ME/CFS Delivery Plan Must Not Be Used to Deflect Calls for Further Action, Campaigner Warns

Thursday 29 October, 2026

Social enterprises say the Government must stop treating the ME/CFS Delivery Plan as the answer to every concern raised by the community and start recognising the urgent gaps that remain.

As part of Bed for Severe ME 2026, an annual campaign raising awareness of severe and very severe ME, social entrepreneur and patient advocate Sally Callow, founder of ME Foggy Dog and Stripy Lightbulb CIC, is highlighting growing concern that the Government's ME/CFS Delivery Plan is not delivering the improvements desperately needed by many people living with the condition.

The issue has become a significant barrier to progress for the M.E/C.F.S. community.

Time and again, when patients, carers, charities and campaigners approach the Department of Health and Social Care, NHS England or Government ministers about the need for improved services, better protection from harm, a national NHS protocol for severe ME, or a reporting system for harm arising from non-pharmaceutical treatments, the response frequently points to the existence of the ME/CFS Delivery Plan.

However, campaigners argue that the existence of a plan does not mean the problems have been solved.

"The Delivery Plan has effectively become a shield against further action," says Sally Callow. "Whenever we propose new ideas or solutions, we are told that the Government already has a Delivery Plan. But many of the problems people with ME/CFS face every day remain unchanged. A plan cannot be considered successful simply because it exists."

While Government communications often state that the Delivery Plan was developed in collaboration with ME/CFS stakeholders, many organisations and patient representatives have publicly expressed disappointment with the final outcome and have highlighted continuing shortcomings.

Bed for Severe ME 2026 is drawing attention to several areas where significant gaps remain:

- No dedicated national NHS protocol for severe and very severe ME.
- No comprehensive national reporting system for recording and learning from harms associated with inappropriate non-pharmaceutical treatments.
- Continued postcode variation in access to specialist care.
- Limited NHS provision for housebound and bedbound patients.
- Lack of accountability when NICE guideline recommendations are not fully implemented.
- Insufficient training and awareness across hospitals, emergency departments, social care and community healthcare services.
- Slow progress from policy commitments to tangible improvements in patients' lives.

For many patients, progress has been measured in years rather than months.

The ME/CFS Delivery Plan process has been underway since consultation and development work began several years ago. Yet many people with severe and very severe ME continue to report major difficulties accessing appropriate healthcare, support and understanding.

For those confined to their beds, often in darkened rooms and dependent on family carers, waiting several more years for meaningful improvements is not a realistic option.

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"The issue is not whether the Delivery Plan exists," says Callow. "The issue is whether it is delivering meaningful change at the pace patients need. For many of the most severely affected people, the answer is clearly no.

A central message of this year's Bed for Severe ME campaign on 29th October is that the Government should not use the Delivery Plan as a reason to reject additional proposals that could improve care and safety for patients.

ME Foggy Dog and Stripy Lightbulb CIC are calling on policymakers to acknowledge that important gaps remain and to be more open to initiatives that complement, strengthen or go beyond the existing plan.

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