ACTION FOR M.E.

THE 25% ME GROUP
SUPPORTING THOSE WITH SEVERE M.E

Severe ME Inquiry Report

7th August 2026

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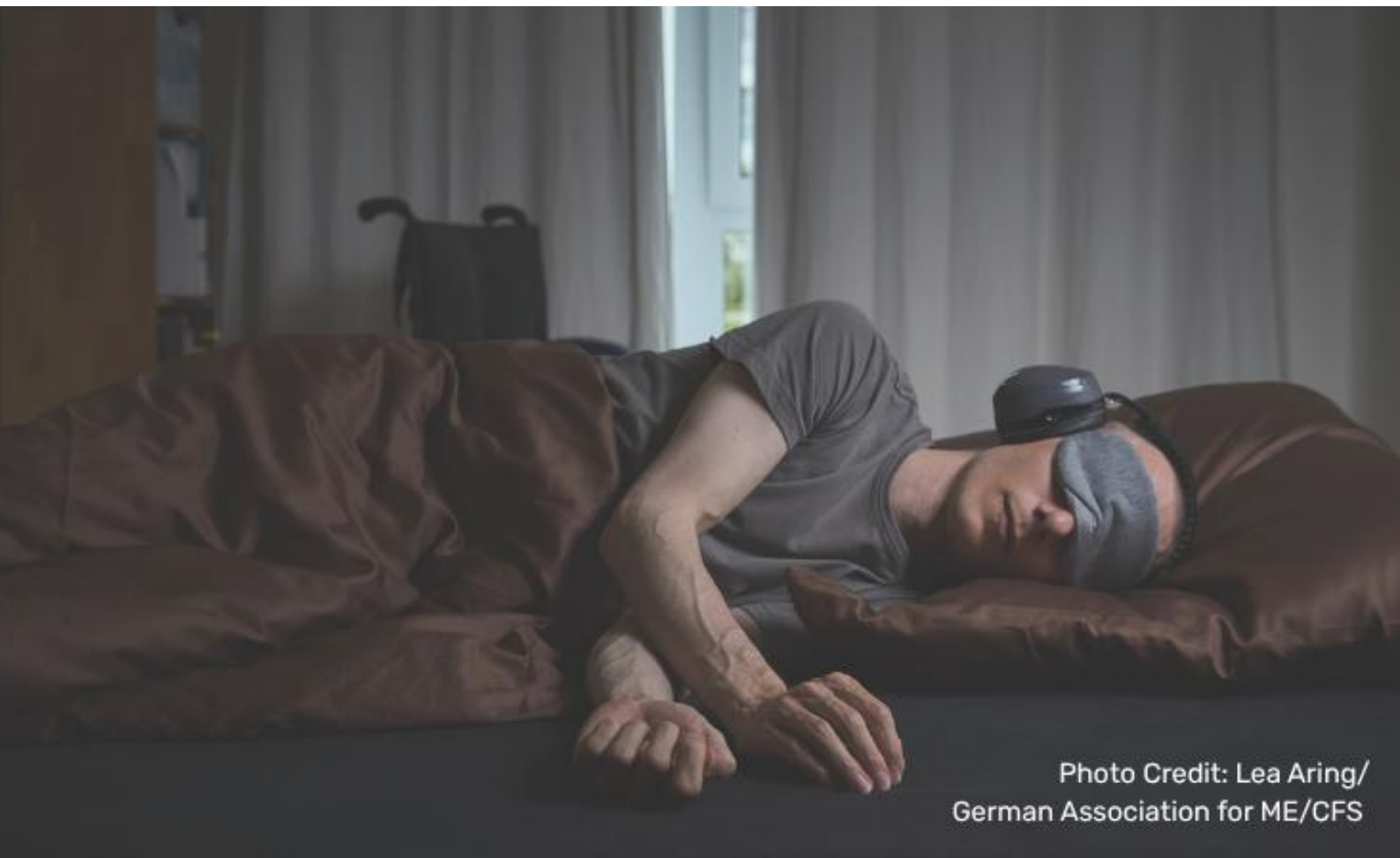

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Foreword – Tessa Munt MP

It is both an honour and a grave responsibility to introduce this report, which gives voice to a group of people whose suffering is too often unseen, unheard, and insufficiently understood. Sadly, for a few, it results in loss of life.

This inquiry set out to examine the experiences of people living with severe and very severe myalgic encephalomyelitis (ME) – individuals whose lives are profoundly constrained by a complex, debilitating, and at times life-threatening condition. The evidence received was compelling, consistent, and deeply troubling. It paints a picture not simply of unmet need, but of systemic failure.

People with severe and very severe ME constitute about a quarter of all those with ME, and so their numbers are not insignificant. They are among those with the worst quality of life in our society. Many are confined to darkened rooms, unable to tolerate light, sound, touch, or even the basic exertions required to communicate or even manage food and water. Yet despite this extraordinary level of need, they are too often excluded from the very systems designed to support them. Healthcare services don't accommodate the specific needs of those with severe and very severe ME, to the extent that trying to use these services may be harmful, making them effectively inaccessible. Social care is insufficient and inflexible. Education systems struggle to respond appropriately. Across all sectors, a lack of knowledge and understanding continues to drive stigma, disbelief, and, in some cases, decisions that actively harm.

What struck me most forcefully throughout this inquiry was the stark injustice at its heart: those who are the most seriously ill are often the least able to access care. Instead, the burden falls – unseen and unsupported – on family carers, many of whom are providing complex and highly skilled care under immense pressure, without training, guidance, or respite.

Equally concerning is the evidence of institutional prejudice and misunderstanding. Too many people with severe ME report that their illness is doubted, their symptoms dismissed, or their needs misinterpreted. In the most distressing cases, this has led to inappropriate safeguarding interventions, including allegations of fabricated or induced illness in children. Such actions can have devastating consequences for families already coping with extreme illness.

This report does not seek to rehearse problems that are already well documented without also setting out a clear path forward. The recommendations presented here are practical, evidence-based, and achievable. They centre on one overriding principle: that people with severe and very severe ME must be able to access safe, appropriate, and compassionate care – care that recognises the reality of their condition and is designed around their needs, not around the limitations of existing systems.

Foreword – Tessa Munt MP (continued)

It is important to acknowledge that this inquiry was not concluded within a single parliamentary cycle. However, the contributions made by individuals with lived experience, carers, clinicians, and professionals were too important to be lost. I pay heartfelt thanks to everyone who shared their experiences, often at great personal cost. This report, brought forward by Action for ME and the 25% ME Group, ensures that their voices continue to inform and shape the work ahead.

There is an urgency to this issue that cannot be overstated. The evidence presented here shows that current failures are not benign – they have serious, sometimes life-threatening consequences. Delay is not a neutral act. Without decisive and coordinated action, people with severe and very severe ME will continue to suffer unnecessarily.

I take heart then at commitments that Prime Minister Andy Burnham made in his first speech, given outside 10 Downing Street. The Prime Minister spoke *of helping people to live well, building a more preventative state, investing in people's success rather than paying for failure*. He concluded that this should be *the moment we bring back hope*. As the report demonstrates, these aspirations resonate so strongly with the dreams of all those who live with severe ME.

As Chair of the APPG on ME, I urge Government, the NHS, Integrated Care Boards (ICBs), local authorities, and all relevant bodies to act on these findings with the seriousness they demand. Change is both necessary and possible. The question is no longer whether we understand the problem – but whether we are willing to respond.

We owe it to those living with severe and very severe ME, to their families, and indeed, to our country, to ensure that this report marks not another missed opportunity, but a turning point, the start of bringing back hope after far too many years of being failed.

Tessa Munt MP

Chair, All-Party Parliamentary Group on ME

7 August 2026

Report

1. Executive Summary

This report presents the findings of an inquiry that was initially started by the All-Party Parliamentary Group (APPG) on ME into the experiences of people living with severe and very severe myalgic encephalomyelitis (ME). Due to changes following elections, the inquiry was not concluded by the APPG.

The inquiry was supported by Action for ME and The 25% ME Group, and drew on evidence from people with lived experience, family carers, clinicians, and professionals across health and social care. This report is a joint report by the two charities to ensure that the energy taken in providing evidence was not lost and will shape the charities' work going forwards.

People with severe and very severe ME experience profound, life-limiting disability, yet face systemic failure across healthcare, social care, and education. Evidence to the inquiry reveals that services are fragmented, frequently inaccessible, and in some cases unsafe. A lack of understanding of the condition contributes to stigma, disbelief, and harmful decision-making, resulting in avoidable deterioration, delayed treatment, and – in extreme cases – life-threatening consequences.

The inquiry identifies consistent and overlapping **failures across systems:**

- **Healthcare services** are not designed for people who cannot tolerate standard environments or processes due to their symptoms, leaving many unable to access essential care.
- **Social care provision** is inadequate and inflexible, failing to meet basic needs and placing unsustainable pressure on family carers.
- **Children and young** people face delayed diagnosis, disbelief, and inappropriate safeguarding responses, including wrongful allegations of fabricated or induced illness.
- **Professional knowledge and training** remain insufficient, driving poor and sometimes unsafe care.

As a result, people with severe and very severe ME are exposed to a postcode lottery of provision, with outcomes dependent on geography rather than need. In the absence of appropriate systems, family carers are forced to provide complex, high-risk care without adequate support or guidance.

This report concludes that the current system is not only failing to meet need but is, in some cases, causing harm. Without urgent and coordinated action, people with severe and very severe ME will continue to experience avoidable suffering, exclusion, and risk.

2. Key Recommendations

Immediate patient safety actions (within 6 months)

These actions are needed urgently to prevent avoidable harm and improve the safety of people with severe and very severe ME while wider reforms are implemented.

1. **Ensure urgent and equitable access to life-sustaining care**
   Introduce national standards for rapid access to nutritional support, specialist input, and hospital care where needed, with clear “red flag” criteria.
2. **Establish a national framework for severe and very severe ME**
   Develop and implement a nationally mandated service model, including a clear service specification and referral pathway, specialist provision, and community care standards.
3. **Protect patients and families from inappropriate safeguarding interventions**
   Strengthen statutory safeguarding guidance to prevent the misinterpretation of ME symptoms as (for example) self-neglect or fabricated and induced illness.

Priority system reforms (within 12 to 24 months)

These reforms are needed to address the underlying causes of poor care and ensure consistent support across England.

4. **Introduce mandatory training across health, social care, and education**
   Require all relevant professionals to undertake ME-specific training when they are caring for a person with severe and very severe ME to enable safe, suitable care.
5. **Strengthen national leadership, accountability, and data**
   Introduce stronger national oversight of severe and very severe ME through dedicated clinical leadership, annual reporting on implementation and outcomes of the ME/CFS Delivery Plan, improved national data collection, and the inclusion of ME within wider health inequalities monitoring and workforce planning.
6. **Improve support for children and young people**
   Ensure children and young people with severe ME can access appropriate healthcare and education that is flexible, based on individual need, and does not require them to exceed their energy limits.
7. **Accelerate ME research and innovation**
   Recognise severe and very severe ME as a national research and innovation priority, supporting the development of diagnostics, treatments and clinical trials while positioning the UK as a global leader in post-infectious disease research.

3. Introduction

Myalgic Encephalomyelitis (ME), also sometimes referred to as Chronic Fatigue Syndrome (CFS) or as ME/CFS, is a "serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients", causing significant functional impairment, ill health and disability.[1] For the purposes of this report, we refer to the illness as ME.

The hallmark feature of ME is post-exertional malaise: exertion-induced worsening of symptoms, which "may be an immediate or a delayed, disproportionate response to physical, orthostatic, or cognitive effort, or sensory stimuli".[2] Additional physical symptoms associated with ME include activity-induced muscle fatigue, pain, cognitive dysfunction, problems with the regulation of pulse and blood pressure (dysautonomia), poor and unrefreshing sleep, and the inability to sustain physical and mental activity. The quality of life of people with ME is acknowledged to be "lower than that of many people with other severe chronic conditions, including multiple sclerosis and some forms of cancer."[3]

It is estimated that up to 1.35 million people in the UK live with ME or ME-like symptoms.[4] This is more than the combined number of people in the UK living with multiple sclerosis, rheumatoid arthritis and systemic lupus erythematosus.[5] As recovery from ME is uncommon and the illness shows two distinct peaks of onset (during adolescence and in the mid-thirties), many individuals experience prolonged ill-health across their prime working years, creating a significant personal, societal and economic burden.[6] This burden falls disproportionately on women: ME is more prevalent in women than in men.[7]

3.1 Definition of Severe and Very Severe ME

Around one in four people with ME are severely or very severely affected by the condition.[8] This means that up to 337,500 people in the UK are currently living with severe or very severe ME, according to recent prevalence estimates.[9]

People with severe and very severe ME live with a severity of illness that few can imagine. At worst, they are bedbound, reliant on round-the-clock care, in significant pain, and unable to sit up, wash, dress or feed themselves. They can face great difficulty speaking and communicating. Some do not have the energy to chew or swallow and so rely on tube feeding for nutrition and hydration. Light, noise and touch are physically painful; people with severe and very severe ME can be too unwell to receive even a gentle hug.[10]

The National Institute for Health and Care Excellence (NICE) define severe and very severe ME as follows:[11]

People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.

People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

3.2 Action for ME and the 25% ME Group

Action for ME is the leading UK charity supporting people of all ages living with Myalgic Encephalomyelitis (ME), providing healthcare services, information and support, and funding research into the condition. The charity also works at government level to ensure the experiences of people affected by ME shape UK policy.

The 25% ME Group is a national charity which has been providing support to people with severe and very severe ME for over thirty years. As the only charity focusing solely on those with the most severe form of the illness, it has a comprehensive understanding of the issues affecting patients and caregivers. The organisation campaigns for greater awareness and understanding of the condition and provides vital services and resources for the community.

4. Purpose of the Inquiry

4.1 Scope

The Inquiry sought to:

- Identify how people affected by severe and very severe ME interact and engage with health and social care and other professionals
- The extent to which public bodies currently consider and respond to the needs and views of people affected by severe and very severe ME in delivering services and support
- The ways in which services and support can be strengthened for people affected by severe and very severe ME

4.2 Aims

The aims of the inquiry were to:

- Collect and analyse evidence from a range of stakeholders about the ways in which public bodies currently deliver their services to meet the needs of people affected by severe and very severe ME, including children and young people, with a specific focus on health and social care
- Develop and disseminate evidence-based recommendations about how health and social care for people affected by severe and very severe ME, including children and young people, can be strengthened
- Ensure that ongoing policy decisions and developments that impact people with severe and very severe ME are informed by robust evidence and by the views, insights and experiences of people affected by severe and very severe ME.

4.3 Methodology

Information and evidence from stakeholders were collated by:

- Developing and promoting a targeted call to evidence that was distributed to the wider APPG membership and a range of stakeholders with lived or professional experience of ME, and, especially, severe and very severe ME
- Holding a series of evidence sessions, some of which were heard by APPG members, to hear the views of people affected by severe and very severe ME, and those in health and social care working with them
- Submissions of written evidence from people living with severe and very severe ME, their families and health and social care professionals
- Reviewing existing information and data regarding the impact of severe and very severe ME, including the Government's 2025 policy paper, 'ME/CFS: the final delivery plan'[12]
- Briefings provided to the APPG by Action for ME and The 25% ME Group

4.4 Evidence

The inquiry heard evidence on health and clinical care from:

- Action for ME and The 25% ME Group
- Two people with lived experience of severe and very severe ME: a woman in her forties who has lived with very severe ME for 12 years and who had worked as a medical professional prior to becoming ill, and a woman in her sixties who lives with very severe ME and has had ME for 30 years
- A family carer whose daughter lives with very severe ME
- Three NHS clinicians with expertise in ME care: a GP with special interest in ME, a specialist occupational therapist, and a specialist physician

The inquiry heard evidence on social care and support from:

- Action for ME and The 25% ME Group
- Two people with lived experience: one who is severely affected and has had ME for 25 years, and one who is very severely affected and has had ME for 30 years
- A family carer who, since childhood, has been caring for two family members with severe ME
- A social worker, who also has a close relative living with very severe ME

The inquiry heard evidence on children and young people from:

- Action for ME and The 25% ME Group
- A parent whose child has had severe ME for 4 years
- Two paediatricians with expertise in ME

5. Findings

5.1 Key themes

Inaccessibility of care and lack of accommodations

Considering the extreme severity of their symptoms, people with severe and very severe ME face barriers accessing services. For example, when inpatient hospital admissions are required – even when transport is provided by the ambulance service, via stretcher – the sensory stimulation of a busy hospital environment can provoke severe, long-lasting deterioration in their condition.

Institutional prejudice as a major barrier to care

Prejudice is described as the biggest barrier to accessing healthcare and support from social services. People living with severe and very severe ME report being stigmatised, disbelieved, treated with disrespect, and blamed for their illness, which can leave them feeling worthless. This is a recurring pattern across services, rather than isolated instances of poor care: one woman living with very severe ME told the inquiry she had lost count of how many times she had been treated in this way.

Unsafe care

People with severe and very severe ME are exposed to clinical risks because existing systems often fail to recognise and respond appropriately to the realities of the illness. The consequences can include avoidable deterioration, medical crises, and, in some cases, death. This is particularly evident in relation to nutrition, where severe swallowing difficulties and malnutrition can be overlooked or misinterpreted. The inquiry heard from one clinician who has had two patients she had admitted to hospital experience delays in access to life-preserving nutritional support after being incorrectly diagnosed with eating disorders.

Lack of professional understanding

Evidence to the inquiry suggests that many of the challenges identified are driven by a systemic failure to equip healthcare, social care and education professionals with an adequate understanding of severe and very severe ME. This lack of professional understanding has far-reaching consequences, contributing to inaccessible services, failures to provide reasonable adjustments, and, ultimately, avoidable harm to people with severe and very severe ME.

Misinterpretation of illness severity as safeguarding risk

A highly distressing theme is the way severe and very severe ME presentations – dark rooms, limited communication, fluctuating capacity, intolerance of touch – are at times misinterpreted as self-neglect, family obstruction, or fabricated and induced illness. This is particularly acute for children and young people, where disbelief and pressure to increase activity or attend school can escalate into safeguarding processes that families describe as "an extremely upsetting and traumatic experience".

Family carers pushed to the limits

Where services are inaccessible or absent, the burden of providing care falls to family members. Caring for someone with very severe ME is intensive and highly skilled work, yet few family carers receive guidance and support (including with skin care, continence and hygiene) and must learn through trial and error. Carers are exhausted, isolated, and financially strained: "pushed to the very limits of our resilience", as one carer told the inquiry.

5.2 Health and Clinical Care

Patchwork service provision

There is no national model, agreed pathway, or detailed operational guidance for severe and very severe ME. One clinician told the inquiry plainly: "There are no detailed national clinical guidelines or pathways for management of severe/very severe cases."

The evidence suggests that although the 2021 NICE guideline (NG206) provides an important framework, it is too brief to resolve the practical questions that arise in day-to-day care for this patient group.[13] Submissions also highlighted the absence of dedicated inpatient beds for severe and very severe ME, and no agreed national "red flag" criteria for hospital admission.

In the absence of a national pathway, services vary widely in accessibility and quality, and access is often shaped by geography rather than clinical need. Very few services accept severe and very severe patients at all; some regions have no meaningful provision, while others rely on a small number of overstretched specialist teams.

For patients, the impact is prolonged unmet need, avoidable deterioration, and (at worst) delays to receiving life-sustaining nutritional support. The impact is felt, too, by

clinical staff. A specialist physician told the inquiry that clinicians are burdened with "responsibility without authority": accountable for extremely unwell patients whose needs they could identify, but without the ability to secure admission, investigations, home visits, or coordinated community support.

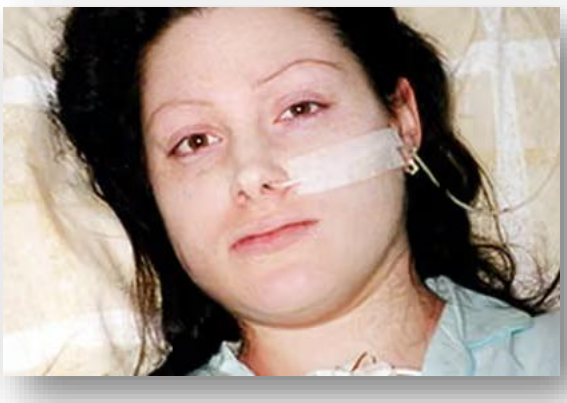
Care is inaccessible because NHS services are not designed for this degree of disability

For people with severe and very severe ME, the principal barrier is not only whether healthcare exists, but also whether it is delivered in a form that is safe and that their bodies can tolerate.

The evidence shows that ordinary features of healthcare delivery (travel, waiting, noise, bright lights) can trigger significant deterioration in this extremely ill patient population. A specialist occupational therapist explained to the inquiry that instances which may seem "trivial" – such as a 90-minute wait for transport home, or care agencies sending carers wearing perfume – can be devastating and even cause setbacks lasting months.

Inaccessible care has a significant knock-on effect. For example, a woman in her sixties living with very severe ME described an instance in which a nurse from the Rapid Response team came to her home and refused to talk quietly, even though she had explained about her ME and cited NICE guidance. The woman had to ask the nurse to leave: "I didn't get the antibiotics I needed and ended up in hospital as a result." This lack of reasonable adjustments places people living with severe and very severe ME in an impossible – and often risky – situation in which they have to avoid NHS healthcare because it is unsafe.

People with very severe ME are at risk of malnutrition



Nutritional decline emerged as one of the clearest examples of serious unmet need. The evidence described people with severe and very severe ME becoming unable to chew, swallow, digest or tolerate food, yet struggling to get timely specialist dietary support or enteral (tube) feeding.

A woman in her forties living with very severe ME told the inquiry about a negative experience in 2023, when she was admitted to hospital to commence naso-gastric tube feeding. Despite a BMI of 16, severe swallowing difficulties, a supportive specialist letter, and confirmation from Speech and Language Therapy that her swallow was unsafe, tube feeding was still delayed: "I was in hospital 10 days before tube feeding commenced". Most tellingly, feeding was only started once "an MRI/MRA diagnosed a

carotid dissection – which meant naso-gastric tube feeding was promptly initiated": in other words, once there was a non-ME diagnosis.

Evidence from clinicians reinforced this concern, describing patients being mislabelled with anorexia nervosa or routed through psychiatric assessment, causing delays to receiving life-preserving nutrition. The evidence suggests that where ME is the primary context, profound physical deterioration may still not be recognised as requiring urgent intervention. A specialist physician told the inquiry that this leads to "malnutrition, avoidable deterioration, hospital admissions, crises, or even death".

Prejudice and lack of knowledge remain barriers to care

One of the clearest themes across the evidence was that barriers to care are not caused only by gaps in provision, but by a deeper and more persistent problem of prejudice and lack of understanding. Submissions described a pattern in which severe disability is doubted, and complex physical symptoms are too readily reinterpreted as psychological or behavioural.

This prejudice takes a heavy toll. One person with very severe ME told the inquiry that receiving poor care is "often worse than receiving no care at all! It undermines our self-worth, sense of identity, and ability to cope with very difficult symptoms".

The evidence suggests that this prejudice is often fuelled by lack of knowledge about the realities of severe and very severe ME. For example, a family carer told the inquiry: "None of the many medical professionals I have spoken to (NHS and private) have seen a patient as severe as [my daughter] during their whole career. They have trouble understanding how someone can have so many symptoms and be so debilitated that they can't simply be assisted to attend an outpatient appointment." This is compounded by a lack of mandatory training for healthcare professionals, as multiple submissions indicate.

Family carers provide specialist nursing care, unsupported

Evidence presented to the inquiry showed that a lack of service provision transfers complex clinical and nursing responsibilities onto families.

A family carer described caring for her daughter who is "very severe, completely bedbound in a darkened room, unable to sit up, has great difficulty communicating… and needs 24-hour care." This carer spoke powerfully of the impact of caring for a loved one who is so extremely unwell: "I regularly feel powerless in the face of such immense suffering"; "it can be very lonely… I regularly experience feelings of grief, loss, anxiety and even despair."

Family carers are providing specialist nursing care with no guidance or support: "Everything I do has been learned through personal experience, learning from other carers and trial and error", one carer told the inquiry.

By contrast, in Norway there is a specialist inpatient unit (Røysumtunet) for severe and very severe ME, which is staffed by ICU-level nurses. Nothing comparable exists in the UK.

Physician-led specialist services are central to good care

The evidence was also clear about what works well. At the centre of positive accounts were physician-led specialist services. One person living with very severe ME spoke warmly of "a very good independent ME clinic… commissioned by my local CCG to provide NHS care". This service is led by a GP with a special interest in ME, who "recognised that I needed tube feeding in 2023, and liaised with the hospital team to make it happen".

More generally, submissions indicate that good care for people with severe and very severe ME is flexible, low-stimulus, and grounded in a biomedical understanding of the illness. It is care that minimises exertion rather than creating it, such as through virtual appointments (including with rest breaks) and home visits.

At the same time, the evidence suggests an underlying tension, which a specialist physician described as a "paradox": what is most accessible and clinically safer for patients – particularly remote care – can feel less safe for staff, as they cannot physically see the patient to assess risk. There is currently no guidance on how to reconcile these competing risks.

5.3 Social Care and Support

Pacing and continuity are critical to accessible care

The written evidence shows that many people with severe and very severe ME are not receiving enough care time to meet basic daily needs such as eating, drinking, washing and toileting. They are certainly not given sufficient care time to allow for essential pacing between these tasks. Contributors repeatedly stressed that severe ME care cannot be rushed, because activity must be carefully spaced to avoid post-exertional malaise. Yet care calls are often too short to allow this, with examples given of carers expected to provide personal care, manage incontinence, and prepare food within thirty minutes.

For people with severe and very severe ME, continuity of care is not simply a preference but is a core part of accessible care. Multiple submissions emphasised the damaging effects of frequent changes of carers and social workers, which force severely unwell people to explain detailed care processes (if they are even well enough to do so), at significant cost to their health.

By contrast, where a consistent care team was in place, people reported better care and less deterioration. One person living with very severe ME told the inquiry that

having a small team of the same four carers "makes such a difference to my life; I don't have to justify my needs and myself all the time".

Inadequate care leaves basic needs unmet and poses risk to health

The consequences of inadequate or inaccessible care are serious. Submissions linked inadequate care directly to weight loss, malnutrition, dehydration, missed medication, increased isolation, and long-term deterioration.

For example, an older woman living with very severe ME told the inquiry that her care arrangements did not allow for sufficient time for carers to cook a meal from scratch using fresh ingredients. Instead, she had to buy ready meals for carers to reheat – but she could not tolerate these, leading to "multiple bouts of diarrhoea daily". As a direct result, her weight plummeted to 34kg and she had to be admitted to hospital for tube feeding.

Across the evidence, the message is that underfunded and inflexible care packages are not merely inconvenient: they are unsafe.

Clinical need is misperceived as self-neglect

A particularly concerning finding is that declining certain forms of care – for example because of pain, hypersensitivity, or the harmful impact of rushed support – can be interpreted by some social care professionals as self-neglect, rather than as a consequence of having severe or very severe ME.

Multiple submissions detailed people with very severe ME being threatened with, or subjected to, referrals to social services for self-neglect. The pain this causes is clear in the evidence. For example, one person living with severe ME told the inquiry that the worry about social workers doing a safeguarding referral hung over her "like the sword of Damocles – it was awful".

Lack of knowledge about ME is prevalent and mandatory training is required

Multiple submissions evidenced the fact that caring for someone with very severe ME requires carers to deviate from processes that they are used to. Hypersensitivity to light necessitates working in a darkened room; carers must speak quietly – and only when necessary – and understand that the person with very severe ME may not be able to communicate with them. This population are typically unable to tolerate scents and so scented beauty products and perfume cannot be worn by carers as it can intensify symptoms or even provoke deterioration. Without a basic understanding of the illness, these clinically necessary adjustments to care can be misinterpreted as unreasonable demands.

The evidence indicated a need for mandatory training to enable all those working in social care – from social workers to individual carers – to develop the necessary skills and knowledge to provide accessible care to people with severe and very severe ME.

Direct payments can improve care, but adequate support must be in place

The evidence suggests that direct payments can offer good outcomes for people with severe ME, particularly where they allow individuals to recruit a small, consistent team of carers or personal assistants who understand their needs.

However, people with severe and very severe ME are often too unwell to manage direct payments, which involves taking on the role of the employer: sorting tax, managing rotas, and conducting interviews, among other responsibilities. Submissions spoke of the need for administration support for people with severe ME to enable them to manage their care through direct payments.

Family carers carry unsustainable responsibilities

The inquiry heard evidence that shows the extent to which unpaid carers – most often partners, parents, and children – are being left to hold together inadequate systems of care. This burden is intensified by the fact that family carers often end up doing work that should sit with formal services: training agency staff, coordinating care, and compensating when care packages fail or do not materialise.

The evidence heard expressed the substantial physical and emotional strain that carers are under. The extreme levels of illness experienced by this population, and the inaccessibility of care offered by social care services, means that family carers can be unable to have any respite from their caring responsibilities. The inquiry heard that carers are left "shouldering immense stress, isolation, emotional and financial challenges".

5.4 Children and Young People

Diagnosis is delayed, leaving families and children vulnerable to harm

A consistent theme in the evidence is that children with severe and very severe ME face major barriers even getting a diagnosis.

Action for ME and The 25% ME Group told the inquiry that "difficulty experienced gaining a diagnosis is widespread" because "many GPs have very limited knowledge of the condition" and there are "only a few specialised services available." Even where specialist provision exists, families can face "extensive waits for an appointment", leaving children dependent on GPs or local paediatricians who may have little knowledge or training on ME.

The evidence suggests that this diagnostic gap has serious consequences. Without timely diagnosis or appropriate early advice, Action for ME and The 25% ME Group summarised, children may be pushed into "school attendance or increasing activity which can worsen their condition." Moreover, a paediatrician described the diagnosis of ME as "the essential ingredient in protecting the child and family", including from

inappropriate accusations of neglect and abuse, so any delay to this process leaves children and families in a precarious position.

Clinical disbelief is prevalent and problematic

One of the strongest themes in the evidence is that children with severe and very severe ME and their families are too often disbelieved by health and social care professionals, with serious consequences. Action for ME and The 25% ME Group summarised that "it is an unfortunate fact that for the more severely ill children there sometimes seems to be a failure to believe that anyone can be so seriously ill with ME".

Similarly, one paediatrician told the inquiry that "the biggest problem is that most doctors confronted with a severe case have never seen one before and respond with disbelief in the diagnosis." This paediatrician explained that this often leads clinicians to "make alternative diagnoses (often psychiatric), subjecting the patient to inappropriate investigations and hospital admissions, which can be very harmful."

Inappropriate diagnoses of fabricated and induced illness leave children and their families exposed to serious harm

A particularly disturbing theme across the evidence is that children with severe and very severe ME are at risk of being wrongly viewed through a safeguarding lens, including suspicion of fabricated or induced illness.

This theme is reinforced strongly by both parent and clinician testimony. A mother reported that her son was offered "an intensive 4-week admission for GET [Graded Exercise Therapy] and physiological input", and that when she refused this, it led to "misdiagnosis and accusations of FII." This led to "a safeguarding referral which placed my child on a child protection plan and myself being accused of neglect", before social services later escalated proceedings to remove her severely ill son from her care. This caused this mother and her family "so much distress" and left her "extremely unwell".

A paediatrician told the inquest that the definition of fabricated and induced illness has been widened in recent decades, increasing "its possible incidence a thousandfold", which "has created a virtual moral panic among doctors and causes many unnecessary referrals". This paediatrician has seen around 200 cases of paediatric ME in which families were threatened with child protection proceedings: "In my experience nearly all the parents swept up in this way are what I would categorise as 'super-parents', and none of them are in any way guilty of fabricating their child's illness, nor of neglecting them nor of emotionally abusing them."

Taken together, the evidence suggests that families affected by severe ME currently lack adequate protection from inappropriate allegations of fabricated and induced illness.

The most severely affected children receive the least support

Both clinicians and families described current health services as too limited and inconsistently resourced to meet the needs of children with severe and very severe ME. One paediatrician explained that his ME service has seen “a reduction in the finance” over time and now consists of only “just under a day and a half” of medical time per week, with “around 100 children on our caseload.” He said the children they “struggle most with” are those in the “severe and very severe group”, in part because of “the challenge of providing home based support across a relatively large geography with a very small team.” His conclusion was striking: “the most severely affected children are often the ones who get the least support because they’re at home.”

The evidence points toward a more localised and practical model of care. Another paediatrician argued that “all but the very severest cases are best nursed at home” and that what is needed is “good community care, with dedicated local consultants willing to do domiciliary visits.” He called for a “bottom up” approach in which general practices and district general hospitals develop named clinicians with an interest in ME.

Being believed is central to good care

Across the evidence, one of the clearest themes is that the most important difference often comes from professionals listening, believing and responding with compassion.

The evidence from a mother whose child has severe ME illustrates this particularly clearly. This mother told the inquiry that one of the biggest barriers her family faced was “the disbelief and not being listened to, not just myself but my child too.” She also described the emotional impact on her son, explaining that Child and Adolescent Mental Health Services (CAMHS) confirmed he was not experiencing a psychological condition and that “the only issue he had emotionally was that no one was believing or listening to him or his mum.”

One paediatrician emphasised that what children need from doctors is for them “to be open-minded, willing to learn and above all to treat their patients with common humanity.” Across the evidence, this was central to safe care that avoids causing and perpetuating institutional harm.

Education systems often fail severely affected children

The written evidence also highlights education as a major area of difficulty. Action for ME and The 25% ME Group’s summary stated plainly that “most children with severe ME will be unable to attend school at all, even on a part-time basis, and will need an alternative that suits their needs.”

However, where diagnosis is delayed or advice is poor, families can face pressure around attendance and activity. A paediatrician told the inquiry that it is “too, too, too common” for parents to report that they have “either been threatened with or actually

been prosecuted for non-attendance", often because "nobody's been able to give a clear diagnosis and therefore the school progressed down the non-attendance route."

At the same time, the evidence is clear that better educational arrangements are possible when schools understand the condition and respond flexibly. A paediatrician described this support as "variable" and dependent on individual staff who understand the illness "and therefore are advocates rather than necessarily the school as a system itself being supportive." This suggests that good educational support exists, but is often dependent on luck.

6. Analysis and Discussion

6.1 Clinical recognition without implementation

The 2021 NICE guideline (NG206), 'Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: diagnosis and management', provides an important national framework for ME care.[14] It recognises that people with severe ME may be unable to carry out activities for themselves, may be housebound or bedbound, and may be extremely sensitive to light and sound; it also recognises that people with very severe ME may be dependent on care, need help with eating and personal hygiene, and in some cases may be unable to swallow and require tube feeding.[15] This description closely reflects the evidence heard by the inquiry, including accounts of people who are bedbound, unable to tolerate light, noise or touch, dependent on round-the-clock care, and at risk of malnutrition.

However, the inquiry evidence shows that recognition in guidance has not yet been matched by implementation. Witnesses repeatedly described the absence of a national service model, agreed pathway, detailed operational guidance, dedicated inpatient provision, or national "red flag" criteria for urgent intervention in severe and very severe ME. This creates a gap between policy intent and lived reality: NICE describes what severe and very severe ME can involve, but local systems often lack the commissioned services, trained staff, referral routes, and escalation mechanisms needed to respond safely

6.2 Health inequality: The more ill you become, the less care you receive

The inquiry evidence demonstrates a clear health inequality: when it comes to ME, those with the greatest level of need often face the greatest barriers to care. Echoing this, findings from over 5000 responses to Action for ME's 2026 Big Survey, recently discussed in the House of Lords,[16] indicate that:

1. **Existing NHS dedicated ME services are inaccessible to those with severe and very severe ME.** Almost two thirds of Big Survey respondents with severe ME and four in five respondents with very severe ME cannot access their local ME service because they are too ill.
2. **People living with severe and very severe ME typically receive no ongoing support from the NHS.** The vast majority of Big Survey respondents with severe and very severe ME receive no follow-up care, monitoring or review from either their GP or specialist ME service. Only one in ten respondents with severe and very severe ME feel supported by the NHS.
3. **Malnutrition is a significant risk for people with severe and very severe ME.** One in four respondents living with severe ME and more than half of respondents living with very severe ME often or always struggle to eat enough to maintain their weight.

The Government's 2025 policy paper 'ME/CFS: the final delivery plan' acknowledges the "inequalities in service provision that need to be addressed", including inequalities which have meant that "those with severe or very severe ME/CFS […] have often felt particularly let down".[17] It also includes a commitment to "explore whether a specialised service should be prescribed by the Secretary of State for Health for very severe ME/CFS".[18] However, recent responses to parliamentary questions revealed that "the action to review a case for a specialised service commission" has been delayed until April 2027 due to the abolition of NHS England.[19]

On 3 July 2026, the Department of Health and Social Care confirmed that officials were continuing "to progress this action as far as possible ahead of April 2027, so that work can continue at pace following the completion of transformation in NHS England", noting explicitly that this "could include convening the clinical committee ahead of time".[20] Considering the depth of suffering and extent of the unmet need expressed across this inquiry – as well as recent evidence from Action from ME's 2026 Big Survey indicating the prevalence of this suffering and unmet need – it is imperative that this clinical committee is established as soon as possible, to avoid any further delays which could place lives at risk.

Moreover, the inquiry evidence reiterates both the importance and the value of ensuring that decisions about severe and very severe ME are informed by those with the greatest expertise, including people with lived experience, family carers, clinicians and voluntary sector organisations. The clinical committee should therefore include

representation from people with severe and very severe ME (including through family carers where necessary), clinical experts from within and outside the NHS (and, where appropriate, international experts), and charities like Action for ME and The 25% ME Group, to ground the development of a specialised service in the fullest available evidence and experience. Ensuring that the most severely affected patients are represented in this process is essential if these longstanding health inequalities are to be addressed.

6.3 Failures in nutritional care can have life-threatening consequences

The 2021 NICE guideline (NG206) identifies that people with severe and very severe ME may experience difficulties getting adequate nutrition and hydration for practical reasons or because of gastrointestinal symptoms or difficulty swallowing.[21] It recognises that people with severe or very severe ME may need monitoring for malnutrition.[22] It recommends that people with severe and very severe ME are referred to a dietitian with a specialist interest in ME.[23] In reality, such dietitians are few and far between and only a minority of people with severe and very severe ME are referred to a dietitian, often only after they have become significantly nutritionally compromised.[24]

Where tube feeding is required, NG206 recommends following NICE guidance on 'Nutrition support for adults: oral nutrition support, enteral tube feeding and parenteral nutrition' (CG32).[25] However, the inquiry evidence shows a failure to adhere to this guidance with delays in the implementation of tube feeding. Witnesses told the inquiry they had become severely malnourished prior to hospital admission with further delays in commencing tube feeding once admitted. There is a gap between NICE guidance and lived experience. There is no agreed pathway and often staff lack education on severe and very severe ME and nutrition leading to inappropriate psychological diagnoses without positive evidence of psychopathology. This can lead to life-threatening malnutrition and lifelong health impacts.[26]

6.4 Reasonable adjustments remain the exception rather than the norm

Under the Equality Act 2010, public bodies and providers of health and social care have duties to make reasonable adjustments so disabled people can access services.[27] Government guidance emphasises that this duty is *anticipatory*, meaning organisations should consider likely barriers in advance rather than waiting for harm to occur.[28] NHS England similarly states that health and social care organisations must remove barriers faced by disabled people and make health services as easy for disabled people to use as for non-disabled people.[29]

For people with severe and very severe ME, reasonable adjustments – such as virtual appointments and pacing between care tasks – can be the difference between safe

care and clinical deterioration. Despite this, evidence heard by the inquiry suggests that there has been a systemic failure to recognise severe and very severe ME as situations requiring anticipatory accessibility planning. Standard models of inpatient, outpatient and social care assume that patients can travel, wait, speak, tolerate sensory stimulation (light, noise, touch), and recover quickly from contact with services. These assumptions exclude people with severe and very severe ME and risk turning services that should be healing into sources of harm. More encouragingly, however, The 25% ME Group and Action for ME have seen a rise in the number of remote outpatient consultations offered to people with severe and very severe ME since the Covid pandemic.

Family carers are similarly impacted by a failure to provide reasonable adjustments. The Care Act 2014, and in addition NICE Guideline 150 ('Supporting adult carers') emphasises assessment, care and support planning, prevention, wellbeing, and carers' rights; carers have a right to assessment where they may have support needs.[30] Yet the inquiry evidence shows that family carers of people with severe and very severe ME are often left providing complex, high-risk, continuous care without adequate support, training, respite or guidance. This puts both family carers and those they care for at risk.

6.5 People with severe ME should benefit from the Government's vision for a National Care Service

The Government has committed to developing a National Care Service built on person centred care, prevention, independence, integration with the NHS and a skilled workforce.[31] For people with severe and very severe ME, the inquiry found that these ambitions remain far from reality. Instead of coordinated, preventative support that enables people to remain well at home, many experience fragmented, inflexible services that contribute to avoidable deterioration and increased pressure on health services. The evidence demonstrates that improving social care for this group is not simply about meeting unmet need, but about delivering the Government's wider reform agenda in practice.

The Government has recognised that high-quality social care depends on a skilled, valued workforce. The inquiry demonstrates why this is particularly important for severe and very severe ME. People with severe and very severe ME can require highly skilled care that depends on carers understanding pacing, sensory hypersensitivity, communication difficulties, nutritional risks and the potential for deterioration following even minor exertion. When those providing care do not possess the requisite skills, services can be inaccessible to this severely ill population.

The inquiry found that (as described above) unpaid family carers often fill in the gaps left by appropriate social care. Supporting unpaid carers is therefore not only an issue of fairness but also a vital component of a sustainable care system. Better

commissioned community support would reduce reliance on family carers while helping people with severe ME remain safely at home, consistent with the Government's vision for a preventative, integrated National Care Service.

6.6 Children with severe and very severe ME are often not provided with a suitable education that considers their health needs

Department for Education statutory guidance states that local authorities must arrange suitable education for children of compulsory school age who cannot attend school because of health needs, including children who cannot attend school at all or can attend only intermittently.[32] This should provide a route to flexible, home-based, remote, part-time or otherwise adapted education where a child's health makes full-time school attendance impossible.

The inquiry evidence shows that this is not consistently happening: families and clinicians reported pressure around school attendance, and education systems that are often dependent on individual advocates rather than reliable institutional understanding. For children with severe and very severe ME, a suitable education is one that takes into account their specific health needs, including post-exertional malaise and sensory intolerance. Otherwise, education systems may unintentionally prioritise attendance over health, pushing children into activity levels that worsen their condition.

6.7 Safeguarding processes are being employed inappropriately

Current NICE guidance for ME/CFS (NG206) emphasises that clinicians must recognise that people with severe and very severe ME "are at risk of their symptoms being confused with signs of abuse or neglect" and outlines that, in situations in which a person with confirmed or suspected ME requires a safeguarding assessment, health and social care professionals who have training and experience in ME must be directly involved as soon as possible.[33] Moreover, guidance produced by the British Association for Social Workers,[34] as well as additional guidance published by Action for ME,[35] warn social workers not to misinterpret ME symptoms as signs of child abuse.

Despite this guidance, the inquiry repeatedly heard that symptoms of severe and very severe ME – including an inability to communicate and sensory hypersensitivity requiring darkened and silent rooms – are being misinterpreted as reasons to evoke safeguarding processes, in both adults and children. For adults, this can result in threats of safeguarding referrals for self-neglect when a person is in fact declining care because it is inaccessible, painful, or harmful. For children and young people, delayed diagnosis and professional disbelief can trigger inappropriate suspicions of fabricated or induced illness and child protection procedures.

The evidence heard by the inquiry indicates that existing guidance – including from NICE and the British Association of Social Workers – is not being followed by all health and social care professionals. This leaves people with severe and very severe ME, and in particular children and their families, at significant risk of physical and psychological harm.

7. Policy recommendations

7.1 Establish a national framework for severe and very severe ME

The Department of Health and Social Care and NHS England should urgently develop and implement a nationally commissioned framework for severe and very severe ME. This should end the current postcode lottery in access to care and ensure consistent implementation of the NICE guideline.

This should include:

- the exploration of a nationally commissioned specialist service for very severe ME, as committed to in the ME/CFS Delivery Plan, including convening the clinical committee in advance of April 2027.
- a clear service specification and referral pathway, co-produced with people with lived experience and clinical experts.
- as part of the Government's proposed National Care Service, introduce national standards for the assessment and commissioning of community-based and domiciliary care for people with severe and very severe ME. These standards should require local authorities to commission care packages that reflect the clinical realities of ME – including sufficient time for pacing between essential tasks, continuity of carers where possible, and staff with appropriate knowledge of the condition, supported by adequate funding to deliver this level of care consistently across England.
- a named clinical lead for ME within every acute NHS trust to support hospital admissions and coordinate care.

7.2 Ensure timely access to safe, life-sustaining healthcare

People with severe and very severe ME should be able to access urgent healthcare without delay and without avoidable deterioration.

The DHSC and NHS should therefore:

- introduce national standards for timely access to nutritional support, including enteral feeding where clinically indicated
- publish clear "red flag" criteria for urgent assessment, admission and specialist review
- ensure ME is clearly differentiated from eating disorders where nutritional support is required
- establish maximum waiting times for clinical decisions affecting patients at risk of malnutrition or medical deterioration.

7.3 Improve professional knowledge and prevent avoidable harm

Professionals across health, social care and education should have the knowledge and confidence to provide safe, evidence-based care.

The Government should therefore:

- introduce mandatory ME training for healthcare professionals, social workers, teachers, SENCOs, attendance officers and CAMHS staff who support people with severe ME
- ensure training reflects NICE guideline NG206, post-exertional malaise and appropriate reasonable adjustments
- provide practical guidance on delivering low-stimulation, home-based and hospital care for people with severe disease.

7.4 Protect patients and families from inappropriate safeguarding interventions

People with severe ME and their families should not face safeguarding investigations because professionals misunderstand the condition.

The Government should:

- strengthen statutory safeguarding guidance to make clear that the symptoms of severe and very severe ME should not be interpreted as self-neglect, fabricated or induced illness, or failure to engage with treatment
- require specialist clinical advice before safeguarding or psychiatric escalation is considered
- establish an independent review process for serious incidents involving inappropriate safeguarding interventions or avoidable harm.

7.5 Improve support for children and young people

Children and young people with severe ME should receive appropriate healthcare and education without being forced beyond their energy limits.

Government should:

- guarantee access to flexible, remote or home-based education, or temporary withdrawal from education where clinically necessary
- prohibit educational attendance enforcement where appropriate medical evidence confirms severe or very severe ME
- require individual education plans based on the child's functional capacity
- improve understanding of ME across schools, local authorities and CAMHS.

7.6 Strengthen leadership, accountability and data

The Government should provide clear national leadership to drive improvement and monitor progress.

This should include:

- appointing a National Clinical Lead for Severe ME
- publishing annual progress reports on implementation & outcomes of the ME/CFS Delivery Plan
- collecting national data on prevalence, service access, outcomes, mortality and serious incidents affecting people with severe and very severe ME
- including ME within wider health inequalities monitoring and workforce planning.

7.7 Accelerate research and innovation

The Government should recognise severe and very severe ME as a priority for research and innovation. Prime Minister Andy Burnham has committed to making Britain a preventative state and helping people to “live well”.[36] Through investment in research and innovation into ME and severe ME, the Government will be able to achieve these commitments.

This should include:

- developing a research and commercialisation strategy that supports the development of diagnostics, therapeutics and clinical trials, building on major UK programmes such as DecodeME and Sequence ME & Long Covid to improve the diagnosis and treatment for those with ME and severe ME.
- positioning the UK as a global leader in post-infectious disease research and innovation.

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