Glimpse into a day in the life of a sufferer of Myalgic Encephalomyeltis/Chronic Fatigue Syndrome

As part of raising awareness of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) leading up to the International Awareness Day on May 12th, I decided that I would document an average day for me, a sufferer of ME/CFS.

Wednesday April 30th, 2014:

11am: I wake up just after 11am, feeling groggy and tired. I lie there for about half an hour, before picking up my phone and looking at messages and social media. I take my blood pressure and heart rate to check how they are due to starting a new medication two weeks ago. The usual spot to the left of my belly button is aching right through to the other side of my body; a sign my food intolerances have been aggravated.

12pm: I drag myself out of bed so that I can get some food to take with my morning medications (which I am late to take due to the unavoidable sleep in). I collect my tablets and food (my Mum makes up my breakfast at the moment, which is an amazing help), and climb back into bed. Feeling tired and dizzy, I eat my breakfast (lunch?!) and, although my bowl of quinoa and chia with raspberries and strawberries is delicious, I quickly move the pillows down again to a position close enough to lying down as possible while trying to allow a position of “I am letting my food go down.” I turn my audiobook on (yep, you caught me – I have started our book club book, “Gone Girl” a day early :-P), and snuggle under the doona to get warm, feeling my eye lids fight the knowledge that it is the afternoon. My heart is thumping after the exertion of eating, and my legs are heavy and wobbly after standing when I put my breaky in a bowl, and got all of my medications together.

1pm: Mum subtlety asks me what time it is. Ten minutes later, she asks me whether I think I should really get up now and move about. My impending nap is clouded by motivational guilt, and I turn the audiobook off. By 1:30pm, I drag myself out of bed, pull on some comfy leggings, and migrate to the couch.

2pm: The awareness that I moved from my bed to the couch is becoming a niggling guilt trip in my mind, and I try to walk around. I make it to the kitchen (the room next to the couch), and feel my stomach start to cramp and ache, so I walk back to the couch. I collect my computer, and migrate 5 steps to the table and start to blog. My mind feels thick and sludgy. I have to frequently remind myself what day of the week it is. I have to check my written list multiple times to see what needs to be done, as I don’t remember otherwise. The sounds of the birds in the trees, and the barking of the neighbour’s dog as Postie goes by hurts my ears. My shoulders start to fill with sharp, burning pain, and the need for a nap grows. I drink glass after glass of water, trying to keep hydrated, which can be difficult, even having multiple litres of water a day. I walk out to the kitchen to make a cup of tea, and load the dishwasher as I wait for the kettle to boil. I live with my family at the moment, and I am amazingly well looked after; something I am forever grateful of. I try to do a little chore here and there, but really, in the scheme of things, my efforts are peanuts compared to how much help I am given. If I were to live by myself, I would be found a week later, rotting in the corner, a cup of cold tea in my stiff hand, and reruns of Veronica Mars playing! It wouldn’t be pretty. I put some leftovers on a plate for lunch, and some healthy frozen brownies to go with my cup of tea.

3pm: I move back to the couch with my laptop, as I am getting too fatigued sitting upright, and I can feel the blood pooling in my legs. I continue to blog in a semi reclined position, and I feel palpitations thumping in my chest. I come across more people on social media who are dealing with similar illnesses, and we share experiences. My tea has made me hot and so I am feeling more dizzy and light headed. I sit up and try to ease the feelings with deep, slow breaths, and cold water to drink.

4pm – 6pm: I keep writing, and chatting to friends on facebook. Mum starts preparing dinner, so I move into the kitchen and sit at the bench to chat with her. I feel tired and woozy, and after a while, have a short lie down. The smells of dinner cooking make me nauseous too, as do a lot of smells, lights and noises, so I often can't stay in the kitchen.

6pm: I eat a healthy dinner with my family. The nausea persists, but I try to eat a reasonable amount. Dinner time often coincides with a dip in energy, and then after dinner, I often pick up and feel my best out of the whole day. I think this is because I have food in my belly, it isn't so bright, it is quieter, it is cooler, and I am sure something in my body clicks on, because it is often like clockwork! I don't feel fabulous, but the energy levels improve (ironically, before bed!).

7pm: After writing in my previous post about the physiotherapy involved in baking, and realising a decrease in healthy sweets in the house, I decide to bake a simple choc chip recipe, which is on my blog here.

8pm: I sit down, back on the couch, and watch tv with Mum. I feel lightheaded, and my arms are tingling and my neck burning.

9pm: I take my sleeping tablets and start getting ready for bed. I usually shower at night these days, because it takes so much energy that when I do it during the day, the inevitable nap needed afterwards chews into the day. I do often find still that at night I need a lie down before I get dressed, which often results in long period of time where I am bargaining with my body to get up and get ready for bed so that I can crawl under the covers and actually sleep!

10pm: I lie in bed and listen to my audio book. I enjoy this time of day because it is quiet and dark, and people aren’t constantly worrying about me and I am not constantly causing people to worry. After months and months of insomnia, I also have a bit of an issue with settling down to try to sleep, because I dread the hours of waiting for sleep. So I often lie here, reading or crafting or talking to friends, when really I should sleep; but the way I see it, if things are hard during the day and I find a slight reprieve at night, why not make the most of it. I do make a conscious effort to not stay up too late though.

I wrote this to show you what an average day is like for me. This is not an “I am taking a lazy day to recoup after a busy week” day. Nor is it an “Oh I am just feeling a bit off today so I thought I should rest” day. Boy, do I wish it was an “I work full time and I finally have a day off and the kids are at school so I am having a rest” day! No, this is a “this is my life, day in, day out” day. I am not lazy. I am not a bit tired because I have been working hard. I am not run down because I spend every spare minute running after kids and keeping a house. This is me, at my current best, trying to live life as positively and happily as possible. I have a condition which means that I am constantly fatigued to some degree, have post exertion malaise, have insomnia, frequently feel achey and in pain, light headed, and brain foggy, and I also have other conditions which add on other issues such as blood pressure, syncope (fainting) and gastrointestinal problems. I try 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 most days! I can not drive, I can not live by myself, I can not do groceries or a day’s worth of meal preparation, and I can not work. As I always say though, this is my life, I have one shot at it, and even though this is my plot at the moment, it doesn’t mean I should miss out on happiness. Sometimes I am a lot more unwell than this day demonstrates, and other days I am better than this day. I still try to see something good within the day though. I know that I am lucky, because so many people have to deal with so much worse. I know that I am lucky because I have hope for improvement, when others don’t. I know that I am lucky 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 know that I am lucky because I have access to medical assistance and medication, even though it is a very slow and painful road.

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is a destructive and horrible condition which effects 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. That is what I used to think about CFS/ME, and I was wrong. It is a condition which needs more research so that a bio marker and subsequent diagnostic tests can be found. We must continue to raise awareness so that more research is done, and more doctors take it seriously. It is a significant and devastating condition which can turn anybody’s life upside down, and the lives of their loved ones.