Part 12

The Emotional Toll on Patients

By

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Scientific research data is important to understanding what can be known about Ménière’s Disease. However, data alone often bypasses the emotional toll the disease takes on patients, their families, friends, and co-workers. I’d like to spend some time looking at that toll in the next two newsletters.

The Emotional Toll on Patients

‘Anecdotal Evidence’ is defined as —

> “evidence in the form of stories that people tell about what has happened to them” Merriam-Webster

As a career journalist I know the importance of anecdotal evidence. I also know that people may not always base what they say on scientific evidence, but they are sharing personal experiences that should not be ignored. That’s something I hear from many Ménière’s sufferers. They miss the person they ‘used to be.’ They often feel ignored or misunderstood by others. I use the term ‘feel’ because it’s emotional in addition to being physical.

Scientists and members of the medical profession who work with Ménière’s patients are familiar with the psychological and emotional toll —

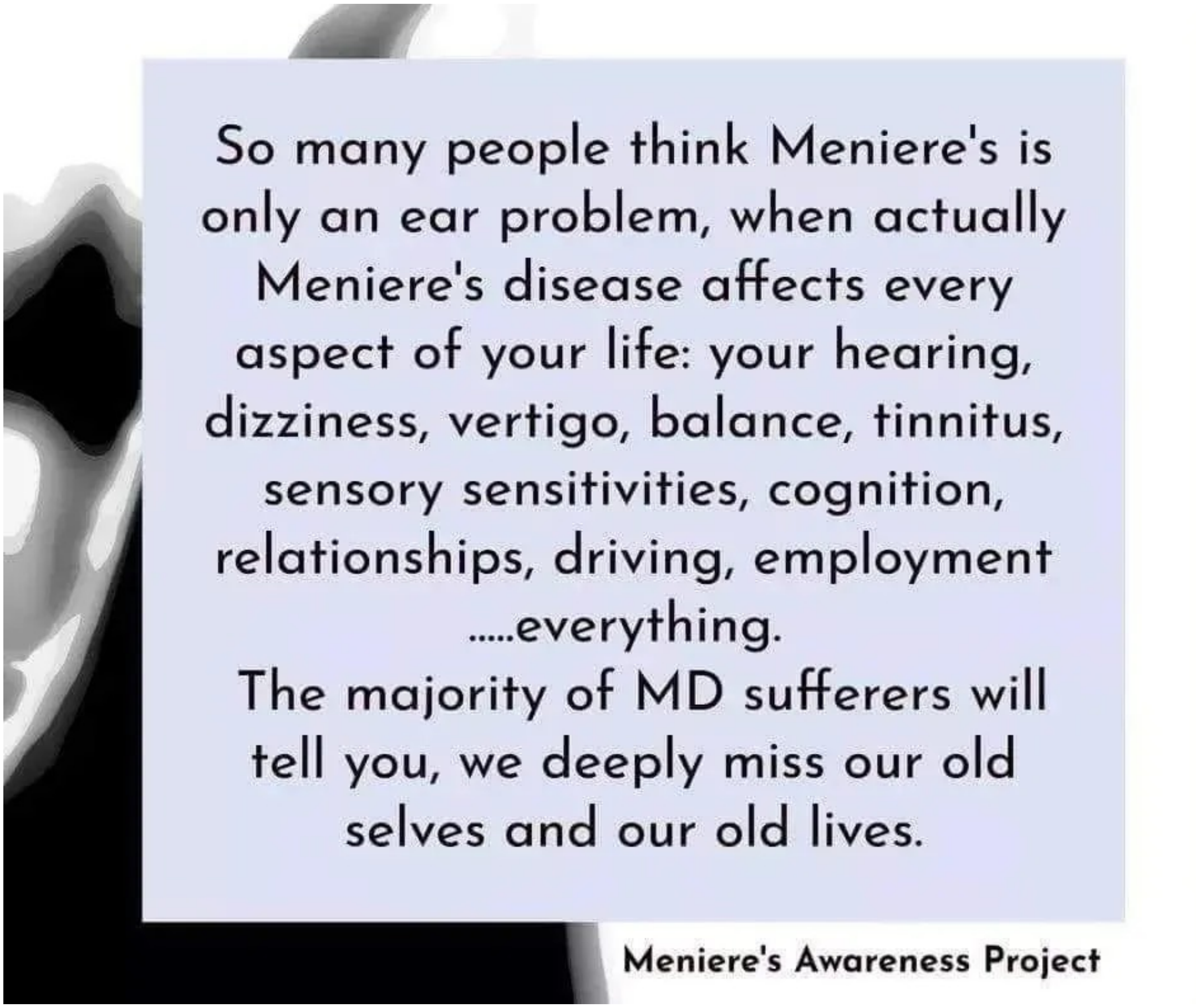
> “The unpredictability and disruptive nature of Meniere’s disease symptoms can lead to increased stress, anxiety, depression, and social isolation if not adequately managed.” Barrow Neurological Institute

"Meniere's disease not only affects your physical health but can also take a toll on your mental and emotional well-being. Feelings of frustration, isolation, or anxiety are common, especially during unpredictable episodes." Harley Street ENT Clinic

"Many physicians have observed that psychological factors play a significant role in the course of Meniere's disease (MD), with Meniere's patients being subject to anxiety and tension states. A lot of research attentions from a psychological point of view have been directed at MD, with earlier researchers focusing on psychosomatic causes of the illness as well as its somatopsychic result. However, the question whether MD is caused by psychological factors or whether the psychological manifestation in MD is as a result of the illness is still unresolved." National Library of Medicine

"The everyday implications of the anxieties stemming from these different attacks resulted in a significant loss of confidence, independence and a deep sense of frustration, particularly for participants whose symptoms were not alleviated with medication. As one participant (Yvonne) said, 'How do you handle it? How do you get on top of it? Can I shoot at it with a machine gun? Can I talk to it? What can I *do*?' This sense of powerlessness extended to partners and close family; as noted by Kosciulek (2010), 'coping rarely takes place in a social vacuum – many stressful events of daily living involve other persons'. Participants expressed resignation that, short of ensuring their partner's physical safety, little could be done to stem the progression of an attack or Ménière's in general." Wiley Online Library

Just In My Head?



So many people think Meniere's is only an ear problem, when actually Meniere's disease affects every aspect of your life: your hearing, dizziness, vertigo, balance, tinnitus, sensory sensitivities, cognition, relationships, driving, employment .....everything.

The majority of MD sufferers will tell you, we deeply miss our old selves and our old lives.

Meniere's Awareness Project

Many Ménière’s patients complain that family, friends, co-workers, and even doctors often tell them that what they experience is ‘just in their heads’ and they need to ‘get over it.’ As a long-time Ménière’s sufferer with a lengthy family history of the disease, I can tell you that response is improper, insensitive, and often incorrect.

I read complaints like those every day in multiple Ménière’s forums where patients ask questions and share their concerns. I’ve also communicated with numerous Ménière’s patients through the years and have heard their concerns firsthand. Many say they feel ‘cursed’ and wish they could ‘die’ because of how bad Ménière’s affects them.

Here are some other things Ménière’s patients have expressed to me or in forums —

- Frustration by sufferers at not being believed about what they say they experience with Ménière’s
- Frustration at being labeled as ‘lazy’ and ‘faking’ symptoms to get out of work or other responsibilities — this can lead to a feeling of being misunderstood which can lead to a host of negative emotional responses
- Frustration that after first being identified as a disease more than 150 years ago Ménière’s continues to have no cure and be no closer to a cure than it was decades ago — many Ménière’s patients complain that the medical community does not take the disease seriously enough to find a cause and cure
- Anxiety and fear at suffering from Ménière’s for months or years and not knowing when or where the next attack will hit them — some emotional counselors call that *anticipatory anxiety*

- Having chronic symptoms that can feel unending and relentless — that can lead to a feeling of 'being alone' in the world which adds even more stress

- Being tired of 'being tired' much of the time — Ménière's fatigue is a tough factor that many patients face every day

- Frustration and anger at not being able to accomplish projects that are important to them

- Tinnitus and hearing loss can make communication difficult, causing a feeling of isolation and impacting their quality of life — it can also lead to the lack of ability to concentrate

- Difficulty in trying to shop at stores because of light sensitivity (photophobia) — patients often shop very quickly to get in an out of stores or ask someone else to shop for them

- Difficulty in trying to find restaurants where patients can both hear conversations and low-sodium food selections — this problem keeps many Ménière's sufferers from going out to eat with family or friends

- Frustration at the loss of some memory during times of ‘brain fog’

- Frustration at how the disease can affect their ‘mood’ — that can lead to interpersonal problems with family and friends

- Frustration at having to cancel personal plans at the last minute because Ménière’s — patients often believe they are ‘letting down’ family and friends, which can lead to depression and feelings of hopelessness

- Loss of control and independence by having to rely on others to help them do even the easiest things (e.g. shopping, driving, visiting family and friends, participating in social events)

- Fear of leaving your home during winter weather because of the possibility of losing balance on snow or ice

- Frustration with vertigo attacks, vestibular migraine headaches, and physical instability when weather systems change (e.g. pressure changes, incoming storms, etc.)

- Avoiding travel, social events, or other opportunities because of fear of having an attack away from home
- Depression and lack of hope from the ongoing physical and emotional impact of Ménière's on their daily lives
- Loneliness and isolation that often come from not being able to attend events with family and friends, or not being invited because people assume you won't be able to come because of Ménière's
- Not having close friends because they don't understand why you are the way you are and even afraid of being around you if you have an attack because they don't know what to do
- Having to stop doing things that used to bring them great joy — that can bring on an intense feeling of loss — many people say they mourn for their "previous self" — they want to return to the way things were before Ménière's
- Having to quit, retire or change jobs because Ménière's made working in their chosen career field too difficult or dangerous — I had to retire early, so I understand that

> frustration — early retirement or the inability to earn a living can lead to financial difficulties that can makes life more challenging

As one experienced Ménière's surgeon told me — "the one thing we know about Ménière's is that we don't know anything about Ménière's." This is a specialist who has performed thousands of intricate surgeries on Ménière's patients. His comment was based on both scientific evidence and professional observation from his many years of practice. That's valid from his perspective and that of many other Ménière's experts I've talked with about the disease.

So many of the stories from Ménière's patients are heartbreaking. I recently communicated with one young man in his twenties who was suffering from tinnitus and vertigo. He worried that he would never be able to get married and have a family because of his condition. Other people worry about raising their young children or losing their jobs because of their Ménière's. I've talked with sufferers who say they've struggled to find a doctor who would take them seriously about their condition. When they did find a medical professional who took them seriously, they were both grateful and loyal to them.

The Medical Profession and Ménière’s

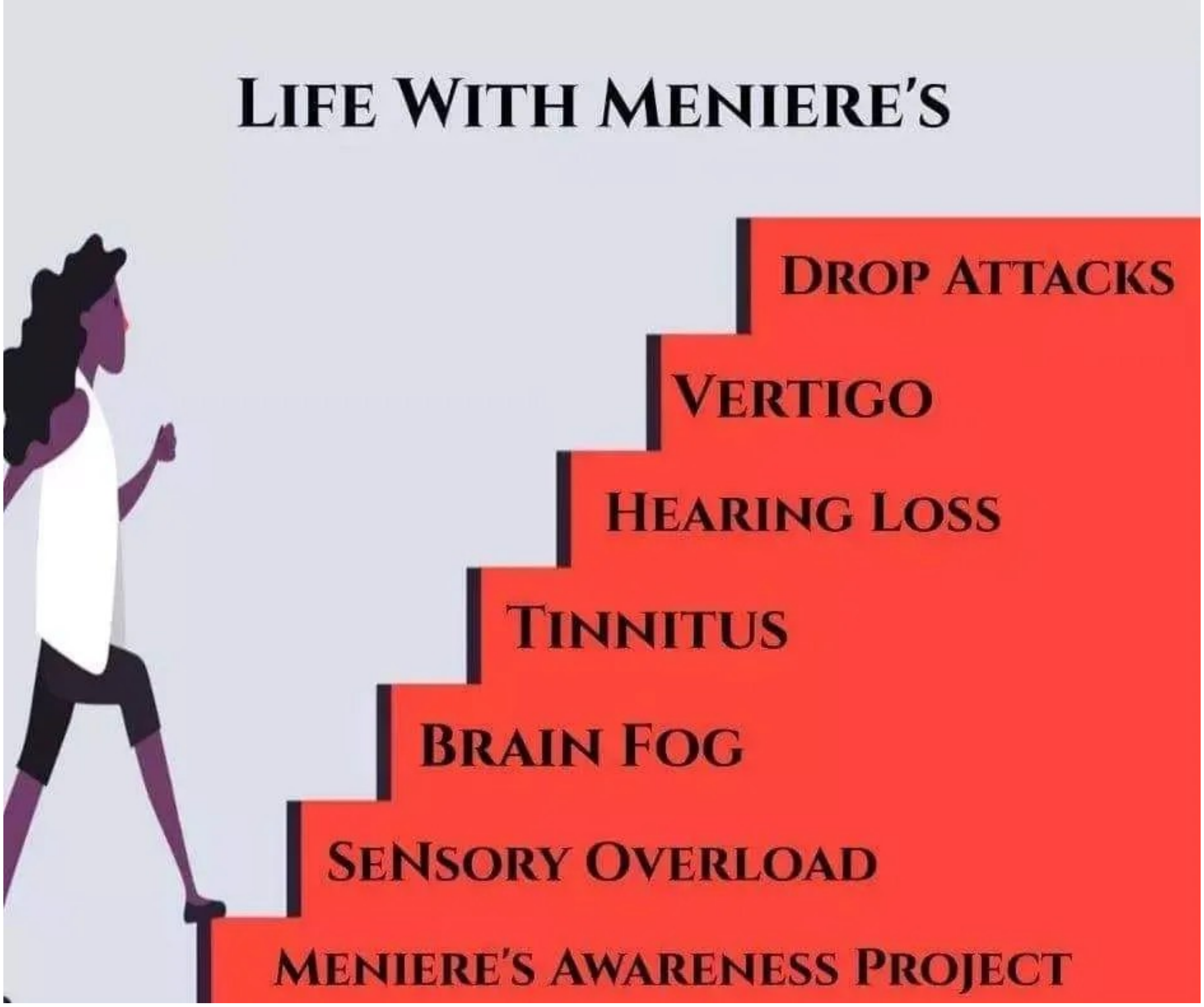
Doctors:
Meniere's isn't
just vertigo,
hearing loss
and tinnitus.
That's
just the tip of
the iceberg.

Meniere's Awareness Project

I have found that many people in the medical profession don’t know much about Ménière’s. Fortunately, in my experience, most expressed an interest in learning more about the disease. I appreciate that attitude. One of the reasons I started this section of my Substack almost three years ago was to give Ménière’s patients scientific evidence they could share with their health providers.

Ménière’s is a rare disease, so the patient who is armed with scientific evidence may be able to educate people in the medical community who don’t know much about it. Having the evidence available during a doctor’s visit may mean the difference between getting real help and being brushed off as not knowing what you’re talking about. Because I have a rare form of a rare disease (e.g. bi-lateral and genetic/familial Ménière’s) I’ve had the opportunity to help medical professionals better understand my physical situation. You never know how something you share may open a door to a medical professional’s understanding to help you and others.

What's the Solution?



While you may not find a permanent solution to your experience with Ménière’s, you can find ways to cope with it —

- Talk with your doctor about foods that may cause you problems — a low-sodium diet is often recommended — find out what other foods may trigger attacks — drinking less caffeine and alcohol can also help — also learn what foods and vitamins can help improve your situation — many medical professionals recommend vitamins B, C, D, and Zinc among others
- Ask your doctor about rescue medication that may help mitigate the severity of vertigo attacks
- Drink more water — stay hydrated throughout the day
- Find a good vestibular therapist — they can help you learn exercises that will help you improve your strength and balance — as important as that is in your 50’s and 60’s, strength and balance become even more vital in your 70’s and 80’s — As difficult as it has been at times, I still try to practice T’ai Chi a few times each week,

along with lifting weights for about 30 minutes, and walking a mile every day I can.

- Learn how to use 'box' breathing, 'belly' breathing, and other types of breathing exercises to calm your mind and body before, during, and after a Ménière's attack

- Get emotional support — that may come from a vestibular therapist, group therapy with other Ménière's patients, trustworthy online forums, understanding family and friends, medical specialists who care about you as a person — it's important that you stay connected to others and don't feel isolated from the world around you

- You may find 'journaling' helpful — write down your thoughts and feelings between attacks — do you find anything in your experience that might help you improve your way of handling things in the future? I have found that doing journalistic research about Ménière's and writing articles for this Substack section has benefitted me personally — the feedback I've received from people who read the articles give me hope that the challenges I've faced with this disease haven't been wasted.

- Stay as positive as possible — I have long been a proponent for memorizing Scripture and found that repeating some of my favorite verses prior to and during attacks help me get through some tough times — I also find great comfort in listening to Christian music when I'm feeling the physical and emotional weight of this disease
- Get physical support — let family and friends know what they can do to help you when you have an attack (e.g. keep you from falling, getting you into bed to lie down, helping you take rescue medication when you're not able to manage that, making you as comfortable as possible during and after an attack, staying with you through the early part of a bad attack — having an understanding 'support team' can take away some of the fear of having attack without having any help — the more family, friends, and co-workers know about what they can do to help you before, during, and after an attack will help you feel less fearful

- If you are alone, have a plan for what to do when you feel an attack coming on — that may mean having a place in your home or work where you can sit or lie down for safety sake — having a wheel chair nearby at home or work will help you navigate to a 'safe place' if you have an attack while alone — sending a quick text message to a family or friend that lets them know you're having an attack can also be helpful — it can be as simple as a one or two word (or number) text since texting during a spinning attack is difficult to do

- Continue to do activities that you enjoy for as long as you can — unfortunately, Ménière's is often about losing things that once brought you great joy, but don't give up — there are days I'm too sick to write, but I write as often as I'm able — the same goes for spending time with my family — sometimes I can't do it, so I treasure the times when I can be with them

- Determine your own methods for socializing — that includes location, noise, letting people know when you need a break or need to leave

- Develop a plan for dealing with attacks — that may include better understanding what ‘triggers’ attacks and deleting as many triggers as you can — keep your rescue medication and a ‘vomit’ bag with you at all times

- Prepare your home and work area with personal safety in mind — that may include no throw rugs, grab bars available in certain areas, shower seats, etc.

- Avoid stress and overexertion — learn ‘coping skills’ to deal with stressful situations — don’t ‘overdo,’ even on things you enjoy — if you have attacks after overdoing something you enjoy, you may find yourself avoiding the things you enjoy — try to not let that happen — don’t give up

- Maintain a consistent sleep schedule — try to go to bed at night at the same time — same with getting up in the morning — if you need an afteroon nap because of Ménière’s fatigue, take one but try to keep it short enough that it doesn’t affect your sleep schedule later that night — taking short naps or just closing your eyes for 10-30 minutes can give your brain a needed rest —

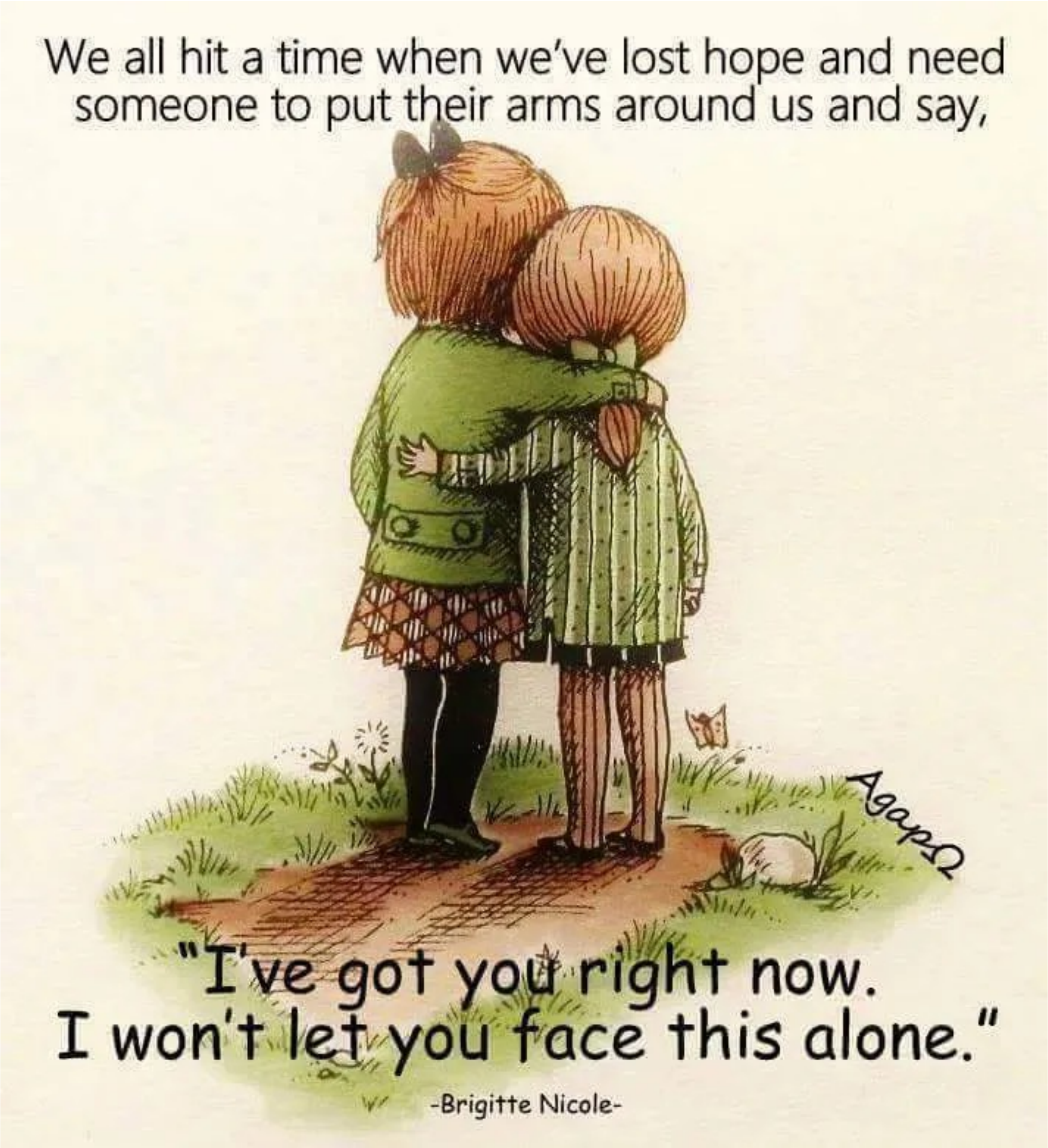
your body and brain are working hard all day to keep you balanced

- If tinnitus makes sleeping difficult, use sound machines, soft music, air filters, or other pleasant sound-generating devices to ‘mask’ that annoying tinnitus
- If possible, turn your better ear toward a person you are talking with — if necessary, explain to them why you are doing that so they will understand
- Purchase ‘safety equipment’ that can help you with loss of balance or instability (e.g. cane, wheelchair, rollater with a seat, grab bars in bathroom/tub shower, shower chair, etc.)
- Use noise-cancelling headphones or earplugs in noisy environments — if you don’t have them with you, plug your ears with your fingers — loud noises can trigger vertigo attacks
- Close your eyes when lighting is uncomfortable or when sights (e.g. television shows, movies, video games, etc.) cause you to feel dizzy — bright, flickering, or fluorescent lights, as well as intense visual patterns are

among the worst — soft lighting is best to use when possible — some suffered have found that blackout curtains are helpful, along with reducing screen time

- Use closed captioning when watching television shows if you have problems hearing the audio
- Don't drive when you are having an especially difficult day or feel like you may be close to having a vertigo attack — ask a friend or family member to drive you
- Let your boss know about your condition and ask them about possible accommodations to make the job work better for both of you — let your co-workers know why these accommodations are being made for you and how they will help you be a better member of the work team

We'll look at the emotional toll on 'Caregivers,' in the next *Ménière*'s *Years* newsletter.



"… rejoicing in hope, patient in tribulation, continuing steadfastly in prayer." Romans 12:12

Here's to hope!