

## Sharing my Husband with Meniere's *Marjorie Ulrich*

In a café, in the City of Orange in country NSW, 30 years ago our lives changed in a split second from relaxed and happy to fear and helplessness. Yes! You guessed it, Len had his first Meniere's attack. He couldn't walk straight and his world was in a violent spin, I had all his weight on me as we weaved our way back to the car, my idea being to take him to the Hospital but Len wouldn't have it, so home we went, got him into bed, located a bucket just in time as the vomiting started, this being at 10am and continued for ten hours.

Meanwhile I was trying to get a doctor out, but I couldn't get past any receptionist and by then our children (all six of them) were petrified and thought Len was going to die. A doctor did come at 6pm and declared Len 'drunk'.

I insisted he examine him, which he did grudgingly and said that Len was suffering from seasickness, then gave him an injection about which he refused to tell me. Well I was pleased to see the back of that doctor and calmed the children down as much as I could, in between running 'the bucket brigade' and washing Len's face and arms with a cold washer.

By morning all was calm and Len's attack was over although his confidence was very low. We saw our own doctor that afternoon and thankfully he understood about Meniere's and started Len on Stemetil but as the attacks continued our doctor referred Len to an ENT specialist in Sydney.

The Sydney specialist was surprised at the good quality of Len's speech despite his hearing loss and asked what type of work he did. When he was told that Len was a full time union official he smiled and said "it's all the talking and listening you do that keeps you going and you must soldier on!"

After some tests and lots of talking he told us about this 'young Turk' at the RPA swinging people around in a chair in the dark to get info on Meniere's. On his advice that it would not give us any more info than he could give us, we decided to steer clear, not realising that many moons later Len would be in that chair!

Len's attacks were often at least weekly and would last between 2 to 8 hours but basically put him out of action for the full 24 hours. I got to know when an attack was coming by the way Len walked – he would become quiet and to touch him he would be 'clammy'. I knew it was just a matter of time before I would have to drop whatever I was doing to get Len undressed and into bed before the onset of vomiting.

I also had to make the room completely dark, so I would get blankets and climb up on a chair and haul them up and tuck them over the curtains and blinds. Once that was done I only had the 'bucket brigade' and sponging to cope with which was about every ten minutes for however the attack lasted. I started to time the gap between the vomiting and once the gap reached twenty minutes or more I knew he would soon stop vomiting and go to sleep and then I could have a shower and relax a bit and have a cuppa and put my feet up but always stay listening!

Once Len was awake he would be starving, so I'd always have a light but tasty meal ready for anytime during the day or night. There were things to do such as getting Len to the bathroom and

back following attacks (he was 15 stone and I was 9 stone). Showering him was hilarious with Len telling me he loves me while I am trying to hold him steady with one hand and wash him with the other. I loved him too, but it can wear a bit thin when I was exhausted from running back and forth with buckets and washers for hours on end as well as tending to the children's needs and knowing that once I've dried him and got clean pyjamas on him that I then have to change the bed again because the sheets were soaked with perspiration.

As I washed them, towels and all, I'd pray Len would not go back into another attack for a day or so – it was a fact that at times he would go straight into another attack and even more one after the other, that was hard work!

Once we explained to the children about Meniere's disease they were able to cope a little better when Len had attacks, but they would become very quiet when they occurred. Len's Meniere's attacks became known as his 'Wobbly' and later the grandchildren understood about granddad having a 'Wobbly'!

Despite the Meniere's we had a very active life. Len continued to work and also attended endless meetings in the community as well as night meetings with union members, civic receptions, formal dinners, and he organised events for official and political dignitaries. Then we took up old time dancing and ended up being the teachers every Monday night plus travel all over the central west to dances, and would be home at 1am then up at 7am to get the children ready for school.

Of course there was sport on Saturday, the girls playing hockey and the boys were in soccer. Len was a soccer referee and I was the taxi service in between baking cakes and slices for our Sunday picnic or barbeque and enough to fill the school lunch boxes and then the dancing at night. On top of all this I attended Technical College one full day a week and two evening classes. I also started a craft class and morning tea on Tuesdays for young mothers housebound with babies and toddlers.

Being based at Orange in NSW, Len had a large area to cover. As well as flying to Sydney on a regular basis he had to fly in small planes to attend meetings of his members working on the gas pipeline from the South Australian Border through NSW to Yass. All this time he was well dosed up with Stemetil and fingers crossed. For me the waiting for him to come home was quite stressful but I had to keep going and keep home life normal even if I was always tired and on edge and waiting for the 'Wobbly' to appear. When Len was under pressure with strikes, meetings, the media etc, he never had an attack, but once the pressure was off then down he would go and have two or three attacks in one day.

After a few years the Meniere's had become so bad that Len could not fly anymore, so had to drive and by now I was having to be with him and drove hundreds of miles on country roads. One trip was to Coonabarabran and as we collected the key at the motel I just knew that Len was going to have an attack. I suggested he not go, but no he went and within the hour when the knock on the door came I knew it was Len, and yes he was in a terrible state, so action stations. . . . *continued on page four*

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He was so bad that I contacted reception to learn that no doctor would come to the motel but they would ring an ambulance. I followed the ambulance so I would know where the hospital was. That's when the trouble started, the doctor didn't know what Meniere's was, and because I told him that Len needed a Stemetil Injection to stop the vomiting, which had eased a bit, the doctor decided we were on drugs and trying to get more! As all this was going on Len, who couldn't hear the conversation, was pleading with me not to leave him in the hospital. The doctor decided he would give Len the injection but he would have to stay in hospital overnight, I said yes that will be fine.

Len was not happy about this and I told him not to worry that I would sort it out once he had had the injection. Len had the injection and we were left alone. I found a wheelchair, got Len into it and left very quickly driving back to the motel. I somehow dragged Len inside and to bed and thankfully he went straight to sleep. After breakfast the next morning I drove back home, it took 6 hours. Len was fine and I was a wreck.

Had a night meeting at Lithgow, we stopped at Bathurst for a meal and Len didn't feel well so I wanted to take him home but no he insisted I drive to Lithgow (can't let the boys down). We were late of course and Len was very unsteady but not vomiting. It took two of us to get him into the hall and he got through the meeting somehow. I was sitting up the back as I often did. We had to stay at Lithgow that night.

By 1985 it was obvious his hearing loss was getting worse, despite the body hearing aid he used, and was beginning to affect his work and he found some days exhausting. Our doctor wanted him to retire but he would not entertain the idea until one day when he got the transcript from a case he was working on in the courts only to find that the Judge had asked him some questions in summing up and Len's answers were not relevant to the questions. He retired that day only 49 years of age and he was devastated.

When Len retired we bought a house at Springwood on the Blue Mountains and are still enjoying the mountains today. Our children had all finished school and live all over the State and Queensland with only one staying at Orange.

We were both on the Disability Pension so had to find a way to supplement the pension and we were in luck. I was a volunteer at the Springwood Neighbourhood Centre and the contract for a cleaner came up and Len applied and got it. We had never used a commercial polisher before, and the first cleaning night was so funny with Len going for walkies in the opposite direction he needed to go. After a few weeks we were asked if we would take on another cleaning job as well, we did and now we worked four days a week.

We had heard that a Meniere's Support Group may be formed in Bowral. Anne Stewart was often mentioned as a contact so I rang her and she was so positive and reassuring, I jumped for joy, I wasn't alone anymore. Even before the Meniere's Group was up and running Anne rang often to check on us and pass on any information as it came to her and at the same time I could ring Anne when I needed a boost to keep going. She was always

there for me. Eventually through Anne Stewart's support we made contact with Professor Gibson.

The balance tests Len had all confirmed Meniere's in both ears. During an examination the Prof had mentioned that the right ear is good for a Cochlear Implant, and the seeds were sown.

We were grandparents by now and had an invitation to the christening of grandchild number five at Miranda in Sydney and as usual started planning for the journey, packing the backpack with Len's gear in the event of an attack on the train which happened quite often. So the day of the christening we set off praying all would go well but it didn't.

We reached Blacktown and Len was hit by an attack. I wanted to get off the train but he didn't so I waited outside the toilet while Len was vomiting his heart out. I knew we would not be spending the day with the family but in whatever hospital we ended up. By Strathfield I'd convinced him to get off the train.

I had to find some help, as he couldn't walk on his own. I asked where the first aid room was and the porter just laughed but he did help me get Len to the Stationmaster's office and when I asked for a bucket they came back with a flowerpot with a hole in the bottom! I was getting a bit tense by now and told them to get an ambulance, as this is urgent.

On arrival the Ambulance Officers apologised for the time taken as the stretcher would not fit in the new lifts (Strathfield Station had just been modernised!) They had had to come down the ramps, so we had to have Len taken back that way to the ambulance where they gave him an injection but Len kept vomiting.

We ended up in Concord Hospital and it was going to be an all day affair so I rang our daughter and told her where we were and to carry on without us. She was in tears, I was in tears. All this started at 9am in the morning and ended at 5pm when I rang our daughter and asked if she could please come and take us home, which she did.

Our problems were getting worse due to my arthritis; I couldn't look after the garden and with Len having to do more, the attacks increased. It was after a period of two weeks when Len had one attack after the another, we realised we could not carry on the two cleaning jobs and maintain the house and garden any longer, so put our names down for a self Care Unit in Buckland retirement Village at Springwood.

In 2001 it appeared the attacks were now only in the right ear, the left ear having reached the 'burnt out' stage, so we went back to Professor Gibson and the Prof agreed that Len could have a Cochlear Implant in the right cochlear and at the same time he would do a Labyrinthectomy (take out the labyrinth of the right ear) which may stop the Meniere's in that ear. This was duly carried out at the RPA on July 16th 2003 and we were given two miracles, Len hasn't had a Meniere's attack since the operation and can communicate so well and hear his grandchildren and the Bellbirds and enjoy music once again. Our lives changed so much since that beautiful July day and I have had to learn to relax and enjoy our good fortune.

We are so lucky! ■