

Hearing Implant Program Family handbook







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Children's Health Queensland pays respect to the traditional custodians of the lands on which we walk, work, talk and live. We also acknowledge and pay our respect to Aboriginal and Torres Strait Islander Elders past, present and future.

Artwork pictured left: Onchan Wayath | Acrylic on canvas | Artist: Sheryl Pamulkar Language: Wik-Alken | Clan: Apalech

Onchan Wayath is the season just after the big wet. The leaves are all bright and colourful at this time. In this painting, Sheryl shows the new leaves on all the mange trees in and around Aurukun.

Cover photo by Mark Burgin. BK0012 updated August 2024.

## Welcome!

You are receiving this booklet as your child has been referred to the Hearing Implant Program at the Queensland Children's Hospital.

When a child is referred to the HIP for cochlear implant candidacy, many tests are done to determine if they would be suitable for a cochlear implant.

This book will show you how the ear and cochlear implants work. It will also cover the process and some of the factors used to determine who is a suitable candidate. This book, along with the information provided by the HIP team will give you the information and tools you need during your family's cochlear implant journey.

### **About us**

Children's Health Queensland and the Queensland Children's Hospital provides safe, high-quality and family-centred healthcare for children and young people from across Queensland and northern New South Wales.

Children's Health Queensland is committed to ensuring every child and young person in Queensland, regardless of where they live, can access high-quality healthcare.

#### **Our values**



## Respect 'We listen to others'



Integrity
'We do the right thing'



Care
'We look after each other'

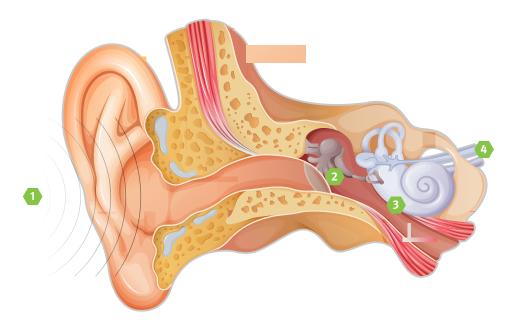


Imagination 'We dream big'



## How hearing works

Hearing is our ability to perceive sound. A reduced ability to hear is called a hearing loss. Hearing loss can vary from mild to total loss of hearing and can occur in one or both ears. Hearing loss in a child may result in delayed speech and language development, social problems and learning difficulties at school, due to missing what is being said.



- Sound travels into the ear.
- 2 The sound hits the ear drum causing it to vibrate. Sound vibrations move three little bones in the middle ear, and travel into the cochlea (the hearing organ).
- 3 The cochlea picks up the vibrations and send signals to the hearing nerve.
- The hearing nerve sends these signals to the brain and hears this as 'sound'.



## What are cochlear implants?

A cochlear implant is a small electrical device that is an option for people who have severe to profound deafness. Instead of making sounds louder, a cochlear implant provides access to sound by direct stimulation of the hearing nerve, with electrical signals. It has an external part (the speech processor) worn on the ear or the head. It also has an internal part (the implant) that is placed under the skin and into the cochlea during surgery.

- The 'speech processor' picks up sound and converts it into a digital code.
- The signal travels to the transmitting coil, which attaches to the head via a magnet.
- Radio waves from the coil carry the coded signal through the skin to the 'implant'.
- The 'receiver-stimulator' converts the digital code to electrical impulses and send them to the electrodes inside the cochlea.
- The electrodes stimulate the hearing nerve, which sends these impulses to the brain where it hears 'sound'.





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## **Getting started**

Your child will be allocated a case manager who will coordinate their care and appointments. Your case manager will also be your first point of contact with any questions you have during the candidacy process.

A team of professionals will be involved, and many appointments will be arranged before a recommendation is made. Professionals involved include an Ear, Nose and Throat surgeon, audiologist, speech pathologist

and a psychologist and social worker as needed.

Your case manager will contact you to arrange an initial meeting for you to meet the team and for the team to find out more about your child and family.

## Communication options available

- Spoken language
- AUSLAN (Australian sign language)
- Sign supported spoken language
- Bilingual-bimodal
- Other system.

Your speech pathologist will discuss these options with you further.

# Meet your Hearing Implant Program team

Each team member plays an important role in supporting your family.

#### **Audiologists**

Work out the degree and type of hearing loss your child has. This will help determine if a cochlear implant is suitable for your child. Your child's age and stage of development will contribute to the choice of test used.

#### Speech pathologists

Assess how your child is communicating. This will help determine if your child's communication skills are delayed compared to normally hearing children their age. This information assesses how well your child is using their hearing and helps predict how speech and language may develop with a cochlear implant.

## Ear, Nose and Throat (ENT) surgeons and medical registrars

Care for your child's medical needs and complete the cochlear

implant surgery. They will be available to answer any questions you may have about the implant, surgery or outcomes.

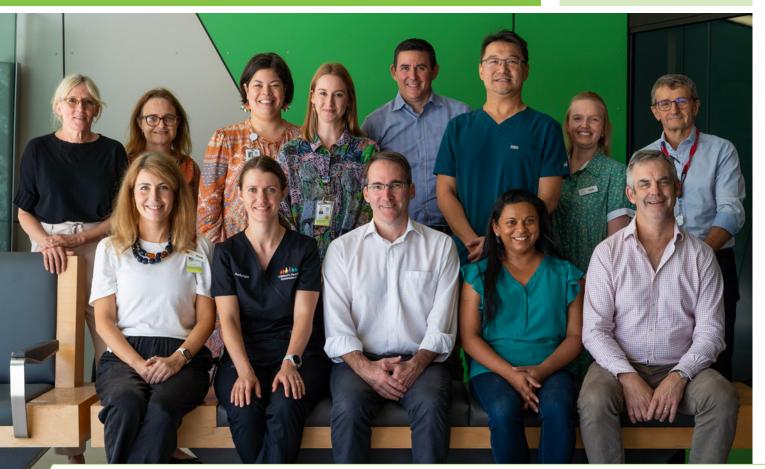
#### Social worker

Provide support to your family to manage the different stages of the candidacy process as well as the post implant process, should it be required.

#### **Psychologist**

Complete a cognitive/ developmental assessment on your child to indicate your child's current abilities and determine if any special management strategies will be required after implantation.

Other people in your child's care team might also include nursing staff, medical imaging, ophthalmologist, paediatricians and geneticists.



## Micah's story

April 2022

A routine newborn screening test identified a potential issue with Micah's hearing when he was just four days old. Further audiology testing then confirmed he had profound permanent hearing loss in both ears caused by a mutation in the connexin 26 gene. This is the most common cause of congenital sensorineural hearing loss.

Micah's mum Amber said the news of Micah's hearing loss was a pivotal moment for their family.

"We experienced so many emotions and grieved at the thought of our son not being able to hear our voices. The future we had envisaged for our family instantly changed course."

After months of rigorous testing, Micah qualified as a strong candidate for cochlear implants which would allow him to hear the world around him and the opportunity, with the help of therapy, to improve his speech.

In June 2021, while the world was dealing with the COVID-19 pandemic, Micah underwent his cochlear implant surgery at the Queensland Children's Hospital, one month before his first birthday.

A few weeks after his surgery, Micah heard sounds for the first time (he reacted to their family dog, Willow barking), and three months later, he was able to say his first word, mum.



Since his surgery, Micah and his family have been working with speech pathologists in at the Queensland Children's Hospital and the Yeerongpilly Early Childhood Development program to teach him how to listen, speak and sign in Auslan.

Now 22 months on, Micah continues to attend weekly Auslan playgroup sessions with dedicated Auslan Language Models and participates in individual sessions with a Teacher of the Deaf.

Micah's family were determined that he would be able to communicate with spoken language in combination with Auslan. "Giving him the chance to develop and grow in both the Deaf and hearing communities means he has the power of choice in how he lives his life." Amber said.

"Micah has adapted seamlessly to the challenges of his condition because he has been fortunate to receive the support he needs from an early age."

"Micah will always be deaf, but he isn't broken – he's perfect in every way," Amber said.

Amber said the whole family feels supported and reassured that Micah's future is in good hands.

"Learning a new language, such as Auslan can seem overwhelming, however, with the right support and being around like-minded families, the journey is part of the rich tapestry of life."

# Factors to consider when determining implant candidacy

The following factors will be discussed with you in further detail at your child's appointments, if you would like your child to have a cochlear implant/s (parental choice):

- How much hearing your child has (also known as residual hearing).
- How old your child was when they developed their hearing loss and how long they have had their hearing loss.
- 3. Your child's current speech and language skills.
- 4. What benefit your child is getting from their hearing aids.
- 5. The cause of your child's deafness.
- 6. Your child's ear anatomy.
- 7. Your child's overall development and abilities.
- 8. The commitment involved in the assessment process and post-surgery appointments.
- Your expectations about how your child will utilise a cochlear implant and your communication goals for your child.

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# Deciding about a cochlear implant

Assessment results will be discussed at a team meeting. A recommendation will be made as to whether your child has met criteria for either one (unilateral), two (bilateral) implants or a cochlear implant might not be recommended.

Your case manager and/or ENT surgeon will let you know the team's recommendation. Your family can then decide whether to go ahead with cochlear implantation for your child.

If you decide to proceed another series of appointments will be made for pre-surgical counselling and to sign a consent for surgery.

A report will be sent to you as well as other professionals outlining the candidacy outcomes. This will occur whether cochlear implantation is recommended or not.





## Surgery at a glance

- The operation takes 1.5-3 hours depending on if both ears or just one ear is implanted.
- 2. In most cases your child will stay overnight in hospital (one parent is also able to stay overnight).
- 3. You can stay with your child during their time in hospital.
- Your child's head will be bandaged for up to a week following surgery.

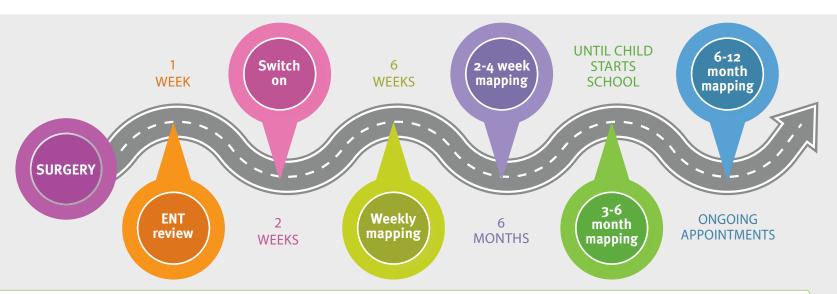
Read more about preparing your child for surgery and staying overnight at the Queensland Children's Hospital.

# What happens after getting an implant?

The needs of each child are different and each child's therapy plan will be unique. Regular programming known as "mapping" and therapy are essential for success with cochlear implants.

Below is an example of appointments throughout your child's time with the Hearing Implant Program.

Speech therapy is often coordinated with mapping appointments.



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## Key steps to success

- 1 Regular attendance at audiology and speech pathology appointments.
- 2 Provide a language-rich environment at home to enable your child to to listen to the new sound provided by the cochlear implant.
- Enabling your child to learn to listen to the new sound provided by the cochlear implant and providing a language rich environment at home.
- 4 Cochlear implant use all waking hours.

## **Keeping on track**

- 1 Check daily to see that the speech processor is working well.
- Keep a supply of spare parts and batteries handy.
- 3 Attend all appointments and call if you're unable to attend.
- 4 Talk to the case manager or other team members if problems arise.

## Support for regional and remote families

Families living in regional or remote areas of Queensland can often find it difficult to access health services compared to those in metropolitan areas. Additional support and services will be available to these families during the assessment and postimplant process, ensuring all children continue to receive the best possible care regardless of where they live.

#### Local services

Where possible our team will connect you with local services for some hearing assessments. Many children in regional areas can also access therapy from local speech pathologists through the Hearing Implant Program.

#### Travel

Travel to Brisbane is required as some pre-implant assessments cannot be performed locally. Regular travel is also required in the weeks and months immediately following surgery, and on an ongoing basis. The Patient Travel Subsidy Scheme can help with flight and accommodation costs and can be accessed at your local hospital.

#### **Telehealth**

For some children, it is also possible for mapping to be conducted remotely via video teleconferencing. This can be discussed further with your audiologist.



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## Frequently asked questions

### Can my child's speech processor get wet?

Yes. Bathing, swimming, and getting caught in the rain is possible with certain brands of cochlear implant. Please discuss your specific needs with your audiologist

### Can my child play sport?

Some sports are not recommended due to risks of damage to the implant. This includes full contact sports such as rugby union, rugby league and boxing. Helmets are recommended for bat and ball sports such as cricket and baseball. Speech processors should also be secured for more active activities.

### Will my child outgrow the cochlear implant and require a new one?

Your child's cochlea is fully formed at birth. The cochlear device implanted in your child is designed to last a lifetime and accommodate for growth in children. The external speech processor can be upgraded as technology improves.

#### Can my child travel via air?

Yes, it is safe for your child to travel on a plane. They can walk through a metal detector while wearing a speech processor. Some people say that they hear a buzzing sound when passing through. The implant may activate metal detection systems; therefore it will be important to travel with the 'Cochlear Implant Patient Identification Card'.

## **Support**

We recognise this is a challenging time for families. Whether you need help attending appointments, accessing information, or simply need someone who can listen, there is support available to guide you through your journey ahead. Parent-toparent support is also a great way to connect with other families who have received a hearing loss diagnosis and share experiences.

To find out more about support available, please contact the Healthy Hearing Family Support (HHFS) on 1800 352 075 (toll free) or email HHFS@health.qld.gov.au

#### More information

<u>Cochlear Ltd</u>

**Australian Hearing** 

Better Hearing Australia

<u>Deaf Connect</u>

<u>Deaf Children Australia</u>

<u>Aussie Deaf Kids</u>

MedEL

**Advanced Bionics** 

Hear For You



### yourQH

yourQH allows you to keep track of your appointments at Queensland Children's Hospital. You can access yourQH on a smartphone via the app, computer, laptop or tablet.

#### Contact us

#### **Hearing Implant Program**

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- e QCH-Audio@health.qld.gov.au



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## The best care for every Queensland child



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