Act for ME A pledge on ME

The Delivery Plan for Myalgic Encephalomyelitis/Chronic Fatigue Symptom (ME/CFS) was finally published in July 2025, marking a long-awaited step forward for those living with ME. Despite its significance, the plan contains several critical omissions that risk undermining its impact.

There is a critical need to accelerate research into ME, and this will require a government-led, strategic approach. Such research will be the key to finding treatments and ultimately, a cure for ME. This is the clearest way to improve the lives of the estimated 1.35 million people living with ME or ME like symptoms. This funding or plan for funding has not been forthcoming and the delivery plan fell short of what was required.

The plan also lacks clear accountability structures with no mechanisms to measure impact or deadlines to hit. We are concerned that despite this well-meaning plan being published, it will have no material impact on the historically stigmatised and ignored ME community.

You can help by meeting with us and pressing the Government to address the shortfalls of the Delivery Plan and to secure the provisions needed to better understand and treat post-viral diseases such as ME.

Join us as we call on the Government to make three key pledges to ensure the Delivery Plan works to help people living with ME and deliver real change.

Our 3 key calls:

1. **Sufficiently fund a very severe ME service:** The Delivery Plan committed to an "exploration of a specialised service for very severe ME/CFS", however there are no guarantees of specialist care if the proposed service is not funded sufficiently. A very severe ME service must also be co-designed by people with lived experience of ME to ensure it is fit for purpose.

2. **Ensure the full implementation of a public awareness campaign:** The public awareness campaign announced in the Delivery Plan lacks the detail needed to reassure the ME community that its messaging will accurately reflect the realities of living with the condition. To achieve this, it must be co-designed with the community so we are clear on what it will seek to convey and how the success of the initiative will be measured.

3. **Strategic approach to research:** The Delivery Plan fails to include a strategic approach to ME research. We must leverage the UK's leading life sciences sector to support the prevention and treatment of ME. The Government has suggested that they do not ringfence funding for condition-specific research, however, a recent FOI by Action for ME shows that there are existing examples of condition-specific funding. If funding for ME research were equitable with other illnesses, £18.5 million of the £5 billion spent annually on health research would be allocated to the disease[1]. However, over the past 10 years only £8.05 million has been spent on ME research in total. We would like to see a strategic approach to ME research, based on our national research hub proposal, that coordinates research capacity and funding to capitalise on recent progress made by the DecodeME study and support the search for treatments for ME.

ACTION FOR M.E.

1 | **UKRI (2024), Available at** https://www.ukri.org/news/largest-study-of-uk-health-research-funding-released-today/