

## 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.**

**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



# 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 £1million 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

## WHAT YOU NEED TO KNOW ABOUT M.E.

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.



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](mailto:admin@meassociation.org.uk)

**ME CONNECT**  
*We're here to help*

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**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**



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## 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.



Go the extra mile for  
**ME**

How you fundraise for the ME Association and for ME is entirely up to you. We are here to support you and to help you to put the FUN into fundraising.

Our fundraisers all share a passion for fundraising for ME. Perhaps a friend or family member has this cruel illness, or perhaps they have it themselves. How we fundraise is very individual - combining our own unique talents, ideas and ambitions with our determination to raise as much money as we can.

Many people do physical challenges - for someone they care about who cannot. But for others, who cannot or who should not be pushing themselves physically, we have a host of creative ideas to get you started.

The world is your oyster when it comes to fundraising! To find out more and keep in touch, look for our private fundraising page on Facebook called 'Purple Fundraisers for ME'. Then ask to join us!

**M.E. Hurts!**

"One day I caught a virus... and I never got better....!"

M.E. often starts that way - with something like a flu virus that knocks you sideways. You expect to get over it in a week or so, but weeks, months and even years go by, and you feel no better... We believe that well over 250,000 people in the UK are living with this nightmare of an affliction.

M.E. stands for myalgic encephalomyelitis. It has other names, including CRS - chronic fatigue syndrome - but the end result is always the same: M.E. hurts! It hurts in so many ways - Physically, Mentally, Socially, Financially, Emotionally...

But don't just take our word for it - we asked our supporters to tell us what M.E. felt like, and this is what they told us.

**M.E. is REAL. It's physical!**

Pain and extreme tiredness are all too common. Pain that pin livers barely touch. Your senses go into overdrive - light and sound can hurt. You sleep but wake unrefreshed. Or worse still, you don't sleep.

"I have to choose between brushing my teeth and washing my hair - I don't have enough energy to do both!"

**M.E. shatters families and destroys friendships**

Around a quarter of M.E. sufferers are so badly affected that they cannot leave their homes, or even their beds. For some, the most social part of their day is when someone caring for them comes in to check up on them.

For many, the effort of just talking on the phone is too much.

**You can't see M.E!**

M.E. is invisible. You cannot tell, just by looking at someone, just how they feel, how much pain they are in, or how much energy it is taking just to talk to you.