

# ReSound

For people with Cochlear Implants


Winter 2023

Issue 76

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Winter in Derbyshire

**Manchester**  
**Cicada**  a charity supporting implant patients

This newsletter has been produced on behalf of the Manchester CICADA Charity

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## Editorial

Welcome to the Winter edition of Resound for 2023.

In this edition we have contributions from several members and are continuing to research opportunities to meet up for events. Apart from the two events recently at Ellesmere port and at Leek we have also identified a location at Riley Green near Blackburn/Burnley as somewhere to get together for those living North of Manchester and are in the process of finding more.

These events will also be focussed in locations which are geographically targeted for smaller groups of people with the aim of allowing more people to meet with others in their area.

Support for potential Cochlear Implant users has always been at the forefront of our activities as is working with the implant clinic.

We have a special item in this issue trying to open up a debate about better communications within the NHS and a

request for feedback from yourselves and your families of your experiences of communications with staff in the NHS in various situations.

A feedback form will be published shortly on the website, to gather information to help us work constructively with the NHS to improve various situations. Any help you can give us with this would be really appreciated.

We have a section on our website with lots of photographs of memorable events that have been run over the years so feel free to browse at:

[www.manchestercicada.org.uk](http://www.manchestercicada.org.uk)

We hope you find this issue of some help and if you've any comments, or stories to send along please let me know.

Kevin Williams - Editor

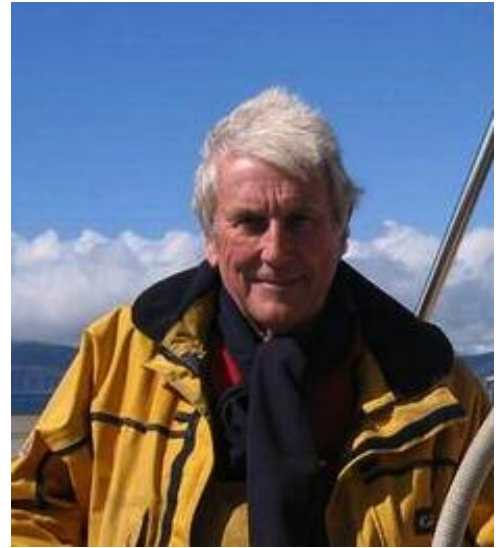
ps. If anyone would like a full size (A3) print of the painting in this or any past issue please let me know.

# SPELLING IT OUT

by John Newton

## SPEECH TO TEXT ON THE PHONE?

Most readers will be familiar with UK Relay but for those who are not it is a system run by British Telecomm (BT) which allows a deaf person to make a phone call and have the respondent's words turned into text which they can read. It has been around for over twenty years but it used to require the user to have a special phone with a screen and a keyboard. The system was repurposed a few years ago to allow it to be run on modern devices like smart phones, tablets and laptops, it was initially called NGTR for New Generation Text Relay. For some reason the latest version is just called UK Relay.



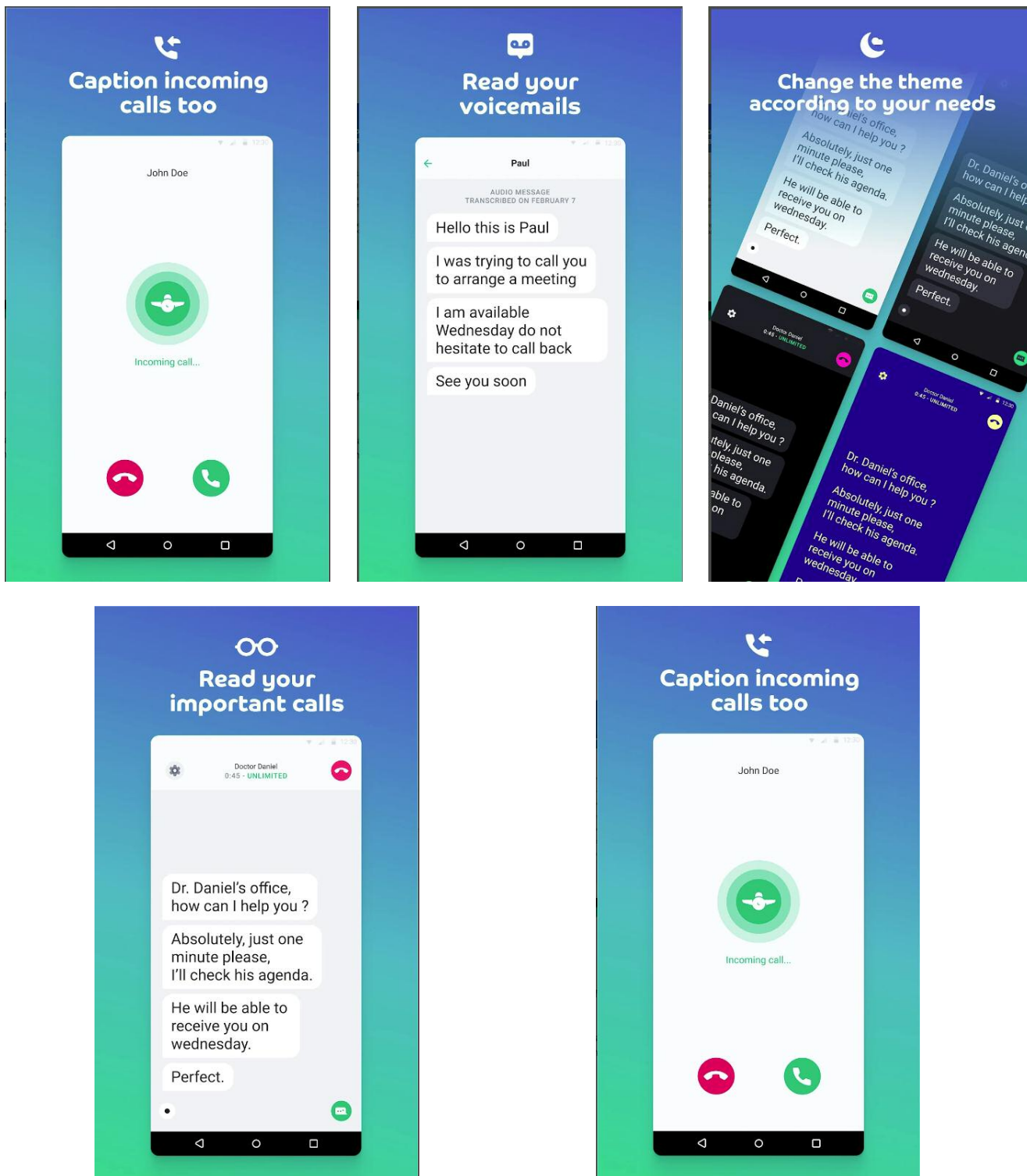
I cannot hear well enough to make voice call so I use the system regularly and find it very valuable. It requires both a good mobile signal and an internet connection, so I usually use it at home and mostly for "business" rather than social calls. (For social calls, the presence of the operator is a bit inhibiting and anyway there are other methods which are more suitable for chatting with your friends and loved ones and which I will come to). However recently it has become apparent that quite a lot of deaf people don't use it for a variety of reasons. The most common seems to be the unhelpful reactions of the people and organisation they call. Quite often the called number don't understand what is happening and hang up. Sometimes they think it's some sort of sales call or even a wrong number. In fact, if the called number just hangs up, the UK Relay operator will ask you if you would like them to redial, if you say yes, on the second attempt you almost always get connected.

The effectiveness of the system has become more important in the last year or so because of the pandemic, and particularly with the NHS. If you need to see your GP now, the default solution is to have a "telephone consultation". If you can't manage voice calls UK Relay is a solution.

However, my experience is that it is not always easy to organise a chat with your Doctor using the system. Obviously doctors have a busy schedule. Mostly they work on the basis of a 15 minute appointment but, of course the actual timing inevitably goes awry as the day progresses. To use the system, I have to initiate the call but the doctor cannot practically undertake to answer at a specific time. The solution which worked for me was to ask the doctor to text me with a number when he or she is ready to talk. I then called back straightaway. Thereafter the chat worked fine, in some respects better than a voice call because you are left with a record of everything the doctor has said.

And there is now a rival/alternative to UK Relay called Roger Voice. This is a commercial project which originated in the USA and which uses computerised translation instead of the human operator. The pricing structure is a bit complicated and, although it is available in the UK, the prices I have seen are in US Dollars. You can call others who

have the app for free, but to call any other number you will have to pay something around £5 a month for one hour of calls or £30 a month for unlimited calls. If you download the app you get an initial 30 minutes free so you can try it out calling any number you like. I used this free time recently to sort out a problem with an insurance policy and it worked fine. The accuracy of the translation is very good with only occasional glitches which are usually obvious except of course that names can get distorted and need to be spelled out.



But what about social calls to friends and relatives? In fact I don't use either of these because like many deaf people I know that, if I can see the speaker's face, I can "hear"

well enough. (presumably by a combination of lipreading and hearing although not consciously). I use one of the various video connection apps such as FaceTime or even video conferencing such as Zoom or Teams. There are others which you may be familiar with. They mostly also have computerised captions available if you want them although I mostly find I don't need them.

And a final thought about this is that people who are not deaf recently have said to me that they use video conferencing all the time and voice only calls less than in the days before Smart phones partly because of the pandemic and also because text messaging is so quick (and cheap).

Perhaps the day will come when all calls are either video or text?

JSN01022023

## Brain flexibility may hasten hearing improvements from cochlear implants

Kickstarting the brain's natural ability to adjust to new circumstances, or neuroplasticity, improves how effectively a cochlear implant can restore hearing loss, a new study in deaf rats shows. The investigation, researchers say, may help explain the extreme variation in hearing improvements experienced by implant recipients.

Unlike hearing aids, which amplify, balance, and sharpen incoming sound, cochlear implants send electrical signals that represent sounds directly to the brain.

Unfortunately, experts say, it can take time to understand the meaning of the signals.

Past studies had shown that, while some cochlear implant users understand some speech hours after receiving their device, others required months or years to do so.

However, the mechanisms that determine how quickly the brain can adjust to an implant have been unclear.

Led by researchers at NYU Langone Health, the new investigation in rats evaluated whether stimulating the **locus coeruleus**, a major site of neuroplasticity deep in the brainstem of mammals, improved how quickly they learned to use their devices.

It showed that within just three days of

receiving their implants, rodents given the extra boost could effectively complete tasks that required accurate hearing.

By contrast, those without the stimulation needed up to 16 days to do so.

"Our findings suggest that differences in neuroplasticity, particularly in parts of the brain such as the locus coeruleus, may help explain why some cochlear implant users improve faster than others," says study lead author and neuroscientist Erin Glennon, PhD, a medical student at NYU Grossman School of Medicine.

In an earlier investigation, the research team found that electrically stimulating the locus coeruleus in rodents increases neuroplasticity and changes how the brain's hearing system represents sound.

However, the new study, publishing online Dec. 21 in the journal *Nature*, is the first to demonstrate that stimulating this brain region hastens hearing among cochlear

implant recipients, according to Glennon. For the investigation, the study authors trained normal hearing rats to press a button after they heard a particular sound and to ignore the button if they heard a different tone.

Once deafened, the rats were unable to complete the task.

Then they were given cochlear implants and retrained to perform the same challenge by relying on the device.

Among the findings, the study showed that locus coeruleus activity changed dramatically as the rats learned to use their implants.

At first, the brain region was most active when the animals received food after hearing the tone and pressing the correct button.

As they learned to associate pressing the button with receiving the reward, activity instead peaked when they just heard the tones.

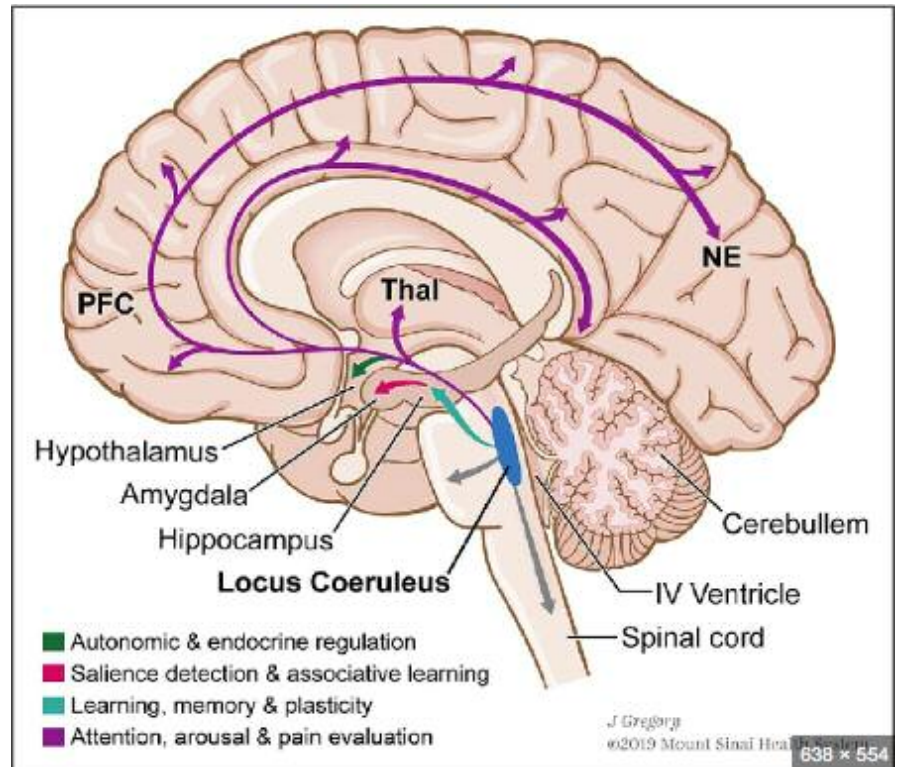
Notably, the faster this change occurred, the faster the rats consistently succeeded at the task.

"Our results suggest that improving neuroplasticity in the locus coeruleus may speed up and bolster the effectiveness of cochlear implants," says study co-senior author and neuroscientist Robert Froemke, PhD, the Skirball Foundation Professor of Genetics in the Department of Neuroscience and Physiology at NYU Langone.

Froemke says the team next plans to explore ways of stimulating the brain region in humans that do not require invasive surgery.

Froemke also serves as a professor in Department of Otolaryngology -- Head and Neck Surgery at NYU Langone.

"Since our goal is to activate the locus coeruleus, we need to determine what noninvasive mechanisms may be used to trigger the brain region," says study co-



senior author Mario Svirsky, PhD.

Svirsky is the Noel L. Cohen Professor of Hearing Science in the Department of Otolaryngology -- Head and Neck Surgery at NYU Langone.

Svirsky, also a professor in NYU Langone's Department of Neuroscience and Physiology, cautions that the rats' hearing was examined using simple sounds in a straightforward task, while humans need to respond to nuanced speech patterns in noisy environments.

Further research, he says, is needed into other brain regions that may be involved.

## Notes

For those of us who by this point in the article have assumed a 'glazed look', here is a short rundown of the important bits of information about the part of the brain involved.

It is related to many functions via its widespread projections. The LC-NA system modulates cortical, subcortical, cerebellar, brainstem, and spinal cord circuits. Some of the most important functions influenced by this system are:

- Arousal and sleep-wake cycle
- Attention and memory
- Behavioral and cognitive flexibility, creativity, behavioral inhibition and stress (psychological)
- Cognitive control
- Decision making and utility maximization
- Emotions
- Neuroplasticity
- Posture and balance

The locus coeruleus is a part of the reticular activating system, and is almost completely inactivated in rapid eye movement sleep.

So all in all its pretty important and may go some way to explaining why different patients adapt at different rates and with variations in eventual benefit.

## Mask wearing affecting deaf people

Mandatory mask wearing saw more than 90% of deaf people struggle to communicate during the pandemic, University of Essex research has revealed.

It also discovered that 76% missed vital information and 59% felt disconnected from society due to the face coverings.

This is because masks restrict the ability to read lips and judge expressions.

It also emerged that over-55s who became deaf later in life found communication using masks more challenging.

And profoundly deaf people and signers experienced more disconnection from society and negative effects on their wellbeing.

Dr Eva Gutierrez-Sigut, from the Department of Psychology, led a team of

deaf and hearing researchers who made sure that the survey was accessible in different sign languages.

Nearly 400 people were surveyed to discover how COVID-19 hit the deaf community and the researcher hopes the findings will now help shape public policy in health emergencies.

Dr Gutierrez-Sigut said: "Mask mandates were vital in fighting the spread of the deadly coronavirus but meant some of our most vulnerable communities were left isolated.

"The pandemic lockdowns were hard for everyone but even more so for the deaf

and hard-of-hearing.

"This research exposes the unexpected consequences policies can have in a fast-moving international emergency and how people can fall through the cracks.

"If the world is gripped by a pandemic again Governments need to do more to be inclusive and engage with communities to find out what they need to thrive and survive."

The paper -- published in Cognitive Research: Principles and Implications -- also uncovered cultural differences in how masks affected understanding, with Brits struggling more than Spanish people across the board.

It is speculated that this is due to differences in mask regulations and that Spaniards made more of an effort to use other means than speaking, such as gesturing, writing, or "some other creative alternatives."

The research also showed that there is no one size fits all approach for the deaf or hard-of-hearing with masks.

Signing, speech reading, and other communication techniques affect comprehension in combination with levels of deafness, whether they can use sign

language, and when hearing loss started.

However, a clear mask which made the entire mouth and lower face visible was the preferred option for many.

Dr Gutierrez-Sigut said: "Most deaf people we spoke to agreed these masks made a real difference and made everything from a trip to the shops to a vital doctor's appointment easier.

"It is worth remembering though that there isn't a one-size fits all solution for these communities.

"The deaf and hard-of-hearing are not a homogenous group and have different needs.

"One thing is clear though, more needs to be done to engage with them.

"To do this we made a real effort to create an accessible study using sign language to reach them.

"We are so thankful deaf and hard of hearing shared their experiences and we hope we can make their voices heard and seen."

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### Story Source:

Materials provided by University of Essex. Note: Content may be edited for style and length.

Customers at East Midlands Airport (EMA) can now communicate through a new British Sign Language (BSL) app.

The logo for SignLive, featuring the word "SignLive" in white text on a black rectangular background.

It will enable people who want to communicate in BSL to connect via video with an interpreter who can provide two-way translation between the customer and an airport team member in a service called SignLive.

According to the census 2021 data, the areas near EMA have the highest percentage of people with BSL as their main language across England and Wales. Mike Grimes, Director of Customer Services and Security, said: "We want all passengers to enjoy their experience of travelling

through EMA, and no one should ever feel excluded from accessing any of our services or facilities.

"We're delighted to announce the introduction of the SignLive app, which will help our Deaf passengers and is another illustration of our commitment to removing all barriers to travel."

"It's one of many initiatives the airport implements after consulting with the advisory group and listening to its disabled customers."



**How Meludia Helps Cochlear Implant Recipients Enjoy Music**

Music training helps you get the most out of your cochlear implant, and we're not just talking about music enjoyment. Music training can help you understand conversations in noisy environments, increase your listening skills, and even tune into emotions. But how can you get started with it?

Let us introduce you to Meludia. This online platform makes music training accessible to you, no matter where you are in the world.

**Meludia: Music Training Made Fun**

Fun, playful, and interactive—that's Meludia.

Look at the star-like interface to see what we mean.

It guides you step-by-step through different skill branches, like melody or rhythm.

In total there are over 600 different exercises, which you can complete at a pace that suits you.



## Tailored to Cochlear Implant Users



One of the great things about Meludia is that it's accessible to everyone. It doesn't matter how old you are, or what kind of musical background you have. There are levels ranging from "discovery" to "expert".

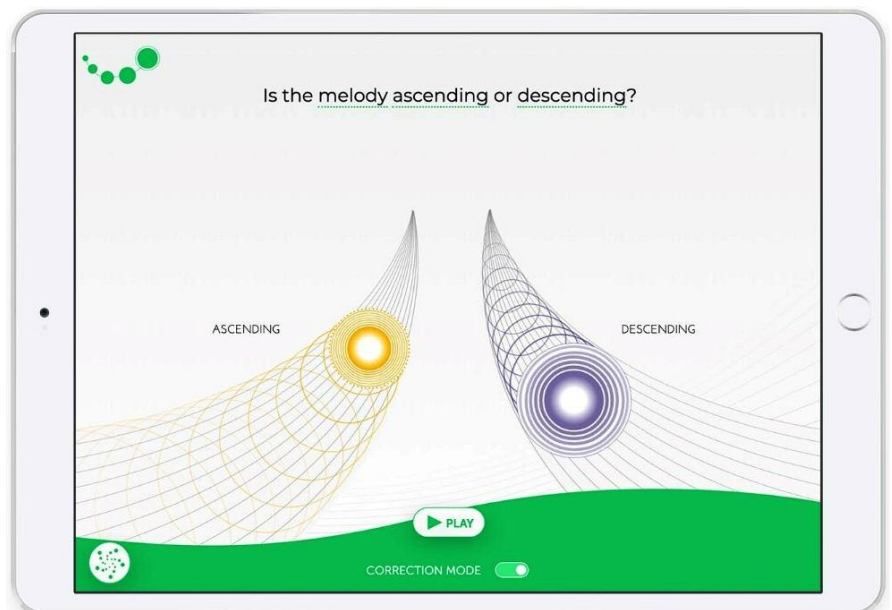
Meludia is suitable for all hearing implant users, but especially cochlear implant users. The platform has been thoroughly tested to make sure that the exercises are suitable for all cochlear implant recipients, regardless of when you got your CI, or how severe your hearing loss is.

## More Than Music

The platform is built to meet all kinds of musical goals, whether you want to finetune your piano skills, or just get back to enjoying your favourite pop song.

But its benefits go beyond music. Studies show that by using music training tools like Meludia you can build your overall listening skills.

It can help improve your listening attention, understanding of speech, and verbal memory.



## Free Access to Meludia for myMED-EL Users

Want to try Meludia for yourself? We're offering 12 months of free access to Meludia through your myMED-EL account. \* Sign up at

<https://web.meludia.com/en/login/medel/sso/login>

Don't have a myMED-EL account yet? No problem! It's free, sign up here

<https://my.medel.com/>

\* This offer is only available from October 6, 2022, to October 5, 2023. Offer may not be valid in all countries due to local laws and restrictions.



hearpeers

### BECOME A MENTOR

- Do you use a MED-EL hearing device?
- Could you help others by sharing your hearing journey?
- Do you want to make a difference?

We are looking for people who are users of MED-EL hearing implants to join our community of Hearpeers mentors across UK and Ireland, offering support and advice to others to make a difference.

#### **What you need to do as a mentor:**

You will support existing and new users by providing information based on your own experiences. Gaining support from other volunteers, MED-EL colleagues and our global Hearpeers community. Share your hearing journey, pre and post implantation, as well as your top tips for life with an implant through our online portal or other platforms.

#### **Interested?**

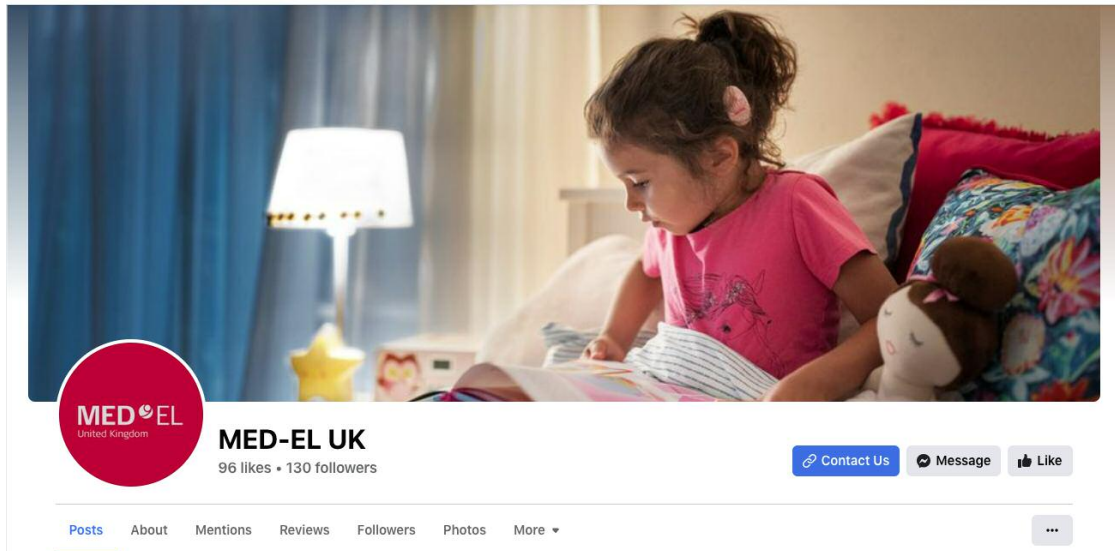
You can contact our Hearpeers Manager, Nicola Pestana to apply or find out more information.

**Tel:**07910028517

**email:**nicola.prestana@medel.com



Alternatively apply directly by scanning the QR Code



We are delighted to share with you the news that MED-EL UK now has its own Facebook page. Launched at the beginning of October, visitors to the page can view posts on news items, product updates, upcoming events, and offers. Why not visit our page today by clicking and give us a like!

<https://www.facebook.com/profile.php?id=100086148147481>

## Hospital Support for D/deaf patients

### Issues for D/deaf while in hospital

For any one of us, a visit to the hospital can be a stressful experience.

Someone going into A&E has to have a short discussion with a receptionist behind a screen to establish their identity and the reason for going there. If you include trying to have that conversation through a mask, then a deaf person struggles to get over the first fence. Muffled conversations are a challenge.

You inform the receptionist that you are deaf and need to lipread and can they tell the medical staff about you. Then you sit down and await your turn to see someone. Of course there is no sequence to this, as some people are quite rightly, prioritized on the severity of their issue, so counting your position in a queue is not an option.

In the larger waiting rooms staff are rushing about coming out of any number of doors shouting peoples' names from behind masks sometimes over fifty feet away in the larger hospitals, so your head tends to start spinning eventually, shades of the Exorcist movie?

Lots of waiting rooms have televisions running news and entertainment stories (without subtitles of course) and so if you have a small amount of hearing left then the TV masks out any attempt to hear your name being called.

Eventually you have to rely on a hearing friend going with you to get over this hurdle or you wait to see if an overstressed member of staff seems to call out someone's name multiple times with no reply so you can venture to ask 'did you say my name?'

Of course from this point onwards you have to explain to every member of staff you meet, triage, first assessment, blood samples (why do they always have a needle to

hand) that you lipread etc. and there can be many steps along the way being sent to different departments, X-ray, CT scan etc. for further clarification of the issue in order to get treated and each visit begins the same way.

### **Issues for staff dealing with deaf patients**

Where to begin with this section?

Working on the front line in the NHS is one of the most stressful and demanding jobs there is and compounding the issue of course is the extra pressure of not making what could be a critical mistake whilst dealing with the number of patients that need looking after.

Most meetings begin with questions about the reason for coming and also any medications that you are on, this of course is interrupted right at the beginning with you having to say that you're deaf, you lipread and they're wearing a mask.

In any conversational situation this certainly disrupts the flow!

What happens next really depends on the experience of the staff member, reactions range from speaking louder, shouting in the ear, a look of panic, or getting some extra staff support. Whatever the reaction, it disrupts the process that the staff member is going through which is designed to get to the root of the problem as soon as possible to move the patient through the diagnostic process to treatment. Deafness is not a visible disability so is always a surprise to the nurse.

### **Support for staff**

The first issue that needs addressing is how to make sure that anyone that you come in contact with during treatment knows you are deaf.

There are wristbands, badges and similar things that you can get from RNID, Hearing link and other organisations that have that information on them. However in an emergency it's not always easy to remember to pick up your wristband on the way out of the house.

The second point is that the health professional has to have some idea what to do about it.

Before Covid (BC) at our local hospital we ran a deaf awareness session for all new staff as part of their induction course which was really effective, but was stopped when Covid arrived.

For staff who have already completed their induction training, it's not easy or practical to ask a ward manager to release them for training, on some measures, it's a low priority as the percentage of deaf people on the wards is usually low.

### **Misconceptions amongst some staff about deaf patients**

How many times has the first reaction to the news about your deafness been 'Do you use sign language?' Unless you were born deaf or live in a family whose first language is BSL then the answer is usually no, those of us who have gradually become deafened or had a trauma do not.

How many staff have a basic vocabulary of BSL even if the patient knew it?

From a practical point of view, at the Doctors' rounds in the mornings on a ward for example, would an interpreter be available on call?

Can you lipread? 'yes reasonably well' then they rush around the bed doing things and talking as they go expecting side on lipreading at the normal speech rate to go on whilst having their back to the window.

OK that's not a personal criticism, we're all human, they have a job to do in a short space of time and are used to chatting to hearing patients as they work.

Have you got a hearing aid? If the answer is yes then many expect you to have normal hearing whilst wearing it. I could write a book about that one!

Again, this is not a criticism, it's part of human nature.

### **Organisational constraints and working practices**

There seem to be several circumstances where communication issues arise, A & E department and outpatient appointments, on a ward awaiting a planned operation and on a ward after an emergency admission.

In only one of those situations would it be possible for you as the patient to try and plan your own communications support, and that is the planned operation.

### **Actions tried so far to improve situation**

- Deaf Awareness training for new hospital staff

- Information Card for Wards

- Ward training sessions

- Investigation into the Patients records system to record that a patient has 'Communications difficulties', revealed that although the database does include a flag for this status, there was no clear procedure to actually update this other than sometime after a patient was in the hospital by a positive action from admin staff.

### **Actual results and constraints**

The deaf awareness training for new members of staff was rolled out and was a regular feature of the induction process before Covid arrived. Subsequent visits to wards by myself showed that many staff remembered the hints and tips that we had discussed and practiced on the courses.

The information cards were issued to ward clerks for use. However although each one was sealed in plastic, there were concerns over possible cross contamination once used.

Originally each card would be on the bedside cabinet of patients but some patients did not want attention being drawn to themselves by it being displayed. It was then placed in their patient notes, but this meant that unless one looked at the notes, other ward staff such as auxiliaries may not have the opportunity to see the card at all.

Having spent some time on the wards myself helping staff with any issues it was often the case that the ward staff changed each week and therefore the new team would need briefing again.

Although a database is kept of all Audiology patients attending the hospital (Tameside General in this case) this was on a totally different database to the main patients records system with the communications difficulty flag on and on enquiry it was thought difficult

to automatically update. The net effect of this is that a patient coming in for elective surgery would not be flagged up with the issue before arriving in hospital thereby preventing any meaningful preparation for assistance in advance.

### **Where we are today**

Deaf awareness training ceased when the covid outbreak began and has not since then been resumed.

I have had no updates on the usage of the patient cards although Manchester Royal Infirmary said at one point they could use it.

### **Going forward and ideas**

Any feedback from you or your family's experiences with the NHS in regard to communications issues would be a great help going forward. We have published a form for this and hope to use this in discussions with the NHS. If you are interested in helping here is the link <https://tinyurl.com/2wcmaaya>

We will recommend to NHS that there is a visible sticker applied to the outside of your patient notes (along the lines of the standard blue logo) to indicate to anyone who looks at your notes so they can prepare better to communicate with you.

We will be re-examining ways of being able to use the patient cards more effectively. We have uploaded the **Patient records card** to the website at this link, <https://www.manchestercicada.org.uk/accessory-help/> so that you can see what it looks like, it is double sided. If anyone wants a laminated version let me know.

Hot off the press! this news item was published yesterday and shows that we are not the only ones who are concerned about the issue.

<https://uk.style.yahoo.com/concern-over-lack-progress-supporting-124306977.html>

## Lip reading corner

In the last Resound, John Newton wrote about his experience at the Association of Teachers of Lipreading to Adults (ATLA) conference, talking to people about cochlear implants. ATLA was very pleased to have John there, as it is important that lipreading teachers have some knowledge of CIs. The conference was a mix of academic presentations, and ATLA focused discussions.

One of the most interesting presentations was given by Dr Helen Pryce, from Aston University. The talk was entitled 'Hearing Loss and Patient Experience (HeLP): Using patient experience to improve audiology services'. I guess this is a topic that will be close to many hearts. She is working on a research project, looking at why audiology services are not always seen as helpful, and to understand what can be done to improve these services. It is a very large project, and they are looking for users of audiology services, and their families, to talk about their experiences. There are surveys, and tools for measurement. If you are interested, the website is:

<https://www.aston.ac.uk/research/hls/hearing-loss-and-patient-reported-experience-help>

I'll look forward to telling you about the results of this research in a few years time.

# Notes

As we move towards a new events program, keep an eye open on the website and Facebook pages for more news of events and meet up's. We would welcome any feedback or suggestions for events, articles for Resound especially on your experiences of the lockdown.

Either email  
secretary@manchestercicada.org.uk

Or write to me at the address below, all submissions are welcome.

## CICADA

Website: [www.manchestercicada.org.uk](http://www.manchestercicada.org.uk)

Facebook group: Manchester CICADA club

Secretary direct contact: Text 07533217730

Main contacts for Cicada listed at the bottom of this page.

## Manchester Implant Centre

The Richard Ramsden Centre for Auditory Implants, Peter Mount Building, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL

Main Contact Details:

Tel: 0161 701 6931 ( Appointments)

Tel: 0161 276 8079 (repairs and spares)

\* Please check the website regularly for updates on what the clinic are doing in the light of the virus outbreak.

<http://www.manchestercicada.org.uk/implant-clinic/>

## National Support organisations

**British Tinnitus Association:**

<https://www.tinnitus.org.uk/>

**Hearing Link:**

<https://www.hearinglink.org/>

**RNID (Action on Hearing Loss):**

<https://www.actiononhearingloss.org.uk/>

**Disabled Travel Advice:**

<http://www.disabledtraveladvice.co.uk/>

**Meniere's Society:**

<http://www.menieres.org.uk/>

**National Deaf Children's Society:**

<http://www.ndcs.org.uk/>

**National Association of Deafened People**

**(NADP):** [http:// www.nadp.org.uk/](http://www.nadp.org.uk/)

## Equipment Suppliers for Deaf People

**Sarabec:** <https://www.sarabec.com/>

**Connevans:** <http://www.connevans.co.uk>

**Hearing Link UK:** <https://www.hearinglink.org/>

**RNID (Action on Hearing Loss):**

<https://www.actiononhearingloss.org.uk/>

## COVID-19 information links.

(Just some official ones which you can subscribe to to get updates)

Main government website which has links to information and also a facility to be on a mailing list for updates which is handy.

<https://www.gov.uk/coronavirus>

Most local council websites now have a corona virus section to tell us what they are doing and what services may be affected.

If you need help for other things during the duration of the virus then contact social services in the first instance.

<b>Chairman</b>	<b>Honorary Treasurer</b>	<b>Hon Secretary</b>
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