ME Association Factsheet

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.

- M.E. is classified by the World Health Organisation (WHO) as a neurological disease. WHO classification is recognised by the Department of Health, the Medical Research Council and NICE (National Institute for Health and Care Excellence).
- M.E. is estimated to affect around 0.2-0.4% of the population (c.250,000 people in the UK) – including children and adolescents.
- M.E. is a devastating disease with no established biomarker. Significant abnormalities in the central nervous system, immune system, endocrine (hormone producing) system, and in muscle (causing energy metabolism impairment), have all been found to be involved in the disease process.
- M.E. affects all social classes and ethnic groups.
- 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 may be involved in predisposing people to develop the disease when a triggering event occurs.
- M.E. has been estimated to cost the UK economy £3.3bn each year *(see page 2)*.
- M.E. can cause greater functional impairment than many other serious medical conditions, including multiple sclerosis and cancer.
- M.E. is not a minor ailment and there is a wide spectrum of severity. Around 25% of people are severely affected – being house-bound, or bed-bound, and often requiring a wheelchair if they can mobilise – at various stages during the illness.
- 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 are often bedbound for most or all of the time, requiring continuous 24-hour care and they may need to be tube-fed.
- M.E. in most cases can be linked to a previous viral infection – from which people do not seem to have recovered. In some cases, M.E. can follow a vaccination, or other known triggering event.
- M.E. is generally regarded as 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.
- 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. 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.

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THE MOST IMPORTANT DIAGNOSTIC SYMPTOMS ARE:

- exercise-induced muscle fatigue,
- post-exertional malaise/symptom exacerbation,
- cognitive dysfunction i.e. problems with short-term memory, concentration, attention span,
- unrefreshing sleep,
- ongoing flu-like symptoms including sore throats and enlarged glands,
- problems with pulse and blood pressure control leading to feeling faint and orthostatic intolerance – caused by autonomic nervous system dysfunction,

OTHER COMMON SYMPTOMS INCLUDE:

- pain – which can involve muscle, joints and nerves
- problems with balance and temperature control
- sensitivity to light and sound
- alcohol intolerance

Drugs can be used to help manage or control some symptoms such as pain and sleep disturbance.

There is no form of curative treatment at present – although several drugs are being assessed in clinical trials.

The most important aspect of treatment is activity management – which involves striking the right balance between activity and rest so as not to exacerbate symptoms. This is known as pacing.

Most people with M.E. will make some degree of improvement over time. However, a significant minority remain permanently and severely affected.

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In 2015 the influential Institute of Medicine in America published a fully encompassing report – Beyond ME/CFS: Redefining an illness – that concluded:

> ***ME/CFS is 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 2020Health report – Counting the Cost – estimated the economic cost of ME/CFS to the UK economy is around £3.3 billion per annum.

The 2007 NICE guideline on ME/CFS is currently being re-written following criticism from the patient community that it was no longer fit for purpose. The ME Association is a stakeholder in the review process and a new guideline is expected in 2020.

The Medical Research Council (MRC) regards ME/CFS as a research priority and issued a highlight notice to encourage research applications – especially in relation to immune system dysfunction and neuropathology. However, most biomedical research continues to be funded by the charity sector, including the ME Association Ramsay Research Fund.

NOMENCLATURE AND DEFINITIONS OF M.E.

M.E. (myalgic encephalomyelitis) is the medical name that was introduced by 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 CFS (chronic fatigue syndrome) by doctors in both the UK and 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 an appropriate name to use as it trivialises the level of suffering, ignores the multisystem 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 the term 'encephalopathy', meaning a significant disorder of brain function, and this has been accepted by NICE and others as an alternative.

The ME Association believes that myalgic 'encephalopathy' may be a more appropriate way of describing the disease and the various abnormalities in hypothalamic, autonomic and cognitive functions and in cerebral perfusion that have been reported in the research literature.

THE ME ASSOCIATION:

- provides information on M.E. and campaigns on issues such as research, the NICE guideline, NHS service provision and treatment
- provides support through our ME Connect helpline, ME Essential members magazine and our website and social media
- funds biomedical research – including the UK M.E. Biobank which is managed by an expert team at the London School of Hygiene and Tropical Medicine – through the Ramsay Research Fund
- is a member of the Forward ME Group of charities and patient representatives that is chaired by the Countess of Mar, and the CFS/ME Research Collaborative, chaired by Professor Stephen Holgate, which aims to raise the profile of M.E. and attract greater research investment

FURTHER INFORMATION:

ME Association: ME/CFS/PVFS An Exploration of the Key Clinical Issues

ME Association: An Index of Published ME/CFS Research

ME Association: Website

ME Association: Ramsay Research Fund

ME Association: Facebook and Twitter