

How do you manage on a day-to-day basis?

This is a question that is often asked especially when someone has been newly diagnosed. Below are some responses from dizzies. We would love to hear how you manage! If you would like to share, please email me. dizzyanne.wfps@gmail.com
Your management tricks may help others.

1. My response is based on the belief/hypothesis that my Meniere's flare up when a virus – likely to be HSV or CMV – that used to lay dormant has become re-activated.

I would immediately take Valaciclovir in the hope of controlling the viral growth (and make an appointment with my GP if the supply is low). Sleep is the most important factor for me – both when a lack of sleep triggers an attack as well as when good sleep aids the healing process. Stress management is also crucial: excessively worrying about the next attack can bring about that very attack.

2. I focus on a healthy diet by cutting out sugar and I stick to a low sodium diet. I aim to drink up to two litres of water a day and treat myself to a weak coffee. Exercise is my “go to” management tool. When I am feeling dizzy, I find a walk really helps me. For stress management I have taken up sketching and when I am in the mood to explore a new area I take photos. As I have had Gentamicin I no longer take medication for Meniere's. Prior to the procedure I was on Serc and if I had an episode, I took a Stemetil.
3. I stick religiously to low Sodium diet, take betahistine 3 x a day and a diuretic in the morning, have stopped coffee. Have stopped working and just potter about the house, go for a walk if weather ok wear a beanie if it's windy lol. Can only drive local so might pop to the shops or catch up with someone for a cuppa (Chai tea). At the moment trying to push myself to do more
4. On a daily basis I manage my Meniere's by taking Betahistine 3x daily, low sodium diet (try to keep it at around 1000mg/day), drink 2-3 litres of water, no alcohol and avoid caffeine (may get a little bit from the occasional chocolate), try to get at least 8hrs sleep each night. I find keeping active and busy helps... I still work 3days (will probably be full time next year). I have a very active and demanding 2 1/2 year old who also keeps me on my toes. I have a very supportive family who help out when needed. I try to have regular massages and manage my stress levels (though this can be hard at times with a young child). I get half an hour brisk walking exercise at least 3 times a week. I use Stemetil to manage nausea or attacks as required. Tinnitus doesn't cause me any issues at present.
5. Sounds like a great idea, I'd be very interested in seeing the document when you get it together. I am newly diagnosed and still working out how to manage and what works. Tinnitus is driving me crazy sometimes. Cut back on salt and drinking lots of water. Can't break my one a day coffee habit though and I exercise 20 minutes to half an hour each day. Meditation helps a little too.

6. I'm newly diagnosed. I find that ignoring the unrelenting roar in my ear and going about my business seems to dim it. Lying around watching it doesn't help. With an episode of extreme vertigo, I draw on what I've learnt in my life about meditation and I resist panic. It's like I say hi there are you. I know this is going to pass and I'm ok. I'm resting stretching and meditation more consistently and I agree exercise feels good and yes, I'm salt sugar and alcohol free. It's all an experiment now as get a sense of what I need. I'm seeing my optometrist next week as I've noticed computer screens are a dizzy trigger so I've put all at home on night screen but can't do that at work. She says she has a gadget that lots of people find helpful. No idea what's she's talking about but I'll shout out if / when I find out

7. In the early years post diagnosis, I was very attentive to diet counting every mg of sodium, trying to find causes. I have learned that stress is a major contributor to my attacks so try to manage that. I've tried numerous medications and what works best for me is 7500mg ginkgo biloba daily. I've had 3-4 injections of steroids into my ear, these work well when I start having attacks. I minimise sodium intake but don't count mg. I have 1-2 coffees a day and can drink alcohol.

8. My day to day treatment for Ménière's
 - 1- Avoid over stimulating my senses
 - 2- drink lots of water
 - 3- avoid salty foods (I never cook with it or add it - but I'm mindful of things I eat)
 - 4- I have a thumbtack in my bedroom wall - if I'm feeling a little giddy I'll do some exercises where I concentrate on the tack and keep my eyes still while turning my head slowly left to right.
 - 5- if I'm bad and can't get out of bed, I need assistance to the toilet and I generally take stemetil and sleep. This is probably once a month.
 - 6- my worst symptoms is my hearing loss, being now totally deaf in my left ear and 15% hearing in right. Waiting on a CI for left ear.I see a Physio weekly for vestibular exercises.
I can have caffeine - I have found sugar and pork my two main food triggers.
I only take stemetil as PRN.
I'm on endep and Setraline for PTSD (not MD related) but feel they help manage my anxiety .
In a mask mandate is happening I can't go out alone because I need a hearing person with me (- I don't usually anyway as I lost my driver's license due to MD.)

9. I've now been undiagnosed for 27 years...I don't have episodes of dizziness I'm dizzy in all waking hours. My sense of balance has deteriorated to such an extent I now can no longer sit in a moving vehicle. So I'm permanently housebound and my days now consist of thoughts how is it that human lack of balance is now probably medically in the too hard basket.....my main question has always been this...how can an ordinary Pensioner in the public system arrange to be heavily sedated be placed sitting up in an ambulance...be taken to a hospital....be continued to be anaesthetised placed in an MRI for brain neck etc pictures...be taken home still asleep and woken up sitting up....all for prevention of my terrible vertigo situation.....The answer is....just not able to be done.... Good luck out there.

10. In reply to your request for the management of my Meniere's, it is a long time since I suffered from active Meniere's. Attacks started in 1974 (I was 16), I was diagnosed in 1975, and the attacks burned out many years ago. I took medications for a while and cut salt out of my diet. With onset of the menopause, I started having mini-attacks, lasting only a minute or so, which I keep at bay with a teaspoon of cider vinegar in hot water, three times a day (i.e. increased potassium). I no longer worry about restricting salt; I eat some salt on salted peanuts which cured what the GP said was sciatica. No medical practitioner has ever shown an interest in ensuring that I have *** enough salt *** in my diet. There are many more low salt food items now than there were in the 1970s – butter, cheese, salad meat, to name a few. I have become sceptical about the value of a low salt diet, given that it never stopped attacks when I was young, my experience with potassium and the fact that the body has systems for dealing with excess salt.
11. When I was having attacks, I lay down until they passed (which could be overnight), but never restricted my activities in fear of an attack (I was a daily cyclist in the 1980s and 1990s). I got on with my life.
12. Well as I am new to it, I am perhaps one of the ones asking all the questions and I'm not sure I have experimented on myself sufficiently yet to have good responses to that. I do plan to over time. Sort of waiting for a 'good time' to risk having a bad reaction to said experimentation. Like how much sodium is low, and how much might having a cheat day impact me? What is that reaction and how long does it last?

At the moment my management is probably just rest when having had a bad day. But the beta-histamine coupled with the low sodium diet definitely has reduced the daily dizziness, head pressure and headaches. Once over the worst (on the lounge perhaps) then being outdoors is my go-to stress reliever. I have been an avid hiker, caver, climber for decades. These remain on the to-do list with care. A day in some sunshine and fresh air definitely helps.

13. I seem to have reached burnout so no longer have vertigo or vomiting, thank heavens, just left with fluctuating hearing and tinnitus. Thinking back to when I had attacks, I always retreated to a comfortable chair that supported my neck - very important. Tissues and container for vomiting were there, and I closed my eyes, kept still, calmed things down with breathing and waited till it all stopped. I tried not to worry too much about 'what if I have an attack when I am out' - which did happen a few times in public but husband or friends helped - though it was in the back of my mind when walking. My balance isn't fantastic, but better than when I was having attacks, and walking helped. Having had a drop attack, I now have an Apple Watch which should alert my daughters plus a local neighbour if that happens again. This is a comfort as I live alone following my husband's death. I appreciate having quite a lot of social contact which always helps of course, though large groups pose stress because of hearing problems.
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15. I wish I knew sometimes. I'm bilateral and have different degree of symptoms in each ear. My left ear gives me constant tinnitus, dizziness, nausea, balance issues and the feeling of motion sickness 24/7. the vertigo attacks are terrible but not as violent as my right ear. When I feel a left vertigo attack I walk around our tennis court following the lines with my eyes until the dizziness passes. sometimes it works other times I end up in bed, I take a valium and a couple of stemetil and try to sleep it off, I don't usually vomit with a left attack. I have to cover my eyes to cut out any light.

My right ear is horrendous. I get very little warning. screaming tinnitus followed almost instantly by extreme spinning which drops me, I have to crawl to the toilet if I can. there's no stopping it. If my wife is home she gives me Valium, Stemetil and Ondansetron, I have to cover my eyes to cut out any light. I vomit for hours. My wife calls an ECP (Extended Care Paramedic) from SA Ambulance. They are fantastic, they give me intravenous fluids with stemetil and other drugs to stop the vomiting. I usually go to sleep and it takes a few days to recover. If the vertigo, vomiting and spinning doesn't stop within 5 or more hours I get transported to hospital for more fluids etc, the last episode lasted 22 hours of full on spinning then weeks of recovery, I couldn't walk for days.

I never add salt to anything, I don't touch caffeine or alcohol, I avoid travelling when the sun will flash in my eyes. During mild symptoms I'll play video games where I can sit still and stare at point on the TV without moving my head or eyes. It distracts me and takes my mind off things.

Serc didn't help, diuretics didn't help neither did grommets or steroid injections. I can't bend over or reach up. I have a grab tool. I avoid loud noise and going out of the house unless urgent.

That's my life.

16. The last time I had an 'episode' was in February this year. However I'm not really sure that episode was a fully blown out attack as there was no spinning just giddiness then the vomiting.

My symptoms come on as such:

Ears fill up, slight light-headedness, eyes lids heavy. For this reason I'm reluctant to drive anywhere not local.

I take Serc & anti-vomit medication & go outside for fresh air even if it's 3am. The fresh chilly air seems to settle me.

Management Plan

I try not to do anything too different to what I've been doing all my life.

In terms of diet: water - love it drink heaps every day pre & post Meniere; more conscious of salt intake & have lowered it

In terms of exercise: swimming; will go back to gym soon

In terms of stress: teaching myself to slow down & refocus my direction inwardly

17. In reference to the below email I am willing to partake in the document you are putting together The symptoms I have now are few but still debilitating enough.

I still feel 'woozy' in the head, especially if I bend down to pick something up from the floor.

Light headedness, tinnitus in my left ear (which I know I am losing more hearing in that ear). A check- up on my hearing is now due, but I have found there are not too many Hearing places who have 'booths' to do the checks. I believe there is at least one in Newcastle. I live in Port Stephens.

My balance is going off (since September 2021)

Tiredness, but that is also from the medication I am taking which is Cinnazarinne (Stugeron)

My medication: I started taking one tablet 3 times a day in mid-2018 . It took a few months to take affect and haven't had an 'attack' since then.

I'm actually feeling better than when I first got this hideous disease in October 2017.

After consultation with my Neurologist, Dr Shaun Watson at Blacktown, he said I can cut back slowly down to nil (if I feel ok with it it)

I am too scared to go to no tablets a day so I just cut back to 2 a day for a few months and am now only taking them one a day. Feeling the same but with less medication.

I avoid caffeine, drink de-caf coffee with no problems.

Less salt.

Eat mainly salads.

Lots of water.

Exercise: I walk up to an hour a day and I try to do this every day BUT with the recent months of rain and winds I have found it impossible to get outside some days.

The winds do my head in.

Have to walk at a good pace and not too fast.

Yes I still drive but only if my husband or someone is in the car with me just to be safe and I don't drive long distances.

So I manage this condition with caution (I feel like one day it's going to hit me hard again) and I have to be aware of my surroundings.

Crowded noisy places don't do me any good either and I tend to not stay in places like that. My head starts to feels 'full'.

18. To your response to managing my day

I had most of the symptoms including the drop fall mentioned on "stuffthat works" I was recommended a book called "overcoming meniere's by Mark Knoblauch , PHD helped greatly.

I manage a low salt , read all labels when ordering food, I can certainly tell the following day if I have accidentally had salt. I stay away from coffee , chocolate and Baileys. I eat rather healthy, make my own meals. I take Stemetil each morning if problem another during the day. I try for 1 liter of water each day.

The one thing I have not overcome is driving, confidence and being dizzy plus I would not like to be the cause of an accident to others or self.

19. I first got symptoms 6 years ago but was diagnosed 2 years ago after losing hearing in one ear, and getting balance issues.

It took a few years (and medication) to learn how to manage the condition.

My philosophy is to 'Keep Moving", doesn't have to be strenuous exercise, but moving enough for the brain to learn to adapt, that is the key.

Any pressure on the inner ear creates symptoms (eg loud noise, changes in atmospheric pressure, driving in the car)

My audiologist gave me 20 decibel ear plugs to use when I am in those situations, they work reasonably well.

Medication consists of a daily diuretic & 4 Serc, & Zofran for nausea.

When the aura comes that a vertigo episode is coming, I head for a safe place to lie down & ride out the storm.

There are no hard & fast rules for Meniere's, so no set rules for management.

20. I hope this isn't too long. It's how I manage from day to day.

I have both PPPD and Menieres, diagnosed in 2018 but have had it for longer.

For my PPPD, which is always hovering, I do ongoing vestibular therapy with Dr Carlo Rinaudo and Occupational Therapist Abe Tedjakusuma at Brain Hub. I practise vestibular exercise most days. The therapy has made me more resilient to push myself with outings and driving short distances. I can sit upright to work at the computer and play the piano again for short bursts. Vertigo attacks seem milder, I believe due to the therapy.

I take Serc - 16mg twice a day which helps keep meniere's attacks less frequent and the vertigo less strong. I take daily magnesium, B Vitamins, Vit D plus K among other supplements that suit me.

I walk every morning - about 5000 steps and try to do a second walk in the afternoon to get to 10,000 steps. I do my best to exercise with strength training, a bit of Qigong and

stretching a few times a week. I'm not a vigorous exerciser, as that makes me more dizzy.

I meditate daily which helps me stay calm when anxiety creeps up. Deep breathing and massaging the Vagus Nerve points on the ear, face and body also really help. There are many Youtube videos on this.

I stick to a low sodium diet between 800 to 1000 mg, spread over the day. I've cut down on gluten and have very little dairy. I'm vegetarian and make most things from scratch using loads of herbs, spices and chilli. I drink a lot of water and have switched to decaf tea (I'm not a coffee drinker) - best brand I've found is Tetley Decaf and I use two bags at a time in a mug.

When I have a Menieres attack, the ear fullness usually lasts between two weeks to several months, culminating in the inevitable vertigo, then I'm back to normal.

While my ear is full, I wear little noise cancelling earbuds called Loop (<https://au.loopearplugs.com/products/experience/>) or big earphones when out and about. They really help cut the hurtful frequencies of things like a boiling kettle, vacuum cleaner, TV, motor bikes etc

When I feel a vertigo attack coming on, I stop everything, take more Serc, possibly take a valium, Rescue remedy, gather all my necessities - water bottle, throw up bucket, discreet underwear in case I can't move, and I lie in a dark room listening to an audiobook until it passes - between 4 and 12 hours. Sometimes I take a sleeping pill. Stemetil doesn't work for me, so I have a prescription for Ondansetron which helps with nausea.

21. I am on a very strict low sodium diet. I try and keep away from artificial sweeteners, colours and preservatives. Eat as fresh as possible, organic wherever possible. Make my own bread. The No Knead Bread Company sell excellent flour and yeast on line. Don't eat any fast foods. When I do eat out I ask for grilled fish or steak. Sometimes I am lucky enough to find a restaurant that will batter some fish in plain flour because I we can't have self raising flour - too high in sodium. That's why we can't eat cakes and biscuits unless we cook our own. I have found some lovely biscuits from a Lebanese shop at Roselands Shopping Centre.

I ask for hot chips with no salt. They often have the chips frozen in a bag, ask them the sodium level on the packet to make sure they are OK. Porridge for breakfast is great. I went without chocolate for about two years and really missed it. I asked my specialist if I could have some and she said a very small amount of dark chocolate. I have been fine with it. I love Health Lab from the health food section of Woolworths.

Also when I leave the house I always carry water and food in my eski that I can eat. I eat frequent small meals.

My GP got me four free visits to a dietitian and I think three or four free ones to an exercise physiologist when I was first diagnosed. They both really helped.

I try not to stress but I find this not easy.

I suffer with asthma. If I don't keep it under control it affects my Menieres.

22. In response to the survey that Professor Gibson is undertaking I will outline my experiences of Meniere's around the time I had my 4th booster shot for COVID. It may be or not be relevant to his survey but I will provide it anyway. I received the vaccination on the 24th January 2022.

5 January	dizziness and nausea
6 January	dizziness
8 January	dizziness and vomiting
16 January	dizziness and vomiting
24 January	dizziness and slight nausea (same day as booster shot)
29 January	dizziness and nausea
13 February	dizziness and nausea
15 February	dizziness and severe vomiting
18 February	dizziness and nausea
26 January	dizziness and severe vomiting for several hours (very bad day!)

I have not had a bad day since the 26 January. I have always had the tinnitus throughout this period and has not abated.

23. I never mentioned a number of things which in retrospect I could have. Since reaching burnout I consume some salt, have recently tried half strength flat white coffees maybe once or twice a month, take many supplements, and am still on Serc twice a day. I think I will try going off Serc very slowly. Like other respondents I drink lots of water, no alcohol and cook my own meals. Chocolate does not trigger an attack.

24. AM: Serc 16mg; Bioceuticals Migraine Care; Blackmores Gingko 6000; Vitamin D and Magnesium

PM: Dothep 125mg, Statin, Sandimigran 0.5mg, I'm going to start taking another Migraine Care at night from today, Serc 16mg

I don't exercise, but should.

My diet is vegetarian with little dairy, no eggs - lots of salad, high fibre breakfast. I don't drink any alcohol and have never smoked. Don't have caffeine or chocolate anymore.