

**PE1463/LLL**

Tess Fleming Letter of 21 February 2016

Dear Convener and Members of the Petitions Committee

First of all I would like to register my disgust after watching the Minister for Public Health in Scotland make disrespectful and inaccurate statements, her preparation clearly mirrors her interest in helping thyroid patients. When the committee member asked the Minister a question regarding the prescribing of NDT - she answered with a laugh mooted an 'anecdotal' reference to T3?

I watched the video three times - speechless!

Secondly I would like to applaud the Convener and the Petitions Committee for their continued support of Hypothyroid patients like myself.

The continuous reference to the British Thyroid Foundation I was hearing I can understand from Endocrinology as they have a vested interest. I'm not sure why the Minister felt the history of the BTF was relevant to the meeting but since it was mentioned, it's not 1991 anymore and patients do not need a BTF information leaflet to educate them on the BTF/BTA anecdotal opinion on thyroid disease. Expert (condescending) advice from the BTF includes painting a door, marriage counselling, social work involvement to alleviate symptoms - I guess they could get some random anecdotal evidence by extrapolating the single, divorced population from the married, people with partners who take levothyroxine and have the audacity to still have symptoms.

The endocrine profession is also of the opinion patients get a 'hit' from T3, at a BTF meeting in Edinburgh a few years ago I listened in disbelief at an endocrinologist describing patients like/want T3 because they get a 'hit'. I take my T3 at bedtime, I have never heard a patient talk about a hit from thyroid medication.

When endocrinologists make mythical statements like this - would the Minister for Public Health rate this as anecdotal or fact?

### **Scottish data**

Given the endocrine professional opinion is that patients who don't feel well on levothyroxine must be imagining their symptoms - maybe the Minister would be able to provide information on how many Scottish patients progress from a thyroid diagnosis to treatment for additional conditions, mental health referrals etc. from available data.

For instance, could any random regions/years with recorded data on ISD Scotland showing a rise in patients with hypothyroidism and go from there - I'm sure the same thing could be done with available prescribed medications data, any trends where a rise in prescribed levothyroxine coincides with a rise in medications such as antidepressants/omeprazole/painkillers? There's a whole list of medications that could apply here but I'm not sure what they are.

We have the data available - why not make the most of it? It would also be interesting to have a regional breakdown of where T3 is being prescribed. Are the majority of the 6000 patients being prescribed T3 from one or two regions?

### **Evidence of the Clinical Data available for Levothyroxine**

How much evidence is available to show the rigorous process, clinical trials of levothyroxine?

What evidence was used to support the decision to make levothyroxine the only treatment for hypothyroidism?

How many recalls have there been of levothyroxine since it was introduced?

If evidence from clinical trials is needed to support T3 - submit the equivalent evidence that was used to support T4 and compare, I'm sure endocrinology will have no problem providing the Petitions Committee with evidence, factual not anecdotal, clinical and scientific data that 100% supported the use of Levothyroxine containing one synthetic hormone replacing Natural Dessicated Thyroid hormone as the drug of choice in hypothyroidism.

Obviously this would include all the robust safety and other evidence that supports T4 the Minister cites at 30 minutes in the video as either unavailable or anecdotal evidence in relation to T3 and NDT.

Is there another specialty in modern medicine today that would fight so hard to block the treatment a patient knows will result in not only feeling their previous healthy 'normal' self again - take back their place in society, join the workforce, live their lives again - I certainly can't think of any?

**Finally the Minister seemed to confuse guidance with guidelines, she did however confirm that a blood test is the marker - not symptoms. Biochemistry Guidelines suggest otherwise.**

### **Monitoring hypothyroidism in Primary Care right now in Scotland**

Normal procedure for this scenario is:

Patient has thyroid function test, GP sees the slightest decrease in TSH, there could also be a slight decrease in T4, basically the patient won't be privy to results unless they ask.

Receptionist calls patient to inform them that thyroid function test result is back and GP has decided a decrease in patients levothyroxine dose is needed.

GP does not check whether there is a logical reason for any change's in TSH for example, is the patient on steroids?

Does the patient have symptoms to warrant a decrease in medication?

There is so many different scenarios that could apply to any change in blood results - none of these scenarios apply, patient gets a call to decrease medication.

That patient is 100% going to experience worsening symptoms of their now under treated hypothyroidism - the patient is fighting cancer, the GP has just set that patient back months by decreasing their thyroid function!! (worse case scenario but any additional chronic condition will apply)

Personally like most knowledgeable thyroid patients today - I refuse to decrease my medication and request a chat with the GP instead. The older generation who are the most vulnerable in this scenario would never dream of questioning a GP - there is glaring patient safety issues and they are ones 'happy' on levothyroxine. They're not 'happy' they just don't know why they feel so tired etc.

That is how GP's monitor hypothyroidism - FACT!

GP's should have a working knowledge at least of monitoring the thyroid function results of thyroid patients. Training is needed.

I asked the GP's at the health centre I attend about all of the above - their official response was absolutely frightening and it was in writing!

**I've never heard of a patient being treated in accordance with these UK Guidelines for the Use of Thyroid Function Tests.**

[http://www.british-thyroid-association.org/info-for-patients/Docs/TFT\\_guideline\\_final\\_version\\_July\\_2006.pdf](http://www.british-thyroid-association.org/info-for-patients/Docs/TFT_guideline_final_version_July_2006.pdf)

The measurement of both TSH and FT4 is required to optimise thyroxine replacement therapy (IV,C). The primary target of thyroxine replacement therapy is to make the patient feel well and to achieve a serum TSH that it within the reference range.

II, B). The corresponding FT4 will be within or slightly above its reference range. The minimum period to achieve stable concentrations after a change in dose of thyroxine is two months and thyroid function tests should not normally be requested before this period has elapsed (IIb,B).

Submitted in support of PE01463

Kind regards

Tess Fleming