#MEAction Scotland's Strategic Priorities: 2024–2026

Who we are

#MEAction Scotland is an affiliate of the charity #MEAction UK. We are a grassroots, volunteer-led group working to improve the lives of the estimated 58,000 people in Scotland with myalgic encephalomyelitis (ME) and part of the global #MEAction movement. ME is a complex, chronic disease that presents with symptoms in multiple body systems and is recognised by the World Health Organization as a neurological disease.

The cost of ME to the UK economy has been estimated at £3.3 billion annually, the equivalent of £17,000 per patient, according to research conducted in 2017.[1] This will have increased considerably since the pandemic.

Our purpose is:

- To raise awareness of the devastating impact of ME
- To campaign for effective support for adults and children and young people with ME.
- To campaign for, promote and encourage participation in healthcare education for doctors and other healthcare professionals.

Our aim is to address the health inequalities that people with ME and other complex chronic illnesses (including Long COVID) experience in Scotland.

Our vision is that health and social care professionals, politicians and policy makers, and the people of Scotland understand and support people with ME and treat them with respect.

There are two core publications underpinning our strategic priorities for 2024–26:

- The NICE guideline on the diagnosis and management of ME/CFS, published in October 2021.[2] We have broadly welcomed its evidence-based recommendations.
- The Health Board Survey, commissioned by the Scottish Government following our meeting with the Cabinet Secretary for Health and Social Care in September 2022.[3] The report analyses survey responses from ten of the thirteen NHS Health Boards in Scotland. The aims of the survey were to understand the barriers and opportunities to implementing the updated NICE guidelines and how NHS Boards can be best supported to create ME-specific care in the future.The survey results showed that implementation of the NICE guideline across Health Boards varied from sparse to non-existent, due to a lack of capacity, knowledge and resources.

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[1] 2020health.org, Counting the Cost

[2] NICE, Guideline for diagnosis and management of ME/CFS [NG206]

[3] Scottish Government, ME/CFS Services in Scotland: Findings from an analysis of surveys

We recognise the urgent need for funding for high-quality biomedical research into the causes of and possible treatments for ME. However, as health is a devolved matter in Scotland and biomedical research requires a UK-wide approach, we have chosen to focus on the areas where we can effect change in Scotland and will support #MEAction UK in campaigning for UK-wide funding.

Long COVID

There is a new cohort of chronically ill people who have developed Long COVID, an illness that is not yet fully understood. It is estimated that around 50% of Long COVID patients have a key symptom which overlaps with ME, called post-exertional malaise (PEM). PEM is the worsening of symptoms following even minor physical or mental exertion. The Centers for Disease Control and Prevention (CDC) in the US has revised its prevalence estimates for ME, and applying this new rate to the Scottish population provides an estimated 58,000 people now have ME in Scotland.[4] This compares to estimates of around 21,000 before COVID.

In relation to Long COVID, we:

- Recognise the problems and distress caused by healthcare professionals who do not believe patients' accounts.
- Anticipate that the recognition of, funding for and research into Long COVID could be beneficial to people with ME.
- Will campaign for both conditions to gain from these mutual benefits and ensure that people with ME and people with Long COVID who have PEM receive the care and research they deserve.
- Will review our strategy towards Long COVID as new evidence emerges in relation to ME.

Building a stronger ME advocacy community

As a grassroots movement, it's important that #MEAction Scotland engages with and empowers the ME community and its allies across Scotland. We recognise that many people with ME will never be able to volunteer with us in person or take part in advocacy in the way they might want, so we aim to provide a range of ways to be part of our work.

Community engagement

We want to ensure that our campaigning reflects the needs of the whole ME community across Scotland. We want to be able to amplify the voices of people with ME and make sure their stories are heard.

In order to share opinions and experiences with each other, we will engage with the ME

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[4] Vahratian A, Lin JS, Bertolli J, Unger ER. Myalgic encephalomyelitis/chronic fatigue syndrome in adults: United States, 2021–2022. NCHS Data Brief, no 488. Hyattsville, MD. National Center for Health Statistics. 2023. DOI: https://dx.doi.org/10.15620/cdc:134504.

community in a number of ways. We aim to share updates about our activity, and Scotland specific issues, regularly on social media to be transparent about our work and give the community the opportunity to comment. Our campaigning work is undertaken by a small core team of volunteers but we know hundreds more support us on Facebook, Instagram and X (previously known as Twitter).

We also gather feedback about our planned activities and engage directly with people as appropriate. This includes reaching out to other individuals and groups doing relevant campaigning work and holding virtual community calls to discuss specific issues. These activities help us connect more directly with people who are unable to volunteer with us but are engaged with the cause and ensures our work is led by the needs of the people it affects as much as possible.

Volunteer Network

Our Volunteer Network of people who have ME or have been affected by ME as a carer, family member or friend, enables our supporters to contribute to our campaign on an occasional basis when they feel able to do so. This helps us to tap into the wealth of talent, experience and wisdom within our community. Having successfully piloted the network in 2024, we hope to grow it over the next year.

Online campaigning

For many people with ME, attending events isn’t possible, so online campaigning will always be a key element of our advocacy work which supports our lobbying activities. We will continue to look for opportunities to create straightforward, clear actions for the community to take part in – such as sharing social media posts, contacting GPs, signing petitions and emailing MSPs – which allow more people to be part of our movement.

Partnership working

We will continue to work in partnership with individuals and organisations who are aligned with our purpose and maintain strong relationships with charities and other organisations that support people with ME in Scotland.

#MEAction Scotland is a member of the Neurological Alliance of Scotland and we also attend regular meetings with a group of stakeholders to discuss key issues for people with ME. We are currently working in partnership on the Learn About M.E. project, led by Action for M.E., to promote Dr Nina Muirhead’s ME/CFS CPD training module in Scotland, which has included attending last year’s Royal College of GP Conference and taking part in promotional podcasts. In the coming year, we will continue to identify areas where we can be stronger together, for example combating misinformation around ME and raising awareness of the new NICE guideline.

➢ Raising awareness of the impact of ME

All our activities contribute to raising awareness of ME and its impact. To achieve our vision, we need to build awareness across a range of different audiences who we will target through press and broadcast media, as well our online activity and direct campaigns.

We will prioritise raising awareness of:

- The changes in the recommendations of the 2021 NICE guideline, particularly around the removal of the recommendation for Graded Exercise Therapy. A widespread understanding of the dangers of exercise is urgently needed.
- The immediate need for effective, ring-fenced funding for health services for people with ME.

Key audiences

To raise awareness of the above points, the following key audiences will be targeted:

1. Scottish Government – specifically Ministers and the Clinical Priorities Unit in the Healthcare Quality and Improvement Directorate

2. Members of Scottish Parliament (MSPs)

3. Medical and other healthcare professionals

4. #MEAction supporters and people with ME who engage with us through social media

5. The wider public who may benefit from information about ME and post infectious illnesses which cause PEM

Millions Missing

One of the key objectives of Millions Missing is to raise awareness of the people with ME missing from society and their previous lives, and to demand support for the ME community.

In the past we have held Millions Missing events, both in person and online but always with the participation of the wider ME community. As part of our continuing commitment to awareness-raising, we will continue to run Millions Missing events in Scotland, deciding on the specific aims and objectives for those events on a year by year basis.

➢ Campaigning for effective support for people with ME

Campaigning is a vital way that we reach politicians and healthcare professionals to communicate the urgent need to address healthcare inequalities and to provide effective support for adults, children and young people with ME.

We have identified a number of key issues for our advocacy activities. These represent the areas that the ME community has expressed support for and we feel we can make the greatest impact. While we will focus on these core areas, we will continue to campaign on other relevant issues as they emerge.

Implementation of the NICE guideline on ME

The 2021 NICE guideline on ME/CFS was a landmark moment for people with ME, as it vastly improves on the standard of care that people with ME should receive. It includes key recommendations relating to diagnosis, management, and specific care for those with severe ME and children and young people, and explicitly states that people with ME should not be offered graded exercise therapy (GET) or any exercise that involves fixed incremental increases in activity. However, since publication, progress has been extremely slow. This was a key area of concern in our last strategy and it is extremely disappointing that it hasn't progressed further.

The guideline does not apply automatically in Scotland and so #MEAction Scotland and other organisations called on the Scottish Government to adapt the new guideline for implementation in Scotland. The Health Board Survey, commissioned by the Scottish Government in September 2022 was only completed by 10 Health Boards and, as a consequence of that, is currently being updated. The survey results received so far demonstrate an awareness of the new guideline among health boards but scanty implementation of its recommendations due to lack of resource, capacity, pathways and training. People with ME are still waiting to see any real change on the ground.

We will work with the Clinical Priorities Unit in the Scottish Government and the regional NHS Health Boards on the following issues:

- Urgent implementation of the key recommendations from the NICE guideline on ME by health and social care professionals.
- Development of services for ME across all regional NHS Health Boards in Scotland.
- Withdrawal of the partially adapted Scottish Good Practice Statement, which does not clearly communicate the recommendations of the NICE guideline.[5]

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[5] #MEAction web article: #MEAction Scotland responds to the Updated Scottish Good Practice Statement

➢ Education of doctors and other healthcare professionals

The new NICE guideline requires doctors and other healthcare professionals to change the way they treat and support ME patients, which will need considerable education and training. We will work to support this through the following core areas of activity:

- Seeking out opportunities to engage with medical royal colleges and medical schools. This will build on our work in 2023 with the Royal College of Physicians Edinburgh and the Royal College of General Practitioners.
- Encouraging doctors and other healthcare professionals to take existing CPD training through NHS Education for Scotland (NES) and Learn about M.E.
- Following our successful campaign for a NES module about ME/CFS, we will continue to campaign for the further development of healthcare education by NES, as NHS Scotland's education and training body.
- As part of the implementation of the NICE guideline in Scotland, we will ask for ring-fenced funding for education and training programmes for GPs, and other medical, nursing and allied healthcare professionals. In addition, we will ask that health boards are issued with clear directions on the need to implement this education and training as a priority, paying particular regard to the harms of Graded Exercise Therapy (GET).