

Just found out your child is deaf or hard of hearing?

Deaf Children Australia | FLYING COLOURS.

You may feel at least a little overwhelmed right now and wonder what the future will look like for your child and family. We put this booklet together to help answer your questions and ease your concerns.

It covers the essential things you need to know after your child's diagnosis. It's full of helpful ideas for navigating your journey, including information about hearing screening, early intervention, dealing with your emotions, finding support and more.

We trust it will help you as you come to terms with the diagnosis. And don't forget, deaf or hard of hearing (DHH) kids grow to become happy and fulfilled adults. Understanding more about what lies ahead can help you support your child to reach their potential and thrive.

"When Emelia was first diagnosed I was worried and scared and had so many questions. However due to Emelia's complicated birth it was very easy for me to also feel blessed that she was still with us. And even if she couldn't hear at all, I knew we would be ok. Emelia is thriving and is a confident, loving child. I know that hearing loss does not affect the person that she is. And I also know that apart from adding a few extra challenges along the way, Emelia will be just fine."

ALEISHA, MUM TO EMELIA

Moderate severe hearing loss

what other parents say

"I didn't know anyone who was deaf and I wasn't sure how this was going to impact my son's life. I was at a loss for how to help my little baby moving forward. I was very lucky to have met a DCA Parent Mentor, Stacey, at one of our early hospital appointments at the Childhood Hearing Clinic (CHC). Stacey was a wonderful counterpoint to the highly medicalised journey we had been on with Hayden to that point.

She made me feel simply like a mum, with a depth of understanding of my situation that only comes from being the parent of a premature baby with a hearing loss. ... Stacey helped me understand what parenting a hard of hearing child might be like and gave me suggestions about things I could do now to help my baby."

HANNAH, MUM TO HAYDEN

Moderate hearing loss

"When we suspected Grace had a hearing loss, I mostly felt fear. Once our suspicions of Grace's hearing loss were confirmed, there was mixed emotions. It's hard to explain, but there was a slight feeling of relief, that's in the context of knowing. But more overwhelmingly we felt great sadness, guilt and fear... Also what would the future hold for Grace, how would she cope, how would people treat her?

Now I feel more confident that Gracie will be ok. She continually amazes me with her progress and her beautiful happy nature and her strong will only draws people toward her rather than away. Everyone who meets Grace loves her and no one is worried about her hearing loss or disabilities. And if they are, then this protective mum will be all over them!!"

STACEY, MUM TO GRACE

Moderate-to-severe hearing loss

YOU'RE NOT ALONE



This may be the first time you are meeting someone who is deaf or hard of hearing.

Understandably you will experience a wide range of emotions and your probably wondering what the future holds. While your head may be spinning, rest assured you will come to accept the diagnosis. Once you have had time to process the news, the diagnosis will seem less overwhelming.



Enjoy your baby

You have a precious new child in your family. Focus on enjoying them and giving them the loving care they need.

This doesn't have to be complicated. Meeting your baby's basic needs for food and comfort, paying them plenty of attention, and giving them opportunities to play and form relationships within your family will help them thrive.

Communicate with your baby

No matter the type of communication you ultimately choose for your family, it's essential to start communicating with your infant immediately and often.

You can do this by smiling, making eye contact, using gestures, and talking and singing to your baby throughout the day.

Arm yourself with knowledge

Building your knowledge helps you feel more in control. But too much information can have the opposite effect!

That's why we built the Flying Colours website especially for parents like you. It's full of important information parents of a DHH child told us they'd like to know, plus lots of links to other resources.

Look after yourself

You need to take care of yourself so you can best take care of your baby. Try to eat well, get some physical activity, and get as much sleep as you can. Accept any offers of help, such as meals, cleaning or help with your other children.

NAVIGATING A NEW NORMAL

95%

OF DHH KIDS ARE BORN TO HEARING PARENTS

Get support

Remember, you're not alone and support is available. Read more about finding support below.

"Sometime in the weeks between appointments, I received his diagnosis letter in the mail. He had a bi-lateral, sensorineural hearing loss .... I had no idea what these words meant and although I had heard the nurse say them at the end of his hearing test appointment, it felt like I was seeing them for the first time. That was when the next part of our story began. The part where researching became my newest infatuation. The part where I realised, he really, actually WAS deaf ... This was it. This was us. This was real and it was no dream or misdiagnosis. This was him. And all there was to do, was, simply accept him."

CHRISTINE, MUM TO CODY
bilateral, sensorineural hearing loss



YOUR SUPPORT TEAM – WHO'S WHO IN THE DHH NETWORK?

Supporting a deaf or hard of hearing (DHH) child is a team effort, and your family is at the centre of that team. Here are some other health and education professionals who often form part of your team.

General practitioner (GP) – to provide day-to-day medical care for your child, refer you to other professionals as needed, and co-ordinate different healthcare services.

Ear, nose and throat (ENT) specialist – who may diagnose the cause of your child's hearing loss and treat any underlying conditions (such as ear infections and fluid build up). Some also perform cochlear implant and grommet surgery.

Paediatrician – who can monitor your child's growth and development and any additional health needs.

Geneticist – who can help you find out if your child's hearing loss has a genetic cause and discuss whether any future children could also be affected.

Ophthalmologist – DHH children are advised to visit an ophthalmologist because they tend to rely more on their vision and because hearing loss is often associated with eye problems.

Teacher of the Deaf [TOD] – these teachers have done extra training to teach DHH children. They work in schools, early intervention services, early childhood programs and people's homes.

Social workers or family support workers – who can give you information and help you access supports available to you, including financial assistance, legal help and early intervention services.

Parent mentors these parents of a deaf or hard of hearing (DHH) child are trained to provide guidance and support in the early days after diagnosis. Families often find it helpful to talk to someone with lived experience of a similar path.

Additional appointments
You might have various other support services and professionals in your team, including:

Speech pathologists to support development of communication skills.

Audiologists to assess, diagnose, and treat Hearing loss.

Child psychologists to provide support for learning and dealing with thoughts, feelings, and behaviours.

Occupational therapists [OT] to help improve everyday function and independence.

Early intervention – making informed decisions

During a child's early years, they are building key communication, language, and social-emotional skills. These skills form the foundations for future learning, identity formation and relationship building. This period is particularly important for deaf and hard of hearing children, who face challenges in communication and language development.

Early intervention is based on evidence showing that a child's brain is primed for learning at certain times. Your child can benefit from receiving services and supports that make good use of these times. This helps give your child the best chance of succeeding at school, work and in relationships throughout life.

FOR EXAMPLE, EARLY INTERVENTION CAN HELP YOUR CHILD BY SUPPORTING THEM TO:

- learn to communicate
- use any hearing they have available
- use assistive listening devices (such as hearing aids or cochlear implants)
- engage in family life

Choosing an early intervention provider

Early intervention should take a multidisciplinary approach. This means different professionals will work with your child to support different aspects of their development.

It should also be family centred. This means it should build on your families' strengths and skills and encourage your involvement.

When you're choosing an early intervention provider, it can be helpful to: start as soon as possible – the earlier your infant or young child starts to listen and recognise language, the sooner listening and language skills can develop.

- contact at least a couple of providers before choosing one
- have a list of questions to ask each provider
- find a handy list of questions about early intervention



LEARN MORE ABOUT HEARING SCREENING

About Hearing Australia

Who they are and how they can help?

Hearing Australia is an Australian-Government funded agency that provides services and devices for people of all ages with hearing loss.

Their Paediatric Program is for Australian citizens or permanent residents up to the age of 26 years who have a permanent or long-term hearing loss. Under the program, eligible children, young people and their families can receive free:

Hearing assessments

High-tech hearing aids

Help to use devices and enhance communication

Device and battery replacements, repairs and updates

Visits to early intervention programs and education facilities

Information sessions and support for families, educators and community groups.

They have over 180 locations, visit hundreds of sites, and offer online and telehealth services.

Find out more at:
flyingcolours.org.au

Communicating with your baby – your informed choice

From birth, children are wired to form relationships and express themselves. To do this effectively, they need language and communication skills. It's essential to start communicating with your baby from birth.

Communication is a two-way process and includes what you say or sign. It also involves things like gestures, eye contact, facial expressions, and body language.

Communication challenges can happen when a DHH child is born to hearing parents. This is because they don't immediately share a common language.

Parents of a DHH child will need to pick a form of communication everyone in the family can learn to use. There are a few types to choose from, and there are no right or wrong choices. Your decision will depend on your family situation and your child's needs.



LOCATIONS **180**

1. 2. 3.

Auditory-oral approaches – which aim to give DHH children skills to communicate with hearing people. They focus on using any hearing your child has, assisted by hearing aids, FM systems and/or cochlear implants, and sometimes lip reading. These approaches do not use sign language or finger spelling to aid understanding of speech.

Sign bilingualism which aims to allow your child to communicate without relying on hearing. Sign language (Auslan) will be their first language, and your family's spoken language becomes their second language, learned either through speech, writing or a sign-supported system.

Total communication which aims to allow easy communication between your child and their family, friends and others they have contact with. It fosters effective communication using a combination of methods, such as lip reading, speech, gestures, body language, Signed English, finger spelling, and hearing devices.

There are three main communication options.

Whichever method you choose requires time and effort to master. Your support team will help you develop an approach that works for your child and family.

Visit flyingcolours.org.au to find out more about communicating with your baby.



"As anybody who has ever attempted to learn a second language will know it is challenging and frustrating... It did however provide us with the ultimate reward of talking to our daughter about the ordinary everyday things."

EMMA, MUM TO DARCY
Bilateral, profound hearing loss

Finding Support

One of the best things you can do now is seek support for your journey. Most families find it very helpful to connect with someone who has lived through a similar experience and can provide insights, advice and support during this time.

Find out more at:
flyingcolours.org.au

Our free Parent Mentor program allows you to speak to another parent who has travelled further along the path with a DHH child. Our trained Parent Mentors can engage with you by phone, text, email, or through online platforms like Skype, FaceTime or Zoom.

Learn more about our Parent Mentor program

We've also produced a series of videos where families share their experience of raising a DHH child.

"When he was first diagnosed it was definitely a shock as we had no one else in the family with hearing loss nor did we know anyone with kids with hearing loss. No one really understood what we were going through...

Then we reached out to the Parent Mentor program. It was so nice to have someone to talk to that understood what we were going through and how we felt. Someone that understood the processes and terminology. They are there for you to ask questions or even just to talk about how you are feeling. You never feel alone when you have a mentor."

SHANNON, MUM TO AUSTIN
mild-to-moderate bilateral sensorineural hearing loss

You're not alone on this journey



Emotions – coping with grief

Grief is one of the most common feelings people experience after receiving their child's diagnosis. This is understandable given you're probably wondering what your child's future looks like and how it will be different to what you expected.

Here are some ideas that can help you deal with grief.

Expect people to respond differently – different members of your family may have widely varying reactions to the diagnosis. People also express grief differently. For example, you might cry a lot, your partner might hold everything inside, and your other children might act out. It can help to remember there are no 'right' or 'wrong' reactions to the diagnosis.

> "I cried every night for a long time after the formal diagnosis; it really came down to the unknown, what will his future look like?"

BIANCA, MUM TO A SON
profound hearing loss

Talk about your feelings – share how you feel with your partner or a trusted family member or friend. This can help you cope better and show people it's okay to talk about your child's hearing loss.

Don't try to be 'strong' – it's normal to feel sad, angry, overwhelmed and more. You don't need to hide your feelings or put on a brave face. Sharing your feelings can help you and your loved ones.

Look after yourself – by eating well, doing some physical activity and getting as much sleep as possible.

Seek support – our Parent Mentor program can be especially helpful during this time.

Be kind to yourself – everyone needs time to get over grief, but the amount of time it takes varies from person to person. Even when you're past the worst of it, feelings of grief can slip out unexpectedly. Don't beat yourself up if you feel like you need more time than others to start coping.

Get professional help – if you continue to struggle accept the diagnosis, it's a good idea to see a counsellor or psychologist.

... take notes and ask questions

www.flyingcolours.org.au

Important questions to ask your healthcare team

In early appointments with different health professionals, you may feel like you're being bombarded with information. It can be hard to take everything in. It's very normal to forget things and to have lots of questions. Don't be afraid to ask your team anything – they know you're dealing with a lot right now.

It's a good idea to write down any questions you have. This can help ensure you remember them at appointments.

Here's a list to get you started.

- What can my child actually hear?
- Can you explain the medical terms in plain English?
- Is the loss permanent?
- Will my child need more testing? And how often should my child get tested?
- Can I watch and film the hearing aid fitting?
- Should I make appointments with other health professionals? For example, a speech pathologist, geneticist, audiologist, or ENT surgeon?
- How do I explain to my other children about my baby's deafness?

Levels of deafness

MILD
[21-40dB]

A child with a mild hearing loss may have difficulty hearing soft speech. The child may also have difficulty hearing normal conversation where there is a lot of background noise.

Some children will use hearing aids.

A child with glue ear will usualy have mild deafness also.

MODERATE
[41-70dB]

A child with a moderate hearing loss will need to wear hearing aids to understand normal speech.

Hearing without the aid is increasingly difficult in a noisy pool environment.

SEVERE
[71-90dB]

A child with a severe deafness can usually follow a conversation in aquiet room whilst wearing their hearing aids.

They will have difficulty understanding normal speech even when wearing their hearing aids in a noisy environment or in a big group or a swimming pool.

They would not detect normal conversation without their hearing aid but may hear loud voices close by.

PROFOUND
[90+dB]

A child with a profound hearing loss will have trouble understanding conversational speech even with their hearing aids, and would not detect even the loudest components of shouting without their hearing aids.

Most children with profound hearing loss have cochlear implants.

Other children mayneed or prefer torely on manual communication skills such as Auslan.

Common terms and acronyms

When your child is first diagnosed, you might attend plenty of appointments with your healthcare and learn terminology you've never heard of before. These words and phrases may pop up time to time along your journey and you might be wondering what they mean. You're not alone. Many parents find it takes some time to get used to the language. **Don't be afraid to ask your health care professional if you're unsure.**

Culturally Deaf:

This term, where the word 'Deaf' is capitalised, describes people who choose to identify as Deaf and mix socially within the Deaf community. The Deaf community has its own language (Auslan), culture (deaf way of doing things) and heritage.

deaf:

Where the word begins with a small 'd', this is a medical term to describe someone who cannot hear. This has become a standard term to describe all types of deaf people. It is often used to cover all types of hearing loss – Deaf, deaf, hard of hearing and hearing impaired.

Hard of hearing:

This term is usually used to refer to people who do not use Auslan as their main communication mode. It refers to people with some hearing, who may or may not use hearing aids. It can also be used as a general term to describe all people with a hearing loss. In Australia, it often means people whose hearing changes later in life.

Hearing impaired:

Like hard of hearing, this means someone who has some hearing and may benefit from hearing aids.

Partially hearing:

This is similar to 'hard of hearing', that is, a person who has some hearing and may benefit from hearing aids.

Not sure how to refer to somebody you meet who has a hearing loss? Ask them! Most deaf and hard of hearing people are happy to let you know their preference.

We've put together a list of the most common acronyms and terminology. Use this as a guide of reference.

ABR
Auditory Brainstem Response

ALM
Auslan Language Model

ANSD
Auditory Neuropathy Spectrum Disorder

AVT
Advisory Visiting Teacher

BAHA
Bone Anchored Hearing Aid

BCHA
Bone Conduction Hearing Aid

BTE
Behind the Ear

CI
Cochlear Implant

CMV
Cytomegaloviral Disease

CODA
Child of a Deaf Adult

dB
Decibel

ECDP
Early Childhood Development Program

EI
Early Intervention

ENT
Ear, Nose & Throat Specialist

EVA
Enlarged Vestibular Aqueduct

HA
Hearing Australia

HOH
Hard of hearing

Hz
Hertz

IEP
Individualized Education Program

ITE
In the Ear

LAC
Local Area Coordinator

MA
Microtia Atresia

NDIA
National Disability Insurance Agency

NDIS
National Disability Insurance Scheme

SSD
Single Sided Deafness

TOD
Teacher of the Deaf

UHL
Unilateral Hearing Loss

VRI
Video Relay Interpreting

VROA
Visual Reinforcement Orientation Audiometry

VRS
Video Relay Service

Fact or Fiction? Decoding online advice for parents

When you first discover your child is deaf or hard of hearing (DHH), you may get bombarded with advice. From friends and family to health professionals, you'll probably hear lots of different opinions.

Scrolling online is an easy and accessible way to find information. Often, a simple click is all it takes to find just what you're looking for. So, how do you sort good advice from bad or work out which is best for your child and family?

Our Parent Mentor Karla, shares concerns parents have expressed and offers sound advice for parents trying to navigate information online.

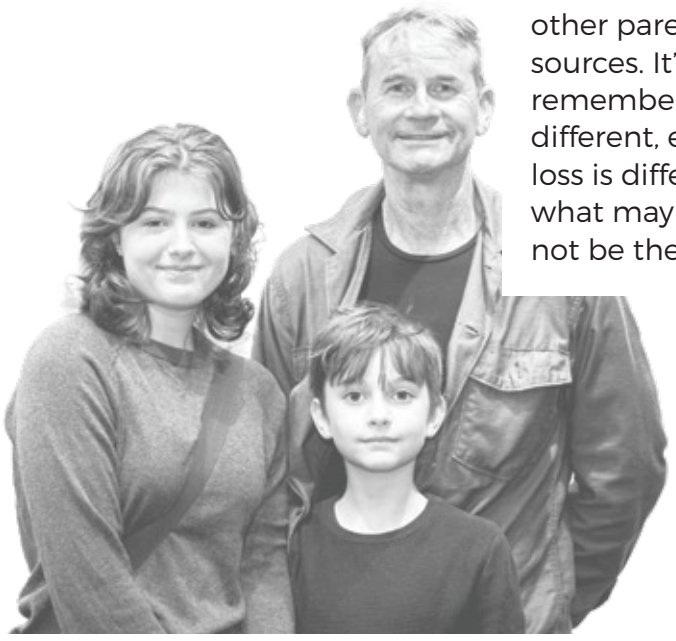
"As a new Parent of a deaf or hard of hearing child, it's normal to feel overwhelmed by all the information you're receiving and needing to make decisions for your child in a space that they are only just learning about themselves.

In my role as a Parent Mentor, I often speak to parents who are encountering a range of emotions and managing changes within the family, who are sometimes left feeling criticised for their choices as well as trying to keep up with differing opinions from friends, family and professionals. More recently, the rise of social media influencers is contributing another layer of stress and worry. Having information at our fingertips is incredibly valuable and in a lot of ways comforting to know your family is not alone.

My role as a parent mentor is to encourage parents to explore options, ask questions, and seek out information from various sources including professionals, other parents as well as online sources. It's important to remember that every child is different, every diagnosis of hearing loss is different and know that what may work for one family may not be the best option for another."

Here are Karla's top tips for parents seeking guidance when making informed choices:

- Seek a second opinion – recognising what is balanced, non-bias and trustworthy information on the internet can be tricky. If you have any questions about what you find online, you can speak to your healthcare team.
- Try to avoid comparing your child's diagnosis or development to what you see online – we all want the best for our children, and it is ok to trust your parent instincts.
- Connect with a support network to swap and share stories as well as information – connecting with other families is a great way to create meaningful connections.
- Any decisions you make now can be changed in the future – it's perfectly normal to make changes as your child develops and grows.



First Signs

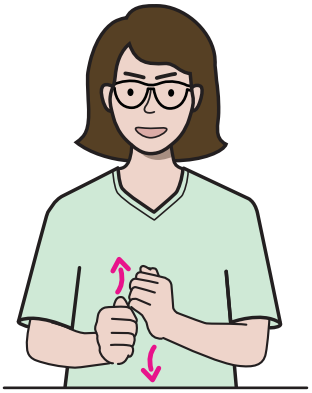
Within weeks of birth, babies start discovering the patterns of language used around them. This is true whether that language is spoken or signed. Children need to be immersed in a language-rich environment to develop strong language skills.

Parents will need to decide on a form of communication that everyone in the family can learn to use and there is no right or wrong choice. Your decision will depend on your family situation and the needs of your deaf or hard of hearing child.

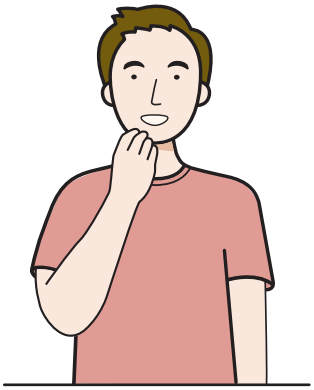
If you are deciding to pursue Auslan, try some of these common baby signs to get started. Using this together with another method of communication can also be effective.

Remember, your healthcare team can assist you with deciding about what type/s of communication could suit your family.

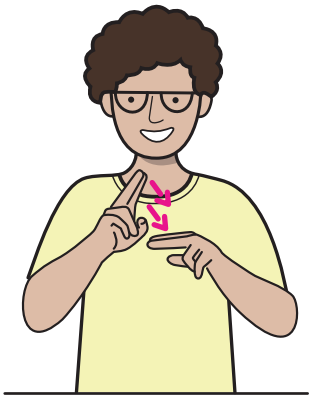
Scan the QR to view videos of the signs



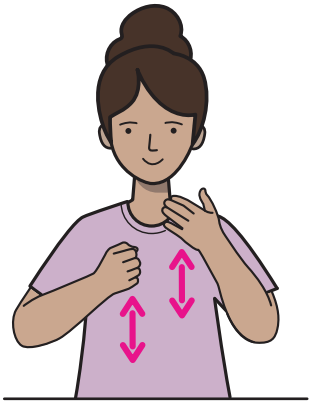
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eat



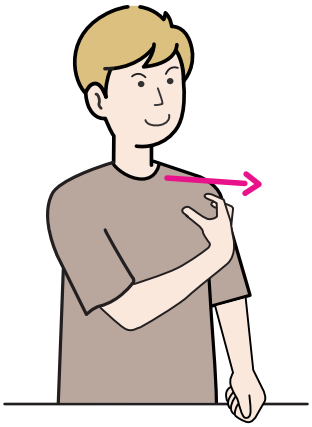
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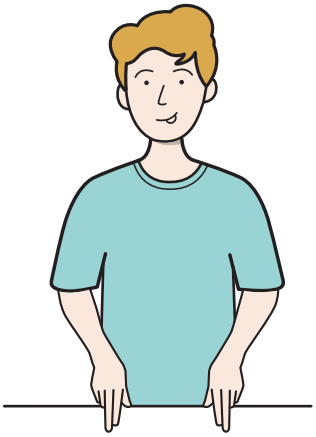
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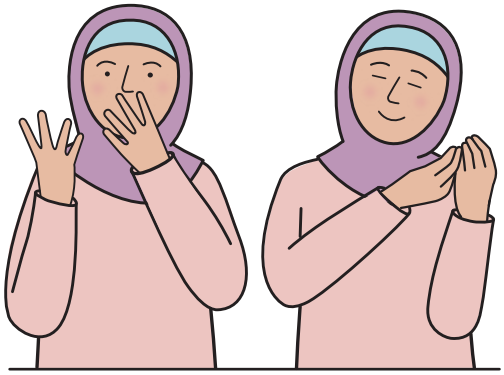
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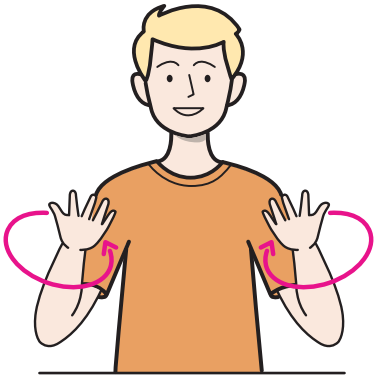
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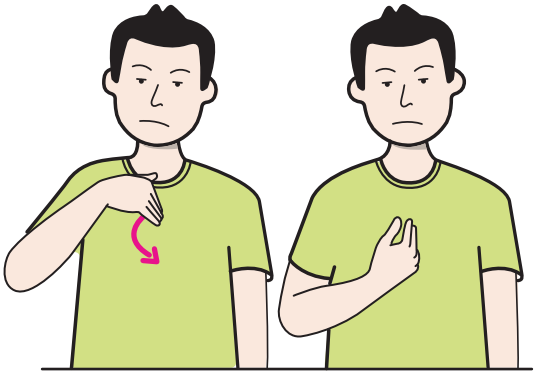
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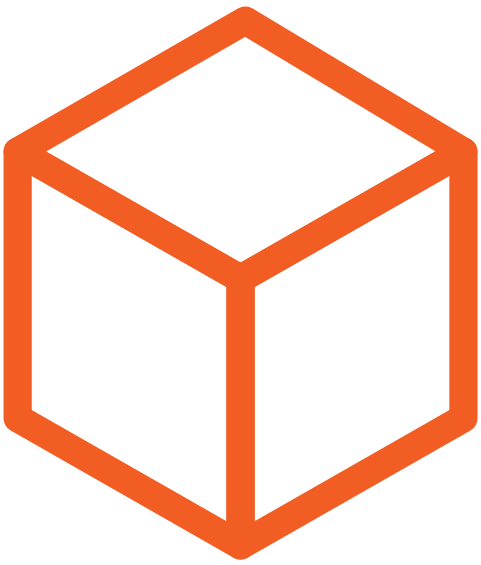
sleep



play



tired



Flying Colours was created especially for families with a child newly diagnosed as deaf or hard of hearing. The website is packed with information, resources and ideas to help you navigate this path.

For further information about this booklet visit:

flyingcolours.org.au

Deaf Children Australia uses the term 'deaf' to refer to all degrees and types of hearing loss.

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Contact DCA

We always love connecting with DHH children and families. If you have any feedback, questions, or ideas, you can contact our head office in Melbourne on

1800 645 916

Or email us at info@deafchildren.org.au

You can find further information, including contact details for our programs and states, on our contact page at **deafchildrenaustralia.org.au**

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