PE1463/DDDDD
Lyndsay Elliott 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 have had poor mental and physical health since my early 30s and have visited my GP many times to have tests related to my concern that my symptoms were due to inherited diabetes and under active thyroid. I was repeatedly told all was normal, and was offered anti-depressants to deal with my symptoms. I repeatedly refused to take anti-depressants as I knew that was not going to deal with the root cause. Fast forward to my 45th birthday and I paid to have a private blood test which showed I had two thyroid anti-bodies which indicate my body was attacking my thyroid and causing it to gradually fail and causing the under-active thyroid symptoms. This is known as Hashimoto’s disease. During these years, I have had to reduce my working hours as I have not been able to work to my full potential and I have struggled with fatigue and anxiety.

Two years and more private money later, I have altered my diet and taken supplements to help reduce the autoimmune reaction, however despite improvements I was still experiencing symptoms. After a bad experience with an NHS endocrinologist, who told me there was nothing wrong with me, I chose to visit a private endocrinologist who was able to prove to my GP that replacement Levothyroxine was now necessary. I have partly responded to this T4 treatment however due to a gene mutation that means I don’t convert the T4 to T3, my private endocrinologist is recommending that I start liothyronine T3 treatment on a 3 month trial. My GP is unable to prescribe this and an IPTR (individual patient treatment request) form has had to be filled in to see if the NHS will support this. I am anxiously waiting for the decision on this.

During this time, I have had to pay privately to get the required blood tests to monitor my condition and I only get the most basic tests on the NHS. I have had to pay for a private endocrinologist, and due to where I live, is a 7 hour round trip. Also, I am potentially having to face the prospect of paying for the T3. It is not right that I can buy the T3 from Germany with a private prescription for significantly less than what it will cost the NHS - the cost of T3 to the NHS needs to be reviewed urgently so that it can be given to the 10% who do not respond fully to T4 treatment.