

#ThereForME

Joint statement for World ME Day - 12.05.2025

Today, on World ME Day, we stand with people affected by ME to deliver a simple message to the UK government: after generations of neglect and empty promises, now is the time for action.

As many as up to 1.3 million people in the UK have ME, including those affected post-Covid. An estimated one in two people with Long Covid meet the diagnostic criteria. The UK's ME community faces a twofold threat: the loss of critical welfare benefits, and a lack of meaningful treatments to pave their way back to work.

Next month the government will publish a new Delivery Plan for ME. Yet, with no targeted funding committed, it is on course to be another missed opportunity.

The UK is a science and technology superpower, yet little has been done to harness this potential. The UK's ME research is so poorly funded that its 'talent pool has dried up'. Calls for funding for a dedicated research platform - a model used successfully for other conditions - have not yet been heeded.

Treatment is similarly dire: care for the sickest is unavailable or inappropriate; there are no specialist nurses; and few clinicians are equipped with the basic knowledge to provide safe care. Emerging treatments that may help manage symptoms remain largely in the private sector, available only to those who can afford them.

While the UK's economic context is challenging, government is about choices. We ask you to choose to invest in this community's future and its potential to contribute to our society.

- **Choose** to build on our country's extraordinary capacity by making the UK a world-leader in the research that ignites a global race to find a cure.
- **Extend** a ray of hope to the teenager lying motionless in the dark, in silence, wondering if they will ever live a normal life again – and the carer that bears witness to their suffering.
- **Chart** a new course for the doctor, powerless to help their patients, stuck in a system that doesn't have the answers.

Today, on World ME Day, we stand with all people affected, in the face of indescribable loneliness, pain and suffering.

We ask you, the UK government, to stand with us and back the Delivery Plan with the resources it deserves.

Now is the time for action.



Bury & Bolton ME/CFS & Fibromyalgia Support Group

ME/CFS Friendship Group in Gloucestershire

ME Group Staffordshire