DEAFNESS FORUM AUSTRALIA

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The Children's edition.

Calls for National Regulation of Audiologists: Townsville hospital failures prompt millions in compensation.

The Queensland government will pay more than $2.2m to families of 97 child patients of a hospital's audiology unit.

By Andrew Messenger for The Guardian.

Townsville University hospital's audiology unit programmed cochlear implants in some children incorrectly, misdiagnosed others, and even conducted hearing tests on an infant who was asleep, a damning independent review has found.

Queensland health minister Shannon Fentiman has called for better federal regulation of audiologists.

The clinic is the only public option for many patients in northern Queensland, who would otherwise be forced to travel to Brisbane for specialised care.

The clinic was poorly organised, staff were overworked, and key protocols did not appear to be followed, leading to poor outcomes, monitoring, measurement, and reporting.

An investigation was conducted and last week a report was published. Read the report. The Queensland government has promised to spend more than $2.2m compensating the families of 97 patients who required additional testing and follow-up care as a result of the errors.

Children left with lifelong developmental delays.

Concerns about the audiology service were first raised in December 2022, after the clinic mistakenly identified a number of babies and children as either having normal hearing or a non-permanent issue when in fact they were profoundly deaf.

An initial investigation identified that the hospital's cochlear implant program was also flawed, with clinicians failing to program the technology in a way that would allow children to hear correctly, leading to developmental delays.

The clinic also failed to properly follow up patients to ensure they were learning to speak.

Health staff identified 341 patients for review, including adults, with 59 requiring a recall, 20 of them urgent.

The Townsville Hospital and Health Service CEO, Kieran Keyes, acknowledged some patients would be affected for life, as a result of developmental delays caused by the mistakes.

Keyes said the hospital had since identified an additional 18 people who were not part of the original risk group.

"We continue to investigate records on a risk basis and will continue to do that into the foreseeable future," he said.

Keyes said it was "destabilising and pretty shattering" to have the community's confidence in the service rocked.

Approximately 40 families of children who experienced the most significant impacts have been offered $50,000 while an additional 57 children recalled for additional testing will be offered $5,000 by the state government.

Reluctance to report concerns.

Conducted by a team of external health service investigators, the investigation found that some team members expressed "reluctance to report concerns due to a fear of receiving a negative response from audiology leadership".

No staff had reported concerns before the inquiry was launched in April, partly due to their lack of understanding of the system for reporting them.

It also uncovered a number of concerns relating to conflict of interest, which "influenced decision making and professional judgment".

The investigation also looked at whether the clinic focused too heavily on scientific research rather than working with patients, with some members of the unit telling investigators that research was perceived as the only way to advance their career, and "was more highly valued than clinical work".

The review ultimately could not determine if the unit's emphasis on research came at the expense of patients but deemed that the workload was poorly managed.

What happens if a child's cochlear implant is programmed incorrectly?

If cochlear implants are not properly mapped (programmed and adjusted), it can result in reduced or distorted perception of sounds, including speech sounds, which can negatively impact speech acquisition.

Here are some of the effects of poor mapping of cochlear implants:

- <u>Reduced speech perception</u>:

  The individual may have difficulty perceiving speech sounds accurately, leading to reduced speech perception ability. This can impact the individual's ability to understand spoken language, follow conversations, and acquire speech and language skills.

- <u>Delayed speech production</u>:

  If the individual is not able to accurately perceive speech sounds, it may result in delayed or inaccurate speech production. This can affect the development of speech production skills, including articulation, pronunciation, and intonation.

- <u>Spoken language delays</u>:

  Language development is closely linked to speech perception and production. This can result in language delays, as the individual may have difficulty understanding spoken language and expressing themselves verbally.

- <u>Reduced speech clarity</u>:

  Improper mapping of cochlear implants can result in degraded sound quality or distorted perception of sounds, including speech sounds. This can lead to reduced speech clarity, making it challenging for the individual to articulate speech sounds accurately, resulting in reduced speech clarity and intelligibility.

Australian College of Audiology commented.

“We recognise the huge life-long impact on these children and their families. As a professional body we are working within the sector to identify and advocate for changes that can guide our clinicians and better support children with Cochlear implants and their families.”

Audiology Australia, representing the clinicians issued a statement.

President Barbra Timmer said “We recognise that this will be a difficult time for many of our members.”

“Our profession is once again faced with sobering reflection as we grapple with the impact of systemic and program issues on the families and children involved,” she said.

“We offer our thoughts to all the directly and indirectly impacted Audiology Australia members and we are here to support you.

“AudA also offers sincere sympathies to the children and families in Townsville who have been adversely affected by inadequate hearing care services,” she said.

“We are currently reviewing the findings and recommendations in more detail to understand how these may be reflected across our own policies and process to strengthen the audiology profession and support our members and clients.

Audiology is a self-regulating profession.

Occupational therapists, optometrists, osteopaths, pharmacists, physiotherapists and podiatrists are among the many who are regulated by the Government’s Australian Health Practitioner Regulation Agency.

Audiologists regulate themselves via their professional body.

Calls for better regulation of audiologists nationwide.

The Queensland health minister, Shannon Fentiman, said it was time for better regulation of audiologists by the federal government, noting the similarity between the issues uncovered in Townsville to those reported in South Australia.

“The South Australian health minister and I will be raising this … at the health ministers meeting”, she said.

“And we will be advocating for audiologists to be the next profession registered by the Australian Health Practitioner Regulation Agency (AHPRA).”

Independent audiologists want external regulation.

Professional body, Independent Audiologists Australia (IAA) said it was saddened but not surprised to see these issues surface in hospitals across multiple states (QLD and SA).

IAA believes that should similar reviews be completed throughout Australia, further issues with quality of outcomes and standards of Audiology care would inevitably be revealed.

IAA was pleased the QLD Health Minister would be advocating for Audiologists to be the next profession registered by AHPRA. IAA urged all State Health Ministers to recognise the importance of external regulation of Audiology as a profession to safeguard against future events such as these, along with other risks to the public that are not well-controlled at present.

Time for audiology to become a regulated profession?

The Australian Health Practitioner Regulation Agency ensures that Australia’s registered health practitioners are suitably trained, qualified and safe to practise. Public safety is its priority.

“We want the public to have trust and confidence in regulated health practitioners.”

Auslan Santa Brings Joy to Deaf children.

More families across Australia will have the chance to share their wish list directly with Santa this year.

Deaf children and their families will be able to communicate in their own language to an Auslan-fluent Santa at select shopping centres.

Jen Blyth, Deaf Australia chief executive officer, grew up with Deaf parents and wishes this was something she had as a child.

"My siblings and I, we could have gone and seen Santa and spoke to Santa. I just think this initiative is so great for children of today."

Launched as a pilot program last year, Auslan Santa was in Westfield shopping centres on the east coast last year with their sessions filling up quickly and being welcomed by the community.

This year Auslan Santa will expand this year to include shopping centres in South Australia, Western Australia and the ACT.

Ms Blyth said last year's launch was a "truly magical experience", with the Deaf and hard of hearing community thrilled to be able to communicate with Santa for the first time.

"Being able to talk to Santa, to ask very explicitly for a cute puppy should be the norm. It shouldn't be that a Deaf kid goes and sits next to a Santa who insists on speaking to them in English - just like everyone else they meet," Ms Blyth said.

Globally, 97% of all Deaf and hard of hearing babies are born to hearing families who have never met a Deaf or hard of hearing person before, and approximately 80% of those parents never learn sign language. This can lead to about 50% of the Deaf community experiencing language deprivation in both their sign language and country's spoken language.

In Australia it is crucial that these babies and children and their families have access to Auslan alongside English and all the other tools like hearing aids and cochlear implants and so on, in order to ensure that their child can communicate in any language.

Ms Blyth said we need to enable access to the Deaf and hard of hearing community and our culture, and Auslan to families immediately after diagnosis.

"More people should learn Auslan and use it, even if they are nervous about getting it wrong. Auslan is a language in itself, it is not "English on the hands", and it is an Australian sign language - everyone should have open exposure to this," she said.

Families wishing to pack their sleigh to attend a session in Auslan can find details and make a booking online at www.westfield.com.au.

Along with Auslan Santa, some Westfield centres also feature an option to visit Sensitive Santa, available for those with sensory challenges, anxiety, disabilities, or families who simply require more time.

Story by Kerem Doruk for the Canberra Times.

Risk of Hearing Loss for Young People in Sports.

The benefits of student sports include getting exercise, learning teamwork, developing discipline, and building friendships. But one of the drawbacks is that, especially in contact sports, young people are at risk for hearing loss.

Unfortunately, this is not something that is top of mind for many athletes and coaches.

In football, for example, there is the possibility of head injury when they're tackling, when they get hit, and when they fall on the ground, and if they fall very hard on their side, they could get a temporal bone fracture or other damage to inner ear structures that could affect hearing.

Contact sports such as soccer and hockey unsurprisingly pose similar risks, but many other sports can also leave students with injuries affecting the ears and head. Fast-moving balls in tennis and baseball as well as errant equipment like rackets and bats can hit students and affect their hearing.

Most hearing care professionals encounter patients with hearing loss from sports injuries because they have had direct ear trauma that ruptured the tympanic membrane or damaged the ossicles in the middle ear. Other patients may come to an audiologist after suffering a traumatic brain injury or concussion that had an adverse impact on the auditory pathways in the brain.

With any concussion, a hearing loss should be ruled out. If a young person experiences any hearing difficulties, tinnitus, vertigo, or dizziness after a collision while playing sports, they should immediately see a physician, and follow up with a hearing care professional for further testing. However, people without noticeable symptoms might not realise they need such medical attention.

Auditory problems may not appear immediately after an accident. They might appear days, weeks, or even months later.

Hearing care professionals know how important all of this is. Unfortunately, not everyone is as aware of athletes' increased risk of hearing loss and tinnitus.

While it may be unrealistic for most young people to wear hearing protection during games because they need to be able to hear their coaches, athletes and coaches should be vigilant in monitoring for signs of any hearing issues so they can be addressed as soon as possible.

To minimise cases of head injuries that may lead to hearing loss, neurosurgeons encourage players to take the following protective measures:

- Use of approved personal protective equipment and fitting head gear
- During exercise, players should work on strengthening their neck and head muscles.

From an article by Melanie Hamilton-Basich in The Hearing Review.

To create an Australian child hearing health outcomes registry.

Australia has well-developed services for Deaf and Hard of Hearing children. All states now have Universal Newborn Hearing Screening and referral pathways for babies on to diagnostic audiology. However, there is no unified way for services to document how these children are faring around the country.

Many Deaf and Hard of Hearing children do not reach their full developmental, learning and health potentials, in part due to inequities in service access. A national data system, linking hearing and related services to measured outcomes, could address these inequities by identifying children who need additional services, and identifying areas for improvement in practices and processes.

What outcomes matter to families of Deaf and Hard of Hearing children?

For A/Professor Valerie Sung, who leads the research project for the Royal Children's Hospital and Murdoch Children's Research Institute in Melbourne, the most common question from parents is "What will the future look like for my child?".

Without outcomes data, the question is difficult to answer. We all want our children to reach their full potential, but what does that mean for families of Deaf and Hard of Hearing children? Part of this work will involve talking to communities around the country, including Aboriginal and Torres Strait Islander families, and Culturally and Linguistically Diverse families, to find out what outcomes are important to children and their families.

Prof Sung's project team will find out what information is already collected by different organisations around Australia, and whether it can be linked up.

She hopes the Australian National Child Hearing Health Outcomes Registry, aka ANCHOR will provide a national evidence base to inform future hearing policies and optimise service delivery models and supports. She believes ANCHOR will provide a pathway to national reporting for developmental, educational, health and wellbeing outcomes, and be a national platform to facilitate population-based research for Deaf and Hard of Hearing children. The registry will specifically include Aboriginal and Torres Strait Islander children whose hearing loss is dominated by early middle ear infections, enabling tracking of identification, treatment, and outcomes.

For more information visit ANCHOR.

Revolutionising Early Hearing Loss Detection in Infants.

Australian research engineers have used cutting edge light technology to capture non-invasive images of brains to help diagnose hearing impairments in infants and prescribe the most effective treatment as early as possible.

Prolonged hearing loss can severely affect how the brain's language areas develop, affecting a child's ability to develop speech and language. Currently, several diagnostic tests are required to accurately determine the extent of hearing impairment in infants. Tests can extend for several months and are stressful for both the child and the parents.

PhD student Ishara Paranawithana and a team of researchers at Monash University Electrical and Computer Systems Engineering and Bionics Institute used functional near-infrared spectroscopy to non-invasively image the brains of a group of normal hearing infants and measure how language areas of their brains develop and interconnect over time as they grow older.

The study analysed the functional connectivity changes that occur in the brains of normal hearing infants to explore how primary language areas typically develop in the first year of life.

Mr Paranawithana said the objective measurements of connectivity from normal hearing infants can be used as potential biomarkers to compare against those of infants with hearing impairment to determine their level of language development.

"Since the age of the infants in our study varied considerably, we could quantify how these regions become increasingly functionally linked together with age and compare with the connectivity levels seen in adults by the end of the first year," he said.

"By establishing the typical developmental trajectory of language areas in early childhood our results help us to better understand the altered connectivity and its effects on language delays often seen in hearing-impaired infants.

"Functional near-infrared spectroscopy is a relatively inexpensive and child-friendly brain imaging technique suitable for clinical use.

“Having diagnostic tools that facilitate early assessment of hearing helps infants with impaired hearing access effective treatments earlier in life, giving them the best chance to keep up with their peers."

These findings will contribute to future expanded capability of a new bionics device developed by the Bionics Institute called EarGenie, which is currently undergoing a clinical trial.

Professor Colette McKay, lead researcher of infant hearing at the Bionics Institute, said this study is critical to understanding how spoken language processing develops in infants.

"The findings will help us track development of spoken language in infants with hearing impairment, and optimise and fast track their early intervention," Professor McKay said.

"Ultimately, we want to give babies the best chance of hearing clearly and learning to talk."

From Mirage News.

Libby Harricks
MEMORIAL ORATION

This December, be part of a convergence of history, science, and innovation at the Libby Harricks Memorial Oration.

Join us at this event to hear directly from Professor Patrick about his journey, the evolution of cochlear implants, and their transformative impact on society.

Since its inception in 1999, this prestigious event has showcased global thought leaders, earning a stellar reputation for its groundbreaking presentations. In its 2023 edition, we are proud to present Professor Jim Patrick AO, a luminary in the field of cochlear implant technology, as our keynote speaker.

Professor Patrick, Chief Scientist Emeritus at Cochlear, stands among the pioneers of the multi-channel cochlear implant, a device that revolutionised the world of auditory science. His collaboration with Professor Graeme Clark led to this groundbreaking innovation, changing the lives of countless people with severe hearing.

The journey of cochlear implants, from conception to a life-changing reality, is a testament to Australian ingenuity. Unlike traditional hearing aids that merely amplify sound, cochlear implants bypass damaged parts of the ear, delivering sound signals directly to the auditory nerve. This technology has enabled people with severe inner-ear damage to perceive sound, greatly enhancing their ability to understand speech and connect with the world around them.

Professor Patrick's contributions to this field are immense. His blend of expertise in physics, communications engineering, and biomedical engineering was crucial in developing key features of the cochlear implant. These innovations laid the groundwork for advanced signal-processing strategies, significantly improving speech understanding for implant users.

His accolades are a testament to his impact. Recognised as one of Australia's most influential engineers, awarded the Order of Australia, and named the NSW Scientist of the Year, Professor Patrick's career is a beacon of inspiration and innovation.

The Libby Harricks Memorial Oration is not just an event; it's a tribute to Libby Harricks, the first President of Deafness Forum Australia, and a celebration of advancements in hearing health.

Tuesday 5 December at Cochlear Headquarters, Macquarie University precinct, Sydney. 6pm for drinks and nibbles.

Captions and Auslan interpreters provided. Admission is free. Numbers will be limited. [Register here.]

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To Identify Core Needs of Deaf Children.

Researchers from three universities in the United Kingdom have teamed up in a bid to discover which questions matters most to the children affected by childhood deafness and hearing loss.

The research project, led by the University of Manchester in conjunction with researchers from Aston University and Lancaster University, will survey people with experience of childhood deafness from across the UK.

Researchers will also seek the views of professionals working with children and young people with hearing loss, such as audiologists, Teachers of the Deaf, speech therapists, and anyone else working with deaf children.

The team will then use the evidence gathered to compile a 'Top Ten' of the most important questions researchers should be trying to answer about childhood deafness and hearing loss.

Dr Anisa Visram from the University of Manchester, said: "Our goal is to find out which research questions really matter to parents and children affected by childhood deafness, so that we, as a research community, can address those needs.

"This research will also help to improve the partnership between researchers and clinicians, which is vital to ensure the right research is carried out, and the results from that research are implemented for the benefit of patients."

"We want everyone to have the opportunity to get their voice heard and we really want this community to stay together after this project has been completed so they're able to continue sharing their ideas with researchers," Dr Visram added.

Ian Noon from the National Deaf Children's Society, said "We know that deaf children can achieve anything that their hearing peers can providing their deafness is identified at the earliest opportunity and when they receive the right and ongoing support. This is why research is crucial, as it provides a better understanding of the key issues deaf children face and support needed to remove barriers preventing all deaf children from reaching their full potential."

Dr Hannah Stewart, lecturer in Developmental Psychology at Lancaster University said "Having a coherent set of priorities will make a huge difference to the under-researched field of children's hearing. The fact that this project will cover all levels of hearing loss and all parts of the UK will give those priorities a much stronger foundation."

From The National Tribune.

It took Oliver almost six years to learn how to play. When he was three years old, he would smile when other children bullied him in preschool.

Oliver's (L) learning fell way behind that of his brother's due to a lack of access to communication.

One afternoon when Oliver's mother Suzie picked him up from daycare, she watched another child scratch his face and arms - but he wasn't crying or trying to get away, he was apologising.

"Sorry, sorry, sorry, sorry," was all her son said until he walked away and played with a toy car, blood seeping from his arms and face.

Doctors believed hours of auditory therapy a week and a cochlear implant would allow Oliver to learn to hear and speak. His mother wanted to teach Oliver and his twin brother Alec Auslan so the family could communicate and, importantly, Oliver could begin to learn a language. But when Oliver's medical team found out they told Suzie to stop it immediately.

"We were told by the majority of our specialists we couldn't sign with him because it would affect his ability to listen with his ears. I was so conflicted by this advice but I didn't want to do the wrong thing by my son so I followed their advice and focused on hearing and speech."

During the first four years of his life, doctors thought Oliver was learning to hear with his implant, but he wasn't. When Oliver was almost five, Suzie was told her son was not meeting language milestones and the doctors recommended she begin investigating other pathways of communication — like Auslan.

"I was shocked and devastated as I suddenly realised I had withdrawn the access my son needed and now he was even further behind."

She eventually found the Deaf Society and was told there was a bilingual preschool in Sydney Oliver could go to. Oliver's Auslan began rapidly improving.

"It was truly amazing because I finally got to communicate and I got to know my son."

Parents of deaf children and deaf Australians told the ABC they fought for years to access Auslan lessons and Auslan interpreters. But they were pushed towards learning to speak and hear as it was believed it would inhibit their ability to function in a hearing world.

Rodney Adams, a former chief executive of Deaf Australia, said support for children born deaf was too often geared towards a medical model that emphasised the importance of speech and hearing, often to the detriment of language development.

“From the time a deaf child is born, parents are told their best chance at a normal life is being implanted with a cochlear implant and learning to hear as soon as possible”, he said.

While Mr Adams said a cochlear implant could be a brilliant tool if it works, he said it could not continue to be the only option available for those with hearing loss.

"Language is a basic human right. I have seen a lot of children experience language deprivation because their cochlear implant never allowed them to hear and speak to a high enough degree to communicate with the hearing world."

By Rachel Clayton for ABC News.

DEAFNESS
FORUM
AUSTRALIA

The Annual General Meeting of the members of Deafness Forum Australia will be held on Thursday 30 November 2023 at 2pm AEDT, 1.30pm ACDT, 11am AWST.

The agenda and meeting papers are published on our website.

Review of the Deafness Forum Constitution.

During the AGM, there will be a short presentation about proposed changes to the organisation's constitution. The Deafness Forum board formed a working group in March 2023 to conduct a review with the purpose of modernising the constitution in line with the Australian Charities and Not-for-profits Commission model. Members will be invited to vote on accepting these proposed changes at a special meeting in 2024.

You can read the details of these proposed changes here.

Acknowledgment.

Hogan
Lovells

We wish to express our appreciation to **Hogan Lovells**, the legal firm that has been instrumental in this constitution review. Their insightful, expert advice ensured legal compliance in drafting and amending sections of our constitution. We extend our sincerest thanks to Hogan Lovells for their exceptional support during this important review.

Toll of Excessive Noise on Children Needs More Attention.

Children exposed to harmful noise—from infant sleep machines to fireworks—are at increased risk for cumulative detrimental effects on their hearing, warns the American Academy of Paediatrics.

Children exposed to harmful noise - from infant sleep machines to fireworks - are at increased risk for cumulative detrimental effects on their hearing, warns the American Academy of Paediatrics.

The Academy emphasised that intensity is just one part of noise exposure; duration and frequency are also important components. Infants and young children are more susceptible to hearing damage than adults because their smaller ear canals intensify higher-frequency sounds, and they must rely on adults to remove them from noisy situations.

Older children and teenagers might not understand the consequences of noise exposure from personal listening devices or attending loud events like concerts and dances.

“The concern is not only with volume, but how long and how often children are exposed to noise," says lead author Sophie Balk, a general paediatrician.

"Common everyday noises, like road traffic or a television playing in the background, can also disrupt sleep, learning, and quality of life. It’s very important to prevent harmful noise exposures starting early in a child’s life.”

Additionally, studies show that harmful noise exposures are higher in people of lower socioeconomic status and in those belonging to historically marginalised racial and ethnic groups, the authors note. They also call for more public awareness of childhood noise exposure and offer a list of recommendations for paediatricians, such as:

- Incorporating information about noise and advice about preventing excessive exposure into health supervision practices.
- Discussing potential hazards of personal listening devices during confidential adolescent interviews or when examining ears.
- Emphasising that the dose of noise - the duration of exposure, not just the volume - is significant.

Jillian Kornak wrote for AshaWire.

'Two-factor' screening of newborns.

Nearly 30 million Chinese individuals experience hearing loss, with around 60% of these cases being hereditary. An estimated 30,000 babies in China born with it each year.

To understand if concurrent hearing screening and high-throughput genetic screening could improve the effectiveness of newborn hearing loss programs, a new study was published in the International Journal of Paediatric Otorhinolaryngology.

Nearly 120,000 newborns from Gannan, Jiangxi province in China were enrolled in this multi-location study conducted in 2019 and 2021.

6.5 percent of newborns failed their hearing screening. Genetic screening revealed that 4 percent carried hearing loss-associated mutations, and most of them had passed the passed the auditory testing.

The results of this study suggest that concurrent hearing screening and genetic screening would greatly improve the effectiveness of newborn hearing loss programs. This integration also facilitates the management of hearing loss present at birth.

By BGI Genomics for Medical Express.

More information: Minghong Zhao et al, Characteristics of hearing loss-associated gene mutations: A multi-center study of 119,606 neonates in Gannan, International Journal of Pediatric Otorhinolaryngology (2023). DOI: 10.1016/j.ijporl.2023.111744.

Gene Therapy for Child with Profound Genetic Hearing Loss.

Pharmaceuticals company Regeneron announced encouraging early results from a child who received gene therapy.

“The children who are being enrolled in the program are often born with profound hearing loss due to mutations in a single gene, otoferlin, which essentially turns off their auditory circuits,” said Professor Manohar Bance at Cambridge University Hospitals NHS Foundation Trust in the United Kingdom.

“Cochlear implants are the current standard of care but are unable to replicate the full complexity and range of sound. With these very preliminary results, we now have encouraging evidence that this gene therapy may be able to help turn these auditory circuits back on. We look forward to following this child and others to determine if DB-OTO gene therapy can restore clinically meaningful hearing as they are learning to interact with the world.”

The majority of permanent, congenital hearing loss cases diagnosed in developed countries are sensorineural and result from a single gene defect, making them suitable targets for gene therapy.

“These preliminary results provide early and encouraging proof-of-concept, as well as our pipeline of gene therapies to address more common forms of genetic hearing loss and other therapeutic areas.”

Read more here.

Helping Your Child Sleep.

Sleeping problems are quite common in deaf children of all ages and not knowing why your child is experiencing them can be frustrating. You are not alone. From the National Deaf Childrens' Society in the U.K., here is a round-up of possible explanations and tips on how to help your child.

There are many possible reasons why your child experiences sleeping problems, for example:

- Darkness may seem even more frightening for a child when there is no sound. They may want to know where their family is and without hearing or using their sight it can be scary for them.
- If your child uses hearing technology, they may not like the quiet when the technology is taken out at night.
- Many deaf children's balance can be affected when hearing technology is removed. Deaf children can rely on their vision to know where they are in relation to objects immediately around them, which can also make them more alert and harder to wind down. They may also feel disorientated.
- Some deaf children have tinnitus which can be loud and intrusive at night time.
- Routines are important for deaf children to prepare to relax into sleep. Try and make sure you establish a routine that works for you and your family. Routines help deaf children feel safe and secure and makes their environment more predictable.

Once you've thought about which of these reasons may apply to your child, there are lots of things you can do that may help.

Janis is mum to Martha (6), who is severely deaf.

"One of the things that's helped is making Martha's bed really cosy and warm. She has a crescent moon shaped pillow which cocoons her and her favourite soft toy perfectly. We also make sure she's tucked in well as feeling cold will wake her. Something else which helps is having some light in the room.

Martha finds waking up and not being able to hear or see anything disturbing, so we make sure she always has enough light to orientate herself. It casts a reassuring blue light, with a moon face on the clock, throughout the night. At 6am the moon turns into a yellow sun and after that Martha knows she can come into our bed for a cuddle and a snooze."

Nicky is mum to Isabelle (2). Both are profoundly deaf.

“Her bedtime routine is particularly solid which is vital because for the majority of it she’s without hearing - in the bath, drying hair etc. While we sign and she lip-reads, the fact she knows implicitly what comes next reduces any toddler stand-offs compounded by a refusal to look at us to communicate.

In the morning, Isabelle doesn’t like to wear her processors straight away, probably not for the first hour in fact. I’m exactly the same. After a whole night of peace, I’m in no rush for a barrage of sound. Once on, she doesn’t take them off until bedtime so we’re more than happy to give her autonomy over when the sounds of her day start.”

Jennie is mum to Olive (3) who has quadriplegic cerebral palsy and is profoundly deaf.

“My husband Rhys lays her down and pats her firmly and rhythmically on her back until she drifts off - this sometimes works well when she wakes in the night. I sit next to her bed and cuddle her into me firmly, sometimes rubbing my palm down the length of her body and arms, as if she’s getting a massage to sleep.”

If your child is frightened or feels isolated at night.

- Leaving a night light or a hallway light on can help, or perhaps rotating light mobiles or even glow in the dark stickers that focus their attention.
- Leave a piece of your clothing with them so they are left with your familiar smell.
- As part of your routine tell them when you’re going to leave the room so they don’t get worried when they realise you’ve gone.
- It’s important to make sure that the child settles in their own bed where possible. If they fall asleep on the sofa or your bed and you move them, when they wake up they will be startled to be in a new place and will need the reassurance to be resettled.
- Reassure them about worries they may have about not hearing things like the smoke alarm in the night – get a flashing smoke alarm.
- It may help to tuck them in tightly so that they feel ‘grounded’. Some children are very sensory-seeking. If you find your child tightly cocooned in the night they may benefit from being tucked in. Weighted blankets can often help younger children feel more secure.

If your child doesn’t like taking out their hearing aid.

- If they’re old enough, you could remove it for them once they’ve fallen asleep.
- It can be left on the bedside table so they can put it back in if they wake up and feel scared.

- Reassure them that any buzzing sound they may hear is normal.
- Let them know they won’t be missing out on anything important or exciting because their hearing technology has been removed.
- Make sure story time happens before hearing technology is removed.

If your child has balance issues.

- It may help to tuck them in tightly so that they feel ‘grounded’.
- Deaf children can rely on their vision to know where they are in relation to objects immediately around them, which can make them more alert and harder to wind down.

Hester is mum to Harold who is deaf.

“Routine has been very useful for us. For the first three-and-a-half months we struggled, Harold didn’t want to be put down to sleep. I introduced a routine of bath, bottle, book and bed far earlier then I intended on doing, and did it around the same time each night. He has similar things around him, he doesn't come back downstairs after his bath and he knows what to expect. I also do the same with him before sleep, for example his sister gives him a hug and I hug and rock him before putting him down to sleep, tucking him in and giving him a kiss on the same cheek. If he stirs in the night I tuck him in again and kiss him on the same cheek and I believe this comforts him as he knows to expect it.”

Nicky is mum to Isabelle (2).

“We realised how important it was to be tactile during bedtime and whilst resettling Isabelle at night. Our touch is the comfort she needs when we can’t use a soothing tone of voice like you may do with a hearing child. This has adapted to her individual needs over the years, from falling asleep in our arms, to holding her hand as she fell asleep, to simply cuddles before bed. Even now, we will sit outside the room with the door ajar until she falls asleep so she has a visual to make her feel secure.”

Jennie is mum to Olive (3) who has quadriplegic cerebral palsy and is profoundly deaf.

“We have a joint bedtime story most nights, which we often sign as we tend to leave Olive’s implants off once she’s out of the bath. We try to stick to routine, but we’re no ‘Gina Ford’ family. Dinner, bath, book and bed is what we attempt... We tried lots of different things and up to now the most successful has been keeping a calm and consistent environment – people talk about ‘sleep hygiene’. For us it’s just staying in her bedroom when she wakes, keeping the same routine, same lighting and no perfume or strong smelling air fresheners (usually a few drops of essential oil on her bedding) – and using deep pressure.”

Vicki is mum to James (17), who is profoundly deaf, and Damian (14), who is severely deaf.

“It might be difficult to do but we adopted the approach of a book and a cuddle in bed until they fell asleep. Then we reduced it to a cuddle and a book and I’d sit on the bed until they fell asleep. Then it became a cuddle, a book and I sat on a chair in the bedroom until they fell asleep and then finally the last move was to sit outside the room.”

If you are struggling with routines.

- You could use a picture diary on your child’s bedroom wall showing the bedtime routine – bath, story, kiss, bed – and take each picture off the wall as it's completed.

- Make sure you do the same thing every time your child wakes up in the night, such as settling them back to bed with a soft toy, a hug or a song.
- Use a vibrating alarm clock for older children so that they're reassured they are waking up at the right time.
- Let your child have a snack which helps produce melatonin. Melatonin is a neuro hormone produced by our brains. It tells us when it's time to wake up and go to sleep. Things like bananas, wholewheat bread and strawberries contain melatonin.
- Electronics, such as TVs, mobile phones, tablets and gaming devices emit a blue light which block the production of melatonin even with a filter on. Therefore, it's important that all electronics are switched off about an hour before bedtime.
- Make sure you chat about the routine with your child during the day when they aren't too tired and they're calm.

Parents we've spoken to have all used slightly different routines. We have included some examples in this article to give you ideas for your own.

Andi is mum to Emma (6) who is severely deaf.

"We stick to a routine every day; bath time, story time, cuddles and then sleep. We bought a Mum and Me Baby Sleep Tight Balm which we apply every night; in Emma's mind this is a magical cream which helps her sleep."

Related resources:

Choices is a free resource to download for families of children who are newly diagnosed with hearing loss from birth to twelve years of age. The book provides valuable information to help families confidently made the right choices for their child throughout their hearing journey.

Aussie Deaf Kids, Parents of Deaf Children, UsherKids Australia and West Australian Foundation for Deaf Children are excellent sources of unbiased information and supports.

Know someone who deserves their own copy of One in Six?

Let us know at hello@deafnessforum.org.au