

The Oxford Auditory Implant Programme

Cochlear Implant Summary

Information for parents and carers



Thank you bringing your child for a cochlear implant assessment. We have agreed that your child is likely to benefit from cochlear implantation.

There are a number of things to consider when making a decision about whether cochlear implantation is the right choice for you and your child. This leaflet has been written to summarise the information we have explained to you about the cochlear implantation process. It is only a summary, so if anything is unclear or has not been fully explained, please speak to a member of the Auditory Implant Programme team (contact numbers are at the end of the leaflet).

What are the potential outcomes with a cochlear implant?

Cochlear implants can give a perception of sound and will allow your child to access (hear) speech sounds. Their brain can then learn to interpret these sounds as speech. It will take time for your child to make sense of the new sounds they are hearing.

The outcomes from having cochlear implants vary. Your child may develop normal sounding speech and understand speech like their hearing friends, but they are always likely to have difficulty in noisy environments and will benefit from extra support at school.

Some children use their cochlear implants to give them an awareness of environmental sounds (the sounds around them), but may not be able to understand speech without lip reading or sign support. Some children are not able to develop clear speech.

There are factors that affect the outcomes with cochlear implants, which means we cannot always predict how well they will work for each child.

Children who were born deaf or became deaf before they learnt to talk, generally learn to hear with cochlear implants more quickly if they are implanted early, ideally before the age of 18 months. Children who have consistently worn hearing aids before they have cochlear implants also tend to adapt more quickly to the new sound they experience with cochlear implants.

There are specific speech and language or developmental disorders that are not related to a child's hearing loss, which may affect the outcomes from cochlear implants

Although children naturally learn to listen and understand speech, they need a lot of exposure to language to develop speech well. This is even more important for children with cochlear implants, if they are to catch up with the speech and language development of their hearing friends. They will need some extra support and rehabilitation to learn to make sense of sound and to understand and develop speech and language.

Which ear will have the implant?

Bilateral cochlear implants (one for each ear) are recommended for most children under 19 years of age. Research has shown that children do better with two cochlear implants, compared to just one. Bilateral implantation is generally what we recommend.

There are some situations where a child cannot have two cochlear implants, such as a physical problem with one ear that makes cochlear implantation on that side impossible or unlikely to be successful. Occasionally children have better hearing in one ear, and it is agreed that the hearing on that side should be kept as it is, so that it can be used with a hearing aid. Generally, though, if your child fits the criteria for a cochlear implant in their better ear, they will do better with two implants.

Funding is available for bilateral cochlear implants for children, if they are carried out at the same time. If you choose to only implant one ear, funding may not be available for the second ear later on.

What happens during the implantation?

The cochlear implants will be put in place during an operation, which is carried out under a general anaesthetic. This means your child will be asleep throughout the surgery.

The operation takes place in the ENT theatres, in the West Wing of the John Radcliffe Hospital. It takes between two and three hours per ear. Your child should be able to go home on the same day, but you should bring an overnight bag in case they need to stay on the ward overnight.

Before the surgery, you and your child will need to come for a pre-assessment clinic appointment. This is usually a week or two before the date of their surgery. This is to make sure your child is fit for the general anaesthetic they will have during the surgery.

Please make sure that you follow the fasting (starving) instructions, which should be included with your child's appointment letter. Fasting is very important before an operation. If they have anything in their stomach whilst they are under anaesthetic, it might come back up while they are unconscious and get into their lungs.

What happens after the operation?

After the cochlear implant surgery, your child will wake up with a small bandage on their head. The time it takes to recover after the operation can vary, but most children feel better very quickly.

Going home

After the operation, your child may feel a little tender, groggy, dizzy and tired, but this should steadily improve over the next few days. Your child should have two weeks off from nursery or school after the operation.

Your child cannot go home on public transport after a general anaesthetic. You will need to take them home by car. This will be more comfortable for them and also quicker for you to return to the hospital if there are any complications on the journey home.

Recovery and wound care

Your child's wounds will have been closed with dissolvable stitches, which do not need to be removed. They will gradually dissolve over the next 12 days.

It is important that your child's wounds remain dry for the first week. Take care not to knock or scratch them when you brush their hair or when putting on glasses. You will need to wait a minimum of 1 week after their surgery before gently washing your child's hair. You can use shampoo and conditioner, but should not rub the wound. If you are unsure whether you should wash your child's hair, you can wait until we see them to first turn on their cochlear implant (about 2 weeks after the operation). Also avoid using other hair products for 1 week.

Flying should be avoided for 4 weeks after the operation. This can be uncomfortable (due to the change in air pressure).

What are the risks?

As with all operations there are some possible complications or risks. The surgeon will discuss these with you when you sign the consent form. The consent form confirms that you agree to the procedure and understand what it involves.

Some of the potential complications and risks:

- Your child may experience some dizziness and/or sickness for a few days after the operation. These symptoms can also occur if your child turns their head quickly or bends down suddenly. This is usually temporary.
- They may find their sense of taste is different on one side of their tongue. This usually improves over time.
- The wound may become swollen and painful, which may be a sign that it has become infected. In the unlikely event that this happens, your child will need to be treated with antibiotics. You should contact the Cochlear Implant programme for further advice. If it is a weekend or after 4.30pm you should go to your nearest Accident and Emergency department and ask to be seen by the On-call ENT doctor.
- Bruising or damage to the facial nerve, which runs near the site of the surgery. This is carefully monitored throughout the operation, to make sure that bruising or damage to the facial nerve very rarely occurs. However, there is a very small risk of damage, which could affect the movement of muscles in the face.
- Your child may notice a change to the level of their tinnitus, if they had this before the operation. It may get louder or may disappear altogether. It will usually return to normal levels after a few weeks.
- The implant stops working. This rarely occurs. If it does, your child will need a further operation to replace the broken or faulty implant.

The cochlear implant rehabilitation process

The initial switching on and fitting of the external sound processor/s will be approximately two to four weeks after surgery.

The first time we stimulate your child's cochlear implant it will be at a very quiet level. We do not want to scare or upset your child. You may not see any reaction from your child at the first appointment, but the nerve of hearing will be being stimulated and the process of rehabilitation will have started.

You will need to bring your child for multiple audiology (tuning) and speech and language therapy (SALT) appointments for the first year after implantation. We will usually try to arrange these appointments on the same day, to reduce your travel time.

Your child is likely to have 3 appointments in the first month, then a further 6 to 10 over the rest of the year. This varies from child to child and depends on how quickly they progress with the rehabilitation process.

It may take a few weeks or months before you start to see your child responding to sound. Although this can be frustrating, it is normal and does not mean the cochlear implant is not working.

After their audiology appointment, your child will usually see a speech and language therapist. They will work with you to develop your child's listening and language skills to their full potential. These sessions will include activities which can be incorporated into play and daily routines, as well as structured listening games and practise. This will help your child to benefit as quickly as possible from their cochlear implant/s.

Your child will need to wear their sound processor/s during all waking hours to get the most benefit. When we see them for tunings, we can connect their processor/s to the computer and share with you how much it has been worn and what listening environments your child has been in (such as speech in quiet/ speech in noise/music, etc.). This is useful in helping us to give

you advice on how best to maximise your child's listening with their cochlear implant/s.

It can be difficult to keep the processors on little ears and toddlers often do not want to wear their processors, especially in the first few weeks. If you need us to, we can help and advise you on how to keep the sound processors on and help develop your child's listening.

If there are any problems with your child's processor use or expected progress, we will work with you and your local team to offer additional support and home visits.

How to contact us

If you have any questions, please telephone or email the Auditory Implant Programme team.

Tel: **01865 234 550** or **01865 234 881**

There is an answer machine on these numbers. If we are not available to answer your call immediately, please leave a message and we will get back to you as soon as possible.

Email: **auditoryimplantprogramme@ouh.nhs.uk**

Website: **www.ouh.nhs.uk/auditoryimplant**

Support groups

We will try to put you in touch with a family of a child in a similar situation to yours, who has had cochlear implants. It is often really helpful to speak to families who have been through the same process. We also have an active local support group which runs events throughout the year for cochlear implant users and their families.

OxCIS (Oxford Cochlear Implant Support Group)

Michele Motteux: Volunteer Advisor and Patient Advocate to the Cochlear Implant Programme.

Email: michelemotteux@hotmail.co.uk

CI Five Counties (UK) Support group

Email: CIFiveCounties@gmail.com

You may also find useful information and support from the following websites:

Action on Hearing Loss

www.actiononhearingloss.org.uk

Advanced Bionics

www.advancedbionics.com/uk/en/home.html

British Cochlear Implant Group

www.bcig.org.uk

British Deaf Association

www.bda.org.uk

Cochlear

www.cochlear.com/wps/wcm/connect/uk/home

Delta

www.deafeducation.org.uk

National Cochlear Implant Users Association

www.nciua.org.uk

The Ear Foundation

www.earfoundation.org.uk

Medel

www.medel.com/uk

Device choice

We have shown you models of each electrode and sound processor that we offer, explained how they work and given you written information for you to read at home. Unless there is a medical or physical reason why one system is recommended, you and your child (if appropriate) can choose which device they would prefer. You are welcome to arrange a time to come and have another look at the models or discuss the device choice further.

This form summarises the options you have already agreed with the Cochlear Implant team about cochlear implantation for your child.

Both ears Left ear Right ear

Implant and sound processor choice:

Advanced Bionics Cochlear Medel

Processor:

Colour:

Date for surgery (if available):

The date for surgery is subject to change, as emergency patients may have to take priority.

The above information has been explained to me by:

Name of team member:

Signature of team member:

Date:

Name of patient:

Signature of patient/parent/carer:

Date:

Name of interpreter:

Signature of interpreter:

Date:

If you have a specific requirement, need an interpreter, a document in Easy Read, another language, large print, Braille or audio version, please call **01865 221 473** or email **PALS@ouh.nhs.uk**

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