

Cochlear Implants

A guide for families



The Ear
Foundation



ndcs
every deaf child

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

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Introduction

If your child has a severe to profound permanent deafness and cannot hear speech sounds with hearing aids, you may be thinking about them having a cochlear implant. It is important that you have as much balanced 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 is in the following four parts:

1. A brief overview of cochlear implants.
2. Finding out more about
 - people who use cochlear implants
 - what a cochlear implant is and how it works
 - how you can go about getting a cochlear implant for your child
 - the assessment process – who and what is involved
 - follow-up care and what you have to do to support your child before and after the operation.
3. Different stories from families and young deaf people who have been through the process of considering cochlear implants.
4. Where to find more information.

This book does not give you detailed information about deafness, how to look after a cochlear implant, or advice about speech and language development. If you have any questions about these, speak to your child's audiologist, their speech and language therapist or the implant team (if you have already been referred to them). You can also contact some of the organisations listed at the back of this book who may have information, books and resources. The Ear Foundation has produced a useful DVD called *Cochlear implants for deaf infants*.

You can also phone the NDCS Freephone Helpline to speak to our audiologist or order one of the following booklets. If you have picked up this booklet, and your child has a mild to moderate deafness or glue ear, the following booklets may be useful to you.

Understanding Deafness

Hearing Aids – a guide

Glue Ear – a guide

Radio Aids – an introductory guide

Helping Your Deaf Child to Learn

Parenting a Deaf Child (CD ROM)

Deaf Friendly Nurseries and Pre-schools

Speech and Language Therapy for Deaf Children

Phone our Freephone Helpline on 0808 800 8880 (voice and text), or email us at helpline@ndcs.org.uk for copies.

Thank you to

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- the members of CICS, and other families who have contributed their stories to this booklet.
- the young deaf artists who have contributed their artwork to the 'Families' stories' section.

A brief overview of cochlear implants

Cochlear implants provide a sensation of hearing to children who have permanent severe to profound deafness and cannot hear the full range of speech sounds with hearing aids. This means that they may be able to hear some sounds, but they cannot hear some of the sounds that make up human speech. A cochlear implant is different from a hearing aid. It has two parts – one part is worn like a hearing aid, the other is surgically implanted.



Your child will need to be referred to a specialist cochlear implant centre. Your child's consultant or specialist doctor can do this. They will talk to you about whether your child is suitable to be assessed for a cochlear implant. This will depend on the type and level of their deafness. A cochlear implant is not appropriate for all deaf children; if your child is reaching their potential by wearing hearing aids, or there are other complicating factors, they may not be referred for an assessment.

The assessment process will help you learn more about your child's deafness, and whether or not a cochlear implant will benefit your child. There is more information on the assessment on page 14. The assessment for a cochlear implant involves a number of hearing tests and other assessments and will require several visits to the cochlear implant centre. This helps the cochlear implant team to build up a picture of your child's deafness and ability to make the most of a cochlear implant. The NHS in England has an expected maximum waiting time of 18 weeks from the time the referral is made. The assessment period and surgery can usually be completed within this time. Occasionally, if you prefer to have more time to think about the options or if your child has additional needs, the assessment period may take longer.



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. You will need lots of balanced information during the assessment, and about the surgery and follow-up care. If your first language is not English, ask for an interpreter at meetings, or for information to be translated. You can also phone the NDCS Freephone Helpline and arrange for our audiology advisor to phone you back with an interpreter.

Having a cochlear implant means making a lifetime commitment to looking after it. This will involve regular visits to the cochlear implant centre, both before and after the surgery. You, your family and professionals will also need to provide a lot of long-term support for your child. It is also important to remember that when the speech processor is taken off (for example, at bedtime), your child is still deaf. We believe that it is important that your child grows up knowing that they are deaf, and feeling positive about their deafness. 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 is 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.

Who uses a cochlear implant?

Would a cochlear implant be right for my child?

Every deaf child and young person who wears a cochlear implant is different. They come from different cultures, communities and backgrounds and from families who communicate in many different ways – some use speech only, some use sign language, and some use a combination of speech and sign language. However, they all have one thing in common – a permanent severe to profound hearing loss. In general, a child would be considered for an implant if

- they have shown little or no benefit from their hearing aids after several months
- they have no medical conditions that would prevent them from having surgery
- the family can attend the implant centre for essential tuning and follow-up sessions
- they have local support from professionals and family members who are committed to using the implant system.



Is my child too young for a cochlear implant?

Most newborn babies now have a hearing screen performed shortly after birth. This means that children who are born deaf are being identified and fitted with hearing aids at a very young age. In general, 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 the device. It is important to remember that it takes some time to find out the exact level of a child's hearing loss and the benefit received from their hearing aids. The cochlear implant team and surgeon will discuss with you the potential risks and benefits when deciding when to perform the surgery. It is now common for children under the age of two years to have a cochlear implant. In 2008, the youngest child to be implanted in the UK was six months old.

Older children and teenagers may also be candidates for cochlear implants. This includes those who have become deaf after learning to speak, for example following meningitis. It also applies to those who have a hearing loss that is getting worse and who now receive less benefit from their hearing aids. Some older children and teenagers may have been assessed for a cochlear implant when they were younger but found to have too much hearing when assessed against the guidelines in place at the time. As the guidelines have evolved over time, those children who use hearing aids consistently and mainly use spoken language to communicate may now be considered suitable candidates for reassessment.

Most young people who were given cochlear implants as young children, rely on and continue to use them into adulthood. It is 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.

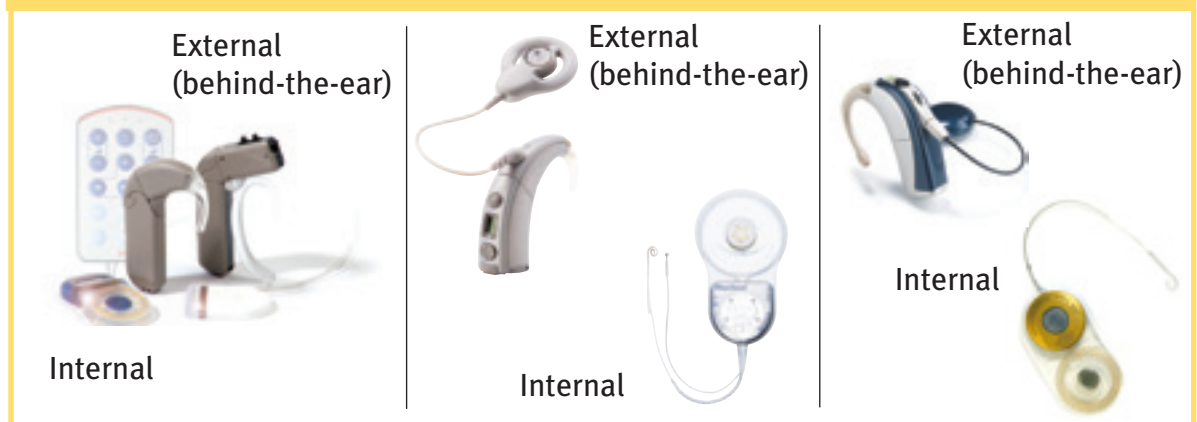
The Ear Foundation carried out research asking teenagers about their views on their cochlear implants. Their comments have been published in our joint booklet *Cochlear Implants; Young People's Views*.

What is a cochlear implant?

What is the difference between a cochlear implant and a hearing aid?

A cochlear implant is a type of hearing aid that turns sound into electrical signals. Instead of simply making sounds louder like a conventional hearing aid would, the cochlear implant provides a sensation of hearing by directly stimulating the auditory nerve using electrical signals. The cochlear implant has two parts – an internal receiver, which is implanted surgically, and an external part, which is worn like a hearing aid.

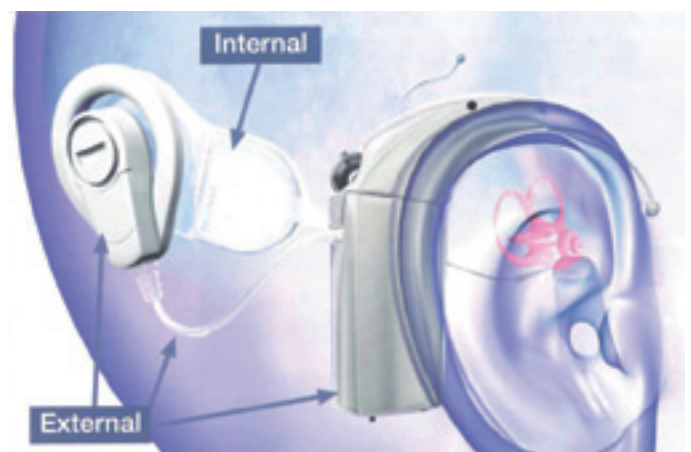
Examples of cochlear implant systems



What are the parts of a cochlear implant?

There are several makes and models of cochlear implant but basically they contain the same parts. The internal receiver is implanted under the skin behind the ear and a number of electrodes are fed through into the cochlea (see page 12). So to have a cochlear implant your child will need to have an operation.

The external part is made up of a speech processor, a lead, a transmitter coil and a microphone. The speech processor is either worn in a harness or belt on your child's body or behind their ear (like a hearing aid). The microphone sits behind the ear. The transmitter coil is held in place over the implanted receiver by a magnet. This external part is only attached once the scar from the operation has healed. The speech processor is tuned in to suit each child.



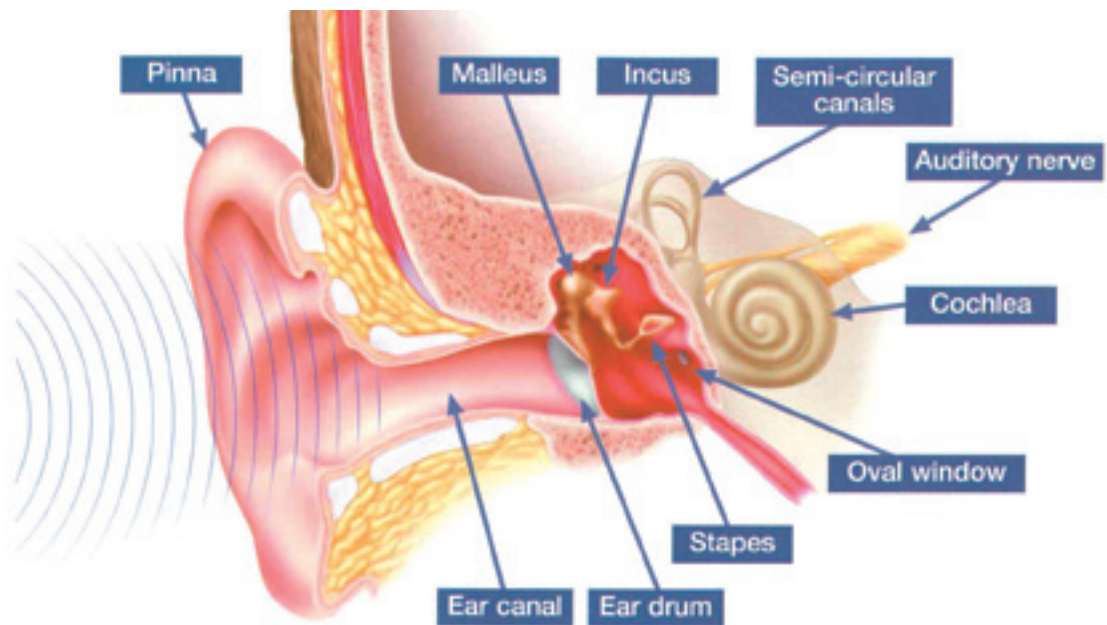
How does a cochlear implant work?

To understand how a cochlear implant works, it is useful to know about how the ear works.

The ear has two main functions.

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

The two functions are closely connected.



The ear is the first part of the hearing system. The pinna is the outer part of the ear that we can see. It gathers sound waves and directs them down the ear canal. The waves then cause the eardrum to vibrate. These vibrations are passed across the middle ear by three tiny bones. These are called

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

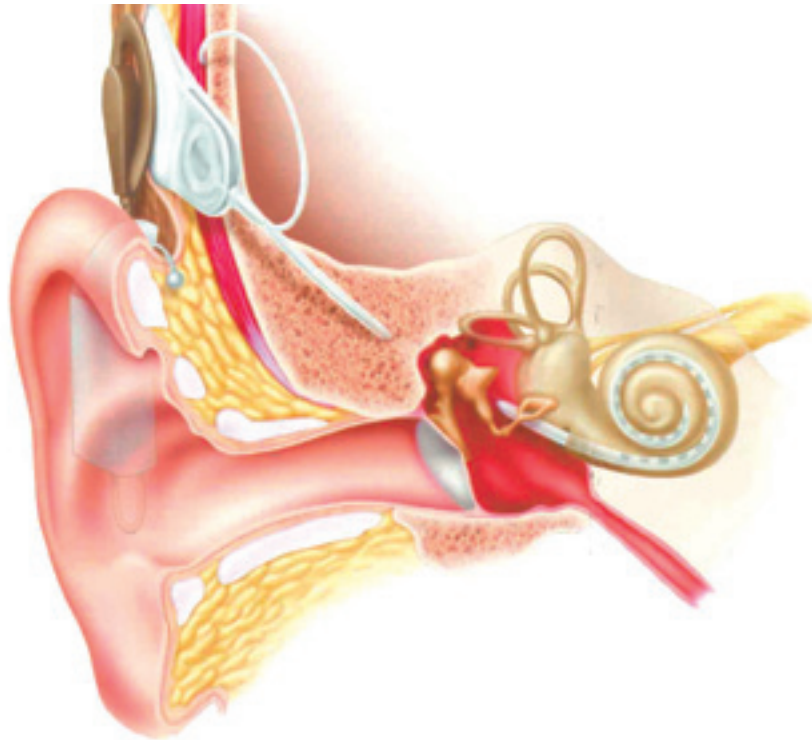
The bones increase the strength of the vibrations before they pass through the oval window into the cochlea.

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

As the hair cells move they create a small electrical charge. The charge moves along the auditory nerve to the brain where it is converted into signals that can be understood.

For an ear to work fully and let us hear the full range of sounds, all of the hearing system must work well. Deafness happens when at least one part of this system is not working effectively.

Implant in place



Cochlear implants work as follows:

- Sound is picked up by the behind-the-ear microphone and is sent to the speech processor. The sounds are then processed, changed into electrical signals and passed along the lead to the transmitter coil.
- The signals are sent by radio waves through the skin to the implanted receiver and down the wire to the electrodes in the cochlea. The number of electrodes for each child may be different.
- When the electrodes receive the signal, they make a tiny current that travels along the auditory nerve to provide a sensation of hearing.

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

The internal part of a cochlear implant (the part that is surgically implanted) is unlikely to need upgrading, unless there are problems. The external parts (the part that is worn like an hearing aid) may change as technology develops, but this should not mean further surgery.

Should my child have one implant or two?

Most people hear better using both ears rather than just one. This is because listening with two ears makes it easier to understand speech when there is background noise, and we are better able to work out which direction sound is coming from. Hearing with both ears is known as binaural hearing.

Today most deaf children use hearing devices in both ears. The cochlear implant team may recommend having two cochlear implants, known as bilateral fitting, or recommend having one cochlear implant and using a hearing aid in the other ear, known as bimodal fitting. This will depend on the level of hearing and the expected benefits of both options.

Once a cochlear implant has been implanted, your child will probably not have the same level of hearing left in that ear. The implant operation can cause changes to the cochlea which would make it unlikely that your child could go back to using a hearing aid in the implanted ear. This is why it is very important for you to talk to your specialist implant team about the options.

If it is recommended that your child has one implant and continues to use a hearing aid in the other ear, you will need to discuss which ear is to be implanted with the surgeon and audiologist. It is important for you to know why the implant team thinks that a particular ear should be implanted instead of the other. It may be because of medical reasons (for example, the scan may show why one ear rather than the other should be implanted), or it could be because of differing levels of hearing in each ear. For children with physical difficulties, the ear to be implanted may be chosen for practical reasons.

For people who do not use one it is very difficult to imagine what hearing is like through a cochlear implant. Most people who become deaf and then go on to use an implant agree that at first the sound they hear through a cochlear implant is very different from sounds they heard before they became deaf. However, after a while sounds become clearer and more natural to the user. To use an implant effectively, the user needs to learn how to identify and interpret different sounds. For a young child, who has never heard before, adapting to the new signal may be easier.

The assessment

If you think your child may benefit from a cochlear implant, you need to talk to your child's ENT consultant or audiological physician. They will be able to tell you whether your child may be suitable for a cochlear implant assessment, and refer you to a specialist centre. There are a number of specialist centres in the UK. Usually you will be referred to your nearest one.

The cochlear implant team will send you an appointment for an initial assessment for your child. You may have to travel some distance to get to the cochlear implant centre. If your household income is below a certain level or you are in receipt of certain benefits, you may be entitled to help paying for travel costs to the cochlear implant centre under the Healthcare Travel Costs Scheme. Funding for cochlear implants is provided by the NHS Primary Care Trust (PCT) or Specialist Commissioning Group where you live. If you have any questions or concerns, speak to your local consultant, GP or the implant team.

The assessment process involves a number of detailed tests and may require several visits to the specialist centre, especially if your child is very young or has any additional needs. During the assessment process you will meet lots of different professionals on the cochlear implant team including:

- audiologists
- medical physicians
- ENT consultants
- speech and language therapists
- teachers of deaf children
- nursing staff
- educational or clinical psychologists
- radiologists.

The implant team will carry out a range of assessments to decide if an implant is appropriate for your child. They will also work with the professionals that support your child locally.

The assessment process will include the following:

- Detailed tests of your child's hearing, both with and without hearing aids. To get the clearest possible picture of your child's hearing loss, your local audiologist should make sure your child has the most appropriate hearing aids and well-fitted ear moulds, and is free from glue ear. Electrophysiological testing may be carried out to confirm the levels of hearing. These are tests to measure your child's response to sound without your child needing to cooperate. These tests may be carried out under sedation or general anaesthetic.
- A medical examination, including a full examination of your child's ear. If your child hasn't already had tests to try and find out the cause of their deafness, these may also be offered. For more information on the tests that can be offered see NDCS's *Understanding Deafness* booklet and *Genetic counselling: information for families* booklet.
- A radiological assessment. This will usually involve MRI (magnetic resonance imaging) and/or CT (computerised tomography) scans so the surgeons can see your child's cochlea, auditory nerve and brain. Scans can show up problems such as ossification in the inner ear. Ossification can occur after meningitis and means that new bone starts to grow in the cochlea. This can make it more difficult for the surgeon to insert the electrodes. Scans can also show other problems in the inner ear and may alert the surgeon to increased risks during the operation. Occasionally children are born deaf because they do not have a cochlea or auditory (hearing) nerve. If the scan shows that your child has no cochlea or auditory hearing nerve, then a cochlear implant will not be possible in that ear.
- An assessment of your child's communication, language and speech skills. These may be carried out at the centre, at home, or at school, with the help of your child's teacher, teacher of deaf children or speech and language therapist.

Any extra hearing loss caused by glue ear may cause a child who is moderately to severely deaf to appear to have a much greater hearing loss. This could mean that without the glue ear, your child has enough hearing not to need a cochlear implant. Glue ear itself does not stop a child from having a cochlear implant, but it is very important that your child's hearing is tested once the glue ear has cleared up to make sure that the true levels of permanent hearing loss are assessed.

Most parents find that the decision to go ahead with the implant is an ongoing process throughout the assessment. If at any time you or your child feel that a cochlear implant is not the right choice, feel free to say so. Towards the end of the assessment you will be invited to discuss the outcome of the various assessments and jointly make a decision with the implant team on whether your child would benefit from a cochlear implant. If possible, your child should be involved in making that decision with you. If you have any questions about the tests, the operation, and what it is like to live with an implant, talk to the professional working with you and your child.

Before and during the assessment you and your child may like to talk to other families about their experiences of what it is like to live with an implant. You may also like to speak to deaf adults about their experiences. Some useful contacts:

- If you would like to talk to parents of deaf children with cochlear implants, contact the CICS support group (see the contact details on page 45).
- Children may like to talk to a trusted friend, family members or professional, such as their teacher, teacher of deaf children or communication support worker (CSW).
- NDCS can put you in touch with a deaf role model: a young deaf adult who will help promote a positive view of deafness, and be a positive role model for your child. Some deaf role models use implants, some hearing aids and some neither. They also communicate in a variety of ways and you can ask for a role model who most closely matches your child's experiences.
- The website www.ci-4teenz.com is useful for older children and teenagers to help them understand what the implant is all about and read the stories of some other teenagers who use an implant.
- The Ear Foundation runs events and weekends for teenagers with cochlear implants (see contact details on page 46).



There are several different makes and models of cochlear implants, but they all work in a similar way. If your child is offered a cochlear implant, you may be asked to choose a particular make and model for them. Some things you may like to think and ask questions about include the following.

- Cosmetic features of the cochlear implant, such as considering how it fits on the ear and how it looks. Older children in particular should be given as much choice in how their implant looks as possible.
- Practical features: how easily can you tell if the battery has run down? Is the system easy to use? For young children, can you tell easily whether the implant is switched on and working well using visual indicators etc? Is the device water resistant?
- Most deaf children who use cochlear implants also use an FM system (radio aid) in school. How easily are the systems set up and how well do they work together? Is the implant easily compatible with other audio equipment?
- What type of battery does the implant take and how long will it last? Can they be recharged? Young children may not be able to tell us when the battery is flat – will it last the whole day at school?
- Reliability of the external parts of the cochlear implant.
- Reliability and safety record of the internal implant: how many people are currently implanted with it and how long the implant is likely to last (known as survival rates). This information is usually available from the implant manufacturer and may be available from their website.

It is a good idea to do some research. Speak to other families about their experiences with different devices or contact the different companies that make cochlear implants. Find out how much experience they have of providing implants for children, and how successful they have been. Discuss any concerns with your implant team.

In certain cases the team may explain to you that your child is not suitable for a cochlear implant. Examples of when a cochlear implant would not be suitable include the following.

- The scan may show that there is no cochlea or auditory nerve, or there may be a problem within the cochlea which makes an implant surgically impossible.
- It may be that your child has enough hearing to be able to benefit over time from conventional hearing aids. If this is the case, the local audiology service will continue to provide the audiological care and support for your child.
- It could be that your child is older and progressing well using alternative methods of communication, such as sign language.
- It may be that your child has additional needs, which may make it difficult or impossible for them to learn to use the new signal.

The cochlear implant team will discuss with you 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 audiology services. The cochlear implant team will go ahead with implantation only if your child has been through the assessment process and you and they agree that your child will consistently, continuously and effectively use a cochlear implant.

Surgery

What happens when my child goes into hospital for the operation?

Fitting a cochlear implant in children is now a well-established surgical procedure. Surgery is usually done as a day case but may involve an overnight stay in hospital. The child will be seen and examined by the medical team, including the anaesthetist. You will be asked to fill in a consent form for your child. You will need to read this carefully to make sure you understand what the surgery will involve.

During the operation, your child will be under a general anaesthetic. The operation usually lasts between two to three hours. If your child is having two implants then the surgery will take longer. A cut will be made on the side of your child's head, usually with little or no hair needing to be removed. The implant will be put in position and some tests will be carried out to check it is working. The surgical wound is closed with dissolvable stitches underneath the skin, so no stitches will need to be removed.



After the operation you will 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 soon after the operation to explain how it went.

You should make sure that you understand the planned follow-up care before you leave the hospital. If an x-ray of your child's ear to show the position of the cochlear implant has not been done, a separate appointment will be made for you. After leaving hospital it is usually not necessary for your child to see your GP, but it is wise for them to be seen by your local ENT consultant about one week after the operation. This is to check that the cut is healing well.

Risks of surgery

There is a risk with any surgery that requires a general anaesthetic. With cochlear implant surgery there are some specific risks. Your ENT doctor will discuss the following risks with you.

Meningitis

Implanting the electrode in the cochlea might slightly increase your child's risk of catching meningitis. This risk is very small.

It is now standard practice to have a meningitis vaccination before surgery, and your implant team will explain this. The vaccine is usually given by your GP.

Other information is available on the British Cochlear Implant Group (www.bcig.co.uk) and the Department of Health (www.dh.gov.uk) websites.

Facial nerve

Many parents are worried about the risk of damage to the facial nerve (the nerve which affects the muscles of the face). However, the risk is very small and the facial nerve will be monitored by the surgical team during surgery. You should discuss this with your implant surgeon.

Infection

Another concern is infection around the implant site, although this is also rare. If your child develops an infection it could result in the implant needing to be removed. If, after your child's surgery, you are concerned that they might have an infection, contact the implant centre as soon as possible for advice. You can also contact your local ENT department and your GP for advice.

Device failure

The implant can occasionally fail for a number of reasons. This would mean that surgery (known as reimplantation) is needed to replace the device. However, reimplantation is usually carried out quite successfully in the same ear.

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

How the speech processor is fitted and tuned

Soon after the operation, your child must go to the cochlear implant centre for a check-up. The external part of the implant (the speech processor) will be fitted and programmed. This is sometimes called 'switch-on'.

The electrical signals produced by the speech processor are very complex and their levels need to be set carefully to suit your child. The process of programming the speech processor is known as 'tuning' or 'mapping'. The audiologist will take a number of measurements. These measurements help the cochlear implant team to develop an individual programme for your child's speech processor. For children with bilateral implants, often the two implants are activated gradually together.

The cochlear implant team will make sure that the levels that are set are comfortable for your child. Sometimes the first 'mapping' is done in one visit but usually it will involve a series of visits to complete all the measurements and choose the best form of electrical stimulation to meet your child's needs.

Support 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 an implant being used effectively or less effectively. As a family, you need to know the vital role you, and other carers of your child, play in helping your child to use their implant and in supporting them to develop their listening, communication and language skills.



Your child will continue to visit the clinic for the process of tuning their implant's speech processor and making adjustments as they learn to interpret the new signals.

It is 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. 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 and sessions with the teacher of deaf children and a speech and language therapist.

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

The teachers of deaf children and speech and language therapists from the implant team may visit your child at home and school to observe and record your child's progress. They will also be able to answer your questions, talk to you about how you can help your child, and explain what you can realistically expect of your child's progress.



As your child becomes older, they need to learn about their implant so that they can become responsible for looking after it. They will learn when to contact the implant centre for changes to the tuning and for repairs, spares, testing and advice. All implant systems have handbooks for users and it will be helpful for your child to become familiar with this. It is important that the implant team provides information that is easy to read and that your child will be able to understand.

If your child develops glue ear or an infection in the implanted ear it is important to contact your GP and get it treated quickly. You should also inform your cochlear implant team.

Communication and language

It is important to remember that it may take a long time for your child to learn to interpret new sounds through the implant. Every child is different and the time it takes will vary with each child. Your child will need to use these new sounds to develop their communication skills and spoken language. For a hearing child this process starts at birth and takes place over years rather than months. For a child fitted with an implant the process might take even longer.

After the speech processor has been fitted, you will need to make sure your child wears the system as much as possible. Practical details (such as the comfort and positioning of any body-worn speech processors or battery packs) are important, as your child will not want to wear the system if it is uncomfortable or keeps falling off! You can help your child to develop listening skills by playing games, singing songs and telling stories. With an older child, you may need to provide support and reassurance as they learn to make sense of the sounds around them.

While your child is learning to listen and interpret the new signals you will need to pay attention to listening conditions so that the background noise is kept at a reasonable level.

Before the implant was fitted your child may have been using sign language because they did not have enough hearing to understand spoken language. When your child is used to their implant, they may hear enough to understand and use spoken language. Many children make the change from sign-based communication to spoken communication naturally, but for some children sign language will remain an important part of their communication and identity. The most important factor is that your child can develop fluent language skills to communicate by whatever method is the most appropriate for them.

The Ear Foundation carried out research asking parents about changes to their child's communication following implantation. Their comments have been published in our joint booklet *Children with cochlear implants: Parental perspectives on changing communication skills*.

Issues around cochlear implants

Cochlear implants are increasingly used with very young children, but some people see them as controversial. Some deaf people believe that cochlear implants are unnecessary and that deaf children should not have one before they are old enough to make up their own mind. Other people believe that a cochlear implant gives 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.

The external parts of the system can usually be upgraded in order to get the most benefit from the cochlear implant without having to change the implanted part. As new developments take place, upgrades should be made available to all children, young people and adults with implants.

The technology of cochlear implants has developed rapidly over the past few years and will continue to do so. Electro-acoustic implants are now available. These devices combine amplification of sound (like a hearing aid) with electrical stimulation (the implanted part) at the same time. These enable people with some useful low and mid-frequency hearing to benefit from the hearing aid part, whilst the electrodes of the implant stimulate the high frequency hearing range and therefore give access to the high frequency sounds of speech.

Research that will help us understand more fully the benefits of binaural hearing is ongoing. This includes attempting to clarify any unique benefits and differences using bimodal (hearing aid and cochlear implant together) and bilateral (two cochlear implants) stimulation.

Some young people who were fitted with one cochlear implant as young children are now asking for a second implant to be fitted. It is believed that the closer in time the two implants are fitted, the better the expected benefits from hearing with them together will be. Research is ongoing to help understand better the changes that occur in the non-implanted side and what length of time between implants may result in a second implant providing less benefit than anticipated.

Future technological developments may include the potential for implanting the whole device inside the head so there would be no (or fewer) external parts.

Safety information

Children with cochlear implants are able to take part in most activities, although sometimes it is advisable to remove the external equipment during the activity (such as football, netball and swimming). In order to avoid damaging the internal part of the implant, children with cochlear implants are advised to avoid contact sports (such as judo, kick-boxing and rugby).

During the assessment for a cochlear implant, you will be given a copy of the safety guidelines that are recommended by the British Cochlear Implant Group (BCIG). The BCIG is a professional body that represents all the people working in cochlear implant centres.

The safety guidelines include information about

- medical matters
- going through security systems
- flying
- using personal stereos, audio equipment, TV and so on
- the effects of static electricity
- interference
- safety at work.



It is important that you read these guidelines and talk to your cochlear implant team about your concerns during the assessment process. You can also phone our Freephone Helpline to speak to our audiology advisor. You can get the most recent safety guidance from your cochlear implant team, or by visiting the BCIG website (www.bcig.org.uk).

The next section of this booklet has families' stories about cochlear implants. They explain how they found the experiences of the assessment, and what life is like with an implant.

Families' stories

The stories that follow are from families of deaf children and young deaf people. They explain these people's experience of making the decision about whether or not to have a cochlear implant. Each story is told in the child's or family's own words. As a parent, you will know that every child is different, and that all parents feel strong emotions when making decisions that affect their child. These stories reflect this, so you may want to take your time reading this section.

Many of these stories mention choices about communication. If you would like to talk to someone about communicating with your child, phone the NDCS Freephone Helpline on 0808 800 8880 (voice and text). We can also send you our factsheet, *Communicating with your deaf child*.



Freddie's story

“Freddie lost his hearing through pneumococcal meningitis at 10 months – we feel lucky. Since then, life has been one huge rollercoaster of emotions. From the low of being prepared for the worst as Freddie lay unconscious in intensive care to the highs of him ordering “mummy, Freddie wants milk downstairs now please”. Like all good rollercoasters, there have been many twists and turns along the way. When we were officially told that Freddie was profoundly deaf it came as no great shock – John and I had already observed him sit through repeated hearing tests blissfully unaware of the ear splitting noise booming from the loudspeakers. It was a humbling experience. By the time cochlear implants were first discussed we had already begun researching the technology.

The initial cochlear implant assessment appointment proved another white knuckle ride – a day filled with anticipation and anxiety. The morning involved a procession of meetings then the hard part – a two hour wait for a decision. Armed with Freddie's MRI scans, our doctor informed us that the meningitis had caused severe ossification in both ears and that unless the surgery was performed quickly they may not be able to physically fit the implant and Freddie would never be able to access sound. Whilst we were taking all this in, our doctor advised that the surgeon had slotted in the operation for four weeks time!

Freddie had his operation on 5 November. It seemed that time stood still for 5 hours as the surgeon, using a specially designed implant, inserted 17 out of the possible 21 electrodes – a considerable achievement given the extent of ossification. Even the surgeon was thrilled. After we learnt that only 70+ people in the world have been fitted with this particular device.

Switch on happened at 18 months – a little longer than usual due to a post op infection and the Christmas holiday season. But the wait was well worth it. To see Freddie smile and his eyes light up was a very emotional moment. However, it took some time for the family to realise that switch on was the start of a long but rewarding journey.

Freddie is now a lively and loveable 4 year old. Like all boys he is into everything and loves dinosaurs. He loves listening to stories and his concentration levels and interaction with other children have improved dramatically in the last year. There is also less stress and frustration for all of us as Freddie makes himself increasingly understood. We are careful to promote language in a natural way which is meaningful and fun. Even simple tasks such as making milkshake are used as colourful word games. The joy is that we never tire of hearing Freddie talk or say new words.

In our desire to extend his verbal communications skills we often forget what Freddie has achieved already and we are always grateful to people who comment on how well he has developed since they last saw him. We find this incredibly motivating.

Freddie has good signing skills and his lipreading abilities never cease to amaze us when he takes off his implant at night. For a while he wouldn't let us take it off at night, but we were advised to encourage him to remove it as it can lead to pressure sores at the implant site.

His 6 year old sister, Holly, is very patient and loving towards him – even when he annoys her – and acts as his interpreter when required. We are conscious to keep Holly informed and involved with all that goes on and give her time too. Our biggest fear at this time is Freddie's lack of co-ordination, which is a problem as he prefers running to walking and has a tendency to bump into obstacles. It is as if he concentrates on where he needs to get to rather than how to get there. He is currently receiving physiotherapy to help with this as he cannot afford to damage his implant.

Freddie has now received his SEN statement confirming his placement at the local hearing impaired unit – which he loves. We are delighted as Freddie is clearly in the right place and receiving the right support for his needs. We feel lucky that the school is on our doorstep.

We have had tremendous help along the way and we are eternally grateful for the support of the local speech and language therapist and educational services particularly in the early days. We don't know what the future holds for Freddie but we remain positive and one thing is for sure it will be one hell of a ride. ”

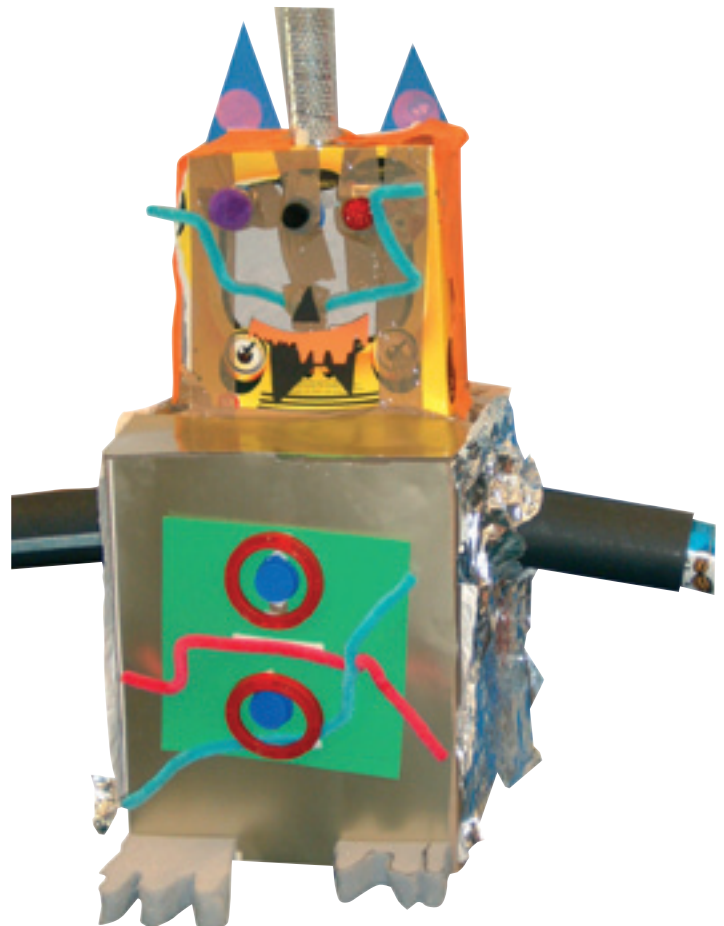
Matthew's story

“ Matthew was 6 months old when he was diagnosed as being profoundly deaf. Our paediatrician referred him almost straight away to the cochlear implant program where we were put on the waiting list.

In the meantime we were to find out that Matthew also suffered from a brain condition called pachygyria that affects both his physical and mental development. As a result of various complications, Matthew was three by the time all the necessary checks had been completed to show that physically he was suitable for an implant. At that time, the implant team had very minimal experience implanting children with learning difficulties and couldn't say that Matthew would gain any more than environmental awareness from an implant. By this time we had been signing with Matthew at home for over 2 years, but he had barely picked up more than a dozen signs and our communication was very limited. We were having to work very hard with him to develop his sign language, and felt that if he was implanted, we would have to change our focus to develop his hearing.

We were concerned that if we couldn't develop communication through his implant, and if we didn't continue to focus heavily on signing, then we might end up with no real communication with Matthew.

It was a difficult decision, but we felt in the end that it would be better not to go ahead with an implant. This meant that we could continue to focus on signing with Matthew without introducing what we felt would have been yet another complicating factor for Matthew. It did take quite some considerable time for Matthew to learn enough signing to communicate at his own level, but he has continued to progress well and can now hold quite a conversation and is never lost for 'words'. We have no regrets about the decision we made, which was right for our son at that time. ”



Anzo's Story

“Our son Anzo was born in July 2005 at a hospital in London, and the next day he was given a hearing test which we were told was inconclusive. We didn't pay much attention to this and took Anzo home where we all enjoyed some wonderful hot summer days and eased into family life. Anzo was a very undemanding baby and always smiling. About a month after he was born we had an appointment with the audiologist. She told us that the tests were not conclusive and we should come back in a month for further tests. She did, however, tell us that we should be prepared for the worst. We walked back home in silence and shocked by what we had heard. We then discussed what we were faced with and decided that regardless of the outcome of Anzo's next tests we would accept it and do whatever needed to be done to help him. He was our little boy and we were determined to give him the best in life.

A month later Anzo was diagnosed as severely deaf in both ears and fitted with hearing aids which he wore all the time he was awake. Over the next few months we had more appointments with the consultant and audiologists. Anzo had further tests and was fitted with more powerful hearing aids. He had support from the Teacher of the Deaf and the Speech Therapist. We also took him for some sessions at Christopher Place, a centre which specialises in speech and language therapy for pre-school hearing-impaired children. In July 2006 Anzo was a year old and at his routine testing we were told by the consultant that he was making good progress and that we should come back in six months. Anzo was developing well generally and beginning to crawl, but his speech development was lagging and we began to suspect that he might not be hearing as well as he should be. We decided that we needed more help. We had heard about Auditory Verbal Therapy (“AVT”) and, although not all the input we had was positive, we decided to go and see them.

It was thus that we arrived at AV-UK. Within minutes, after we had done the introductions and had a cup of tea, they told us that there was a problem with Anzo's hearing – he wasn't hearing any high frequency sounds. They advised that we get Anzo's hearing aids re-tested to see if they were working properly and we also went to a private paediatric audiological service. She recommended that we consider cochlear implants (“CI”) for him and explained that it would be best for him to be implanted before his second birthday. It was the first time that we had a proper and full explanation of Anzo's problem. It cost us £150, but it was the best £150 we had ever spent! Now that we knew exactly what Anzo's problem was we could start finding the best solution for him.

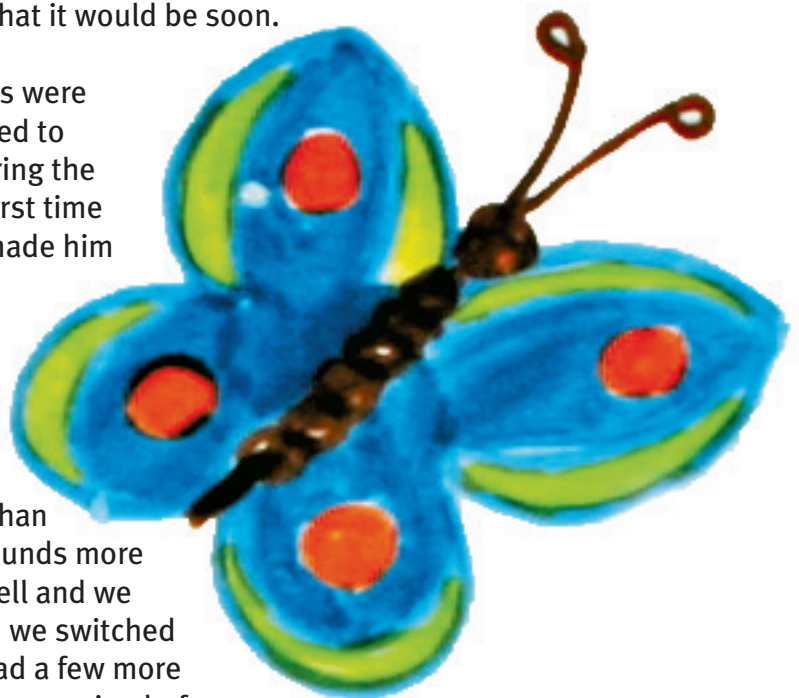
We then embarked on a massive search for all the information we could get about CI – how they work, the technology, the pros and cons, the risks, unilateral versus bilateral CI, simultaneous or sequential bilateral CI, the manufacturers, etc. We also had to decide on which Implant Centre to choose for his assessment, surgery and follow-up. AV-UK had told us about CICS so we called and they gave us very good support and advice over the phone. They also sent us the CICS pack which had very valuable and essential information. We went to our first CICS event where we met with parents and children who helped guide us to the right decisions for Anzo. We joined the NDCS and found their website and publications, particularly the CI guide for families, very useful.

Anzo's story continues overleaf

Anzo's consultant at the cochlear implant centre told us at the very first meeting in October 2006 that she would support simultaneous bilateral implants for Anzo unless his assessment showed any reason not to. Over the next few months we went through the arduous assessment process and Anzo was a star throughout. He hardly ever cried or complained and smiled his way through it all. But mainly he and his team got on well and they were able to complete the assessment in February 2007. At the Panel meeting the team presented their report, stated that Anzo was an ideal candidate and recommended him for simultaneous bilateral implants. Anzo's surgeon warned us that it might be difficult to obtain funding for simultaneous bilateral CI as Anzo would be the first child without meningitis to be funded for such surgery by the NHS. He did, however, promise to fight hard for the funding. They applied for funding to our PCT and we waited for a couple of weeks. We then wrote to the PCT asking for a prompt decision, reminding them that Anzo had no speech despite wearing hearing aids since age two months, that the operation had to be done before his second birthday to gain maximum benefit, pointing out the benefits of bilateral CI and the cost benefits of simultaneous CI as opposed to sequential bilateral CI. We also copied the letter to our MP and local Councillors. Although we did not get a response from any of the Councillors, our MP immediately contacted us and offered to meet with us. However, before the meeting with our MP took place, we received a letter from the PCT informing us that they had agreed to fund Anzo's simultaneous bilateral CI. We were over the moon!

Although Anzo's operation was quite long – over six hours – he recovered amazingly quickly and was running around the ward the next morning. He had some x-rays taken which were pronounced satisfactory and was discharged before lunch. Over the next three weeks before switch-on, he had no hearing and was much quieter than before. He resumed his nursery, where he goes two full days per week. He was generally still in a good mood but occasionally we could see that he was frustrated with his total deafness and he would throw tantrums. We could not wait for his switch-on and kept telling him that it would be soon.

On 21st May 2007 Anzo's devices were switched on and he was delighted to have full hearing, although hearing the high frequency sounds for the first time was a bit of shock for him and made him cry. He then had more follow up mapping appointments. We noticed a big change in Anzo - he seemed much happier and more confident of himself. He was also clearly hearing much more and better than before and was even copying sounds more accurately. His mapping went well and we were given four programs which we switched on progressively at home. We had a few more appointments for fine-tuning the mapping before we left for the John Tracy Clinic ("JTC") in LA in early July.



We realised that Anzo's implants were really just the beginning and there was considerable follow-up therapy that would be required and to this end we were committed to giving Anzo the very best support that we could. We decided to continue AVT for Anzo, which we believed to be the most effective form of therapy for him. We also felt that Anzo should continue attending his local nursery for two full days a week. He has received very good support there including daily one to one sessions initially with his teacher and later with his LSA, and a mainstream environment which should help him in his eventual transition to a mainstream school. We also decided to reinforce this with attendance at an auditory oral school. So we contacted Christopher Place where Anzo started in September 2007. At Christopher Place Anzo started in the Big Toddlers group with five other children and is now in the nursery which he attends three mornings a week. He has regular one to one speech & language therapy. The result of all this work is that in twelve months Anzo's comprehensive and expressive vocabulary has exploded. His speech is now much clearer and he is getting better at listening, processing, repeating and putting into context new words, phrases and short sentences. A year ago he had practically no spoken words, at Christmas he had about 20 words and now he has several hundred! Recently, he was assessed and accepted to two schools to start in Reception class next September (2009) when he will be four. We have chosen the school that we believe will be best for him.



It is important to remember that it is us, the parents, who are the best hope for our children and it is up to us to fight for what we believe is best for them. It is also important that we share our knowledge and experiences and unite our efforts in fighting to get the best for them. ”

A child with sequential bilateral implants and a big gap between them!

“ Bradley was born profoundly deaf into a hearing family with no history of deafness. He had four older hearing siblings. He received his first implant at age 3 and a half and immediately heard sounds for the first time. In the summer following implantation, the whole family attended the John Tracey summer school in California, where we discovered that his deafness was most probably due to Waardenberg syndrome, but more importantly, learnt how to encourage Bradley to listen with his cochlear implant and to get tips on how to develop his spoken language. We came back with high expectations of what Bradley could achieve.

We decided to send him into our local village infant school with support, believing that he would learn language by listening to and copying his hearing peers. This did seem to be the case. He copied in a mainstream school admirably, overcoming the various acoustic and social issues that did sometimes arise.

However, by the time the transition came for secondary school, the language of the curriculum was so much harder. Bradley got very tired listening to copious amounts of new and complex information in all the various subjects. He needed to listen hard to the answers of his peers and to formulate his own ideas and opinions. The concentration was more difficult. He would turn his head around so that his friends could speak into his implanted ear.

We began to explore the idea of a bilateral implant. It was obvious that the UK was behind many other countries with this concept. The implant team was supportive, recognising that Bradley was a very good unilateral user. However, this was pioneering stuff. There was no known cases of the results of a bilateral after such a long interval. These were not ideal conditions. Eventually Bradley had his bilateral when he was nearly 11, eight years after his first. The results were amazing. Within 6 months, he could hear nearly as well in his newly implanted ear. His listening in the classroom was easier. He could have friends sitting on either side of him. He could hear more easily in noisy situations, and got less tired listening in day to day life. Most importantly, he hears with both ears, and that just has to be better.”



William's story

“What follows may prove uncomfortable reading. I have not written it seeking sympathy, neither have I written it to worry parents considering an implant, nor to criticise any of the medical and professional teams that have been so supportive over the last five years. I have no “deafness” agenda. All I ask is that with children like William, where deafness is just one of a complex web of issues, we do not lose sight of what best serves the child as a whole.

When a child is born every family sets out on a journey. When that child is disabled the road they travel is far from smooth. We started our journey with our first son, William, in March 1999. Within a few days it was clear that things were not exactly as they should be. We were fortunate to have an understanding and trusting team of GPs and health visitors who never once questioned our concerns or observations and over the following months helped us through the rounds of tests and referrals.

William was diagnosed as profoundly deaf, but there was more. He was slow to achieve the landmarks that most babies do, slow to lift his head, slow to sit and walk. Without boring you with the history of scans, tests and consultations, by the age of 18 months William was diagnosed with CHARGE syndrome.

In many ways it was good to have a name to put to William's problems and we at last knew where the boundaries lay. Whilst the diagnosis identified a number of problems, we became absorbed by his hearing loss. We started to sign with him from early on and began investigating the possibility of an implant. After the usual assessment process and some pauses for other minor operations, the team at the hospital undertook the surgery in April 2002. We were no strangers to hospitals and surgery - in his three short years William had been anaesthetised at least seven times.

After switch-on William made slow progress, everyone taking hope from his happiness to wear his headset all day from the very beginning. Six months on and after a change in mapping strategy he made a step forward and started to turn to claps – a revelation to us. He no longer needed to be within waving, touching or stamping distance in order to get his attention.

In April 2003, just as we started to see a brighter future for William, it all stopped. What started as a slightly prominent implant site became a patch of red skin, and a cause for concern to the surgeon. This in turn became emergency surgery to reposition the package and ended in the discovery of a large infection necessitating the removal of the implant. The hospital had no hesitation in offering re-implantation on the other side.

Sitting with William in the recovery room at the hospital the questions started spinning around my head. As the next few days and weeks passed more questions kept coming. Could we put William through this again? What if a second implant failed or the infection recurred? What if he made better use of a second implant and then it failed and we had to take away this gift of sound? If we did re-implant what kind of life would we let him lead, worried that the slightest knock could cause damage?

William's story continues overleaf

These are all the kinds of questions asked the first time around, but this time we knew that he had made slow and limited progress with the first implant and the question “How much benefit would William really get from an implant?” became central. Thank goodness for my husband, a kind and loving man who nonetheless has the ability and strength not to let raw emotion cloud his judgement. He said “Don’t try and make a decision, identify the questions we need answering, answer them and then the decision will have made itself.” He was right.

With the help of the hospital team we spent time looking more closely at CHARGE syndrome and the success of implants for children like William. Very little data exists, however, what soon became clear was that the children we had heard of remained reliant on signing; implants gave them environmental cues, which are of course helpful but they remained signers. Whilst the hospital put the infection down to nothing more than bad luck, we never stopped wondering whether there was something about William that made him more susceptible to it and we were not about to try again with an implant just to disprove that hunch.

The more we thought about it the more we realised that William was not just a deaf child. His CHARGE syndrome, the way his brain and body worked was at the heart of this issue. We needed to look at William as a whole, not just his deafness. We had been so focused on helping to give him some hearing that we had tended to ignore other issues like his general but significant developmental delays. We had come to understand that these had a greater impact on his ability to adapt to and process what the implant was giving him than we had previously realised. By this time we were anticipating William’s move from nursery to school and were determined that it should be as smooth as possible for him. Without an implant we had a stable, immovable baseline for everyone involved in his care to start with.

Whilst we will never regret our initial decision to have an implant, with hindsight we realise it had been a huge distraction for everyone around him. Although we had continued signing with him, we had been pinning too much hope on the chance of him becoming oral. Without even realising it, we had stopped pushing ourselves to expand our own and his signing vocabulary – we were treading water. Family and friends at times seemed to forget he was deaf; it was as if by seeing him with the implant they thought it was just a matter of time before he would be talking like any hearing child.

The discovery of the infection really made us stop and reassess William’s situation in a way I think we might never otherwise have done and by doing so we reached a greater understanding of our child and his situation. In the past we used to say William was a deaf child who just happened to have CHARGE syndrome. Now we say William has CHARGE syndrome, which includes being profoundly deaf.

I will never forget my journey home from London after telling the hospital team that we would not be opting for another implant. I sat waiting for a feeling of sadness and panic to overwhelm me; instead I was enveloped by a wave of relief and determination to do all I could for William as he is now. It may appear to some that we gave up too soon on the implant. We should have tried again for William’s sake. In truth, we were given the opportunity to stop and look closely at William as a four and a half year old. We were able to look back and realise how much more we understood about him, his abilities and our expectations than we had two years before.

More than a year on from the removal surgery and William has settled well into a mainstream school with a unit. He has signed support all the time and is making slow but steady progress. At home we are all happily signing, including his two year old brother, and continue to feel that we have made the right decision for William. The path may have changed direction, but our journey with William continues. ”

Adam's bilateral cochlear implants



“ Adam had pneumococcal meningitis when he was 8 years old and became profoundly deaf as a result. Until then he had experienced no hearing difficulties. He was particularly poorly initially and spent considerable time in hospital. Prior to discharge he was fitted with bilateral hearing aids. Straight away he said they were rubbish. Maybe he would adapt the professionals thought but Adam remained adamant they were rubbish and demonstrated no benefit at all from his left one and very little from his right.

It was about six months after the meningitis Adam had his first implant. At this point he was still not well enough to return to school and his speech had become very 'slushy'. The first tuning session Adam shrieked with delight that it worked. We all sounded like robots but soon he began to adapt to our voices and about 2 months post implant he turned to me and said I sounded like mummy. Not like I used to sound he said but he was able to recognise my 'robot' voice.

Time passed by and Adam started to say he wished that he could hear the same with both ears 'like I used to be able to do'. He did remember after all what it was like to have two working ears. He was never able to identify which direction a sound was coming from. When Adam had his annual review by his consultant Adam was asked how he was and he said 'good but I wish both ears were the same'. At which point it was said 'well why shouldn't they be?'. This was in June 2006. The battle began, Adam's consultant applied for funding. We received a phone call in August to say funding had been denied, we will try again. It was denied at the second attempt too and so at that point we were advised to make an appeal. As parents we were prepared to go to whatever lengths were necessary. After all Adam wanted both ears to work again. We spoke to many people, mostly those who had not been successful in gaining funding, web sites, support groups, everywhere it was possible to get information from. We received a letter to give us a date for an appeal hearing. We had two weeks to get everything together. A number of people wrote some incredibly supportive letters regarding the Adam before meningitis and the Adam since meningitis. One evening Adam came to me and said he wanted me to read his story. Immediately this was going to form the back bone of our appeal.

Our appeal was held in May 2007 almost a year since the original request for funding. Nervously our case was presented. The tears flowed and we left the room knowing we would be contacted the next day.

Great joy... our appeal was successful. The panel had agreed that two ears were better than one.

Adam's surgery took place in August 2007, he had his first tuning session the day before his birthday in September. It could not have been a better birthday present. From that day to this Adam has gone from strength to strength. He hears well in most situations, occasionally back ground noise will aggravate him and make it more difficult to hear. He has achieved great results in his SATS. Despite missing virtually a full school year he has achieved great things and having two ears has very much contributed towards this. Adam attends Mainstream school and has just started at Secondary school. He uses radio aids in class. ”

Natalie's story

“When our daughter Natalie was born in 1993 she was very ill. After many tests it was found that she was suffering from congenital Cytomegalovirus (CMV); this can have many side effects of which Deafness is one. At four months old she was diagnosed as being profoundly Deaf and was referred to hospital for assessment and hearing aids.

Ironically, prior to having Natalie I had worked in Deaf and other special schools and had a good knowledge of British Sign Language (BSL), so as soon as we knew that she was Deaf I started using BSL with her. Other members of the family – her dad, grandparents, aunts and cousins all went to college to learn it too.

Because of her other medical conditions, she couldn't lie on her tummy and do the “usual” baby things, so we spent a lot of time looking at books and other things about the house, just showing and describing things to her. She seemed to soak up language and used her first sign (bird) at about 10 months. From then on she never stopped and her signing skills have always been above age appropriate.

The subject of cochlear implantation arose when she was about 18 months old. It was still very new back then and the expectations were not high - “she may get an awareness of some environmental sounds”. It was a very tough decision to make particularly as it appeared that some CMV children were not doing well with implants.

Communication was not a problem with us, but there is a big hearing world out there and one day she would have to go out into it! Even if she only heard environmental sounds, we hoped it would help keep her safe e.g. if she could “hear” a lorry or us shouting “stop”. Even the strongest hearing aids were of no use to her; we wanted to give her every opportunity in life, if we left it until she was old enough to decide for herself, it would be too late; We thought long and hard and finally decided to give the go-ahead, we would give her this opportunity and if it didn't work or if she didn't like it, then when she was older it would be her choice not to use it.

She received a body worn implant just before her 3rd birthday and was “switched on” in September 1996. This went brilliantly until they tried to turn the “volume up”; she didn't like it and got very upset, so for the next few weeks it was left on a very quiet volume. Also, for the first few weeks she hated it when it was first turned on. We had to make sure there was absolute silence, switch it on, on a low setting, and then gradually increase it as she got used to the sounds going in. Once she had it on, she was fine and it didn't bother her at all.

This lasted about four weeks after which we have never really had a problem. She has four electrodes turned off, as she doesn't like the feeling/sound that they produce, but this has never been a problem. After the initial few weeks she has never looked back! She started responding to sound within weeks and was answering to her name by Christmas. She had never really used her voice before, but it was only a matter of months before she was saying “mmmm” for mummy and “u” “u” for woof, woof!

When she was nine she received a behind the ear processor which helped to increase her “hearing” range. She has continued over the last eight years to make steady progress and now considers herself to be bilingual. She is age appropriate and fluent in both BSL and spoken English.

Natalie's story continues overleaf

Until last year she went to a fully integrated mainstream unit and did well, but as she grew older it became apparent that her needs were changing and so we moved her to an Independent Bi-lingual Deaf School.

The implant has far exceeded all of our expectations – she can even use a phone with familiar adults. She has just passed her year 6 SAT's English exam and gained level four and next year will be starting to learn her third language - French. Natalie is very proud and happy to be Deaf, but she is equally as happy and proud to have her implant. As she herself says: "It has given me the best of both worlds!"

The implant is not a miracle cure for Deafness, she is Deaf and will always be Deaf; we felt then (and still do) that it was simply the best available hearing aid. If when she is older she chooses not to use it, it will be her own decision and we will agree with her, knowing that at least we have given her the opportunity to make that choice. ”

Mike's story

“ Michael contracted pneumococcal meningitis in April 1994 when he was 16 months old. He was very ill and in hospital for 16 nights. I stayed in with him and just before leaving hospital I noticed that he wasn't using his right hand. The physiotherapist came to see him and said that his whole right side was affected and that he even had a crooked smile. The hemiplegia, as it is called, was caused by brain damage from the meningitis.

Hearing tests in July and August that year showed he also had a moderate to severe hearing loss. Michael was fitted with behind the ear hearing aids. In October 1994 he went for more tests and was found to be profoundly deaf. Body-worn were suggested and we agreed to Michael being put forward to a Cochlear Implant Programme.

Further tests and an MRI scan showed that Michael's cochleas had ossified with bony scar tissue and he therefore had no residual hearing. This made the decision much easier for us, as without an implant he would spend the rest of his life in silence. Michael had his implant in August 1995. Due to the ossification he only has eight electrodes. The implant was turned on in October 1995 with just five electrodes tuned in at first.

For the first few years Michael was not very co-operative or reliable with tuning. This made it very difficult for the Implant Centre who didn't want to make sounds too loud and put him off wearing it. It was 3 years before Michael was reasonably reliable at tuning and by this time he was up to all eight electrodes.

He has only been consistently reliable for the last year. A month after his meningitis Michael started attending a Special Nursery mainly for O.T. and Physio. He could not use his right hand and it took him 10 months to learn to walk again. He still has a marked limp. A teacher of deaf children visited him at home and we were advised against signing. In January 1996 when Michael was 3 he started nursery at an oral Hearing-Impaired Unit. He coped with nursery and then reception but Year 1 was too much for him. Michael became very frustrated and I battled to get him to school

each morning. He was subsequently diagnosed with learning difficulties and it became clear his needs could not be met in mainstream.

With no special schools for the deaf in Hampshire and not wanting him boarding at 7, Michael went to a special school for physically disabled children. A Teacher of the Deaf, Physiotherapists and O.T.s are based at the school and Speech and Language Therapists visit weekly. The classes consist of just 6-8 children and they use total communication (S.S.E. with speech) and picture symbols to help with reading.

At home we also started using sign support with Michael. I learnt B.S.L. at college and as a family we started going to Sign Language Workshops specifically for children, which are very helpful. Michael's right arm and hand can still cause him problems though with his signs being difficult to understand. He has been at the same school now for 4 years and is staying there as the school goes through to 16. Although way behind his hearing peers, Mike (as he insists on being called now) is making steady progress and despite his difficulties he is now much happier.

Michael had a handful of words before he had meningitis but virtually all of his words went overnight. When Michael had his implant we were told that children normally started talking after 1-2 years. Whilst he responded to some environmental sounds, years went by with Michael saying very few words.

However we saw a big improvement in his speech with the introduction of sign support and the vastly improved confidence that he gained from going to the special school. Over the last two years Michael has been coming out with phrases and sentences and I have found myself correcting his grammar!

Although most people outside the immediate family cannot understand Mike's speech, at home he sometimes drops his signs now. Despite getting through quite a few 'V' mics Michael's processor only broke down once in 8 years. However after a febrile convulsion in December 2002 Michael started complaining about high pitched sounds.

One electrode was subsequently turned off which meant he lost two channels (because he has so few electrodes they are 'doubled up'). He has picked up environmental sounds for some time and reliably responded to his name for the last 2 years. However he still only picks out one word from a sentence without sign support. In July 2004 Mike received a B.T.E. processor. It was quite disconcerting at first, as we were getting no responses from him at all. However after a couple of weeks he was back to hearing us call him when he is up in his room.

People often ask if Mike's implant has 'worked'.
My answer is yes, but it wasn't an overnight success. ”





A family's story

“ In 1990 our first son was born. Thirteen months later he was diagnosed profoundly deaf. He was fitted with hearing aids but we had no communication with him, which was very frustrating for him and ourselves, therefore we went to sign language classes. Three years later we had our second child, a daughter, who at six weeks old was too found to be profoundly deaf. She too was fitted with hearing aids.

Although our son did get a little benefit from his aids our daughter didn't. However, they both seemed happy and we were just relieved to have some communication with them through sign language. However in the back of our minds we always wondered if we were doing the best for them. They both attended special schools and nurseries with a unit. At this particular time there was lots of publicity about the “Bionic Ear” – the cochlear implant.

We read about it and read about it and decided to find out more and so went to an information day run by a paediatric cochlear implant centre. We listened to lots of stories, all different cases. At this time our children were 6 and 3 years old. We gave it a tremendous amount of thought and decided to look at the possibility of offering our children what we decided was just the best hearing device on the market.

We didn't want to change them into hearing, after all we were proud of them but just wondered if in the long term it would make their life easier as they got older. After lots of tests and assessments we decided to go ahead with it, it wasn't easy especially when we had to think of the risks involved, although small, we had double the chance.

As our son was classed as being older than recommended at the age of eight, we felt he was old enough to talk it through a little. He was afraid, and so after lots of consideration we decided to let our daughter who was nearly five have it done. After all she didn't really get any benefit from hearing aids and so this had to be worth it. Also we felt that if our son saw his sister come through it all then he would feel happier about it. So that was what we did. It was a very difficult time. Their operations were just six months apart, thus giving us some time with each child individually post-op. The check-ups and tuning were quite exhausting for them and for us. However, looking back it was all well worth it, from our point of view and our children's.

Yes, they are still deaf and always will be, and are proud of being deaf. We still use sign language but don't rely on it as much as before their implants. They are able to join in things easier with the hearing world but still like to be part of the deaf world too. You could say they have the best of both really which is all we wanted. As they grow into adults it is their choice which route they take but at least we know we have offered them everything available.”

Holly's parents' story

“Holly was born partly hearing. Her parents and grandmother (mother's side) are profoundly deaf, her brother Lee is hearing. When she was under 1 year old, we took her to the Audio department at a hospital in London to check if she is deaf because we noticed she did not response when the noise was loud comparing her to her brother who picked up the sound well.

After the Audio team tested her they told us that she was partly hearing and provided us one hearing aid to change to each ear every hour but the hearing aid kept whistling, its affected her partly hearing ear and it deteriorate rapidly then she became profoundly deaf. They also provided another hearing aid for the other ear. We continue to contact the audiologist until they transferred her to a different hospital. They replaced her hearing aids to the powerful ones she used them when she went pre-school and at home. She find that it didn't really helped her and one day she surprisingly, asked us that she wanted to have cochlear implant which stunned us and had to do some thinking about the idea. She wanted an implant because some children at her school had one and she noticed that they are listening and speaking well better than she is. We discussed the ideas with the audiologist before we decided and the doctor explained that it was at an early stage for Holly, and better to wait until she is a bit older. Holly constantly tells us the hearing aid isn't helping her. We again discussed with the doctor and we agreed to send her to a hospital for children in London.

The assessment took nine months for further tests and finally the implant team took their meeting and agreed that Holly is suitable to have one. Holly was very happy and looking forward to having it. The operation took place April 1996 she was six and a half years old. The operation was successful and took 5 hours.

One month later we returned to the hospital to receive new speech processor and accessories for implant. We had to go to there for the next three days for the 'switch on'. She responded all various of sounds she is able to hear the sound different between high and low pitches. Which she never done with the previous hearing aid, she can hear bird pecking which was her first sound as she walked out of the hospital on the first day, microwave beeping, kettle boiling, etc. We were amazed when she tells us about the sound she could hear that she never did with hearing aid. My son Lee told us that he could hear Holly's voice much clearly than before. We find cochlear implant is a great benefit for Holly it is really worthwhile. Holly's languages at home are sign language for her grandmother and us but with her brother she speaks. She signs with most deaf people so they can understand but speaks with hearing people. She also lipreads but can hear without looking.

Now she is 15 years old and she is still attending mainstream high school, which is the local school. She uses behind the ear processor not body processor. She has had it for eight years now and is very happy with it. She did not regret having the implant. She is very helpful to us when we are out shopping, or hospital or whatever. She interprets for us because we find it hard to understand what they are saying sometimes but Holly had a good communication with the hearing people. ”

Holly's story

“I've had my implant since I was six half, and had it for eight years now. When I first had my implant switched on it took me a while to get used to it because it sound totally different to my hearing aid. Hearing aid never really helped me because it was always whistling. I constantly took my hearing aid off, I couldn't understand what anyone was saying, with my implant it helped me a lot and I picked up lots of sounds.

My first sound was hearing bird pecking on the ground, as I walked out of the hospital after the first day of switch on, it was amazing. It was much better than what I expected of it. I don't regret having it and I never will, I don't think I'd be where I am now if I didn't get the implant. I know it sounds terrifying going through operation just to get an implant, but it is really worth it. I know for a fact that my listening skills had improved over the years since having it and my speech. I sometimes feel like I'm a hearing person when I can hear people talking without looking and forgetting that I got my implant on because I can't feel it, but I know deep down I never will be hearing. I am in both deaf and hearing world and I would like that to continue. I go to local mainstream school and I am coping very well there.

I have supporters in some of my lessons to take notes or anything like that although I don't think I need it because I understand my teachers well. I am in my last year at school and I am hoping that I will do well in my GCSEs next year. After that I will go onto college to study childcare because I want to work with deaf children in the future.”

Kasima's story

“ At an early stage of my daughter Kasima's life it became apparent that she had some difficulty with her hearing, by the age of two she was diagnosed as being profoundly deaf. Over the years learning to adapt to her circumstances was very difficult and put the family under a lot of pressure.

After many consultations and meetings Kasima at the age of nine years old was referred to hospital to undertake medical tests to ascertain if there was anything that could be done to increase her hearing levels.

In 1995 Kasima was operated on and was implanted with a cochlear implant. This was a very stressful but exciting time for Kasima and the family, possibly we were told, Kasima would be able to hear sounds of some sorts if the operation went successfully. One month after the operation the day of truth had arrived; we were due back at the hospital to switch the implant on. Everything seemed to be fine and they set the implant up to receive 18 channels. On returning home I noticed Kasima becoming really excited and enthusiastic, what happened next was amazing. Kasima with the car window wide open started to hear sounds; you could see she was unsure about placing the sounds to visual items. Kasima then began to constantly inquire to what made what sound and where that sound came from. She was so excited, when we reached home she was showing everybody the hearing device and then the doorbell rang and she moved towards the door and that was the emotional sight for me as I now realised what this device meant in relation to Kasima's life.

Just being able to do something as simple as answering the front door, something that we take for granted on a daily basis. As time went by Kasima gradually became familiar with everyday sounds like the TV, microwave, Hoover and doorbell, family member's voices and tones. Along with the joy of being able to hear sounds Kasima from an early stage took great responsibility for the up-keep and maintenance of her hearing device, cleaning it regularly and changing the batteries.

Returning to the hospital three months later the speech therapist and the audiologist were shocked and surprised at the progress Kasima had made so they decided to increase the channel input by two - up to twenty. After the review Kasima started to engage with the local speech therapist with the implant. During her speech therapist sessions she began to pronounce her nouns and vowels and started to develop single words that later began to developed into sentences of five to six words. During this period we put a lot of hard work into supporting Kasima's speech at home.

By being the first person to undertake speech therapy with the aid of a hearing device in Leicester Kasima became a pilot study, which due to the overwhelming success of her interaction, many other families began to engage. Over the years I spoke to numerous families encouraging their participation. For me as a parent I have seen how a cochlear implant has increased the levels of participation of which my daughter has been able to engage.

This participation was enforced with the constant support of Kasima's teachers at both primary and secondary School. Both schools encouraged and liaised fully with myself to make any transitions as smooth as possible. The teaching staff used Kasima and her

Kasima's story continues overleaf

implant as a highlight to what is achievable, not allowing her disability to act as an excuse for her to fail.

A major contribution to all of this is Mrs B who is a specialist teacher of the hearing impaired, she was the first person to guide and support us with the cochlear implant. After a short consultation with Mrs B we felt any opportunity to benefit our daughters future was the correct way forward, with this we agreed to undertake the tests to see if Kasima meet the criteria of the implant. Over the years Kasima has gradually worked her way through junior and secondary school, having just completed her G.C.S.E's achieving and A* for Art and Design in which Kasima has a special talent. She also obtained two B's and a D, which is an outstanding achievement.

In September 2004 Kasima started Full Time College enrolling to undertake a BTEC National in Art and Design. In summary as a family the cochlear implant has been an inspiration to my daughter and to my family. The channels and avenues Kasima has been able to access with the support of the family and outside agencies has been amazing.

I would like to take this opportunity to thank everybody who has been involved at whatever level over the years, your constant support and help is greatly appreciated.”

Michael's story

“ In 1988 at 3 years of age following losing my hearing due to meningitis I was implanted with a cochlear implant, which after a lot of hard work and support from many people has benefited me greatly.

I began my education in a school for the deaf when I was three and gradually continued my education in mainstream. An award I'm very proud of is gaining a “ Civic Citation” for the progress I have made in mainstream school. I enjoy my part time job at ASDA where I have worked for over two years gaining skills and experience in many areas of retailing including having sole responsibilities for bicycle assembly !!!

Recently I have been involved in talking to young deaf people and their parents and giving the implanted person's view at conferences. I gained three 'A' levels and I decided to study for a degree in Design Technology for industry straight after the summer. Though I was a little apprehensive I really was looking forward to starting a new life away from home and supporting myself! I now believe it was a very good choice as the note takers were a great help! I now have a good circle of friends who I regularly go out with to the union and the clubs!

”

Where to go for more information

You can phone the NDCS Freephone Helpline for more information or to speak to our audiology advisor.

The National Deaf Children's Society

15 Dufferin St, London EC1Y 8UR

Freephone Helpline: 0808 800 8880 (voice and text),
open between 9.30am and 5pm, Monday to Friday

Fax: 020 7251 5020

Email: helpline@ndcs.org.uk

www.ndcs.org.uk

On the NDCS website, *Parent Place* (www.ndcs.org.uk/applications/discussion) is a message board for parents. You can pass on a message about your own experience or search for messages on any aspect of childhood deafness and view other parents' questions and answers to each other.

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.

www.bcig.org.uk

Cochlear Implanted Children's Support Group (CICS)

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

CICS, PO Box 28843, London SW13 0WY

Phone:

South: Tricia Kemp: 020 8876 8605 (voice)

North: Deborah Faithfull: 01904 744 639 (voice)

Midlands: Carmen Burton: 01332 365 528 (voice)

Email: info@cicsgroup.org.uk

www.cicsgroup.org.uk

Cochlear Implants for Teenz website

This website has information for teenagers about cochlear implants. It has interviews and comments from teenagers who wear implants, and information about other organisations that might be useful.

www.ci-4teenz.com

Deafness at Birth website

This website provides information about the Department for Education and Skills' Early Support Programme and other useful organisations.

www.deafnessatbirth.org.uk

The Ear Foundation

This is a charity that bridges the gap between hospital specialists, families, and children and young people who have a cochlear implant. There is a full programme of parent, family and professionals courses, which take place throughout the year.

The Ear Foundation, Marjorie Sherman House, 83 Sherwin Road, Lenton, Nottingham NG7 2FB

Phone: 0115 942 1985

www.earfoundation.org.uk

Meningitis Research Foundation

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

Meningitis Research Foundation, Midland Way, Thornbury, Bristol BS35 2BS

24-hour helpline phone: 0800 8800 3344 (voice)

Fax: 01454 281094

www.meningitis.org

National Cochlear Implant Users Association (NCIUA)

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

Mrs Alison Heath, MBE, Longacre, Horsleys Green, High Wycombe, Buckinghamshire HP14 3UX

Email: alisonh@horsleys.demon.co.uk

www.nciua.demon.co.uk

You can also ask your team to put you in touch with families who are going through the assessment process, or whose child has already had an implant fitted.

NDCS provides the following services through our membership scheme. Registration is simple, fast and free to parents and carers of deaf children and professionals working with them. Contact the Freephone Helpline (see below) or register through www.ndcs.org.uk

- A Freephone Helpline 0808 800 8880 (voice and text) offering clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.
- A range of publications for parents and professionals on areas such as audiology, parenting and financial support.
- A website at www.ndcs.org.uk with regularly updated information on all aspects of childhood deafness and access to all NDCS publications.
- A team of family officers who provide information and local support for families of deaf children across the UK.
- Advice on special educational needs (SEN) disability discrimination in education and welfare benefits.
- Representation at SEN and Social Security Appeals Tribunals from our Legal Casework Service.
- An audiologist and technology team to provide information about deafness and equipment that may help deaf children.
- A children's equipment grants scheme and the opportunity to borrow equipment to try out at home.
- Family weekends and special events for families of deaf children.
- Sports, arts and outdoor activities for deaf children and young people.
- A quarterly magazine and regular email updates.
- An online forum for parents and carers to share their experiences, at www.ndcs.org.uk/parentplace.

NDCS is the national charity dedicated to creating a world without barriers for deaf children and young people.

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0808 800 8880 (voice and text)

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

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