



Ein cyf/Our ref: MA - P/VG/2014/19

Mark Isherwood AM
AM for North Wales
National Assembly for Wales
Cardiff Bay
Cardiff
CF99 1NA

24 May 2019

Dear Mark,

Further to business questions on 14 May, I am writing to update you on the actions the Welsh Government is taking to support people living with Myalgic Encephalomyelitis (ME) / Chronic Fatigue Syndrome (CFS). I am grateful for the work that you continue to undertake to raise awareness of this condition both in and outside the Senedd.

The Welsh Government also recognises the impact that ME/CFS has on the lives of individuals and has put in place a national steering group to consider what further support can be provided and to share good practice. The group is chaired by Owen Hughes (Consultant Counselling Psychologist and Head of Pain and Fatigue Management Service at Powys Teaching Health Board) and consists of representatives from health boards, service user representatives, interested third sector organisations, volunteer support groups and Welsh Government officials. The work of the steering group is currently focusing on care pathways for ME/CFS so that health professionals have clear information on how to help people with these conditions and patients know what to expect.

With regard to NICE guidelines, whilst I acknowledge the concerns that Dr Muirhead has raised, the guidelines remain extant and should be followed by clinicians in Wales until such time that they are revoked or replaced. This may happen as a result of the review which is currently underway and I wish to assure you that we have shared all relevant information with Steering Group members and have encouraged them to feed in Welsh views through the review consultation process.

My officials have assisted Dr Muirhead with her research with medical students and the national steering group has been liaising with Dr Muirhead in relation to this work.

I have also asked the Welsh Association of ME & CFS Support (WAMES) to consider working with the national steering group to submit a proposal to Health Education and Improvement Wales (HEIW) for consideration and advised that the group may also wish to consider developing a training package to assist with more accurate diagnosis for the e-learning platform for GPs. My officials have initiated discussions with HEIW to consider

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1NA

Gohebiaeth.Vaughan.Gething@llyw.cymru
Correspondence.Vaughan.Gething@gov.wales

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

training provisions for healthcare professionals and work with the group to consider methods regarding how this can be improved.

Finally, my officials are currently working on a range of documents and guidance relating to chronic conditions. The Welsh Government has recently published *Living with Persistent Pain in Wales* (<https://gov.wales/people-experiencing-persistent-pain-guidance>) which provides guidance for anyone living with persistent pain, regardless of the condition. Work is also well underway to develop guidance for NHS staff relating to arthritis and associated conditions with the intention to go to consultation later this summer.

I hope you found this information useful.

Yours sincerely,

A handwritten signature in black ink that reads "Vaughan Gething". The signature is written in a cursive style with a large initial 'V' and a long, sweeping tail on the 'g'.

Vaughan Gething AC/AM

Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services