

03 July 2020

Urgent SOS from LongCovid sufferers

To:

Rt Hon Boris Johnson MP, Prime Minister

Rt Hon Matt Hancock MP, Secretary of State for Health and Social Care

Prof Chris Whitty, Chief Medical Officer for England, UK Government Chief Medical Adviser

Dr Patrick Vallance, UK Government Chief Scientific Adviser

Mr Simon Stevens, Chief Executive Officer NHS England

John Connaghan CBE, Chief Executive NHS Scotland

Mr Andrew Goodall, Chief Executive NHS Wales

Mrs Valerie Watts, Chief Executive of The Health and Social Care Board for Northern Ireland

Mr Duncan Selbie, Chief Executive Public Health England

We are writing on behalf of thousands of forgotten victims of Covid-19 who have been sick since the early days of the outbreak. They are struggling to get help from the medical community for their continuing disease and feel abandoned by the government.

The Covid-19 pandemic is estimated by the ONS to have infected around 7% of the UK population [1], [2] or approximately 4.6 million people; other studies suggest that the proportion infected could be as high as 25% [3]. In the early stages of the UK epidemic, government briefings and press reports were focussed on those who had severe symptoms and were at risk of being admitted to intensive care. People who had what were described as 'mild' symptoms were advised to stay in place and only present to hospital if their condition became critical. As a result, a significant number of sufferers battled with their symptoms at home, relying on advice from 111 which was not always helpful.

Throughout this period the general public have been assured by government and public health sources that most 'mild' or 'moderate' cases, not requiring hospital admission, resolve within two weeks. However, it is becoming increasingly clear that for many this is far from the case. Analysis from the COVID Symptom Study recently suggested that as many as one in ten people with Covid-19 are sick for three weeks or more [4] and reports in the press are starting to emerge describing a pattern of illness experienced by many which is completely at odds with the prevailing view about this virus.

This is a novel disease; we acknowledge that it is far from being fully understood and that doctors are therefore on a steep learning curve and may have scant information. Nevertheless, there exist in the UK many thousands of people who have contracted Covid-19 and continue to suffer an array of debilitating symptoms, many of which can be severe and frightening, persisting for weeks or months.

Research into this cohort has so far been limited; many in the UK will not have had access to a swab test during the early stages of their illness due to the decision by the government to halt testing and tracing in the community. It is becoming apparent that a substantial proportion of long-term patients do not test positive for IgG antibodies [5], [6] leading to the possibility that most may not meet the inclusion criteria for clinical trials. At present there is no certainty whether long-term sufferers are still infected with remnants of the virus in their organs, vascular or neurological systems – prompting fears about chronic Covid-19 disease - or if the continuing symptoms are an excessive immune response, raising the spectre of a chronic auto-immune condition.

Despite the lack of comprehensive data, it is clear from the testimonies of the many thousands who have turned to online forums and support groups that not only were most of them healthy before they contracted the virus, large numbers were extremely fit. A shocking lack of attention has been paid to this significant group of people of all ages, and many sufferers feel badly let down by the medical establishment. Unfortunately, numerous people who have been infected with Covid-19 are being told that they are suffering from anxiety, and diagnoses of post viral syndrome/fatigue are frequently handed out when the range of symptoms suggest otherwise. Countless sufferers are forced to return to work, risking serious consequences for their recovery. An assumption that patients are no longer infected could have major implications for public health. Some GP's are honest enough to admit they do not have the tools to help their patients and that they themselves need to consult the media for information.

There appears to be very little focus on the part of government on the ongoing very poor health of potentially hundreds of thousands of people. It is imperative that the needs of this group are addressed, and sufferers given the support they need. Not only is this a calamity for each individual, it is a serious matter for an economy which is already facing an existential struggle: large numbers on long-term sick leave will significantly impact the workforce as it emerges from furlough. Wide-ranging research into the mechanism of disease in long-term Covid-19 patients needs to be initiated urgently to identify potential therapies and to establish how many people are affected. Protocols and care pathways must be drawn up and multi-disciplinary clinics established without delay throughout the country to enable them to have the best chances of recovery. Primary care physicians need to be kept up to date with the latest research and given the right information in order to care for their patients and treat them appropriately.

This situation cannot be allowed to persist; should the UK suffer a second wave of infections the numbers in this cohort will grow considerably. The impact of continuing inaction could be catastrophic.

To summarise, we ask for the needs of these individuals to be addressed by

1. The establishment of a working group to investigate long-term Covid-19, headed up by a designated medical professional who will be responsible for implementing the following strategies:
2. The commissioning of urgent research into long-term Covid-19 disease in order to investigate its causes and identify a range of interventions to treat patients
3. The development of protocols and care pathways to ensure that all practitioners are empowered to treat long-term Covid-19 patients appropriately
4. The creation of multi-disciplinary clinics in all parts of the UK for the assessment, testing, diagnosis and care of long-term Covid-19 patients
5. Consideration of the economic implications, including making provision for long-term sick leave, financial support and taking steps to ensure employers are made fully aware of this situation

Signed

For longcovidSOS

Sandra Edwards
Ondine Sherwood
Layth Hishmeh
Frances Simpson
Caroline Eccles

And 1000+ others

References

- [1] Office for National Statistics, "Coronavirus (COVID-19) Infection Survey pilot: 28 May 2020," London, 2020.
- [2] P. Roxby, "About 7% have had coronavirus, says ONS survey," *BBC News*, 2020. .
- [3] Michael Addelman, "'Over 25% of the UK likely to have had COVID-19 already,'" *The University of Manchester*, 2020. [Online]. Available: <https://www.manchester.ac.uk/discover/news/over-25-of-the-uk-likely-to-have-had-covid-19-already/>. [Accessed: 18-Jun-2020].
- [4] COVID Symptom Study, "How long does COVID-19 last?," 2020. [Online]. Available: <https://covid.joinzoe.com/post/covid-long-term>. [Accessed: 18-Jun-2020].
- [5] Archyde, "Most Covid cases are not found with antibody tests," 2020. [Online]. Available: <https://www.archyde.com/most-covid-cases-are-not-found-with-antibody-tests/>. [Accessed: 18-Jun-2020].
- [6] W. A. Haseltine, "The Way That Covid-19 Tricks The Immune System Could Result In More Severe Illness," *Forbes*. [Online]. Available: <https://www.forbes.com/sites/williamhaseltine/2020/05/27/a-nasty-trick-in-the-covid-repertoire/#1c185b5a69e6>. [Accessed: 20-Jun-2020].