

PE1463/BBB

Petitioner Letter of 2 December 2014

Dear Convener and members of the committee,

Thank you for hosting the discussion with representatives of SIGN last week. I am cautiously pleased to see that you are prepared to request SIGN carry out some work into the issue of thyroid testing and treatments. It seems important to point out that recent new guidelines from the American Thyroid Association run to 207 pages long and so, with this in mind, I wonder whether the remit might be better focussed on a subset of this disease that relates specifically to the patients who, once diagnosed, remain unwell on Levothyroxine?

The Technologies Scoping in February quotes a figure of between 5-10% of patients reporting unresolved symptoms on Levothyroxine. I seriously question this figure and, in my advocacy work would estimate the real number to be far higher. The major problem we face is that currently, the Royal College of Physicians have a policy statement for the diagnosis and treatment of Primary Hypothyroidism which states "We recommend that those patients whose thyroid blood tests are within the reference ranges but who have continuing symptoms, whether on Levothyroxine or not, **should be further investigated for non-thyroid cause of the symptoms.**" This is outrageous abdication of responsibility and akin to a cardiologist sending a patient ill on statins to a psychiatrist. For many people the only medication on offer does not work and it is these patients who would benefit from further guidelines specifically looking at the reasons why they are not responding to Levothyroxine, despite normalised TSH and FT4, for example, by testing the Free T3 levels among other things.

Patients also need to know why Natural Desiccated Thyroid hormone is not being prescribed, despite evidence that patients do well on it and, in fact prefer it in many cases. As the Technologies report says, Natural Desiccated Thyroid is available on the NHS as a special yet is rarely, if ever, prescribed. T3 medication is frequently in short supply so a look at these issues would be very worthwhile for patients.

If SIGN would be prepared to take an in depth look at these two sub sections of thyroid treatment, it would be of immense benefit to patients who are currently dismissed as suffering from somatoform or Chronic Fatigue Syndrome.

Yours sincerely

Lorraine Cleaver
Petitioner