

Meniere's Lifestyle Changes for some in 2023

I asked if there were lifestyle changes for those with Meniere's over the last 12 months. Here are some responses I received:

Response:

I was formally diagnosed with Meniere's Disease in August 2023 this year, and had my first full-on attack in June 2023 which was when the doctor there suspected I had Meniere's and referred me to an ENT specialist to confirm it. So, I had a lot of lifestyle changes this year!

- **A new specialist** – My ENT specialist has been very helpful in explaining the disease and ways to help cope with this disease
- **New medication.** Previously, I hardly took any medication, but since the onset of this disease, I've had different medications for the symptoms, such as Stemetil, Phenergan, Ondansetron. Sometimes, they help, sometimes they don't, but I think it's to do with timing it for better effect.
 - I had Stemetil at first which seemed to be helping with coping with the symptoms during attacks.
 - At first, I didn't find Phenergan effective, but if I timed it early enough, it seems to help control the symptoms, but it does make me drowsy, feel slightly off-balance and affects my concentration.
 - I'm trying out Ondansetron now. It helps with nausea but didn't stop the vomiting for me.
- My **diet** has changed dramatically.
 - I changed to a low-salt diet and that made a huge difference to the frequency and intensity of attacks and reducing symptoms. I'm now cooking a lot more at home, and modifying recipes to make them low sodium. I don't eat proper Asian meals anymore, but I found a whole new range of meals to explore.
 - I eat much more healthily now. More fresh foods, no junk foods.
 - No more high-sodium takeaway meals.
 - Less dining out, except for places where I can order meals that can be made low-sodium, like fish and chips without salt, or steak without salt or seasoning.
 - I still miss the foods I used to eat
 - I drink lots of water now, aiming for about 2L a day
 - I stopped drinking coffee or tea. Before, I would drink lots of coffee every day, which probably was not a good idea anyway. Instead I am now drinking fruit teas, and the occasional decaf coffee or decaf tea.
- **Shopping habits have changed.**
 - It takes longer to go shopping as I would look at the labels for the sodium content. I now look for low sodium foods. It's incredible how high sodium many processed foods are! It always feels like I've hit the jackpot when I discover something that I can eat, eg corn chips with no salt added at Harris Farm, or Maggie Beer low-salt vegetable stock and low-salt chicken stock.
 - There were times I didn't like going to the supermarket because looking up and down the aisles affected me, but now, I'm ok with going to the supermarket.
- **Meal prep.** I do a lot of meal prep nowadays, and I always take little meals or snacks with me when I go out.

- **Sleep** – I make an effort to sleep earlier and get more sleep. I used to be able stay up late, but now I can't as I notice it seems to be trigger for attacks.
- **Remedial massage** – I go to a remedial massagist regularly now and that seems to help with reducing the symptoms in the early stages.
- **Meditation** is helping me in coping with the symptoms. It has been helping me feel more on top of this disease rather than being a victim to it.
- **Vestibular Physiotherapist** – I went to one for the first time. She is close to where I live. She was great in assessing where I was at vestibular-wise, and she recommended exercises I can use to aid in recovery and tips on aiding recovery, particularly encouraging me to get up and start walking as soon as I possibly can.
- **Exercise** –
 - I walk regularly now with my husband. This helped me regain confidence in going out and about.
 - I tried out Tai Chi for the first time, and this is helping me with my balance
 - I'm thinking of trying out forms of exercise such as yoga or Pilates, perhaps in the New Year.
- **Avoiding going out to movies or noisy venues**
 - There are many times where my affected ear is sensitive to sounds eg closing a door or music I normally enjoy listening to
 - So now I am avoiding going to the cinema, which is unfortunate because there are some movies I would like to see. I may opt to see it at home with the volume turned down. I may try using one of those Loop earplugs.
 - I am watching quieter movies at home. Before, I would hardly watch any movies at home.
 - Now, I prefer quieter activities
- **New learnings**
 - The resources from this support group website have been fantastic in helping me find out more about Meniere's from different perspectives, and hearing about people's lived experiences has helped me feel less isolated as I work my way through this journey.

Response:

Things I trialled but found they didn't make a difference for me:

- low sodium diet
- Serc

Things I've trialled that work for me:

- no (or minimal) alcohol
- no caffeine
- Ginkgo
- hearing aids
- a chiropractor and regular neck adjustments

Response:

- The biggest change for me this past 3 months has been my 30% hearing in my right ear returning to normal. This was following dental work and returning to eating chicken and eggs (was vegan since 2015).
- I am having a cone beam CT scan early February and a sinus CT next week. If they both come back normal then I am going to get a referral to see my neurologist.

Response:

In regard to the last 12 months the only notable aspect for me has been to increase my attendance at yoga classes, which I find to be marvellous for strength, balance (both physically and mentally), and community with a wonderful group and a fantastic teacher.

Response:

As you may have seen I've been away overseas (maybe not) and I had the best time. I was not as careful with food as I have been for the last 10 years and all seems to be ok. I am back to be slightly more careful now home but all is going really well.

Response:

Here are the changes I have made, since being diagnosed about six weeks ago. Touch wood, since being diagnosed, I have not had any dizzy attacks.

My changes have been based on what I initially read on the internet when I was first diagnosed- which were mostly from the USA, and written by university medical people or government medical agencies.

I never been a smoker or an alcohol or coffee drinker- so those three suggestions were no problem.

Likewise, **I have not been adding salt to my meals for many, many years**, so that suggestion has also not been a problem.

Perhaps my biggest change has been to stop drinking black tea, and switching over to herbal teas. (Thank goodness for "T2"!!!).

I have also become much more aware of the salt/sodium content of the foods I do buy. I have seen several definitions of "low salt" foods, which are a guide, but I am also now aware of what quantity of some of these prepared foods I do eat at one sitting. As I see it, if a food has a reasonably high sodium/100grams value, but I only eat a small quantity at one sitting, then that is OK by me.

For five or six years now, **I have been trying to go for a one hour (about 5.5 kms) walk "most" afternoons, and so I have been keeping this up.** As part of my diagnosis, I had a full head MRI scan, and that came up all clear.

Almost 12 months ago, I had hearing aids proscribed for a loss of hearing ability. Part of this, I now realise, was due to the Menieres symptom of one ear feeling continually partially blocked, to a greater or lesser degree. While the aids have helped (and I certainly notice their helpfulness if I go out and forget to put them in), they have not been as helpful as I had hoped. I am going back to the hearing people soon, to have a check-up before the 12

month “warranty” period expires. Now I can tell them of my diagnosis- should that have any impact on how they set the aids up.

One of my big fears, is that when I try to purchase travel insurance for some travelling I would like to do, that having Meniere’s will affect the cost (over and above my age premium!!). I certainly will be mentioning it to the insurance company, as a precaution.

Response:

I’ve been lucky enough to be Meniere free these past 2yrs (almost) I’m still unsure what I’ve done or not done to achieve this. In any case I’m very grateful.

Response:

My ENT told me a year ago not to make another appointment but to leave a message if I really wanted to talk to him. He was looking for a better work life balance and I took this to mean I didn't need him as much as some of his other patients. Between that and being told my vestibular system wasn't damaged enough for vestibular rehab to be beneficial - I've just been soldiering on, with major episodes every 4, 5, 6 months coming out of the blue and lasting up to 5 hours with a long tail (2-3 weeks) of mild vertigo that responds to my medication (which now includes valium).

One big lifestyle change this year is that in the aftermath of major episodes, **I don't feel safe to undertake long drives 2-4 hours or longer myself as I previously did and have to rely on Zoom and Teams to attend meetings - not always satisfactorily.** I hope my confidence will come back eventually - or should I accept that it's just not safe?

I've been going regularly to exercise physio for two months now hoping that will help with balance and confidence.