

HEARING MATTERS



WAITING TO HEAR

Cochlear implants:
The promise of
a better life

ACC UNDER
FIRE

QUIETER
CLASSROOMS

AUDITORY
PROCESSING
DISORDER

NEW PHONE
CAPTIONS

HOTEL
SURVEY

Much has been happening at NFD in recent months, with the Hearing Therapists Association of New Zealand joining as a member group, the NFD team restructuring, and implementing overseas research projects for our Strategic Plan Working Group.

Other activity includes updating our website with the Ministry of Health, ACC and Veterans Affairs policies for funding hearing aids; advancing the introduction of captioned telephony in New Zealand; sending an information pack to all MPs highlighting inadequate funding for cochlear implants, and the plight of school children with auditory processing disorders; and talking with government agencies about the Text 111 service for people who are Hearing Impaired.

We have also submitted a combined case, with eight appellants, to the Human Rights Commission (HRC) alleging that ACC is discriminating against people with noise-induced hearing loss, on the grounds of age and disability. The HRC advises that our complaint falls within the scope of the New Zealand Bill of Rights, and they are inviting ACC to attend mediation.

As you can see, our work outputs are very high and so too are the demands on our service. In our busiest month we recorded over 600 emails and calls to enquiries. This is a huge increase from 150 per month in late 2009.

We depend entirely on much-appreciated grants and public donations to carry out our essential work, as the government does not fund our work at all.

This is the first issue of our magazine with its new name, and my thanks to all who entered the competition. We have chosen the title on a report recently released by Action on Hearing Loss in the UK, and also used by Courtenay Hearing Centre in Wellington for their e-newsletter (thanks for your permission), because indeed, hearing matters!

IN THIS ISSUE

News	4-7
Our work	8-10
ACC under fire	8
Auditory Processing Disorder	9
Captioned telephony	10
Cover story: Waiting to hear	11-15
Cochlear implants	
Annual appeal	16
Safe Sound Indicators	
Newborn screening checks	17
Hotel survey	18
Snippets	20



Louise Carroll and Peggy Sue, the Foundation's unofficial mascot

Waiting to hear

During Deaf Awareness Week we focused on two issues where inequitable policy means the Deaf or Hearing Impaired are being put on waiting lists: for cochlear implants, and for hearing aids to help with Auditory Processing Disorder (APD). Our cover story is about cochlear implants, with profiles of people young and old who are at different stages of the process – from joining the waiting list, to rehabilitation, to 'up and running'. I hope you find their stories informative and inspiring. We beg the government to think of the plight of those who are 'waiting to hear', and to act compassionately.

In closing I would like to welcome our new Policy Manager Dara McNaught, whom some of you may know as the researcher who worked extensively with us on ACC issues in 2010. I would also like to pay tribute to Chris Peters, who worked tirelessly as an advocate and support person for the Hearing Impaired. We salute you Chris, and look forward to working with you in the future.

A handwritten signature in cursive script that reads "Louise Carroll".

Louise Carroll QSO JP GDPPA (Mgmt) MPM (Mgmt)
Chief Executive Officer

Editor

Louise Carroll QSO JP
E: louise.carroll@nfd.org.nz

Contributors

Bill Keith
Sandra Rhodda

Front cover photo: Jill Huszak

Consultant: Clickety-click

Design and printing: Norcross Printing Group Ltd

Hearing Matters is published by The National Foundation for the Deaf Inc. The contents are copyright and may not be reproduced in any form without the written permission of the publisher.

Contact

The National Foundation for the Deaf Inc.
11 York St, Parnell, Auckland 1052
PO Box 37729, Parnell, Auckland 1151, New Zealand

Ph: 0800 867 446 or 09 307 2922

Fax: 0800 332 343/09 307 2923

E: enquiries@nfd.org.nz

www.nfd.org.nz

NFD Team

Chief Executive Officer: Louise Carroll
Manager, Sustainability: John Shaw
Manager, Administration: Sara Huszak
Manager, Policy: Dara McNaught
Administration Assistants: Anna Gatland, Erica Siviter
IT and Administration Assistant: Jaspal Kaur
Finance Officer: TBA

NFD Council

Chair: Professor Peter Thorne Deafness Research Foundation

Deputy Chair: John Harwood The Hearing Association

Member Organisations: Council Representatives

Professor Suzanne C Purdy Deafness Research Foundation

Julie Hill, Leigh Martelli NZ Audiological Society

Alan Bensley, Judith Sosich NZ Federation for Deaf Children

Malcolm Giles, Michel Neeff NZ Society of Otolaryngology, Head & Neck Surgery

Janice Mitchell, Lee Schoushkov Pindrop Foundation

George Dodd, James Whitlock The Acoustical Society of NZ

Dick Earle The Hearing Association

Anne Greatbatch, Jacqui Taylor The Hearing Therapists Association of New Zealand

NFD Board

Chair: Lance Steven

Deputy Chair: Jemini Patel

Rebecca Davis

Stewart Forsyth

Mary Hackett

Geoffrey Lawson

NEW BOARD MEMBERS

Geoffrey Lawson

Geoffrey has recently retired after 30 years at senior management level in the corporate world.

As he uses hearing aids, he understands very well the challenges and difficulties facing the Hearing Impaired in business and everyday life.

'I have the time and energy to devote to the Foundation. I'm keen to use my considerable business experience, and my belief in the inherent goodness of people in an area where I have a personal stake.'

Geoffrey and his wife Debra, a teacher, live in Ponsonby and have three adult children.

Mary Hackett

Mary has a clinical and business background, and chaired the Bay of Plenty District Health Board for nine years. She has worked with iwi and local Sikh and Bangladeshi communities. As a consultant, her work covered Maori health, ACC and health care of the elderly.

A mother and grandmother, she lives with her husband, who has marked hearing loss.

'I'm looking forward to working with the Board and hopefully making a contribution to the Foundation.'

Access tourism: testing the waters

We are working with the New Zealand Tourism Research Institute (NZTRI) at AUT University to understand the needs of people with hearing loss in terms of tourism, travel and hospitality.

NZTRI's programme includes researching and developing access tourism in New Zealand.

Access tourism is tourism, travel, and hospitality for people with permanent or temporary disabilities; seniors, parents with strollers, and anyone needing improved access.

Earlier this year, the institute ran two online surveys for people with hearing loss – one aimed at people living in New Zealand (160 responses), and the other at those in other countries (nearly 200 responses).

Participants were asked to comment on how well New Zealand tourism offerings cater for people with hearing loss, and to describe any barriers they faced as visitors.

They were also asked to comment on how they could be encouraged to travel more often in, or to, New Zealand, how often they take a holiday and how much they spend.

NZTRI presented their findings to NFD at the end of September, and our next issue will feature an update.



www.nztri.org/accesstourism



Hearing therapists join NFD

In July this year the Hearing Therapists Association of New Zealand became the latest organisation to join us.

'The best way to gain recognition and services for New Zealand's Hearing Impaired is for all in the sector to work together. The Hearing Therapists Association brings a new dimension to our work and our representation. We are delighted to have them join us,' said Louise Carroll.

Hearing therapists' services include hearing tests, help with hearing aids, and onward referrals.

PRIZEWINNERS!

Congratulations to the latest lucky winners of our prize draw. They each won \$1000 worth of petrol or food vouchers.

Christine and Dough Ryrie, Wairakei (March)
Mr J Shephard, Drury (July)

As part of our fundraising efforts, everyone who donates \$25, \$30 or \$50 through our 0900 number goes into the prize draw, which is made each quarter.

If you would like to support us and get the chance to win this prize, please email your name and telephone number to enquiries@nfd.org.nz

GRADUATE ON THE MOVE

Last year, Gemma Shea, who is Hearing Impaired, was awarded a Deaf Educational Scholarship provided by the NFD Trust. She's now on course for a career in auditing and accounting. After gaining high marks in her final year of a Bachelor of Commerce, she was offered a position this year with the Christchurch branch of Audit New Zealand.

Her work involves travelling to see clients in Canterbury, Timaru, the West Coast and Nelson. 'It's somewhat challenging as there is so much client interaction! But I have been enjoying all the opportunities with them.'

Gemma says the scholarship was an immense help. 'It gave me that extra motivation to do well in my final year, and set me up to get a graduate job.'



Gemma Shea: 'The scholarship gave me extra motivation.'

Research trip: working smarter

Our Strategic Plan Working Group is developing the Foundation's Strategic Vision 2020.

As part of this process, I was asked to investigate leading organisations in the UK, Australia and the US. The aim was to better understand:

- their organisational structures
- how they support and deliver services to those facing the challenges of living with their disability.

We need to look at how our sister organisations deliver services, and take the most effective elements on board for New Zealand – especially in this time of severe financial

constraints. If there is a more cost-efficient way of working, we need to know about it.

This was a unique opportunity to discuss with my peers internationally the best possible structure for the NFD, based on an appropriate, accountable and transparent model, and to learn how sector tensions are managed globally.

Our thanks to The Oticon Foundation who generously granted funds to the NFD, supporting research visits to Action on Hearing Loss in the UK and the Deafness Forum of Australia.

Louise Carroll, CEO

Trans-Tasman links

In August CEO Louise Carroll and Sustainability Manager John Shaw visited Canberra, where they met with the Deafness Forum of Australia (DFA) staff and Board.

A Memorandum of Understanding, framing the future relationship between the two groups, is now being drawn up. The focus is on collaborating in the areas of advocacy and financial sustainability.

We also exhibited the Safe Sound Indicator (see p. 16) at the DFA's Communications Access Expo, at Parliament House during the Australian Hearing Week. This generated huge interest and positive feedback.



Beyond Hearing Aids – Taking the Next Step

MED^oEL

MED-EL offers a comprehensive portfolio of hearing implants for all types and degrees of hearing loss. They ideally suit the needs of older adults who do not benefit from hearing aids.

- Vibrant Soundbridge® Middle Ear Implant System
- MAESTRO™ Cochlear Implant System
- EAS™ Hearing Implant System



medel.com

You can hear more with Cochlear™



9 out of 10 adults and children in New Zealand choose Cochlear™ when selecting a hearing implant

Why? Because only Cochlear has a range of solutions that deliver **total hearing performance** so you can be confident you will hear your best in any situation.

- ✓ Hear clearly in noisy places like at work, school or in restaurants
- ✓ Hear well in quiet situations, like at home
- ✓ Benefit from technology that can help enhance your music enjoyment
- ✓ Use the phone with ease

When hearing aids aren't the answer

Hearing aids help a lot of people however they can't help everyone. When people with hearing loss don't benefit from hearing aids, experts consider a hearing implant may be a more effective long term solution. Hearing implants send sound directly to your hearing nerve, bypassing the damaged parts of your ear so you can hear again – or for the first time.

Connect to life

Cochlear is the Australian company leading the world in hearing implant technology, spending more on research and development than other implant manufacturers. So what does this mean for you or your child? We listen to what you want and deliver beneficial, proven and innovative hearing solutions to meet your needs.

But don't just hear it from us, visit www.cochlear.com and be inspired by stories from some of our 250,000 Cochlear recipients – the largest community of hearing implant users in the world.

Now it's your turn to hear your best.

Talk to your healthcare professional about Cochlear hearing solutions or visit www.cochlear.com

Counter signals

A two-way card helps customers and frontline staff

If you have hearing loss, you'll welcome the sight of these yellow cards (shown here with our receptionist Anna Gatland) at the bank, shop and other businesses – wherever you have to communicate with someone at the counter.

The aim is to help the Hearing Impaired do their daily business. The cards come in a clear plastic stand that sits on the counter, so that customers and staff can each see the message aimed at them. For the public, the card invites them to tell staff if they have a hearing problem. On the staff-facing side, it gives tips on how to speak effectively – face the person, speak clearly and slowly, don't shout.

Thanks to a \$50,000 grant from the ASB Community Trust, we are giving out 20,000 cards and 10,000 stands to Auckland businesses. Sponsored by Youthtown, a further 20,000 cards and 1,000 stands will go to Auckland and other centres around the country.

To order a free counter stand, please call us on 0800 867 446.



NFD Trust scholarships and grants 2011

The NFD Trust operates entirely independently of The National Foundation for the Deaf. This year the Trust provided over \$38,600 in grants to individuals and organisations.

Training and Development Scholarships

- Jeanette Anderson: Diploma of Hearing Device Prescription and Evaluation
- James Bichan: Postgraduate Diploma in Sign Language Interpreting
- Gethin Bridge: AUT Diploma in NZSL Interpreting
- Gaylyn Cavanagh: AUT Diploma in NZSL Interpreting
- Theresa Cooper: Postgraduate Diploma in Museum Studies at Massey
- Alisha Davidson: BA – NZSL English Interpreting
- Kelly Hodgins: Postgraduate Diploma in Sign Language Interpreting
- Tracey Jane Napa: AUT Diploma in NZSL Interpreting
- Robyne Nash: AUT Diploma in NZSL Interpreting
- Tote Hemehehema: AUT Diploma in NZSL Interpreting
- Jasmine Reti: AUT Diploma in NZSL Interpreting
- Shizue Sameshima: Postgraduate Diploma in Auslan interpreting (NZSL version)

Deaf Educational Scholarships

- Ashleigh Bode: Beauty therapy course
- Lucy Croft: LLB/BSC
- Lisa Evans: PhD
- Alesha Hudson: Diploma in Ceramic Art
- Nicholas Jones: National Diploma of Architectural Technology

- Nicholas Lessing: MIT Electrical Circuits course
- Nicole Musson: Bachelor of Art and Design
- Rathana (Kim) Srey: Graphic design course
- Angela Treanor: Diploma of Information and Library Studies

Noonan Bequest

- Victoria Clark: 2012 NZ Girl Guiding Jamboree in Rotorua
- Olivia Patterson: laptop, as required by school
- Lauren Taylor: replacement computer for school work
- Canterbury Parents of Deaf Children: Annual Family Camp, midwinter family event, spring event, Christmas party
- South Canterbury Society for Deaf Children Inc: to enable 13 families to have a recreational weekend in Greymouth

Grants received by The National Foundation for the Deaf

We gratefully acknowledge funding from the following agencies:

ASB Community Trust
 A K Franks Trust
 Four Winds Foundation
 Lottery Minister's Discretionary Fund
 Maurice Paykel Trust
 New Zealand Community Trust
 N R Thomson Charitable Trust
 Oticon Foundation
 Pelorus Trust
 Pub Charity
 Sky City Trust
 Todd Foundation
 Youthtown Trust

ACC's age and disability rules under fire

The National Foundation for the Deaf and National Grey Power have combined forces to oppose the ACC's thresholds for injury-related hearing loss.

ACC uses a stringent, and some would say harsh, assessment of hearing injuries. Last year it accepted only 42% of claims.

6% disability threshold

Under the threshold, you must have 6% hearing loss or your claim is rejected. However, noise attacks the tones of our hearing that we use for speech discrimination, and because of the way different tones are rated, it can take a lot of damage in that area to get a total 6% loss.

'We all react differently to damaging noise levels. The only fair and rational way of dealing with hearing injury claims is to treat them individually,' said our CEO Louise Carroll.

12.5% age threshold

Grey Power National Chairperson Roy Reid said, 'ACC should be paying for injury-related hearing loss rehabilitation, and this is not currently happening because of the two discriminatory thresholds.' The condition mostly affects those over 50, and the average age of claimants is 69.

'ACC is using the age argument to introduce part-charges for hearing aids. We are seeing those who cannot afford what ACC decides is their share, going without rehabilitation altogether. Funding for half a hearing aid doesn't work!' said Louise Carroll.

Green Party support

The Green Party has assured The National Foundation for the Deaf that they are committed to changing the law to make it fair and just. 'We opposed the changes to hearing loss criteria for ACC, and we believe in a case-by-case approach to the needs of people with hearing loss. The threshold is discriminatory and we support your position,' said Green Party MP Catherine Delahunty.

Human Rights Commission may mediate

In August we submitted eight combined cases to the Human Rights Commission, which advised that they fall within the scope of the NZ Bill of Rights Act. The Commission is now considering mediation for the participants and ACC.

By early September we had 27 further claimants seeking our advice on the best path for hearing loss rehabilitation.

As a nation we do not accept neglect of our elderly citizens, and both organisations believe the Prime Minister needs to act now to stop the situation deteriorating.

Government funding stops short

If you're an adult who needs hearing aids, or have been denied ACC cover, the Ministry of Health will only partly fund your hearing aids (unless you're under 16, or meet other specific conditions). You get \$511 per aid every six years, but have to pay the difference.

Many older people on limited incomes are now being forced to go without hearing aids, which reduces their quality of life.

Need support for your ACC claim?

By September about 60 people had contacted us, seeking information and support to go through the ACC review process. If you need help, please call Freephone 0800 867 446.

And don't forget, your donation helps provide this essential support.

E: enquiries@nfd.org.nz

Donate online: www.nfd.org.nz

Emergency texting

The police, fire and ambulance services are working with us to introduce emergency texting for the Deaf and Hearing Impaired – TXT 111.

The New Zealand system is dependent on cell phone sites for coverage, which means that it may not be available if you're not in range of a site.

Australia is rolling out a system based on GPS (global positioning system), and it will be interesting to see how that evolves.

We expect the New Zealand service will be up and running next year.

Auditory Processing Disorder

For many children with APD the struggle is too much, and they become disruptive. Treatment can change their lives, but the funding has been cut.

In our last issue we featured an in-depth report on APD (Auditory Processing Disorder). Here's an update on the situation that children with APD and their families are facing in New Zealand.

Ministry denies link with learning difficulties

This year the Ministry of Health stopped funding hearing aids for APD children, who are now referred to the Ministry of Education. In most cases the Ministry rejects their applications, denying a causal link between APD and learning difficulties.



Experts say that APD is often linked to problems with reading and communication.

Yet an abundance of literature and experience confirms that children who can't hear properly need special help with language and reading.

An Auckland University study of 49 APD children by Professor Suzanne Purdy found that 94% of them had a reading disorder and/or language impairment.

'Common sense tells us that deafness adversely affects language development and hence literacy. There is a wealth of evidence that hearing impairment affects literacy,' said CEO Louise Carroll.

APD children miss out

It is unfair that children with APD-related hearing loss do not receive the support given to other hearing-impaired children – namely free hearing devices, special educational support and the Child Disability Allowance, which helps to cover the extra costs incurred by families raising a child who has a disability.

What is APD?

Auditory Processing Disorder is a hearing disorder that affects how the brain processes speech. While the ear 'hears' sound normally, people with the disorder find it difficult to process sounds and to understand what they have heard.

We've all come across the child who doesn't pay attention, is disruptive, and under-achieves despite evident high potential. They may be diagnosed with an attention disorder, or dismissed as slow or plain naughty.

In fact, the cause could be APD. It affects up to one in 20 children, and while many will grow out of it, adults also suffer from the condition.

Diagnosis

APD is often misdiagnosed as a learning disorder. Even if a child does get assessed for hearing loss, unless the APD tests are done the parents may be given false reassurance that he or she has normal hearing.

Treatment

Children with APD do best with an FM hearing aid system: the child wears a hearing aid, and the parent or teacher wears a transmitter.

Donate Now >>

DONATE ONLINE

You can now donate securely on our new donation web page at www.nfd.org.nz

Click on the Donate Now button on the home page and then follow the prompts. Your donation starts working right away, supporting NFD's essential services. You'll receive an instant receipt by email.

Supporters can also set up a regular, monthly or quarterly credit card donation.

Reclaiming the phone

Imagine not being able to use the phone – to chat to your family or friends, make an appointment, call a taxi. Now all that will change.

From the end of this year, CapTel (captioned telephony) will bring the telephone back to thousands of New Zealanders whose hearing has forced them into isolation.

We and others in the sector have been working for some time to bring captioned telephony to New Zealand. We are looking forward to working with the NZ Relay provider, Sprint, to ensure as many people as possible can take advantage of it.

CapTel provides live captions of spoken phone conversations, for an experience that is as close to a real-time phone call as modern technology allows. Steven Joyce, Minister of Information and Communication Technology, says the service will be among the best in the world.

The service will also allow relay calls from cell phones, following consultation next year with user groups on how the service should operate in New Zealand and what types of smartphone. This follows the introduction last year of video relay, which allows the Deaf community to talk to the relay assistant in sign language.

New Zealand Relay already provides a text-based relay service, but it relies on the relay assistant typing what the other person is saying, causing time lags and frustration for both parties to the call.

A minimum number of clients must sign up before the CapTel service will start.



Captioned telephony

- A high-speed phone relay for the Hearing Impaired.
- Captions show on a tiltable screen on the telephone.
- Growing in the US by 20% per year.

Benefits

- No silences and delays – the relay assistant doesn't have to type what the other party is saying.
- The call is natural. You can hear the other components of speech – the tone of voice, pauses, and when they chuckle or get excited.
- It's instant and as effective as a normal phone call.

The service is most popular among those who have started to lose their hearing because of age or other factors. New to hearing loss, they want to make phone calls as they used to.

How it works

- Using the phone provided, you place your call through the relay service.
- You talk with the other person in the normal way. You can hear their voice, but because of your hearing loss you cannot understand what they are saying.
- The relay assistant listens only to the other person and simultaneously 're-speaks' what they are saying.
- Voice recognition software converts their words into captions. These show on your telephone screen at almost the same time as the person is speaking.



Image: Ultratec Inc.

Waiting to hear

Simple surgery and smart technology open up a world of sound. But if you're on the waiting list, you live in hope.



Rachael Morris (p. 13):
'I've lost a huge amount of confidence.'

The cochlear implant – the bionic ear – is one of the miracles of modern science. Implant wearers often say, 'I've got my life back.'

Increased funding now allows deaf children to get an implant without a long wait. But this is not the case for adults who have become profoundly deaf and for whom a cochlear implant is the only way to restore their hearing.

For these people the bar is set much higher than for those with other forms of deafness that can be treated by surgery. The government funds only 20 implants per year. Earlier this year, 225 adults were waiting for assessment or for funding.

Health insurers will consider covering the cost of the procedure, but not of the device itself, which is the largest expense. In Australia, insurers are required to fund implant procedures and devices.

In the *New Zealand Medical Journal* of 27 August 2010, Robert Gunn, otologist and cochlear implant surgeon, wrote: 'Why should the disability of loss of hearing be treated differently from that of loss of mobility or of vision? We have to do better for our severely-to-profoundly deaf adult patients in this country.'

We believe that being put on a waiting list is an unconscionable demand on people who are desperate to integrate and contribute. ▶

Holding out for surgery

'I don't really fit into a deaf world, but I no longer fit into a hearing world either.' Angela

'I am running out of strategies and options.' Garry

'This is my dream for [my mother], and for us. Three generations no longer sharing in a world of silence, but sharing in a world of sound.' Donna

Who is suitable?

People who have severe or profound hearing loss, and can no longer hear with hearing aids. Assessment includes evaluating your ability to pick up speech, how well you have been able to hear in the past, and other audiological, surgical and psychological factors.

Adults born profoundly deaf and for whom hearing aids don't work are usually not suitable. Others who may not be suitable are those who:

- have pure nerve deafness rather than cochlear deafness
- have had meningitis that has caused bone to fill the cochlear channels
- have a very deformed cochlea
- are not fit enough for surgery.

Who provides them?

There are two implant programmes, based in Auckland and Christchurch. The north-south boundary runs from Gisborne through Taupo. Ear specialists or audiologists

usually refer candidates to the programmes for assessment. They are then given a place on the waiting list according to their need.

What does it cost?

About \$50,000. That includes the cost of the cochlear implant, the external processor, the operation, and audiological services over two years as you learn to hear again. Upgrades (about every six years) cost \$9000 on the Northern Programme.

Who pays?

Public programmes

The Ministry of Health funds implants for 20 adults nationally each year, although extra funds are sometimes available. It funds implants for all children who need them.

Private funding

You can pay for your own implant if you wish.

Cochlear implants

What is a cochlear implant?

It's a hearing device that directly stimulates the hearing nerve. It is not a hearing aid – hearing aids make sound louder.

How it works

An external speech processor fits behind the ear. The signal is transmitted through the skin to a receiver that has been inserted surgically.

How it is installed

The surgeon places a receiver under the skin, and feeds the electrode array through the mastoid bone and part of the middle ear into the cochlea. This usually takes about two hours, and you stay in hospital overnight.

What happens next?

The external processor is fitted about three or four weeks later. It is switched on, and tested. Mapping (tuning) the implant continues over a few weeks. The implant is readjusted annually.

Dangers

Your balance can be affected, but this is usually temporary. In extremely rare cases the facial nerve could be bruised or damaged.

Benefits

The main benefit is being able to hear again. Wearers may also acquire better speech, and many can use the phone.

How soon will hearing improve?

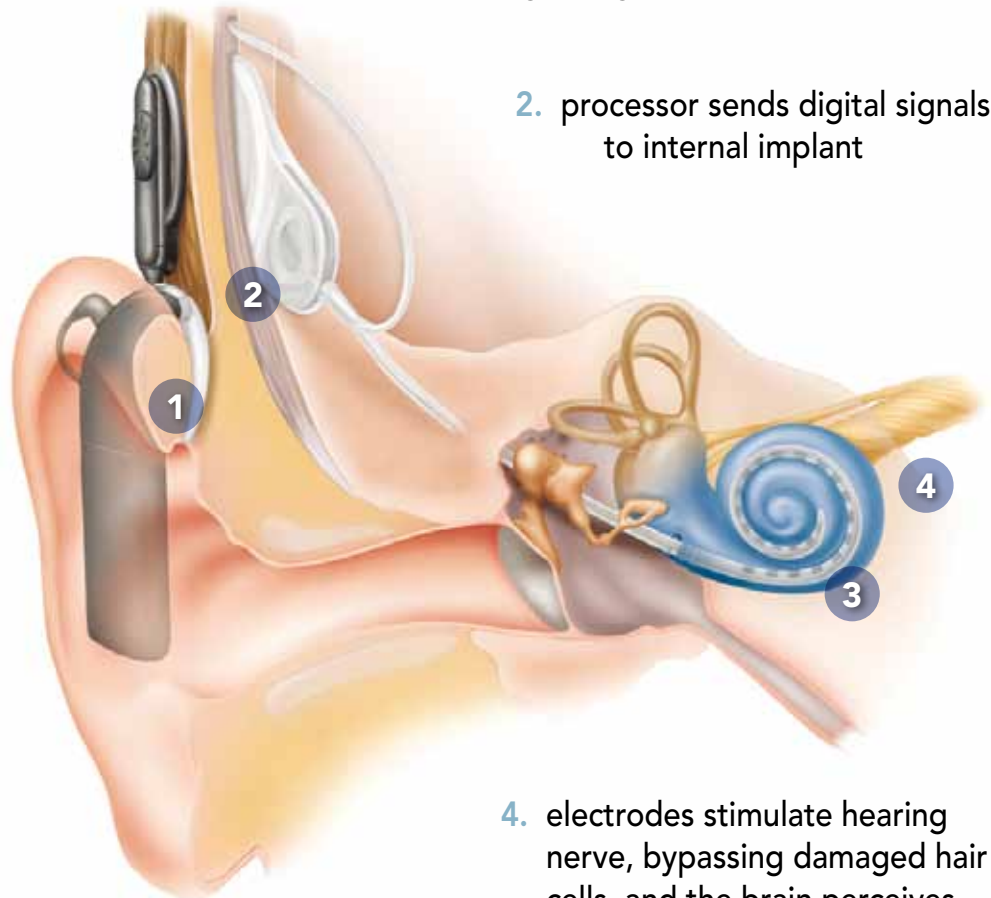
It can sometimes happen in a matter of days or weeks.

Success rate

Specialists say there are few total failures, but there are degrees of success. The longer someone has been unable to hear, the longer it can take to get a good result. The highest failure rate of the devices over many years is 3%. Failed implants can usually be replaced.

1. external speech processor captures sounds and converts it to digital signals

2. processor sends digital signals to internal implant



3. internal implant turns signals into electrical energy, sending it to an array inside the cochlea

4. electrodes stimulate hearing nerve, bypassing damaged hair cells, and the brain perceives signals: you hear sound

Image: Courtesy of Cochlear Ltd

Southern programme

Adults and children

Ph: 0800 500 405

E: scipa@extra.co.nz

www.scip.co.nz

Northern programme

Adults

Silvia Rosioru

Ph: 09 373 7956

E: s.rosioru@auckland.ac.nz

www.clinics.auckland.ac.nz

Children

Gurdeep Singh

Ph: 09 579 2333

E: Gurdeep@hearinghouse.co.nz

www.hearinghouse.co.nz

More information: www.nfd.org.nz/8/Sound-Advice

We talked to six people about their experience of cochlear implants, at different stages of the process.



Rachael Morris
Waiting

Age: 45
Hearing: Hereditary hearing loss, hearing aids both ears
Implant status: On waiting list since August 2011
Funding & programme: Public, Northern Programme

'I try to stay positive.'

Impact of hearing loss

I've lost a huge amount of confidence over the past couple of years and suffer quite low self-esteem. The main difficulty is conversing with people in everyday situations.

My social life is less active – it can be very stressful at a restaurant or pub because of the noise, so we tend to entertain at home. I can only use a speaker phone, and still find that difficult.

Family life

My husband and children are affected most days by having to repeat themselves and telling me, 'I told you about that the other day.' It causes arguments and stress for everyone at times.

Having three children [16, 11 and 9] is hard enough without having to deal with my hearing loss as well. But they are starting to understand things more as it gets worse, and they try to be patient.

Work

I haven't worked for two years as I'm very limited in what I can do. The phone is definitely out and verbal conversation is very difficult, especially with more than one person. I loved working as a conference co-ordinator, where I spent most of my time interacting with people, but I can no longer do that. I then went into accounts, which was more suited to my hearing loss.

I've recently joined a talent and modelling agency, and I'm hoping I can use my talent and not my ears.

Waiting

I feel happier as I now have some hope to cling to. But I'm frustrated that there is no funding for me, and knowing it will be some time before I can get an implant. I try to stay positive – which is not always easy – and keep focused on trying to deal with everyday life. There is light at the end of the tunnel, and we will all reach it in time.

Since this was written, Rachael has been offered part-payment for an implant. She has been told her costs will be \$20,000+, with 5-yearly upgrades at \$15,000 each.



Donna Allan
In rehab

Occupation: Office administrator
Hearing: Deaf since birth (rubella)
Implant status: 1 implant right ear, 2011
Funding & programme: Public, Southern Programme

'I'm still learning to process sounds.'

I was brought up to speak orally and lip-read. I spent my life trying to fit in with the hearing world and the Deaf world. I always felt like an outsider because I couldn't join in conversations, and I hated that feeling. At work I tend to concentrate on doing my job and only speak when I need to.

Opting for an implant

I decided to have an implant after seeing a friend going through the process, and the positive effect it had. I was on the waiting list for over two years.

Switch-on

I was switched on in July this year: sound was a big ball of mumble/jumble and so unclear!

Rehab

I see a hearing therapist weekly. I'm going regularly to Christchurch for the mapping process (programming) with my audiologist, and a session with the rehabilitationist. This involves listening to recorded speeches or texts, and pronunciation.

I can hear noises and voices a bit better but it is still not clear. I'm still learning to process and distinguish sounds, but I also lip-read and use my hearing aid. My husband is helping me with speech therapy.

Challenges

I do find it quite loud, and listening gets quite tiring. I can have slight nausea when it's too loud. I used to start with the volume low, then increased the volume and the length of time I wore it. I'm learning to listen with my implant and not use my hearing aid too much.

The future

I look forward to being able to hear without lip-reading, watch movies without using captions, use the phone without feeling agitated, and take part in discussions with ease and confidence.

How she rates the implant: It's too early for me to say.



Benji and Sadie Implants in infancy

Age: Benji 3,
Sadie 18 mths
Hearing: Both profoundly deaf
Implant status: Benji at 8 mths, Sadie at 7 mths
Funding & programme: Public, Southern Programme

'It becomes second nature.'
Nicola and Tony with (from left), Sadie, Olivia, Benji.

Nicola talks about their experience

Learning your child is deaf

It's a grieving process – it's unexpected. At five weeks I suspected that Benji couldn't hear. He had tests, and then the implant. With Sadie it was grief again, but it didn't last as long, and she was picked up earlier.

Opting for an implant

We felt quite confident. We wanted their first form of communication to be spoken. We were never persuaded – we were informed about all the options.

Habilitation

In the first year, we went to Christchurch about 10 times for habilitation, and we have wonderful support from our local adviser. This is amazing technology, but it's not instant hearing. You have to teach them to listen, and that sound has a meaning and a consequence.

Family commitment

The whole family has to get on board – we had to educate grandparents, aunts and uncles. Olivia [5] is great, she's like another teacher. Once you get past that first year, it becomes second nature and you start seeing progress.

Preschool

We're off to a good start with Benji in preschool at the right age. He can talk with teachers and friends. Background noise can cause problems, but a teacher of the Deaf ensures he's getting access to the language.

Challenges with infants

Sadie's Nucleus 5 is lighter and smaller, but we find it hard to keep on. There are accessories that can help, but we use wig tape to stick the processor behind the child's ear.

Benefits

We're so grateful that they can hear. Having it so young, they have such good access to language and vocabulary.

The rewards? When you can see that things are clicking and they do understand you. And when they say Mum for the first time.

How they rate the implants: Access to sound: 10/10, design/function: 8/10



Bob Abbott Implant 2 years ago

Age: 81
Occupation: Retired chartered accountant
Hearing: Hereditary otosclerosis, both ears
Implant status: 1 implant, 2009
Funding & programme: Public, Southern Programme

'It's an ongoing miracle.'

I used a hearing aid from age 30, and my hearing got progressively worse. I had perfect pitch, but music became a drone. Eventually hearing aids weren't enough, and the next step was an implant.

Hearing loss is very isolating. You're loath to join in a conversation, because if they've moved on they'll think you're mad. You experience frustration, misunderstandings, put downs.

Switch-on

At switch-on, it was immediate – I think my auditory nerve was stimulated from years of hearing aids. I could hear whole words, and speech was clear, not Donald Duck stuff. It was a tremendous moment.

Rehab

Penny [the rehabilitationist] was fantastic. I had a good response, but some things such as single words out of context were very hard. We did weekly then monthly mappings, and I attended a support group.

Benefits

It's an ongoing miracle: talking and understanding among family and friends, initiating a conversation, hearing birds, the dog snoring, not using the 'T' switch on the phone. I enjoy music again, though it sounds different. A friend said, 'Bob's come back to us.'

How he rates the implant: 11/10

Breakthrough: from Bob's diary

Switch-on day with Leonard, the audiologist. Betty [pictured] and my son Chris with me. Hooked up waiting for sounds.

Handed a biro to click (very high tech!) when I hear a beep.

All communication by note. Then the beeps start and continue up and down the scale for the next hour.

Then switch on.

Then the moment. I hear so clearly Leonard say in his Irish accent, 'Hello Bob, can you hear me?'

And I reply with an emotional 'YES'.



Jasmin
Implant 2 years ago

Age: 17

Occupation: School student

Hearing: Hereditary hearing loss, hearing aid right ear

Implant status: 1 implant left ear, 2009

Funding & programme: Public, Northern Programme

'I knew it would help me communicate better.'

My hearing loss was not complete, but it was getting worse. When I was 10, I was against having an implant. I was nervous, and I didn't want to shave my hair. But I changed my mind by Year 10. I knew it would help me communicate better.

The main problem was communicating at school. It was an all-girls school and it was really noisy. It was only towards the end of that year that I got friends, and in Year 11 I went to a mixed school.

Switch-on

I waited about a month before switch-on. It sounded like a high-pitched vacuum cleaner with a fire engine in the background. It took me two weeks to hear some words in the metallic sounds.

Rehab

I took one week off school. I listen to my music quite a lot, so picking up on words was faster. Listening to the lyrics, I would read them so my brain could suss them. I wasn't stressed by the background noise, probably because I was used to being among noisy girls.

Benefits and challenges

In the long run it's worth it. I get along better with my brothers now. Music sounds clearer, not as tinny.

Some of the annoying things are that you can't swim with it, and if you lean on something, your implant will come off. If the magnet isn't set right it can dig into your skin. People with hearing can focus their hearing on one person. We can't do that because the implant is bionic, so in some situations I lip-read.

Plans

I'm hoping to be a radio presenter, and a column writer – I had an article about being deaf in the *New Zealand Herald*. I like expressing my opinion!

How she rates the implant: Probably 10/10



Waru Herbert
Implant 4 years ago

Age: 62

Occupation: School caretaker, relief teacher

Hearing: Profoundly deaf

Implant status: 1 implant, 2006

Funding & programme: Private, Northern Programme

'Life is much easier.'

I had one poor ear from a young age, but I coped for many years. I enjoyed singing and playing the guitar.

Deciding to have an implant

After a sudden illness, I became completely deaf in both ears. I still attended church, and [my wife] Elaine was my strength and support. You can draw away from people, but I had to push through and fit in with the conversation. A specialist referred me for implant surgery and I was ready for whatever happened.

Switch-on

After three weeks, switch-on was quite scary. I had to start again, training with the computer. It took a while to learn.

Rehab

I had three months of rehab, continually adjusting. I had to listen carefully to voices – for instance, 'what' and 'hot'. I kept saying, 'I can do this,' to help the audiologist know I was going to get better.

Benefits

After five years, it's levelled off. Life is much easier – the big thing is knowing you can communicate. With that comes relationships. I can relate more to our children and grandchildren, and that brings them closer to me, and vice versa. At work it's a huge help, and I'm now doing some relief teaching.

Challenges

In public places, you get a number of sounds. I am mapped to block out background noise, and I can adjust the processor. Music is still hard, but I'm getting used to it.

Advice

Go for this technology. Don't be afraid of it, it's made me a different person – more outgoing. For those out there wanting changes, may this make them brave enough to take them.

How he rates the implant: 10/10.

There's a kind of hush ...

Around the country, preschoolers are keeping the noise down.

Classroom noise can cause permanent damage to young ears. Teachers' hearing can suffer too, especially on indoor days in winter. But thanks to generous community support, over 900 early education centres are quieter places.

The secret? A small 'traffic light' box that flashes green, amber or red as classroom noise levels increase to 90 decibels, which is loud enough to harm your hearing. Known as a Safe Sound Indicator (SSI), it's an easy way for children to see when they are getting too noisy.

Each SSI costs \$292.50 – a big expense for many preschools. Our national appeal, launched in April, aimed to get an SSI into as many centres as possible. Over 700 individuals, Hearing Associations and community groups responded generously, knowing that their donation would benefit a centre in their own community. Many have donated the full cost, or more. For example, the Temuka Lions Club has provided two to local centres, and the Ashburton Hearing Association has donated five. Grants have also come from community funding bodies.

'The SSI is a valuable aid, and teachers are finding that the children are regulating their noise levels,' said Louise Carroll. 'This is an investment in the future and it's all go.'

We're receiving orders and enquiries about the SSI on a daily basis, and primary schools are now buying them.

Donate to the SSI National Appeal

Download a donation form at www.nfd.org.nz: click on the link beside the SSI photo halfway down the home page.



Louise Carroll with preschoolers. 'We hope the lessons the youngsters learn will stay with them for the rest of their lives.'

Green light

Here's a sample of the many positive comments we've received from staff at early childhood centres.

Mangere Bridge Kindergarten

It is an excellent way for children to self-monitor noise levels and adjust their activities.

Te Akoranga Kindergarten, Kawerau

We've got it in the kitchen area. It's creating lots of conversations and awareness of loud noise.

Pukekohe High School Childcare Centre

The children have responded really well to it, they notice it and are conscious of it. They even tell the teachers when they are being too loud!

Wendy – early childhood centre teacher, Wellington

I have known about these machines for a while, and hoped we might see them in centres eventually. Thanks heaps for investing in the ECE environment.

Raglan Childcare & Education Centre

What a great idea! It has already made a difference to our noise levels with the children self-monitoring (and 'other monitoring' of course!) by simply glancing up at it. The improvement is much appreciated by our teachers.

Kaurilands Community Kindergarten, Titirangi

We are very excited about this device and feel the children will gain valuable learning from it.

A sight for sore ears

Responding to nearby sounds, the Safe Sound Indicator flashes three lights:

- green (up to 80 decibels)
- amber (warning – 85 decibels)
- red (stop – 90 decibels).



At 90 decibels, the noise is in the danger zone for causing hearing loss.

The device was developed over several years by The National Foundation for the Deaf from a concept by 10-year-old school girl Jamie Fenton. Now 17, Jamie has been named 2011 Young New Zealander of the Year.



Is she entering an unsafe sound zone?

Right from the start: screening newborns for hearing

Since 2007 this free programme has been changing the lives of our children.

Up to 170 New Zealand babies are born every year with mild to profound permanent hearing loss. Most have no family history and no other risk factors. In the past, the problem was often not picked up until a child was about four. This delay had a major impact on their social, educational and cognitive development.



The National Screening Unit's (NSU) Universal Newborn Hearing Screening and Early Intervention Programme

aims for early detection, helping children to reach their full potential. Newborns are screened before they leave hospital or by one month of age. Parents can then get support and advice to help their baby communicate and develop language.

A network of services

The programme leader, Vickie Rydz, says it required links between audiology, maternity and child health services, and training a team of screeners.

'Training for audiologists was also provided – working with newborn babies presented a whole set of new challenges!'

Babies born in hospital are usually offered screening before going home, and home-birth infants can be screened at a hospital or health clinic.

If a hearing loss is found, many services are on offer, including ongoing audiology and medical support as required. Ministry of Education advisers help families to access education resources that help children stay on track.

'This could have a huge impact on the lives of a number of children. You only have to look at young Jackson [see inset] to see the difference early detection can make,' said Vickie Rydz.



Jackson and Anna

Ashburton baby Jackson Reed was just two days old when he was routinely screened as part of the programme. His mother Anna says she was surprised when something was picked up.

'We went back to hospital for the second test and it became clear Jackson had a hearing issue. That was scary, because we didn't know the extent of the problem.'

Moulds of Jackson's ears were taken ('It was a challenge to keep him still!'), and he received a hearing aid. Now two years old, Jackson is thriving – attending preschool and starting to talk.

A Ministry of Education deaf adviser will support the family until Jackson is 18.

At a glance

From 1 July 2007 to June 2011:

- 102,500 babies have been screened.
- About 2% of families declined the service.
- 95% of babies complete screening by one month of age.

- On average, 1.6% of infants are referred to audiology.
- 120 babies have been referred to the Ministry of Education.
- 15 babies have been referred for cochlear implants.

www.nsu.govt.nz

Hotels could do better

A survey of hotels by Be.Accessible, before the Rugby World Cup, found that few addressed the needs of the Hearing Impaired or Deaf. Here are the common issues, and some solutions.



Check-in should include a disability question.

Alarms

Many people with hearing impairment have slept through alarms in hotels and motels. People who are Deaf will generally not hear alarms at all.

Solutions

- Connect alarms to the light system in the guest room and bathroom – either all lights or those in strategic spots. Or install a strobe light.
- Give guests a pager-type repeater that vibrates or flashes when the alarm goes off. They can wear it when in their room, and put it under the pillow at night.
- Install a flashing light on the room's telephone, labelled to show there is an emergency call.
- Include a disability question during check-in. Ask guests if they have a disability, what it is, and if they have special needs.
 - Questions should include, 'Do you have a hearing loss?' Many Hearing Impaired, particularly the elderly, do not see their hearing loss as a disability, or are embarrassed by it.

ELECTION 2011

It's election year, and New Zealand's electoral agencies aim to make it as easy as possible for all voters to take part in the general election on 26 November. This year it's more important than ever – we'll also be voting on the way we choose our politicians.

Enrolling

All registered voters received enrolment update packs at the end of May. These let people check their enrolment details. If you didn't get one, you aren't enrolled to vote. Here's how you can enrol:

- Freetext your name and address to 3676.
- Get a form online at <https://secure.elections.org.nz/app/enrol>
- Pick up a form from a PostShop.

Websites

- Information about the election: www.elections.org.nz
- Details on the Referendum on the Voting System: www.referendum.org.nz
- Animated clips about voting system options: www.referendum.org.nz/resources

DVDs

The Electoral Commission has produced two DVDs for those with hearing loss:

- What you need to know about enrolling and voting. In New Zealand Sign Language with English subtitles.
- All about the Referendum on the Voting System, with English subtitles. It explains the referendum questions, what happens as a result of the referendum, and your election-day voting system options.

Find out more

- The DVDs are at libraries, Citizens Advice Bureaus, and organisations such as the Hearing Association.
- View the DVD material online, and request a copy: www.elections.org.nz/study/disability-resources/resources-for-the-hearing-impaired.html



- If a guest has a hearing loss, assign a staff member to check their room in an emergency, if there are no other solutions.
- Arrange for an emergency message to automatically overlay on the television in guest rooms.

Telephones

People who are Hearing Impaired often can't hear well on the phone. Those who are Deaf usually do not hear on the phone at all.

This can rule out staff phoning to alert a guest to an emergency such as a fire. It can also rule out guests phoning the management if they need a doctor, or other emergency help.

Solutions

- Put an emergency light on the guest room phone that flashes when the hotel alarms ring.
- Install a panic button on the phone. This could also be used by other guests, such as the elderly and those with English as a second language.

Privacy

People may choose to talk more loudly to a guest with a hearing loss. People with a hearing loss may also talk more

loudly because we tend to talk the way we hear. At check-in and check-out, this more public exchange of personal information can lead to loss of privacy or dignity.

Solutions

- Encourage people with hearing disabilities to inform staff. Do this with signs at the reception desk, bars, restaurants. Signs are available from The National Foundation for the Deaf (call 0800 867 446).
- Arrange to speak in a quieter place where guests won't inadvertently share personal information with others.

Television

People with hearing disabilities often rely on subtitles, available on several television channels in New Zealand.

Hotels sometimes present safety and other information on their in-house television, but generally, they don't provide captions.

Solutions

- Install televisions with access to subtitles embedded in broadcast television programmes.
- Caption all hotel safety messages and other information on in-house television.



Ensuring a Hearing Future™ MED-EL Electrode Arrays: Engineered for Hearing Preservation

- The softest and most flexible available
- Designed to preserve neural structures through lateral wall placement
- Ideal for round window insertion
- Available in numerous sizes and variations for different anatomical needs

MED^oEL




medel.com

Enjoying your meal?

Next time you're eating out, take note of the sound as well as the flavours.

The Acoustical Society of New Zealand encourages people to rate their dining experience on www.acoustics.ac.nz

Answer seven simple questions about how the noise affected your experience. The Society comes up with a 1–5 star rating based on the criteria shown below, and adds the restaurant to their growing list.



★ Lip-reading would be an advantage
★★ Take earplugs at the very least
★★★ Boisterous but not too bad
★★★★ Comfortable conversation
★★★★★ The place to be and be heard

For more information, contact The National Foundation for the Deaf:

Sara Huszak

Ph: 0800 867 446 E: sara@nfd.org.nz

If you're looking for a pleasant, quiet space to eat, try one of the eateries that rated 5 stars:

Delicious, Auckland

Embargo, Hamilton

I 62 Café, Wellington

Cashmere Club, Christchurch

Royal remarks

A professional lip-reader caught the murmurs of the royal party during the wedding of Prince William and Kate Middleton. Tina Lannin's transcript included comments from Prince Phillip and Prince Harry. At the altar, William said to his bride, 'You look lovely ... You look beautiful.' And he joked to Kate's father Michael Middleton, 'We're supposed to have just a small family affair.'

Silence is golden ...

... and it can be better for learning. Victoria University's School of Architecture is testing ways to make primary schools quieter. Researchers are prototyping acoustic ceiling forms and an acoustic pod to create a silent zone for students. The aim is to reduce the medical, social and language issues in noisy classrooms, which affect the ability to learn. The Oticon Foundation granted \$13,000 for the research.

Signs online

Want to know how to sign 'apple' or 'zoo'? From A to Z, you can now learn sign language on the internet.

Victoria University has launched an online dictionary of New Zealand sign

language (NZSL) – our third official language. Produced by the university's Deaf Studies Research Unit, the site features about 4000 signs. You can search for words or the visual features of signs. Video clips show how to make each sign.

The resource will raise the public profile and accessibility of NZSL for all New Zealanders, said David McKee, director of the unit.

www.nzsl.vuw.ac.nz



Advertisers: support our magazine

Hearing Matters reaches a broad cross-section of New Zealand's Deaf and Hearing Impaired community – more than 450,000 people.

To discuss sponsorship and advertising, please contact:

John Shaw, Manager, Sustainability

Ph: 0800 867 446

E: john.shaw@nfd.org.nz