

**Shaping our future together to end the ignorance,
injustice and neglect of people with M.E.**

Action for M.E. strategy 2022 – 2027

We are Action for M.E.

We are an organisation for people with M.E. led by people with M.E. Over half of our Board of Trustees have direct experience of M.E. as do many of our staff and volunteer colleagues. Researchers and healthcare professionals work with us, using their personal, professional and clinical experience to help shape our work and our priorities.

This is a key overview of our ambitions for the next five years. We are developing our strategy in partnership with children, young people and adults with M.E., their loved ones and carers, and others who share our values and ambitions. This has included learning from the services and support we provide, our surveys and consultations, workshops and discussion groups, and from wider engagement with the M.E. community.

Our ambitions

On the following pages, we set out four ambitious outcomes which we believe will help us end the decades of ignorance, injustice and neglect faced by people with M.E.

Underpinning each ambition is our focus on ensuring we reach underserved communities, so they have better access to healthcare, information and services.

Ambition 1: The lives of people with M.E. are improved by effective access to the information, support and advocacy they need.

Action for M.E. will:

- grow our support services to reach more children and adults with M.E. and their families
- increase our reach to currently under-served communities with a specific focus on people from Black and other minority ethnic groups and those with more severe M.E.
- address the isolation and loneliness of people with M.E. via our online forums, workshops and podcasts
- address the ignorance and stigma of M.E. by providing resources to people with M.E. and education and healthcare professionals.

Ambition 2: The health of people with M.E. is improved via access to our holistic Healthcare Services, and the National Institute for Health and Care Excellence (NICE) guideline for M.E. being effectively implemented across NHS services.

Action for M.E. will:

- evidence the need and benefit of holistic M.E. services by measuring and evaluating the impact of our Healthcare Services
- launch a new children and young people's counselling service
- increase access to counselling for adults
- increase the number of appointments offered by our doctors
- explore and implement the most effective way to expand our nursing service
- explore and establish the most effective way to provide a regional outpatient provision
- provide 100% bursaries to increase access to Healthcare Services
- work collaboratively with Forward-ME (www.forward-me.co.uk) to ensure the 2021 NICE guideline for M.E. is effectively implemented across NHS services.

Ambition 3: Increased funding for high-quality research by more researchers leads to effective treatments for M.E.

Action for M.E. will:

- aim to deliver £2 million investment via our Breakthrough-ME research strategy (www.actionforme.org.uk/breakthrough-ME)
- drive M.E. genetics research forward through a virtual Genetics Centre of Excellence and Genetics Research Summit with the Medical Research Council Human Genetics Unit at the University of Edinburgh
- ensure patient and public involvement is at the heart of driving research forward
- address the shortage of M.E. researchers by investing in a Future Leaders programme
- co-deliver DecodeME (www.decodeme.org.uk), the world's largest genetic M.E. study, and seek to expand this research model to provide greater insight and research opportunities
- work collaboratively to ensure progress in M.E. research is accelerated, ensuring M.E. is included in Long Covid research.

Ambition 4: The UK Government establishes and leads a national strategy for M.E.

We want a national strategy for M.E. led by the UK government with a clear implementation plan and outcome measures, overseen by a national lead for M.E. This must include a specific research strategy with increased investment leading to validated treatments and, one day, a cure.

The life-changing symptoms experienced by people with M.E. are being mirrored by more than half of those with Long Covid, already an estimated 1.3 million people in the UK alone. Some are starting to be diagnosed with M.E. and face the same lack of care and treatment – a direct result of historical neglect of M.E. and other post-viral illnesses.

We will not stop until we end the ignorance, injustice and neglect experienced by children and adults with M.E.

Action for M.E. will:

- continue to advocate on behalf of people with M.E. and ensure the voices of people with M.E. are heard
- evidence the need for investment in services, healthcare and M.E. research
- ensure that improving the lives of people with M.E. stays at the forefront of investment by the UK Government.

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