

Long COVID has resurfaced tensions over treatment of chronic fatigue syndrome

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Many long COVID patients are experiencing extreme fatigue, a situation which has reignited the polarisation in approaches to treatment and rehabilitation of chronic fatigue syndrome (CFS), according to a special report today.

The BMJ reports on examples where doctors have been challenged for speaking out in the media after talking about the role of [exercise](#) in rehabilitation.

But it also finds that beyond the controversy, some clinicians see an opportunity for long COVID to progress the understanding of post viral syndromes and to acknowledge they are a very real condition.

CFS, also known as ME (myalgic encephalomyelitis), is a complex long-term illness often triggered by an acute infection with a wide range of symptoms that can have a significant effect on [daily activities](#), the most common being extreme fatigue.

In 2011, the PACE trial found that both [cognitive behavioural therapy](#) (CBT) and graded exercise therapy (GET) led to greater improvements in some participants than medical care alone. But the results led to controversy as some CFS/ME advocates object to suggestions that their illness has a psychological element.

And tensions have now resurfaced with the advent of the pandemic and long COVID.

Around 376,000 people in the UK report symptoms more than a year after COVID-19 including [extreme fatigue](#) and other symptoms similar to post-viral fatigue syndromes and ME/CFS.

Freelance journalist Melanie Newman spoke to clinicians and academics involved in ME/CFS and long COVID research, and found that what advice is given, what research is conducted, and how it is communicated has become a highly sensitive issue.

Some have been challenged for speaking out. For example, Michael Sharpe, a professor of psychological medicine, was castigated for

suggesting the disease is "all in the mind" or created by the media, while an activist asked for Trish Greenhalgh, professor of primary care at Oxford University, to be removed from a conference because she had previously commented on exercise and PACE in a public webinar.

Professor Paul Garner at the Liverpool School of Tropical Medicine, who had recovered from long COVID, says some advocates actively oppose research on exercise. "They believe the disease lasts for life," he says. "They reject any research that examines psychological approaches to treatment or that evaluates the role of progressive physical activity in recovery in ME/CFS, and I would assume by extension to long COVID."

Charles Shepherd, medical advisor at the ME Association told the *BMJ*: "We are not against exercise. Our view is that graded exercise can be harmful."

Ben Marsh, an NHS consultant paediatrician who contracted viral pericarditis in 2017, thinks physical therapy should be treated like medication or surgery, with patients told about possible side effects and what to look out for.

Newman spoke to other doctors and healthcare professionals helping long COVID patients and found them to be very aware of these concerns and quietly working out how best to treat each patient without causing them harm.

Results are—predictably, given the early stage of the research—mixed, she writes, but CFS/ME specialist Rachael Rogers at the Oxford long COVID clinic, says the key is careful screening, assessment and individualised treatments.

Respiratory consultant Paul Whitaker, who set up the first long COVID clinic in Yorkshire, says: "For my longstanding patients with long

COVID who fulfil the criteria for CFS they do seem to get worse with strenuous aerobic exercise. However, long COVID is a very diverse group and there are many others who do need an exercise based regimen." Defining which groups will benefit from exercise remains a challenge, he adds.

In a linked commentary, Carolyn Chew-Graham, GP and professor of general practice research and colleagues argue that patients with long COVID are still struggling to get their voices heard above doctors. They believe that this is a form of "structural iatrogenesis," where patients are harmed by power imbalances in the bureaucratic and cultural systems within medicine.

People with long COVID describe feeling "gaslighted" because the opinions of a few have tended to dominate the evolution of treatment, investigation, and a growing knowledge base, they write.

More information: Chronic fatigue syndrome and long covid: moving beyond the controversy, *The BMJ*, DOI: [10.1136/bmj.n1559](https://doi.org/10.1136/bmj.n1559) , www.bmj.com/content/373/bmj.n1559

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