

PE1463/EEEEEE

Morag Webster submission of 26 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?

After partial thyroidectomy in 1993, my health declined progressively. I had to give up a career at Guide dog for the Blind, my home, my friends and my independence. I was misdiagnosed as depressed/bipolar. I was first diagnosed hypothyroid in 1997 after being admitted to hospital after becoming suicidal within days of being prescribed Prozac. The hospital endocrinologist and psychiatrist had prescribed Liothyronine, though this medication was discontinued by my doctor. The GP at that time argued that my symptoms were not related to thyroid and had refused treatment stating "there was nothing wrong, it's all in my head!!!" I was admitted again as symptoms quickly returned. I had been prescribed nearly every anti-depressant available, including Lithium and ECT, to little improvement, further tests showed now I was definitely hypothyroid due to Lithium (98). This time prescribed Levothyroxine by hospital. Again, my GP refused to continue treating me claiming there was nothing wrong with me!

For 5 years I was unable to work, sleeping 20hrs a day, gained 5 stone, even my parents argued with doctors that I wasn't depressed and something else was wrong. I almost gave up. A close relative had visited and explained our family history of thyroid disease and begged me to seek a 2nd opinion. I was put on a trial of Levothyroxine by a different GP in 2003, but no official diagnosis was made. A case of wait and see. In last 10yrs I have reported various symptoms, fibromyalgia, chronic fatigue, infertility, palpitations, dry eyes/skin, severe constipation/gluten intolerance, again I was told my results were normal and it can't possibly be thyroid related.

The nature of this disease forced me out of work again in 2006. The only way I have managed to work was to become self-employed. It has allowed me to manage my work load, without stress/pressure from an employer/co-worker. Perhaps because I am not entitled to sickness benefits, it had made me determined to find that balance. I became quite ill again and was eventually admitted to hospital A&E by ambulance after reacting to Teva Levothyroxine 2017. (It contains Mannitol, which many patients reported severe reactions to, including 2 other members of my family, 1 of which

suffered a mild heart attack!) Yet again GPs referred to mental health/stress, even though I had had no reason for stress, but I knew something wasn't right with medication or my levels as I had never felt "normal" for well over 10yrs! It was Doctors from A&E that finally referred me to endocrinology and cardiology. I demanded to see a Thyroid Specialist asap and met with a specialist privately as the waiting time to see an NHS endocrinologist was 5months.

The specialist could relate to all my symptoms and medical (family) history, including the "bipolar" episode, (which turned out to be directly related to thyroid levels and inconsistent treatment) but also noted a conversion problem and suggested a trial of T3 with T4 . The specialist wrote to my GP to prescribe T3 as this was still available on the NHS. However, this was dismissed as unlicensed medication, too costly and had no clinical evidence that it worked. (In fact, my GP insinuated that I could have paid the specialist to say anything i wanted!!)

I have seen an NHS endocrinologist 3 times in last year and there has been no discussion about trialling T3, putting a clinical case to multidisciplinary team or the risks and benefits to T3 treatment. It seems as long as my tests fall 'anywhere' in the reference range, I'm deemed "normal".

I do appreciate that T3 is not for everyone and it does need careful monitoring. I have tried and tried to get NHS GP and endocrinologist to work with me. But being constantly told "my symptoms are in my head" does not instil confidence in the very people i am supposed to trust.

In 25 years living with hypothyroidism, I've have found GPs and NHS endocrinologists rely solely on test results. I have never met any that fully understand "signs and symptoms" nor are aware of recommendations issued by British Thyroid Association and British Thyroid Foundation.

Since reaching an optimal dose of T3, it has been like turning a light switch on. I have gone from hardly able to climb up and down stairs, walk any distance, in constant crippling pain, feeling that of a 90yr old with onset dementia/poor memory/concentration, feeling as if my body was slowly painfully shutting down to now feeling alert, optimistic, energetic, free of pain, dizziness, fatigue, better digestion, sleep better. I can work, walk dogs, do housework and garden all in same day now! I finally feel I've got quality of life and my mojo back.

I have had to pay for my own blood tests and educate myself through books and support groups how to interpret those tests, some of which are not available on the NHS. Thyroid UK have been invaluable in helping to get to the route cause of my health problems.

It is immoral and unethical that GPs completely ignored Endocrinologist and Psychiatrist diagnosis again and again. It is clear that there is need for better education on Thyroid disorders in General Practice or accept liability.

I've had to come to terms with losing my 20s, my friends, relationships, career, and ability to have family of my own, because of this disease. Its only now I find out my

life could have been very different had the primary care provider been aware and treated me when i was first diagnosed!!!

I have several members of my family who have suffered exactly the same symptoms yet are also treated for fibromyalgia (various pain meds) antacids, betablockers for palpitations, statins for high cholesterol, antidepressants, various heart medication, laxatives, all of which are associated by Hashimoto's. Since I have switched to T3 I've no need to be prescribed anything else.

I have also raised the issue of costs with my MP and Mr Fitzpatrick, who seems to think it is acceptable for Liothyronine to have come down by 15%. He seems ignorant of the fact that the price had risen 6000% in last 10 years!
1000x25mcg Tiromel =€35 the equivalent here in the UK is around =£10k.