



CapTel is for the chop despite the harm this decision will cause

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It is imperative that the Federal Government continue to fund the CapTel relay service and reverse its decision to axe the service!

What music sounds like through an auditory implant

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New approaches may hold the key to helping people with implants enjoy music again. One possibility is modifying musical tracks or even writing entirely new music specifically for implants.



The brain can hear better after vision loss

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Research has suggested that the brains of people with vision loss can adapt and "rewire" to enhance their other fully functional senses.



One in Six Australians live with deafness and ear and balance disorders.

Our mission is to *Make hearing health & wellbeing a National Priority for Australia*

Government determined to axe CapTel phone service from National Relay Service

A CapTel phone allows a person to hear another person and read captions of everything that is being said during a phone conversation.



Photo: A CapTel phone installed in the main entrance of Redland Hospital (QLD) is making life a little easier for patients and visitors who are hearing impaired.

This letter we received (published with permission) is just one example of the harm this decision will cause.

The Hon Paul Fletcher MP
Minister for Communications, Cyber Safety and the Arts
Paul.Fletcher.MP@aph.gov.au
Level 2, 280 Pacific Highway Lindfield NSW 2070

Dear Sir,

With reference to the government's plans to remove the subsidy and close down the CapTel Communications systems for people with disabilities i.e. deafness, I am writing to you on behalf of my mother Mrs (name withheld) aged 93 years who currently requires CapTel to communicate as she is profoundly deaf.

My mother lives in a retirement village in Brisbane, and is self-sufficient in the majority of tasks except for the ability to use IT technology. I live in Sydney, so I am not able to make phone calls for her thus leaving her without a support system.

I cannot believe that the government wants to save money at the expense of people who have the disability of deafness and who depend on this service. You are not even replacing it with an alternative.

My mother at her age, uses this phone service as an aid to fill in the numerous requests of places like Centrelink, make appointments to see doctors, specialists etc. and to communicate with her remaining friends and family. I am totally shocked that you as a government don't see this as a

problem. I have heard suggestions like – “provide the person with an amplified telephone”, well that is a totally useless suggestion because if you can’t hear then you can’t hear an amplified telephone either !!!!

I have heard that you could connect a signal to a computer – my mother is 93 years of age and is of the belief that electrical items should be turned off at night-time for her safety and in case of a fire. What use would it be to have a computer which is either off or a person who is unfamiliar with using a computer with advanced technology at her age.... Absolutely ludicrous suggestions.

If you remove this system and don’t replace it with an equivalent, you are sentencing this type of person to a life of loneliness, solitude and lack of social content, thus ensuring a quicker trip to a care centre on the government’s cost system.

I cannot believe that this government which my mother has voted for all her life would treat her in such a poor and cavalier fashion and ignore the basic need for human contact and socialisation. Where are the Liberal / National Party’s values anymore?

To say I am shocked is an understatement and I have been in touch with the Deafness Forum and other bodies to see what could be used to replace this equipment and their reply is “absolutely nothing”.

I look forward to hearing from you with what methodology you are going to use to overcome the government’s rather short-sighted initiative in this area.

Yours faithfully
(name withheld)

Statement from AccessComm

As the distributor of the CapTel handset, Accesscomm knows how important it is to thousands of hearing impaired Australians who use CapTel to stay connected, for work and everyday life.

Since CapTel was launched, the cost of supplying and installing CapTel handsets has been subsidised by the non-profit Conexu Foundation. However, the captioning has been provided by the National Relay Service. From next year, the NRS is moving to a new contractor which will not support relay captioning for CapTel handsets or any other all in one captioning handset. CapTel users will be forced to revert to a computer-based caption service or the slower and smaller captions on TTY screen.

It is extremely disappointing, discriminatory and frustrating for CapTel users to be denied the best phone service for them and their families – a service they have been happily using for years. It is imperative that the Federal Government continue to fund the CapTel relay service and reverse its decision to axe the service!

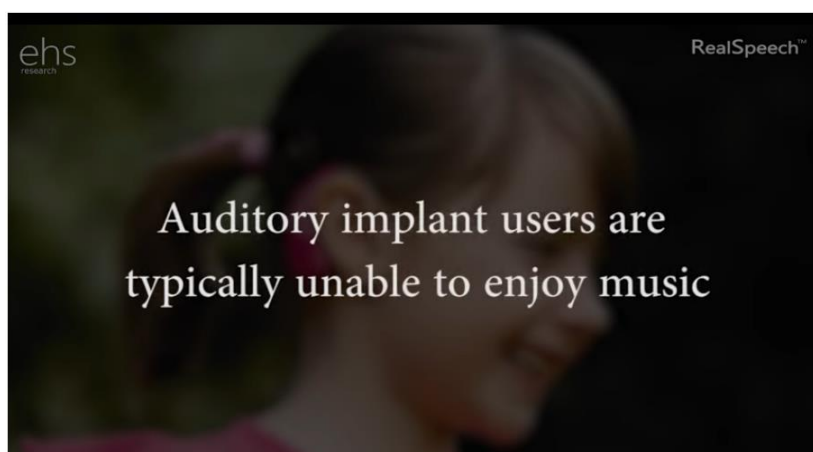


What music sounds like through an auditory implant



For some people with severe hearing loss, it is possible to restore their hearing with an auditory implant (also known as cochlear implants). These electronic devices are surgically implanted into the inner ear, converting the sound from the world into electrical signals that are sent through the auditory nerve to the brain. The damaged parts of the ear are bypassed and people are – almost miraculously – able to hear again. With practice, auditory implant users emerge from a world of silence able to hear the doorbell, to use the phone, to talk and laugh with their friends. Unfortunately, though, music can be hard to enjoy. Smooth melodies become harsh buzzes, beeps and squawks.

People with auditory implants find that much of what they used to love about music is now absent. The implant is poor at conveying the pitch of voices and instruments, as well as the quality (timbre) of the music. This can make it hard to follow the melody, understand the lyrics, or separate one instrument from another. As you can hear in our simulation (below), almost all of the raw, untrammelled emotion that Ed Sheeran brings to his performance of Thinking Out Loud is lost, leaving the music abrasive and flat.



Video: a simulation of what music sounds like through a cochlear implant. <https://youtu.be/57WXFrnjzCU>

The experience of implant users differs hugely across people, and this video demonstration should not be used as a reference point for those considering getting an implant.

This poor transmission of music through the implant can have an enormous impact on people's quality of life. Music is all around us, not just at home or in concerts but also in the background in cafes, pubs, shops, TV shows and films. For people with auditory implants, this can make it hard to enjoy things they previously loved to do.

The trouble with music

In healthy hearing, the sound of music is captured by the activity of thousands of highly sensitive "hair cells" – sensory receptors that respond to minute changes in pressure in the ear, translating sound into electrical activity that can be interpreted by the brain. This extraordinary sensory system is able to code the tiny fluctuations in sound that we interpret as notes, instruments, timbre and emotional resonance. It is this complex coding that allows us to enjoy the melodic voice of Mr Sheeran. In an auditory implant, that system is replaced by a tiny number of micro-electrodes – usually between eight and 22. These electrodes are only able to transmit very crude pitch information, missing the more detailed sound information.

Over time, some people with auditory implants are able to adjust to their new hearing, finding ways to enjoy and love music again. They often find that they must actively learn to enjoy music again to adjust to their new experience. Others have decided to engage with it differently, reading the lyrics while they listen to improve their understanding. Because the implant is able to transmit rhythm much more effectively than pitch, some users find that they can only enjoy certain, more rhythmic genres of music (such as the Michael Jackson song in our simulation). Some, amazingly, have even learned to play instruments when using an implant.

Novel approaches

New approaches may hold the key to helping people with implants enjoy music again. One possibility is modifying musical tracks or even writing entirely new music specifically for implants, with qualities that can be more easily transferred by existing technology. For example, researchers have found that increasing the volume of the vocals and removing harmonic instruments improves the experience of listening to pop music.

Another option is changing the way that sounds are processed by the implant before sending the signals to the auditory nerve. Several implant makers now advertise their cutting-edge processing as best for listening to music. However, most implant users are still unable to enjoy music.

It may be necessary to take a radically new approach. We think that the information bottleneck at the implant could be bypassed by providing sound information through the sense of touch. We have recently used this approach to improve implant users' ability to understand speech in complex sound environments – perhaps we can improve their experience of music too.

Authors

Sean Mills (Post-Graduate Researcher in Tactile Neuroscience, University of Southampton) and Mark Fletcher (Research Fellow in Auditory Neuroscience, University of Southampton) writing for The Conversation, <https://theconversation.com/heres-what-music-sounds-like-through-an-auditory-implant-112457>

Australians locked out of NDIS because they declined invasive surgery, advocate finds

Australians are being denied access to the National Disability Insurance Scheme because they have declined to undergo invasive surgery or take psychiatric drugs.

Under NDIS rules, a person must have a permanent condition and there must be no “appropriate evidence-based clinical, medical or other treatments” available that would be likely cure their condition.



Administrative appeals tribunal decisions reveal cases where NDIS claimants were rejected despite having what one advocate described as ‘reasonable’ causes to decline treatment. Photograph: Mick Tsikas/AAP

Administrative Appeals Tribunal decisions reveal cases where claimants were rejected despite having what one advocate described as “reasonable” causes to decline treatment.

“Informed consent is a medical principle,” said Disability Services Consulting’s Sara Gingold, who reviewed the eligibility decisions.

In one case, a disability pensioner who developed chronic back pain after a work accident was rejected for failing to adequately explore surgery.

The man uses a walker and occasionally a wheelchair and said he had difficulty using the toilet and could not shower himself. He declined invasive surgery after he said he was told by the surgeon operating that it would only have a 50-50 chance of success and carried a risk of exacerbating his condition.

“They were knocked back from the NDIS,” Gingold said.

Other cases reviewed showed people were rejected because they had not accessed treatments which they said they could not afford and which they told the tribunal were not available in the public health system. This included those who said they could not afford bariatric surgery or to see a psychiatrist.

In one decision, a tribunal member said the NDIS Act made no reference to whether a person could actually afford the treatments they were required to try before accessing the scheme.

Gingold acknowledged it made sense that participants should be required to seek treatment.

But she said they also had the right to decline those that were more controversial, which carried side effects they did not want to encounter, or which they could not afford.

The cases reviewed by Gingold represent only those applicants who have taken their case all the way to the tribunal – a tiny fraction of overall rejections.

The Guardian, <https://www.theguardian.com/australia-news/2019/jul/11/australians-locked-out-of-ndis-because-they-declined-invasive-surgery-advocate-finds>

Elderly locked out of the NDIS by Jane Hansen writing for the Sunday Telegraph

Senior citizens are demanding an end to the age limit on the national disability insurance scheme, claiming they are being short-changed.

On Chris English's 69th birthday he fainted and fell face-first on the back deck of his daughter's house. The freak accident left him a quadriplegic. He needs 24-hour care and cannot get out of bed or even eat without help.

If he was under 65, Mr English would be covered by the NDIS but because he's older, he is only entitled to an aged care package.

Mr English spent 12 months in hospital but, now home, his 64-year-old wife Bobby is his main carer. She has to ration the care he can receive from helpers on his aged-care package of \$50,000.

"If we kept up the care of two hours a day, seven days a week (by the end of the year) it will go over by \$8000 with no money left over for respite if I fall ill," Mrs English said.

The Albion Park (NSW) couple rely on their two children aged 38 and 41 to come and help each day. "I rely on my son and daughter to put him to bed each day," Mrs English said.

She has begun a petition and already has 6500 signatures to present to the Minister responsible for the NDIS, Stuart Robert.

"Regardless of age, people over the age of 65 should be able to access NDIS benefits to support them in receiving the care they need," it reads.

Mrs English said the NDIS is far more generous than the aged-care system and aims to meet disability, not the ageing process.

A Department of Social Services spokeswoman said "the NDIS is not intended to replace the health or aged care systems. For those 65 and over, there is a range of supports available".

Deafness Forum believes that the age for accessing the National Disability Insurance Scheme should be increased to 67 years at the same rate as access to the aged pension.

Focus groups about Accesshub

Accesshub is a telecommunications information website provided by the Australian Government.

Accesshub provides a range of information resources about **how to use the National Relay Service** as well as information about mainstream communications equipment and services which may be suitable alternatives to the national relay service for some people. Accesshub can be found at <https://www.communications.gov.au/what-we-do/phone/services-people-disability/accesshub>

The Government has contracted ACCAN (Australian Communications Consumer Action Network) to research the ways in which people who are Deaf, Deafblind, or have hearing or speech impairment use the new Accesshub website.

ACCAN will hold focus groups in Sydney, Melbourne and Hobart to hear from people who use the NRS and have used Accesshub.

There will be three focus groups specifically for people who have hearing impairment:



- The **Sydney** focus group will be held on **Wednesday 21 August** from 9.30am-12pm. The venue is Vision Australia: Level 7, 128 Marsden St, Parramatta.
- The **Melbourne** focus group will be held on **Tuesday 27 August** from 9.30am-12pm. The venue is CAE: 253 Flinders Lane, Melbourne.
- The **Hobart** focus groups will be held on **Wednesday 28 August** from 9.30am-12pm. The venue is the Old Woolstore Apartment Hotel: 1 Macquarie Street Hobart.

The focus groups will go for about 2.5 hours. When you arrive there will be an information sheet and consent form to fill out, as well as a short questionnaire. During the focus group, we will ask questions about the Accesshub website. Participants will be encouraged to offer feedback and insights on the current Accesshub website, and how it could be improved.

Participants will receive a **\$100 gift card** to thank them for participating in the project. Light refreshments will also be provided. All of the focus groups will be live captioned.

ACCAN is able to support participants to attend the focus groups if needed, for instance, by providing cab charge vouchers or travel reimbursements, or arranging accessibility supports.

If you are interested in participating in this project, please contact Meredith Lea from ACCAN. Meredith can be contacted via email at: Meredith.Lea@accan.org.au or on the phone: (02) 9288 4000. Please be sure to provide any details about your accessibility requirements (e.g. if you require an interpreter or a hearing loop) and/or your dietary needs.

Victoria's Parliament to create resources in Auslan



The idea for this project came from The Deafhood YMCA Youth Parliament team 2017 of which Cate and Sara from the video were both members.

We will be running two workshops for members of the deaf community to participate in the creation of these resources:

10:30am to 12pm, Sunday 25 August and 6pm to 7:30pm, Tuesday 27 August 2019

They will be held at Our Community House, 552 Victoria Street, North Melbourne.

To register your attendance for the workshops, or if you have any questions, please email: news@parliament.vic.gov.au

How the brain adapts to hear better after vision loss

By [Maria Cohut](#) for Medical News Today

People with severe visual impairments can perform better than fully-sighted people on hearing tasks. And people who lost their eyesight early in their life can hear sounds better than people without vision loss.

Research has suggested that the brains of people with vision loss can adapt and "rewire" to enhance their other fully functional senses.

Scientists in the US and UK did MRI scans of the research participants' brains as they listened to pure tones — tones that sound the same at different frequencies — and analyzed what happened in their auditory cortexes in the brain.

The scans revealed that this brain region was better able to capture specific finely tuned frequencies in those with vision loss.

The researchers hope that pursuing this path of investigation will allow them to better understand the underlying mechanisms through which the brain adapts to changes in the five senses.

<https://www.medicalnewstoday.com/articles/325032.php>

Training resources for hearing assistance in aged care services and hospitals

It's never too late to hear better

70% of Australians aged over 70 have some hearing loss. This increases to around 85% in residential aged care. However, staff of age care service providers and in hospitals are seldom adequately trained to assist those with hearing loss.

An effective hearing assistance program benefits staff as well as those they care for and, if performed systematically, should not be time consuming.

These resources may also be useful for family carers and volunteers who support hearing impaired people in the community.



Deafness Forum has created free resources for hearing assistance training

- Instructional video designed to fit within a 30-minute in-service session or for continuing professional development (CPD) purposes. Also suitable for pre-service training.
- Hearing Assistance Online Course is ideal for CPD purposes. The course includes videos, multiple choice quizzes and a certificate of satisfactory completion is available.
- Happy Hearing app for on-the-job reference to hearing assistance skills and information including that which is in the above instructional video. It is available in Google Play and the App Store. The app is suitable for use by residential and home care staff, in hospitals, as well as by family carers and volunteers.
- Good Practice Guide for Hearing Assistance (including management of hearing loss in aged care) provides extra reference material and suggestions for starting an effective hearing assistance program (regularly updated).
- Poster series designed to encourage the use of appropriate communication techniques as part of a plan to improve hearing support in aged care and hospitals.
- Teaching-learning modules – a series of four modules for students and teaching staff in the Diploma of Nursing HLT54115, Certificate III in Individual Support CHC33015 and in Cert IV in Ageing Support CHC43015 and also for CPD purposes.

Visit the Deafness Forum website to access these free resources.

<https://www.deafnessforum.org.au/resources/training-resources-in-hearing-assistance-in-aged-care-services-and-hospitals/>

Preventing hereditary deafness



Scientists have used a novel gene-editing approach to salvage the hearing of mice with genetic hearing loss and succeeded in doing so without any apparent unwanted-target effects.

The animals -- known as Beethoven mice -- were treated for the same genetic mutation that causes progressive hearing loss in humans, culminating in profound deafness by their mid-20s.

The new approach involves a gene-editing system that is better at recognising the disease-causing mutation seen in Beethoven mice. The refined tool allowed scientists to selectively disable the defective copy of a hearing gene called *Tmc1*, while sparing the healthy copy.

The researchers at Harvard Medical School and Boston Children's Hospital report their system managed to recognise a single incorrect DNA letter in the defective copy among 3 billion letters in the mouse genome.

Much more work remains to be done before even a highly precise gene-editing therapy like this one could be used in humans, the researchers cautioned. However, they said, the work represents a milestone because it greatly improves the efficacy and safety of standard gene-editing techniques.

"To be sure, this is the first step in a long journey. But what we have here is proof of principle that demonstrates this highly specific, highly targeted treatment could be developed to selectively silence genes that carry single-point mutations and potentially treat many other forms of human disease."

The team said the results set the stage for using the same precision approach to treat other dominantly inherited genetic diseases that arise from a single defective copy of a gene. It could correctly identify 3,759 defective gene variants collectively responsible for one-fifth of dominant human genetic mutations.

The mice carrying the faulty *Tmc1* gene are known as Beethoven mice because the course of their disease mimics the progressive hearing loss experienced by the famed composer.

The cause of Ludwig van Beethoven's deafness, however, remains a matter of speculation.

<https://www.sciencedaily.com/releases/2019/07/190703121434.htm>



Ella was a speaker at the NSW Parliamentary Friends of Hearing Health and Deafness event in Sydney, organised by Hear For You and supporters.

Ella moved the audience to tears with her heartfelt speech, explaining to NSW parliamentarians that her moderate hearing loss from birth was only discovered at ten years of age, and that her school peers do not know about deafness or hearing health.

"So I had my hearing tested and found out that I needed hearing aids and in the classroom I would benefit from an FM. The adjustment was difficult for me. It required me to change schools so I could receive the support I had missed out until the diagnosis. The support I have continued to receive has been essential to my improvement at school. I am still working out how to cope with my hearing loss as new situations arise."

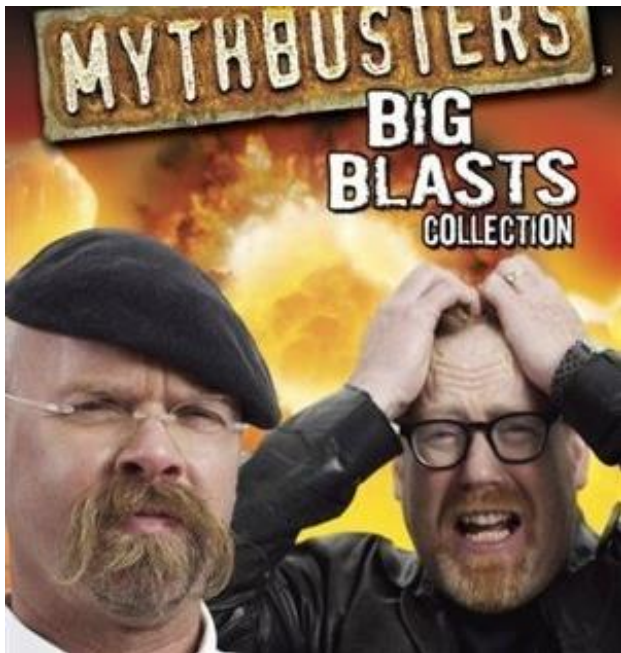


"Hi, my name is Elisha and this is my sign name. I am 11 and I'm deaf. But my mum, my dad and my sister, they're all hearing. But I'm really lucky because they learnt how to sign just for me."

And so began Elisha's chance to shine as she signed her speech at the NSW Parliamentary Friends of Hearing Health and Deafness event.

"I really think that the Government needs to make sure that in all mainstream schools deaf children have access to professional interpreters so that they can access the same level of education that hearing students do."

Congratulations Elisha, thank you for sharing your story and raising awareness for deafness and hearing health.



Adam Savage (Myth Busters) opens up about his experience with hearing loss and why getting hearing aids was a life-changing decision.

This video is sponsored by Widex.

<https://www.tested.com/tech/883570-adam-savage-talks-about-his-hearing-loss/?fbclid=IwAR1uNGjLC-U4-yN7SIy-cTrbDOuj3sxe58rr18-Ji0aLN-nf1pEQZ9E6KNw>

Know someone who might like to get their own One in Six?

Drop us a line: hello@deafnessforum.org.au

We acknowledge the traditional owners of country throughout Australia, and their continuing connection to land, sea and community. We pay respect to them and their cultures, and to elders past, present and future. We acknowledge the challenge of overcoming high levels of ear health issues among First Nation people and its role in Closing the Gap. We acknowledge the risk to indigenous sign languages and the importance of Auslan.

People with disability are subjected to isolation, exploitation, violence and abuse in institutions. We thank the Australian Parliament for its bipartisan support of a Royal Commission into the evil committed and being committed on people with disability.

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