# Severe M.E. Week: Urgent Government Action Needed to Stop Neglect and Hidden Harm

**Monday 3 August, 2026**

As Severe M.E. Week 2026 begins, social enterprise M.E. Foggy Dog is issuing an urgent warning: people living with severe Myalgic Encephalomyelitis (M.E.) are facing systemic neglect within the NHS, and without decisive Government intervention, thousands will continue to suffer preventable harm.

In early 2024, M.E. Foggy Dog launched a national campaign calling for a dedicated NHS protocol for severe M.E. The response was extraordinary. 5,220 people with M.E**.,** many severely ill, housebound, or bedbound, signed the open letter. Reaching people with M.E, particularly those severely impacted, is notoriously difficult due to the nature of the disease, yet thousands still found a way to add their names. Their message was unequivocal: severe M.E. patients are being harmed, neglected, and left without safe, appropriate care. A protocol is urgently needed.

Despite the scale of support and the severity of the issue, nothing meaningful followed. Across 2024 and 2025, successive Secretaries of State responded with the same generic reassurance that the ME/CFS Delivery Plan and updated NICE guidelines would resolve most of the problems raised. It is now clear that they have not, and never could have. NICE guidelines are not mandatory, NHS training is not compulsory, and neither mechanism addresses the realities of severe M.E. or the dangers patients face every day.

The consequences of this inaction are stark. Severe M.E. is a complex neuro?immune disease that can leave people unable to sit upright, speak, or eat without triggering symptoms. Some patients have died from malnutrition caused by misunderstanding and neglect. Clinicians who understand the disease and attempt appropriate “off?label” care risk referral to the General Medical Council simply because no NHS protocol exists to guide or protect them. Meanwhile, misinformation continues to circulate within, and cascade down to patients, from official NHS sources, reinforcing outdated and harmful narratives that directly impact patient safety.

This crisis is compounded by another long?standing and largely invisible problem: M.E. patients have no way to report harms from non?pharmaceutical treatments, the very interventions most commonly recommended for them. Since August 2021, M.E. Foggy Dog’s Shake It Up campaign has been working to expose and challenge the widespread false belief that non?pharmaceutical treatments cannot harm patients. We know this is not true. These interventions are not regulated, yet they continue to be recommended across the NHS, including rebranded forms of Graded Exercise Therapy and Cognitive Behavioural Therapy, despite NICE advising that they should no longer be offered as treatments for M.E.

NICE has stated that clinicians may use their clinical judgement, but must be prepared to justify their decisions to the GMC. By the time cases reach the GMC, harm has already been done. And because there is no centralised system for reporting harms from non?pharmaceutical treatments, patient groups have no way to prove the damage being caused. M.E. patients of all severities have been left with nothing, no adequate care, no care pathway, no protection, no recourse, and no mechanism to stop harmful practices. This must change.

The scale of the crisis is far larger than most people realise. Over 1.3 million people in the UK currently meet diagnostic criteria for M.E. 403,000 have a clinical diagnosis of M.E. (sometimes also referred to as Chronic Fatigue Syndrome - M.E/C.F.S). At least 100,000 are living with severe or very severe M.E., and many more are at risk of deterioration due to viral infections, stress, or simply doing too much. People with moderate M.E. live with the constant fear that one wrong step could push them into severe disease. Yet they must navigate not only the illness itself, but also the inadequate, inconsistent, and often negligent care offered by the NHS.

Sally Callow, Founder of M.E Foggy Dog said -

“Severe M.E. patients are being failed every day. Without Government?level action, neglect and harm will continue unchecked. We cannot wait any longer for safe care, accurate information, and proper protection. The crisis is escalating, and decisive leadership is now essential.”

Public misunderstanding adds another layer of harm. Many people have encountered individuals who describe their “CFS” as mild or short?lived, and these personal anecdotes often dominate social media. While everyone’s experience is valid, these narratives frequently ignore the 400,000 people in the UK

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currently suffering from M.E., including the 25% who are severely or very severely affected. Misinformation from individuals cannot be controlled, but misinformation from official sources must be stopped.

The situation has now reached a point where Government?level intervention is the only way forward. It will take far too long for NHS staff and management to become adequately educated through voluntary training or optional guidelines. Severe M.E. patients cannot wait another year, another election cycle, or another plan that does not address their reality. Without equitable biomedical research funding, the risk of deterioration into severe M.E. remains present for most of the community, we just don't know who is at risk and who is not. The number of people with severe M.E. will continue to rise unless action is taken.

M.E. Foggy Dog is calling on Rt Hon Yvette Cooper MP, the new Secretary of State for Health and Social Care, to take this issue seriously, to champion equitable research funding from the Treasury, and to work with the organisation to implement a forward?thinking NHS protocol that protects patients and clinicians alike. The open letter demonstrated the scale of public concern, the past few years have demonstrated the consequences of political inaction.

Severe M.E. Week is a time to acknowledge the people who are too ill to speak for themselves, too ill to leave their homes, and too ill to advocate for their own safety. This year, the message is simple: the crisis is deepening, and only Government intervention can stop it.

**ENDS**

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