

What you need to know about M.E.

M.E. (myalgic encephalopathy or encephalomyelitis) is a complex multisystem disease with a wide range of disabling symptoms.

the ME association



June 2019

M.E. FACTSHEET

■ M.E. is estimated to affect about 0.2-0.4% of the population (that's around 250,000 people in the UK – including children and adolescents).

■ M.E. can cause greater functional impairment and poorer quality of life than many other serious medical conditions, such as multiple sclerosis and cancer.

■ M.E. has a unique and defining clinical feature known as post-exertional malaise – a delayed exacerbation of symptoms that can follow even minor physical or mental exertion.

■ M.E. researchers have discovered significant abnormalities in the central nervous system, immune system, endocrine (hormone-producing) system, and in muscle (causing energy metabolism impairment). All have been found to be involved in the disease process (*see the latest Research Summary at the MEA website*).

■ M.E. is classified by the World Health Organisation (WHO) as a neurological disease. The WHO classification is recognised by the Department of Health, the Medical Research Council and NICE (National Institute for Health and Care Excellence).

■ The NICE clinical guideline, aimed primarily at people working in the NHS, is currently being rewritten. This follows stakeholder pressure – including from the ME Association – that the existing guideline was unfit for purpose. The new guideline is expected to appear in October 2020.

■ M.E. is the commonest cause of long-term sickness absence from school.

■ M.E. can affect more than one family member – suggesting that genetic factors are involved.

■ M.E. has been estimated to cost the UK economy £3.3 billion each year.

■ M.E. is **diagnosed** following careful assessment of clinical history, physical examination, exclusion of other possible causes of symptoms and the application of diagnostic criteria. There are currently no blood or other diagnostic tests available.

■ M.E. is not a minor ailment. It has a wide spectrum of severity. Around 25% of people are severely affected at various stages of their illness; they can be housebound or bedbound, and often require a wheelchair to mobilise.

■ M.E. can affect some people very severely, leading to atypical seizures, speech and swallowing difficulties and extreme intolerance to light and sound. These people will be bed-bound, require continuous 24-hour care and may even need to be fed by tube.

■ M.E. in most cases can be linked to a previous viral infection from which people do not seem able to recover.

■ M.E. is a fluctuating condition – meaning that the symptoms can vary in form and intensity throughout the day, from day to day, and week to week – making it very unpredictable and hard to manage.

■ M.E. is a devastating disease with no established biomarker. Research funding from central sources has been woefully inadequate. Much of the knowledge gained so far has come from studies paid for by the charity sector.

■ The ME Association has invested over £1m in biomedical research and believes research offers the best hope for greater understanding and effective treatment.



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Symptoms

M.E. is diagnosed following a significant reduction in pre-illness activity levels and an inability to return to normal function.

The most important diagnostic symptoms are:

- Post-exertional malaise/symptom exacerbation (PEM) – often with a delayed impact. It can last for days or weeks before normal function is restored. PEM can also trigger a relapse.
- Activity-induced muscle fatigue brought on by trivially small exertion (physical or mental) relative to the patient's previous activity tolerance.
- Cognitive dysfunction – problems with short-term memory, concentration, word-finding, inability to form coherent sentences.
- Sleep problems – sleeping too little or too much, vivid dreams, unrefreshing sleep.
- On-going flu-like symptoms – including sore throats and enlarged glands, fever-like sweats, lethargy.
- Orthostatic intolerance – problems with pulse and blood pressure control leading to feeling faint or dizzy when upright.

Other common symptoms include:

- Pain – which can involve muscle, joints and nerves.
- Problems with balance and with temperature control.
- Sensitivity to light and sound.
- Alcohol intolerance.
- Gastro-intestinal symptoms.

Treatment

Drugs can be prescribed to help **manage** or control some symptoms such as pain and sleep disturbance. There is no curative treatment – although several drugs are being assessed in clinical trials.

The most important aspect of ongoing care is **activity management**. This involves striking the right balance between activity and rest so as not to exacerbate symptoms. This technique is known as Pacing.

Most people with M.E. will have **some degree of improvement** over time. However, a significant minority remain permanently and severely affected and many will see fluctuations in severity over a period, with some getting progressively worse.

Nomenclature and definitions of M.E.

M.E. (myalgic encephalomyelitis) is the medical name that was introduced by the medical journal *The Lancet* to describe an outbreak of the illness at the Royal Free Hospital in London in 1955. M.E. is the name that is preferred by people with the disease.

M.E. was renamed as chronic fatigue syndrome (CFS) by doctors in both the UK and the USA during the 1980s.

People with M.E., as well as patient support charities and a significant number of health professionals, do not feel that CFS is appropriate because it trivialises the level of suffering, ignores the multi-system symptomatology and can encompass people with 'chronic fatigue'.

The term 'encephalomyelitis' is not a pathologically proven explanation for what may be happening within the nervous system. Consequently, it often causes dissent among doctors.

The ME Association therefore proposed after a vote of its members the term 'myalgic encephalopathy', meaning a significant disorder of brain function. Since then, Myalgic Encephalopathy has been accepted as an alternative by NICE and other institutions.

In 2015, the influential Institute of Medicine in America, now known as the National Academy of Medicine, published a fully encompassing report – *Beyond ME/CFS: Redefining an illness* – that concluded:

'ME/CFS is a serious, chronic, complex and systemic disease that frequently and dramatically limits the activities of affected patients. In its most severe form, this disease can consume the lives of those whom it afflicts. It is "real". It is not appropriate to dismiss these patients by saying, "I am chronically fatigued, too"'

In 2017, a report published by the 2020 Health social enterprise think tank – *Counting the Cost* – estimated that the economic cost to the UK economy is about £3.3 billion a year.

The 2007 [Nice Guideline on ME/CFS](#) is currently being rewritten following criticism from the patient community that it is no longer fit for purpose. The ME Association is a stakeholder in the review process. A new guideline is expected in October 2020.



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The Medical Research Council regards ME/CFS as a research priority and has issued a **highlight notice** to encourage research applications –especially in relation to immune system dysfunction and neuropathology. However, research remains severely underfunded in the UK with most of the contributions still coming from the small charity sector.

The ME Association uses its dedicated **Ramsay Research Fund** to follow up promising lines of study. So far, the fund has invested over £1 million in biomedical research and continues to seek good quality applications.

We are the main continuing funders of the **UK ME/CFS Biobank** run by the Cure-ME team at the London School of Hygiene and Tropical Medicine.

The ME Association:

- Provides information on M.E. and campaigns on issues such as research, the NICE Guideline, NHS service provision and Social Care.
- Provides support to individuals through our ME Connect helpline, ME Essential membership magazine and our website and social media.
- Funds biomedical research – including the UK ME/CFS Biobank which is managed by an expert team at the London School of Hygiene and Tropical Medicine – through our Ramsay Research Fund.
- Belongs to the Forward ME Group of charities and patients' representatives chaired by The Countess of Mar. We are also on the executive board of the CFS/ME Research Collaborative chaired by Professor Stephen Holgate. This aims to raise the profile of M.E. and attract greater research investment.

Further information:

M.E. Research Summary <https://tinyurl.com/y32sc7to>

Ramsay Research Fund Factsheet <https://tinyurl.com/y5nmfmoq>

ME Association: Our clinical and research guide <https://tinyurl.com/y6uddnwm>

MEA: Index of published ME/CFS research <https://tinyurl.com/y2lvqndl>

ME Association: Website <http://www.meassociation.org.uk>

ME Association: also on Facebook, Twitter and Instagram



ME Essential, our quarterly membership magazine

To find out how you can get on the mailing list, please phone our office on 01280 818 968 or email: admin@meassociation.org.uk

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