

**PE1463/WWW**

Debra Conlon Letter of 25 February 2016

Dear Convener and Committee Members

Please treat this letter as a submission to the committee in relation to the above petition and publish accordingly.

I wish to register my concern and frustration at the recent debate held on 9th February in relation to this petition. I consider it disrespectful to the petitioner, Lorraine Cleaver, and persons involved in the committee, that both the Health Minister Maureen Watt and Professor Graham Leese attended this pre arranged meeting and seemed ill informed and unprepared. This smacked of arrogance and disinterest, which unfortunately is the attitude most thyroid patients have come to expect from the medical professionals involved in treating thyroid disease.

My personal experience relates to my husband, Kevin Conlon, who was diagnosed with Graves disease/Hyperthyroidism in July 2014. As an experienced user of the many wonderful NHS services available to us in Scotland, I am shocked at the level of care afforded to patients with thyroid disease. It is by far the most stressful, frustrating and frankly terrifying experience I have had to cope with in 28 years of being my husband's full time carer. My husband sustained a Spinal Cord Injury, as a result of a road traffic accident 33 years ago, which left him totally paralysed. We have therefore encountered many different professionals and specialities over the years. Dealing with the challenges of Graves Disease has highlighted a dreadfully inadequate area of medicine.

As a result of the Graves Disease my husband now has numerous health issues, too many to list. He now suffers from Atrial Fibrillation, he has waited 18 months to be referred to a Cardiologist, despite his Endocrinologist stating at each appointment that a referral had been done. At the moment he is still waiting to be seen and has spent 18 months on Warfarin treatment, when he should have been referred for Cardio Version treatment. Every minute of my day is spent checking his pulse, blood pressure and heart rate and remaining vigilant.

He was put on Betablockers at initial diagnosis, these were never adjusted to take account of what is known as Block and Replace treatment, leading to a situation two months ago where his heart was basically grinding to a halt. One week prior to this heart stopping issue his Endocrinologist stated no adjustment in medication was required ! Fortunately I am vigilant and relatively well versed in medical issues and knew something was seriously amiss ! The Betablockers were tapered down and stopped.

Presently awaiting an appointment with Gastroenterology to investigate bowel issues.

I am not exaggerating when I say practically every bodily function is NOT functioning. This disease and frankly woeful treatment has had an enormous effect on my husband's health and on the level of care I need to provide. When I request

that certain tests need to be carried out or that I am concerned as there seems to be something amiss with the treatment plan I am viewed as difficult. Endocrinologists do not like informed patients!

Meeting Lorraine Cleaver has been a lifesaver for me and many others, she has provided guidance, direction and support that has empowered so many dreadfully unwell people to take control of their care. Unfortunately this comes at a price, people are having to pay for diagnostic tests and source medication such as NDT, paying for all of this when many are too unwell to work and as such are on low incomes.

This is a shocking state of affairs and I have to admit that I had no idea how serious an issue this is until my husband became unwell. The financial cost to the NHS of illnesses linked to poorly treated Thyroid Disease is sure to be staggering, and totally unnecessary when the evidence is out there in abundance on all the patient forums, that people can be treated effectively using a range of medications and correct testing. Is it too much to ask that the relevant professionals put patient safety and wellness at the heart of a forward thinking review of guidelines, research, medical training and develop a Thyroid Treatment Protocol to be proud of. Take a holistic approach and treat the person according to symptoms. The world is watching Scotland with interest in this field, Lorraine's petition is followed from as far afield as Canada, USA, Australia.

I urge all involved to embrace this and allow this petition to continue. Many thanks to the committee.

Yours sincerely

Debra Conlon