

Hearing loss and your baby: the next step

An information resource for families in NSW

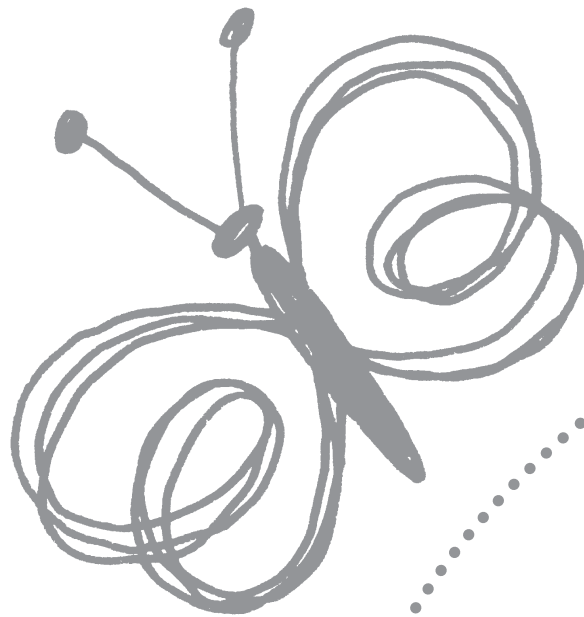


A NSW Statewide Infant Screening-Hearing Program initiative

NSW  **HEALTH**

Hearing loss and your baby: the next step

An information resource for families in NSW



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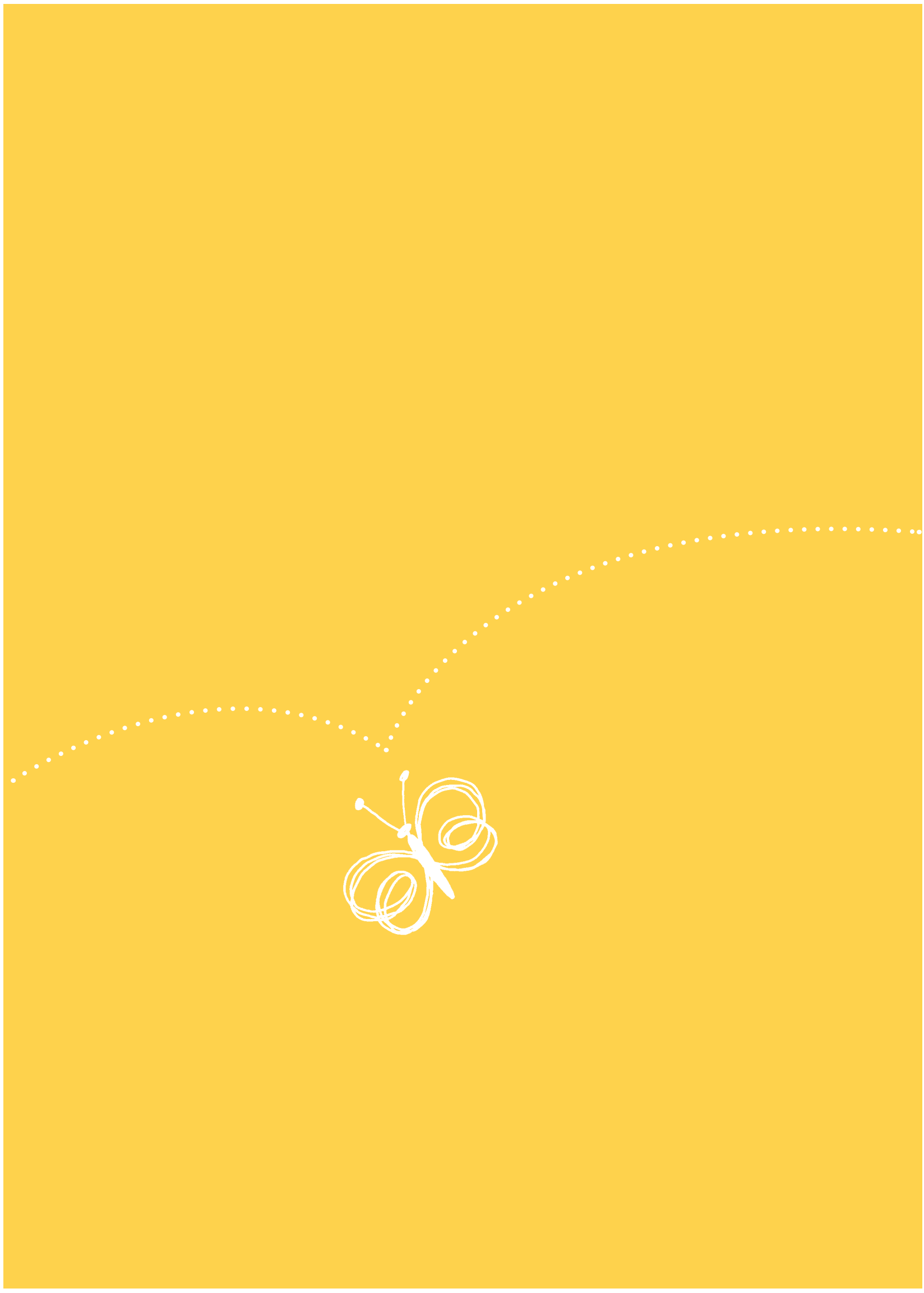
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Introduction

Hearing loss and your baby: the next step. An information resource for families in NSW was developed as part of the Statewide Infant Screening — Hearing (SWISH) Program to assist parents with the challenges they face when they discover their baby has hearing loss.

The Statewide Infant Screening — Hearing (SWISH) Program

The NSW Statewide Infant Screening — Hearing (SWISH) Program is aimed at identifying all babies born in NSW with significant permanent bilateral hearing loss by 3 months of age, and for those children to be able to access appropriate intervention by 6 months of age. Identification is achieved through universal hearing screening of all newborns.

Technology is available to diagnose hearing problems in the neonatal period. Early identification and intervention are important, with research

suggesting that intervention commencing by 6 months of age may result in optimal speech and language development and minimise the need for ongoing special education.

Each Area Health Service has a SWISH Coordinator/s responsible for implementing and managing the screening program across all facilities in their Area. This model allows SWISH Coordinators flexibility to meet unique needs in their Area Health Service. SWISH Coordinators have adopted innovative approaches to ensure maximum screening capture such as service agreements with private hospitals and employing dedicated screeners to meet local needs (eg. Indigenous and culturally and linguistically diverse populations).

The screening section of the program involves the screening of all newborns in NSW using Automated Auditory Brainstem Response (AABR) technology. If newborns do not pass hearing screening they are referred

for diagnostic audiological assessment. Parent/carer brochures describing the SWISH program are available in English and 16 other community languages, in both paper form and via the NSW Health website.

SWISH diagnostic audiology services are provided through the three tertiary paediatric hospitals which are the acute care hubs of the three paediatric services networks which cover the state. Newborns receive an audiological diagnosis, as well as medical assessments to assist with selecting appropriate intervention. The SWISH Travel Assistance Scheme was established to reimburse parents for the cost of travel where they live a considerable distance from a tertiary paediatric hospital.

Following diagnosis, newborns are referred to intervention services appropriate to the degree of hearing loss, specific medical diagnosis and parental preference.

Glossary



A

Acoustic nerve

The eighth cranial nerve, combining the nerves of hearing (cochlear) and balance (vestibular).

Acquired deafness

A loss of hearing that occurs or develops some time during the lifespan but is not present at birth.

Amplification

The use of hearing aids and other electronic devices to increase the loudness of a sound.

Assistive Communication (listening) Devices

Equipment that can be used with or instead of hearing devices to help deaf and hard of hearing people. For example, an amplified telephone, vibrating alarm clock or hearing loop system.

Atresia (aural)

An ear malformation in which there is an absence of the external ear canal, usually with abnormalities of the outer ear, and/or middle ear space.

Audiogram

A chart used to record the results of a hearing test. It includes a table and a graph for each ear showing how well a person can hear sounds at various frequencies at the time of testing.

Audiological assessment/evaluation

A range of hearing tests, which show the type and degree of hearing loss.

Audiologist

A person trained in audiology; a specialist in the problems of hearing and deafness.

Audiology

The study of hearing and hearing impairment.

Auditory Brainstem Response (ABR) test

An objective test (performed while the baby is sleeping) that can be used to assess hearing function in infants and young children. An electroencephalographic (EEG) response is measured from electrodes placed on the scalp that measure the response of the baby's hearing nerve to sound.

Other terms are: Brainstem Evoked Response (BSER), Brainstem Auditory Evoked Potential (BAEP), and Brainstem Auditory Evoked Response (BAER).

(Automated) Auditory Brainstem Response ([A]ABR)

Similar to Auditory Brainstem Response (ABR) (see above) except the waveforms generated are measured against a template to determine a pass or refer result.

Auditory Neuropathy/Dysynchrony (AN/AD)

A name for a pattern of test results and is not a diagnosis or condition. AN/AD occurs when sound enters the ear normally, but the transmission of sound from the inner ear to the brain does not occur in a normal way.

B

Bilateral hearing loss

A hearing loss in both ears

Binaural

Relating to both ears



Glossary

C

Canal, ear

The passage from the pinna to the eardrum through which sound waves travel.

Cerumen

A yellow or brown wax-like substance ("earwax") produced in the outer one-third of the external ear canal.

Cochlea

The snail-shaped tube, in the inner ear, where sound is converted into nerve impulses to be sent to the brain.

Cochlear implant

A medical device that is surgically implanted and bypasses damaged inner ear structures and directly stimulates the auditory nerve, helping individuals who have severe to profound hearing loss to interpret sounds and speech.

Conductive hearing loss

One of three types of hearing loss (see Hearing loss).

D

Decibel

A unit of measurement of sound. When testing hearing, dB is used to indicate the loudness or intensity of a sound. A whisper is about 20 dB, ringing telephone is around 80dB and a jet engine taking off is about 150dB.

Diagnostic audiologic evaluation

A range of hearing tests conducted by an audiologist to determine a person's hearing status. These tests will confirm whether or not hearing problems exist, and if so, to what degree.

E

Ear, external

The external ear consists of the pinna (the part we can see), the ear canal and the outer surface of the eardrum.

Ear, inner

Comprises the vestibule, the semi-circular canals, the inner surface of the oval and round windows, and the cochlea.

Ear, middle

Includes the eardrum, three tiny bones called the ossicles, and the eustachian tube.

Earache

Any ache or pain arising in the ear. Technically it may be referred to as otalgia.

Eardrum

The eardrum is a thin membrane that separates the ear canal and the middle ear. The medical term is tympanic membrane.

Ear specialist

Commonly referred to as an ENT (Ear, Nose and Throat) specialist.

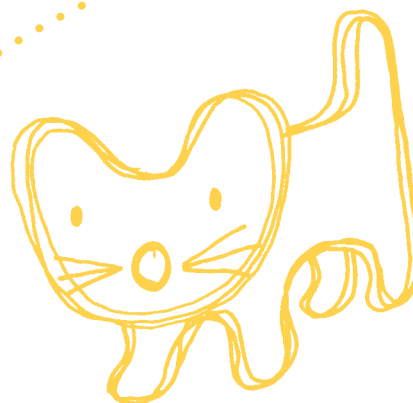
Ear wax

Wax in the external ear canal; see cerumen.

Eustachian tube

A passageway between the middle ear and the back of the throat that allows air to move in and out of the middle ear. This makes sure that the air pressure inside the middle ear is the same as the air pressure on the outside of the eardrum.

Glossary



F

Feedback

The whistling sound sometimes produced by a hearing aid.

Frequency

The psychological response to frequency is referred to as pitch. Frequency is measured in hertz (Hz) and kilohertz (kHz). 1000Hz = 1kHz.

G

Genetic deafness

Deafness transmitted by faulty genes.

Glue ear

A common complication of middle ear infections. The "glue" is a thick sticky fluid that stays in the cavity of the middle ear after the infection clears up. Glue ear makes it harder for sound to travel from the outer ear to the inner ear.

Grommets

Plastic tubes inserted into a child's eardrum as a treatment for glue ear.

H

Hair cells

The hair-like structures in the inner ear that transform sound waves into electrical impulses that are then relayed to the brain via the auditory nerve.

Hearing aid

An electric amplifying device designed to make sounds audible to the individual with a hearing loss.

Hearing aid, Behind-the-Ear (BTE)

A type of hearing aid designed to fit behind the ear, which transmits sound to the ear canal via tubing and a custom earmold.

Hearing aid, Completely-in-the-Canal (CIC)

A type of hearing aid that is micro-miniature in size and fits entirely within the ear canal to most closely imitate the natural hearing process. It is custom-designed to fit the contours of the wearer's ear canal.

Hearing aid, In-the-Ear (ITE)

A type of hearing aid that fits within the outer ear or ear canal. It is custom-designed to fit the shape of the wearer's ear canal.

Hearing loop system

An Assistive Listening Device that consists of microphone(s), an amplifier, and a loop of wire that may be worn around the neck or is installed around part of a room. Sound is transmitted directly into headphones or hearing aids worn by people within the area enclosed by the loop, thereby reducing the effects of background noise and distance.



The International Deafness Symbol is usually displayed where a hearing loop is installed in public places.

Hearing loss, conductive

Impairment of hearing due to the failure of sound pressure waves to reach the cochlea through the normal air conduction channels. This type of deafness is often responsive to medical or surgical treatment.

Hearing loss, mixed

A combination of conductive and sensorineural hearing loss.



Glossary

Hearing loss, sensorineural

A type of hearing impairment caused by damage that occurs to the cochlea. Sensorineural damage is usually irreversible.

Hertz (Hz)

When testing hearing, Hz is used to indicate the pitch or frequency of a sound. A 250 Hz sound is a very low frequency and an 8000 Hz sound is a very high frequency.

Hearing screening

Determines if hearing is normal at the time of testing, or if more testing is necessary. A screening test is not the same as a diagnostic evaluation, which assesses hearing more thoroughly. If there are any problems on a hearing screening, hearing will usually be re-screened. If necessary, after the second screening test, there may be a referral for a diagnostic audiologic evaluation.

I

Impression

A cast made of the contours within the external ear, from which an earmold (for BTE instruments) or custom shell (for ITE, ITC and CIC instruments) is made. Impressions typically are made using a silicone or material which is of soft consistency for insertion into the ear canal.

L

Lip read

To understand by close observation of the speaker's lips. It is now more commonly known as speechreading, since facial expression and gestures enter into communication.

M

Microtia

Abnormal growth of the outer ear. Severity varies from minor skin tags or differences in ear shape to complete absence of the outer ear.

Mixed hearing loss

One of three types of hearing loss (see Hearing loss).

N

Nerve, cochlear

The branch of the eighth cranial (acoustic) nerve that arises in the cochlea and conveys sound stimuli to the brain.

O

Ossicles

The small bones of the middle ear that convey sound impulses from the eardrum to the oval window. They are known as the hammer (malleus), anvil (incus), and stirrup (stapes).

Otitis

A broad term for inflammation of the ear.

Otitis Media (OM)

A middle ear infection. Children with recurring ear infections may experience fluctuating hearing loss and may be at risk for speech and language delays.

Otoacoustic Emissions (OAE)

A hearing test that uses a microphone placed in the ear canal to measure sound waves generated in the cochlea in response to clicks or tone bursts.

Glossary



P

Perforated eardrum

An eardrum that has been ruptured by accident or disease.

Pinna

The portion of the ear that is visible on the side of the head.

Profound deafness

Extreme hearing impairment bordering on total deafness.

Pure tone

A continuous signal of sound at a single frequency, commonly used in basic hearing screening tests.

R

Risk factor

A factor that may increase the chance of an infant being born with or developing a hearing loss. Risk factors may include family history of hearing loss, meningitis, congenital infection, very low birth weight.

S

Statewide Infant Screening-Hearing (SWISH)

The program by which all newborns in NSW are offered hearing screening within the first few days of birth.

Severe deafness

A level of deafness where a hearing aid will be necessary.

Sign language

A system of conventional symbols or gestures made with the hands to help the deaf communicate. It is distinct from finger spelling.

Stethoclip

A device that enables a hearing person to listen to a hearing aid to make sure that it is working.

T

Tympanic membrane

See ear drum.

U

Unilateral hearing loss

A hearing loss in one ear only.



How do I use this resource?

What is this resource?

This resource is for you to use when your baby has been diagnosed with a hearing loss. The resource contains two parts. The main part of the resource contains information on hearing loss that you will need over the coming months.

The smaller pages, in the plastic sleeve, are for you to insert into your infant's Personal Health Record.

Content

The main part of the resource is for you to keep at home and is filled with information on:

- Hearing and hearing loss
- The professionals that you may meet
- How you can communicate with your baby
- Where you can find further information
- Terms you may need to know

There are sections in this folder devoted to each of these topics. The information is not intended to answer every question you may have however it will enable you to ask more questions and know where to go to find further information.

The information has been compiled from common questions parents ask after discovering that their child has a hearing loss.

Advice and support from other parents

This resource was developed in collaboration with parents whose children have a hearing loss. These parents will share their experiences and advice with you throughout this resource.

Section 8: Building blocks contains a parent to parent guide, written by parents of a child with a hearing loss, for other parents.

A resource folder that you can keep, use and add to over time

This folder contains information that will be useful to you in the first weeks and months after you discover that your baby has a hearing loss. It is hoped that you will continue to use and add to this folder as your child grows.

This folder is a way of keeping all the information you are given on your baby's hearing loss in one place and is intended to be a point of reference.

Any resource materials you have been given can be stored in Section 9: Resources and additional information.

How do I use this resource?



Personal Health Record, “My First Health Record”

The smaller pages, in the plastic sleeve, are for you to insert into your infant’s Personal Health Record, “My First Health Record”.

The Personal Health Record, “My First Health Record” contains information about all aspects of your child’s health and is a record of their development from birth to school age. It contains information on the health checks that are required at the different stages of their development.

The pages for you to insert into your infant’s Personal Health Record relate specifically to their diagnosed hearing loss.

The Personal Health Record is to be taken to every appointment that you attend with your child. This includes appointments with GPs, medical specialists and other health professionals.

The pages contain spaces for you to fill in.

- Information on diagnosis — this is to be filled in by your baby’s diagnosing audiologist. It has the specific information on the severity of hearing loss in each ear and recommendations.
- Professionals — this has spaces for you to fill in the names and contact information for your baby’s treating specialists.
- Planning calendar — this is a good way to visualise appointments your baby is scheduled to attend over the whole year.
- Schedule of appointment costs — this is a good way to keep track of the costs of medical and other services that relate to your baby’s hearing loss. Most audiological services are free of charge.
- Early intervention — this is a checklist to help you choose an early intervention service that is right for your baby.



Next steps for your baby

Today's tests have confirmed that your baby has a significant hearing loss. You may be required to attend a number of appointments in the coming months with a number of different professionals.

Your Audiologist will tell you who they are and will make arrangements for you to see them if necessary.

Each professional will provide you with more information about your baby's hearing loss.

At times you may feel overwhelmed with information. This is a guide to explain who you may see in the next couple of months.

The next steps you need to take include recording all the information on your baby's diagnosis. This information can be recorded on the smaller pages which are designed to be included in your baby's Personal Health Record.

The pages are designed so you can clearly set out information on your baby's diagnosis and details of the various professionals who make up your baby's health care team. A yearly planning calendar for appointments, a schedule of appointments and costs and an early intervention service checklist are included.

Referral to Australian Hearing

Australian Hearing provides comprehensive hearing services to children (up to the age of 21). *Australian Hearing* has a Paediatric Services Program which aims to support deaf and hearing-impaired children and their families to optimise each child's speech, education and communication development.

The services provided by *Australian Hearing* include:

- comprehensive hearing assessments for children of all ages
- fitting and updating the latest technology devices
- evaluation of each child's performance with hearing devices
- providing batteries, replacement parts and upgrade processors for children and young people using cochlear implants

Australian Hearing is part of the Commonwealth Department of Human Services.

You will be seen by experienced Paediatric Audiologists who will discuss your baby's hearing in detail and provide more information about early intervention services. *Australian Hearing* will continue to assess your baby's hearing over the coming years. You will be provided with a handbook called *CHOICES*, which will be given to you by your Audiologist at *Australian Hearing*.

Next steps for your baby



Investigations

Many babies and children will be seen by their own Paediatrician or General Practitioner.

These doctors, who specialise in the health of children, are able to provide regular on-going checks of the baby's general health and developmental progress, including speech. They may be able to discuss and arrange investigations into the cause of the hearing loss or refer you to a specialised clinic. Some tests (eg for infection) need to be done in the first month of life to be truly helpful, others (eg for genetic causes) can be done later.

The Hearing Support Service (Sydney Children's Hospital, Randwick), John Hunter Hospital Audiology Department and the Deafness Centre (The Children's Hospital at Westmead) aim to provide families with easy access to the expertise that may be required in determining the possible cause of your baby's hearing loss.

For further information please contact the:

- Hearing Support Service (Sydney Children's Hospital, Randwick) on (02) 9382 1297,
- Deafness Centre (The Children's Hospital at Westmead), on (02) 9845 2139 or
- John Hunter Hospital, Audiology Department (02) 4921 3548.

Ear, Nose and Throat consultation

Any child with significant hearing loss should obtain an appointment with an Ear, Nose and Throat specialist.

The Ear, Nose and Throat specialist can also supply you with a letter of clearance for *Australian Hearing* saying that there are no medical concerns about fitting a hearing aid.

Social work

A Social Worker is available to provide counselling, advocacy and support on both an emotional and practical level.

A Social Worker can assist and support you and your family process some of the feelings that you may be experiencing at the moment, and can assist you in locating support and intervention services for your child. See Section 7: Support.



Questions for the Audiologist

How much hearing does my child have?

What do these terms mean: sensorineural, conductive, mixed, mild, moderate, severe, profound, auditory, neuropathy?

Is the loss permanent?

Do you need to do more testing?

How often should I have my baby's hearing re-tested?

Can you tell if the hearing loss will get worse or change?

Do both ears have the same loss?

How will the hearing loss affect my baby's speech and language development?

Does my baby need a hearing aid? Does my baby need hearing aids for both ears?

Will my baby need a hearing aid forever?

How much will the hearing aids cost?

What will my baby hear with the hearing aids?

Does my baby need to wear a hearing aid all the time?

How often will the hearing aids need to be replaced?

Will the hearing aids need new parts?

What should I do if my baby won't wear the hearing aids?

Is a cochlear implant an option for my baby?

Where else should I go to get help for my baby's hearing?

What other ways can I help my baby?

What do the hearing aids look like?

Adapted from "Audiologist Questions",
Department of Health and Human Services,
Centre for Disease Control, USA pamphlet

Your baby's health care team



There are many professionals that may form part of your baby's health care team.

The Personal Health Record pages have a section to record contact information your baby's specialists.

Audiologists

Audiologists are health professionals who identify, assess and provide management for hearing, balance and related disorders to individuals of all ages. They provide counselling to both patients and their families. They manage and supervise programs and services related to auditory disorders. Audiologists are often part of a large team of specialists dealing with hearing or related disorders.

ENT specialists (Otolaryngologists)

Ear, Nose and Throat (ENT) specialists are doctors who are specially trained in disorders of the ear or nose or throat. They perform surgical operations when required and are able to advise and treat ongoing middle ear disease. Some ENT specialists also perform cochlear implants in children who are felt to benefit from this device.

Eye specialists (Ophthalmologists)

Ophthalmologists are doctors specialising in conditions or diseases of the eye. It is advised that all children with hearing impairment have an eye check performed by an Ophthalmologist. Occasionally, deafness is associated with eye problems.

Geneticists

Geneticists are doctors who are specially trained in advising about the nature and inheritance of certain conditions which may suddenly appear or keep recurring in families. Many types of deafness have a genetic background.

Paediatricians

Paediatricians are doctors who are specially trained in the management of childhood problems. Many babies have a check by a Paediatrician at birth. The Paediatrician will follow up any other problems which may be identified and help monitor the child's progress in all areas of development.

Social Workers

The SWISH Social Workers are concerned with the emotional and social well-being of families after the diagnosis of hearing loss in a new born baby. Social Workers can work with families to assess support needs, provide counselling, education, information and assistance in accessing services and resources.

Speech Pathologists

Speech Pathologists are trained in assessing all forms of communication in babies and older children. They can advise on whether the child's speech is progressing normally. The Speech Pathologist also manages programs for parents on how to improve their child's speech and language skills.

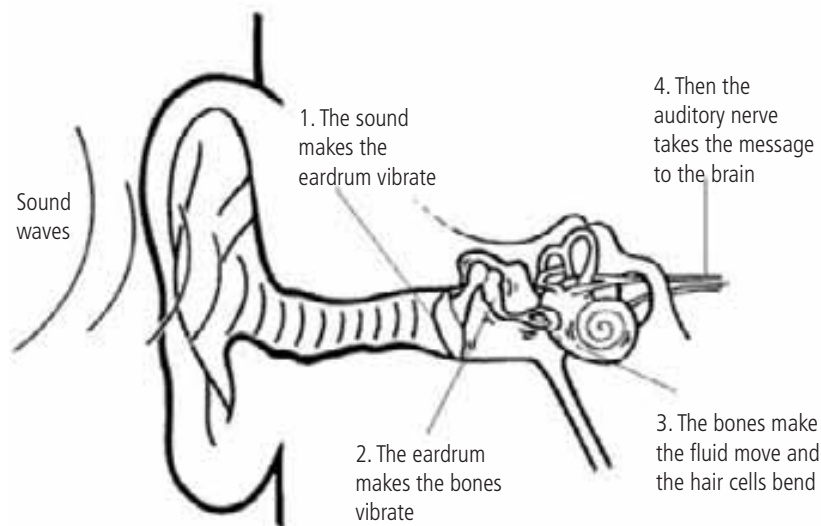
Teachers of the Deaf or hearing impaired

A Teacher of the Deaf is a teacher who has undergone normal teacher training and then received extra training in assisting babies and children with hearing loss. All of the various early intervention programs for deaf children have Teachers of the Deaf available to assist newly diagnosed babies and their families.



Hearing and hearing loss

How the ear works



There are three parts of the ear:

Outer	Middle	Inner
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Structure and function of the ear

Hearing is one of the human body's most complex systems.

The ear changes sound waves into electrical impulses through a series of chain reactions.

The brain then recognises these impulses as specific sounds.

Outer ear

The outer ear consists of the pinna (the part we can see), and the ear canal. Sounds travel through the ear canal and cause the eardrum to vibrate.

Middle ear

The middle ear includes the eardrum, three tiny bones called the ossicles, and the eustachian tube. The function of the eustachian tube is to make certain that the air pressure inside the middle ear is the same as the air pressure on the outside of the eardrum.

When sound travels through the ear canal, it causes the eardrum to vibrate and from this vibration, the tiny bones (ossicles) also move. The last tiny bone, called the stapes then pushes on a membrane that leads into a

structure called the cochlea. The cochlea is found in the inner ear.

Inner ear

Where hearing is concerned, the most important parts of the inner ear are the cochlea and the cochlear nerve. The cochlea is a complicated structure that contains tiny hair cells and fluids. When sound occurs, the hair cells react and send nerve impulses to the brain via the cochlear nerve. Once the brain receives the message, we know we have heard something.

Types of hearing loss



The type of hearing loss your child has is dependant on which part of the ear is affected. There are three types: conductive loss, sensorineural loss, and mixed loss.

Conductive loss

A conductive hearing loss occurs, when there is a problem in the external or middle ear and sound is not able to reach the inner ear loudly enough.

Conductive hearing loss can often be treated by an Ear, Nose and Throat specialist. Some examples of mostly temporary conductive hearing loss are:

- Blockage of the ear canal with wax
- Otitis Media
- Perforated eardrums

Sometimes conductive loss can also be permanent. Some examples of these would be:

- Absence or malformed middle ear bones
- Absence of ear canal

Sensorineural loss

A sensorineural hearing loss involves damage to or malfunction of the inner ear (cochlear or hearing nerve). This kind of hearing loss is usually permanent. It can be present at birth or may be acquired (e.g. from serious infections such as meningitis).

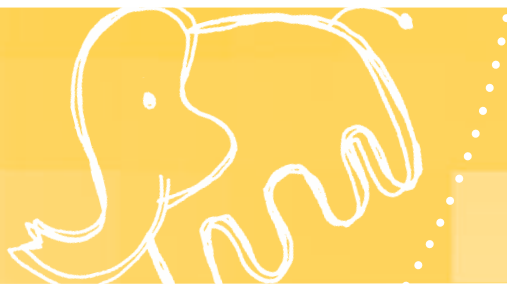
Some causes of congenital (from birth) hearing losses may be:

- Hereditary defects
- Damage due to contact with certain viruses such as Cytomegalovirus (CMV) or Rubella
- Complications due to prematurity

It is possible to have a combination of both conductive and sensorineural hearing loss. This is called a mixed hearing loss.

Understanding hearing loss:

“I get frustrated that people do not know more about deafness — they do not understand that there are degrees of deafness, but it is really about education and my children are their best advert. People are amazed that they are ‘deaf’.”



Types of hearing loss

Middle ear infection

Inflammation in the middle ear is usually caused by infection. It is known as otitis media.

How is it caused?

Otitis media is caused by a virus or bacteria that leads to a build up of fluid behind the eardrum.

This condition can result from a cold, allergy or respiratory infection. The accumulation of fluid in the middle ear may cause earache, swelling and redness — which is called acute otitis media and also prevents the eardrum from vibrating properly, which may result in (temporary) hearing problems.

Symptoms to look for in children may include:

- Scratching or holding the ear
- Crying
- Hearing loss
- Fever
- Sleeplessness
- Irritability
- Discharge from the ear

How is middle ear infection treated?

Mild cases of middle ear infection often resolve of their own accord over a short period of time. More persistent or chronic cases frequently need medical attention, and it may be essential to be referred to an Ear Nose and Throat (ENT) specialist.

Treatment of acute otitis media is mainly with antibiotics. Sometimes if the build up of fluid lasts for a long period of time it may develop into glue ear. In some of these cases insertion of ventilation tubes (grommets) may be necessary.

What is a grommet?

A grommet is a tiny tube inserted into the eardrum. It allows air to enter the middle ear space thereby preventing the accumulation of fluid. This normally results in improved hearing. Grommets stay in the eardrum for 7-12 months and fall out on their own.

Types of hearing loss



Permanent unilateral hearing loss

What is unilateral hearing loss?

A unilateral hearing loss affects only one ear. It can range from very mild to total hearing loss on the affected side.

Causes of unilateral hearing loss

Some children are born with unilateral hearing loss (congenital). Sometimes the hearing loss occurs later on in life (acquired).

Some congenital causes may include hereditary factors or problems during pregnancy.

Some acquired causes may include hearing loss after illnesses such as mumps or meningitis.

For the majority of cases, the exact cause remains unknown.

It is important that children with unilateral hearing loss have a medical consultation as very occasionally it is related to other medical conditions.

What are the effects?

Children with unilateral hearing loss can have difficulty:

- Hearing in noisy surroundings
- Localising sound
- Hearing when sound is on the same side as the affected ear
- Some children can have some difficulty with speech development

It is important to note that many children have no problems with speech or academic achievement at all.

Unilateral hearing loss:

About the diagnostic process —

“The Audiologist seemed to want to play up the fact that he hears on one side, but we really only heard ‘he is deaf on one side’. We were devastated, and terrified about the future. This was our first experience of deafness and we didn’t know what to expect.”



Types of hearing loss

Audiological management

- Assuming the better ear has normal hearing, there is no definite evidence to say that a hearing aid is the most appropriate way of managing a unilateral loss.
- This is more likely to be the case when the loss is mild or moderate in nature. A decision can be made in consultation with your Audiologist, and may have to be made over time.
- Decisions made now can always be changed later.
- When your child is older, some assistive devices may help — for example, sound field amplification systems.

Why is monitoring important?

- A small number of unilateral hearing losses may develop into bilateral hearing losses. Consequently, regular monitoring of hearing thresholds is strongly recommended.
- If your child has an ear infection, seek medical advice immediately. An infection in the better ear will have a greater impact on the hearing.

- Parents are generally the best people to look for signs that suggest your child may not be hearing so well. If you think there is a change in your child's response, have your child's hearing tested immediately.
- Be aware of normal language milestones — keep a diary of all your child's language gains and compare this to normal milestones. Should your child not be progressing, seek advice from appropriate professionals.

About strategies —

“Our son now attends a play group for hearing impaired toddlers and we've been to information seminars for parents. The more we talk to the Audiologists and Teachers, the more we're learning about the strategies that we'll use as he grows. We're learning to be advocates for him into the future.”

About explaining to people —

“Sometimes it's frustrating when other parents ask why he isn't aided and treat his unilateral hearing loss as 'no big deal'. Some professionals take the same approach. Sometimes my wife feels the need to defend our son when people say he's not deaf.”

Types of hearing loss



Auditory Neuropathy/Dysynchrony (AN/AD)

What is Auditory Neuropathy/Dysynchrony?

Auditory Neuropathy/Dysynchrony (AN/AD) occurs when sound enters the ear normally, but the transmission of sound from the inner ear to the brain does not occur in a normal way.

It has been estimated that it occurs in about 1 in 10 children who are thought to have a severe to profound hearing loss.

AN/AD is a name for a pattern of test results and is not a diagnosis or condition.

What are the possible causes for obtaining these types of results?

This is still not as yet fully understood but some of the reasons may involve the following or even a combination of factors:

- Damage to the inner hair cells in the cochlea
- Damage to the hearing nerve itself
- In a few cases, the auditory system may not yet have matured

Risk factors

This pattern of test results appears to occur in patients who have risk factors such as premature birth, asphyxia or hyperbilirubinemia. Family history may be an underlying feature as well.

What are the effects of AN/AD?

- Various levels of hearing loss
- Fluctuating hearing loss
- There may be difficulty understanding speech clearly

How can AN/AD be managed?

The decision on management for AN/AD children is made by parents with the aid of your baby's health care team as would be the case for any hearing impaired child. Children with AN/AD benefit from an individualised plan.

A choice of management options may be appropriate for a period of time with the choice in most cases to change options later if necessary. The following may be considered in your child's case:

- Hearing aids
- Cochlear implantation
- Early intervention programs (refer to Section 6)

Important notes

Absence of or abnormal Auditory Brainstem Response (ABR) results does not necessarily mean a profound hearing loss. It does however mean that the type of intervention will not always be straightforward.

Many children with an AN/AD are able to make effective use of their hearing.

We cannot predict the impact of an AN/AD on the child at this stage, but a series of test results and observations from parents and professionals will help in determining the best pathway for your child.



Types of hearing loss

Severity of hearing loss

Good hearing is essential for the development of speech and spoken language. Early identification of hearing loss in babies and the appropriate intervention and/or treatment helps to reduce potential speech and language problems.

If your child has a problem with hearing we need to know how much loss is present (degree of loss), and what type of loss it is.

There are varying degrees of hearing loss, ranging from mild to profound. The degree of hearing loss is related to its potential effects on the child's development.

The following classifications of hearing loss describe the effects on the child's hearing.

Mild hearing loss (21-45dB)

If your baby has a mild hearing loss they will have trouble hearing at playgroup or family gatherings, even though they can often manage quite well in quiet situations.

Moderate hearing loss (46-65dB)

If your baby has a moderate hearing loss it is very hard for them to understand what you are saying, especially when there is background noise. With this level of hearing loss babies can be given hearing aids very early otherwise their speech and language development will be affected.

Severe hearing loss (66-90dB)

If your baby has severe hearing loss they cannot hear normal conversation and so they will not learn to speak naturally by themselves. They will need hearing aids and other assistance to develop speech and language as normally as possible.

Profound hearing loss (91dB+)

If your baby has a profound hearing loss they cannot hear people talking and cannot hear most sounds in the environment. Children with this degree of loss may be offered the option of having a cochlear implant. These babies will need assistance to develop speech and language as normally as possible.







Frequently asked questions

Why was the hearing loss diagnosed so early?

Newborn hearing screening programs, like SWISH, were put in place to identify babies with hearing loss as soon as possible after birth. Hearing screening at an early age is strongly supported by parents of children with hearing loss. While it can be upsetting and difficult in the beginning, parents recognise that early detection results in better outcomes for their child.

What is the advantage of having an early diagnosis?

An early diagnosis provides your baby with the opportunity of access to language and communication at the most important time for language development. Research shows that babies whose hearing loss is diagnosed early and who receive appropriate intervention will have improved speech and language outcomes. Communication and language, either spoken language or sign language, is important for learning as well as social and emotional well-being.

How does the Audiologist know for sure my baby has a hearing loss, he or she's so little?

The tests done with your baby to diagnose his or her hearing loss are highly reliable and objective. Your baby's ear, nerve and brain responses to sound are recorded on a computer. The Audiologist is trained to interpret the readings and diagnose hearing problems.

Will my baby grow out of it?

A baby's hearing can change as they grow older, but it is extremely uncommon for a child's hearing to improve as they grow. Devices such as hearing aids or cochlear implants can assist your baby to make the most of his or her hearing.

“To those parents who have just found out their baby is a ‘SWISH’ baby, I would advise you read as much information as possible at first. This was very confusing for us initially, but slowly you learn where you stand. We then used our own parental instinct (you can never be wrong with that). There is an abundance of help out there and we found everyone we spoke to be very helpful and kind. So be strong and stand up for what you believe.”

Frequently asked questions



Can it get worse? How will I know if it gets worse?

Some hearing losses can get worse over time. Your baby's hearing may temporarily get worse when an ear infection is present. Your professional team will closely monitor your baby's hearing. If you are concerned because your baby is not responding to sounds, you should discuss this with your Audiologist.

Can my baby hear any sounds?

The number of sounds your baby can hear depends on the type and severity of the hearing loss your child has. Most children with hearing loss are able to hear some sounds.

How will my baby be able to communicate?

Early diagnosis and intervention has given your baby the best chance of developing good communication skills. We all use various methods of communicating — speech, writing, gesture, hand movements and body language. Your baby will be no different. He or she may learn to communicate by speaking, or by using sign language, or a combination of both. You don't need to rush to make a decision about what is the best method of communication for your baby — for many families, it is a decision made over time as they get to know their baby and the needs of the family. Communicating with your baby is important, not how you do it.

Will my baby learn to talk?

Most children with hearing loss can learn to talk. How well they are able to communicate using speech depends on many factors, for example, how severe their hearing loss is, how much help they receive from hearing assistance and how much intervention they receive to assist them to speak.

Will we need to learn sign language?

Your baby may learn to communicate best using speech, or they may learn best by using sign language (or maybe even through a combination of both). If your child uses sign language you will need to learn signing to be able to communicate well with your child.

Many families find sign language convenient in situations where their child cannot wear a hearing aid or cochlear implant such as in the bath or at the beach. A number of organisations offer courses in Auslan (Australian Sign Language). Ask your Audiologist for information about courses in your area.

“We are advocates for our kids hearing whilst they are growing — and information is the key to supporting them well. I am learning that the more info I have, the better armed I am to be the best Mum I can be for them.”



Hearing loss and your baby: the next step

Frequently asked questions

Can I get a second opinion?

As always, you are free to seek a second opinion about your baby's hearing. Your GP or Early Childhood Health Clinic can advise about how to access a second opinion. The tests conducted in the first assessment are highly accurate, and you should be prepared that the results of the second opinion will more than likely match the first test results.

There are a number of other areas on which you may want to seek a range of advice, such as the best early intervention service for you and your baby. The more you know about your options, the more confident you will feel in managing your baby's hearing loss.

What caused my baby's hearing loss?

There are many different causes for a baby's hearing loss. The hearing loss may be due to genetics, an illness your baby has had, or the way he or she grew before being born. Often there is no apparent cause for a baby's hearing problem. Your Paediatrician will be able to provide further information about the cause of your baby's hearing loss.

What other tests can be done?

If you would like more information about the cause of your baby's hearing loss, your Paediatrician can recommend various tests which may help to indicate the cause of the hearing loss. Sometimes, it is also recommended that other members of the family have their hearing tested.

Will the doctor find that anything else is wrong?

In some babies, hearing loss can be linked with other problems eg. cleft palate, heart problems and some syndromes, but most often parents are already aware of these problems before the hearing loss is diagnosed. Your Paediatrician will discuss all the areas of your baby's health and development with you on your visit.

If I have another baby, could he or she have a hearing loss?

If the cause of your baby's hearing loss is genetic, there is a greater chance of having another child with a hearing loss. You should ask for genetic counselling if you are concerned.

What is the difference between hearing impaired and deaf?

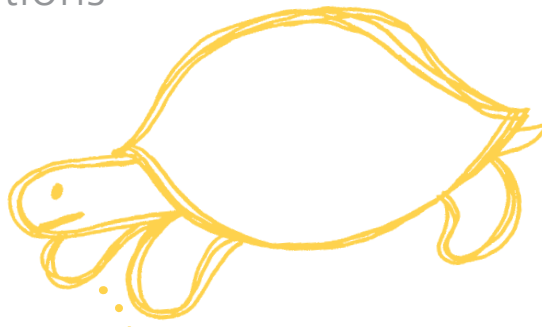
Hearing impaired and deaf, along with other words such as hard of hearing and hearing loss, are all used to describe people who have difficulty being able to hear a range of sounds clearly.

In general, people who are hearing impaired or hard of hearing mainly use their hearing (with the assistance of amplification such as hearing aids or cochlear implants) to communicate. People who are deaf mainly rely on their vision to communicate, for example, lip-reading or sign language.

Will my baby have to wear hearing aids forever?

Hearing aids will help your baby to make the most of his or her hearing. The Audiologist at *Australian Hearing* will discuss this further with you.

Frequently asked questions



Will a cochlear implant help?

Cochlear implants are most helpful for children who have severe to profound levels of hearing loss and receive little benefit from hearing aids. Cochlear implants are not suitable for all types of hearing loss and involve complex surgery and ongoing therapy. The Audiologist at *Australian Hearing* will discuss with you whether a cochlear implant may benefit your baby, and refer you to a cochlear implant centre, if necessary.

Will my child need to go to a special school?

Most children with hearing loss attend mainstream schools. Some children need extra help in the classroom, and some need to be involved in classes designed to help children with hearing losses. Getting the right help to ensure your child learns well is the most important consideration.

As a parent of a hearing impaired child, will I be able to return to work or study?

While he or she is young your child will need extra help to learn to use their hearing and learn to communicate. This will involve regular appointments with and visits from many professionals. You will also need to do activities at home with your child to help them to learn. Because of the time these activities will take, you may need to reconsider the priorities for your family. Some parents postpone their return to work while others find returning to work manageable.

Can I get financial help for travel costs?

Please refer to Section 7.

What other assistance is available?

Please refer to Section 7.

“Research and learn as much as you can about the subject in question. Do this by talking to professionals, by reading literature on the subject, but most importantly, network with other parents. And remember, there is no right way for everyone — you just have to watch and look for signs that a certain method is not working and be prepared to be flexible!”



Communicating with your baby

Communication

Your baby's hearing loss has been identified early which is best for the development of good communication skills. Your baby may learn to communicate in a number of different ways through speaking, sign language or a mixture of both.

The decision does not need to be made now. There is no 'prescription' — the best communication method will depend on your baby's individual needs and what works for your family.

Tips for parents

Effective communication begins at birth through...

- Sound and gesture
- Facial expressions
- Cuddling and holding your baby
- Hugging
- Touching and playing games
- Making funny faces
- Gazing into your baby's eyes

How do babies communicate?

- Smiles — 'I'm happy'; 'Let's play'
- Crying — 'I'm hungry, wet, in pain'
- Coos — 'I feel good'.
- Squealing — 'Do it again!'
- Vocalising
- Pointing & reaching — 'I want that'

Bring the child's focus to your face

- Talking encourages your baby to look at your face. This will help him or her as he or she learns to read lips and/or speak.
- Look into your baby's face from about 20 to 25cm away — the best distance for babies to focus.
- Even if you decide to use sign language, your baby will need to watch your face.

Get baby's attention before you talk

- Move hands and body so your baby can see you are talking to him or her.
- Encourage your baby to focus on your face — move a toy near to your baby's face, then move it to your face so he or she looks at you when you talk.
- Tap on the toy several times before you say something about it.
- Touch your baby's arm or foot to get him or her to look at you, then start your conversation.

Changing the environment

- Minimize the distance between you and your baby when talking to him or her. Come even closer in a noisy environment.
- Move away from or reduce background noise when you want your child to listen to you.
- Position your baby so that you are often within sight.
- Ensure there is good lighting in the room.