



*Promoting effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK*

## **Statement on long COVID and ME/CFS by the International Alliance for Myalgic Encephalomyelitis December 2020**

*IAFME is a formal collaboration between national organizations representing patients with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS).*

SARS-CoV-2 (COVID-19) continues to affect millions of people globally. While some people recover, other people have a delayed recovery and across the world we are now seeing the emergence of a significant group of people who are struggling with a wide spectrum of symptoms similar to ME/CFS, many weeks or months after their initial COVID infection.

From our experience we know that, like ME/CFS, long COVID is both a real and highly disabling condition. There are, of course, many differences in our experience of long COVID and its relationship to ME/CFS but we have come together as an alliance to share the similarities in our experience in the hope of better outcomes for patients, and their families, experiencing both long COVID and ME/CFS.

### **Stop, Rest, Pace**

We counsel individual patients, medical providers and people operating at all political levels associated with health to advise patients to stop, rest and pace. Patient organisations working in ME/CFS will often have tools or services to assist with this. We encourage medical professionals and long COVID patients to contact ME/CFS organisations in their own country to share appropriate resources and assistance available.

Better outcomes by far are found from advising patients not to push and, as with ME/CFS, not to focus on exercise. Patient health and quality of life is maximised by advocating for and advising that they rest, manage their activities and that their symptoms are treated - as possible and appropriate.

### **Opportunity for Research**

The sudden, dramatic rise of COVID-19 provides a real opportunity for much-needed research into post viral conditions – research which will help both people with long COVID and people with diseases such as ME/CFS. We urge Governments and philanthropists to seize this opportunity to understand what is delaying (or preventing) recovery and - crucially - what restores health to those patients who recover.

We will continue to work collaboratively to ensure that this opportunity is not lost. The neglect of people with ME/CFS must stop. We hope that some good may come from the pain and suffering caused by this pandemic in that it may finally help us to see the investment in research, treatments and care that every single adult and child with ME/CFS and their families deserves.

International Alliance for ME Statement, signed by XXX as a member.

- Our alliance seeks to facilitate a coordinated, simultaneous dialogue with policymakers at national and international levels, increasing its potential impact.
- We encourage the pooling, sharing, and dissemination of advocacy and communication of resources.



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- We promote the expansion of engagement with relevant stakeholders - worldwide organizations sharing the same message is much more powerful than an isolated voice.

Refer also to US ME/CFS Clinician Coalition Letter: Post-COVID "Long Haulers" and ME/CFS October 30, 2020 found at: <https://tinyurl.com/y28w3t95>