

The Canadian Hard of
Hearing Association was
formed to give visibility to
an invisible disability.
It promotes self-help among
hard of hearing and deafened
persons and encourages
support for individual and
collective action.



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Canadian Hard of Hearing Association, Sudbury Branch

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Approaching Meniere's Disease Positively — There is Hope

Meniere's Disease is a Condition Affecting the Nerves of One or Both Inner Ears.

By Karen Henderson

I wrote this letter to one individual reader way back in 2004. He had responded to a website first set up in 2000. The website started off with "Do you suffer from dizzy spells? Have you been diagnosed with Meniere's Disease?"

We had no idea that David was doing this! But it was his attempt to help others with this debilitating condition. He knew he could help. Then we had to hustle to deal with the influx of emails!

Like many other Meniere's disease sufferers, this gentleman was very concerned at not getting any helpful and hopeful information about Meniere's: the outlook for his future was dismal.

At that time, there were very few Internet

sites discussing Meniere's disease. So in 2004, in response, I wrote this

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Dream Home Opens & virtual tour on!



The Ultimate Dream Home officially opened for public viewing on Friday, November 24th. And with it, came the new virtual tour of the home that stands on Noah Court in the Minnow Lake area of Sudbury. Viewing hours are 9 a.m. to 6 p.m. Thursday through Sunday this year.



The Hearing Husband Speaks

By Gael Hannan

I frequently write about Doug, aka the Hearing Husband, because he's the most important relationship in my life, the person I spend the most time with. He is both my major support team *and* the leader of the opposition.

I'm sure this is typical for most intimate relationships, many of which must deal with one or both people living with a disability. In ours, it's my profound hearing loss. (He also has a profound listening problem, but that's another story.)

Ten years ago, I wrote an article, What the Hearing Husband Really Thinks. The initial interview didn't go so well, showcasing that this is a sensitive issue. And that remains ture today because hearing loss affects communication which is the cornerstone of any relationship.

So, a decade later, here's an edited version of the original article.

"You want me to WHAT?" he asked.

I tried again. "For this week's blog, I would like you to answer some questions about what it's really like being married to a woman with hearing loss."

He thinks a moment. "No."

"Why not!?"

"Because my gut tells me this won't go well. When people say what they really think, shit can hit the fan."

"The fact you just said that tells me there are issues that need to be aired. C'mon, it will be fun - we've talked about this stuff before."

"No. Write about something else."

"OK, what if I promise, that no matter what you say, I won't punch you in the face or move to separate beds."

He sighs, which is as close to a 'yes' as I'm going to get.

"OK, thanks honey. Here's a list of questions that you can think about and then give me the answers on paper. That way you won't have to look me

in the eye when you say stuff you think might upset me. Which it won't, I promise."

Before heading off with the questions, the Hearing Husband looks at me as if for the last time – as if our relationship is about to take a sharp turn over a road of hot coals or cold thumbtacks.

When you first met me, did my hearing loss give you any concerns about going forward with our relationship? (Give examples and don't mention that we worked together.)

On the contrary, that was part of who you were. I thought that someone who had such a fun personality and did well in spite of her hearing loss was going to handle life's other challenges too, and therefore be a great partner going forward. I was right! But I can imagine that it would be hard for couples when hearing loss occurs later in their relationship.

You proposed to me when I wasn't

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Join us for a ratime Canadian Hard of Hearing Association Association des malentendants canadiens

A Haunting In Venice

A Hercule Poirot murder mystery

Thursday, December 14th, 1 p.m.

CHHA Sudbury Office — 435 Notre Dame Ave., suite 101

All Movies shown with subtitles. Venue is Looped for those with telecoils. Personal FM's Available. Refreshments provided.

Seating is limited, please reserve your seat early.

¥523-5695

Hearing Husband Speaks . . .

(Cont'd from page 2)

quite awake and didn't have my hearing aids in. Did you:

a. Plan this as a practice round, hoping that I wouldn't open my eyes when I did?

b. Forget that I was hard of hearing?

c. Hope that I wouldn't speechread you correctly and would answer 'no', thereby letting you off the hook?

None of those quite fit. You're an excellent speechreader. I'd wanted to ask you the night before and I was running out of opportunities and nerve. I remember looking at you for 15 minutes or so, saying it over and over; it was a relief when you finally opened your eyes and could see what I was saying!

What are the major challenges in this relationship with hearing loss?

Losing sight of the puck when the captioning covers it during a TV hockey game. (And this is not a minor thing, I love watching hockey!)
Truthfully, the biggest challenge is making sure our time with

friends and family is accessible for you, because of your great love for conversation. Sometimes I just leave it up too much to you, to ensure the environment is right.

[Me: "C'mon, how about when I get huffy based on what I thought I heard you say?"

Him: "Minor stuff."

After 25 years, would you say that you are more, or less, patient with my hearing loss?

More patient. 25 years mellows you a lot.

How would you rate yourself as a hearing partner? Give examples.

This question is a setup! I will say *only* that how *you* score *me* is what counts. We're still together after 25 years – you want more backup than that?

If you could change anything about our relationship with hearing loss, what would it be?

Not a thing about you, but I get frustrated with myself when I forget to face you or walk away while talking. And when you get visibly irritated when I repeat something while overenunciating.

Any additional comments?

I love you - ok, are

we done?

What was he worried about? Hearing loss touches every family differently; some couples crack under the strain, but we're lucky because the Hearing Loss Woman and the Hearing Husband are only two of the names we go by....

Meniere's Disease . . .

(Cont'd from page 1)

long letter, explaining what I knew about Meniere's Disease, little realizing it would take a few more years before we realized that some THING(s) caused these symptoms...that you could track them, and that there would be things you could do to help yourself.

Sadly, the medical community still maintains this old thinking ("incurable, you have to live with it"), but luckily, we all know differently now.

Here now, in 2023, I thought it would be interesting for you to read "our thinking" and explanations that we had for these balance and hearing symptoms. I have made a few comments just to show how things have changed. In this newsletter I am also sharing the story that started me on the "cause and effect' journey.

This is my original 2004 response to a very fearful reader. But I felt it was necessary to update the information a little for 2023. So the "new" information shows up just a little differently.

Meniere's Disease is a condition affecting the nerves of one or both inner ears.

I want to share a little about a very disruptive and debilitating condition. I wrote about it a while ago, but not in much detail. Through thousands of emails, I have learned a lot: about health care and about people, and it's time to say a little more.

Normal Far Function

Each inner ear has two nerves running side by side: the balance (vestibular) nerve and the hearing (acoustic) nerve. Normally the balance nerve will send and receive messages twenty four hours a day to keep your body in whatever position you choose to be in... bending over, shifting your weight, turning your head, etc. And the

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Hearing Hacks to make social events more satisfying for everyone involved

Part 1: Dining Out

By Gael Hannan and Shari Eberts

Socializing with hearing loss can be a loud and stressful experience. Today's popular restaurant décor includes hardwoods, mirrors and metal — all surfaces that reflect noise rather than absorb it. At cocktail parties, many voices talking at once will make it hard to pinpoint the voice you are trying to hear. People with hearing loss often opt for an easy out — dominating the conversation or nodding, smiling and hoping your responses are appropriate.

But that's not you, is it? Use these Hearing Hacks for a more satisfying experience for everyone.

Choose a quiet place:

 Read restaurant reviews for noise ratings or consult a crowd-sourcing app that ranks restaurants in a geographical area by ease of conversation.

- Use online pictures as clues about the décor's potential for noise. Look for sound-absorbing surfaces like carpets, drapes, cushioned seats, cloth tablecloths and acoustic tiles.
- Ask others for ideas — everyone is looking for a quieter place these days.

Plan ahead:

- When you make the reservation, specify your needs. Don't just ask for a quiet table. Mention your hearing loss and ask for a table in the corner or by a wall.
- Consider eating at off hours when restaurants are quieter (although dinner at 2 p.m. might be a bit early for some people). Management may be more open to requests like turning down the music at those times.
- Dine outside if the weather permits.
 Outdoor spaces

- have fewer hard surfaces to reflect sound and more organic material to absorb it.
- Limit your group's size to 4-6 people for easier conversation and lipreading.
- Request a round table. Group conversation is easier because everyone will be equally visible for speechreading. Or choose a booth that absorbs sound and contains the conversation to the confined space.

Make environmental changes as needed:

- Become confident in asking for another table (if the first one is inadequate) or for the manager to lower the music.
- Ask to see the specials in writing rather than spoken by the waiter. Alternatively, ask the server to stand close to you and articulate the specials clearly.

Pick the Right Seat:

When dining with a

- large group, seat yourself in the spot that works best for you.
- Position yourself in the center to be closer to a larger number of diners.
- Sit with your back to the wall to reduce distracting noise behind you.
- Situate difficult-tohear people across from you for easier speechreading.

Use Technology Fixes:

- Ask your Hearing Care Professional to create a restaurant program for your devices that blocks out background noises and focuses on voices.
- Use an assistive listening device that brings voices into your ears, such as a remote microphone that your dinner companions can clip to their clothing or that can be put on the table.
- Use a speech-totext app to understand what others are saying.

Meniere's Disease . . .

(Cont'd from page 4)

acoustic or hearing nerve is there to receive and interpret sounds so they will have meaning for you.

For instance, if you are exposed to loud noise, you will be able to do some correction because it feels so uncomfortable. And, normally, sound-wise, you have a lot of silence interspersed with ordinary noises or unusual tones. You can handle all this nicely.

If you are exposed to some balance problem, chances are you won't know about it, but the brain senses this imbalance and sends a message asking the inner ear's "vestibular" or balance nerve to correct it. Unless you are "hearing -impaired" you will have these nerves working properly, but you most likely take their activities for granted. And it's important to know that each ear and its parts functions fairly independently. Just as one hand can manage lots of activities, so can the ears.

Although it can be troublesome and often terrifying, Meniere's is not something that's

> contagious. Meniere's symptoms usually occur

in only one ear. It affects both ears in only about 30% of people.

Signs & symptoms that cause most of the difficulty are characterized by abnormal sensation of movement (vertigo), loss of hearing, and noises or ringing (tinnitus) in one or both ears, and pressure or fullness in the ear.

Vertigo is most easily explained as the sensation of a room spinning out of control, but there are different degrees of this spinning. For some people it's a very fast spin...for others, it gets to the point of dropping to the ground without any prior warning! And still for others, it's a gentle movement, still unpleasant, but the person can "live with it". For some, it's a dizziness that comes and goes...usually without warning.

Tinnitus is noise: again different degrees of loudness or shrillness.

Hearing fluctuation is the changes of the sounds: high or low pitches.

Pressure or fullness in the ear is the sensation that there is "something" in the ear...a very frustrating and uncomfortable feeling.

Our nerves automatically carry through with these messages or commands. It is your body's intention to be "in balance" at all times, so it adjusts for any differences.

Why do some people get Meniere's Disease?

This is seen as a degenerative condition. This is not part of the normal aging process (otherwise we would all be getting this).

That means something has worn down or been damaged. Most people get some or all of these symptoms of Meniere's disease in different degrees or intervals at some point in their lives and think nothing of it. With Meniere's sufferers, these "normal" activities seem to be hindered, impaired, or completely incorrect. So messages are either not going to be received correctly or will it be misinterpreted and returned with a false command, because the nerves that should be receiving the "information" are not healthy (for whatever reason).

You may not think very much about these symptoms until you have someone close to you do something very strange.

But I would like to be just a bit clearer, so if you ever have an occasion to see this in real life, your reactions will be sympathetic, helpful, and resourceful. For instance, being able to hear someone speak (acoustic) to you one minute and not being able to hear them at all the next second, is rather unnerving and distressing.

But standing upright one minute and finding yourself on the floor, cut over an eye, is entirely another shocker! This is not a conscious or chosen activity. The person simply has no control over the episode. Something at that point has disturbed the inner ear's balance nerve, in a very direct and severe way.

Causes?

There are many theories, and none are definite. Some of the medical community feel this is the body working against itself (auto-immune), others feel it's a virus, and many just feel it's there because something has damaged the inner ear nerves or tissue. It's virtually impossible to take a direct look at the inner ear's working.