



A Brief Guide to Myalgic Encephalomyelitis (ME) in Scotland

What is Myalgic Encephalomyelitis (ME)?

Myalgic encephalomyelitis (ME), sometimes referred to as Chronic Fatigue Syndrome (CFS), is a profoundly debilitating neurological disease affecting multiple systems within the body. The cause is unknown, although onset often follows a viral infection such as glandular fever. Around half of people with Long COVID have ME.^{1,2} There is currently no cure.

What are the symptoms?

ME impairs the body's ability to produce energy, so organs and systems cannot function properly. This leads to a range of debilitating symptoms, most notably Post-Exertional Malaise (PEM), which is a disproportionate worsening of symptoms after even minimal cognitive, physical, emotional, or social activity. PEM can last days or weeks and may cause permanent relapse. Other symptoms include cognitive impairment ("brain fog"), sensory sensitivity, gastrointestinal issues, pain, orthostatic intolerance, and autonomic dysfunction. Severity varies; some people can work part-time, while around 25% are house- or bed-bound. People with ME report lower quality of life than those with many other serious illnesses, including multiple sclerosis, stroke, renal failure, and lung cancer.³ ME can be fatal in severe cases.⁴

Who is affected?

There is no accurate data on the number of people with ME in Scotland. Latest research from the University of Edinburgh suggests that 33,000 have ME, and a further 76,000 have Long COVID with ME symptoms, bringing the Scottish combined total to 109,000. ME affects people of all ages, ethnicities and socio-economic groups. Around 80% of people with ME are women. There are significant health inequalities in diagnosis, with rates varying by ethnicity, deprivation, age and geography, reflecting unmet need rather than lower prevalence.^{5,6} Children are also affected, and longitudinal studies have shown ME to be the single biggest cause of long-term school sickness absence.⁷

ME is a major source of economic inactivity

The total annual economic burden of ME in Scotland was estimated in 2017 at around £17,000 for each person with ME. The majority of this is the cost of informal care and productivity losses, as most people with ME are of working age.⁸ Productivity losses of carers, which can be substantial, are not included in this figure. Only 12% of people with ME are in full-time paid work, education or training and a further 21% are in part-time work, education or training.⁹



Training and education for healthcare professionals especially GPs

There are no specialist consultants in Scotland, so care of people with ME falls to GPs. Clinicians in Scotland are expected to refer to the National Institute for Health and Care Excellence (NICE) guideline on diagnosing and supporting people with ME (2021).¹

However GPs do not receive adequate training, and their awareness of the NICE guideline is very poor. In a recent survey of practising GPs, 70% thought ME was rare, and 30% thought it was psychological and not physical.¹⁰ A typical GP practice of 10,000 patients can expect to have 200 people with ME but many go undiagnosed or are wrongly diagnosed, for example with depression.

Training for healthcare professionals, especially GPs and paediatricians, is needed urgently to ensure that healthcare is delivered in accordance with the NICE guideline. Early diagnosis and proper management are vital for patients and could help prevent some from deteriorating and give the best chance of long term improvement.

Developing new services

Current ME services in Scotland are woefully inadequate. A 2024 Scottish Government review found that only three NHS Boards had dedicated ME services: NHS Lothian, NHS Greater Glasgow and Clyde, and NHS Fife. These services focus on rehabilitation and self-management, with no little or no medical input. The service in NHS Fife consisted of a single specialist nurse who sadly died and the vacancy has not been filled.¹¹

The Scottish Government committed £4.5 million in recurring funding from 2025/2026 to deliver new specialist support for Long Covid, ME/CFS, and other similar conditions, in all NHS Boards. This is a welcome foundation, but the challenge of establishing services where they have not previously existed should not be underestimated. Specialist services need to be staffed by skilled consultants or specialist GPs, occupational therapists, and physiotherapists as a minimum, all needing to be trained. The NHS workforce does not yet have the capability to deliver this.

Referral pathways need to be developed in all NHS Boards, with cross-boundary and regional working arrangements established where boards are unable to sustain standalone services. Particular attention needs to be paid to the needs of those with very severe ME; existing services offer nothing to these patients, and there is not a single bed in NHS Scotland which meets their needs.

“[ME is] the greatest medical scandal of the 21st century”
George Monbiot, The Guardian



Investment in research

Biomedical research into ME is widely recognised as having been chronically underfunded for decades, both in the UK and overseas. Under-investment in research has resulted in a lack of knowledge about the causes and mechanisms of ME, a lack of diagnostic markers, and no effective treatments.

In Scotland there has been one landmark study into ME: DecodeME, a £3.2m genetic study looking at the differences in DNA between people with ME and healthy controls, led by Prof Chris Ponting at the University of Edinburgh.¹² Researchers examined the DNA of 18,000 people with ME and identified eight genetic signals linked to ME risk, showing that immunological and neurological processes are likely to play a part in ME/CFS. The initial results were released in 2025.

DecodeME was funded by the Medical Research Council and the National Institute for Health Research, and is the most significant UK ME study ever to have been carried out. Its results have set clear targets for further work, and while there is some funding for smaller follow-on studies there is no funding for major studies to continue the research.

Other research priorities were identified in 2022 through a Priority Setting Partnership between researchers, people with ME and their carers, set up by the James Lind Alliance and partly funded by the Scottish Government.¹³

In 2025 the DHSC published a delivery plan for ME/CFS, a multi-year strategy to improve ME research, attitudes and education.¹⁴ However again there is no dedicated research funding.

“I’ve worked across many different diseases, and it is clear that ME research does not get even one-tenth of the funding it deserves. The quality of life for people with ME is measurably worse than patients with other serious illnesses.”
Prof Chris Ponting, DecodeME Principal Investigator

#MEAction Scotland is a volunteer-led charity which campaigns to improve the lives of people with ME in Scotland. If you would like to find out how you can help please look at our website: meaction.org.uk/about/about-scotland-scottish-parliament or email us at: scotland@meaction.org.uk.



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