

**PE1463/A**

David Stewart MSP  
Convener  
Public Petitions Committee

27<sup>th</sup> February 2013

Dear David

I am writing to the Public Petitions Committee with regard to PE01463 on thyroid disorders. If I had known that the committee were taking oral evidence, I would have attended.

However, I hope you will be able to take my comments in this letter into consideration during your deliberations.

I also include some background information by way of my contribution to the Parliamentary debate on the Patient's Rights Charter, a motion I previously submitted and a series of PQ's asked and associated answers.

I believe that the way thyroid patients are being dealt with in Scotland and across the U.K, is unacceptable and is undoubtedly negatively impacting on the NHS, not to mention wider society, in wrong diagnosis and treatment and economic inactivity. It is also very firmly a matter of inequality as Thyroid problems are predominantly gender specific and occur most frequently in women.

As you can see from the enclosed information, I have been working on this issue for some time.

You may also note that one of the PQ answers refers me to the NHS Inform site for information. This site states that an *"Underactive thyroid is usually not serious"*.

Unfortunately I feel that this statement holds the key to why so many women are suffering on the wrong medication, the wrong levels of levothyroxine or with the wrong diagnosis. This life-long debilitating chronic health condition is extremely serious even although a great many sufferers respond well to levothyroxine.

However, the thyroid gland controls a person's health and well-being and no amount of artificial replacement is going to be able to fully replicate the natural function.

Further there are many substances that can affect how thyroid replacement hormones work for example grapefruit, tea and soya can all have an adverse effect but no fact sheets are given to patients on this and there is no information on 'NHS Inform'. It can also be helpful to take appropriate supplements like selenium and other vitamins and minerals but again no information is provided.

Thyroid disease is one of the most prevalent diseases affecting women and unfortunately the blood tests, coupled with GP's and other clinicians who believe that the test is paramount rather than the patients symptoms, are leading to people remaining ill who could be much improved with appropriate treatment.

I have also lost count of the number of women who have told me that their results are "border-line" hypothyroid so their GP doesn't prescribe T4 and they remain ill: sluggish, depressed, and piling on weight. In other countries where the tests parameters are different these women would be on levothyroxine and would be well again.

Thyroid problems not only cause obesity but also memory problems, sluggish thinking, short temper, dry skin, hair loss, depression and can lead to suicide.

Although I am not clinically trained, I am convinced following my own experience that many women diagnosed with M.E. actually have a conversion problem and would recover if given T3. I would therefore wish to see every person who has been diagnosed with M.E. but has an underactive thyroid to be given the simple blood test to ascertain if they are converting from T4 to T3.

At this point I would like to share a short version my own story with your committee and would be willing to come as a witness to the committee. None of us likes to have their health issues made public but I admired Sandra Whyte and Lorraine Cleaver for being brave enough to share their health information with the committee and this has inspired me to offer my experience in the hope that it may save lives or at the least make some women's lives better.

I was diagnosed with an underactive thyroid in my early 30's following a number of years of increasing illness. It can be genetic and my mother suffers too. My GP prescribed levothyroxine and very quickly I saw a difference and felt as if I had been brought back to life. For many years I managed on T4, although never really well, until I stopped smoking. I believe that this might be relevant and that research is needed into the effects of stopping smoking on patients with hypothyroidism.

Over a period of years from around 2005 until 2009 I became increasingly ill with symptoms ranging from depression, dizzy turns, and exhaustion to short temper, headaches, fibromyalgia and further hair loss. Initially I was misdiagnosed with the menopause, then depression. Following emergency admission to hospital *via* ambulance after collapsing, I was released still unwell and diagnosed with a kidney infection and low blood pressure.

Eventually I became so ill that I was referred to a neurologist. This of course was the wrong speciality but like so many sufferers of thyroid disorder I was probably considered to be suffering from mental ill-health.

I was tested for many diseases including Lyme disease and Atkins disease, I was put on a heart monitor and I was given a brain scan. In the meantime I was becoming too ill to work and eventually, after collapsing at a parliamentary evening event, I was signed off work. The final analysis was that I had M.E.

I fought this 'dustbin diagnosis' and argued that as I already had an existing chronic condition, I should have it fully explored before accepting that I had M.E. I was referred, at my request, to Dr Anthony Toft at the ERI in Edinburgh.

I was accompanied by Margaret McGregor of the British Thyroid Foundation to my initial appointment at the ERI as by this stage I was extremely ill and disempowered. I assumed that I needed a higher dose of T4 than the blood-test suggested but a simple test carried out by Dr Toft, after speaking to me and examining me, showed that I was not converting the T4 to T3.

I would like to emphasise that it only took Dr Toft one simple blood test to diagnose my illness after years of ill-health, expensive tests and misdiagnosis by other health professionals.

I was immediately put on T3 and within a few weeks I began to feel better and a few months later I was back in Parliament.

Dr Anthony Toft is a leading Scottish endocrinologist, who changed his view of treatment and diagnosis over a decade by watching and listening to his patients and seeing the results of different treatment including T3 rather than just T4.

He has now retired and I am seeing his replacement at the ERI as very few endocrinologists will prescribe T3. G.P's are not allowed to prescribe it themselves.

It is terrifying to think that if my consultant becomes unavailable I may not be able to get T3 and would become desperately ill again.

I did not get any apology or explanation for my misdiagnosis although I persuaded the neurologist at Monklands Hospital to communicate with Dr Toft so that other patients might not suffer in a similar way.

My anger at my treatment and misdiagnosis led me to accept an offer from the occupational health G.P., who I was also attending, to go to CBT and that was helpful to my return to work program.

I have been considering for some time making my story public in the hope that it might help others and encourage changes in the NHS. It is not, though, easy to discuss these very personal health issues and so I have been waiting until I felt the time was right to do so.

I hope your committee will decide to fully investigate this health scandal and as such help save lives and improve the situation for many women.

Please do not hesitate to contact me if you require further information or wish to take oral evidence from me.

Yours sincerely,

**ELAINE SMITH MSP**