

## ME Awareness Day 12<sup>th</sup> May 2015 – Employers Advice Guide – The Facts.

Myalgic Encephalomyelitis or Encephalopathy (M.E.) is also diagnosed as Chronic Fatigue Syndrome (CFS) or Post Viral Fatigue Syndrome (PVFS).

M.E. is defined as a neurological illness by the World Health Organisation. It is thought that around 250,000 men, women and children in the UK have M.E., although it is most common in women aged 25-50. In the working population, as many as 1 in 250 may have M.E.



M.E. The diagnosis is defined as a persistent or relapsing unexplained chronic fatigue with the following characteristics – fatigue lasting six months, fatigue of new onset, fatigue that is not the result of physical illness or not alleviated by rest.

Symptoms can include persistent exhaustion ('fatigue'), pain, sleep disturbance, 'flu-like' symptoms such as headache, sore throat, painful lymph nodes, dizziness and/or nausea and problems with memory and concentration. Levels of severity range from mild and functioning to housebound or bedbound.

As M.E. is a fluctuating illness, symptoms can also vary day-to-day. This can make it difficult to maintain a consistent level of working, which can be frustrating and challenging for both the individual and the employer.

**Fatigue:** M.E. fatigue feels very different from ordinary tiredness. Simple physical and/or mental activities can leave a person with M.E. feeling shattered and struggling to function with the increase in their other symptoms. The impact may be felt straightaway or take a day or two to take effect.

**Pain:** Pain may manifest as aching muscles or joints, nerve pains or pins and needles, headache or migraine, twitching muscles or cramps. There may be abdominal pain, stomach or bowel problems.

**Cognitive difficulties:** These may include reduced attention span, short-term memory problems, word-finding difficulties, inability to plan or organise thoughts or loss of concentration – often described by people with M.E. as 'brain fog.'

**Other symptoms:** The illness may affect mood and people with M.E. can also experience poor temperature control, loss of balance, dizziness on standing up, hyper-sensitivity to light, sound, odours, certain foods, some medications, alcohol and other substances.



The fluctuating nature of M.E. can make it difficult for someone with the illness to maintain a consistent level of working. A task that is easily manageable one day may prove impossible the next. Even when a person's condition appears to have stabilised, it is common for people with M.E. to experience relapses or setbacks, when their health deteriorates again for a period of time. This may happen if they have been pushing themselves too hard.

**Treatment:** There is as yet no cure for M.E. Treatment consists of symptom management and coping strategies, eg. medication for pain and following a programme such as pacing for energy management,

cognitive behaviour therapy and/or graded exercise activity. The type of CBT is important. This must include challenging and changing the pattern of fatigue. CBT has demonstrated improvement rates of around 70% compared with improvement rates of around 75% with GET.

Pacing involves taking short, regular rest periods throughout the day, identifying activities which use energy (physical, mental or emotional), establishing a sustainable baseline for each activity, once the baseline is established, increasing that activity by no more than 10%, until a new sustainable baseline is achieved.



Evidence shows that poor predictors of outcome include: Membership of a self-help group, receipt of sickness benefit, claiming a disability related benefit, low sense of control, strong focus on symptoms, pervasive and a passive activity pattern. Research evidence also shows that the duration of illness does not predict the outcome.

Most employees diagnosed with ME are likely to be covered by the disability aspects of the Equality Act 2010 because the condition affects their day to day living.

Evidence-based guidance for employers, 'Occupational aspects of chronic fatigue syndrome/myalgic encephalomyelitis', says reasonable adjustments may include measures such as: changing locations of work, working from home, modifying work hours, reducing workloads, reducing physical tasks, making provision for a wheelchair and flexibility in working patterns. For people with mild or moderate M.E., the earlier such adjustments are made, the easier it will be for them to remain productive.

Potential changes to physical features, eg. Making premises wheelchair accessible or providing practical aids and equipment to help the employee do their job, may be funded through the Access to Work Programme.



For employees with long standing ME, the local Access to Work team, accessed through the Job Centre Plus network, is a useful support resource for employers. In addition, the Local Employment Advisor also accessed through the Access to Work network is able to provide advice with regards to grants and Government funded initiatives that are available to support employees back into the workplace and assist the employer in making reasonable adjustments.

With appropriate treatment, 40% of individuals with ME or CFS are seen to improve over time. Without treatment, only 5% of individuals with ME are likely to recover.

Unfortunately for both employees and employers the timeframes for recovery in respect of ME or CFS are calculated in terms of years and not months. On average it is not unusual for an individual with profound symptoms to take between 3 and 5 years to achieve a level of recovery that enables them to return to work on a consistent basis.

Useful Information:

[www.actionforme.org.uk](http://www.actionforme.org.uk)

[www.mesupport.co.uk](http://www.mesupport.co.uk)

[www.meassociation.org.uk](http://www.meassociation.org.uk)

[www.nhs.uk/conditions/chronic-fatigue-syndrome](http://www.nhs.uk/conditions/chronic-fatigue-syndrome)