

**PE1463/XXXX**

Margaret Tough submission of 2 June 2019

I am writing to you today regarding the planned closure of petition PE 01463.

In December Mr Fitzpatrick said he would write to the Health Boards clarifying the Scottish Government's position on T3 which he did in February. He said "*I re-emphasise that the Scottish Government's position is that T3 can be prescribed by an endocrinologist if it is considered to be the safest and most effective course of treatment for an individual*". I had thought this long fight for T3 with NHS Tayside would now be over, but how wrong could I be, this statement was made in December 2018 we are now in June 2019 and for me nothing has changed. I still have not been given T3 and NHS Tayside are adamant they stand by their original decision.

I asked my MSP'S office to forward my story to Jeanne Freeman so she herself could see and come to understand my predicament. She responded saying

*" NHS Tayside have commented about their non-formulary procedures thus: "Any requests submitted by a clinician to initiate T3 prescribing are reviewed locally using a robust nonformulary request process. This non-formulary request process involves application by the referring clinician for non-formulary medicines. This is then reviewed by a panel of independent clinicians who make a decision based on the evidence supplied. This outcome is then returned to the referring clinician who can appeal if they think there are sufficient grounds. Given this, there should be no expectation that these applications are automatically accepted. This approach ensures robust governance of the prescribing non-formulary medicines allowing the delivery of essential medicines to those who in the judgement of the panel would benefit, or where there is no other safe therapeutic option. This system also promotes formulary adherence and reduces the risk of non-evidence based individual prescribing decisions."*

I am fully aware of their non-formulary process having been through it over a year ago when my request was denied on the grounds of "*the evidence of clinical benefit not matching the costs for this therapy*". I spoke to my MSP'S office about this "robust non-formulary process" because I wondered if there were any endocrinologists on this panel, so they wrote asking the question of NHS Tayside. Their reply again was "the evidence for clinical benefit did not match the cost of the therapy". They did not even acknowledge that the question had been asked. If they would not answer the question I decided to see if I could find out about this non-formulary process for myself on Google. I was surprised to find, in less than five minutes, in a file detailing the process. It seems the clinician wishing to prescribe a non formulary medication has to first has to seek peer support for the application before submission of the request. I found this interesting, as two endocrinologists are of the opinion that I should be prescribed T3. The members of the panel involved in the decision process are also named, but I cannot see an endocrinologist on there, so how can a non specialist in endocrinology dismiss a request supported by two endocrinologists? Perhaps there may be other members of the panel, who are endocrinologists but not listed, however if there had been been I believe NHS Tayside would have been very, very keen to highlight the fact to my MSP'S office very strongly.

The letter also went on to say " persistent symptoms in patients who are biochemically euthyroid with LT4 monotherapy may be caused by several other conditions unrelated to thyroid function, for example endocrine and autoimmune disorders, haematological conditions, nutritional deficiencies, metabolic syndromes, concomitant drugs and lifestyle, and that their cause should be fully investigated by the clinician." I am surprised by this as I would expect NHS Tayside to know, as they are responding regarding my case, that other conditions have been explored by my endocrinologist. He found I was vitamin D deficient, this was treated with a high dose of vitamin D for 50 days to bring the level up and now I take an over the counter vitamin D daily to maintain the level, the vitamin D has made no difference to my symptoms. He also found my cortisol levels to be a bit high on two overnight dexamethasone tests but after further investigation at Ninewells my levels were found to be normal. My endocrinologist has said that he can nothing wrong with me apart from autoimmune thyroid disease.

I had hoped that the intervention of Jeanne Freeman and Joe Fitzpatrick as well as my MSP'S office would have resolved the situation by now but NHS Tayside, but it seems nobody has the power to say to NHS Tayside what you are doing is wrong, you are denying patients life changing medication that is available on the NHS due to cost and choosing to overrule and ignore specialist clinicians opinions, this is not acceptable and must stop immediately.

I have included NHS Tayside's non-formulary policy as a link [here](#). I can only hope this disgraceful situation draws to a close very soon.