

July 8th, 2021

Sajid Javid MP
House of Commons
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Dear Secretary of State,

Congratulations on your appointment. You have assumed your new role at a pivotal moment in the pandemic, and have an opportunity to act now to prevent further suffering.

We trust you are aware of recent estimates from the [REACT-2](#) study of 2 million people affected by Long Covid. It concerns us that Long Covid has been mischaracterised in parts of the media as mild, lingering symptoms and that this has led to a minimisation of the health and economic ramifications. [Research](#) shows that there are [over two hundred symptoms](#) in multiple systems of the body up to and including potentially permanent organ damage. This leads to immense physical suffering and disability.

Long Covid Support is a peer support group of 42,000 people living with Long Covid, and membership continues to grow at pace. Regardless of the severity of their initial illness, many of our members have been incapacitated and unable to undertake their work, education or caring responsibilities for more than a year, with no prognosis. When evaluating policy we urge you to take account of the devastating and prolonged impact that Long Covid can have on people of all ages, and the resulting impact on the country's productivity and economic prosperity. We therefore urge you to:

Support those living with Long Covid

We welcome the investment announced to date, but emphasise the need to address significant concerns in relation to patient safety on account of inconsistent, inequitable and inadequate access to services. There is [evidence of serious pathology](#) being detected even more than a year post symptom onset in the small proportion of those who have been able to access the appropriate specialist investigations, raising the question of the number of people with undiagnosed serious conditions. Patients are receiving advice, for example about physical exercise, which is [not appropriate in all circumstances](#) and potentially unsafe, and many are [self-administering potentially harmful treatments](#) or combinations of treatments without medical supervision, in the absence of adequate support from formal services.

Our urgent recommendations are as follows:

- **Expand service provision to enable inclusive and equitable access** to assessment, treatment and rehabilitation at the earliest opportunity to maximise chances of recovery and resuming work, education and/or caring responsibilities. Currently Long Covid clinics are not available in the devolved nations, and our most recent [survey](#) indicates that only half of patients in England seeking referral are successful. Some clinics are refusing to see patients before they have been ill for a certain amount of time - counter to the NICE guideline - as a means of managing capacity. We hope the newly announced investment will help, but also that our results can be used to drive and support improvements. We will continue to monitor the experiences of our members in England to evaluate this.

- **Count Long Covid to better plan health and social care support:** Many doctors are [not applying the SNOMED code](#) for Long Covid, and coding is not applied retrospectively. Digital health records are often incomplete, not joined up, or not associated with Long Covid. We call for the establishment of a patient registry that would also serve to follow up any potential longer term consequences of Covid-19. Despite the [ONS](#) estimating 741,000 people in England up to 2 May were experiencing symptoms of at least 12 weeks' duration, the NHS England 10 point plan estimated only 342,000 would need NHS support.
- **Support NHS staff with returning to work:** Many caught Covid-19, and have gone on to develop Long Covid. A significant number are either unable to work at all or to their previous capacity, or are working, unsustainably, while still ill, reducing the health of an already stretched workforce. More and more of our members report losing their jobs with NHS Trusts due to Long Covid. Yet there are skills shortages; 35,000 unfilled nursing roles within NHS England alone. We assert that it is not only possible, but essential, to retain and rehabilitate staff, through appropriate occupational intervention, workplace adaptations and flexibility within the NHS. Greater access to effective measures such as extended phased returns, occupational health and vocational rehabilitation support would cost less than the significantly greater economic burden of chronic ill health, unemployment and the loss of skilled workforce. The government has devoted large amounts of money to keeping businesses afloat and to preserving viable jobs. Preserving the health of the workforce is of equal importance in limiting longer-term costs and contributing to economic growth.

Prevent further people being affected by Long Covid

Findings of government funded and other studies of Long Covid serve as grave warnings of the need to prevent further cases:

[REACT-2](#), Imperial: Almost one in five people reported having had COVID-19, either suspected or confirmed by PCR test, **"one-third of whom reported persistent symptoms at 12 weeks"**.

[ONS](#): 385,000 (40.0%) [of people still living with Long Covid] first had (or suspected they had) COVID-19 **at least one year** previously. Symptoms adversely affected the day-to-day activities of 634,000 people (65.9% of those with self-reported long COVID), with 178,000 **(18.5%) reporting that their ability to undertake their day-to-day activities had been "limited a lot"**.

In your own words you stated that Covid cases could soon rise to above 100,000 per day, which would suggest at least 30,000 new cases of Long Covid per day. It is likely that children and young working age people will be disproportionately affected, as will frontline workers. Long Covid already disproportionately impacts those of lower socioeconomic status and inequality gaps are likely to widen. We are pleased that vaccines have currently weakened the link between hospitalisations and deaths, but they do not necessarily protect against Long Covid; Tim Spector of the Zoe Covid Symptom study, states that [double vaccination reduces the chances of developing Long Covid by only 30%](#). Vaccinations may protect you from having severe acute disease but they do not necessarily prevent you from having [Long Covid](#).

The government has announced plans to lift restrictions, however there are measures that could allow greater freedoms while also minimising further transmission, disability and death, as well as disruption to the economy and education. The only way to prevent Long Covid is to prevent initial infection with SARS-CoV-2.

Our urgent recommendations are as follows:

- **Communicate an updated list of acute symptoms of Covid-19** in both adults and children to allow people to apply for PCR tests and to prevent unwitting spread, including taking account of the differing presentations of the Delta and new variants (e.g. Lambda).

- **Recognise that children and young people develop Long Covid.** If you expect a peak of c.100,000 infections per day, many of which will be among young people, it follows that tens of thousands of children and young people will develop Long Covid. This is an accumulative burden, considering many children and young people have not recovered from the first wave. As stated this week by the Chief Medical Officer, '[I think we will get a significant amount more Long Covid, particularly in the younger ages where the vaccination rates are much lower.](#)'
- **Continue to publish daily reports of Covid-19 statistics, and include reference to Long Covid:** Long Covid is rarely mentioned in public messaging relating to the pandemic. Raising awareness of this will encourage vaccine uptake, safe behaviours and avoid the negative impact that serious long-term illness can have.
- **Require the use of [appropriate PPE](#) for all health and care staff** working with patients with confirmed or suspected Covid-19. Surgical masks provide inadequate protection.
- **Reinstate the advice for face coverings to be worn in schools,** given the rapid increase in infection rates of the Delta variant and the disproportionate rise in school-aged children causing community transmissions, missed school due to self-isolation, and further Long Covid cases in children.
- **Provide grants for equipment to improve ventilation and air quality** in schools, healthcare settings, public transport, workplaces, and arts/leisure venues. The school holidays provide a valuable opportunity for such equipment to be installed.
- **Offer vaccination to children and ensure that higher education students are fully vaccinated by September,** with the aim of reducing individual risk, as well as that of communities and wider society, and educational disruption.
- **Provide adequate and flexible financial and occupational support, in conjunction with employers,** to allow people with Covid-19 to self-isolate and then stay at home until they fully recover, to prevent progression to Long Covid through a premature return to work due to financial pressures.

The primary focus within government policy on hospitalisations and deaths has created a blindspot with regard to those who survived COVID-19 yet remain unrecovered. People affected by Long Covid require multidisciplinary support from both primary and secondary care services. In view of the alarming statistics of the prevalence, persistence and impact on function of Long Covid published by the ONS, Imperial's REACT-2 study and others, there is an urgent need to factor Long Covid into policy, to avoid further moral and economic cost of the mass disabling of people of all ages.

Long Covid is a threat to the long-term health of the nation. A significant proportion of people who have not yet been infected are destined to suffer the long-term consequences of SARS-CoV-2; those who already have Long Covid are not being adequately supported and are at risk of reinfection. In your role as Secretary of State for Health and Social Care the nation looks to you to protect the health of citizens. You have the power to prevent new cases of Long Covid through suppression of the virus, and to make changes to help existing cases. We implore you to do everything in your power to do both.

Long Covid Support

Christina Barrett, Joanna Clynes, Karen Cook, Maddy Corper, Jo Dainow, Sophie Evans, Louise Fairbrother, Claire Hastie, Monique Jackson, Francesca Lo Castro, Lesley MacNiven, Margaret O'Hara, Clare Rayner, Natalie Rogers, Nikki Smith, Polina Sparks, Cathy Thomson

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