

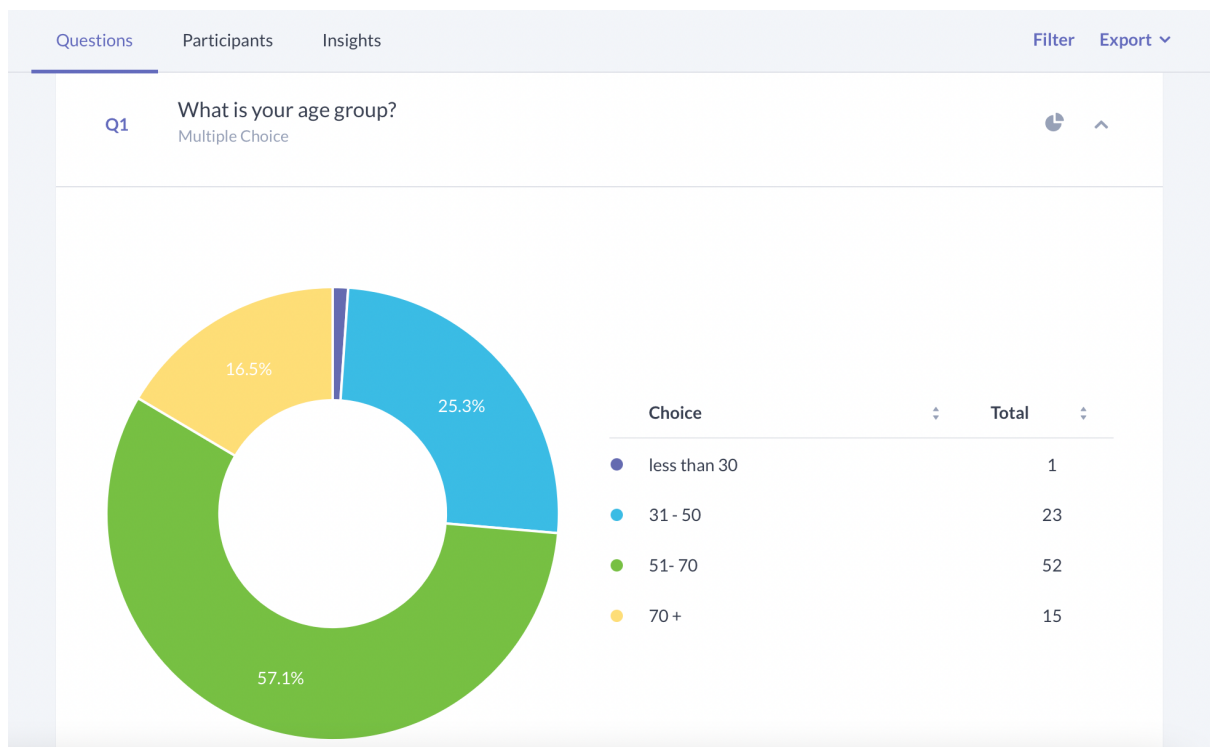
# VERTIGLOBAL

SURVEY results ending 25 June 2022 at 5pm

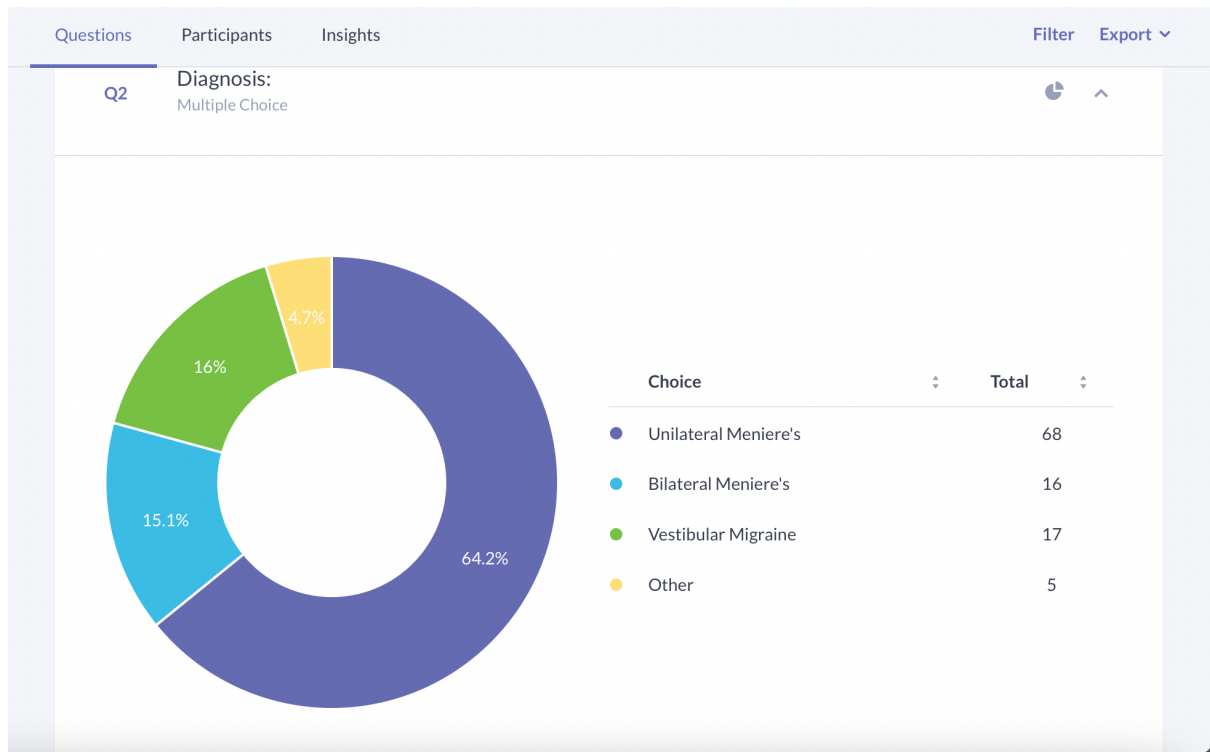
Over a 5 day period

92 Participants

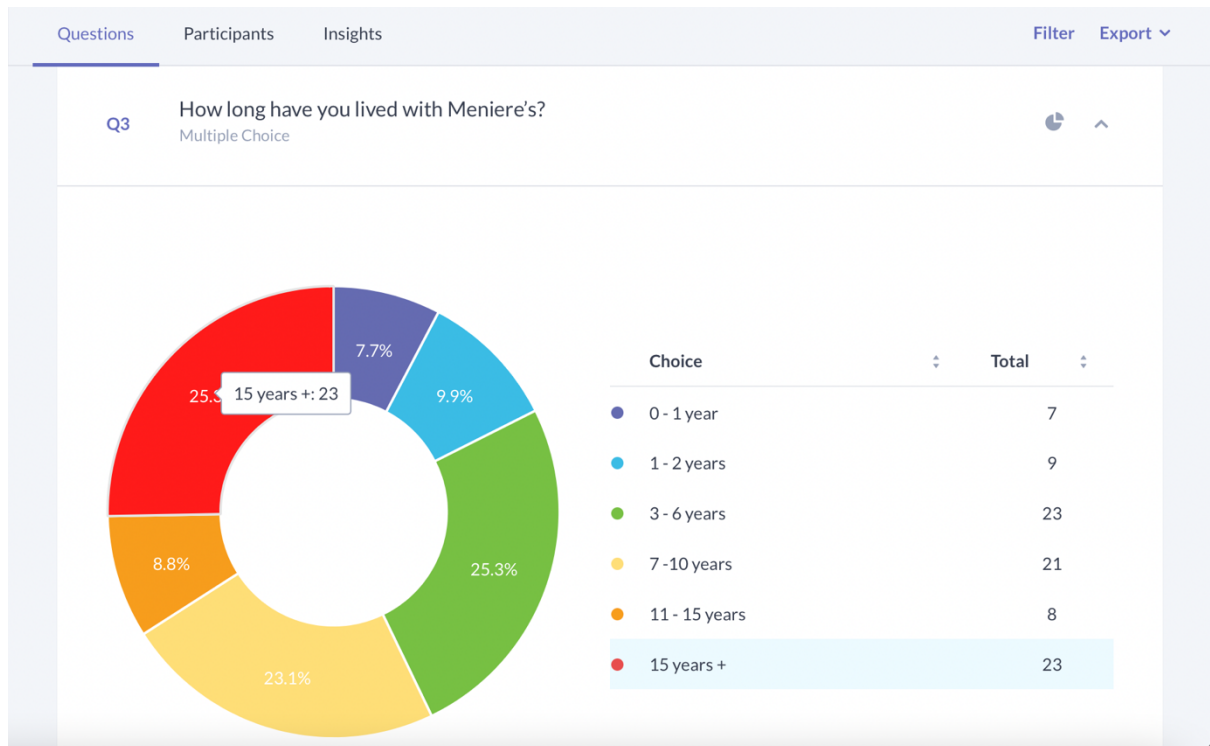
**Question 1:** 91 Answered 1 unanswered



**Question 2:** Answered 90 Unanswered 2



**Question 3:** Answered 91 Unanswered 1

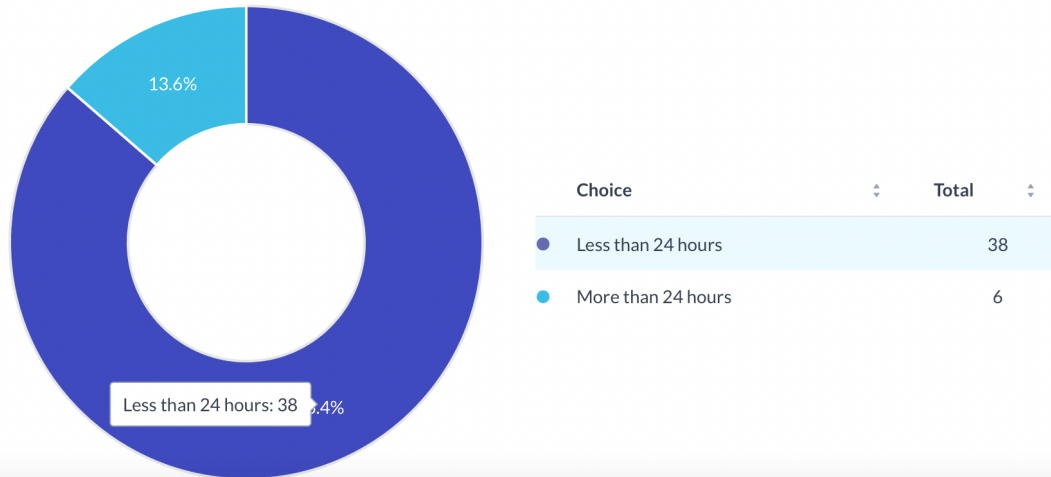


**Question 4:** Answered 44 Unanswered 48

Q4

Have you needed to go to an emergency hospital during a Meniere's episode? If yes, how long were you in emergency? If not applicable, go to question 7

Multiple Choice



**Question 5:** Answered 42 Unanswered 50

### What was your experience in emergency regarding treatment, diagnosis, recommendations and follow up?

Not correctly diagnosed with Meniere's. Treated as BPPV instead

Terrible, One occasion has I had taken too much Betahistine which causes too much acid and chest pain was thought to have heart attack and made to see cardiologist. Another occasion Dr xxx

told me I have a good wife as she came to the hospital with me, when I told her I couldn't drive she did not believe me told me I need to see a psychologist when I refused she threatened to call the police to have me detained, when I did see the psychologist she told me I am handling a very difficult situation exceptionally well and that I needed to see a competent Dr. A Dr caused my MD to greatly worsen when she forced me to do Epley manoeuvres and told me you won't get better if you don't do as I say, at least she made me go deaf so that hearing loss was enough to pass the magic threshold that for diagnosis. Just recently went to ENT xxx who would not prescribe the essential medication, Betahistine because he said it doesn't work, even though it has been working for 10 years and became ill within 2 days of not taking adequate dose. It is ridiculous waiting a year and spending \$600 to see an ENT then only get a reference for a hearing test that you can get anytime for free, then having to wait another 6 months to get another ENT appointment. It is ridiculous having to go to a GP every 3 weeks to get a script especially with the price of fuel and the cost of prescriptions of less than 200 tablets, having to spend \$60 on an appointment, \$80 on fuel and \$70 on 75 tablets, when \$110 can buy 200 tablets

when my first attack happened, my husband called emergency, they came to my house but thought all the symptoms are because of food poison, and gave shot to treat my nausea. And gave me report recommending to follow up with gp.

They totally missed diagnosed me when I first went in. Even on my subsequent visits they seemed to have little understanding. For example, I'm extremely light sensitive when having a severe attack and yet they insisted on having the lights on. That meant I was intense pain and continually throwing up. They have little or no understanding or knowledge of the disease.

O/N ECG and BP monitoring

Terrible. I rather avoid hospitals as there's no much difference regarding treatments. Plus had bad allergic reaction started shaking struggling to breathe itching all over from the meds ED doctor gave me intravenously which was meant to help with Meniere's attack . There's minimal understanding of the disease within the health services as bright lights, noisy environment with lots of movements expedites the condition and further increases the discomfort and stress. There's very little follow up management as were told nothing more can be done or offer than what's already doing. Was told to tough up, ride it out and hope for the best during each episodes. You pretty much feel like that someone handed you a life sentence of this dispicable vile tormenting disease for the remainder of your time. Your willpower and determination gets put to the test each time that you sometimes wonder whether it's even worth living as bit by bit a piece of you is stripped away. You begin to lose your identity and become this figure of being where you doubt hesitate avoid isolate from so so many people and things in life that brought happiness fulfillment satisfaction confidence independence pride achievements. You end up feeling burdened useless misundetstood trapped exhausted where you begin to think about giving up but don't want to hurt the ones you'd leave behind. The hospital gives same medicine just intravenously to whats being prescribed for home. At least being hone the environment is more controlled darkness silence minimal disturbance..Long term use of meds becomes ineffective plus develops additional health issues such as early onset dementia and kidney disease. rWhen it only reduce the level of nausea piss more sleep more develop sensitivity or adverse reactions to other meds but doesn't address the source of the problem bur give you additional to deal with. As if it's not punishment enough of what us Meniere's sufferers endure we ger hit up with more. You dont die fron Meniere's Disease but it can kill you by your own hands as it's mentally physically and emotionally challenging. Hence " Life Sentence"

Stemitil injection. Once symptoms subside. Sent home.

I didn't go to emergency during my first acute attack about 15 years ago. I was on a rural property and my husband was working in the city so I just stayed in bed until I

could walk again. I went to my GP about 3 days later once I could walk again and was told it was likely viral vertigo (it happened regularly after that).

By the time I got seen to it had mostly worn off. I was given Ondansetron to help with the vomiting if needed and told to go and see my ENT.

I received steroid injection and stayed the night then was told come back next week to receive a dexamethasone injection into the ear, which I did.

I was checked by a Dr....blood pressure, signs of a stroke etc. The wait was very long after I was moved to the hallway so my son, who had meet me at the hospital, and I left. I had an app with my GP as a follow up.

I able to converse with hospital or ambulance staff and tell them what treatment I need. Eg medication/drip. There is never any dispute about my condition nor do I have follow ups.

Treatment was IV anti nausea. Had to request fluids after vomiting/diarrhoea for 8 hours. Was moved constantly within ED even though every movement resulted in vomiting. Was sent home at midnight (once I could almost walk in a straight line) to an empty house with a "you just need to sleep it off". No follow up. Followed up with GP & ENT myself. Now manage episodes myself.

Stemetil drip or injection and irregular monitoring until well enough for discharge

I'm new to this. Diagnosis was probable had a few repeat episodes since then. Lost hearing after developing tinnitus in one ear

Lack of knowledge of the condition. Had to tell the medical staff what to do. They had to google the condition.

Just told to follow up with my specialist

Was given Stemetil and wait time was so long I felt well enough to leave. Said to follow up with my GP/ENT. I already had a preliminary diagnosis... was just waiting for an MRI.

It took a long time for the doctors to verify it was vertigo. I got an injection of stemetil and a tablet of ondasetron. Which it doesn't seem to work stop the spinning. I had to wait in a room 3 hours without a comfortable bed or chair.

I didn't get treatment. I was told that although the Dr/nurses understood that I was unable to function at all without treatment, there were other people in need of help. I couldn't walk unaided, was constantly vomiting, had severe vertigo and couldn't keep anything down. It was suggested that I go to a private out of hours medical practice. Which I did. I wouldn't bother going to emergency again after this.

My emergency visits were prior to official diagnosis, so they didn't necessarily treat correctly at the time due to the unknown

Gave me fluids, ondansetron and sent me home. Not interested in Ménière's at all. No recommendations except to rest and keep fluids up. No follow up

Was sent through to doctor's surgery. Doctor great.

The registrar hadn't had any experience with inner ear steroid injections for Ménière's so was unable to do. They weren't really sure what else to do to help me settle during a heavy Ménière's attack, so gave me Valium and prescribed more Valium to take on the way home. Sent home after four hours in emergency.

Visit 1 - put on a drip overnight and discharged the next morning. No follow up by hospital but saw regular ENT. Visit 2 - put on a drip then moved to a ward the next day. Stayed for 2 nights and had assessment by a hospital neurologist and follow up outpatient visit to the same neurologist a few weeks later.

Nothing they can do.. simply prescribe medication.. prednisolone or betahistine.. they recommend seeing an ENT or having an audiology test.

They had little to no idea about the disease and didn't treat me with anything other than a sodium drip which isn't helpful due to the high levels in it. Ambulance staff gave me more meds than hospital and understanding of what was needed.

Full neuro assessment, CT, bloods, urine analysis. Treated by paramedics with ondansetron. In ED with stemetil and regular obs. Saw Physio and OT pre discharge to assess balance. Directed to follow up privately with neurologist and ENT at my expense

An emergency nurse (RPA) who lived with Meniere's told me this is what I have, they'll do this this and this then send you home to your GP who will probably know nothing and send you to a specialist. It will be 3 months until you get back to work and come to terms with it. No one else will know what to do. He was SPOT ON!

Specialist now retired told me it's something I need to live with. And doctor was unbelievably nasty. Finally found Dr Carlo Rinaudo (Chiro) who helped immensely and Joey Remeny (Rock Steady) plus Pilates and Anne Ellias (Meniere's Support groups coordinator). Average GP knows nothing or very little. Thank god for that nurse.

I was put on a drip and received a Stemetil injection. One doctor was fantastic and suggested strategies to help me manage. Most doctors said nothing. My GP is wonderful.

I found that the doctors had little knowledge of Meniere's disease, and often had to go and research it, then came back to me. Because I only went when my dehydration from excessive vomiting during vertigo, I always had a drip for rehydration. In my opinion, I think the doctors and nurses should ask more questions about what the patient knows about their disease, instead of being told it is all in my head, or do I hear musical tunes in my ear - when referring to tinnitus. There were no recommendations, and no follow up.

I was sent home by the GP as he said he couldn't find anything wrong with me and he made me feel that I had been lying to him about my symptoms.

Some staff had never heard of it. Those that had were very understanding.

Thought I was having a stroke

Ruled out a stroke but then a misdiagnosis of benign positional vertigo rather than Meniere's Disease

Initial investigation ruled out stroke; after several hours, diagnoses of severe Meniere's attack on left-hand side with viral labyrinthitis on the right-hand side were made. I was given several anti-emetic injections and prescribed three stemetil tablets per day. I was told the viral labyrinthitis would probably take 7-10 days to go away. The first three days were AWFUL. In almost 20 years with Meniere's this has been the only time I've needed to attend an emergency department and it was scary.

I went at the time of my first vertigo episode 35 years ago. I was diagnosed with labyrinthitis and given a stemetil injection. No follow-up was suggested.

Terrible, no one knew anything about any treatments then I was given a drug called Phenergan which made me unwell and hallucinating and told to go home.

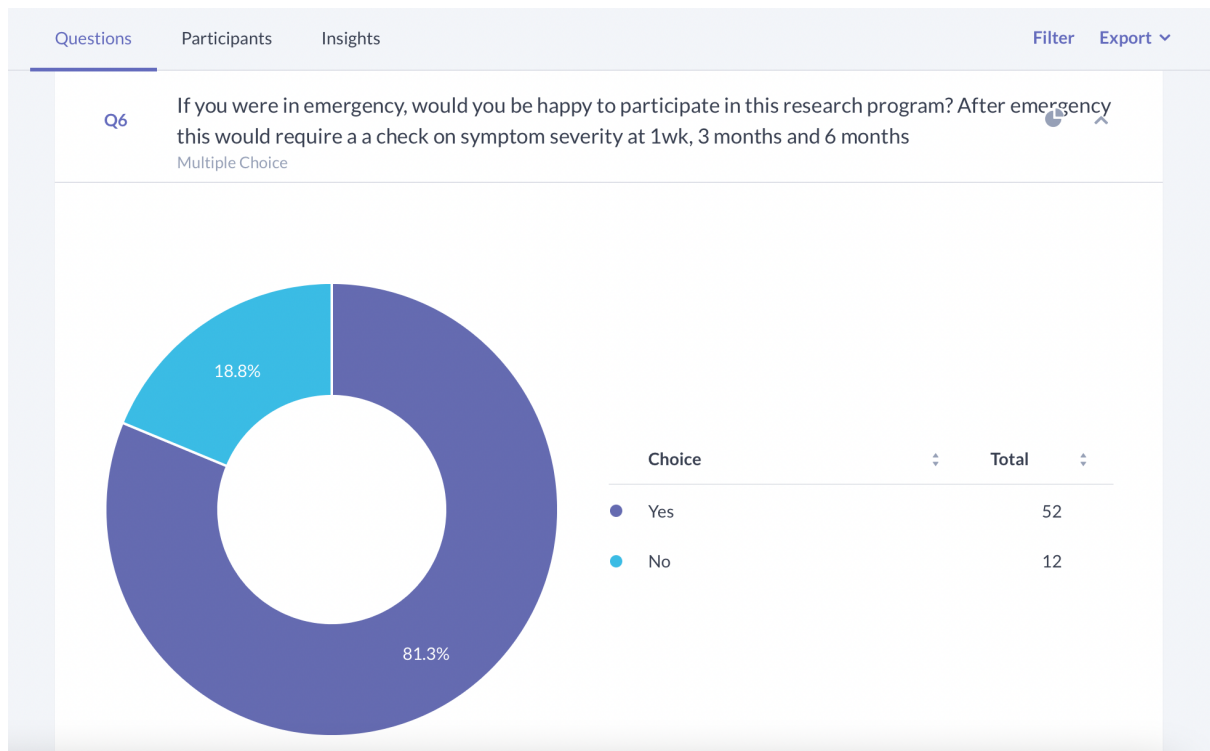
Stemetil injection

Diagnosed but no on going treatment or follow up

Very good, San Hospital at Wahroonga diagnosed it & sent me to an ENT Specialist

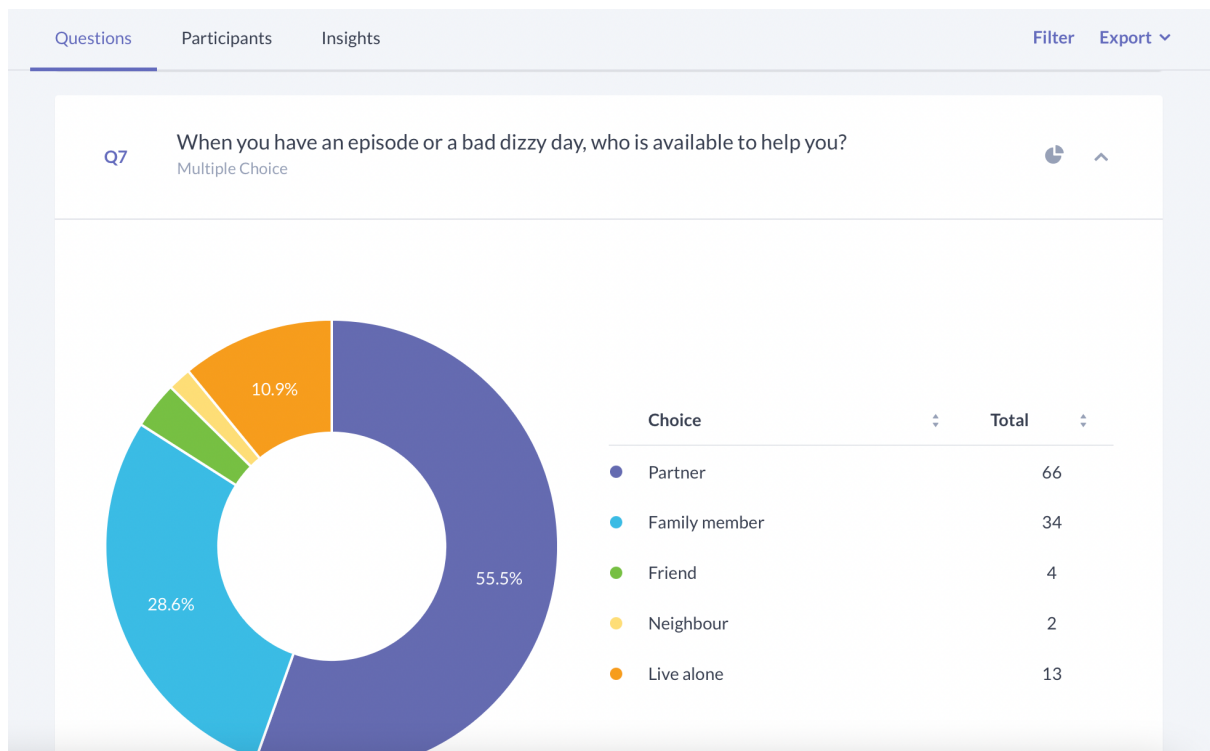
Some experience were just sleep it off and go home after a Stemetil injection . One experience where they ordered many tests stayed longer than 24 hours. Follow up at hospital for results to tests, then report back to local GP. Now I go home instead of emergency department.

Question 6: Answered 64 Unanswered 28



Question 7: Answered 91 Unanswered 1





**Question 8:** Answered 86 Unanswered 6

**Are you currently having regular episodes and if so, how often?**

Not often - difficult to provide a frequency

smaller ones about every 2 weeks, larger ones about every 3 months

not often, have been attack free for 6 months, but still has other Ménière's symptoms.

No. I'm lucky to be having a stable period.

OK for the past 2-3 months after 7 or 8 episodes every few days, each lasting 2 - 4 hours. These attacks started soon after my booster Covid shot (Pfizer). I had also experienced some mild dizziness after my initial Covid shot (Astrazenica). My previous (initial) series of attacks had happened 6 years previously.

Every few months

Yes daily weekly seasonal winter spring the worst Weather pressure changes too

They come in clusters, the last was April

Not at the moment. Touch wood.

Every day

NO I have PPPD 24/7 unless I am sleeping. I do not know if it is related ? PLEASE START RESEARCH STUDIES ON PPPD.

No but am very careful at all times

Not so much Ménières but dizziness and fatigue periodically.

Not at moment

Acute dizzy episodes 1-3 a year Disequilibrium/balance -constant but wanes good/bad Vestibular migraine (with aura) - 2 episodes 2022 Vestibular migraine without aura - weekly, sometimes daily

I have learnt to recognise when I am close to an attack and I increase my Serc and water intake and massage my shoulders and neck. I get dizzy every few days as I have a head cold, but it's been 3 years since I've had vertigo.

Daily it's there while awake

I do not have anymore episodes at present. I had endolymphatic sac decompression in 1995 and dexamethasone injection in the other ear in 2008. I haven't had any attacks since then but I live salt free and avoid things which would affect my Balance.

No

I have had Menieres since I was 47. I am now 62. Until recently my infrequent attacks ( 6 monthly ) represented as fullness, hearing loss and some tinnitus. I am now concluding a 4 week episode which has been quite challenging. I experienced a couple of sudden drops which were frightening. Additionally I had a number of " smaller spins " when turning my head or scanning print or my iPhone too quickly. I know diet is known to be a factor and I have taken some convincing but am now laser focus on a low salt and sugar diet and minimise processed food consumption.

Every 4 - 6 months

Every day

No

I feel like I may be in the burn out stage....I'm hoping so!

No. When really run down, bad head cold or stray from a clowns non processed low salt diet.

I keep a record of my bad attacks. With the medication I have been prescribed, I can mostly manage it myself. I have days where I feel 'off' but not so dizzy that I must lay down. I've had one bad attack this year that required an ambulance.

Irregular now due to medication and effective rescue meds.

No , used be very regular and violent but not so in recent months , only mild vertigo and nausea

Most days over the colder months.

Still early days. Just got quite bad with onset of the flu

Not often now

Three to four times per week., vertigo Twice month... nausea Constant... balance issues, tinnitus, brain fog, fatigue

Yes constantly dizzy but full episode every 6 weeks or so.

No

Currently in Burnout with Meniere's Disease Vestibular Migraines vary, sometimes a couple of times in a week and sometimes weeks apart, partly controlled by diet plus daily amitryptiline and vitamins and minerals

No

Almost every day

No, currently in remission

I currently have small bursts of vertigo. Last a few seconds. Probably 2-3 times a week. Symptoms can vary from month to month.

I have suffered with severe vertigo and have called an ambulance twice when I've been on my own. During Covid, I could not get an ambulance and I had no way to get to hospital. I have suffered with weekly attacks but the last 2 months have been relatively clear.

Once or twice a year.

No, currently under control with no major attacks for some years.

I am in the last stage, so rarely experience attacks often any more. Perhaps just a couple of times a year as I manage with low sodium diet and serc medication

Semi-regular, once a month

No, it has settled a bit. Usually one every three months or so

Yes. Almost constant at present. Very debilitating. Have had to quit my job. Can't drive.

Not regular. Triggered with stress, diet and TMJ

Weekly

No currently in remission

Daily mild symptoms, feelings of being off balance.

I had an endolymphatic sac decompression in Dec 2019 (left ear) which has helped. I do not get severe vertigo anymore but mild mini episodes.

No

At least once per month since November 2020

Not if late thank god. Been a few months

Unsteady most of the days, brain fog, dizzy but able to function

Yes- after seven years of no episodes I have had 11 in the past four months

Yes. Usually once or twice a month.

On Serc three times a day currently so have mild dizziness almost daily but not the severe vertigo attacks

No, right now I am good. And please god I stay that way.

Fortnightly generally March through to August.

No

No, not often. I manage my condition very well . An episode can occur unexpectedly.

No. I had gentamicin injected into my middle left ear to stop the vertigo in 2004. However, I am experiencing some slow spinning occasionally, tinnitus and hearing loss in my good ear. I'm wondering if I going bilateral.

I seem to have episodes now only every few months.

No

Rare vertigo episodes but chronic imbalance every day

No - after three gentamicin injections, I no longer have severe vertigo spells.

no

Around once a month.

Had had my last episode of severe vertigo 4 months ago. I have intermittent days when I feel dizzy and nauseous and stumble to my left side at times when I get up and walk

Several slight spins every day

Not presently. Just minor ones from time to time

I suffer vertigo on a daily basis, some days severe, some days not so much

Not evenly spaced but have had three episodes of extreme vertigo this year, and "buzzing" ear and muffled hearing at least half the time

no.

Approximately two days per week are affected by bad vertigo and I have a lot of falls as well as walking into walls. Sigh.

No

Every 3-6 months

No

No. Under control.

No

Not know . Had Gentamicin ablation

Had regular episodes at work and colleagues would drive me home. Since retiring only had 2 episodes in past 6 months, live alone and am happy to take medication and go to bed and sleep it off.

No

Not currently

Once per 2 months

**Question 9. Answered 88 Unanswered 4**

**What are your major fears regarding episodes and living with MD?**

Vertigo attacks

Police harrasement they tell me they dont like the look of me. Social occasions, community expectations.

no warning of attack; no normal eating and social life; reduced living quality

I can fall suddenly, so worry about falling and getting a serious injury. I fear bleeding out from a head injury. I also fear having an extreme attack when I'm outside, as I lose control of my body

I dread the possibility of the disease going to my other ear, which is also hearing compromised. I have been assessed and found eligible for a cochlear implant, but am as yet undecided as I worry about the possibility of that procedure causing more vertigo attacks. When I'm experiencing attacks I worry about having an attack when I'm away from home or driving. These attacks are 100% debilitating!

Having an attack while driving, in social situations, or at work.

That my kids will get it

Losing hope giving up on life if not able to have it controlled managed Being bed ridden more than being able to do things (eg 5 days bed 2 days out) is the start of suicidal thoughts You feel half dead as not able to do much you're fighting with the disease constantly You're left watching life passing by in front of you. Having it rubbed in your face of all things you loved cherished and wish you could do again but knowingly it'll never happen. Its hard to adjust and accept

The unpredictability and the loss of hearing

I hate acute attacks and nausea. worried will come without warning in public. Stops me travelling. Dietary limits very different.

Falling over, can't walk for long, feel unstable on my legs.

Meniere's attacks . No Cure . Losing my hearing.

Going into the spins

Severity and how sudden attacks are. No warning.

Having an episode when I am not at home. It can happen so quickly and people around do not understand what is happening. Fear of the uncontrollable vomiting or worse.

My boss has allowed me to work from home because she saw me struggling to walk down corridors. I work on a university campus with lots of stairs and narrow passages which makes things worse. My fear is that a new supervisor would not know this, and despite seeing ENTs, immunologists, neurophysio, dizziness specialists over the years, I don't have a formal diagnosis because there have been conflicting opinions including searching for early MS symptoms because I have a hand tremor sometimes. Emergency management needs to be supported by proper interest in balance and dizziness after patients leave, otherwise they will end up back in emergency because of the levels of fear involved in losing your balance. The first episodes are utterly terrifying because you have no idea of what is going on. Your world shifts literally and figuratively.

That I have passed it to my children. That I can't work when I have an attack.

Falling

The spinning, lying on the floor for hours not able to get up. Throwing up and having diarrhoea at the same time and are totally dehydrated. Sometimes I wished I rather be dead, but I made it I am better now.

Losing my hearing as I am musician. I have a CI in my right ear and it does not process music well. I rely on my good ear ( normally 80%) but in the middle of an attack I am virtually profoundly deaf. When my good ear is experiencing MD the notes are all out of tune on guitar and piano. Very sad indeed.

Having an acute attack when travelling or away from home.

Not having any type of life. Can't plan anything as I might be dizzy or have vertigo so I'll have to cancel. Not reliable for work. Have trouble driving. Losing my hearing. Not being able to care for my child or go and do anything fun anymore



The anxiety of never knowing when they're going to happen, being unable to commit to a job, because your unreliable and the embarrassment of vomiting, loss of balance in public while trying to find a quiet place to ride out the vertigo attack.

It will return!

The on going battle to function to some normalcy every day. And how bad it can get and if they don't find a cure.

That I will have a bad attack in public, where people would not know my condition or symptoms. I wear a medic alert bracelet. (Other wise people may mistake me for being intoxicated)

First year hardly left the house due to fear of episode. 5 years on and I'm aware of impending episodes and have effective rescue meds that mostly work. Other effects make living normally difficult. Possibly VM causing these effects as well

Falling, spinning, vomiting for hours, diarrhoea, bursting blood vessels in eyes and face , not being able to help myself and having to rely on partner . Also afraid of driving in heavy traffic in case of sudden onset and danger of hurting someone else if accident happens. Avoid shopping centres , large cinemas and anywhere with bright or strobe lighting.

Falling whilst alone.

Total hearing loss Increasing severity of episodes

Not being able to work, having attacks while out. The feeling of helplessness and hopelessness during an attack and after the fear of it happening again.....and again.

Having a serious fall and no help

It's the most evil experience anyone can go through, I fear I'll try to kill myself during an attack just to make it stop. I also fear that the attacks won't stop, and I'm terrified of the next one.

Vertigo out in public away from home, catching public transport, falling and getting injured

That it may hit at any time and when it does it may last forever

That I will become bilateral

Constant fear of being unable to function when having an attack

The effects of vertigo resulting in uncontrollable vomiting and diarrhoea

The Vertigo! The vomiting! Not knowing when it will strike. The unpredictability of it. The fact that there is no clear treatment pathway to cure MD. Being caught out in public if I have a major attack.

Being at work and not being able to get home. I literally have to lie down where I am and I cannot move for up to 7 hours. I cannot even get up to vomit. I just lie there convulsing into a towel.

Vertigo attacks and being stuck somewhere without help.

It is completely debilitating - you can't function at all and are very vulnerable. Vertigo attacks cause nausea and vomiting for hours, you can't keep anything that might help down long enough to help. Anxiety levels are high during periods of regular attacks, with the fear of an attack causing social isolation just to avoid a possible attack. Lack of understanding creates more isolation - this is an invisible disease.

That it will occur while driving, in a public place or alone. It is such an unknown disease that people almost this you're out of it on alcohol or something

That I cannot accomplish life goals that I want to complete. That I will not be able to be an independent adult financially, physically ect

Being able to keep working, returned to driving but occasionally need to pull over and fearful that I will have to stop again. Costs of monthly medication, specialists, physio etc.

Falling, especially in public.

Inability to function, tinnitus volume increasing, further hearing loss/deafness, nausea, dizziness

Having episodes away from home and support person. Biggest fear is completely losing my hearing.

The sudden onset, being unable to get home quickly and safely. Not having someone who can help when attacks are occurring or to assist.

Vertigo while driving or out. An episode while looking after my grandchildren.

Severe vertigo is debilitating and wears me out with recovery to normal functioning taking about 1 week. The unpredictability of when an attack will occur (eg. out and about, away from home) whereas if it occurs at home I can make it to bed and wait for the vertigo to pass.

Ageing and being alone. Access to medical support as I live in a regional town.

Not being able to get on with life..

Being in public and not being able to help my self or get home safely.

Living life

The uncertainty as to when it will happen next

Becoming bilateral and/or totally deaf in one or both ears. And having to deal with these symptoms forever. And losing my drivers license

Having severe vertigo episodes in public places. Not being able to drive. Losing my independence. Losing my hearing. Social isolation

It will happen while out and about and no one will help as they will think I'm drunk. That it comes back and I will end up homeless as rent and my daughter has know moved out and has become an ED nurse.

Injury as a result of sudden drop syndrome. It's ended my career as a pilot.

That the tinnitus will become unbearable

The episodes, they are frightening and very difficult to control. I am thankful I have a very supportive husband.

Vertigo. Being in public and having a violent, debilitating vertigo attack for 4 hours plus, where I can only lie on my left side and stare at something that doesn't move for the entire episode - vomiting so much that I end up vomiting bile and then froth. Having a vertigo attack at work (in front of students), where I can't be moved because it makes the spinning impossibly worse. Having a drop attack and breaking something - hitting my head and damaging where I have a Cochlear Implant.

It's not fear so much as dread of the symptoms of severe nausea, feeling of blocked ear and lack of hearing in one ear, the dizziness that accompanies that and knowing that the only way the earth fullness will subside is with a vertigo attack. The vertigo attacks are the worst - I've had one that lasted 12 hours. I couldn't even move a finger with feeling like dying. Couldn't get up to go to the bathroom or sit up to vomit, so lay in my own filth for 12 hours.

I worry I will have an attack alone in a public place or have a drop attack (haven't experienced any yet).

Losing independence. Needing walking aid all the time. Being unable to drive

It is just a crippling disease which robs you of any life at all. One is in constant fear of an attack or drop attack and that constant anxiety exacerbates the symptoms. Secondary fears include loss of job/income, social interaction, friendships, partner, and profound depression.

uncertainty about my ability to function as when I was younger

That I will develop drop attacks and start to fall without any warning and that my unilateral Meniere's will become bilateral.

Scared how long an episode will last. My last menieres vertigo episode lasted about 4hrs. I was totally incapacitated during those 4hrs. I had brain fog before and after the episode. I could not drive for a week after.

Having an attack when I'm not home and on my own

Having 4 hour episodes of vomiting and not being able to move. Don't go out much due to fear of having an episode.

Having another fall that causes major injury (ended up in hospital only once so far)

Not knowing when or how severe Driving my your self Drop attacks

Having an attack when I am out alone. They come on with very little warning, and then I am not able to walk (have to crawl if I am alone at home) and can experience nausea/vomiting unless I am able to take Valium and sleep for at least 6-12 hours, depending on the attack.

My major fear currently is going bilateral.

In the past few months I've had several bad falls - luckily no broken bones. My major fear is having a very bad fall in the tiled areas of my home (kitchen, bathrooms and laundry) causing fracture/s and possibly losing consciousness when my husband isn't at home.

Currently none.

The room spinning violently, the dizziness unable to reduce the dizziness in any way and the violent vomiting and bowel movement that comes with an attack of Meniere's. Fearful of being somewhere where I need to have access to a bucket for the vomit and be near a bathroom/toilet for the bowel movement.

Drop attacks

Being in public when attack starts. Not being able to get home.

Being left lying on ground in a pool of vomit as people walk by

In case it starts in the other ear

Having to rely on strangers for support when I have an episode outside of home, example gym supermarket. The general public are usually very kind to support me. I do not travel far from home any more, so can leave my car and get a taxi home. Also being without spew bags. I never leave home without 2 in my handbag and Stematil. (Dissolve in mouth, otherwise it is vomited up.)

That I will have a major episode in a public place or when driving - just of the horror of the experience basically.

Inability to care for my children when partner's away, having an accident due to an episode - especially with children in my care, potentially losing my hearing, loss of independence, loss of quality of life

That it may progress and become bilateral.

Inability to work, injuries due to unbalance, loss of hearing

**Question 10. Answered 89. Unanswered 3**

**Where and what was your worst experience during an episode?**

at work

Driving a tractor, the world was spinning, just held on tight to the steering wheel didn't know which way was up thought I was upside down. Not knowing which office to point at the toilet, constant violent dry reach feeling like I am going to turn inside out. Not being able to tolerate light sit, lie down stand up or move, just lying in a bath of water with a candle for light in silence. Being so exhausted from walking a little way resting on seat next to war memorial in Swan Hill woke up surrounded by people commemorating the battle of Long Tan.

home, really bad vertigo and vomit, can not stand up and walk

I have mainly had bad episodes at home, where I can't walk and am lying on the floor throwing up. I can't even use my phone when in this state. Luckily my son found me and took me to hospital. I nearly collapsed when out for a walk with friends once. Luckily they found a place for me to rest for a few hours and looked after me till I recovered enough to get home. I use to be very social, but stay home most of the time now. It gets lonely, but I'm safe at home.

1. In an upstairs restaurant where I had to be supported to a car by 2 strong men and driven home lying prone and finally escorted home where I had support waiting. 2. Needing help to get to a toilet after several hours into an attack.

At home. Vertigo and nausea all night.

In my bed I couldn't move for 8 hours and had to urinate on myself

Going for a walk on a lovely summer's night alone Unexpectedly my legs gave way and dropped. Couldn't get up. Didn't have phone on me. Everything spinning grabbing holding onto the dirt grass. Called out for help. People passed by but

nothing. Felt like hours being alone can't focus can't move feeling scared humiliated losing faith in humanity wanting to die eventually a resident across the road called the police. Police dropped me off at a friend's house who knew what to do when I have an attack.

Stranded in a car park on my own, managed to ring my husband.

At work. Had to go and sit in car for ages waiting for friend to come and drive me home and had to wait so long before lying down I vomited when I got home.

I had a very short blackout episode about three years ago, it was early morning going to the bathroom, I supported myself with the wall it felt like two seconds .

Diminishing hearing in right ear.

At home alone and went into a spin At work and went into a spin

Just drove to shops. Turned off engine and had a Ménière's episode. Partner came and rescued me.

At a shopping centre, alone. Had left my mobile at home (never again). Managed to find a seat & tried to wait it out. Friend happened to pass, understood my situation & got me home.

My first episode at home was the worst - crawling across the floor because the room was spinning. Most humiliating is work. I work at a uni and people passing me in the corridor as I clung into the wall joked about having lunch in the tavern. I think they thought I was drunk. I had two flights of stairs to traverse to go to the toilet and the whole day was a nightmare. My husband had to pick me up and we had to travel the 45 minutes there a few days later to collect my car.

Throwing up in a garden outside a cocktail bar at 5pm on a Friday after 1 cocktail. I couldn't move or open my eyes as the world was spinning so fast, and I had to wait there for an hour for someone to come and get me because taxis wouldn't accept me.

13 May had a full on vertigo attack lasted 15 mins but was very unsteady for hours I bent down to put boots on

Spinning, throwing up, diarrhoea lying on the bathroom floor for hours not able to move.

Vomiting on the bedside table drawer because I didn't want to vomit on the new carpet! Having an attack whilst driving and not being able to get home.

Just recently at home in a Singapore hotel ( after a a 2 day flight ). The room spun all night and I was wiped out for 2 days.

The first episode out of the blue. Luckily I was at home but thought I was having a stroke or ruptured brain aneurysm. Dizzy, vertigo & vomiting every 15 minutes.

I had a drop attack where it felt like I was pushed into the wall and I couldn't get up. Severe vertigo and vomiting all over the floor. Hardly any hearing left and the attack went for hours

Having to disembark from a train and vomiting on a train station for a hour or more waiting to be picked up by my husband.

Every episode is bad. Whenever I felt one was about to happen I knew that I had a few minutes to get somewhere safe. Medication that I am now on keeps these episodes more under control. Before medication an episode meant that i could not walk straight, the world was spinning, my eyes wouldn't stay still, I would vomit really badly for about an hour, go totally deaf in my left ear then I would go to sleep. If I could sleep for about 2 hours I would wake up weak but fine. Everything under control!

Unable to lift my head or any part of my body without Feeling like my eyes rolling back and forth and the non stop nausea and vomiting. Complete feeling of helplessness.

Home alone. Having to use the phone to call 000. A certain amount of information needs to be given - it's hard to convey. I have installed a coded keypad outside for access to the house key for ambulance staff.

First ever episode so had no idea what was happening. Alone in a different town. Severe vertigo, uncontrollable vomiting & diarrhoea until passed out. Couldn't move to get phone so couldn't call for help. Woke up on bathroom floor covered in vomit and faeces without knowing why. Extremely distressing event. I still worry about this happening again and carry my phone around the house with me. I don't go anywhere without rescue meds and vom bags. My friends and family are all



aware of the possibilities. (4 1/2 years ago). Always have Plan B in case - in all situations

Several but most public and mortifying experiences have been A) sudden attack in a restaurant with friends , violent vomiting and vertigo for hours in restaurant bathroom B) an awful episode on a train resulting in ambulance to hospital emergency for several hours , and C) a violent episode on holiday in Tasmania also ending in an ambulance to hospital emergency for overnight stay

Drop attack while walking. Hurt myself and hit my head. Couldn't get up for about 20 minutes.

Feelings of dread and uncontrollable nausea

Being with my preschooler alone and not able to care for him. He actually looked after me! Being thought drunk when I asked for help to get on train to get home from work.

Vomiting non-stop for eight hours, holding my head so I didn't move it. With constant attacks of vertigo. Had diarrhoea following this that lasted 10 days.

I have had attacks at home, outside, in tourist attractions, at sporting venues.. everywhere. The spinning and violent vomiting that just won't stop, the screaming tinnitus, the motion sickness, I can't see, I shit or piss myself. I'm so scared of the next attack that I know is coming at any time.

At home vomiting and unable to move for hours until someone came home

I had a severe episode in 1996 that last for weeks. The intense part was 3-4 weeks and I have lived in a state of unbalance ever since

Sitting outside our caravan reading and having my 1st drop attack. Felt like someone spinning my chair round and round and I ended up face first on the concrete slab. I had black eye, contusions and bruising across my forehead, stitches in my lip, 2 broken teeth and bruises on arms and legs.

After surgery for a cochlear implant. Severe spinning to the point I could not walk unaided. Could not open my eyes as the whole room spun

Lying on bathroom floor, being as still as possible but having to get backside on toilet and head in bucket simultaneously. Or earlier at playgroup with 2 year old toddler having another mother drive me and my child home while I vomit out my passenger car window.

At home with husband and a 6month old baby. Severe vertigo and vomiting and no meds on hand because no one had told me I should have them on hand all the time (not prescribed them). Episode lasted about 3 hours and ambo was called... Ondansatron administered and taken to ED.

The most severe episode was at home. I only just made it to the toilet to vomit and then I couldn't make it to my bed which was about 5 steps away. I stayed on the floor between my bathroom and bed for four hours. I could not get up to go to the loo and my body ached from lying still on the hard floor. But I couldn't move.

At a conference, after I gave my presentation a vertigo attack came in and I had to sit in a lounge not being able to move and feeling very nauseous.

An attack at work when I just had to sit with a bucket waiting for my husband to come and pick me up. No one to look after our young children so they had to come too. Then got stuck with a flat car battery on the way to emergency, only to be told that they couldn't help as I wasn't sick enough (still with bucket, vomiting constantly). Had to go back in the car (worst place to be during an attack is in a moving vehicle), to try and find an after hours medical practice. All just to get a Stemetil injection to stop the torture. Extremely stressful for my family.

When my children were very young, I was driving and could feel an attack coming on. Just literally just made it home, immediately started vomiting, could barely walk and room spinning etc. I had my three daughters with me. 4.5yr old, 2yr old and 11 month old. My 4.5yr old daughter had to look after her baby sisters and get them out their car seats, keep them safe and also try to phone her Army officer Dad, who she couldn't get hold of.

The first two years were the worst. Completely bed ridden from episodes that would last several days. Vomiting. Unable to sleep or walk.

Fell down the stairs, luckily only bruising, lacerations and sprained knee

While driving. Trying to stay on road. Pulling over several times.

At home thank goodness, couldn't get out of bed for 25hrs

Thankfully it was at home in front of a lot of guests we had over for a birthday celebration. I was unable to control the vomiting associated with the Ménière's attack and move quickly to a private area.

At work, not knowing what was happening, no one understanding what i was experiencing, not knowing how i was going to get home, i was suffering nausea, dizziness, tinnitus, stiff neck and shoulders, loss of balance.

At work, having to be picked up as unable to drive. Vomiting and being unable to move for fear of falling.

The vomiting resulting in dehydration. After hours doctor on two occasions (2004 and 2014) called an ambulance to take me to hospital.

In Easter Island, January 2020. It was a "double-header" - hours of rotational vertigo and vomiting, settling for a short time, and then a resurgence. I had meclazine and valium with me but couldn't keep even a sip of water down. It also involves a lot of time on the toilet shitting.

Feeling like I wasn't present..

Dizzy and nauseous for days

I was at home, sudden symptoms upon waking.... spinning, vomiting, diarrhea, total chaos and frightening to say the least

A bad episode means vomiting off and on for a couple of hours and then needing to sleep it off for many hours

I've only had them at home but having them with a small baby was scary and not knowing what was going on or having the rescue meds.

Vomiting and vertigo episode which was severe and I thought wouldn't stop. Thankfully my bad episodes have been at home

In class in front of 30 children.

At home, unable to walk. Sudden drop on a separate occasion was not nice, again at home.

I can't move my head at all and unable to walk

The spinning and vomiting is always the worst experience. My fear is being away from home.

At home, stuck on the toilet floor, unable to move for 4 hours. Vomiting from the vertigo. After 4 hours, I managed to crawl on my hands and knees to my bedroom, where I climbed up onto the bed and slept. When I woke up, I was in a very awkward position on the bed. Honestly, every episode of vertigo is despicable. I used to lie in bed wishing I was in heaven singing with the angels, free from the Meniere's Monster. Your location doesn't matter. It's the severity of the spinning and the deep dark pit that you enter, breathing in a particular way to put off the violent vomiting as long as you can. It's the absurdity of it all. Everything in your body tells you that you are spinning, but in reality you are not. It's like torture.

At home - 12 hours lying in bed feeling nauseated, the room spinning, couldn't move - even moving my eyes with eyes closed was horrendous. Couldn't get up to go to the bathroom or throw up. Worst experience of my life.

At home...my husband couldn't hear me & I crawled to the bathroom & could go no further & suffered vomiting and diarrhoea on the floor.

My bedroom on assignment in Afghanistan. Could not even crawl to bathroom to vomit

Drop attack in the bathroom at night - fell back against the marble vanity and opened a big cut on my head - ambulance to the hospital to treat it. Alternately, the terrible anxiety of coping with an impending attack while teaching a class at university- frequently until illness forced retirement.

Mostly mild experience while at home

At work, throwing up, being unable to get myself home due to the vertigo and having to have my partner or daughter come to collect me.

4 hrs of relentless vertigo with tinnitus that was very loud. I also had a roaring sound which I get often but it was that was so loud during the attack that it was like being tortured. I had vomiting and nausea and diarrhoea. I was totally incapacitated

Double vision, and vomiting lasting hours, feeling of spinning head over heels, not knowing what was floor and what was ceiling. Having to crawl on hands and knees to get to the bathroom. Fortunately I was at home and there was someone in the house who could phone the doctor

My first major episode was driving home from work. Had to pull into a service station who called an ambulance

Had a fall in our kitchen (drop attack), hit my head on the corner of a cupboard. Split my head open, needed about a dozen stitches. Plus had mild concussion.

At work Vomiting uncontrollably

All are pretty much the same but one stands out with very severe vertigo and vomiting, then needing to take several Valium spaced throughout until the world was still again. Fortunately I was at home, during lockdown. At the time I was having episodes every 2 or 3 days, and was not able to leave the house. After several months I was able to get an appointment to see an ENT and began Serc which seems to have been effective for at least some of the time, and I got a formal diagnosis of Meniere's.

Drop attacks - fear that I will be unsafe when I have a sudden fall. I've only had two, but the first was at work and I split the back of my head open when I crashed on the way to the floor.

A fall in the kitchen caused me to do 'the splits' which was very painful. I didn't know an unfit, over-60 year old body could do that. Took several days to recover!

Probably at work 30+ years ago. I had quite a severe vertigo attack and was ill and had to be driven home.

On a train; on public transport and had to get off the train far from my home and look for a secluded private place like a park or some bushes to try keep my head still and vomit violently and also be ready for the bowel movement by having to remove my trousers so they would not be soiled. I was fortunate it was at night and I wasn't noticed by people around and I could vomit on the grass and pass the motion there and then clean myself as I had tissues in my bag. But had to sit there for over an hour till the dizziness subsided and I could safely stand/walk to get home. It was frightening and scary having this occur especially away from home.

2017 at Home

At work. My first episode.

Wheel chair out of the zoo while vomiting

Attack while driving car

In the very early days at home. My first episode I could not get to bathroom due to vertigo. Sweating, vomiting and diarrhoea. Thought I was going to die and was frightened who would find me in such a mess. I lived to see another day... 😊😊😊 another time I was really really bad and wanted to call ambulance but could not get to front door and unlock it and could not make the 000 phone call. I have now an Apple Watch and a key safe outdoors. We learn to make adjustments to make ourselves feel secure.

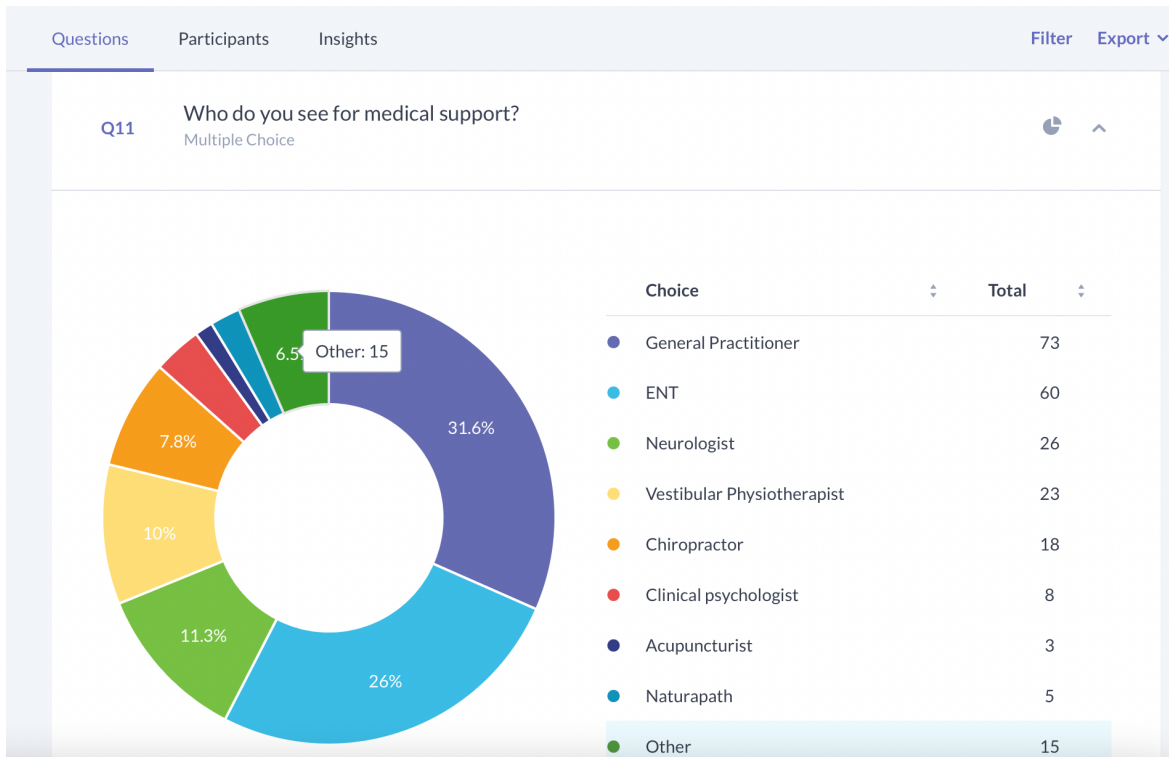
On a freezing night in Canberra Unable to move to get warm clothes or a blanket, throwing up for hours in a rented apartment unable to get help because I couldn't get to my phone

Thankfully I was at home. Being in the sole care of 3 young children when I was physically unable to walk or care for myself and my partner was away.

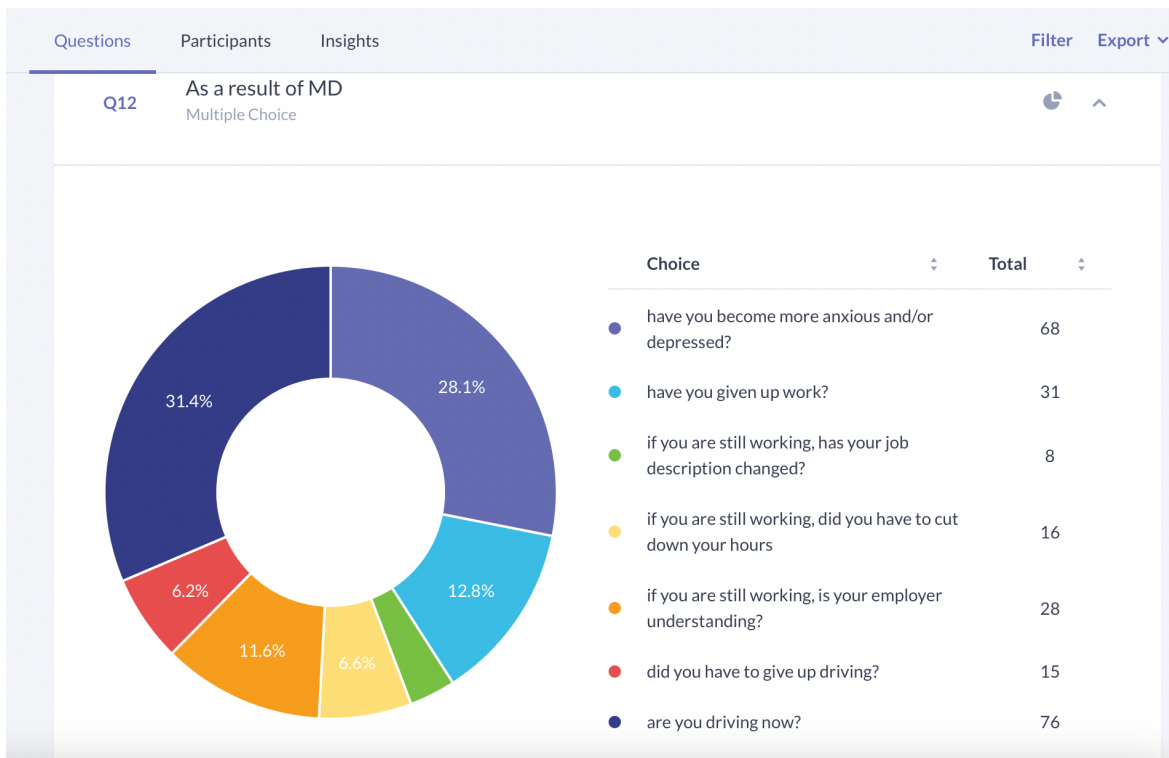
Driving a vehicle becoming extremely dizzy and disoriented, resulting in hours long episode.

Not able to get home. I was in a yoga class and became very ill. Could only move if I closed my eyes

**Question 11 Answered: 90 Unanswered: 2**



**Question 12 Answered: 88 Unanswered: 4**



**Question 13 Answered: 69 Unanswered: 23**

**Would you like to add to the above to help researchers get a better understanding of living with MD?**

out of work for up to 6 months

You can't live properly with MD. You merely exist. You can't even think, you can't find words you want fast enough to have a conversation and it is exhausting trying to comprehend what people are saying after a few minutes. I don't think anybody understands how totally debilitating MD is or how crucial a low sodium diet is.

It's like living with a bomb, you don't know when it will explode.

I find I overheat and get very tired. My Meniere's ear can turn bright red and red hot. I just have to go to bed when this happens. My body often overheats. It's very debilitating. I would like a way to stop this happening.

I am retired so the previous questions are not really relevant. I used to teach music but my hearing is now so severely compromised that music sounds so out of tune that I no longer can enjoy it and I finally stopped teaching. I no longer enjoy listening to music and I believe a cochlear implant would further add to this discomfort with sound quality.

It may not be a life-threatening illness but it's life-debilitating.

Your life becomes a game of Russian Roulette. If it lands on Black it's a bad day, if it lands on Red it's a good day. You'll never know how you'll be the next day. Therefore, hard to make plans in advance as often cancelled due to the disease. It's an absolute nightmare. I wouldn't wish it upon anybody. Not even my worst enemy. Let there be a light at the end of this Meniere's tunnel.

You lose confidence, every aspect of life changes. Socially- diet, going out for meals is an issue. Increasing deafness- communicating and participating in groups of more than three or four people. I now have a cochlear implant in one ear and 20% hearing left in the other. Hearing is still fluctuating and will quite likely finish up with a second CI. Learning lip reading and making changes to the house to accommodate my deafness. Crowded places are unpleasant, music is awful as I am missing frequencies. Doing tasks that require balance? Travelling is unpleasant, distance car travel often leaves you feeling disoriented. I have to try and reinvent myself and change my expectations. I often feel I'm an observer rather than a participant.

Urgently need something that either prevents or stops vertigo in its tracks.



Firstly give away your ladder I was told by Prof Hamalgy from RPA, you learn quickly your limitations on what you can do , one thing I can still do is driving, thank goodness for that.

PLEASE start researching PPPD

When I was still working my employers and work mates were very understanding

Some answers and not be fobbed off by ignorant health professionals.

It is so awful when your having continual attacks. Even having the confidence to venture out even for a walk is difficult because of the fear of falling, stumbling, vomiting...being away from the safety of home.

I was in my 30s with young children when this began for me. I am still working but only because my employer witnessed this transformation and because I was experienced at what I do (online learning designer) they wanted to support me. In the last three years I have needed to remove some aspect of the work (presenting workshops). It's episodic and unpredictable so hard for me to plan anything and it has taken me years and years to find the specialists to help - a neurophysio has been the most effective. I swim in the ocean to fight off a balance issues and found out myself that floating on my back in the sea is somehow helpful over summer when my balance was terrible. Dancing and forcing myself to ride a bike have also helped despite this all being counterintuitive when you are dizzy. Being sedentary in any way seems to worsen symptoms. For me, safe exposure ro the dizziness helps more than the special head movements that GPs try and do (which make things worse).

I have never had vertigo without both of my ears being blocked. I often have one ear blocked for 6+ months, but once both ears are blocked I can get vertigo within days. I have also discovered that for me issues with my neck then trigger the final vertigo (lying on the couch with head up against a 90 degree end, ages at the hairdresser basin etc). I also know that dehydration and really tight shoulder and neck muscles can trigger the blocked ears. And dizziness from the blocked ears is very common. The dizziness is real but as it's unseen and you can appear normal on the outside there is the constant feeling that people think you're making it up.

I still have problems with flickering lights, like disco lights this will trigger an attack or going on a walking machine in a gym or being in a totally dark room then I have a panic attack. Otherwise I would say the 2 operations saved me, I can do most of the things a normal person without Menier's can do.

Happy to help in any way I can. Can visit you if that helps.

Research the causes & triggers for developing MD. Help to research & develop medications to help in acute attacks.

It's extremely debilitating and the symptoms change all the time. Hearing fluctuates, dizziness comes on suddenly. I'm not sure of the triggers to attacks. Everyone seems to be different. It's very scary having this disease.

When going through bad clusters of MD it is very difficult to hold down a job. You also need lots of support from family.

Yes

Just for it to be more publicly aware. Ways to cure it.

The first three year of being diagnosed were quite mild. Since retiring MD has ramped up. I would have found it very difficult to work. I've had 4 grommets inserted in my ear (not always successful) and I've had an Eustachian tube dilation (unsuccessful)

This illness is so widely misunderstood and an almost invisible illness to most, except those of us who suffer with it. It is so debilitating, caused me to lose a valuable work contract as I would suddenly be throwing up in the office, forced an early retirement when I was not ready but had to accept , causes anxiety every time you walk out the door as you constantly worry about the "what if I have an attack" , causes those close to you to always be vigilant too , and it is exhausting . And exhaustion, anxiety and stress can all be triggers that can set off an episode so it is a vicious cycle.

Yes

Doctors really need to be educated better to deal with treating their Menieres patients.

Yes, happy to help

We sufferers are so devastated of this disease, we are so desperate for help.

Complete change of lifestyle and living with the constant thought in your mind to be aware of your surroundings in case of an attack

MD has stopped me from working and living a full family and social life, particularly since 1996. I was first diagnosed as a 17 yo in January 1968. I had a number of years in remission which was bliss from my mid 20s to around 40 yo. At that time I was able to go on a Disability Support Pension. Apparently that has been made a lot more difficult to obtain which shows a total lack of understanding. MD attacks can strike at any time and in any situation. That is no fun to live with and contributes to high anxiety levels which then lead to more attacks. I have to watch what I eat and drink at all times. It takes time and effort to work out triggers. I want a cure or at least a better method of controlling this beast of a disease so other people don't have to suffer.

I have since had a series of 3 Gentamicin injections in my ear, I was quite deaf in that ear anyway. This has stopped my extreme vertigo and drop attacks.

We just need more understanding of the condition

The volume of background noise adds to the tinnitus further reducing hearing acuity and trying to constantly think about what people say to you is exhausting

Vertigo is something no one can truly understand unless they have experienced it themselves. I would not wish it upon my worst enemy. Healthcare workers need to show compassion (I am a healthcare worker myself). I think for me personally I would like a cure for the vertigo... the rest I can live with if I need to (hearing loss, tinnitus) although not ideal. It impacts the whole family. It impacts mental health. Oral Stemetil is useless if you have no warning of an attack... Ondansatron wafers are possibly more helpful as you don't need to ingest it. Need to address GP reluctance to prescribe more than a week or two of Betahistine at a time (it is non PBS so 10 repeats is fine!) also reluctance to prescribe Stemetil or Ondansatron regularly... I tell the pharmacist I have migraines so I can get 5 Stemetil tabs over the counter.

I find that I have to exercise regularly and keep my body moving. I feel as though movement is helping to move the fluids around my body and stops it 'pooling' in my middle ear. It seems silly, but that's what it feels like. My first symptoms came on after working from home when I was working on a big project. I was literally getting out of my bed and sitting at my computer all day for months. I'm a lawyer so it is a very sedentary occupation.

Medications don't seem to stop attacks so the anxiety and fear is always in my mind . I can't do the things I used to do like gym classes , fasts head movements and socialising

Any program that provides early diagnosis, treatment options and raises awareness would benefit sufferers. This disease stops people functioning - you can't look after yourself during an attack, let alone be responsible for others. On a good day you can be off balance, dizzy, have screaming tinnitus, various other noises, a feeling of constant pressure in the affected ear (doesn't sound terrible but is), poor depth perception and hearing loss. No one else can see any of these symptoms, so add isolation and depression to the list. That's on a good day.

General practice physicians do not properly understand Menieres, and that it's not just loss of hearing and odd dizziness. The implications of non stop tinnitus, daily dizzy spells, the vertigo episodes, the unknown balance issues. The longer term difficulty of working. This is very hard to get recognised as a disability or to obtain Centrelink help when you're unable to work at all.

Yes

My employer has been good but worry about me travelling. Had to get equipment to assist in dealing with hearing loss. sometimes colleagues get frustrated. Used to drive a lot and now fearful after recently returning to driving. Have had to pull over on a couple of occasions You tend to start lacking confidence in yourself and what you can do. It is challenging going from feeling confident to having that eroded

Not at this stage. I'm just grateful someone is doing this.

It is not a pleasant illness. Once a Meniere's attack occurred I had to remain motionless for several hours until the attack subsided. Any slight movement of the head or body brought on the vomiting. I was unable to continue doing any activity for the duration of the attack (for me several hours or on occasions up to two days at a time) and the recovery period to feeling 'normal' again was a few days after the attack subsided. Attacks occurred in clusters (spaced apart by a few days or weeks) and over time resulted in increasing hearing loss and sensations of imbalance. The endolymphatic sac decompression operation I had in December 2019 has resulted in reduced attacks and if they occur they are mild but I could also be approaching the burn out stage. I have recently retired due to my age rather than Meniere's. However, the disease had impacted at times on my ability to work (the financial side and being productive), social life and psychologically due to the unpredictability of when an attack may occur. I have 'lost' many days of my life to this insidious disease and hope that researchers can find a cause and cure,

especially so the newly diagnosed do not have to go down the path that I have gone over the last 22 years.

Here's a description of what happens I wrote to explain to a friend: My attacks are always heralded by a lower ab pain and need to poo urgently. But then further need to poo as the fullscale vertigo and vomitting continue. Even when nothing in stomach & it gets down to retching and acid bile. The vertigo is not dizziness or lightheadedness. It is such that you cannot walk or stay upright - sometimes have to crawl, and the whole room is spinning. It is like being in a child's playground merry-go-round while totally drunk. You cannot get off, and someone then spins it in the other direction. The walls sway from side to side and the floor rocks like a boat in huge seas. Tho you have to go to the toilet it is agony to wipe your bum because that involves movement. Sometimes it takes 10 mins to muster the courage to tear off paper and make the tiny twisting movement necessary to wipe. I have hand sanitiser so I don't have to turn to the basin. My eyes drip fluid (distinct from crying which also happens), nose runs, dribbling, coughibg phlegm, peeing and sweating. It is like the body wants to expel EVERY bit of fluid. Vomitting goes on & on every few mins for between 3 & 4 hours. Vertigo continues. Agony to close eyes. Eventually (btw 3 & 5 hrs later) I get so tired I am able to close my eyes and sleep. After a first sleep I then take a diazepam (valium) & have a 4 hr sleep. That's how long it works for me & is good! When I wake from that sleep the vertigo will have stopped (then worn out for several days & unbalanced & wobbly) I tried taking a stemetil (anti nausea drug) and ended up with uncontrollable tremors in legs and arms - like an epileptic or Parkinsons sort of reaction. So I'm sitting on the toilet, holding a bucket and jerking legs and arms banging a drumbeat on the bucket! I scared the life out of son and Husband (who I am so lucky to have on bucket duty...) I read the leaflet on possible side effects of stemetil (the ones you never read til you HAVE to!) and sure enough, tremors can be one. I know when I am halfway thru. I hit a nadir - like an instant depression comes over me & a feeling of loss and self pity. Then I climb up again into a sense of relief at feeling able to sleep. And sense of humour returns. ☑I bought a proper bedpan. A plastic bag lined box was not ideal last time. I quite literally could NOT get out of bed..... When not having full-scale attacks, many days (mostly when there is a low pressure system), I often feel fatigued, off-and-on dizzy, my ear is always full (like you have water in it days later aftwr swimming), an tinnitus. Unless you stand on my left side I probably can't hear you, and if we go for a walk together, ai may well wobble into you from time to time. If you invite me to an activity, I will sincerely want to come, but ease don't be upset if I have to cancel at the last moment. This insidious disease is a day to day and moment to moment proposition.

Yes

We need to find a way to slow the disease if there is no cure.

I would try to avoid going to hospital as I feel the trip to the hospital will exacerbate the MD attack. Best to take it easy and let it happen. Others may feel differently

Yes

Make it clear that we are not making it up and this is a real thing

Please listen to what we say, it's a horrible disease and changes the way we live.

I have ticked some boxes that will confuse you with are you working or are you not etc. I did leave teaching at one stage, but 6 years later, was able to do part time teaching by the grace of God. I do drive most of the time, but at other times I can't depending on if driving makes me nauseous, or if the movement of the traffic affects my eyesight. When my MD was at it's worst, I withdrew socially, due to fear of having a vertigo attack when I was out of the house. I never went anywhere without my husband or my parents. I withdrew socially due to not being able to hear properly. I lost my hearing. I was extremely limited in physical activity choices, food choices, my weight dropping to 45kg at one stage. In 2004, I chose to have gentamicin injected into my middle ear to stop the vertigo (and of course destroying my balance cells), because of my deep depression, and the fact that I didn't want to be here anymore. I had to relearn to walk with my new balance. Meniere's disease affects you physically, socially, emotionally, psychologically. It leaves you on your hands and knees in the darkness, searching for the missing pieces of your old, happy self. It's a disease that you would never wish on anyone, even your worst enemy. I have counselled people on line, talking them out of suiciding. People are screaming out for help. We need to find solutions or a cure that works for everyone. It is extremely hard to get NDIS for Meniere's. The assessors just do not understand. If you also want to get a better understanding of what living with Meniere's is like, you can read the novel I wrote with a main character with Meniere's. It's called 'The Colour of Broken' - under my pen name - Amelia Grace. Profession Bill Gibson read it and said that the symptoms of MD are exceptionally well. I have donated around \$6000 from profits to help Meniere's research in Australia. I also created a Meniere's Journal for people to track symptoms daily. I am happy to send you copies of these if you request them.

After starting with my vestibular therapist I have become less anxious and have even started driving again. I do my eye and balance exercises daily. I can go out more often and sounds and lights don't bother me as much. I take Serc to keep the Ménière's attacks at bay and eat a low sodium diet. I also suffer from PPPD - Persistent postural perceptual dizziness which has improved since doing therapy.

The hot sweats & then freezing even with several hot water bottles. I often could only eat apples & drink clear liquids for about 3 days after an attack.

Managing overall health but particularly stress and anxiety are critical to minimising impact. Getting right diagnosis is really important. I know multiple people who have been told they have MD but are not deaf at all

Imagine being absolutely unable to plan your month, week, even day ahead - being victim to unprovoked and sudden, severe vertigo at any time. Living in constant fear and anxiety. Being powerless to change that. A living hell.

I never thought that I would see a chiropractor or naturopath as I have a real skepticism for these practices but I am so desperate for something that will ease my symptoms, I have tried both. Living with the reduced balance, hearing loss and constant tinnitus is exhausting and while I try not to let it bother me I do feel as though I am always asking people for help or accommodations to allow me to navigate daily life. It's frustrating and even though I wouldn't describe myself as depressed or anxious there is a part of me that worries about how this disease will continue to affect me and my quality of life.

Your whole life is affected by menieres. I can no longer do the job I used to do as menieres episodes have increased a I cannot predict how I will be each morning when I wake up. There needs to be more awareness made to medical practioners who often dismiss a patient who presents with symptoms of MD as I myself was.

I have had MD over 50 years, bilateral for 30 years. I also have PPPD. I now have burn out in my initial ear and don't get so many attack of vomiting. With only having hearing in one ear and also thyroid eye disease I find my balance is affected. I go to Pilates each week to conserve my core strength and I see a vestibular physiotherapist and specialist optometrist who work closely together. I spin out several times a day but am normally able to regain my focus and balance. Most days I manage quite well

I feel very isolated. Some people are understanding about your limitations and dietary needs but not many.

I had to retire early, I don't know from day to day how my health will be. For the last few years i have 2 or 3 good days a week, the rest of the week is a write off. I have a restricted licence(put myself on it) i only drive around my local area, never outside of the city limits. I have to avoid crowded areas & loud noises. stress will set of an episode real fast. Chronic fatigue is also a issue for me. Tinnitus is something I have got used to, would love some peace & quiet.

I would not have been able to continue to work (I had just retired). An episode is completely debilitating! The world just doesn't stay still. It is hard when there is no set way to manage Meniere's and very much trial and error: for example Serc seems to have an impact for me, but I also have a very low salt diet (around 800mg/day) and no caffeine. I used to love going out to dinner but have not experimented with allowing more salt yet as I really dread the thought of having an attack. It is not life threatening but certainly life changing.

When the MD attacks were frequent I would have vertigo for 10 hours straight. I needed to keep my eyes open the whole time. It was exhausting. Afterwards, I just wanted to sleep and rest for hours and hours. It made it difficult to work, but I forced myself. Fortunately, a senior work colleague had the same complaint so he was very understanding. Also, when staff saw me have an attack at work, they really could understand what was happening. I lost LOTS of weight because I was throwing up every 2 days or so and in between I felt nauseous. Finally, my neurologist prescribed Moduretic and that at least stopped the severe nausea. Over a period of 4 years the vertigo attacks steadied to 3 times a week and at most 5 hours' duration. I soldiered on with work but in the end I 'retired' because teaching became difficult with problematic hearing. My hearing in the affected ear is almost completely gone and I just hope that the other ear doesn't become affected. I still, as far as possible, maintain a low sodium diet which makes eating out difficult, so has social implications. My neurologist suggested to maintain the diet to help keep the 'good' ear unstressed. One side of my family has MD dotted throughout, so it seems to be a family thing in my case.

I rarely leave our apartment and can only do so if my vertigo is mostly absent. I don't want to have a fall outside and I don't want to cause anyone else to fall if I lose my balance. Living with Meniere's means things like having a sick bucket in every room, a torch in every room to cope with blackouts, stemetil at the ready and having a very understanding, loving partner. For years, a salt-free diet worked wonders but in the last few years, the impact on my life has become very unpleasant. I may have to pursue other more aggressive forms of treatment in the medium-term future.

I have not had a serious attack for 20 years or more and consider that I am in the burnout phase. I live with diminished balance due to inner ear damage and my balance varies day to day but not to the extent that I am incapacitated.

Yes

Constant fear & anxiety , had to go on SRI's Would not socialise or go out much.



MD is a revolting disease as is unreliable and you are not sure when to expect the next turn... I learn to live with it and the associated issues, tinnitus, hearing loss and ear fullness. I have also had breast cancer but can assure you MD is much much worse. I do my best to keep living a full life, I walk go to gym , seek out friends to keep busy and do my best to be independent. My kids, family and friends are wonderful and support me if I am in trouble. Good luck with your research.

As far as possible I have eliminated sodium (salt) from my diet and that seems to help. I stopped seeing the neurologist because he was no help and didn't really seem to care. The diuretics he prescribed were discontinued and he couldn't even be bothered to prescribe an alternative. My ENT on the other hand is a great support and monitors my hearing regularly.

After my first two meniere's episodes I also started suffering from Mal de Debarquement syndrome. It's lasted for several months after my last two international flights. Is there a link here somewhere??

**Q14. Answered: 64 Unanswered: 28**

**Would you have any concerns about this program? If so, why?**

need to have more information

No

I don't want to exacerbate my symptoms. Even though I'm stable I still have the overheating issue

No

In the midst of a major attack you cannot get to the emergency dept as you cannot move at all so I don't know if anyone would actually use it

No

People once diagnosed need to be supported in the long term. This is a life changing journey.

No.

No, I would like to see this develop into a positive outcome, as there are a lot of people with MD out there.

No

No.

Anything that helps is good

It needs good follow up after ED - meds are part of the solution not the only solution

No

No concerns

I personally wouldn't do any experience in regards to my balance. I can live the way I am now. I am too scared to be off my balance again.

No concerns

No concerns. Not enough is known or understood about MD.

No

No

No

No. I think it's great

No. What ever help is available is a good thing. It's a very misunderstood/unknown problem.

No. Great idea!

No, anything that helps advance the understanding and treatments for MD should be approached with an open mind as research is vital to enable better understanding and care

No

No, the more research the better

I'll try anything

That it is not available in Western Australia. I'm not certain how tracking eye movements alone with give a diagnosis. I have had a whole lot more tests than that. The worst being when hot and cold water and hot and cold air is put through each ear

No

No, it sounds like a good start

No! Any research in this area can only be beneficial. Thank you!

No. I think it is something that must be done. This disease is so debilitating. It seems like it is a simple malfunction that will have a simple solution.

No, as long as it is intended to support sufferers and maintains confidentiality.

No, I think this condition needs programs and research

No, I think anything is worth trialling. Ultimate aim is you want your life back.

No. If something could help for a quicker diagnosis of Meniere's disease to assist someone with understanding what is happening and why then that is a good thing.

No

No

No- any help would be appreciated

No

Possibly, triggers ?

No

No

Not at all. I have volunteered at the University of Queensland's Brain Centre twice, as a Meniere's research subject. If there is a way to help find solutions for Meniere's, I'm all for it.

My main concern would be having to depend on my partner to bring me to the hospital and also I worry that the tests could bring on an attack. I would probably be anxious before hand requiring a lot of self calming so as not to bring on an attack.

No

No

Anything that can help anyone who is new to this disease has got to be good.

No

No.

No I think it's a great idea. Maybe also explaining drop attacks may help as well as that caused my last Ed trip.

No concerns

It sounds great. Anything to help people work out a plan and understand and manage vertigo better has to be a good thing!

Just getting to a convenient nearby hospital if the program is not offered at all local hospitals.

No. Just getting medicos to understand Meniere's Disease is an excellent start. 20 years ago the ENT specialist told me "don't eat vegemite or pizza and you'll be fine". There's much more to treating Meniere's than that!

No

No not really however, you would need to tell me what information you require from me and why

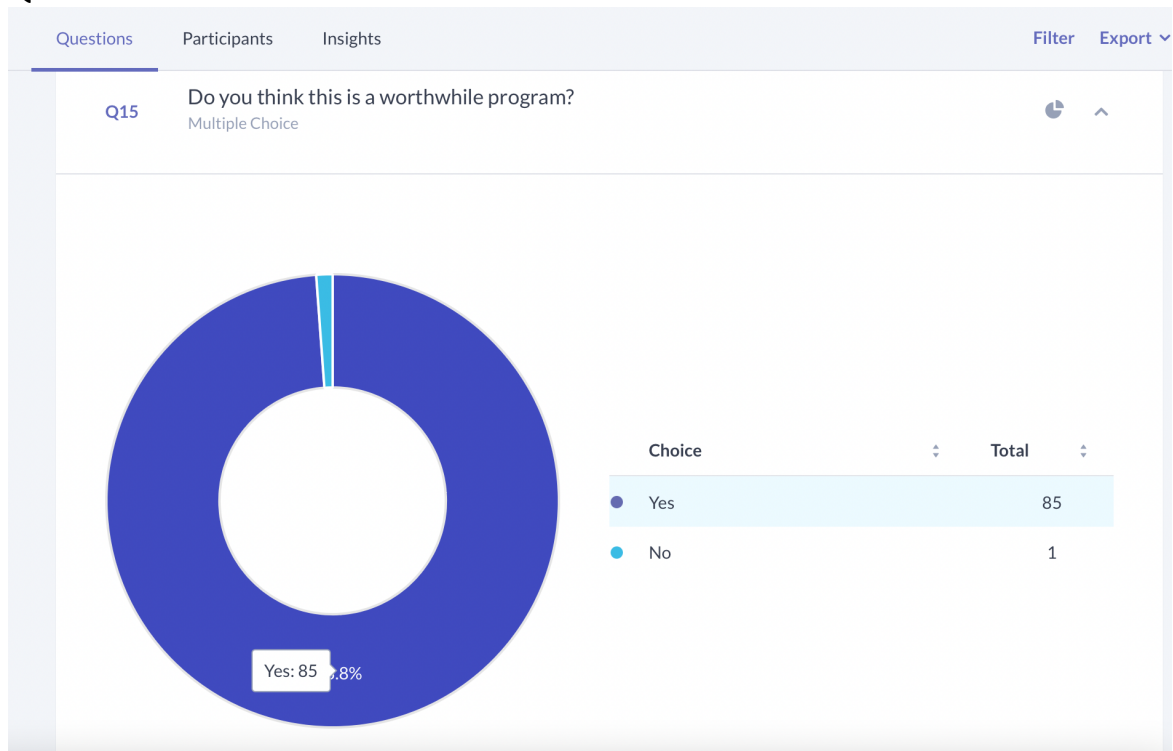
No

No concerns

No good follow up.

I hope I never have to go to an emergency department for vertigo but if I did it would be good if there were people there whp knew what to do that would help - I didn't thi nk there was anything..

**Question 15: Answered: 86 Unanswered: 6**



**Q16: Answered: 49 Unanswered 43**

## Do you have any suggestions for improvement

Can you include all major hospital in this procedure; not just the selected few you have listed. This information is required Australia wide,

Not at this stage

Would have been lovely to have a program like this several years ago. About a year ago a lady in my residential complex was discussing several weird experiences with me that her doctor didn't think were anything strange. The experiences sounded like Meniere's and I asked her to make an appointment with Dr Bill Gibson. Sure enough, she has Meniere's Disease. Getting the information on Meniere's out there to GP's & hospitals will help others with an earlier diagnosis. An early diagnosis means patients can make changes in their diet and lives to reduce the deterioration in hearing and balance. Learning to live with MD is the only way forward.

I have never experienced disbelief in regard to MD and its symptoms, however, I believe that some people have had doctors who think they are malingering or making things up. Unbelievable. NOBODY wants to get this (or any vestibular disease for that matter). It is horrible.

Should be offered at any hospital Sydney Northside as well

not at this time

Just informing re drop attacks.

I think it sounds an excellent idea. I'm fortunate as my Father had MD so my diagnosis was made quite quickly after onset

No

None

Referral to relevant professional/s; introduction to other members of the Ménière's community.

No

Just to understand that everyone is different and presents differently and has different symptoms. Also that people with these vestibular conditions are usually very anxious people and require a calm attitude and understanding.

Will Brisbane hospitals be involved? Please add: \* Money spent on medications - it's an expensive disease to have. When I wasn't working, I was meant to have 3 Serc a day. I only took 1 or 2 because we couldn't afford for me to take the correct dosage. \* PTSD due to severity of vertigo \* Money spent on treatments and rehabilitation.

Please...just keep trying to help us.

No as I don't really know what it is.

No

No.

Make it in all hospitals. I live near a rural town.

I don't know enough about it yet

The sooner the better.

I think exercise is the key. Exercise that gets our blood moving through our body.

See previous comments. Possibly NDIS recognition of the disease? And or disability support pension for those that really need it... hopefully it won't be me but you never know.

Not at this stage

It is only a start not a solution, that needs to be acknowledged

I wish I did

No

Needs to be available in rural hospitals also. Living with Meniere's makes traveling difficult.

Implementation as soon as possible to improve diagnosis and outcomes for patients presenting with acute vertigo and nausea etc etc which can often be dismissed or misdiagnosed

No

Any research into this horrible disease will be an improvement.

Menieres is a a disease that many GPs don't even understand. Unless you lived it you don't understand what we go through so it would be great to have a team of trained hospital staff that understand our needs.

Lobby Government to add Betahistine to the PBS list of medications.

Doctors need to be more aware of this disease. They think it's all in your head. It took me years to be diagnosed by then I was a total mess.

No

Education to doctors and pamphlets for them to give to us on what to do when we get vertigo. I still have no idea what I should be doing when I get an attack. I always just sleep it off now but that can be a horrid few hours.

No

No comment

No. Research has come a long way since I had my first attacks.

Start reseaching PPPD

Finding a cure or some sort of treatment help us to have a better quality of life, being able to walk normally is one.

No



Having a diagnosis is the first step, what next?

To the doctors, specialist, researchers etc who chooses to be ignorant and obnoxious when the Meniere's patient is trying to explain and or suggest an alternative and you refuse to listen or be open minded or even consider a trial. Because you took it as an offense thinking we're trying to tell you how to do your job. But that never been the case for us Meniere's sufferers, we just want to be able to find a solution that'll help manage control our illness so we can reclaim our lives back. Those of you who does and have such approach of being offend by patients making suggestions ought to look at a different profession cuz you suck at this one. You ain't a team player working together aiming for the same goal.

Would be something when you're not mid attack that could be helpful

The more education and therefore understanding of this disease by medical staff the better! I have been surprised how little some GPs seem to know about it.

I don't know what program you are talking about

All GP's and ENT's need educating and should be sent a fact sheet and information about common misunderstandings.

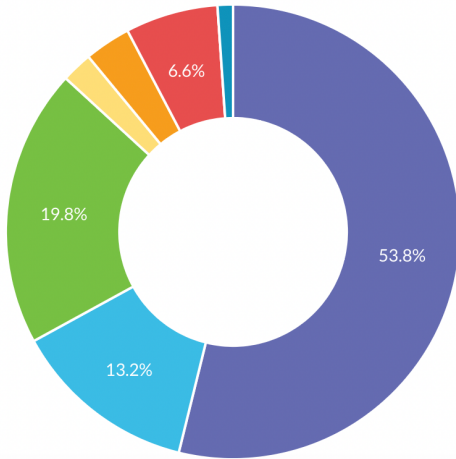
NA

Question 17: Answered: 91 Unanswered : 1

Q17

### What state or territory do you live in?

Multiple Choice



Choice	Total
New South Wales	49
Queensland	12
Victoria	18
Tasmania	2
South Australia	3
Western Australia	6
Northern Territory	0
Australian Capital Territory	1