THE FAMILY BOOK

— TE PUKAPUKA O NGA WHĀNAU

An introduction for the families and whānau of children diagnosed with a hearing loss

REVISED 2013
THANK YOU

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Flip the book over to find stories from families and young people.
Dear parents, families, and whānau

You’ve been given this book because you’ve just been told your child, or a child you care about, has a hearing loss.

You’re probably struggling to deal with this news. It’s likely you’ll have so many questions you really don’t even know where to start. This book was written to help you.

Deafness and hearing loss is not just about how much a person can or cannot hear. It’s about being able to learn and mix socially with other people.

Without sound it is difficult to learn words, the common building blocks of language. So some children will learn to use their hands – and their lips, face and body gestures – to communicate. This is sign language, which has a rich and proud culture associated with it.

Some may receive hearing aids or a cochlear implant, followed by intensive therapy so they can learn to speak.

Some children will use a mix of both hearing devices and sign language to communicate.

Many people have strong views about which of these approaches to choose. This can often present challenges for parents trying to decide what’s ‘best’.

The side of the book you’re looking at now gives an overview of hearing loss. With input from parents and professionals, it is meant as a basic introduction.

When you flip the book over, you can read stories from other parents who have stood where you now are. You are not alone. The stories include the views of young adults who describe their experience of growing up deaf.

Everyone’s situation is different, but all offer valuable first-hand information.

In the near future you’ll be making decisions about how you want your child to learn to communicate. A good thing to remember is that there is no one ‘right’ method of communication – what’s best is what works best for you and your child.

Best wishes from everyone who helped with this book.
SECTION 1
DIAGNOSIS
**MY CHILD HAS A HEARING LOSS. WHAT’S GOING TO HAPPEN?**

This page will help you understand where different professionals may start working with your child.

You will get help from the start

The first thing likely to happen within 48 hours of diagnosis is that a Ministry of Education Advisor on Deaf Children (AODC) will contact you. This is the person you will have the most contact with – specialist staff, including an AODC, will support you while your child is at school. They can answer many of your questions.

**Our Advisor**

________________________________________

________________________________________

**Contact details**

________________________________________

________________________________________

**What happens next?**

**Diagnosis by audiologist**

- Notifies Advisor on Deaf Children (AODC)
- Contacts you within 48 hours

**Notifies ENT specialist**

- Notifies ENT specialist
- Appointment with Ear, Nose and Throat specialist (ENT) within a few days

**Early Intervention Teachers**

- Early Intervention Teachers – will help support you/your child to learn

**Speech-Language Therapist and others**

- Speech-Language Therapist and others provide support

**Not all children will have involvement with all of these people.**
Your feelings

For most people, being told your child is deaf or has a hearing loss can be very painful. It’s natural to feel strong and mixed emotions – whether the loss is mild or severe. Suddenly the future looks very different.

If your baby’s hearing loss has been diagnosed as a result of the Newborn Hearing Screening Programme this news may be a total shock. There may be no one else in your wider family with any hearing difficulty. Around a quarter of children diagnosed with hearing loss have no known history of this in the family.

You may be deaf or hearing-impaired yourself and therefore better prepared for this possibility.

Or, if you’re a parent whose child is older, it could be a relief to get this diagnosis as it may answer concerns you have had about your child’s behaviour or development.

Whatever your situation, it is normal to experience sadness, guilt, anger or denial and to worry about this added new responsibility. Everyone is an individual and will react and cope differently.

Grief.
Parents usually grieve for the life they had expected for their child – one without such a complication. Allow yourself to grieve – it’s natural.

Guilt.
One or both parents may feel a sense of guilt that something they did caused the hearing loss or that they didn’t notice their child’s hearing loss sooner. It is important for parents to accept that they are not to blame.

Fear of a future that will be different from most other families’ experiences.

Anger may be triggered when least expected or when a parent finds it hard to fully express how they feel. Sometimes anger can be directed towards a partner, other adults, other children who can hear, family members or professionals.

Everyone’s emotions work differently and when this difference is between the mother and the father there is a potential for tension and lack of understanding.

What helps?

Taking ‘time out’, doing physical exercise and remembering to have fun can help. Even a gentle walk can be good for clearing the head.

It can help to talk about how you are feeling with someone you trust and respect. Or to talk with a professional counsellor – either alone or as a couple.

Beacon NZ

Beacon NZ is a free parent mentoring service. The person you talk with will have a child with a hearing loss. They have been professionally-trained to help families who have just been given a diagnosis and can help you understand the emotional journey you may be on.

Freephone 0800 535 636
Or email beacon.newzealand@gmail.com

Deaf Aotearoa

Deaf Aotearoa provides information and advice for Deaf people and their families and whanau. See www.deaf.org.nz

Parent to Parent

Parent to Parent provides support for families where a child has any special need, disability, or health impairment. See www.parent2parent.org.nz

“Our world crumbled that day and the sense of grief, loss and devastation was massive. As a first time mother I was shattered. Words can’t truly express how I felt that day but it was like losing a child, the child you picture whilst being pregnant, and the life they might lead when growing up.”

Corina, mother of baby Emily
Some parents may have a feeling of sadness that stays for a long time. Most parents say they learn to live with this feeling as they accept the reality of the diagnosis and form a new picture of what the future looks like.

Sometimes emotions are triggered when important stages of a child’s life are coming up, such as when they start pre-school or school, or become a teenager.

With time, parents usually find that happiness becomes a more dominant emotion in their lives. Increasingly there are days when the focus is not on their child’s hearing but on normal family life.

Talking with other parents

It’s good to talk. Many parents say one of the things that really helped was talking with other parents who had been in the same situation. As well as getting emotional support from someone who understands, parents find there’s a lot of information they can share.

The New Zealand Federation for Deaf Children coordinates support groups for families throughout New Zealand. It also has free information kits for families who have just been told their child has a hearing loss.

Contact:
NZ Federation for Deaf Children Inc.
Freephone 0800 DEAFCHILD (0800 332 324)
Text 027 214 6901 or email deafchildren@xtra.co.nz

Will my child be okay?

Every child is different, so it is hard to predict just how well any child will do. Your love, acceptance and support will help.

Children with similar levels of hearing loss may progress very differently despite early diagnosis, appropriate hearing aids and the best efforts of their parents and teachers.

Some factors will have an important influence:
- the age when the child was diagnosed and started receiving help
- the amount of language they are exposed to
- the quality and amount of support from professionals
- the amount of family support
- their natural abilities
- whether or not they have other difficulties
- the amount of hearing loss and part of ear/s affected.

Audiologists say that in most cases hearing aids, Frequency Modulation systems (FM systems), or cochlear implants will greatly improve a child’s ability to hear sounds and to learn and understand speech.

Deaf or deaf?

Where a capital ‘D’ is used to write Deaf this refers to people who identify with Deaf culture and communicate by NZSL. A small ‘d’ refers to deafness generally. See section 3 for more information.

“The road ahead with Emily is unknown. We don’t know what her future is going to look like but as a family we’re damned excited about creating it with her. Signing or hearing, it’s going to be a great future regardless.”

Corina, mother of baby Emily
Early diagnosis is good news

Since the Newborn Hearing Screening programme started in 2007, hearing loss is being diagnosed much earlier. This means many more children are now getting help to learn to communicate by whatever method suits them best in their critical early learning years.

From an early age, most children with a hearing loss can receive hearing aids to help them make the most of what hearing they do have. They will then learn to communicate mainly by listening and speaking. There are several kinds of hearing aids and children will need new ones fitted as they grow. They will get support with using these and with learning.

Children with a severe or profound loss may receive a cochlear implant. Some people think of these as a ‘bionic ear’ because these can unlock the world of sound for even the most profoundly deaf. These children have intensive therapy to help them turn the sounds they are now able to hear into recognisable speech.

For cultural reasons, children and their families may learn sign language and use this instead of, or as well as, receiving hearing aids or a cochlear implant.

As children grow up

You will find deaf and hearing-impaired adults living fully independent lives, getting married, having families, competing internationally in sport and working in all types of jobs and careers: builders, doctors, shop assistants, business people, labourers and politicians.

Technology is increasingly making communication easier. This includes cochlear implants, texting, Skype, as well as electronic home and office equipment made especially to assist people with hearing loss. Employment law means employers have to be responsive to the needs of employees who are deaf or have a hearing loss.

“He is a lucky wee bloke: his hearing loss was diagnosed early, the technology exists to do something about it… It is very likely his life will unfold almost exactly as it would have if he’d been born with no hearing loss.”

Tamati’s mum.
Who will be helping us?
There may be lots of new people involved in your family’s life. Some professionals you are likely to meet early on are:

- an audiologist
- an Advisor on Deaf Children (AODC)
- a habilitationist
- a family counsellor
- an otorhinolaryngologist (ORL) – also known as an Ear, Nose and Throat (ENT) surgeon

The roles of these and other professionals are explained on page 74.

Paying for services
When your child is diagnosed with a hearing loss, most services to support your child’s hearing are free until your child leaves school. In New Zealand, most parents make use of our free public health and education systems. Hearing aids may be free for some people throughout their lives.

Some parents may choose to pay for private professional support, such as the services of a private audiology clinic, or a private speech-language therapy centre. Other parents may choose a mix of the two.

Understanding the professionals
Professionals will use a range of words you may never have heard before when discussing your child’s hearing. Over time, your knowledge about hearing loss, your child’s hearing levels and the technical language around this will grow, but at first you may feel you’re on a steep learning curve.

If a professional tells you something you don’t understand, ask them to explain it more fully for you. And if you still don’t understand, ask again.

Mild, moderate, severe and profound hearing loss
The situation and outlook for every child is different. Many factors affect the language, cultural practices and identity of a child with a hearing loss and their family. The extent of the loss or the supports a child needs will not be the only determining factors. As a general guide, if your child has:

- mild hearing loss – they will have difficulty hearing people speak in noisy situations and may need hearing aids.
- moderate hearing loss – they will have difficulty hearing people speak without the use of a hearing aid.
- severe hearing loss – they can just hear a voice if the person is shouting into their better ear but they are unlikely to understand what has been said. They will need powerful hearing aids or a cochlear implant.
- profound hearing loss – they may hear occasional sounds such as loud noises, but will not understand anyone talking to them, even if that person is standing close. They will need to rely on a cochlear implant, lip reading and/or sign language.

Remember: every child will be different.

See section 7 for more on this and the kind of support children are likely to need at school.
Different ways of communicating

Most people take communication for granted. We talk, we listen, and we gesture with our hands, face and body.

When your child is diagnosed with a hearing loss you will be asked to think about several different ways of communicating and which of these might work best in your situation.

Current research shows the best approach is to be flexible and encourage your child to explore as many communication options as they can.

There are two main ways deaf people communicate in New Zealand: with voices and with hands.

Voices: spoken communication

There are three parts to this.

- Speaking – involving the muscles and movements of spoken language. Speech features the use of sounds in syllables, words, and sentences.
- Listening – using hearing aids or a cochlear implant.
- Lip reading – learning to recognise the lip patterns made by other people that relate to the syllables, words, and sentences of speech. This can be combined with other forms of communication as people often look at facial expressions and lips to get meaning or expression.

Hands: manual or visual communication

Hands rather than the voice are used to convey meaning. There are several systems that come under the broad heading of manual communication.

- New Zealand Sign Language (NZSL). NZSL has its own grammar structure and comprises hand movements combined with facial grammar, expression, lip patterns and a system of body postures. NZSL is the main signing system used in New Zealand and is one of this country’s three official languages.
- Signed English – this is rarely seen. It uses some Australian signs and some contrived signs.
- Sign-supported English – signs are used to represent spoken language such as English. The key signs are used while speaking.

NZSL is more than just a form of communication. Similar to other languages, it also belongs to a cultural group. NZSL unites many who are Deaf into a distinct community. For more on this see Section Three: Deaf culture.

Whatever method you choose – and there is no right or wrong one – it is very important your child learns to interact and respond to other people as early as possible. This will be the key to their ability to socialise and learn.
**Strategies that may be used alongside either of these**

- Fingerspelling – 26 signs are used to represent the 26 letters of the alphabet.
- Gesture – natural movements of the body, especially of the hands and arms.
- Mime – often used informally with deaf children until language is established.
- Written – using pen and paper.
- Makaton – internationally recognised signs and symbols providing limited language and communication for children and adults with a range of disabilities and learning difficulties.

You may use one method or a mix of several. You may start out one way and later change to another. Every child is an individual and every family is different. Choose what suits you.

**Helping your child emotionally**

All of us thrive on a sense of belonging and self worth. Being open and confident about your child’s hearing loss will encourage them to feel good about it too. This can often also influence the attitudes of family, friends and others. You can lead the way.

**Making friends**

Like any other child, your child will want to make friends early on. While most other children they meet are likely to be hearing, you can also introduce them to other babies or children who are deaf, through parent support groups or ECE centres and schools for the deaf.

Children with hearing loss are usually able to interact socially on the same terms with children who do not have a hearing loss.

**What should I expect at home?**

It’s important your child grows up as closely as possible to the way any hearing siblings and other children do. You need to have fair yet realistic expectations of them to help them develop into strong and independent adults. Unless there is another physical or special reason not to, they should be expected to take part in the same daily routines as the rest of the family, such as drying dishes, making their school lunch and tidying their room – so that it is clear they are part of the family.

“**Why can’t I hear?**”

There will come a time when your child will want to know why they can’t hear as other children do. They may want more and more details as they get older.

Keep your answers simple and use language appropriate to their age level. Only respond to what has actually been asked, rather than going into a long explanation – children’s attention spans are usually short. If they want to learn more, they will ask.

**Older deaf people as role models**

Many children think their hearing loss will fix itself as they grow up. Some deaf children who have not met older people who are Deaf even think that the Deaf adults just died off. As children learn to understand more, they can benefit from meeting older deaf or hearing impaired role models. Meeting older people who are deaf helps children develop their own Deaf cultural identity, psychologically, socially, and emotionally. They can meet others through groups such as Deaf Actearoa or Deaf Societies throughout New Zealand.

**The Hearing House** runs a workshop-based mentoring programme for deaf young people and teenagers, led by hearing-impaired adults.

See page 79 for more details.
What about brothers and sisters?

If you have other children, involve them in the special activities you do with your child who has the hearing loss. All of your children will learn and benefit from each other.

Here are some ideas:

• Listen to what brothers and sisters think or want to contribute. Let them teach you what it’s like for them, and ask them for feedback.
• Help them accept that their brother or sister has a hearing loss and encourage them to be open and honest about their feelings.
• Show all your children you value them individually, reminding them of the good things about being part of your family.
• Help them to understand why there are times when their sibling needs more attention but try to schedule special one-on-one time with brothers and sisters also.
• Recognise stressful times within your family and plan to minimise negative effects, for example by giving siblings some strategies to cope with transitions that may be difficult for the child with a hearing loss.
• Allow your children to settle their own differences between themselves and praise them for doing so.
• Don’t forget to laugh and have fun together.

Adapted from “Brothers and Sisters - Special Part of Exceptional Families” T.H. Powell and P.A. Gallagher, 1992.

As well as adjusting to a sibling with hearing loss, brothers and sisters may be faced with awkward and hurtful questions, such as “What are those funny things in your sister’s ears?”, “Why does your brother speak funny?”, “What’s wrong with her?”

Siblings need to know how to respond. If they have a good understanding of their brother’s or sister’s hearing loss this will help them answer those tricky questions in a way that also educates other people.

Different behaviours explained

Sometimes your child may behave in a way you do not understand. Here are some examples and possible solutions.

**COVERING BOTH EYES**

If your child can’t see you they may think they are stopping you from communicating something to them, similar to the way other children may block their ears. Take a short break and try again.

**WAKING IN THE NIGHT UPSET OR UNSETTLED**

Your child cannot hear they are okay at night, so try using a nightlight so they can see that everything is okay.

**RUNNING THEIR HAND ALONG THE WALL IN A DARK HALLWAY**

They are doing this to help themselves navigate better. Leave the hall light on.

**SQUEALING, SPEAKING LOUDLY, OR YELLING**

Sometime a child does this to ‘test’ whether they can hear themselves, or they may want your attention. They may have no idea how loud they are. Explain to them that it is okay to do this outside, but inside it can hurt other people’s ears.

**THROWING TANTRUMS**

Most children do this at some stage, but a hearing-impaired child may be doing so because they are having difficulty communicating. There is no ‘best’ way to deal with this, but encouraging your child to use their language may help identify the cause.

**DOMINATING SOCIAL SITUATIONS OR CONVERSATIONS**

Your child may do this so they don’t have to try and understand what the other person is telling them. Encourage them to take turns.

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**Parent to Parent** can offer support to siblings aged 8 to 18 through their SibSupport programme. See [www.parent2parent.org.nz](http://www.parent2parent.org.nz)
**Tips and ideas**

- Love and encourage your child. Smile often - because what they see means so much more to a child with a hearing loss.

- Coming to terms with and having a good acceptance of your child's hearing loss will help your child's sense of self-worth.

- Talk to other people and read as much as you can so you have plenty of information to base your decisions on.

- Talk to your baby even if he or she is profoundly deaf. They will still learn from you by doing this and it's never too early to start.

- Consider learning sign language with your child even if they are not profoundly deaf.

- Think about using teletext captioning on your TV even before your child learns to read - so they can begin to understand the importance of written communication.

- No matter how much you do for your child, you may always feel that it is never enough. Don’t let anyone intimidate you or make you feel guilty because you can’t manage more. Everyone has different strengths and limits of coping.

- For many children, how successful they are will depend on how positively you, your other children, and other significant adults - such as grandparents - respond to the hearing loss.

- Every smile, funny face and word counts. Their coos, gurgles and leg and arm movements are how they are communicating back to you.