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.

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- 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. can cause greater functional impairment and poorer quality of life than many other serious medical conditions, including 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. research has discovered 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 (see Research Summary).
- 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).
- The NICE clinical guideline, which is aimed primarily at 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 in 2020.
- 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 are involved.
- M.E. has been estimated to cost the UK economy £3.3bn each year (see page 2).
- 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 and there is a wide spectrum of severity. Around 25% of people are severely affected – being housebound, or bedbound 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 will be bedbound, require continuous 24-hour care and may require tube-feeding.
- 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 considered 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 has been woefully inadequate from central sources with much knowledge coming from studies funded by the charity sector. The ME Association has invested over £1million in biomedical research and continues to believe 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, lasting days or weeks before function is restored. PEM can also trigger a relapse;
- Activity-induced muscle fatigue precipitated 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;
- Sleep problems – sleeping too little or too much, vivid-dreams, unrefreshing sleep;
- Ongoing 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/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,
- Gastrointestinal 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 – 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 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 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 Myalgic Encephalopathy has been accepted by NICE and others as an alternative.

In 2015 the influential Institute of Medicine (now the National Academy of Medicine) in America 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 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, research remains severely underfunded in the UK with most of the contribution still coming from the small charity sector.

The ME Association Ramsay Research Fund has invested over £1million in biomedical research and continues to seek good quality applications.

The ME Association:

- Provides information on M.E. and campaigns on issues such as research, the NICE guideline, NHS service provision and care
- Provides support through our ME Connect helpline, ME Essential members 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 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:

- M.E. Research Summary
- Ramsay Research Fund Factsheet
- 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: Facebook and Twitter

Our quarterly ME Essential magazine goes out to all members

If you would like to receive it regularly, please phone our office on 01280 818 968

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Do you need to talk?

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November 2018