



Me versus The Mask

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Where are the captions?!

During an emergency good communication becomes of much greater importance. But during the current virus emergency communications have been poor for people with a hearing impairment. Why the reluctance to get the message out as widely as possible?

Mild-to-moderate hearing loss in kids leads to changes in how brain processes sound

Deafness in early childhood is known to lead to lasting changes in how sounds are processed in the brain, but new research shows that even mild-to-moderate levels of hearing loss in young children can lead to similar changes.

Understanding CHARGE syndrome

A free online course is launched to raise awareness of CHARGE syndrome among health and educational professionals and to strengthen the capacity of families and care givers.

Disability Royal Commission

People with disability can be severely affected by emergencies and may be at a higher risk of experiencing violence, abuse, neglect and exploitation at these times. The Royal Commission invites the community to give its views on emergency planning and response.

Me versus The Mask: A pandemic hearing problem

By Gael Hannan for Hearing & Technology Matters



As we crawl our way through this global pandemic, I understand the need for masks. But that doesn't mean I have to like them.

People with hearing loss are not good at masked communication because it cuts off the vital information we get from lipreading. Before the pandemic, my suffering was limited to trying to understand a mask-wearing aesthetician giving me a pedicure. Now, masks are everywhere.

I decided it was time to do my bit to plank-the-curve and start wearing a mask, partly because it's now a recommended practice and partly because of that *other* virus going around – a nervous distrust of people who may not be following the pandemic safety rules, therefore putting the rest of us at risk. Besides, how hard could it be to wear a mask?

Perfect timing – a kind neighbor had been making masks for the local community. We took a couple of her free, sterile, and packaged masks with us when we went shopping for supplies. The Hearing Husband decided to wait in car and catch up on the news while I shopped. But first I had to put on my new and very bright green mask.

I hooked the elastic holders over my ears and discovered the mask wasn't *quite* wide enough. My pinnae (the flappy part of the ears) were pulled forward over my ear-holes, causing the behind-the-ear part of my hearing aid to pop out and dangle beside my head. I tried to stretch the mask a bit wider, but it popped up over my eyes, momentarily blinding me. The Hearing Husband kept checking messages on his phone, ignoring my frustration in the seat beside him, as well as my running narrative that was rapidly turning the air blue.

Patience is not my best quality. I yanked out my hearing aid and put it in the glove compartment, hooked on the mask as best as I could and marched into the store, with my ears were still folded in half. I was keenly aware of my odd appearance; the bright green mask coupled with my red Inuit-design parka had turned me into a walking Christmas card, and breath-induced steam was escaping upwards and clouding my glasses.

Without the hearing aid, my cochlear implant (CI) was on its own. My brain is used to getting its information from the partnership of my left-side hearing aid and right-side cochlear implant. Forced to fly solo, the CI could pick up the high-pitched music over the store's PA system, but it struggled with the overall noise (which also ignited some serious tinnitus). Most shoppers

appeared to be in pairs and all were engaged in discussing their shopping lists. I couldn't help hearing two people interacting urgently, loudly, and with lots of arm waving.

Her: Do we need pasta!

Him: We have enough pasta!

Her: We don't have rotini!

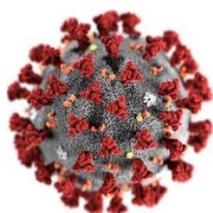
Him: But we have penne!

Her: Right! Go get some coconut milk while I choose the cheese!

Him: No! YOU get the milk and I'LL stay with the cheese.

Her: OK, fine!

I'm thinking, is all this yakking *absolutely necessary*? You're not wearing masks and your droplets are hosing down the cheese! Cover your gobs or stop talking or both. (It's clear that a side effect of this pandemic is crankiness.)



The checkout clerk didn't speak as loudly. I asked her to repeat herself, but not using speech. Because I need to read lips, I bizarrely assumed that people can't understand *me* from behind *my* mask. Instead, in a universally understood gesture, I raised my eyebrows and cocked my ear towards her. This seemed to work. She repeated, but because of her amazing skill of talking *without moving her lips*, I understood nothing. I replied using my own special skill of bluffing (pretending to understand when one doesn't have a clue) and shook my head *no*.

As I picked up my bags, I heard Ms Softly-Voiced say something along the lines of *have a nice day*. For some explicable reason, instead of saying *you too*, I bowed to her. Bowed! Had my neighbor sprinkled some dementia powder in my mask before packaging it? Or did I bow simply because nothing is normal now?

To be fair, my neighbor's only crime was sewing the masks based on the average facial dimensions of her and her husband, which are clearly smaller than ours. The Hearing Husband is 6'6" with a proportionately-sized head while I, although shorter, have a more, uh, *significant* nose that pushes the mask outward, making it harder for the elastics to hook my ears comfortably.

Back at the car, I was over my snit and by the next stop, I had the process nailed. I entered the butcher's with my mask, hearing aid, CI sound processor and glasses all in place. I stood well back from the counter. I used my voice. I did not bow.

Dislike of masks aside, I was doing my bit to stay healthy, lick this pandemic and keep the economy moving.

<https://hearinghealthmatters.org/betterhearingconsumer/2020/me-vs-the-mask-a-pandemic-hearing-problem/>



Tips for communicating with hearing impaired patients during COVID-19

- **Speak slowly and clearly. Do not shout!**
- **Show your face if it is safe to be unmasked**
- **Write down key points**
- **Embrace technology. Live captioning on telehealth or transcription apps for calls**
- **Act out instructions**
- **Check for understanding**
- **Encourage questions**



betterhearing.org.au

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DEAFNESS FORUM OF AUSTRALIA

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Where are the captions?!

During an emergency good communication becomes of much greater importance.

The need for communications to be visible for hearing impaired people becomes essential, but sadly during the current virus emergency communications have been poor for people with a hearing impairment.

Why the reluctance to get the message out as widely as possible?



It is profoundly disappointing when our Prime Minister broadcasts uncaptioned community updates on the pandemic crisis via social media channels.

It sends a message that excluding members of the community from participating in the nation's affairs is okay.

It's time that the Government stood up for its constituents who need captions by insisting that all of its broadcasts, whenever and wherever they appear, will be captioned.

Emergency broadcasts and Government announcements on television must have captions that are a permanent feature of a broadcast or recorded video, so they appear in replays, on catch-up TV services, secondary channels and on social media.

We support the current accessibility inclusion in Government announcements that includes a sign language interpreter for the 10,000 Australians whose first language is Auslan.

However, there are 1.2 million who rely on captions every day.

Captions are important for people for whom English is a second language, children with learning difficulties and particularly people who may use hearing aids or cochlear implants, and the many people who have no aided support to assist with their hearing.

Captions are vital aids for hearing impaired people away from home and seeing and trying to listen to an uncaptioned emergency message on a TV they cannot control, for example at airports, hospital waiting rooms and hotels.

It really is up to the Government to make the change.

The ripple effect would be significantly beneficial for the community for many years to come.

It is disappointing that local companies that make a profit from providing captioning services do not invest in our advocacy for greater use of captioning.



Hearing Services Program

The Government has announced the arrangements for Hearing Services Program clients and NDIS participants to commence on 1 July 2020.

We reported in the last edition of One in Six that before this announcement, advocates were concerned that consumers would not be given adequate time to prepare for changes, should they be introduced. A Government taskforce announced these arrangements after consultations with Deafness Forum and its members, and other organisations.

The new arrangements will address the concerns that have been raised by Deafness Forum and its member organisations over a number of years, particularly in relation to services to children with hearing loss.

From 1 July 2020 the Hearing Services Program (HSP) will operate alongside the NDIS and will continue providing hearing services to eligible HSP clients. The paediatric service offering under the HSP is not being rolled into the NDIS.

Clients of the Community Service Obligations (CSO) component of the HSP, including children and young adults under the age of 26 years will continue to receive hearing services from Hearing Australia under the CSO Program.

CSO program clients will continue to receive services

- from appropriately skilled audiologists
- that are person/family centred and are based on the latest research evidence
- that are available at locations in urban, rural and remote areas
- that are delivered consistently across Australia and monitored through a comprehensive quality framework

The statistical information on hearing impaired children and young adults in Australia will continue to be maintained by Hearing Australia and published annually.

If CSO clients require supports that are beyond the scope of the HSP and they meet the access requirements for the NDIS then the additional supports, where reasonable and necessary, may be funded through the NDIS, for example: early intervention therapy, Auslan language development and assistive technology that is not available under the HSP.

People with hearing loss aged 26 and over who are not eligible for the HSP can test their access to the NDIS and if they meet the access requirements they will be able to receive reasonable and necessary hearing services and supports funded under the NDIS.

Deafness Forum will continue to advocate for support for people with hearing loss on low income who do not qualify for the HSP or the NDIS.

Mild-to-moderate hearing loss in children leads to changes in how brain processes sound

Deafness in early childhood is known to lead to lasting changes in how sounds are processed in the brain, but new research shows that even mild-to-moderate levels of hearing loss in young children can lead to similar changes.

Researchers say that the findings may have implications for how babies are screened for hearing loss and how mild-to-moderate hearing loss in children is managed by healthcare providers.



The structure and function of the auditory system, which processes sounds in the brain, develops throughout childhood in response to exposure to sounds. In profoundly deaf children, the auditory system undergoes a functional reorganisation, repurposing itself to respond more to visual stimuli, for example. However, until now relatively little was known about the effects of mild-to-moderate hearing loss during childhood.

A research team led by Dr Lorna Halliday, now at the MRC Cognition and Brain Sciences Unit, University of Cambridge, used an electroencephalogram (EEG) technique to measure the brain responses of 46 children who had been diagnosed with permanent mild-to-moderate hearing loss while they were listening to sounds.

Dividing the children into two groups -- younger children (8-12 years) and older children (12-16 years) -- the team found that the younger children with hearing loss showed relatively typical brain responses -- in other words, similar to those of children with normal hearing. However, the brain responses of older children with hearing loss were smaller than those of their normally hearing peers.

To confirm these findings, the researchers re-tested a subset of the group of younger children from the original study, six years later. In the follow-up study, the researchers confirmed that as the children with hearing loss grew older, their brain responses changed. Responses that were present when the children were younger had either disappeared or grown smaller by the time the children were older. There was no evidence that the children's hearing loss had worsened over this time, suggesting instead that a functional reorganisation was occurring.

"We know that children's brains develop in response to exposure to sounds, so it should not be too surprising that even mild-to-moderate levels of hearing loss can lead to changes in the brain,"

says Dr Axelle Calcus, lead author of the paper, from PSL University, Paris. "However, this does suggest that we need to identify these problems at an earlier stage than is currently the case."

"Current screening programmes for newborn babies are good at picking up moderate-to-profound levels of hearing loss, but not at detecting mild hearing loss. This means that children with mild hearing impairment might not be detected until later in childhood, if at all," says Dr Lorna Halliday from the University of Cambridge.

"Children with hearing problems tend to do less well than their peers in terms of (spoken) language development and academic performance. Detecting even mild degrees of hearing impairment earlier could lead to earlier intervention that would limit these brain changes, and improve children's chances of developing normal (spoken) language."

Journal Reference: Axelle Calcus, Outi Tuomainen, Ana Campos, Stuart Rosen, Lorna F Halliday. Functional brain alterations following mild-to-moderate sensorineural hearing loss in children. eLife, 2019; 8 DOI: 10.7554/eLife.46965

From Science Daily, <https://www.sciencedaily.com/releases/2019/10/191001160150.htm>



Deafblind Australia

This is an opportunity to join an ongoing project with Deafblind Australia.

Over the next 3 years Project Officers Adrienne Harper-Pike and Ben McAtamney will be facilitating a project aimed at addressing the concerns of the Deafblind community around information gaps and specifically the NDIS.

The project will involve a series of workshops to be held around the country and as part of designing and planning these workshops they are seeking people with deafblindness to form a reference group to help the Project Officers plan the content that will make up future workshops.

They are also asking for expressions of interest from Deafblind community members who are interested in becoming (paid) facilitators of these workshops further along in the project.

Please follow the links here for video information in Auslan with English voice over and English captions:

Call for Expressions of Interest: <https://youtu.be/kKrDim78RyI>

Frequently Asked Questions: <https://youtu.be/yR5zvMrAdfI>

To take part in the project please send your personal contact details by 22 May to Ben.McAtamney@deafblind.org.au

Understanding CHARGE syndrome

CHARGE Syndrome Association of Australasia has created a free online course that offers quality education on the latest knowledge and research on CHARGE syndrome from the world's foremost experts in the field.

This online course will significantly raise awareness of CHARGE syndrome among health and educational professionals and will strengthen the capacity of families and care givers in supporting individuals with CHARGE syndrome.

FREE enrolment at <https://understandingchargesyndrome.org/>

Effort: 6 weeks spending 2 hours per week self-paced.

The course is always open - making it easy to access the information any time you need it. The Academic Leads are:

- Dr Kim Blake (Paediatrician, Canada)
- Dr. Daniel Choo (ENT specialist, US)
- Dr Jeremy Kirk (Endocrinologist, UK)
- Meg Hefner (Genetic Counselor, US)
- Prof Nancy Salem-Hartshorne (School Psychologist, US)
- Prof Tim Hartshorne (Psychologist, US)
- Rob Last AM (Teacher of the Deaf, Australia)
- David Brown (Deafblind Consultant, US)
- Kasee Stratton-Gadke (Psychologist, US)
- Angela Arra (Complex Care Nurse, US)

CHARGE syndrome, also known as CHARGE Association, is a specific set of birth features. The major diagnostic criteria were based on the letters in CHARGE. Not all individuals with CHARGE syndrome will have all the symptoms, and each of the symptoms can vary in their degree of severity.

Coloboma of the eye - a cleft or 'keyhole' in the eyeball

Hear defect - usually corrected by surgery

Atresia of the nasal choanae - blockage at the back of the nasal passage

Restricted growth and/or development

Genital and/or urinary abnormalities

Ear and vestibular abnormalities, deafness - varying degrees

We don't know how many people there are in Australia with CHARGE Syndrome. The worldwide occurrence is 1 in every 10,000 - 15,000 births.

For more information visit <https://www.chargesyndrome.org.au>

Disability Royal Commission

Emergency planning and responses

Australia is currently in the midst of an unprecedented emergency with the COVID-19 pandemic, following the summer bushfire crisis. People with disability can be severely affected by emergencies and may be at a higher risk of experiencing violence, abuse, neglect and exploitation at these times.

The Disability Royal Commission invites the community to give its views on emergency planning and response.

An issues paper asks questions to help people and organisations to provide responses.

The Royal Commission encourages responses from individuals and organisations to the issues paper by 17 July 2020.

Responses can be in any language. The Royal Commission will translate them to English.

<https://disability.royalcommission.gov.au/publications/emergency-planning-and-response>

Rights and attitudes

The Royal Commission has released an issues paper on rights and attitudes. The Commission wants to learn more about how people understand the rights of people with disability.

It also wants to know how lack of awareness of those rights might contribute to people with disability experiencing violence, abuse, neglect and exploitation. It's interested in how these rights are respected, promoted and kept safe in laws, policies and practices.

The issues paper also seeks feedback about community attitudes towards people with disability. The Commission wants to hear about how attitudes towards people with disability develop and spread and what can be done to improve them.

The paper includes questions to help you provide responses by 31 July. The issues paper along with an easy read version and an Auslan summary are available. There is information about how to respond included in the paper, and on the Royal Commission website.

Responses can be in any language – they will be translated into English.

<https://disability.royalcommission.gov.au/publications/rights-and-attitudes>



Royal Commission

into Violence, Abuse, Neglect and
Exploitation of People with Disability

Deafness Forum's work in promoting the Disability Royal Commission is enabled by a financial grant from the Department of Social Services.



The Disability Information Helpline is now available for people with disability who need help because of coronavirus (COVID-19).

The Helpline can help families, carers, support workers and services, too.

Contact the Disability Information Helpline on 1800 643 787.

The Helpline is available Monday to Friday 8am to 8pm (AEST) and Saturday and Sunday 9am to 7pm (AEST). It's not available on national public holidays.

Visit www.dss.gov.au/disabilityhelp for more information, including Auslan and Easy Read materials.

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 of disappearing 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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