

**P-05-926 To Provide a Chronic Fatigue Department in Wales, Correspondence –
Petitioner to Committee, 10.07.20**

I am still not satisfied that the problem is being treated as a separate case to the ME/CFS but am hopeful that future individuals will be looked at and taken seriously. I feel that I was not. Please see paragraph 1.

1. *1. 'It would also be good if money could be dedicated to ensuring that other people with post viral symptoms are well supported. It is too late for many who have already been harmed by neglect, disbelief, inappropriate advice and exercise therapy in Wales' fatigue and pain clinics, but future patients could be spared that.'* I would like to remind you that I have had chronic Fatigue for the past 23 years with no offer of help or referral to a Consultant. I reported to my GP with a very high temperature which I'd had for 5 days [31st May 1996] and it was noted that my temperature was 104!!! There would appear to be nowhere in Wales to send a patient to: or that is the case for those in South Wales. I feel that I have been badly let down. A new acquaintance says that she was!! Where? Why wasn't I?

2. *'On behalf of people with ME and Covid-19 survivors WAMES asks that Wales develops a strategy to recognise and treat illnesses triggered by all viruses.'*

I would think that as I did not show any signs of infection at the time [31st May 1996] that my high fever was due to a virus.

3. *'Concern has been raised by the NHS in Wales that "a national strategy for [Covid-19] rehab would be required. They claim provision is "patchy" and without help people's lives will be harmed.'* (6) *WAMES agrees, and has been calling for a national strategy for caring for ME and post-viral sufferers for many years.*

It has to be! To avoid the long term chronic condition of ME developing.

4. *'Fortunately the professional group physios4me (7) have been quick to produce clear guidelines to enable doctors and therapists to identify and support patients with ongoing problems. Many people with ME wish their doctors in the past had done this for them!*

With CFS [my case was not diagnosed as I am frequently told by my GP] you live a life that is an existence. The inability to function, think or concentrate is hard. To say you are not well and are unable to help with certain things is difficult for people to understand. I was always an active person and this inability to do anything for any length of time without suffering extreme tiredness for 3 to 4 days is an absolute misery. *I have not suffered with pain.*

5. *'WAMES believes this could mislead the health community into believing ME is a pain syndrome, and lead to ME being over looked, or worse, included in pain rehabilitation programmes, which have already caused such setbacks (and distress) for people with ME in the past. This approach fails to address the most pressing issues, that of the unique characteristic of ME - exercise intolerance and the post-exertional response (PEM) - and the lack of medical expertise in post viral conditions in general and specifically neurological ME, in Wales.*

This is exactly the problem!

I looked up PEM and this is the outcome.

What does PEM feel like?

PEM is not just **a feeling** of severe fatigue; it is **a full-body assault**. **A** physician with CFS says, "My **PEM feels like a** worsening of my baseline CFS symptoms - more fatigue, headaches, neck/ back muscle achiness (but not outright pain), problems concentrating/ reading

[PEM Series - Solve ME/CFS initiative](#)

*Post-exertional malaise (**PEM**) is the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks.*