

## PE1463/PPP

Lisa Thompson Letter of 11 February 2016

Dear Committee Members,

RE: [PE01463: Effective thyroid and adrenal testing, diagnosis and treatment](#)

I have followed the above petition closely, including the petition meeting on 9th February 2016. I watched in anger and disbelief and felt compelled to write in support of the petition.

The Cabinet Minister, Maureen Watt, at no point addressed the issue of what the petition is asking. I actually found a large amount of what she said to be confusing, extremely misinformed and she even made a statement that was not true - that one of the petitioners had said the current guidelines were in fact suitable. Her comment about the people who completed the Thyroid UK survey being "more involved" is just a ridiculous statement, of course they will be, and all the more reason to listen and take action. Professor Graham Leese at no point appeared willing to discuss the patients who do not do well on T4 only treatment, instead he stonewalled the many anecdotal experiences from these patients, particularly when Elaine Smith MP, specifically questioned him about what can be done for them, referring to guidelines which is what the petition is already questioning. Later, he repeatedly talked about clinical studies with no specific reference. Professor Leese appeared exacerbated on occasions at being asked straight forward questions by the Committee.

I like many, many thousands of thyroid sufferers on T4 only treatment (Levothyroxine) remained symptomatic, personally for me it has been 19 years, with countless different medications prescribed to treat them. I have been taking NDT for 1 year now, together with a very small dose of Levothyroxine, this combination that has been tailored to my needs, in line with full thyroid panels of bloods including T3. ALL my symptoms have gone away. I am no longer tired, I do not ache anymore, I do not suffer any depression or brain fog, no dizziness or swollen throat, no respiratory problems and many others. I have a wonderful quality of life again thanks to obtaining a private prescription for my current medication, and getting bloods done, all of which I pay for - which is proving very expensive, but it has transformed how I feel, I have worked from home running a business for years, this has allowed me to cope with the fatigue. I am no longer taking other medications which were, at best, just bandaging over the problem that my ineffective thyroid treatment was causing. Left how I was I would not have been able to draft this letter to you, my cognition was appalling, it is now restored.

There are so many people affected and to see the Professor and Cabinet Minister so ill prepared and unwilling to have any respect and belief in patients who remain symptomatic, was very hard to watch. For anything to change this must be the first step, doctors would not tell a heart or rheumatoid patient there are no other choices of medication if they had continuing symptoms, they would be offered an alternative. There are five different statins currently on the NHS, diabetes has different forms of insulin, with different manufacturer's not one monopoly, as it is for T3. Professor Leese twice stated "only in very exceptional circumstances is T3 given" - Why?

Where is the evidence for this, when they don't even test our T3?. Where is the data that T3 or NDT are unsafe? Those making the decision on our wellbeing keep saying it but refuse to show the evidence, I cannot find any research that shows it is unsafe, NDT was used safely and effectively for decades. I could be sceptical and speculate it just does not make money for drug companies.

We are told over and over that the 'vast majority' of patients respond to T4 only medication, by this they are in fact recognising that there ARE a significant minority that do not and it is ruining lives, we desperately need other treatment options and much easier access to them.

I wish to sincerely thank the Committees response to both Professor Leese and the Cabinet Minister, this gave myself at least some hope for change.

Please see enclosed my photo on Levo then on NDT, clear facial swelling has gone in the absence of any significant weight loss.

Yours sincerely,

Lisa Thompson

