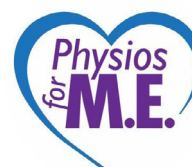


Building an NHS that's there for Long Covid and ME

July 2024

#ThereForME



About this policy brief

This policy brief was drafted by Karen Hargrave, who developed ME in 2020 as a result of Long Covid. Karen is a carer for her husband, who has suffered from Very Severe Myalgic Encephalomyelitis (ME)/Long Covid since 2022. Karen is the co-founder of #ThereForME, along with Emma Gore-Lloyd, also a carer to a partner with Very Severe ME/Long Covid. #ThereForME is a patient- and carer-led campaign calling for an NHS that's there for people with ME and Long Covid. The campaign is supported by 15 organisations working with and for people with ME and Long Covid.

Many thanks to all those who contributed to the policy brief, first and foremost the 328 people who used their valuable energy to share their stories with us. Thanks go to those who supported the development of the policy brief: Nick Hargrave, Kim Brown and Suzy Foster (for their strategic brains), Jess Rennoldson and Sara Hussain (for expert design and editing) and all those who shared their feedback.

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



Contents

About this policy brief / 1

Contents / 2

Executive summary / 3

Recommendations / 5

Introduction / 7

Data from the Long Covid and ME communities: a stark reality / 10

The opportunity for Labour – three commitments to build an NHS fit for the future / 11

Area 1: An NHS that is there when people need it / 11

Area 2: Care in the community and at home / 16

Area 3: Harnessing the UK's science and technology expertise to advance meaningful treatment for patients with Long Covid and ME / 18

Recommendations and the way forward / 22

Endnotes / 24

Executive summary

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

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

4 Building an NHS that's there for Long Covid and ME | Policy brief

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. 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.
- 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).

6 Building an NHS that's there for Long Covid and ME | Policy brief

- 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).

Introduction

The Labour government comes into office at a time of crisis in the NHS with a powerful promise: to transform a broken healthcare system, building an NHS that is fit for the future. The Covid-19 pandemic continues to exact a heavy toll on the NHS and society, depleting the resilience of an overstretched NHS, while devastating lives, families and futures.

Among the most heavily impacted are those who have developed Long Covid. The Office for National Statistics (ONS) estimates that in early 2024, two million adults and children in England and Scotland had ongoing symptoms after a Covid infection, over 1.5 million of whom reported that their daily activities were limited by Long Covid, including 381,000 whose daily activities were limited 'a lot'.¹⁴ Of those who had Long Covid for at least 12 weeks and provided a date when their symptoms began, over half had been affected for at least two years.

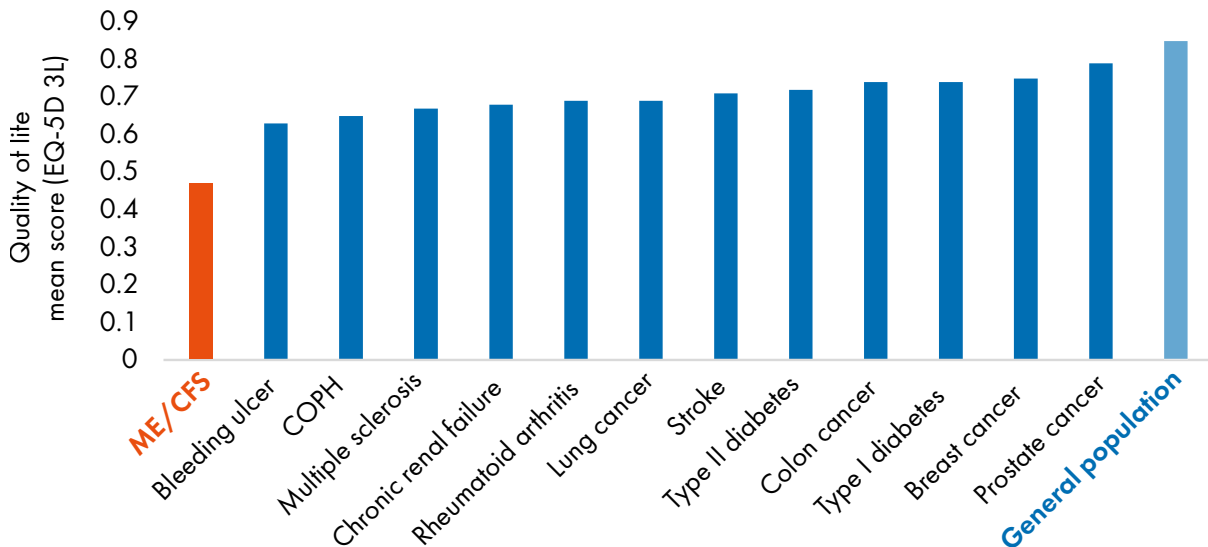
A significant proportion of Long Covid patients – by one estimate approximately half – meet the diagnostic criteria for myalgic encephalomyelitis (ME, sometimes referred to as ME/CFS – Chronic Fatigue Syndrome). Long Covid patients meeting the diagnostic criteria for ME include those with some of Long Covid's most life-altering symptoms, which are simultaneously the most difficult to treat. For example, symptoms that include debilitating cognitive dysfunction and the severe exacerbation of symptoms following minimal exertion. Patients with ME have one of the worst qualities of life of any disease: lower than various forms of cancer, multiple sclerosis or chronic renal failure (see Figure 1).

As this paper highlights, patients with ME have long been dismissed and overlooked, facing decades of inadequate care and insufficient funding for research into treatments. For decades, the belief that the disease is psychosomatic has hindered desperately needed biomedical research, leaving patients without treatment or a cure. This has shaped the care available for Long Covid patients in the UK today, many of whom – like patients with ME before them – feel let down by the NHS.¹⁵

I think it is easier for the government to believe these are psychosomatic disorders and therefore those that suffer them don't deserve/need any help. We need a change in understanding across all of society to understand there are biological causes for these conditions and we need research to find cures, and in the meantime, decent care and understanding.

ME/Long Covid patient, affected for 2–5 years

Figure 1 Mean score of quality of life ratings by disease



Source: CrunchME (<https://pitch.com/v/the-human-economic-cost-of-mecfs-d89c37/0659ef4e-b047-4633-ae1b-e4cf4d090cd9>)

In 2022, the government set in motion a process to develop a new cross-government delivery plan for ME/CFS, recognising challenges faced by patients accessing care.¹⁶ While this presented an opportunity to transform care for people with ME in the UK – including many with Long Covid meeting the diagnostic criteria – two years later the plan still has not been published. An early draft was criticised by some in the ME community as lacking ambition and urgency.¹⁷

Each story of a patient with Long Covid or ME is an individual tragedy. Taken together, it is a story of a vast loss to the UK's society and economy. Most starkly, this is an issue that the UK cannot afford to ignore in the context of crippled public finances, a low-growth economy and record numbers of people out of work due to long-term illness.¹⁸ A recent Organisation for Economic Co-operation and Development (OECD) working paper estimated that the costs of Long Covid could be as high as \$141–317 billion per year across OECD countries. 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.¹⁹

9 Building an NHS that's there for Long Covid and ME | Policy brief

This paper highlights an opportunity for a new Labour government to put its public service mission into action through a new approach for people impacted by Long Covid and ME. It explores how Labour's aspirations for the NHS measure up against the experiences of people with Long Covid and ME, highlighting recommendations for first steps to signal commitment to doing things differently.

Ultimately, this paper calls for 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's there for them when they need it, offering safe care and access to the best that modern science can offer.²⁰

Data from the Long Covid and ME communities: a stark reality

This policy brief draws on data from an online survey conducted from 10 June to 6 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 NHS care, and their perceptions of efforts in the UK to advance treatments.²¹

The survey had 328 responses: 50 were carers for people with Long Covid or ME, 189 patients with Long Covid, 148 patients with ME (55 said they had both) and 9 who considered themselves recovered from Long Covid or ME.

Of those surveyed, over half (53%) considered themselves or the person they cared for moderately affected, facing significant limits to daily activities and often being housebound. Significant proportions of respondents also reported mild (17%) and severe (23%) symptoms. A minority reported symptoms that were Very Severe (6%), leaving them (or, in most cases, the person they cared for) bedbound, with limited or no ability to communicate and being reliant on full-time care. Notably, even those with symptoms considered 'mild' by standard severity scales used to quantify ME symptoms suffer from symptom flare-ups that can significantly impact their quality of life.²²

Considering that the survey may not be fully representative, patients' voices are situated in the context of wider research, echoing many of the challenges highlighted here.

The opportunity for Labour – three commitments to build an NHS fit for the future

There are three Labour commitments, included in Labour's mission to build an NHS fit for the future, that could have the biggest impact. This chapter offers an outline of current shortcomings in these areas, with the final section exploring how these commitments can best be delivered to support people with Long Covid and ME.

- Area 1: An NHS that is there when people need it
- Area 2: Change so that more people get care at home in their community
- Area 3: A revolution in technology

Area 1: An NHS that is there when people need it

Labour has identified a fundamental challenge facing the UK's health system: as a result of systemic challenges, the NHS is no longer there for people when they need it.

Many people with Long Covid and ME identify with this challenge. Over two-thirds (67%) of those who responded to our survey felt that the NHS had not been there for them when they needed it.²³ In 2023, an ME Association survey of over 7,000 people in the UK with Long Covid and ME found that just 8% of people with ME, and 15% of those with Long Covid, rated the care they had received from the NHS as good or excellent – a finding that held across all UK regions.²⁴

Long Covid itself is one battle, trying to get help from the NHS is another on top of it – and so few of us have the energy to push for more help. No one is listening.

ME/Long Covid patient, affected for 2–5 years

Some patients who answered our survey spoke about positive experiences, often with individual clinicians who had treated them with empathy and understanding. However, too many others have traumatic experiences of healthcare where they have felt dismissed and/or disbelieved.²⁵ Many feel that their symptoms have been inappropriately

12 Building an NHS that's there for Long Covid and ME | Policy brief

psychologised, in spite of guidelines from the National Institute for Health and Care Excellence (NICE) recognising ME as a 'complex, chronic medical condition affecting multiple body systems' and mounting evidence documenting biological abnormalities in patients with ME and Long Covid.²⁶

The stigma and ignorance about ME in the NHS means that I try very hard to avoid mentioning ME in a medical setting, as I don't have the energy to 'defend' the way the illness affects me and bat away their suggestions that are often condescending, belittling and potentially harmful.

ME patient, affected for over 10 years

In my first year I had to visit A&E on numerous occasions. It was horrendous: I was left for hours until I wet myself (I couldn't move at the time and didn't have a call button). I've been shouted at by a doctor that all my results were normal so there was nothing acutely wrong with me. I have been told to stand up, [told that] I can walk, when I had been left in a wheelchair.

Patient with Long Covid, affected for 2–5 years

Labour's manifesto rightly puts patient safety at the heart of its plans to transform the NHS. Yet for some patients, experiences of seeking healthcare for Long Covid or ME have been so traumatic that they are reluctant to seek care again. Multiple patients told us that they would be reluctant to seek NHS care in the future even if experiencing life-threatening symptoms, expressing a sentiment that they would 'rather die at home'.

Even more concerning is that some patients and carers have witnessed their condition worsening in the course of or following NHS care. In some cases, this is due to the exertion involved in seeking healthcare, particularly where accommodations are not made to ensure care is accessible. In other cases, patients have deteriorated as a result of inappropriate care, including advice to increase activity or exercise – leading to a (sometimes long-term) deterioration in symptoms.

I feel completely abandoned by the NHS on the thing that has changed my life. On the odd occasion I have been to GP for other stuff they have been kind, caring, helpful and I have had my needs met. Presenting with LC/ME gets me disbelief, disinterest and no help at all.

ME/Long Covid patient, affected for 2–5 years

Only rehabilitation online exercise classes were on offer which left me 100% bed bound in a dark silent room for days at a time, unable to lift arms or move in bed, increased breathlessness and increased sensitivity to light and sounds [...] Attending the fatigue clinic was too much for me to manage and helped tip me from mild to severe. Over a decade later and I still haven't recovered.

ME patient, affected for over 10 years

The patients with the most severe ME and Long Covid symptoms are receiving the lowest standard of care.²⁷ Not a single person answering our survey who considered themselves or the person they cared for Very Severely affected felt that the NHS had been there for them. There are no specialist inpatient services for people with Severe or Very Severe ME or Long Covid.²⁸ Several patients and their carers reported being discharged from specialist services when their symptoms became severe, either due to an inability to attend appointments in-person or due to clinicians not feeling that their services were appropriate for severely affected patients.

When patients with the severest forms of ME or Long Covid end up in hospital due to life-threatening complications there is no NHS protocol to guide the care. Patients with Very Severe forms of ME or Long Covid are often unable to eat and digest food easily, meaning that they may require support with hydration and nutrition to avoid dehydration and malnutrition.²⁹ Patients and carers across different NHS trusts have reported traumatic experiences involving long and detrimental hospital stays, a breakdown of trust with clinicians, and delays introducing life-saving interventions.³⁰ For example, in a recent case reported by the BBC, the father of a young woman with ME spoke about how his daughter had 'dramatically deteriorated' in hospital and spoke of 'serious mistakes', expressing fears that his daughter would die in hospital.³¹

They have watched my teenage daughter deteriorate and have refused to engage with external expertise despite having advised us to seek it out and promises to learn from external experts. Six letters to the hospital CEO from external experts expressing concern about the management of my daughter's care [are] not even acknowledged.

Carer for patient with Very Severe ME/Long Covid

For years we had no support and had to deal with several situations that actually made her condition and our situation worse, when all we wanted was help and support. We were taken through child protection and I was accused of Munchausen by proxy.

Carer for patient with Very Severe ME

Even for patients experiencing less acute symptoms, for many, the interventions that are provided by the NHS fall short of their expectations.³² Many spoke about specialist ME/CFS services being limited to a 10-week fatigue management course, which many did not consider particularly helpful.

Some Long Covid clinics have offered a wider variety of services, including respiratory physiotherapy, and screening for co-morbidities and post-Covid damage to vital organs, with experiences differing significantly geographically.³³ Yet, even the best-equipped Long Covid clinic has little to offer beyond lifestyle advice when it comes to those meeting the criteria for ME, who suffer from some of Long Covid's most life-altering symptoms. Despite an evolving understanding of the condition and appropriate management due to emerging research, the NICE Guidelines for Long Covid have not been updated since 2021.³⁴

I am lucky as under Leeds [Long Covid clinic] and they seem to be much more with it in regards to new research etc. but I am only ever seen by [an occupational therapist] and physio. There are no doctors that patients see.

Patient with ME/Long Covid, affected for 2–5 years

I'd say that individual NHS practitioners have been there for me, but the system itself definitely has not. I think the [Long Covid] clinics in England were just a fob off to make it look like they were doing something without backing them up with the necessary funding or research input that they need to really make a difference.

Patient with Long Covid, affected for 2–5 years

Deepening healthcare inequalities, a two-tier system has emerged for Long Covid and ME in the UK, driven not just by long waiting lists but an inability to access meaningful care through the NHS. Over 70% of people who responded to our survey felt that they had to look outside the NHS to access care, reflecting similar figures from research by the Health and Social Care Alliance Scotland.³⁵ For many, this involves seeking information online and engaging with social media support groups to find strategies for managing symptoms.

Almost half (48%) of those who answered our survey had turned to private healthcare, including to access diagnostics and emerging treatments not routinely available in NHS practice, and in cases where there are no specialist services available in their area.³⁶ For some patients, the private sector gave them the first opportunity to feel listened to by a clinician familiar with cutting-edge research and established practice in treating symptoms of ME.³⁷ Notably, many of those answering our survey who said that they had not looked outside the NHS for care said that this was because they could not afford to do so.

[A private specialist] visited me at home and it helped a lot – partly through treatments such as LDN [low-dose naltrexone] but also just reassurance about pacing and resting.

Recovered Long Covid patient, affected for 2–5 years

Affording [private care] will be difficult, as I am on Universal Credit since it's so hard for me to work, but if I could get my health back, at least to a functional level, it would be worth it.

ME/Long Covid patient, affected for over 10 years

We've had to go into the private sector to find anyone who really understands severe forms of ME/LC or is willing to prescribe medication or treatment to try to relieve symptoms or improve our son's condition. The NHS seems only to be able to do very basic management e.g. provide advice on nutrition to ensure he gets the right dietary input through liquid meal replacements. There is a sense that 'we can't cure this we can only keep him stable' and unwillingness or inability to go further.

Carer for patient with Very Severe ME/Long Covid, affected for 2–5 years

Area 2: Care in the community and at home

Labour has committed to a 'Neighbourhood Health Service', implementing change so that people can get the care they need at home and in their community.

Only a small minority (4%) of those answering our survey said that they felt supported by the NHS to manage their symptoms at home. For many, Long Covid and ME services are simply not accessible from home. Our survey captured the stories of patients who were unable to access remote appointments or home visits. Many others struggled to navigate inflexible appointment booking systems due to cognitive difficulties.

I've had to order a heart monitor privately as the NHS wasn't flexible to arrange to come out to me, or show my dad how to fit it. I'm bedbound.

Long Covid patient, affected for 1–2 years

I've been losing my hearing for 6 months in one ear but not even bothered to call the GP as I have no way to find the energy to attend an appointment [...] I keep putting off the now very noticeable hearing loss as a priority because I can't imagine how to find the energy for a GP visit, let alone referral on to hospital.

Patient with ME, affected for over 10 years

It took me 10 years to persuade my surgery to put me on their official housebound register. Even now I'm on there they consistently refuse to give me home GP appointments and keep telling me to come into the surgery on days when I can't even get out of bed.

Patient with ME, affected for over 10 years

Labour rightly identifies general practice as the bedrock of the NHS. However, the patients we surveyed told us that too often, in-depth knowledge of ME and Long Covid in primary care is the exception rather than the rule. The ME Association's 2023 survey found that, while NICE had in 2021 changed its guidelines for the treatment of ME/CFS, few had noticed any change in their care since. In May 2023, just 28% of NHS Trusts and Integrated Care Boards were implementing the 2021 NICE Guidelines.³⁸ Instead, patients have had to inform and educate their healthcare providers themselves about the Guideline's recommendations, including that exercise is no longer considered an appropriate treatment.

For those who feel that the NHS had been there for them, in many cases this is due to their experiences with their GP. A significant number of people spoke about having 'good' GPs who listened to them with empathy and had been willing to explore treatment options based on the patient's own research. However, this was often framed as being in spite of, rather than being enabled by, the wider NHS system.

Found the one [doctor] in my practice who takes me seriously. It took 10 of them. But she listens, is open to ideas and my research and most importantly, is empathetic which makes the conversation so much easier.

Long Covid patient, affected for 1–2 years

My GP has been great, but he doesn't know Long Covid research or ME/CFS (he didn't know what PEM [post exertional malaise] is). So there is a lot of pressure on me to interpret and understand information about Long Covid for us to try to use.

Long Covid patient, affected for 2–5 years

Overall, less than a third felt that their GP understood and gave them the care that was required for complex needs due to ME or Long Covid. This echoes findings from a

recent Long Covid SOS study, which found that almost two-thirds of those they surveyed reported their GP being unable to help them, while almost one in 10 reported that their GP had told them they were suffering from anxiety.³⁹

Lack of knowledge about ME and Long Covid within primary care is particularly concerning given a lack of long-term support elsewhere in the NHS. Few Long Covid or ME/CFS clinics are equipped to maintain contact with patients long-term.⁴⁰ People told us about a lack of long-term monitoring in primary care and lack of long-term specialist input. Patients also suffer from a lack of continuity of care. Many Long Covid and ME patients, suffering from an energy-limiting condition, are exhausted from having to explain their complex symptoms to multiple healthcare professionals time and time again.

They [GPs] have an automatic 'we do not know about Long Covid' response, which is very unhelpful when you have been asking them for help from this illness for over 4 years.

Carer for Severe ME/Long Covid patient

I have no-one to discuss it with. No point discussing with my GP as there's nothing they can/will do. They referred me to the CFS clinic 7 years ago, which was pointless in the end, and when I was discharged. That was the end of my ME/CFS care.

ME patient, affected for 5--10 years

Area 3: Harnessing the UK's science and technology expertise to advance meaningful treatment for patients with Long Covid and ME

Labour has committed to harnessing technological advancements and the UK's scientific expertise to advance care for patients within the NHS.

The UK is a science and technology superpower, home to the first Covid vaccine and world-leading research institutions. Yet not enough is being done to make the most of these assets for patients with Long Covid and ME. Just 2% of those answering our survey felt that the UK was making the most of its science and technology expertise to advance

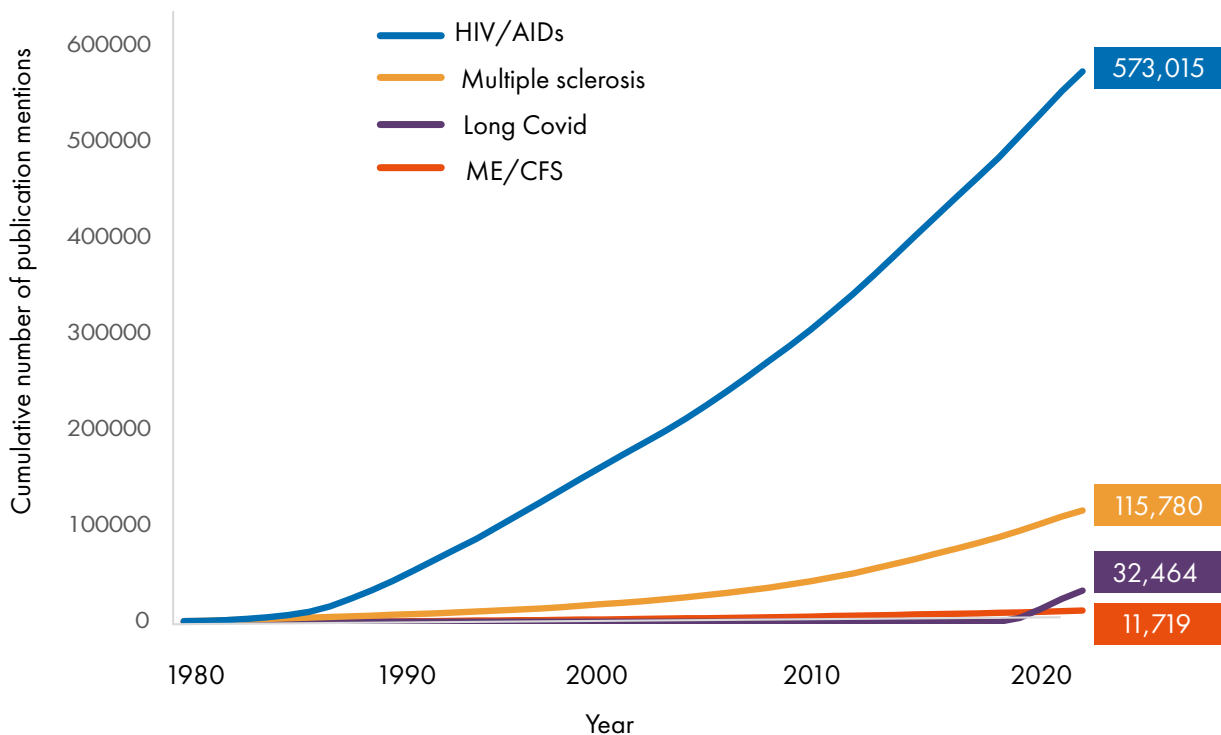
19 Building an NHS that's there for Long Covid and ME | Policy brief

meaningful treatments. Many with Long Covid feel that they are being left behind in a country that has moved on from the height of the pandemic, contrasting a lack of urgency in finding treatments to the extraordinary efforts that went into the rapid development of Covid vaccines.

Research on ME has been systematically underfunded for decades in light of its high disease burden, with a skew towards psychosocial rather than biomedical research. In the UK, from 2015 to 2020 just £6 million was committed in funding for ME/CFS research through the UK National Institute of Health Research (NIHR) and UK Research & Innovation (UKRI) Medical Research Council. This is compared to £53 million for Parkinson's disease research and £22 million for multiple sclerosis, each of which affect approximately half the number of people in the UK estimated to be living with ME prior to the pandemic, with many more now likely meeting the diagnostic criteria.⁴¹

There has been a vast increase worldwide in funding for Long Covid research, but this has not been sufficient to recover lost ground from decades of underfunding.⁴² In 2023, cumulative research publications for Long Covid and ME/CFS combined totalled just over 44,000: around a third of the number of research publications on multiple sclerosis and less than 10% of those focused on HIV/AIDs (see Figure 2).

Figure 2 Cumulative publications mentioning ME/CFS, multiple sclerosis and HIV/AIDs



Source: CrunchMe (<https://github.com/crunchme/pubmed-publications-analysis>, based on PubMed data)

The UK government committed funding for Long Covid research early in the pandemic, with almost £40 million of research funding in 2021.⁴³ However, no further funding calls have been issued since then, with most of the initially funded studies complete or nearing completion, and no pipeline of further studies. Some patients answering our survey were concerned that studies with Long Covid patients had duplicated existing ME research. They felt that promising work – including the UK-based Decode ME initiative – has been driven forwards by talented individual researchers rather than a system-wide approach.⁴⁴ Patients also expressed concerns that emerging research, including potential treatments, is not filtering down fast enough into clinical practice.

The Department of Health and Social Care Interim Delivery Plan on ME/CFS, commissioned in 2022 and still under review, highlights plans to undertake a landscaping review of national and international research work as a basis for future investment.⁴⁵ However, with delays to the delivery plan, there are concerns that undertaking such a review could cause further deferrals to expanding research investment, particularly since significant landscaping work is already in place. Future research investments could draw on work by CrunchME: a volunteer project, mapping out the research, clinical, technological, and advocacy ecosystem around ME, Long Covid, and other infection-associated chronic conditions, both in the UK and internationally.⁴⁶ Their aim is to provide a foundation of evidence and insight to new and existing members, and so accelerate progress towards treatments and cures.

The funding rates for research are a pittance compared to other conditions. We want to be well, we want to work, we want to lead active lives – help us! Please.

ME patient, affected for over 10 years

I welcome funding and research into this subject, but it should focus on real biomedical, scientific research. Too often, money is wasted on psychological or exercise-related 'research', instead of investigating the causes and effects at a micro level [...] We don't need more good money being thrown at bad science.

ME patient, affected for 5–10 years

Our survey highlighted opportunities to better leverage science and technology to advance care for people with Long Covid and ME. Patients' suggestions included clinical trials within the NHS for off-label medications, funding research into biomarkers, and using technology to enable remote clinical trials that could be done from home.

Long Covid experts have highlighted that enough is already known about Long Covid and ME to be building more ambitious, full-scaled randomised control trials for varied therapeutics.⁴⁷ Thus far, the missing pieces are funding and political will.

Some also pointed to existing examples of technology used for at-home symptom monitoring, which could be adopted within the NHS to great effect. For example, Visible is a UK-based digital care platform designed for the millions of people living with a complex chronic illness. The platform uses wearable technology to help patients manage their condition by predicting symptom flare-ups, and to measure their condition via digital biomarkers. It is notable that Visible was conceived and developed by people with Long Covid in an attempt to help themselves and others.

Research needs to be particularly focused on diagnostic tests and treatments - ideally fast track trials of repurposed existing drugs.

ME/ Long Covid patient, affected for over 10 years

My most useful intervention has been heart rate monitors [to track symptoms and manage activity] but the NHS doesn't do them or even have any useful advice. The new Visible app is brilliant – the NHS should be getting behind it.

ME patient, affected for 5–10 years

Recommendations and the way forward

The communities behind this paper ask for a discussion with the new Labour government to explore the following recommendations.

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

- a. Setting high expectations for the NHS, articulating a vision from the top of government in relation to NHS care for patients with ME and Long Covid, for an NHS where patients are listened to, believed and where they can access safe care, building on the best that modern science can offer. This should include accessible, multi-disciplinary and long-term care, within their home or community (wherever possible).
- b. Appointing a Minister for Long Covid and ME, signalling that improving patient care is a priority for a Labour government.
- c. Prioritising the urgent publication of the new cross-government delivery plan for ME/CFS, ensuring that it meets the aforementioned priorities.
- d. Demonstrating that the Labour government is committed to patient safety for people with Long Covid and ME by developing an NHS Severe ME Safe Hospitals protocol.⁴⁸ This should draw on UK and global expertise on Severe ME, as well as applicable UK standards. For example, the 2021 NICE Guidelines for ME/CFS and relevant Care Quality Commission regulations (e.g. regarding Duty of Candour and Meeting Nutritional and Hydration Needs).

2. Make the most of the UK's science and technology expertise to advance treatments for people with Long Covid and ME. This should include:

- a. Committing at least £100 million of annual funding for Long Covid and ME research.⁴⁹ Research funding should prioritise biomedical research, biomarkers and treatments, and should draw on patients' lived experience and research priorities.
- b. Convening UK-based researchers, pharmaceutical companies, technology companies and patient advocates to develop a strategy for mobilising the UK's science and technology expertise to accelerate treatment for Long Covid and ME.
- c. Ensure that emerging research in the UK and globally filters down into clinical practice in the NHS. For example, by committing to updating the NICE Guidelines for Long Covid on the basis of new research.

3. Do more with the tools we already have while waiting for new treatments to be developed. This should include:

- a. 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). This should include making relevant training available so that all primary care practitioners are familiar with symptoms of ME and appropriate management.
- b. Support access to emerging treatments within the NHS, including as part of clinical trials. Access to treatments should be based on evidence of safety and efficacy. For example, promising candidates that are currently undergoing clinical trials in the United States include Low Dose Naltrexone and Pyridostigmine.⁵⁰
- c. Leverage technology-enabled solutions that already exist. For example, exploring the uptake of wearables (e.g. via Visible) for remote monitoring and symptom management within NHS ME and Long Covid care.
- d. 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) and extending Covid Infection Survey monitoring year round.

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 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).

14 See footnote 2.

15 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.

16 Department for Education, Department for Work & Pensions and Department for Health and Social Care (2024) 'My full reality: the interim delivery plan on ME/CFS' (www.gov.uk/government/consultations/improving-the-experiences-of-people-with-mecfs-interim-delivery-plan/my-full-reality-the-interim-delivery-plan-on-mecfs).

17 ME Action (2023) '#MEAction UK's Response to DHSC (My Full Reality: The Interim Delivery Plan on ME/CFS)' (<https://www.meaction.net/2023/10/03/meaction-uks-response-to-dhsc-my-full-reality-the-interim-delivery-plan-on-me-cfs/>).

18 Barnett, J. (2024) 'Record number out of work because of long-term sickness'. The Times, 17 April (www.thetimes.com/business-money/article/record-number-out-of-work-due-to-long-term-sickness-8n8cxd0h3).

19 See footnote 11.

20 Labour Party (2024) 'Labour's Manifesto: Build an NHS fit for the future' (<https://labour.org.uk/change/build-an-nhs-fit-for-the-future/>).

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

22 Action for ME (n.d.) 'Functional ability scale' (www.actionforme.org.uk/uploads/pdfs/functional-ability-scale.pdf).

23 Turk, F. et al. (2024) 'Accessing care for Long Covid from the perspectives of patients and healthcare practitioners: A qualitative study' *Health Expectations* 27:2 (<https://doi.org/10.1111/hex.14008>).

24 ME Association (2023) 'Count ME In: Campaign Summary' (<https://meassociation.org.uk/wp-content/uploads/THE-ME-ASSOCIATION-2023-COUNT-ME-IN-CAMPAIGN-REPORT-14.09.23.pdf>).

25 Similarly, the ME Association's survey of over 7,000 patients with ME and Long Covid found that 'not being taken seriously' was one of the key barriers leading to delayed diagnosis.

26 See for example: Arron et al. (2024) 'Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: the biology of a neglected disease' *Frontiers in Immunology* (<https://doi.org/10.3389/fimmu.2024.1386607>); Appelman et al. (2024) 'Muscle abnormalities worsen after post-exertional malaise in long COVID' *Nature Communications* (<https://doi.org/10.1038/s41467-023-44432-3>); Kahn et al. (2023) 'Differential Cardiopulmonary Hemodynamic Phenotypes in PASC Related Exercise Intolerance' *ERJ Open Research* (<https://doi.org/10.1183/23120541.00714-2023>); Vanderheiden et al. (2024) 'Vaccination reduces central nervous system IL-1 β and memory deficits after COVID-19 in mice' *Nature Immunology* (<https://doi.org/10.1038/s41590-024-01868-z>).

27 All-Party Parliamentary Group on ME (2022) 'Rethinking ME' (<https://appgme.co.uk/wp-content/uploads/2022/05/Rethinking-ME-a-report-by-the-APPG-on-ME-2022.pdf>).

28 See footnote 13.

29 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).

30 See for example: Baxter, H., Speight, N. and Weir, W. (2021) 'Life-Threatening Malnutrition in Very Severe ME/CFS' *Healthcare* (<https://doi.org/10.3390/healthcare9040459>); O'Neil, S. (2022) 'My daughter couldn't be saved but there's hope for other ME patients'. *The Times* (www.thetimes.com/uk/healthcare/article/my-daughter-couldnt-be-saved-but-theres-hope-for-other-me-patients-j7lbgg68k); BBC (2023) 'Family calls for feeding change to save Exeter ME patient'. 1 March (www.bbc.co.uk/news/uk-england-devon-64809671); Fry, E. (2024) 'I can't walk, talk or eat – doctors don't believe what's wrong with me and I think I'm going to die'. *Mirror*, 4 April (www.mirror.co.uk/news/health/severe-killing-me-doctors-wont-32491644);

31 Jackson, L. (2024) 'I'm scared my daughter will die in hospital'. *BBC*, 11 July (www.bbc.co.uk/news/articles/c9rry6lr54lo).

32 See also: 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/).

33 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>);

34 NICE (2024) 'COVID-19 rapid guideline: managing the long-term effects of Covid-19' (www.nice.org.uk/guidance/ng188).

35 BJGP Life (2024) 'Long COVID: why are people still struggling to access care?' (<https://bjgplife.com/long-covid-why-are-people-still-struggling-to-access-care/>).

36 According to 2023 ME Association survey data, not having a specialist service in the respondent's area was the top reason for not using an NHS referral service: this applied to 29% of those surveyed with ME and 21% of those surveyed with Long Covid. See: ME Association (2023) 'Count ME In: Campaign Summary' (<https://meassociation.org.uk/wp-content/uploads/THE-ME-ASSOCIATION-2023-COUNT-ME-IN-CAMPAIGN-REPORT-14.09.23.pdf>).

37 Patients turning to private care for Long Covid is also highlighted here: 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/).

38 Action for ME (2023) 'Patchy, Misunderstood and Overlooked: Implementation of the NICE Guideline [NG206] on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in England' (www.actionforme.org.uk/uploads/images/2023/05/Action_for_M.E._FOI_report.pdf).

39 Long Covid SOS (2024) 'GP Engagement with Patients with Long Covid: Report based on Survey carried out by Long Covid SOS February – March 2024' (https://3ca26cd7-266e-4609-b25f-6f3d1497c4cf.filesusr.com/ugd/8bd4fe_57703701d6d14c979cd8d953c803bf1d.pdf).

40 See footnote 35.

41 Analysis based on data from <https://gtr.ukri.org/> by Peter White and colleagues. More details available on request.

42 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): 879 ([https://doi.org/10.1016/S1473-3099\(23\)00440-1](https://doi.org/10.1016/S1473-3099(23)00440-1)).

43 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/).

44 DecodeME (n.d.) 'About our ME/CFS research study' (www.decode.me.org.uk/about-us/).

45 See footnote 16.

46 CrunchME (2024) 'CrunchME' (<https://crunchme.notion.site/CrunchME-bdad59a761ae4ff495fc82686a6ab7b9>).

47 Unite to Fight (2024) 'Prof. Daniel M. Altmann: Immunology of Long Covid (UniteToFight2024 Day 1, Block 1)' (www.youtube.com/watch?v=92McJwxHi_4&ab_channel=UniteToFight).

48 Areas covered should include specialised care pathways, education and training, research and innovation. See Callow, S. (2024) 'Press Release – Open Letter to Secretary of State for Health and Social Care Victoria Atkins MP' (www.mefoggydog.org/2024/02/13/press-release-open-letter-to-secretary-of-state-for-health-and-social-care-victoria-atkins-mp/).

49 £100 million annual research funding was recommended by the All-Party Parliamentary Group on Coronavirus: 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/).

50 Cabanas, H. et al. (2021) 'Potential Therapeutic Benefit of Low Dose Naltrexone in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Role of Transient Receptor Potential Melastatin 3 Ion Channels in Pathophysiology and Treatment' *Frontiers in Immunology* (<https://doi.org/10.3389/fimmu.2021.687806>); Joseph, P. et al. (2022) 'Neurovascular Dysregulation and Acute Exercise Intolerance in Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A Randomized, Placebo-Controlled Trial of Pyridostigmine' *Chest* (<https://doi.org/10.1016/j.chest.2022.04.146>).