Welcome to the Great Ormond Street Hospital (GOSH) Cochlear Implant Programme

This booklet explains about cochlear implants and what to expect when your child comes to GOSH to be assessed to see whether one is suitable. It also explains about the operation to fit a cochlear implant and what happens afterwards.

The Cochlear Implant Programme at GOSH is one of around 20 in the UK and to date has carried out over 500 cochlear implants. The implant team is ‘multidisciplinary’, comprising people from many different relevant specialist areas. These people include consultant audiovestibular physicians, ear, nose and throat (ENT) surgeons, audiologists, speech and language therapists, teachers of the deaf, hearing therapist and clinical psychologists.
How do we hear?

The ear consists of three parts: the outer ear, the middle ear and the inner ear. Sound waves enter the ear canal and make the eardrum vibrate. The sound then passes through the middle ear via the three small bones of hearing (ossicles), on to the inner ear that is filled with fluid. The movement of fluid in the cochlea stimulates hair cells inside it to trigger a nerve impulse, which is carried to the brain by the auditory nerve. The brain then interprets these nerve impulses as sound.

In some people, the hair cells inside the cochlea become damaged, either before birth or later on in life. This is called ‘sensori-neural deafness’. In this condition, although sound travels through the ear in the usual manner, the hair cells are not stimulated and so no nerve impulse is sent to the brain. The hair cells can be damaged to such an extent that no sound is heard, or, in some cases, only loud noises can be heard. Some people can be fitted with hearing aids, which amplify (make louder) sounds until they can be picked up by the hair cells. However, this will not benefit people whose hair cells are too damaged to pick up any sound and in these cases a cochlear implant may be suggested.
What is a cochlear implant?

A cochlear implant is an electronic system that stimulates the auditory nerve directly, bypassing the hair cells in the cochlea. It can give a sensation of sound to profoundly deaf children who have been unable to hear using the most powerful hearing aids available. Over a period of time after cochlear implants have been fitted, children can learn about the sounds around them and may use these to help their lip-reading. In time, some children may learn to understand and use speech without needing to lip-read, and may even be able to use a conventional telephone.

Cochlear implants will not ‘cure’ your child’s deafness but they should provide a useful sensation of hearing sound. However, it takes a lot of time, patience and practice to use them as well as possible.

Each cochlear implant system is made up of two components that work together to send nerve impulses to the brain. The speech processor (which looks like a hearing aid) is worn behind the ear and picks up sound that is converted into an electrical signal. From this processor, the electrical signal then passes to the coil so it can be sent to the receiver that is under the child’s scalp. This then converts the signal into a tiny electrical current that eventually stimulates the auditory nerve. The nerve carries signals to the brain. When the brain decodes these signals, your child can have a sensation of hearing.

MED-EL Opus 2 Speech Processor
There are several groups of children who benefit most from having a cochlear implant. They are:

- those who have lost their hearing after learning to talk
- those who have hearing loss that is getting worse over time
- those who are born deaf or become deaf within the first few months of life and who have a cochlear implant by the time they are four years old.

While these groups benefit most obviously from cochlear implants, the team may not automatically exclude your child from assessment if their hearing problems are not on this list. However, it is important to keep in mind that they may not benefit from implants, and many children are better helped by other kinds of hearing aids.

The degree to which your child develops their speech and language will depend on a variety of factors including age of implantation, access to sound before implantation, amount of language acquired before implantation, amount and quality of rehabilitation, other difficulties and more. It is not always possible to predict how much your child will benefit from their implants.
Assessing your child

As the process of having a cochlear implant and learning to use it is a very long one, you and your child will need to go through a thorough assessment programme before deciding whether to go ahead. This means that you will have the chance to talk to the team about any concerns or questions and meet other families with children with a cochlear implant. Members of our team will visit your child’s school or nursery, if appropriate. If your child has a local speech and language therapist, we will also contact them for information. It is important to have the support of such people locally, as they will also be involved in the period after the operation when your child is learning to use the cochlear implant. Your child will be helped to get the maximum benefit from their cochlear implant if you, they, the medical team and other people involved with them, for example at school, all work together.

Your child will need various tests and checks, which take place over several appointments. These include:

- **General health check** – your child’s general health will be checked by the consultant audiological physician (doctor who specialises in hearing).

- **Ear check** – the consultant audiological physician or audiologist will also regularly check your child’s middle ear. If your child has glue ear this may affect their hearing and an operation to insert grommets to correct this may be suggested.

- **Hearing tests** – your child will need tests to check how much they can hear with and without hearing aids. This will include behavioural tests where your child responds to sound. Your child will also need a test called an Auditory Brainstem Response (ABR). This is a test that measures the response of the hearing nerve to sounds. It is usually carried out under sedation or general anaesthetic during your child’s computerised tomography (CT) scan.
Child care pathway within the Cochlear Implant Programme

1. Initial assessment with the team
2. CT and MRI scans and other investigations as required
3. Cochlear Implant Programme assessment
   - Audiology: Approx. 3 appointments
   - Speech & language therapy: Up to 3 appointments
   - Clinical psychology: 2 to 3 appointments
   - Teacher of the deaf: 1 school/home visit
4. Team decision followed by meeting with parents and choice of device
   Arrangement of funding from local services if cochlear implant is not offered, children are referred back to original doctor
5. Pre-operative appointment
6. Operation
   - 1 to 2 day stay
7. 2 weeks after surgery 2 switch on appointments
8. Mapping appointments
   - Map 1: 2 weeks after switch on
   - Map 2: 4 weeks after switch on
   - Map 3: 3 months after switch on
9. Speech and Language Therapy/AVT Appointments
   - Up to eight therapy sessions in the period following Map 2
10. Review appointments
    - At 6, 9, 12, 18 and 24 months after switch on
11. Assessment reviews
    - Speech and language therapy reviews annually until age of 5 years
    - Audiology reviews annually until age of 16 to 18 years
    - Transfer to adult Cochlear Implant Programme
    - Medical, psychology, teacher of the deaf and hearing therapist follow-up as appropriate
12. School/home visits
    - As appropriate by speech and language therapists, hearing therapists and teachers of the deaf
In addition to these tests, a questionnaire will be used to find out about your child’s ability to hear sounds at home and, if appropriate, at school.

Computed Tomography (CT) scan of the cochlea – this is a scan to check the bony formation of the cochlea. The surgeon needs to make sure that there are no problems with the cochlea which could make inserting the implant more difficult. These scans are usually carried out while the child is sedated or under a general anaesthetic as they need to remain absolutely still for the period of the test.

Magnetic Resonance Imaging (MRI) scan – this is another scan that gives very detailed pictures and helps to identify the auditory nerve. This scan may be carried out under sedation.

Vestibular balance and vision tests – your child will also receive these tests as your hearing and balance systems are linked.

Hearing aid check – Your child’s hearing will be tested while wearing hearing aids. The team may wish to try different models of hearing aids or new ear moulds.

Communication skills – the team will assess your child’s communication. The more we know about the child’s skills, personality and interests, the better we are able to help with the learning process afterwards.

Psychological assessment – all children are routinely assessed by a Clinical Psychologist, who will find out about your child’s general development, learning style and ability. They will also discuss any concerns about your child’s behaviour and emotional well-being.

Further tests – additional tests may be required to look at the cause of hearing loss.

If you agree, some of these tests will be recorded on video, so the team can refer back to them later on in the process. You will be invited to sign a consent form before the assessments start.
Team meeting and decision making

When we have the results of all these tests, the team will meet to decide whether to offer your child cochlear implants. You will be given the opportunity to meet with the team to discuss the outcome of the assessment. If you decide to proceed with cochlear implants, we will arrange a device choice meeting and apply for funding from your local service.

The operation

What happens before the operation?

You will already have received information about how to prepare your child for the operation in the Welcome to our hospital booklet and your admission letter. The doctors will explain about the operation in more detail, discuss any worries you may have and ask you to give permission for the operation by signing a consent form. Another doctor will also visit you to explain about the anaesthetic.

If your child has any medical problems, particularly allergies and constipation, please tell the doctors about these. Please also bring in any medicines your child is currently taking.

What does the operation involve?

The operation takes about three to six hours and is carried out when your child is deeply asleep under a general anaesthetic. Your child will need to have a small amount of hair shaved off for the operation, but again this is done once they are asleep. The surgeon makes an incision (cut) behind their ear, and drills through the bone, through the middle ear and into the cochlea. The electrode array is inserted into the cochlea. A ‘bed’ is made in the bone behind the ear to hold the receiver and internal magnet. The surgeon use dissolvable stitches to close the cut.

Once the cochlear implant is in place, it will be tested to ensure that it is working correctly.
What are the risks of the operation?

Any surgery carries the risk of bleeding or infection during or after the operation but this is small. Your child will be given an injection of antibiotics during their operation to reduce this risk. Any anaesthetic carries a risk. After an anaesthetic some children may feel sick and vomit. They may have a headache, sore throat or feel dizzy. These side effects do not usually last long and are not severe.

Your child may also feel dizzy for a while after the operation due to the balance mechanisms of their ear being disturbed during surgery. There is also a chance that your child could have ‘ringing in the ears’ temporarily after the operation.

There is a small risk that the operation may damage the facial nerve, which runs between the bone at the side of the ear and the middle ear. This could result in weakness down one side of the face. The nerve is closely monitored throughout the surgery.

The nerve that takes taste sensations from the tongue to the brain is also very occasionally damaged, resulting in taste disturbances after the operation.

If your child has unusual inner ear anatomy, your consultant will spend additional time discussing this with you.

People with cochlear implants are able to lead normal lives as long as they take a few sensible precautions. These include:

- avoiding trauma to the head
- care with medical procedures - always check that your medical professional is aware of the implanted ear
- care with electricity and static
- seek medical attention if you see any signs of infection
What happens after the operation?

Your child will return to the ward after starting to recover from the anaesthetic. They will have a large pressure bandage around the head and may need an intravenous drip (infusion into a vein) of fluids and drugs for the first 24 hours. They will also have an x-ray to check that the implant is in the right place in the cochlea. Your child will be able to get up the day after the operation, and by the second day are usually back to normal and playing with other children on the ward. They will usually be able to return home after one or two days, but will need to come back for regular appointments. We will send you the date of their next outpatient appointment in a letter.

Coming back to the hospital ‘Switch on’ and ‘Mapping’

The first ‘switch on’ appointment usually takes place around three weeks after surgery and will then involve frequent visits to the hospital on a regular basis. This is so that the settings on the implant can be altered as it settles into the cochlea and as your child gets more used to detecting sounds. An ENT doctor will attend the first appointment to check that your child’s scar is healing well.

The audiologist will start by connecting the speech processor to a computer and activating the implant gradually to establish your child’s level of hearing. They will also program the processor so that the volume of sound your child can hear is comfortable and not too loud. This process is known as mapping. The audiologists tend to be cautious, and set the levels of stimulation low to begin with, so that your child is not overwhelmed by sound. The level is gradually increased as your child becomes accustomed to the sound from the implant.
The ‘switch on’ process takes place on two separate sessions in the cochlear implant department. Following switch on, regular mapping appointments are required to ensure that your child’s speech processor remains optimally programmed.

**Learning to use the cochlear implant**

Like the mapping process, it may take a while for your child to learn to use the cochlear implant. The learning process is a collaboration between the team at GOSH, your family and your child’s teachers and speech and language therapist. Members of the team will make regular visits to their local colleagues to plan the learning process. The specialist teacher of the deaf may visit your child’s local teachers to make suggestions about the first listening games which will encourage him or her to learn about sound. The team’s speech and language therapist will also liaise with his or her local colleague to plan activities. They will also offer you and your child up to eight therapy sessions at the hospital as a supplement to any therapy you may be receiving locally. The local Speech and Language Therapist and/or Teacher of the Deaf will be invited to attend one of these sessions to ensure effective liaison. It is important that your child learns to wear the speech processor all his
or her waking hours. The sooner he or she learns to enjoy improved access to sound, the sooner he or she will start to make progress with listening.

Children who have never heard sound or who have a limited experience of hearing can take a long time to learn how to hear. The sound that the implant produces through electrical stimulation is very different from the sound produced from a hearing aid. Therapy following implantation aims to help your child understand the new sounds they hear. It also aims to encourage your child's listening and spoken language development through carefully graded steps.

The team will monitor your child’s listening, language and communication skills over time. You will need to visit the hospital annually for the first five years for formal assessment of your child's progress.

However, if you or any professional working with your child have concerns about your child’s progress, appointments may be arranged with the cochlear implant team. Intervention can be offered as needed from the Clinical Psychologists, Teachers of the Deaf, Hearing Therapists and Speech and Language Therapists.

We hope you have found this introductory booklet helpful. If you have any questions or require further information, please contact the team.
If you need more advice from the Cochlear Implant Department at GOSH, please telephone 020 7813 8316 from Monday to Friday, 9am to 5pm or email cochlearimplants@gosh.nhs.uk

You can get further advice, and contact with people in similar situations, from:

**The Royal National Institute for Deaf People (RNID):**
Information line: 0808 808 0123
Textphone: 0808 808 9000
Email: Informationline@rnid.org.uk

**National Deaf Children’s Society (NDSC)**
Information line: 0808 800 8880
Voicetext open 10am – 5pm Monday – Friday
Email: helpline@ndcs.org.uk
Website: www.ndcs.org.uk

**Cochlear Implant Children’s Support Group**
Website: www.cicsgroup.org.uk

**Ear Foundation**
Tel: 0115 942 1985
Website: www.earfoundation.org.uk