

**P-05-926 To Provide a Chronic Fatigue Department in Wales, Correspondence –
Petitioner to Committee, 26.10.20**

Thank you for your letter of 5 August regarding the petition for a Chronic Fatigue Department in Wales and seeking a response to the recommendations made to the Committee by WAMES.

The Welsh Government has recently restructured its advisory groups on arthritis/musculoskeletal(MSK)conditions, chronic pain, ME/CFS and fibromyalgia into a single broader advisory group encompassing all of these conditions.

Whilst encompassing all of these please make a centre available for all people who suffer from fatigue to be referred! There has to be a centre to cover all aspects of illnesses here long-term FATIGUE is part/or a whole of the ailment. This has not been the case in the past [I am going back over 24 years and as recently as 2] which equals no hope of help with no referral to see a specialist.

The rationale for merging these groups was to pool resources and expertise to tackle common issues; to share good practice; and to provide a unified stronger voice. The revised advisory group will consider all aspects of the pathway for conditions currently treated within pain or MSK settings, including ME/CFS.

Without knowing the true total numbers of people suffering with Chronic Fatigue how can it be taken seriously? How do you know the full extent of people suffering who need help? How do you know the proportion of people in Wales who suffer this illness? All wasted lives.

This ranges from the development of self-management approaches and digital learning, improving health care professional training, ensuring accurate recording of conditions and optimising the configuration of specialist services.

Without General Practitioners knowing of a centre to refer their patients' one is left in limbo. [About 12 years ago – in my case – I was to be referred by one GP and did not hear anything. Today I am told 'You've never been diagnosed'. How could I be?

The first meeting of the revised group was planned to be held in the spring but was delayed due to Covid-19. It is hoped that this meeting will now take place later this year.

This new approach was subject to a targeted consultation and received significant support from stakeholders, with the majority in full support of a more cohesive approach to providing support and treatment for pain, MSK and fatigue related conditions.

There were three stakeholders (as highlighted by WAMES) who raised concerns about the approach and my officials have put a number of safeguards in place to address these, including reconsideration of the name of their con? group and allowing for a trial period. I have asked that all of the recommendations made by WAMES be shared with the revised advisory group for their consideration.

WAMES advise that they have previously tried to engage with the service for a number of years to provide more focus on ME/CFS education.

Taking a fragmented approach to education one condition at a time may yield some results in the short term but take up is likely to be limited.

As such the Welsh Government's preferred approach is to drive forward this agenda by working with relevant organisations such as Health Education and Improvement Wales (HEIW) to consider education and training to a range of conditions within the group's remit.

This approach identifies similarities between conditions where they exist to avoid duplicated learning whilst clearly outlining differences between conditions and the treatments required.

Important to isolate/diagnose, yet treat each type of illness presented.

Training programmes will require strong patient involvement and representation and the approach would also include expert opinions on how treatment and support are to be delivered.

We would also welcome health care professionals with a special interest in ME/CFS making themselves known. To date these have been few in number.

Please find some who will seriously want to investigate and explore the cause/reason for Chronic Fatigue alone. Pain is probably associated with other illnesses but not necessarily CF.

WAMES mention Dr Nina Muirhead as one such professional and my officials have engaged with Dr Muirhead consistently for the past few years.

The new advisory group approach will promote task and finish groups that focus on specific topics and relevant specialists will be invited onto these groups to help develop approaches and guidance.

Assessment is needed

The Welsh Government and the National Health Service in Wales rely on the expertise of NICE guidance to support health and social care professionals to deliver treatment. We are not in a position to disregard the agreed clinical advice provided by this professional body unless there is a groundswell of support to do so from the clinical community. To date this has not been forthcoming.

I appreciate there are strong feelings towards the current NICE guidance, however this guidance has not been revoked and remains extant. We have been clear that we await the outcome of the NICE review and will reflect on any changes.

In relation to historical teleconferencing issues, the development of home and online working has been a revolution regarding meetings. Officials are attending online meetings daily without issue. It has also increased parity for those living further away or unable to travel.

The Neurological Conditions Implementation Group (NCIG) has previously determined that ME/CFS should not be included in their remit. This was because health boards were unable to form a consensus as to whether ME/CFS was treated as a neurological or a pain condition. Unless new evidence emerges that demonstrates that ME/CFS should be coded as a neurological condition, it is unlikely NCIG will amend their decision. Even if they were to, this would bring with its own challenges, namely that there are over 250 neurological conditions and it is not possible to have a dedicated works team for each and every one of these conditions.

There is not always pain with Chronic Fatigue. Whilst there may not be a cure has it been explored seriously? Has anyone looked at a very high fever and its outcome, resulting in Chronic Fatigue?

This is now evident with COVID-19