



ME and long Covid

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"The term 'long Covid' is commonly used to describe signs and symptoms that continue or develop after acute Covid-19. It includes both ongoing symptomatic Covid-19 (from 4 to 12 weeks) and post-Covid-19 syndrome (12 weeks or more)."

This description is taken from the [National Institute for Health and Care Excellence \(NICE\) rapid guideline for Covid-19: managing the long-term effects of Covid-19](#), first published in December 2020 and most recently updated in January 2024.

Studies suggest that around 10–20% of people infected with SARS-CoV-2 may develop symptoms consistent with a long Covid diagnosis.

However, long Covid currently lacks clear diagnostic criteria and has been linked to over 200 different symptoms.

Some individuals with long Covid experience a form of organ damage (e.g. lung or heart), others experience post-viral fatigue without post-exertional malaise and finally, a sub-set of people experience symptoms that strongly resemble the experience of people with ME.

Findings indicate a significant overlap between long Covid and ME in symptoms like persistent fatigue, cognitive impairment and post-exertional malaise.

A [recent systematic review](#) found that over half of long Covid patients met the diagnostic criteria for ME.

Some [studies](#) have identified common biological mechanisms and gene expression patterns.

A [2023 study](#) found 73 different genes associated with long Covid. Of these identified genes, 9 were also found in genes previously linked to ME in another [analysis](#).

Despite these advances, more research is needed to understand the disease mechanisms of long Covid and the similarities between ME and long Covid.

According to anecdotal evidence, the recovery trajectory for individuals with long Covid varies significantly: some recover relatively quickly, others experience a delayed recovery, and some do not recover or even worsen over time.

This highlights the complexity of the condition.

From years of experience, the ME community knows that managing post-exertional malaise (PEM) with pacing is essential for improving quality of life.

It is therefore recommended for people with long Covid to avoid pushing through symptoms, as overexertion can exacerbate fatigue and other symptoms.

The emergence of long Covid in the last few years has increased the interest in post-infectious conditions, creating more opportunities for funding and studies that could also benefit ME research.

Action for ME is committed to ensuring that this opportunity is not missed, and that ME and long Covid researchers collaborate to secure the investment in research, treatments and care that every individual with ME and their families deserve.

The [World ME Alliance](#) (Action for ME is a founding member) has [written about](#) co-morbidities with ME, including long Covid.

More information and support for people experiencing long Covid can also be found, [here](#).



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