

## PE1463/NNN

Lee Dutton Letter of 15 February 2016

The undernoted testimony is submitted in relation to PE01463 to the Parliament and is in response to the last meeting of the committee on 9<sup>th</sup> February 2016 to hear evidence from the Health Minister and others.

1. I would like to commend the committee for their interest and for appearing to be really well informed and concerned in what, for many thousands, is a life changing, challenging, frustrating and (if treated as it usually is in this country) for many, a dangerous illness.
2. I have to say, however, that in listening to the proceedings I felt something close to despair and certainly shared the frustration and disappointment of the petitioner at the committee meeting.
3. I was staggered at the lack of preparedness, the lack of professionalism and the inarticulate nature of your witnesses. The minister attributed a satisfaction with guidelines that don't exist and that the petitioner would never endorse. Their testimony was complacent, vague and parroted the established position on thyroid treatment that is failing thousands of NHS patients.
4. This a very serious issue and we as a community need to see changes - if not for ourselves than for the future such patients - so we can know that everything we have suffered and continue to suffer, has not been in vain, that something will be learnt, that our experiences will be acknowledged. I would beg the committee not to give up, to persist and hold the medical establishment to account for stories like mine.
5. My story is below; one of many thousands of similar stories...
6. I was a hard working professional; on my feet all day, a keen walker, an artist, a published writer, a singer and a mother of three. Ten years ago I started to feel tired, too tired. Bit by bit I became quite unwell, very tired, gaining weight I could not lose, then I started to get pain through my body, muscles and joints. Time and time again I went to the GP asking for my thyroid to be tested. When it finally was, I was told it was nothing to do with my thyroid and that I had 'fibromyalgia'.
7. My life started to unravel; work was exhausting, I stopped doing my weekly walks, I would fall asleep in my lunch breaks at work. I was prescribed huge amounts of powerful and, alas, damaging painkillers and anti depressants (though I never once felt I was in any way depressed I was told they would help with pain). I was given meds for my stomach acid, beta blockers and blood pressure tablets. I gradually became more ill, eventually having to stop work. This had a huge impact on my life. Then one of the cruellest blows.. I had to stop singing, as my voice became more and more hoarse. St this point I sought the advice of accredited and highly experienced complimentary therapists, to try and get a diagnosis. While I sought their advice I was sent for months of speech

therapy and an investigation of my vocal cords; nothing was found, of course. This, and all my meds, must have cost the NHS a fortune.

8. By now the complimentary clinicians were all coming up with the same diagnosis, all independently of each other; they all said I had serious adrenal and thyroid issues and that i must get it sorted or diagnosed quickly. By now the raft of drugs I had been given were becoming very detrimental to my health; But every time I went to a GP I was told I was 'within the standard TH range'.
9. Eventually I begged to be tested one more time and, at last, I was shown to be overactive. I was eventually told my only option (not true) was to have RIA treatment to destroy my thyroid and was assured that thereafter 'one wee tablet would sort me out'.
10. The impact of the lack of diagnosis due to the 'flawed mantra' of the TSH, test and the refusal of GP's to treat by symptoms (like so many I was told it was 'lifestyle' or other issues and not my thyroid), meant I lost the ability to earn an income in a job I loved, the choral singing i had done since I was 12 stopped, I could no longer make my voice work or stand for two hours to sing one of the great oratorios. My husband has lost the wife he thought he had and despite running a busy Architectural Practice through the recession, has had, at times, to act as my carer.
11. I have been put on various levels of levothyroxine... the only accepted treatment, a blunt instrument sold for profit by the pharmaceutical industry on the basis that a single artificial chemical can fix complex hormonal imbalances, if you can just get the dosage right! I am still very unwell. I fear I will never be well on this blunt and inappropriate mono therapy.
12. Like thousands of others I have bought a T3 and Levo combination online from a good pharmacy in Canada but I am afraid to start it even though I know it could change my life. I have nothing to lose in taking it - I feel there is no medical risk - but I do fear angering and possibly losing my GP and therefore not being monitored; not that monitoring using only the TSH test is worth much. I have asked for my t3 levels to be checked and have been told that NHS labs won't do it.
13. The committee needs to address these issues; please, please continue to do so. The NHS is failing thyroid patients and seems unwilling to consider any change to assessment or treatment despite overwhelming evidence. How wonderful it would be if the Scottish health service were a force for enlightened and patient centred thyroid treatment and changed things for the better; the financial saving to the NHS would be significant, but more importantly the impact on the health and well being on thousands would be a fitting legacy.

Lee Dutton