



Building an NHS that truly supports people living with long COVID and ME: government action needed now

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The COVID-19 pandemic has transformed our understanding of healthcare challenges, with long COVID emerging as a significant current and ongoing public health issue.¹ For governments across the four UK nations, this presents both a challenge and an opportunity to build a National Health Service (NHS) that truly responds to the needs of all its patients, particularly, those with long COVID and myalgic encephalomyelitis (ME).

A recent policy brief draws on the results of an online survey carried out in June–July 2024, which asked patients with long COVID and ME to evaluate parts of Labour’s mission plan for the NHS against their experiences of care.² The report uses data from over 300 responses from patients and carers to identify the issues being faced. It also highlights challenges for the new Labour government in the UK to take clear steps to ensure the NHS provides for the needs of people living with long COVID and ME. While the brief focuses on the UK, there are lessons for governments across the world.

The policy brief is part of #ThereForME, a patient-led and carer-led campaign, supported by 18 organisations and smaller initiatives, calling for an NHS that is there for people with long COVID and ME. In August the campaign shared the policy brief’s findings with the UK Secretary of State for Health and Social Care, through an open letter signed by over 2600 patients and carers.

A grim reality for long Covid and me patients

Long COVID, a chronic condition in which symptoms persist long after the initial COVID-19 infection, affects up to two million adults and children in England and Scotland.³ More than 1.5 million of these people report that their daily activities are limited due to the condition.³ Of these patients, around half meet the diagnostic criteria for ME, a condition characterised by debilitating symptoms including cognitive dysfunction and severe fatigue.⁴

Patients with ME have faced major challenges in the healthcare system, having one of the worst qualities of life of any disease,⁵ and in the past often being dismissed or overlooked. The most severely affected can no longer speak or swallow, are dependent on full-time care and sometimes need to be hospitalised to avoid life-threatening complications.⁶ The challenges faced by these patients highlight the urgent need for an NHS that can provide comprehensive and compassionate care.

Economic and social impact

The social and economic impact of long COVID and ME is profound. According to a recent Organisation for Economic Co-operation and Development (OECD) working paper, the costs associated with long COVID could amount to between \$141 and \$317 billion per year in OECD countries.⁷ People with long COVID have been

found to be three times more likely to give up work compared with those without ongoing symptoms,⁸ with the UK having record numbers out of work due to long-term illness.

The personal stories of people affected by long COVID and ME reveal a disturbing pattern of unmet needs and inadequate care. Many patients report feeling dismissed and treated with disbelief by healthcare professionals, and some have seen their condition worsen because of poor NHS care. Such experiences highlight systemic failures that need to be addressed to restore confidence and ensure safety for these populations. This is not about individual clinicians but system-wide failings. Healthcare workers are being failed just as much as patients by not having the right tools or institutional support to provide appropriate care to long COVID and ME patients.

Three key areas for improvement in the NHS

The policy briefing outlines three critical areas where the Labour government can make effective changes to improve care for patients with long COVID and ME²:

1. An NHS that is there when people need it
 - ▶ Current deficits: Two thirds of respondents said that the NHS is not there for them when they need it. Many have sought private healthcare because of the lack of adequate support from the NHS. Those who are severely affected, and their carers, feel completely let down by the system.
 - ▶ Recommendations: The government must articulate a clear vision for an NHS where long COVID and ME patients are listened to, believed and receive safe, accessible and long-term care. This includes the urgent publication of the cross-government implementation plan for ME/chronic fatigue syndrome and the appointment of a Minister for long COVID and ME.
2. Care in the community and at home
 - ▶ Current deficits: Access to community-based care is very poor. Only 4% of respondents felt supported by the NHS to manage their symptoms at home. Many clinicians lack knowledge about ME and long COVID, leading to inadequate long-term monitoring and support.
 - ▶ Recommendations: There is a need for better support in primary care to ensure that clinicians are well informed and that patients have access to continuity of care. The introduction of technology-enabled solutions, such as wearable devices for remote monitoring, can significantly improve patient management at home.
3. Harnessing science and technology
 - ▶ Current deficits: Only 2% of patients feel that the UK is using its science and technology expertise to advance treatments for long COVID and ME. There

is a significant gap between new research and clinical practice.

- **Recommendations:** The government should commit to providing at least £100 million a year in research funding for long COVID and ME, focusing on biomedical research and clinical trials. Collaboration between researchers, clinicians and patient advocates is crucial to developing effective treatments and ensuring that new research findings are incorporated into clinical guidelines.

The way forward

To truly transform NHS care for people with ME and long COVID, the government must take bold and decisive action. This includes not only increasing funding for research and improving clinical care but ensuring that the voices of long COVID and ME patients are central to health service planning and policy development.

An NHS that is responsive to the needs of all its patients—including those with chronic and often misunderstood conditions such as long COVID and ME—is not just a promise but a necessity. By prioritising these recommendations, the Labour government can make significant progress in building a healthcare system that is inclusive, compassionate and equipped to meet the challenges of the future.

Conclusion

The COVID-19 pandemic has highlighted shortcomings in our healthcare system and the urgent need for reform. For long COVID and ME patients, the road to adequate care has been long and fraught with challenges. However, there is an opportunity for a new Labour government to put its public service mission into action through a new approach for people with long COVID and ME. The government can signal a commitment to doing things differently and to a transformation of care so that people with long COVID and ME can access treatment that lives up to Labour's vision for healthcare in the UK: an NHS that is there for them when they need it, offering safe care and access to the best that modern science can offer.

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