# Glimpse into my atricle contribution for Your Zen Life!….ME/CFS International Awareness Day – May 12th

I wrote an article for International Awareness Day for the Your Zen Life website, and it was published last week! If you are interested in reading it, it is on the website at http://www.yourzenlife.com/post/me-cfs-international-awareness-day-may-12th, or read below.

Did you know that May 12th is International Awareness Day for Chronic Immunological and Neurological Diseases?

One of these represented conditions is Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS). There are thousands of people suffering from this misunderstood condition, yet a conclusive diagnostic test and treatment remains elusive.

During my childhood and teens, I developed various symptoms which became more severe over the years. After countless doctor visits and invasive tests, repeatedly being told nothing was wrong, and feeling like I was going crazy, I was diagnosed at age 26 with fructose malabsorption in 2011. This seemed restrictive and overwhelming, and then more tests showed that I had other severe food intolerances (wheat, dairy, egg, peanuts, and grains to name the main ones). My diet became very strict, and there were months of gruelling elimination diets to test my tolerance levels. Once I understood which foods I could eat however, my gastrointestinal symptoms improved enormously, and with a lot of experimentation, the meals I made became delicious and nutritious, despite the restrictions.

Although my stomach health was drastically improved, I was still having health problems. In 2012, I was diagnosed with a thyroid autoimmune condition. Then, tests which showed that I have had Glandular Fever in the past contributed to a diagnosis of ME/CFS in 2013. I have had chronic orthostatic hypotension since I was a child.

In January 2014, I finally discovered that the fundamental cause of this is Postural Orthostatic Tachycardia Syndrome (POTS). All of this currently means that working, exercising, socialising and independence are a distant memory.

ME/CFS is a debilitating chronic condition which affects many people of all ages and both genders. We are not lazy. We are not “a bit tired” because we have been working hard. We are not run down because we spend every spare minute running after kids and keeping a house. I have a condition which results in constantly feeling fatigued to some degree, no matter how much rest I have. I get severe post exertion malaise, which means even the slightest increase in activity can cause me to come crashing down for days of exhaustion. Ironically I also have insomnia too, and can lay awake until the early hours of the morning, despite my tiredness. I frequently feel stiff and in pain, faint, nauseous, and have brain fog (confusion and trouble concentrating).

I aim to live life day by day, get the most out of it as possible, enjoy myself and be productive. These goals can be much easier said than done some days! I cannot drive, live by myself, do groceries or a day’s worth of meal preparation, and I cannot work. As I always say though, this is my life, I have one shot at it, and even though this is my lot for the moment, it doesn’t mean I should miss out on happiness. Some days I am considerably more unwell, and barely move from my bed or couch. Other days I feel a bit better, and might leave the house briefly with a family member or friend. I still try to see something good within the day, despite how I may be feeling. I know that I am lucky, because many people have to deal with conditions which are worse. I feel grateful because I have hope for improvement. I feel blessed because I have a loving, generous and caring family, who support me in every way possible, and make me laugh and keep me going. I am fortunate because I have access to medical assistance and medication, even though it is a very slow and painful road, with no definitive plan for treating this condition as yet.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a destructive and horrible condition which affects many. Please don’t write it off as “a cop out”, or the name of conditions which doctors just cluster together because they don’t know what else to call it. It is a condition which needs more research so that a bio marker and subsequent diagnostic tests can be found. Hopefully, raising awareness will ensure people who have ME/CFS will be provided with the appropriate support and respect from the medical profession, and from the people they meet in their everyday life. It is a significant and devastating condition which can turn anybody’s life upside down at any time, and also the lives of their loved ones. Please consider taking part in raising awareness by looking up local or online events happening on May 12th. This can include awareness programs, such as the Light Up The Night Challenge, or the Thunderclap Campaign, donating money for research and support, or sharing the information which you have learnt here today.