Glimpse into the specialist appointment

I haven’t written for a while. Basically, I was a little lost for words after my specialist appointment!! But today I find myself lying on the bed feeling pretty gross, reading motivational articles, books and blogs about good health, clean eating and wellness, and I feel inspired to find those words!

The much anticipated and nerve wracking specialist appointment was for the most part worthwhile and helpful. The doctor was very keen to listen and help, and although not that much older than me he seemed to know his stuff (though I do have to remember I am getting old and having a doctor my age is more likely now!). I do feel frustrated because he said he doesn’t think all my symptoms are from the autoimmune disease, so yet again another doctor raises the possibility of something else going on, but can’t bring an answer with that suggestion! My blood boils when I hear a doctor say “something else is going” because it is never followed by “and that something else is….”!

He did a thorough examination, and listened to my lengthy list of symptoms. Much to my relief he has ruled out arthritis or other autoimmune joint related disorders, which I was concerned I was developing.

He wants to improve my dizziness and light headedness, which is such an issue for me. Over the years, doctors have mentioned the availability of drugs to improve my low blood pressure to help this (I generally sit on a BP of about 90/60mmHg, and drop to a systolic pressure of about 80 or lower when I stand, which makes for staying upright or seeing through black vision a tad interesting!!). So he has suggested starting Fludrocortisone, which is a steroid that causes fluid and salt retention so as to increase the blood pressure, and hopefully result in more upright-ness and less starry vision!! (though maybe I will become a big puffy ball of oedema! Attractive!). It seems like a fairly hardcore drug with many potential side effects, but I think I have decided that I will give it a go, taking in the fact that being light headed and dizzy has caused me to leave work countless times over the years, and is the main reason I haven’t driven for the past 3 months.

The part of the consultation that left me speechless was the bit where he suggested I may have Grave’s Disease, not Hashimoto’s disease!! This is the same as Hashimoto’s in that it is an autoimmune disease that attacks the thyroid, but it causes too much thyroid hormone production, as opposed to too little. I had queried this myself in my weeks of reading, but I don’t fit some of the symptoms, and in trusting my GP, I had discounted it. (But I don’t fit all the Hashimoto’s symptoms either, and most patients rarely fit all the symptoms on a list). It turns out that I was right to fight for a specialist appointment, because a test to check for Grave’s disease, that could have easily been done during the multiple blood tests I have had done, hasn’t been done!!

So, just in case I hadn’t been frustrated enough by the painfully slow progress so far, I have been taken off the carbizamole for a month to see what happens!! So another 4 weeks of getting nowhere, and potentially getting unwell again (how does one look forward to a month like that?!). At the end of the month, I will have more blood tests to reveal whether I do have Grave’s, or to confirm the Hashimoto’s diagnosis, and then we will decided whether I need Carbizamole or Thyroid Hormone replacement. Comical really! I remember my GP saying, “you have an autoimmune disease that is affecting your thyroid. We will call it Hashimoto’s; it could be something else, but we will call it Hashimoto’s’.”!!!! Excuse me, if there was a test to decide whether it is Hashimoto’s or Grave’s, why didn’t we do it?! Ok, rant over □

Fortuntately, I haven’t got suddenly and severly unwell like the first time I came off the Carbizamole. However, I have slowly developed more symptoms or had symptoms increase in intensity in the past 2 weeks that I had less of on the Carbizamole, such as a pounding and racing heart, nausea, a sensitive stomach, weakness and lack of stamina, light headedness and today’s new sensation of too much blood in my eyes, as if I am hanging upside down! I have my fingers and toes crossed that I am not developing hyperthryoidism again, but I have to look at it positively that it is more controlled this time and if it happens, at least we will know why.

I am so glad that I stood up to my GP and requested a specialist appointment despite his adamant determination to keep me on. GPs do a fantastic job, particularly my GP who was the first person to look at my symptoms from a different angle and discovered the autoimmune disease, but they might miss something in the more specific areas (it would be impossible to even contemplate that they would know everything about everything!). I am so glad I had people encouraging me to push for it.

Unfortunatately when I have a good day and do a few things, it is inevitably followed up with a day feeling wiped out and miserable (an indication that work would just about kill me at the moment! It definitely got close to doing so for most of 2012!). Yesterday I managed a nice day out with Mum, and even though we took it very easy and had lots of rests and cups of tea, today I feel like even sitting up is too uncomfortable. So I have resigned to my comfy bed with a relaxing playlist on my iPad, an array of books, including the new ”I Quit Sugar” by Sarah Wilson and I feel a nap coming on! (Sarah Wilson is my inspiration as she avoids fructose like me, and she has autoimmune disease too -she has had Grave’s and now has Hashimoto’s, yet she has it controlled and is for the most part healthy and leads a busy life!).

So I will finish up now, but will aim to update with some new recipes etc soon!