

Living with Mal de Debarquement Syndrome



Jane Houghton

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"Life on the ocean wave" a phrase that conjures up images of thrilling and exciting times, but imagine for one moment quite literally feeling that you are on the high seas every waking minute of your life, believe me, then it becomes a living hell.

This all started for me over seven years ago. It was Friday 13th July, 2001 (maybe I should have taken that as an omen). I and five other family members spent a long weekend aboard a luxury pleasure boat in Palma Spain. It was a lovely break; we would wake up each day to blue skies and crystal clear calm waters. After breakfast we would set sail to discover yet another perfect place to drop anchor and go for a swim, often returning at full throttle crashing over the waves, it was exhilarating, idyllic. Only one thing marred it, once back on dry land I continued to feel 'all at sea' - the sink in the marina wash rooms would float up to meet me, in a restaurant the table would bob and weave about. I asked the others in my party if they were experiencing the same feelings they looked at me as if I was mad.

Back home after a week the feelings hadn't subsided. I decided to visit my GP. He said that I hadn't found my 'land-legs' yet and prescribed some anti-motion sickness tablets. They didn't work, nor did any of the others that he went on to prescribe. The sensation of being on a rough sea was constant, no let up, even when lying down in bed. Everyday tasks that we take for granted became so difficult; using a computer, ironing, vacuuming etc all increased the level of motion I felt.

My GP decided to send me for an MRI scan. By now I was frantic, believing that I had a brain tumour (what else could be affecting my vision?) Thankfully it came back negative, but still no clue as to what was wrong with me. Then came a series of visits to both neurologists and ENT consultants, numerous hearing and visual tests and still no positive findings. It was now Christmas, the ENT consultant apologised saying that although he firmly believed there was something wrong with me, he just didn't know what, especially with not having any positive test results to work from. I remember leaving the hospital in floods of tears. Was it all in my mind; was I going mad or having a break-down?

By the end of January 2002 I was suicidal, no quality of life left. My GP, relieved that I had something he could actually treat, put me on anti-depressants. The rocking and swaying sensation was far worse than it had been on the boat, I felt constantly nauseous. Also I had developed tinnitus in both ears (never even had so much as an ear ache before this, was never travel sick) I couldn't believe this was it, no concrete diagnosis, just labelled under the vast umbrella of a 'balance disorder'. I started to surf the internet for clues/answers.

In February 2002 just over six long months after that fateful boat trip I got a reply to an email I had sent to the American Vestibular Disorders Association (VEDA) explaining my symptoms and how they came about. They said from my descrip-

tion it pointed to a condition called Mal de Debarquement Syndrome, French for quite literally 'disembarking sickness' (MdDS for short). They told me where to find further information (www.mddsfoundation.org). Now I had to set about being medically and professionally diagnosed. Once again I turned to the internet for help. Eventually I came across the National Hospital of Neurology and Neurosurgery in London who had actually seen cases of MdDS before. I had my first appointment with them in September 2002.

Now over seven years later there is no improvement, if anything I am worse, other problems have appeared, all linked and tied up in the mystery and misery of MdDS. I see the world as constantly moving. This illusion of movement has got worse over time, a type of gaze instability/visual disturbance whereby objects jump and shimmer in front of you, often like looking at things through a heat haze. As well as 'seeing' the world move I also 'feel' it as well. Again, for someone who isn't living with MdDS it is difficult to describe but imagine when you are in a plane and you can feel inside your head when the plane changes altitude or banks to the left or right, all very dis-orientating. I live my life 'like constantly trying to walk on a mattress or trampoline.' However, I must stress at this point that there is no rotational or 'spinning' vertigo with this condition. Also, it is not 'attack' based with periods of normality. Weirdly enough the only relief a MdDS sufferer gets is when they are back in motion.

Back then I naively thought there would be a miracle cure, some tablet I could take to make it all go away. Quite simply there isn't. The best 'treatment' on offer are vestibular exercises which do help if you have an actual balance problem with your MdDS (fortunately I don't) but they do nothing to help the 'moving illusions and sensations' of the condition. In June 2004 I decided to seek a second opinion, I went to the Leicester Balance Centre. They are more brutally honest with me (which I appreciate) and basically say that at present there is no effective treatment for MdDS. I still remain a patient of theirs.

To help turn something with such a huge negative impact in ones life into a positive I try to raise awareness. Probably because of my determined 'doggedness' I am one of the few lucky ones who has actually been diagnosed. Raising awareness is crucial in helping sufferers know that it 'isn't all in their head'. For me it just helps to feel that I am doing something positive by 'spreading the word' and raising its profile. I set up a UK basic website for help and support to others who find themselves with this little known and little understood disorder. (www.mdds.org.uk)

Over the years the contact and feedback that I have had makes me question just how 'rare' it is. Travel is available to everyone these days, we are all aware of the risks of DVT and flying, why isn't this the same for MdDS? I am not trying to 'harm' the travel industry in any way or sensationalise the problem. It's merely about being informed. ♦