Links between ME/CFS and Long COVID Position Statement

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Statement

Emerge Australia recognises the converging evidence linking ME/CFS with Long COVID. Scientific studies of Long COVID have demonstrated similar symptomology with ME/CFS, with the most frequent shared symptoms of people with Long COVID and ME/CFS being post-exertional malaise (PEM), cognitive difficulties and fatigue[1].Future research is essential to better understand both conditions and to develop effective treatments. Given post-exertional malaise is a core and/or common feature of both conditions, Emerge Australia advocates for clinical management approaches that minimise the risk of harm: pacing, rest and stepwise symptom management.

For many people, ME/CFS develops after a viral infection. ME/CFS can be triggered by a wide variety of infectious agents, including Epstein Barr virus, Ross River virus or Human Herpes Viruses [16] and now recent evidence suggests the SARS-CoV-2 virus could be added to this list [1,6,17].

Long COVID is a post-viral illness triggered by the SARS-CoV-2 virus. There are many overlaps between ME/CFS and Long COVID, both in terms of symptoms and pathophysiology, suggesting the two conditions are likely related.

Like those living with ME/CFS, many Long COVID patients experience PEM, making increased activity and exercise potentially harmful. This is inclusive of graded activity and graded exercise. In the absence of evidence-based treatments, Emerge Australia advocates for harm minimisation in the clinical management of Long COVID. This is best achieved with pacing, rest and stepwise symptom management.

Given this relationship, Emerge Australia advocates for more research into both ME/CFS and Long COVID. A better understanding of one is likely to lead to an improved understanding of both and, ultimately, more effective treatments. Emerge Australia welcomes the Long COVID Inquiry Report's recommendation of funding for research and patient care. [14]

Emerge Australia will continue to support those with Long COVID, in addition to our ME/CFS community, because both patient cohorts struggle to get help, falling through the cracks of our health and social care systems.

Background

Coronavirus disease 2019 (COVID-19) is an infectious illness caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV- 2)[2]. Noteworthy, a significant number of ME/CFS studies attribute illness onset to a viral infection[3]. Well after their initial acute infections, multi-system disturbances affect both Long COVID and ME/CFS patients[4], resulting in similar lingering and debilitating symptoms[4]; with nearly 50% of Long COVID patients meeting ME/CFS diagnostic criteria, 6 months post their initial infection[1,5,6]. Extensive research likening Long COVID to ME/CFS indicates that a lot can be learnt from existing ME/CFS knowledge, without having to 'reinvent the wheel'. Existing research also highlights the significant opportunity that Long COVID presents to dramatically advance our knowledge of ME/CFS and provide real, tangible treatment options for both conditions[7].

Evidence

While some Long COVID patients have persistent symptoms due to organ damage from the SARS-CoV-2 virus [7], others have persistent symptoms with no clear cause. The symptoms of the latter group of Long COVID patients appear remarkably similar to symptoms experienced by people living with ME/CFS[5,6], as evidenced by recently published studies [1,5,6].

A large 7-month international study with more than 3000 participants found that 89.1% of participants with Long COVID experienced post-exertional malaise (PEM), the hallmark symptom of ME/CFS, in addition to fatigue (80%), 'brain fog'/cognitive dysfunction (85.1%) and difficulties sleeping (78.6%)[6].

Emerge Australia Inc.
Level 7, 276 Flinders Street
Melbourne VIC 3000

The study of orthostatic symptoms in Long COVID patients showed no difference when compared to ME/CFS patients, with all Long COVID patients fulfilling ME/CFS criteria by the end of the research study [5]. In a prospective observational cohort study, 19 of 42 (nearly 50%) patients studied, fulfilled the diagnostic criteria for ME/CFS[1].

Furthermore, like ME/CFS, early studies suggested deconditioning as a viable explanation for exertional intolerance in Long COVID patients. More recent studies utilising invasive cardiopulmonary exercise testing (iCPET) to study exercise pathophysiology have since provided evidence against deconditioning as the sole explanation for exercise intolerance.

These studies instead suggest that similar exercise pathophysiology underlies both Long COVID and ME/CFS, which may explain exercise intolerance in these patients [8,9 10]. Noteworthy, like ME/CFS [11], many Long COVID patients implementing exercise-based rehabilitation have reported suffering adverse effects, exacerbating their condition[12]. Some Long COVID patients have reported that even with minimal physical exertion, their symptoms significantly worsen, rendering them bedbound for several days [13,14]. Recognising these similarities between Long COVID and ME/CFS will have significant implications for the ongoing management of Long COVID patients.

Abnormal findings in ME/CFS that have also been observed for Long COVID include diminished natural killer cell function, T-cell exhaustion, mitochondrial dysfunction, vascular and endothelial aberrations and altered neurological functions[7,15]

Emerge Australia acknowledges the Long COVID inquiry report released by the Federal Government in April 2023. This report stated there may be a crossover between Long COVID and ME/CFS, but recommended they be treated separately[18]. Although the committee deliberately separated ME/CFS from Long Covid, as discussed above, research has noted the many overlaps between these post-infection diseases, and their crippling impact on the community and the economy.

Emerge Australia strongly advocates for more research into the overlaps between ME/CFS and Long COVID. While a "diagnosis and treatment gulf for long COVID" has been reported, there remains an even bigger diagnosis, management, and treatment gulf for those with ME/CFS.

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