

ME/CFS: Key Facts

- ME/CFS (myalgic encephalomyelitis/chronic fatigue syndrome) is a complex multisystem disease with a wide range of disabling symptoms.
 - It 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.
 - Sound epidemiology is lacking. However, it is estimated that ME/CFS affects around 250,000 people in the UK - including children and adolescents, where it is the commonest cause of long term sickness absence from school.
 - ME/CFS affects all social classes and ethnic groups.
 - ME/CFS is not a minor ailment and there is a wide spectrum of severity. Around 25% of people are severely affected - being house-bound, wheelchair-bound or bed-bound - at some stage in the illness.
 - Several quality of life research studies have shown that the level of disability can be profound with research studies confirming that the functional impairment across various domains is just as great, or greater, than many other serious medical conditions, including cancer and multiple sclerosis.
 - Most people with ME/CFS will predate the onset of their symptoms to a viral infection - from which they do not recover. In some cases the illness follows a vaccination.
 - The unique and defining clinical feature of ME/CFS is post-exertional malaise/symptom exacerbation - a delayed exacerbation of symptoms that follows even minor physical exertion.
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- The most important **diagnostic symptoms** are:
 - exercise-induced muscle fatigue
 - post-exertional malaise/symptom exacerbation
 - cognitive dysfunction = problems with short term memory, concentration, attention span
 - unrefreshing sleep
 - problems with pulse and blood pressure control leading to feeling faint and orthostatic intolerance. This is caused by autonomic nervous system dysfunction
 - on going flu-like symptoms including sore throats and enlarged glands
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- Other **common symptoms** include:
 - pain - which can involve muscle, joints and nerves
 - alcohol intolerance
 - problems with balance and temperature control
 - sensitivity to light and sound
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- Some people with **severe ME/CFS** have atypical seizures, speech and swallowing difficulties - the latter may require tube feeding.

- ME/CFS is a fluctuating condition - meaning that the symptoms vary throughout the day and from day to day and week to week.
- ME/CFS is diagnosed on the typical clinical history and excluding other causes of an ME/CFS like illness. There are no blood or other diagnostic tests available.
- The most important aspect of treatment involves activity management - which involves striking the right balance between activity and rest. This is known as pacing.
- Drugs can be used to help with 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 NICE guideline on ME/CFS is currently being re-written following criticism from the patient community that it was no longer fit for purpose.
- Abnormalities in the immune and endocrine (hormone producing) systems, muscle (causing energy metabolism impairment) are all involved in the causation of ME/CFS. Genetic factors may also be involved as it sometimes affects more than one family member
- 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, most biomedical research is funded by the charity sector, including the MEA Ramsay Research Fund.
- Most people with ME/CFS will make some degree of improvement over time. However, a significant minority remain permanently and severely affected.
- A recent report has estimated that the economic cost to the UK economy in terms of lost taxes, NHS spending, benefits payments etc is around £3.5 billion per annum.

NOTES ON NOMENCLATURE AND DEFINITIONS OF ME AND CFS

- ME (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. ME is the name that is still preferred by people with this illness
- ME was renamed and redefined as CFS (chronic fatigue syndrome) by doctors in both the UK and USA during the 1980s. People with ME, 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 brings in people with various forms of undiagnosed chronic fatigue.

THE ME ASSOCIATION IS HELPING TO MAKE THE UK A BETTER PLACE FOR PEOPLE WITH ME.

We provide information to people with ME/CFS and also campaigns on issues such as research and NHS services.

The ME Association also provides support through our ME Connect helpline and MEA Facebook page.

We support and fund biomedical research into ME/CFS - including the ME Biobank at the Royal Free Hospital in London - through the Ramsay Research Fund.

ME Association head office: 7 Apollo Office Court, Radclive Road, Gawcott, Bucks, MK18 4DF
Telephone: 01280 818964 between 9.30am and 3.00pm

Visit our [website](#) for information, news, and research, about the neurological disease, myalgic encephalopathy/chronic fatigue syndrome, and follow our community discussions on [Facebook](#) and [Twitter](#).

The ME Association:

Helping make the UK a better place for people with ME/CFS

Registered charity number: 801279