PE1463/GGGG

Thyroid UK Letter of 21 September 2016

Response to the Scottish Government letter of 2 August 2016

Thyroid UK is disappointed that the Scottish Government is taking the line that our survey was "not a scientific survey and is thus likely to have an over-representation of people with adverse symptoms." And "It may not therefore be truly representative of all people on thyroxine."

Our survey showed that 12% of respondents did not do well on levothyroxine. This is lower than the figure of up to 16% stated in recent research and therefore we feel that our survey should be taken more seriously than it appears the British Thyroid Association and the Scottish Government are taking it.

Perhaps if the British Thyroid Foundation had agreed to place the survey onto their website for their members to participate in, it would have been taken more seriously.

The Scottish Government asked Thyroid UK to run this survey and we expected that this anecdotal evidence would have been accepted. Evidence-based medicine is not always the best evidence since research regarding T3 cannot seem to come to any clear conclusion leaving many patients very ill and debilitated.

In regard to our recommendations:

Recommendation 1

We note that you state that the whole range of thyroid function tests is only sometimes needed. In our experience and in those of many patients, only the TSH test is carried out by most doctors. In some areas the FT4 test is carried out, but rarely is thyroid antibody testing done even though this would inform both the doctor and the patient of autoimmune disease. FT3 testing is almost always missing from the panel. We are afraid, therefore, that testing is not personalised to the individual patient unless the patient requests these and even then, refusal is common.

Many patients decide to purchase private thyroid function tests which often show up problems that the doctor cannot see with only a TSH or FT4 test, especially Hashimoto's disease.

The Scottish Government has stated that the way testing is done at the moment is "less costly to the NHS than using a battery of tests for all individuals." And this is the crux of the matter. However, not doing all the tests only causes the patient to return more often to the doctor's surgery, surely costing more than a full thyroid function test.

Recommendation 2

In respect of giving a trial of levothyroxine to patients with a high TSH, Thyroid UK completely agrees that patients with a high TSH and no symptoms do not require treatment. However, we speak to many, many patients who have a

TSH above the top of the range and who have many symptoms. These patients are most definitely NOT being given treatment. Doctors are either not reading the guidance or are ignoring it.

As for giving these patients a full clinical examination and assessment first, it is very rare for the doctor to do this. We are often told that the doctor did not touch the patient. They simply look at the test results and tell them it's normal, no action required.

The published data may show that the average TSH when people start thyroxine is around 8mU/L but how long has that patient been suffering symptoms before the doctor started treatment. We speak to many patients with a TSH at the top of the range or just over who have many symptoms but are not given treatment.

We would like to reiterate that without a full thyroid panel, including thyroid antibodies, doctors cannot differentiate between autoimmune thyroid disease and non-thyroidal illness especially if the doctor has only requested a TSH test.

Recommendation 3:

You state that laboratories usually undertake what is requested of them. Unfortunately, however, laboratories do not *usually* undertake FT3 testing even if a doctor has requested it. If a doctor asks for a test, he has a reason for it. He knows the patient – the lab technician does not. We are constantly informed that the doctor was not given a reason for the test rejection.

Recommendation 4

You state that if a test is "refused" as opposed to a clinician being guided by the biochemical experts that a test is unnecessary, then this should be and usually is discussed with the individual.

In our experience, however, patients are simply told, "The lab refused to do the test". If the doctor is not informed as to the reason the test was refused, how is he supposed to inform the patient? This is not as "rare" as the Scottish Government believe it to be.

Recommendation 5:

You state that there is no agreed role for DIO2 testing which is not recommended in any guideline and that it would be unreasonable for GPs to know any detail on this. If it is not possible for GPs to be given training regarding DIO2 genetic testing for patients who do not find all their symptoms resolved on levothyroxine, then the patient should be referred to an endocrinologist who does understand genetic testing.

There is an interesting systematic review – Genetic variation in deiodinases: a systematic review of potential clinical effects in humans – which can be found here: http://www.eje-online.org/content/171/3/R123.full.pdf

Recommendation 6:

In respect of ensuring that patients' hormone levels are restored to a level that is optimal for them, your letter states that what may feel optimal to a person from a symptomatic point of view may be harmful and it is the obligation of the doctor to point this out and discuss the implications.

This implies that once the doctor has discussed the implications of increasing levothyroxine dosage with the patient, he would give an increase of levothyroxine. However, even though patients are willing to try an increase in dosage to see if it alleviates their symptoms, many doctors will not do so.

Recommendation 12

In regard to keeping patients on the same brand of levothyroxine, your comment that there is the same amount of levothyroxine in each medication is not strictly true. There is a range that each tablet has to come within as there is with liothyronine and NDT. It is possible that one brand has slightly more thyroxine in their tablet than another brand. Apart from that, it is often the fillers and binders that cause problems for patients and these are also different in the different brands.

Recommendation 15

In regard to patients with hypothyroidism being given key information about their condition, you mention that the British Thyroid Foundation has a number of leaflets.

Thyroid UK also has a number of leaflets available from our website. However, this does not detract from the fact that doctors should be giving patients more information about their condition as well as pointing them in the direction of patient support groups.

We note that all through the recommendations, the Scottish Government state "All treatment decisions are a matter for discussion and agreement between the individual and the doctor concerned" and "It is a primary duty of a doctor to do no harm."

In our experience, there is very rarely a proper discussion between the doctor and the patient. Generally, the patient asks for a trial of levothyroxine, T3 or NDT and the doctor refuses. That is not a proper discussion. If the patient does try to discuss further, the doctor makes it clear that he is not willing to discuss it.

Unfortunately, although it is the duty of a doctor to do no harm, many patients feel that they *are* being harmed due to the guidance for the diagnosis and treatment of hypothyroidism and due to the fact that they are not being listened to.

We know that some doctors do feel constrained by the guidance of the British Thyroid Association and Royal College of Physicians. It needs to be said that this is "guidance" not "law" and that perhaps doctors should be made aware of this and be allowed to treat their patients using their experience.

The problems of the cost of liothyronine has now compounded all of these issues and many patients who have been on liothyronine for years and feeling very well are now being refused this very essential drug because it will save the NHS money. This is unacceptable and Thyroid UK will be campaigning strongly regarding this.