



# Long Covid Minister needed to respond to growing crisis

Official statistics indicate there are currently hundreds of thousands of people living with Long Covid in the UK. Many of those who contracted Covid-19 at the start of the pandemic are still experiencing significant symptoms almost a year on from their initial infection; some have already passed that grim milestone.

Meanwhile, we can expect case numbers of Long Covid to rise significantly as people continue to become infected; recent data shows that at least 1 in 10 people still experience symptoms 12 weeks after initial infection.<sup>1</sup>

The implications of Long Covid for individual patients, our health service and wider society are multifaceted, complex and likely to be long-term. There has been some progress to put in place support for people with Long Covid, but many are yet to receive help.

## Call to action

Patient Safety Learning and patient group Long Covid Support are calling for an urgent and significant increase in the scale and pace of the response, and a coordinated, multi-stakeholder approach. We are calling for this to be set up and led by a dedicated Minister for Long Covid, responsible for:

- Assessment of the issues affecting people with Long Covid, whether or not they were hospitalised (physical and mental health, employment, welfare, education).
- Delivery plans for meeting the needs of people living with Long Covid.
- Cross-government coordination and communication.
- Public information and awareness raising around Long Covid.
- Data collection, measurement and reporting on the number of adults and children with Long Covid to inform service planning and funding.
- Identifying research needs, commissioning research and ensuring this informs service delivery.
- Delivery of a communication and engagement strategy to all key stakeholders.

## Concerns about patient safety and support

Patients living with Long Covid have been left 'joining the dots' to try to understand how they can access safe, quality care and what they can do to improve their health. Their physical and mental health, employment and economic circumstances have, in many cases, been affected by the barriers they have faced.

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<sup>1</sup> Office for National Statistics, The prevalence of long COVID symptoms and COVID-19 complications, 16 December 2020.

<https://www.ons.gov.uk/news/statementsandletters/theprevalenceoflongcovidsymptomsandcovid19complications>

Those living with Long Covid have highlighted a number of concerns, from which we have identified eight key themes:

### **1. Inconsistent care and contradicting advice**

- Serious clinical symptoms are not being investigated consistently or referred on to the appropriate specialties. There are concerns that failure to investigate could have a negative impact on health outcomes.
- In July 2020, the National Institute of Clinical Excellence cautioned against the use of graded exercise therapy (GET) for patients recovering from Covid-19.<sup>2</sup> However, contradictory advice is still being given around GET as a safe rehabilitation approach, with many raising concerns that it could be deeply harmful.<sup>3 4 5 6</sup>
- Inconsistencies of access to Long Covid assessment centre services, particularly in Wales, Northern Ireland and Scotland.
- Huge variations in the medical support and care given. There is a risk that existing health inequalities may be widened as a result of this.

### **2. Employment and welfare**

- There is a lack of wider understanding about the debilitating impact of Long Covid and how it affects people's lives and ability to work.<sup>7 8</sup> This can lead to inadequate support from employers and an inconsistent approach to benefits.
- Government benefits do not address the devastating economic impact that Long Covid has had for many people.

### **3. Children with Long Covid**

- More work needs to be done to understand how Long Covid is presenting in children and to raise awareness of the profound impact Long Covid can have on young people.<sup>9</sup>

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<sup>2</sup> Torjesen, Ingrid, NICE cautions against using graded exercise therapy for patients recovering from covid-19, BMJ 2020; 370:m2912. <https://www.bmj.com/content/370/bmj.m2912>

<sup>3</sup> Health and Service Executive, Long Covid and the Workplace: What does the evidence support in terms of intervention, 13 January 2021. [https://www.contractsfinder.service.gov.uk/Notice/bcb0ea50-41c3-4d19-a4e1-9d1d1a429359?utm\\_medium=email&utm\\_campaign=2021-01-14&utm\\_source=SavedSearch](https://www.contractsfinder.service.gov.uk/Notice/bcb0ea50-41c3-4d19-a4e1-9d1d1a429359?utm_medium=email&utm_campaign=2021-01-14&utm_source=SavedSearch)

<sup>4</sup> Torjesen, Ingrid, NICE backtracks on graded exercise therapy and CBT in draft revision to CFS guidance, BMJ 2020; 371:m4356. <https://www.bmj.com/content/371/bmj.m4356>

<sup>5</sup> #ME Action Network, Long COVID Patients Warned Of Damaging Exercise Programme, 3 November 2020. <https://www.meaction.net/2020/11/03/long-covid-patients-warned-of-damaging-exercise-programme/>

<sup>6</sup> Tuller, David, Trial By Error: Professor Paul Garner's BMJ Blog Post on His Powerful Cognitions, 28 January 2021. <https://www.virology.ws/2021/01/28/trial-by-error-professor-paul-garners-bmj-blog-post-on-his-powerful-cognitions/>

<sup>7</sup> The Guardian, Many 'long Covid' sufferers unable to fully work six months later, 5 January 2021. <https://www.theguardian.com/society/2021/jan/05/many-long-covid-sufferers-unable-fully-work-six-months-later>

<sup>8</sup> People Management, Should HR be worried about long Covid, 28 January 2021. [https://www.peoplemanagement.co.uk/long-reads/articles/should-hr-worried-long-covid?fbclid=IwAR3CSblxfQYrhdyXc0oRgU\\_DJsztOaDUEsLpz2OuRMOaHJ1Rq-QEHp3XFQQ](https://www.peoplemanagement.co.uk/long-reads/articles/should-hr-worried-long-covid?fbclid=IwAR3CSblxfQYrhdyXc0oRgU_DJsztOaDUEsLpz2OuRMOaHJ1Rq-QEHp3XFQQ)

<sup>9</sup> University of Cambridge, Video: Long Covid Kids – 5 News, 24 November 2020. <https://paediatrics.medschl.cam.ac.uk/blog/2020/11/24/video-long-covid-kids-5-news/>

- The assessment services, which were part of the five-point plan laid out by the NHS to address Long Covid, do not include services for children.<sup>10</sup>
- There needs to be better information available to schools on how they can support children living with the effects of Long Covid and any reasonable adjustments that may be necessary to support their educational and health needs.

#### **4. NHS workforce and resource planning**

- Service provision must accurately reflect the vast number of people living with Long Covid in the UK who were and were not hospitalised. This is necessary for the NHS to understand the scale of the challenge and to effectively mitigate against a pandemic of chronic ill health. There are concerns that the wide-ranging needs of these patients may not be adequately reflected in NHS workforce planning, service delivery and funding.
- A large number of NHS staff are living with Long Covid, unable to work at all, or to their previous capacity.

#### **5. Knowledge gaps among health professionals**

- There is a poor understanding among some health professionals of Long Covid, how to diagnose it and how it can impact people's lives. This can result in misdiagnosis or a disbelief that patients are still unwell.
- Some patients are finding they are unable to access further assessment or treatment due to their GPs not believing they have Long Covid, distance from clinics, not having been hospitalised or not having a confirmed positive test result (despite Royal College of GP's guidance to the contrary).<sup>11</sup>
- Some GPs are unaware of the location of assessment clinics or how to refer patients to services (e.g., the 'Your Covid Recovery' tailored rehabilitation programme).
- There does not seem to be a clear strategy for training healthcare professionals on case recognition and referral pathways.

#### **6. Data, research and insight gaps**

Including, but not limited to, the following:

- Currently there is insufficient understanding of the risk factors, mechanism or pathophysiology of Long Covid, appropriate diagnostic techniques as well as prevention or treatments.
- There is a lack of research into the debilitating impact Long Covid can have on children's health, education and wellbeing.<sup>12</sup>

#### **7. Public health messaging not reflective of Long Covid**

- Public health messaging and reporting do not include the proportion of both adults and children who are experiencing Long Covid.

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<sup>10</sup> NHS England and NHS Improvement, NHS to offer 'long covid' sufferers help at specialist centres, 7 October 2020. <https://www.england.nhs.uk/2020/10/nhs-to-offer-long-covid-help/>

<sup>11</sup> Royal College of General Practitioners, Management of the long-term effects of COVID-19, 30 October 2020. [https://elearning.rcgp.org.uk/pluginfile.php/149508/mod\\_page/content/72/V2GA%20for%20publication%20updated%20Management%20of%20the%20long%20term%20effects%20of%20COVID-19\\_formatted\\_29.10.20.pdf](https://elearning.rcgp.org.uk/pluginfile.php/149508/mod_page/content/72/V2GA%20for%20publication%20updated%20Management%20of%20the%20long%20term%20effects%20of%20COVID-19_formatted_29.10.20.pdf)

<sup>12</sup> The BMJ Opinion, Counting long covid in children, 16 October 2020. <https://blogs.bmj.com/bmj/2020/10/16/counting-long-covid-in-children/>

- Public health messaging (and the NHS website) does not reflect the range of initial acute symptoms of Covid-19 or those experienced by people living with Long Covid.
- Public health messaging does not reflect the severity and relapsing nature of Long Covid.

## **8. Communication and engagement gaps**

- There is no patient and public involvement strategy for Long Covid.
- Assessment centres (previously referred to as Long Covid clinics) are being established but there is lack of information about the services they provide, where they are, how patients can access them and how clinicians can refer.
- It is unclear what treatments and support are available post-assessment, and what resources are needed to meet this growing need.
- There does not seem to be a clear strategy for providing health professionals with the necessary information to be able to support Long Covid patients.

Currently there is no coordinating task group or Government body specifically working to understand the whole spectrum of issues relevant to Long Covid and how they intertwine.

## **Long Covid Minister and cross-government task force**

We are calling on the Prime Minister to appoint a Minister for Long Covid. This role would be responsible for coordinating a UK Cross-government task force, accountable for broad oversight and action relating to the Long Covid crisis. This multi-stakeholder approach would go far beyond the remit of the current NHS England Task Force for Long Covid.

### **Membership**

To respond to the broad spectrum of issues, we would anticipate that this Task Force would involve collaboration between officials from departments across the government, including:

- Department of Health and Social Care
- Department of Work and Pensions
- Public Health England
- HM Treasury
- Department for Education
- No 10/Cabinet Office C-19 Taskforce
- NHS England and NHS Improvement
- NHS England and NHS Improvement Long Covid Task Force
- Northern Ireland Executive
- Scottish Government
- Welsh Government

### **Communication and engagement**

There is an urgent need for a Long Covid communication and engagement strategy, to include information and updates for patients, clinicians, relevant organisations and the public.

This needs to be a genuine two-way process with proactive action to inform, support and educate, and to obtain feedback from all relevant parties. The effectiveness of these

communications must be monitored to ensure that key stakeholders are receiving the information and guidance they need to support people living with Long Covid.

Patient engagement is proven to be a key factor in designing effective services and improving clinical outcomes; it should never be viewed as 'nice to have' or applied in a tokenistic way. Those with lived experience of Long Covid must be seen as partners at every step of the response, with a clear involvement strategy to ensure that decisions 'about them' are not made 'without them'. To undervalue this input would be incredibly short-sighted and would contravene NHS policy.<sup>13</sup>

The Task Force should be responsible for delivering the communication and engagement strategy to help address the concerns we have outlined in the eight themes. Engaging with organisations outside of the cross-government task force will be essential and should include:

- Long Covid peer support groups and those with lived experience
- Patient information experts
- Occupational health experts
- Royal colleges
- Trade unions
- Citizens Advice

## Conclusion

More must be done to ensure that people living with Long Covid are able to access safe, quality care and that every effort is made to empower those around them to support their recovery.

We believe that a multi-stakeholder approach, led by a dedicated Minister, is key to responding to, and planning for, the growing challenges of Long Covid. The current absence of oversight and accountability poses a risk to patients and must be addressed urgently.

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<sup>13</sup> NHS England and NHS Improvement, NHS England Patient and Public Voice Partners Policy, July 2017. <https://www.england.nhs.uk/wp-content/uploads/2017/08/patient-and-public-voice-partners-policy-july-2017.pdf>