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When my sons were born deaf

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What it's like to be a deaf novelist?

Books have always provided me with a sense of solace and companionship when I found the hearing world overwhelming. Growing up I filled notebooks with the things I was afraid to say aloud. Libraries, too, seem designed for me – a place where one isn't supposed to talk, equality under the rule of silence.

Promising scientific find

An international team of researchers has identified 10 new genes linked with hearing loss and also located the part of the ear affected. Their findings cast doubt on the belief that age-related hearing impairment originates mainly from sensory hair cells. "This study points to genes we could target for screening purposes, drug development and even gene therapy in the future."

Google smart glasses translate languages as real time captions

Google has created a prototype of smart glasses that can show live language translations to the person wearing them. Someone with the augmented reality glasses might be able to understand what another person is saying just by reading captions that are presented through the lenses while the other person speaks.

Currently **one in six** Australians suffer from some form of hearing loss. This may increase to one in four by 2050. *Access Economics 2006*

Deafness Forum Australia is a Voice for All. It is the peak body representing the views and interests of the 4 million Australians who live with hearing loss, have ear or balance disorders, people who also communicate using Australian Sign Language, and their families and supporters. Our mission is to make hearing health & wellbeing a national priority in Australia.

I believed I was being punished when my sons were born deaf



By [Madeline Cox](#) for [news.com.au](#)

The very first deaf person that Felicia ever met was her newborn son. The first-time mum had given birth less than 24 hours earlier when doctors broke the news that her baby couldn't hear.



Initially, Felicia blamed herself for her son's deafness, questioning whether she could have done something differently during her pregnancy. She was also questioning whether she and her husband's past drug use may have caused their baby to be born unable to hear. Both Felicia and her husband are former addicts, who met shortly after they both got out of an in-patient drug rehabilitation facility.

So in the beginning she "blamed" her drug use for her son's deafness.

"I hated myself and thought I was being punished," Felicia revealed.

But it couldn't be more wrong as testing has confirmed that Felicia's son's deafness was caused by his genes. Although Felicia was relieved to learn that she hadn't caused her son's deafness, it was still a huge thing for her and her husband to come to terms with.

"We grieved together and on our own, but in the end, we knew we could either grow and learn or let it completely tear us apart."

Thankfully, Felicia and her husband chose the first option – and began learning how best to meet the needs of their deaf child. They began learning sign language and also got their son fitted for bilateral cochlear implants so he can hear sounds when he wants to.

In the middle of all of that, the couple also began trying for another baby – sadly experiencing a stillbirth and three miscarriages until they finally had their rainbow baby. Once again, their baby was born deaf, just like his big brother.

"People ask me if it is difficult to have two deaf children – and yes it is – but it's also beautiful. They have a bond and a connection like no other."

Labradoodle gives owner a new 'leash' on life

Adelaide Hills retiree, Bronwyn Paddick, has an incredibly special bond with her dog Spud. He has transformed her life and has been trained to save it as well.

Their relationship is a heart-warming 'tail', with Bronwyn leading a much happier and safer life since the Hearing Assistance Dog moved into her home at The Laurels Retirement Village 18 months ago.

Spud saves Bronwyn from potentially life-threatening situations, alerting her to dangers in the home and notifies her when alarms go off. The highly intelligent pooch also makes sure that the door and phone get answered.

"At home I am no longer ruled by uncertainty and even fear," she said.

"The day-to-day-tensions – what if there is a fire, the dinner boils over, the oven alarm is not heard, or my partner (Sue) needs help – are answered by Spud's intervention.

"The doorbell and the phone get answered as well now because Spud gives me a touch and then takes me where I need to be.

"This is the kind of work he does that other people do not see that keeps me safe at home."

The three-year-old engaging and curious canine is a popular personality at The Laurels Retirement Village, despite being bigger and more energetic than most of the other canine residents.

"He brings big smiles from a lot of the residents," Bronwyn said.

"In fact, people tend to remember Spud's name before mine! Many people ask me if he makes a real difference – I can say without doubt that he does.

"He has enriched my life. By addressing my fears, he has also brought me comfort, fun and a sense of safety in a warm bundle of love."

Spud was gifted to Bronwyn by Australian Lions Hearing Dogs, a charity that has a 'pawsome' and enduring association with RetireAustralia, the operator of The Laurels Retirement Village.

Spud is one of three Hearing Assistance Dogs that have lived at The Laurels in recent years, and RetireAustralia is contributing towards the training costs of a future hearing dog that residents named 'Laurel'.

Australian Lions Hearing Dogs CEO David Horne said the contribution was valuable, given the charity is 100% funded by donations and sponsorship, and training can cost upwards of \$37,000.

"We are incredibly grateful for the support from RetireAustralia," he said.

From [Australian Seniors News](#)



What it's like to be a deaf novelist

From [The Guardian](#)

"Sometimes I turn off my hearing aids and dip below the surface of the sound." Sara Nović explains the challenges of being a deaf author and why deafness is still used as a synonym for stupidity



My first novel has recently become an audiobook to which I will not listen. The characters have been assigned voices and accents and inflections that I'll never hear. This is not a complaint, exactly; to have written a book that someone wants to publish in any and all formats is a writer's dream. But to hold some disc or drive that contains a thing I made, transformed into a new thing I can no longer understand, is a predicament in which few writers find themselves.

This disconnect will appear with increasing frequency as I embark on a series of literary events following the launch of my novel. As an audience member I have been to my share of readings in New York. I go because I am in love with books; I go to be with my friends. But even as a spectator they require a lot of concentration, and sometimes when I've worked myself into a cross-eyed headache I turn off my hearing aids and dip below the surface of the sound, let myself drift in the quiet. At my own events I won't have the choice to opt out.

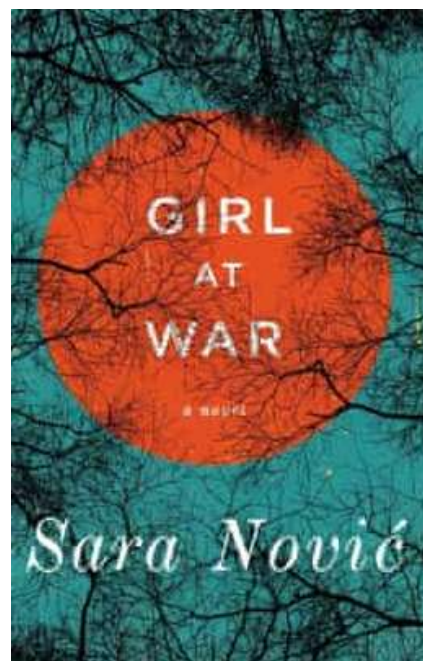
So far I have read in public only three times, each distressing in the regular ways (an audience!), with the added terror of exposing an increasingly unknowable part of myself – my voice. I can feel my words in my chest and mouth, but can't be sure of what they sound like out in the world. As far as I'm concerned my voice has no echo; it does not stick to the tape recording. What does it mean to perform for an audience with such limited control of your output?

Books have always provided me with a sense of solace and companionship when I found the hearing world overwhelming. Growing up I filled notebooks with the things I was afraid to say aloud. Libraries, too, seem designed for me – a place where one isn't supposed to talk, equality under the rule of silence.

Since my hearing loss was progressive, I was educated in spoken English alongside my hearing peers; later, when that became too difficult I learned American Sign Language (ASL) and used interpreters in class. When given the choice between the two, my preference is by far for ASL, in which at least I do not feel self-conscious. But having been brought up in the hearing world with an English education, and now in turn writing and teaching in English, I spend much more time immersed in English than I do in ASL. My ASL is fluent, and I can dream and think in sign, but it is not my primary thinking language.

In reality, the language – or linguistic modality – in which I am most fluent is written English. When I'm writing, my mind and body need not be translated for a hearing audience. I don't worry that I am unclear, that my lips and tongue will revert to their unpractised ways under pressure, or that I'm speaking at the wrong volume for the background noise I cannot gauge. When I'm reading a book, I do not have to guess in the way that I do when lipreading – paper never covers its mouth or turns its head.

And yet there is a disconcerting entanglement between speech and the practice of being a writer. I frequently see advice from famous authors – [Stephen King](#) among them – that you absolutely must read your own work aloud in order to edit it properly. Without listening to your words in your own voice, you can neither fully understand what you've written nor hear how to fix it. At best this kind of advice leaves me feeling a little left out, but at worst, I wonder: am I making mistakes a hearing writer wouldn't?



Sara Nović's novel *Girl at War* is published by Little, Brown.

Another part of writing that seems inextricable from hearing is dialogue. Someone who writes dialogue well is said to "have an ear" for it. I don't think I write dialogue well. Whether this is just your average writerly paranoia or is linked to the physiology of hearing loss, I can't say. Relevant here is a cultural divide between the deaf and hearing worlds with regard to frankness.

By nature of its visual modality, sign language is more direct than spoken language; there are no euphemisms in ASL. Further, the threshold for "rude" or "inappropriate" is much higher in the deaf world. Stemming perhaps from the days before SMS and email, when it was harder to keep tabs on a deaf person's wellbeing, there is no shame in bluntly discussing one's feelings, plans and bodily functions with friends, or even acquaintances.

In the writing world, any trace of this directness translates as "bad dialogue". "That's not how people talk," my workshop mates have said. And of course, they're right.

In English the phraseology of silence and deafness overwhelmingly signifies the negative. To hear is synonymous with understanding – "I heard about that" or "I hear you" suggests the speaker's knowledge, comprehension, or capacity for empathy on a given topic, whereas, across the headlines, cries for justice or peace often "fall on deaf ears". So as long as deafness is a synonym for stupidity or wilful ignorance, d/Deaf and signing people will continue to be "othered" into a position of inferiority. ([capital "D"](#) is used to refer to those who associate with the Deaf community.)

In the face of all this, it's perhaps unsurprising that the works of fiction written in English by d/Deaf writers can be counted on one hand. It is important to note that sign languages foster a rich tradition of storytelling and slam poetry, but books written in English – many d/Deaf people's second language – are few. On the other hand, this means the experiences of Deaf characters present a rich and relatively unmined cache of material with which to work. Plus, being a Deaf writer means I can write anywhere without being distracted – I wrote most of my first book on the New Jersey Transit Northeast Corridor line.

And while writing in a language that works against me can sometimes seem a less-than-ideal occupation, what is the job of a writer if not to reinvent language, or at least to create the space and tools for the silenced?

I am reminded of Chinua Achebe quoting James Baldwin, who expresses frustration with the limits of the language: "My quarrel with the English language has been that the language reflected none of my experience. But now I began to see the matter in quite another way ... Perhaps the language was not my own because I had never attempted to use it, had only learned to imitate it." Achebe goes on to say: "I recognise of course that Baldwin's problem is not exactly mine, but I feel the English language will be able to carry the weight of my African experience. But it will have to be a new English." And while Baldwin's and Achebe's problems are much bigger than mine, I can look at the successes of these literary giants and extract a hope that English, with a little work, can carry the Deaf voice, too.



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Having a hearing loss creates barriers to getting and maintaining employment due to reduced capacity to communicate, as well as affecting personal relationships, individual self-esteem and confidence.

Read Our Lips Australia is a self-paced e-learning platform that is dedicated to supporting those with hearing loss and their families, by improving their quality of life through increased communication skills.

The skills you learn in the course can help you understand what someone is saying in different environments and contexts.

For more information visit www.readourlips.com.au

Barbie unveils doll with hearing aids

By Leah Dolan for [CNN](#)



Barbie, the 63-year-old American doll manufacturer, is releasing a new set of dolls in June as part of its ongoing efforts towards diversity and inclusion.

From creating the brand's first ever Barbie with hearing aids, to a Ken doll with the skin condition vitiligo, 2022's Fashionista line up will help kids "see themselves reflected," said Mattel's Global Head of Barbie Dolls, Lisa McKnight, in a press statement.

She added that children should also be encouraged to play with dolls that don't resemble them to help them "understand and celebrate the importance of inclusion."

For the Barbie with hearing aids, the company sought the expertise of Dr. Jen Richardson, a leading practitioner in educational audiology, to help accurately imitate behind-the-ear devices for the toy. Richardson said the ponytailed-Barbie complete with hot pink hearing aid could inspire those who have experienced hearing loss. "I'm beyond thrilled for my young patients to see and play with a doll who looks like them," she said in a press release.

Changes have been made to the stereotypical Barbie body type, too. From smaller chests to fuller-figures and even slender, less-muscular male dolls, the new toys are intended to be more representative of varied body types.





There is good news from the Minister for Disability Services in Western Australia, Don Punch.

TV announcements and advertisements about public health or emergency information such as COVID will now come with open captions. Here is Don Punch's announcement on his [Facebook page](#):

"I'm sure everyone here will be very familiar with the WA Government's COVID communications campaigns - with frequent ads on TV and posters in the windows of most businesses across the State.

"I'm pleased to announce that [WA Government](#) COVID-19 television advertisements related to public health or emergency information are now more accessible than ever.

"These ads will now be supported by open captions, ensuring all deaf and hard of hearing people can access this important information wherever they go, without having to have closed captions enabled.

"Thanks to Barry MacKinnon and the [Deafness Council W.A.](#) for your advocacy in this area - it is great to see WA now leading the nation as best practice for these announcements."

Telethon Speech & Hearing Centre for Children welcomed the news. "This development to provide equitable communication access means all Western Australians can now keep up to date with the latest news and advice around COVID-19."

Deafness Forum's chair David Brady said, "It is a case study in patient, respectful advocacy. Thankyou to Minister Punch and congratulations to our member Barry MacKinnon and his key supporters, my fellow director in Perth Raelene Walker and the CEO of Telethon Mark Fitzpatrick.



**11th National
Deafblind Conference**
30 June - 1 July 2022 | Fremantle



The [11th National Deafblind Conference](#) will bring together individuals and organisations working to ensure that deafblind are included in service delivery and design, decision making processes, advocacy, research and meaningful community involvement.

Promising scientific find: ten new genes linked to hearing loss

The number of people worldwide with some form of mild-to-complete hearing loss is [projected](#) to increase to about 2.45 billion by 2050.

That's worrying, since age-related hearing impairment is the third highest contributor to global years lived with disability, and has been [associated](#) with depression and anxiety.

Currently, there is no preventative treatment for hearing loss and therapeutics are only available in the form of [hearing aids](#) or [cochlear implants](#).

Now, in a [new study](#) published in *American Journal of Human Genetics*, an international team of researchers has identified 10 new genes linked with hearing loss and also located the part of the ear affected – the stria vascularis.

Their findings cast doubt on the belief that age-related hearing impairment originates mainly from [sensory hair cells](#) – sensory cells in the outer ear that amplify sound, and in the inner ear that transform sound-induced vibrations into electrical signals interpreted by the brain.

The researchers instead identify the stria vascularis, which is a part of the cochlea that powers the hair cells' mechanical-to-electrical signal conversion, as a target for potential treatments to help people experiencing hearing loss.

Researchers found 48 genes associated with hearing loss, including 10 novel variants newly-linked to hearing. These new variants highlight the importance of genes expressed in the cochlear lateral wall (which includes the [spiral ligament](#) and stria vascularis) in hearing loss.

To further investigate the role of these organs, the researchers looked at RNA-sequencing data from studies in mouse cochleae and brains and mapped the common variant genomic results to cells from the stria vascularis – indicating its importance in the mechanism of hearing loss.

"It was hypothesised since the 1970s that the stria vascularis may play a role in hearing loss in humans, but the molecular evidence for this was missing until today," says co-main author Christopher R. Cederroth, an associate professor at the Karolinska Institute, Sweden.

Co-main author Frances Williams, a professor of genomic epidemiology at King's College London in the UK, adds: "This study points to genes we could target for screening purposes, drug development and even gene therapy in the future.

"This study provides a solid foundation for ultimately improving therapies against hearing loss."

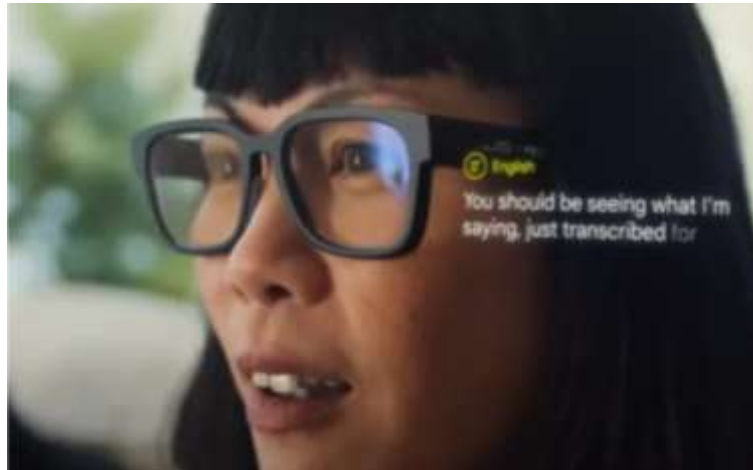


By [Imma Perfetto](#) writing for [Cosmos](#).

Google smart glasses prototype that translates languages as real time captions

[Google](#) has created a prototype of smart glasses that can show live language translations to the person wearing them.

Someone with the augmented reality glasses might be able to understand what another person is saying just by reading captions that are presented through the lenses while the other person speaks.



It's unclear if Google's glasses will ever hit the market, but the prototype provides a sense of where Google thinks augmented reality can be helpful.

The company first ventured into smart glasses roughly a decade ago, but Google Glass was unappealing to most consumers due to a limited launch, high initial pricing and privacy concerns. Google, though, has appeared to keep [pushing into the space](#). In 2020, it acquired North, which was an Amazon-backed company that made smart glasses.

By [Jessica Bursztynsky](#) for [CNBC Tech](#)



Welcome to Cheryl, Tania, Fiona, Renee, Renae, Kerry, Eleanor, Rachel, Rebecca, Melinda and Kay at NSW Department of Education who signed on this month to receive One in Six!

The [New South Wales Department of Education](#) is responsible for the delivery and co-ordination of early childhood, primary school, secondary school, vocational education, adult, migrant and higher education in NSW.

MED⁹EL

Have you subscribed to our NEW "Rehab at Home for Adults" Video Series?

This 13 episode series gives hearing implant users the tips and resources they need to achieve everyday listening goals.

JUST RELEASED - Episode 2

Our second episode is out now: "[How to Wear Your Audio Processor Every Day](#)".

As cochlear implant recipient John shares in the video, this can be the hardest part for new users, but it's the most important foundation to achieve other listening goals.

We invite you to share this with your users who might like to benefit from having their own [Rehabilitation coach Rebecca](#) with them at home.

2 Minute Watch - How to Wear Your Audio Processor Every Day

Featuring Australian recipient John, and Rehabilitation Manager Rebecca Claridge.



[Read More](#)

New research

- [Inner Ear Immunity](#)
- [Noise Reduction Preferences in Teenagers and Pre-teens](#)
- [Efficiency of a novel middle ear pressure device for intractable definite Meniere's disease and delayed endolymphatic hydrops after certification by the public health insurance system in Japan](#)
- [Otitis Media and Its Association With Hearing Loss in Chinese Adults: A Population Based Study of 4 Provinces in China](#)
- [Lab Evaluation of Novel Hearing Aid Coupling Method](#)
- [Long-Term Impedance Trend in Cochlear Implant Users with Genetically Determined Congenital Profound Hearing Loss](#)
- [Endolymphatic hydrops in the unaffected ear of patients with unilateral Ménière's disease](#)
- [Neural activity of the auditory cortex predicts speech recognition of patients with asymmetric hearing loss after cochlear implantation](#)
- [Physiology and Biophysics of Outer hair cells: The cells of Dallos](#)

Free webinar

[National Acoustic Laboratories webinar: Exploring Apple AirPods Pro as hearing devices](#)

What are the hearing accessibility capabilities of AirPods Pro, and how can I set up and personalise them for people with hearing loss? A free webinar on Thursday 26 May.



Understanding key terms relevant to the NDIS

Curtin University and the National Disability Insurance Agency are undertaking a research project to explore how people understand key terms related to and used within the NDIS.

They are looking for adults aged 18 years and over who are members of the disability community to give their feedback and perspectives. Participation in this research (ethics approval HRE2020-0631) will include an anonymous online survey.

If you have any questions about the survey, please email: emily.darcy@curtin.edu.au

Click the link to begin the survey, https://curtin.au1.qualtrics.com/jfe/form/SV_bjCzXVDXUiMOIIu

Advocating for less noise and more quiet



Over the years, groups and organisations have been formed to deal with the growing noise problem in our world.

In New York City, I have assisted local community groups in their efforts to reduce the city's noise. On a larger scale, I have become affiliated with some more national organisations. One of them, Quiet Communities Inc. (<https://quietcommunities.org>), is a non-profit group that aims to work with communities throughout the U.S. to reduce the harmful noises in their environments. I am most involved with two of its programs: Quiet American Skies and Quiet Coalition. The Quiet American Skies program works with anti-noise aircraft groups across the United States and assists with their efforts to provide a safer, quieter, and healthier aviation system. The Quiet Coalition is comprised of a group of health, science, and legal professionals concerned about the impacts of noise on health. This group hopes to encourage public officials to study the growing literature on the link between noise and health to move forward in introducing public policies to address the issue of noise pollution and provide for a quieter and healthier environment.

I recently joined the Board of Right to Quiet in Canada (<https://quiet.org>). This group was established to raise public awareness of the dangers of noise pollution to our health and well-being and to advocate for better legislation and the comparable enforcement of this legislation to reduce noise. As its name indicates, Right to Quiet views quiet as a basic human right.

More closely related to noise and hearing has been my association with the Center for Hearing and Communication (CHC) (www.chc.org) in New York City. In 1996, I was especially pleased to join Nancy Nadler, the Deputy Executive Director of CHC, in initiating International Noise Awareness Day (INAD), celebrated on the fourth Wednesday of April. While INAD was a New York City event at its inception, it is now celebrated throughout the United States and globally (<https://noiseawareness.org/>).

As an academic, I endorse research, but when it comes to noise, I believe there is sufficient research to link noise to hearing deficits, health issues, and learning loss, allowing legislators to introduce policies to reduce environmental noise pollution.



By Arline L. Bronzaft, PhD, Professor Emerita, City University of New York. For [Canadian Audiologist](#)

Wear a face mask if you can't physically distance



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

Contact us to receive this publication in an alternative file type.

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