

Unilateral -v- Bilateral Meniere's

Survey Results

Survey in Black - January 2023 – (153 Participants)

Survey in Red: Some data from November 2019 (144 participants)

Numbers represent participants

Question 1: Gender?

Female:	113	110
Male :	40	34

Question 2: Age Range

to 30	1	Under 30 -	4
31-40	13	31 to 50	40
41-50	28		
51-60	32	51 to 70	84
61- 70	45		
70+	34	71 +	16

Question 3: Diagnosis

Ménière's disease	150
Vestibular Migraine	34
Other	12

Question 4: When were you diagnosed with Meniere's?

less than 1 year ago	13
2 years ago	18
3-5 years ago	33
6-10 years ago	27
11 years ago	60

Question 5: When were you diagnosed with Vestibular migraine?

Less than one year ago	4
1 to 5 years ago	28
6 to 10 years ago	5
11 years ago plus	5
Not Applicable	104

Question 6: Are you unilateral or bilateral?

Unilateral	95	98
Bilateral	53	48

Question 7: If bilateral, when were you diagnosed?

at the same time as my initial diagnosis?16

< than a year later	5
1-2 two years later	7
3-5 years later	6
6-10 years later	7
11 years +	13
Not applicable	91

After Meniers diagnosis	
0- 5 years later	18
6-10. Years later	7
11+	15

Question 8: (see below)

Question 9: Do you wear hearing aids?

Yes	75
No	76

Question 10: Do you wear a hearing aid

In one ear:	45
In two ears?	33

Question 11: Do you have a cochlear implant?

Yes. 17
No: 129

Question 12: Do you have one or two implants:

One implant	18	9
Two implants:	2	2

Were you at the time of the implant:

Unilateral	4
Bilateral	6

Question 8: If bilateral, how are you managing?

(56 Answered)

- Also have vestibular migraine so with that in mind am okay however definitely effecting my life. Have gone back to work full time however thinking not a good thing to have done. Light headed most of the time.
- I have hearing aids.
- Medication is holding back the big vertigo attacks. Lost hearing in left ear, 50% left in right ear, hearing aids are effective. Balance was very poor, but vestibular exercises have allowed a reasonably normal life.
- MD took out my right ear in 2017. My left ear now has severe hearing loss as of 2023
- Meds, dex injections, dietary, struggling
- t's tough enough with just one, feel for those with Bi
- N/A
- n/a

- One day at a time. Warn everyone that my arrangements at a moments notice. Make sure I take notice of my own signals - well mostly. Refuse opinion of others that it is all in my head- (read imagination)
- I have a cross system hearing aids First ear is in burn out so I have less attacks but difficulty with balance. I go to Pilates every week for balance and to build up core strength
- Hearing Aids
- Adapting and trying to overcome the anxiety that comes with this awful disease
- I was diagnosed as bilateral but they must have got that wrong because only my left is deaf. I have had this disease for 25+ years. Hideous but I do go into remission and do have an amazingly beautiful life
- Hearing aid in left ear, cochlear implant in the right ear. Daily vestibular rehabilitation therapy exercises. Struggle with a lot of day to day things. Unable to drive
- I'm also completely deaf in my Left ear and tinnitus rages everyday all day. My right ear has only about 80% hearing with a hearing aid with 80% clarity, some tinnitus but it's overshadowed by my left ear. I have fullness all the time in my head. Without my hearing aid BlueToothed to my phone I can't take phone calls. I now don't wear my left hearing aid as the damage to my left ear internally doesn't give me the clarity to hear what's being said when I us both hearing aids, the distortion from my left hearing aid is overriding what clarity I have in my right eat. Chris M
- Ok but very concerned about losing my remaining hearing
- Vertigo and vomiting ceased a few years ago, only fluctuating hearing, tinnitus and fullness now
- I've lost my hearing, wearing hearing aids, tinnitus is extremely loud. Trying to manage a normal working life but some days are extremely hard
- Fine now. It ended up being problems with my jaw even though all doctors have disagreed. Have no symptoms whatsoever now
- I have cochlear hydrops. In general I manage ok but have periods when I flare. The anxiety can be quite stressful at times but manage with a low dose of anti depressant
- It's really hard, my balance is deteriorating, I try to walk a lot, and do balance exercises
- I was managing somewhat ok until I had my second bout of Covid. 12 months later I am struggling with the combination of menieres and long Covid. Absolutely struggling!
- I had endolymphatic sac decompression on the left side in 1995 and dexamethasone injection in the right side in 2008. Both were successful except hearing loss after the steroid injection. I watch my salt intake and with a lot of exercise I can mange my life very well.
- Learning what I can do and can't also avoiding salt and holding on to things when off ballence
- Serc once a day as they make my dizziness feel worse
- Early-lots of room spins etc +2 yrs, no room spins but all other symptoms remain. +30 yrs thick heads loss of balance never completely free poor night sleep stiff neck lack energy etc
- Badly I take betahistamine twice a day, stemetil once a day, very low sodium diet, no chocolate or sweets
- With reduced salt, sugar, caffeine and alcohol intake it is mainly in control at the moment
- Been bilateral for 30 years. Have severe chronic vestibular disorder

- Not well.
- Very difficult, it's another level being bilateral. A lot of grief and fear involved. Hearing aids, continuing diet no salt or processed food, no alcohol. Endolymphatic sac decompression in the worst ear. Alternate therapy, reiki, reflexology, yoga, chiropractic. I'm a stay at home parent so have plenty of time to rest which is important for me as I'm always so tired.
- Ok. No dizziness but need hearing aids
- Hearing loss in what was my "good ear" has been very challenging. I have been bilateral for just over 2 years and I'm still coming to terms of life with hearing loss in both ears. The loss in my most recently diagnosed ear is not as bad as the other ear. However, I do worry that the remaining hearing in this ear will deteriorate to the same level over time.
- No vertigo in better ear yet
- Fine now. After hearing aids adjustments.
- Cochlear Implant and Hearing Aid
- Doing well for a few years and dreading when I go downhill again. Taking Serc and water pill and Super B vitamins.
- Managed with Betahistine 24mg twice daily and low salt diet. Hearing is my main issue, only had approx 6 vertigo attacks.
- I am now severe to profoundly deaf, I communicate using Auslan (Australian Sign Language) at first I feel into deep depression but I'm doing better now I'm a part of the deaf community
- ok
- Mostly ok, but it can be very frustrating and I'm worried about losing all my hearing.
- Hearing aid in left ear and Cochlear Implant in right ear
- No well
- I am not managing. Was diagnosed by gp just before the pandemic and have been waiting to see ENT for 3 years now
- I have a cochlear to help with hearing. I will be getting second one this year. I have had gentamicin treatment on both sides and I am undergoing vestibular physio. I have balance problems but it is working out for me. The vertigo stopped me from living as I wanted to so I decided to risk the treatment to give me some quality of life and thankfully it is working.
- Hearing and noise very distressing other than hearing aid not much
- Hearing aid in the better ear. Bicos for the bad ear. Hearing aid has not worked for it. I also use Auslan.
- I am coping ok sticking to a strict low salt diet. My vertigo attacks have settled down and I have not had an attack since Nov last year. Previous to August 2022 I had not suffered from any menieres vertigo attacks for 5 years and was just left with tinnitus in my left ear, fullness etc.. Suddenly last year in August I started having attacks again. The attacks have now settled down and I have tinnitus in my right ear which is different to and way worse than my left. Specialist is hovering between bilateral menieres and/or vestibular migraines..... so ??????????
- Serc x2 three times a day, moduretic x1 daily, stemital x 1 daily, valium and ondastetron when needed. Low salt diet. Profoundly deaf on right ear now with CI, left hearing diminishing and will need hearing aid within a year. Balance and tinnitus is work in progress

- Just, recently the other ear started playing the game.
- I have answered as having meiosis in one ear, ie Unilateral. But am unsure if this is the question or does it relate to migrant headaches??
- I don't know if I'm Uni or bilateral. First I have heard of that.
- Low salt diet, no noise surrounding. No caffeine and SERC tablets
- Balancing is my main concern, but I have learnt to know my limitations with knowing not what to do.
- N/A
- I've given up all drugs, they do nothing. Serc is a placebo. I've tried many treatments, nothing works. I now just deal with the attacks as they come.