

PE1463/OOO

Andy Thompson Letter of 11 February 2016

Hello Mr McMahon,

I will try and keep this short. I have recently watched the above and am very grateful that people like yourself, and your colleagues, are willing to genuinely look into this matter. I applaud the committee's directness and intellect in the face of being patronised by Professor Leese.

For 20 of the 22 years we have been married my wife has taken Levothyroxine (T4). Whilst it has clearly kept her alive she has suffered with many symptoms that have had a very serious negative effect on her quality of life (and our family too). The list of medications prescribed to her is very long and varied and also undoubtedly costly (including IVF for our second daughter, no issues with our first child who arrived before my wife became hypothyroid). Quite simply the quality of her daily life was very poor when on T4 only. The most astonishing thing is the continual total lack of interest (from GPs particularly) in listening to her symptoms and even considering it could still be her thyroid... just because her blood tests are 'within range'.

In the last year she has, under supervision from a private Endocrinologist, been taking NDT (the drug used for decades before T4 - which to my knowledge, and I have researched, patients did not have further complications) alongside a small dose of T4. This regime is used to balance the levels of both the inactive T4 and active T3 - the difference in my wife is absolutely incredible (physical and mentally). Very quickly the symptoms she suffered for 20 years diminished and then simply vanished!!

I personally am angry at the medical community for refusing to listen to the minority who remain symptomatic when on T4 only (20 years is a very long time). Maybe if a more visible symptom occurred they would have to listen and could not 'fob' their patients off so easily. This attitude may possibly be a consequence of the existing treatment guidance, meaning GPs and Endocrinologists do not currently actually have any option, even though both T3 and NDT are available.

Therefore, the key point to resolve before any alternative treatment protocols are accepted is - **do we all accept that some patients remain symptomatic when on T4 only even if blood tests (TSH usually) are 'in range'**. Only when this is accepted will the use of alternate medications for these poor people, who remain symptomatic, be possible - they maybe a minority but they are sizeable in numbers. On behalf of the many who suffer, and their family members who helplessly watch their suffering, my wife and myself, I thank you and your colleagues for tackling this subject. I accept my wife's story is anecdotal but for us the improved quality of life is nothing short of remarkable and very real - unfortunately it has been a difficult 20 years and also a difficult (and expensive) process to make my wife well again.

Kind regards and thank you,

Andy Thompson