



Information for families

Down's syndrome and childhood deafness



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

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Introduction

All children use what they see and hear around them to learn about their world and to develop communication and language skills. Good hearing plays an important role in developing speech skills. Children with Down's syndrome all have some degree of learning disability, and at birth it is impossible to tell what degree that is. Many children with Down's syndrome also have some degree of deafness. Deafness that is not diagnosed or managed can have a negative effect on a child's social and language development, especially if a child has a learning disability. This booklet explains about different types and causes of deafness, how hearing is tested, what the results of a hearing test mean, and how deafness can be managed or treated.

If you would like more information about any of the topics covered in this booklet, phone our Freephone Helpline on **0808 800 8880** (voice and text), send an email to helpline@ndcs.org.uk, or visit our website at www.ndcs.org.uk.

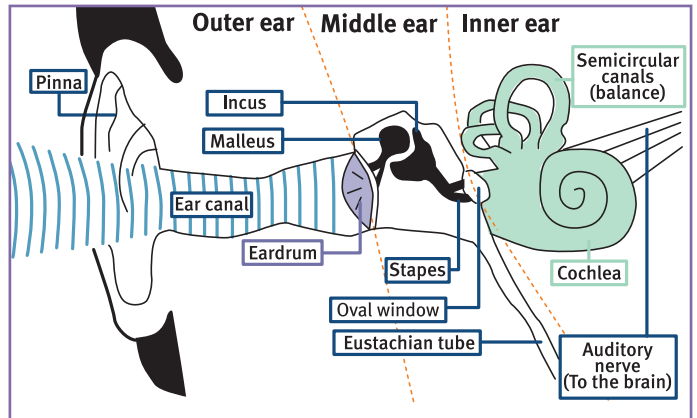
For more information on Down's syndrome, phone the **Down's Syndrome Association** on **0333 121 2300**, send an email to info@downs-syndrome.org.uk or visit their website at www.downs-syndrome.org.uk.

For other sources of information go to p15 'Where can I get more help?'

We use the term 'deaf' to refer to all levels of hearing loss.

We have produced this booklet with The Down's Syndrome Medical Interest Group (UK) and The Down's Syndrome Association. We are grateful to Mr Patrick Sheehan, Consultant Paediatric Otolaryngologist, and the Audiology Department at The ENT and Hearing Clinic for Children with Down's syndrome at Manchester Children's Hospitals, for their help in preparing this booklet.

The ear and how it works



There are different types of deafness.

Conductive deafness is when sound cannot pass efficiently through the outer and middle ear to the inner ear (cochlea and auditory nerve).

The most common type of conductive deafness in childhood, and in those with Down's syndrome, is caused by 'glue ear'. There is more information on glue ear in the next section.

Sensori-neural deafness is caused by a fault in the inner ear (most often because the hair cells in the cochlea that turn sound waves into electrical signals are not working properly) or the auditory nerve (the nerve that carries the electrical signals from the cochlea to the brain). Sensori-neural deafness is permanent. A very small number of children with Down's syndrome are born with this type of deafness and some develop sensori-neural deafness as they get older, particularly through adolescence and into adult life. About 10% to 15% of children with Down's syndrome have sensori-neural deafness.

Mixed deafness is when children who have sensori-neural deafness also have conductive deafness.

Glue ear

Glue ear is a build-up of sticky fluid in the middle ear. For the ears to work properly the middle ear needs to be kept full of air. The eustachian tube usually keeps the middle ear full of air. It runs from the middle ear to the back of the throat. In children, this tube is not as vertical and wide as it will be when they get older. As a result, it doesn't work as well. In children with Down's syndrome, this tube can be particularly narrow. If the eustachian tube becomes blocked, air cannot enter the middle ear. When this happens, the cells lining the middle ear begin to produce fluid. With fluid filling the middle ear, it becomes harder for sound to pass through to the inner ear and sounds become more muffled.

About 60% to 70% of children with Down's syndrome have a conductive deafness caused by glue ear. Glue ear sometimes causes pain or ear infections. For most children glue ear is a temporary condition and they grow out of it by about the age of eight as their eustachian tube and other cavities grow larger. However, children with Down's syndrome often get glue ear before the age of one and because their eustachian tubes stay small throughout their life, it may last to the age of 10 or even longer. For this reason a 'wait and see' policy is not recommended. Depending on the child and the degree of deafness caused by the glue ear, several options are available.



Antibiotics, antihistamines and decongestant medicines

If the glue ear seems to be triggered by an ear infection, or by repeated infections of the respiratory tract (the breathing passages), your doctor may prescribe a six-week course of low-dose antibiotics. This may be combined with a decongestant medicine to dry up the fluid being produced. For some children this clears up the problem so that no further treatment is necessary. Some may benefit in the short term but need a further course of antibiotics the next time they get an infection. For those waiting for grommets to be fitted, this treatment is sometimes a useful measure to keep the problem at bay and improve hearing until the operation can be done.

Decongestants are usually given as medicine (such as Sudafed). Nose drops (such as Otrivine) are not recommended for long-term use and can lead to too much mucus being produced once the immediate effect of the drops wears off.

Evidence suggests that antihistamines are not effective in managing glue ear in children with Down's syndrome.

Grommets

If glue ear does not respond to antibiotics or clear up by itself in a few months, an operation to clear the fluid from the middle ear may be recommended. Under a general anaesthetic, the eardrum is punctured with a very fine instrument and the fluid sucked out. A grommet (a tiny plastic tube sometimes called a ventilation tube) may be inserted into the hole to keep it open for a while. This will help air to circulate to prevent further fluid from building up. It stays in the eardrum for about six to eight months (on average) and then the eardrum naturally pushes it out and the hole heals by itself. Sometimes larger tubes called T-tubes are used. These stay in the ear longer. The grommet can easily be removed from the ear canal, in the ENT clinic, or it may fall out unnoticed, in a lump of wax. You do not need to look for the grommet, or consult your GP, unless you have problems. Your ear, nose and throat clinic and audiology department will usually check your child's grommet and hearing around three to six months after the operation.

Sometimes, removing the adenoids is also recommended. Adenoids are fleshy pads at the back of the nose and throat area. If they enlarge they may block the end of the eustachian tube. Removing the adenoids may mean that the child is less likely to get glue ear again once the grommets have fallen out.

These operations can occasionally be difficult or impossible in young children with Down's syndrome because the ear canal may be so narrow that the surgeon cannot operate. In this situation hearing aids may be helpful until the child is a little older and the operation to insert grommets can be performed.

For about one in five children without Down's syndrome who have had grommets, glue ear comes back again. This may mean that further grommets need to be fitted. This is much more likely in children with Down's syndrome but, because the glue is more sticky, the grommet itself often becomes blocked and the improvement in hearing may be short-lived. It is possible to put grommets in about three times, but it is not good practice to perform repeated grommet surgery because every time one is put in, the eardrum has to be punctured. And every time one falls out, it leaves a tiny scar. Because of this, some ENT doctors and audiologists recommend hearing aids as the preferred treatment for glue ear in children who have Down's syndrome. It is very important that an ENT doctor regularly monitors the glue ear, even if it is not being treated with grommets, to check for possible complications from the glue ear. For more information about hearing aids, go to page 9.



Tips for children with grommets

If your child already has grommets the following tips may be helpful:


- Some surgeons recommend that children do not swim while they have grommets in. This is because the grommets allow water to get into the middle ear and a small percentage of children with grommets may develop ear infections as a result. Other surgeons allow swimming with some precautions. If your child's surgeon says that your child is allowed to swim, the following simple precautions are helpful.
 - Try to stop your child from diving or jumping into the water as this forces water through the grommet into the middle ear. If you can, try to get your child to wear a swimming cap when swimming.
 - Don't take your child swimming for at least three weeks after the grommets have been fitted, to allow for the operation site to settle down.
 - Do not let your child swim in lakes or pools that do not have chlorine in them. The water in these places usually contains bacteria and infection is more likely.
- Soapy water is more likely to pass through the grommet into the middle ear. If the water is dirty it will infect the middle ear. When bathing your child, wash their hair first before washing their body so the water is not too soapy, and rinse the hair off in clean running water. Then put a shower cap on your child. This way the child can play in the bath without getting dirty soapy water in the ear.

Remember that grommets are ventilation tubes and not drainage tubes. **Any discharge (leak) from the ear is abnormal.** For a couple of days after the operation, there may be a discharge (occasionally bloodstained). This is usually because the surgeon placed antibiotic drops in the ear at the time of the operation. After the first couple of days there should not be any discharge. If there is see your GP for advice and antibiotic drops. Any prolonged discharge from the ear should be assessed by your ENT doctor.

Alternative treatments for glue ear

Some parents have found that adjusting their child's diet can help reduce the amount of mucus they produce and so reduce the effects of glue ear.

There is also a range of alternative treatments that may help glue ear. On the whole, there is very little scientific research available to support them.



If you would like more information about diet or the alternative treatments available, download the factsheet *Treatments for Glue Ear* from our website at www.ndcs.org.uk.

Other things that can affect the hearing

Wax

Wax is a common problem for children and adults with Down's syndrome because it easily blocks the narrow ear canals and can cause hearing difficulty. For children who use hearing aids, wax can cause feedback (a whistling noise). You can buy ear drops for wax removal but when the ear canal is very narrow, it can easily become even more blocked by the drops and wax combining. It is a good idea to ask your audiologist to check your child's ears every four to six months and arrange for wax to be removed by your ENT doctor if necessary.

Middle-ear infections

Middle-ear infections are common in children. The most common is acute otitis media which causes severe earache and a high temperature. Most infections clear up without any long-term effects once they are treated with antibiotics. However, sometimes repeated infections can cause the eardrum to weaken and could eventually leave a permanent hole (perforation). A hole in the eardrum exposes the middle ear. It can then easily become infected leading to long-term discharge from the ear.

Sometimes longer-term problems can arise. They can lead to a second and more serious form of middle-ear disease known as chronic otitis media. Chronic middle-ear disease is usually associated with a smelly discharge from the ear and deafness, but rarely pain.


It is important that you see your doctor if your child has a discharge from their ear. Most infections clear up with a course of antibiotics, but if infections become frequent or long term it is important that your child sees an ENT doctor to examine the ears.

Cholesteatoma

Cholesteatoma is a cyst or pouch of skin within the ear. It is usually due to repeated infection, which causes skin to grow inwards from the eardrum. The first sign may be a persistent smelly discharge from the ear. If left untreated, it could get bigger and destroy the delicate bones within the middle ear and so cause permanent deafness. So it is necessary to remove the cholesteatoma before it can cause damage. If they have a chronic discharge from the ear over a long period it is very important that your child sees an ENT doctor for assessment and advice.

Hyperacusis

Hyperacusis is sensitivity to noise. Studies have shown that a few children with Down's syndrome are particularly sensitive to noise. These children may be distressed in some situations especially when there is a lot of background noise. If this seems to be a problem, discuss this with your child's audiologist.



There is also more information about hyperacusis on the Tinnitus and Hyperacusis website at www.tinnitus.org.

What should I do if I am worried about my child's hearing?

All children with Down's syndrome should have their hearing tested regularly. Depending on the type and degree of deafness, this might be every three to six months for young children and every year for older children. If you are worried about your child's hearing or feel that their hearing has changed between appointments, ask for an earlier appointment. The Down's Syndrome Medical Interest Group publishes guidelines for professionals on the frequency of hearing tests. Their contact details are at the end of this booklet.

Your child will need to be referred to your local audiology service for hearing tests. You can ask your GP, health visitor or paediatrician to refer you.

How is hearing tested?

It is possible to test the hearing of all children from birth. There are two different types of test that can be carried out to find out about your child's hearing – objective tests and behavioural tests. Responses to hearing tests depend both on how the ear and its nerve connections are working as well as the stage of general development a child has reached. For example, a two- to three-year-old child with Down's syndrome may be tested using a hearing test normally used with an 18-month-old baby. Usually, several different tests need to be done over a period of time to be able to build up an accurate picture of your child's hearing.



Objective hearing tests

Otoacoustic emissions (OAE)

The otoacoustic emission test is commonly carried out as a matter of routine shortly after birth. It works on the principle that a healthy cochlea will produce a faint response when stimulated with sound. A small earpiece (containing a speaker and microphone) is placed in the child's ear and a clicking sound is played. If the cochlea is working properly, the earpiece will pick up the response. This is recorded on a computer and tells the tester whether more tests are needed.

A poor response to an OAE test does not necessarily mean that a child is deaf. Background noise, an unsettled baby, or fluid in the ear at the time of the test can all make it difficult to record the tiny response. The tester will explain the results to you and explain the next steps.

Auditory brainstem response (ABR)

Before testing, the audiologist will place three small sensors and a set of headphones on the child's head. During an auditory brainstem response test, the child does not have to do anything. The computer measures the electrical signal sent by the hearing nerves. This is then recorded. For an accurate result, the child must be very still and quiet throughout the test. In young babies it can be done while they are asleep. In slightly older children, a light sedative or anaesthetic may be offered.

The test measures whether sound is being sent from the cochlea and through the auditory nerve to the brain. It can be used as a screening test (Automated Auditory Brainstem Response – AABR) where the computer judges whether a response is present at quiet levels of sound, or diagnostically where different levels of sound are used and the audiologist interprets the results to find the quietest level of sound being detected by the hearing nerves at the frequencies tested.

In very young children and children who are not developed enough to have behavioural hearing tests, the results of the ABR test can be used to accurately fit hearing aids if these are necessary.

In older children, this test may be used to confirm the results of their behavioural test.

Behavioural tests

As your child gets older, their audiologist will get more information about their hearing. Tests involving toys and games are used as part of the assessment, and it involves your child listening to different sounds as part of a game.

Visual response audiometry (VRA)

Visual response audiometry is suitable for children from about six months of age. Using a machine called an audiometer, sounds of different frequencies and loudness are played through speakers. When the child hears the sound, they will turn their head and get a visual 'reward', such as a toy or puppet lighting up. The test can check the full range of hearing but does not give specific information about each ear. If your audiologist feels it is important to get information about each ear, this test can be done with small insert earphones.

Pure tone audiometry (PTA)

From about the age of three or four, children are actively involved in their hearing test through a technique known as conditioning. Younger children are taught to move a toy (for example, putting a peg into a board) each time they hear a sound. Older children are asked to respond to sounds by saying yes or pressing a button. Sounds are played through headphones, insert ear phones or sometimes through a speaker (when the test is known as soundfield audiometry).



Bone conduction

All of the tests above are described as testing using air-conduction. That is, sounds passing through the ear canal and middle ear before reaching the cochlea. The tests can also be carried out using bone conduction. A small vibrating device is placed behind the child's ear. This passes sound directly to the inner ear through the bones in the head. This technique is useful for identifying whether a hearing loss is conductive or sensori-neural.

Speech discrimination tests

Speech discrimination tests check the child's ability to hear 'words' at different volumes. The tester asks the child to identify toys or pictures, or to copy words spoken by them or from a recording. From this the tester can assess the quietest level at which the child can correctly identify the words used. This test can also be used to assess lip-reading and signing skills.

Tympanometry

Tympanometry is not a hearing test. It is used to check how well the eardrum and moving parts of the middle ear are working. A small earpiece is held gently in the ear canal. A pump causes the pressure in the ear to change. The eardrum should move freely in and out with the change in pressure. The earpiece measures this movement. If the eardrum is not moving freely there is likely to be some fluid ('glue ear') or another problem with the middle ear.



Tips on getting the best results from hearing tests

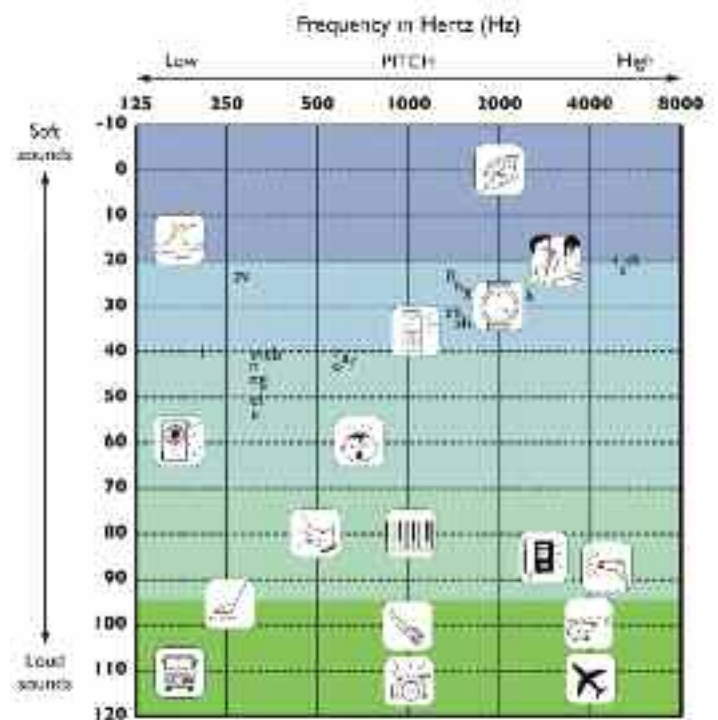
All the hearing tests described above are harmless and painless. Nevertheless, a trip to the hospital or clinic can be daunting for some children. It may take a child with Down's syndrome longer to understand how the audiologist wants them to respond, and it may be more difficult to keep them interested in the tests. For these reasons it is important that the children are seen by people who have experience and an interest in children with additional needs.

Also, children can get very bored waiting to see the doctor or audiologist. This can mean that they don't get as involved as they can in hearing tests. Some clinics have a waiting area with games and toys, and you could ask if you can wait there. Or you could take a book, activity or something to eat and drink to keep your child occupied while you are waiting. If you know that your child will sleep at a particular time of day, or be more alert

or co-operative at certain times, let the clinic know so that they can arrange an appointment time that best suits getting accurate test results. Ask for a longer appointment and one at a time when your child will be at his or her best.

What do the results of the hearing test mean?

Your child's test results will be written on a chart like this, known as an 'audiogram'.



There are different levels of deafness. These can be described as a decibel (dB) hearing level (how loud a sound has to be for your child to hear it) or described using terms such as 'mild', 'moderate', 'severe' or 'profound'. The very quietest sounds are at the top of the chart, getting louder as you look down it.

Your child's deafness may also be described as 'high frequency' or 'low frequency' and is measured in hertz (Hz). We commonly think of frequency as the pitch of a sound. A piano keyboard runs from low pitch on the left to high pitch sounds on the right and the audiogram is the same.

On the audiogram above we have added pictures of common sounds. These give you an idea of how loud and at what frequency the sounds occur.

There are also speech sounds drawn on the chart. You can see that all the sounds of speech occur over a range of frequencies. Try saying some of the speech sounds out loud while looking at the chart. The sounds m, b, and d are on the left-hand side and part-way down the chart. This means that they are at a lower frequency and are slightly louder than say f, s, and th which are higher in frequency and are much quieter. So it is important to be able to hear across the frequency range at a quiet level to be able to hear all the sounds of speech clearly.

Ask your child's audiologist to explain your child's test results and how they will affect your child's ability to hear speech. Your audiologist will need your permission to share the test results with other professionals (such as the speech and language therapist or school). It is a good idea to ask your audiologist for a copy of each hearing test for your own files and to take them with you when you visit the audiology department or ENT doctor.

Will my child's hearing change over time?

All hearing losses are different. Some will change over time, others will stay the same. If you think that your child's hearing has changed, talk to your local audiology service.

What can be done to help?

Specialist support services

If your child has a hearing loss, your local audiology and education services will give you and your child support. Your audiologist will refer you to a teacher of the deaf who will be able to give you advice on encouraging good communication, using hearing aids, schooling and who is responsible for making sure your child has any appropriate support they need in school. You may also be offered an appointment with a speech and language therapist.

You may also be offered specialist equipment to help improve your child's hearing. Depending on the type and level of the deafness, there are several options available.

Hearing aids

Hearing aids can be useful for children with any level of deafness. The type of hearing aid that will be suitable for your child will depend on the type and level of deafness they have. Hearing aids work by amplifying (making louder) sounds going into the ear. Hearing aids come in a range of styles. Good-quality, digital hearing aids are available free of charge for all children on the NHS. Most children use behind the ear hearing aids in each ear.



The hearing aid sits on the top of the pinna (the outside part of the ear) and is connected to an earmould that is specially made to fit in the child's ear. Many children with Down's syndrome wear behind the ear hearing aids very successfully. Children with Down's syndrome often have very small and very soft pinna that can make keeping a behind the ear hearing aid in place difficult. It is also common for children with Down's syndrome to have very small ear canals. This can sometimes make it difficult to get well-fitting earmoulds. It may also mean that any wax produced quickly builds up in the ear canal.

The narrow ear canals and build-up of wax can cause some children difficulty in wearing behind the ear hearing aids as sound from the hearing aid 'bounces' back off the wax or the wall of the ear canal, causing whistling or 'feedback' from the hearing aids. If your child has any of these problems, talk to their audiologist about possible solutions.

Every hearing aid is programmed for the ear it will be worn behind. When the hearing aids are fitted you will be shown how to use them effectively as well as how to clean and maintain them and how to change the batteries. You should be given written information to take home. Your audiologist and teacher of the deaf will discuss when the best times are to use the hearing aids.

If you would like more information about hearing aids you can download the booklet *Hearing Aids – Information for families* from our website at www.ndcs.org.uk.

Wearing hearing aids and glasses together

There is usually room behind the ear for both the hearing aid and the arm of glasses. Occasionally the arm of the glasses may need to be adjusted and your optician can help you with this. Sometimes a different model of hearing aid might be tried. If the ear is naturally cupped forward, surgical tape (such as Micropore) or wig tape help to hold the hearing aid in place. Your audiologist can usually supply this tape.



Tips for getting children to wear hearing aids

Introducing hearing aids to a young child can be difficult for the child and you. Some children immediately accept the hearing aids and wear them without complaining. Other children struggle and complain.

When a child first starts wearing hearing aids, it is important that they wear them regularly. This allows the child to get used to them and lets you and the audiologist see what benefit they are having.

The first task is to encourage your child to like their hearing aids. Your own attitude towards them is important. If you are positive, your child will be more positive about wearing them.

Remember that you are putting something in your child's ear that has not been there before. If you are fitting hearing aids to your baby, the chances are that he or she will not be bothered by them unless you are nervous or upset.

Getting children to wear hearing aids

Here are some useful tips from parents

- 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, easier to put in and more comfortable. You can also try putting the aids in before your baby or young child normally wakes up, so that they are already in place. (But never leave babies and young children alone with hearing aids as they may put them in their mouths.)
- Try making putting on their hearing aids part of your child's dressing and undressing routine. Put the hearing aids in when they get up and take them out when they go to bed. It will become normal for your child to wear hearing aids whenever they are awake.
- Slowly build up the length of time that your child wears their hearing aids. Depending on how your child is taking to the aids, you could start with just a couple of minutes several times a day. If you are feeling stressed because you have already put the aids in many times that day, and each time your child took them out within seconds, stop trying and have a rest. Your child will sense that you are feeling stressed and this will only make it more difficult. Try again later or the next day when you are both feeling a bit more relaxed.
- Have something ready to distract your child, such as a favourite toy. Perhaps you could even have a special toy that they play with only when they are wearing their hearing aids.
- Your child may remove their hearing aids if they are uncomfortable or painful. 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 that the settings on the hearing aids are correct and talk to your child's audiologist or teacher of the deaf.
- Keep the hearing aids in a special and safe place. If your child takes their hearing aids out, take your child with the hearing aids to the special place and put them away. They will learn to put the aids in the special place when they take them out, and you won't have to go looking for them every time they disappear.
- Try to meet other parents so they can share their experiences with you. This may also give your child the chance to see other children wearing hearing aids so they know 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.
- Hearing aids are available in different colours, so your child can choose their favourite colour. You can also decorate the aids with stickers and personalise them. This can also help you to tell which hearing aid is for which ear. Earmoulds also come in different colours and can have pictures, logos or glitter inside the plastic.
- Let your child have choices. Ask if they are going to wear their hearing aids. Perhaps offer them two of their favourite things to choose from as rewards when they wear their hearing aids.
- You may find that your baby's hearing aids whistle when you feed them or when they are lying down. The whistling is called feedback, and it happens because the microphone on the aids is close to something solid, like a mattress. Arranging pillows behind a baby, holding them in a different position or temporarily turning their hearing aids down or off while they are feeding can help.
- You can ask the hospital about hearing aid retainers (huggies). These are bands that clip around the aid and the child's ear. They secure the hearing aid to the ear. Surgical tape or wig tape can also be used.

These tips are only the starting point, and you don't need to follow them all.

Try the tips that you think may work for you and your child.

Bone conduction and bone anchored hearing aids

Children with Down's syndrome who have a conductive hearing loss and have problems wearing behind the ear hearing aids may benefit from a different type of hearing aid. Bone conduction hearing aids use a vibrating pad that allows sound to be conducted through the bone rather than through the middle ear. They are worn on a headband with the vibrator behind the ear, resting on the mastoid bone (part of the skull behind the ear).

Children who have a permanent conductive hearing loss and find a bone conduction hearing aid effective may also be suitable for a bone anchored hearing aid. These hearing aids have a sound processor that clips onto a fixture (known as an 'abutment') attached to a small titanium screw that has been implanted in the skull just behind the ear. Through the abutment, the sound processor is directly connected to the skull bone which the cochlea (inner ear) forms part of. This allows sound to be transmitted more directly to the inner ear.



In very young children when the skull bone is too thin to firmly hold the fixture the sound processor attaches to, or in older children who are not suitable for surgery, a bone anchored hearing aid worn on a soft headband can be used. The bone anchored hearing aid worn on a soft headband is taken on and off like other bone conduction hearing aids and can be used permanently or temporarily during the assessment stage.



There is more information about bone conduction and bone anchored hearing aids in our booklet *Bone Anchored Hearing Aids – Information for parents and families*.

Cochlear implants

Cochlear implants may be useful for children who have severe to profound sensori-neural deafness and cannot hear the full range of speech sounds with hearing aids. A cochlear implant is different from a hearing aid. It provides a sensation of hearing by stimulating the auditory nerve using electrical signals. The implant has two parts – a receiver which is implanted under the skin behind the ear and an outside part which is worn like a hearing aid. The decision to have a cochlear implant is an important and difficult one for many families. Children have to be referred to a specialist centre to be assessed over a period of time before a decision to go ahead can be made. If you think your child may benefit from a cochlear implant, ask the doctor in charge of your child's audiological care to refer you to a cochlear implant centre.



There is more information about cochlear implants in our booklet *Cochlear Implants – A guide for families*.

Radio aids – what is a radio aid?

There are many situations in which your child may find it particularly difficult to listen.

The three main situations are where

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

A radio aid can help to overcome these problems. For example, if your child is using a radio aid in school, a teacher standing at the far end of a noisy classroom should sound as if he or she is standing directly in front of your child.

A radio aid consists of a transmitter worn by the person who is speaking (for example, a teacher), and a receiver worn by your child. The radio aid works by making the sound the child needs to hear clearer in relation to other unwanted noise.

Who can a radio aid help?

If your child benefits from their hearing aid or cochlear implant, they may find a radio aid useful. This is because a radio aid will work with your child's hearing aid or cochlear implant to make it easier for them to concentrate on the sounds they want to hear.

Children with all levels of deafness have benefited from using radio aids. Radio aids do not amplify sounds in the same way as hearing aids, but they help your child to concentrate on the particular sounds or voices they need to hear. Your child's hearing aids are chosen to suit their deafness and the radio aid is set up to work properly with the hearing aids. So the benefits of a radio aid are limited by the suitability of the hearing aids.

Soundfield systems

Soundfield systems should not be confused with radio aids, although they are designed for similar purposes. Soundfield is an increasingly popular system in schools. The systems are designed to improve listening conditions for all children in the classroom. They can be used with or without hearing aids.

How do soundfield systems work?

A soundfield system includes a microphone, worn by the teacher. This is linked to an amplifier, (by radio transmitter or an infra-red transmitter to avoid the need for wires and allow the teacher to move around the room).

The soundfield system makes the teacher's voice louder. However, the aim is not to produce a very loud sound. Soundfield is not like a public address system. The aim is to produce a clear and consistent level of sound throughout the classroom. The teacher's voice is made just loud enough to be heard above unwanted background noises. A soundfield system that is set up correctly may not be noticeable. The teacher may have controls to set the correct level of sound for the room.

Who can it benefit?

Most children who wear a hearing aid or a cochlear implant will still need to use a personal radio aid. The group most likely to benefit from a soundfield system is children with mild deafness who may otherwise be given no extra support at school. There are a large number of children who could fit into this category, including those with mild or unilateral (one-sided) deafness.

A soundfield system is also very helpful to the teacher. As well as helping them to avoid straining their voice, research has suggested that soundfield systems can improve discipline and concentration for all children.

Will soundfield systems solve all the problems of poor sound quality in a classroom?

If it is practical to improve the quality of sound (acoustics) in a classroom (for example, by lowering ceilings, changing wall coverings and adding soft flooring) this should be the first step. Fitting a soundfield system in a room with very poor acoustics could make listening conditions more difficult, rather than improving them.



There is more information about radio aids and soundfield systems, used with or without hearing aids, in our booklet *Radio Aids – An introductory guide*.

How will I communicate with my child?

Children with Down's syndrome communicate in a number of ways. Depending on their age, ability and level of deafness, they may use spoken language, makaton (a language programme using signs and symbols, often used by people with communication and learning difficulties), sign language or a combination of these. If your child is a baby, you will also be communicating by using facial expressions, body language, gestures and tone of voice to show love and let your child know that you are there. Developing good communication skills that are appropriate for your child's and family's needs is vital. Speech development may be delayed and it can be very helpful for families to learn some sign-based language to help the child communicate. Learning and using sign-based languages early on will not prevent speech from developing as long as normal spoken language and signs are used together.

It is important to remember that you do not have to make a choice for life. The communication method you choose may change as you learn more about your child's needs and preferences.



Communication tips

No matter which way you and your child communicate there are some tips that will help.

- Always give your child plenty of time to respond to anything you say. Make sure you have your child's attention before you start to talk to them.
- Make sure you are facing your child and maintaining good eye contact. Try to be on the same level as them, and allow some space for signing or lipreading if used.
- Use a well-lit room and don't have your back to a window, as this creates a shadow and makes it difficult to read facial expressions or to lipread.
- Speak clearly, naturally and at a normal pace. Don't shout, as it can appear to your child that you are angry. It also distorts lip patterns.
- Try to make sure that background noise is kept as low as possible. Even with hearing aids, it can be difficult to pick out what is being said. A room that is carpeted or that has curtains will help cut down the effects of noise in a room.
- If your child doesn't use sign language, use gestures and facial expressions to support what you say.
- While speaking don't smoke, eat or block the view of your face. Keep beards or moustaches trimmed and also remember that glasses and sunglasses can make it difficult to maintain eye contact.
- When in a group, speak one at a time. Indicate when a different person is speaking so that your child can keep up.
- Make sure you let your child know when there is a new topic of conversation.
- Some words or signs may not be easily understood, in which case use a different word or sign with the same meaning.
- Pause between sentences and check your child has understood you, and that you have understood them. Encourage them to stop you if they don't understand what you are saying.

Where can I get more help?

For more information on Down's syndrome and childhood deafness you may like to contact the following.

NDCS Freephone Helpline

15 Dufferin Street, London, EC1Y 8UR

Phone: 0808 800 8880 (voice and text) • Email: helpline@ndcs.org.uk

Web: www.ndcs.org.uk

Down's Syndrome Association

Langdon Down Centre, 2a Langdon Park, Teddington, TW11 9PS

Phone: 0333 121 2300 • Fax: 020 8614 5127 • Email: info@downs-syndrome.org.uk

Web: www.downs-syndrome.org.uk

UK Down's Syndrome Medical Interest Group (DSMIG)

Evidence based information for health care professionals on hearing problems in Down's syndrome but including resources for parents. For medical queries use the online form on the website below.

Email: info@dsmig.org.uk (non-medical queries only)

Web: www.dsmig.org.uk

The ENT and Hearing Clinic for Children with Down's Syndrome

Royal Manchester Children's Hospital, Oxford Road, Manchester, M13 9WL

Phone: 0161 701 5039 • Email: Patrick.Sheehan@cmft.nhs.uk

Web: www.cmft.nhs.uk/downs-ent

The Down Syndrome Educational International

The Sarah Duffen Centre, Belmont Street, Southsea, Hampshire, PO5 1NA

Phone: 023 9285 5330 • Fax: 023 9285 5320 • Email: enquiries@dseinternational.org

Web: www.dseinternational.org/en/gb

The Makaton Charity

Manor House, 46 London Road, Blackwater, Camberly, Surrey GU17 0AA

Phone: 01276 606760 • Fax: 01276 36725 • Email: info@makaton.org

Web: www.makaton.org

Signalong Group

A sign-supporting system based on British Sign Language and designed to help children and adults with communication difficulties, mostly associated with learning disabilities.

Stratford House, Waterside Court, Rochester, Kent ME2 4NZ

Phone: 0845 450 8422 • Email: info@signalong.org.uk

Web: www.signalong.org.uk

Notes

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NDCS provides the following services through our membership scheme. Registration is simple, fast and free to parents and carers of deaf children and professionals working with them. Contact the Freephone Helpline (see below) or register through www.ndcs.org.uk

- A Freephone Helpline 0808 800 8880 (voice and text) offering clear, balanced information on many issues relating to childhood deafness, including schooling and communication options.
- A range of publications for parents and professionals on areas such as audiology, parenting and financial support.
- A website at www.ndcs.org.uk with regularly updated information on all aspects of childhood deafness and access to all NDCS publications.
- A team of family officers who provide information and local support for families of deaf children across the UK.
- Specialist information, advice and support (including representation at hearings if needed) from one of our appeals advisers in relation to the following types of tribunal appeals: education (including disability discrimination, special educational needs (SEN) and, in Scotland, Additional Support for Learning (ASL)); and benefits.
- An audiologist and technology team to provide information about deafness and equipment that may help deaf children.
- Technology Test Drive – an equipment loan service that enables deaf children to try out equipment at home or school
- Family weekends and special events for families of deaf children.
- Sports, arts and outdoor activities for deaf children and young people.
- A quarterly magazine and regular email updates.
- An online forum for parents and carers to share their experiences, at www.ndcs.org.uk/parentplace.
- A website for deaf children and young people to get information, share their experiences and have fun www.buzz.org.uk.

NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people.

**NDCS Freephone Helpline:
0808 800 8880 (voice and text)**

Email: helpline@ndcs.org.uk

www.ndcs.org.uk

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