National
Deaf Children's
Society

Cochlear implants

For families

www.ndcs.org.uk

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

Contents

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.

1 Introduction

If your child has a severe to profound permanent deafness and gets limited or no benefit (can't hear speech sounds) with hearing aids, you may be thinking about them having a cochlear implant. To make a decision on what's best for your child, it's important that you have as much information about the process as possible. The aim of this book is to give you clear, balanced and accurate information about cochlear implants.

This booklet covers the following areas:

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

On our website you can find more information about cochlear implants, stories from families and deaf young people who have been through the process of considering cochlear implants, and videos of families sharing their experiences at www.ndcs.org.uk/cochlearimplants.

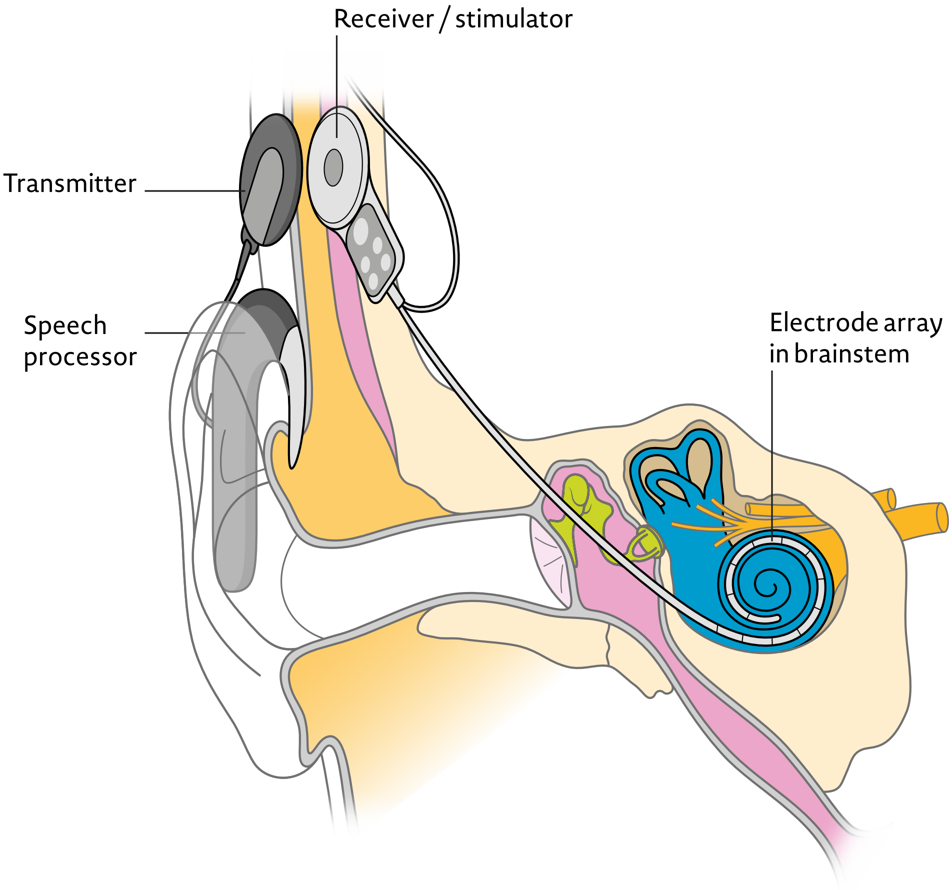
2 What is a cochlear implant?

In contrast to a hearing aid which makes sounds louder, the cochlear implant provides a sensation of hearing by bypassing the damaged hair cells in the cochlea and directly stimulating the auditory nerves using electrical signals. To date, there are just over 17,000 people in the UK who use cochlear implants.

Cochlear implants are unable to restore normal levels of hearing and the degree of hearing provided can vary from child to child. However, the majority of children who have permanent severe to profound deafness and who couldn't hear the full range of speech sounds with their hearing aids, can now access these sounds and understand speech and language using just their cochlear implants. Other children can't follow conversation without additional visual information, such as lip-reading or using signs, but the cochlear implants help them to recognise voices and improve their lip-reading skills. A smaller number of children gain less benefit from their cochlear implants but have improved awareness of environmental sounds, such as doorbells, traffic noise and other sound around them.

What is a cochlear implant made up of?

There are a variety of makes and models of cochlear implant available and they have similar designs and features. Cochlear implants have two parts – an internal receiver which is implanted surgically and an external part, which is worn over the ear like a hearing aid.



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How does a cochlear implant work?

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. Working together they help us hear and process sound.

The ear has two main functions which are closely connected:

- it receives sound and converts it into signals the brain can understand
- it helps us to balance.

The ear is the first part of the hearing pathway that gets sound to the brain where it is interpreted and understood. The pinna is the outer part of the ear that we can see. It collects sound waves and directs them down the ear canal towards the eardrum. The eardrum separates the outer ear from the middle ear. The middle ear is filled with air and contains three tiny bones (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 and these vibrations are passed across the middle ear by the bones. The bones increase the strength of the vibrations before they pass through the oval window into the cochlea.

The cochlea looks like a snail's shell. It's filled with fluid and contains thousands of tiny sound-sensitive cells. These cells are known as cilia or 'hair cells'. The vibration of the bones in the middle ear enters the cochlea and causes the fluid to move. This in turn causes the hair cells to bend. The movement of the hair cells is similar to the movement of 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 where it's converted into signals that can be understood.

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

Cochlear implants work as follows:

- The microphone picks up the sound from the area around the wearer and the speech processor converts the soundwaves into a digital code which is then sent to the transmitter coil.
- The transmitter coil (which is attached to the head via a magnet) sends the digital code through the skin to the implanted receiver which is located just under the skin. The receiver converts the digital code to an electrical signal. This signal is then sent from the implanted receiver via a wire to the electrode array (series of evenly spaced electrodes) which has been inserted inside the cochlea.

- The electrodes stimulate the cochlear nerve fibres and send the signal to the brain.
- The brain interprets these signals so the wearer can understand what was heard.

The sound perceived through a cochlear implant is not the same as the sound heard with normal hearing. A cochlear implant uses electrical stimulation rather than the amplified sound of hearing aids. Cochlear implant wearers who have previously heard naturally often describe the sound as being robotic or tinny. However, with time the brain adjusts to the new signals and what is heard becomes more natural.

4 Deciding to have cochlear implants

Before deciding to go ahead with a cochlear implant for your child, you will need time to think about the long-term commitment you are making. It's important to get balanced information during the assessment and about the surgery and follow-up care.

Families who go through the assessment process will make the decision on whether a cochlear implant is the right option for their child in partnership with the professionals from the cochlear implant team. For some families this can be a difficult decision as there are so many things to consider. Having lots of balanced information and speaking to families with experience of the process may help you make your decision. It's important that if your child is old enough, you and the professionals involved listen to their feelings about cochlear implants and involve them as much as possible in making the decision.

If English isn't your first language you can ask for an interpreter to come to meetings with you or for information to be translated into your chosen language. You can also phone our Helpline and ask for our audiology adviser to phone you back with an interpreter.

Having a cochlear implant means you have a lifetime commitment to looking after it. This involves regular visits to the cochlear implant centre, both before and after surgery. You, your family and professionals will also need to provide a lot of long-term support for your child. It's important to remember that when the speech processor is removed, eg at bedtime, your child won't be able to hear you.

When you start thinking about cochlear implants and finding out more information about them you will come across different views regarding implanting children of a young age. Some people in the Deaf community do not feel that deafness needs to be cured and that a deaf child should be old enough to make their own decision before being implanted, whereas others see deafness as a condition which can be helped by technological intervention and that a cochlear implant can give a profoundly deaf child their best and only chance of gaining access to spoken language. If you are interested in finding out more about this debate, it's a good idea to talk to deaf people with and without cochlear implants and to families and deaf children themselves about their experiences and feelings.

Most parents find that the decision to proceed with the implant is an ongoing process throughout the assessment (see p13 for further information on the assessment process). If at any time, you or your child feel that having an implant is not the right choice you should say so. If you've got any questions about the tests, the operation and what it's like to live with an implant, talk to the professionals working with you and your child.

It's important for your child's self-esteem and confidence that they grow up knowing that they are deaf and feeling positive about their deafness. It's important that as children grow up they are given information about their cochlear implant and the opportunity to become independent in looking after it. That way they are more likely to become confident and be able to advocate more effectively for their needs as a teenager and young adult. If your child is older when you are first thinking about a cochlear implant it's important that they are fully involved in the assessment process, discussions and decision to have one.

You can ask your cochlear implant team to put you in touch with families who are going through the assessment process, or whose child has already had an implant fitted. You may also feel you would like to speak to deaf adults about their experiences.

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Who is suitable for a cochlear implant?

The National Institute for Health and Care Excellence (NICE) has produced guidance on who should be considered a candidate for a cochlear implant. The guidance defines children with severe to profound deafness (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) in both ears, and who do not receive adequate benefit from acoustic hearing aids, as candidates for cochlear implants. Adequate benefit is defined as speech, language and listening skills appropriate to age, developmental stage and cognitive ability.

NICE also recommends that:

- Cochlear implantation should be considered for children only after an assessment by a multidisciplinary team (see p13 for more information on the assessment process).
- 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 (an implant in each ear), to be fitted during the same surgery.

Cochlear implant manufacturers continue to invest time in research and development, making more options and features available for the wearer as well as advances in design by making the speech processor smaller and slimmer whilst creating improved sound processing strategies to improve speech understanding.

The design of the electrode array is also continually being improved by making it softer and more flexible so that it is less likely to cause damage to the delicate and sensitive structures of the inner ear.

Some children may be suitable for new electro-acoustic (hybrid) implants. This type of implant is for those with some low and mid-frequency hearing but with a severe to profound loss in the high frequencies. The implant combines amplification of sound acoustically via the hearing aid part of the implant with electrical stimulation via the cochlear implant in the same ear. Overall this may give the individual greater speech recognition than with hearing aids or cochlear implants alone. For more information on the assessment process and individual considerations see pages 13–18.


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6 What age can my child have a cochlear implant?

Babies who are born deaf or become deaf very early in childhood:

Most newborn babies now have a hearing test shortly after they're born. This means that children who are born deaf are identified and fitted with hearing aids at a very young age. The evidence suggests that the younger a child is when they receive their cochlear implant, the more likely they are to get the most benefit from it. It's important to remember that it takes some time to find out the exact level of a child's hearing loss and to work out the benefit they get from their hearing aids.

The cochlear implant team and surgeon will explain any potential risks and benefits with you before deciding to perform the surgery. It's now common for children to be implanted before they are a year old. Early implantation and support is most likely to achieve the development of speech and language skills in a similar way to hearing children of the same age. The most intensive period for speech and language development is during a child's first three years of life when the brain develops and builds the neural pathways essential for being able to hear and understand sounds in the usual way.

Older children and teenagers:

Older children and teenagers may also be candidates for cochlear implants, including those who have become deaf after learning to speak, for example following meningitis. Those who have progressive or acquired hearing loss and now get less benefit from their hearing aids may also be candidates for cochlear implants. Some older children and teenagers may have been assessed for a cochlear implant when they were younger but didn't fit the criteria to be implanted at the time. Children who use hearing aids consistently, and mainly use spoken language to communicate, may now be considered for reassessment.

7 The assessment process

The assessment will be done at a specialist cochlear implant or auditory implant centre. There are a number of specialist centres around the UK and you will usually be referred to your nearest one. The implant centre will accept referrals from your GP, ENT consultant, paediatrician or audiology professional.

You may have to travel quite far to get to your nearest cochlear implant centre. You might be entitled to have some help with your travel costs through the Healthcare Travel Cost Scheme (HTCS) if you receive either Income Support, Income-based Jobseeker's Allowance, Pension Credit Guarantee Credit, are named on an NHS tax exemption certificate or qualify under the NHS low-income scheme.

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 a number of further appointments for detailed assessment involving hearing tests and other assessments which can sometimes take most of the day. 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.

The NHS in England has an expected maximum waiting time of six weeks for the first assessment and 18 weeks for treatment from the time of referral. The assessment period and surgery can usually be completed within this time.

Occasionally the assessment period may take longer, for example if your child has additional needs, assessment requirements, needs repeated tests or you may want more time to think about the options available. The implant team should keep you informed as to how the assessment is progressing.

Throughout the cochlear implant assessment process you will meet a multidisciplinary team including:

- 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 www.bcig.org.uk. You can also find more information on the people you may meet throughout the process here www.ndcs.org.uk/healthservices.

During the assessment process:

- You will be given information about your child's deafness, cochlear implants, the procedure and the rehabilitation programme after surgery. The implant team will work alongside the professionals who support your child locally such as 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 will be offered further testing to try to find out the cause of their deafness (known as aetiological testing) and you may be referred for genetic counselling.
- Your child will have a radiological assessment using MRI and CT scanning. 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 to evaluate 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 regarding 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.

Find further information on hearing tests in our resource Understanding your child's hearing tests, available online at www.ndcs.org.uk/understand.

As well as the various tests and assessments, the cochlear implant team will discuss the ongoing care and support that is necessary to help your child get the most benefit from the implant. They will look at the long-term support that will be provided by parents, family, the local authority and local audiology services. The cochlear implant team will only recommend implantation if your child has been through the assessment process, that you understand the commitment that is required to start this journey and you and the cochlear 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 outcome of the assessment, or the expected outcomes with cochlear implants for the child. These are unlikely to stop them going ahead with an implant but need to be understood and addressed during the assessment process:

Glue ear is a very common condition during childhood and 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 much more significant hearing loss. This could mean that without glue ear, your child has enough hearing not to need a cochlear implant. It's therefore very important that glue ear is treated and your child has a hearing test once it has resolved to measure the true level of sensorineural deafness.

Children with **additional needs** can, and do, benefit from implants. Nowadays 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.

Problems such as **new bone growth within the cochlea (ossification) following meningitis** - can 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 is more difficult, the results can be variable and it's not possible to predict how effective the cochlear implant will be.

Very occasionally, children may be **born without a cochlea or auditory nerve (hearing nerve)**. If the scan shows that either is absent, then it will not be possible to have a cochlear implant in that ear. The implant team may then discuss an Auditory Brainstem Implant (ABI).

An ABI works in a similar way to a cochlear implant but rather than stimulating the auditory nerve, the ABI stimulates the auditory brainstem directly, bypassing the ear and auditory nerve, to provide a sensation of hearing.

You can find more information about Auditory Brainstem Implants on our website www.ndcs.org.uk/implants.

At the end of the assessment process

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

Where applicable, your child should also be involved in the decision-making process. If you've got any questions about the tests, the operation and what it's like to live with an implant, you should speak to the professionals working with you and your child.

Once all the assessments are complete the implant team will arrange to meet with you to share the results and advise on whether they feel cochlear implants will be suitable for your child. There will be times when the implant team feel that a child is not suitable for a cochlear implant.

This could be for the following reasons:

- The results of the scan show that there is no cochlea or auditory nerve or that there is a problem with the cochlea which makes an implant surgically impossible.
- Your child may have enough residual hearing to benefit from conventional hearing aids. If this is the case the implant team will make recommendations on hearing aids, and your local audiology department will continue to care for and support your child and monitor any changes in their hearing.

If your child's hearing changes in the future a referral back to the implant centre can be made for re-assessment.

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

Once the decision has been made

Once you and the implant team have made the decision to go ahead with the surgery they will arrange a pre-operative appointment with the ENT consultant. In this appointment the ENT consultant will discuss the surgery and any risks with you. See pages 22-23 for more information on the surgery. If your child hasn't already been vaccinated against meningitis, then it will be recommended before surgery.

The implant team will be able to give you information about voluntary services and support groups and you will also have the opportunity to make contact with other families whose children are of a similar age and have already received a cochlear implant.

Which cochlear implant would be best for my child?

There are several different makes and models of cochlear implant and they all work in similar ways. The majority of UK implant centres offer a choice of two or more devices. The different manufacturers include Cochlear, Advanced Bionics, Medel and Oticon Medical.

There is currently no evidence that children perform better with one manufacturer's device over another and the results tend to be similar for all. In rare situations ie due to the anatomy of the inner ear, the surgeon may recommend a specific device if they think it's easier to implant when compared to another make of implant.

Before you make a decision, you may wish to consider the following:

- Speak to other families about their experiences of and decisions about individual devices.
- Ask how many cochlear implants the surgeon has implanted of the make and model you are interested in, and the experience of the team, particularly in providing these implants to children, in particular very young children. To ensure a high level of experience, the implant surgeon should carry out at least 10 surgical procedures per year.
- Cosmetic features of the cochlear implant, such as the size of the speech processor, how it fits on the ear, how it looks and the colour. Older children should be given as much say as possible in how their implant looks.
- The reliability and robustness of the external parts of the cochlear implant.
- The reliability and safety record of the internal implant. How many people are currently implanted with the make and model you are interested in and the expected lifespan of the implant. You can find this information on the implant manufacturer's website.
- Does the electrode array come in different lengths? Which one will preserve your child's residual hearing?
- Does the manufacturer support backward compatibility? If a speech processor is backwards compatible, this means it will be easier for your child to upgrade to the latest processor technology, even years after receiving their implant.

- Is it possible to upgrade the internal part of the cochlear implant without further surgery to take advantage of future coding strategies? Coding strategies attempt to provide the user with the most useful electric representation of the original acoustic signal in order to improve the speech perception of patients.
- Is the cochlear implant MRI compatible?
- Battery life and type of battery the implant uses: can they be recharged? Will they last a whole day at school? Disposable batteries may last a few days but it will depend if your child uses a radio aid as well, as this can drain the power. When it comes to rechargeable batteries the battery life reduces with each charge so it might be helpful to give your child some spare disposable batteries to take with them.
- How easy is it to tell if the battery has run down? Is the system easy to use? With young children, is it easy to tell if the implant is switched on and working well using the visual indicators (light indicators on the process will flash or change colour to update you on the status of the processor).
- Is it water-resistant or waterproof?
- Compatibility of the implant with radio aid systems and other audio equipment. A brand comparison of the different cochlear implants can be viewed on **www.cochlearimplantonline.com**.

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 speech processor can be changed as technology develops and improves, but this shouldn't mean further surgery.
- To keep up with changes in technology, it's recommended that speech processors are upgraded every five years, and when clinically appropriate. For example, where there's evidence that the upgrade will offer additional benefit over the current device being worn.


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Will my child have one or two implants?

Bilateral cochlear implants are usually recommended for most children.

Hearing with both ears means we can understand speech in background noise, and we can localise sounds to work out which direction the sounds are coming from. For children who get little or no benefit from their hearing aids and fall within the criteria, the cochlear implant team will recommend having two (bilateral) cochlear implants. It's been shown that children perform better with two implants than they do with one.

Most children in the UK will have 'simultaneous' bilateral cochlear implants, which means your child will receive both implants at the same time in one surgical procedure.

'Sequential' implantation is where your child receives one implant and after a period of time receives the second implant ie two separate surgical procedures. This is only recommended if your child already had a cochlear implant in the other ear when the NICE guidance was issued.

There may be occasions where the implant team recommends your child has a cochlear implant in one ear and continues wearing a hearing aid in the other ear (bimodal fitting). This depends on the level of hearing and also the expected benefits of both options.

If it's recommended that your child has one implant and continues to wear the hearing aid in the other ear, you'll need to discuss with the surgeon and audiologist which ear will be implanted. It's important to understand why the implant team recommends a particular ear be implanted instead of the other. It may be because of medical reasons (eg the scan may indicate why one ear should be implanted when compared to the other), or because of differing levels of hearing in each ear. For children with physical difficulties, the ear may be chosen for practical reasons (eg one arm/hand may have better function than the other and be able to put on and adjust the speech processor more easily).

9 Funding

Cochlear implants are funded centrally by NHS England. Provided children meet the identified criteria as set out by NHS England and NICE, funding will be paid directly to your specialist service and individual families shouldn't have to apply for funding.

If a child does not exactly meet the criteria as set out in the recommendations made by NICE but it's still felt that an implantable device is the most appropriate clinical option for them, then an Individual Funding Request (IFR) may need to be made.

Cochlear implants are also centrally funded by the equivalent bodies for Wales, Scotland and Northern Ireland.

10 Surgery

Many hospitals have information online about how to prepare yourself and your child for a stay in hospital and surgery. Ask your implant team if they have a liaison nurse For more general information search 'can I stay with my child' on the NHS website: **www.nhs.uk**.

Parents who have already been through the process will often be able to pass on valuable information on practical issues involved with surgery.

Implant manufacturers produce online videos, children's stories and colouring books with information about cochlear implant surgery which helps to explain to young children what's going to happen.

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

The surgery is usually done as a day case but might sometimes require an overnight stay in hospital. Your child will be examined by the medical team and anaesthetist and you'll need to fill in a consent form for your child. It's important that you read this carefully to make sure you understand the procedure and what the surgery involves. Ask your surgeon and anaesthetist if there's anything you're not sure about.

The operation will be done under general anaesthetic and usually lasts between one-and-a-half and three hours. If your child is having two implants then the surgery will take longer as it can take one to two hours per ear. They may need to shave a small amount of hair from behind the ear and a small cut is made on the side of your child's head. The internal receiver is then 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.

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, but if not a separate appointment will be made to do this. Although it isn't necessary to see your GP after leaving hospital, it's a good idea for your child to be seen by your local ENT consultant a week after the operation to check the wound is healing well.

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

Risks of surgery

There are risks associated with any surgery that requires a general anaesthetic. With cochlear implant surgery there are some specific risks which your ENT doctor 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. Vaccination for meningitis is recommended before your child is given a cochlear implant and this 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 and monitors are used through 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 this surgery include a metallic taste in the mouth and balance problems or dizziness. These are usually short-term and quickly resolved.

If you have any concerns about the surgery, speak to your surgeon or any member of the implant team.

11 Switch on

Two to four weeks after surgery an appointment is made to fit and start programming the speech processor (the external part of the implant). Each speech processor is individually programmed. The electrical signals produced by the speech processor are very complex and their levels need to be set carefully to suit your child. Programming the speech processor is known as 'tuning' or 'mapping'.

The electrodes are stimulated to find the levels of stimulation that create sounds which are comfortably loud and tolerable. The measurements made help to develop an individual programme for your child's speech processor. With bilateral implants, both the implants are gradually activated together.

Lots of adjustments will be made in the beginning as your child starts to adapt to the new sounds, and the electrode beds into the cochlea. There will be regular appointments during the first year to work out the appropriate programming settings. While the number of sessions can vary, you would usually go to a minimum of six appointments in the first year. After this, your child will attend the implant centre for annual review and programming.

Your child's initial response to sound through the implant may not always be positive and may produce a variety of reactions. They may smile, look surprised or they may even cry or look frightened. Your child may need lots of positive encouragement and time to adjust to the new signal. Each child is an individual and it's perfectly normal for a child to respond differently when the implant is activated. It may depend on your child's previous experience with sound.

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After the operation and tuning

After the implant is fitted, your child will need long-term support from you, the cochlear implant team and local professionals. This support and care can make the difference between whether the implant is effective or not. You and other carers of your child play a vital role in helping your child use their implant and in supporting them to develop their listening, communication and language skills.

Your child will go back to the clinic so the implant's speech processor can be tuned and adjustments can be made as they learn to interpret the new signals.

It's important that you know the level of commitment that will be needed, particularly in the early years following implantation. Appointments at the implant centre mean you may need to take time off work and be away from the rest of your family. You can ask your implant centre for a schedule of expected visits, both before and after the implant operation.

The sessions in the clinic will include time for the audiologist to tune the processor. There may also be a medical check to assess the wound site and make sure the scar has healed as expected. You may also have sessions with the Teacher of the Deaf (ToD) and a speech and language therapist (SLT).

It's important that you, your child's school and the cochlear implant centre keep in touch so that there's open communication between all those caring for and working with your child. It also means that any problems with the equipment can be reported and fixed quickly and that everyone has access to the right spares and accessories.

The ToD and SLT from the implant team may visit your child at home and school to observe and record your child's progress. It's also a good idea to keep your own notes and observations so you can discuss them with the implant team if you have any concerns. They'll also 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.

As your child grows up they need to learn about their implant and how it works so that 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. All implant systems have handbooks and apps for users and it will be helpful for your child to have a look through these as well. It's important that the implant team provides information that is easy to read and that your child can understand.

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.

You can find more information on glue ear on our website www.ndcs.org.uk/glueear.

13 Communication and language

It's important to remember that it may take a long time for your child to learn to interpret new sounds using the implant and it will take a lot of patience and practice. Every child is different and the time it takes to adjust will vary with each child. Your child needs to use these new sounds to develop their communication skills and spoken language. For a hearing child this process starts when they're born and carries on over the years, whereas for a child with an implant the process may take longer.

Ask your SLT and ToD for a list of games and activities that will help your child learn about new sounds and develop their listening skills. The cochlear implant manufacturers have online resources aimed at children of all ages to help them learn to listen and help with their language skills. You can find these resources in section 19 of this booklet (page 38).

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

Before implantation, British Sign Language (BSL) may have been your child's main communication method if they did not have enough hearing to understand spoken language. There is still some conflict of opinions between professionals as to whether sign language should be used with children who have been implanted. Some professionals feel it hinders the development of spoken language while others feel it supports their communication. Most parents have found that once their child has adapted to the implant, the reliance on signing starts to diminish. The process of changing from sign-based communication to spoken communication occurs naturally, but for some children, sign language will remain an important part of their communication and identity. Regardless of which method is used, the most important factor is that your child can develop fluent language skills to communicate by whichever method is appropriate and most effective for them.

Having an alternative method of communication, such as BSL, is often beneficial if a situation arises that makes it impractical for your child to wear their implant, such as when undertaking water-based activities, or when the speech processor is faulty.

14 Wearing options for little ears

As babies and toddlers grow, they start to explore their surroundings, feeling, touching and pulling everything that's in reach and that includes their cochlear implant.

It's really important your child wears their cochlear implant as often as possible so they can learn to listen and hear which will help them with the development of speech and language. This can be easier said than done and is something many parents find frustrating. Losing the implant is also something that concerns lots parents but there are many options available to help keep it in place.

Retainers and headbands help stop the cochlear implants falling off and each manufacturer has their own wearing option. An alternative option to having a behind-the-ear processor is to have one that is worn on the body, ie off the ear.

Some parents have designed their own headbands and retention solutions and shared their ideas online. We have included some suggestions that you will hopefully find helpful.

Head/hairbands:

- Malinka **www.malinka.me.uk/cochlear-implant**
- Hearing Henry **www.hearinghenry.com**
- Ear Suspenders **www.etsy.com/uk/shop/EarSuspenders**
- Valentine's Little Ears **www.etsy.com/uk/shop/ValentinesLittleEars**

Retainers

- My Little Ears **www.malinka.me.uk/cochlear-implant**
- Ear Gear **www.gearforears.com**

15 Growing up with an implant

Most young people who were given cochlear implants as young children, rely on and continue to use them into adulthood. It's important that teenagers are given up-to-date information about their cochlear implant system so that they can become independent in their understanding and care of the system and make informed choices about their own care.

There are online communities and forums where teens and their families can connect, share stories and support each other.

You can find more information on their websites:

- Advanced Bionics: I'm Not All Ears

  www.advancedbionics.com/uk/en/home/support/listening-resources/teens.html
- Phonak: Hearing Like me

  www.hearinglikeme.com/category/community/teens
- Cochlear: Cochlear Communication Corner

  www.cochlear.com/us/communication-corner
- Medel: HearPeers forum

  forum.hearpeers.com/

16 Safety information

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

BCIG have issued new safety guidelines which incorporate the advice and specific information from each of the main cochlear implant manufacturers. You can find more information on their website **www.bcig.org.uk/safety**.

When your child is fitted with their cochlear implant, you will be given a user guide for the device. The user guide contains information that is specific to their device and contains essential safety information.

Parents of children who have a cochlear implant are encouraged to contact the manufacturer of their device directly for specific information or advice.

The safety guidelines include information on: medical and dental treatments, therapy and surgical procedures.

Waterproof cochlear implants

At the time of writing the only waterproof speech processor is the Neptune made by Advanced Bionics. Children who have compatible internal parts may be able to upgrade to the Neptune when their next routine upgrade is due.

The Neptune can be submerged in water up to depths of three metres and used safely in the pool and bath. Although it's designed for use while children play in the sand and splashing in the sea, the manufacturers do not recommend it be immersed in salt water due to the corrosive effects of the salt.

Cochlear (Nucleus 5, 6 & 7 and Kanso), Medel (Sonnet, Opus2 & Rondo) and Advanced Bionics (Naida CIQ 90) cochlear implants are often described as water-resistant. Whilst protected from dust and water, they are splashproof and not suitable for swimming, bathing or immersing in water.

Each manufacturer has designed its own water accessory to protect the speech processor and enable your child to enjoy playing and having fun in water. It is sometimes included free of charge in the starter kit you receive when your child is first fitted with their cochlear implant. Alternatively it can be purchased directly from the manufacturer.

Children with cochlear implants or hearing aids usually have great difficulty hearing in their swimming classes, even when wearing their waterproofed cochlear implant, due to the poor acoustics in swimming pools.

Daily checks of your child's cochlear implants

You should carry out the following checks on the external parts of the implant – the speech processor and the transmitter coil. Your child's implant team will show you how to do these checks on the make and model of cochlear implant your child wears. Your implant team will provide you with a set of replacement leads and coils that you can change yourself at home. When you use your replacement parts 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 so don't throw it away unless you've been told to do so.

Checking switches and controls:

- Make sure the settings are the same as those given by your cochlear implant centre – if not, reset them, if you know how, or take the system back to the centre.

Checking batteries and battery contacts:

- Make sure you are using the type of battery suggested by your child's cochlear implant centre.
- Ensure the batteries are fitted correctly and check the power levels if you have a battery tester.
- 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 speech processor and the transmitter coil. If the connection is loose, contact the cochlear 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 speech processor and also advise on checking the telecoil. Some types of listening earphones can also let you judge the quality of the sound. Make sure that you listen at a comfortable sound level and, if you can, make sure that the sound quality is clear and without any crackles. If not, contact your child's implant centre. The speech processor may have its own self-check function. Make sure that you know about this and what to do if it finds a fault.

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

17 Batteries

Batteries can be disposable or rechargeable and the batteries for your child's cochlear implant speech processors will 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.

Batteries are provided free on the NHS and are usually small button batteries which are disposable and can't be recharged.

Always make sure the tamperproof battery lock is on to stop your child from opening the battery cover.

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

- from a local health centre/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 could go to a high street chemist and buy batteries for hearing aids that would be suitable as a short-term option for a cochlear implant.

Some audiology and implant services will ask you to return old batteries when you request new ones.

Keep your used batteries in the original packaging to keep them safe and so you can make sure no old batteries have gone missing. Batteries from speech processors are extremely dangerous if swallowed.

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

18 Assistive listening devices (ALDs)

Cochlear implants wearers are mostly able to hear speech well when in an ideal listening situation, however it is to be remembered that the information received from a cochlear implant is significantly reduced when compared to that of typical hearing and there will be situations where your child will find it more difficult to hear.

By improving these listening conditions, there will be less effort required to concentrate and your child will be less tired.

Situations when it is difficult to listen are when:

- there is unwanted background noise e.g. classrooms
- sounds are echoing around the room (reverberation)
- there is a distance between the person who is speaking and the deaf child
- in group situations.

ALDs can help overcome these problems, enabling the wearer to hear people speaking or sound from other equipment more clearly.

ALDs can be useful for deaf children when watching TV, using computers, games consoles, MP3 players and smart phones. Children with implants aren't always able to hear all of these devices with their cochlear implants but using an ALD may make it possible for many of them.

Assistive listening devices can connect to cochlear implants in three ways:

- Telecoil (loop systems)
- Bluetooth streaming
- FM technology.

Loop systems and Bluetooth streamers with neck loops

Streamers can also allow your child to wirelessly connect their cochlear implant to a wide range of sound sources, such as TVs, telephones and Bluetooth enabled devices such as mobile phones, laptops and tablets. This means they can use a streamer to listen to music, or even use apps such as Google maps to get directions straight into their hearing devices. Most streamers also allow you to make phone calls via the streamer. Many come with a wireless clip-on microphone, effectively turning the streamer into a kind of radio aid, although the quality isn't as good.

Streamers are generally worn around the neck or clipped to clothing. Generally each cochlear implant will have its own Streamer that it's compatible with eg Advanced Bionics and the Phonak Com Pilot, Cochlear and the Mini Mic 2+.

The Advanced Bionics Naida cochlear implant Connect receiver is compatible with the Naida cochlear implant Q90 sound processor. Once connected, the sound processor is able to connect directly to any Bluetooth enabled device.

Bluetooth technology uses a lot of power, and so the batteries will need changing frequently.

To try out different products to see if they might be helpful contact the NDCS Technology Test Drive by calling the Freephone Helpline on 0808 800 8880 or go to www.ndcs.org.uk/technology where you can also find more detailed descriptions of what products are available.

Made for iPhone (MFi)

The Cochlear Nucleus 7 incorporates Made for iPhone (MFi) technology enabling it to connect directly to an iPhone, iPod or iPad.

Personal FM radio aids

A radio aid consists of two parts, a transmitter worn by the person talking e.g. a teacher, and a receiver worn by the child. A microphone picks up the speaker's voice and the sounds are then transmitted by radio waves to the receiver. The receiver then picks up the radio signal directly from the transmitter. You can connect the receiver directly to the cochlear implant by a lead or by direct input with a receiver.

Deaf children find it particularly difficult to hear in situations where there is competing noise or where there is an increase in distance between the child and the person speaking. Radio aids are widely used by deaf children of all ages and can be highly beneficial in a variety of situations, particularly in educational settings where there can be a lot of background noise and reverberation caused by sound bouncing off hard surfaces.

Radio aids also help in a number of other situations including:

- group activities
- in the car – FM systems reduce the problems that exist due to the engine noise and lack of visual clues particularly for children/babies strapped in their car seats
- in playgrounds and outdoors
- when shopping or on outings.

For further information on FM systems visit www.ndcs.org.uk/radioaids or contact our Freephone Helpline on 0808 800 8880.

Customising speech processors

The current range of NHS hearing aids and cochlear implants features a selection of colours, including bright primary colours, softer pastels, metallics and animal print.

If your child wants their cochlear implants to be colourful, ask your audiologist about the range of shades or designs available for their model. If you can't get coloured options from your audiologist, there are ways you and your child can customise the technology.

Cochlear implant covers and colours

Ear Gear comes in a range of colours for a variety of hearings aids and cochlear implants. These covers are removable and help protect the aids against moisture and dirt. These are available at **www.gearforears.com**.

Skinit covers are available for the Cochlear and Advanced Bionics sound processors. These are available at **www.skinit.com**.

Other covers are available through Connevans, these are available at **www.connevans.co.uk**.

The Advanced Bionics waterproof Neptune cochlear implant comes in a range of colours. A free app on the Advance Bionics website and Apple iTunes store allows you to design a Neptune with your choice of colours. You can find more information on the Advanced Bionics website **www.advancedbionics.com**.

Charges for lost or damaged speech processors

The NHS provides speech processors on a permanent loan basis. They remain the property of the NHS rather than the wearer and NHS equipment should always be returned when it's no longer needed.

The current range of speech processors cost around £5,500. Parents and carers are expected to take reasonable care of their child's speech processors. The implant teams are expected to provide retention accessories and advice on their use to ensure that speech processors can be worn securely and without fear of them falling off and being lost. The NHS is legally allowed to charge for the loss or damage of equipment (except in Scotland). Your implant team will provide guidance on action to be taken should loss or damage occur to one of your child's speech processors.

Insuring speech processors

The NHS can't insist that parents insure their child's speech processors, as they remain the property of the NHS rather than the wearer. However, some parents choose to insure against the risk of being charged for any loss or damage.

Most household insurance will cover this (let the insurance company know and have the speech processors listed as a named item on the policy). To make sure you have adequate cover, speak to your implant team about the costs of your child's speech processor.

When travelling abroad, you may wish to purchase travel insurance to cover the speech processor and external parts of the implant. Most travel insurance does not cover you for pre-existing conditions (including deafness) so it's important to check with your insurer before travel. It might be that you need to use a specialist company that will cover pre-existing conditions.

Holiday loan

Holiday loans are provided by each manufacturer in case your own speech processor should develop a fault whilst away. This service has a small cost involved. If you want to borrow a speech processor for a holiday, contact the company for more information and they will issue you with a form. Once completed, return it to the company and they will get in touch with your implant centre to obtain the mapping information. You'll need to make sure you give enough notice when applying for a loan.

19 Useful contacts

Most young people who were given cochlear implants as children, rely on and continue to use them into adulthood. It's important that teenagers are given up-to-date information about their cochlear implant system so that they can become independent in their understanding and care of the system and make informed choices about their own care.

There are online communities and forums where teens and their families can connect, share stories and support each other.

Find out more on these websites:

- Advanced Bionics: I'm Not All Ears

  www.advancedbionics.com/uk/en/home/support/listening-resources/teens.html
- Phonak: Hearing Like me

  www.hearinglikeme.com/category/community/teens
- Cochlear: Cochlear Communication Corner

  www.cochlear.com/us/communication-corner
- Medel: HearPeers forum

  forum.hearpeers.com

Additionally:

- Children may like to talk to a trusted friend, family members or a trusted professional such as their ToD or communication support worker.
- The Buzz is a website we run for deaf children and young people aged 12-18 to make friends, get support and share experiences. **www.buzz.org.uk**

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.

Website: **www.bcig.org.uk**

Cochlear Implanted Children's Support Group (CICS)

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

Email: **info@cicsgroup.org.uk**

Website: **www.cicsgroup.org.uk**

Home Counties Cochlear Implant Group (HCCIG)

An informal group for cochlear implant users, their families and people awaiting implants.

The group is based in North London but members range from as far south as West Sussex up to North Hertfordshire and Essex.

Email: **hccigs@gmail.com**

Website: **www.hccig.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)

Website: **www.meningitis.org**

National Cochlear Implant Users Association (NCIUA)

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

Website: **www.nciua.org.uk**

Auditory Verbal UK (AV UK)

Auditory Verbal UK is a national charity which teaches deaf babies and children to listen and speak using Auditory Verbal Therapy, so that they can achieve their potential in life.

Email: **info@avuk.org**

Website: **www.avuk.org**

Online resources for listening and developing language skills:

Advanced Bionics

www.advancedbionics.com/uk/en/campaign/babybeats.html

Cochlear

www.cochlear.com/uk/home/support/rehabilitation-resources

Medel

www.medel.com/en-gb/support/rehabilitation

University of Southampton

www.southampton.ac.uk/mfg/music-info/children.page

20 Our information and support

Joining the National Deaf Children's Society gives you access to a wide range of services that can support you at different stages of your journey and your child's development. We want to do all we can to give you the confidence to support your child and make decisions.

The right information, at the right time

We offer free, balanced information about all aspects of childhood deafness, both on our website **www.ndcs.org.uk** and in our publications. Our online content and information booklets can help you make some of the difficult decisions you'll be faced with.

Helping you make informed choices

Every deaf child is different and families should be able to make decisions that are right for them. That's why we give independent support, setting out all the options, so families can make informed choices about how they want to communicate, or which type of hearing technology is best for them. We never promote a particular approach, and we're always clear about the impact it will have on a child's life.

Support when you need it

Any questions? We're here to help.

Freephone Helpline: **0808 800 8880**

helpline@ndcs.org.uk

www.ndcs.org.uk/live-chat

About us

We're here for every deaf child who needs us – no matter what their level or type of deafness or how they communicate.

Visit our website **www.ndcs.org.uk** or contact our Freephone Helpline to find out how we can support your child at every stage of their life. Join us for free and you'll be able to:

- download or order our free information
- come to our events
- be a part of our online community
- borrow equipment through our technology loan service
- read about other families' experiences in our quarterly magazine and email updates
- access support.

National
Deaf Children's
Society

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

Freephone Helpline:

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

www.ndcs.org.uk

Published by the National Deaf Children's Society

37–45 Paul Street, London EC2A 4LS

Tel: 020 7490 8656 (voice and text) Fax: 020 7251 5020

This publication can be requested in large print or as a text file.

For resource references or to give us your feedback email informationteam@ndcs.org.uk.

The National Deaf Children's Society is a registered charity in England and Wales no.1016532 and in Scotland no. SC040779. A0232 August 2020.

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