

Building an NHS that's there for Long Covid and ME

#ThereforME

Executive summary

July 2024

The Labour government comes into office with a powerful promise: to transform a broken healthcare system, building an NHS that is fit for the future.¹ The Covid-19 pandemic continues to exact a heavy toll on the NHS and society. Among the most heavily impacted are up to two million adults and children affected by Long Covid – an infection-associated chronic condition where symptoms persist after a Covid infection – including over 1.5 million who report their daily activities being limited by Long Covid.²

A significant proportion of Long Covid patients – by one estimate, approximately half – meet the diagnostic criteria for myalgic encephalomyelitis (ME, sometimes referred to as ME/CFS – Chronic Fatigue Syndrome).^{3,4} This includes patients with life-altering symptoms including debilitating cognitive dysfunction and the exacerbation of symptoms following exertion.

Patients with ME have one of the worst qualities of life of any disease but have long been dismissed and overlooked.⁵ The most severely affected patients are reliant on full-time care, sometimes becoming unable to speak or swallow and requiring hospital care to avoid dehydration and malnutrition.⁶

Patients with ME have faced decades of inadequate care and insufficient funding for biomedical research, which have shaped the NHS care available to Long Covid patients today.⁷ From 2015 to 2020, just £6 million was committed in UK funding for ME research, compared to £53 million for Parkinson's disease and £22 million for multiple sclerosis.⁸ There has been an increase worldwide in research funding for Long Covid, including some investments in the UK. However, this has been nowhere near sufficient to recover lost ground from decades of underfunding research for ME and other infection-associated chronic illnesses.⁹

2 Building an NHS that's there for Long Covid and ME | Executive summary

The lack of appropriate care and treatment for patients with Long Covid and ME is an issue that the UK cannot afford to ignore, with record numbers out of work due to long-term illness. A recent Organisation for Economic Co-operation and Development (OECD) working paper estimated that the cost of Long Covid could be as high as \$141–317 billion per year across OECD countries.¹⁰ Analysis by Long Covid Support estimates that excess costs to the NHS of Long Covid alone will be at least £268 million over the next two years.¹¹

Via an online survey, we asked over 300 people living with Long Covid and ME to evaluate parts of Labour's mission plan for the NHS against their experiences.¹²

There are three Labour commitments that could have the biggest impact, where people with Long Covid and ME highlight current shortcomings:

1. An NHS that is there when people need it

- **Two thirds told us that the NHS has not been there for them when they needed it.** Many have felt dismissed and/or disbelieved. Some have deteriorated during or following NHS care, highlighting failures in terms of patient safety.
- **Over 7 in 10 told us they had looked outside the NHS for support.** Many who can afford it, and even some who are struggling financially, are turning to private healthcare to access basic care, emerging treatments and knowledgeable clinicians.
- **Not a single respondent who was very severely affected felt that the NHS had been there for them.** There are no specialist inpatient services for Severe ME in the UK and no NHS Protocol to guide hospital care for life-threatening complications.¹³

2. Change so that more people get care at home in their community

- **Many have struggled to access care in the community.** Only a small minority (4%) told us that they felt supported by the NHS to manage their symptoms at home.
- **Much more could be done to provide appropriate support in primary care.** Many answering our survey spoke about limited knowledge of ME and Long Covid among clinicians and felt they had been left without long-term monitoring or support.

3 Building an NHS that's there for Long Covid and ME | Executive summary

3. The promise to introduce a revolution in technology

- **Far more can be done to leverage the UK's science and technology expertise to accelerate treatments.** Just 2% felt that the UK was making the most of its science and technology expertise to advance treatments for Long Covid and ME.
- **Patients highlighted opportunities to better leverage science and technology** including through clinical trials within the NHS, funding research into biomarkers, and mobilising technology for at-home symptom monitoring.

Recommendations

Considering the shortcomings above, the following recommendations are outlined for Labour to deliver on its public service mission for patients with Long Covid and ME.

1. Commit to an NHS that is there for people with Long Covid and ME:

- Articulate a vision for an NHS where Long Covid and ME patients are listened to, believed and where they can access safe care, building on the best that modern science can offer.
- Prioritise the urgent publication of the cross-government delivery plan for ME/CFS, ensuring it meets these priorities.
- Appoint a Minister for Long Covid and ME to signal that improving patients' care is a priority for a Labour government.
- Develop an NHS Severe ME Safe Hospitals protocol to ensure the safety of patients accessing hospital care for life-threatening symptoms.

2. Make the most of the UK's science and technological expertise to advance treatments for Long Covid and ME:

- Commit to at least £100 million of annual research funding for Long Covid and ME. This should prioritise biomedical research, developing biomarkers and trialling treatments, led by patients' lived experience and priorities.
- Convene UK-based researchers, clinicians, the private sector and patient advocates to develop a strategy for accelerating treatments.

4 Building an NHS that's there for Long Covid and ME | Executive summary

- Ensure that emerging research filters down into clinical practice in the NHS. For example, by committing to update the 2021 NICE Guidelines for Long Covid based on new research.

3. Do more with the tools we already have:

- Commit to and take accountability for implementing the 2021 NICE Guidelines for ME/CFS. The guidelines should be applied to all patients with an ME/CFS diagnosis (including those with Long Covid).
- Support access to emerging treatments within the NHS, including as part of clinical trials.
- Leverage technology-enabled solutions in the NHS to better support patients to manage their symptoms at home e.g. using wearables for remote monitoring and symptom management.
- Mobilise tools to measure and reduce the ongoing health burden of Long Covid in the UK. For example, by supporting the wider roll-out of air filtration systems within key public services (e.g. healthcare settings and schools).

To read the full report go to: <https://linktr.ee/ThereForME>

This is a patient- and carer-led production supported by:



Endnotes

- 1 Streeting, W. (2024) 'The NHS is broken: Health and Care Social Secretary Statement' (www.gov.uk/government/speeches/statement-from-the-secretary-of-state-for-health-and-social-care); Labour Party (2024) 'The Labour Party Manifesto 2024' (<https://labour.org.uk/change/>).
- 2 The figures used here are from the Office for National Statistics (ONS) 2023–24 Winter survey. The ONS defines Long Covid as ongoing symptoms more than four weeks after a Covid-19 infection. Clinical definitions tend to focus on those whose symptom duration has exceeded 12 weeks. Of those who provided a duration to the ONS survey 87% had symptoms for 12 weeks or longer. However, many did not do so, making the true figure of those affected for over 12 weeks difficult to estimate. See ONS (2024) 'Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024' (www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/selfreportedcoronaviruscovid19infectionsandassociatedsymptomsenglandandscotland/november2023tomarch2024).
- 3 Davis, H.E., McCorkell, L., Vogel, J.M. and Topol, E.J. (2023) 'Long COVID: major findings, mechanisms and recommendations' *Nature Reviews Microbiology* 21:133–146 (<https://doi.org/10.1038/s41579-022-00846-2>).
- 4 'ME' is primarily used here as the term preferred by many patients. 'ME/CFS' is used where the term features in specific documents or research being discussed. For example, in relation to the cross-government delivery plan for ME/CFS.
- 5 Preston, R. (2023) 'The Human & Economic Cost of ME/CFS' (<https://pitch.com/v/the-human-economic-cost-of-mecfs-d89c37/0659ef4e-b047-4633-ae1b-e4cf4d090cd9>).
- 6 NICE (2021) 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management' (www.nice.org.uk/guidance/ng206/chapter/Recommendations#care-for-people-with-severe-or-very-severe-mecfs).
- 7 The 'NHS' is used here to refer to the NHS across England, Scotland, Wales and Northern Ireland, recognising that healthcare is devolved and differences exist in approaches to Long Covid and ME.
- 8 Commitments included here are those through the National Institute of Health Research (NIHR) and UK Research & Innovation (UKRI). Analysis based on data from <https://gtr.ukri.org/> by Peter White and colleagues. More details available on request.
- 9 APPG on Coronavirus (2022) 'Long Covid report (22 March 2022)' (www.pslhub.org/learn/coronavirus-covid19/appg-on-coronavirus-long-covid-report-22-march-2022-r6432/); NIHR (2022) 'Researching long COVID: addressing a new global health challenge' (https://doi.org/10.3310/nihrevidence_50331); Greenhalgh, T., Darbyshire, J.L., Lee, C., Ladds, E. and Ceolta-Smith, J. (2024) 'What is quality in long covid care? Lessons from a national quality improvement collaborative and multi-site ethnography' *BMC Medicine* (<https://doi.org/10.1186/s12916-024-03371-6>); The Lancet (2023) 'Where are the long COVID trials?' 23(8): p.879 ([https://doi.org/10.1016/S1473-3099\(23\)00440-1](https://doi.org/10.1016/S1473-3099(23)00440-1)).
- 10 Gonzalez, A.E. and Suzuki, E. (2024) 'The impacts of long COVID across OECD countries' (<https://doi.org/10.1787/18152015>).
- 11 Analysis by Long Covid Support based on an estimate of average excess costs of £2,235 per year for each Long Covid patient compared to all pre-pandemic control groups. See Yi Mu et al. (2023) 'Healthcare

6 Building an NHS that's there for Long Covid and ME | Executive summary

Utilisation of 282,080 Individuals with Long COVID Over Two Years: A Multiple Matched Control Cohort Analysis' (https://papers.ssrn.com/sol3/papers.cfm?abstract_id=4598962). The figures given here are based on figures for new Long Covid cases from the ONS winter survey, including only those who report being affected 'a lot'. Further details are available on demand.

12 Labour Party (2024) '5 Missions for a Better Britain: Build an NHS Fit for the Future' (<https://labour.org.uk/wp-content/uploads/2023/05/Mission-Public-Services.pdf>).

13 Merritt, A. (2023) 'Death prompts Devon hospital chief to speak out on "ignored" illness'. DevonLive (www.devonlive.com/news/devon-news/death-prompts-devon-hospital-chief-8940687).