

**First written 2008 updated annually. (Current as of May 2018)**

## MY STORY

***I first developed Ménière’s when I was 18 years old, in 1963.*** I was living in Woomera, Australia and medical professionals were sparse in the desert. The occasional mild dizziness was put down to an English person being less than cautious in the hot desert summer. Tinnitus was present but was relatively insignificant. Ménière’s was not suggested at this stage.

Settling in Adelaide in **1969** for the birth of my daughter the attacks began again although mild at this stage. My neighbour suffered hay fever, and I suspected my condition may be connected with allergy, as each time she had streaming eyes and nose, I suffered a dizzy attack. I drew the conclusion there may be an excess of fluid in my ears causing dizziness rather than having the typical hay fever symptoms. I took my suspicions to my doctor and ultimately the ENT specialist. Ménière’s was diagnosed. Stemetil was recommended but failed to prevent symptoms. It is prescribed for nausea and was ineffectual for the Ménière’s attacks. Several years passed as I coped with the seasonal dizziness. Many months free from the condition allowed me to continue my part-time singing career and raise my child.

By **1984** attacks became more severe and life began to be severely disrupted as a result. More was known about the condition so with further investigations it was suggested I consider Endolymphatic Shunt surgery, which I readily agreed to despite the odds against a trouble free outcome. This brought relief from the attacks, though a predicted loss of hearing as a result of the invasive surgery was a huge disappointment. A permanent post-nasal drip is a constant concern. I recovered well from the surgery. I’m told this procedure is no longer performed as a matter of course, I suspect as a result of permanent hearing loss. It’s a price to pay – to be considered.

As a singer I was often concerned should I lose hearing in both ears. As singers are right ear dominant I was still able to pitch perfectly despite diminished hearing in the left ear. During my singing career of thirty years, approximately 500 performances and 60 productions I only missed one performance as a result of Ménière’s. I often wonder if adrenaline has a part to play in the control of this condition.

During this newfound freedom in **1992** I began facilitating a group that helps women realise their potential through making sound, life-changing decisions. This instigated much research on health and issues relating to creating a balanced life in all areas. I was led to think laterally, be questioning and value the positive aspects of life. The adult study and ultimate teaching has gifted me with the tools I have had to utilise in the last few years.

Since the surgery, which gave me 15 years without any symptoms of Ménière’s, many life changes occurred. Adding to my stresses was a new marriage, stepchildren, breast cancer, arthritis, menopause, and loss of both parents. Stress and trauma exacerbated the condition and I worked hard to overcome depression at times.

Then in **2000** the return of vague dizzy spells and fluctuating Tinnitus began. Spasmodic Benign Positional Vertigo has plagued me for years but I could sense this was something different. I tried Serc, again with no success so I tried to ignore it for a few years. I began to sink into a depression and lived in fear of the unknown.

By **2003** I had suspicions about excessively loud Tinnitus and increased dizzy spells. Investigations by the ENT guy brought a new list of options to consider. 1. The old shunt wasn’t working. 2. Brain tumour. 3. Some other condition. 4. Ménière’s in the other ear. No 2 & 3 were eliminated.

It was recommended by the ENT specialist I try a combination of Serc, Aprinox and Slow K (a synthetic potassium). Within days of taking this combination of drugs I become violently ill and was on the verge of collapse. A locum summoned during the night recommended I might be allergic to all or some of the medication and upon further investigation I discovered this to be so. Valium was spoken but disregarded. Later in **2003** my hearing diminished almost entirely in the opposite ear over a period of 3 days. It was frightening and Ménière's was not my first thought as the possible cause as I felt quite well at the time. I visited the doctor, chiropractor, dentist, audiologist and finally ENT specialist who eventually made the firm diagnosis of *bi-lateral Ménière's*. The severe hearing loss is permanent. I was devastated.

The Shunt procedure no longer an option, Gentamycin injections were considered and rejected due to my unknown response to predicted side effects. (I am allergic to various drugs.)

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Serc was tried again – it too rejected. Ginkgo Biloba was tried and rejected due to severe headaches developing.

(For those with diminished peripheral circulation it can be beneficial, however I don't have that condition.) Restricting salt in the diet was also suggested. As the least invasive I began reading labels and adjusted my diet accordingly.

'Drop Attacks' began occurring. This is a sudden 'blacking out' for a second or two, causing the person to stagger or sometimes fall to the ground. There is usually little warning and people who experience it should be aware of the dangers. ***The Ménière's attacks I suffered occurred 3 or 4 times a week and became severe and extremely debilitating. Typically I have sudden onset dizziness, nausea quickly followed by vomiting, loss of control over bladder and bowel action, disorientation, extreme anxiety, inability to think or act logically. Generally I cannot move from fear. Basically, at the time, dying would be preferable. These attacks happened any time, anywhere. There's one restaurant that has to change ownership before I can return!***

During this time, through a combination of work issues, age, cost-cutting etc. my husband became unemployed one year before official retirement. If ever there was a case of Divine Intervention this was it. As the attacks worsened my life became an endless series of specialist visits and lengthy bed rest. I more or less cancelled my life. My husband became full-time carer. I had to give up driving. I went nowhere on my own. I did nothing except watch a little TV and read when the dizziness wasn't too extreme. I struggled with household chores. My emergency kit consisting of bucket, water, towel and spare undies, accompanied me wherever I went. Hearing on the phone was now impossible. Tinnitus became so loud; I can only describe the sound and loudness by demonstrating to someone to place the motor part of a hairdryer next to their ear. I became isolated, depressed, dependant, despondent, bereft of quality of life. I wanted to die. Again!

After nine months of horror attacks, a period of adjustment began. In between days of malaise I had a day or two of feeling well. During this time I researched options and alternative modalities. I spent a great deal of time taking care of myself.

In **2004** I was issued with two hearing aides. My hearing has been permanently damaged and is not going to return but now at least I have some hearing, albeit somewhat distorted. People began acknowledging I had a 'real' condition and brought ideas, books and printed information as an adjunct to all my own investigations. I am fortunate to have several caring friends in non-associated medical professions who have helped with research providing valuable information. The Internet has opened up many doors of education on the condition with up-to-date options and support. With renewed hope I began my plan of attack on a life that was not being well lived. I took control!

A heart attack in 2014 can now be added to my list of medical issues but nine months on I am still doing everything I did a year ago and no return of Meniere's. Further dietary changes have been beneficial and heart is back to being healthy with only minimal medication. Blood pressure is good due to low salt diet. I continue reading labels – finding alternative methods of making healthv. flavoursome meals and petitioning

manufacturers to produce low salt alternatives. A knee replacement in 2016 held me back for a few weeks but I recovered quickly and now back to full fitness with lots of walking. I still teach groups part time, attend a drumming group and aquarobics class weekly.

LISTED BELOW are the things that brought me to a place of wanting to live again. I owe my current wellness to this *combination*. I cannot say for certain if any *one* of these is responsible for my current good health. The salt issue is probably the most likely and I adhere to a strict low salt diet.

**Tinnitus Remedial Therapy.** I attended a 12-month University clinical investigation as a volunteer. By keeping records and reporting to monthly sessions we learned about the biology of the ear, causes and therapy for the ear and Tinnitus. A remedial tape was issued which I found less than helpful, possibly because my condition was assessed as severe and unrelenting.

**Music Therapy** is a method of assisting in ear health encouraging the ear to hear, as well as reduce Tinnitus and help with Ménière's. It can also aid many other medical conditions. It requires the user to listen to  
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impregnated classical music for three hours every day for at least a period of three months. This may sound excessive but one becomes so used to listening it becomes a comforting medicine. Two months and two weeks into the therapy my Tinnitus went from a roaring engine to a gentle hum overnight. I was overjoyed and greatly encouraged. I continue to use this daily for half an hour to an hour. © Copyright June Stephenson 2018

**EMDR.** (Eye Movement Desensitisation and Retraining) A friend who is a Psychologist suggested something I had not heard of as a possible aid to Ménière's. This is a method of retraining the brain to be distracted from that which is causing trauma. It involved 8 sessions of one-hour duration. During the 12 weeks of treatment I gradually became well, with no dizziness. Since this treatment I have not had one major attack. This is a landmark! It was suggested, and it has been proved to be the case, I may have a 'shadow' of an attack and should take the necessary precautions and be aware of stress levels and activities.

**Chiropractics.** I am fortunate to have a chiropractor as a very dear friend. He has researched Ménière's and has recommended a specialist cranial chiropractor who also performs Kinesiology. This has helped adjust the upper few vertebra and jaw and ear. After a couple of sessions initially I now only visit 3 or 4 times a year as maintenance.

**Nutrients.** As a cancer survivor I developed a more healthy diet supported by nutrients appropriate to age and other medical conditions. As our fruits & vegetables are depleted of the nutrients our grandparents enjoyed I felt the need to supplement them. I now take Calcium/Magnesium, Vitamin C, Cruciferous, Glucosamine (without chondroitin, which can cause headaches), Multi-minerals or Colloidal Minerals and Goji Juice. Many of these I obtain through a company that backs up its claims with bountiful research and one-on-one consultation. (GNLD)

**NOTE. It is recommended any person wishing to add any supplements to a regular diet should discuss their case with a health professional.**

**MSGV** = Ménière's Support Group of Victoria. (No longer operating but a new support group is now listed at the end of this.) Highly recommended, this valuable support group has given me the resolve to push through the tough times and explore all options. Regular newsletters and meetings provide information with guest speakers bringing their knowledge and the latest medical findings. Sufferers of Ménière's rarely meet anyone else with the condition so being able to share experiences is hugely beneficial. I was in the dark depths when I first rang them and the "angel" on the phone gave me the first glimmer of hope. To know of other sufferers, ongoing research & support has put me on the right road.

**Salt.** The book 'Salt Matters' by Dr Trevor Beard became an invaluable source of information prompting a 24-hour urine collection to establish Sodium/Potassium content within the body. A low count (below 50 mmol's

per 24 hours) is optimal for Ménière's sufferers. Several months of carefully monitoring my salt intake brought me to this level. It is imperative that **everything** you eat is examined for its salt content. Obviously all processed foods contain far too much salt. Surprisingly this includes sweet goods. For those with Ménière's the ideal diet consists of only fresh foods; meat, fish, fruit, vegetables, nuts and seeds. It is recommended that foods containing over 120mg of salt/sodium per 100gm of product be avoided. Almost anything in a can, jar, bottle or packet is off the list. There are very few exceptions and you will get to read a lot of labels finding them. Say goodbye to bacon, anchovies, capers, salted nuts and olives. Be aware celery and some seafood has a naturally high salt content.

Some medication has a high salt content, get used to reading all labels and asking your chemist for guidance. A low salt diet has the added bonus of reducing blood pressure which is good for those with heart / vascular conditions and stroke. Tap water contains salt so buy a filter.

**Medication.** Some medication has a negative effect for those with Ménière's. Any Drug Guide will tell of the side effects of medication, many of which cause dizziness & nausea. Valium has often been recommended. During the worst of my attacks and after consultation and reassurance by my doctor I eventually was forced to experiment with its effects. I found it most beneficial when taken immediately an attack was imminent. Taken only once, occasionally, it was not addictive. I haven't needed it for two years. Be guided by your health professional.

**Accupuncture.** The jury is still out on whether this actually has a lasting effect. It helped me in the early stages of Bi-lateral Ménière's. I see a Chinese guy who is traditionally trained and acupuncture has helped me for many conditions.

**Water / Alcohol.** Drink plenty of water – it flushes the toxins and excess salt. It is recommended you drink less alcohol as this can exacerbate Ménière's. The same is said for coffee.

**Exercise.** Whilst it may not always be possible, exercise, especially walking briskly, can help.

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I swim, attend weekly aquarobics classes and take a long walk a couple of times a week. Other exercises appropriate to age are beneficial. I find drumming and weights suit me. As my balance has been severely affected some activities are more difficult.

**Stress.** Stress definitely exacerbates Ménière's and should be addressed as a matter of priority. I meditate regularly and note when my stress levels are high and take the necessary steps to alleviate stress. Exercise helps, as does yoga. I remove myself from stressful situations and rarely watch the news. Negative influences over a period of time can gradually increase stress until it becomes a problem requiring attention.

**Being Involved.** I am naturally a social person and it was difficult for me being so isolated during the worst of the illness. I began to be in touch with friends again on the phone and email. I joined two new social groups involving activities: African Drumming and Aquarobics. I attended theatrical and sporting events and generally took part in normal life despite severely diminished hearing, dietary requirements and a 'drunken' gait. Everyone has something that restricts their life by the time they reach my age – mine are just a bit different. Vive la difference!

**Positive Attitude.** I chose to be happy! I chose to be well. I was determined and positive that I was doing everything within my power to keep well. And if I felt a little off colour I would grant myself a day off to rest and review my strategies. I now had knowledge and fortitude to keep me on track.

**Naughty June.** Against the wishes of my ENT specialist I have taken risks. I was told I shouldn't fly but as I began to feel well I took a flight to Queensland to warm my arthritic bones in the winter of 2006. Flying for 3 hours at 46,000 feet was an adequate test for my next planned adventure. Six months later an opportunity presented itself and I began to plan a return trip to the UK to visit ageing family. I warned everyone there of my

condition and supplied dietary requirements of basic foods, with the promise of being the cook whilst in their home. I took adequate travel insurance and in April 2007 (two years after wishing I was dead) I took off, alone, to Britain and Ireland. I had ten weeks of flying and driving hither and thither. Magic! I felt as if I was alive after a very long sleep. My poor husband spent the entire time waiting for the phone to ring with bad news but I was absolutely fine. Everything went according to how I planned it. Positive thinking, careful planning and wise judgements kept me well and extremely happy. Now I believe *anything* is possible.

\*\*\* During the 60's English migrants were encouraged to take 'salt tablets' to "replace the salt lost through excessive perspiration." Woomera of course is a desert community and yes! There was excessive perspiration with there being little or no air-conditioning. As one of those migrant families we took salt tablets for about 18 months. I am the only one who developed Ménière's. I have a suspicion this may have been the instigator of the condition or perhaps it exacerbated it.

I would be interested if any research or investigations have been made to this effect and would appreciate any feedback on this particular issue.

As an adjunct, I found the more I read the more depressed I became. Knowledge is power, and education brings choice but too much knowledge can be overpowering when you are 'suffering' the condition. It can make you feel hopeless and as if you are wading through a quagmire of a dark, heavy substance from which there is no escape. My personal thoughts are, when you become well again, then is the time to read all you can, be dogmatic about finding alternative remedies and aids. Try everything until you find what suits you best and don't be afraid to think laterally and try alternative remedies if conventional medication fails you as it did me.

**It is important to always be guided by a health professional knowledgeable with the condition before embarking on new therapies or remedies.**

**The two questions I'm asked the most by people who don't know much about the condition...**

#### WHAT HAS HELPED YOU TO COPE?

Keeping a positive attitude and taking control of what I do and what I ingest. Extensive personal research has shown me there is more knowledge and further research happening every day. The condition is now becoming known to the general public and with the recognition comes funding for further investigations in finding a cure.

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I have shared my Ménière's story with those closest to me. My husband, daughter and many caring friends finally recognise I am 'coping with' not 'suffering from' this condition and can at last make fun of my stumbling and mis-heard words.

A paradigm shift in thought is what I needed. With all the information and advice that I have accumulated I found the way to better health is through positive thinking. Much of my life has had to change since bilateral Ménière's but when I accepted that, I discovered appropriate alternatives. When lifelong interests are no longer a possibility, look for other interests. I gave up singing and took up drumming. Gave up bush walking and took up photography. Gave up dancing and took up aquarobics and swimming.

#### WHAT WOULD YOU SAY TO SOMEONE WHO HAS THIS CONDITION?

Be diligent in seeking information and consider all options presented to you. Don't necessarily take the easy preference, or one opinion. If considering any of my suggestions try the low salt diet first. Never give up hope of having a plateau of symptom free time. Eventually Ménière's may burn out – it *is* a rare possibility. When feeling well enough, it is important to your well being to be part of some social activities and keep physically active. It is so easy to withdraw and become isolated. If at first going out is not an option, have people come to you regularly for a book club or table games session or just a cup of tea and chat. Embrace family and share your good and bad days with those who care about you. See the beauty in small things. Take

baby steps and give yourself time to adjust to living with a condition that can be well managed. Get adequate rest and decrease stress levels.

The will to live is involuntary; the *way* to live is optional and necessitates choice and decisions.

You will die *with* Ménière's but not *of* it. Someone famous but anonymous once said, "This too shall pass."

And it will! Like Pandora's Box; when all else fails you must always have HOPE.

### **USEFUL BOOKS, ADDRESSES AND WEB SITES:**

Google: "EMDR therapy" – spend a while searching various sites, some are Australian, most are from the USA. They will give a variety of conditions helped with this therapy.

EMDR Association of Australia, Mark Grant , Wyong Medical Centre,

Margaret St., Wyong, NSW 2259 Phone (02)4353 2188

Email: [markgra@ozemail.com.au](mailto:markgra@ozemail.com.au)

Note: Not all Psychologists use EMDR. Eye movement can be uncomfortable for Ménière's patients so ensure an alternative method is used. My therapist uses a "tapping on the back of the hand" method.

Google: "Chiropractors Association of Australia"

Note: Not all chiropractors use the methods I required for cranial adjustment.

Note: Not all Chiropractors are listed with the CAA.

MSGV: Ménière's Support Group of Victoria. Sadly no longer operating.

<https://sydneymenieressupportgroup.com>

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Book: "Sound Therapy – Music to Recharge Your Brain." By Patricia & Rafaele Joudry.

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Golden Neo-life Diamite International (Nutritional supplements) [www.gnld.com.au](http://www.gnld.com.au) or contact my very helpful supplier who is always willing to help and research. Her name is Kirsten at [daretobehealthy1@gmail.com](mailto:daretobehealthy1@gmail.com)

Book: "Salt Matters – A Consumer Guide" by Dr Trevor Beard. ISBN number 0-7344-9610-X