

PE1463/ZZZZ

Frances Beck submission of 21 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 was diagnosed with primary hypothyroidism over 16 years ago and functioned reasonably well on the standard levothyroxine treatment to begin with.

I became increasingly unwell and was diagnosed with fibromyalgia in 2012 after being tested for every other conceivable condition, the symptoms of which mirror those of undertreated hypothyroidism, and am convinced that if my hypothyroidism was optimally treated, my fibromyalgia would be 'cured'. I have been unable to work since then (I am a trained secondary school teacher), a situation that I am deeply unhappy with and over the last 7 years have been researching and trying to get well again so that I can get back to work.

I came across an enormous amount of anecdotal evidence that showed that some people do not fare as well on the standard levothyroxine treatment, particularly after a long period of time, and how they became well again after becoming optimal on natural desiccated thyroid treatments. Unfortunately, there is little in the way of robust scientific research on this as the pharmaceutical industry and even many endocrinologists are not interested in finding out about alternative treatments and discovering optimal levels for individuals to allow them to be well. The testimonials of many hypothyroid patients, mostly women, speaks volumes though.

Having ruled everything else out and trying a variety of medications to help me function better (to no avail), I asked my GP to prescribe natural desiccated thyroid in place of levothyroxine. My blood tests had revealed that my TSH (Thyroid Stimulating Hormone) and T4 levels were within the very wide normal range, but my T3 levels were at the lowest level or just below the normal range.

I was told that I would not be prescribed natural desiccated thyroid treatment in any circumstances (NHS or private), but that I would be referred to an endocrinologist at the hospital for them to decide whether I could be prescribed synthetic T3 (liothyronine). I consider myself lucky to have been prescribed T3 along with the

standard T4 treatment since March last year, which has made a marked improvement in my energy levels but I still have hypothyroid symptoms. I have asked for the dose of T3/T4 to be increased, as my blood levels for T3 and T4 are still on the low side of the wide normal range, but have been refused as my TSH levels are borderline low and they fear me becoming hyperthyroid.

It is well known among experts that TSH levels are not an effective measurement of thyroid disease when the patient is taking T3 and/or natural desiccated thyroid treatments because the TSH naturally lowers, and it is paramount that T3, T4 and reverse T3 (not currently tested on the NHS), in addition to iron and adrenal levels, are looked at as a whole. NHS endocrinologists seem only concerned with TSH levels and as such I remain unwell. I do not wish to become hyperthyroid myself but I would like my levels to be optimal for me, for the hypothyroid symptoms to be eliminated and allow me the opportunity to be well again and a fully functioning individual, but I seem to be fighting a losing battle.