

As I step on the escalator, a wave of relief hits me; I am normal again, if only for a couple of seconds. My name is Michael, I am 22 years old and I live in Sweden. I have suffered from Mal de Debarquement syndrome for two years now. It started the third of July 2008 after a month of backpacking across Europe via planes, trains and boats... I had experienced some strange episodes of dizziness during the trip – such as waking up in the middle of the night feeling like I was falling through the ground – but I didn't think too much of it as each dizzy spell faded quickly. Then I woke up rocking one or two days after coming home and it basically hasn't stopped since.

Symptoms:

I don't want to go into too much depth describing the symptoms as there really is no way of doing justice to the horror of never feeling like you're being still – ever. My brother at one point said: “but what's so bad about feeling like you're on a boat (the typical description of MdDs)? I like being on boats!”. Well he wouldn't like being on this one... Your brain is in constant turmoil because it knows something's wrong, and hence constantly sends out signals of immense distress, but the only question it seems to come up with is “is the world moving, or am I moving?”. It's as if the answer “I am still and the world is still” no longer exists. The only time I get relief is when I am in passive motion such as in a car or bus – or an escalator for that matter; sadly I often pay with higher symptoms afterwards. The worst time of the day for me is when I lie in bed at night hoping I can fall asleep as I'm constantly feeling like I'm being tossed around.

Diagnosis:

Unfortunately very few are aware of this condition here in Sweden, and even fewer accept that the symptoms don't always come on immediately upon cessation of motion-stimuli (such as when you step off the boat onto solid ground). Hence it's been a struggle every step of the way for me, and I still haven't received a formal diagnosis. After going from doctor to doctor, one being more clueless than the other (especially the part of me feeling completely normal while in passive motion seemed to confuse them), I started searching through the internet. It didn't take me long to find the MdDs foundation's webpage, and the symptoms matched a hundred percent. I finally knew what I had; reading that there was no cure and that treatment-options were very scarce, I stopped bothering about doctors.

How has this affected my life?

It has and continues to take away my youth. After months of bad symptoms it calmed down for me and continued to calm down the following year. I was at a place where symptoms were really low and though bothersome at times, they were not debilitating; suffice to say I was incredibly thankful as I could resume my life... Then I went to Turkey on vacation, and now symptoms are worse than ever before. This is extremely tough because when symptoms go up your life's basically taken away from you. You are constantly fatigued from having to balance, you feel horrible all of the time because of the symptoms and you can't think straight due to the cognitive effects.

However the worst part of this horrible illness must be the constant disbelief and the way you're treated as a consequence. Doctors do their tests and when they can't find something they conclude you must be mad and that you're making it all up, and when you go from doctor to doctor without finding any answers your family starts to think you might be too...

I've never felt more alone in my life. The emotional wounds have healed now but the scars are still there, and they will be till the day I die.

Michael Heller – July 8th 2010