

P-05-926 To Provide a Chronic Fatigue Department in Wales, Correspondence: Welsh Association of ME & CFS Support (WAMES) to Minister for Health and Social Service, 12.05.20

WAMES
The Coach House,
Frongôg
Aberystwyth
Ceredigion
12 May 2020

Minister for Health & Social Care

cc Deputy Minister for Health & Social Care
Chief Executive for NHS
Chair Petitions Committee
Kevin Frances, Directorate for Health Policy

Dear Vaughan Gething,

Today, 12th May 2020 is International ME Awareness day. The WAMES blog and social media this week contains stories of the devastating effect ME has on people's lives. ⁽¹⁾

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.

Today is also Day 51 of the Covid-19 lockdown in Wales. 2 months ago we could not have imagined that we would be drawing your attention to Myalgic Encephalomyelitis (ME) in the middle of a pandemic!

We do so because over the last few weeks media and research reports ^(2,3,4,) have made it clear that a number of people who survived the SARS and MERS pandemics a few years ago did not recover, but went on to develop neurological and post-viral symptoms. For some this led to full blown neurological ME.

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.

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, to avoid the long term chronic condition of ME developing.

Many people with ME wish their doctors in the past had done this for them!

The physiotherapists have been guided by international research evidence on the nature of the dysfunction in ME and particularly the Workwell Institute's findings on exercise intolerance in ME. They have also drawn on the long clinical experience of Dr Charles Shepherd of the ME Association.

Unfortunately NICE has still to catch up, and due to the Covid-19 crisis the publication of the revised NICE guidelines for ME/CFS has been delayed, possibly well into next year.

It is good that the Welsh Government has 'announced an extra £10m to help people recovering from coronavirus.' 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. The paucity of testing for Covid-19 means that many in Wales could have had the virus and be unaware they might face a backlash in the future and won't be recognised as needing specialised advice.

People who already have ME are finding that catching Covid-19 leads to a relapse in symptoms. As people with ME have not been placed on the 'at risk' from Covid-19 list, this can cause added difficulties in gaining support as they continue to shield. **Is there a way that people with ME who are very ill can be placed on the 'at risk' list?**

Currently the Welsh Government has placed ME and CFS in an advisory group with pain syndromes, hoping to find ways to improve NHS handling of common issues: 'the need for patient and professional education, effective diagnosis, self-management techniques.'

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.

WAMES calls on the Welsh Government to lead the way in caring for ALL survivors of viruses, without discrimination.

Best wishes,

Jan

Jan Russell

Chair/ Cadeirydd,
Welsh Association of ME & CFS Support
Cymdeithas Cefnogi ME a CFS Cymru

Refs

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4. https://www.huffingtonpost.co.uk/entry/coronavirus-could-leave-you-with-symptoms-of-post-viral-fatigue_uk_5eb3e88dc5b6526942a29dfc
5. <https://le.ac.uk/news/2020/may/coronavirus-me-risk>
6. Coronavirus: NHS faces 'massive' challenge helping patients recover.
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7. www.physios4me.com