Part 13

The Emotional Toll on Caregivers

By

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Here's how I opened the last newsletter —

> "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."

What would we do without the people who 'care' for us? They are usually family, neighbors, friends, or co-workers. The more they understand about Ménière's Disease and its effects, the more they can do to help us. However, those of us with the disease should remember that our illness also takes a toll on them — the ones who 'care' for us.

I mentioned in the last newsletter that Ménière's sufferers need physical support. We should let family and friends know what they can do to help us when we have a vertigo attack (e.g. keep us from falling, get us into bed to lie down, help us take rescue medication when we're not able to manage that, make us as comfortable as possible during and after an attack, stay close by during the really bad parts of an attack, etc.). Having an understanding ‘support team’ can take away some of our fear of having these terrible attacks.

However, being a caregiver for someone with Ménière’s takes a toll on them as well — an emotional toll that can affect them for years. Being a ‘caregiver’ begins with learning about the disease and how it impacts the ‘Ménière’s sufferer’ —

> “Coping with Ménière’s disease is challenging because attacks are unpredictable, it is incurable, some of the symptoms are not obvious to others, and most people know virtually nothing about the disorder. Many people with Ménière’s disease are thrust into the role of educator—they must teach themselves, their family, friends, coworkers, and sometimes even health care professionals about the disorder and how it impacts them.
>
> Key features of communicating with family and friends include informing them about what might happen with the onset of an acute attack and how they can help. If a low-sodium diet is effective, family and friends should be informed about how important it is for them to support

adherence to the diet regimen. Changes in lifelong eating patterns can be easier with the assistance of others.” VEDA

The Emotional Toll on Caregivers

Learning about Ménière’s Disease is one way to help caregivers cope with what you (and they) are facing. However, knowing about a disease and experiencing the effects of a disease on someone you care about are usually different. One person on a Ménière’s forum described watching a loved one go through a vertigo attack as ‘heart-wrenching.’

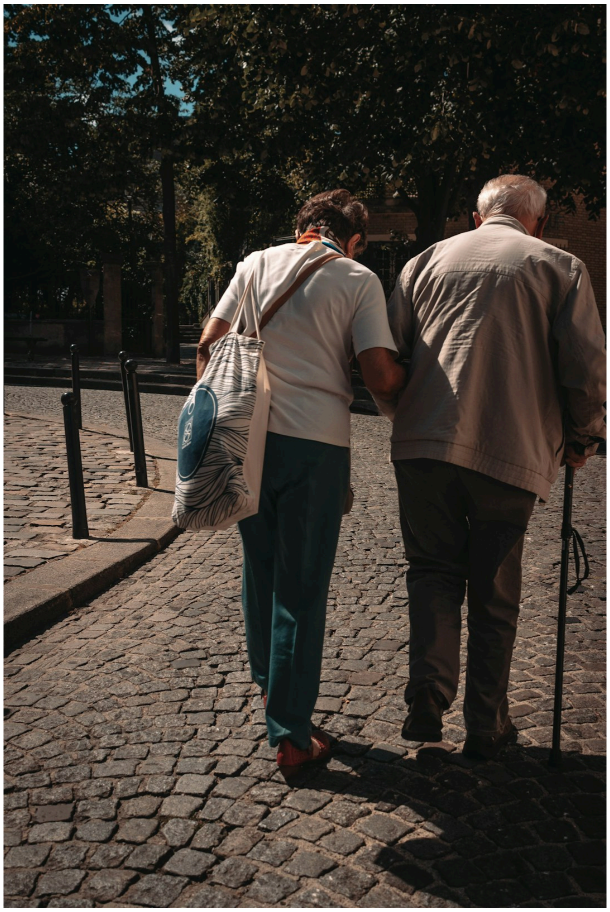

Photo by Mathias Reding on Unsplash

If you are 'caring' for someone with Ménière's, here are some ideas and actions that may help you —

- First, it's natural to feel deep emotions for someone in your life experiencing Ménière's vertigo attacks. Those attacks can be frightening to both the sufferer and the caregiver. Fright often occurs because little is known about what's happening, why it's happening, and what the future holds. That's why getting answers to your questions from knowledgeable medical professionals as soon as possible can help both the caregiver and the patient emotionally. My wife and I will be forever thankful to a friend who recommended a doctor who has helped us tremendously through the years — both physically and emotionally.

- Second, remember that someone else's Ménière's Disease is not your 'fault.' Don't get caught up into feeling guilty about it. There are so many different reasons why people have Ménière's. One of my reasons is 'familial' (genetic). That's certainly not the fault of my wife, friends, or neighbors. It is what it is. Best thing for me and anyone who 'cares' for me is to learn as much as possible about Ménière's and what to expect as the disease progresses.

- Third, caregivers should remember to take 'care' of themselves. Caring for someone with Ménière's Disease is tough and may be difficult for a long period of time. Many family caregivers, especially spouses, often feel alone. Be kind to yourself. Give yourself the opportunity to feel what you feel. Don't 'stuff' your feelings. Realize that you are also 'suffering' as you watch a family member or friend suffer. Don't think of taking care of yourself as being 'selfish.' It's not. Doing things to help yourself is healthy and smart. Also, develop your own 'support network' of family and friends. Burnout is a real problem for caregivers. You may experience feelings of isolation, frustration, exhaustion, and being overwhelmed. Find people who can care for you and your emotional needs while you care for the physical and emotional needs of your loved one or friend who has Ménière's Disease.

Ways You Can Help Yourself

Here are some ideas that may help ‘you’ as you care for someone in your life —

- Ask questions about what can ‘trigger’ the attacks. You can look back at previous newsletters I’ve written that address many of them. Once you know more about what triggers the person you’re caring for the better you’ll be able to help them have fewer attacks or at least mitigate the seriousness of the attacks. You may want to work with the Ménière’s patient you are ‘caring for’ to develop a journal that lists foods, stimuli, events, etc., that may lead to an attack. Keeping a journal may help both of you to better understand how to best deal with the effects of the disease.

- Go to doctor appointments with the person you are caring for and ask questions that help you understand the disease and its impact. Be honest with doctors and nurses about how being a caregiver is affecting you. In my experience, doctors and nurses who care for their patients also demonstrate care for the caregivers.

- Vertigo attacks, as awful as they can be, don't last forever. The person you are caring for may look fine one moment, then have a serious attack that lasts for hours, but they almost always get through it. You can speak kindly to the Ménière's patient you're helping and comfort them as they go through an attack. That means the world to someone going through the attack. I appreciate the kind words shared with me as I suffered through one attack after another through the years. When the attack subsides and the sufferer goes to sleep or is at least able to rest somewhat comfortably, give yourself a 'break.' Get some rest yourself. Read a book. Listen to some favorite songs. Call a friend. Don't let worry take over your emotional health.

- Let the person you're 'caring for' talk about their experience. What they share may give you clues to ways you can help them better and may also calm some of your worries and fears. The more attacks I experienced through the years, the more I was able to tell my wife that it would eventually pass and we'd get through it together. Talking honestly about how each of you 'feel' about the attack may help you both deal better with future attacks (and the future).

- Caregivers, especially family members, are also impacted by sudden changes in plans because of a Ménière’s attack. Having to tell other people you can’t come to a planned event because you’re caring for a loved one or friend who is having an attack or an especially bad day can be stressful and even embarrassing.
- Months and years of having a chronic disease like Ménière’s can take an emotional toll on sufferers. It can also take a toll on ‘caregivers.’ Everyone needs to understand that. Ménière’s affects sufferers in different ways. Medical experts talk about a variety of ‘stages’ that a patient may go through during their life with Ménière’s. That means ‘caregivers’ will also go through those stages with the patient. Learn as much as you can about what the future ‘may hold’ for your loved one or friend because that will impact your future as well.

Giving Care

Ménière’s Disease is just one of scores of illnesses that require family or friends to care for sufferers. Whether you are caring for someone with Ménière’s Disease or another illness, someone who has been injured or had surgery, or an elderly person who can no longer take care of themself — be sure to take care of yourself.

Resources

A Caregiver's Guide to Meniere's

Understanding the Emotional Toll of Caregiving

Easing the Waves: A Practical Guide on How to Support Someone with Meniere's Disease

Taking Care of Yourself: Tips for Caregivers

Caregiver stress: Tips for taking care of yourself

Taking Care of YOU: Self-Care for Family Caregivers

Self-Care Tips for Caregivers: Your Health Matters, Too

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

Here's to hope!

Next Time

We’ll look at the latest medical research in the next *Ménière’s Years* newsletter.