



## Media Briefing Guide

We welcome media coverage that shines a light on people experiencing Long Covid and helps us achieve our objectives:

- Secure rehab, research and recognition for people with Long Covid
- Ensure there is no discrimination on the basis of test results or hospital admission
- Avoid being labelled with existing terms until more is known
- Help others find us by referring to the website where appropriate
- Ensure consultation with those with lived experience of Long Covid in the design of research, rehabilitation and/or treatment (“nothing about us, without us”)

### **Help us to secure rehab, research and recognition for people with Long Covid**

Researchers behind the Covid Symptom Study app estimate that 250,000 people in the UK have symptoms of Covid-19 for a month or more<sup>1</sup>.

We welcome announcements to put in place support for people experiencing prolonged, debilitating and often alarming symptoms, but it is early days and we need to ensure that the large numbers of people experiencing Long Covid are able to access proper care and support, wherever they live. It is also crucial that employers and society more generally are aware of the scale and impact of Long Covid. In short, we are calling for rehab, research and recognition.

### **Help us ensure there is no discrimination on the basis of test results or whether admitted to hospital**

It is vital that there is no discrimination for those who were never offered a test or who were tested far too late for the test to have a chance of being effective. Timing of tests is important, and even then there is a high rate of false negatives. There are difficulties with antibody tests too, as some people do not make antibodies, it is unclear how long they last, and there are issues with the sensitivities of the tests. It is a complex area, but in summary it is clear that negative results are not sufficient to exclude a current or previous infection with SARS-CoV2.

Even people who weren't hospitalised have been incapacitated for months with debilitating and frightening symptoms. Indeed, some are taking longer to recover than those who were admitted to hospital (even ITU).

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<sup>1</sup> <https://twitter.com/PaulGarnerWoof/status/1280420058444042240?s=20>  
<https://sg.news.yahoo.com/long-tail-coronavirus-prolong-suffering-months-110830077.html>

## **Use the Long Covid term to avoid us being labelled with existing terms until more is known**

We are keen that people keep an open mind about what is occurring in those with persisting symptoms of Covid-19, and so we are trying to avoid the use of existing terms (e.g. post viral fatigue or ME/chronic fatigue syndrome) until more is known. Learnings from other communities may have relevance to Long Covid, but it is important that persisting symptoms of Covid-19 have research of their own. We hope that research into Long Covid may also be of help to those affected with other chronic conditions.

While some medical professionals may understand that PVF (post viral fatigue) can encompass more than fatigue, use of this term may alter the perception of the range and severity of symptoms in the eyes of the public and, importantly, employers. People may experience symptoms that have persisted since the outset of their illness, other symptoms may emerge many weeks or months later, and many people experience a relapsing-remitting pattern. For this reason we are trying to avoid the prefix of “post-” until further research has been completed.

Symptoms are diverse and can span respiratory, cardiovascular, neurological, dermatological or renal issues, some of which can be serious (e.g. strokes, pulmonary embolisms). Some of us don't have fatigue at all. We are keen that people align around the term Long Covid, as this keeps things open.

## **Help others find us by referring to the website where appropriate**

Our LongCovid.org website is a useful landing point for people, whether or not they are users of social media, and includes links to the Facebook group, free-to-use visual assets and a contact email, as well as other useful information.

Including mention of the website will also allow researchers and others to get in touch, helping us to ensure consultation with those with lived experience of Long Covid in the design of research, rehabilitation and/or treatment (“nothing about us, without us”).