Proposed Urgent Safety and Support Measures for People with Very Severe Myalgic Encephalomyelitis

Submitted to the Department of Health and Social Care (DHSC) and NHS England (NHSE) July 2026

Executive summary

In March 2026, the DHSC and NHSE announced a delay to the commitment included in the Final Delivery Plan to explore whether a specialised service for very severe Myalgic Encephalomyelitis (ME) should be prescribed by the Secretary of State. In response, Forward ME has consulted its members to identify immediate steps to improve patient safety and prevent deterioration. These align with the Prime Minister's ambition to move to more integrated, preventative, person-centred care. We propose the following actions:

- Introduce a **patient safety improvement programme** aimed at eradicating preventable harms, ensuring that avoidable deaths become 'never events' (see 3.1.1 for details);
- Develop comprehensive **national guidance for the management of very severe ME**, including nutritional failure, applicable to both hospital and community settings. If requested by the DHSC, Forward ME can convene an expert panel of clinicians to commence this work;
- Establish a national **NHS clinical support group on very severe ME,** consisting of clinicians who have experience of working with people with very severe ME, to provide an escalation pathway for complex cases and to support national care quality improvements (see 3.1.3 for details);
- Ensure that the **template service specification** under development includes robust advice for ICBs on caring for people with very severe ME and that ICBs are strongly encouraged to put these measures in place (see 3.1.4 for details); and
- Establish **workforce education measures** to improve the uptake of NHS e-learning modules among medical staff caring for people with very severe ME.

The delay to exploration of a specialised service work does not remove the need to address immediate patient-safety risks. Forward ME therefore requests early engagement with the DHSC and NHSE to agree a roadmap for next steps, including developing a specialised/highly specialised service. Crucially, people with lived experience of very severe ME (via carers and advocates) must play a key role in the development of any service, aiming to ensure that any proposed service model is responsive to need.

1. Background

Multiple studies have demonstrated that very severe Myalgic Encephalomyelitis (ME) is associated with a profound and debilitating reduction in quality of life, frequently exceeding the levels of functional impairment observed in many other long-term illnesses, including heart failure and cancer.

People with very severe ME are typically confined to bed 24/7 in a darkened and quiet room. They require 24/7 care and are often tube-fed, sometimes requiring total parenteral nutrition (TPN). They are typically extremely sensitive to light, sound, touch, movement, and smells and are orthostatically intolerant. Simply turning in bed can result in symptom exacerbation.

For a comprehensive account of the clinical characteristics that distinguish very severe ME from other levels of severity, please refer to '*Epidemiology, clinical definition and assessment of people with very severe ME/CFS: Implications for the development of a national specialist referral service*". In this paper, Dr Charles Shepherd highlights the absence of existing care frameworks that address, recognise, or accommodate the needs of people with very severe ME, leaving this group without safe clinical pathways, appropriate medical oversight, or protection within the healthcare system.

2. Current context and key issues

People with very severe ME are among those most at risk of avoidable harm and preventable patient safety incidents due to entrenched gaps in training, service delivery, and research. The 2024 Prevention of Future Deaths

(PFD) report concerning Maeve Boothby-O'Neill described NHS services for severe and very severe ME as *'non-existent'*.[1] It also highlighted *'extremely limited training for Doctors on ME/ CFS and how to treat it - especially in relation to severe ME'* and that there was '*no current available funding for the research and development of treatment and further learning for understanding the causes of ME*.' The 2025 PFD report concerning Sarah Lewis reiterated these concerns.[2]

Government responses to these Prevention of Future Deaths reports acknowledge profound failures in care for people with ME, especially for those who are most severely affected.[3] The reports state intentions to drive coordinated action across DHSC and NHSE. In its responses the DHSC accepted that current provision is inadequate and reported reconvening the ME/CFS Delivery Plan group to address deficits in clinical education, service standards, and research. NHSE reported developing a national service specification and considering how specialist provision for very severe ME could be strengthened.

The National Institute for Health and Care Excellence (NICE) stressed that its guideline (NG206) is still not being properly implemented and highlighted ongoing failures in diagnosis and care.

The Ministerial Foreword to the *ME/CFS Final Delivery Plan* acknowledges the significant patient safety concerns including preventable deaths encountered by people with ME, committing to rendering these '*never events'*.

The ME/CFS Final Delivery Plan states as an action point:

> *DHSC, with NHS England, will explore whether a specialised service should be prescribed by the Secretary of State for very severe ME/CFS. Initial discussions with NHS England have already taken place. Requires further development and expert clinical advice.*

Despite these acknowledgements and commitments, people with very severe ME remain unable to access the care and support to which they are entitled. There are still no commissioned NHS services providing safe, NICE-compliant support to people with very severe ME. Although online training modules have been developed, these are optional and would benefit from being more widely promoted. As a result, people with very severe ME (including children and young people) continue to remain at the same risk of deterioration and harm both in hospital and in the community, with an ongoing risk of preventable deaths. People with very severe ME are often subjected to extended and harmful in-patient stays or remain at home with no / limited access to appropriate medical care and support. They are also disproportionately subjected to the misapplication of psychiatric assessments and safeguarding frameworks due to a lack of professional education and misinterpretation of severe illness.

Forward ME are therefore requesting an urgent response from the Secretary of State for Health and Social Care that takes into account the profound impact of very severe ME, the lack of appropriate care, and the escalating risks faced by people remaining without safe clinical pathways or support.

3. Proposed approach

3.1 Phase 1: Short-term patient safety improvements (FOR URGENT CONSIDERATION)

Forward-ME, including representatives who are carers of people with very severe ME, would welcome the opportunity to work collaboratively with the DHSC and NHSE to agree an approach to address immediate patient safety risks. Recognising that a phased approach is likely to be necessary, Forward ME presents the following short-term measures. These have been formulated to be implemented at pace with the primary objectives of mitigating patient safety risks, prioritising the prevention of future deaths and improving the level of potentially life-saving support.

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[1] PFD Report for Maeve Boothby O'Neill.

[2] PFD Report for Sarah Jayne Lewis:

[3] A response was issued to the PFD for Maeve Boothby O'Neill by DHSC and NIHR, and from NICE. Responses were issued to the PFD for Sarah Jayne Lewis from DHSC, NHSE and NICE.

3.1.1 Patient Safety Improvement Programme

Introduce a patient safety improvement programme aimed at ensuring that preventable harms, including avoidable deaths, become '*never events*'. Suggested components include:

- Routine checks and medical care for people with very severe ME from appropriately trained GPs, nurses, and ME specialist teams in accordance with NG206;
- Ensuring that the Single Patient Record flags essential reasonable adjustments for people with very severe ME so clinicians can instantly see what is needed and deliver care safely;
- Implementing a safe nursing care policy and associated training for those working with people with very severe ME. This should be applicable in in-patient settings and community services (with a view to preventing in-patient stays through early intervention);
- Advice and guidance for GPs supporting people with very severe ME and dealing with complex cases in the community;
- Clear accountability arrangements for complex cases where there are concerns regarding patient safety, risk of harm or preventable death; and
- Application of the Patient Safety Incident Response Framework (PSIRF)[4] whereby carers, patients and staff report and escalate systemic safety risks and ensure accountability within the NHS.

3.1.2 National Clinical Guidance

Develop comprehensive national guidance for the management of very severe ME, including nutritional failure, applicable to both hospital and community settings. This should be developed in consultation with experienced clinicians and patient advocates. Forward ME would be pleased to be asked to convene a team of expert clinicians to produce this guidance. This should be informed by '*Epidemiology, clinical definition and assessment of people with very severe ME/CFS: Implications for the development of a national specialist referral service*' and should include:

- Nutritional support, hydration, and broader management issues, informed by NG206, CQC Regulation 14 and CG32; and
- Standards of care for hospitalised patients with severe and very severe ME, drawing on the Royal Devon's '*Planned and unplanned admission process for severe or very severe adult ME patients - clinical guidance*'.[5]

3.1.3 National NHS Clinical Support Group

Establish a national NHS clinical support group consisting of clinicians, including those in the private sector, who have experience of working with people with very severe ME. Until longer-term arrangements for specialist care are established, the group would:

- Act as an escalation pathway to advise on care in complex cases - in hospital or the community - consistent with NG206;
- Support accountability for the prevention of avoidable harm and deaths;
- Facilitate continuous learning and quality improvement; and
- Promote safe and appropriate care nationally.

Given the long history (which remains current) of neglect and mistreatment experienced by many people with ME, membership of the group should be developed in consultation with organisations representing people with ME and carers to ensure meaningful representation and trust.

3.1.4 Integrated Care Board (ICB) Service Specification

Ensure that the template service specification under development includes robust advice for ICBs on caring for people with very severe ME and that ICBs are strongly encouraged to put these measures in place. Forward ME

[4] NHSE '*Patient Safety Incident Response Framework*'

[5] Royal Devon University Healthcare NHS Foundation Trust (2024) '*Planned and unplanned admission process for severe or very severe adult ME patients - clinical guidance*'.

would be happy to co-produce an addendum to the current draft specifying how ICBs should provide care in the interim i.e. until a specialised service is established (a further addendum could then describe this pathway.)

The ICB service specification should:

- Avoid creating situations where patients are nominally included within services that lack the expertise to manage very severe illness safely;
- Recommend that ICBs establish service-level agreements with experienced specialist private providers so that the most severely affected patients can access funded expert care immediately until the equivalent level of expertise is available within the NHS;
- Recognise existing specialist private providers as preferred providers where patients are already receiving care from them;
- Include references to national guidance and accountability structures applicable to people with very severe ME - in hospital or the community; and
- Provide guidance regarding Continuing Healthcare (CHC) eligibility and assessment in the context of very severe ME.

3.1.5 Workforce Education

Ensure that the planned public awareness programme includes reference to very severe ME to help raise awareness of risks and in doing so prevent deterioration of those currently less severely affected.

Explore immediate measures to improve the uptake of the NHSE e-learning module *Support and Clinical Management of Severe ME/CFS*[6] among clinicians supporting patients with very severe ME, including the possibility of introducing a mandatory requirement, and clearly showing how the small investment in time to complete the module can contribute to improved outcomes for patients. A recent FoI request[7] demonstrated that these modules are not achieving either the necessary reach or impact on the workforce.

3.2 Phase 2: Medium and Longer-Term Improvements

Alongside immediate measures, meaningful discussions should begin without further delay regarding a sustainable NHS service model to provide support in the medium to longer term for people with very severe ME. Although NHSE and the DHSC announced a delay in formally commencing exploratory work regarding the commissioning of a specialised service, Forward ME understands that discussions continue.

The following principles are recommended in terms of any longer-term improvements to service provision, including the potential commissioning of a specialised service:

3.2.1 Collaboration, Consultation and Co-production

It is critical for effectiveness and safety of any service that it is co-designed from the outset with those most affected by very severe ME. As people with very severe ME are highly unlikely to be able to contribute directly, co-design should be informed by their carers and advocates. Forward ME would be pleased to facilitate their engagement with DHSC and NHSE processes and, where appropriate, work on their behalf.

Forward ME would also encourage the DHSC to make use of the substantial body of data collected as part of the public consultation informing the Final Delivery Plan to identify specific findings in relation to severe and very severe ME and explore how this data might inform next steps.

3.2.2 Building on what already exists

Existing service specifications, including the Suffolk and Northeast Essex model, should inform the development of future services. While NHS capacity develops, it is also recommended that private providers with trusted expertise could play an important interim role and build of trust in future services, critical to the success of long-term improvements.

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[6] NHSE *'Support and clinical management of severe ME/CFS'*

[7] ME Association '*NHS England's ME/CFS e-Learning Modules FOI Results reveal lack of uptake*'

Medium to long-term service improvements can also draw on existing NHS models that have established benefits in context of other conditions. For example, a virtual ward model could be explored to support people with very severe ME safely within their homes and communities. Similarly, specialist ME nursing could enable ICBs to better support patients in the community (building on the Suffolk Northeast Essex specification).

Services should be aligned with the NHS 10-year plan, including in terms of support to care in the community (see 3.2.3) and the appropriate use of digital technologies.

3.2.3 Care in the community wherever possible

Patients with very severe ME should be supported at home whenever possible, with hospital admission considered a last resort when unavoidable.

Importantly, however, it cannot be assumed that people have family, carers, or a safe home environment. Some live alone, are isolated, or lack anyone able to provide even essential care in a way that prevents deterioration. As such, systems must also protect those without informal support and ensure their needs are met safely and equitably.

3.2.4 Developing the evidence base on very severe ME and clinical management

Improved NHS provision of services to people with very severe ME would provide access to a key patient cohort for research, often under-represented in existing studies. This could support efforts to develop an evidence base on the effective clinical management of very severe ME, potentially drawing on the NIHR Programme Grants for Applied Research mentioned in the Final Delivery Plan. Applied research could include the piloting of care models and approaches. Other research and learning opportunities could include reviewing definitions and coding practices, improving prevalence estimates, establishing a national registry, and collecting outcome data relating to interventions and service delivery.

Research and learning efforts could be coordinated by a National Centre of Clinical Excellence for ME/CFS. Given that much of the current expertise resides within charities, collaborative networks, and the private sector rather than the NHS, a national centre would consolidate expertise, promote knowledge transfer, support workforce development and succession planning and document, and disseminate best practice. Discussion would ascertain whether this is feasible as a virtual team or whether several in-patent centres would be beneficial.

4. Anticipated improvements

It is anticipated that the approach proposed above would deliver the following benefits:

- Significant improvements in patient safety;
- Reduced risk of avoidable harm and preventable deaths;
- Potential reductions in number of hospital admissions and length of hospital stays;
- Reduced cost to the NHS;
- Improved quality of life for people with very severe ME and their carers;
- Alignment with NHS strategic priorities, including greater use of technology and community-based care;
- Data collection opportunities, where evidence is currently severely lacking; and
- Capacity building - enabling development of expertise and improved patient experience / outcomes.

Note about Language Matters: *This document has been compiled in line with the language principles set out in the Draft Language Matters Guide Framework submitted in May 2026. The summary version will be with DHSC at the end of July.*

About Forward ME*: Forward ME is a coalition of UK-based charities, voluntary organisations and campaigning bodies, researchers and clinicians working together to improve the lives of people with ME/CFS. By bringing together leading voices in medicine, research, support, advocacy, and policy, our coalition provides a unified platform to influence change at a national level.*