

On 17th April 2013, Lyn Mynott conducted an interview with Lorraine Cleaver one of the ladies responsible for the Scottish Parliament Petition.

Lorraine: I became very ill and very thin immediately after my only child was born and had repeated visits to doctor. I was told it was viral. It was only a year later, when I weighed about 6 stone and had an obvious goitre, that I was referred to an endocrinologist.

Lyn: So when you eventually saw the endocrinologist, were you diagnosed with anything?

Lorraine: He did some antibody tests and I was then diagnosed with Graves Disease.

Lyn: Did the treatment for Graves' disease work very well? Did you improve?

Lorraine: Yes, carbimazole worked very well and I became stable quite quickly. However, they took me off carbimazole 6 months later and I became hyperthyroid again so he advised me to have my thyroid removed.

I was supposed to have a sub-total thyroidectomy in the hope that the remaining half would function as a normal thyroid but post surgery, I had a haematoma and almost suffocated. I had to have an emergency evacuation of the haematoma whilst wide awake and with no pain relief. The surgery lasted 8 hrs during which I lost my parathyroid glands and the remaining thyroid gland died atrophied with the trauma.

Lyn: That sounds awful! What happened after the operation?

Lorraine: In the weeks afterwards, I started to develop symptoms – I was always cold and tired and I my hair was falling out in clumps. I suggested to my doctor that I must be hypothyroid now and I was told that it was not likely. They did tell me that it might have been the trauma of the two operations in 24 hours. I think it was finally four months after surgery that they acknowledged that I had hypothyroidism and gave me some medication, by which time I was almost completely bald.

Lyn: Unfortunately, many patients have similar symptoms after thyroidectomy and are not treated. What happened then?

Lorraine: They then put me onto levothyroxine.

Lyn: Did you do well on levothyroxine?

Lorraine: I did fine on levothyroxine for about 5/6 months and then I started to have chest pain, palpitations, weight gain, joint pain, hair loss again, ringing in my ears. I had so many disparate symptoms which they told me was nothing to do with the thyroid.

Lyn: How long did that go on for?

Lorraine: Some time. I went downhill further so my GP was at a loss because she trusted the endocrinologist who said it wasn't thyroid related. My bloods were normal so she sent me to a rheumatologist for the crippling joint pain and he diagnosed me with fibromyalgia without touching me or taking my blood for testing or checking my blood pressure. He didn't get off his chair. In five minutes I had a diagnosis of fibromyalgia and a prescription for tramadol.

Lyn: This is a common problem. Doctors do various tests and they come back normal and many people are diagnosed with either fibromyalgia or ME. What happened after your diagnosis?

Lorraine: I still trusted the med establishment and I thought I would have to learn to live with Graves' disease, hypothyroidism, hypoparathyroidism and fibromyalgia.

As the months turned into years, I developed panic attacks, really shocking panic attacks that would come out of the blue. I had tachycardia, ectopic heartbeats, obesity, high cholesterol, high blood pressure.

Finally, I was about to commit suicide a year and a half ago. I just could not continue living a half a life. I slept for 20 hrs out of 24.

Lyn: That's very sad. What changed your mind?

Lorraine: My husband found Thyroid UK and its online community, HealthUnlocked, and I started to read and I could not believe what I was reading because most people on there were the same as me and I finally realised this was all thyroid related after all.

I read all the information on Thyroid UK and I learned that I possibly had a problem with my thyroxine not converting. I saw Dr Skinner and a blood test confirmed that I wasn't converting and Dr Skinner suggested T3. However, my GP had previously suggested T3 and I had tried it and hadn't got on with it.

Dr Skinner then prescribed me natural desiccated thyroid (Erfa) and it saved my life.

Lyn: Well, Lorraine, that's a story and a half, isn't it?

Lorraine: Yes, it's a success story isn't it?

Lyn: So, now you are on Erfa, what other medications are you taking?

Lorraine: Well, I **was** on betablockers, tramadole, antidepressants, sleeping tablets, non steroid anti-inflammatory tablets and inhalers. I was on so many meds when I was taking levothyroxine. Now, I just take Erfa – I don't need the other meds.

Lyn: That's such good news! Has there been any other treatment that has made a difference to you apart from Erfa?

Lorraine: Well, learning about my depleted vitamin and mineral status has been a huge benefit because my iron, Vitamin B12 and Vitamin D were all very low.

Supplementing with those and selenium has made a massive difference to my life and my health.

Lyn: That sounds really good. What made you start looking into your vitamin and mineral status?

Lorraine: Well, it was the people on the Thyroid UK online community, HealthUnlocked really. Regular contributors to the site were really patient with me and didn't bombard me with too much info. They went through it stage by stage because it took a long time for information to stick because I was so ill and my brain fog was so bad.

Once I was on Erfa, I started slowly on that and then I started to address my low iron, Vitamin B12 and Vitamin D.

Lyn: So, once you were on Erfa and your vitamins and minerals, how did this affect you?

Lorraine: I improved 100%. I lost 3stone, my blood pressure is now perfect as is my cholesterol. I don't sleep more than 7 hours a night now and I have a social life again. I am no longer a hermit and I have my "fight" back.

Lyn: I am so pleased to hear that. What made you join Sandra and Marian in petitioning the Scottish Parliament last year?

Lorraine: Well, I originally was going to petition them about the difficulty I have accessing my thyroid medication. Dr Skinner is my prescriber and he is repeatedly called before the GMC. If anything happened to him I would have great difficulty in accessing my lifesaving medication. My GP said she was unable to prescribe it because it was unlicensed.

So I spoke with my Member Scottish Parliament (MSP) and he advised me to petition the Scottish Parliament. While I was compiling that, a mutual friend had already been in touch with Marian and Sandra about another matter and he knew they were petitioning the Scottish Parliament because of their own thyroid problems and he put us in touch with each other. We then decided that we would be stronger if we worked together. The Scottish Parliament only accepts one petition on any one subject per year so this was a good way for the three of us to get the bigger picture heard.

Lyn: After you attended the meeting at the Scottish Parliament, they asked several organisations to write submissions about their views on the petition and the problem of thyroid diagnosis and treatment. Thyroid UK was asked, among others, to send in their submission. The Royal College of Physicians and the World Health Organisation were also asked to submit their views. They did not, however, respond at all. Why do you think that is?

Lorraine: Honestly, I think that they are aware that this is a massive issue, a potential health scandal and in having an open and honest dialogue, it may be that

they would be forced to admit previous errors in their way of thinking and treating thyroid disorders.

Now, that's natural, because medicine does make wrong turns, and things are revised and treatments are changed. I'm very unsure why they are so unwilling to look at this issue again. My only inkling is that it is predominantly a female issue and we consume a lot of medications when we are not properly medicated for all the accompanying symptoms so, who knows, maybe it's just too big an issue.

By not replying to the Scottish Parliament's question though, I think it shows the contempt with which we are held as a community.

Lyn: It does seem strange that they haven't responded especially since they quote on their website, "We are a forward-looking organisation, relentless in our pursuit of improvements in healthcare and the health of the population."

There was another Public Petition Committee meeting on Tuesday 16 April 2013 that you and Sandra attended. Tell me about that.

Lorraine: That was a very successful meeting. The meeting was held in order that the committee decide whether the petition should be carried forward or to close it down. They decided it was a serious issue and that they wanted a short-life working group set up to examine all the available clinical evidence on the treatment of patients suffering from thyroid and adrenal disorders. The reason for the short-life working group is because if they don't put a timescale on it these things can rumble on indefinitely.

At the meeting, John Wilson, MSP, stated, "The recommendation is that we ask the Scottish Government to establish a short-life working group to look at the issue, but if it is not prepared to do that I am keen that we get an assurance that one of those committees would carry out such an inquiry, because I would not want us to pass the petition on to either committee only for it to shut down the petition. In such circumstances, we would have no recourse—we could not reopen it"

He also showed his concern that this petition progressed when he said, "It would be useful for us to agree to write to the Scottish Government to ask whether it would be minded to set up a short-life working group. If it is not minded to do so, we should find the time to carry out an inquiry."

Elaine Smith, MSP, who spoke for us at that meeting informed us afterwards that two further thyroid patients had committed suicide this year and it's just too serious to let it go.

Lyn: That's so sad. We need this petition to change things, don't we?

Lorraine: Yes. This is a serious issue. When I contemplated suicide, I had counted the tablets and I had them stored and ready to go. Thank God my husband found the Thyroid UK site and the online community because if you don't know that your myriad of problems are thyroid related and your GP or endocrinologist tells you it's nothing to do with your thyroid, you are going to believe that you are mentally ill or

seriously ill and no one is going to help you. So this is a life or death situation for many, many people.

The Scottish medical establishment and the Scottish Government have a history of groundbreaking decisions in medicine – Dolly, the sheep is just one example. They are very advanced and have a very good reputation for dealing with medical issues and I think, if Scotland makes changes, the rest of the world will follow.

Lyn: I do hope so. The problems of thyroid disease and adrenal diagnosis and treatment would not have got this far without you, Sandra and Marian taking it to the Scottish Parliament. You are all so brave to be doing this and Thyroid UK takes its hats off to you.

Lorraine: We wouldn't have got this far if it hadn't been for finding Thyroid UK because I wouldn't have survived. I know that sounds gushing and extreme but I really had not the first clue about where to go with my health. I had private healthcare so I saw the supposed best endocrinologists available and I became more and more ill so finding the right information, a good doctor and the correct meds saved my life.

Lyn: I'm so pleased that we helped you and thank you so much for allowing us to interview you.

To keep up to date on all progress of the Scottish Thyroid Petition go to:

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