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The needs of patients with long covid must not be ignored

Members of Long Covid SOS write an open letter to the new secretary of state for health and social care

The covid-19 pandemic continues to have an impact on the nation's health. It is encouraging that deaths are now at a comparatively low level, but sadly morbidity as a result of SARS-CoV-2 affects a large number of people, many of whom are effectively disabled and unable to work and live a normal life. The Office for National Statistics estimates that two million people in the United Kingdom have long covid, of whom 384 000 are severely affected. One startling statistic is that more than 2% of 35-49 year olds in the UK have had long covid for more than a year: equivalent to around 266 000 people out of a total of nearly 900 000 in their prime working years with long covid.

With so many people of working age affected, this widespread health burden falls on both the NHS and the economy. NHS England has been ahead of the curve in setting up clinics to treat people with long covid, but at present there are no validated treatments, no prospect of a cure, and the best that can be offered is symptom relief. Moreover, the clinics are accepting no more than 5000 new referrals each month. NHS England's stated priority is "to ensure that those with the most clinically urgent needs are diagnosed and treated rapidly": at this rate it will take more than five years for those currently most severely affected in England to be seen.

The impact on the economy is already being felt. The numbers of workers neither employed nor seeking work due to long term sickness have been rising throughout the pandemic and the Bank of England highlighted the contribution long covid has made towards an estimated 440 000 missing workers. More than 10 000 long term absences among NHS staff are covid related. The Institute for Fiscal Studies recently reported that 110 000 workers are on sick leave due to long covid—but these are the ones lucky enough not to have lost their jobs.

Numerous people with long covid find themselves in a catastrophic situation whereby they are unable to work and support their families, and some are being forced to sell their homes. Social care, healthcare, and education are the sectors most affected: in these cases the probability that covid-19 was contracted at work is high yet the condition has not been classified as an occupational disease and many are left with no compensation as a result.

Although daily covid-19 infections are dropping they remain significant with around one in 75 people in the UK infected as of 16 September 2022. The problem of long covid is not likely to go away for some time.

We urge you to prioritise the needs of this group of people, many of whom are essential workers, carers, parents, and children. Long covid is the "pandemic after the pandemic" and cannot be ignored.

We ask you to:

- Increase dedicated funding for the NHS, including general practitioners, so that more people can be seen and helped to deal with what is, for many, a life altering condition.
- Enable the National Institute for Health and Care Research to fund more urgent research into post covid-19 sequalae so that effective treatments can be rapidly identified and approved, enabling people to rejoin society and contribute to the economy. Ongoing data monitoring and risk management are also crucial to understand and mitigate the impact of long covid.
- Help people who cannot work: recognise that long covid is an occupational disease, that a proportion are disabled, and improve links between the departments of Health and Social Care and Work and Pensions so that those affected can receive the compensation and benefits they deserve. Those able to return to work, especially in public service, should be offered support so that they can do so safely.
- Improve covid safety measures in public indoor places such as schools so that transmission can be limited over the coming months.

Competing interests: OS is a member of the NHSE national long covid Taskforce, a member of the NIHR Expert Group on Long Covid and on the steering committee for the STIMULATE-ICP study. AB has received grant funding from AstraZeneca, NIHR, UKRI, European Union, and the British Medical Association. He is PI of the STIMULATE-ICP study (https://www.stimulate-icp.org/). He is also a trustee of the South Asian Health Foundation. None further declared.

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