



**Cymdeithas Cefnogi
ME & CFS Cymru**

**Welsh Association of
ME & CFS Support**

Information sheet for Health Professionals

ME & CFS

ME or CFS is a potentially disabling and chronic condition that is classified by the World Health Organisation as a neurological disorder in section G93.3 of ICD10 (International Classification of Diseases, number 10). WAMES chooses not to enter the debate about whether Myalgic Encephalopathy or Myalgic Encephalomyelitis is a more accurate term as both could eventually be superseded. We believe the use of the term Chronic Fatigue Syndrome is unhelpful as it focuses on only one of the symptoms. We also find that doctors use it as an umbrella term for a variety of medical conditions with a fatigue element and the physical illness of ME is often confused with a more general, often psychologically caused, chronic fatigue. We therefore choose to use the term ME.

EPIDEMIOLOGY

According to the prevalence figures used by the English CMO's report in 2002, there could be as many as 11,700 people in Wales who suffer from ME and CFS. They include people of all types, both sexes and all ages. The youngest person diagnosed, that we know of, was 5 years old.

SYMPTOMS

The trigger can vary, but most patients have reported becoming ill after a virus, undetected bacterial infections, vaccinations, allergies or food sensitivities, and exposure to chemicals. Typically patients fail to recover from the virus, vaccination reaction etc, unlike others around them.

The condition is characterised by extreme debilitating and disabling exhaustion, muscle pain and a severe 'flu-like' malaise. People can experience a wide range of symptoms, the ones most frequently reported (not in any order) include digestive problems, difficulties with concentration and memory, loss of balance, sleep disorders, mood swings, migraine-type headaches, persistent sore throat & swollen glands, visual disturbances and poor temperature control.

Patients can remain seriously ill for many months, the severity of symptoms fluctuating from hour to hour and day to day. Symptoms become worse after physical and mental exertion, although the reaction can be delayed a day or more. This post-exertional response and the relapsing remitting progress of the condition are classic signs.

PATHOETIOLOGY – RESEARCH FINDINGS

There is a great need for research into the biological cause/s of the illness. There are a number of difficulties with comparing conclusions from current research, the primary one being that studies use a variety of patient selection criteria (Oxford, London, CDC1992/1994 or Fukuda, or one of their own devising). None of them is ideal but the Oxford criteria conforms least to our members' experience of ME. WAMES is calling for researchers to recognise that there are a number of subgroups under the CFS banner and that a standardised set of criteria for ME patients should be agreed, perhaps based on the London and the very impressive Canadian criteria.

Some of the most significant research findings of the last 20 years show:

- Immunology – immune activation (Bennett 1997) & episodic immune dysfunction (Klimas 1990)
- Muscle studies – evidence of post-exercise fatigue (Paul 1999) & oxidative defects in muscle energy metabolism (McCully & Natelson 1999)
- Central Nervous System involvement – disturbances in the autonomic regulation of cardiovascular reflexes (Bou-Halaigah 95) & Neurally mediated hypotension or NMH (Peterson)
- Hypothalamic dysfunction – hypocortisolaemia (Demitrack 91) & adrenal gland atrophy (Scott 99)
- Neurotransmitters – abnormalities involving serotonin, acetylcholine and dopamine
- Neuro-endocrine – disturbances in hypothalamic function, especially reduced output of cortisol and enhanced output of prolactin (Richardson 1995)
- Neuroimaging – MRI scans show reduced hypoperfusion (Costa et al 1995)
- Genetics – overactive genes found to be causing problems in immune system, neurological function and mitochondrial metabolism (Kerr et al 2005) & differences in gene expression between rapid & slow onset, even after 10 years of illness (Whistler, Vernon et al 2003)

PROGNOSIS

Progress is difficult to predict. Some make a gradual return to full health over a few years, especially if they have had an early diagnosis and follow an appropriate management plan. The majority will make variable progress struggling with relapses and remissions, with some reaching 70-80% of previous level of health. Children appear to have a better prognosis than adults. About 25% of patients remain severely disabled and are either bed bound or housebound.

ILLNESS MANAGEMENT

There is no cure at present. Research based on a psychological aetiology concludes that GET can reverse muscle de-conditioning and CBT can alter faulty illness beliefs. There is no evidence however to show that de-conditioning exists or to prove the efficacy of these treatments for any ME patient, and especially for the severely affected and the young. Patient surveys report that exercising and over activity in the early stages of the illness can lead to the condition becoming chronic.

Currently, the provision of health care for ME patients in Wales is totally inadequate. Patients have experienced disbelief, disinterest, misdiagnosis, hostility and inappropriate referrals and treatment prescriptions. This means that all sufferers, not just those who are housebound, can feel isolated and neglected. Parents of ill children can be accused of abuse, and desperation pushes people to try a wide range of expensive private therapies or to travel hundreds of miles to England for a specialist consultation.

WAMES agrees with the English CMO's report that it might be possible for the majority of patients to be diagnosed and managed within the primary care system, although there will be a need for local & tertiary specialists within Wales as travel can cause a deterioration in symptoms. It would be logical for these to be sited within neurological services units, following the example of the National ME Centre in England.

It has been found that an early diagnosis and plenty of rest in the early stages, and during relapses, can help to limit the effects of the illness. Every person is different and it is important patients learn what helps them, so WAMES recommends that patients receive guidance in devising individual management plans and that their progress is monitored. These plans could include:

- energy management & coping strategies
- dietary advice
- symptom relief through pharmaceutical provision and other methods
- passive exercises, especially for the severely affected
- home nursing, care support and mobility aids
- education & employment arrangements (part time, home tuition, e-learning etc)
- advice on where to find help applying for benefits
- referrals to appropriate specialists when new symptoms arise or to check diagnosis