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Newsletter

NATIONAL COCHLEAR IMPLANT USERS ASSOCIATION NEWSLETTER

'Time to Talk about Cochlear Implants': increasing cochlear implant referrals in the audiology services

Anne-Marie Dickinson, Specialist Audiologist, Withington Community Hospital

Anne-Marie is a member of the British Academy of Audiology Service Quality Committee. The committee aims to move the profession forward in terms of quality of services. In January she wrote an article BAA magazine about cochlear implant referral and this talk builds on what was said in that article.

Nigel Williams, Anne-Marie Dickinson and Carl Verschuur at the Summer Meeting 2019

Anne-Marie said that when she was doing her PhD she learnt about the limitations of hearing aid technology and the differences cochlear implants can make, but the facts about cochlear implants are not well known among non-implant Audiologists. They are expensive procedures but they are highly cost effective interventions because the outcomes for people who have them are so good. This is not widely known. At the Richard Ramsden Centre they publish their results in terms of speech scores and also what the patients said about their implants and the outcomes they get, but this is rare.

The statistics about cochlear implant referral and uptake are not very accurate but it is estimated that <7% of eligible adults have an implant. About 50% of those assessed at the cochlear implant centres are found not suitable or do not want an implant, so approximately 14% of eligible adults are assessed for an implant. Not all adults offered an assessment will want one but most do so it is likely that less than 20% of eligible adults are actually being informed about implants and being made aware that they are available. This is not acceptable. It is important to consider how cochlear implants are discussed with patients. The amount of time spent with the patient and the quality of the discussion is vital. The patient needs to understand exactly what can be gained from an implant so they can make a well-informed decision.

There has been some really interesting research about this. Research has looked into how confident audiologists are when interpreting the guidelines and actually having a discussion with patients and their families. The studies showed confidence was low but that a small amount of training on candidacy criteria made a big difference. This definitely suggests that there is a training issue in the profession. It was felt that the specialist knowledge needed to discuss implants was not provided by the standard training route. The three year university training course is essentially a healthcare science degree and the proportion devoted to cochlear implants minimal. So specialist training has to be put in place. The Ear Foundation presented a report to the British Audiology Association conference last year and this identified the need to for training,

straightforward referral routes, streamlined administration and really good communication between the cochlear implant centres and the referring centres.

In my role as a technical assessor of the clinical competency of various services in the independent sector I always asked services how they refer adults for cochlear implants. The routine answer in the independent sector was 'we don't know anything about implants, it is not our area'. This means that hearing care high-street providers have no referral pathway for people needing a cochlear implant assessment, it's at the discretion of the audiologist or the hearing aid dispenser. Audiologists in the independent sector rely on hearing aid technology but it does not answer their patient's problems. The outcomes of frequency lowering (a technology often aimed at adults with severe to profound deafness) are not in the same ballpark as outcomes with a cochlear implant. There is an acknowledgement that something needs to be done about cochlear implant referral in the independent sector but a huge amount of training and service development is required. Sometimes NHS departments feel that only a couple of senior staff need to know about implants. But patients need to have a consistent message about how cochlear implants work and they may need to have a conversation about an implant assessment with several members of staff before they decide if they want to go. It may be a conversation with someone they know very well, such as the assistant audiologist, whom they often see for hearing aid repairs. So everyone in the department should understand the benefits of cochlear implants, not just senior staff.

What is the existing training for implant referral? Often training for a cochlear implant referral might be one visit from a cochlear implant centre every few years and for a few hours only. This does not leave people confident that they can identify candidates and have a discussion about cochlear implants. It needs training which is interactive, looks at case studies and which supports people by letting them observe a discussion. In the NHS, there are often preconceived ideas about what type of patient may be suitable for a referral. The article which I wrote focused on this and gave a table of appropriate referrals, it described type of loss, duration of loss, cognition, the language people spoke and age; all of which are no barrier to implantation.

Often when an implant is first discussed people will say that they don't want an operation and that they are too old. It is important not to leave the conversation there but to make sure patients have all the information. Sometimes it is best not to talk about cochlear implants initially but to talk about hearing loss and what it means in terms of damage to their inner ear; to explain, because of the damage, there are limitations with hearing aid technology and hearing aids cannot work well because the inner ear cannot pick up the sound and transmit it to the brain. Then it is possible to talk about cochlear implants and how they work differently. This means the patient can fully understand why hearing aids are not working for them and fully understand why a cochlear implant is being suggested. Then they can make the decision themselves about whether they want to find out more about cochlear implants.

This conversation makes sure that patients are not waiting for a hearing aid to become available that will solve all their problems. What I put across in my article is that patients should have enough information to make a fully informed choice about whether they want to go ahead with assessment or not. Often when patients say yes to an assessment they feel that they are actually saying yes to an implant and that is something we have to counsel carefully about. We say that they are going to find out more information and the centre is the best place to get it from. It is important to take time over this discussion. Sometimes it takes a number of appointments and the patient may want to bring in family members.

As well as counselling and training there are also clinical procedures that could be adjusted to help with the referral process. Maybe there could be a report template so that administration is minimised and it is clear where the referral goes and who can make the referral. Being able to ask questions informally to staff at the implant centre helps and is a great form of training as the information can be shared among the department. There should be some kind of notes made to record what happens during an appointment in terms of implant referral discussion. It should be the norm for cochlear implants to be discussed when the patient has a severe profound hearing loss.

Most professionals appear unaware of the low referral rate for cochlear implants and when training courses are offered few attend. It may be that online training should be offered so that they do not have to attend meetings. The patient

needs to be supported actively to live the life they want to lead and we need to think of rehabilitation as a holistic view. We need to think about their environment, their personal factors, what they want to participate in, their hearing loss, and what activities they want to do, in order to question more carefully about what is a good outcome with hearing aids. Thankfully this teaching is being done more and more at university. Audiology is not just about giving people hearing aids, it is about providing people with rehabilitation so they can live with their hearing loss, so they are fulfilled and can 'live-well' with their hearing impairment. Cochlear implant referral counselling is a vital part of that rehabilitation.

I feel awareness needs to change and that, as a profession, we need to alter our approach. We need to make sure people have the right information and we need to make sure cochlear implant referral is an integral part of our policies and procedures. Onward referral is within the NICE procedures but actually this guideline is not enough. Implant referral needs to be within professional procedures (e.g. by the British Academy of Audiology, British Society of Audiology and British Society of Hearing Aid Audiologists), so that audiologists in the NHS and independent sector offer a standardised, high-quality implant referral counselling service.
My article was just a start and I have been pleased with the response it had. The British Academy of Audiology are going to produce and animated video raising awareness of implants and giving information to reduce barriers. It will be dispersed on social media and twitter. It will send the message that cochlear implants work and information about how to access them. It will be for GPs, ENT doctors, audiologist and the general public. Please share this video widely to help spread the message. Thanks for your support.

Manufacturer's News

From Advanced Bionics - Naída CI Connect

Stream Direct. Hands Free. Any Device.
Technology lets us connect with family and friends in a simple and seamless way. Hands free phone calls and direct media streaming are a part of everyday modern life. And Bluetooth® connects the devices we love. At Advanced Bionics, we believe that cochlear implant patients should be able to stream directly and call hands free from any device.

Phonak + AB have developed Naída™ CI Connect — an elegant, design-integrated solution for the Naída CI Q90 sound processor.

Stream Direct – Nothing in Your Way
Stream phone calls or your favourite music via Bluetooth without the hassle of a body worn device. Stream the sound from your TV directly to your sound processor with a simple plug-and-play solution.

Call Hands Free – Multitask While Calling
With Naída CI Connect, hear the phone ringing directly in your sound processor, and answer calls without even touching your phone. Your Naída CI Q90 becomes a Bluetooth wireless headset with built-in microphones that pick up your own voice for phone calls. Enjoy hands free calling and multitask while using your phone.

Connect to Any Device – Your Phone, Your Choice.
Whatever type of phone you use, Naída CI Q90 connects to it. It works with Android™, iOS, and any feature phone. And not just phones: Naída CI Q90 connects you to all Bluetooth enabled tablets, laptops, and MP3 players.*

For more information visit AdvancedBionics.com or email info.uk@advancedbionics.com

** Compatible with Bluetooth® 4.2 wireless technology and most older Bluetooth phones. Visit our website to check device compatibility.*

From Cochlear

The Nucleus® Smart App: First for iPhone. First for Android.

With a Cochlear™ Nucleus® 7 Sound Processor, you can live a life without limits. You can work, play and do everything in between. And with the Nucleus Smart App, designed specifically for the Nucleus 7 Sound Processor, you can enjoy added peace of mind and increased insight into your hearing progress in the palm of your hand.
With the Nucleus Smart App, you can find a lost Nucleus 7 Sound Processor using GPS technology. This tells you the last location the sound processor had contact with your compatible smartphone1. Hearing Tracker information and the built-in data logging of the sound processor also helps your hearing health professional troubleshoot problems or make adjustments.
With the Nucleus Smart App, you can:

- Access your hearing information - View time in speech and listening environment data.
- Find a lost processor - Get help locating a misplaced Nucleus 7 Sound Processor with the 'Find My Processor' function.
- Adjust your sound processor volume and settings to focus on the sounds you want to hear, without carrying a separate remote control.
- Check sound processor status and battery level to make sure your equipment is working properly.
- Enjoy True Wireless™ freedom - Start and stop streaming from a Cochlear True Wireless device with just a tap on your compatible Apple or Android device[1]

To experience all the features of the Nucleus Smart App, download free from the Apple App Store or Google Play Store.

[1] *For a list of compatible Apple and Android devices visit www.cochlear.com/compatibility.*
Android and Google Play are trademarks of Google LLC.

iPhone, Apple and the Apple App Store are trademarks of Apple Inc.

JOIN THE LARGEST COMMUNITY OF COCHLEAR DEVICE RECIPIENTS

Whether you have been recently implanted or started your hearing journey years ago, as a Cochlear™ recipient you can become part of a very special family – one united by sound and connected by Cochlear. By joining Cochlear Family, you're entitled to a whole host of benefits that come from being a member of the largest community of cochlear device recipients.

We understand you want to know more about your device and how to live your life with a hearing implant, so we created the Cochlear Family programme to help you get the most from their hearing. The programme provides answers to your day-to-day questions and delivers information about our latest technology releases and how they could help you get more from your hearing.
Exclusive to members, you also receive free shipping to your home on all purchases from our online store and with email alerts, you are first to hear about special offers and events.

Going somewhere? Our Cochlear™ Travel Programme has got you covered. As a member of the Cochlear Family you'll receive a 25% discount off our Full Back-Up plan, designed to ensure you won't miss a moment of your holiday should you lose or damage your sound processor.

Learn more and become a Cochlear Family member today, for free and with no obligations, at www.cochlear.com/family **Now available SONNET 2 with app and AudioLink connectivity**.

From MED-EL

Don't fit your life around your audio processor — choose a processor that fits your life! With automatic sound management including adaptive intelligence, the AudioKey app, an all-in-one connectivity device with the AudioLink, and the new FineTuner Echo remote, the new SONNET 2 package is now available in the UK.

NEW: SONNET 2 for easy listening
Whether at school, or in work; on the playground, or at the beach; our new SONNET 2 is made for you.

With the special Adaptive Intelligence and noise reduction feature you never need to change a setting again thanks to an intuitive design that detects changes in the environment and adapts for you, whether you're listening to music or with friends in a busy restaurant. This means that you / your child always has optimal hearing, even in the most challenging environments.

Adaptive intelligence and noise reduction are standard within the latest Automatic Sound Management technology, only from MED-EL.

NEW: AudioKey app for iOS and Android
With the new AudioKey app you can change settings, 'find my processor' to an exact location, and check advanced hearing stats including accessory use —all directly from your Android or iPhone.

NEW: FineTuner Echo
Don't worry if an app isn't for you, the new FineTuner Echo remote control makes it easy to change settings and it even allows you to test the microphones of your audio processor, so you can quickly check if your device is working correctly.

NEW: Guardian Controls only with MED-EL
The AudioKey "Guardian Role" allows parents to check their child is hearing their best, adjust the settings on their child's audio processor from their phone, and keep a record of their hearing stats. AudioKey is also the only app that allows parents to pair more than one audio processor (or bilateral pair) with their phone, which is ideal if you have multiple children with cochlear implants.

NEW: Connect whenever, wherever, and to whatever with AudioLink
Why use multiple wireless streamers for different situations when you can simply have one! The AudioLink is an all-in-one device that's ideal for making calls, listening to music, docked next to the TV, and even acts as a remote microphone for meetings or at school. Included as standard with all SONNET 2 kits so you don't have any extra expense.

To find out more visit www.medel.com/sonnet2

From Oticon Medical

With the launch of Neuro 2, the smallest ever Behind-The-Ear (BTE) cochlear implant sound processor, Oticon Medical continues to bring expertise in micromechanics, sound processing and usability into the field of cochlear implants.

Award-winning design
Neuro 2 sets new aesthetic standards with an organic shape that is discreet and comfortable for users of all ages. Its design is characterised by an attention to detail that gives outstanding reliability and usability. This can be seen in its IP68 ranking – the highest protection in the CI industry against water and dust, reached without the need for any external accessories – the ultra-strong transparent cable, and features like the voice-activated microphone check and the battery door lock.

"Our uncompromising commitment to design excellence in the Neuro 2 has already resulted in a number of design awards, including the prestigious Red Dot Awards 2017 and 2018, the Good Design Award 2017, and the iF Design Award 2018," says Jes Olsen, President of Oticon Medical.

Taking the strain out of hearing
In addition to the multi-awarded design, Neuro 2 features unique technologies based on BrainHearingTM, the Oticon Medical philosophy to make listening and understanding as easy as possible and that frees up cognitive energy. These technologies include the surrounding mode with speech prioritization called Speech Omni, and the output compression system called Voice Guard, designed to preserve 95% of speech.

The perfect partner with Oticon hearing aids
For users who already use an Oticon hearing aid, the Neuro 2 provides the perfect match of sound processing technologies. Built on BrainHearing™, the two instruments share the same technologies and optimize the two acoustic inputs, so all important information is combined into a rich sound experience.

For more information, please visit www.oticonmedical.com/Neuro2

Designing and Assessing the Feasibility of a Randomised Controlled Trial of Bilateral Cochlear Implants in Adults

- Padraig Kitterick, Head of Hearing Sciences in the School of Medicine, Nottingham University

For about two years we have been running a project which looks at whether we can do a clinical trial for a very large piece of research on bilateral cochlear implants for adults. As it is not a clinical trial itself but lays the foundation for a future trial it is called a foundation study.

The updated NICE guidance does not recommend bilateral implants for adults but it does not say that they do not provide benefits. They agreed that they do provide additional benefits over one implant. In particular they quoted input from patients themselves which said that two implants can help reduce listening difficulties and improve spatial hearing, that is whether the sound comes from this side or that side, so that they can help reduce listening effort and fatigue and can provide benefits to overall health and wellbeing. NICE want us to measure quality of life - health and wellbeing – not how good someone is on a test of speech understanding or sound localisation.

The question is can we do that? As the trial will cost money and will need the support of the companies the answer to this question is important. Will patients agree to take part and will they agree to be randomised so that whether they get one or two implants will be outside their control. This is necessary as the quality of life of people who have one implant needs to be compared with people who have two and, in order to measure this, the participants need to be willing to complete questionnaires.

The size of the trial, or how many patients are needed, is another matter that has to be resolved. If a big change is expected only a few are needed but if it is only a small and subtle difference many more need to be recruited.

A survey of candidates, existing implant users and clinical professionals has already been done. There were people awaiting an implant, people who had only been implanted a few weeks and people who had been using their implants for a long time. There were also unilateral and bilateral implant users. Almost 100 cochlear implant users and 40 health care professionals took part. Many issues came up. Only patients who were considered suitable for two implants would be randomised to get one or two. Both the clinical team and the patient would have to agree to this. Residual hearing is a huge issue as many people are unsure about which ear to go for. Should they have the poorer ear implanted and have a hearing aid in the better ear and so on. Another point that arose is that there is no really good accessible information about the benefits and risks of two implants versus one. A website with videos of people who have two implants or one implant talking about their experiences and the issues they have to deal with might help.

We asked participants two key questions. The first was do you think adult candidates would consider participating in the clinical trial. The health care professionals were a little more optimistic about the trial but in general three quarters of the implant users and clinicians thought that people would consider participating in the trial. About two thirds of the implant users and candidates in the survey would themselves have considered participating in the clinical trial.

The second part of the study involved screening adults who were going through the assessment pathway. Five auditory implant programmes were involved: Nottingham, St Thomas', Manchester and Southampton. To date they have screened nearly 350 candidates who were eligible for two implants and could participate in the trial. The acceptance level was sufficient to support a subsequent trial. All this happened in six months but we have yet to complete the analysis of the quality of life data.

There is a study management team and a steering group with an independent chair and independent members to oversee how we do the study. Our patient representative on the study management team is Richard Byrnes of the NCIUA.

Northern Cochlear Implant Social Group

Hello everyone... My name is Sue Clay. I host the 'Northern Cochlear Implant Social Group'. My husband and I founded the group in January 2017 after we became aware that candidates would like to meet other users who had also been through the CI journey to talk about their experiences. We are a very friendly group where users of all CI brands are welcome to come along and meet others to have a chat. Everyone is made to feel part of our close CI family. Our members are at different stages of their journey - some are just beginning, some have had the operation and awaiting activation while others have had their CI's for a while.

We hold meetings twice every month. One social is held on the First Monday of the month, in the bustling City of Sheffield at the 'Quaker Meeting House' just a short walk from the ancient Cathedral of Sheffield. The other meeting is held on the last Saturday of every month in the market town of Worksop at the 'Crossing Church and Centre'. New members are always welcome. You have no need to register.

Just pop along on one of the days advertised. Below is a fb link to our group:
https://www.facebook.com/groups/1433315196830 82/

For details of other support groups please see our website: www.nciua.org.uk/regional-groups/

DIARY DATES

November Forum on Saturday 2nd November at Claydon Hotel, St. Mary Street, Cardiff CF10 GD.

Please see www.nciau.org.uk/events/ for further details.

National Cochlear Implant Users Association

President:	Jackie Ashley
***Chairman**	Nigel Williams e-mail: chair@nciua.org.uk
***Vice Chairman**	Tricia Kemp E-mail: vice.chair@nciua.org.uk
***Treasurer**	Paul Tomlinson E-mail: treasurer@nciua.org.uk
***Secretary**	Dr Ray Glover 11 Hamilton Close, Bicester, Oxfordshire, OX26 2HX E-mail: secretary@nciua.org.uk
***Editor**	Alison Heath E-mail: editor@nciua.org.uk
***Committee Members**	Jenny Burdge, Richard Byrnes,

Registered Address:
NCIUA, 11 Hamilton Close, Bicester, Oxfordshire, OX26 2HX
Registered Charity No. 1073222
Web Site: www.nciua.org.uk E-mail: enquiries@nciua.org.uk