



Your Child's Hearing: Useful information and people you might meet

Your child was seen in the Audiology Department and the results have indicated a permanent hearing loss.

This folder will introduce the people and services who will be working with you and your child in the coming months. It can also be used to keep all the letters, reports and information you are given about your child's hearing loss to build up a detailed record of their care.

Audiology

The Audiology Department sees patients of all ages who have hearing and balance disorders. The department carries out a variety of different tests, depending on the age and ability of the patient and whether they have any specialist hearing problems, including hearing loss and tinnitus. Once the tests are completed the team can make recommendations and provide appropriate treatment.

The Audiology service is based at:

Royal Devon & Exeter Hospital
Barrack Road
Exeter
EX5 2DW

Telephone: 01392 402223

email: cse.audiology@chimehealth.co.uk

The Audiology team sees children from birth to adulthood living in Exeter, Mid and East Devon for detailed hearing assessments, advice and appropriate management of permanent hearing loss. This will include fitting hearing aids and other appropriate listening devices together with specialist advice and information.

We often work closely with colleagues in education as well as medical colleagues including consultant paediatricians and ear nose and throat consultants.

Members of the Audiology Team



Caroline Payne
Paediatric Lead



Ben Gillett
Paediatric Lead



Magda Vorster
Specialist Audiologist



Inarie Badenhorst
Specialist Audiologist



Claire Burns
Specialist Audiologist



Dee Lawrence Szabo
Specialist Audiologist

Babcock Deaf and Hearing Impairment Team

Our team includes Advisory Teachers of the Deaf and Advisory Deaf Inclusion Workers

We support Deaf/ Hearing Impaired children, young people and their families from birth to 25 years of age. We provide support in the home, in early years settings, in schools and in further education settings.

Our team offers advice and guidance on a range of issues appropriate for your child's age and needs:

- Helping families understand the diagnosis/ implications of hearing loss.
- Information about communication modes eg English, British Sign Language, Cued Speech.
- Amplification needs and aids (hearing aids, cochlear implants, Assistive Listening Devices).
- Advice on educational provision eg early years settings/ schools/ colleges.

There is also a Multi-Sensory Impairment team who support children with a clinical diagnosis of both a visual and a hearing impairment who may be identified as Deafblind.

The Babcock LDP Team is based at:

2nd Floor, Milford House

Pynes Hill

Exeter

Devon

EX2 5GF

Telephone: 01392 287239

Email: lian.badcock@babcockinternational.com

www.babcockldp.co.uk/disadvantaged-vulnerable-learners/send/sensory-impairment

Happy Hands

Happy Hands is organised by Babcock LDP and is a support/ play group where you can meet other parents and deaf/ hearing impaired adults.

It provides a stimulating environment for your child to meet other deaf/ hearing impaired children.

Each session involves Singing/ Signing/ Stories/ Craft Activities/ Snacks

Central Devon (Exeter) group is held on the 2nd Wednesday of the month (1.00-2.30) term time only at:

Chestnut Avenue Children's Centre, Exeter, EX2 6DJ

North Devon (Bideford) group is held on the 1st Wednesday of the month (1.00- 2.30) term time only at:

East the Water Primary School, Mines Road, Bideford, EX39 4BZ

South Devon (Newton Abbot) group is held on the 3rd Wednesday of the month (1.00- 2.30) term time only at:

Highweek Children's Centre, Coronation Rd, Newton Abbot, TQ12 1TX

Ear, Nose & Throat Department

The Ear, Nose and Throat (ENT) Outpatient Department is located in area J of the Royal Devon & Exeter Hospital.

In addition to providing a general ENT service the Department has a variety of specialist skills. The Department works closely with Audiology, Speech and Language Therapists and Hearing Therapists in order to offer the best possible service to its patients.

Your child may see an ENT consultant to review test results or for an opinion on ear surgery or ear wax removal.

Paediatrician

The Department of Paediatrics Outpatients Department is located in area J of the Royal Devon & Exeter Hospital.

A specialist paediatrician may offer an appointment to you and your child or they may work with your child's named paediatrician. The paediatrician will check the general health and development of your child and other tests may be offered to try and identify the cause of your child's hearing loss. They may also refer you to see a clinical geneticist.

Ophthalmologist

The West of England Eye Unit (WEEU) is based at the Royal Devon & Exeter Hospital near the main entrance.

Your child may be referred for a specialist test of their eyes and vision. It is important that any visual problems are detected as early as possible for children who have a known hearing loss.

Devon Specialist Child Assessment Centre (Honeylands)

Honeylands provide specialist assessment and intervention for children aged 0-5 years in Exeter, east and mid Devon with significant developmental difficulties. The multi-disciplinary team works with families and community services to provide services which are tailored to individual children's needs both in the Centre and in the community.

They provide a single point of access for the referral and assessment of children with significant developmental difficulties aged up to 5 years. Some children are referred early in their lives, particularly children who have been patients on the Neonatal Unit. Other children have difficulties which are noticed later, for example when they begin pre-school.

A multi-disciplinary approach is followed to find out as much as possible about children who have been referred, before arranging appointments to begin their assessment.

There are many different types of specialists who work in the team at Honeylands – Paediatric Doctors, Clinical Psychologists, Speech and Language Therapists, Physiotherapists, Occupational Therapists, Specialist Nursery Nurses, Early Support Advisory Teachers, Orthoptist, Music Therapist and Portage Workers.

Honeylands is part of Integrated Children's Services so they can link into the wider ICS Team to provide access to social care and respite services.

Honeylands Specialist Children's Assessment Centre can be contacted at:

Pinhoe Road Exeter

EX4 8AD

Telephone: 01392 467 473

(available Monday to Friday, 8.30am - 5pm)

West of England Hearing Implant Programme

The West of England Hearing Implant Programme (WEHIP) provides cochlear implants for adults and children throughout the South-West. It was established as the Regional Centre in 1995 and now carries out around 100 operations a year.

The multi-disciplinary WEHIP team includes ENT Consultant Surgeons, Audiological Scientists, Teachers of the Deaf, Speech and Language Therapists, Clinical Psychologists and a Paediatrician. Careful assessments are carried out to check whether a child referred to the team might benefit from an implant and information is shared to help families decide whether they want to go ahead.

The external parts of a cochlear implant look rather like an ordinary hearing aid. There is careful follow-up, where families, local professionals and the WEHIP team work closely together to help the child make best use of the implant and if possible, learn to listen and talk. Teachers and therapists on the team carry out home and school visits, and families attend audiology clinics in Bristol, Taunton and Exeter.

Early referral, assessment and implantation make a significant difference to how well children do with their implants. The aim is to implant children who are born deaf at around their first birthday.

For families with profoundly deaf children needing more information about cochlear implants please see the WEHIP website or contact the programme directly:

Paediatric Team

West of England Hearing Implant Programme

Children's Hearing Centre

Level D, St Michael's Hospital

Bristol

BS2 8EG

Telephone: 0117 3421607

Text message: 07468 756052

Email: wehip@UHBW.nhs.uk

www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/other-services-in-bristol/west-of-england-hearing-implant-programme

Specialist Speech and Language Therapy for Deaf and HI children

Who do we provide a service to?

- Babies to school leaving age children with moderate to profound bilateral sensori-neural hearing loss with priority given to pre-school and early years for targeted input.
- Regular therapy provided to primary school children.
- Assessment and advice given to secondary school age children.
- We provide advice, support and targeted therapy to children who are registered Deaf Blind. The sensory loss must be the primary diagnosis. Assessment and advice are provided for children on the Deaf Blind register for dual sensory loss as part of a profile of other complex needs.

All the children we see are also supported by a Teacher of the Deaf.

We do not provide a service for

- Children with Unilateral or mild hearing loss. Second opinions and advice can be given if sought by a named Speech and Language Therapist working with the child.
- Children with a diagnosis on the Autistic Spectrum Continuum although we can help with advice if the child also has a diagnosed hearing loss.
- Children with severe and complex needs in special schools. Advice and support can be given to the Speech and Language therapist supporting the child if they use hearing aids or Cochlear Implants.

Further information on speech and language services is available on the websites:
<https://www.devon.gov.uk/educationandfamilies/special-educational-needs-and-disability-send-local-offer/support-for-different-types-of-need/speech-language-and-communication-needs>

<https://childrenandfamilyhealthdevon.nhs.uk/slt/>

The Speech and Language Therapy Advice Line is available Monday – Friday 2pm-4:30pm tel: 0333 321 9448

Devon Children and Families Partnership

We are passionate that every child in Devon should have the best possible start in life and the opportunity to thrive. To help, we are working together to be there for children and families with the right support, at the right time, and in the right place.

<https://www.dcfp.org.uk/>

Early Help

Early help is the extra support your family can get if you need it. It may be that you want to prevent a problem or change things for your family before the problem becomes more serious.

It is not a specific service or team, it's an approach that brings people together from a range of services and teams who will work together you're your whole family to help improve the situation for everyone

It can offer support to families from pre-birth to adolescents with all sorts of issues from parenting, employment and school attendance to emotional well-being or anti-social behaviour.

<https://www.dcfp.org.uk/early-help/>

contact email for mid and east Devon is: Earlyhelpmideastsecure-mailbox@devon.gov.uk

for Exeter is: Earlyhelpexetersecure-mailbox@devon.gov.uk

Devon SEND (Special Educational Needs & Disability)

Every child deserves the best possible start in life and the opportunity to thrive. Some just need a little extra help or special support to achieve their potential.

Devon's SEND Local Offer and strategy has been produced in collaboration with families and set out how we will help improve outcomes for children and young people with special educational needs and disabilities and their families.

These priorities make up our SEND Local Offer, which includes the education, health and social care services and support for children and young people (0-25) with special educational needs and disabilities (SEND).

The four areas of need are:

Communication and interaction

Cognition and learning

Social, emotional and mental health

Physical and sensory.

Website: <https://www.devon.gov.uk/educationandfamilies/special-educational-needs-and-disability-send-local-offer>

Signpost Plus

Devon's Family Information Service for Children with Additional Needs

The Signpost Plus co-ordinators can help you get information about the local and national services and support available to you and your child.

Snippets are a weekly round-up of information relating to Children with additional needs, produced by Signpost Plus.

<https://childrenandfamilyhealthdevon.nhs.uk/signpostplus/>

<https://www.facebook.com/SIGNPOSTPlus/>

National Deaf Children Society

Our vision is a world without barriers for every deaf child. Together we overcome the social and educational barriers that hold deaf children back.

Families: We help families give the best possible support to their deaf child every step of the way.

Children: Deaf children and young people are at the heart of our work. We make sure their needs come first, and we help others do the same.

Choice: We give expert unbiased support to help deaf children and their parents make informed choices about their lives.

Challenge: We work together with others to positively challenge unfairness.

The Freephone Helpline provides emotional and practical support where a trained team offers clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.

Children and Families Support Officers can provide individual support for families. Their role is to empower deaf children, young people and their families to make informed choices. They provide information and support on a range of topics including education, welfare benefits, social care, discrimination, independence and communication. They can be accessed via the Helpline.

NDCS Helpline: 0808 800 8880 Text:07860 022888

Available Monday to Friday 9am to 5pm

Email: ndcs@ndcs.org.uk

The NDCS also provides a variety of literature covering a vast range of topics available for download to parents.

The NDCS run weekends for families of children diagnosed with hearing loss where parents can learn more and meet other families. They also organise regional and national events for children and young people with hearing loss.

www.ndcs.org.uk

Local Deaf Children's Societies

North Devon (NDDCS)

This parent led group offers support and activities for families in North Devon and Torrington and can be contacted via

email: northdevon@ndcsgroup.org.uk or phone 07947 684203

or Facebook: North Devon Deaf Children's Society

Plymouth (Plymouth DCS)

This group is made up of parents of hearing impaired children, their families and other people concerned with deaf children. They hold fundraising events and activities for the children.

<https://www.deafsociety.co.uk/>

https://www.facebook.com/plymouthdeafchildrenssociety?_rdr=p

email: plymouth@ndcsgroup.org.uk

Details of other groups in the South-West are available via the NDCS website

Devon Children's Hearing Services Working Group

Who are we?

We are a group made up of health, education and social care professionals, volunteers and parents of deaf children who care about supporting deaf children and young people.

What do we do?

We work together to agreed 'terms of reference' to improve services for deaf and hearing-impaired children and their families in this area.

When & Where do we meet?

We meet in the Exeter area; the venue may vary. We meet four times a year for 3 hours, on a Thursday morning.

How can I be involved?

Your views and experiences as Parents and Young People are important to us to help improve services – you can:

- Talk to any professional working with your child to share your views.
- Join the South West Every Deaf Child Matters Facebook Group
swedcm.weebly.com/facebook-group.html
- Join our CHSWG group as either a regular member or request to attend a meeting.
- View our minutes on the CHIME website or ask to join the circulation list.

Contact:

Ben Gillett
Telephone: 01392 402223
email: ben.gillett@nhs.net

Support Websites

www.ndcs.org.uk

The National Deaf Children's Society provide information and advice for deaf children and young people and their families.

www.contact.org.uk

Contact-a-family is a national organisation offering information support and advice on local services for families with disabled children.

www.bcig.org.uk

The British Cochlear Implant Group provides further information about cochlear implants.

www.chimehealth.co.uk

The website for Chime Social Enterprise who provide audiology services for children in Exeter, East and Mid Devon.

www.babcockldp.co.uk

The website for Babcock LDP who provide educational support for children with hearing impairment and deafness in Devon.

www.devon.gov.uk/educationandfamilies/special-educational-needs-and-disability-send-local-offer

Devon County Council website provides information and advice for families of children with special educational needs and disabilities.

www.dcfp.org.uk/early-help/

Provides information on how to obtain early support for your child and family.

www.pinpointdevon.co.uk

Information on help and support services and community groups available in Devon.

www.childrenandfamilyhealthdevon.nhs.uk/signpostplus/

Devon's Family Information Service for Children with Additional Needs

www.uhbristol.nhs.uk

The website for the University Hospitals in Bristol where the cochlear implant service is based.

<https://swedcm.weebly.com/facebook-group.html>

A Facebook group for families of children with hearing loss in this area.

www.avuk.org

Promote Auditory Verbal Therapy with the aim to enable deaf babies and children to have the opportunity to listen and speak as equals alongside their hearing peers.

www.cuedspeech.co.uk

A charity based in the UK providing family support, training and information to help deaf people see what you are saying with Cued Speech.

www.british-sign.co.uk

Provides on-line British Sign Language training and support.

www.signature.org.uk

Promotes British Sign Language Courses and helps you find a class near you.

Information on Hearing Aids

Helping to keep hearing aids in place

Your baby or child will probably have times where they remove their hearing aids. This is very common in the initial stages of adjusting to hearing aid use for toddlers or older children. Young babies will not initially be able to remove the aids, but once they pass 6 months of age will discover the aids are there and pull them out in the same way they grab anything at this stage.

We can provide the following to help keep aids in their ears:

Toupee tape: double sided tape which sticks the hearing aids behind the ears and prevents them flopping about and drawing the child's attention to the aids.

Hearing aid clip: attaches round the hearing aids and clips to your child's clothing. If the hearing aids are pulled out, they are less likely to be lost.

Huckies: These are stretchy bands that attach to the hearing aid and circle the ear helping to keep aids in the correct position.

Other suggestions that some parents choose to investigate:

Hearing Aid Headbands: Bespoke headbands with pockets to hold the hearing aids in place.

www.hearingaidheadbands.co.uk

Bonnet: this fits over the head covering the ears and is tied under the chin. To ensure sound of the hearing aids is not affected, mesh sides are recommended.

www.aussiedeafkids.org.au/build-a-bonnet.html

Earmoulds

Inserting earmoulds can be tricky on a small or wiggly child. The moulds are often made of a soft material which can be a little tacky on the skin particularly when moulds are new.

We can provide KY jelly which helps moulds to slip into the ear canal more easily.

We can also provide Otoform Creme which can help when earmoulds are becoming a little loose due to growth. This helps manage any intermittent whistling (auditory feedback) from the aids while new moulds are being processed.

Customising your child's hearing aids

Hearing aids are available in a choice of colour, but once this is decided it is likely to remain the same for a couple of years until hearing aids are upgraded.

Earmoulds can be ordered in a range of colours, with glitter effect and sometimes with pictures embedded. Please ask your audiologist about the range available for your child's earmould type.

Stickers are provided in the care kit issued at the fitting appointment – your child can use these to decorate their hearing aids.

Some parents and children may want to investigate other ways to decorate and customise their hearing aids. The NDCS website provides some useful information on ideas and where to start looking.

www.ndcs.org.uk/information-and-support/childhood-deafness/hearing-aids/decorating-your-childs-hearing-aids-or-cochlear-implants

Tips on getting your child to wear hearing aids

- Hold the earmoulds in your hand for a couple of minutes before trying to put them in. This makes them warmer and less of a shock for your child. It also makes them softer and easier to put in and more comfortable. You can also try putting the hearing aids in before your baby or young child normally wakes up, so they are already in place. Never leave babies or young children alone with their hearing aids as they may put them in their mouths.
- Slowly build up the length of time that your child wears hearing aids. Depending on how your child is taking to the hearing aids, you could start with just a couple

of minutes several times a day. If your child keeps taking them out, stop trying and have a rest. Try again later or the next day when you are both feeling more relaxed.

- Try distracting your child with their favourite toy when you're putting the aids in or put them in while your child's concentrating on something else e.g. the TV.
- Try making the hearing aids part of your child's dressing and undressing routine. Put the hearing aids in when they get up and take them out at night.
- If you notice your child removing their hearing aids after loud noises or because their ears hurt, or if your baby blinks often when they are listening to sounds around them, check the settings on the aids and talk to your child's audiologist or Teacher of the Deaf.
- Your baby's aids may whistle when you feed them or when they are lying down. This is called auditory feedback, and it happens because the microphone on the aids is close to something solid. Arranging pillows behind your baby, holding them in a different position or temporarily turning their aids down while they are feeding can help.
- You could also encourage your child to wear one aid at first and slowly extending the time they wear it. When they wear it all day, introduce the other aid.
- Try to meet other families with a deaf child so that your child sees they are not the only one. It may also be useful to meet adults with hearing aids so that your child can see that people of all ages wear them.
- Books like *Freddie and the Fairy* and *Dachy's Deaf* are helpful. Further suggestions are available on the NDCS website:

<https://www.ndcs.org.uk/information-and-support/parenting-and-family-life/families-magazine/reviews/books/>

- You could use a sticker chart to record every time your child wears their hearing aids or cochlear implants and give them a special treat if they wear them for a week.

More information and support is available on the NDCS website:

Expectations on use of hearing aids

Your child's age at the time hearing aids are first fitted, the degree of his/her hearing loss, and the amount of amplification provided are all factors which will affect how your child responds to sounds when he first begins wearing hearing aids.

- When you first put hearing aids on, some young children become very still as they hear voices for the first time. They do not know what voice is or what it means, but if they see their parents smiling at them and moving their mouths as this sound is occurring, they may be reassured that they are safe!
- Some children begin crying as the hearing aids are placed, so the first sound they hear is their own cry (though they don't know that's what it is). Some children are startled by this noise and stop crying to listen!
- A baby up to the age of 5 - 6 months may startle to sounds or show surprise when a sound occurs by widening his eyes, starting to cry, stilling, ceasing crying or movement.
- A child older than six months may look up when a sound occurs then may look around. He has no idea what made the sound or what it means, but it is an unusual event for him if he is hearing for the first time. Be sure you show the child what is making the sound and repeat the sound. It is very important that the child start learning that sounds mean something, or he may stop responding to them.
- A child with a profound hearing loss may receive sound at very soft levels. He may not give much indication that he is hearing, since he has not yet learned to listen for these.
- For a child with a profound hearing loss, talk in normal tones within 6-12 inches of the child's hearing aids about things he is doing or seeing. Use a lot of intonation in your voice, play with animals, and vocalise the sounds they make. Use the gesture of pointing to your ear and then to his ear to indicate that he is hearing something however faint.

What if he cries or pulls the hearing aids out?

- Working through your child's resistance to having the hearing aids put on takes courage! You must be convinced that the benefits the child will get from wearing hearing aids will outweigh the child's discomfort to adjusting to something new. Your child does not yet know that the hearing aids will bring him sound. Talk and laugh with your child as you put the aids on – surely this can't be all bad if mum is smiling!
- The caregiver must be the one who makes the decisions about when the child's hearing aids are removed. When the child takes an aid off, calmly replace it and distract them with a toy or game. If it is close to the time when you would be removing his aids play with him for at least five minutes before doing so then tell him, 'Time to take your hearing aids off'.
- Remove the hearing aids without a lot of fanfare. Do not associate removal of the aids with expressions of relief or happiness.

The sooner you establish full-time use of hearing aids, the sooner your child will be able to rely on hearing as a way of getting information.

- A normally hearing baby listens for about 10 hours a day, 365 days a year. That adds up to 3,650 listening hours per year!
- A normally hearing toddler or preschooler listens about 12 hours per day 365 days per year. That adds up to 4,380 listening hours per year.
- If a toddler or preschooler only wears amplification at preschool (about 2.75 hours a day) it would take 9 years for the child to have as much listening experience as a hearing preschooler or a preschooler with hearing loss that wears amplification all waking hours (12 hours).

The day your child begins wearing hearing aids is the day you start helping him overcome some of the challenges created by hearing impairment.

Excerpts reprinted with permission from *For Families Guidebook (1997)*. Hearing & Speech Institute, Portland Or, and Talk Around the Clock, AG Bell Association for Deaf and Hard of Hearing (2003) (Reproducible materials for families.)