

P-05-926 To Provide a Chronic Fatigue Department in Wales, Correspondence – Petitioner to Committee, 08.12.19

When responding, you might want to consider the following:

What are your thoughts on the attached document?

Does it adequately address the issues that you raised?

Do you have further questions in response?

Is there anything additional that you would like the Committee to know at this stage, either in response to this document or as an update to the Committee?

My response

When was the Steering Group established? Is this a recently organised group? If so, why has it taken so long to set up? I have been suffering for 23 years!

Steering group consists of: Health Boards, Service User representatives, third sector organisations, volunteer support groups and Welsh Government.

Who are the service users? Where do they come from when there is no specific place to get help?

Health boards are responsible for providing services for those living with ME/CFS. Betsi Cadwaladr University Health Board has a dedicated ME/CFS service along with the majority of other health boards and Powys Teaching Health Board runs a pain and fatigue management service. All these with the option to utilise specialist centres for ME/CFS depending on their location. Clinicians in South Wales can for example refer to the Bath Centre for Fatigue Services with Clinicians being expected to follow the NIHCE guidance.

I have not been referred anywhere, until last January/February when I was sent to see a doctor in General Medicine at Llandough Hospital [23 years down the line]. There was no help here as he sees many individuals with Chronic Fatigue but was unable to offer any assistance. Again no recommendation to be seen at a 'Specialist' clinic. I feel as if I've been passed on there just to get me out of the way! Why have we not got a place in Cardiff or nearby where we can talk through the problem?

I was told there was not a place in the whole of Wales where one could be seen regarding Chronic Fatigue so I searched on line last year and came across a clinic in Bristol. Nothing else showed up. I wrote to Elinor Hammond in February last year asking if I could be referred to them by our Health Board. I was not on the list for payment to be made for this. Forms had to be submitted and were sent to my practice along with a Policy. No forms were completed as the Policy, I am told, is about an inch or so thick with no time to read them! So, again, no help has been forthcoming.

I note your response to my statement "without a Chronic Fatigue department there can be no research - that it is not technically correct". You say 'it is possible that the existence of a specialist clinic could potentially add to the visibility of the condition'

Is it not important to know the extent of the condition?

Regarding the Myers infusion.

I eventually found a doctor in Cardiff who administered this infusion but found it had no effect on my body. The reports from individuals on the web sites were very promising. I have tried numerous alternative therapy treatments over the years to put an end to the fatigue. All to no avail. More research would be welcome.

I know I am not alone with this terrible disease. It would be wonderful to find an answer so that lives could be satisfied and fulfilled.

I will keep trying to find answers by using any alternative methods that sound as if they'll help.

Yours sincerely

Marjorie Lasebikan