

PE1463/TTT

Lillian Swallow Letter of 24 February 2016

Ladies and Gentlemen,

Thirty odd years ago I was diagnosed with hypothyroidism. I have a family history of it. I was put on levothyroxine and was fine for ten years. Then over two years various things happened to me and each and every one was thoroughly investigated. When I mentioned thyroid I was told it could not possibly be as my TSH was within range (1.6 I believe). I was getting worse:

Plantar fasciitis - had injections at hospital Very swollen legs that were hard and shiny - ignored Constant cystitis - had a procedure in hospital under anaesthetic. Chronic constipation no bowel movement for several days then a day or two of diarrhoea (Had barium enema). This was truly awful. So many things I had to cancel if a day of the runs. Dread making appointments. Also when constipated because of the uncomfortable feeling my appetite was poor, yet I kept putting on weight. After having bought some expensive theatre tickets and on the day I got diarrhoea so could not go, I never bought any tickets for anything and ended up being more of a hermit.

Then there was the carpal tunnel symptoms. Numb and tingling hands and lower arms. Very distressing as I just had to wait for them to stop. Sore gritty eyes, and I think the very worse was the unexplainable fatigue. It felt like I was trying to move around whilst buried in concrete plus the tiredness. My sore eyes made me close them and the tiredness put me to sleep instantly. I would be talking to someone and in the middle of talking to them I would go to sleep. In the middle of typing an email I would find I had dropped off to sleep. This was not at night but in the morning or afternoon. I lost all concentration so no longer got pleasure from reading. My family were neglected so was my house and myself. I was the living dead. There were times when I did consider what the difference would be with me as I was and me being dead and I couldn't think of any.

Another thing that kept happening to me was that I kept falling down stairs. I broke my toe the day before going on holiday once. Luckily I did not break anything else. I would bump into things as well. I had constant sinus problems.

As GP and hospital were not interested in anything but the TSH I went to a private lab for a test. The results were FT4 near bottom of range but FT3 below range. I took these results to my GP and was told they take no notice of T3 but would increase the levothyroxine. This made no difference.

I found a private doctor who did take notice of low T3 and prescribed it for me. Almost immediately my bowel movements improved then I found I was not dropping off to sleep all the time. I was able to stay up to an adult bedtime and be awake in the morning. The numbness in my hands went until eventually I didn't have to think about my body. I could make arrangements and know I will be able to keep them.

Of course all doctors and consultants over the years did not like this and argued with me.

One GP told me I must stop. So I did. Within three months not only had I put on three stone I had the constipation then the runs back and lost my appetite. The numbness in my hands came back plus the fatigue and tiredness. I was even sent to a sleep clinic but once back on T3 discharged me as clear.

Yes, I did go back on it as I decided I preferred to feel alive than dead.

After 12 years of being well on it one of the doctors at the hospital decided he would do some tests to show me that I did not need it. However the tests proved that I do need it. If I had not been able to follow the path I did for whatever reason (cost or ability) I would probably have died of possibly a heart attack or stroke years ago and it would be put down to anything but lack of thyroid hormone.

The education about thyroid conditions of doctors and nurses leaves a lot to be desired. Needless to say although I am now prescribed T3 it is much too little and I have to buy more to add to it. As this is a life-long condition I add Natural Desiccated Thyroid which contains T3 but also other thyroid hormones and calcitonin which protects the bones.

All those horrible things no longer happen when medicated properly.

Sincerely

Lilian Swallow