

## ME & CFS - facts & figures

1. ME (Myalgic Encephalomyelitis) is [classified by the World Health Organisation](#) as a neurological condition at [ICD-10 G93.3](#) and can be fluctuating, long term and disabling.
  2. Patients prefer the term ME. The medical profession use CFS or Chronic Fatigue Syndrome as an alternative. CFS is an umbrella term for many different conditions which have fatigue as their primary symptom. The terms ME/CFS and CFS/ME are also used.
  3. The prevalence of ME & CFS based on [research from 2004](#) is 0.2 – 0.4% of the population. Therefore there are an estimated 12,000 patients in Wales and 250,000 in the UK. Roughly 10% are children under the age of 16. ME & CFS affects people of all classes, ages, and ethnic groups. Females are thought to outnumber male patients 2:1. There is an annual incidence of 1,300 in Wales.
  4. An estimated [25% are severely affected, either house or bedbound](#) and not able to self care.
  5. There is currently no single identifiable cause although many triggers have been identified, such as viruses, vaccinations, toxins and pesticides. Often patients are diagnosed with Post Viral Fatigue Syndrome (PVFS) if a viral trigger is identified.
  6. [ME/CFS is the most common cause of long term absence among school children: 51% compared to 23% for cancer and leukaemia, 13% for general medical or surgical conditions, 12% for musculo-skeletal problems, 5% for psychiatric disturbance and 5% for virus infections.](#) (Dowsett EG, Colby J. Long term Sickness Absence due to ME/CFS in UK School. An epidemiological study with medical and educational implications. Journal of Chronic Fatigue Syndrome, 1997; 3 (2): 29:42)
  7. [Early diagnosis](#) and appropriate management advice is thought to [improve the chance of recovery](#). Until a diagnostic test becomes available diagnosis has to be made by [identifying the symptom pattern and ruling out other conditions](#). Accurate diagnosis is difficult to find in Wales.
7. The distinctive characteristic of ME is that symptoms become worse after physical and mental exertion, although the reaction may be delayed by a day or more (post-exertional response) and a return to previous level of health can be unpredictable. Main symptoms:
- severe 'flu-like' symptoms
  - sore throats
  - muscle and joint pain
  - cognitive impairments such as poor concentration, memory problems and word finding difficulties amongst other symptoms
  - sleep disturbance, unrefreshing sleep
  - inappropriate loss of physical and mental stamina with slow recovery
  - body temperature disturbance
  - dizziness & vertigo
  - swollen glands
  - headaches of new pattern, type or severity
- Additional symptoms can include:
- sensitivity to light, noise, some medications, alcohol, chemicals
  - nausea, loss of appetite, digestive disturbance
  - children's initial symptoms can be stomach pains and headaches
  - severe symptoms include blackouts, temporary partial paralysis, loss of speech, loss of swallowing function

8. Progress is difficult to predict. A small percentage of people make a complete recovery over time but are still subject to relapse when they have an infection. Some reach 70-80% of previous level of health and are able to live a 'normal' life with adjustments, such as loss of social life or part time working although this may take some years to achieve. The majority follow a fluctuating pattern with good and bad periods of health. Although not unknown, continued deterioration is rare. Roughly 25% are severely disabled and in need of continued care and support. Young people under the age of 20 are more likely to recover than adults but some children do remain ill into adulthood.

9. There is currently no cure or treatment and what helps one person may not help another. What seems to help most in the early 'acute' stage of the illness is rest.

10. Patient surveys show [pacing](#) is the most helpful management approach. Medication, lifestyle changes, diet and complementary therapies also help relieve symptoms.

11. [NICE guidelines](#) recommend Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET) for mild to moderately affected adult patients only, although the evidence is acknowledged to be meagre. Patient experience and biomedical research findings highlight the inappropriateness and potential harm of GET for all people with ME.

12. Research has found evidence of gene dysfunction and dysfunction in many of the body's systems including the immune system, neuroendocrine system, autonomic nervous system and muscles.

13. A [2007 study](#) calculated the economic impact of ME on the UK at £6.4 billion per year, although the cost in terms of personal loss – both financial and emotional – is incalculable to the person with the condition and to their families, carers and friends. <http://www.afme.org.uk/res/img/resources/Facts%20and%20Figures.pdf> p7

14. There are no ME or CFS specialists in Wales, and little or no training about ME and CFS is given to health professionals or allied staff. In June 2010 the Health Minister told LHBs to develop services for people with CFS/ME.

15. In 2011 for the first time the [MRC offered £1.5 million](#) funding for new research into the mechanisms of CFS/ME. <http://www.mrc.ac.uk/Fundingopportunities/Calls/MechanismsofCFSME/MRC007715>

16. Due to a lack of understanding of the nature and severity of ME and CFS patients and their families can face difficulties:

- Accessing suitable education when part time education or home tuition is refused.
- When parents of children with ME are suspected of causing the child harm because s/he does not recover as expected.
- In employment when employers do not make 'reasonable adjustment' under the Disability Discrimination Act for their employees with ME.
- Accessing Benefits
- Accessing social care