

15th June 2021

Dear Health Minister,

WAMES has read in the media with mixed emotions about your decision to give £5m to fund a long COVID recovery programme. Of course we are pleased to see such swift recognition and desire to help people who have very recently experienced post viral illness. On the other hand we are incredulous that once more long standing post-viral patients are being ignored.

It is true that the Welsh Government backed a Task & Finish Group report on ME/CFS in 2014 giving guidance to Health Boards in improving care for people with ME, but no money was promised. The aim then was for ME patients to be cared for within existing services and we note that the same is planned for long COVID. This approach has NOT worked for ME.

Health Boards have failed to take the illness seriously. They have failed to: ensure doctors are equipped to diagnose; give helpful management advice; plan a pathway through existing services; or make adjustments to enable the severely affected to access care. A couple of HBs have actively included ME patients in inappropriate pain services, which has caused some trusting participants to suffer severe relapses.

Over the last year researchers and the media have highlighted the range of viruses that are known to have triggered long term ME. The previous SARS-CoV-1 virus was one of them and already some people affected by the current SARS-CoV-2 virus meet the diagnostic criteria for neurological ME. Doctors and researchers are suggesting that 10-15% of post COVID sufferers will develop ME, which will add significantly to the current top estimate of 13,000 people with ME in Wales. Not all current patients with ME have proof of which virus triggered their condition and have consistently faced disbelief, as a number of those with suspected COVID have.

It is important that ALL people suffering post viral symptoms, whatever the triggering virus, are helped to avoid long term complications. Many people with ME wonder if they could have recovered if they had been able to take time for their bodies to recover and hadn't been pressured into returning to work and education early on, or faced the stress of disbelief and stigma.

The postponed revision of the ME/CFS NICE guidance is due out in August and we are hopeful that the proposed warning in the draft against exercise therapy will be retained. However the previous positive recommendations in the guideline were ignored by the NHS (e.g. help devising a management plan), so without leadership, money and monitoring of NHS implementation, WAMES are not hopeful that healthcare for people with ME will improve, even if the guidance is evidence based.

We would like to draw your attention to a report submitted to the House of Lords Select Committee on Risk Assessment and Risk Planning in January which highlights the severe impact ME can have on individuals, families and society. It outlines the measures that need to be taken: to research; record prevalence; identify workplace shortages; issue guidance; encourage flexibility in employment; and plan to prevent and treat post-covid-19 ME/CFS. <https://committees.parliament.uk/writtenevidence/21844/pdf/>

**What steps will you, as Health Minister, take to ensure current patients with ME, and an increasing number of future patients, will receive the acknowledgement and care they deserve?**

Sent in anticipation,   Jan

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Chair / Cadeirydd

Welsh Association of ME & CFS Support

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