



Long Covid Support Group  
[www.longcovid.org/](http://www.longcovid.org/)

Rt Hon Jeremy Hunt  
Chair, UK Health and Social Care Committee

28 August 2020

Dear Mr Hunt

We are writing - as British citizens living with Long Covid - to ask your Committee to ensure that the UK government *sets up a multi-disciplinary Long Covid taskforce*, including researchers, professional bodies, and representatives of peer-led groups, to address the urgent needs of people living with persistent, ongoing symptoms of COVID-19, generally known as Long Covid, including the six actions we highlight below.

The peer-led groups that we belong to were founded in the UK - one of the countries that experienced a major epidemic early on - and they bring together thousands of long-term survivors living with Long Covid. The UK-based Long Covid Support group was founded on May 2, 2020 to provide peer support and to share information amongst people experiencing ongoing symptoms of COVID-19. We are now among the largest in the world with over 19,000 members - and with people now joining from a range of countries. This is just a fraction of the estimated 500,000 people in the UK already living with Long Covid, and the many more expected to become ill with subsequent waves of infection.

We are grateful to the Health and Social Care committee for shining a light on the failures in the UK's response to COVID-19 and pressing for better responses by our government. Many of us bear witness to those failures having become ill because the right action was not taken at the right time; we were poorly informed and poorly supported. A large number of us served on the front line of the response to COVID-19, many of us in the earliest days of the pandemic. Our persistent, ongoing health challenges are distressing not only because they were avoidable, but also because far too many of our peers in the health and social care sectors are failing to respond with the care and support that we desperately need, because they do not have the information they need to provide the right responses now. Sadly too many of our UK members are reporting experiences of extremely poor, uninformed and dismissive responses from professionals in health and care sectors when we turn to them for help. This is not the fault of individuals, rather that the systems are failing us - when we try to access health care, social care and benefits - often because there is inadequate awareness about the thousands of us who have not received a positive test result or been hospitalised (research from Prof Spector's group shows that 12% of people have COVID-19 symptoms

after one month; the Dutch Lung Foundation research of 1600 people showed that 91% of people with Long Covid were never hospitalised, yet often experience as many and often more severe symptoms as those who were).

Most of us are experiencing real challenges with employment and support structures which do not meet our needs. We need better action by government so that there is better economic support and social safety nets, and to help employers to understand why many of us need more time to recover and recuperate, with staged returns to work and an appreciation of the relapses and resurgence of symptoms (especially shortness of breath, chest pain and fatigue) that many of us face. Many of us who are health and social care workers are struggling to return to work in a way that lets us recover well and continue to serve the NHS which (like all employers) needs to make reasonable accommodation for its staff who are facing Long Covid. We look to the NHS to be a beacon of good practice as an employer - especially given the circumstances of our illnesses.

We have given extensive evidence to the All Party Parliamentary Group (APPG) on Coronavirus and applaud them for their report. Much of this evidence draws on the peer-led discussions about many aspects of living with Long Covid including the symptoms that many of us experience. Through our connections with each other, we share tips of how to manage the unexpected multiple ways in which our bodies continue to struggle many months after our initial acute infections, yet we lack any reliable access to services. There are some encouraging steps - such as the recent launch of the NHS 'Your Covid Recovery' website and the £8.4 million investment in the PHOSP-COVID study - but these are focused on people who were previously admitted to hospital, and there is an alarming lack of attention to those of us who experience persistent, often debilitating, symptoms in the community. The vast majority of people with Long Covid were never hospitalised and never tested, although many of us have had multiple trips to A&E; we are not recovering as quickly as many people who were in Critical Care, and our symptoms are poorly understood.

We are deeply concerned that there is insufficient research into the range of areas needing attention (including accurate data on all affected - not only those testing positive; the natural history of disease courses, and outcomes; improved diagnostic technologies; and treatment and care for all, not only for people in the acute phase). We worry that the realities of our situation are poorly acknowledged and therefore not helping to drive better public health messages - bluntly that acquiring Coronavirus can lead to long term debilitating and distressing symptoms no matter your age, underlying health or fitness.

There has been insufficient attention to the disproportionate impact of Long Covid, and the varied disease outcomes, on socially and economically marginalised communities. We acknowledge that there has been relatively good public discussion of the epidemiology that shows the uneven impact of COVID-19 on many populations, and the Office of National Statistics (ONS) has provided clear data of the excess mortality among people from Black, Asian and other Minority Ethnic communities, as well as people working in (mostly) low paid public facing professions, as well as a clear relationship between mortality and co-morbidities such as diabetes that are often diseases associated with social and economic deprivation. However, it is likely that many people with Long Covid are already experiencing economic challenges and these social and economic disparities will create additional burden and challenges for recovery for people living with this long-term, intermittent condition which complicates our ability to work.

Our asks of the UK government draw on our submissions to the APPG on Coronavirus, our regular ongoing discussions, as well as regular exchanges with other support groups, which are growing all over the world as the pandemic gathers pace. For the UK, we are confident that if government acts urgently these ongoing failures can be redressed by ***setting up a multi-disciplinary Long Covid taskforce***, identifying urgent and concrete steps to address the following six actions:

### **1) Improve (Continuing) Professional Education**

This is a top priority. Most of us were never hospitalised, and yet we are all experiencing persistent, intermittent, and/or often worsening symptoms months after the acute phase, and we need medical help. At the outset we were encouraged to avoid seeking medical care where possible which most of us adhered to, given the so-called mild nature of symptoms. Many of us who went to A&E were sent home to recover alone. However, now that we are seeking help for continuing or worsening symptoms we discover that few medical practitioners are well informed and able to support us. Many of us have distressing tales to tell of being dismissed by health care workers; and where they are engaged they are often unsure about how to help. At last some good resources are emerging - such as this guidance for GPs: <https://www.bmj.com/content/370/bmj.m3026>

We urgently need the Department of Health and Social Care to develop and disseminate more targeted information with urgent guidance, including on treatment, management of symptoms and on rehabilitation support to 111 and 119 advisers, GPs and all clinical staff in frontline services, leveraging the various royal colleges and other structures.

### **2) More and better research**

We are pleased that - at last - government is backing the excellent work by Prof Tim Spector's ZOE Team, and we hope that more and better ways can be identified for this to feed into public health and policy decision making. For many of us, reporting in the app daily has been an essential part of our journey with COVID-19 - helping us to track our own health, and to encourage others to keep a check on their symptoms. We all value playing a part in research efforts and we are astonished that there is not more coordinated effort to understand what is going on, including stronger coordination and collaboration with researchers from other hard-hit countries, including China, Brazil, Italy and the USA. There is an urgent need to scale up the full range of research, including (but not limited to) biomedical, psycho-social and behavioural research to improve global understanding, to improve our wellbeing and to enhance the national response. While we appreciate the strong national focus on a vaccine, this is unbalanced. Some of the areas where people with Long Covid urgently need more research include:

- **Natural history of COVID-19** - some researchers are beginning to define different disease courses. We need more information about that and the varied patterns that we see anecdotally, including the many and varied clinical presentations of the disease, including the various symptoms associated with Long Covid; many of us had very different symptoms at the outset, and some of us have never experienced the three "officially recognised" symptoms. We need to understand the disease course and epidemiology better (Is the estimate that we are "1 in 10" correct? And if so, what is the denominator?) and to understand the biological mechanisms (is this persistent virus? immune response? auto-immune?) Is this a recurring, relapsing condition? Different assumptions are being made, that may or may not be right, that long Covid relates to post-viral fatigue, ME/CFS or Sepsis. We need much better scientific

understanding of this, as well as careful consideration of how this could be presenting as an entirely novel syndrome.

- **Nomenclature:** We need the right people to work together to understand not only the medical facts but also the best terms for the diversity of presentations. Various terms are used, including "mild" "asymptomatic", "acute", "chronic" "lingering", "persistent", "long haulers", "Long Covid". It will help us and health professionals to develop and agree more precise definitions. Is this best described as a Syndrome (a collection of various conditions, not all of which occur in all people, and sparked by a virus - as AIDS is to HIV)?
- **Risk factors and potential causes of Long Covid** - there are a growing range of theories about the range of biological and social risk factors that may underpin the development of Long Covid, and some speculation that this may be disproportionately experienced by different groups (e.g. women, young people, people who were extremely fit before they acquired the virus, people who have experienced trauma or depression). These observations may just relate to who becomes active in our support groups, but merits research, especially to drive public health programmes, and we need these researchers to be central to the national response and the Long Covid task force that should be established.
- **Exercise and Long Covid?** There are many reports of exertional fatigue and relapses associated with even the mildest activity or exercise so that "graded exercise" (also often recommended for people with ME/CFS) leads to a worsening of our symptoms. We need better information about the best rehabilitation support, especially around the role of exercise, as scientific understanding of the mechanisms of symptoms grows.
- **Diagnostic reliability** - A positive test result (antigen - swab - or antibody) should not be used as an access point to services and care - nor should the lack of diagnostic test results be used to deny access - until the tests are refined and become more sensitive and specific. Most of us were not tested in the acute phase because we were instructed to stay at home (and so could not access tests, which were also in short supply at the time most of us were infected); we have had to manage our symptoms syndromically (by symptoms not tests). A good proportion of us have since tested antibody negative and there are theories that Long Covid may be associated with a weak or abnormal immune response at the outset, as well as the growing understanding that antibody levels fade over time. We need more and better diagnostic capacity as the use of testing as a public health intervention grows.
- **Viraemia and ongoing or intermittent infectivity** - we urgently want to know if the contagious phase is restricted to early infection (including the pre-symptomatic phase)? Or might infectivity and/or viraemia resurge with symptoms over time, as with other viral conditions? How can people living with Long Covid access repeated antigen tests (if we wish) to help inform us whether we are contagious to others? And what steps are underway to make sure that more sensitive tests are developed that respond to the growing challenges?
- **Impact of SARS-CoV-2 on different organs:** We need to accelerate understanding of the biological mechanisms of the multi-system (including respiratory, cardiac and

neurological) effects of SARS-CoV2. Are the wide range of effects on cognitive function, metabolism, cardiac symptoms treatable? Are they reversible? What treatments can be trialled and made available, including through accelerated access schemes?

- **Therapeutic research:** We appreciate the growth of research for treatments for the acute phase and towards a vaccine. However, we desperately need medical interventions to assist those of us living with this in the long term. We long to return to "normal life" and to be able to work full-time again. And given our numbers, at a purely economic level, the UK needs us to become active members of the workforce again, not forced into a life of dependency.

### **3) Quality psychosocial and mental health services**

The government has emphasised the impact of COVID-19 on mental health since the outset and we applaud them for that. However, the needs that we face as we live long term with this condition are complex and evolving. We need high quality mental health services to be responsive and well informed about our needs; and we need a range of psychosocial support services as we live with this uncertain situation and all of the questions that it creates for the future, including the varied impacts on our employment and family life as well as health.

### **4) Better public health programmes**

Most public programming and messages remain focused on the ideas of COVID-19 as either a death sentence for the elderly and/or people in care homes or a mild bout of flu-like illness in younger people. We attest to the fact that it can be very different. There needs to be much better messaging about Long Covid from the government. Journalists are beginning to reflect our stories and we need public acknowledgement that so many of us are living with Long Covid, including children. This also means involving us more fully in the development of health promotion and public health programmes, which is good practice for all health conditions. This will help people to understand that avoiding COVID-19 also means avoiding the debilitating, long term conditions that thousands of us are now living with. We believe that a better public discussion of the realities of our lives would help to underscore why it is important to avoid COVID-19 at a time when public commitment to continued action is waning. Involving us in the centre of debates would help to tackle the stigma and discrimination that many of us experience, and address the complexity and uncertainty of current public health information, which is inevitable with new conditions but causing increasing levels of confusion.

### **5) Help NHS and social care workers to return to work safely**

Many of us acquired COVID-19 in the course of our work, and many of us are struggling to return to work in a way that lets us recover well, and manage our often erratic and changing health status, while continuing to serve the NHS and social care sectors where we became unwell. All employers need to make reasonable accommodation for staff who are facing Long Covid - and we hope that the government will assist them to do just that for the increasing numbers of us. Given that Long Covid is an occupationally acquired condition for many of us, we expect the NHS and social care providers to act as a beacon of good practice in developing flexible and compassionate employment practices, engaging the Health and Safety Executive, RIDDOR in reporting occupationally acquired cases, as well as NHS occupational health Departments to assist staff to return to work. Sadly few people living with long COVID report that experience from their employer - distressing not only on a personal level, but also because it prevents them from playing an active role in society.

#### **6) Fund patient-led support groups**

In all other conditions affecting thousands of people one of the most effective elements of the response is peer support. We are voluntarily providing peer support through our groups but it is no longer tenable to manage this. When we started we were engaging with a handful of people but now that our numbers are so vast, we need to establish better structures and funding is essential for us to provide the reliable support, information and advocacy that our community deserves.

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We welcome the hard work of your committee and appreciate anything you can do to bring these concerns to the attention of the Secretary of State for Health and Social Care as well as leading researchers in order to scale up efforts and improve the national effort.

Your sincerely

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