**From:** jan@wames.org.uk <jan@wames.org.uk>
**Sent:** 09 February 2022 12:14
**To:** 'Correspondence.Eluned.Morgan@gov.wales' <Correspondence.Eluned.Morgan@gov.wales>
**Subject:** Long COVID & ME/CFS
**Importance:** High

Dear Ms Morgan,

We at WAMES were pleased to hear your announcement yesterday about the development of services for people with long COVID and that they would be tailored for the individual, close to home. We are particularly concerned about long COVID, because a proportion of them are already meeting the criteria for ME/CFS, as I mentioned when I wrote to your predecessor in May 2020 and you back in June last year. It was therefore a big surprise that when you talked about how little was known about the condition in the early days of the pandemic, and about the desire to learn from patients, you did not also acknowledge that post-viral illness is not new and there is much to learn from those with other post viral illnesses, including those with ME/CFS.

Can you imagine how people with ME felt when you assured people with long COVID that “we haven’t forgotten you”? Long COVID has been recognised for less than 2 years. People with ME/CFS, another post-viral illness, have been largely ignored for decades. You mentioned you had been learning from patients in the Swansea Bay LC service. People with ME have been telling politicians, Health Boards and professionals for decades about the extent and severity of their symptoms and debility, and that they wanted to be believed and not pushed into psychology services or down the exercise therapy route. Nobody listened. At least not enough to actually speak up for us, let alone develop ‘appropriate’ patient-centred services. We were fed excuse after excuse – ‘financial restraints’, ‘no clinical champions’, ‘not enough known about the condition’, and more recently ‘too busy with COVID’. We feel like the poor country cousins that are not thought fit for normal society and nobody wants to befriend!

You said people would not need a positive COVID test to access services. Will we reach the stage where only patients who meet ME/CFS criteria from 2020 onwards will be able to access services because they are deemed to have Long COVID, and those who became ill prior to that, following Epstein Barr Virus, Coxsackie, Gastric viruses etc. will be exempt? Will services acknowledge the overlap with ME/CFS? Will those services be assessing patients for a symptom many with Long COVID share with ME/CFS - Post-Exertional Symptom Exacerbation (PESE), also known as Post-Exertional Malaise (PEM)?  This is important so that patients are not unknowingly prescribed exercise therapy, which can delay or stall their recovery. Although fortunately so far there have been few children with recognised long COVID there are a number of children with ME/CFS who have struggled to have their PESE recognised by paediatricians. Perhaps long COVID children have faced the same disbelief and are therefore not counted. A knowledge of PESE is needed in paediatric medicine also.

You mention setting up an expert group on long COVID. Surely this should cover all post-viral illnesses on an equal footing? Is there an expert on ME/CFS included on that group? Admittedly there are no clinical experts in Wales, but there are health professionals with ME, and a lecturer at the Cardiff University Medical school with ME. Will patients be invited? Will other post-viral conditions be explored in the COVID Evidence centre? This is a great opportunity to learn from, and about, a much wider group of patients with viral triggers and overlapping symptoms. Will the Welsh Government post-viral lead, that I believe you intend to appoint, be exploring how long COVID and other post-viral illnesses can be treated with equal seriousness and equal commitment to service development?

Pre-pandemic, following a standard algorithm, we estimated there were 13,500 people with ME/CFS in Wales, most of them being met with disbelief, apathy or helplessness by NHS Wales. That number will grow. How many will be tempted to re-label themselves as Long COVID just to get a fair hearing from their GP? Will those with ME/CFS whose condition has been made worse by COVID receive an informed and appropriate response from GPs and the long COVID services? Can you commit to working towards an equitable quality of service for all post-viral illness?

You were right when you said during question time at the press briefing that ‘Our words have impact and we’ve got to be very, very careful not to incite people.’ Please be aware your words can also plunge people into despair!

I look forward to hearing how the Welsh Government will be funding and supporting a better understanding of ME/CFS, PESE/PEM and the dangers of exercise therapy, alongside the wider range of support needed for those with post COVID symptoms. We are looking for a speedy implementation of the 2021 NICE guideline, (which, if further motivation is needed before action will be taken!) will also benefit people with Long COVID.

Best wishes,   Jan

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Chair / Cadeirydd

Welsh Association of ME & CFS Support
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