Glimpse into another diagnosis – POTS & RBBB

My health journey has taken another turn in the past fortnight. Mid February, I visited a cardiologist, after having had a tilt table test performed in December, and discovered that I have Postural Orthostatic Tachycardia Syndrome (POTS). This explains a great deal, such as the light headedness, dizziness, palpitations, low blood pressure, nausea, brain fog and fatigue. It is mind blowing for me that this hasn't been discovered sooner. I have had the symptoms since I was a child, and although I've had other diagnosis made such as Chronic Fatigue Syndrome, and although it is a bit like the chicken or the egg in terms of determining which symptom or condition came first, it is amazing that it has taken til I'm nearly 30 to make the diagnosis. There have been several chances for this diagnosis to be made in the past, and it took me requesting the tilt table test (the diagnostic test used to diagnose issues related to blood pressure and heart rate) to actually get it done. I really can't stress enough how important it is to be your own advocate in the health care setting.

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I have been to so many doctors over the years that I have lost count. I have been willing to try anything to improve my health; endless tests, medication and supplements, natural therapy, physical therapy – the list goes on.

I have said this before and been proven wrong, but I really do hope that this is the last of the diagnosis — that knowing that I have POTS, as well as Hashimoto's Thyroiditis, Myalgic Encephalmyelitis, Fructose Malabsorption and multiple food intolerances, explains all my issues, and that now it is a matter of improving these conditions as much as possible, and maintaining a healthy lifestyle so that no other problems develop (which is possible with these conditions).

When I was 16 (in 2000), I had cardiac tests done because I was fainting and having palpitations. Apart from postural hypotension, nothing was determined as a point to focus on for change. I had stress tests, a holter monitor, echos, ecgs – I am not sure why I did not have a tilt table test, or if they were available then.

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In 2012, I visited a new GP for yet another attempt to get a new perspective. On the first visit, she was confident that we would sort my health problems out. Among other tests, she wanted to do a tilt table test after some initial blood tests. When I returned another day to get the referral, I mentioned I had seen a holistic doctor (with the same medical credentials as her, but he focuses on holistic medicine) and she went on such a rant about how detrimental the natural health profession is, that she wouldn't give me the referrals that she had planned to, and I uncharacteristically left in tears.

In 2013, I visited yet another new doctor, who specialises in myalgic encephalmyeltis. He suggested that my low blood pressure could possibly be the actual cause of all my issues (hallelujah!). I went back to my GP, and asked for a referral to a cardiologist, and any tests that I could do that would be of interest to the cardiologist; i.e. the tilt table test. My GP did not see that this would be of much use, but as he knows that I am willing to try anything at this point and leave no stone unturned, he wrote the referrals.

■ In December 2013, I finally had a tilt table test done. As I wrote about in a previous blog post here, the cardiologist who performed the test gave me an unbelievable and unprofessional lecture about how I should just change my attitude; he had no knowledge whatsoever of what my attitude is like; he presumably based this on the diagnosis from my GP that I have Myalgic Encephalmyeltis/Chronic Fatigue Syndrome. Obviously not acknowledging my issues, he completely missed the fact that on the test he was performing, were the diagnostic signs of POTS and Right Bundle Branch Block (a problem with the electrical pathways in the heart). I am a paediatric cardiac nurse, though I haven't worked in over a year, and even though I was fainting during the test and was quite a distance from the screen, I thought I could see notable changes on the ecg and heart monitor. It is beyond my comprehension that this doctor firstly felt it appropriate to lecture me on my attitude while, secondly, missing a diagnosis! Had I followed his word that nothing was wrong and cancelled my appointment in February this year, I would have yet again, missed the diagnosis.

■ Over the past week, I have commenced a medication for the Postural Orthostatic Tachycardia Syndrome, which will hopefully control my increased heart rate (tachycardia) when I change my position (postural/orthostatic). I have started on metoprolol; a beta blocker. There are two other drugs that I may trial if this one is unsuccessful. It has been a tough week, as this medication has really knocked me down. I have a very low blood pressure to begin with, despite having a medication to increase it, and this drug is lowering it further as a by product of decreasing my heart rate. However, the long run hope is that in lowering my heart rate, my heart will be able to pump more efficiently, therefore increasing my blood pressure. I can only wait and hope!

I am still learning about this new condition. I will add the experiences I have and what I learn to my blog updates. I am hoping that my body adjusts to this new medication soon. I know you will all be understanding if my blog posts may be a little slow while I adjust to the medication :-).

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