



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

We are representatives from Forward ME which is an advocacy group comprising charities, clinicians, and allied health professionals, led by the Countess of Mar and Carol Monaghan, MP.

Our common goal is to support people with Myalgic Encephalomyelitis (M.E.) and Post-viral fatigue syndrome (PVFS), and to raise awareness among other health care professionals and the wider community.

Post-Covid Syndrome

A diagnosis of M.E. often follows a distinct and prolonged viral infection and a period of post-viral fatigue syndrome.

As you are no doubt aware there has been increasing discussion recently about a similar post-Covid syndrome where people still struggling with symptoms are also known as 'long-haulers.'

This is occurring in a significant minority of people who have survived the initial Covid-19 infection but who continue to experience debilitating symptoms; some of which appear to be unique to Covid-19, while others are remarkably like M.E.

Research has indicated that up to 10% of anyone who contracts a viral infection will experience a post-viral fatigue syndrome¹ and this figure may apply to covid-19 survivors as well.

As you are likely to encounter patients recovering from Covid-19 infection who will fall into this category, we wanted to alert you to the best practice approach to management and rehabilitation.

Post-Covid Rehabilitation

Instead of the usual 'reconditioning', we recommend that these patients should be helped to adopt a paced approach to activity management.

This is used to avoid symptom exacerbation or post exertional malaise, a primary symptom of M.E., which can result in greater incapacity and even relapse. Similar issues also seem present in people struggling to recover from Covid infection.

The ME Association and The Royal College of Occupational Therapists have both published guidance on management and pacing for Post-Covid patients.²⁻⁴

Other strategies that might prove useful include ensuring individualised care and support, adequate rest, sleep, and nutrition. People suffering these lingering symptoms and the symptoms unique to Post-Covid will need appropriate help and ongoing care.

We believe it is possible to draw upon the experiences of patients with M.E. in effectively managing those with post-Covid syndrome. The following podcast features Dr Charles Shepherd from the ME Association and physiotherapists from 'Physios for ME'.

It discusses the rehabilitation needs of patients who are showing signs of post-viral and post-Covid syndrome and M.E.:

<https://www.youtube.com/watch?v=OyFNVayKYCg>



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Graded Exercise Therapy

It is important that patients receive the right care in a timely manner.

We feel it is vital that they do not receive graded exercise therapy (GET) as a matter of course because M.E. research and patient experience has shown it to be ineffective and harmful in many cases. This was highlighted in a survey commissioned by Forward ME and completed by an academic research group from Oxford Brookes University. It found that 80% of people with M.E. reported having adverse events because of GET⁵.

The report concluded, "GET is shown to cause considerable deterioration in physical and mental health". The National Institute of Health and Care Excellence (NICE) issued a statement cautioning against the use of GET in Post-Covid cases and noting that existing recommendations relating to M.E. were under review⁶.

The British Medical Journal (BMJ) also covered this announcement saying that, "Graded exercise therapy may not be appropriate for treating post-viral fatigue in patients recovering from covid-19"⁷.

Abnormal responses to exercise in ME

There is now extensive evidence to show that people with M.E. have abnormal responses to exercise and while we don't yet know if this might apply to post-Covid survivors, it is possible there will be similarities and we would urge caution with any exercise as a precaution.

These abnormalities include reduced maximum heart rate⁸⁻¹⁰, reduced maximum oxygen consumption¹⁰⁻¹², reduced cardiac output^{8,9,13}, insufficient blood pressure increase on exertion^{11,14}, decreased capacity to use oxygen⁸. anaerobic threshold and maximum exercise are reached at much lower oxygen capacity^{10,15}, exhaustion reached more rapidly and accompanied by relatively reduced intracellular concentrations of ATP¹⁶, increased intracellular acidosis in exercising muscles and reduced post-exercise recovery from acidosis^{17,18}.

Also, activation and worsening of symptoms which can be immediate or delayed by several days^{19,20} – when exercise is repeated the next day, abnormalities are more severe²¹ – decreased cognitive functioning and prolonged reaction time²², and a prolonged recovery period – usually 24 hours, often 48 but can last days, weeks or cause a relapse^{8,21,23}.

We hope that the information provided is helpful and we would be grateful if you could disseminate this information to all clinicians and allied health professionals where appropriate.

Yours sincerely,

On behalf of Forward ME



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Further reading and references:

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3. The Royal College of Occupational Therapists free guidance on Post-Covid Syndrome: <https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy>
4. ME Association full range of free leaflets on Covid-19, Post-Covid, and ME: <https://meassociation.org.uk/product-category/covid-19/>



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