

From: claire.hastie@longcovid.org

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**Subject: Urgent: Long Covid Hearing and Commons Debate**

Dear Member of Parliament,

**Long Covid Hearing and Commons Debate**

I am writing to urge you to participate in the Commons debate on Long Covid, scheduled for January 14th, as well as the APPG on Coronavirus oral hearing about Long Covid among health professionals on Tuesday 12th from 11:30am-1:00pm.

I founded the Long Covid Support Group on Facebook, with 33,000 members and growing. Long Covid is a huge problem, with large numbers of people of all ages (including children) incapacitated for months with alarming and evolving symptoms; many of our members were previously healthy and fit.

I outline below some key points to highlight the importance of supporting people with Long Covid, and of preventing others from experiencing its life changing effects.

**Long Covid affects vast numbers of people, and has a significant impact on people's lives and ability to work**

- According to initial ONS data, at least 10% of people testing positive for Covid-19 experience symptoms that last for 12 weeks or more.  
<https://www.ons.gov.uk/news/statementsandletters/theprevalenceoflongcovidssymptomsandcovid19complications>
- Almost 70% of people with Long Covid who fell ill prior to June are not working or working reduced hours on account of their health, even after 7 months.  
<https://twitter.com/athenaakrami/status/1343166511842787328?s=21>
- Members of our group have had life changing effects from Long Covid. They are losing their livelihoods, struggling to access benefits, and are experiencing significant mental health issues among their painful and frightening symptoms. Many - even those who were not hospitalised - have had experiences when they thought they might die.  
<https://www.longcovid.org/stories>

**We could do more to prevent Long Covid**

- Make Long Covid part of the narrative:  
Bring Long Covid into the public consciousness via platforms such as the Covid briefings and news reports to encourage compliance with public health measures. When reporting the numbers of cases, we suggest including a phrase such as '...an estimated 10% of which are likely to experience the debilitating symptoms of Long Covid for 3 months or more'.
- Communicate the diversity of symptoms:  
Symptoms are so diverse and poorly communicated that many are unaware that they have Covid or Long Covid, with obvious risks to public health. We urgently need to make people

aware that many people do not experience the three symptoms recognised by the NHS of fever, cough and loss of smell and taste. Instead, people should be encouraged to seek tests if they experience any unusual symptoms. We ran an ad campaign on social media in the summer that sought to highlight this.

[https://twitter.com/long\\_covid/status/1291774134385545221?s=20](https://twitter.com/long_covid/status/1291774134385545221?s=20)

- Evaluate the merits of early intervention (for example with antiviral medications) ahead of vaccine rollout:  
Research from Hong Kong indicates that early intervention with antivirals may prevent Long Covid, a route that perhaps ought to be explored while the vaccine is rolled out. Professor Hung's presentation begins at 1:22 in the link, he talks about antiviral treatment at 1:29 and provides more detail in the Q&A at 2:03. <https://www.youtube.com/watch?v=LmjJ2yuhT-o&feature=youtu.be>

#### **We welcome initial steps to support people with Long Covid, but more needs to be done**

- People with Long Covid should be included on the clinically vulnerable list for vaccines as we were clearly extremely vulnerable to the disease the first time and are likely to be so again - potentially more so, given our weakened condition.
- The NICE guideline on Long Covid is welcome, but we are concerned about shortcomings and potential detriment to patients from the current version.  
[https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(20\)32705-7/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(20)32705-7/fulltext)
- We are pleased about the recent announcement in relation to Covid clinics in England, but our members are reporting mixed experiences of these, to the extent they've been able to access them, and members in the devolved nations are struggling to access support.
- The £10m invested in England to date is little more than symbolic. There is  
<https://www.google.co.uk/amp/s/inews.co.uk/news/real-life/long-covid-clinics-coronavirus-locations-symptoms-months-795388/amp>
- It is good news that the NIHR has called for applications for funding research into Long Covid patients who were not hospitalised. The threshold for admission has at times been extremely high; large numbers of our Facebook group members report having visited A&E multiple times with red flag symptoms (as identified by 111) yet were sent home. Many of those who were not admitted to hospital have experienced frightening episodes from which they were surprised to wake, and it is not unusual to be taking longer to recover than those who were hospitalised.
- People with Long Covid need support in returning to work, and employers need more information relating to Long Covid and the debilitating effects it can have. Those no longer able to work need advice from the DWP and to be able to access disability benefits.

#### **Patient groups like the Long Covid Support Group play a vital role**

- Members of our Long Covid Support Group on Facebook tell us it is an absolute lifeline as a source of information, compassion and support, and a huge help to mental health. In our tightly moderated private group, in which every post is approved by our team of volunteers who work tirelessly across time zones, our 33,000 members have a safe space to confide in and support others, and often share concerns that they do not feel able to share with family or friends. Our regular online gatherings are a further source of comfort, particularly to those experiencing social isolation.

- Outside of the group, we have been highly active in the mainstream media as well as on social media in our efforts to raise awareness of Long Covid. We also collaborate with multiple research teams, helping to shape studies through patient involvement (including as co-applicants for funding). In December we were delighted to work with ISARIC and GloPID-R to organise the Long Covid Forum research conference, at which Director General of the WHO Dr Tedros spoke. <https://isaric.org/event/long-covid-joint-research-forum-virtual-events-9-10-december-2020/>
- Our group in turn needs support in order to continue with our advocacy model.

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I hope this letter has convinced you of the importance of attending next week's APPG hearing and Commons debate on Long Covid. I would be very happy to provide more information if that would be helpful, and trust that people with Long Covid can count on your support to help them access help.

Best wishes,

Claire Hastie