

To whom it may concern,

This letter was formulated by UK doctors with Long Covid. You are receiving this letter because the patient (or service user) suspect they have **Long Covid** and need help:

- 1) They may have difficulty advocating for themselves in isolation, possibly because of the severity of their symptoms or a previous healthcare experience.
- 2) A longer assessment may be needed as this is generally a complex, multi-system illness. Access to local Long Covid clinics may not be available or the resources/referral pathways available to them, if they do exist, may be limited. The research around Long Covid is still evolving.
- 3) This letter will signpost some resources and tips.

Diagnosis of COVID-19 is clinical

COVID-19 case definitions do not rely on testing, but **clinical** and **epidemiological** criteria (1,2). A **negative test does not rule out** COVID-19. In the case of a negative SARS-CoV-2 PCR test, the sensitivity of PCR could be as low as 60% but at best is 78% (3). Please also keep in mind that an antibody response may not develop in the first place and that the duration of the antibody response is unknown (4–6).

SNOMED-CT code: 1325161000000102 Post-COVID-19 syndrome (disorder) - GB/UK

Useful Resources

There are resources being gathered on this wiki here by verified UK doctors on SARS-COV-2, COVID-19 and Long Covid which are useful to healthcare professionals. It remains in development but there are many useful links including relevant guidelines and patient information leaflets:

- Main page: <https://ukdoctorslongcovid.miraheze.org/>
- LC presentation: https://ukdoctorslongcovid.miraheze.org/wiki/Long_COVID:_presentation
- LC management: https://ukdoctorslongcovid.miraheze.org/wiki/Management_of_Long_COVID

Tips

- Listen and believe this individual about what they are describing and its severity (7). Be aware and then place your unconscious and cognitive biases aside about what a person with Long Covid looks like (8,9).
- Long Covid is often complex and can warrant the input of multiple teams, disciplines and referrals (please see the Long Covid wiki). Threatening pathology can exist with **delayed onset or delayed diagnosis** including in patients who were not hospitalised e.g. myocarditis, PE (10,11). Over reliance on scoring criteria not specifically validated in COVID-19/Long Covid may be misleading or falsely reassuring and lead to misdiagnosis, e.g. one study in COVID-19 patients showed no statistical difference in the Wells score between PE and no PE (12). Psychological input may be necessary and helpful but avoid giving your patient the impression you believe this is psychogenic in aetiology.
- **Graded exercise therapy is not recommended** for fatigue/post-exertional malaise (13–15); pushing beyond the energy envelope causes significant distress and is a trigger for relapse. This is not the same intervention as exercising *within* the energy envelope.

- **Right to Choice:** Especially at the point of referral, please explain to the person their legal rights or otherwise under the NHS Choice Framework as they apply to your devolved authority. All should consider the team's familiarity and management approach with Long Covid when discussing the referral (16).
- **Fit note:** When issuing a statement on fitness to work, with appropriate discussion, it is better to make a reference to Long Covid (or your terminology of choice but this should explicitly state the pathology as related to COVID-19) so that the person with Long Covid can access special entitlements and discuss occupational concerns, including occupational support.

You are likely in the majority of healthcare professionals going the extra mile to do a great job. Your care in looking after this individual is very much appreciated by them but also the Long Covid community.

Yours sincerely,

The undersigned are doctors who also have lived experience of Long Covid.

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