SOUND WAVES

INFORMATION FOR PARENTS ON UNILATERAL HEARING LOSS

aussie deaf kids

Acknowledgements

This information was developed by Aussie Deaf Kids, an organisation dedicated to improving the outcomes of children with a hearing loss by providing support and information to families raising a deaf or hard of hearing child in Australia.

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A special thanks to the parents in our online group who have provided their experiences and insights into the information families need in the journey with their child with a unilateral hearing loss.

Dear Parents

When your young son or daughter has been diagnosed with a unilateral hearing loss, it is not an easy time for families. The diagnosis often comes as a shock. Most parents know little about hearing loss in children and there is a lot to learn.

My daughter was diagnosed with a profound unilateral hearing loss in her left ear when she was 4. It did not come as a bolt out of the blue—she had been slow in talking—but the diagnosis consumed me for a while. I tried to imagine what the world must sound like to her. I thought of all the stories I had read to her that she had probably never heard properly and I thought of all the times I had whispered 'I love you' in her left ear. A thousand questions ran through my head – the biggest one being about starting school. I wanted a crystal ball to see what the future might hold.

What I have learnt is that while I worried about her, she simply got on with the job of living a full and independent life. With our love and support along the way, she has followed her own dreams and become the person she wants to be.

All of our stories are different. Whether we find out our baby has a hearing loss through newborn hearing screening or later in childhood, we need information and knowledge to guide us to make decisions and help us raise a happy, confident and independent young person. Living with unilateral hearing loss is different to living with a hearing loss in both ears or hearing in both ears and it is evident from the messages posted to the Aussie Deaf Kids online group that finding information about unilateral hearing loss, its impact on a child and how to successfully manage the hearing loss has been difficult for families.

This is a guide to help lay the foundations for your child to grow into a healthy adult—a person who works, plays and loves. We have drawn on the current research on unilateral hearing loss as well as the experiences and thoughts of families who participate in the Aussie Deaf Kids online group.

Thank you to the parents in our online group who have shared their thoughts and wisdom. Aussie Deaf Kids could not have produced this information booklet without assistance of the Inger Rice Foundation. We are very grateful for their support.

Ann Porter AM
Founder, Aussie Deaf Kids

P.S. We have used the abbreviation UHL (unilateral hearing loss) throughout; it is a term you will become very used to.

You are worried about seeing him spend his early years in doing nothing. What! Is it nothing to be happy? Nothing to skip, play, and run around all day long? Never in his life will he be so busy again.

~Jean-Jacques Rousseau, *Emile*, 1762

While we try to teach our children all about life, our children teach us what life is all about.

~Angela Schwindt

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Using this guide

This guide is divided into two parts:

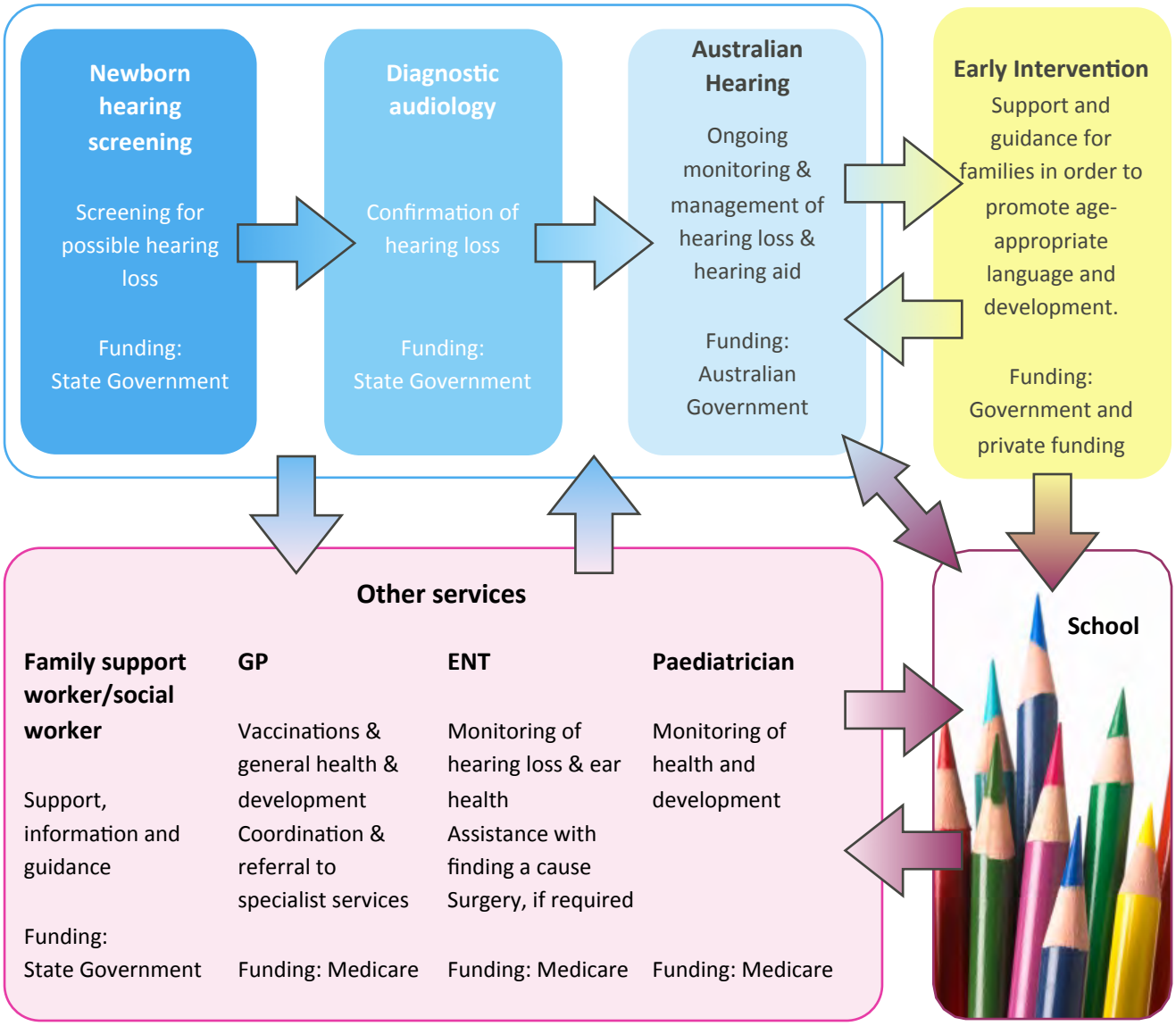
Part 1: *Road Map for Families* provides information, hints and tips to help you explore what your child's hearing loss might mean for you, your child and your family from the time of the diagnosis through to when your child starts school. It will help you lay the foundations for a successful, healthy life for your child.

Part 2: *Understanding UHL* provides technical information about unilateral hearing loss to help you make sense of the physical aspects of this condition. It also explains the various devices available to optimise your child's hearing and provides links to further information.

Quotes

You will also notice quotes scattered throughout the guide from parents of children with UHL. These are true reflections that other parents want to share with you. We are sure that many of the sentiments will resonate with your own experience.

THE PATHWAY FROM NEWBORN HEARING SCREENING



PART 1: ROADMAP FOR FAMILIES

THE FACTS IN BRIEF

A unilateral hearing loss (UHL) affects one ear only. The child can hear normally in one ear and has some difficulty hearing with the other ear. The hearing loss can range from a mild loss to a profound loss where the child hears very little with that ear.

Approximately one in 1000 children is born with UHL and this can be detected through a newborn hearing screening program. UHL, however, can occur throughout life and it is possible for a child to acquire a unilateral hearing loss anytime after birth.

1. The good news:
   - your baby can hear
   - your baby will speak, read and enjoy music
   - there is technology available that can improve your baby's ability to hear and listen.

2. A child with unilateral hearing loss may have difficulty:
   - understanding speech in noisy environments
   - identifying where a sound is coming from
   - hearing when someone speaks on the affected side.

3. You need to keep in mind that:
   - unilateral hearing loss has the potential to have a impact on your baby's learning, communication and socio-emotional development
   - some children with UHL may need assistance to develop age-appropriate speech and language
   - a small percentage of children with UHL will lose the hearing in their hearing ear.

4. With your love, support and commitment your child:
   - will attend mainstream school, make friends and play sport
   - can develop age-appropriate speech and language skills.

You can start today to help your baby achieve his or her language and learning milestones.

"Eventually you realise that you have a child that can accomplish everything and more! You will see that with determination and support they will get through their school years and out into our wonderful world!"
[Parent]

LAYING THE FOUNDATIONS

Finding out our baby has a hearing loss can be a difficult time for families. Most children with a hearing loss are born to hearing parents who have no idea about hearing loss in children. There is usually no family history of deafness. It is hard to get things into perspective.

It is fortunate that the thing your baby needs most at the moment is loving and responsive care. We know a lot about the development of a baby's brain and it is clear that what a baby experiences in the early years will profoundly affect how his or her brain will develop. You will play an important part in providing the nurturing and stimulation your baby needs for healthy cognitive and emotional development.

The simple things are important from the beginning:

- Loving attention - healthy early development needs nurturing and dependable relationships
- Meeting your baby's needs for food and comfort. Responding lovingly to your baby's cries gives them the safety and security they need to start exploring the world
- Talking and singing
- Reading from an early age
- Playing simple games

All these activities and interactions with people are "vital nutrients for the growing and developing brain." [1] Even though you are in the process of making decisions about the management of your baby's hearing loss, you can be laying down the foundation for future success and learning.

Start communicating today

Babies start communicating right from birth. They communicate their feelings and needs to us very efficiently by crying. Babies understand our communication too. They calm when they hear a familiar voice. They listen intently and watch our faces when we talk and sing to them. They are developing the skills they need to understand language.

Communicating with your baby with UHL is no different to any other baby and there are plenty of opportunities throughout the day to chat to your baby and enjoy the interaction you share.

- Talk to your baby throughout the day. Let him or her know what you are doing. 'Mummy needs a cup of tea. Should we put the kettle on?' 'I can hear Daddy's car!' 'Let's go for a walk and get Sophie from preschool.'

- Babies love that high-pitched sing-song voice that adults use when talking to them. Parents across many cultures use 'motherese.' We speak in a higher pitch and accentuate the words. There is abundant evidence that this attracts a baby's attention and helps the baby to understand speech.[2]
- Sing songs and rhymes. Rhymes can play an important part in language development. Babies love the high pitch, slow pace and rhythm. Rhymes spoken in this way help babies to isolate individual sounds and trains babies to hear individual sounds in words clearly. 'Rhymes continue to promote language and communication skills. They provide repetition of familiar words and actions, and opportunities for imitation, turn taking, making requests and having requests understood.' [3]
- Read to your baby. Your baby will enjoy being close to you and listening to your voice. From the beginning, your baby will look forward to these shared times together and you will be building the foundations for a love of language and reading.
- Read the same books over and over again. Children love to hear a story again and again. 'Before long they begin to understand the look of print, the way words work in sentences, and how the world works—why this happens, and that happens—and how it all come together to mean something. In other words they learn to read.'[4]

When you are sharing these special moments, be close to your baby. Nappy changing is a great time for chatting and singing. This can be gentle soothing songs or more boisterous action rhymes.

If you are sitting with your baby in your lap, have him or her facing you, so he or she can see your facial expressions and hear you clearly. When reading to your baby, make sure the better ear is closer to you and remember to whisper I love you in that ear too!

Age-appropriate language

The impetus for newborn hearing screening was the research that showed that babies who were diagnosed with a bilateral hearing loss early and received good early intervention, were likely to have age-appropriate language when they started school. So the goal for your baby with a unilateral hearing loss is the same, i.e., age-appropriate language.

"Watch your child's milestones but remember that children develop at different rates. Have their speech and development monitored by a professional for a 2nd opinion." [Parent]

Your baby may not receive early intervention but by surrounding her with language at home and keeping an eye on her language development, you are keeping an eye on your goal of age-appropriate language.

There are many speech and language milestone charts available, including on the Aussie Deaf Kids website. Children develop speech and language at different rates and these are a guideline only. If you are ever concerned about any aspects of your baby's development consult your GP for advice.

Further reading

- Language and Learning: Babies and Toddlers http://www.aussiedeafkids.org.au/babies-language-and-learning.html

COMING TO TERMS WITH YOUR CHILD'S HEARING LOSS

"Speak to your support network and family and explain what is going on. I actually wrote up a sheet with the information..." [Parent]

When a baby is diagnosed with a hearing loss, parents feel a myriad of feelings and hundreds of illogical thoughts race through our heads. This is all quite natural. We may feel sad, angry, confused, vulnerable and guilty. Most of us cry. The thought of what may lay ahead for your baby can be overwhelming. Fortunately, most of us are very resilient and these feelings turn into positive action. We start coping with this new reality.

Coping successfully

The support of family, friends and professionals is so important in coming to terms with your baby's hearing loss. Don't try and do this alone.

Having a baby with a hearing loss affects the whole family. Parents may feel and react differently. Talk to your partner about how you are feeling and be aware of their needs as well. It can also be beneficial to share your feelings with family and friends you trust and love. Being honest and open with family and friends will help them understand that it is OK to talk about your baby and his or her hearing loss and help you to better deal with the situation. If you have other children, be aware of their feelings and needs.

In the first few weeks after your baby's diagnosis, it can be difficult to concentrate and 'get your act together.' Accept help from family and friends. A good meal, babysitting or taking your other children to school are all things that will help you and allow them to show you that they care.

Take care of yourself. Eat well and get as much sleep as you can. Exercise is a wonderful way of relieving stress and providing a sense of well-being. A walk each day is good for you and your baby!

If you are finding it difficult to come to terms with your baby's hearing loss, talk to a counsellor. All the newborn hearing screening programs have social workers or counsellors who can listen to you and help you work through your feelings and overcome any obstacles.

'Grief becomes a sadness that enables parents to appreciate what they have; anger becomes energy to make changes; guilt becomes a commitment; recognition of vulnerability becomes a means by which parents reorder their priorities; and the resolution of confusion becomes motivation for learning.' [5]

Many parents of newly diagnosed babies also find it helpful to talk to other parents who have walked the road before them. The bond between two parents with similar life experiences can be quite special. We realise we are not alone – there is someone else who understands. You can ask the newborn hearing screening team about parent mentoring or parent groups in your area. Aussie Deaf Kids has an online group for parents whose children have a unilateral hearing loss.

We do tend to continue to ride the roller coaster of emotions throughout the life of our child. Times of transition and change, particularly, can bring back some of those feelings; it is part of being a parent.

"Allow yourself time to be sad (but not in front of the child), it is a huge shock for us, but it's just life for them!!" [Parent]

"When we received the diagnosis it was a huge shock, how, why, what next.... I went into over drive trying to do everything possible to make it better. " [Parent]

Myths and facts about grief[6]

MYTH: It's important to 'be strong.'

FACT: Feeling sad, confused and overwhelmed is a normal reaction to finding out your child has a hearing loss. Crying doesn't mean you are weak. You don't need to 'protect' your family and friends by putting on a brave face. Showing your feelings can be a help to you and them.

MYTH: If you don't cry, it means you are not sorry about the diagnosis.

FACT: Crying is a normal response to sadness, but it is not the only one. You may feel just as sad as others but have other ways of showing it.

BUILDING A GOOD TEAM

As the parent of a child with UHL, having a good team of health professionals around you who can guide and support you is invaluable.You and your family are the most important people on your baby's team. Professionals will come and go but you are there for the long haul. If you have a good rapport with your team members, you will feel more comfortable expressing your concerns and communicating your needs to them.

General Practitioner

Finding a good General Practitioner (GP) can be a useful asset for the whole family. Build a relationship with your GP. Educate your GP about UHL. Your GP can be a great coordinator when you are seeing a number of different services and specialists. Your GP will be able to make appropriate referrals to a paediatrician and Ear Nose and Throat surgeon (ENT) who will monitor your baby's development and hearing. It is often useful to ask for recommendations from family and friends with young children about good GPs in your area.

Audiologist

After the diagnosis of a hearing loss, children are referred to Australian Hearing. Australian Hearing is a Commonwealth Government Authority that provides a full range of hearing services to children and young people up to 26 years of age. If your child is not fitted with a hearing aid, your Australian Hearing audiologist will work out a management plan with you. This is likely to include a combination of routine hearing monitoring, usually by the audiologist who initially referred you and reviews at key stages of your child's development at the Australian Hearing centre. If your child's hearing will be monitored by an audiologist outside Australian Hearing, you want to find an audiologist with experience working with young children. You may need to do a bit of research to find a suitable paediatric audiologist. The Audiological Society of Australia has a directory of audiologists on their website.

Family support worker

Newborn hearing screening programs usually provide access to either a social worker or a family support worker. Their role is to guide and support you until you are engaged with the appropriate services. The social worker or family support worker can help you with information about hearing loss and early intervention services for babies with UHL. They can advise you about any financial or other assistance that may be available to you.

Parents talk about parent-to-parent support

"Finding [Aussie Deaf Kids] was the best help in the early days. You tend to get bogged down with so much information you read and find online. However, chatting with real people, who share very similar stories is the best help you can get." [Parent]

"Speak to other parents who are going through the same or similar thing. They often have tips that can help you negotiate the bumps ahead." [Parent]

"I am greatly thankful… for all the information and support in past 3 years which this online group has given me, right from my darkest hour of bringing myself to terms with the diagnosis in my child to being able to enjoy his infancy and childhood immensely and normally as I should." [Parent]

Early intervention service

Early intervention provides services to families to assist their child to get the best start in life. The goal of early intervention is to help the baby with a hearing loss to learn to communicate, to use any available hearing and to interact socially. The professionals at the early intervention services have special training in hearing loss, its management and language development.

Early intervention for children with UHL is a new area and may not be available to all families, particularly those in regional and rural areas. Your audiologist or family support worker should be able to tell you about early intervention services for children with UHL in your state. You may need to pay a fee for early intervention but this should not deter you. If cost is a problem, visit the early intervention services and talk the issue through with them.

When attending appointments

- Take a list of questions with you. We often forget the most important questions when we visit the doctor or audiologist.
- No question is too silly – someone has always asked the same question before you.
- Make sure you understand the answers to your questions – don't go home confused. Ask for a professional interpreter if you are not fluent in English.
- Make sure you get copies of reports and test results for your records. These can be very useful over time.
- It is OK to question a professional's recommendations or ask for a second opinion. You must feel comfortable with the management of your baby's hearing loss.

Parent mentor

Parent-to-parent mentoring programs are available in some states. Parent mentors have children with a hearing loss and have been trained to guide and support you in the early days. Many parents of newly diagnosed children find that talking to another parent with a child with UHL is very helpful. They have the understanding and knowledge that comes from the lived experience.

Aussie Deaf Kids has an online group for parents of children with UHL. Parents share ideas, information and experiences and learn from each other.

Parents talk about professionals …

"I have been impressed with the way that the system has proceeded. We have had wonderful people help us along the way and follow up on how things are going." [Parents]

"I would have loved to have professionals (doctors) support with unilateral hearing loss rather then just be told not to worry about it the child will cope fine (which as a mother I knew was not so)." [Parent]

"I think professionals need to be more up to date in their knowledge of UHL. The old 'they can hear in one ear so will be fine' theory is outdated, but unfortunately still what the majority of parents are still hearing."

CREATING A GOOD LISTENING ENVIRONMENT

You already know how important it is to fill your child's life with language. You want your child with UHL to clearly hear all the songs you sing, the stories you share and the snippets of conversations that make up your family life. As hearing parents, the things we take for granted are not always easy for a child with UHL. But you can take some steps to create an environment at home that will make it easier for your child to listen.

The three main barriers to understanding speech for anyone with a hearing loss are:

1. Distance from the sound
2. Background noise
3. Reverberation

Distance from the sound

Loudness and pitch of sound, as well as the distance from the sound, are all important in our ability to hear. Children with a hearing loss will have a reduced hearing range. Your child may have difficulty understanding what you are saying when you are talking from a distance.

Fortunately, much of our communication with young babies is done at close range – they are usually only an arms length away as we cuddle, play and attend to their needs.

You do need to be aware of the impact of distance on your growing child's listening ability. When you call from the next room for your child to put away the toys and they do not do it, they may not have heard your request. This is one of the dilemmas of being the parent of a child with a hearing loss – have they not done it because they couldn't hear properly or are they being disobedient?

Background noise

We all know the experience of trying to make out what someone is saying to us in a bar or a rock concert. We know the person is talking to us and we can probably catch a few words and get the gist of the conversation. We probably know something about the topic and can use our knowledge and experience to understand what is being said. And we are hearing with two ears.

Background noise is a problem for all children and anyone with a hearing loss. Young children are unable to 'predict from context.' They have limited vocabulary and experience and can't fill in the missing pieces as adults can. For children with normal hearing, their ability to understand sentences in noisy environments does improve through the early childhood years. They reach adult levels of speech understanding in noise in their teens. Children and adults with a hearing loss will always find background noise challenging.

What can you do?

Homes with young children are noisy places. It is part of the fun of having children! But there are times when limiting the background noise can make it a lot easier for your child with UHL to learn and understand what is being said.

- Read to your child in a quiet environment and make sure their hearing ear is closest to you.
- Turn off the TV/radio/music at mealtimes. Sit at the table together and chat.
- Vacuum cleaners, washing machines and lawn mowers all make it very difficult for your child to understand what you are saying to them. Be aware of this if you are giving them instructions or warning them about something.

Families spend a lot of time in the car and these can also be difficult listening environments for the child with UHL.

- If you are chatting to your kids in the car, turn off the radio and wind up the windows. Your child with UHL should be sitting with their ear with the hearing loss closest to the window.
- If you are listening to music or a talking book, wind up the windows.

Reverberation

Reverberation is the persistence of sound in a room after the original sound has stopped - like an echo. A room with 'good acoustics' is designed to reduce reverberation and makes it easier for understanding speech. Reverberation time depends mainly on the size of a room or space and the surface materials used in the room. An empty bedroom with wooden floors has a longer reverberation time than when the room has carpet, furniture and curtains.

What can you do at home?

Reverberation is usually more of a problem for children in the classroom than at home. However, contemporary homes with open plan living, timber floors and blinds on the windows are not the easiest listening environments for anyone with a hearing loss. Soft furnishings that absorb sound will reduce reverberation and make listening and understanding easier at home.

- Carpets are better than hard floors
- Curtains are better than bare windows or blinds

Small things can make a difference in improving the listening environment for your child at home. Reducing noise and reverberation will help your child to listen and understand speech and participate fully in your family's life.

SOUND LOCALISATION AND SAFETY

One of the difficulties people with a unilateral hearing loss have is understanding where a sound is coming from. We need sound to reach both our ears to localise the sound. Our brain receives the sound signal from both ears and is able to interpret where a sound is coming from with accuracy.

With a unilateral hearing loss, your child's brain may only receive the signal from the better ear and, while your child will hear the sound, she will not be able to tell where it is coming from. The greater the degree of hearing loss, the more difficult localising sound will become.

The most noticeable difficulty for families is when calling your child. You will need to tell them exactly where you are or they will not be able to find you.

Road safety

An inability to localise sound has a more important impact—safety, particularly on the road. Good road safety behaviour starts early. Children learn from watching their parents and they copy their behaviour. Set a good example from the start:

- Cross at traffic lights
- Don't cross the road between parked cars. Children cannot see an approaching vehicle and the child with a unilateral hearing loss may not hear the car or know which side the sound is coming from.
- Car parks can also be hazardous for the same reason.

Generally, children under 10 need active adult supervision when crossing the road. They have difficulty judging how far away a car is and how fast it is going. Children also find it hard to identify if a place is safe to cross the road. Learning to cross the road safely takes time and practice. Walking with your child to the shops or school is an ideal time to teach how to cross the road safely.

You may need to modify 'Stop – Look – Listen' when teaching your child about road safety.

STOP: 'Is this a good/safe place to cross?'
LOOK: 'Is the car coming towards you or is it driving away?
'Is the car going fast or slow? Can the driver see you?'
LISTEN: 'Can you hear any traffic? Remember you need to look and see where it is coming from!'
THINK: 'Do you think it is safe to cross now?'

Bicycle safety

All children need to be taught cycling safety. Start teaching them good riding habits when they get their first bike. Children with a unilateral hearing loss may experience two additional difficulties when riding their bike.

- When riding on the pavement, they may not hear when a car is pulling out of a driveway and the driver may not be able to see them. They need to be taught to be cautious at each driveway.
- When riding on a bike track, they may not hear another bike coming from behind or be able to decide which side to move when the rider rings their bell. Rear vision mirrors or learning to ride on the left side of the path so that other bikes can overtake easily may avoid a few unnecessary mishaps.

Talking to your child about their UHL and the extra precautions they need to take will help them to understand their responsibilities and keep them safe.

MAKING INFORMED CHOICES

Parents are faced with all kinds of decisions throughout the life of their child. As the parent of a child with a unilateral hearing loss, these decisions may be about choices that are new to you. Most families know little about hearing loss when their child is diagnosed.

Knowing you are making the right choices at the right time can often be clouded by stress or by the differing views of professionals, family and friends. The amount of information given to you can be overwhelming given the complex nature of many of the issues. How can you make the right choices?

Understanding informed choice

Each of the two words in 'informed choice' highlights an essential aspect of the decision-making process. Parents need to be informed about their options, but this is not sufficient. Parents also need choices. The choices may not always be available but you need to know about them so you can weigh up all your options.

The purpose of informed choice is to ensure that all parents decide for themselves on the care that best suits the needs of their child and family. Every family is different and the choices you make should reflect your family's desires, beliefs and values.

This does not mean you need to make these decisions on your own. The relationship you have with the professionals looking after your child is an important one and should be seen as a partnership of two experts. The professionals are experts on hearing loss and you are the expert on your child and his or her needs. The professional's role is to help you think through the decision-making process, focus on key issues and evaluate your options.

"If you are not happy with a doctor, health care professional, school, etc, it is Ok to question them and to get 2nd opinions. I have found that not everyone has the same opinion on treatment or the options available. But again, being informed and knowledgeable is helpful." [Parent]

"Find as much as possible about the condition that you are facing. Have the facts so that informed conversations can occur with doctors, teachers and other people that you will be in contact with. Knowledge is power." [Parent]

Becoming informed

Reliable information is crucial if you are to make an informed choice. There are many ways for you to find the information you need:

- Face-to-face discussions with professionals and service providers
- Written information
- Talking to other parents with a child with UHL
- Websites, blogs, online groups
- Discussing your options with family and friends.

Wherever you find information, it must be reliable, up-to-date and should be based on good research. However, there are a number of areas of hearing loss where research is ongoing. Research may not always be conclusive and you may not always be able to find definite answers.

The information you get from other parents may not be based on research but on the 'lived experience.' This can provide you with some valuable insights into how a chosen option may affect your child and family. Remember this information may be coloured by the views and experiences of the individual, so do not rely on this information alone. Compare their experiences and information with other sources and seek the opinion of professionals looking after your child.

You should feel confident that you understand the information and what each option means for your child and family now and in the future. Don't be afraid to ask questions. When someone uses a word you don't understand, ask that person to explain what the word means. Discuss the information with a trusted professional and ask questions. Don't be afraid to say what you think and know.

Comparing options

- What are the options?
- What would happen if I did nothing?
- What are the possible benefits and risks of each option?
- How would this decision affect my child?
- How would this decision affect our family?
- How much time do we have to make a decision?

Be an active decision-maker

Parents who participate actively in the decision-making process, e.g. by asking questions, giving their opinions and expressing concerns, make better decisions.

You can become an active decision-maker by seeking information about your options from a variety of sources. Prepare your questions before visiting your service provider. Ask these questions and expect to receive answers. Some parents are reluctant to ask questions. They worry about appearing ignorant or are concerned about challenging the professional's authority. Remember there is no such thing as a silly question. Be confident in your knowledge as the parent of your child and your ability to play an active role in the decision-making process.

What to do if your choice is not available

For parents to be fully informed of their choices and options, professionals should discuss all choices, even those that are not readily available to your family. It is not appropriate for the professional to filter or censor the information or gently lead you to make decisions that fit comfortably with the available options.

The reality is that the choice or option you decide is best for you may not always be available.
You can do several things in this situation:

- Ask for support from your professionals to see if your choice can be made available.
- You could consider a compromise that you feel is acceptable.
- You could consider taking the big step of moving to an area where the service you want is available.
- You could lobby for change. Many services for deaf children in Australia were developed because parents knew about them and then lobbied governments and service providers to offer that service to their children. This is not an easy road and can take a lot of time and energy. You could consider meeting with other parents who want a similar service and make a case for it to be introduced in your area.

Making decisions is not always easy

Making decisions can be difficult and it can be tempting to think the professional knows best. The professionals are the experts in their area and sometimes have strong views about one choice or another. This can be confusing and difficult at times. But you know your child and situation better than anyone. The choice should be yours alone. Trust your instincts as a parent and if you feel you need more time or more information, the professionals should help and support you in this.

Decisions are not set in stone. You can change your mind although some decisions are more difficult to change than others. Choices that are right when your child is young may no longer be appropriate as they grow. Don't blame yourself if a previous decision has not worked out. You made the best decision you could at the time. You might want to look at other options now. A professional can help you to re-evaluate your options and support and guide you in making new decisions for the next stage of your child's life.

Migrant families and Indigenous families making decisions

Informed choice is particularly difficult for families from different cultures and families that speak languages other than English such as some migrant and some Indigenous families. The information you need may not be available in your home language.

You should feel confident that you understand your options and have been given the information and support you need to make the right decisions. These decisions should meet the needs of your child and reflect your family's culture, beliefs and values. Ask for an interpreter. Ask for information in your first language. If this is not available, ask your professionals to assist you to find the information in a language or format that you understand.

ADVOCATING FOR YOUR CHILD

Parents want what is best for their children. They also understand the needs of their child and are the best people to speak up on behalf of their child to get the services and support they need. It is an unfortunate reality that the services and support you think would benefit your child, are not always be available for a child with UHL. As parents, you may need to go into bat for your child. And to do this effectively you will need to learn to advocate.

Advocacy is about speaking on behalf of your child to negotiate for services and support. The time where many parents with a child with UHL need to become effective advocates is when their child goes to school. But there will be many situations before school that your advocacy skills can benefit your baby. Finding early intervention and starting child care or preschool are all situations where you may need to negotiate for your child's needs.

Being an advocate for our child is not always easy. You need to know what you want for your child. You need to be well-informed. You need to plan and prepare. You will need documentation to support your arguments. You need to negotiate - to be calm but assertive.

"Be an advocate for your child. Unfortunately we have to be 'pushy' at times so our children get what they are entitled to." [Parent]

There are a few things you can do in preparation.

- Maintain a good working relationship with the professionals working with your child. Ask them questions and make sure you understand the answers. Don't be afraid to contact them; you will probably learn from each other's perspectives.
- Become informed about unilateral hearing loss and possible effects and outcomes for children with UHL.
- Keep up to date on the research and any new or discontinued services for children with UHL. Joining a peak body such as Deafness Forum will keep you up-to-date on all issues around hearing loss in the community.
- Learn the rules, terminology and jargon. For example, Pamela Wright in her article, *Advocating for your child—getting started,* [7] says that terms such as 'appropriate' education or 'access to the curriculum' are more effective terms than 'the best' education when advocating for support at school.

- Keep good records. This may include reports from professionals or written notes from a phone call or meeting. A follow-up letter or email after a phone call or meeting will clarify for everyone what was said and what was agreed.
- Learn how to state your case clearly, calmly and confidently to achieve maximum benefit for your child.

Teach your child

In turn, you can teach your child to advocate him or herself. You will not always be on hand to speak up on your child's behalf. Give your child the confidence to speak up and be clear about their needs. Your child could benefit from meeting someone older than them with a unilateral hearing loss – sharing personal experiences with a mentor can provide confidence and guidance for young people negotiating their needs at school and the wider world.

Parents talk about advocating for their child

"Be the advocate for your child. Nobody else is going to know exactly what your child's needs are or how they are going to need support or help. Go about it in a friendly way and ask for help. Ask, 'what can you do for my child'. Quite often if you ask, help can be given."

Parents talk about their child speaking out

"He actually tells people that he is hearing impaired on the right side and can they talk on the left side." [Parent]

"From an early age we encouraged her to tell people she couldn't hear on her left side. She was always good at making sure she sat where she could hear properly. It made it a lot easier for everyone" [Parent]

KEEPING RECORDS

As the parent of a child with a hearing loss, you will accumulate a lot of paperwork. Keeping good records that are organised and easy to find is a good idea.

Why is keeping records important?

There are a few good reasons to keep records:

- To keep track of who you see and the outcome of each visit. Ask each professional to send a copy of their report to you for your records.
- To keep an accurate medical history for your child. You will be asked the same questions again and again and it helps to have all the information in one place.
- Keeping records such as test results and school reports, shows you how your child is progressing and can help you decide when changes may be needed.
- There may be times when you need to advocate for your child to receive the services or support they need. Good records and documentation is vital in assisting you to be a good advocate for your child.

Getting started

A complete well-organised record system needs a bit of effort on your part but will save you time and frustration in the long run. Motivating yourself to get started is the first step. And then developing a routine for maintaining records will help you keep up-to-date relatively easily.

The following list of possible records may help you get started:

- list of professionals and their contact details
- medical reports
- audiograms and audiological reports
- educational assessments and reports
- important correspondence (mail and emails) from professionals and service providers
- manuals and warranties for any devices
- records of repairs and replacement parts for hearing aids and other assistive listening devices.

Although one parent will probably take responsibility for keeping the records together, it is a good idea for the other parent to know about the system, e.g., where the records can be found and what they contain.

How should you store the information?

Having one place to store records can save time and energy. You can decide whether to store information in hard copy format or organise a computerised system. Personal electronic health records are also options which allow you to access your health records anywhere in the world.

1. Hard copy records
   This is the simplest system. All you need are a few files, an index system and a hole punch. The system doesn't need to be elaborate but needs to be organised, complete and kept up-to-date.

2. Computerised records
   Paper records can become bulky over time. A system on your computer may be more convenient. Remember to back the information up regularly. Maintain your computerised records by scanning any documents or asking the professional to email you a copy for your records. As with hard copy records, the system should suit your needs and be easy to organise and keep up-to-date. Having information in digital format is also convenient when you go on holiday. Copy the latest audiogram and reports to a USB memory stick and keep this in your suitcase - you have no way of knowing when it may be needed.

STARTING SCHOOL

Starting school is an exciting time in any child's life. It can also be a time of some stress for families with a child with UHL. Is my child ready to start school? Which school will best suit my child's needs? Will the school provide the right listening environment for my child? All these questions need to be considered when choosing a school for your child.

A school will appreciate knowing well in advance (at least six or nine months before school starts) that your child will be attending their school. This will give them time to prepare for your child's arrival.

Is my child ready to start school?

School readiness depends on many things, including the child's age and level of maturity. Listen to the advice from preschool teachers and health professionals and weigh this up against what you know about your child.

Providing a stimulating learning environment at home will set the foundations for a successful transition to school. These include:

- reading a wide variety of books to your child including fiction, non-fiction, nursery rhymes and poetry
- visiting interesting places and providing them with a broad range of experiences
- playing with numbers and letters
- giving your child opportunities for social interaction with family and friends
- supporting and nurturing your child's early friendships
- teaching your child about their hearing loss and what they need to do to hear properly e.g. your child should know where to sit to hear the teacher
- giving them opportunities to advocate for themselves - you will not be at school all the time to do this for them
- building their confidence in small supportive settings so that they feel comfortable getting their listening needs met when they are at school.

Which school will best suit my child's needs?

Choosing the right school for your child with UHL can be a difficult decision. You will need to start your research and preparation early. Children with UHL will attend mainstream schools and it is unlikely that they will receive any additional support at school. So you need to be sure that the school will be understanding of your child's needs and provide him or her with assistance they need to have full access to the curriculum.

It is a good idea to visit the schools in your area and get a feel for each one. You might like to visit the school on one of their open days. Take your child along and get some idea about what they liked and didn't like about each school. Talk to other parents and children attending the school – they can provide you with valuable insight into the school community. And, finally, make an appointment to visit the school, talk to the principal and have your questions answered.

Will the school provide the right listening environment for my child?

Children with UHL need to concentrate harder to listen. This can make them tired, which makes learning more difficult. A good listening environment at school makes a considerable difference to children with UHL.

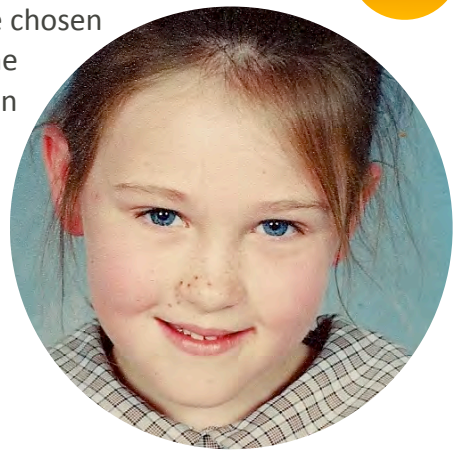
Consider the following questions when deciding on a school:

- *Are there any deaf children in the school?* If there are, the staff are likely to have a better understanding of the needs of your child and there may be a visiting teacher of the deaf who can provide the class teacher with some advice.
- *How many children in each class?* The bigger the class size, the noisier it will be and this will make it more difficult for your child to hear and listen.
- *Where is the school located?* Schools on the main road may be noisier and make it more difficult to listen.
- *Have the classrooms got good acoustic treatments?* Classrooms with carpet on the floors, curtains on the windows and acoustic tiles on the ceiling provide an improved listening environment. Try and avoid demountable classrooms and classrooms divided by a sliding screen which can be made into a large classroom.
- *Does the school have soundfield systems in any of their classrooms? If not, what processes would need to happen to get a soundfield system in your child's class?* Soundfield systems make it easier for all children in the classroom to hear. Ask the school if it would support you with any lobbying or fundraising.
- *What opportunities are there for parents to be involved?* As parents of a child with UHL, you will need to advocate for your child and build positive relationships with everyone who is involved with your child through the school day. The key to a successful partnership with the school is good communication and a willingness to be involved and contribute to the school community as a whole.

Have I made the right decision?

There are many reasons why families choose schools. A school might have a particular religious affiliation or there may be a family tradition around attending a school. Many families like to send all their children to the same school and the child with UHL may follow his or her older siblings to the same school. It will take time before you know whether you have made the right decision.

Families need to be flexible. What works for one child, may not work for your child with UHL. Several families in our online group have chosen to change schools to one that can better accommodate for the needs of their child with UHL. While changing schools is not an easy decision to make, it is an option worth keeping in mind, if necessary.

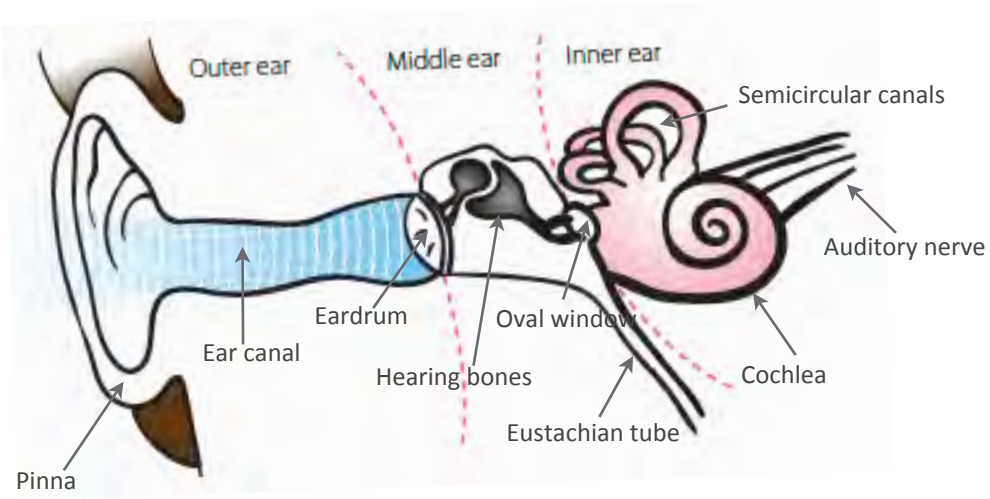


PART 2: UNDERSTANDING UNILATERAL HEARING LOSS

HOW WE HEAR

You will receive detailed information about how we hear from your newborn hearing screening program or Australian Hearing. Table 1 provides a brief overview.

The ear can be divided into three sections that work together to conduct sound from the environment to the brain where it is processed. A problem at any site within the ear can lead to a hearing loss. The type of hearing loss will depend on the site of the problem.



Structures of the ear

Table 1: Understanding the ear and how we hear

Section of ear	Consists of:	Function	Type of hearing loss
OUTER EAR	• Pinna • Ear canal	Transmits vibrations (sound waves) from outside the ear, down the ear canal to the eardrum.	Problems in the outer ear result in a **conductive** hearing loss, e.g. ear wax, otitis externa and microtia & atresia.
MIDDLE EAR	• Eardrum • Air-filled cavity containing three tiny hearing bones - the hammer (malleus), the anvil (incus) and the stirrup (stapes). • Oval and round window membranes • Eustachian tube	• The vibration of the eardrum moves the three hearing bones. the stirrup is attached to the oval window membrane and moves the membrane in and out. • The Eustachian tube connects the middle ear with the back of the nose and throat. the Eustachian tube adjusts the air pressure in the middle ear cavity.	Problems in the middle ear result in a **conductive** hearing loss, e.g. otitis media (glue ear) and cholesteatoma.
INNER EAR	• Cochlea • Semicircular canals	The cochlea is a small snail-like structure containing fluid and thousands of microscopic hair cells sitting on a membrane which runs the length of the cochlea. The movement of the hair cells creates electrical impulses which are carried by the auditory nerve to the brain. The semicircular canals are responsible for our sense of balance.	Problems in the inner ear result in a **sensorineural** hearing loss.

Air conduction vs. Bone conduction

Sound waves can reach the cochlea (inner ear) through two routes. Most of what we hear is due to sound waves travelling through the air. Sound waves travel from the outer ear to the middle ear and into the cochlea in the inner ear. This is known as '**air conduction**.'

Sound waves can also reach the cochlea through vibration of the bones in the head. This is known as '**bone conduction**.'

DESCRIBING A HEARING LOSS

A unilateral hearing loss (UHL) affects one ear only. The child can hear normally in one ear and has some difficulty hearing with the other ear. There are different types, degrees and configurations of unilateral hearing loss and this will impact on how the hearing loss is managed.

Types of hearing loss

The type of hearing loss depends on the site of the problem in the ear which may be anywhere from the outer ear through to the middle ear, inner ear and the auditory nerve which carries the sound impulses through to the auditory cortex in the brain.

Conductive hearing loss

Hearing loss associated with outer or middle ear problems is known as conductive hearing loss. Problems such as wax build up, middle ear infection (otitis media) or deformity of the outer or middle ear structures prevent sound being conducted to the inner ear. Sound is softened, making hearing difficult. Conductive hearing losses can often be treated with either medication or surgery.

Sensorineural hearing loss

Sensorineural hearing loss results from dysfunction in the inner ear and/or the auditory nerve. Most sensorineural hearing loss is due to abnormalities in the hair cells in the cochlea. Causes of hair cell abnormality include certain genes as well as external causes such as damage from loud music or infections. The quantity (loudness) and quality (clarity) of sound is affected in sensorineural hearing loss. Sensorineural hearing loss is permanent and cannot be treated with surgery.

Mixed hearing loss

A mixed hearing loss occurs when the cause of the hearing loss is both sensorineural and conductive. For example, a child with microtia and atresia with subsequent conductive hearing loss may also have a sensorineural hearing loss.

Table 2: Describing hearing loss

Type	Degree	Configuration
Hearing loss is categorised depending on what part of the auditory system is affected	The hearing loss is categorised according to the severity of the hearing loss	The overall picture of the hearing loss is described
• Conductive • Sensorineural • Mixed	• Mild • Moderate • Severe • Profound	• Unilateral or bilateral • Congenital or acquired • Fluctuating or stable • Progressive • Sudden • Flat loss • Ski slope loss

Degrees of hearing loss

Hearing loss is described as mild, moderate, severe and profound. The degree of hearing loss depends on how loud sounds need to be before the ear detects them.

Although your child is able to hear normally on one side, sounds coming from the direction of the deaf side are softer when heard by the hearing ear. This is due to the 'head shadow effect.' The sound must pass through or around the head to be heard by the functioning ear and results in a drop in the intensity or loudness of the sound. The child may hear the sound but it will be softer.

There is a difference between an 'audible' sound and an 'intelligible' sound. A child may be able to hear that someone is talking (the sound is audible) but not be able understand what exactly is being said (the sound is not intelligible). We have all had this experience in a noisy environment when we know someone is saying something to us but are unsure what they are actually saying. As adults, our experience may allow us to *infer* what is being said; we catch a few words and can therefore understand the gist of the conversation. Children cannot do this. They do not have the experience or mastery of the language to be able to pull the threads of the conversation together. Children need consistently intelligible speech to understand what is being said to them.

Parents often wonder what their child's hearing loss sounds like. There are simulators available for bilateral hearing loss but not unilateral hearing loss. By blocking one ear with an ear plug or cotton wool for a day, you can get some understanding of good and difficult listening environments for people with UHL.

The information below gives some indication of the degrees of hearing loss. This does not reflect the impact on the child with UHL when listening with both ears.

Mild hearing loss
The quietest sounds the child can hear on the side with the hearing loss are between 26 and 40dB. The affected side will not detect sounds below this level, such as a mosquito or rustling leaves.

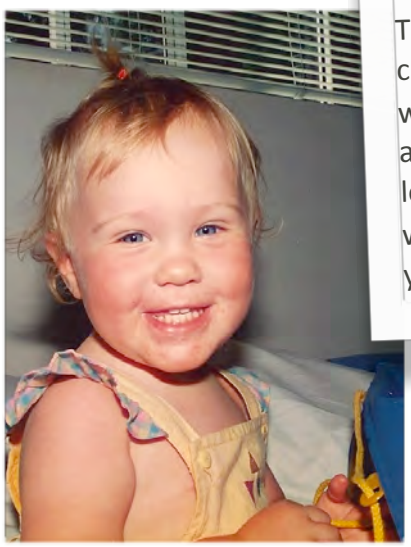
Moderate hearing loss
The quietest sounds your child can hear on the side with the hearing loss are between 41-60dB. The affected side will not detect sounds below this level, such as whispering or some conversations.

Severe hearing loss
The child can hear sounds between 70 and 90dB. The affected side will not detect sounds below this level, such as most conversational speech, traffic noise and the vacuum cleaner. Sounds that are very loud to the hearing ear, will be very soft to the affected ear.

Profound hearing loss
The child can only hear sounds louder than 90dB on the side with the hearing loss. Sounds that are very loud to the hearing ear, will be very soft or undetectable to the affected ear. This is also sometimes referred to as single-sided deafness (SSD).

Hearing loss can also be…

- *Flat loss* - the hearing loss is similar across all frequencies. This is most common in conductive hearing loss due to ear canal atresia.
- *Ski-slope hearing loss* - the hearing loss gets gradually worse towards the higher frequencies. The audiogram looks like a ski-slope. This is the most common type of hearing loss. The child might have a mild loss in the low frequencies dropping to a severe loss in the high frequencies.
- *Reverse slope hearing loss* - the hearing loss is greatest at the low frequencies and gradually improves towards the high frequencies. The audiogram looks like the reverse of the ski-slope loss. The child might have a moderate loss in the low frequencies and near normal hearing at the high frequencies.
- *Fluctuating hearing loss* - the hearing loss changes; some days it is better than others. A fluctuating hearing loss is typically found with middle ear infections.
- *Progressive hearing loss* - the hearing loss gets worse over time.
- *Sudden hearing loss* - the hearing loss occurs suddenly. A sudden hearing loss requires immediate medical attention to find a cause and possible treatment.
- *Congenital hearing loss* - the child is born with the hearing loss.
- *Acquired hearing loss* - the child develops a hearing loss sometime after birth. This may occur after meningitis or cholesteatoma.
- *Bilateral hearing loss* - the child has a hearing loss in both ears. A small percentage of children with a unilateral loss will develop a hearing loss in the other ear as well.



Your child's hearing loss

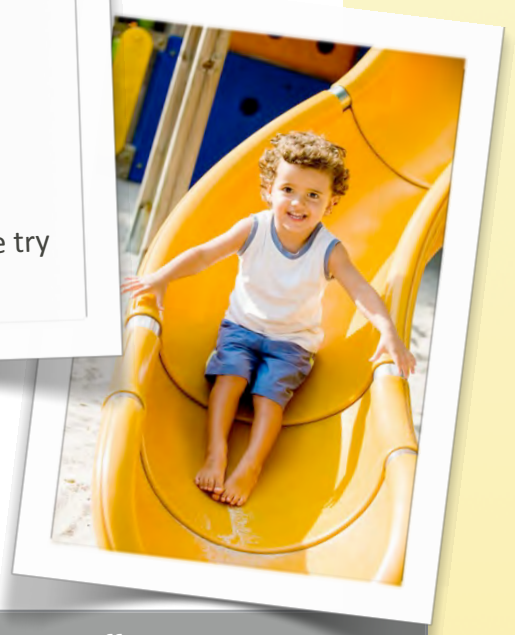
The audiologist at Australian Hearing will record your child's hearing on a graph known as an audiogram and will discuss your child's audiogram with you. The audiogram will explain the type and degree of hearing loss and the frequencies affected by the hearing loss. This will assist the audiologist to discuss the management of your child's hearing loss with you.

Parents talk about names for each ear

"I haven't referred to his right ear by anything other than his right ear, but he is now using the terms 'good ear' & 'bad ear'. I am very keen to find alternatives to this." [Parent]

She calls her right ear (my bad ear) and her left (my good ear) – it's how she describes it best" [Parent]

"He sometimes calls his right ear his bad ear, but we try to discourage it".[Parent]



Source of sound	Decibel level	Exposure effect
Normal breathing	10dB	
Mosquito	20dB	
Whisper	30dB	
Normal conversation (at 1 metre)	50 - 65dB	
Laughter	60 - 65dB	
Vacuum cleaner/hair dryer	80dB	
City traffic (inside car)	85dB	
Truck traffic	84 - 90dB	Prolonged exposure to any noise above 90dB can cause gradual hearing loss [8]
Motorcycle	88 - 100dB	
Lawnmower	85 - 90dB	
Tractor	98dB	No more than 15 minutes exposure recommended without hearing protection [8]
Train	100dB	
Jackhammer/power saw	110dB	Regular exposure of more than one minute risks permanent hearing loss [8]
Stereo	110-125dB	
Rock concert	110 - 140dB	
Jet take off	130dB	

FINDING A CAUSE

One of the first questions parents ask when their child is diagnosed with a hearing loss is 'Why?' Mothers often join our online group and are so worried that they did something before or during their pregnancy to cause their child's hearing loss. But rest assured, this is extremely unlikely.

Hearing loss can either be congenital or acquired. 'Congenital' means that the hearing loss was present at the time of birth, or occurred very soon after birth. An acquired hearing loss occurs after birth perhaps as a result of disease or injury.

The terminology about causes of hearing loss can be rather confronting but, in reality, knowing the cause doesn't usually change how the hearing loss will be managed.

Congenital hearing loss

About 3 in 1,000 babies are born with some degree of hearing loss. Congenital hearing loss may be due to either genetic factors or factors what occurred before, during or just after the baby was born.

1. ***Genetic factors***
   Although 9 out of 10 deaf children are born to hearing parents, approximately 50% of hearing loss in children has a genetic cause. Genetic causes have to do with the baby's genes. Genetic deafness may be inherited from one or both parents.
   - **Syndromic hearing loss**
     About 30% of children with genetic hearing loss have a 'syndrome.' This means there are other features or conditions associated with the hearing loss. Each syndrome is relatively rare.
   - **Non-syndromic hearing loss**
     The other 70% of children with genetic hearing loss have hearing loss that is 'nonsyndromic.' This means there are no other conditions linked with the hearing loss. Over 100 different genes have now been identified that directly cause or are associated with non-syndromic hearing loss.

Genetic deafness may be present at birth or start later in life. It may also be stable or get worse over time.

2. ***Non-genetic causes***
   In about 25% of deaf children, their hearing loss is the result of another cause. Non-genetic causes of hearing loss include:
   - An infection that the mother might have had during pregnancy. Cytomegalovirus (CMV) is the leading cause of pre-lingual unilateral hearing loss in children in the United States. [9]
   - Prematurity.
   - Some medications given to babies and young children to treat serious infections.

3. ***Idiopathic causes***
   In approximately 25% of deaf children, there is no known cause for their hearing loss.

Acquired hearing loss

Children can develop a hearing loss anytime after birth. This can be due to an illness such as meningitis, medications, recurrent severe ear infections or injury.

Investigating the cause

Many medical tests can be carried out to try and find the cause of your child's hearing loss. A cause is not found in over 50% of children investigated but it can be helpful to families to know what didn't cause the hearing loss, e.g. you may find the cause isn't genetic.

Families with a child with UHL are not always offered a full 'aetiological investigation,' i.e. investigation of the cause of the hearing loss. Speak to your GP or ENT and let them know if you want to investigate the cause more fully. Tests you may request include blood and urine tests, imaging such as an MRI scan, genetic counselling and genetic testing.

For more information

Medical assessments for children with permanent hearing loss
http://www.aussiedeafkids.org.au/medical-assessments.html

MAINTAINING GOOD EAR HEALTH

Your baby can hear with one ear. This is an asset that must be protected. There are three additional issues that may have an impact on hearing in either ear through your child's life:

- Ear wax
- Ear infections
- Noise

Ear wax

The ear naturally produces wax (or cerumen) to protect the ear canal. Ears are usually self-cleaning. The wax and dirt move away from the ear drum to the opening of the ear canal and the wax can be removed with a damp cloth.

Sometimes there is a build up of wax in the ear canal and it blocks sound from reaching the eardrum. This will make it more difficult for your child with UHL to hear. A build up of wax in young children is usually only noticed during routine ear examinations at the doctor or audiologist.

Ear drops that soften the wax are available from the chemist and this may be all that is needed.

Always visit your GP if you are concerned.

Do not insert any foreign objects into the ear canal!

For more information

Ear wax management
http://www.aussiedeafkids.org.au/ear-wax-management.html

Ear infections

Ear infections are common in young children and can cause temporary hearing loss and impact on speech development and learning.

Ear infections can occur in the outer ear (otitis externa) or the middle ear (otitis media).

- Otitis externa is an inflammation of the outer ear. The infection may be bacterial or fungal. The outer ear is often painful and sensitive to touch and your child may have a temperature. Otitis externa may affect hearing if it persists.
- Acute otitis media is a bacterial inflammation of the middle ear. Fluid builds up behind the ear drum causing pain and possible fever.

- Otitis media with effusion or 'glue ear' occurs when fluid remains trapped behind the ear drum. A child with glue ear may have no symptoms but the doctor can see the fluid during an ear examination. if the fluid remains in the middle ear for a long time or returns frequently, it can affect a child's hearing.

Preventing ear infections

While you may not be able to prevent ear infections, you can certainly reduce your child's risk of ear infections.

- Immunise against pneumococcal disease. This is a major cause of otitis media. Children with a pneumococcal middle ear infection will have a temperature and ear pain and can be quite irritable. Most pneumococcal infections can be prevented with vaccines. The pneumococcal conjugate (7vPCV) vaccination is part of the routine immunisation schedule for babies at 2, 4 and 6 months.[10]
- Wash your hands to prevent the spread of the germs that cause colds and flu.
- Avoid smoking. Babies exposed to smoking have more ear infections.[11]

Treating ear infections

Mild infections can be treated with paracetomol (such as Panadol).

See your family doctor if your child:

- Has a high fever or bad earache
- Has an ear discharge that lasts more than 24 hours
- Seems to be getting worse or you are worried at any time.

If you are worried about your child's hearing, arrange an appointment with your family doctor (GP). Your GP will examine your child's ears and should be able to tell if glue ear is present. If there is any pain or sign of infection your GP may prescribe a course of antibiotics. Your GP may want to wait to see if the glue ear clears up by itself before referring your child to an ENT specialist. [11]

For more information

Glue ear: A guide for parents
http://www.aussiedeafkids.org.au/glue-ear-a-guide-for-parents.html

"…if she is sick, I am off to the doctor to just make sure all is okay." [Parent]

Noise

Noise induced hearing loss (NIHL) in an increasing problem in society. “The effect of noise is cumulative, based on frequency of participation, total time of exposure and intensity of the sound (level in decibels). If you need to raise your voice or shout in order to be understood in background noise, then the noise has the potential to damage hearing.[13]“ Of particular concern to hearing professionals is the impact of noisy leisure activities on hearing. Your child with UHL needs to be taught from an early age about protecting their hearing from hazardous levels of noise.

Children learn from observing their parents. Start today to protect *your* hearing so your child will learn from your example.

Protecting you and your child from noise

- Educate your child from the early years on the importance of ear protection.
- Turn down the volume when listening to music in a confined space.
- Turn down the volume on personal stereo headsets. The volume of a personal stereo should be at a level where you can still hear someone speaking to you an arm’s length away. Use of noise-cancelling headphones can also help to eliminate external background noise and allow the MP3 player to be played at lower volume.
- Be aware of equipment around the home that is loud and potentially damaging to hearing, e.g. lawnmower, leaf blower, hair dryer and toys.
- Always wear hearing protectors when carrying out noisy tasks and help to develop good habits in your children from the early years.

LISTENING DEVICES

There are a number of listening devices, which may enhance your child's listening experience. These include hearing aids, Remote Microphone or FM systems, implantable devices and sound field amplification systems.

Listening devices may provide listening benefits but they will not 'fix' your child's hearing loss. Even when UHL is identified at an early age and treatment in terms of device fitting is offered, it is important to remember that the difficulties arising from the presence of UHL cannot be compensated for entirely by fitting of personal hearing devices. The use of these devices enables sounds on the affected side to be audible, but does not restore normal hearing to the affected ear.

Listening devices and UHL – the evidence

There is currently no high-quality evidence on how best to manage unilateral hearing loss in children.[14]

Hearing loss and brain development

In recent years, we have learnt a lot about the development of the human brain and there is evidence about the importance of building good neurological pathways in the early months and years.

There is also evidence that most babies with hearing loss in both ears (bilateral hearing loss) who are diagnosed early and provided with hearing aids and good early intervention will develop age-appropriate language skills by the time they start school.[15]

It seems logical that doing the same for babies with UHL would support the development of their binaural neurological pathway. However, high-quality scientific evidence is lacking to guide clinical decisions on the management of unilateral hearing loss in children.

How effective is amplification?

Some studies have looked at the effectiveness of amplification in mild and unilateral hearing loss and show that the use and benefit of amplification varies amongst individuals.[16]

Device benefit cannot be predicted by the degree of hearing loss, age or gender. No study shows consistently high success rates of amplification.[17,18]

One small study at Children's Hospital of Philadelphia concluded that it was worth trialling a hearing aid with children who had a unilateral hearing loss. The study found that approximately 65% of the client group aged 2-17 liked or loved their hearing aids. Hearing loss in the impaired ear ranged from mild to moderately severe. While many clients showed an improvement in listening related tasks there was more variability as to whether the children also benefitted from the aid in psychosocial areas such as confidence, general disposition and frustration level.[19]

Another study on mild and unilateral hearing loss in children found that 26% of children with a unilateral hearing loss wore their hearing aid all the time while 50% of the children never wore their aid. [20]

An Australian study found the success of hearing aids may be linked to parents' and teachers' estimates of the difficulty caused by the child's hearing loss and parental attitude towards hearing loss and hearing aids. [17]

CROS aids have been reported to be more successful if there is some slight degree of loss in the better hearing ear. [21]

A survey of teenagers and young adults by Australian Hearing included data from 472 clients with normal hearing or a mild hearing loss in the better ear. These clients showed much greater variability in aid use, aid benefit and satisfaction with their device than clients with greater degrees of hearing loss.

- 21% of these clients did not wear their device at all
- 33% wore it for less than an hour per day
- 21.5% of these clients indicated that the main reason for not wearing their aid/s was that they either didn't need help with their hearing or that the hearing aid/s did not help them.[22]

Careful monitoring of personal FM fittings is also required to ensure that optimal use continues with time. A study by Australian Hearing found that use of personal FM systems decreases over time. Only 50% were still being used 12-18 months after being provided.[23]

Language development

Recent research on an Australian population of children with *bilateral* hearing loss revealed that maternal education, degree of hearing loss and cognitive ability were significant predictors of early language development.[24] The evidence on effectiveness of early amplification for early language development of children with UHL is lacking.

Children with UHL have normal hearing in their better ear. Many of them develop normal speech and language and perform well in preschool settings. By school age, current literature suggests that approximately 25% of them may experience academic difficulties in formal schooling and require support services.[25]

The effect of age of fitting on language development of children with hearing loss in *both* ears suggests that deferring device fitting from 6 months to 24 months of age is estimated to reduce standardised language scores by only 1.1 points for a child with 30 dB hearing loss; and 4.6 points for a child with 50 dB HL in the better ear.[26]

As an example, if a child who has 30 dB hearing loss in their *better* ear and was fitted with hearing aids at 24 months of age obtained a score of 89 in a language assessment, that same child is estimated to have obtained a score of 90 had the hearing aids been fitted at 6 months of age.

As children with unilateral hearing loss have hearing within the normal range in their better ear, the research suggests that for most children with unilateral hearing loss, delaying hearing aid fitting from 6 months to 2 years is not expected to result in a significant delay in language development.

Knowing early about the presence of hearing loss may create time for the family to get used to things, make plans, prepare for work ahead, and know their child has a hearing loss in one ear right from the start.[27]

In light of the limited scientific evidence available, the Clinical Practice Guidelines published by the American Academy of Audiology Task Force on Pediatric Amplification in 2013 have made the following recommendations/statements:

- For a child with unilateral deafness, an FM system with the wireless remote microphone receiver coupled to the open, good ear may be preferable to a CROS configuration in classroom situations.
- Use of a bone conducted signal may be considered an option with children who have unilateral hearing loss [28].

Options for intervention

The following table summarises available options that may be suitable for your child. There is currently a lack of high-quality evidence to guide best practice management of children with unilateral hearing loss. Therefore, the audiologist at Australian Hearing will provide you with information on possible technology solutions for your baby, consider your child's listening needs and difficulties, and guide and support you in whatever decision you make about fitting.

Table 4. Summary of management options for children with UHL

INTERVENTION	0-6 MONTHS	7 MONTHS - 1 YEAR	1-3 YEARS	3-5 YEARS	SCHOOL YEARS
UNAIDED		Visual reinforcement audiometry around 10 months		Pure tone audiometry around 4 years	Remote microphone (FM system)
WEARABLE DEVICES	• hearing aid • bone conduction aid	• hearing aid • bone conduction aid	• hearing aid • bone conduction aid	• hearing aid • bone conduction aid • remote microphone system *	• hearing aid • bone conduction aid • remote microphone system
IMPLANTABLE DEVICES	Not indicated at this time	Regulatory and surgical guidelines specify a minimum age for undertaking various types of implant surgery. The minimum age varies according to the type of device.			• bone anchored hearing aid • cochlear implant
WHOLE ROOM SYSTEMS				• sound field amplification*	• sound field amplification

* The applicability of Remote Microphone/FM and Sound field systems will vary depending upon the child's lifestyle and pre-school setting. Sound field systems are most useful for activities that involve group instruction and are likely to have greater benefits in school settings.

If you decide against a hearing aid now, you can always review your child's needs with Australian Hearing in the future. And vice versa: you may decide to trial a hearing aid but feel there are no noticeable advantages for your child, and discontinue its use. Keep in mind that you can revisit options in the future as the listening demands of your child changes with age or type or degree of hearing loss.

1. UNAIDED CHILDREN

If you decide against fitting a device, your child with unilateral hearing loss will be reviewed by Australian Hearing at around 10 months of age, around 4 years of age and again prior to starting high school. Functional tests can be undertaken to determine if the hearing loss is affecting your child's listening in everyday situations and whether any listening device may be of some benefit.

It is recommended that you -

- Have your child's hearing tested once a year – talk to your Australian Hearing audiologist about your options.
- Monitor your child's language and other developmental milestones and seek advice from your GP if you are concerned.
- Create a language rich home environment – talking, singing, reading
- Create a good listening environment at home – quiet spaces and times where background noise is minimal
- Contact Australian Hearing if you are concerned that your child is experiencing listening difficulties in everyday situations.

2. WEARABLE DEVICES

Hearing aids

Hearing aids amplify sound but they do not provide perfect hearing. A hearing aid may be helpful in the ear with the hearing loss.

Hearing aids today are digital. They can be adjusted by an audiologist using custom software to:

- set a specific amount of amplification at each frequency to suit the hearing level of the user
- control feedbacK
- reduce potential discomfort arising from amplifying loud noises and
- suppress background noises.

In Australia, children with a permanent hearing loss who use a hearing aid receive free audiological care through Australian Hearing which is funded by the Australian Government.

Types of hearing aids

There are broadly three types of hearing aids available for children with UHL.

1. **Air Conduction hearing aids.**
   Air conduction aids send amplified sound into the ear canal via an ear mould. There are two styles available, only one of which is suitable for infants.

   - *Behind-the-ear hearing aid (BTE)*
     This aid fits behind the ear and is attached to an ear mould which sits in the ear canal and transmits sound from the hearing aid into the ear. This hearing aid will provide greatest benefit to children with a moderate to severe unilateral hearing loss. It is fully subsidised and available from Australian Hearing. These hearing aids can also be used with an FM system at school.

   - *Custom Aids, such as "In-the-Ear (ITE), In-the-Canal (ITC) or Completely-in-the-Canal (CIC) aids.*
     For these types of hearing aid, the sound amplifier sits into a customised shell that is made to fit the child's ear canal. These aids are not suitable for infants, but are an option for children in primary school and above, when the growth of the ear canal has slowed and the child is not at risk for swallowing the aid or batteries. Custom aids are available fully subsidised from Australian Hearing and many can be used with an FM system at school.

2. **CROS (Contralateral Routing of Sound) hearing aids**
   CROS aids have two parts and look like conventional hearing aids. A microphone in the hearing aid on the deaf side transmits sound to the hearing aid in the hearing ear. The CROS aid can be beneficial when speech is on the deaf side. CROS aids are fully subsidised and available through Australian Hearing.

3. **Bone conduction hearing aid**
   In certain circumstances, a child cannot wear or benefit from the use of a behind-the-ear hearing aid. This includes children with a profound hearing loss (also called single-sided deafness) and those with microtia and atresia. Bone conduction hearing aids transmit sound through the bone of the skull directly to the cochlea, bypassing the outer and middle ear. Bone conduction is not as efficient as hearing through the air but it is an alternative for children who cannot use a traditional hearing aid. A number of bone conduction hearing aids are available but not all are fully subsidised by Australian Hearing.

"My son has issues (like most UHL children) with noisy environments and localising sounds. He commenced kindy this year so I decided to try a BCHA for him." [Parent]

"I really didn't care about the research that had been conducted saying that the hearing aid may not be helpful, I knew we were experiencing issues at home, so thought we can only try." [Parent]

How much do hearing aids cost?

The cost depends on the type of hearing device and whether it is available through Australian Hearing or not.

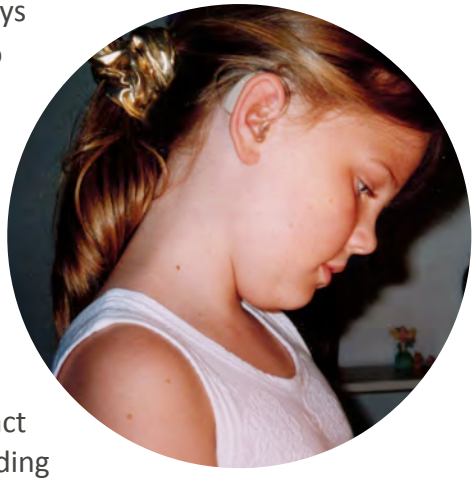
- Some hearing aids and wireless technology such as FM systems are fully government-subsidised and are provided at no cost to children under 26 years of age through Australian Hearing.
- Some hearing aids have more features or improved technology and, while they are available through Australian Hearing, you will need to contribute to the cost of the device.
- Some hearing aids are not available through Australian Hearing and parents will need to organise their purchase independently. Technology is changing rapidly and the list of available aids through Australian Hearing does change so it is always worth checking with your audiologist at Australian Hearing first.

Australian Hearing currently covers the cost of maintenance of the hearing devices used by children with UHL.

What to expect from a hearing aid

Because babies with a UHL have normal hearing in one ear and are most likely responding to a wide variety of sounds, it can be difficult to observe changes related to hearing aid fitting. Depending upon the degree of unilateral hearing loss the most obvious change is likely to be an improvement in the baby's ability to correctly identify the source of a sound. Remember, though that the responses of very young babies are subtle, even with normal hearing in both ears.

The responses of older children are also varied. Children diagnosed with unilateral hearing loss when they are older are not always compliant with hearing aid use. Their brain may need time to adapt to the new sounds and you may need to show some patience and perseverance with them. Encourage them to use the hearing aid at home first, in a quiet environment, and build up the amount of time they wear the hearing aid. Wearing the hearing aid when watching television is often a good place to start.



Older children also tend to worry about the cosmetic appeal of the hearing aid. Your response to the hearing aid will impact on how your child feels about wearing it. If you fuss about hiding the hearing aid with their hair, or remove it for photos or special occasions, you may be giving them the message that the hearing aid is something they should hide and this can result in an unwillingness to wear it.

The most successful hearing aid users understand why they need a hearing aid and are able to tell other people about their hearing loss. Teach your child to confidently explain why they need a hearing aid.

Babies and hearing aids

If you decide on a hearing aid for your baby, the two main challenges are:

- stopping it whistling, and
- keeping it on!

Ear moulds sit in the ear canal and transmit sound from the hearing aid into the ear canal. When ear moulds are loose, they cause the hearing aid to whistle which is uncomfortable for everybody. Babies' ear canals grow quickly and the ear moulds will need to be replaced frequently in the early months. This involves the audiologist taking an impression of the ear canal and sending this off to the ear mould manufacturers. The ear mould will take a couple of weeks to be made and can be posted to you which is usually more convenient. The ear mould comes with longer tubing than is necessary and you will need to carefully trim the tubing to the right length for your baby. Ask the audiologist to show you how to do this the first time. Rubbing some ear mould lubricant (available from Australian Hearing) around the mould may also stop the whistling. The lubricant creates a better seal and reduces the amount of feedback which causes the whistling.

The second challenge is keeping the hearing aid on as the baby grows. They tend to pull them out and this can be frustrating, particularly when you are not around to see where it has disappeared. Babies tend also to put the aids in their mouths. The hearing aids have small batteries and although the battery case door is tamper-proof, it is best to avoid the possibility of your baby accidentally swallowing a battery or an ear mould.

There are a couple of solutions here and the most popular one with mums appears to be using pilot caps on the baby for a time. They are made from soft fabric and fit snugly over the ears and tie under the chin. These make it more difficult for a young child to pull off the hearing aid. They can be purchased at a number of the early intervention services. The baby soon grows out of this phase and it is worth persisting if you have decided on using a hearing aid.

For more information

- Hearing aids
  http://www.aussiedeafkids.org.au/hearing-aids.html

Remote Microphone and FM systems

Wireless technology such as personal FM systems is improving rapidly with the widespread use of smartphones and other mobile digital devices. Wireless technologies help to eliminate the difficulties caused by background noise, distance and acoustics and are particularly helpful in the classroom. This is the most effective listening device for children with UHL in the classroom. An FM or other wireless system provides the best available access to the teacher's voice.

A wireless system consists of a transmitter and a receiver. In the classroom situation, the teacher wears a small lapel microphone which is attached to the transmitter. The transmitter sends the sound via a wireless connection to the receiver, which is usually attached to the hearing aid.

If a child does not wear a hearing aid, there are other wireless options available through Australian Hearing. Some are fully subsidised and others require a contribution from the family. Maintenance for all devices is covered by Australian Hearing.

"He wears a hearing aid and uses an FM at school. He loves both of them and would not be without them. He loves school and has great friends. He is confident and a very bright child. His hearing loss and health problems have not slowed him down, or stopped him doing anything." [Parent]

"The aid we use is an FM system. We considered classroom noise levels and was worried that our daughter would miss hearing the teacher/classroom discussions."

3. IMPLANTABLE DEVICES

Implantable devices may be a solution for a child with total deafness in one ear, or children who are unable to wear other hearing devices. These devices all have an implanted part and an external sound processor which is worn much like a hearing aid.

Implantable devices require surgery and there are a number of regulatory and surgical guidelines which specify a minimum age for undertaking various types of implant surgery. The minimum age varies according to the type of device.

The cost of the surgery and the device may be refundable under some private health funds. Some sound processors for implantable devices other than cochlear implants are provided fully subsidised through Australian Hearing for children who meet clinical candidacy criteria. Australian Hearing covers the cost of maintenance of implantable devices used with UHL at their centres for both fully subsidised and privately purchased devices.

Implantable devices can be broadly categorised into three types

1. **Bone anchored devices** transmit the sound through the bones of the skull to one or both cochleas. Different devices have different ways of attaching the sound processor to the implant in the skull.
   - Bone anchored device with an abutment that protrudes slightly from the skull. The sound processor attaches to the abutment.
   - Bone anchored device where the implant sits under the skin of the skull. The processor attaches to the implant by magnet.

2. **Middle ear implants** deliver sound to the cochlea on the side of the implant using mechanical vibrations. The implanted device sits under the skin.

3. **Cochlear implants** provide the sensation of hearing by directly stimulating the auditory nerve using electrical signals. The internal receiver is implanted surgically.

There is limited scientific evidence for the benefits or otherwise of implantable devices in children with UHL. Most studies have been done on adults and often on those who have lost their hearing later in life. Some studies report improvement in speech perception in noise and sound localisation while others find less consistent results.[29-34]

Due to the paucity of scientific evidence, the decision to implant remains a very individual one for each family. To implant or not will be a big decision for your family and it must be one that is right for you and your child. The section "Making informed choices" may help as you look at the options and work through what will be best for your child in the long-term.

Last but not least, remember that whatever decision you make about the management of your child's unilateral hearing loss, every child will benefit from living in a home environment that promotes a love of language and learning.

2. WHOLE ROOM SYSTEMS

Sound field amplification systems

This is an option for children when they start school.
A large part of the school day is spent listening. Children listen differently to adults. They lack the experience and environment. Children need a quieter environment and a louder signal-to-noise ratio than adults in order to learn. The better a child can hear, the more he will learn.

The goal of sound field amplification is for every child in the classroom to hear the teacher's voice, no matter where they are sitting and where the teacher is facing. Sound field amplification systems overcome adverse classroom conditions, such as poor acoustics and high ambient noise levels and make it easier for all children to hear the teacher. The advantage of a sound field system is that individual children are not singled out as requiring assistance.

Several sound field systems are available using different technologies. However, all increase the signal-to-noise ratio in the classroom and consist of a transmitter microphone, receiver/amplifier and speakers. The systems with four speakers mounted around the classroom will provide the best quality sound. There are also portable devices, which are less costly, and parents and teachers report good results.

If your child uses a personal FM system, then using a sound field system as well provides little or no additional benefit. If the personal FM system will be used in a class that also uses a sound field system, talk to your audiologist about the best way to combine use of the two technologies so that your child can continue to get the full benefit of their personal device.

Funding for soundfield systems

There are a variety of options for funding of soundfield systems:-

- The school may fund a soundfield systems for the classroom
- Some parents have chosen to purchase a portable system for their child's classroom.
- Lions Hearing Dogs supply a limited number of soundfield systems to primary schools each year. The application form is available on their website (http://www.hearingdogs.asn.au).

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Last word

What does it matter that we've taught this girl to read and write and to spell, and to do all the things that we think are essential, if no one along the line taught her the sacredness of being alive and taught her the dignity and the wonder of her own personal self worth?

Leo Buscaglia

About Aussie Deaf Kids

Aussie Deaf Kids is committed to improving outcomes for children with a hearing loss through providing online support and information to families raising a deaf child in Australia.

At Aussie Deaf Kids we believe that:

- It is the family who will bear the main responsibility for the child with a hearing loss from the time of diagnosis through to their transition to adulthood.
- Feeling skilled and informed is critical to the family's sense of competence, their ability to make the right decisions, and their ability to support their child's well-being and development.
- Timely and meaningful information enables parents to make informed decisions and take an active role in the management of their child's hearing loss.
- Information empowers parents and provides them with a sense of self-esteem and confidence in their ability to raise their deaf child to lead a full and independent life.
-

Aussie Deaf Kids achieves it goals by:

- Providing comprehensive information on hearing loss in children at www.aussiedeafkids.org.au
- Supporting parents through two online groups – one for families whose child has a unilateral hearing loss and the other for families with a child with a bilateral hearing loss. These groups provide a friendly and supportive environment for parents to discuss issues, ideas and concerns about raising a child with a hearing loss.