

**Meningitis
now**

Meningitis and childhood deafness

**A guide
for families**





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

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We use the term 'deaf' to refer to all types of hearing loss from mild to profound. This includes deafness in one ear or temporary hearing loss such as glue ear.

We use the term 'parent' to refer to all parents and carers of children.

1

Introduction

Deafness is one of the most common after-effects of bacterial meningitis. Approximately one in ten children who survive bacterial meningitis develop deafness as a result of the illness. Viral meningitis is not associated with deafness.

Meningitis can affect anyone, of any age. However, babies and children under five years are the group most at risk of contracting it, followed by young people aged 15 to 19.

This booklet has been written for parents of children who have had meningitis and has information on:

- › the hearing tests that are carried out following meningitis
- › the effects of any deafness
- › what can be done to help.

It also details the support that's available to you.

Meningitis can also cause a range of other physical, cognitive and psychological after-effects that can impact on a child's social and educational development. For more information, contact Meningitis Now's nurse-led helpline on **0808 80 10 388** or visit their website at **meningitisnow.org**.

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What is meningitis?

Meningitis is the inflammation of the membranes (meninges) that surround and protect the brain and spinal cord. It's usually caused by a bacterial or viral infection. Children with suspected meningitis will usually have tests in hospital to confirm the diagnosis and check whether it's a result of a viral or bacterial infection. Bacterial meningitis will usually be treated in hospital.



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Hearing tests

It's recommended that all children who have had confirmed or suspected bacterial meningitis or meningococcal septicaemia are offered a hearing test within four weeks of being well enough to have one, and preferably before they are discharged from hospital. It's not necessary for children who have had confirmed viral meningitis to be routinely referred for a hearing test. However, if you have any concerns, ask your paediatrician or GP for a referral.

Deafness usually happens early on in the course of the illness, and you may notice it before your child has the first hearing test. If the deafness is mild, it may not be as obvious, so it's important that children are tested early. Sometimes the deafness can get worse or change over time (fluctuate) in the early days, but it normally levels out (stabilises) during the first few months following the illness. You may then be offered several appointments to monitor their hearing, but if you have any concerns about your child's hearing or feel that their hearing has changed, you can always ask for another appointment.



Children can have their hearing tested from birth onwards. There are a variety of tests that can be used to find out how much hearing your child has – the tests used will depend on your child's age and stage of development. All babies in the UK are offered a routine hearing screen within weeks of birth. Babies who have had meningitis during the newborn period will not be offered the routine screen and will instead be referred directly to an audiologist for more detailed testing.

If your child does have a hearing loss, your local audiology and education services will provide support for you and your child (see page 27).



To find out more about the different hearing tests your child might have, and what will happen, read our booklet 'Understanding Your Child's Hearing Tests' at [ndcs.org.uk/hearingtests](https://www.ndcs.org.uk/hearingtests).





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Types and levels of deafness

Types

Sensorineural (or nerve) deafness is the type of deafness that can follow on from bacterial meningitis. Sensorineural deafness happens when there is damage to the inner ear (most often because the hair cells in the cochlea are not working properly) or the auditory (hearing) nerve that carries sound signals to the brain. Sensorineural deafness is permanent. Meningitis can cause sensorineural deafness in a number of ways. The most common cause is the infection spreading into the cochlea, damaging the hair cells. Another possible cause is inflammation of the auditory nerve. Deafness can range from mild through to profound and can affect one or both ears. See the next page to find out more about what these levels of deafness mean.

Conductive deafness happens when sound cannot pass efficiently through the outer and middle ear to the cochlea and auditory nerve. The most common reason for conductive deafness in children is glue ear. Glue ear is a build-up of fluid in the middle ear that makes it harder for sound to pass through to the inner ear. Glue ear is usually temporary and often clears up on its own without needing any treatment. However, for some children glue ear may persist longer term. Although meningitis doesn't cause glue ear, glue ear is so common during childhood that it's possible your child may have a bout of it at some point, causing fluctuations in their hearing, and it may even be present when their hearing is first tested following their illness.



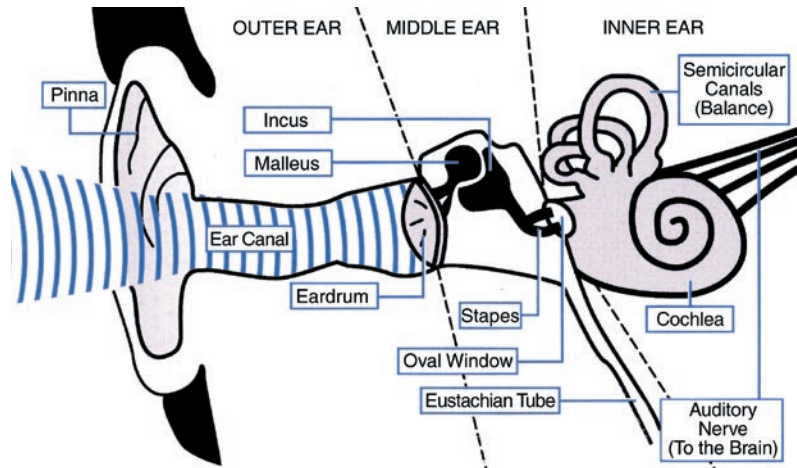
For more information about glue ear and the treatments available, read our booklet 'Glue Ear: A guide for parents' or visit ndcs.org.uk/glueear.

Levels

There are different levels of deafness, described as mild, moderate, severe or profound, and deafness can affect both ears (bilateral deafness) or one ear (unilateral deafness). Your audiologist will take you through the results of your child's hearing tests and talk to you about the sounds your child can and can't hear. As deafness can vary hugely, your child's level of hearing loss will determine what support they need.

Some of your child's test results will be written on a chart, known as an audiogram. It shows you how loud a sound has to be, and at what frequency, before your child can hear it.

If you're unsure about any of the information you've been given, you can go back and ask the audiologist to explain. Take a list of questions with you to your audiology appointments and make sure you fully understand the answers they give. Ask for copies of test results and reports for your records.



“We had to take it a day at a time to begin with, and we face new challenges all the time.”



For more information on understanding your child's hearing tests, including how to read audiograms and which questions to ask your audiologist, visit [ndcs.org.uk/hearingtests](https://www.ndcs.org.uk/hearingtests).

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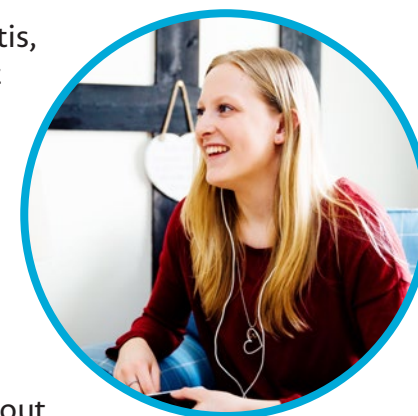
How will deafness affect my child?

The ways that your child will cope with their deafness will vary greatly. The issues for a young baby will be very different from those of a teenager. If you have a good understanding of your child's deafness, it will help you when you are explaining it to them (if they're old enough) or to other people involved with your child. If you have a baby or young child, your most important consideration may be finding a way of communicating with them and developing their language. You may need to make decisions about hearing aids, implants, or support at nursery or school. Make sure you have access to the full range of information so that you can make the choices that are right for you and your family. Your local education and audiology services can help you to find the information that you need.



You may also find that your child's behaviour has changed. Their attention span may be shorter, or they may have temper tantrums or become more clingy. This may be as a result of any deafness and frustration caused by difficulties communicating or may be related to having been through a serious illness. Other children in your family may also become unsettled if your child is getting a lot of the family's time and attention. This can present new challenges for you.

A serious illness, such as meningitis, can have a deep emotional effect on any child. For an older child or teenager, this may mean that they need extra help to find new ways of communicating with you, and that they take a long time to accept their deafness. They'll need time to understand how their deafness will affect their life, and to talk about how they're feeling. Your child's school or college should be able to tell you about the extra support they can provide when your child returns to education.



For access to professional support services and specialist information about the after-effects of meningitis, phone Meningitis Now's nurse-led helpline on **0808 80 10 388**.

For more information and support about all aspects of childhood deafness and the choices you have, contact the National Deaf Children's Society's Freephone Helpline on **0808 800 8880** (voice and text), or by emailing helpline@ndcs.org.uk.

“I didn’t have any idea of the options out there, so I almost went through a grieving process – grieving for what my little girl had lost.”

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How will I communicate with my child?

Learning and wanting to communicate is something that occurs naturally in all children. Being deaf might make this more challenging but, with the right support, commitment and encouragement from families and professionals, deaf children can learn to communicate as well as other children.

With the use of hearing aids, implants and other specialist equipment, most deaf children now use their hearing to listen and learn one or more spoken languages. Many deaf children also:

- › use some sign language in addition to spoken language
- › use sign language as their first language and main way of communicating and learning
- › use a mixture of methods.

If your child is a baby, you’ll also be communicating by using your face, voice and body to show love and let your child know that you’re there. If they’d already started to develop language before having meningitis, you’ll need to get information on the best way to help your child to continue with this. You may also need to think about the support available locally, the way that your family communicates at the moment, and whether the communication method you choose is suitable for your child’s abilities or health.

Remember, you don’t have to make a choice for life. You may want to change your approach as you learn more about your child’s needs and preferences. If you have an older child, quickly finding a way of communicating with them is vital for their emotional wellbeing and confidence.



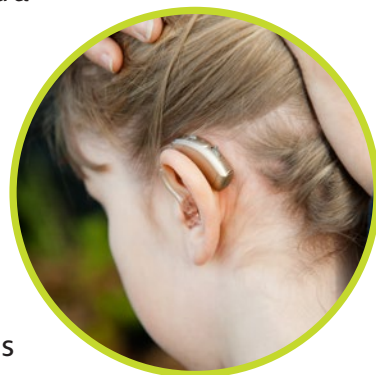
Find out about different ways to communicate at [ndcs.org.uk/communication](https://www.ndcs.org.uk/communication).

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Hearing aids and cochlear implants

Hearing aids are useful for children with most levels of hearing loss. The type of hearing aid that will be suitable for your child will depend on the type of hearing loss they have. Hearing aids can help your child to make sense of speech and a wide range of sounds.

Children who have a severe to profound deafness and can't hear the full range of speech sounds with hearing aids may be suitable for cochlear implants. A cochlear implant is different from a hearing aid. It gives a sensation of hearing by directly stimulating the auditory nerves using electrical signals. The implant has two parts – a receiver which is implanted surgically, and an outside part which is worn like a hearing aid.



The decision to have a cochlear implant is an important one, and it's important that you and your child have enough information to make a decision about the best option. However, following meningitis, your child should be referred to a cochlear implant centre as quickly as possible if your audiologist believes they may benefit from a cochlear implant. This is because of the risk of ossification (see page 18). The team at the cochlear implant centre will help you decide if a cochlear implant is an option and will provide you with all the information you need to make an informed decision. It's important to understand that a referral to a cochlear implant centre doesn't mean your child has to get a cochlear implant.



For more information on hearing aids and cochlear implants read the National Deaf Children's Society's booklets 'Hearing Aids: Information for families' and 'Cochlear Implants: Information for families'.

“At first when I was told I was deaf, I didn't want to accept it, but over time I got used to it and it's just become normal now really. Being deaf is nothing to be scared or ashamed about.”

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Ossification

A possible after-effect of meningitis is ossification (an increase of bone growth in the cochlea). This can occur in the weeks and months following infection. If you're considering a cochlear implant for your child, ossification can make it more difficult to have the electrodes of the receiver package surgically inserted. However, it rarely prevents it, and you should discuss this with the specialist involved. A CT or MRI scan will be carried out to assess the amount of any ossification. The extent of any ossification may impact on how much benefit children receive from their cochlear implants. Therefore, children who have had meningitis that has caused a severe to profound deafness should be offered a 'fast-track' assessment for cochlear implants. Following assessment and the decision that they are suitable candidates, children are usually offered bilateral cochlear implants (one in each ear).



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Balance

The brain uses information from the eyes (what we see), our body (what we feel) and the inner ear to maintain our balance. The vestibular (balance) organs in the inner ear are made up of semi-circular canals (three fluid-filled tubes and movement-sensitive hair cells) and the otolith organs. As we move, this causes the fluid to move over the tiny hair cells, and this creates signals that are sent to the brain about our position and movements.

As well as deafness, meningitis can also cause issues with balance if the infection affects the vestibular organs in the ear. Children may experience a feeling of dizziness and/or imbalance. In younger children, poor balance system function can make it difficult for them to learn to do tasks that need good balance, such as sitting and walking. However, the brain is often able to make up for a weak vestibular system, and children often develop ways of managing any imbalance on a day-to-day basis.

Sometimes, poor balance function can result in longer term balance difficulties, and balance function assessment, safety advice and specialised physiotherapy may be helpful for children with vestibular dysfunction.



For further information on the balance system, testing and disorders, visit [ndcs.org.uk/balance](https://www.ndcs.org.uk/balance).



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Tinnitus

Tinnitus may also be an after-effect of meningitis. Tinnitus means any sound that's heard in the ears or head that hasn't come from an external source. These sounds might be described as ringing or buzzing for example. Most people have experienced tinnitus at some time, for example noticing a ringing in the ears following a live music concert or night out at a club. However, a much smaller number are worried or bothered by their tinnitus. Both hearing and deaf children can have tinnitus.

If your child is showing signs of having tinnitus after recovering from meningitis, talk to your GP, audiologist, AV physician or ear, nose and throat (ENT) doctor.



For more information on hearing loss and tinnitus, download the factsheet produced by Meningitis Now and Meningitis Research Foundation: meningitisnow.org/how-we-help/resources/view-download-order/fact-sheets.



“I’m proud of being deaf. We had a day at school to help the other children understand what it’s like. Sometimes being deaf is hard, but I can still do anything.”

11 Pneumococcal vaccination

If your child is assessed as a suitable candidate for a cochlear implant, you will be advised that your child should have a pneumococcal vaccine before surgery. This is because implanting the electrode in the cochlea might slightly increase your child's risk of developing pneumococcal meningitis. This risk is very small. It is advised that the pneumococcal vaccine is given to all existing and prospective cochlear implant recipients, including those who have previously suffered from pneumococcal meningitis or a pneumococcal infection. The vaccine is usually given by your GP.



12 How technology can help

Technology, such as hearing aids and implants, allows most deaf children to hear sound close to typical hearing levels, however, it cannot replace normal hearing. There are also many different technology options and adaptations available to make listening as easy as possible for your child. They include:

- › voice-to-text software for computers
- › subtitles on television, DVDs and in cinemas and theatres
- › notetakers and communication support workers in school
- › radio aids
- › textphones that give access to phone calls.



There are lots of equipment available which can help your child to be aware of what's happening around them and help them to be independent. Doorbells, alarm clocks and phones can all be connected to a flashing light to alert your child; alternatively your child could use a personal paging system which connects to all these items. Personal paging systems can be used by more than one person in a household.

Telephones are one of the main ways we keep in touch with friends and family, contact others or get help in an emergency. If you have a conventional home phone with no special features, you could adapt it by using an amplified phone (a phone with a built-in amplifier to increase the volume) or a textphone.

Watching TV and enjoying music is a big part of growing up and helps children develop social and communication skills. If your child uses a hearing aid or a cochlear implant, using a TV listening product or subtitles can make watching TV together a more enjoyable experience for the whole family. Music players (including portable music players such as mp3 players), DVD players, gaming devices, tablets, and laptops can be connected to products that can help deaf children to hear them better.



For more information on technology and products for deaf children read the National Deaf Children's Society's booklet 'How Technology Can Help'.

Radio aids

Modern hearing aids and cochlear implants allow most wearers to hear quiet speech in ideal listening situations. However, most speech is heard in less than ideal listening situations, and there are times when your child may find it difficult to hear and listen.

Situations when it is difficult to listen are when:

- › there is unwanted background noise
- › sounds are echoing around the room (reverberation)
- › there is a distance between the person who is speaking and the deaf child.

Radio aids can help overcome these problems. They are used widely in schools and other education settings to help deaf children hear their teachers and other students better, although they can be useful in many other situations too. A radio aid consists of a transmitter, worn by the speaker (a teacher for example), and a receiver, worn by your child. The radio aid works by making the sound the child needs to hear, such as the teacher's voice, clearer in relation to unwanted background noises regardless of where they are in the room.



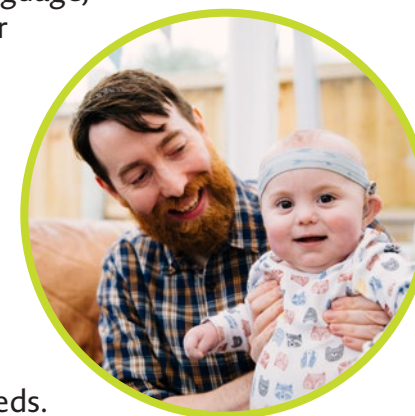
For further information, please read the National Deaf Children's Society's booklet 'How Radio Aids Can Help'.

“It was very unlucky that she was so ill, but we’ve been incredibly lucky afterwards to receive such great support.”

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What support is out there for us?

You’ll know your child better than any professional who works with you, but once permanent deafness has been diagnosed, your child should be referred to the education authority’s specialist hearing impairment service and receive support from a Teacher of the Deaf. They will visit you to support you with using hearing equipment, help you with communicating with your child and developing their language, give information on the options for early years or school placement, and will be responsible for making sure your child has the support they need to help them make friends, hear what is going on, and learn and progress. You will also be referred to a speech and language therapist if this is needed. How often they visit will depend on you and your child’s needs.



In addition to hearing loss, the after-effects of meningitis can be complex, affecting children both physically and mentally. Evidence from a study commissioned by Meningitis Trust (now known as Meningitis Now) shows that children who have had meningitis are more likely to have a low IQ and difficulties with memory, organisation and planning. They are also significantly more likely to have anxiety and behavioural disorders. These after-effects can have a huge impact on children’s education, but aren’t always recognised as complications of the disease.

For more information contact the Meningitis Now’s nurse-led helpline on **0808 80 10 388**.

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Our information and support

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

The right information, at the right time

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

Helping you make informed choices

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

Support when you need it

Any questions? We're here to help.

Freephone Helpline: **0808 800 8880**

helpline@ndcs.org.uk

[ndcs.org.uk/livechat](https://www.ndcs.org.uk/livechat)



About Meningitis Now

Meningitis Now saves lives and rebuilds futures by funding research, raising awareness and providing support for people whose lives have been changed by meningitis.

Meningitis Now's nurse-led helpline is available in over 240 languages through Language Line and can also be accessed by text relay service – call **18001 0808 80 10 388**

helpline@meningitisnow.org

[meningitisnow.org](https://www.meningitisnow.org)





About us

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

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

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

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

Freephone Helpline:

0808 800 8880 (voice and text)

helpline@ndcs.org.uk

ndcs.org.uk

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For resource references or to give us your feedback
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