Light Protest Calls Out Government Over the Neglect of People With Very Severe Myalgic Encephalomyelitis (ME)

Thursday 4 June, 2026

#MEAction UK projected messages onto locations in central London on 3rd June 2026 to urge James Murray, the Health Secretary to establish specialised NHS services for the most severely affected Myalgic Encephalomyelitis (ME) patients.

The very severely ill are often bed bound, tube fed and live in the dark, isolated from life with a lower Quality of Life score than other major diseases, including heart failure and cancer.

The tragic deaths of Maeve Boothby O'Neill, Sophia Mirza, Merryn Crofts, Kara Jane Spencer, Ella Copley, illustrate how medical care for the very severe is non-existent. The coroner at Maeve Boothby O'Neill's inquest said, 'that provision of care for patients with severe ME such as that which Maeve suffered from was and is non-existent'.

"The most severely ill people with ME have sent images to light up London because the Health Secretary has left these patients in the dark. The sickest ME patients are dying without specialised care. We need action now" said #MEAction UK Chair Denise Spreag.

Lizzy who has had ME since she was 14 said, 'I have had ME for 17yrs, since I was 14, and despite remaining positive, there is no denying how much I have lost to it. Moments with family, life events that only come around once, my independence, mobility, my hobbies, hopes, voluntary work. A career, relationships, even my ability to digest foods. We have faced stigma, lack of specialist medical care, and medics from other specialties having to step in to try to help before it's too late. I have so much to give, so many skills, interests, so much knowledge, and drive, if only I was well enough to apply it fully. We deserve better.'

Another very severe ME sufferer, 'C' said, '33 years like this. No medical help, whatsoever, too ill to see family or friends. It could have been so different!'

The decision to set up this service lies with James Murray, the Secretary of State for Health and Social Care. #MEAction UK calls on the Health Secretary to stop stalling and start the service.

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