Covid-19: What do we know about “long covid”?

As recognition grows that many patients have long lasting effects, Elisabeth Mahase examines the evidence and the response

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What is it?

“Long covid” is a term being used to describe illness in people who have either recovered from covid-19 but are still reporting lasting effects of the infection or have had the usual symptoms for far longer than would be expected. Many people, including doctors who have been infected, have shared their anecdotal experiences on social media, in the traditional media, and through patients’ groups.

Paul Garner, professor of infectious diseases at Liverpool School of Tropical Medicine, detailed his seven week experience with the virus for BMJ Opinion, describing it as “frightening and long.” As with many of the accounts being shared, Garner was not admitted to hospital, but he reported a long list of symptoms lasting weeks and leaving him feeling unable to function.

The Royal College of General Practitioners says it expects GPs to see an influx of patients with “long covid” and has called for a rapid review of the requirements for returning GPs to see whether the streamlined approach introduced during the pandemic can be maintained. Its chair, Martin Marshall, says, “The pressures in general practice prior to the pandemic have been well documented, but we are now gearing up for the wave of new pressures coming our way as a direct result of covid-19.

“There will be a significant influx of patients with lingering ‘long covid’ illness, both physical and emotional, and GPs must have the necessary resources and support to care for patients and help them come to terms with and readjust to the aftermath.”

What does the evidence say?

Aside from anecdotal evidence, there is as yet little research on this issue. However, it is being actively discussed within the research community. Writing in JAMA, a team of researchers from Italy reported that nearly nine in 10 patients (87%) discharged from a Rome hospital after recovering from covid-19 were still experiencing at least one symptom 60 days after onset. They found that 13% of the 143 people were completely free of any symptoms, while 32% had one or two symptoms, and 55% had three or more.

Although none of the patients had fever or any signs or symptoms of acute illness, many still reported fatigue (53%), dyspnoea (43%), joint pain (27%), and chest pain (22%). Two fifths of patients reported a worsened quality of life.

Meanwhile, the team behind the UK Covid-19 Symptom Study app, which collects symptom information from nearly four million users, says their data show that one in 10 people with covid-19 are sick for three weeks or more. The team said, “Most health sources suggest that people will recover within two weeks or so. But it’s becoming increasingly clear that this isn’t the case for everyone infected with coronavirus.” The app was developed by the health science company ZOE, and the data are being analysed in collaboration with researchers at King’s College London.

Are there any support services for affected people?

NHS England is set to launch an online portal later this month where people who are suffering long term effects of covid-19 (not just patients who were admitted to hospital) can communicate with nurses, physiotherapists, and mental health specialists. The service will give people access to a local clinical team that will respond to inquiries and to an online peer support community, exercise tutorials, and mental health support.

“Evidence shows that many of those survivors are likely to have significant ongoing health problems, including breathing difficulties, enduring tiredness, reduced muscle function, impaired ability to perform vital everyday tasks, and mental health problems such as post-traumatic stress disorder, anxiety, and depression,” NHS England’s announcement said. Later in the summer, it said, the service will make personalised packages of support available, although access to these will require a face to face assessment. People without online access will be provided with printed materials, “depending on demand.”

Patients’ groups are also providing peer support, and one such group on Facebook called the “Long Covid Support Group” already has more than 7000 members. This group is calling for “proper rehab, research, and recognition.” The hashtag “longcovid” is being used on social media to share personal experiences.

What more is needed?

SARS-CoV-2 is a very novel virus, only reportedly appearing in the human population at the end of 2019, which means there is still much that the medical and wider research community do not know. To solve this, well conducted long term research is needed. A new study to assess the long term effects of covid-9 on hospital patients was announced on 5 July by the health and social care secretary for England, Matt Hancock. The Post-hospitalisation COVID-19 Study (PHOSP-COVID) aims to recruit 10 000 patients across the UK, who will be followed for more than a year.
The study is being run by the University Hospitals of Leicester NHS Trust and has been funded by the Medical Research Council, UK Research and Innovation, and the National Institute for Health Research. However, since it does not include milder cases that do not require hospital care, it will exclude many patients with stories like Garner’s.

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1 Garner P. For 7 weeks I have been through a roller coaster of ill health, extreme emotions, and utter exhaustion. BMJ Opinion. 5 May 2020. https://blogs.bmj.com/bmj/2020/05/05/paul-garner-people-who-have-a-more-protracted-illness-need-help-to-understand-and-cope-with-the-constantly-shifting-bizarre-symptoms.