Glimpse into Chronic Fatigue Syndrome

A couple of weeks ago, I went to see my doctor, and came out feeling like we had had a break though. I have been seeing him for close to a year now, and he has tested me for so many conditions in an attempt to explain my symptoms. I have had several tests come back out of whack, and now, along with a new result showing that I have had Ebstein Barr Virus in the past, combined with my symptoms and ruling out other similar conditions, he has officially diagnosed Myalgic Encephalitis/Chronic Fatigue Syndrome. Along with that I already knew I also have Hashimoto's Thyroiditis (an autoimmune condition), multiple food intolerances, Fructose Malabsorption, low parathyroid function, and a couple of other things I will have to monitor.



It felt like a breakthrough, but in reality, it doesn't change much. It doesn't bring with it a cure, or a specific treatment plan. Chronic Fatigue Syndrome can be seen as a "cop out" diagnosis. I know I did before I read a lot about it. It seemed like a "well, we don't know what else it is, so let's call it this" diagnosis. But really, why would you give or want a diagnosis of a condition that doesn't have a cure or treatment plan? A condition which is only at the early stages of being researched, so there is only minimal understanding of it? It is not a diagnosis that helps. Though, I have been through so many, many tests, that now we have come to this diagnosis, at least the testing will slow down, which is a great relief.

Chronic Fatigue Syndrome is also so badly named. It used to be known as Myalgic Encephalitis, but the common name now is Chronic Fatigue Syndrome, or CFS. There is a lot of

controversy surrounding the name, and quite rightly. Sure, it paints an effective picture regarding the most debilitating symptom of the syndrome: fatigue (which also leads people to wrongly think
"oh well, you're just tired, right?" No! The difference between fatigue and tiredness is like the difference between migraines and headaches! People who call a typical headache a migraine infuriate people who actually do suffer from the crippling pain that comes with migraines, along with the associated vision disturbances, hallucinations, vomiting etc! Being chronically fatigued means all over body exhaustion after the mildest activity or exertion, and it is not relieved by resting or sleep). However, to be diagnosed with CFS, you must have at least four symptoms from a specific list, as well as severe fatigue lasting for more than 6 months, which is not improved by rest. This list is:

- Neuro-cognitive impairment (substantial difficulties in thinking, concentrating, memory loss, vision, clumsiness, muscle twitching or tingling)
- Muscle and/or joint pains
- Headaches of a new type, pattern, or severity
- Sore throat, tender lymph nodes and a flu-like feeling
- Non-refreshing and/or disrupted sleep/insomnia
- Malaise after exercise
- A drop in blood pressure, feeling dizzy or pale
- Palpitations, increased heart rate or shortness of breath with exertion or on standing
- Allergies or sensitivities to light, smells, touch, sound, foods, chemicals and medications
- Gastrointestinal changes, such as nausea, bloating, constipation, diarrhoea
- Marked weight change – extreme loss or gain
- Inability to cope with temperature changes.

Other symptoms associated with chronic fatigue are: Irritable Bowel Syndrome, multiple food intolerances and chemical

sensitivities. A small number of patients have cold intolerance, Restless Leg Syndrome and Irritable Bladder Syndrome. Thyroid issues are also quite commonly connected to CFS.

Lucky me….I can tick off most of the symptoms on this list!



We expect so much from the science and medical world. I have definitely come to realise this with my health issues. You have a problem, and with all our amazing technical and scientific advances, you just expect that someone will be able to explain and fix that problem. Then we are aghast when it is realised that no, there is no answer at the moment. This also leads people on to doubting the severity or reality of the illness, because surely, if it were serious, we would understand it and be able to treat it, right?! But really, we can not expect to have knowledge and experience on every single occurrence and issue; that would be wildly unrealistic. Humans are amazing, and we have come a long way, but we are yet to know everything about our world! CFS fits under this category, like conditions such as cancer and diabetes also do. We know a certain amount about it, but there is still a lot of research to be done. There is no lab test to identify it yet, for example, and not a definitive reason behind what causes it. There are links to autoimmune disease becoming apparent, specifically thyroid antibodies (which I have in quite a large number), and these findings need to be studied further.
Over 4,000 research articles have found that CFS is associated with problems involving:

- The immune, neurological and hormonal systems
- Blood pressure, the circulatory and cardiac systems
- The body’s ability to produce and transport energy
- Biochemical abnormalities
- Digestion
- Viral or other infections

One day, we will figure more out about it. In the meantime, we need to be patient, cope with it as best as we can, and not trivialise it just because we lack total understanding.

CFS can range from:

- Mild – the person's activity is reduced by at least 50 per cent
- Moderate – the person is mostly housebound
- Very severe – the person is bed-bound and dependent on help for all daily care.

The main treatment for CFS at the moment is to take care of your body. Rest, eat well; treat your body with care and respect. Exercise can help some people, but not everyone. It is important that an activity plan is started very slowly, and increased gradually. When beginning an activity program, some people with CFS may only be able to exercise gently for a few minutes. People with chronic fatigue syndrome must learn to pace activities. The goal is to balance rest and activity to avoid deconditioning (loss of strength) from lack of activity, and flare-ups of illness due to overexertion (doing too much)…which is a very tricky goal to say the least!

I find this quite difficult. It is such a game of luck; keeping your fingers crossed that you don't overdo it! I have recently come to the conclusion that where I am at now, after some improvement, I can do a light activity over a few hours in one half of the day, and then for the other half, I must rest.
I have set a goal that I do something social with friends at least once a week (so that I don't go insane!). So if I have morning tea and a chat at a café in the morning, then the afternoon needs to be resting; sitting or lying down, doing only a simple activity, such as reading or watching a movie. Even that plan, can sometimes still see me come undone.

For example, last week, one day I stayed in bed til late morning, got dressed and ate, and then a friend drove me to Spotlight and we bought a few craft items to replenish my stocks for my at-home rest entertainment! We came back and had a cuppa together on the couch. My friend went home, my mum prepared dinner for me, I rested in the evening, then went to bed. Not a high energy day for a 29 year old by any means! However, the following day, I got up late morning, had a shower and made my breakfast, and then sat at my computer for a short while, and as I attempted to type this blog post, I was fighting to keep my eyelids open! I was exhausted! It is definitely hard to gauge how much to do.



Treatment of CFS is also based on treating the symptoms exhibited. Dealing with the pain for example. This can be frustrating because the more I learn about well being and nutrition, I understand how important it is to work at the cause, not just the symptoms it is creating. But of course, at the moment, that is unknown.

The prognosis for chronic fatigue syndrome (CFS) in adults is only fair to good; children have a better prognosis with treatment. In general, patients who are diagnosed within the first 2 years of symptoms respond better to symptomatic treatment than those patients diagnosed after 2 or more years of having the disease. It is unclear how possible a full recovery is from CFS. Some research shows that it is infrequent (only 5% to 10% of adult patients diagnosed), claiming the prognosis usually ranges from fair to poor. Other information shows that some people improve well, others get back a certain level of their previous health, and others do not improve.

Here are a few of the links that I have found useful:
http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Chronic_fatigue_syndrome

http://www.medicinenet.com/chronic_fatigue_syndrome/article.htm

http://chronicfatigue.about.com/b/2011/09/21/thyroid-disease-in-fibromyalgia-chronic-fatigue-syndrome.htm
http://cfshealthcentre.com.au/

CFS might not be well understood yet, but we can do our best to learn as much as possible from the research that is out there, from each other, and from ourselves. Pay attention to your body, listen to what it needs, and look after yourself as best as you can (and ask for help when you are too unwell to do it yourself). You also really need to be your own advocate. Learn as much as you can, and fire any question you have at your doctor! Nothing is too silly to ask! If your doctor hasn’t treated a symptom of yours that is really disrupting your life, you must push until he or she does. Live as healthy a life as you can (in all areas), and your body will respond. Enjoy the small moments, don’t let the negatives pull you down, and keep plodding, one foot in front of the other!!

