#ME ACTION SCOTLAND

# 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. Several preliminary studies are showing that nearly half of people with Long COVID have ME.[1,2,3] There is currently no cure.

## What are the symptoms?

ME impairs the body's ability to generate and produce energy, meaning systems and organs cannot function properly.[4,5,6] This results in a variety of debilitating and disabling symptoms, the cardinal feature being post-exertional malaise (PEM). Post-exertional malaise is a worsening of symptoms that can follow minimal cognitive, physical, emotional or social activity, or activity that could previously be tolerated. It can last for days or even weeks, and can result in a permanent, non-recoverable relapse. Other symptoms include cognitive impairment ('brain fog'), sensory sensitivity, gastrointestinal symptoms, muscle and joint pain, orthostatic intolerance and autonomic dysfunction. Individual symptoms vary; someone with mild ME may be able to work part-time, while those who are severely affected (around 25% of cases) are too ill to leave their house or even their bed. ME patients score more poorly on quality of life surveys compared to patients with all other diseases measured, including multiple sclerosis, stroke, renal failure, and lung cancer.[7] ME can be fatal in severe cases.[8]

## Who is affected?

Before the COVID-19 pandemic there were over 21,000 people in Scotland with ME. ME affects people of all ages, ethnicities and socio-economic groups.[9] Around 80% of people with ME are women.[10] Children are also affected, and longitudinal studies have shown ME to be the single biggest cause of long-term school sickness absence.[11]

## ME is a major source of economic inactivity

The estimated cost of ME to the Scottish economy is £360m per annum, or £17,000 for each person with ME per year. The majority of this is the cost of informal care and productivity losses, as most people with ME are of working age.[12] 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.[13]

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## Training and education for healthcare professionals especially GPs

There are no specialist consultants in Scotland and only one specialist nurse, so care of people with ME is the responsibility of GPs who do not receive adequate training in how to diagnose and manage it. In a recent survey of practising GPs, 70% thought ME was rare, and 30% thought it was psychological and not physical.[14] A typical GP practice of 10,000 patients can expect to have 20-40 people with ME but many go undiagnosed or are wrongly diagnosed, for example with depression.

In October 2021 a new National Institute for Health and Care Excellence (NICE) guideline on diagnosing and supporting people with ME was published bringing the prospect of positive change in the care of people with ME. Of particular significance is the removal of Graded Exercise Therapy (GET), a treatment that is risky and often harmful to people with ME.[15]

The NICE guideline does not apply in Scotland and there is no Scottish Intercollegiate Guidelines Network (SIGN) guideline for ME. GPs (and in the case of young people, paediatricians) are expected to use the 2010 Scottish Good Practice Statement (SGPS).[16] However GP awareness of the SGPS is poor and it has not yet been updated in line with the new NICE guideline.

Training for healthcare professionals, especially GPs and paediatricians, is needed urgently to ensure that healthcare is delivered in accordance with the new 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.

## Investment in services

The NICE guideline sets out that all people with ME should be referred to a specialist team to develop an individual care and support plan. The specialist team should also offer clinical support to GPs or paediatricians who are managing the care of people with ME. This represents a significant change to current practice and implementation will require substantial investment in both training and infrastructure.

A specialist team should have access to a multidisciplinary range of health and social care professionals including medical specialists, physiotherapists and occupational therapists. Three outpatient appointments with a nurse or Allied Health Professional per person with ME per year in Scotland would cost around £6.5m.[17]

The National Clinical Director Jason Leitch has written to NHS Boards advising them of the new NICE guideline and highlighting the need for investment to increase the number of specialist clinics and specialists with expertise in ME, but no extra money has been offered to NHS Boards for the implementation of the guideline.[18]

## Lack of investment in research

The main reason there is no treatment or cure is the lack of money spent on biomedical research for the last 30 years, both in the UK and overseas. In Scotland the latest figure was approximately £1 per patient per year - the comparable UK figure is £80 per patient per year for multiple sclerosis, a condition in which patients have a better median quality of life than people with ME. 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.[19]

The Scottish Government has provided funding for two research projects in the past 10 years:

- 2018: £45,000 for a three-year PhD project, with the shortfall made up by charity Action for ME.[20] While this funding is welcomed, it is less than £1 per patient per year.
- 2020: Contributed to the James Lind Alliance to help set up a Priority Setting Partnership to identify the top 10 research priorities for ME/CFS (also funded by the National Institute for Health Research and the Medical Research Council). This work was completed in May 2022 and provides key information to ensure future research funding can be directed at the areas most likely to be beneficial to people with ME.[21]

There is one notable UK research study currently underway: DecodeME, which aims to analyse the DNA of 25,000 people with ME. It received £3.2m of funding from the Medical Research Council and the National Institute for Health Research and is led by Prof Chris Ponting at the University of Edinburgh.[22]

> *"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

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