

PE1463/BBBBB

Marnie Mclean submission of 16 June 2019

This whole issue is largely one of health inequality for women as they make up the vast majority of sufferers. However, it should be noted that men and children can also be profoundly affected. Thyroid disease affects health and well-being, both physical and mental, and can reduce the ability to contribute to society and the economy. The treatment in Scotland for many patients, particularly those with an underactive thyroid, is less than ideal and must be addressed as a matter of priority.

At least 10% of those with an under active thyroid are known to 'not do well' on the standard treatment regime, yet they are very seldom offered any alternative treatment, although alternatives exist and have been seen to be effective. What is the medical solution for them?

The blood tests for hypothyroidism do not give a full picture of thyroid hormone function, hence many sufferers are deemed 'borderline', are undertreated or may remain undiagnosed- Is this acceptable in 21st century Scotland?

I think you should know a bit about my background and medical history before making such judgment **ONLY** based on my TSH (Thyroid Stimulating Hormone). So here goes...

I had been trying unsuccessfully for a family for around three years. I was referred to the Fertility Clinic for investigations. Now having researched what to do when you are trying for a baby, I did stop smoking but I really struggled to lose weight. I would prepare and eat my food sticking to a diet and going out jogging every morning. However, I would lose maybe 4lbs and put back on 4lbs, but despite my 100% efforts I could not lose weight. This was extremely disheartening.

When I met with my fertility Doctor he advised me to lose weight and I burst out crying that I found it so difficult. He was going to conduct some blood tests and he said he wanted me to get the blood tests done every 3 months. I did not know what they were for.

At an appointment with a GP I was told that my Thyroid was "Borderline" and "We shall just keep monitoring it" to see if it gets better. I had been crying hysterically in her office for almost an hour at that point. **You trust what you are told by the health professionals.** IF I HAD KNOWN THEN WHAT I KNOW NOW I WOULD HAVE WENT DOWN THE NEGLIGENCE ROUTE. (From memory, at that point I think my TSH was around 9, my T4 was 8 and my antibodies were around 1000. **CLEARLY OUT OF RANGE!!**)

Fast forward almost a year later, I am off work and received a call from my fertility doctor questioning why I wasn't being treated as my antibody levels were so high. I did not understand what he meant. He then wrote to my GP practice.

At the subsequent appointment (with a different GP), I was immediately prescribed levothyroxine. Then, after 3 years of trying, I fell pregnant. I believe that my body had been screaming out for this hormone and that the timing is no coincidence.

I had a healthy enough pregnancy, although they did have to check for gestational diabetes and the birth itself was quite horrific that led to an emergency section. Concerned that I may be difficult to conceive again, I started to try for family right away and fell pregnant straight away. I am so grateful to that Fertility Consultant as I believe that I wouldn't have a family and I fear I would still be a mess without him intervening.

During this second pregnancy, my thyroxine more than doubled and I had a lot of trouble towards the end as the baby was quite large. This also ended with an emergency section.

It was after having my children that my symptoms really began to worsen. Before being treated for an Underactive thyroid, my eyesight went really bad, my back teeth started to crumble, I was bloated and swollen, and my once thick hair was falling out. My weight increased with no real change in my diet. I started to feel permanently hungover- everyday, despite not drinking alcohol. I had headaches all the time; my nails became flaky and brittle. There was no change in my periods, they had always been very, very heavy with bleeding for 10 days with clots, bleeding through the super plus tampons AND towels. My memory was shocking. Sometimes during conversations with people my brain would go completely dead and I would have no idea what I was talking about. It was being switched off. My moods were up and down, crying for no reason and getting flashes of anger really quickly.

After being prescribed thyroxine, I actually felt worse but of course I had been pregnant and not known yet. Anyway, after my pregnancies, the pain began. I was still swollen, very over weight and extremely, sore. The pain in my muscles and joints were so bad that I contemplated suicide as I felt I couldn't go on. I was a burden to my family who had to do everything for me as well as look after my baby and toddler. The pain was unbearable. Some days it took me all my strength to get up out of bed. Then there was the fatigue. I fell asleep wherever I sat down. I was completely exhausted and in pain. Sore aching muscles and joints. It was a different kind of tired. Not a normal tiredness. My hair loss got worse. I saw my GP regarding the pain and it was then she diagnosed Fibromyalgia. There was no cure but I could manage my pain with Naproxen and Paramacetol.

On my return to work I actually thought that as crazy as it sounds that Dyslexia could come on all of a sudden. Everything I looked at was jumbled and made absolutely no sense to me. I couldn't cope at work at and handed in my resignation. They offered me a position for fewer hours as a career regression to see if this would help and I took it.

I lived like this for a while. The next visit I had to the doctor was because I had developed a lump in my throat and no matter how much I swallowed it was always there. I sometimes would choke on my food and I had to prepare myself to swallow. My voice got so hoarse it almost disappeared. I was diagnosed with Hashimoto's Thyroiditis and this causes the thyroid to swell. No one had ever told me I had an autoimmune disease. **HASHIMOTOS**. No one. I was just told I had an underactive thyroid but not to worry as you get a pill that fixes it.

This was a pivotal moment in my life as it was the first time someone had said you have this disease. This led me to find out and research all I could. My health was in my hands. I had to get better.

Over the course of the next couple of years, I learned about my basal temperature. No wonder I was always freezing- holidaying in Florida with jeans and a parka, everyone else in shorts and t-shirts. Not being able to keep up with friends walking. Branded lazy. I was exhausted and couldn't understand it.

I learned how to get all my ducks in a row. What needed to be tested and that my T4 and T3 levels should be optimal. When my T4 is even mid range, I feel like a Zombie and the swelling, pain and fatigue comes back again. Driving when my T4 is under 20 is dangerous. Being undertreated underactive thyroid has been likened to drink driving. I paid close attention to what my levels were like and how I felt, keeping a pain/symptom diary. It was during my research I learned how the Thyroid gland worked and why my symptoms weren't really getting any better. My doctor agreed to test my T3. It was I think around T3 4.7 so this was low and not optimal at all. The doctor agreed to trial me on T3. Almost a week in, and I remember driving home. I felt good. There was no pain, my head was clear. I felt normal. I felt like Marnie. I felt how I was supposed to be. My body was also so clearly lacking this hormone. The **active** hormone.

Believe me I have done my research. I have been on countless websites learning how to get myself better. I am very much accountable for my own health. My T4 and T3 are now "Optimal" and completely in range and I feel great. There are no underactive or overactive symptoms. My fibromyalgia and fatigue have disappeared!! My period is now what I would regard as normal- I am still heavy but only bleed heavy for 4 days and then it tapers off - there is no clots. Again, this is no coincidence with the combined treatment. If you view my antibodies blood results you will see them decrease steadily over time – NOT Fluctuate. I imagine if they were tested again today they may actually be in normal or borderline.

I was actually devastated when my T3 was stopped by the NHS. Why this was allowed to happen is a great travesty. One company in the UK being able to supply the NHS and bump up prices the way it has is immoral but it makes you ask the questions who also is benefiting from this? I found out that I would no longer be prescribed T3 when I picked up my prescription which included a scrawled note stating that it wouldn't be being renewed. There was no phone call or appointment to discuss my options.

I made an appointment with my doctor to discuss options and they acknowledged that this was uncalled for and should not have been done in the manner he had. We discussed in length T3, that I had to source it over the internet and every time I have to source another supplier I take my health into my hands and it is a risk. A risk I feel I have been forced to take because of the T3 removal.

The doctor suggested it would make my bones and heart weak. Well so does aspirin really, but it's still on the market. I offered to take a full Bone Density Scan if that were a concern. I weight train 3-5times a week so I am positive I am taking the correct steps in decreasing my risk. T3 has allowed me to do this. I am a Fitness

Instructor!! Teaching Classes 4 nights a week. I would have never been able to do this undertreated. There were also concerns over my heart health. When I was undertreated, my resting heart beat was in the 50s. It is now a healthy 66. At one point during my mid 20s I actually thought I was taking a heart attack. Although there is no medical note of this, I again believe it was because of an underactive thyroid which we all know can slow everything down. Organs and intestines. I had extreme constipation as well. I would also welcome a heart scan/ monitor. The doctor did not believe that all my symptoms cleared up with the addition of T3. I was sorry my doctor didn't believe me and I asked to be referred to my antibody levels, which had steadily decreased. I was asked how I monitor my levels at the moment. and I said when well if I get heart palpitations I know I have taken too much T3 or a change in supplier has brought potency issues, I decrease my dose until it levels out. In the summer, I need less, so I take a 20mgs every other day instead of twice a day. My T4 levels have remained consistent these last few years. Although the doctor listened and he wasn't going to re-instate my prescription he did agree to regular T3 tests so I could keep on top of my health.

I have no option but to source the T3 needed over the internet. I find that a combination treatment is better for me, however, you need to look at why there is only **one** UK company pedalling Liothyronine at the high prices they are. Who is benefiting? It certainly isn't the patients. ... whose pockets are being lined??? All these issues need to be looked at. And we can't all be crazy!