



Health and Social Care Committee

House of Commons London SW1A 0AA

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From Rt Hon. Jeremy Hunt MP

12 October 2020

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

Letter by Email

Dear Matt,

Re: Long COVID follow up letter

Thank you for your letter of 14 September, in response to the letter that I received on 28 August from the Long Covid support group. It was also helpful to hear your remarks when you gave evidence to the Committee on 8 September, as well as your response in Questions last week. I also note the announcement by NHS England last week which was a very promising start to providing effective care for those with Long Covid.

I am pleased to hear that the government is committed to meeting the needs of the growing numbers of people living with Long Covid in the UK. This must now translate into concrete action and proper funding allocations to reflect the urgency that this situation demands of us, including a timeline that makes it clear when new services will become available.

Most of the examples given in your reply describe services provided to people who have been hospitalised. However – and as the letter from the Long Covid support group explained - the majority of people with Long Covid were not in hospital. The recent report on Long Covid from the Tony Blair Institute reflects this:

<https://institute.global/policy/long-covid-reviewing-science-and-assessing-risk>

Your response did not address the request in the letter from the Long Covid Support Group to **set 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.** We know that in countries with impressive and effective responses to the Covid crisis - and other major health challenges - such national (and often sub-national) coordinating bodies provide opportunities to explore a broad range of perspectives and expertise, including from those familiar with the lived realities of the disease to guide action. This structure is missing from the UK and I urge you to put a body of this type in place to oversee and scale up efforts, ideally for the whole response, and at very least to co-ordinate efforts to scale up the response for people living with Long Covid as a matter of urgency. Such a body would assist in building understanding of this evolving situation, and would ensure that the range of health services and research, as well as employment support and other broader interventions, are put in place.

I would also appreciate a full reply to the specific question on **improving (continuing) Professional Education about the symptoms and effects of Long Covid.** Your response describes guidance for people discharged from hospital when, as I note above, most of those with Long Covid were not hospitalised and many present with a very different set of symptoms than those who were. When will the Department issue guidance for the care of people who have Long Covid and were never hospitalised? This needs to include guidance *on treatment, management of symptoms and on rehabilitation support to 111 and 119 advisers, GPs and all clinical staff in frontline services* and is

essential for the delivery of quality care, and to end the dismissive attitudes reported by far too many people with Long Covid when they attempt to access health services.

I am pleased to hear that “the Department is considering options for further research into the longer-term effects of the virus in those who did not require hospitalisation”. Please can you provide an update on the status of these plans, including when information will be made available widely? The report referred to above – which draws heavily on the excellent work by Prof Tim Spector's ZOE Team – demonstrates the urgent need for investing in better research to inform patient care as well as public health and policy decision making; it notes that far more research is needed. I will be interested to hear if the plans that are being developed will invest *in the full range of research, including (but not limited to) biomedical, psycho-social and behavioural sciences*. As explained in more detail in the original letter from the Long Covid group, future research should include: *the natural history of COVID-19, risk factors and potential causes of Long Covid, exercise and Long Covid, diagnostic reliability, viraemia and ongoing or intermittent infectivity, impact of SARS-CoV-2 on different organs and therapeutic options for people with Long Covid*.

I appreciate the new efforts mentioned in your letter to expand and strengthen community health and care services. You reference 'My COVID Recovery' – noting that this is geared to those who were hospitalised. Yet despite the promises and commitments to this service, I am hearing directly from many people with Long Covid that access to this service is not fully operational in most parts of the country, and that there are long wait times even for initial assessments.

As mentioned last week's announcement of new NHS Long Covid clinics is welcome. Yet there remain concerns that an investment of £10 million will not meet the extent of need throughout the country, as well as clearing the backlog for so many people who have been waiting months for access to care. I would therefore be grateful for information about the timeline for commissioning these clinics and the time it will take to scale up and reach everyone who requires this service.

Please could you also elaborate on the response regarding mental health services as they relate directly to Covid. It is encouraging to understand that there will be extra investment in mental health services more broadly, but the response does not address the specific Long Covid related needs. Peer support groups of people living with Long Covid report real and growing concerns of suicidal thoughts amongst their group by people many of whom were previously high performing professionals who were fit and well, and who now struggle with the recurrent uncertainty of their illnesses and the lack of access to supportive services. I trust that the NHS Long Covid clinics will be inclusive of quality mental health services, and that mental health care providers in all settings will be sensitised to the specific needs of this growing group of patients.

The letter from the Long Covid groups also raised specific questions regarding public health programmes – including those that increase knowledge of the risk of Covid - to reflect the realities of living with Long Covid. Your response did not address how people living with Long Covid will be involved in shaping such programmes (as is good practice under international guidance for public health programming). How will the department address their request to be involved *more fully in the development of health promotion and public health programmes, which is good practice for all health conditions... [and to] help to tackle the stigma and discrimination that many [people with Long Covid] experience, and address the complexity and uncertainty of current public health information?*

There is an urgent need to emphasise these risks to the many young people currently acquiring Covid-19. Many have understood that their risk of mortality is low, but most appear to be unaware of the risks of acquiring the complex long-term condition known as Long Covid. As the report from Tony Blair's institute shows, Long Covid is being seen at increasing frequency among adults aged 18-60, people experiencing these lingering long-term symptoms tend to be younger than people admitted to hospital with Covid and there are twice as many women with Long Covid as men. Our growing epidemic will have substantial impacts on society and the economy, as well as individual lives. Hearing the voices of people most directly affected, and making the risks of Long Covid explicit, would support adherence to public health guidelines. We know from public health interventions for other conditions that this approach is likely to be effective.

I also appreciate the full list of materials regarding support for NHS workers. However, these principally address how to avoid the risk of infection, and fail to address the central point made by the Long Covid support group regarding the many NHS (and care) workers who are struggling to get employers to support their return to work. The NHS is already beginning to lose many talented and highly skilled staff who acquired Long Covid – most of whom were occupationally exposed through their frontline work caring for others. There is a substantial risk that we will lose many more highly trained individuals without better, focused employment support. This should include protection of full pay, and guidance to line managers on how to handle absences and phased returns, support and advice for handling relapses and to flex to respond to the lived experience of those with this complex and evolving condition. Too many doctors, nurses, and other health professionals and carers are currently having to leave employment. I would therefore be grateful for a response reflecting how we will support our workforce living with Long Covid, rather than merely being referred to guidelines that cover the equally urgent question of avoiding Covid.

Finally I appreciate the response that you are continuing to review the level of peer support investment and availability. Self Help UK clearly plays a small role in this, and it is evident that further investment is urgently required. The numbers of people living with Long Covid is rising rapidly and we must find ways for their organisations to be supported so that they can provide each other with quality peer support, as well as ensuring that we develop the health services that are so urgently needed.

I look forward to hearing from you and once again am most grateful for the additional work that is clearly taking place to support the needs of those with Long Covid.

Best wishes,

A handwritten signature in blue ink that reads "Jeremy". The signature is written in a cursive style with a large initial 'J'.

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