

**SURVEY RESULTS: 22 September 2022**  
**139 took part in this survey**

**DIAGNOSIS AND TREATMENT OF MENIERE'S DISEASE:**  
**(Numbers relate to the total responses for each choice)**

**Question 1: Age range**

from 0-30 years old	0
from 31 to 40 years old	6
41 to 50 years old	29
51 to 60 years old	34
61 to 70 years old	48
71 +	22

**Question 2: Gender**

Male	25
Female	114
Other	0

**Question 3: The following questions relate to your dizziness symptoms: How long ago was your first symptom of dizziness?**

This year	5
last year	6
2 years ago	7
3 years ago	18
5-10. years ago	42
more than 10 years	61

**Question 4: When was your last episode of dizziness?**

Today	13
Days ago	33
Weeks ago	21
Months ago	28
More than one year ago	26
More than 3 years ago	9
More than 5 years ago	7
More than 10 years ago	2

**Question 5: Which statement applies to your dizziness? (if both apply, select)**

My dizziness happens in episodes. That is, sometimes they are worse than others	115
I feel dizzy/unstable most of the time	30

**Question 6: If you had/or are having dizziness episodes, do the episodes feel the same each time?**

Yes, the episodes feel the same	47
No, the episodes can be different	85
I don't have episodes	7

**Question 7: During the worst of the dizziness symptoms, how often did the episodes occur? (Please choose the best fit)?**

Several times a day	29
Every day	16
Every few days	35
Approx. once a week	8
Approx. every two weeks	11
Approx. every month	6
Approx every 2-3 months	14

Approx. every six months	5
Approx. every 12 months	3
More than 12 months part of the time	12

**Question 8: Usually, how often did the episodes last?**

2-5 minutes	7
6 minutes to an hour	22
1 hour to 6 hours	60
6 hours to 24 hours	28
2 days	3
3 days	4
4 days	2
More than five	9
No episodes, I am always dizzy	4

**Question 9: Have you ever seen an ENT (or neurotologist) for your dizziness symptoms?**

Yes	134
No	4

**Question: 10: Have you ever seen a physiotherapist for your dizziness symptoms?**

Yes	73
No	66

**Question 11: Have you ever been to an emergency department because of your dizziness symptoms?**

Yes	69
No	70

**Question 12: If yes, how many times have you visited an emergency department due to dizziness symptoms?**

once	32
twice	11
three times	10
four times	5
five times	4
more	10

**Question 13:**

**Since the start of your dizziness symptoms, approximately how many times have you seen a general practitioner (GP) about your dizziness?**

Less than 3 appointments	38
4 to 6 appointments	29
Between 7 and 10 appointments	24
Between 11 and 15 appointments	13
Between 16 and 20 appointments	15
Between 21 and 30 appointments	3
Between 31 and 40 appointments	4
Between 41 and 50 appointments	5
Between 51 and 100 appointments	4
More than 100 appointments	4

**Question 14:**

**Since the start of your dizziness symptoms, approximately how many times have you seen a specialist doctor about the symptoms? (include all appointments to ENTs, neurologists, respiratory doctor...**

1 appointments	8
2 appointments	15
3 appointments	7

between 4-6 appointments	33
7-10	32
11-15	11
16-20	9
20 plus	22

**Question 15:**

**From you first episode of dizziness how long did it take to get a diagnosis? Approximately**

3 months	49
6 months	18
A year	22
2 years	8
3 years	10
4 years	2
5 years	7
More than 5 years	18
Have not. yet been diagnosed	4

**Question 16:**

**How many different diagnoses have you had over time for your dizziness?**

1	64
2	38
3	23
4	4
5	2
more	2

**Question 17:**

**Have you ever been diagnosed with: (you can select more than one)**

Ménière's disease	136
Vestibular migraine	50
Benign paroxysmal positional vertigo (BPPV)	36
Vestibular Neuronitis (VN)	3
Labyrinthitis	20
Other	13
Have not been diagnosed	1

**Question 18: If Other, please specify:**

IIH, stenosis of sinus, jv compression

PPPD

PPPD

Vestibular Neuritis Secondary Endolymphatic Hydrops Left  
Peripheral Vestibulopathy

Nil

Bilateral diseases now for the past 5 years

Initially Rheumatoid arthritis with viral labyrinthitis

Trigeminal neurologia

Also possible TMJ

Persistent postural perceptive dizziness

Sinusitis, ear infection

PPPD

Possible stroke, on initial presentation at emergency department

Started at age 8 still to this day go doesn't believe I have any  
problems only get help from er

Vertigo

Low iron

ME/CFS and POTS

diviticulitis

Autoimmune inner ear disease

BPPD

**Question 19:**

**Were you told that your current diagnosis is?**

Possible	8
Probable	17
Definite	113
Have not yet been diagnosed	1

**Question 20:**

**Who diagnosed your current diagnosis?**

General Practitioner (GP)	9
Ear, Nose and Throat Specialist (ENT)	83
Neurologist	21
Physiotherapist	1
Neurotologist (specialised ENT)	17
I diagnosed myself	2
Other	6

**Question 21:**

**If other, who diagnosed you?**

GP first recognised M but I was sure it was just a virus. Following a collapse at work and ambulance ride I finally properly put myself in the hands of the professionals.

ENT specialist

Neurologist

NA

Immunologist

Otologist in 1984

ENT for Menieres, Neurologist for Vestibular migraine

Prof. Bill Gibson

Ent made initial diagnosis and then prof gibson did a conclusive diagnosis

Er doctor

Professor

Audiologist

Both an ENT and a neurologist

Prof Gibson after seeing neurologist Phil Cremer

otologist

**Question 22:**

**Have you ever had surgery for your dizziness symptoms? (you can select more than one)**

Yes - A grommet insertion	27
Yes – shunt surgery	2
Yes – endolymphatic sac	8
Yes - nerve section	2
Yes – neurectomy (retrolabyrinthine vestibular or cochleovestibular neurectomy)	0
Yes – labrinthectomy	3
Yes - superior canal dehiscence syndrome	0
Yes – not sure what type	2

No – I have never had surgery for my dizziness 104

**Question 23:**

**Have you ever had medication for your dizziness symptoms? (you can select more than one)**

Yes - Serc, Stematil	126
Yes – Migraine medication	34
Yes - Antihistamine	28
Yes - Anti-anxiety medications (eg Valium, Xanax)	49
Yes - Water Pills (diuretics)	71
Other	21

**Question 24:**

antiviral

Ondansetron

Sturgeon

Stugeron

Ondanestron as stematil gave me Parkinson's symptoms

Palexia

Vitamin B2

Cinnarizine (Stugeron)

ondestan

Gentramycin

Gentamicin injection into inner ear to damage cochlear hairs to stop vertigo signal being sent to the brain

A naturopath finally gave me medicine that really helped me

NA

Betahistine

I take 1 Span K (Potassium Chloride 600mg) once a day with meals  
and I take 1 Dithiazide (Hydrochloride) 25 mg once a day

Pro-calm - anti nausea

Gentamicin injected into the middle ear to stop the vertigo.

Inderal, high doses of Vit D, Urea

Blood pressure tablets for migraine and preventative medications

Celery tablets for fluid retention.

Naproxen, Sandomigran, Topiramate, Amitriptyline

Stemetil, Urea

Stemital. Nurofen

Prednisone Methotrexate

Serc

Cinnarazine

Cinnazarinne

**Question 25:**

**Have you ever had any of these other treatments for your dizziness? (you can select more than one)**

Gentamicin Injections (in the ear)	9
Steroids Injections (in the ear)	28
An injection in the ear but not sure what	1
Physiotherapy (e.g. exercises)	38
Psychotheraphy	3
Non medication migraine treatment	3
Other	15

**Question 26. If other, please specify:**

Had a short course of oral steroids prescribed by ENT when hearing loss pattern first emerged, perhaps 2 or 3 years prior to dizzy spells emerging in case it was something that this could fix.

Eustachian Tube Dilation

I could only select one..

Steroid injections Zanax

Vestibular Physiotherapy

Psychologist for associated anxiety

Steroids taken orally

Bioceuticals Migraine Care, Blackmores Gingko 6000mg, Magnesium

Acupuncture

Chiro

Regular massage around the rightside of neck

Gentamicin injection into inner ear Steroid injection in ear  
Vestibular rehab with Physio

Selection of more than one was not working , so have had steroid injections, gentamicin and physiotherapy

Naturopathic medication

Cinnarizine, methotrexate, Mycophenolate

Magnesium supplements

Sorry meant to leave all fields blank. Have had no other treatments.

Chiropractic

Chiropractic, acupuncture

Acupuncture

And steroids injection

Atlas adjustment chiropractor

Upper cervical chiropractor treatment

Please note - unable to select multiple options to previous question- add steroid injections and physio.

**Question 27:**

**Do you have a cochlear implant?**

Yes	10
No	127

**Question 28:**

**Do you have any other comments about diagnosis of your dizziness or information that is relevant to this survey?**

No

Most of the information that was helpful came through internet-sourced support group Whirled Foundation at the time of the onset of clusters of vertigo episodes, followed by Sydney based support group.

I had 2 significant injuries and a major operation to repair my ear.. I believe this is the cause of my symptoms

14 attacks within 5 weeks in 2020, 19 attacks within 6 months in 2021. Since changing to a whole foods, fruit and vegetable diet and with the addition of a daily diuretic in June 2021, all symptoms have since ceased and hearing now remains stable.

my first 3 attacks were violent sickness and nausea. After that it was just unbalance which I worked through with little or no rest.

I was extremely happy to get my diagnosis at last. It took 36 years and some strange alternatives. Even saw a physiatrist. It is now 14years since I have had a really bad fall and they were a constant happening before.

My dizziness has become worse since losing hearing on one side and also developing thyroid eye disease. The vestibular physiotherapist says you need eyes and ears to work well together for balance to be stable without any dizziness

I avoid dizzy spells by being vigilant about my movements. Minimal head movements, minimal turns, slow turning, daily exercise and seniors balance exercises, not overheating, chilled water in summer, controlled bending over to pick up something, so far so good.

Sometimes I think that doctors don't look at the whole picture and should be looking at your whole health such as heart blood pressure there could be some other underlying symptoms which could be associated and not picked up. I'm not a doctor but just putting it out there.

Much more known how to detect since being diagnosed in 1982

Considering a cochlear implant for hearing loss due to Meniere's

I was diagnosed in my first episode by a family GP who was already treating my aunt and great aunt in January 1968

My episodes are very much related to periods of Stress & Anxiety, usually a month or so of prolonged stress or a sudden onset of intense stress or emotions. My episodes are daily and last for weeks and months. Each episode the time frame has been less since the last two. First episode pre-diagnoses was 3 months of daily dizziness nausea and vomiting. Prior to my Menieres diagnoses I was diagnosed with Labirinthitis with episodes that occurred daily for up to 2 weeks and would occur once a year, usually with wet, stormy weather and stress combined. It's been 2 years since I have had a big episode. The last one came on upon notification of the Pandemic and work from home orders by my boss, it came on instantly and lasted 2 months.

Ménière's disease is mostly burnt out. I continue to see an audiologist.

nature of dizziness changed with the menopause

I was born profoundly deaf in left ear, discovered at age 7 years (probably from my Mother's Rubella during pregnancy). Good hearing in right ear gradually deteriorated with episodes of hearing loss - some lasting for months - resulting in fitting of hearing aid in right ear at about age 30. Hearing has worsened over time, needing more powerful aid and now severe loss. Violent dizzy spells over many years got worse about 5 years ago, with frequent drop attacks which have now abated with

medication and exercises. My Mother wore 2 hearing aids & one daughter has a Cochlear Implant.

I can have no episodes for a prolonged periods and then many episodes over a few months.

I have frequent ear fullness, tinnitus and fluctuating hearing loss.

I suffered drop attacks

Not diagnosis but I recommend acupuncture Once a month sessions for a year and no serious episodes Stopped treatment and severe attacks returned Now back to every 6 weeks sessions

Ménière's disease hit me hard and fast . Lost 80% hearing in my left ear instantly when I had my first vertigo episode. Within 6 months of vertigo onset I was experiencing daily vertigo episodes and up to 6 episodes a day, hence gentamicin treatment after 8 months

Seem to be in "burn out" stage. Lost most hearing in left ear.

22 years ago the ENT doctor told me to just learn to live with it

NA

Long term Menieres. New awareness of PPPD explains much.

Born deaf and high blood pressure

8 years before my menieres diagnosis an audiologist said she thought I had it based on hearing tests and dizziness but ent doc said I didn't so my hearing became much worse over the next 8 years without medication.

Vomiting comes with dizziness. Stress is a very strong trigger to my Meniere's attacks, plus lack of sleep

I also have a hand tremor which developed in the last 12 months so this has created even more confusion about probably Meniere's.

I try and cut out as much salt as I can in my diet, my hearing (even though I have hearing aid) getting worse and down the track will probably think about a Cochlear implant.

Fortunately haven't suffered such severe an attack such as first episode which seemed to last approximately 6 weeks and since then mostly slight balance loss and continuing hearing loss/problems.

I wish I had received my diagnosis earlier. I would like to consider other treatments or lifestyle changes to alleviate stress which exacerbates symptoms.

I carefully watch all my triggers: sodium, sugar, caffeine, alcohol, water, stress etc. for me this is essential. I am very mindful of the levels of tinnitus and feeling of ear fullness and use these as a guide. This way I have only had one attack in the last few years. I am very noise sensitive so have to take care in choosing where I socialise. It surprises me that this survey didn't include preventive measures.

I had 2 electrocochleograms

I think you need to go to specialists to be diagnosed and you need to self manage and drive your treatment and options

I was diagnosed after hours of testing

I am an ICU Nurse of over 40 years and have read extensively on this subject. There seems to be vague diagnoses from numerous health professionals who label sufferers as having vestibular migraine or Menieres. I believe this is because they have no idea what else to say and prescribe drugs which treat the symptoms but not the cause. I am of the opinion that the majority of issues in patient employment from the neck.

Mine is under control most of the time, the treatments are working and I keep my sodium intake low, but by far the biggest factor is keeping my stress levels low.

I believe I am in burnout as no longer having dizziness. I did have two drop attacks however in the past which your survey does not check.

I now don't take serc as it did not help me.

It took nearly 20 years and three different neurologists to arrive at a final diagnosis. The first two only focussed on basilar artery migraines. The third, a vertigo specialist, initiated the diagnostics for Menieres Disease. There are not enough trained and skilled

neurologists in Australia to meet the needs of MD patients, or people symptomatic for MD.

Hearing fluctuations, Methotrexate appears to be having a positive impact. Not so much with the dizziness.

I have suffered from vertigo, severe dizziness, I am constantly dizzy. I suffer tinnitus all the time just changes in sound, noises and loudness. I have some type of ear fullness, when it becomes very full I know a vertigo attack is imminent. I have hearing loss in one ear. I have suffered 3 to 4 episodes over 30 plus years. Since the last episode approximately 18 months ago it has been relentless. I lost hearing. Constant dizziness and vertigo ranging from seconds to hours. Both rotational but mainly inside me.

It's the worst

It's absolute hell

Looking back, I had classic Ménière's symptoms but it took some time to get all the information and then get into an ENT. I believe it would be useful for more GPs to be familiar with Meniere's and to feel confident in beginning treatment eg. with Serc. Diet also seems to help me so could be a gentle recommendation before having an official diagnosis from an ENT. (I wish there were more low salt options easily available everywhere!)

You need to define "dizziness". Vertigo is different from dizziness. My answers are now confused because I thought you were talking about dizziness & later I thought you must be including vertigo.

The diagnosis and guidance from my GP and ENT was correct and invaluable in eventually managing the symptoms.

I used the Meniett machines which help me

Dizziness is a secondary symptom of my Meniere's I predominantly have tinnitus and hearing issues.

Developed continuous pulsatile tinnitus in my right ear 4 years ago, ENT not worried but I feel it's to do with compressed arteries in my canal somewhere, can hear the blood flow.

WORST WAS APPRX 6 MONTHS AND EVERY DAY, ALTHO THAT NOT AS BAD AS THE START OF A "RUN" WITH IT, which could last 5 hrs. No drop attacks but seems almost permanent hearing loss in left ear, balance disorders, but grateful not to have had an bad attack for 3 yrs, alho now a prob with so much wax build up. Not sure if thats related.

Not enough doctors believe patients!! We may look normal but hid it well

I suffered vertigo for approximately 21years the tinnitus, nausea, deafness and dizziness and vertigo has only come on together over the past 4-5 weeks

I haven't had a Meniere's attack since GP put me on medication for anxiety about 2 years ago. [Fingers firmly crossed].

Had two episodes of severe debilitating vertigo but ongoing dizziness which ranges from feeling off balance and as if I'm on a boat to just light brief head spins - my blood pressure has always checked out to be perfect.

Dizzy episodes and frequency were before my Vestibular nerve resection surgery

Some GPs dont believe it exists.

Single sided deafness.. Initially a BAHA (12years ago) then followed by a cochlear implant (7 years ago)

Was put on steroids for a year then immunosuppressants then found out it was caused by tmjd after being told it was definitely Ménière's

In retrospect, I realise I was wrongly treated for VM when what I had was PPPD. Further, I was wrongly fearful of gentamicin injections for a long time because of the effects of the original dosing protocol. It would have been very helpful to have had this knowledge ages ago - but it seems our knowledge of MD is still evolving.