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

This leaflet provides information to help in the understanding of M.E, its symptoms and treatments.

- M.E. is estimated to affect around 0.2-0.4% of the population (c.265,000 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 characteristic 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 determined significant abnormalities in the central nervous system, immune system, endocrine (hormone producing) system, and in muscle (causing energy metabolism impairment).
- 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 has been delayed due to the coronavirus but is expected in 2021.
- 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.
ME FACTSHEET

WHAT YOU NEED TO KNOW ABOUT M.E.

to light and sound. These people will be bedbound, they require continuous 24-hour care and may need tube-feeding.

- M.E. in most cases is triggered by a known event such as an acute infection. People with M.E. often report that they don’t feel as though they have recovered from the symptoms even after the infection has passed. In other cases, M.E. can develop following different triggers.

- 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 £1 million in biomedical research and continues to believe research offers the best hope for greater understanding and effective treatment.

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 2020 Health 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 Dr Charles Shepherd is an expert witness on the guideline committee. A new guideline has been delayed due to the coronavirus but is expected in 2021.

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.

In January 2020, a major new application from the ME/CFS Biomedical Partnership was submitted to the MRC that would result in a genetics study on 20,000 people with the condition. This £3.5million bid could provide answers to important questions about causation. The ME Association has been involved in this vital initiative since the beginning and we hope to share some good news about the funding very soon. Please register your interest as it will need the full support of the M.E. community if it is to succeed.

However, in general, 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 in recent years and continues to seek good quality applications.

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Our quarterly magazine ME Essential goes out to all members

If you would like to receive it regularly, please phone our office on 01280 818 963 or email: admin@meassociation.org.uk

ME CONNECT
We’re here to help

Do you need to talk?
CALL US AT
ME CONNECT ON
0344 576 5326
10am-12noon, 2pm-4pm, 7pm-9pm every day of the year
WHAT YOU NEED TO KNOW ABOUT M.E.

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 and Instagram

The ME Association website shop:
You can download leaflets and buy gifts from our website shop or by downloading and completing our Order Form. If you are a member of the ME Association, you will receive an order form with your quarterly magazine.

The following literature is available to download or order:

Medical Management
Leaflets about the medical management of ME/CFS – 51 topics covered.

ME Connect
Useful leaflets based on the concerns expressed by people who have used our ME Connect helpline.

Diet & Nutrition
Our dietary advisers provide key information to help you maintain a healthy diet even when ill.

General Information
Guides to going to university and travel insurance – with other great leaflets.

Fundraising Leaflets
You’ll be welcome to download our free fundraising leaflets.

Benefits & Social Care
Includes guides to Universal Credit and PIP and obtaining Social Care.

‘To Whom It May Concern’ letters
For when you need to explain to others how M.E. can affect your ability to do things.

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