

**Thyroid UK Response to Scottish Parliament in respect of
The Consideration of Petition PE1463**

Calling on the Scottish Parliament to urge the Scottish Government to take action to ensure GPs and endocrinologists are able to accurately diagnose thyroid and adrenal disorders and provide the most appropriate treatment.

What are your views on what the petition seeks?

Thyroid UK (previously Thyroid Action Group) was set up in 1999 by Lyn Mynott to support patients who were ill with symptoms that could be due to thyroid disease and related disorders such as adrenal insufficiency. Lyn Mynott herself was ill for 15 years, diagnosed with fibromyalgia, and finally became well once she started taking levothyroxine and, later, T3 and then natural thyroid hormone. Her thyroid blood tests were always “normal” which was why she was ill for so long.

Since starting Thyroid UK we have received many thousands of letters/emails from people needing our help. We have specific information on the various aspects of thyroid disease which we suggest they take to their GP or endocrinologist, should they manage to get a referral.

Thyroid UK completely agrees with the petitioners that action should be taken to ensure that GPs and endocrinologists are able to accurately diagnose these disorders. We firmly believe that action needs to be taken to change how thyroid disease and adrenal disorders are tested, diagnosed and treated.

What are your views on the discussions that took place at the Committee meeting on 5 February?

Sandra Whyte and Lorraine Cleaver mentioned some of the problems of diagnosis and treatment of thyroid disease and Thyroid UK concurs with their statements. Thyroid UK is very pleased that the Scottish Parliament is looking into this matter and hopes that they receive full and complete answers to their questions from all parties.

What evidence is there that the conditions to which the petitioners refer are currently misunderstood or being misdiagnosed by medical practitioners, or that the treatment being prescribed is not effective in a significant proportion of cases?

Hypothyroidism affects a lot of people, mostly women. The incidence of overt hypothyroidism is 2% women and 0.2% men and the incidence of subclinical hypothyroidism is 6-8% women, 3% men.¹

In the book, “Thyroid for Dummies”, the authors, Alan L Rubin MD and Dr Sarah Brewer state, “In the United Kingdom alone, an estimated 4.5 million people have a thyroid problem out of a population of 60.4 million. a further two million people are believed to have over or underactive thyroid glands that remain unrecognised, although these cases are often mild.”

Hypothyroidism can cause problems for doctors. The Pharmaceutical Journal stated, “.... large numbers of thyroid function tests are carried out because patients describe vague non-specific symptoms. Doctors are frequently faced with decisions on the management of patients who have little or no clinical signs of thyroid dysfunction, but have abnormal tests.”²

The reference range for thyroid function tests is based on a normal bell-shaped graph, with serum levels of TSH and FT4 outside the 95% reference interval described as pathological and therefore some people within the normal range will have hypothyroidism.

The range generally for TSH is around 0.5 – 5.0. The UK Guidelines for the Use of Thyroid Function Tests 2006 states, *“If the serum FT4 concentration is normal, but the serum TSH concentration is greater than 10mU/L, then treatment with thyroxine is recommended (II, B).”*³ (These Guidelines urgently need updating since a review should have taken place in 2009.)

This means that there are many patients with a TSH above 5 but below 10 who are not being treated, even though they have many signs and symptoms of hypothyroidism. These patients are often given antidepressants.

American endocrinologists decided a few years ago, that patients with a TSH higher than 3 should be treated and I believe a similar decision was made in Sweden.⁴

When a patient visits a GP with symptoms of an underactive thyroid, they usually recognise the symptoms of hypothyroidism and send off for a TSH test (sometimes also an FT4 test). If the results are outside the range then they are deemed to have hypothyroidism and the GP will prescribe levothyroxine. In many cases, the patient will become well again and will only need to see the GP on an annual basis for testing.

However, if the test result is “normal”, the doctor will dismiss hypothyroidism and often offer antidepressants. In some cases, the patient is sent for further tests but these usually return with a normal result and the patient is left to live with the symptoms and no further help is given. Some patients are referred to psychiatrists but in most cases, the psychiatrist sends them back to the GP stating that the patient’s problem is physical.

Thyroid UK believes that many patients with fibromyalgia and CFS/ME actually have undiagnosed thyroid disease (and Vitamin B12 deficiency).

The Royal College of Physicians et al wrote a statement entitled, “The Diagnosis and Management of Primary Hypothyroidism” dated 19th November 2008 in which they state, *“This statement refers only to primary hypothyroidism. Secondary hypothyroidism is a different condition and should be managed by accredited endocrinologists in the same way as all other pituitary diseases.”*⁵ However, in reality, this very rarely happens. Thyroid UK hears many stories of how a referral is refused because the doctor feels all the patient needs are antidepressants.

Primary hypothyroidism is the term given to hypothyroidism caused by a problem within the thyroid gland itself. Secondary hypothyroidism is the term given to hypothyroidism caused by a problem outside of the thyroid gland such as a pituitary problem or lack of conversion from T4 to T3.

In our experience, many people who have finally been given a diagnosis of hypothyroidism have done the rounds of non-endocrine specialists because thyroid blood tests have come back “normal”. The cost to the NHS has never been looked into but we believe it is extremely high.

One problem that some patients with seemingly normal test results may have is that the TSH test may be misinterpreted.

Dr Rudolf Hoermann and John Midgley have recently done studies that show that TSH is not log-linear, as previously thought – “Recent evidence questions the log-linear standard model of the TSH-FT4 relationship and suggests that more complex modeling may be more appropriate.” and “In the present study, we propose a hierarchically structured model of the hypothalamic pituitary thyroid interaction where the regulation involves patterns of operative mechanisms unique to the different functional thyroid states.”⁶ In other words, not everyone is the same and the TSH ranges taken from the general public are not suitable for everyone.

If this model was used, it could conceivably find that many patients with “normal” test results need treatment and some patients with “abnormal” test results do not need treatment.

There are other papers in a similar vein so researchers are starting to look for reasons why the TSH test may not be picking up all cases of hypothyroidism. These papers are very complex and therefore need to be discussed fully by experienced and open minded endocrinologists.⁷

In respect of T3 testing, many doctors in the UK do not have access to T3 testing. The problem is that even if doctors ask for the test to be done, the biochemist at the local laboratory can over-ride this decision and send the test back without the T3 test being done, often with a note to say that “the TSH is not out of range and the test is therefore not necessary.” This is something that Thyroid UK does not agree with. The biochemist has not seen the patients’ notes nor, indeed, seen the patient. We were told many years ago that this is due to the cost of the T3 test since it is more expensive than the other thyroid tests.

Thyroid UK believes more T3 testing and treatment should be available due to the following:

- In March 2012, the European Thyroid Association ETA Guidelines: The Use of L-T4 + L-T3 in the Treatment of Hypothyroidism were published giving recommendations on how to prescribe T3 along with T4 medication.⁸

However, many GPs are not aware of these guidelines and it is possible that clinicians will not use them because they are not UK Guidelines.

- In May 2009 Panicker et al published a study that showed why some people did better on T4 plus T3. They identified a faulty gene, the DIO2 gene, which caused the brain to lack T3, even though the blood tests looked normal.⁹ There is a test to see if a patient has this faulty gene but it is not available on the NHS.

However, the RCP do not support the use of thyroid extracts or levothyroxine and T3 combinations. *“Although some patients wish to take Armour, for instance, because they perceive it to be ‘natural’ rather than ‘synthetic’, there have been no scientific studies that compare it to thyroxine, and there is a theoretical reason based on the ratio of T3 to T4 to believe it could have adverse effects.”*¹⁰

Many patients take natural thyroid hormone because it makes them feel better, not because it is natural. The late Dr John Lowe, in his rebuttal to the RCP, stated that, in fact, there was research done to show that levothyroxine was equal to natural thyroid hormone. However, now we are told that there should be research carried out to show that natural thyroid hormone is as good as levothyroxine, even when it is well known that levothyroxine does not suit everyone.¹¹

Some endocrinologists, however, are prescribing natural thyroid hormone. There have been some reports of natural thyroid hormone helping patients (see attached papers).¹²

Thyroid UK believes that doctors need better training in thyroid and adrenal conditions. They should be made aware that if a patient on levothyroxine still has symptoms, they should be referred to an endocrinologist for further investigation and indeed, this is what the Royal College of Physicians state in their “statement”.⁵

Unfortunately, there is a misconception that thyroid disease is easily dealt with and that taking a little white pill will allow the patient to become healthy again.

There are, though, some doctors who understand that the patient needs T3 but are afraid to prescribe it in case they get into trouble or even that their senior colleague has forbidden them to prescribe it.

It is well known that many patients do not do well on levothyroxine and have ongoing symptoms. The World Health Organisation was aware of these problems way back in 1994 as you can see in the attached copy letter to Mrs Diana Holmes.¹³

Many letters have been written to the Department of Health in England by patients about these problems but, unfortunately, the Department of Health simply refer the patient to the RCP “Statement” and the current 2006 Guidelines, which is of no use to patients.

In some patients, problems with their adrenals need to be addressed. If there is a problem with the pituitary gland then the adrenal glands can also be affected, which can also impact on thyroid levels. However, testing for low adrenals can also be problematic. Many patients have an ACTH test (synacthen test) which comes back “normal” and the patient is then discharged.

However, in 2011, the Society for Endocrinology stated in a letter to a patient, “Our Clinical Committee ... agree with your analysis of the situation that if a patient receives the short synacthen test and the results come back as in the normal range, but the patient still exhibits clinical symptoms of adrenal insufficiency, then further testing to rule out hypopituitarism should be arranged for the patient.”

Confirmation of this statement in a patient information leaflet and/or guidelines is still awaited.

Thyroid UK believes that until a completely reliable test is available with properly trained doctors to interpret the results, then doctors should at least give a trial of thyroid hormone, as they do antidepressants, to see if the patient improves, especially if thyroid disease is already in the family.

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13 Letter received by Mrs Diana Holmes From World Health Organization dated 26th

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