

## **PE1463/RRR**

Fiona Hutton Letter of 24 February 2016

Dear Convener and members of the Committee,

Please consider this letter as a submission to the committee for the above petition. After watching the meeting on the 9th February and just recently having an appointment with an Endocrinologist, I felt I had to send a letter of support to the Petitioner, Lorraine Clever.

I was angered, although not surprised, by the attitude and responses from Prof. Graham Leese and Health Minister Maureen Watt. This is the attitude the most thyroid patients have to encounter from Doctors, GP's and Consultants at, at most appointments, and it was the same disregard I was treated with at my most recent consultation.

A brief history of my story is as follows:

I was diagnosed as Hypothyroid in 2009 (although my symptoms had been present and worsening for many years before this) and prescribed 50mcg Levothyroxine, with no other explanation or information provided about my condition, just that I would have to take this pill for life. Initially I felt a little better, but after 3 months my symptoms returned. Blood tests returned normal, but my doctor at the time suggested dosing symptomatically and increased the Levothyroxine to 75mcg, where it has remained to this day, despite my health getting progressively worse. At various points I have been prescribed anti-depressants to improve my energy levels, the contraceptive pill to help with heavy menstruation and extreme PMS (even though I have been trying to get pregnant) and 3 times in the last 6 years I have needed iron supplementation. The last two years have been the worst of my life, health wise. I have been poked and prodded, tested for and ruled out sleep apnea, various bowel diseases, ovarian cancer, Lyme's disease, food intolerances, blood test after blood test, costing our NHS a fortune, and no one thought to look at the disease I already suffer from. I have had to give up my dream of becoming a Paramedic because I can't pass the medical. I have turned down nursing jobs because I am not capable of working 12 hour shifts. My sick days in the last year have increased significantly.

Before all this started, I was an extremely active young woman, playing many sports including volleyball, tennis and climbing. I no longer able to do any of these activities, instead I need a nap after walking the dog. I'm 35.

Last year I suffered from my 3rd miscarriage and have since been on a mission since to educate myself as much as possible about my thyroid condition (something doctors do not like, an educated patient!). It frightens me that my GP didn't know to increase my Levothyroxine as soon as pregnancy is confirmed. It frightens me how little my GP knows about Thyroid disease in general! What frightens me more is how little the specialists seem to know, and how little they seem to care.

My appointment with the Endocrinologist went as suspected and I am left feeling helpless with nowhere to turn, except to the internet and self-medication. He was unwilling to discuss alternative treatments with me (T3/T4 combo, NDT) and was very dismissive of my symptoms. According to the endocrinologist, T3 is an unimportant test and he can tell all he needs to know from my TSH blood test. I had to literally beg him to run tests for me, and even then he admitted that the lab probably wouldn't run the T3 test. My GP had also asked for T3 which the lab didn't do. I don't understand why doctors seem to be held to ransom by a laboratory?

There are other treatment options available to thyroid patients, however they seem to be being withheld through ignorance and/or Big Pharma manipulation. There are not enough studies, and certainly no conclusive scientific research that shows a clear superior performance from either Levothyroxine or T3/T4 combo treatment or NDT. The only evidence we have is from patient experience, which would suggest that the current diagnosis and treatment 'Best practice' is falling woefully short, and leaving hundreds of thousands of predominantly woman suffering for years, myself included, and also my mother who has been 'borderline' hypothyroid for years with no treatment, and has just recently diagnosed with Fibromyalgia. To me it's negligence.

I appreciate the committee continuing to look into this, and was heartened by the line of questioning. It gives me some hope for change in the future. You can understand that, like yourselves, thyroid patients are left with more questions than answers on a frequent basis!

Could it be possible for all thyroid patients treated by the NHS in Scotland to be sent a questionnaire regarding their treatment and its effectiveness? I think the medical profession might be shocked at the results!

I look forward to the next discussion.

Best regards,

Fiona Hutton