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BMJ WEBINAR

Long covid: How to define it and how to manage it

On 3 September *The BMJ* hosted an online webinar on the diagnosis, management, and prognosis of “long covid.” An expert panel discussed its symptoms, course, and character and suggested strategies for managing it. **Nikki Nabavi** reports

Nikki Nabavi *editorial scholar*

Definition

Panel member Nisreen Alwan ([box 1](#)) began the discussion by defining long covid as “not recovering [for] several weeks or months following the start of symptoms that were suggestive of covid, whether you were tested or not.”

Box 1: The webinar’s expert panel

- Nisreen Alwan—associate professor in public health, University of Southampton, and honorary consultant in public health, University Hospital Southampton NHS Foundation Trust. Has personal experience of long covid
- Paul Garner—professor, Centre for Evidence Synthesis for Global Health, Liverpool School of Tropical Medicine, and coordinating editor, Cochrane Infectious Disease Group. He has personal experience of long covid
- Fiona Godlee—editor in chief, *The BMJ* (chair)
- Trisha Greenhalgh—professor of primary healthcare, Nuffield Department of Primary Care Health Sciences, University of Oxford, and practising GP
- Nick Peters—professor of cardiology, Imperial College London, and consultant cardiologist
- Valentina Puntmann—senior clinical investigator in cardiovascular imaging, University Hospital, Frankfurt
- Tim Spector—professor of genetic epidemiology, King’s College London, and leader of the Covid Symptoms Study

“Profound fatigue” was a common symptom in most people with long covid, she said, but added that a wide range of other symptoms included cough, breathlessness, muscle and body aches, and chest heaviness or pressure, but also skin rashes, palpitations, fever, headache, diarrhoea, and pins and needles. “A very common feature is the relapsing, remitting nature of the illness, where you feel as though you’ve recovered, then it hits you back,” she said.

Nick Peters added to this definition by highlighting a “distinction between very sick people who have recovered to an extent and [and have been] left with some impact of their severe sickness, versus those who had a relatively mild sickness from the start, in whom it is ongoing.”

Alwan described the fluctuations of her own illness: “It’s a constant cycle of disappointment, not just to you but people around you, who really want you to recover.”

Paul Garner, who also has long covid, described it as a “very bizarre disease” that had left him feeling “repeatedly battered the first two months” and then experiencing lesser episodes in the subsequent four months with continual fatigue. “Navigating help is really difficult,” he said.

Tim Spector said that his team at the Covid Symptom Study had identified six clusters of symptoms for covid-19,¹ a couple of which were associated with longer term symptoms, indicating a possible way of predicting early on what might occur. “If you’ve got a persistent cough, hoarse voice, headache, diarrhoea, skipping meals, and shortness of breath in the first week, you are two to three times more likely to get longer term symptoms,” he said.

He said that patterns in the team’s data suggested that long covid was about twice as common in women as in men and that the average age of someone presenting with it was about four years older than people who had what might be termed as “short covid.”

But Spector added, “We do seem to be getting different symptom clusters in different ages, so it could be that there is a different type in younger people compared with the over 65s. As we get more data we should be able to break it into these groups and work out what is going on ... which could be very interesting and help us to get early interventions for those at-risk groups.”

Peters said that the data showed fatigue was the most common trait in people who had symptoms beyond three weeks. He also said that around 80% of people who had symptoms lasting more than three weeks reported “having had clear good days and bad days.”

Cardiovascular effects

Valentina Puntmann, who coauthored a research paper in *JAMA Cardiology* examining the cardiovascular effects in unselected patients with covid-19,² discussed one of the study's findings: the relatively high frequency of postviral or inflammatory myocarditis in people who have had covid-19.

She said, "We were all focusing on the lungs and respiratory symptoms to begin with, but the virus attacks the same receptor that is in the heart too, not just the lungs. Many patients who have had heart failure in the past who have now been very unwell with covid symptoms have sustained arrhythmias, meaning their hearts were beating very fast whilst they were ill, and they then went on to develop heart failure."

"If you have pre-existing cardiac conditions, and cardiomyocytes express the ACE2 receptor that the covid virus likes, you are more likely to develop the cardiac symptoms. Taking ACE inhibitors can be used as a preventive measure."

Puntmann said that the illness was "obviously a huge stress on the heart, particularly for those with pre-existing conditions, which can lead to hypoxia and ischaemia of the heart. The clinical course of covid-19 is also much worse in individuals with a troponin leak."

Management

Alwan explained that as someone with long covid "you learn your patterns, learn what brings on utter exhaustion or the other symptoms, and try to avoid those things."

She added, "I'm fairly driven, and I thought I could beat this virus. A friend told me to stop dominating the virus and start accommodating it. Once you start accepting that, it becomes a bit easier. You have to drop your baseline by 90%; you are a different person."

Trisha Greenhalgh said that although many patients referred to long covid clinics were slowly getting better, some were not and urgently needed referring from primary care.

"It should be a story of gradual improvement, and if it's not, consider referring," she advised. She added, "The interface between the GP and the specialist investigations and monitoring is something we have to work on."

Greenhalgh and Matthew Knight, a respiratory physician who ran a clinic for people recovering from long covid, coauthored a recent *BMJ* article on the management of post-acute covid-19 in primary care.³ A major purpose of the paper, she said, was to reassure GPs that they have the clinical skills to manage these people, such as "listening to the patient, documenting what the symptoms are, how they change and how they fluctuate, and being alert to symptoms that might suggest they need referring."

More broadly, Alwan said that long covid cases should be incorporated into covid-19 statistics. "We are missing a huge opportunity to quantify and measure long covid in the same way that we're doing with positive test results and deaths," she said.

Garner called for research specialists to work together to create better guidance on how to improve investigation in patients with enduring symptoms. "We need rapid interdisciplinary communication," he said.

1 Wise J. Covid-19: Study reveals six clusters of symptoms that could be used as a clinical prediction tool. *BMJ* 2020;370:m2911. doi: 10.1136/bmj.m2911 pmid: 32690476

2 Puntmann VO, Carerj ML, Wieters I, et al. Outcomes of cardiovascular magnetic resonance imaging in patients recently recovered from coronavirus disease 2019 (covid-19). *JAMA Cardiol* 2020. doi: 10.1001/jamacardio.2020.3557. pmid: 32730619

3 Greenhalgh T, Knight M, A'Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care. *BMJ* 2020;370:m3026. doi: 10.1136/bmj.m3026 pmid: 32784198