

# Hearing

June 2024

## Health series



## Our Information Team and resources are here to help



Please see our website for up-to-date information:

[downs-syndrome.org.uk](https://downs-syndrome.org.uk)

If you have any questions, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on [info@downs-syndrome.org.uk](mailto:info@downs-syndrome.org.uk).

**Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300**

## Key Points

- Hearing impairment is common in adults and children who have Down's syndrome.
- People who have Down's syndrome of all ages must have regular hearing tests.
- Children and adults can, and do, effectively use hearing aids.

**The majority of people who have Down's syndrome will experience hearing impairment at some point in their lives.**

This may be temporary hearing impairment or permanent life-long hearing impairment. There are a number of reasons for the high rate of hearing impairment in people who have Down's syndrome including a weaker than average immune system, differences in the structure of the face and ear, and increased incidence of chronic ear disease.

Hearing impairment should always be considered as a potential cause or aggravating factor where a person has behaviour changes, poor mental health and/or a loss of cognitive skills.

## Why is hearing important?

Hearing plays a vital part in every child's development. If undiagnosed or untreated, hearing impairment can impact on language development, learning, social skills and behaviour.



Early episodes of severe ongoing hearing impairment have a more serious impact on the development of speech and language for children who have Down's syndrome than for typical children.

*Best practice guidance for the management of hearing issues in Down syndrome* from the UK and Ireland Down Syndrome Medical Interest Group (DSMIG) contains the following recommendation:

*'A multidisciplinary team approach should be applied for the management of hearing issues in the child with Down syndrome. This should include a paediatric audiologist, otolaryngologist and paediatrician, with strong links to speech and language therapists and teachers for the deaf. Correspondence should be routinely shared with the parents/carers and, with parents' consent, with all members of the team.'*

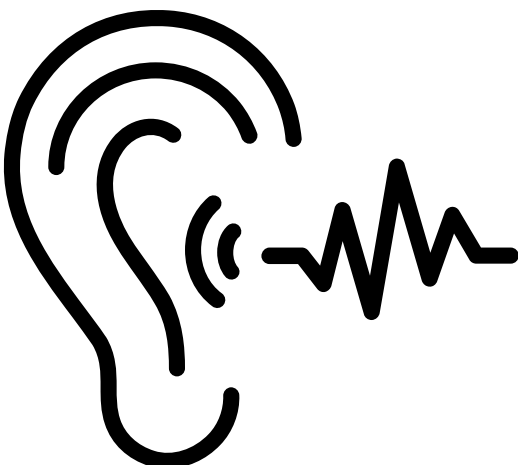
**NB:** An otolaryngologist is an ENT specialist

### **Siobhan Brennan (Audiological Scientist) writes:**

***"The impact sound can have on each person is incredibly diverse. An unexpected door slam can scare us. Music can reduce us to tears. Even the sound of crisps when we eat them can make them taste better! Our relationship with the wide range of sounds around us is utterly personal, goes far beyond listening to speech and can significantly influence our mental health. When hearing is impaired, the impact that it has on each person will be different....."***

***.....A major advantage of communication is the enjoyment of the company of others and there is so much more to speech than the words that are being said. Words convey more than facts or information; they are used to share emotions. We can get so much pleasure and comfort from the sound of another person's voice, particularly those who are close to us. If a hearing loss is not managed effectively, the hearing loss can cause challenges in meeting a person's needs, because it will affect their quality of life and can prompt behaviour that challenges."***

## **How does the ear work?**



If our ears are working well, they capture sound waves and convert them into messages that our brains can understand. The ear has three main parts: outer, middle and inner; and it is made up of bones, hairs, cells and nerves. Each part of the ear needs to be in working order for us to hear well. The ear flaps or pinnae (the visible part that we normally think of as ears) gather sound waves and send them to the ear canal. The ear canal connects the outer ear flap with the inner ear. Sound travels down the ear canal to the ear drum and makes it vibrate. The vibrations move a tiny chain of bones in the middle ear.

The bones transmit the vibrations to the inner ear (cochlea). The inner ear is filled with liquid and lined with cells that have tiny hairs on top (hair cells). The liquid carries the vibrations to thousands of hair cells. The hair cells carry a message to the auditory nerve that is connected to the brain and the brain interprets the sounds we're hearing.



## Signs that a person may have hearing impairment

Although the behaviours listed here may be due to a person's learning disability or personality, they may also indicate the person has a hearing impairment. If you have any concerns about your child's hearing or about the hearing of someone you support, the GP can make a referral to the local audiology service.

- Difficulties with balance.
- Poking and rubbing ears frequently.
- Lack of response when their name is called.
- Discharge from ears and/or ears that have a bad smell.
- Looks at faces intently.
- May appear to hear some voices better than others because they are pitched differently.
- Finds it hard to follow a conversation in a group.
- Background noise makes it harder for the person to hear conversation.
- Jumps if someone whom they haven't seen or heard comes up to them from behind.
- Sits close to a TV or other screen and turns their head.
- Mouth breathes and has a stuffy blocked nose a lot of the time.
- Difficulty modulating the volume at which they speak (e.g. very quietly or very loudly).
- Loss of independence.
- Low mood.
- Decline in cognitive ability.
- Social withdrawal.
- Frustration.
- Reduced communication.
- Delayed speech and language development.



## Types of hearing impairment

### Conductive hearing loss



This is usually a temporary hearing difficulty where sounds cannot pass freely into the inner ear and it is by far the most common form of hearing impairment in children who have Down's syndrome. The cause of this temporary hearing impairment is usually glue ear (the medical term for glue ear is Otitis Media with Effusion or 'OME' for short). Glue ear is a condition where there is a build-up of non-infected fluid (glue) in the middle ear and the Eustachian tube which prevents the ear drum from vibrating properly. The Eustachian tube connects the back of the throat to the middle ear. Its function is to keep the middle ear filled with air to enable the ear drum to move freely and to drain secretions effectively. It is not clear what causes the build-up of fluid although it appears to be related to an issue with the Eustachian tube.

The ability to hear in children with glue ear may fluctuate from day to day or it may be impaired all of the time. There may be a few children who are still hearing normally or who experience only mild hearing impairment. Studies show that as many as 35 per cent of children who have Down's syndrome have glue ear at birth; by the age of one this rises to 93 per cent and by the age of five years it has dropped to 68 per cent. The condition seems to be more persistent in children who have Down's syndrome and the glue formed is usually thicker than is seen in other children. Glue ear can also occur in adults.

Children who have significant laryngopharyngeal reflux may be more likely to develop glue ear. Reflux is the regurgitation of acid stomach contents back into the gullet (oesophagus) and even up to the back of the throat. In some cases, the stomach contents can flow up the Eustachian tube causing a blockage. In some people reflux causes heartburn and indigestion, but when it does not, it is called laryngopharyngeal reflux or silent reflux.

National Institute for Health and Care Excellence (NICE) have a guideline '*Otitis media with effusion in under 12s*' (published 30th August 2023) in which it is recognised that glue ear is particularly common in children who have Down's syndrome.

It covers identifying and managing glue ear in children younger than 12 years. Whilst this NICE guideline may be useful for families and carers, please bear in mind that it is primarily written for healthcare professionals and the terminology used reflects this.

The guideline is free to download here: [Overview](#) | [Otitis media with effusion in under 12s](#) | [Guidance](#) | [NICE](#)

Hearing aids or the insertion of ventilation tubes (grommets) are the two main treatment options for glue ear. Treatment will depend on the individual child and the degree of deafness caused by the glue ear.

DSMIG *Best practice guidance for the management of hearing issues in Down syndrome* suggests that:

*'Each child's case should be considered on its own merits by a multidisciplinary team with experience in dealing with glue ear in children who have Down syndrome. If your child has recurring glue ear and/or middle ear infections, adenoidectomy may be considered as a treatment. This operation may also be considered if your child has chronic nasal obstruction and obstructive sleep apnoea. Adenoidectomy is a surgical procedure performed to remove the adenoids. Adenoids are a mass of lymphoid tissue located behind the nasal passages.'*



## **Ventilation tubes (Grommets)**

A ventilation tube (grommet), made of plastic or metal is inserted by the Ear, Nose and Throat (ENT) surgeon into a tiny cut in the eardrum to keep it open for a while. This operation is done whilst the patient is under general anaesthetic. On average, a grommet remains in the ear for between six to eight months until the eardrum begins to heal over and it is pushed out. Sometimes the ventilation tube will be taken out at the ENT clinic. The purpose of the tube is to maintain air pressure in the ear, which prevents further fluid building up, and it aids the draining away of existing fluid. Smaller ventilation tubes may have to be used because children who have Down's syndrome often have narrower ear canals. Smaller tubes are more likely to work their way out of the ear earlier than larger ones. The audiologist and ENT clinic should check your child's hearing and ventilation tube at some point between three and six months after the operation.

Your child may find that noises sound much louder than they are used to for a few days after the operation. It may be difficult or impossible to insert a ventilation tube in some young children who have Down's syndrome because their ear canal is too narrow for it to fit.

For some children who have Down's syndrome the benefits of this procedure will be short lived. They will go on to have further episodes of glue ear and some will need further ventilation tube insertions. Repeated insertion of tubes increases the risk for complications such as infection and permanent perforation of the ear drum. The treatment options in each child's case should be considered on their merits by the child's multidisciplinary team and parents.

Many adults will have had glue ear when they were children which may have required treatment with ventilation tubes. In most people issues associated with glue ear will have disappeared when they reach teenage years. However, a small number of adults will have a perforation of (a hole in) the ear drum. They may cause little problem apart from mild to moderate hearing impairment. However, the perforations may become infected resulting in occasional or frequent discharge from the ear. Your GP should examine the ear for perforations as part of the Annual Health Check. Discharge indicates that the ear is infected. The GP may take a culture swab before treatment of the infection begins. Your GP may prescribe antibiotic ear drops and/or oral antibiotics once results of the culture swab are known. If the discharge has not settled after two weeks of treatment, a referral to the local ENT clinic should be made.

## **Sensorineural hearing loss**

This is a permanent hearing impairment that happens where there is damage in the inner ear. The hearing nerve can sometimes also be affected. Studies show that approximately six per cent of babies born who have Down's syndrome have sensorineural hearing loss. This increases to approximately 20 per cent in adolescence and early adulthood.

Children and adults with sensorineural hearing loss should be actively encouraged to use hearing aids. Some children who have Down's syndrome and severe to profound sensorineural hearing loss have had cochlear implants fitted successfully.

## **Presbycusis (age-related sensorineural hearing loss)**

This is common in adults who have Down's syndrome. This type of high frequency hearing impairment may start in early adulthood. High frequency hearing impairment often means that the person is less able to distinguish different sounds. The person may be able to hear sounds but may not be able to discern what is being said. Noisy environments may make high frequency hearing more difficult for the person.

It is possible to have both [conductive](#) and [sensorineural](#) hearing loss.





## Other things that can affect hearing

### Hyperacusis

Some people who have Down's syndrome can be particularly sensitive to everyday sounds; this is known as hyperacusis. It may cause distress for a person in certain situations, particularly where there is a lot of background noise.

### Ear Wax

In children and adults conductive hearing loss can also occur as a result of a build-up of ear wax or an ear infection. Children and adults who have Down's syndrome should have regular dewaxing (seek GP's advice about this).

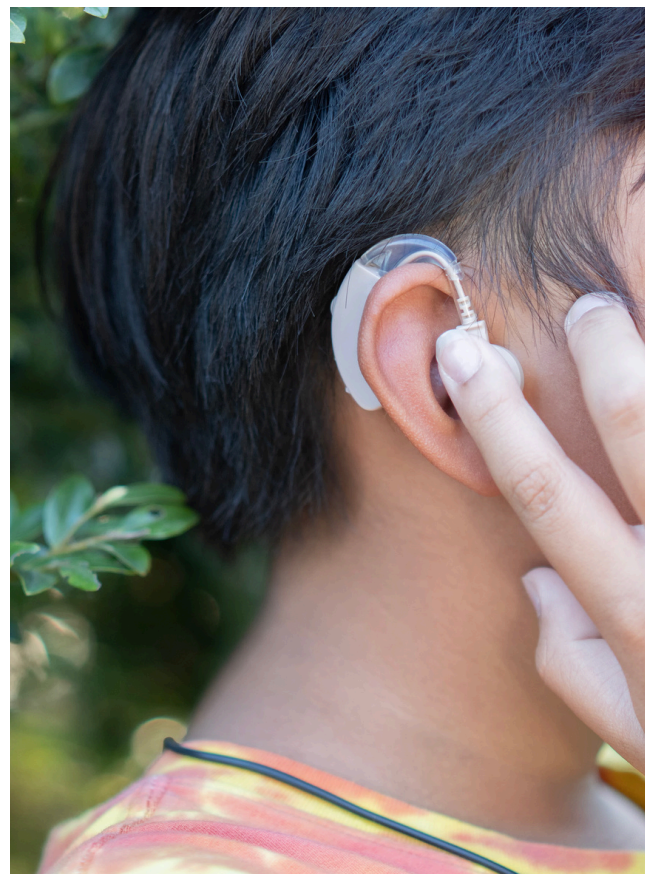
### Cholesteatoma

A Cholesteatoma is a cyst or sack which forms behind the eardrum and grows in to the middle ear. Cholesteatoma usually only occurs in one ear. If left untreated it can permanently damage the ear and result in hearing impairment. The two most common symptoms are hearing impairment and persistent smelly discharge from the ear. If, after examining your ear with an otoscope, your GP suspects you have Cholesteatoma, they will refer you to the local ENT clinic.

### Hearing Assessment

It is vital that children and adults who have Down's syndrome have regular hearing assessments.

- All babies under 3 months of age should be offered universal new born hearing screening
- Between the age of 8 months and 1 year of age all children who have Down's syndrome should be offered a hearing assessment
- A child should be offered a hearing assessment once or twice a year until the age of 6.
- A hearing assessment should be included in the school entry health check.
- A hearing assessment should be offered every 2 years from the age of 6, or more frequently if required.
- From the age of 35 an annual hearing assessment should be offered.





***Audiology is an exciting profession, with fantastic technology and assessment techniques. The problem is, most people don't know about this. Most people are shocked when I tell them that I routinely carry out hearing tests on people whilst they are asleep. It is perhaps surprising, but it is possible.***

***Those who have had experiences of Audiology often describe the hearing tests they have had; sitting in a small soundproof room in silence, wearing a pair of headphones and pressing a response button every time they hear a sound. Yes, this is the most common way of testing hearing, but it is by no means the only way. The problem is, many people do think this is the only way and if a person is not able to do this, then they cannot have their hearing tested.***

***Unfortunately, it is something my colleagues and I hear all too often; 'You wouldn't be able to test their hearing, they have learning disabilities.***

***The fact is, many people with learning disabilities can complete a routine hearing test successfully with no adjustments whatsoever. And for those that can't, we must make reasonable adjustments. Most of the time, these adjustments are small and easy to make, and it is our responsibility to do this.'* - Dr Lynzee McShea Senior Clinical Scientist Audiology**

## **Hearing Assessments For Children**

Hearing assessments should be carried out by a paediatric audiologist with experience of evaluating the hearing of children who have Down's syndrome. As there is a higher incidence of sensorineural hearing loss in people who have Down's syndrome as well as conductive hearing loss, the frequency range tested should include 8000Hz whenever feasible, as this may be an early indication of impending sensorineural deafness.

When you are booking an appointment for your child's hearing assessment, think about the timing of the assessment. If your child is at their best in the morning, request an early morning appointment. Remind them that your child has Down's syndrome so consideration can be given to whether extra time will be needed for the assessment to take place.

The hearing assessment tools used should be appropriate to a child's developmental stage rather than their age. For example, a two to three-year-old child who has Down's syndrome might be assessed using a hearing test normally used for an 18-month old baby. There are two types of tests that can be carried out to learn more about your child's hearing; objective tests and behavioural tests.

Usually several tests will need to be carried out over time to enable the audiologist to get a complete understanding of your child's hearing. Children should have regular objective hearing tests until they are developmentally able to respond to behavioural hearing tests.

Behavioural hearing tests require children to make a response when they hear a sound, such as by looking toward the source of the sound, dropping a building brick in a bucket, raising their hand, or pressing a button.

There are a number of different ways to test hearing. These are the hearing tests that are mainly used for children:



## Objective Tests

### Otoacoustic Emissions (OAE)

A computer attached to a small earpiece plays quiet clicking noises and measures the response from the inner ear. This test identifies babies born with [sensorineural hearing loss](#). It can sometimes wrongly identify a small number of babies who do not have a hearing impairment. There are a number of factors which may make it difficult to record the inner ear's response. The person carrying out the test can explain the results of the test to you and any next steps that need to be taken.

### Auditory Brainstem Response (ABR)

Sensors are placed on the child's head and neck to check the response of their nerves to sound played through headphones. These tests are usually performed under sleep sedation or general anaesthesia.

## Behavioural Tests

### Play audiometry

This test involves a listening game that uses toys to maintain the child's attention and focus to the listening task. For example, the child holds a block, waits and listens for the sound. When the child hears the sound, they drop the block in a bucket. This 'listening game' is demonstrated to the child by the audiologist, and once the child understands the game testing is underway.

There are some hearing tests, such as pure tone audiometry, speech perception and tympanometry that can be used to test adults and well as children.

## Hearing Assessments For Adults

There is information about hearing assessments, reasonable adjustments and supporting adults to have a hearing assessment at our website here: [Health and Wellbeing - Downs Syndrome Association](#). Anyone with sudden unexplained hearing impairment should be referred for an audiological assessment. If an older adult is displaying signs of confusion or changes in behaviour, it is always a good idea to check for an underlying medical cause such as hearing impairment. We have come across a few cases over the years where too much ear wax, which affects the person's ability to hear, has been misinterpreted as Alzheimer's disease or other forms of dementia.

It is important for those around an older teenager or adult (e.g. family, friends and professionals) to communicate and share information about hearing loss in those for whom they care (with the person's consent if over the age of 16 years). It is also important to make sure the person is fully involved in discussion and decision making about any intervention/treatment. There is information about making everyday decisions post 16 at our website here: [Children, Families & Education - Downs Syndrome Association](#).

Please note that questions about hearing should be included in the learning disability annual health check with the GP (from 14+ years).

There are various ways to test an adult's hearing. Here are some of the more common tests:

### **Pure-tone audiometry**

A machine generates sounds at different volumes and frequencies. The sound is played via headphones or speakers. By changing the level of the sound, the audiologist can work out the quietest sound a person can hear.

### **Bone conduction**

The behavioural tests described so far use air conduction; sounds passing into the ear and middle ear before reaching the inner ear (cochlea). The same tests can also be carried out using bone conduction. A small vibrating device placed behind the ear passes sound straight to the inner ear through the bones in the head. This can help the audiologist identify which part of the ear isn't working properly; whether hearing loss is sensorineural or conductive.

### **Speech perception test**

This test assesses a person's ability to recognise words at different volumes without visual clues. The person may be asked to copy words spoken by the audiologist or from a recording. From this the audiologist can work out the quietest level at which the person can recognise the words used during the test. Sometimes background noise is introduced during the test.

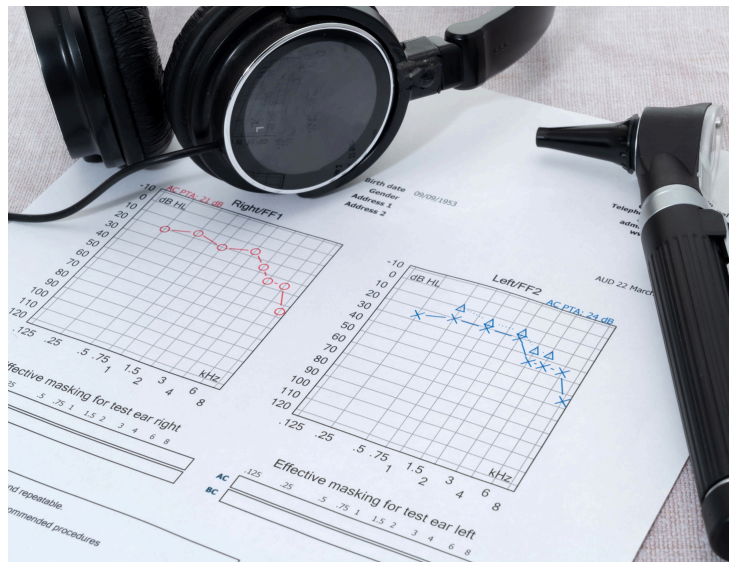


## Middle ear test - Tympanometry

For good hearing the eardrum needs to be flexible to enable sound to pass through it. Tympanometry is a test to assess how flexible the eardrum is. If the eardrum is too rigid, as is the case when there is fluid behind it as a result of glue ear, sound will bounce back instead of passing through the eardrum. A small rubber tube is placed at the entrance to the person's ear through which air and sound pass. If the eardrum is not moving freely this indicates the presence of fluid (glue ear) or another problem with the middle ear. Tympanometry should be carried out every time a person who has Down's syndrome has a hearing assessment.

## Audiogram

The results from a hearing test are written on a chart known as an audiogram. The audiologist will explain what the test results mean. It is a good idea to ask for a copy of the audiogram for your own records.



## Hearing Aids

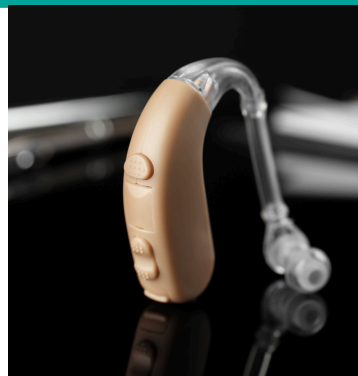
Hearing aids can be very effectively used by children and adults who have Down's syndrome.

Digital hearing aids are available as standard, for free, from the NHS. These hearing aids are programmed according to hearing impairment of each individual – it is therefore essential that an accurate hearing level is obtained before the hearing aid can be fitted. This may involve more than one visit to the audiology department. There are different types of digital hearing aid but they all work the same way to make sounds louder and clearer. The audiologist will tell you which hearing aid will manage your hearing loss successfully. A perforation in the ear may affect the type of hearing aid provided.



## Remember, hearing aids are only useful if:

- They make the right sound louder.
- They fit and work properly.
- They are worn regularly.
- There is something interesting to listen to.



## Main types of hearing aid

### Behind the ear (BTE) hearing aids

This is the most common type of hearing aid provided by the NHS. BTE hearing aids rest behind your ear and send sound into your ear. There are different versions of this hearing aid with each one getting the sound to your ear in a slightly different way.

### In the ear (ITE) hearing aids and in the canal (ITC) hearing aids

ITE and ITC hearing aids have their working parts in the ear mould so the whole aid fits inside your ear.

### Completely in the canal (CIC) hearing aids

Completely in the canal (CIC) hearing aids fit further into your ear canal than ITC aids; they are available at a wide range of NHS sites (although not all).

### Invisible in the canal (IIC) hearing aids

IIC hearing aids are quite new and available to buy privately. They are fitted very deeply in the ear canal.

### CROS/BiCROS hearing aids

These are for people with hearing in one ear only. Wireless versions are available from the NHS.

### Bone-conduction and bone anchored hearing aids (BAHA)

A bone conduction hearing aid delivers sound to the inner ear through the bone rather than through the middle ear via a vibrating pad (bone conductor). They can be worn on a soft headband with the bone conductor placed just behind the ear or it can be attached to glasses. This hearing aid may be suitable for those with conductive hearing loss who cannot tolerate or are unable to wear a behind-the ear hearing aid.

A BAHA may be suitable for those with permanent conductive hearing loss who have had a positive experience with a bone conduction hearing aid. A port (also known as an abutment) is attached to the skull during minor surgery. The sound processor can then be clipped on to the port. Once in place the processor is directly connected to the skull bone and thus also connected to the inner ear. This means sound can be transmitted more directly to the inner ear. The processor can be unclipped as and when you need to (e.g. when you have a shower or go swimming).

You can't always choose the type of hearing aid you get from the NHS. But you will be given digital hearing aids that fit comfortably and suit your particular hearing impairment. Your audiologist will programme your hearing aids to meet your hearing needs.

## **Rechargeable Hearing Aids**

An increasing number of NHS sites are now offering rechargeable hearing aids

## **Supporting children to wear a hearing aid**

Some children need support to get used to wearing a hearing aid. They may need ongoing help to realise that a hearing aid is helpful. A specialist teacher of the deaf can help children accept and learn to use their hearing aids.

An audiologist or hearing therapist can provide advice about supporting the person to get used to the hearing aid before and after the fitting. A hearing therapist can also advise family members about ways to adapt their verbal and non-verbal communication in order to support good communication with a person with hearing impairment.

Hearing implant centres (specialist NHS services) assess, fit and provide long-term support for implantable hearing equipment, such as cochlear implants, middle ear implants and bone-anchored hearing aids.





## **Making the most out of behind-the-ear hearing aids:**

- Relax – if you are relaxed, your child will be more relaxed.
- Warm the ear mould in your hands before trying to insert them.
- Try to make putting the hearing aids in part of a dressing routine.
- At first try to relate the hearing aid fitting with something positive e.g. play time, especially using ‘noise making’ toys.
- Praise good behaviour and play singing games.
- When inserting the ear moulds try to get your child to occupy their hands with a toy (or food).
- Leave the hearing aids in for as long as possible and try to build on this time each day until the ultimate goal of all day use is achieved.
- Observe your child’s response to sounds – especially loud sounds. If loud sounds upset your child make an appointment back at the audiology department and explain your observations.
- If your child is old enough let him/her choose the hearing aid and ear mould colour.
- Don’t worry if you cannot insert the ear mould correctly every time. Just try later.
- Don’t look for response immediately to sounds, let your child learn to hear and enjoy the listening experience.
- Toupee tape, double-sided adhesive discs and hair bands can all help to keep hearing aids in place.

If your child experiences feedback (whistling) try:

- Turning volume down slightly but remember not all hearing aids have a volume control. If feedback is a persistent problem, ask your audiologist for a hearing aid with a volume control.
- Make sure the ear mould is fitting well – there shouldn’t be any gaps.
- Check the tube is not split, damaged or discoloured.
- Book an appointment to see your audiologist to check the ear canals for a build-up of wax. The audiologist or ENT doctors may try to remove the wax.

If there is no sound from the aid – check the battery.

## **Making the most out of a BAHA worn on a soft band**

To obtain maximum benefit from this hearing aid, the band should be tight to apply a slight pressure to the hearing aid, but not so tight that it leaves marks on the head.

Try putting the hearing aid on when brushing your child’s hair.

Leave the hearing aid on for as long as possible and try to build on this time each day until the ultimate goal of all day use is achieved.

Soft bands can be washed and replaced as necessary. Ask for a spare – bands are available in different colours and designs.

## Supporting teenagers and adults to wear hearing aids

Often it is best to gradually introduce the person to a hearing aid. Sometimes putting the hearing aid on without turning it on may help the person get used to it being there before having to adjust to the sound.

Over a period of days or weeks gradually turning up the volume of the hearing aid may help the person to accept the device.

When the volume of the hearing aid is initially turned up, it may be a good idea to make sure the person hears something rewarding that they really like (e.g. a favourite song).

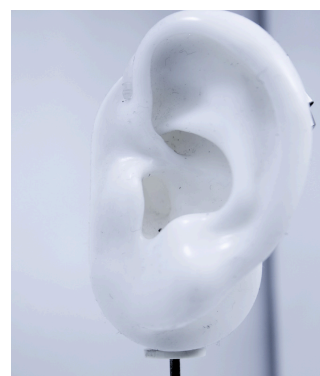
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Hearing implant centres (specialist NHS services) assess, fit and provide long-term support for implantable hearing equipment, such as cochlear implants, middle ear implants and bone-anchored hearing aids.



## Other hearing technology

Here are some examples of the main types of hearing technology. [RNID](#) and the [National Deaf Children's Society](#) have more detailed information about hearing technology at their websites. Different technologies are sometimes provided free of charge by services within a local authority or from the NHS. Who provides the technology usually depends on the function of the particular piece of technology.



## Soundfield Systems for classrooms

A soundfield system is an amplification system that provides an even spread of sound around a room. It allows all students to hear well wherever they are seated in a classroom and whichever direction the teacher is facing. The teacher's voice can be better heard above any unwanted background noise. This will benefit all children in a classroom not just the child who has Down's syndrome and hearing impairment.

## Radio Aids

Hearing aids may not be as effective in places where there is a lot of noise such as in a busy classroom. Radio aids help make sounds clearer using a transmitter. In a classroom setting for example, the teacher wears a transmitter and their pupil with hearing loss wears a receiver. The radio aid picks out the sound the child needs to hear (e.g. the teacher's voice) making it clearer in relation to any background noise. Radio aids are usually supplied by local authority sensory support services.

## Loop Systems

A sign depicting an ear and the letter 'T' tells you that the place you are in has a loop system. If you have the 'T' programme on your hearing aid or implant the loop system will help you to hear more clearly. Some audiologists will decide not to activate the 'T programme' in the hearing aids of young children because understanding how to use the programme is complicated.

## Communicating with a person with hearing loss

### What helps:

- Get the person's attention before you start speaking to them.
- Give the person time to respond to what you are saying.
- Make sure the person can see your face when you are talking to them.
- Try to keep good eye contact.
- Try to be on the same level as the person you are talking to.
- Try to make sure background noise is minimal, where possible speak to the person in a quieter place.
- Allow space for signing if used.
- Remember to use a well-lit room.
- Try to avoid having your back to the window as this can make it difficult for a person to read facial expressions.
- Speaking clearly and at a normal pace. Shouting is not helpful!
- Use clear gestures and facial expressions to support what you are saying.



## Education, Health, and Care Plans (EHCPs), Statements and Individual Development Plans (IDPs)

Health and social care service providers should be involved at all stages of the Plan/Statement process. Health has an impact on education therefore the Plan/Statement should explain health issues, particularly vision and hearing, and be clear that education takes these into account as recommended, for example, for seating position, teaching and learning resources, and equipment such as glasses, magnifiers, hearing aids and soundfield systems.

Information about writing health advice in an EHCP for children who have Down's syndrome can be found at the website of the UK and Ireland [Down Syndrome Medical Interest Group](#).

### Local Offer (England)

Local authorities in England must publish a 'local offer' which details health, education, and social care services for children with SEN and disabilities (including hearing impairment). The 'local offer' can be found on your local authority's website.

### Specialist services / professionals you may encounter

**Audiologist** - An audiologist is a hearing specialist who performs tests to determine the type and degree of your hearing loss and can advise on the options available. They also make ear moulds, fit hearing aids and review progress.

**Hearing therapist** – Hearing therapists work in the NHS usually within hospital audiology departments. They can help with adjusting to hearing impairment, getting used to wearing hearing aids and can make suggestions about useful local services and equipment.

**Otolaryngologist** - Ear, Nose and Throat (ENT) Surgeon - Otolaryngologists are surgical specialists who diagnose, evaluate and manage a wide range of diseases of the head and neck, including the ear, nose and throat regions.

**Teacher of the deaf** - A qualified teacher who is also qualified to teach deaf children. They provide support to deaf children, their parents and family, and to other practitioners who are involved with a child's education.



***Make sure everyone supporting a child or adult with hearing impairment understands the nature of the hearing impairment and, if they have a hearing aid, the absolute necessity of their being supported to wear it.***

# Annual health checks for people who have Down's syndrome (aged 14 years plus)

Please note an annual learning disability health check is not a replacement for a full hearing assessment by an audiologist. An annual health check should take place in addition to other regular health screening and general GP/hospital appointments.

If there are any concerns about hearing at all or if it has been more than two years since the last hearing test ask the GP for a referral to audiology.

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

## Who can have one?

Anyone who has Down's syndrome aged 14 years or over can have an annual health check.

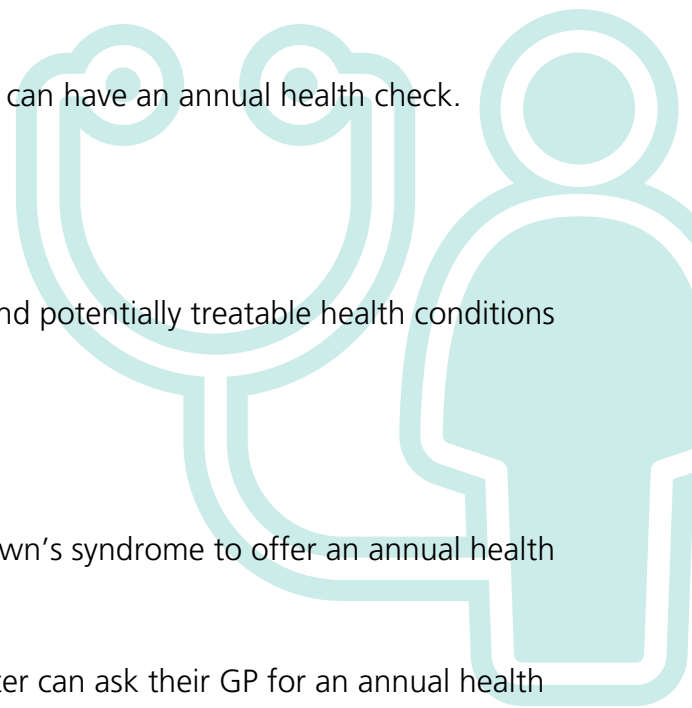
## The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions
- action can be taken to address these health needs.

## How to get an annual health check

- The GP may get in touch with the person who has Down's syndrome to offer an annual health check but this doesn't always happen.
- A person who has Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.



## What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person who has Down's syndrome to have a routine blood test a week or so before the annual health check.

## Who attends the annual health check?

If the person who has Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

## How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

## What areas of health should be looked at as part of the annual health check?

We have produced a checklist for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. You can find the checklist at our website here: [Health and Wellbeing - Downs Syndrome Association](#).

## What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.



## GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centred health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent:

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

There is information about making everyday decisions post 16 at our website here [Children, Families & Education - Downs Syndrome Association:](#)

***It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.***





## Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

***If a patient who has Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.***

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