

chapter 1: what happens now?

TYPICAL PATHWAYS

When a child is first diagnosed with a hearing loss, apart from dealing with a range of complex emotions, parents find they are suddenly very busy with so many different people to see and places to go. There is, however, a fairly standard pathway which is recommended for families in these early days. A Family Support Facilitator (see page 4) can help you with each step in the process if needed.

- Your child will have attended audiology by this stage for a full hearing test. If you haven't already had contact with a Family Support Facilitator (FSF), you will probably be referred at this stage.
- The audiologist will recommend that your child sees an Ear Nose and Throat specialist (ENT) and organise an appointment with Australian Hearing.
- The ENT will confirm whether your child can get hearing aids fitted and will also organise other assessments including blood tests, and appointments with a paediatrician, and possibly a geneticist and an ophthalmologist. Chapter 2 gives more detail about each of the recommended assessments.
- Australian Hearing is an Australian Government service which provides hearing devices including hearing aids. They will discuss the different hearing technology options with you and provide you with a book called *Choices* which contains detailed information about the ear, how we hear and what happens with hearing loss.
- The paediatrician will provide advice and support on the health and development of your child.

- During these early months, your child will, ideally, start attending an 'early intervention' service to support their communication development. The different types of early intervention services are explained on the following pages and contact details of different services are in the back of this book. Your FSF can talk about the options with you and link you with the service of your choice.

While this may all seem like a bit of a whirlwind, your child will gain the greatest advantage from the early diagnosis of their hearing loss if they start receiving regular support for their communication development in the first few months of their life.

The flowchart on the next page will give you a sense of the order in which things might occur. The following pages provide more information about the new people and services who will probably be involved in your family's life.

You might also like to look at the Frequently Asked Questions and the Glossary at the back of this book. These will help you with some of your questions and explain the new terminology you will come across.

Life will be busy in these early days, but take one step at a time. Even taking small steps in planning for your baby's future will help you discover the many possibilities open to your child. Section two of this book aims to help you with your feelings at this time, in particular what your baby's hearing loss means for you and your family. When you have a chance to step back and think about the longer term, you will find that most, if not all your hopes and dreams for your child can be realised.

Life will be busy in these early days, but take one step at a time. Even taking small steps in planning for your baby's future will help you discover the many possibilities available to your child and family.

PATHWAYS FOR ASSESSMENT, SUPPORT AND EARLY INTERVENTION

YOUR BABY HAS A SECOND 'REFER' RESULT ON NEWBORN HEARING SCREENING

Your baby's hearing screener will refer you to a **Family Support Facilitator**

Family Support Facilitator

- provides you with information
- discusses practical help you might need
- discusses audiology appointment process

If you are not already connected with a **Family Support Facilitator** your audiologist will offer to organise this for you.

Your Family Support Facilitator

will assist in exploring:

- Communication options (spoken language and sign language)
- Early intervention services
- Support services
- Financial support

Early Intervention

It is recommended that your child starts early intervention to support their communication development as soon as possible, preferably no later than 6 months of age.

Geneticist

For newborns, a genetics appointment is recommended at 6 months of age. For older children, your paediatrician or ENT will suggest the best timing.

Your baby's hearing screener will refer your baby to an **audiologist** for a full hearing test

Audiology assessment

Hearing loss diagnosis

Your audiologist will offer to organise an appointment with an **Australian Hearing audiologist**

Australian Hearing

The Australian Hearing audiologist will explore the different hearing technology options with you, provide information on early intervention services, and provide you with the resource book 'Choices.'

If hearing aids are to be fitted and your child has received hearing aid clearance from an ENT, Australian Hearing will fit your child's hearing aids.

Paediatrician

An assessment with a paediatrician is recommended within 2 months of hearing loss being identified.

Ophthalmologist

For newborns, an eye examination is recommended at 6 months of age. For older children, your paediatrician or ENT will suggest the best timing.

Your child is referred to an **audiologist** for a hearing test

Ear Nose and Throat Specialist (ENT)

Your audiologist will tell you if they can refer you directly to an ENT, or whether you need a referral from your GP or paediatrician

ENT assessment

The ENT will confirm that your child can go ahead with hearing aid fitting at Australian Hearing. This is called 'hearing aid clearance.'

The ENT will talk to you about making referrals for your child to have a number of other assessments

Recommended for all children

- Paediatrician
- Ophthalmologist
- Hearing tests for parents and siblings
- Geneticist and genetics counsellor
- CMV test from newborn screening card (heel prick test)
- Blood tests
- Urine tests

Recommended for some children

- MRI Scan
- CT Scan
- Electrocardiogram (ECG)
- Other blood tests

IT IS RECOMMENDED THAT YOUR CHILD'S OVERALL DEVELOPMENT AND COMMUNICATION PROGRESS IS MONITORED CONTINUALLY, AND FORMALLY REVIEWED ON A REGULAR BASIS.

PROFESSIONALS AND SERVICES: WHO THEY ARE AND WHAT THEY DO

The table below will help you to keep track of who is in your child's life. This page has a list of doctors you may consult and the next page lists some of the other professionals you may consult. Pages 11-12 lists the services available to support families.

You may wish to write down the names and details of the people you have had contact with. If you notice that you haven't been referred to someone who you think you should see, talk to your Family Support Facilitator or another professional about this.

DOCTORS	CURRENT CONTACT		NAME / CONTACT DETAILS
<p>Ear Nose and Throat Specialist (ENT) ENTs are doctors who specialise in assessing, diagnosing and treating problems of the ear, nose and throat. They can treat middle ear problems and investigate the possible cause of your child's hearing loss. It is essential that all children who have a hearing loss see an ENT.</p>	Yes	No	
<p>Paediatrician A paediatrician is a doctor who specialises in the health and development of babies and children. Working together with your child's ENT they can help explore the possible cause of your child's hearing loss, and assess and provide support for any other concerns about your child's health or development. It is recommended that all children who have a hearing loss see a paediatrician.</p>	Yes	No	
<p>Geneticist A geneticist is a doctor who specialises in finding out whether certain conditions or illnesses have a genetic cause. This can also help in understanding whether your child may have any other health or development needs, and assist with your future planning. It is recommended that all families of children who have a hearing loss consider seeing a geneticist.</p>	Yes	No	
<p>Ophthalmologist An ophthalmologist is a doctor who specialises in diagnosing and treating eye problems. It is recommended that all families of children who have a hearing loss consider seeing an ophthalmologist.</p>	Yes	No	
<p>Cardiologist A cardiologist is a doctor who specialises in diagnosing and treating heart problems. Only a small number of children who have a hearing loss will need to see a cardiologist.</p>	Yes	No	
<p>Nephrologist A nephrologist is a doctor who specialises in diagnosing and treating kidney problems. Only a small number of children who have a hearing loss will need to see a nephrologist.</p>	Yes	No	
<p>General Practitioner (GP) A GP is a doctor who diagnoses and treats a variety of medical issues for patients of all ages. A GP has an important role in co-ordinating the overall health care of an individual, particularly when they are seeing many different specialists. A GP can also make referrals to specialists such as an ENT or a paediatrician.</p>	Yes	No	

EARLY INTERVENTION PROFESSIONALS	CURRENT CONTACT		NAME / CONTACT DETAILS
<p>Audiologist Audiologists specialise in assessing, diagnosing and managing hearing and balance problems, including the fitting and management of different hearing technology, such as hearing aids and cochlear implants.</p>	Yes	No	
<p>Hearing Loss Family Support Facilitator From the time a child is identified with a hearing loss, through to the end of Year 1, Family Support Facilitators from the Queensland Hearing Loss Family Support Service are able to provide families with information and support, as well as assistance with service co-ordination and planning.</p>	Yes	No	
<p>Advisory Visiting Teacher: Hearing Impaired (AVT:HI) AVTs are teachers who have specialist knowledge and skills in the education of children with a hearing loss. They contribute to the developmental and educational programs of children in regular classrooms in government and some non-government schools, Special Education Units, Special Schools, Early Childhood Development Centres, playgroups and childcare programs. AVTs also provide a home visiting service in certain circumstances.</p>	Yes	No	
<p>Speech Pathologist Speech Pathologists specialise in assessing and diagnosing communication difficulties. They also assist people to develop their communication abilities to their full potential, through spoken, signed, written or other means of communication. Speech Pathologists also assess and treat feeding (ie., eating and swallowing) difficulties.</p>	Yes	No	
<p>Teacher of the Deaf Teachers of the Deaf are teachers who have specialist training in teaching children with a hearing loss. In Queensland, they work in different roles in different services, including: classroom teachers in Education Queensland schools; classroom teachers in non-government schools; Advisory Visiting Teachers in government and non-government schools; and as Auditory-Verbal Therapists within early intervention programs.</p>	Yes	No	
<p>Auditory-Verbal Therapist An Auditory-Verbal Therapist is qualified as either an audiologist, speech pathologist, or teacher of the deaf and has further specialised training in Auditory-Verbal practice. Auditory-Verbal practice involves working within the guidelines of the 10 Principles of Auditory-Verbal Practice.</p>	Yes	No	

SERVICES	CURRENT CONTACT		CONTACT DETAILS
<p>Australian Hearing (AH) AH is a free government service available to all children and young adults under 21 years. AH provides services such as hearing assessment, hearing aids, and other listening devices. AH also provides families of children who have a hearing loss with the book 'Choices,' which outlines information about hearing loss and communication development options.</p>	Yes	No	
<p>Deaf Children Australia (DCA) DCA provides information, advocacy, support services and resources for children who have a hearing loss and their families.</p>	Yes	No	
<p>Deaf Services Queensland (DSQ) DSQ works with the community to improve the lives of people who are Deaf or hard of hearing. DSQ provides Auslan interpreter services as well as Auslan classes. They also provide information and resources on deafness and hearing loss and refer families to relevant services.</p>	Yes	No	
<p>Education Queensland Early Childhood Development Units (ECDU) ECDUs are located across Queensland and provide early intervention programs for children from birth to five years. Some centres have a specific focus on supporting the needs of children who have a hearing loss. Communication development options supported by ECDUs include spoken language development as well as sign language development.</p>	Yes	No	
<p>Hear and Say Centre Hear and Say has five early intervention centres specialising in supporting children to develop spoken language through listening using Auditory-Verbal Therapy. Hear and Say provides a range of services including one-to-one therapy, web-based therapy programs for children in regional and remote areas, outreach visits, playgroup, audiology services and a cochlear implant program.</p>	Yes	No	
<p>Parents of Children who are Deaf or have a Hearing Loss (POD Queensland) POD Queensland provides peer support to families. All families are welcome regardless of whether their child uses spoken language, sign language or a combination of both. POD holds regular meetings, social events and information workshops. One-to-one support is also available.</p>	Yes	No	

SERVICES	CURRENT CONTACT		CONTACT DETAILS
<p>Royal Institute for Deaf and Blind Children (RIDBC) RIDBC Teleschool is an early intervention service that provides early education services to children from birth to 18 years who have a significant hearing loss and live in a rural or regional part of Australia. Based in Sydney, therapists provide services using videoconferencing, the internet, email, the telephone, and occasional face to face visits.</p>	Yes	No	
<p>Royal Children's Hospital Cochlear Implant Program (RCH CIP) and Mater Cochlear Implant Clinic (MCIC) The RCH CIP and the MCIC teams assess children for suitability for cochlear implants. They carry out cochlear implantation for appropriate children, contribute to the management of children's cochlear implants, and support children's listening and communication skill development. These multidisciplinary teams include ENTs, audiologists, speech pathologists, social workers and psychologists.</p>	Yes	No	

FINANCIAL AND TRAVEL SUPPORT	CURRENT CONTACT		CONTACT DETAILS
<p>Queensland Health Patient Travel Subsidy Scheme (PTSS) PTSS provides financial assistance to help with the cost of travel and accommodation for patients who have to travel more than 50km to get medical and audiology services.</p>	Yes	No	
<p>Centrelink (Carers Allowance) The Carer's Allowance is available through Centrelink to assist with the extra costs of supporting the needs of a child who has a hearing loss. Your Family Support Facilitator can provide information on how to apply for this support payment. You can also contact Centrelink directly on 13 27 17.</p>	Yes	No	

Take the opportunity during your appointments to ask questions. Sometimes, it can be hard to think on the spot about the things that you want to find out and so it might help to have a list of questions prepared before your appointments.

WORKING WITH PROFESSIONALS

With so many people working with your family, life can sometimes seem like a real juggling act! This section offers some suggestions about how to get the support you need. You may also wish to refer to Chapter 6 which is about learning to trust your judgement as a parent, and establishing what you want from professionals and services.

MAKING APPOINTMENTS

Here are some points to think about when you're making appointments. Services won't always be able to fit in with all your preferences, but it's worth letting them know what works best for you.

- What days and times are better for you to go to appointments than others? What times are particularly inconvenient?
- Is it possible to plan appointments with different professionals on the same day or during the same trip if you're travelling from a regional or rural area?
- Do you know which professionals do home visits and provide outreach services?

GOING TO APPOINTMENTS

When going to appointments:

- Do you want someone to go with you?
- A friend or family member might help you get the most out of your contact with professionals. They might pick up extra information, or simply offer support during and after the appointment.

- Are you clear about what is being said?
- If you're not sure you understand what a professional is telling you, it's okay to ask them to explain things more than once, or in a different way.
- Do you want to ask for the important points to be written down?

This can be helpful if you are going to appointments on your own or if there are too many details to remember everything you are told.

ASKING QUESTIONS

Take the opportunity during your appointments to ask questions. Sometimes, it can be hard to think on the spot about the things that you want to find out and so it might help to have a list of questions prepared before your appointments. It is also useful to write a list of new questions after you've finished an appointment.

In your *Possibilities* kit is a pad of pages with the heading 'Our questions' that you can use for this purpose. A list of 'Frequently Asked Questions' is at the end of this book. These may clear up some of your own questions and also generate more questions. Remember, there is no such thing as a silly question!

References

Aussie Deaf Kids, n.d., 'Building Blocks: a parent to parent guide for families whose baby has been diagnosed with a hearing loss', viewed December 2007, http://www.aussiedeafkids.com/pdf/building_blocks_boy.pdf.

