The National Hearing Implant & Research Centre
Beaumont Hospital/Children's University Hospital Temple Street
☎ (01) 809 2191
☎ (01) 809 2013

Text phone: 087 953 5423
e-mail: cochlearimplant@beaumont.ie

Helping Deaf Children to Hear and Talk

Original written by:
Jennifer Robertson, Claire Sheehan & Jaclyn Smith
with contributions from all the Cochlear Implant Team
Revised 2020 by Jennifer Robertson
Cover Drawings by Marie Denham

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The Paediatric Cochlear Implant Programme

The National Paediatric Cochlear Implant Programme was established in 1995 as an extension of the Adult Programme, and in 2018 became known as the National Hearing Implant & Research Centre (NHIRC). It is based in Dublin at Beaumont Hospital and the Children's University Hospital, Temple Street, and is supported by the resources of these major teaching hospitals. All assessment and rehabilitation takes place in Beaumont Hospital, and surgery takes place in Temple Street Hospital.

There is a multidisciplinary team consisting of:

- Consultant ENT Surgeons
- Teachers of the Deaf
- Speech and Language Therapists
- Audiological Scientists
- Clinical Psychologist
- Medical Physicist
- Specialist Nurse
- Cochlear Support Workers
- Administrators

There is also access to:

- Interpreters
- Radiology Department
- Consultant Geneticist
- Consultant Ophthalmologist
- Consultant Paediatrician

The Paediatric Programme is committed to achieving a comprehensive family friendly service for the assessment and management of children with a severe/profound hearing loss. The NHIRC has developed programmes recognised both nationally and internationally for children and adults. Since July 2014 bilateral cochlear implants have been offered to children suitable for two implants.

The Service

Our service assesses children, including those with complex needs, for suitability for cochlear implants. If deemed appropriate we then offer the necessary medical, surgical and post-operative management and rehabilitation. Cochlear implantation in young children requires a unique combination of technology, skills and long-term child and family support, while the child learns to use the new auditory sensation provided by the implant system. Our facilities and staff provide this comprehensive range of services.

The Technology

Cochlear implantation is now established as a routine clinical procedure to provide useful hearing sensation to those with a severe/profound hearing loss. For young children with severe to profound hearing loss, cochlear implants provide the opportunity to learn to communicate effectively using spoken language. The NHIRC regularly reviews the technology used, ensuring the latest developments are available. Since July 2014 bilateral cochlear implants are offered where appropriate, as per international best practice.

What is a Cochlear Implant?

A cochlear implant is a highly sophisticated electronic device that provides a hearing sensation for people with a severe/profound hearing loss. It replaces the function of the damaged inner ear (cochlea) by electrically stimulating the hearing nerve (also known as the auditory or VIIIth nerve) to produce a sensation of sound. It can improve communication abilities and give awareness of everyday sounds. Over many years improvements to cochlear implant technology have provided benefit to every age group of recipients.

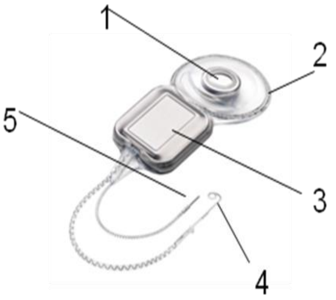
How Does a Cochlear Implant Work?

A cochlear implant sends an electrical message through a wire called an electrode directly to the hearing nerve, bypassing the damaged or absent hair cells in the cochlea. This means, provided the hearing nerve is still working, deaf people can hear sound. With developments in technology and with expanding cochlear implant candidacy criteria, many people can now benefit significantly, and their quality of life can be improved with cochlear implants.

The cochlear implant consists of both internally implanted and externally worn components.

The Internal Device

The internal device consists of a receiver, stimulator and electrode array. Figure 1 shows the Nucleus system. The electrode array consists of 22 active platinum electrode bands. It is inserted into the cochlea by the surgeon, and the 22 electrodes can stimulate multiple sites within the cochlea to give a hearing sensation for all speech sounds. The electrodes of the cochlear implant are connected to a small control circuit called the receiver-stimulator. There is a magnet to enable the external transmitter coil to be held in place (see below). All of this is placed under the scalp during surgery.



1. Magnet
2. FM Receiver
3. Electronic package
4. Electrode array
5. Reference electrode

Figure 1: The Nucleus cochlear implant

The External Components

The external part of the equipment consists of a battery (or rechargeable cell) driven sound processor. The processor is connected to a transmitting coil by a cable. There is a magnet in the middle of the coil that holds the external device onto the implant that is underneath the skin at the back of the ear. Over the years there have been several different models of sound processor, both body worn and ear level. Pictured below (figure 2) is the Nucleus 7 sound processor and the Nucleus 7 processor being worn (figure 3). Young children, and occasionally some adults, are provided with a body worn configuration initially. The external sound processors are fitted about one month after surgery.

Figure 2: The Nucleus 7 sound processor

How Do You Hear with a Cochlear Implant?

The ear level microphone (1) picks up sound, which is then sent to the sound processor. The sound processor converts the sound information into an electrical signal. This information is then sent to the transmitting coil (2), and crosses the skin to the internal receiver stimulator via radio signal. This signal is then decoded to determine which electrodes should be stimulated and at what level of stimulation. The appropriate electrodes in the cochlea (3) are stimulated and they send electrical impulses to the auditory nerve (4). The auditory nerve sends the signals to the brain where they are interpreted as sound. This whole process happens at the same speed as normal hearing.

Figure 4: Transmission of sound using the cochlear implant

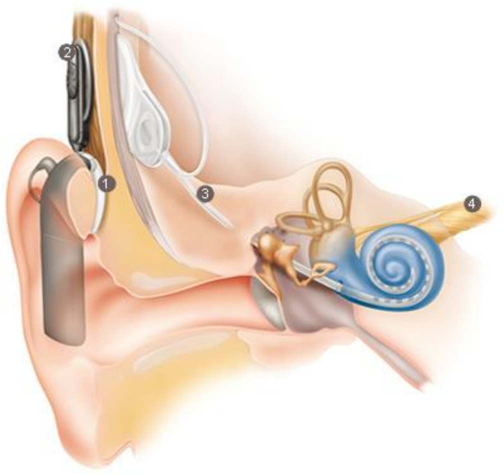


Figure 3: The sound processor being worn

The external parts of the implants can be removed at any time, for example, when sleeping. When they are removed, no hearing sensation occurs.

Who Is Suitable?

We consider children for implantation if the following criteria are met:

- Bilateral severe/profound sensori-neural hearing loss.
- Aged under five years if spoken language has not developed.
  Ideally, children born with a severe/profound hearing loss who have not acquired spoken language should receive their cochlear implant before the age of five. Otherwise it becomes increasingly difficult for the child to make sense of the new auditory sensation, and to learn to listen and talk. **If the child has already acquired spoken language, age is not a factor.**
- Limited auditory speech perception ability.
- Have parents who understand the long-term commitment involved in cochlear implantation and will ensure attendance at the NHIRC for ongoing management.

- Have local professionals who support the process of cochlear implantation and will provide consistent oral/aural input whatever the educational or communication setting.
- Appropriate inner ear and hearing nerve anatomy as shown on MRI scan.

Children with additional disabilities or complex needs are also considered for cochlear implantation.

What Factors Influence Progress with a Cochlear Implant?

The cochlear implant provides the severely or profoundly deaf child with access to auditory speech information. Following implantation the child has to (re) learn to "listen" and use the information provided by the implant/s. Some children learn to make better use of this auditory information than others. Good listening skills are the essential building blocks for developing spoken language.

There are several factors that can affect how a child develops listening and talking, including:

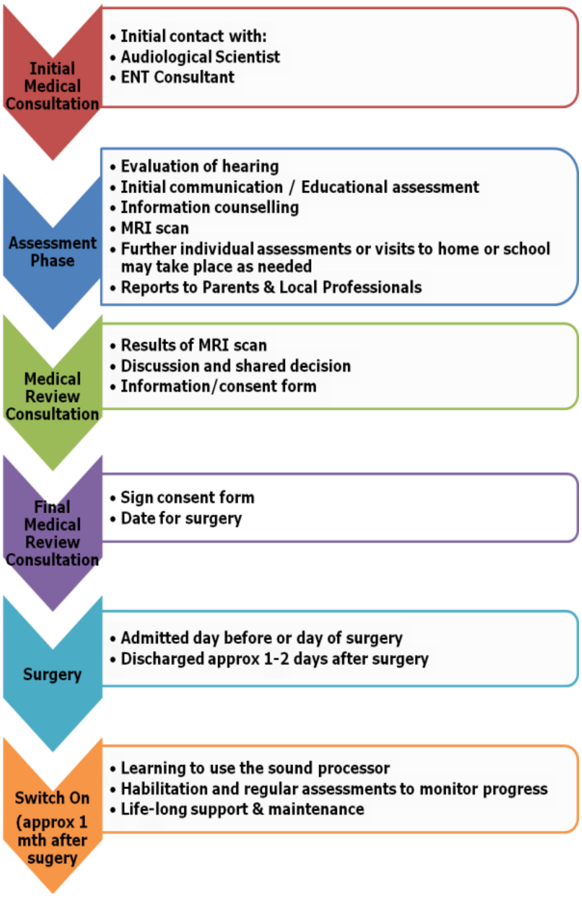
- Age at implantation
- Age at onset of hearing loss
- Duration of severe/profound hearing loss prior to implantation
- Degree of residual hearing and hearing aid use prior to cochlear implantation
- Presence of additional needs
- Presence of auditory processing difficulties or additional language difficulties
- Cause of deafness
- Experience using an implant
- Communication mode
- Educational setting
- Consistency of (re) habilitation and support from family, peers and professionals
- Auditory memory
- Attention skills
- Ability to learn
- Consistency of processor use post implant
- Child's own motivation and personality
- Ability to confirm appropriateness of child's cochlear implant tuning via methods such as soundfield or speech testing

As each child is an individual, we aim to ensure that the expectations of the child's family and friends are realistic and achievable.

The Cochlear Implant Process

The decision to offer a deaf child cochlear implants begins a life-time's support, through childhood, adolescence and into adulthood. If the decision is made to go ahead with cochlear implantation, the time from initial consultation to implant surgery varies depending on assessment needs and waiting lists, but is usually about 9 months.

Paediatric Cochlear Implant Programme Assessment Schedule



Initial Medical Consultation
- Initial contact with:
- Audiological Scientist
- ENT Consultant

Assessment Phase
- Evaluation of hearing
- Initial communication / Educational assessment
- Information counselling
- MRI scan
- Further individual assessments or visits to home or school may take place as needed
- Reports to Parents & Local Professionals

Medical Review Consultation
- Results of MRI scan
- Discussion and shared decision
- Information/consent form

Final Medical Review Consultation
- Sign consent form
- Date for surgery

Surgery
- Admitted day before or day of surgery
- Discharged approx 1-2 days after surgery

Switch On (approx 1 mth after sugery
- Learning to use the sound processor
- Habilitation and regular assessments to monitor progress
- Life-long support & maintenance

The Assessment Phase

The assessment phase is very important and will be carried out in conjunction with the family and local professionals. After referral, the parents and child attend a medical appointment during which they meet the ENT medical team, and are told about the various assessments that are part of the process.

Audiological Evaluation

The next phase will involve an audiological evaluation of the child's hearing to confirm the type and degree of hearing loss and to establish the auditory benefit the child is gaining from their hearing aids.

Auditory Brainstem Response (ABR) testing will be arranged for children who are too young or unable to participate in co-operative behavioural hearing tests. ABR testing is an objective hearing test performed either under sleep (with very young babies) or under a general anaesthetic. Several appointments for hearing assessments may be required to ensure that the hearing test results are consistent and accurate.

It is ideal for children to attend the NHIRC with hearing aids as a hearing aid trial is critical before a final decision can be made about cochlear implantation. Hearing aids are fitted and maintained through local audiology services. It is important that the best hearing aids and earmould combinations are provided to determine the benefit obtained from high powered digital hearing aids.

Assessment of what sounds the child hears with hearing aids may indicate that despite being a good hearing aid user, the child is not hearing enough speech information for good spoken language development. In this case cochlear implantation will be considered. On the other hand, assessment may indicate that the child has good access to auditory speech information and is making good progress with acquiring spoken language. Therefore, cochlear implant/s may not be currently indicated. However, such children will continue to be carefully monitored for any changes or deterioration in hearing levels or functional listening ability.

If a child has a hearing loss due to meningitis, the assessment procedure will be expedited as in some cases the inner ear can become blocked by the formation of bone (ossification), which could make it very difficult or impossible for the surgeon to place the implant electrodes accurately in the cochlea. Therefore, the decision to proceed with implants may be made more quickly, in which case this would be discussed with the family in detail by the implant team.

Speech & Language Assessments

During the assessment phase the child will also attend for appointments with a speech and language therapist on the team to assess their communication, listening skills and pre-verbal development. If the decision is made to go ahead with cochlear implantation, this will include an assessment, the results of which will be used as a baseline from which to monitor progress over the coming years.

Teacher of the Deaf

A teacher from the NHIRC team will liaise with the child's local Visiting Teacher for Deaf/Hard of Hearing Children (VTDHH) or Teacher of the Deaf in a school/unit for baseline pre-operative assessment of receptive and expressive communication, educational placement, and use of hearing aids. Outreach visits to home or school may be arranged if needed.

Scans

A Magnetic Resonance Imaging (MRI) scan is carried out under sedation or general anaesthetic unless the child is older, as it is essential to lie completely still. An MRI is a sophisticated scan, which is used to assess the structure of the inner ears, the auditory nerves and the brain. An appointment will be made a few weeks later with the medical team who will explain the results of the scan. If the child is suitable for cochlear implantation, the surgeon will also explain the risks of the operation and any further assessments that may be necessary.

Psychological Assessment

The clinical psychologist with the Hearing Implant Centre may also meet with the family and the child. Often it is important to find out about children's understanding or cognitive abilities, their behaviour and their social development and play skills. The psychologist can assess these areas using formal tests. This information is sometimes important in deciding whether to proceed with a cochlear implant and can help in making a decision about the child's schooling. The psychologist can also meet with parents or children if they are worried or upset about any other issues.

The psychological assessment process can often take up to two or three appointments to complete but this will be discussed at the time.

Onward Referrals

As a significant proportion of hearing loss has a genetic basis, or is associated with other medical issues, children are referred to a paediatrician for further assessment as required. Often parents would like to find out why their child is deaf. In a number of cases, the paediatrician or the geneticist is able to pin point the cause of the hearing loss and may be able to advise parents of any risk that future children, or their children's children, may inherit the deafness. Not all genes or other factors causing a hearing loss are known. Some parents decide that they do not wish to know if a gene has caused the hearing loss. Any referral for genetic testing is based upon parental request. Hearing loss can occasionally be associated with syndromes and other medical issues, consequently, the child may be referred to other medical specialists e.g. to the ophthalmologist to have their vision assessed etc.

Group Information Sessions

Parents will be given the opportunity to attend information and support meetings within the department. This will include information on cochlear implants, development of spoken language, realistic expectations etc. There will also be an opportunity to meet children with cochlear implants and their parents. This helps to develop a better understanding of the whole process and the level of commitment required to maximise the benefits from the cochlear implant.

Making the Decision

There will be ongoing discussions about making the decision regarding implantation e.g. whether everyone concerned feels that it is the right route forward for the child.

If the child is old enough, he/she will be encouraged to participate fully in the decision. Families should make sure they know how their child feels about having cochlear implants, as his/her feelings are very important.

The Final Decision

Following completion of all the assessments the team will meet with the family and discuss the suitability of cochlear implants for the child.

Remember, any final decision to proceed with cochlear implants lies with the family!

A final visit to the implant centre is arranged in order to confirm the decision, and to discuss any final issues before final consent is given and a date for surgery is arranged.

Surgery

What Does the Operation Involve?

Patients are admitted to the hospital either a day before or on the morning of their implant operation. During the operation, the surgeon implants the internal parts of the cochlear implant/s underneath the skin. There will be a small scar that is generally covered by hair. The body of the implant sits just behind the ear and the delicate electrode array is inserted into the inner ear (cochlea). Intra-operative checks of electrode function, called NRT (Neural Response Telemetry), will be performed. This ensures that the electrodes are working properly, and also gives the scientist some important information to use at the initial tuning and fitting of the sound processor.

How Long Does the Operation Take?

The operation takes approximately 4 hours if two cochlear implants are being inserted, and less for only one implant. After surgery children remain in hospital for at least 24 hours, but in most cases are up and out of bed the following day ready for discharge! The child will have a large bandage on their head for 24 hours, but after that no further dressing is required.

Are There Any Risks?

There are some risks involved with the cochlear implant operation but no more than the risks involved with any major ear surgery. The risks associated with cochlear implant surgery include:

- Risks associated with the use of general anaesthesia, as for any surgery
- Risk of inflammation or infection
- Disturbance or damage to the facial nerve leading to a facial paralysis
- Stiffness or numbness around the ear
- Disturbance of taste or balance
- Possibly changes in head noises (tinnitus).
- Possible inability to fully place the electrode within the cochlea.

Vaccinations against meningitis are mandatory prior to surgery as there have been some reports that patients with cochlear implants, and/or inner ear malformations may have a slightly higher risk of meningitis. The vaccinations significantly reduce any such risk.

The cochlear implant surgeon will discuss the risks in more detail before the operation.

While it is important to be aware that these complications can occur, in practice there have been very few significant negative side effects worldwide for people receiving cochlear implants.

Fitting of the Sound Processors and Initial Tuning

Approximately one month after surgery the child will attend the Hearing Implant Centre to have the external sound processors fitted and "switched on".

The external sound processors are placed on the child. Some children need to be coaxed to accept what is a new and unfamiliar device. If hearing aids have not been worn consistently it may take some time to persuade the child to wear the sound processors.

When the system is in place, the audiological scientist connects each sound processor to a computer and performs the electrode checks again (telemetry) to ensure that the internal component is still working correctly.

An initial programme or MAP will then be made, primarily based upon the NRT measurements obtained during surgery. Programmes are made to use the NRT measurements cautiously as a "guide" for the initial programmes. Older children will participate in further co-operative testing that gives us feedback on their individual programme needs. When the sound processors are switched on, usual reactions from children include:

1. No reaction
2. Stilling, looking bemused
3. Searching
4. Getting upset
5. Turning / running to parent(s) for reassurance

There are no typical reactions as each child is different. Although we do not wish to surprise or frighten children with the new sensations, any adverse reaction should be looked at as a positive indication that the child responded to the strange sensation. Alternatively, some children just do not react behaviourally, despite neural response telemetry having indicated that the nerve is responding to sound. Once the cochlear implants are switched on the child needs time to adapt to the new sound quality. If the brain has not heard sound before the sounds will be very strange at first. The MAPs in the sound processors will need to be fine-tuned over the coming months.

The biggest changes in sound quality will generally happen in the first few months, and frequent tuning sessions will be required initially.

What Happens After Initial Tuning?

Following the initial tuning the child will attend for further tuning sessions until the audiological scientists are satisfied that the MAPs give the child good access to the full range of speech sounds. This is when the real work (and hopefully fun!) begins.

There will be regular appointments with the speech and language therapist over the next few months to work with the child to facilitate listening and spoken language development. More importantly the speech and language therapist will work with the family to help the family learn how best to do this at home and in everyday life – families are the most important people on the rehabilitation team!

After the first year, depending on the level of support available locally and how the child is progressing, the frequency of appointments with the speech and language therapist at the NHIRC will reduce. The support of local professionals is required wherever the child lives to ensure that the child makes the most use of the sound provided by the implant.

The NHIRC team works closely with the family and local professionals. Outreach support is also provided to the child's home and school to ensure that everyone involved locally has the necessary expertise and skills to support use of the implants. The most important members of the team are, however, the child and the family themselves. While other team members provide advice and guidance, it is the support and language rich environment provided by the family that plays the main part in determining the child's effective use of their cochlear implant.

In addition to ongoing speech and language therapy sessions to facilitate listening and spoken language development, the speech and language therapist also carries out regular formal assessments to monitor progress. These are carried out at set intervals:

- Pre-cochlear implant
- Year 1,2,3,4,5,7 and 10 post implant

The results of these assessments help us to plan therapy programmes best suited to the child's needs, and are always made available to parents and local professionals to make sure that we are all working together. Over time the NHIRC speech and language therapist aims to hand over much of the regular therapy to the local speech and language therapist, but will always be available to liaise and advise as necessary.

The NHIRC teacher will continue to liaise with the child's teacher of the deaf regarding optimization of cochlear implant use, assistive technology, and resources to support different aspects of the primary and secondary school curriculum, and staff training to secure a smooth transition into primary or secondary school. Outreach visits may be arranged to the home or school for the child as the need arises.

Outcomes

Every child who has a cochlear implant is an individual, and as such outcomes and progress vary hugely from child to child. However, the NHIRC in Ireland has now been running for some considerable length of time, and we are able to provide information about predicted outcomes and average performances. But it is important to remember that there are many factors that affect performance and each child's individual situation should be discussed with the team.

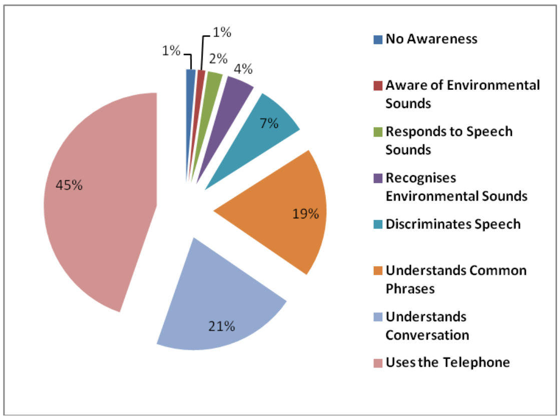
Functional Hearing

The Categories of Auditory Performance (CAP) scale was devised by Archbold et al (1995) and measures a child's progress in ability to make sense of the sound provided by the implant, categorising auditory perception as outlined below:

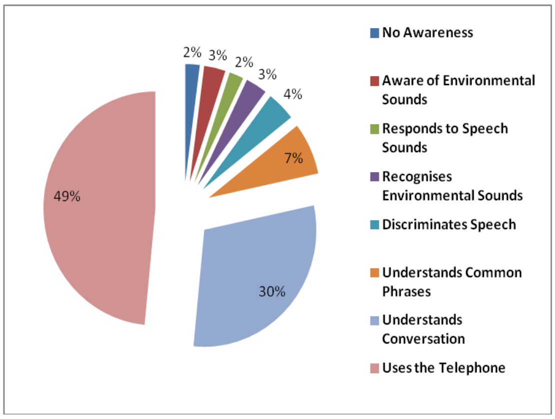
- 0: no awareness of sound
- 1: aware of environmental sounds
- 2: responds to speech sounds
- 3: identifies environmental sounds
- 4: discriminates some speech sounds without lipreading
- 5: understands common phrases without lipreading
- 6: understands conversation without lipreading
- 7: uses the telephone with a known speaker

Outlined below are charts that should give some idea of outcomes for speech understanding using listening only five years post implant.

Category of Auditory Performance
5 Yrs Post CI:
All Children Implanted
National Hearing Implant & Research Centre



Category of Auditory Performance
5 Yrs Post CI:
Children Implanted by 2 Years
National Hearing Implant & Research Centre



As approximately 40% of deaf children have additional needs, for example learning difficulties, autistic spectrum disorder, additional speech and language difficulties, this will also impact on outcomes for this cohort of children. Children with no additional needs are likely to make progress more quickly, and to achieve better listening and spoken language skills in the long term.

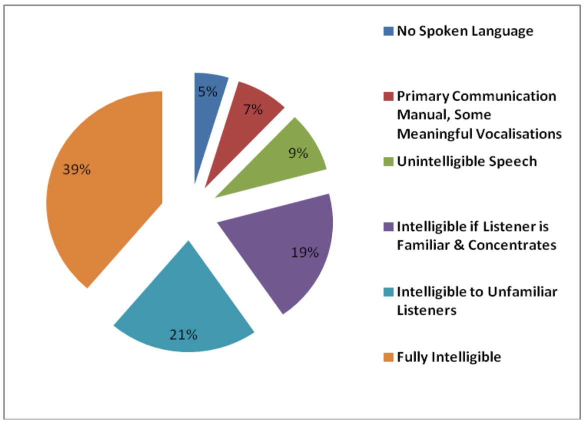
Speech Intelligibility

The Speech Intelligibility Rating scale (SIR) was devised by Dyar and Allen (1998) and measures the progress in speech intelligibility for children acquiring spoken language post implant, and the rating scale is outlined below:

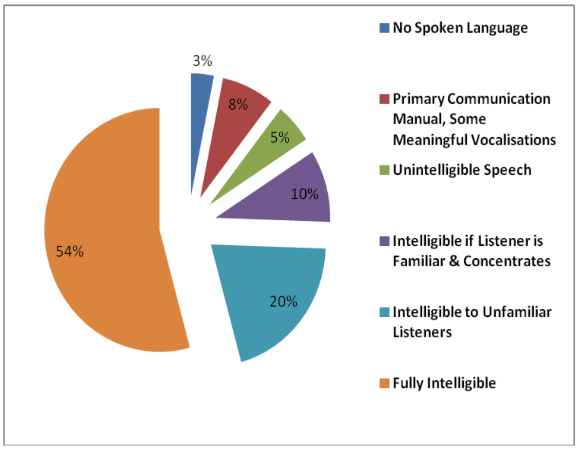
- 1: pre recognisable words in spoken language
- 2: primary mode of communication is manual, vocalisations may give some additional information
- 3: speech is unintelligible
- 4: speech intelligible to a listener who concentrates and lipreads
- 5: speech intelligible to listeners with little experience of deaf speakers
- 6: speech intelligible to all listeners

The charts below show speech intelligibility outcomes five years post implant. As with listening skills, the children with additional needs are likely to struggle more to achieve intelligible speech.

Speech Intelligibility Rating 5 Yrs Post CI:
All Children Implanted
National Hearing Implant & Research Centre



Speech Intelligibility Rating 5 Yrs Post CI:
Children Implanted by 2 Years
National Hearing Implant & Research Centre

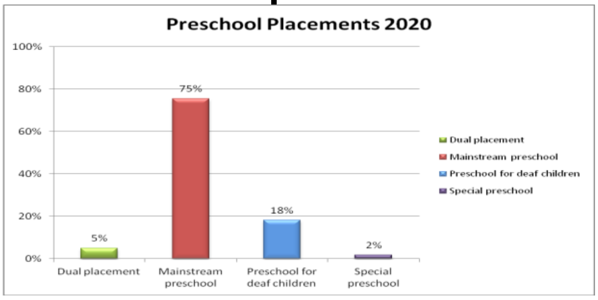


Educational Placement

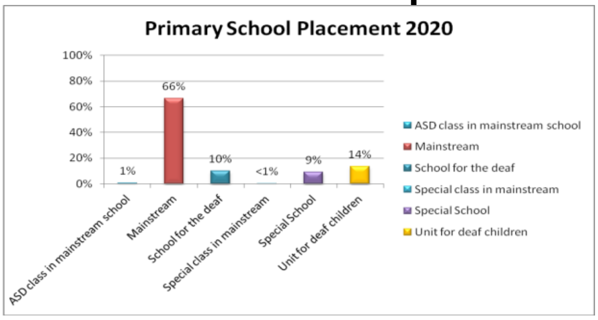
There are many options with regard to educational placement for children with cochlear implants. Some attend their local mainstream school, some attend a school for the deaf and some attend a unit with facilities for deaf children attached to a mainstream school. Some children with additional needs may attend a special school. Again every child has different needs and the visiting teacher of deaf and hard of hearing children, implant centre teacher of the deaf and other team members will help with making the right decision regarding school placement for each child. Now that the NHIRC has been running for almost 25 years, many implanted as children have made the transition to adulthood, and a number have progressed to third level education and beyond.

The charts below show current numbers attending the different types of school.

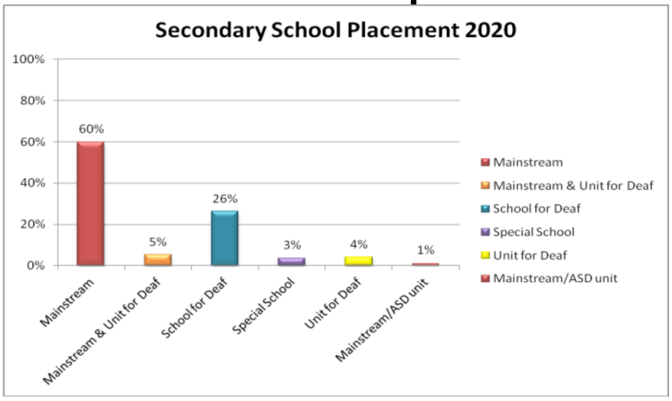
Pre-school placement of children with cochlear implants



Primary school placement of all children with cochlear implants



Secondary school placement of all children with cochlear implants



Frequently Asked Questions (FAQs)

❖ Can my child participate in sports with a cochlear implant?

Yes. The implant should not prevent participation in leisure activities, with a few exceptions eg. *boxing, rugby,* and *martial arts*. It is advised that a helmet be worn for any contact sports to avoid damage to the internal or external components of the implant. When swimming the processors can be removed or a special swimming accessory (Cochlear Aqua +) can be worn over the processors to allow continued use in the water.

❖ Are there any costs I need to cover for the operation/ implant/ processor?

No. The National Hearing Implant & Research Centre provides a public service and can therefore offer all services and devices free of charge to patients who are implant candidates. However, you are responsible for travel costs to and from appointments, although in some circumstances you may be able to obtain financial assistance through your local Community Welfare Officer. If you do not have a medical card you will also be charged for the stay in hospital, which you can reclaim if you have medical insurance. You will also be responsible for the cost of batteries for the sound processors.

❖ Where do I get spare leads/accessories?

The NHIRC is able to supply a limited number of spare leads and accessories per patient. However, the family is able to purchase extra accessories directly from the implant manufacturer or Chime. Some parts have a one year warranty, after which they will need to be purchased privately if a replacement is needed, and other optional accessories also need to be purchased separately. This will be clearly explained before surgery.

❖ Can I have a spare processor?

No. We are only funded to issue each patient with one processor per internal implant as they are very expensive.

❖ Can I purchase a spare processor?

Yes. The team can provide you with information as to how you can purchase your own sound processor. Just keep in mind the cost is approximately €6000 per processor.

❖ What happens if I go on holiday and need spare parts?

You are able to avail of the 'Travel Programme' from the implant company (Cochlear Europe Ltd), which includes all spare parts and a sound processor. There is a fee for this service and it is an agreement between you and the implant company.

❖ What is the life expectancy of the external sound processor?

The sound processor is an electronic device and is therefore subject to faults or breakdowns. A well-minded processor should last for 3-5 years.

❖ What happens when the implant is not working/ broken?

You can do minor repairs (i.e. replacing leads) at home. However, if the processor is still not functioning properly it can be checked over by someone on the team during standard working hours. If we are unable to fix the processor we will issue you with a replacement and send the other for repair.

If this still does not solve the problem, NHIRC will arrange a troubleshooting appointment for you to attend in person.

- **When the internal implant is in place, does it stay there for life?**

The system is designed to accommodate growth so that very young children can be implanted. Like any electrical device, cochlear implants can and do break down, however the failure rate is extremely low. It is usually possible to replace the implant if there is an internal problem.

If later in life technological advances would be of benefit replacement may also be considered.

- **Can patients hear when they wake up after surgery?**

Not yet. The surgeon has only fitted the internal parts of the device. There is a wait of approximately one month after surgery before the external parts of the device can be fitted and activated. This is to allow healing to take place, and for any swelling or tenderness around the implant site to subside.

It is important for you or other family members to ask any questions that you have. If you are unsure about anything please ask. It can be useful to make a note of any questions that you may have so that you do not forget when you are in the hospital.

Do not hesitate to ask. It's your child and we will do our best to answer your questions.

Testimonials

Michelle & Scott, parents of Jayden.
Bilateral cochlear implants December 2018, aged 1.

Jayden failed his new born screening test but because he was born by C section they thought it could have been fluid and brought him back a week later but he failed again. He was referred to an audiologist where he was diagnosed profoundly deaf.

It felt like our world had fallen apart we were in shock as there was no history of hearing loss on either side of our families. Things moved really fast. Jayden was given his first set of hearing aids a couple of weeks later. After a week or so you could notice he was hearing some sounds and the first time he reacted to his name being called is something we will never forget. Jayden underwent all the tests to see was he a valid candidate for cochlear implants and he was. A couple of days after his first birthday Prof Viani and her team worked their magic and preformed surgery on Jayden. For the month after surgery until switch on it was very difficult, as during recovery you can't wear hearing aids and as it was over the Christmas period it just seemed worse.

The day of switch on arrived and even though they prepare you not to expect much you still hope, and we were a bit disappointed when he didn't react. Over the coming weeks and numerous appointments for tuning you could notice a huge difference in Jayden. He was babbling and uttering a few words - we were so happy. As the weeks and months passed he went from strength to strength.

Jayden is now nearly 3 and the happiest boy there is. He loves doing all sorts of things. His favourite is reading his ladybird books in his own words, playing with his farm animals, cars, trains, and when he and his sister sing all kinds of songs together.

The help we have gotten from the cochlear implant team in Beaumont hospital, Jenny his speech therapist, Beng Ling his visiting teacher and Chime has been amazing and we will never be able to thank them enough for what they have done, not just for Jayden but for us as well.

It has been a crazy journey from what felt like our world had fallen apart to where we are now. Jayden getting the operation is the best decision we have ever made.

(Written 2020)

Earl and Suzanne, Parents of Beth Unilateral Implant July 2017, aged 5 ½

Beth was born in April 2012 with asymptomatic cytomegalovirus. Her initial audiology assessments showed that she had full hearing at birth however by the time she was 15 months old her hearing had deteriorated to a bilateral moderate hearing loss. She was fitted with hearing aids but over time her hearing deteriorated further and at a meeting with the CI team in early 2017 it was decided that Beth would benefit greatly from a unilateral implant. Surgery took place in July 2017 and she was switched on a month later just in time for starting school!

In the days and weeks that followed switch on it became clear how much Beth was benefiting from the implant. She took to it straight away and hasn't looked back since. Beth is now in 2nd class and doing really well. She has perfect speech and is keeping up with her classmates academically. She started swimming lessons which was made possible by the implant aqua kit and loves playing GAA. She has even performed onstage with her Encore musical theatre group. Her hearing loss has not held her back one bit!

We cannot thank the cochlear implant team enough. The advice and support they have given to us on our journey has been unbelievable.

(Written 2020)

Pili, Mother of Iban First implant 2006, aged 1 year 5 months; second implant 2020, aged 14

Our son Iban was born in 2005. He is profoundly deaf and received his first cochlear implant when he was 18 months. I remember how his father and I felt after we got the news of Iban’s hearing loss. There was a sense of grief, uncertainty, and terrible worry about the future.

Over the following months and with the support of the cochlear implant team in Beaumont Hospital, we learned about the cochlear implant program, what it involved, and the expected outcomes for recipients. As reassuring as this was, we did not know how it would work out for us or if Iban would ever hear or speak.

An extra dimension in our situation was that I am Spanish. Until his implantation I had always spoken to Iban in Spanish, despite him not hearing me. That was what came naturally to me. After switch-on we were faced with a choice: focus all our efforts on helping Iban learn to hear and speak in English or introduce Spanish and potentially jeopardize his chances by bringing him up in a bilingual household. This was an incredibly difficult decision to make, and without the expertise and support of our Visiting Teacher of the Deaf we would not have been equipped to make the right one. I wanted to talk to Iban in Spanish, but I was afraid it would not work out and precious time would be lost. I also feared that if we did not try, I would not be able to pass on my culture, my personality, and my terrible Spanish jokes! It also saddened me that he would not be able to have a relationship with my mother, his cousins, and my friends when we went to Spain on holidays. This would have been a huge loss in his life. So, I spoke to him in Spanish; I spoke to him non-stop! I played nursery rhymes, sang songs, we watched children's videos and read books together, all in Spanish. Whenever my mother came to visit, she too spoke and played with Iban in Spanish. Everything else in Iban's life was done through English: creche, school, friends, and the relationship with his father and grandparents.

Iban is now 15, fully bilingual and has completed a Spanish language proficiency exam accredited by the Spanish Government consisting of written, oral, and aural sections. His English is also fantastic (better than mine!) and he is doing great in school.

A few months ago, Iban made the decision to get a second implant. He is making progress, but nothing compared with what we experienced when he received the first one. We believe that early intervention was key for Iban's success.

For us, giving Iban a cochlear implant was miraculous, and we never regretted the decision for one second. We are forever thankful for this amazing technology and for all the support we got from the cochlear implant team in Beaumont and from our Visiting Teacher of the Deaf.

(Written 2020)

Patricia, Mother of Ria Unilateral implant 2009, aged 1 year 9 months

Ria lost her hearing following meningitis back in December 2008, she was 20 months old. We were so lucky she pulled through but were obviously devastated when her deafness was diagnosed. We hadn't even heard of cochlear implants before then but were so thankful that they existed and that she was a suitable candidate. We hadn't time to think, she was due to have the surgery in January and time was of the essence due to inner ear complications after meningitis. We were stopped in our tracks again though when she got a particularly bad dose of chicken pox. She went through an awful lot in those 2 months but finally had her surgery In Feb and switch on in early April. She would have been the first candidate for 2 implants at the time but one ear wasn't viable. Prof Viani was a godsend, she was so warm and kind and even acknowledged to me after that she had spent sleepless nights worrying about the possible unsuccess of the surgery and was already thinking about the next step if it didn't work! I'll never forget her kindness and care.

The good news is that the implant worked a treat! With the help of Jenny and the staff at Beaumont and Aisling Relihan, our CEIS (Clare Early Intervention Service) speech and language therapist Ria is now on a par with her peers. She worked really hard and put in lots of practice and by the age of 5 was released from CEIS services as she had reached all her milestones. She plays soccer (Club & County), football (Club & County), camogie and basketball. She also attended Speech & Drama all through primary school and successfully competed in Feile na hInse, winning silver for her solo drama piece. I put a lot of Ria's success down to her love of reading and would encourage every parent to get their child reading. Simple books at the start, lots of repetition, reading the same books over and over until they have all the words – a simple thing but it does develop a love for reading which will stand to them later on. She has started secondary school, a few challenges there (mostly with the technology, typical teenager stuff!) but none insurmountable! Will have her first report card soon but she seems to be doing very well. The world is her oyster and there is nothing she can't aim for. We are very proud of the young woman she has become and look forward to the next chapter and what it will bring!

If I can ever be of any help to any parent considering cochlear implants for their child and looking for re-assurance please feel free to call me. I know I spoke to a mother in Galway at some stage when I felt we had plateaued in our development early on and she told me to get the simple books, just a few words per page, and that was some of the best advice I got when I needed it most.

Best of luck to anyone beginning this journey

(Written 2020)

And written by Ria herself:

Hi, my name is Ria & I'm 13 years old, a newly-minted teen 😊. I got my cochlear implant when I was almost two so I don't remember any of it but I am really glad my parents made the decision for me to get the implant, I'm sure they were very confused about what to do but I couldn't imagine my life any other way.

I just started secondary school this year and I was nervous about it at first but now after a couple of months I'm really loving it. I use the Roger *(an FM system)* at school but I didn't want to bring it in for the first few weeks as I was scared of what my classmates would think. After some chats with my Mam and one of the teachers at school I finally started using it, my teachers are really nice about it and don't make it too obvious.

I went to a small primary school and am now in a big secondary school so there were lots of new things to adapt to, but that was the same for most people! We were worried about the masks but my teachers all wear shields so that's working out fine.

I love sport and am very competitive! I play football for my Club, Fergus Rovers, and am also on the Clare Development Football Squad. I play soccer for Fern Celtic and am on the

Clare Gaynor Cup team. I play basketball for Clare Comets and camogie for Ballyea (I hope they will be sending me for Clare trials when they start!). I can't sing for peanuts and although I tried music it wasn't for me. I did hiphop & set-dancing for a few years and loved those but sport is my thing. The only thing my mam wouldn't let me try was rugby and I really wanted to!!
Ria X

(Written 2020)

Marie and John, Parents of Niamh and Roisin
Niamh: First implant 2010, aged 6; second implant 2017, aged 13
Roisin: First implant 2016, aged 5; second implant 2017, aged 6

We have two daughters who have bilateral cochlear implants. Our first daughter Niamh was a late diagnosis and got fitted in the hearing aids when she was almost 2 years old. Whilst these gave her access to speech and sound, she was hugely behind her peers in terms of vocabulary and comprehension. She received her first implant just after her 6th birthday. With huge input from the audiologist and SLT in Beaumont, the visiting teacher and local SLT, it resulted in a phenomenal transformation as her speech, and comprehension went into a new level.

When Roisin was born in 2011, she was closely monitored as she had a mild hearing loss and was fitted with hearing aids just after her 2nd birthday. However the hearing in her left ear deteriorated significantly and it was implanted. Twelve months later her right ear needed to be implanted for a similar deterioration.

In the meantime, Niamh continued with just one implant and appeared to have reached a plateau. In January 2017 at the age of 13 years, she received her second implant. Initially she found it strange and difficult to get used to it. However the audiologist persisted and now she wouldn't go anywhere without them.

The girls love the access they now have to music and partake in classes. They love to watch movies with their other siblings and friends. Best of all is that they love to swim using their aqua kits.

Overall, cochlear implants have had a huge positive effect on our family.

(Written 2020)

Useful Websites

In the Ireland and the UK, there are 4 main manufacturers of cochlear implants:

www.cochlear.com

Advanced Bionics

www.advancedbionincs.com

www.medel.com

www.oticonmedical.com/cochlear-implants

Other useful websites include:

www.chime.ie

Our New Ears Facebook page
www.facebook.com

National Deaf Children's Society

www.ndcs.org.uk

British Cochlear Implant Group

www.bcig.org.uk

www.elizabeth-foundation.org

www.deafeducation.org.uk

Information for teenagers
www.ci-4teenz.com

www.avuk.org

Comprehensive website for current and future CI users
www.cochlearimplantHELP.com