



## Temporary lifeline for CapTel users

"When I received the CapTel I was so overjoyed I burst into tears. I had developed a phobia about using the telephone. CapTel allowed a new world for me."

## Kara the avatar

"There's no correlation between being deaf and being smart, so why were there no deaf students at the university? When I talked to the deaf education centres I found out we don't have enough teachers who know sign language in New Zealand."



## Protecting the rights and equality of people with disability

U.S. presidential campaigner Elizabeth Warren is ensuring that technology advances in a way that promotes independent living and accessibility. "It's a crime that the most versatile device on the planet, the computer, has not adapted well to people...who need assistive technology."

## Children with Usher Syndrome inspire new book

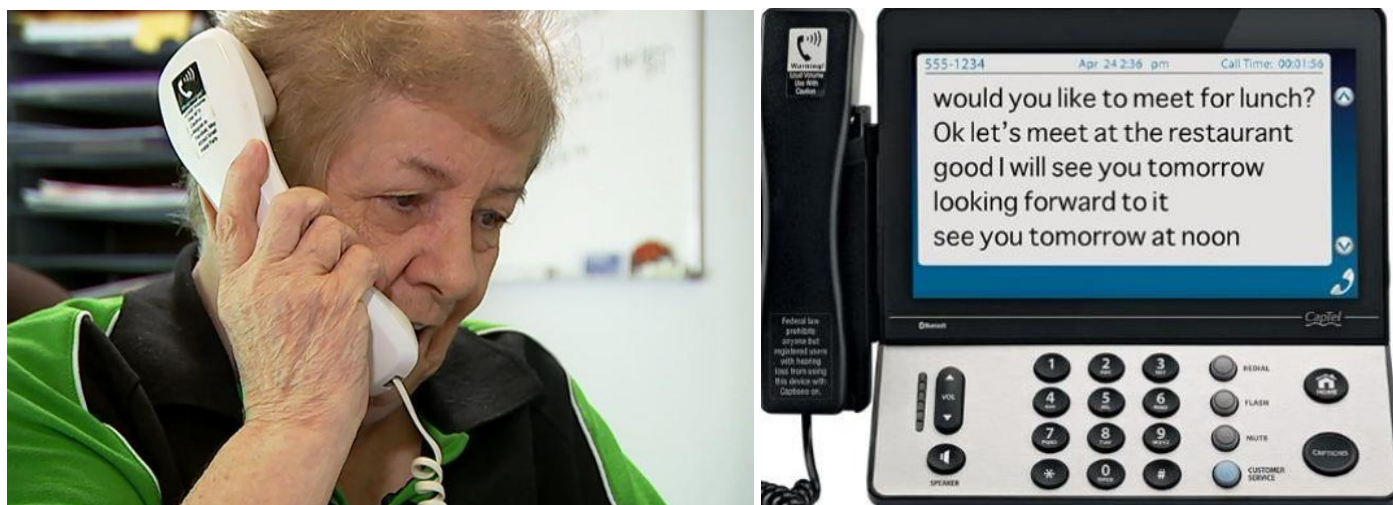
"I feel I've been given these children for a reason. It may not ever reveal itself to me, but I do worry about the day they might question, Why them? Why has God made me this way?"



## Dancing while deaf

Dance may be a visual art form, but it's tightly intertwined with sound. Learning to dance without two fully functioning ears remains a challenge. But today, dancers with full and partial hearing loss are becoming more visible, thanks to growing opportunities, high-profile role models and even Instagram.

## CapTel steps in to keep text-captioned telephones running for Australia's deaf community



CapTel's US operation has stepped in to temporarily keep their text-captioned telephone service running for Australia's deaf community despite the Federal Government cancelling its deal with the service provider.

### **Key points:**

- The Federal Government did not renew the CapTel deal, saying the rising cost was not sustainable
- The service was set to end after January 31, but CapTel is continuing captioning for Australia
- The captioning is being temporarily provided from the United States

Thousands of hearing-impaired Australians feared losing the service as of February 1 after the Department of Communications declined to renew the United States service provider's contract with the National Relay Service (NRS) in favour of another company.

But in a letter to users of the phone handsets — which display words on a large screen in near real-time so deaf and hearing-impaired users can make calls and see responses — CapTel said the captioning service would continue to be delivered as an interim measure outside of the NRS.

Captioned Telephone International president Rob Engelke wrote to users telling them he was optimistic the Federal Government's decision could change, but for the "near term" captions would be delivered from US captioning centres.

"I have been genuinely moved by the outpouring of heartfelt messages from Australians who are clearly distressed and frightened about living without CapTel," he said.

"CapTel has been available for over 10 years in Australia and I believe it is not acceptable to leave CapTel users without access to family, friends, employment, emergency services and the myriad ways that all of us use the telephone."

"Therefore, as a temporary measure, I have instructed our American captioning centres to support existing Australian CapTel handsets so that they will continue to operate with captions while we investigate long-term options based in Australia."

For Christine O'Reilly, the CapTel phone changed her life. Ms O'Reilly's hearing has been deteriorating since childhood and now at 62, she is profoundly hearing impaired.

"We are humbled, joyful and extremely grateful," she said about Mr Engelke's announcement.

"This is the epitome of empathy and human kindness. A small business extends a helping hand to vulnerable people in a charitable way. It does what a Government with billions at its disposal and driven only by a budget bottom line refuses to do.



"Accessible communications for all is a basic human right and not one that should be borne by private enterprise."

Ms O'Reilly said although this is a small victory, the fight does not stop "until CapTel is restored to being funded by the Government as it should be".

The Government's decision has been criticised by disability advocates, with many users facing the prospect of reverting to what are known as TTY teletypewriter phones — technology first introduced in the 1980s.

Other options offered by the Department of Communications are internet-based call captioning and apps designed to work on mobile phones and tablets.

But users said many of the online options were much slower and less user-friendly, requiring them to fill in multiple fields just to initiate a phone call.

And advocates point out the average age of CapTel phone users is more than 80.

Critics say the decision has come down to money. The cost of the NRS has blown out in recent years, from \$26.3 million in 2015-16 to \$31.2 million in 2017-18.

Much of that increase was due to the popularity of CapTel phones, which were paid for on a per-minute-of-use basis.

The new NRS contract awarded last June provides for \$22 million per year over three years.

Until recently there were more than 3,500 CapTel handsets distributed across Australia. The Department of Communications estimates about 1,000 are still active.

Before the news that CapTel would temporarily continue the service, Minister for Communications Paul Fletcher said he hoped the owner of CapTel technology, Ultratec, could reach an agreement with the new NRS contract holder in the future.

<https://www.abc.net.au/news/2020-02-01/captel-to-keep-text-captioning-service-temporarily-running/11920730?fbclid=IwAR1nNjMmSqrtrBrxkWWLXzNEGri8NXzLVnmoXKMmzEPRSHZIO- pWIq1Z4s>





By [Ahmed Khalifa](#)

### **I learnt a new phrase recently: 'deaf anxiety'.**

After reading and learning more about, I realised that whenever I get anxiety, it is mostly likely because of my lack of ability to hear. And the more I read about it, the more I realised that it resonates with me and it's definitely a thing. It also made me aware that it's a topic that we should be talking about more often.

When growing up, I taught myself to do many things in my community of able-bodied people, just so I can blend in:

- The correct way to pronounce certain letters and words
- Learn to lipread
- Analyse the environment to see if I can work there
- Focus all the time so that you don't miss anything
- Find out when is the best time to use a phone
- Work out whether that person will understand me or not
- Work out what the hell that person is saying

Not only I had to blend in and act like a hearing person by doing all of the above, but I also learnt to combine that with some fake smiles, nodding and laughter along the way. There we go...now I'm doing it right. (Meanwhile, I'm finding it difficult to breathe, your heart starts beating faster and you feel all tense inside).

That is how I managed to blend into a community of able-bodied people and to pass as a 'normal hearing person'. Society is constantly asking me to take a test and I must pass it if I want to be part of it. So I need to be on my toes if I want to pass that test. Failure was a scary option for me, but that does happen and it makes you feel like failure. But that's OK, because I then remind myself that I get to take that test again... and again ...and again. Forever.

In my head, the worst thing for me to do is to make other people go out of their way. The idea of doing that...well, that's just plain damn rude, isn't it? How dare I do that? (Breathe...breathe...) I am making things difficult for myself by keeping quiet and not interrupting other people. But that's OK, because I'm being polite and that's how we should treat our fellow citizens. So let's ignore that tense feeling around my heart, and battle on. (Literally after writing the above, I had to stop and take a break. No wonder deaf anxiety is not talked about often).

## AI-powered avatar making content accessible to Deaf



Niki, Kara's hyper-realistic avatar, is responsible for translating a variety of media content

[The Lightbulb](#) asks innovators and entrepreneurs how they turned their ideas into reality. We talk to Arash Tayebi, co-founder of Kara Technologies which uses AI and digital humans to translate content into sign language.

### **First of all, give us your elevator pitch for Kara.**

Kara translates different materials – books, audio, video – into sign language. We do this by using artificial intelligence (AI) and hyperrealistic avatars to provide accessibility to deaf people.

### **What sort of background do you come from?**

I've just finished my PhD in telecommunications at the University of Auckland, so my background is in engineering, specifically electrical engineering. I got the idea for Kara around two years ago in December 2017.

### **So what was it that sparked the idea for Kara? What was your lightbulb moment?**

I have this disease called [Ménière's disease](#) (an inner ear problem that affects your hearing and balance) and because of that I lost hearing in my left ear. This made me more interested in the [deaf] community so I started talking to deaf education centres. I realised we didn't have that many deaf students in the engineering department and I wondered why that was. There's no correlation between being deaf and being smart, so why were there no deaf students at the university? When I talked to the deaf education centres I found out there was a huge gap because we don't have enough teachers who know sign language in New Zealand. That's when I thought we could make virtual teachers who knew sign language and were available 24/7. That's where it all began.

### **How does Kara translate books/audio/video into sign language?**

Sign language is a complete language. It has its own grammar, it has its own vocabulary, and it has its own culture, so providing a seamless translation is very complicated. What we did is we broke it down into three levels. With level one translation we use human plus avatar. With level two translation we use less human and a bit of visual intelligence towards the avatar. And with level three translation we only AI plus avatar. At the moment, we're at level two.

## **In what contexts will Kara be used? What use cases do you have in mind?**

Recently we received some help from the NZSL (New Zealand Sign Language) board, so we're going to provide a translation of five books with the help of Kelston and van Asch deaf education centres. The books are going to be narrated with sign language and [you'll be able to see] how efficient and effective it is to use technology to increase children's knowledge.

We want to try and get deaf children to learn by themselves. [It's not meant] as a replacement for teachers, but as a complementary tool to help make them independent learners. We want to make it available New Zealand-wide for every single deaf child.

## **There are already solutions for people with hearing difficulties in terms of subtitles for TV shows and movies, so what's the benefit of having these materials conveyed via sign language rather than the written word?**

Our focus is mainly on children and for children, reading can be difficult. Also, for some deaf people, English will be their second language and sign language will be their main language. So I think these materials could have more effect if they're presented in sign language. Of course, subtitles are great, but I think a better solution is if we can coincide it with sign language translation since this is the natural language deaf people communicate with.

## **What's been your biggest challenge so far?**

The thing that makes us different from animals is language, and language is the most complicated tool that we as humans have developed. So our current challenge is how can we make sure nothing is going to be 'loose' if we provide translations in a cost-effective manner? How can we ensure that? That's one of the challenges we're trying to solve... we want to make sure we're really delivering what we're claiming.

## **After research and development, how are you planning to commercialise your product?**

We're a social startup/enterprise so we're looking to generate some revenue. At the moment we're figuring out what the best business model for us will look like.

From The Spinoff, [https://thespinoff.co.nz/business/27-07-2019/the-ai-powered-avatar-making-content-accessible-to-the-deaf/?fbclid=IwAR2UFD\\_0QL45ViC0gIDGnn-uEtYjalMOMB1XKrdjpQZqw\\_11gaZ9qxbF\\_A](https://thespinoff.co.nz/business/27-07-2019/the-ai-powered-avatar-making-content-accessible-to-the-deaf/?fbclid=IwAR2UFD_0QL45ViC0gIDGnn-uEtYjalMOMB1XKrdjpQZqw_11gaZ9qxbF_A)

There are approximately 11,000 deaf people who use NZSL as their primary form of communication. NZSL is one of three official languages in New Zealand, along with English and Te Reo Maori. NZSL has its own grammatical structure which enables users to communicate fully and express thoughts and emotions. However, it differs from spoken languages because it is solely visual.

The recognition of New Zealand Sign Language through the New Zealand Sign Language Act 2006 was a major step forward in improving the lives of Deaf people. However, this recognition is still too recent to have had a significant impact on the many inequalities that Deaf people face on a daily basis.

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# Elizabeth Warren has a plan to make technology work for people with disability -- not against them

By [Dell Cameron](#) for Gizmodo



US Democratic presidential candidate Sen. Elizabeth Warren.

Citing the hard-fought victories and tireless dedication of disability activists like Judith Heumann and Joyce Ardele Jackson, Senator Elizabeth Warren unveiled an exhaustive plan to support the equal opportunity and self-determination of Americans with disabilities—pledging to ensure that advancements in technology will be used to improve their lives, rather than discriminate against them.

Part of Warren's 2020 presidential platform, the 16-page plan, titled "[Protecting the Rights and Equality of People with Disabilities](#)," aims to fulfil the promise, Warren said, of the Americans with Disabilities Act (ADA), the 1990 law, which aimed to eliminate discrimination by requiring employers and public entities to offer reasonable accommodations to those with disabilities, among other measures.

A core pillar of the plan is ensuring that technology advances in a way that promotes independent living and accessibility.

According to the World Health Organisation, by 2050 over [900 million](#) people will have some type of disabling hearing loss. In the United States, nearly [13 per cent](#) of people have a disability, according to U.S. Census Bureau surveys.

Technology has in many ways improved the lives of people with disabilities, but it can also be isolating and exclusionary, particularly when accessibility is an afterthought of designers and engineers.

In 2017, Vint Cerf, who's recognised as one of the "fathers of the internet" and is himself hearing-impaired, sharply criticised as "almost criminal" programmers who've failed to consider people who experience hearing, visual, and motor problems.

"It's a crime that the most versatile device on the planet, the computer, has not adapted well to people who need help, who need assistive technology," Cerf [told CNET](#) at the time. "People with disabilities are still fighting for economic security, equal opportunity, and inclusion—and they are not fighting alone."

Senator Warren's plan — which also addresses needs like affordable health care and economic self-sufficiency and would open new offices aimed at protecting disability rights at the U.S. State Department and elsewhere — calls for a reduction in the cost of assistive technologies. A specific method of enforcement mentioned by the plan is using the [1980 Bayh-Dole Act](#) to effectively ignore the exclusivity of patents on assistive technologies when companies fail to make products affordable.

"If companies that used government funding to develop their products are unwilling or unable to offer key assistive technologies at reasonable prices, my administration will use its authority under the Bayh-Dole Act to licence patented innovations to companies that will ensure that technologies are available to the public on reasonable terms," Warren said.

Warren, a liberal candidate who's led the call to "[break up Big Tech](#)" and plans to pay for many of her campaign promises by implementing a new tax on the wealthiest Americans, reintroduced in the Senate last month the Accessible Instructional Materials in Higher Education (AIM HIGH) Act, which is intended to help students with disabilities get the same access to educational materials and technologies as students who do not have disabilities.

"Despite strong anti-discrimination laws, students with disabilities still face discriminatory policies and practices that disproportionately impact them," Warren said.

In addition to ensuring "full accessibility" to federal agency websites and other technologies, Warren plans to implement an \$US85 (\$121) billion federal grant program to expand broadband access across the country and will work to pass the Digital Equities Act, which among other goals seeks to fund projects that will improve the online accessibility of social services.

"The rapid pace of technological advancement has brought many positive changes for people with disabilities, improving their health, safety, and ability to interact with the world," Warren said. "But technology also poses risks when it is used in ways that discriminate against individuals with disabilities or exclude them from an increasingly digital world."

Added Warren: "People with disabilities are still fighting for economic security, equal opportunity, and inclusion—and they are not fighting alone."

<https://www.gizmodo.com.au/2020/01/elizabeth-warren-has-a-plan-to-make-technology-work-for-people-with-disabilities-not-against-them/>



# Mum releases second book based on sons with rare genetic condition Usher Syndrome

By [Emilie Ng](#)



Julianne Schmid has spent the past few years preparing her sons, who were born deaf, to hear the world differently.

The Mackay mum even wrote a book on the daily life of her two boys, titled *Bill and Hug – A Dragon’s Tale*, which explores the experience of two sibling dragons with hearing aids.

In August 2018, Will and Hugo were diagnosed with Usher Syndrome 2C, a sub-group of a rare genetic condition that causes hearing loss and deterioration of vision.

The boys have been using hearing aids since they were several weeks old, after not passing the Queensland Government’s free hearing screen but, due to Usher Syndrome, will most likely be legally blind by the time they are adults.

The particular strain of their condition is so rare that Mrs Schmid and her husband Peter were unaware they were carriers of the gene.

“We’re yet to meet another 2C in Australia,” Mrs Schmid said.

Though Usher Syndrome was not life-threatening or life-shortening, Mrs Schmid said there was a large stigma attached to the condition.

“I think it’s just because one sense is already compromised, then a second sense they learn to rely on becomes compromised as well, so a lot of people see that as cruel; they don’t think it’s the responsible thing for parents to do to a child,” Mrs Schmid said.

She even experienced a negative attitude in the health sector.

When the Schmids received Hugo and Will's genetic testing results, they were nine weeks pregnant with their third child.

"The fact we were already pregnant was a shock to the genetic counsellor," Mrs Schmid said.

They were told about a test for Usher Syndrome that could be performed in utero, with the option to terminate the pregnancy if the results came back positive.

"I thought, what was the point in testing in utero, because abortion was not an option for us," she said.

"It was our choice to have that little life.

"Maybe it was my Catholic upbringing, but I felt responsible for this little person and wanted to give them the best life I could.

"The most confronting part to me was my other two children weren't being valued.

"The fact that they were throwing that (abortion) around, what about the two children I've already got? What value does that have on them?"

For Mrs Schmid, Hugo and Will have eternal value, a life given to them by God.

"I feel I've been given these children for a reason. It may not ever reveal itself to me, but I do worry about the day they might question, 'Why them?', 'Why has God made me this way?', 'If the Bible says God can heal the deaf and blind, why hasn't God healed me?'

"I don't know how I will respond at this particular time.

"A part of me thinks, 'Why not you? You've been given a family that can support you and help you grow'.

"But I think I would be angry too, but for my own faith, I feel like everything happens for a reason."

One of those reasons could be the second book Mrs Schmid has released.

A month after her boys' Usher Syndrome diagnosis, Mrs Schmid and her husband travelled to Melbourne to attend a conference for families of children with the condition.

On the plane ride home, Mrs Schmid brainstormed a second book to help raise awareness of Usher Syndrome.

She released her book Shine Brighter, which she also illustrated, last month.

Mrs Schmid also consulted Guide Dogs Queensland and Vision Australia to ensure the book was appropriate for a low-vision audience.

The book's protagonist is a star – chosen because sound doesn't travel through space – and lives largely in darkness and silence, wearing a cochlear implant and hearing aids.

With the help of the moon, the star begins to find hope (and a pair of glasses to see).

It's a small reflection of the way Mrs Schmid sees her boys.

"I think the world is still their oyster and they can do whatever they want to do," she said.

“They may not be able to drive a car but they might be independent in other ways, as far as independence and career is concerned.

“It’s a bit confronting that their future might mean extra assistance; it might mean a guide dog, or walking with a cane, but ultimately I just see them as who they are. They just see and hear the world a bit differently.”

A portion of Mrs Schmid’s book sales will be donated to Usher Kids Australia, but she said the story could help any child with a disability or who struggled.

She said she was inspired by people she had met who have Usher Syndrome, though from the more common sub-groups, who have gone on to become successful athletes, engineers and teachers.

She hopes the book could do the same for children with this condition.

“There are amazing options for people who are deaf blind,” she said. “They can be independent but their independence is different to a hearing and seeing person.”

<https://catholicleader.com.au/uncategorized/mum-releases-second-book-based-on-sons-with-rare-genetic-condition>

## Libby Harricks Memorial Oration 2020: ‘Indigenous Ear and Hearing Health: Tackling the silent epidemic’

Deafness Forum of Australia and Audiology Australia present the annual Libby Harricks Memorial Oration. The Oration series raises awareness of issues of hearing health, deafness and ear and balance disorders.



The 2020 Oration will be presented as a keynote address at the Audiology Australia conference by Clinical Professor Harvey Coates AO DM MS FRCS(C). His topic is to be ‘Indigenous Ear and Hearing Health: Tackling the silent epidemic’.

**Date:** Sunday 3 May 2020

**Time:** 4.30 – 5.45pm

**Place:** Crown Ballroom, Crown Towers, Perth WA.

Entry to the 2020 Libby Harricks Memorial Oration is **free** if you register [here](#)



## What it's like to move to music you can't hear?

By [Rebecca Ritzel](#) for Dance Magazine

Paul Taylor rather famously never allowed mirrors in his studio, believing they fostered bad habits. But spend a few hours in the studio with Deaf and hard of hearing dancers, and you'll never look at your reflection in the same way again.

"Some dancers use mirrors just for vanity," says Lexine Brooks, a Deaf dancer who began training at age 2. For nearly two decades, she's learned choreography in all sorts of ways, including an FM system that amplified her teachers' instructions in her ears. Today, she prefers to learn dance through American Sign Language and counting—as well as keeping an eye on the mirror.

Brooks is a member of Gallaudet Dance Company, a 65-year-old performance troupe at Gallaudet University for the Deaf and hard of hearing in Washington, DC. At one fall rehearsal, members spent an hour watching intently in the mirror while choreographer Teresa Dominick, a Gallaudet alum, held her hand high and beat out an eight-count with her fingers. Dominick, fluent in ASL, is able to sign and count at the same time—a top priority for the dancers.

Also possible thanks to studio mirrors: Moving in sync with partners on the opposite side of their V-shape formation once Dominick started up music that not all of the dancers could hear to the same extent.

"Gallaudet Dance Company is no different than other dance groups," Dominick says.

"We just use a different language to communicate and utilize different cues."

Dance may be a visual art form, but it's tightly intertwined with sound. Even as the field strives to be more inclusive, learning to dance without two fully functioning ears remains a challenge. But today, dancers with full and partial hearing loss are becoming more visible, thanks to growing opportunities, high-profile role models and even Instagram.



## The Drive to Dance

Brooks began dancing for the same reason as many hearing kids: She saw a live performance—in her case *Swan Lake*—and knew dance was something she wanted to do. But other Deaf children are drawn to dance after feeling left out of team sports. Deaf-from-birth dancer Zahna Simon, who today serves as the assistant director at the Bay Area International Deaf Dance Festival and the Urban Jazz Dance Company, remembers being in fourth grade, loving movement and struggling to play softball. Then she visited a friend's ballet class.

"I instantly connected with ballet as I watched the teacher physically demonstrating it, making direct corrections on the students," says Simon. "I knew I could learn to dance by watching and wouldn't have to struggle with following conversations."

She no longer struggled to communicate with teammates but still faced challenges.

"My teachers told me early on, 'You are going to have to work three times harder,' " says Annemarie Timling, a Gallaudet dancer who is hard of hearing and trained at North Star Ballet in Fairbanks, Alaska. "I would go home and count through music in my head. And I was always watching, making sure I was in sync with my peers."

From childhood through high school, Alvin Ailey American Dance Theater's Samantha Figgins trained alongside her twin sister, Jenelle. And when Figgins says "alongside," she's referring to years of strategically positioning herself at the barre so that if her deaf right ear was facing the instructor, she could follow her twin sister. At home and after class, Jenelle (now with Aspen Sante Fe Ballet) would review combinations with her.

"Jenelle was my angel," Figgins says. "I wouldn't be the dancer that I am today without her."

Still, Figgins worried about appearing antisocial to her fellow dancers, when in reality, she never snickered in class because she couldn't hear other dancers' jokes. She also knew that if she lost her place, it would be nearly impossible to catch up.

"I have to stay laser-focused and make sure I'm not distracted," she says. Figgins believes that sense of hyper-focus has ended up being the key to her professional career.

More at <https://www.dancemagazine.com/deaf-dancers-2641619050.html?rebellitem=3#rebellitem3>

## Sarah posted on Facebook

Thank you for sharing ❤️ As a bilateral HI ballroom dancer this is so relatable. You do really have to work 3 times harder than everyone else on every step of every dance.

I totally agree with comments in the story regarding watching choreography and peers in person or in the mirrors. Then trying to be in sync with the correct beat without being in front or behind.

The struggle is real!

Balance and everything else that comes with hearing loss is so much more of a challenge every time you dance but is so worth it when a routine comes together.

Even preparing for my dance exams especially at higher levels makes music selection is a mission in itself.



So very sad to learn of the passing last month of Ms Roma Wood OAM.

Roma was a past president of Better Hearing Australia Sydney branch (1995-98) and its Vice Patron from 2015. She was awarded a Churchill Fellowship to study hearing rehabilitation services in Europe and the U.S. Deafness Forum created the Roma Wood OAM Award at its national Captioning Awards.

Throughout her long and productive life Roma provided education and support to many Australians who lost their hearing in their lives through rehabilitation, taught lip-reading, and how to use hearing devices.

Deafness Forum chair David Brady said, "Roma was a true champion and her passion for captioning meant a great deal to so many Australians who would not have had access to broadcast programs and social media information."

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

Drop us a line: [hello@deafnessforum.org.au](mailto: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 have and continue to be 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 on people with disability.

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