

Cochlear implants

For families



Our vision is a world
without barriers for
every deaf child.



Contents

1. Introduction	4
2. What is a cochlear implant?	5
3. The hearing pathway	6
4. How cochlear implants work	8
5. Making a decision about cochlear implants	10
6. Who is suitable for a cochlear implant?	14
7. The assessment process	16
8. Choosing a cochlear implant	22
9. Cochlear implant surgery	24
10. Switch-on	26
11. Listening and language	28
12. Customising sound processors	30
13. Keeping cochlear implants on little ears	32
14. Taking care of cochlear implants	36
15. Safety information	39
16. Managing cochlear implants around water	40
17. Batteries and battery safety	42
18. Assistive listening devices	44
19. Growing up with an implant	47
20. Useful contacts	48
21. Other resources	49

! We use the term ‘deaf’ to refer to all types of hearing loss from mild to profound. This includes deafness in one ear or temporary hearing loss such as glue ear.

We use the term ‘parent’ to refer to all parents and carers of children.

Throughout this resource we use the following terms.

- ▶ We use ‘your doctor’ to mean the doctor in charge of your child’s audiological care. This may be an audiovestibular physician, ear, nose and throat (ENT) specialist, or community paediatrician in audiology.
- ▶ ‘Your family’ includes your child’s grandparents on both sides.

1 Introduction

Your child may be offered cochlear implants if they:

- ▶ have severe to profound permanent deafness, and
- ▶ get limited or no benefit from hearing aids.

Learning as much as you can about the process will help you make the right decision for your child. This booklet aims to give you clear, balanced and accurate information about cochlear implants.

This booklet covers the following topics:

- ▶ about cochlear implants
- ▶ the assessment process
- ▶ using a cochlear implant.

We are the National Deaf Children's Society, the leading charity for deaf children. We are here for you and your family. For more information and support, contact our Freephone Helpline.

Tel: **0808 800 8880**

Email: **helpline@ndcs.org.uk**

SignVideo: **ndcs.org.uk/helpline**

Live chat: **ndcs.org.uk/live-chat**

If English is not your first language, you can ask us to phone you back with an interpreter.

With thanks to our colleagues at the British Cochlear Implant Group (BCIG), Advanced Bionics, Cochlear, and MED-EL for their support in updating this resource.

2 What is a cochlear implant?

Hearing aids work by making sounds louder. Cochlear implants provide a sensation of hearing by bypassing the damaged hair cells in the cochlea. They use electrical signals to directly stimulate the auditory nerves. As of 2024, around 20,000 people in the UK use cochlear implants, including around 7,000 children and young people.

Cochlear implants do not restore normal levels of hearing. The degree of hearing provided can vary from child to child.

Most children who have permanent severe to profound deafness, and who couldn't hear the full range of speech sounds with hearing aids, can access these sounds and understand speech using cochlear implants.

Other children will need extra visual information to follow conversation, such as lip-reading or using sign language. The cochlear implants help them to recognise voices and develop their lip-reading skills.

A smaller number of children get less benefit from their cochlear implants but have improved awareness of environmental sounds, such as doorbells, traffic noise, and other sounds around them.

There are lots of different makes and models of cochlear implant available. They all have similar designs and features. All cochlear implants have two parts:

- ▶ an internal receiver, which is surgically implanted
- ▶ an external sound processor, which connects to the internal receiver via a magnetic transmitter.

Most external sound processors are worn over the ear, like a hearing aid. The sound processor is attached to the transmitter with a coil. These are called behind-the-ear sound processors.

Some newer models of sound processor are built into the same unit as the transmitter. These are called off-the-ear sound processors.



Advanced Bionics Ultra 3D internal receiver



Advanced Bionics Sky CI M behind-the-ear sound processor



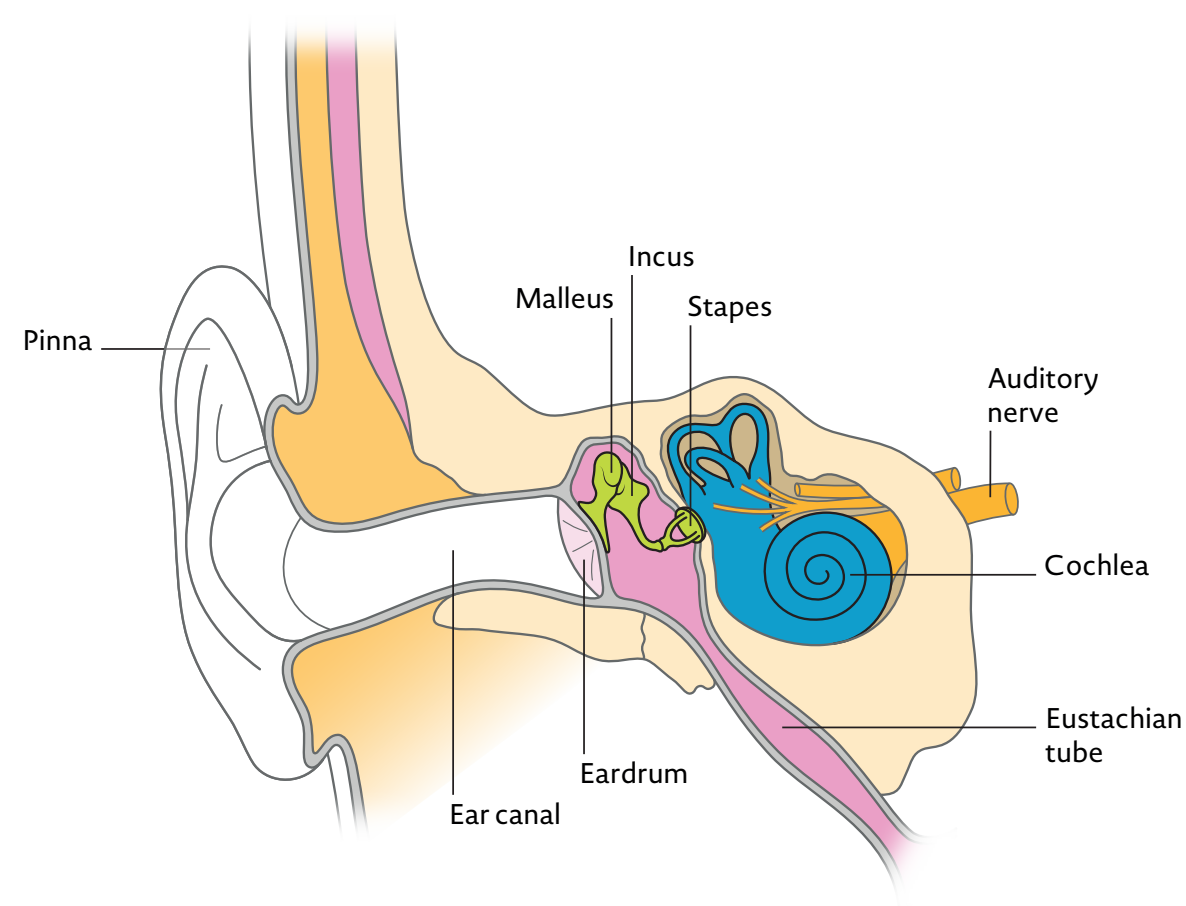
Cochlear Nucleus Kanso®2 off-the-ear sound processor

3 The hearing pathway

To understand how a cochlear implant works, it helps to know how the ear works.

The ear is made up of the outer, middle, and inner ear. Together, they help us hear by receiving sound and converting it into signals the brain can understand. This process is called the hearing pathway.

The ear also helps us to balance.



Outer ear

The outside part of the ear (the part you can see) is called the pinna. The pinna collects sound waves and directs them down the ear canal towards the eardrum. The eardrum separates the outer ear from the middle ear.

Middle ear

The middle ear is filled with air and contains three tiny bones, known as ossicles. The bones are called:

- › the malleus (also known as the hammer)
- › the incus (also known as the anvil)
- › the stapes (also known as the stirrup).

Soundwaves cause the eardrum to vibrate. These vibrations are passed across the middle ear by the ossicles. The bones increase the strength of the vibration before they pass through the oval window into the cochlea.

Inner ear

The cochlea looks like a snail's shell. It's filled with fluid and contains thousands of tiny, sound-sensitive cells. These cells are called hair cells. The vibration of the bones in the middle ear enters the cochlea and causes the fluid to move. This makes the hairs on the hair cells bend. The hair cells move like seaweed on the seabed when waves pass over it.

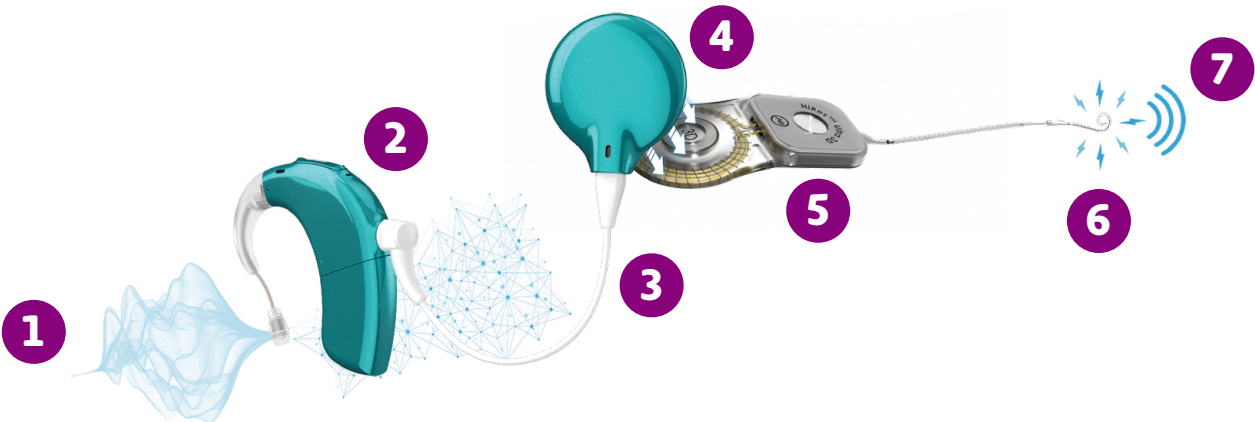
As the hair cells move, they create a small electrical charge. This charge moves along the auditory nerve to the brain. Here, it's converted into signals that can be understood.

To be able to hear the full range of sounds, every part of the hearing pathway must work well. Deafness happens when at least one part of the hearing system is not working effectively.



4 How cochlear implants work

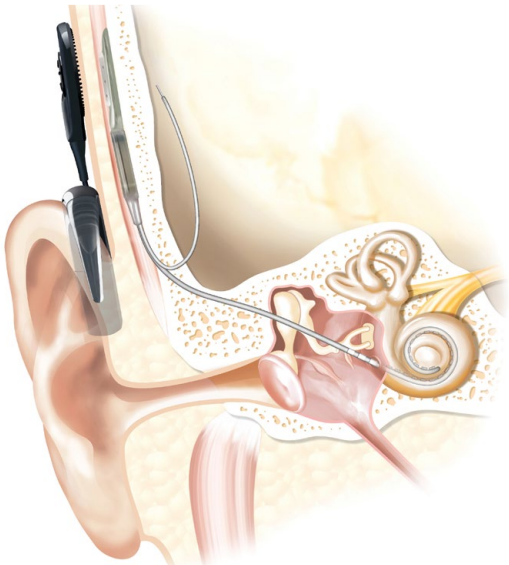
Cochlear implants work by bypassing most of the hearing pathway. They use electrical signals to directly stimulate the auditory nerves.



- 1. The microphone picks up sounds.
- 2. The sound processor converts the sounds into a digital code.
- 3. The digital code is sent to the transmitting coil, which passes it through the skin to the internal receiver.
- 4. The internal receiver converts the digital code into an electrical signal.
- 5. The electrical signal is sent along a wire to the electrodes in the cochlea.
- 6. The electrodes stimulate the cochlear nerve fibres, and they send the signal to the brain.
- 7. The brain interprets these sounds so the wearer can understand what was heard.

The sound perceived through a cochlear implant is not the same as the sound heard with typical hearing or hearing aids. Whereas hearing aids amplify sound, cochlear implants use electrical stimulation.

Cochlear implant wearers who have previously heard naturally often describe the sound as being robotic, tinny, or sounding like chipmunks. Over time, the brain adjusts to the new signals and the user will find their hearing sounds more natural.



5 Making a decision about cochlear implants

If your audiologist thinks your child could benefit from cochlear implants, they'll ask if you'd like to be referred to a cochlear implant centre. Agreeing to this referral doesn't mean you've committed to having the surgery. Choosing whether to go ahead with cochlear implants is a big decision. The professionals working with your family will understand that you need time to think about the options. You can say 'no' at any point of the process, right up until the day of the surgery.

At the cochlear implant centre, your child will be assessed to see whether cochlear implants might benefit them. During the assessment, you can ask questions and find all the information you need to make a decision. The professionals from the cochlear implant team are there to support you. They want you to understand:

- › what happens during the surgery
- › the care your child will need afterwards
- › what it's like to live with cochlear implants.

If you don't understand something, ask for it to be repeated or explained again.

If your child is old enough, ask them how they feel about cochlear implants. Involve them as much as possible in making the decision. Before your child's appointments, help them to make a list of any questions they want to ask. At each appointment, check that they've understood everything you've discussed before you leave the room.

Having a cochlear implant means you have a lifetime commitment to look after it. This involves regular visits to the cochlear implant centre before and after surgery. Your child will need long-term support from you, your family, and professionals.

 If English is not your first language, you can ask for an interpreter to come to appointments with you. You can ask for information to be translated into your chosen language. You can also phone our Helpline and ask our audiology adviser to phone you back with an interpreter. Visit ndcs.org.uk/helpline.

When you start learning about cochlear implants, you'll find people have different opinions about giving them to young children.

Some people in the Deaf community believe a deaf child should be old enough to make their own decision before getting implants. Some people see cochlear implants as trying to 'cure' deafness. Other people think deaf children should be given cochlear implants early on because this gives them the best chance of developing spoken language.

Some parents of children with cochlear implants teach them to sign as well as speak. This means they can choose whether to wear their sound processors when they're older.

It's a good idea to talk to deaf people with and without cochlear implants about their experiences and feelings. It's also a good idea to talk to other families who've been through the decision-making process. If your child is old enough to decide whether to get cochlear implants for themselves, meeting other deaf children who do or don't use cochlear implants may help them to understand what's involved.

You can ask your Teacher of the Deaf or cochlear implant team to put you in touch with other families of deaf children who've been through the decision-making process. You may also find it helpful to join your local deaf children's society or deaf club.

 Find your local deaf children's society at ndcs.org.uk/localgroupsmap.

All the cochlear implant manufacturers offer mentoring schemes. The scheme will match you with another family or a cochlear implant user who can tell you about their own experience.

- › **Advanced Bionics**
Email hear-uk@advancedbionics.com to be matched with a mentor.
- › **Cochlear**
Email hearnow@cochlear.com to be matched with a mentor.
- › **MED-EL**
Visit hearpeers.medel.com/en_gb to connect to a mentor.

It's normal to feel worries and doubts during the assessment process. If you or your child ever feel that having an implant is not the right choice, you should say so.

Cochlear implants do not restore hearing and deaf children with cochlear implants are still deaf. Lots of children with cochlear implants can hear and process speech. However, it's important for your child's self-esteem and confidence that they grow up knowing that they're deaf and feeling positive about their deafness. As they get older, give your child information about their cochlear implant. Encourage them to look after it themselves. This will help them become confident about asking for what they need.

There is no 'right' or 'wrong' answer to whether your child should have cochlear implants. Every deaf child is different, and what works for one family may not work for another. Learning about what it's like to live with and without a cochlear implant will help you to make the right decision for your child.



“Kaya was born profoundly deaf. I knew cochlear implants were an option, but when I began to research the process, I was put off by the thought of an invasive surgery when my daughter was a healthy, happy baby.

Kaya wore hearing aids until she was three. One day she took them out and refused to put them on again. She’s made her communication preferences clear and has flourished using British Sign Language (BSL).

Learning BSL opened a new world to me, and I fell in love with the Deaf community and culture. I stopped thinking about deafness as a disability as I met so many positive Deaf role models. Kaya is happy being Deaf, has no interest in the world of sound and can express herself beautifully in sign.

If Kaya decides she wants a cochlear implant in the future, I would 100% support her decision. I feel that she deserves autonomy in making that choice.

My advice to another family would be, ‘don’t be afraid to say no’. I feel that many parents are rushed into making the decision before they’re fully informed and before the child can express their own preference.

To me, Kaya is perfect exactly the way she is, and her Deaf identity is something to be proud of and celebrated. I like the perspective that people are disabled by barriers in society, not by their impairment.”

Jes is mum to Kaya (5) who is profoundly deaf and uses British Sign Language (BSL).



“My parents were asked if they wanted me to have cochlear implants when I was a few months old, but my mum and dad weren’t sure if I’d like having a cochlear implant as I was always pulling my hearing aids off! They decided to let me decide for myself when I got older.

Now that I’m older, when I go for hearing tests, I’m constantly asked if I want to consider getting implants. It’s annoying because it feels like the doctors are trying to fix me, but I don’t need fixing! I’m happy the way I am.

If I lost all my hearing then cochlear implants might be useful, but I have a bit of residual hearing and can manage at home without my hearing aids.

Getting a cochlear implant is a personal choice and it’s different for everyone. I like the way I hear and having an operation doesn’t appeal to me at all. I think my parents made the right decision.”

Daisy (12) is profoundly deaf and wears hearing aids.



“Holi was diagnosed as deaf when she was two-and-a-half and referred for cochlear implants on the same day. Because of the delayed diagnosis, Great Ormond Street Hospital fast-tracked the implantation process, and Holi had implantation surgery four months later.

For us, the implantation process was much easier than the journey before her diagnosis. It was exciting to learn about the options available.

My best friend is a Teacher of the Deaf. She’s been an amazing support for our family. Some of her colleagues wear cochlear implants and said they didn’t regret getting implants for themselves. Giving my child the opportunity to hear felt like an obvious choice. The hardest part was just after switch-on, as Holi didn’t initially want to wear her processors, but we persevered. It felt hard at the time, but you have to weather the storm to see the rainbow at the end!

We never take Holi’s cochlear implants for granted and understand that what was right for us may not be right for another family. I still believe it’s imperative to bring Holi up as a proud deaf child and to make sure she can sign, so Holi’s sister Mia and I have been learning BSL.

It’s important to do what’s right for your child and your family, and to seek advice, information and help from different sources. Do your own research as well as listening to the health professionals. Overall, we have no regrets about getting Holi implanted.”

Kate is mum to Holi (3) who is severely to profoundly deaf and wears cochlear implants.



“When I was 12, the audiologist suggested I get cochlear implants. I was referred to the cochlear implant centre. The audiologist and the Teacher of the Deaf from the cochlear implant centre explained everything to me.

My mum and dad helped me decide whether to get cochlear implants by talking through what life would be like with implants. I decided to get them as they can help me hear more than I could with my hearing aids.

After the implantation surgery, I had to wait two weeks before the cochlear implants were switched on. I couldn’t hear anything during that time. It was very quiet. Now I’ve got used to the implants, I can hear much more accurately.

My advice to another deaf young person considering having cochlear implant surgery would be to stay calm. If your audiologist tells you that cochlear implants might help your hearing, I’d recommend having them because my life has kind of changed.”

Lewis (13) is profoundly deaf and wears cochlear implants.

6 Who is suitable for a cochlear implant?

The National Institute for Health and Care Excellence (NICE) produces guidance on medical treatments and procedures. Their guidance on cochlear implants says that children may be eligible for cochlear implants if they:

- ▶ have severe to profound deafness in both ears. This is defined as hearing only sounds that are louder than 80 dB HL at two or more frequencies of 500 Hz, 1,000 Hz, 2,000 Hz, 3,000Hz and 4,000 Hz
- ▶ do not receive adequate benefit from acoustic hearing aids. 'Adequate benefit' is defined as speech, language and listening skills appropriate to their age, developmental stage, and cognitive ability.

NICE also recommends that children who are eligible for cochlear implants should have the following treatment.

- ▶ Children should be assessed by a multidisciplinary team to make sure they're suitable for cochlear implants.
- ▶ As part of the assessment, children should usually have a trial of appropriate hearing aids for at least three months.
- ▶ Children should be offered bilateral cochlear implants (one in each ear), to be fitted during the same surgery.

Cochlear implant manufacturers are always working to improve implant technology. Over the years, sound processors have become smaller and slimmer, with more options and features. Manufacturers are working to improve sound processing strategies, making it easier to understand speech. The design of the electrode array is also being improved by making it softer and more flexible. This will make it less likely to cause damage to the inner ear.

NICE guidelines are updated regularly. When you speak to deaf young people or adults about their experiences with cochlear implants, remember that they may have been implanted when the guidelines were different. Things that affected their decisions or implantation experience may no longer apply. If you're told something about the implantation process that worries you, it's worth checking if that part of the process is still the case.

NICE guidelines only apply in England and Wales. However, health authorities in Scotland and Northern Ireland use similar criteria.

Babies and toddlers

In the UK, most newborn babies now have a hearing test shortly after they're born. This means that children who are born deaf are often fitted with hearing aids at a very young age.

Evidence suggests children who get cochlear implants when they are young are more likely to get the most benefit from them. The most intensive period for speech and language development is during a child's first three years of life. This is when the brain develops to hear and process speech. For this reason, children who are born severely to profoundly deaf, who are fitted with cochlear implants before the age of three, are more likely to develop speech and language in a similar way to hearing children of the same age.

However, it takes some time to find the exact level of a child's hearing loss and work out the benefit they get from hearing aids. In some parts of the world, children are routinely implanted before the age of one. This is not currently common in the UK. The cochlear implant team and surgeon will explain the potential risks and benefits with you before deciding to perform the surgery.

Older children and young people

Older children and young people may also be candidates for cochlear implants. This may include:

- ▶ children and young people who have become deaf after learning to speak, such as because of meningitis
- ▶ children and young people who have progressive or acquired hearing loss and now get less benefit from their hearing aids
- ▶ young people who were assessed for a cochlear implant when they were younger but didn't meet the criteria at the time. Severely to profoundly deaf people who use hearing aids consistently, and mainly use spoken language to communicate, may now be considered for reassessment.



7 The assessment process

If you agree to be referred for a cochlear implant assessment, this will be done at a specialist cochlear implant or auditory implant centre. The implant centre will accept referrals from your GP, ENT consultant, paediatrician, or audiology professional.

There are several implant centres around the UK. You'll usually be referred to your nearest one, although you have a legal right to choose a different centre if you want. In most cases, it's sensible to be assessed at your local centre to make travelling to follow-up appointments easier.

You may have to travel quite far to get to your nearest implant centre. You might be entitled to help with your travel costs through the Healthcare Travel Cost Scheme (HTCS) if you:

- › receive Income Support, Income-based Jobseeker's Allowance or Pension Credit Guarantee Credit
- › are named on an NHS tax exemption certificate
- › qualify under the NHS low-income scheme.

Some centres offer a combination of virtual and face-to-face appointments. This can reduce the number of trips you need to make. If you're struggling with travel arrangements, speak to your implant team or GP. There may be more support in your local area.

The implant team will give you an appointment for an initial assessment which will determine your child's suitability for a cochlear implant. There will usually be several more appointments for detailed assessment involving hearing tests and other assessments. These tests help the implant team to build up a picture of your child's deafness, how much benefit they get from using their hearing aids, whether a cochlear implant is likely to provide additional benefit over their hearing aids, and their ability to make the most of a cochlear implant.

Some of these appointments will be very lengthy and can sometimes take most of the day. If you have other children, you may need to arrange flexible childcare for appointment days.

How long the assessment process takes

How long your child waits for their cochlear implant surgery will vary depending on where you live and how long their assessment takes.

Each nation has its own targets for waiting times which NHS trusts and health boards are expected to meet. The targets set out how long a patient should wait between the time that they're referred for medical treatment and the date that the treatment takes place. You can find out about waiting times in your area using the following websites.

- › **England:** myplannedcare.nhs.uk
- › **Scotland:** nhsinform.scot/waiting-times
- › **Wales:** 111.wales.nhs.uk/plannedcare
- › **Northern Ireland:** online.hscni.net/my-waiting-times-ni

In some cases, your child's surgery may be delayed because the assessment period itself is taking longer than expected. This could be caused by:

- › the complexity of your child's condition
- › the cause of your child's hearing loss
- › how your child uses their hearing aids
- › your child's ability to adapt and acclimatise to an implant
- › medical suitability for surgery
- › your availability to attend multiple hospital appointments.

The implant team should keep you informed as to how the assessment is progressing.

📄 If your child has developed severe to profound deafness because of meningitis and you're considering getting cochlear implants, you may be 'fast-tracked' through the assessment process because of possible side effects caused by meningitis. Order or download our resource *Meningitis and childhood deafness* to find out more. ndcs.org.uk/meningitis-and-childhood-deafness.



People you'll meet

The cochlear implant assessment is done by a multidisciplinary team. A multidisciplinary team is a group of professionals from lots of different backgrounds. The team should include:

- › audiologists
- › audiovestibular physicians
- › ENT consultants
- › speech and language therapists
- › Teachers of the Deaf (ToDs) and/or Auditory Verbal Therapists
- › nursing staff
- › educational or clinical psychologists
- › radiologists
- › paediatricians.

 You can find a list of specialist cochlear implant or auditory implant centres at bcig.org.uk.

During the assessment

The assessment process includes the following steps. These can be done in any order.

- › You'll be given information about your child's deafness, cochlear implants, the procedure, and what happens after surgery.
- › The implant team will work with the professionals who support your child locally such as Teachers of the Deaf (ToDs), Speech and Language Therapists (SLTs), occupational therapists and teachers. Appointments may be at the cochlear implant centre or at home, and may include nursery or school visits.
- › A detailed history of your child will be taken.
- › A full examination of your child's ears will be carried out.
- › You'll be offered further testing to try to find out the cause of their deafness (known as aetiological testing). This may include genetic testing. Genetic testing is a personal choice and you can opt out of this test.

 Find out more about genetic testing, including stories from other families, at ndcs.org.uk/genetic-testing.

- › Your child will have a radiological assessment. This usually involves an MRI scan, unless there's an anatomical reason to get a CT scan instead. These tests look at the anatomy of the cochlea, the balance organs, auditory nerve (hearing nerve) and the brain. They also help to see whether it's possible to insert the electrodes or not.

- › Your child will have detailed age-appropriate testing, with and without their hearing aids, to give a functional assessment of their level of hearing.
- › Tympanometry will be used to evaluate your child's middle ear function.
- › Your child may have a further trial of hearing aids for at least three months.
- › Your child will have objective hearing tests including an auditory brainstem response (ABR) to confirm the function of the auditory nerve pathways.
- › Your child may be referred for balance/vestibular assessment.
- › Advice will be given about vaccination to reduce the risk of pneumococcal meningitis.
- › Your child's communication, language and speech skills will be evaluated. The tests may be carried out at the implant centre, at home, or at school by the implant centre's ToD and SLT.

 Learn more about hearing tests in our resource *Understanding your child's hearing tests*, available at ndcs.org.uk/understand.

As well as the various tests and assessments, the implant team will talk to you about the ongoing care and support your child will need to get the most benefit from an implant. They'll look at the long-term support that can be provided by parents, family, your local authority, and local audiology services. The implant team will only recommend implantation if:

- › your child has been through the assessment process,
- › you understand the commitment that is required to start this journey, and
- › you and the implant team agree that your child will consistently, continuously and effectively use a cochlear implant.

The assessment process sometimes highlights issues or conditions that might affect the assessment outcome. These are unlikely to stop them going ahead with an implant, but need to be understood and addressed during the assessment process.

Glue ear

Glue ear (also known as otitis media with effusion) is a very common condition during childhood. It happens when the middle ear (behind the eardrum) becomes filled with sticky fluid. Glue ear is often temporary and may resolve without the need for any treatment. However, it may cause a child who has moderate to severe deafness to appear to have a more significant hearing loss. This could mean that without glue ear, your child has enough hearing not to need a cochlear implant. It's very important that glue ear is treated and your child has a hearing test once it's resolved to measure the true level of sensorineural deafness.

Additional needs

Children with additional needs can, and do, benefit from implants. Many deaf children with additional needs are implanted early in life before their other needs are identified or known about. Sometimes the assessment process helps identify other needs. Each child needs to be assessed as an individual. Very occasionally, it may be felt that a child's additional needs could make it difficult or impossible to learn to use the new signal that the child is hearing through the cochlear implant. The implant team will discuss this with you and make alternative recommendations for supporting your child if needed.

Ossification

Children who become deaf after having meningitis may experience ossification. This is when new bone grows within the cochlea, which could make it difficult for the surgeon to insert the electrodes. If the cochlea has partially ossified then implantation is still possible and the results are usually still good. If there's complete ossification, surgery to implant may still be possible but will be more difficult. In these cases, results can be variable and it's not possible to predict how effective the cochlear implant will be.

Auditory brainstem implants

Very occasionally, children may be born without a cochlea or auditory nerve (hearing nerve). If the scan shows that either the cochlea or the auditory nerve is absent, then it will not be possible to have a cochlear implant in that ear. The implant team may then ask if you'd like to consider an auditory brainstem implant (ABI).

An ABI works in a similar way to a cochlear implant. Rather than stimulating the auditory nerve, the ABI stimulates the brainstem directly, bypassing the ear and auditory nerve, to provide a sensation of hearing. The electrode array of the ABI is placed in a region of the brainstem called the cochlear nucleus.

 You can find more information about auditory brainstem implants on our website at ndcs.org.uk/implants.

After the assessment process

Deciding whether to proceed with cochlear implants is an ongoing process throughout the assessment period. If you or your child ever feel that having an implant is not the right choice, you should say so. The implant team will understand if you need more time to think before making a final decision.

If your child is old enough, they should be involved in the decision-making process. If you have any questions about the tests, the operation, and what it's like to live with an implant, you should speak to the implant team.

Once all the assessments are complete, the implant team will tell you whether they feel cochlear implants will be suitable for your child. If you and the implant team choose to go ahead with the surgery, the implant team will arrange the operation. They'll also arrange a pre-operative appointment with the ENT consultant. The pre-operative appointment is a last opportunity to discuss what exactly happens during the surgery and any risks involved. See page 24 for more information about cochlear implantation surgery.

There will be times when the implant team feels that a child is not suitable for a cochlear implant. This could be for the following reasons.

- ▶ The scan shows that there is no cochlea or auditory nerve.
- ▶ The scan shows a problem with the cochlea which makes an implant surgically impossible.
- ▶ Your child has enough hearing to benefit from conventional hearing aids. If this is the case, the implant team will make recommendations on hearing aids. Your local audiology department will continue to support your child and monitor any changes in their hearing. If your child's hearing changes in the future, they can be referred back to the implant centre for re-assessment.

A report will be sent to the professional who made the referral explaining the reasons why a cochlear implant has not been considered suitable. The report will include recommendations for future management along with any other suggestions.



8 Choosing a cochlear implant

There are several different makes and models of cochlear implant. They all work in similar ways. Most UK implant centres offer a choice of two or more devices. The NHS offers cochlear implants produced by:

- › Advanced Bionics advancedbionics.com
- › Cochlear cochlear.com
- › MED-EL medel.com.

There is currently no evidence that children do better with one manufacturer's device over another. The results tend to be similar for all.

In rare cases, the surgeon may recommend a specific device if they think it's easier to implant because of the anatomy of your child's inner ear.

Speak to other families about their experiences of individual devices.

If you have the option to choose your child's cochlear implants, there are lots of things to consider. Think about the below questions. You can get information from your implant team, from the manufacturers' websites, and by asking people who have cochlear implants already.

If you're worried about making a choice, ask the implant team what they recommend. Remember, all the cochlear implants offered by the NHS are reliable options.

- › **How many times has the surgeon implanted the make and model of cochlear implant you're interested in?**
Ask how often the team has provided these implants to children of a similar age to your child. To ensure a high level of experience, the implant surgeon should carry out at least 10 surgical procedures per year.
- › **What does the sound processor look like?**
Find out about things like the size of the sound processor, how it fits on the ear, and whether it's available in different colours. If your child is old enough to make their own decision, ask them how they'd like their sound processor to look.
- › **How reliable is the sound processor?**
Sound processors should last for at least five years.
- › **How reliable is the internal implant?**
Find out how many people are currently implanted with the make and model you're interested in, and how long the implant is expected to last. Most people use the same internal receiver for several decades. However, your child will probably need re-implantation at some point in their adult life. In rare cases, some children may need to have re-implantation surgery during childhood.
- › **Does the manufacturer support backward compatibility?**
If a sound processor is backwards compatible, it will be easier for your child to upgrade to the latest processor technology.
- › **Will it be safe for your child to have MRI scans with this make and model of cochlear implant?**
Find out more about safety in MRI scanners on page 39.

› What kind of battery does the sound processor use?

Most modern cochlear implants use rechargeable batteries. Some use disposable batteries. Find out more about batteries on page 42.

› How can you tell if the battery has run down or the cochlear implant isn't working?

If your child is very young, flashing lights on the processors make it easy to tell if the implant is switched on and working well. Older children may prefer more subtle ways of checking their implant's battery and function, such as notifications on an app.

› Is the sound processor waterproof, or does it come with waterproof casing which can be used while swimming?

Find out more about using cochlear implants around water on page 40.

› How does the sound processor connect to assistive listening devices like radio aids?

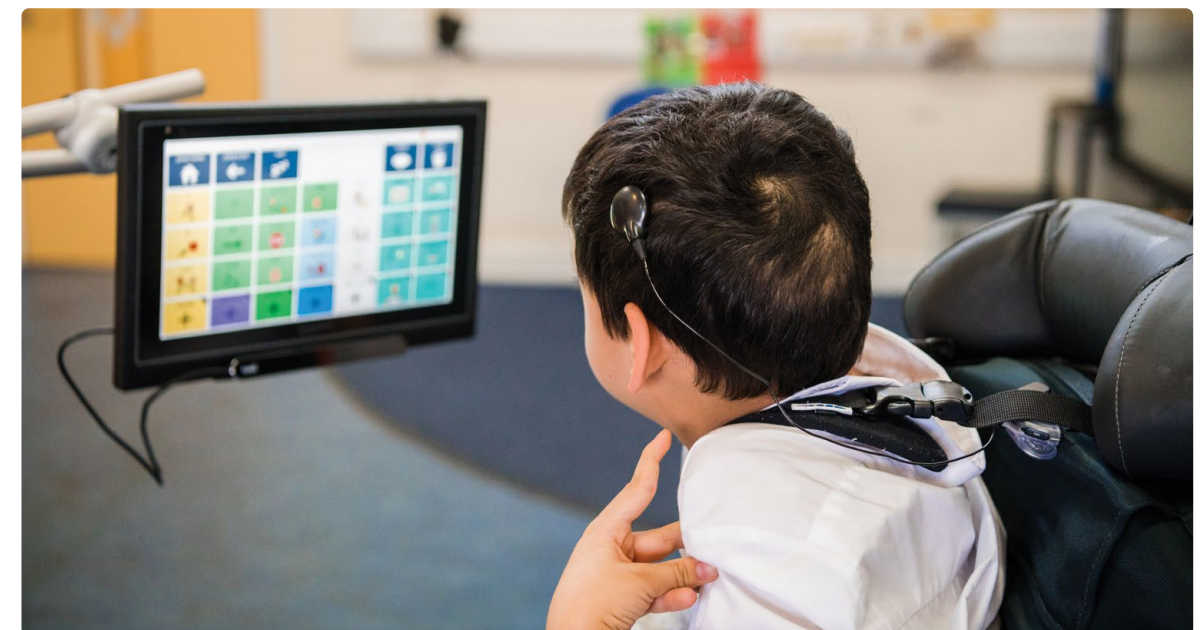
For example, Sky Marvel sound processors from Advanced Bionics have Roger receivers built in. This means that users can connect to a Roger radio aid without needing to attach an external receiver.

Other makes and models of sound processor will connect to wireless technology in different ways.

How will changes in technology affect my child's cochlear implant?

The part of a cochlear implant that is surgically implanted is unlikely to need upgrading, unless there are problems. The external sound processor can be changed as technology develops and improves. This shouldn't mean further surgery.

It's recommended that sound processors are upgraded every five years if clinically appropriate. If your child has had their sound processors for five years and there's evidence that a new model will work better for them, they may be upgraded.



9 Cochlear implant surgery

Many hospitals have information online about how to prepare yourself and your child for surgery. Ask your implant team if they have a liaison nurse who can talk to you and your family about what to expect.

You could also ask parents of children with cochlear implants for their tips.

Implant manufacturers produce online videos, children's stories and colouring books with information about cochlear implant surgery. These help explain the surgery to young children.

One or two weeks before surgery, you and your child will go to the hospital for a pre-operative appointment. They'll check your child and make sure they are fit for the general anaesthetic and operation.

On the day of the surgery, your child will be examined by the medical team and anaesthetist. You'll need to fill in a consent form. It's important that you read the form carefully to make sure you understand the procedure and what it involves. Ask your surgeon and anaesthetist if there's anything you're not sure about.

The operation will be done under general anaesthetic. If your child is having two implants, the surgery will take around three to six hours. The surgeon may need to shave a small amount of hair from behind the ear. Next, a small cut is made on the side of your child's head. The internal receiver is put in and secured beneath the skin and the electrode is inserted into the cochlea. Tests will be carried out to check it's working. The wound is closed with dissolvable stitches underneath the skin so no stitches need to be taken out later.

After the operation, you'll be able to see your child in the theatre recovery area. A dressing may be placed around your child's head, which will probably be removed the day after surgery. The implant surgeon will usually want to see you on the same day as the operation to explain how it went. Be aware that hospital staff are unlikely to know any sign language, which may leave your child feeling confused or worried if they wake up and try to sign.

 Order copies of our leaflet *Communicating with deaf children* to hand out to the staff looking after your child at ndcs.org.uk/communicationflyer.

Some children go home the same day of their operation. Some children might need to stay in hospital overnight.

Before leaving the hospital, you'll be given a follow-up care plan. If there's anything you're not sure about, ask a member of the team or nursing staff. An X-ray may have already been done to show the position of the cochlear implant. If not, a separate appointment will be made to do this. You do not need to see your GP after leaving hospital. The implant centre will arrange a post-operative appointment one to two weeks after the operation, to check the wound is healing well.

Children are usually up and about one to two days after surgery. It's usually advised they have two weeks off school or nursery to recover. The implant is activated around three to four weeks after surgery, which gives the incision enough time to heal properly.

After the surgery, your child won't be able to wear their hearing aids. If you don't already use sign language, it's a good idea to learn some basic signs before the operation. This will help your child communicate in the weeks before their cochlear implant is switched on.

 Order or download our children's comic, *Chloe gets cochlear implants*, to explain the surgery to your child and their siblings. ndcs.org.uk/chloecomix

Risks of surgery

There are risks associated with any surgery that requires a general anaesthetic. There are some specific risks to cochlear implant surgery which your ENT surgeon will discuss with you.

Meningitis

Although the risk of contracting meningitis in those with cochlear implants is very small, it's slightly higher than in the general population. It's recommended that children are vaccinated against meningitis before cochlear implant surgery. The vaccination is usually given by your GP.

Facial nerve

The facial nerve is very close to the area that will be operated on. However, the risk of the nerve being damaged is very small. Monitors are used during the surgery to avoid this happening.

Infection

Infection around the implant site is rare but can happen. If it does become infected, the implant may need to be removed. If, after your child's surgery, you are concerned that they might have an infection, you should contact the implant centre as soon as possible for advice. You can also contact your local ENT department and your GP.

Device failure

The internal receiver package and electrode are sensitive electronic devices which occasionally stop working as they should. This requires surgery (known as re-implantation) to replace the device. Re-implantation is usually carried out quite successfully in the same ear.

Some other side effects of cochlear implantation surgery include a metallic taste in the mouth and balance problems or dizziness. These are usually short-term and get better by themselves. If you have any concerns about the surgery, speak to your surgeon or any member of the implant team.

10 Switch-on

Two to four weeks after surgery, your child will have an appointment with the cochlear implant team to fit their sound processor (the external part of the cochlear implant).

At this appointment, the team will start programming the sound processor to suit your child. This is also known as 'tuning' or 'mapping.' During a tuning appointment, the team stimulates the electrodes in the cochlear implant. They'll measure which levels create sounds which are comfortably loud for your child.

When your child's implant is activated, they'll react in different ways. Be prepared that they may not have a positive reaction. They may cry or look confused or frightened. They may not respond at all.

The way your child responds could depend on their previous experience with sound. Your child will need lots of positive encouragement and time to adjust to the new signal. Every child is an individual. It's normal for every child to respond differently.



"The implant was turned on and it wasn't like you see in the news. Nothing happened. Those internet videos are so misleading. It took a long time and a lot of work for Genevieve to process sound."

Mary is mum to Genevieve (8) who is profoundly deaf after contracting meningitis at five weeks old.

In the beginning, the team will need to make lots of adjustments as your child starts to adapt to the new sounds and the electrode beds into the cochlea.

This means your child will need regular appointments during the first year. The number of sessions can vary. Most people go to at least six appointments in the first year.

After the first year, your child will attend the implant centre for a review and programming once or twice a year.



"We were expecting a massive reaction, even though we were told there might be no reaction. Harry's eyes went wide but he didn't cry. But audiology don't give them the full volume and range to start with as they don't want to scare them.

There have been gradual changes to his behaviour since – it's been a longer process than we thought. He has to go back for appointments every few weeks for tuning and mapping. But in the first week he started turning for his name, which was an emotional thing for us, and then he started repeating 'mama'."

Lucie is mum to Harry, who had cochlear implants fitted when he was one year old.

The implant team will be able to answer your questions, talk to you about how you can help your child, and explain how you can expect your child to progress.

In addition to tuning appointments, you may also have sessions with a Teacher of the Deaf (ToD) and a speech and language therapist (SLT) from the implant team. The ToD and SLT may visit your child at home, and later at school, to observe and record your child's progress. The implant team's ToD and SLT do not replace any services you're getting from your local ToD or SLT. You should still be getting regular input from your local ToD and SLT.

It's a good idea to keep your own notes so you can discuss any concerns with the implant team.

If your child develops glue ear or an infection in the implanted ear, you should contact your GP and get it treated quickly. You should also let your cochlear implant team know.

As your child grows up, they'll need to learn about their implant and how it works so they can be responsible for looking after it. They'll learn when to contact the implant centre for changes to the tuning and for repairs, spares, testing and advice.



11 Listening and language

It will take lots of patience and practice for your child to learn to interpret new sounds using their implant. Every child is different and some children take longer than others.

Many children who use cochlear implants go on to develop spoken language. To develop spoken language, children need be able to hear and understand speech sounds. For a hearing child, this process begins the day they're born and continues throughout their childhood. For children with cochlear implants, the process will take longer.

Ask your speech and language therapist and Teacher of the Deaf for a list of games and activities that will help your child learn about new sounds and develop their listening skills. All cochlear implant manufacturers have online resources aimed at children of all ages to help them learn to listen and help with their language skills.

- › Advanced Bionics: BabyBeats
advancedbionics.com/gb/en/campaign/babybeats.html
- › Cochlear: Hearing activities for babies and preschoolers
cochlear.com/uk/en/home/ongoing-care-and-support/rehabilitation-resources/babies-and-preschoolers
- › MED-EL: Rehabilitation resources
medel.com/en-gb/support/rehabilitation
- › University of Southampton: Music listening for young cochlear implant users
southampton.ac.uk/mfg/music-info/children.page

It's important that your child wears their cochlear implant as much as possible so they can learn to recognise sounds and make sense of the noise around them. Playing games, singing songs, and reading stories will help to develop these skills.

Always be aware of listening conditions. Keep background noise at a reasonable level. Make sure your child's processors fit comfortably and securely so that they can wear them continuously when they're awake.

As your child adapts to their cochlear implant, they may begin to develop speech. If your child learned to sign before their implantation surgery, they may start to speak more and sign less. For many children, sign language will continue to be an important part of their communication skills and deaf identity. It can also be useful in situations where your child isn't wearing their cochlear implant, such as at bedtime or in the bath.

Some professionals believe that children who wear cochlear implants shouldn't use sign language any longer. However, there is no evidence that learning sign language prevents a child learning to speak. In fact, recent research shows that exposure to sign language increases language and cognition skills in deaf children. Bilingualism also has lots of benefits for a developing child's brain.

Regardless of whether your child uses speech, sign or a combination of both, the most important thing is that your child can develop fluent language skills to communicate in the way that is most appropriate and effective for them.



"If she's cross and has had enough, or if she's tired, she'll take her implants off. She's getting better at telling us when she takes them off and she'll tap her ears or tell us that she wants them back on too. On the days she wears her implants, it's clear she loves listening and enjoys sound.

We try not to make her put them on though, as the whole reason we got implants for her was so that she could make the choice. If she's said no, we try and respect that and we then sign."

Jennie is mum to Olive (4) who is profoundly deaf and has cerebral palsy.



12 Customising sound processors

Most models of sound processor come in a range of colours. Your implant team can tell you about the colours available for your child's sound processors. As most children will use the same processor for at least five years, it's a good idea to choose a colour or design they won't grow out of too quickly.

Decorating your child's sound processors is a great way to help children feel more confident about their deafness. Adding removeable accessories and decoration allows you to change how the processors look to match your child's interests and personality.

For young children, choosing bright colours makes it easier to find sound processors if they get lost! If your child wears two cochlear implants, using different colours or designs for each processor may help them to remember which sound processor to wear on each side.

As your child gets older, encourage them to decorate their sound processors themselves if they want to. Use Instagram and Pinterest to find inspiration. Lots of deaf young people find that decorating their cochlear implants helps them to think of their hearing technology as a cool accessory rather than a medical device. It can also lead to more positive conversations about deafness and deaf identity.

Cochlear implant covers and skins

Cochlear implant covers and skins are a fun, safe way to customise sound processors and are designed to be easily removeable.

- › Ear Gear comes in a range of colours for a variety of cochlear implants. These covers are removable and help protect the processors against moisture and dirt. gearforears.com
- › Hearoes make skins for both hearing aids and cochlear implants. They also offer a range of cable twists to cover and protect the processor coil. hearoes.co.uk

Other covers are available through Connevans. connevans.co.uk



"I decided to decorate my cochlear implants for prom because I wanted them to match my dress and I wanted them to stand out. I am proud of my Deaf identity!

I bought cochlear implant skins from a business call Hearoes and I added the gems by myself. When I was younger, I used to be embarrassed about being deaf and wanted to fit in with everyone else. If I could talk to my younger self, she would be proud! Wearing decorated cochlear implants makes me feel confident and proud to be a cochlear implant user and it's my superpower! It makes me who I am."

Kara (18) is profoundly deaf and wears cochlear implants.



! Make sure that any customisation can be removed and that it doesn't affect the functionality of the sound processor. Never glue anything directly onto the casing and do not use paints or nail polish.

13 Keeping cochlear implants on little ears

As babies and toddlers grow, they start to explore their surroundings, feeling, touching and pulling everything that's in reach. For deaf toddlers, that often includes their sound processors.

It's important your child wears their sound processors as often as possible so they can learn to listen, hear, and make the most of their cochlear implants. This can be easier said than done! It's something many parents find frustrating. As each sound processor costs the NHS around £5,000, it's important that you try not to lose them. There are accessories available to help keep them in place.

Cochlear implant accessories

Retainers

Retainers, sometimes known as 'huggies', help keep behind-the-ear processors in place. A retainer has a thin plastic tube that goes around the outside of the ear (the pinna). Attached to this tube are two circular bands of soft plastic which are pushed over the sound processor to keep it in place.

Retainers are available from outlets such as:

- › Cochlear
cochlear.com/uk/en/home/products-and-accessories/our-accessories
- › Ear Gear
gearforears.com



Headbands and hats

There are some specialist hats and headbands that can help keep sound processors in place.

- › Angeliques
angeliqueshearingbands.co.uk
- › Malinka
Malinka.me.uk
- › Ear Suspenders
Etsy.com/uk/shop/EarSuspenders

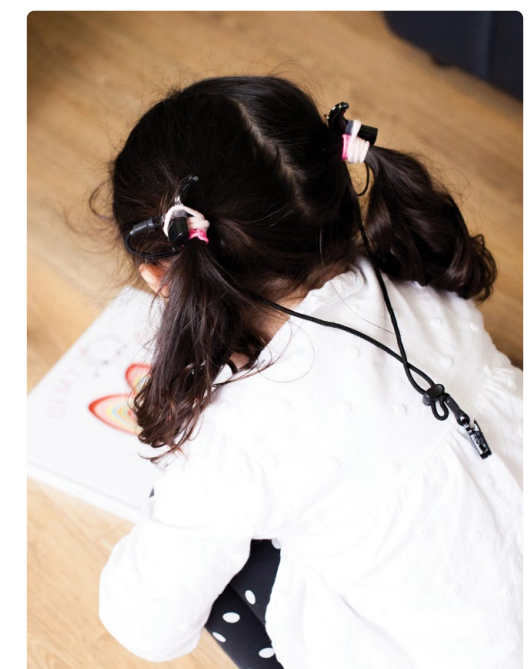


Clips and cords

If you're worried about your child losing their sound processors, you could use a cochlear implant clip. The clip goes on your child's clothing and has a cord that attaches to their sound processors using plastic bands or retainers. Some of these clips come in fun animal shapes, such as dinosaurs.

Earmoulds

Earmoulds like the ones used for hearing aids can be made for cochlear implant sound processors. These help them avoid falling off. You can ask your cochlear implant team or local audiology clinic to fit earmoulds for your child's sound processors.



Why children remove their sound processors

It's common for babies to take their sound processors off themselves. Often this is just a developmental stage. Soon, other things will occupy their attention. You may need to take their sound processors away for a short time and try again later while they're distracted by something else.

Sometimes, babies and young children will take off their sound processors when they're bored or feel there's nothing interesting to listen to.

Occasionally, the sound from the sound processors may be causing genuine discomfort. If your child develops a habit of taking off their sound processors, talk to your implant team, audiologist or Teacher of the Deaf.

Listening to sound through cochlear implants can be very tiring. Even deaf adults sometimes remove their implants when they're tired. You should encourage your child to wear their sound processors as much as possible. However, it's important that they learn to associate them with positive experiences. Give your child the option to remove them when they really need to. Pay attention to signs that your child is becoming tired or overwhelmed. Encourage them to tell you or another adult that they want to take them off.

Top tips

Make sure sound processors are comfortable

If your baby blinks often when listening to sounds around them, this may be a sign that the noises they're hearing are loud or surprising. Young children may remove their sound processors if loud noises are uncomfortable. If your baby or toddler is doing either of these things a lot, check the settings on the processors and talk to your child's implant team.

Make wearing sound processors part of a routine

- ▶ Slowly build up the length of time that your child wears their sound processors. You could start with just a couple of minutes several times a day. If your child keeps taking them off, stop trying and have a rest. Try again later or the next day when you're both feeling more relaxed.
- ▶ Try to make wearing sound processors part of your child's dressing and undressing routine. Put the sound processors on when they get up and take them off when they go to bed. It'll become normal for your child to wear their sound processors when they're awake.
- ▶ Try putting the sound processors on before your baby or young child normally wakes up so that they're already in place. Never leave babies and young children alone with their sound processors as they may put them in their mouths.
- ▶ Keep the sound processors in a safe place. If your child takes their sound processors off, take your child and the sound processors to the safe place and put them away. Your child will learn to put the processors in the safe place when they take them out and you won't have to go looking for them every time they disappear.

Make sound processors fun

- ▶ Have something ready to distract your child, such as a favourite toy. Perhaps you could even have a special toy that they have only when you're putting the sound processors on.
- ▶ Decorate the processors with stickers and personalise them. Find out more on page 30.
- ▶ Look online for toys with cochlear implants, or toy implants which you can attach to a soft toy. Talk about when the toy can take their implants off and where you'll put them to keep them safe.

Meet other cochlear implant users

- ▶ Meet other parents of deaf children so they can share their experiences with you. Meeting other children wearing cochlear implants may help your child to feel that they aren't the only one.
- ▶ Look out for TV shows or opportunities to meet deaf adults with cochlear implants. Explain to your child that people of all ages wear them.



14 Taking care of cochlear implants

Daily checks

When your child is young, you should carry out daily checks on the external parts of the implant (the sound processor and the transmitter coil). Your child's implant team will show you how to do these checks.

Your implant team will provide you with a set of replacement leads and coils that you can change yourself at home. When you use a replacement part, don't forget to let your implant team know so that they can give you a new spare. They'll probably ask you to send the faulty part back. Don't throw it away unless you've been told to do so.

As your child gets older, encourage them to take responsibility for checking their own sound processor and transmitter coil.

Checking switches and controls

- ▶ If switches and controls are enabled on your child's sound processors, check that these are functional. Check there is no visible damage to the processor.

Checking batteries and battery contacts

- ▶ Make sure you're using the type of battery suggested by your child's cochlear implant centre.
- ▶ Ensure the batteries are fitted correctly. If your child's sound processors connect to a mobile phone app, you can use this to check the battery levels. If you're not sure whether the app is accurate, you can use a battery tester (if you have one) to check the power levels of the battery.
- ▶ Check that the battery contacts are clean and not rusty. If they are, contact the cochlear implant centre.

Checking leads

- ▶ Check that there are no obvious signs of wear and tear or damage. Replace the leads if you're not sure.
- ▶ Check the connections between the sound processor and the transmitter coil. If the connection is loose, contact the implant centre.

Listening check

- ▶ Daily checks should be carried out on your child's equipment. Depending on the cochlear implant your child has, this can be done using either a signal check device or listening earphones. Your child's implant team will show you how to do a listening check on the sound processor.

Some types of listening earphones also let you judge the quality of the sound. Make sure that you listen at a comfortable sound level. If you can, make sure that the sound quality is clear and without any crackles. If not, contact your child's implant centre.

The sound processor may have its own self-check function. Make sure that you know about this and what to do if it finds a fault.

Some models of cochlear implant can now be checked remotely. This means your cochlear implant team can test and map your child's cochlear implants virtually, without needing you to come into the implant centre. This is especially useful if you live a long way from the cochlear implant centre or if travelling to appointments is difficult. The implant team will tell you if it's an option for your child's make and model of cochlear implant.

! If you find a problem when doing your daily checks, contact the cochlear implant centre for advice.

Cleaning

Ask your implant team or the cochlear implant manufacturer how to clean your child's sound processors. Each cochlear implant manufacturer has their own advice on how to clean their processors. For light dirt or soiling, most will recommend wiping with a dry cloth.

Charges for lost or damaged sound processors

The NHS provides sound processors on a permanent loan basis. They always remain the property of the NHS rather than the wearer.

You're expected to take reasonable care of your child's sound processors. The implant team will give you accessories and advice to make sure that sound processors can be worn securely. Find out more about keeping your child's cochlear implants on on page 32.

Your implant team will tell you what to do if your child's sound processors are lost or broken, or if their internal implant gets damaged.

The NHS is legally allowed to charge for the loss or damage of equipment in England, Wales and Northern Ireland. However, most services don't charge for the loss of children's sound processors since it's difficult to prove that loss or damage was due to negligence (the fault of the parent or child). If they do charge, they usually charge around £100 to £150 for each processor, and they can't charge families in receipt of certain welfare benefits. This is a very small fraction of what the sound processor really costs to replace. Speech processors cost the NHS over £5,000 each. It's very important that you try your best to keep them safe.

Some modern cochlear implants are compatible with a smartphone app which you can use to track the sound processors using GPS. This is especially useful if your child has a habit of removing their processors, as you can then use the app to find them. The cochlear implant service will tell you if your child's cochlear implants connect to an app. Ask the team if you need help downloading the app to your smartphone.

Insuring sound processors

NHS sound processors can't be insured as they're the property of the NHS. However, some parents choose to insure against the risk of being charged for any loss. Most household insurance will cover this. Let the insurance company know and list the sound processors as a named item on the policy.

When travelling abroad, you can buy travel insurance to cover the sound processor and external parts of the implant.

Most cochlear implant manufacturers offer a holiday loan kit which includes spare processors in case they get damaged or lost while you're away.

Private cochlear implants

Private cochlear implants are your property and you're responsible for the full cost of any repair or replacement. If you have them insured, you'll need to contact your insurance company for details of how to claim on your insurance policy.

Airplanes and airport security

There's no need for your child to remove their sound processors to go through airport security. NHS advice is that metal detectors and security scanners should not damage cochlear implants. However, hearing technology can activate the alarm at security. It's a good idea to let airport security know that your child has a cochlear implant. Some implant centres will give you a Patient Identification Card which you can show to airport security to let them know about your child's cochlear implants. However, these cards aren't necessary. You can just tell airport staff about your child's implants when you go through security.

When flying, your child will not need to turn off their cochlear implants for take-off or landing. If their cochlear implants use Bluetooth to connect to a wireless device, they may need to switch this to flight-safe mode during take-off and landing but can turn it back on during the flight. It's best to check with the airline staff before flying. Most implant centres will have a letter for patients who are about to travel which explains the importance of keeping the device on during travel.

Sleeping

There's no reason why a child can't wear sound processors at night. Most children don't find them very comfortable to rest on and choose to remove them when they sleep.

15 Safety information

Children with cochlear implants can take part in most activities. Sometimes, it's a good idea to remove the sound processor to stop it being damaged, such as when playing football or netball. To avoid damaging the internal part of the implant, children with cochlear implants are advised to wear head protection for some activities. Most children with cochlear implants avoid contact sports where a knock to the head is likely, such as judo, kick-boxing and rugby. Where head protection is recommended, choose a helmet which leaves enough space over the implant site to stop any pressure.

When your child is fitted with their cochlear implant, you'll be given a user guide for the device. The user guide contains information that is specific to their device. It will contain essential safety information. The safety guidelines include information on medical and dental treatments, therapy and surgical procedures.

If you need specific information or advice, contact the cochlear implant manufacturer.

It's especially important to check whether your child's cochlear implants are compatible with MRI scanners. Share this information with your child's doctors and other family members. The British Cochlear Implant Group (BCIG) has guidelines around MRI scans for cochlear implant users at bcig.org.uk/safety.



16 Managing cochlear implants around water

Most modern cochlear implants are described as dust and water resistant. This means that they meet level IP67 or IP68 of the International Standard IEC60529. They can be submerged in 1 or 1.5 metres of freshwater for up to 30 minutes. These devices are splashproof and should not be damaged by small amounts of water, like being out in the rain. They are not suitable for swimming, bathing, or wearing in the sea.

Each manufacturer has designed its own water accessory to protect the sound processor. This enables your child to swim and playing in water with their implants on. For example, Cochlear implants worn with the Cochlear Aqua+ kit can be continuously submerged in up to 3 metres of freshwater for up to two hours. This means children can use them safely during swimming lessons. Water accessories are sometimes included free of charge when your child is first fitted with their cochlear implant. Otherwise, you can buy them from the manufacturer.

Even if your child uses their cochlear implant with a waterproof kit, they may still struggle to hear while swimming. Swimming pools usually have poor acoustics. Some models of cochlear implant can be used alongside assistive listening technology to support listening in the pool, such as radio aids worn by swimming teachers. Some manufacturers produce assistive listening devices specifically for swimming. For example, Advanced Bionics cochlear implants fitted with a waterproof battery can be worn with the Advanced Bionics Aquamic, a fully waterproof headpiece microphone. This allows the user to listen directly through the open microphone, rather than listening through a microphone housed inside a waterproof accessory.



Advanced Bionics AquaCase with AquaMic



Advanced Bionics waterproof battery

 If your child is about to start swimming lessons, download or order our free resource, *Deaf-friendly swimming toolkit: A guide for professionals, to share with their teacher.*

If your child’s cochlear implants get wet

Even if your child’s sound processors are described as dust and water resistant, they may still be damaged by prolonged exposure to water, especially salt water.

Most sound processors come with a ‘drying box’, which removes light moisture from the sound processor. This can include sweat and condensation. Speech processors should be put in the drying box overnight.

Drying boxes can be electronic or non-electronic. Non-electronic drying boxes have tablets or capsules which remove moisture from the processor.

Be sure to use the drying box that came with your child’s cochlear implants. Other brands may not work.

If your child’s sound processor is fully submerged in water for longer than is recommended, or if it shows signs of rust or water damage, contact your implant centre for advice.



17 Batteries and battery safety

Cochlear implants use either rechargeable batteries or disposable batteries. The implant centre will tell you which type of battery your child's implants use. They'll show you how to replace or recharge them.

Rechargeable batteries

Most new models of cochlear implant use rechargeable batteries. Rechargeable batteries last for between 19 to 40 hours. Battery life varies depending on the type of battery used and whether your child also uses assistive listening devices such as a radio aid. Most cochlear implant users charge their sound processors when they take them off at night. It is safe to leave the batteries charging overnight.

Over time, you may notice your child's rechargeable batteries need to be charged more frequently. This is because the length of time a rechargeable battery lasts reduces every time it's charged. It's a good idea to carry a spare battery and battery charger with your child, just in case a battery runs out unexpectedly.

Disposable batteries

Disposable batteries are small button batteries, provided for free on the NHS. Disposable batteries need to be changed regularly, between once a day and once a week. Battery life can vary depending on the programmes that your child uses and whether they use any assistive listening devices, such as a radio aid.

Your implant team will usually provide a quantity of batteries. If you run out, you should be able to get a small supply:

- › from a local health centre or GP surgery near your home
- › through a Teacher of the Deaf so that they can be collected at your child's school
- › by post.

In an emergency, you may be able to buy disposable button batteries from a chemist or corner shop. These may be advertised as hearing aid batteries. Button batteries come in different sizes. Take your child's old battery with you to help you find the right size.

Keep your used batteries in the original packaging to help you make sure old batteries have not gone missing. Some audiology and implant services will ask you to return old batteries when you request new ones. Otherwise, you can recycle them at recycling centres or at battery recycling points at most large supermarkets.

! Cochlear implant batteries are extremely dangerous if swallowed. Always make sure the tamperproof battery lock is on to stop your child from opening the battery cover.

If you think your child may have swallowed a battery or inserted it into their ear or nose, take them to your nearest A&E department. If your child uses disposable batteries, take along a packet of batteries so that doctors know exactly what they're dealing with.



18 Assistive listening devices and wireless connectivity

Most cochlear implant users can hear speech when they're in an ideal listening situation. However, the information received from a cochlear implant is significantly reduced compared to the sound heard through typical listening. There will be situations where your child will find it more difficult to hear.

Some deaf children learn to 'mask' in situations where they cannot hear well. They may appear to hear more than they can. Signs that your child is struggling to hear may include:

- › appearing bored, distracted, or fidgety
- › excessive tiredness (also known as concentration fatigue)
- › misunderstanding or not following instructions
- › waiting for other children to start an activity or take the lead before they join in
- › preferring to play alone or refusing to join in with a group.

Improving listening conditions means that your child will require less effort to listen. This will reduce their concentration fatigue.

Cochlear implant users find it especially difficult to hear in situations where:

- › there is unwanted background noise (such as school classrooms)
- › sounds are echoing around the room (known as reverberation)
- › there is a distance between the person speaking and the deaf child
- › they are in group situations.

Assistive listening devices can make it easier for a cochlear implant user to hear people speaking or sound from other equipment more clearly.

Your child's cochlear implants can be wirelessly connected to a range of audio sources, such as computers, phones, tablets, and televisions.

Bluetooth

Bluetooth is a wireless communication technology. It allows electronic devices to connect with each other over short distances. Most modern sound processors have integrated Bluetooth functionality. However, they need to be paired to devices to transmit audio directly to the sound processor. This is straightforward to do.

There are different types of Bluetooth, known as protocols. The Bluetooth protocol of your child's cochlear implants will determine which devices they can connect to directly. Your child's audiologist will know which devices your child's cochlear implants are compatible with.

Bluetooth functionality can drain cochlear implant batteries more quickly. If your child's cochlear implants are streaming via Bluetooth for long periods of time, the batteries may need to be recharged or replaced more often.

Wireless technology is improving all the time. For example, manufacturers are currently working on the development of Auracast™. This will allow cochlear implant users with new models of sound processor to stream public audio directly into their cochlear implants.

Streamers

Some cochlear implants do not have Bluetooth functionality. An assistive listening device called a streamer can be used instead. Streamers send audio wirelessly from a phone, tablet or computer to your child's cochlear implants. Most streamers also have a built-in microphone. They can be used to transmit speech directly to your child's cochlear implants.

The in-built speakers of electronic devices often produce poor quality sound. Using a streamer can help your child receive better quality sound to their cochlear implants. Cochlear implant manufacturers usually produce their own streamers that only work with their own hearing devices. For example, the Cochlear phone clip, TV streamer and Mini Microphone 2+ (pictured) are compatible with sound processors produced by the Cochlear company. Some streamers work with lots of models of cochlear implant. Ask your child's audiologist if you're not sure which streamers will work with your child's sound processors.



Cochlear wireless accessories

Radio aids

Radio aids are a form of assistive listening device. They can be plugged into devices to send audio wirelessly to your child's cochlear implants.

A radio aid has two parts:

- › a transmitter worn by the person talking, such as a teacher
- › a receiver, worn by the child.

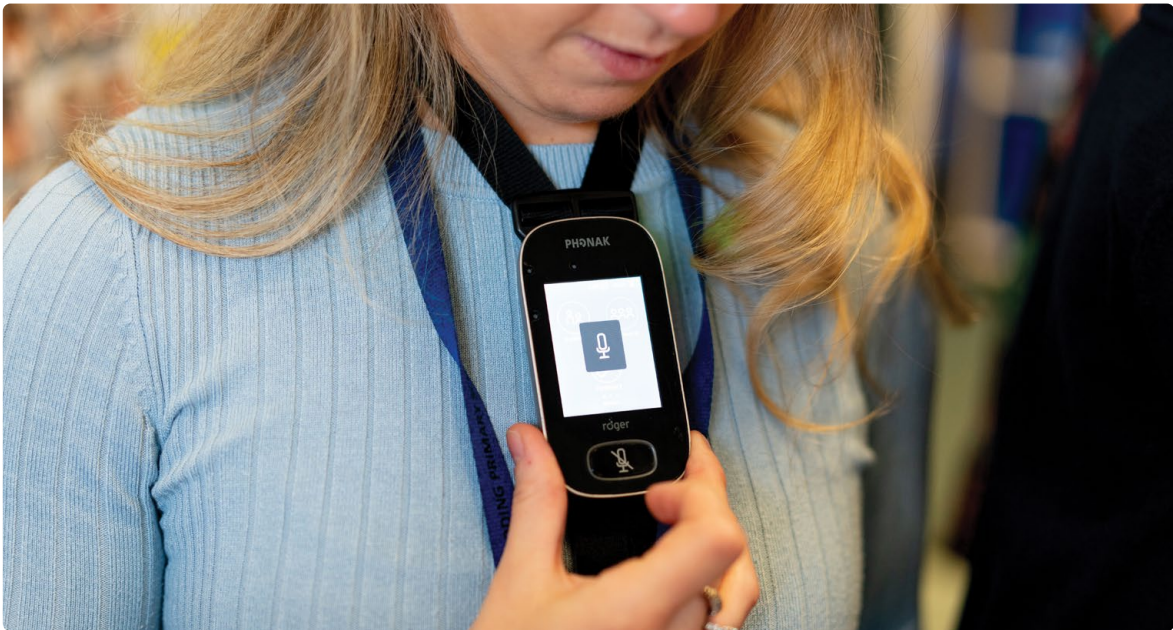
A microphone picks up the speaker's voice. The sounds are sent by radio waves to the receiver. The receiver picks up the radio signal directly from the transmitter.

You can connect the receiver directly to the cochlear implant by attaching an integrated receiver.

Cochlear implants produced by Advanced Bionics have a receiver built into the processor. This means you can connect the cochlear implant to the radio aid without needing to add a receiver.

Lots of deaf children find radio aids essential to support their learning in school. Radio aids also help in a number of other situations including:

- › group activities
- › in the car, so that your child can hear your voice over engine noise
- › in playgrounds and outdoors
- › when shopping or on outings.



Phonak Roger touchscreen radio aid

Telecoil

Loop systems and neckloops use the integrated telecoil (T) programme in your child’s sound processors. The T programme picks up magnetic fields from a loop system and converts these into sounds in the implant.

Loop systems are often installed in loud public places such as train stations, banks, churches, or theatres. You can see whether a loop system is available by looking for the T symbol.

These days, children who use cochlear implants are less likely to use loop systems as other wireless technology has developed. However, in places like theatres or places of worship, it’s worth asking whether a loop system is available as it may allow your child to understand more of what’s being said.



19 Growing up with an implant

Most young people who were given cochlear implants as children will continue to use them into adulthood. It’s important that children and young people are given up-to-date information about their cochlear implant system so they can develop independence and make informed choices about their own care.

Once your child is old enough to do so safely, encourage them to take responsibility for basic care like replacing or recharging their cochlear implant battery. As they get older, encourage them to take the lead during medical appointments. If your child uses sign language, ask the hospital to provide a sign language interpreter for all appointments so that your child can be fully involved in their medical care, instead of relying on you or another family member for support.



20 Useful contacts

All cochlear implant manufacturers have their own communities providing support to children and young people who wear cochlear implants and their families.

Advanced Bionics

advancedbionics.com

Email hear-uk@advancedbionics.com to be matched with a mentor.

Cochlear

cochlear.com

Email hearnow@cochlear.com to be matched with a mentor.

MED-EL

medel.com

Visit medel.com/en-gb/about-medel/united-kingdom/join-our-community to join the MED-EL community.

Visit hearpeers.medel.com/en_gb to connect to a mentor.

There are lots of other organisations across the UK who can also provide support.

British Cochlear Implant Group (BCIG)

The BCIG is a professional body that represents all the cochlear implant centres and other specialist medical professionals in the UK.

bcig.org.uk

Cochlear Implanted Children’s Support Group (CICS)

CICS is a support group for parents. It’s run by parents whose children have cochlear implants.

cicsgroup.org.uk

Meningitis Research Foundation

A charity that supports families whose children have had meningitis or septicaemia.

24-hour helpline phone: **080 8800 3344 (voice)**

meningitis.org

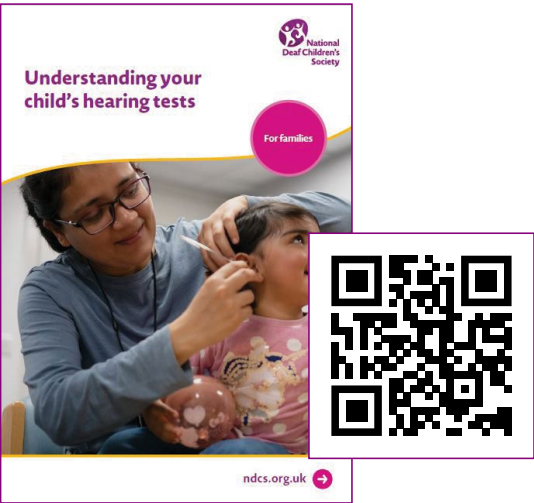
National Cochlear Implant Users Association (NCIUA)

This is a group run by and for cochlear implant users in the United Kingdom.

nciua.org.uk

21 Other resources

Understanding your child’s hearing tests



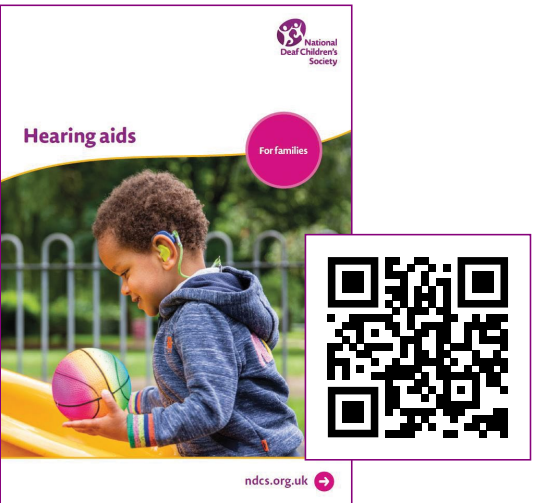
ndcs.org.uk/understand

Chloe gets cochlear implants



ndcs.org.uk/chloecomix

Hearing aids: A guide for families



ndcs.org.uk/hearingaidsguide



Scan the QR codes and log into your account to download or order resources today!

Looking for something else? We have lots more resources on our website at ndcs.org.uk/resources.

Notes

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Notes

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**We're the National Deaf Children's Society,
the leading charity for deaf children.**

Freephone Helpline:

0808 800 8880 (voice and text)
helpline@ndcs.org.uk

ndcs.org.uk



We're always looking for ways to improve our information.

Use your smartphone's camera to scan this QR code and share your feedback on this resource.

You can also give us your feedback by emailing your comments to **informationteam@ndcs.org.uk**

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