implant but I still sign at home with my mum and my friends, and my hearing husband still signs when I'm not wearing the implant.

After I was activated as a cyborg, I realised that the cultural commentary and medical advice coming from hospitals about implants can feel quite negative or scary. It focuses on the risks and on managing expectations. Understandably, no one makes any promises. This influenced me in the past; I couldn't see the benefit. Implants sounded crude and experimental.

People would say, "Is there anything you can do?" and I would say, "No, no one is drilling into *my* head, thank you very much." So I didn't know that implants were good for people who became deaf, like me. I didn't know that an implant could remove everyday anxiety. I didn't know that it would allow me to stop using interpreters at work. I'd been using sign language interpreters and live text reporters for one-to-one work meetings all of the time. I didn't know that an implant would enable me to stop that.

Thinking about implantation made me shudder. I even thought the radio headpiece on the side of people's heads was bolted on. I stigmatized it all in my imagination.

When I got an implant, and I found how life-changing it really was for me, I remembered my old prejudices and fears. It made me want to change the public narrative about it – to tell the truth as I saw it. My experience of implants has been really joyful, positive and incredibly profound. I've since written a play about the complexity of being a deaf cyborg, *Augmented*, which I hope to tour widely when possible.

Sometimes people tell me they think they'll be too old to implant. The benefits of implants for older people has actually been discussed in Parliament. I believe that being able to follow speech easily again removes the crushing sense of isolation we feel when we go deaf. It connects us more to the world; we can join in with family and friends. It allows us to follow speech, even at this time of social distancing, when the phone and video calls become crucial for staying in touch with loved ones. Being 'switched on', as I mentioned, was a culture shock. In the first two weeks, I was able to follow speech independently without lipreading and hearing people were soon treating me very differently. As a social experience, it was like going deaf in reverse – and this strangeness of being in the world with an implant continues, six years on. Hearing people usually treat me like I'm hearing now but, inside, I'm still deaf.

Hearing people also treat me better than they did before my implant. They are warmer to me (I think because I'm warmer to them!). I get more work. I no longer find other people stressful and tiresome. They trust me more (even if, at heart, I know I'm still deaf and if my battery were to go flat, we'd be back to square one. I'd have to lipread them and they might give up on me and say they'll "tell me later").

Being a cyborg involves holding this contradiction within myself and feeling happy and sad at the same time about it all. Being a cyborg is also about asking: what do I do about my amazing dual identity? For me, it means that I don't erase my deafness. It means I definitely don't hide how proud I feel to be a cochlear implanted person. A deaf cyborg.

Sophie in rehearsals for her new play, *Augmented*, based on her cochlear implant experiences and directed by Rachel Bagshaw

PHOTOGRAPHS: JUSTIN MUNITZ, DAVID MONTEITH HODGE

Each generation has found a different way to be in the world.

AUGMENTED

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Discipline with small children can be a daily battle, even with perfect hearing - or so I gather from my friends' stories! With hearing loss, it becomes even more challenging, writes **Vicki A**

Diary of a deaf parent

My girls are now seven and four so luckily we're (mostly) past the toddler kicking and screaming stage. However, we do still get a lot of temper tantrums, whining and crying and increasingly, with the older one, very long and drawn-out conversations about *why* exactly she's not allowed to do whatever it is I'm saying no to!

All logic out the window

The key thing I've discovered over time is that I just cannot hear or lipread them at all when they're whining, crying or shouting, as it completely distorts their lip shapes and makes lipreading impossible. If they're hurt, that's less important as I just comfort them straightaway and often the other one, if they're around, can give me their version of what's happened until the injured one has calmed down enough to tell me!

When they're angry or upset about something, though, it's really hard. All logic goes out the window. They completely forget (or quite possibly don't care) that I can't hear them, and calming them down can take a while. If they're just a bit grumpy, me saying "Mummy can't lipread when you shout/whinge" can work – after all, they need me to hear what they want! But when they're really upset, the best way I've found to deal with this is to get down on their level, maintain eye contact and try to explain I can't hear them – so they need to take a deep breath, and then tell me, slowly, what's wrong.

It doesn't always work but they do try. Luckily, we haven't yet got to the point where they're using the fact I can't hear to their advantage. I'm guessing it will happen, at some point, and I'll have to figure out new tricks to deal with that then!

▶

Next time I'll be talking about going back to school with assemblies and meetings, and how weird it feels to be asking for help to hear in those situations as the parent, rather than the child.

Safety seems to go hand in hand with discipline, especially with deafness thrown into the mix. It's everything from the school run, to playing at friends' houses, to keeping them safe when I'm alone overnight. Even when we're walking from the carpark to school, I need to balance lipreading them to catch their chatter and today's important news, with also needing my eyes for the roads to cross and the scooters to avoid!

Talking to other parents while walking can be really tricky. I don't want to be rude, but i do really struggle to maintain enough eye contact to keep up a conversation while also keeping the kids safe by the roads. We manage by them holding my hand and not running off, so I can walk/talk/lipread/cross roads in one big multitask and bend down while walking with them to lipread as much as I can. There's also a lot of "Oooh, that sounds interesting, can you tell me the rest when we're in the car because Mummy can't lipread you that well right now." However, on a windy day, all bets are off; I give up on hearing and just shepherd them back to the carpark where we can catch-up.

Playing at friends' houses is, of course, changing as they get older. When they were little, it was mums having a coffee while the kids played at our feet, so it was pretty easy to keep an eye on things. These days, they tend to tear off up the stairs to their friends' rooms and, since I can't hear if I can't lipread, I don't know straightaway if they fall or shout or have an argument.

Luckily, the other parents tend to be pretty understanding and my kids know that if they need something, they have to come and get me. When we have friends dropped off at ours, I do a regular sweep of the bedrooms while 'doing jobs', so the kids don't feel spied on but I can also make sure they're okay!

Everything is a balancing act: always acting interested, not rude, even though I can't hear every word; keeping the kids safe but also giving them their independence. It can get pretty exhausting at times!

Different way of learning

Finally, overnights present their own challenges. We got rid of the baby monitors a while ago (sooner than I wanted, but much later than most hearing people keep them I guess).

When I'm alone with the children overnight, I make sure that I put my hearing aids back in when they go to bed. It's a bit of a pain, as I like a break from wearing them after a day at work – but it also means I'm much more likely to hear them calling out. I leave the hallway door open until they're definitely asleep, so I don't miss any last calls for "Mummy, I need a drink" or "Mummy, I feel sick!"

Once I go up to bed, I now have a super fire system that the local deaf association provided and the fire service fitted for us. It means that I have complete confidence that if the alarm went off, I'd be straight up – it's got a fierce vibrating pad as well as flashing lights. Not even I can sleep through that!

Despite groundbreaking medical advances in the past century, some conditions still perplex scientists. One such is tinnitus, which was mentioned in Babylonian texts 2,700 years ago

The enigma of tinnitus

It's estimated that almost a third of people worldwide will experience tinnitus at some point in their life. This number is likely to rise, as increases in life expectancy and exposure to loud music are all reasons people develop tinnitus. For one in eight people, tinnitus never goes away.

Despite being more important than ever to find a cure, research is still ongoing to find one.

Difficult to quantify

One reason it's so difficult to find a cure is because tinnitus is hard to quantify. There's no reliable, objective way to directly measure the severity of someone's tinnitus – which means researchers have to rely solely on an individual's description of their symptoms. Consequently, it's very hard to establish a diagnosis and whether a treatment has worked.

Scientists also don't know why some people develop tinnitus and others don't. More than 200 conditions are associated with developing it; from head or neck injuries to circulation problems to a side-effect of some medications. Although hearing loss and loud noise exposure have been identified as the biggest risk factors in developing tinnitus, not everyone with hearing loss has tinnitus – and not everyone with tinnitus has hearing loss.

> "I didn't really know about the risk of loud music when I was young."
> Bronagh

A further barrier to finding a cure is that tinnitus is not fully understood. Although various theories exist, none can fully explain all aspects related to how ▶

What is tinnitus?

Tinnitus is characterised by hearing unwanted sounds – such as a ringing, buzzing or humming noise – in your ears or head. Although the condition is more common in older adults – possibly due to the natural ageing process – tinnitus can affect people of all ages, including young children. When tinnitus is severe, it can make it difficult to hear, concentrate, relax, sleep and focus. Those who are severely distressed by tinnitus even report an inability to work. Being unable to escape or control tinnitus might lead to feelings of frustration, anxiety and depression. These different individual reactions show how varied the tinnitus experience can be – and why the search for a cure is such a challenge.

the sound is produced, why only some people become aware of these internally generated sounds, and why the sound may persist for years.

Current theories indicate that developing tinnitus involves multiple complex processes taking place in various parts of the brain. This makes it difficult for drug companies to know what area of the brain to target when developing a medical treatment. Although many drugs have shown promise in improving tinnitus during trials, none of these reported improvements could be reproduced later on, safely, and over a long-term period.

In fact, during many of these trials, people taking placebo drugs reported similar improvements to their tinnitus symptoms. There are many reasons why these drugs might not have worked long-term – including being unable to ensure patients were taking the correct dosage without triggering other side-effects, and uncertainty regarding which type of tinnitus the drug should target.

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

Ways to manage tinnitus

While there is, as yet, no cure, there *are* a number of things that people can do to help them manage the condition. In some instances, medical interventions may help when tinnitus is related to an underlying condition such as an ear infection, jaw problem or high blood pressure. Often, addressing any hearing loss issues can help significantly.

Strategies such as mindfulness and relaxation techniques, or sound therapy can also be beneficial in helping people manage their symptoms.

Bronagh, 37, a teacher from Belfast, developed tinnitus aged 12

"When I was in secondary school, I used to go to a youth disco which had big speakers playing very loud music. My ears often rang after a night there. One particular night, I stood very close to the speaker – and the ringing never went away. When I was 19, I was referred to ENT but the doctor I saw was very dismissive, telling me there was no cure and I'd just have to live with it. In 2017, my tinnitus became particularly bad and affected my work, family life and sleep – living in a busy household with three young children can be noisy and, as a teacher, classrooms can be noisy places, too. I went to see another GP who, thankfully, was more understanding and gave me some medication to try and another referral to ENT.
I wish I'd known about the damage that music at unsafe levels can cause – just one night out and you could end up living with tinnitus every minute of every day for life."

ILLUSTRATION: SHONAGH RAE

"Long meetings with lots of people take it out of me. Now my friends and family realise that if I leave the room for a bit, it's not me being anti-social."
Graham

Currently, the approach seen to be most effective in reducing distress and increasing quality of life is cognitive behavioural therapy (CBT). This uses various techniques to help change negative thoughts and responses to tinnitus.

There are, however, very few specialists who deliver CBT for tinnitus specifically. Cost, and a lack of resources, are further barriers for tinnitus treatment, but access to online therapy might be one way to address these issues.

Although it remains an enigma, there is more research into tinnitus than ever before – and clear indications of progress regarding our understanding of tinnitus and how to treat it.
Courtesy of Dr Eldre Beukes, Postdoctoral Research Fellow at Anglia Ruskin University

Dr Ralph Holme, Director of Research at Action on Hearing Loss, talks about some of the projects our charity is funding to understand tinnitus better.

"Our research to date has helped identify regions of the brain involved in tinnitus that act like a 'volume control' – amplifying signals from the ear when they're weak and turning activity down when they're strong.

"Tinnitus may develop when the brain's 'volume control' becomes set too high. It suggests that we might be able to treat tinnitus by developing drugs or other methods able to turn activity down in these parts of the brain. A lot of research efforts are now focusing on this.

"Our research has also shown that exposure to loud noise can trigger hyperactivity in parts of the brain that process sound. Importantly, if signals from the cochlea to the brain are blocked soon after the onset of tinnitus, then this tinnitus-related hyperactivity is reduced. However, if the signals are blocked later on, then there is no effect.

"This points to a two-stage process in the development of tinnitus: an initial stage, driven by signals from the cochlea, followed by a second phase, where tinnitus becomes established in the brain. This

Professor of forensic biology, Graham Williams, 43, has been profoundly deaf since birth and has had tinnitus all his life

"My tinnitus takes the form of whirring noises, clicks, whistling and even the occasional explosion. There are certain things that trigger it; the biggest being excessive background noise and fatigue and then I generally need a quiet dark corner somewhere. Long meetings with lots of people really take it out of me. Ultimately, I find the best cure (albeit only temporary), is a good night's sleep. But if the tinnitus is excessive, then I struggle to drop off and this is when I really suffer. One of the best ways for me to deal with tinnitus is to avoid getting it in the first place. However, this means avoiding social situations where there is background noise, so it can be rather isolating. Now my friends and family realise that if I leave the room for a bit, it's not me being anti-social; I'm simply trying to avoid triggering my tinnitus."

could mean that we will need different treatments, depending on how long someone has had tinnitus.

"Our current projects are looking at how stress, anxiety and sleep influence tinnitus – which may suggest new ways of treating it. We're also funding research that could lead to objective ways of measuring tinnitus. This is vital so that researchers can reliably monitor the effectiveness of new treatments being developed.

"Also, in the next issue of this magazine, we'll report on a project we're funding to investigate non-invasive brain stimulation techniques – and whether these can 'turn down' tinnitus-related brain activity."

How to find support

We have plenty of information about tinnitus on our website – what it is, what causes it, and what support is available to help you manage it.

Find out more online at: **actiononhearingloss.org.uk/hearing-health/tinnitus/**

Call our Tinnitus Helpline Mon-Fri 9am-5pm on 0808 808 6666 (freephone); 0808 808 9000 (freephone textphone) or email: tinnitushelpline@hearingloss.org.uk

The British Tinnitus Association (BTA) also provides information and support, including a network of independent tinnitus support groups across the country.

Find out more at: **tinnitus.org.uk**

Call the BTA Tinnitus Helpline on 0800 018 0527 or you can text 07537 416841 or email helpline@tinnitus .org.uk

Retired firefighter Glen Mitchell was 53 when he took his own life in 2011, 12 weeks after developing severe tinnitus.
His wife Linda now campaigns for better awareness of the condition

"It all started when Glen and I went to our local pub to watch a live band. They were so painfully loud we had to leave early, as it was unbearable. The ringing in my ears afterwards faded the next day but Glen's continued. He cherished silence at bedtime but because of the various noises, as well as ear pain and spasms, he was unable to sleep. This, combined with the anxiety that his tinnitus would never go away, contributed to a very rapid mental decline. Eventually, he got a much-needed referral to ENT and we were given some help but no ongoing monitoring or regular appointments. By this time, Glen also developed hyperacusis (a sensitivity to sound) and his mental health was getting worse. It was a vicious circle that we just couldn't break. He took his own life, 12 weeks after that night at the pub. How a humorous, loving man, full of life, could have got to that point so quickly is just devastating. I'm determined that lessons be learnt from Glen's death. I am really passionate about supporting GPs to become more knowledgeable about tinnitus– and the potential impact the condition can have – so they're more able to treat patients and improve their quality of life before things escalate. It doesn't need to get to such a tragic point and I want to encourage anybody out there with tinnitus not to lose hope. There *is* help out there."

Significant others

One volunteer's gut feeling about a need to help 'significant others' understand the experience of hearing loss has led to a successful pilot

People with hearing loss quite often feel frustrated at the lack of understanding about their experience, especially in situations when an unheard question is deemed not worth repeating, and the dreaded utterance: "It doesn't matter, forget it!"

After chatting with a young person who was struggling to support her partner with his hearing loss, Brighton-based volunteer, Jenny, had an idea: a workshop that would provide people and their loved ones an opportunity to talk through some of the communication challenges they face, together. "People with hearing loss can often feel left out and isolated because they can't fully follow a conversation, or laugh at jokes around the dining table when everybody else does," says Jenny. "They are surrounded by their loved ones – the very people who care about them – and yet can feel very lonely."

Jenny's intuition proved to be spot-on. Nearly 50 people attended the first 'Significant others' workshop in Brighton in November last year. Hearing therapist Wendy Horton delivered a two-hour session for people and their family member, friend, or loved one. Topics covered included: understanding hearing loss and how the ear works; different types and degrees of hearing loss; the emotional aspects and its effect on our well-being; and lipreading training.

"Hearing loss and deafness can often be a bit of a mystery to those who've never experienced it themselves", says Wendy. "It can be difficult to fully understand why a person with hearing loss can apparently be hearing reasonably well and then, for no obvious reason, will struggle to hear, or mishears, or just seems to retreat into a 'world of their own'. The aim of the workshop was to give the significant others a greater understanding of the everyday challenges facing people with hearing loss, as well as working on skills to help improve communication all round." Feedback from participants was certainly positive, such as: "I feel like I've gained new skills – particularly how to be more specific when talking to someone who has hearing loss, to ensure they know the subject I am talking about – and to use gestures to emphasise my point." Another said: "It was a unique opportunity to let other people know what it is really like to have hearing loss.

"The workshop provided plenty of information and understanding of the technical aspects of hearing loss, as well as the issues that can arise and make communication difficult."

Jenny's inital gut feeling has paid off. She says: "I'm delighted about such a good turnout and positive feedback from attendees. We will be planning another session in Brighton this year.

"These workshops are an opportunity to provide useful tools to overcome some of those communications barriers, and raise awareness of what it really means to be living with hearing loss." Because, yes, as we all know – it *does* matter.

For volunteering information, go to: actiononhearingloss.org.uk/volunteering, or call the team on 01273 840960 (tel)

Kevin Taylor reports on language translation technology that can help ease communication wherever you are.

A world of conversation

Have you ever been in an awkward situation where you wished you were fluent in the local language? Perhaps a mix up with a hotel reservation or the waiter doesn't bring what you ordered – or even something more serious, such as help in an emergency. A phrasebook might help but can take ages to fumble through and, even then, you might still be misunderstood. Perhaps it's time to ditch the phrasebook for a tech solution instead. There are two choices: a language translation app on your smartphone, or a handheld language translator.

Language translation devices have become quite popular lately. Both portable and easy to use, they translate a multitude of languages. There are many available; the question is, why would you need a dedicated device when there are free or low-cost language translation apps? The makers of language translation devices say they are easy to use and, in unfamiliar surroundings or high-crime areas, you might not want to take out your smartphone to translate directions (especially if it has all your personal information, flight details, e-ticket access and so on). They have a point. One option, then, is to have both.

We tried out a popular language translation device, Pocketalk, and compared it to the Google Translate app to get an overview of the difference between dedicated devices and apps, and to highlight what's possible – but remember, there are many other translation devices and apps available.

Pocketalk Classic

A device that instantly translates speech (picked up on its built-in microphone) and displays it as text in your chosen language on a small screen. Pocketalk also provides synthesised voiced translation through a built-in speaker.

Pebble-shaped, it fits snuggly in the palm of your hand, looks neat, and its size and weight means it can easily go in a pocket or bag. It can also hang around your neck with the optional lanyard.

The device has a small (2.4in) colour display, two 'Talk' buttons – and nothing else. It's designed for simplicity.

For translation, it needs a connection to the internet. It can do that in two ways: it has a fitted pre-paid global SIM card to connect to a mobile network, or there's the option to connect to wi-fi. So unless you're somewhere really remote, where there's no mobile network or wi-fi, it can translate just about anywhere you go.

To translate, for instance, English to French, you press and hold down the 'Talk' button, wait for the bleep, and then start speaking. When you release the button, translation appears on the screen and is read out through the built-in speaker (most language translators work this way). The person you're talking to can reply by pressing a second talk button, and you'll be able to read what they said in English. Each translated word appears on the screen as you speak but only when you've paused, or stopped speaking, does the whole sentence appear.

Pocketalk can translate 72 languages as well as English to Welsh, Welsh to English, English to Irish and Scottish Gaelic and Gaelic to English.

It will translate up to 30 seconds of speech before the device times out, in which case you have to press and hold the Talk button again to continue with further translations.

The instructions recommend speaking at a distance of 10cm from the device. Over a greater distance, we found that Pocketalk did a good job of maintaining accuracy but this did decline when there's a lot of background noise and it took longer for the translation to appear on the screen.

The normal default setting for the display text size is small but you can increase it. In fact, there are four text size options – small, normal, large and max.

Voiced translation through the speaker is clear, but not that loud even on the higher volume settings. There's no option to listen through headphones, which could be a problem if you're somewhere noisy.

Summary

Pocketalk ticks a number of boxes for features and ease of use. It has a decent display (though not up to smartphone standards in terms of size or resolution). It can connect to wi-fi and 3G mobile networks, which offers greater coverage in terms of where you can use it.

Pocketalk is not the only language translation device out there of course; there are many others, ranging in price and features, as well as language translation apps for Android and iOS devices. But remember that cheaper devices may only connect via wi-fi, and very cheap ones don't have a display and only provide a voiced translation.

Pocketalk Classic and other voice translation devices are available from Amazon and other retailers.

This product is not available from Action on Hearing Loss web shop.

Google Translate

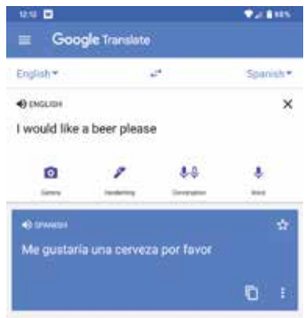
In many ways, the Google Translate app is similar to Pocketalk, but works on a smartphone and is free. You'll need access to wi-fi or a mobile network.

In conversation mode, you don't have to keep a button pressed down while speaking, which is a big advantage. It can translate more than 100 languages to English, for as long as you want. This helps create a natural flow to conversation rather than having to keep stopping and starting.

Translated speech appears as text on the phone display (you can't change the text size) and simulated speech through the phone speaker.

Google Translate has some handy features. There are four language input modes: camera, handwriting, conversation and voice. In camera mode, for instance, the app will translate signs and notices and handwriting mode allows you to write on your device screen the text you want translated.

For more information, go to: translate.google.com



Stop Press:

A newer version of Pocketalk with added features will soon be available – visit the website: pocketalk.net/product/pocketalk-voice-translator

Speech-to-text

One of the (perhaps unintended) quirks of Pocketalk Classic is the ability to translate spoken English into English text on the display and becoming a speech-to-text translator – an added bonus for anyone with hearing loss. Google Translate doesn't do that, but there is Google Live Transcribe, a free app specifically for transcribing speech for people with hearing loss and deafness.

For more information, go to: android.com/accessibility/live-transcribe

There are also language and speech-to-text apps for iOS devices such as iTranslate. ***Visit the apple.com/ios/app-store for all the apps available.***

The table below shows the main differences between language translation devices and apps.

A handheld translation device costs less than an average smartphone, and it doesn't hold all your personal information, contact numbers, addresses, and so on. Then again, if you already have a smartphone, the Google Translate app is free.

Language translation in hearing aids

In early 2019, Starkey announced language translation as part of their Livio AI hearing aid and Thrive Hearing iPhone app. The app translates what you say and displays it on the phone screen for the other person to read in their language. When they speak back, the app (in addition to showing the translation on the screen for you to read), will stream a simulated voice of the translated language direct to the hearing aid. This is part of a general trend where technology allows hearing aid manufacturers to add useful and innovative features to their instruments.

starkey.co.uk

At a glance	Google Translate app (other language translation apps are available)	Pocketalk Classic (other language translation devices are available)
Text size settings	No	Yes (small, normal, large, max)
Voiced translation	Yes	Yes
Speech-to-text (English)	No – use Google Live Transcribe app instead	Yes for Pocketalk – for other language translation devices, check product features/ specification or contact the supplier/manufacturer
Screen size	Depends on smartphone/tablet, but generally larger than most handheld language translators	Limited – smaller than a smartphone/tablet
The need to 'press and hold' a 'Talk' button	No (conversation mode)	Yes (press and hold for up to 30 seconds of conversation)
English to Welsh and Gaelic and vice versa	Welsh only	Yes
Data connection	Wi-fi and mobile network	Wi-fi and mobile network (Global SIM included)

Keep us in the loop

Two of **Vera Brearey's** passions are local history and archaeology. If there's a local talk, lecture or day school, she's there – especially if the venue has a hearing loop! But there are a few things about loop systems she wishes were more widely understood...

They are powered by electricity, not magic

Sadly, many people don't realise that loop systems need a power supply to operate. Sometimes I know that a particular venue has a loop system but I'll still check before the talk begins that it is turned on.

"Goodness", the reply will come, "does it need to be? I had no idea. I don't even know where the switch might be."

So yes, they run on electricity and they need to be switched on.

The speaker needs to know where the microphone is

Somewhere in the room, there will be a microphone. Its purpose is to pick up the sound of a speaker's voice and relay it directly to our hearing aids. It may be built into the ceiling (so the speaker just needs to be relatively close to it), it may be a clip-on microphone that the speaker needs to wear, or it may be handheld – but speakers need to know where it is and to use it. Yes, even if it is handheld...

They go wrong

It's a piece of electrical equipment. At some point, it will break down. My deaf friends and I sometimes spend time comparing notes about a particular loop ("is it just me, or is the loop crackling very badly today?") Or it may completely stop working.

Venue managers then need to contact the company who installed it or, if they don't know, another specialist maintenance company (look online) so that it gets fixed.

What is a hearing loop?

A hearing loop is a special type of sound system for hearing aid users. The hearing loop provides a magnetic, wireless signal that's picked up by your hearing aids when on the loop or 'T' setting.

- **High-quality sound straight to your hearing aids**
- **Minimises distracting background noise**
- **No need to use a receiver or headset**
- **It's discreet**
- **Cost-effective, as any number of people with hearing aids can use the system within the looped area**

Tell people that the loop is on

Organisers of an event should first check that it is switched on, then say something like: "The loop is on, if people with a hearing aid with a loop setting would like to use it." This avoids people unnecessarily fiddling about with their hearing aids (to see if the loop is on) then interrupting the speaker's flow (to ask if the loop is on when it doesn't seem to be). It only takes a few seconds to ensure that everyone is clear from the start.

There are different kinds of loop system

There are systems that operate in rooms and there are table-top loop systems (often marketed as service counter systems) which help when we're talking to, say, a cashier in a shop. The latter has a range of about a metre, whilst a room loop system may cover a very extensive area. Not understanding what sort of loop you need can cause severe problems.

A couple of months ago, I went along to an event at a venue where the loop is notoriously dodgy, so I checked with the person on the door. "Yes, the loop is definitely working today!" she said brightly. Being a suspicious soul, I plonked myself near the front anyway. The meeting began. I switched the hearing aid in my left ear and cochlear implant speech processor on my right to their loop settings. Nothing in either ear, so it wasn't imagination. One device might, conceivably, have been playing up but not both of them simultaneously.

From where I was sitting, I could hear quite well, actually, so I sighed soundlessly and tuned in to the meeting. After a while, the person chairing asked if there were any questions before moving on to the first speaker? I stuck my hand up, said the loop wasn't working and could it please be switched on. The Chair replied confidently: "Oh, it definitely is working madam; I'm sorry if it's not helping you," and he picked up and waved about a plastic box, approximately the size of a briefcase. Hmmm. I let it go. But, at the end of the meeting, I explained to him that said box contained a table-top loop with a range of about a metre – no help at all in a room seating around 80 people.

There was a happy ending to this story, though, because the room loop was finally repaired as a result. Hurrah.

You can download our free factsheet 'Understanding wireless technology for hearing aids', which tell syou more about hearing loops, from our website actiononhearingloss.org.uk

Ask the experts

Q I wear hearing aids in both ears. I've had a personal radio for many years which I carry in a breast pocket and use one earphone in my right ear so that I can still hear external sounds in my left ear. This has worked well for many years with the volume on full. Over the last year, however, the sound has become almost inaudible and I've replaced the ear phones with no effect. Can you recommend a personal radio that might meet my needs – or is there such a thing as an amplified earphone?

Kevin Taylor, Technology
If you have maxed out the volume on your radio all these years, it might have given up and gone faulty – but if not, you can get small inline battery-powered headphone amplifiers to boost the volume.

The other possible option is to try an ear hook or amplified neckloop, as this incarnation of loop technology can turn a hearing aid into a versatile personal listening system. However, this is only possible if your hearing aids have a 'T' (loop) setting.

There's also a possibility of your hearing loss having got worse so, as well as boosting volume levels, you might want to consult your audiologist for a further hearing check.

Q I find that with cinemas, TV and radio, the speech is usually fairly quiet – then suddenly your ears get assaulted by unexpected shouting or a very loud music. Could someone please tell sound engineers that the delicate, hair-like receptors in our ears can be damaged by loud noise, and can lead to hearing loss!

Jesal Vishnuram, Technology
Films in cinemas are screened as intended by producers. Sound producers decide how the sound should be experienced when watching a film – and cinema providers have no control over this. Volumes are, by law, required to be at safe levels – so while some scenes can be very loud, as they're not consistently at that loud level, they're not damaging to your hearing (but can still be uncomfortable for some viewers, of course).

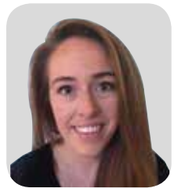
We're currently working with technology companies on how we can develop devices to give people a more personal sound experience so that everyone can choose how they view films, TV and other entertainment.

Currently, you can get loop systems in cinemas which allow you to listen to the audio through a loop transmitter and where you can control the volume at a comfortable level. These will connect directly to hearing aids if you have a Telecoil setting. If you don't wear hearing aids, you can buy loop receivers that work with headphones.

Q I've had hearing loss with tinnitus and a 'full' feeling in my right ear for nearly three weeks. I've been prescribed antibiotic tablets and now a spray but nothing seems to be working. My GP maintains I have an outer ear infection but I wonder if it's in the middle ear. Can an outer ear infection cause tinnitus?

Francesca Oliver, Audiology
An ear infection (whether it is outer or middle) can cause a temporary reduction in hearing in the affected ear.


Kevin Taylor
Technology


Francesca Oliver
Audiology


Dr Tracey Pollard
Biomedical Research


Jesal Vishnuram
Technology


Vai Maheswaran
Audiology

This, in turn, can cause an increase in tinnitus symptoms. The good news is that when the infection clears, in the majority of cases, the hearing returns to normal and the tinnitus symptoms reduce. If you are still concerned by your symptoms, it might be a good idea to see your GP again.

Q Do you have any suggestions for how best to clean headphones? I've seen one manufacturer warn not to clean with alcohol wipes as this can damage the surface of the headphones. Is it as simple as a dry cloth or cotton bud?

Kevin Taylor, Technology
It's best to be guided by the manufacturer's instructions for cleaning headphones and earbuds. All the ones I've seen suggest using non-alcohol and non-abrasive cleaning products, such as a light soapy solution. On some headphones, you can remove the ear cushions for clearing (I've done that with a few in the past but found they were hard to put back on).

With earbuds, the tips can be removed and cleaned in a light non-alcohol/ non-abrasive soapy solution.

A dry cloth might work, but it depends on how much cleaning is required. Often oils from skin contact can build up that a dry cloth can't remove (hence the light soapy solution).

There are headphone cleaning wipes, cleaning tools and cleaning kits available, on sites like Amazon, which might be worth a look. For cleaning hearing aid tubes, you can get dry boxes that circulate warm air to dry them out and some have ultraviolet lights to help kill off bacteria.

Q I keep fit by attending yoga and Pilates classes but am finding it increasingly difficult to follow the teachers' instructions (I wear two hearing aids). Any ideas?

Vai Maheswaran, Audiology
If you haven't already done so, try positioning yourself at the front and letting the teacher know that you have hearing difficulties. You could also speak to your audiologist to see if your hearing aids can be adjusted – some have additional programs which can enhance hearing speech in noisy environments. On the other hand, if you feel your hearing has deteriorated of late, you could request a reassessment, where you'll have a hearing test, hearing aid maintenance or maybe an upgrade.

There are also assistive listening devices available to buy which could help (such as the Roger Pen). Some manufacturers offer clip-on microphones (where the speaker wears the mic and then the hearing aid user can hear their voice clearly over background noise.) Again, it might be worth speaking to your audiologist about suitable technology compatible with your type of hearing aids.

If you have a question for any of our experts, write to: Dawn Dimond, Action on Hearing Loss magazine, 1-3 Highbury Station Road, London N1 1SE or email: dawn.dimond@hearingloss.org.uk

Tech for a new decade

For the latest in technological wizardry, there's nowhere better to start a new decade than with the Consumer Electronics Show (CES) 2020. Held every January in Las Vegas, it's the largest event of its kind. This year, among the mini drones, robotics and new concept electric cars, were some exciting innovations for people with hearing loss and deafness.

HeardThat app

Harnessing the computing power of smartphones for hearing assistance took another step forward with the new app, HeardThat. Developed by Singular Hearing in Canada, the app promises 'more voice, less noise' by filtering out background noise in social situations – making conversations easier to follow for people with hearing loss. HeardThat uses advanced machine learning algorithms to listen to the noisy environment, then delivers 'de-noised' speech to a Bluetooth-enabled hearing aid paired to the user's smartphone, or paired/connected earphones. Once product testing is complete, the app will be available for Android and iOS devices sometime this year.
To find out more, visit: https://heardthatapp.com

Virto Black

Hearables have caught on with consumers who are eager to ditch the tangle and inconvenience of wired earphones. They fit snuggly in the ear, look a bit bulkier than earphones, and have become increasing sophisticated – some even allow you to optimise the audio to your hearing profile. It's perhaps not too surprising, then, to see the launch of a fully functioning, connected behind-the-ear (BTE) hearing aid packaged as a hearable. 3D-printed and assembled by experts, the Phonak Virto Black hearable is custom-made and boasts Marvel technology for universal Bluetooth streaming from Android and iOS devices (and almost any other Bluetooth-enabled audio device). It also works with a range of Phonak remote wireless microphones and streamers. It will most likely appeal to anyone looking for an alternative to a conventional looking BTE hearing aid. Having launched in the US, Phonak is yet to confirm its availability in the UK.
To find out more, visit: https://www.phonak.com/us/en/press/phonak-unveils-virto-black-at-ces.html

OrCam Hear

Comprehending speech in a noisy crowd is especially difficult with hearing loss, and developers in Israel have come up with a possible solution. OrCam Hear is a wearable device fitted with a camera that uses artificial intelligence (AI) to combine lipreading and voice separation capabilities. It can identify and isolate the speaker's voice from background noise and chatter, and even has the ability to switch between speakers when conversation shifts from one person to another. It then instantaneously relays the filtered speech through Bluetooth hearing aids.
To find out more, go to: www.orcam.com

Bluetooth LE Audio

One of the most significant announcements to come out of CES 2020 was from the Bluetooth Special Interest Group. LE Audio is a new Bluetooth audio standard that will allow manufacturers to enhance and develop innovations on future wireless audio devices. Besides improved sound quality and extended battery life, LE Audio will open up the possibility of location-based audio sharing that could mean better access for visitors with hearing loss at public venues.
www.bluetooth.com/learn-about-bluetooth/bluetooth-technology/le-audio

Snapdragon

One thing you can be sure of at CES is the launch of new phones. This year was no exception, with 5G and foldable handsets, and Qualcomm's next generation Snapdragon processors that will boost the performance of new smartphones from mid-2020. Faster processors will almost certainly improve speech-to-text translation – particularly regional accents and where there's a lot of background noise. Also, AI processing that works on the phone rather than on a remote server will mean less reliance on mobile networks and Wi-Fi.
www.qualcomm.com

A grey area

There is increasing evidence of a link between dementia and hearing loss. We're working in partnership with Alzheimer's Research UK to fund research to help us understand why, reports **Dr Tracey Pollard**

There is strong evidence that mild hearing loss in middle age doubles the risk of developing dementia in later life; this rises to three times the risk with moderate hearing loss, and five times the risk when the hearing loss is severe. It's also the case that hearing loss can be misdiagnosed as dementia, or make the symptoms of dementia appear worse.

We don't yet fully understand the link between dementia and hearing loss, or the biological or cognitive processes that underlie both.

One possible explanation for the link could be inflammation of the nerve cells that make up the brain (known as 'neuroinflammation' – see panel, right).

From animal studies, we know that neuroinflammation occurs after exposure to noise that's loud enough to cause hearing loss. It can also occur during the decline in cognitive ability that comes with ageing. It's even thought that neuroinflammation plays a role in the causes and effects of Alzheimer's disease itself.

With neuroinflammation thought to be involved in all of these conditions, it might, then, underlie the link between hearing loss and dementia. The neuroinflammation associated with hearing loss could worsen age-related cognitive decline; thereby increasing the chance of developing dementia.

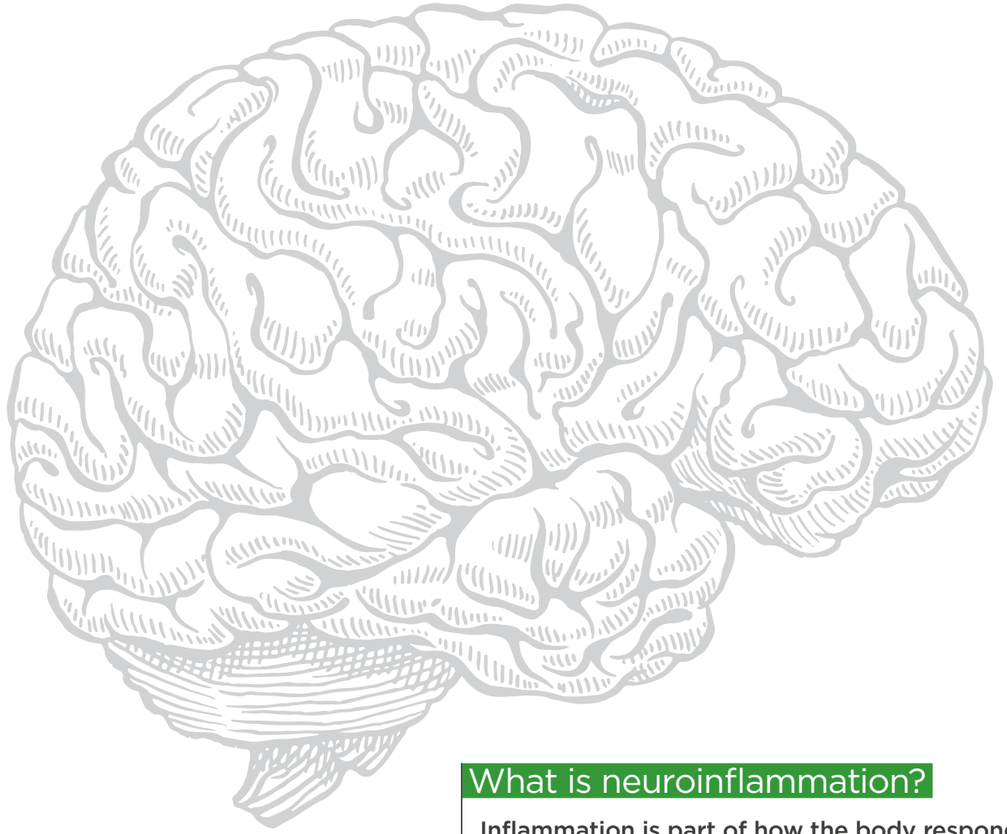
In our third year of a joint project with Alzheimer's Research UK, Dr Brian Allman at the University of Western Ontario in Canada will study whether brain inflammation could be the link between the two conditions.

His team will study the changes in the brain that occur during noise-induced hearing loss and whether these changes might speed up the learning and memory impairments that normally occur in old age. The team will then investigate how hearing loss worsens these cognitive problems and brain changes in a way that is specific to Alzheimer's disease.

Implications for millions

Researchers will expose rats to loud noise when they are young, and then track changes in their brains linked to neuroinflammation throughout their lives. By using a combination of non-invasive brain imaging, behavioural tests of learning and memory, and microscopic analysis of brain structures and pathology on the same rats, the researchers will be able to connect changes seen in the brain imaging studies with the underlying pathology shown under the microscope. The study will use both normal and genetically-modified rats (the latter are susceptible to developing brain damage consistent with that shown in people who have Alzheimer's).

This project is one of the first investigations into the biological processes that link hearing loss, age-related cognitive decline, brain inflammation and Alzheimer's-related pathology. We hope that the findings will, ultimately, lead to the development of treatments, such as drugs aimed at reducing the risk of dementia associated with hearing loss. If so, this could have considerable implications for millions of people in the future.



What is neuroinflammation?

Inflammation is part of how the body responds to damaging or disease-causing agents, such as bacterial (or other) infections, damaged cells, or other irritants.

It is a protective response, involving cells of the immune system and the substances they produce. The purpose of inflammation is to eliminate the original cause of damage to the body and to clear away any damaged cells and tissues. It's a crucial part of our immune response – without it, the body cannot respond appropriately to damage or infection. However, chronic (persistent) inflammation can also cause problems, and is linked to a range of conditions from allergies to cancer.

Neuroinflammation is inflammation in the central nervous system (the brain and spinal cord). Just like inflammation elsewhere in the body, it can be caused by infection or injury, or exposure to certain toxic substances. Chronic neuroinflammation is linked to ageing, and is also thought to underlie a number of neurodegenerative diseases, such as Parkinson's, multiple sclerosis, and Alzheimer's.

This term we've been concentrating on vowels. They're not as easy as the consonants; they change with regional accents, and often don't have clear shapes, but they're an important additional – and sometimes only – clue.

In English we use about 21 different vowel sounds, but they fall roughly into only four different lip shapes. A lot of them are just a jaw drop (look in the mirror at the words 'nut', 'cat', 'let'). Some have a whistling shape (have a look at 'shoe', a strong shape and hides the consonants around it). Then we have the smiley vowels, like 'see' and 'hill', and last, there's the rounded closing shape, which is a bit like a goldfish opening and closing its mouth (look at 'coat', 'hound' and 'mouth'. Some words, of course, are a bit of a mix of shapes, like 'nail'. Practice is the key with lipreading – watch the way people speak and see what you can pick out.

We've also talked about travelling with a hearing loss. The Hidden Disabilities sunflower lanyard scheme, launched at Gatwick airport in 2016, works really well. Wearing it is a good way to indicate to people around you that you may need additional support, help or a little more time. It's been adopted in the UK by all of the major airports, many supermarkets, railway stations, leisure facilities, in the NHS and an increasing number of small and large businesses and organisations. At airports, anyone wearing one will have priority at security, and may get priority boarding (for those travelling with them, too). This service is most important when things go wrong, such as if your flight is delayed, and you need to be informed.

Don't forget that you can also get a disabled rail pass; it's cheaper than the older persons pass, and gives a third off the cost of tickets for you and another person travelling with you. It also works at any time of day.

City Lit college in London runs about 15 weekly lipreading classes as well as the Lipreading Teacher Training Course.

To find a lipreading class near you, go to atlalipreading.org.uk

Stop press

There's been a lot of advice in mainstream media about coronavirus, including that we should call 111 if we're worried – which is great if you can hear on the phone or use the text relay service. But did you also know you can use NHS 111 online to contact them by email? There's not been nearly enough publicity for this service but do make use of it if you need, and stay safe. Go to: 111.nhs.uk

Molly Berry, lipreading tutor, would like a word...

MORE than lipservice

SPOTLIGHT ON communication support

All situations covered

It's vital that people who are deaf or have hearing loss are able to communicate clearly and confidently in a wide range of situations. Action on Hearing Loss is experienced in providing communication support for hospital appointments, court appearances, job interviews, training courses, counselling sessions, religious ceremonies and many other occasions.

Registered communication professionals

Whether you need to make a one-off booking, or arrange a longer term contract, we'll ensure you receive support from someone with the specialist skills to meet your specific needs. We only work with communication professionals registered with NRCPD, RBSLI or, for assignments in Scotland, SASLI*.

We can supply:

- sign language interpreters
- lipspeakers
- electronic and manual notetakers
- speech-to-text reporters
- interpreters for deafblind people.

* THE NATIONAL REGISTERS OF COMMUNICATION PROFESSIONALS WORKING WITH DEAF AND DEAFBLIND PEOPLE (NRCPD), REGULATORY BODY FOR SIGN LANGUAGE INTERPRETERS AND TRANSLATORS (RBSLI), SCOTTISH ASSOCIATION OF SIGN LANGUAGE INTERPRETERS (SASLI).

"I have had the pleasure to work with Action on Hearing Loss over the last few years for sourcing British Sign Language interpreters for many of my clients and have always received a very good service. The staff are friendly and helpful – even with very short notice or last-minute requests for interpreters, they will do their utmost to help us fulfil the booking."
Lee Haden, Reading Borough Council

How to book

Contact us Monday to Friday, 8.30am to 5pm, on
0845 685 8000 (telephone),
18001 0845 685 8000 (textphone),
07537 410 086 (SMS only) or email
communication.services@hearingloss.org.uk
We also have an out of hours 24/7 service
call 0700 341 8352 18001 (telephone) or 0700 341 8352 (textphone).
For more information, visit: louderthanwords.org.uk/communication-support

Reviews

by Jean Straus

Aural Diversity

A large raised wooden platform fills a dark room: some people are sitting upright on the platform; others lying on the floor. Contact with the platform means everyone is experiencing Sensonic, a composition creating vibrations of low frequency sounds that may be felt but not 'heard' in the conventional sense.

Downstairs, a couple listen to a tinnitus relief soundtrack through user-controlled headphones. In another composition, Overflown, four members of the audience have been brought into the performance space, striking tuning forks at various intervals, accompanying instrumentalists.

Part happening, part experiment, this was the musical embodiment of a newly-coined concept, Aural Diversity, which, quite simply, means we all hear differently. Whether we're unable to differentiate pitch, struggle with tinnitus, or are sensitive to sound itself, shouldn't we all have the possibility of experiencing music and sound in a way that works for us? The concert (one of two), was part of a weekend conference at Leicester University dedicated to Aural Diversity. Andrew Hugill, Professor of Creative Computing, and John Levack Drever, Professor of Acoustic Ecology and Sound Art, and Head of the Unit for Sound Practice Research at Goldsmiths College, organised an event with a range of speakers who were all, in their way, re-interpreting the aural experience.

When you question, you can change things, and this project's mission is to influence policy and future work in fields such as music, audiology, sound studies, environmental design and hearing aid manufacture. The point this project is making is not to take anything for granted about how people are experiencing sound. As Andrew (photo right) says: "Our hearing changes all the time – we all experience varying amounts of hearing loss as we age. Changes in hearing need not necessarily mean loss: some hearing may actually become more acute."

He adds that he's surprised how little people think about differences in hearing. "I think this may be because people with hearing differences generally tend to be quite pragmatic and stoical about their problems and try their hardest to minimise or ignore them. People who have 'normal' hearing, on the other hand, cannot imagine what it is like to be otherwise. So, apart from among the D/deaf community and, more recently, cochlear implant users, I think hearing difference has been regarded as a minor inconvenience rather than a significant challenge. Also, I think it is invariably discussed in pathologised language, such as 'loss', 'impairment' and so on. I like to see it as a form of diversity which, if not exactly to be celebrated, may at least be understood."

Aural diversity, an event with a range of performers, speakers and listeners

Hugill hopes that by "giving it a name, it can become more recognised than at present. I would like to think it can change policy, especially in respect of equality, diversity and inclusion."

It's shocking really, isn't it, that we have neural diversity, bio diversity and, of course, there's cultural, racial and religious diversities as well – so isn't it about time we paid attention to the many kinds of hearing?

If you want to get involved, find out more at auraldiversity.org or email andrew.hugill@leicester.ac.uk

Poetry in motion

Poet Lisa Kelly, Chair of Magma Poetry, invited acclaimed poet Raymond Antrobus to co-edit the Deaf Issue of Magma Poetry Magazine – one of the foremost contemporary UK poetry magazines that celebrated its 25th anniversary last year. The Deaf Issue aimed to give a platform to d/Deaf poets across the range of hearing loss experience.

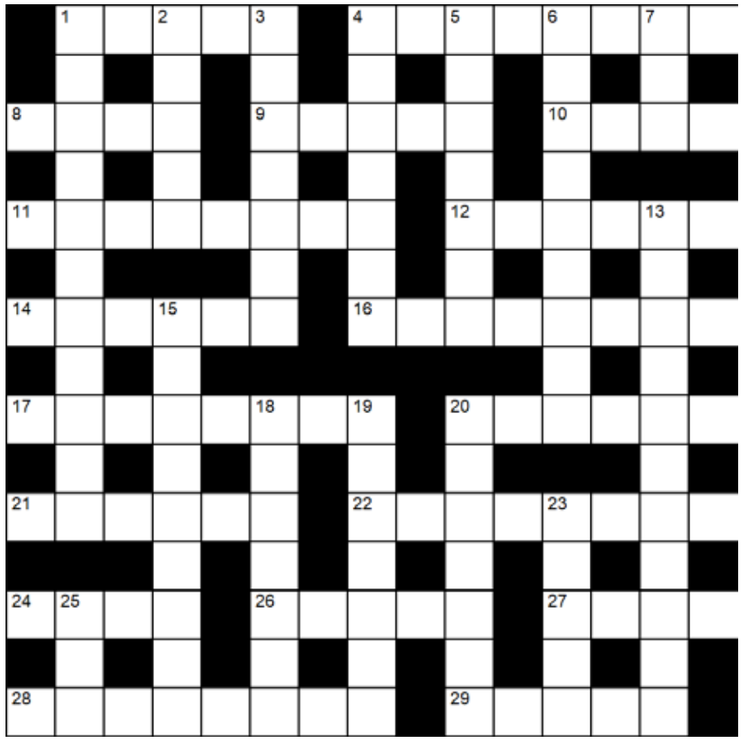
The Poetry Library acknowledged the Deaf Issue as a ground-breaking issue, and Magma went on to create an event, 'How We Hear', at London's Southbank with poets from the Deaf Issue.

We have free copies of the Deaf Issue to give away to the first 50 people to request one. Write to Action on Hearing Loss magazine, 1-3 Highbury Station Road, London N1 2SE or email dawn.dimond@hearingloss.org.uk

Lisa's debut collection for Carcanet Press, 'A Map Towards Fluency', charts her experiences with single sided deafness through mumps as a child and learning British Sign Language

Crossword

Look out for anagrams in clues marked *



Across

1 Communicates in BSL, "Zodiac elements" (5)
4 Scotland's 'Granite' city, where you can help raise money in its June 'Kiltwalk' (8)
8* Same odd flat-topped hill (4)
9 A physical indication of indifference (5)
10 Northern UK organisation dealing with deaf issues (abbrev.) – in disco dance! (4)
11* Dates he's changed for e.g. hands-free devices like stethosets (8)
12 Theatrically expresses feeling ... in demo test (6)
14 Stress ... it's a manner of speaking! (6)
16* Try audio mobile concerned with hearing (8)
17 Embarrassing mistakes, old-fashioned underwear! (8)
20 Insane to free a Spanish city (6)
21 Waffle mixture (6)
22* Wrongly interprets sounds – awful shame, sir! (8)
24 Personal audio features in rehearsal (4)
26 Prison room with nothing for musical instrument (5)
27 Pin down fingertip growth (4)
28 Male clothing makes fellows curse? (8)
29 Performing actions in judo in gym (5)

Down

1* Term for inner ear hair cells– i.e. or elastic, maybe (11)
2 e.g. mesh filter to protect hearing aid from wax (5)
3* Have an inkling ... about cup sets (7)
4 Condition of an absent or blocked ear canal – in theatres, I assume (7)
5 Strongly encourage school chief to be an intellectual (7)
6* Adversely affected sound? Or test did, perhaps (9)
7 Self-importance in allegory (3)
13 Describes loud shrill noise (from operation on lobe?) (3-8)
15* Abnormal bone growth, e.g. in ear canal – so six toes affected! (9)
18* Layman's term for otalgia – A&E reach out (7)
19 Less difficult (7)
20* A BAHA implant is attached to this skull bone – admit, so unusual (7)
23 Boredom – from cerumen? Nuisance! (5)
25 Most common cause of loss of high-frequency sounds in nonagenarians! (3)

Wordsearch

20 words with a seasonal theme

ANEMONE APRIL FOOL CALF
CHICK COLT EASTER FAWN
FEAST FESTIVAL HOT CROSS BUN
LAMBS LENT LILAC MOTHERS
DAY NEST PANCAKE DAY PEONY
SPRING VALENTINE VIOLET

(N.B. LENT is a separate entry in the grid, not part of VALENTINE)

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

Solutions Winter 2020

PHOTOGRAPH: SHUTTERSTOCK

Winners Winter 2020

The crossword winner:
Bernice Drake from Bristol

The wordsearch winner is:
Carolyn Godfrey from Essex

Please send your entry or entries with your name, address and membership number, by **17 June 2020**, to:
Action on Hearing Loss Magazine, 1-3 Highbury Station Road, London N1 1SE

For terms and conditions, please go to actiononhearingloss.org.uk/terms

Prize giveaway

Win a hearing aid compatible, CL100 corded, white, amplified, big-button phone (crossword) or a large number, amplified, vibrating alarm (wordsearch)

Mailbag

David bests Goliath

I recently welcomed the arrival of another movie channel but was sadly disappointed that a well-known and respected company like Sony didn't feel any obligation to add subtitles to their films when a small private company like Talking Pictures, with far fewer resources, has been making great efforts to do this. Well done Talking Pictures. Shame on you, Sony.

Nella Hope, Cirencester

Teletext turnoff

It was only after reading about it in a letter in the Daily Telegraph that I became aware that the BBC would discontinue its Teletext service on January 31. This could cause concern to many deaf people – it is certainly of concern to me. I have written to BBC Complaints.

Dr L Tragen by email

A novel idea

I would like to inform members that places are available on the free, 10-week online Creative Writing course that I run. Ten students have completed the course over the past two years and have felt supported and encouraged in their writing. Two students are continuing with more extended novel writing. Conventional writing classes, workshop-style, are the ideal, but may prove frustrating for people who are hard of hearing. So if you would like to make a start, or even pick up again on something you started some time ago, here's your chance. Submissions of work are welcome by email or post. An introductory sheet and suggestions for the first piece of writing can be obtained from me at: davidstuart114@gmail.com

David Stuart by email

Sunflower lanyard

I have searched your website for information on the sunflower lanyard scheme (a discreet way for people with hidden disabilities to show that they need additional support or just a little more time) and found zero results. There is a detailed article on the RNIB website explaining how it works and how to get involved. The scheme could be of great benefit to those of us with hearing loss.

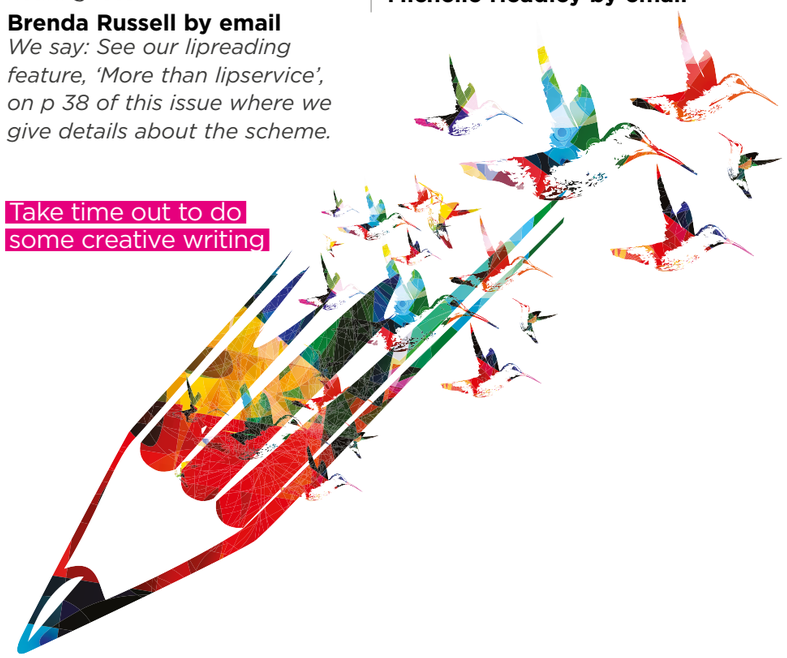
Brenda Russell by email

We say: See our lipreading feature, 'More than lipservice', on p 38 of this issue where we give details about the scheme.

Neat(e) idea

Are members aware of an app called Welcome from the company Neatebox? This free app allows people with accessibility requirements to request visits to participating venues, such as airports, banks, and so on, and for customer service to be aware, in advance, of any specific assistance you need (such as a quiet area, or if you're a sign language user). As Neatebox is based in Scotland, inevitably there are more companies and organisations registered with Welcome there, with a handful in the rest of the UK. I've supported Neatebox from the very beginning because I could see the potential of this service but the more people that use it, the more chance it has of expanding. For details, see neatebox.com

Michelle Headley by email



Take time out to do some creative writing

STAR LETTER

Big it up

I can relate all too well to Caroline Jackson's letter last issue (Getting the message). I am now 80 and profoundly deaf. I can generally communicate face-to-face but cannot hear in the busy places such as the GP surgery, hospital, A&E and dental waiting rooms.

Over the years, I've found it best to over-emphasise my disability and now proudly wear a badge stating the fact. I tried all the ones commercially available but they are too discreet! I eventually found a few 38mm blue ones simply stating 'DEAF' in large capitals. These always produced the desired response but often needed attention drawing to them, so I found a supplier that created even larger ones (50mm or 2") and had a few made in yellow and blue, at under a £1 each, delivered to me.

The result of wearing one of these was immediate – literally, doors opened for me. In the A&E department, a slip of paper was attached to my notes, simply saying 'deaf' and that accompanied me through the system where I was clearly identifiable. I've even been stopped and asked where I obtained the badge and have carried a spare to pass on.

The moral is simple; if you don't advertise your disability, help won't be forthcoming.

Dave Thompson by email

Badges available from: www.hearinglink.org/shop-badges/

Write to: Letters to the Editor, Action on Hearing Loss, 1-3 Highbury Station Road, London N1 1SE or email dawn.dimond@hearingloss.org.uk
Please note, letters may be edited.

For latest updates on what matters to you, follow us on Facebook and Twitter

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@ActionOnHearing

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5 FACTS ABOUT Clare Baars-Gordon

Our new Head of Volunteering Development

1

I was lucky enough to have Deaf peers in my classes at secondary school, which is where I picked up British Sign Language (BSL) as well as an understanding of how important it is to adapt to include people with specific communication requirements.

2

Action on Hearing Loss was the first charity I ever worked for and I'm delighted to have re-joined! During my time away, I gained my level 6 Certificate in BSL and am as passionate about inclusion and accessibility for the D/deaf and hearing loss community as ever. In recent years, I've learnt a lot about a diverse range of volunteering opportunities at other charities including Alzheimer's Society, Teenage Cancer Trust and the National Trust. I've been managing volunteers for nearly seven years, and national teams for the last three years.

3 **The Volunteering Development Team work on all things volunteer-related, from recruitment to the annual volunteering awards. We simply couldn't deliver all the information, support and services we do without our volunteer community, many of whom have personal experience of hearing loss.**

4

I'm really looking forward to continuing to develop volunteering here so it remains a place where people feel their time, skills and expertise are making a real difference. I feel proud to be returning to a charity that's had so much success delivering services, and campaigning against hearing aid cuts, and for improved understanding of hearing loss within the NHS and the wider community.

5 **In my free time, I also volunteer with a heritage project and enjoy lindy hop dancing and a bit of gardening, too.**