People living with hearing loss and their care-givers
Report on a survey

www.deafnessforum.org.au

Notes:

20 percent of people who participated in this online survey conducted by Deafness Forum of Australia in July 2021 were aged 20 to 50. 80 percent of people were aged 51 years and over.

70 percent said they were women. 30 percent said they were men.

Question: Have you had hearing loss since you were young?

Response:

55 percent said yes. 45 percent said no.

Question: Has your hearing become poorer as you aged?

Response:

90 percent said yes. 10 percent said no.

Question: Was your hearing damaged by loud noise?

Response:

25 percent said yes. 75 percent said no.

Question: Of all the symptoms that you experience (or your loved one experiences) because of hearing loss, what are the 1-3 symptoms that have the most significant impact on quality of life?

Response:

Communication difficulty
Balance difficulty
Tinnitus

I am Profoundly deaf. Use cochlear implant. Have overwhelming, distressing reverberation of sound when using the implant. I am unable to understand, benefit from visual cues because due to the rapid speech of today's society.

Difficulties in normal conversation. Difficulties in a "crowd" of more than 4 people talking. Feeling isolated when hearing aids are removed as in going to sleep.

Can no longer have a quiet conversation with anyone - e.g. children, friend in a cafe, friend in any gathering at all. Shopping is difficult - at the checkout, asking for help.

Inclusion

1. Missing bits of conversations (even with well functioning hearing aids).
2. Reduced ability to participate in society. A) Workplace - reduces ability to obtain work (if one pre declares) & function in a work environment/maintain employment (even without discrimination) socially. b) significant impact of this on relationships, opportunity for relationships, community interaction & reduced ability to participate in some leisure activities eg music, movies.
3. Independence & personal safety: reduced ability even while wearing aids, to pick up safety cues, hear vital announcements etc.

Symptoms - tinnitus, anxiety, depression. Impacts - missing or misunderstanding what people have said at social events and at work; no ambition because it's too hard to take on a role that requires full hearing; missing music and bird sounds.

Tinnitus

Tinnitus/ Physical discomfort/sound sensitivity

1. being able to hear easily, especially when there is background noise and/or poor acoustics in the room
2. not being able to enjoy films/tv/live entertainment as much as I used to
3. missing out on humour/jokes

Being unable to understand in conversation, it is difficult to rely on lip reading in person (line of site). I am unable to use a telephone so I can no longer work or stay in touch with people. This is particularly bad as my mother still lives overseas.

Both spouse and I struggle in the usual culprits, noisy restaurants, long distance from speaker and so on.

1. Anxiety over missing hearing something important
2. Difficulty in speaking with a call centre especially those offshore
3. Failure of others to understand how exhausting hearing impediment can be.

Not being able to purchase analogue hearing aids anymore, which give me greater clarity (yes I've tried countless digitals). Audiologists not letting me have input on hearing aid adjustments and thinking they know everything (despite them never wearing hearing aids). Social isolation and embarrassment due to communication difficulties.

Understanding conversation
Concentration tiredness - switched on all the time
Lack of great quality captions on ALL media from social media videos to free to air tv

Hearing background noise, location, discriminating what said. Often not hearing grandchildren with repeats. Hearing loss from age 35 due to acoustic neuroma left, right mild and stable, with age.

Question: How do these symptoms impact specific activities that are important to you?

Response:

Work can be difficult. Social situations are hard to navigate. I get frustrated and anxious.

I am only able to use this technology for short periods of time. Am excluded from social activities/negative impact on relationships due to other's misconceptions related to profound deafness/impact on health care, leading to misdiagnosis, being labelled confused when I haven't understood - unsafe!!

Social isolation mainly. I can't easily - as in before I became so deaf - participate in normal group chatter.

I have very few friends. None that I visit. I don't/can't join clubs. I don't go to movies (can't hear). Or plays or concerts. Can no longer listen to music - on radio or in a concert. Deafness prevents me doing those things. Is this a big whinge? Yes! I can't make phone calls - can't hear the speaker - on mobiles or landlines. Modern landlines are often not good.

Feeling left out and deprived.

Ability to earn an income
Loss of income leading to other reduced opportunities
Limit social interaction and as hearing further declines this situation increases

Really miss dancing and listening to music all the time - while I cook, in the car... No longer listen to the radio and don't follow the news (pick up important info from Expression Aus. Miss info at meetings and feel like an idiot because I never know what's going on. Can't take calls at work, and have to continually explain to the front desk why. Most of all - miss the casual conversation between my family members - can't always ask them to repeat,

The tinnitus competes with noise making it extremely difficult to hear.

Totally impact the quality of my life. My relationship with my ‘self’ my loved ones. I am Short tempered and suffer high anxiety. No-one considers tinnitus as a serious health condition. This makes me despair. I cannot read, rest and relax with screaming ears. It has totally ruined the quality of my life.

Conversations
Watching tv, live entertainment

I am unable to interact with anyone normally. I have to rely on my wife interpreting if the message is at all complex (for instance visit to the doctor). I attend yoga and tai chi sessions and find being unable to interact with other members frustrating - at least one of my instructors has agreed to wear a lapel microphone so i can get at least part of the lesson.

We have to make the adjustments

Day to day living and sometimes hesitancy to seek advice on matters I perceive as being unimportant to others.

A lot. I am extremely isolated. I stay home and just don't even bother with anything anymore. With my old analogues I could hear and understand really well, with digitals I can't even understand my children properly.

Running a small business, impossible to use the phone, stuffing up bookings/appointments
Relaxing with friends is certainly not relaxing!
Availability and choice is limited

Avoid larger noisy gatherings eg restaurants. Means not engaging activities in noisier situations where could meet new people or learn new skills - retired so avoid. Missing conversation and what happening friends lives. No live theatre as I can't follow dialogue. Day to day communication at home if even small amount noise. monitoring own voice level so often yelled at at home by husband for talking too soft or loud. Driving and not hearing passengers. Not hearing all what my grandchildren say.

Limit ability to participate in leisure and community activity, due to not 'hearing' everything (or missing some).
Health impact - increased stress, social isolation, increased risk of dementia

Question: What are you doing (or what is your loved one doing) to help address hearing loss, and how well is this working?

Response:

I'm doing everything I can! Mini mic, request captioning, fighting with the NDIS!

I have spent many years as an advocate for myself and the hearing impaired community.
I self-advocate, tell others my communication needs and the strategies that will help me
I use a cochlear implant, but it has limitations

Try to gain one on one, or one on two, in groups to enable some sort of conversation. But - it becomes very difficult as people do tend to want to 'move on' in large groups.

I have very good hearing aids as hearing aids go - but they were expensive - $10,000 plus! EVERY FEW YEARS...

Top of the range hearing aids with Bluetooth. Lip reading. Captions. Let people know I am profoundly deaf.

* Worn hearing aids for 19 years
* Currently seeing a Speech pathologists for some behaviour learnings to help me moving forward with ongoing/further decline
* Seeking more technology to provide better communications opportunities even with further hearing decline
* participation with a hearing advocacy organisation.

Learning Auslan, slowly building friendships in the Deaf community, trying to get husband and kids to learn Auslan too. They are not against it, but life moves quickly, hard even to have a short Auslan conversation with my husband every day. On my 2nd pair of hearing aids - bluetooth has helped a lot, but they are worse than useless in seminars or restaurants or parties etc.

I have hearing aids.

I have hearing aids but they are too expensive and the system clumsy. Audiologists not available on weekends, batteries run down quickly and I doubt whether hearing aids are eco friendly and safe for the environment. Where do all the little batteries go? System isn't working at all. People can't afford hearing aids and audiologist visits so easier to go without and suffer. Unacceptable.

I have hearing aids, an FM system, and a bluetooth device which I wear nearly all the time. They are very good, however they are not perfect, especially when the background noise and acoustics change from setting to setting.

I have a cochlear implant and make extensive efforts with rehabilitation programs both via the computer and weekly speech pathology sessions.

We have adjusted our lives to avoid difficult situations. Both wear hearing aids.

I use quite effective devices and I never try to hide my hearing loss.

Years of advocacy and trying to find a decent audiologist. Given up now.

I've had hearing devices since I was 8, I should know what works.
Only watch pay tv/streaming.
Hoping to find a receptionist to meet and greet at work.

Husband has a degree of loss too- he does nil, denies, verbally aggressive to me if can't hear me.
Me- not as much as should, my fault. Irregular hearing aid use- limited help in noise, where need most as cannot get benefit of processing that uses binaural processing capabilities in modern hearing aids. My Roger micfm was great but broke and still not working despite being sent twice for repair. Tell people about loss as needed- eg, friends, shop assistants, phone, etc, and ask for repeats if can't hear. Use bicros aid in car if driving friends. Position self to favour good ear. Should get new hearing aids and replace faulty Roger pen mic as know technology in biCROS aid processing has improved- but I am too stingy to spend money on them as self funded retiree and prioritising other things. My own fault/choice. Organise social outings, catch-ups with friends that are with just one or two at a time and involve venues or activities where not a lot of noise- eg, quiet cafes, often with outdoor seating, walks, bush walks, drives with hearing aid on. Had withdrawn a lot but became quite lonely, depressed because of it, and missing stimulation of good conversation and activities with others- so decided to start reconnecting with friends and being the instigator of activities in places that not challenging to hearing. Now very happy and socially active. Also have started reaching out, visiting, doing things with, for other friends, acquaintances that lonely (eg, through death of spouse, physical limits, hearing loss)-rewarding, stimulating, and helps both of us).
Husband's denial of hearing loss (his) and impatience, etc, no longer such an issue as I have now filled my life with others that can interact and converse with.
I am lucky enough to have good health, mobility and freedom to do this. And of course the financial means.

Question: What are the downsides to the way you are addressing it?

Response:

Frustration, anger, feeling of helplessness.

Nothing changes in the hearing community. There continues to be lack of accommodation eg audio loop technology / rapid unclear speech which people either cannot or won't change.

It's hard work! After some group meetings or social occasions with lots of people I go home feeling thoroughly exhausted!

I miss people. I write emails rather than phone. I miss films, concerts. I don't go to art galleries - I talk too loudly :-)

Blue tooth goes off. Batteries go flat. Not everyone is helpful.

Lack of money for better quality hearing aids & technology
Need to also find $ for general exercise support- this will both assist dealing with my broad wellbeing- which includes increasing fatigue due to 'listening/hearing' efforts

Family not really taking up the Auslan challenge - they are happy to, but kids aren't at home anymore and it's hard to make it happen. Technology (aids) not all it's cracked up to be.

Hearing aids are extremely expensive and don't necessarily correct the loss without over-correcting the bit of hearing I do have left.

Cost. Lack of understanding about Tinnitus and support strategies from even the most professional audiologists and doctors. Hugely disappointing.

Juggling between devices; devices aren't a straight swap for having good hearing,

It is a lot of effort on my part and the lack of progress is frustrating I feel this would be better spent elsewhere in my life.

Sometimes the individual cannot solve the problem,

I sometimes receive an inappropriate response when I indicate I am having difficulty hearing and frequently that others often revert to unaware behaviour after a short interval then I get exhausted reminding them of my difficulty.

Stress, anxiety, depression due to isolation and nobody understanding.

Smart arses who think they know better - ill-informed and bias towards inspirational quick fixes.
Not wearing hearing aids- am aware of the impacts of this in terms of auditory stimulation, etc. Not joining with one group of friends who only ever seem to meet in noisy restaurants -but nothing to stop me organising 1:1 with any of them. Bad example to 6 year old grandson who has hearing aids - he totally accepts them so far and is an excellent aid user despite my bad example. Also I am a bad example to others who may need hearing aids, most of whom would benefit- but so far have persuaded a few to get them by explaining benefits and why I don’t get as much benefit (no hearing one ear and mild other), and admitting that I am doing wrong thing by not wearing, and telling them they can get free trial.