

PE1463/CCCCC

Anonymous submission of 19 July 2019

This is one of the longest running petitions in the history of the Scottish Parliament – it was lodged on 19 December 2012, almost seven years ago. Meantime, thyroid patients continue to suffer while nothing much has changed at the sharp end for them.

This disease mainly affects women and, amongst other things, raises the serious issue of gender inequality. I cannot help but think it would be taken more seriously if it affected the sexes equally. Thyroid disease does not just impact health and well-being, both physical and mental, it also often leaves patients unable to contribute to society and the economy because of its debilitating consequences. I myself had to give up my profession because of it.

The current blood tests used to detect and monitor hypothyroidism do not give a full picture of thyroid hormone function, hence many sufferers are either not diagnosed, under-medicated or told they are not ill enough to be treated at all. Even those who do receive treatment are not left symptom free because of the medical profession's fixation on a one-size-fits-all-Levothyroxine approach.

The treatment for the majority of patients with underactive thyroid is seriously inadequate and must now be addressed as a matter of urgency. Too much time has already been wasted and too many people, myself and members of my family included, continue to suffer.

In addition, at least 10 per cent of patients with under active thyroid do not respond well to the standard treatment regime of Levothyroxine (T4), yet they are rarely offered any alternatives, although these do exist and are known to be effective at improving symptoms and quality of life. In particular Liothyronine (T3) and Natural Desiccated Thyroid, which was the only treatment available until Levothyroxine was created.

This inadequate diagnosis, testing and treatment condemns thyroid patients to a very poor quality of life and what, is in effect for many, a slow death with a number of comorbidities, including obesity, heart disease, hypertension, asthma and diabetes to name a few.

I suffer from difficult to treat hypothyroidism, caused by Hashimoto's Disease, and have done for most of my adult life. As a result, I had to give up my career as a broadcast journalist, then as a lawyer, and finally as a university law lecturer. I thought it was the stress of my work that was making me ill so changed my career several times to try to deal with this. It turned out that it was, in fact, the illness that made me unable to cope with any kind of demanding work at all.

I ended up taking voluntary severance from my university employment and had a couple of years off before finding some part-time work. I eventually worked part-time freelance from home as an editor, journalist and proofreader which gave me more flexibility to accommodate my illness. Of course, this adversely affected my income

and ultimately my work pension on reaching retirement age (60) which I did last year – a clear and direct economic impact.

On reflection, it took circa 10 years for me to even get a diagnosis during which time I suffered a myriad of symptoms including debilitating fatigue that no amount of sleep could assuage, massive weight gain, brain fog, poor concentration and memory, loss of drive, regular upper respiratory tract and chest infections, persistent cough subsequently diagnosed as adult onset asthma, breathlessness, choking fits, muscle cramps, repeated Candida infections, extreme heat intolerance despite low body temperature, dry skin and hair, easy bruising, wrist pain, vertigo and balance issues, tingling in my feet and hands, indigestion and irritable bowel syndrome, fluid retention causing puffy face and hands, high blood pressure, PMT and heavy periods, loss of libido and wanting to be on my own.

Because I was cycling between under and over active, which I now know is typical of Hashimoto's Disease, but which I did not know then as my antibodies were not tested, my GP said my presentation was confusing and labelled me as 'difficult'. It is not uncommon for this to be said about women with thyroid disease – shades of the 'hysteria' branding of women in the past.

The thyroid gland affects many systems of the body so when it is failing it does cause a wide range of apparently disparate symptoms. You would expect doctors, and especially endocrinologists, to know this.

My GP finally tested me and found my TSH (thyroid stimulating hormone) was above the normal reference range which is indicative of hypothyroidism but was not minded to treat me despite my many symptoms. I remember noting at the time that it represented a 150 per cent change in my thyroid function and insisted on seeing an endocrinologist. This is a diagnostic test but once on treatment it is of limited value. Even so, doctors generally only test TSH rather than do full thyroid function tests which are much more enlightening.

The endocrinologist agreed to prescribe Levothyroxine and initially it did make me feel better though it did not get rid of all my symptoms. He warned me that I could develop osteoporosis and heart problems if I was overmedicated so I paid for a private bone density scan so that I would have a base line bone density measurement. It turned out I already had osteopaenia. I know now that this was most likely as a result of the periods of over activity with my Hashimoto's disease which increases bone turnover but no one told me about that then either or thought to check my Vitamin D status. I was told to have another bone density scan when I was 60 which I did. I am pleased to advise that there had been no further deterioration in my bone density other than that consistent with age despite me being on T3 for some considerable time. At that appointment the nurse practitioner took blood and discovered that my Vitamin D status was very low and asked my GP to

prescribe this for me. I subsequently found out that my folate and iron were low too and that vitamin and mineral deficiencies are common amongst patients with thyroid disease, including Vitamin B12 deficiency. Getting these optimal is a vital component of thyroid health. Since increasing my level of Vitamin D I have hardly had a cold and have had no upper respiratory tract or chest infections. My general health is much better.

Back then I just thought that was as good as it gets and that I had no option but to put up with my ongoing symptoms. When the benefit of Levothyroxine tailed off and my symptoms got worse again, despite increases in my dose, I went all round the houses trying to get myself sorted seeing various doctors, nutritional therapists, and others at my own expense. Nothing worked.

Eventually I sought a referral to the leading NHS endocrinologist at the time. I was prescribed a small amount (20 mcg) of another thyroid hormone, Liothyronine (T3) as well as Levothyroxine (T4). T3 is the active thyroid hormone and is bio available whereas T4 is not and has to be broken down into T3 to work. This quickly improved my brain function but it did not alleviate all of my other symptoms. The fatigue was as bad as ever – after some time, I was sent to a sleep clinic and I was diagnosed with obstructive sleep apnoea and given a CPAP machine for this. I now know that this condition is common in people with an underactive thyroid – and of course the associated weight gain does not help. This has helped but not completely dealt with the fatigue. My weight has never gone down and, no matter what I do, I can't lose it.

The endocrinologist was adamant that I could not have any more T3 and so I remained on 20 mcg plus T4 in varying doses up to 200 mcg to try to improve my quality of life. While on T3, my TSH was to all intents and purposes suppressed and remains so to this day. My research indicates that once on T3 this is not a good indicator of thyroid function as it is a pituitary hormone but doctors and endocrinologists do seem to fixate on it and want it to be in range thereby treating patients by numbers and not by symptoms or wellbeing.

In 2015 my GP tried to take my T3 off me for reasons of cost as this had risen by around 6000 per cent because of alleged profiteering by the manufacturer. (This is currently with by the Competition and Markets Authority for a final decision) I disputed this and paid for a private genetic test as by now I began to suspect I had some issue with converting the inactive T4 hormone into the active T3 one. And I did – the test showed I had the DIO2 genetic issue from one parent and this means that I don't convert well.

I saw a local NHS endocrinologist as my GP could not get the NHS lab to test my Free T3 and she told me she would not have prescribed any T3 for me but would not take it off me as my previous endocrinologist had given me it and she refused to look at my genetic test. Her response was to increase my T4 to 225 mcg. She also could

not get the lab to test my Free T3 but only my Total T3 which is arguably not as useful.

I then found out that my previous endocrinologist was now consulting privately and arranged to see him. He agreed to reduce my T4 and increase my T3 in the light of the genetic test information and my ongoing unresolved symptoms. Via private testing I discovered that my Reverse T3, which is thought to block thyroid hormone receptors, was too high. My thyroid antibodies were also too high which meant I have Hashimoto's Disease. I never in all the years I have been ill had this diagnosed on the NHS! Over a period of time my endocrinologist increased my T3 and reduced my T4 till I am now on T3 only at 60 mcg. Since switching to T3 only my Reverse T3 and thyroid antibodies are back within the normal range. I have had to have these tests done privately at my own expense as the NHS apparently no longer tests Free T3 – even though I am only taking T3 so it is essential to monitor my condition. I personally monitor my temperature, blood pressure and pulse and have done for many years.

I am much better on T3 only and have had some further symptom relief but some do still persist including fatigue and weight gain. It is now much easier and cheaper to have genetic testing done and I have found out that I also have a defect in my DIO1 gene which means that I am at risk of decreased thyroid hormone metabolism in my peripheral tissues.

My endocrinologist recently retired and I am now without an endocrinologist who understands T3 and the implications of my defective genes on thyroid function. I have been referred to another endocrinologist who I was told was knowledgeable about T3. I saw him at the end of March 2019. He was clearly unhappy with me being on T3, despite me having no symptoms of over medication, told me he was not interested in my genetic issues, or my record of temperature, blood pressure and pulse. He took my pulse which was within normal parameters and told me he would see me once a year to check my bloods. I was very disappointed at this as I had hoped to find an endocrinologist that I could work with to optimise my thyroid health. I am now considering making a formal complaint about this – something that to date I have never done.

Compared to many thyroid patients I am fortunate – I am able to research my condition, pay for private tests and doctors, and advocate for myself. Many can't do this and that is a serious health inequality which must be of concern to MSPs and the Scottish Parliament.

I hope my story gives an idea of what it is like to suffer from hypothyroidism and of the impact it has not just on health and wellbeing but on every aspect of your life.