

WHAT IS ME/ CFS?

By Dr Anne MacIntyre

ME stands for Myalgic Encephalomyelitis - this name was coined in 1956.

- Myalgia = muscle pain
- Encephalomyelitis = inflammation of the brain/spinal cord.

There is little scientific evidence for inflammation of the brain; a better name would be Myalgic Encephalopathy = something wrong in the brain.

ME is a potentially serious, disabling and chronic illness, affecting the brain, muscles and immune system. It causes profound exhaustion, pain, and mental confusion. Doctors and scientists are still confused about what causes ME symptoms, and the impact on sufferers' lives is often underestimated.

A newer name is Chronic Fatigue Syndrome, or CFS. However it only describes fatigue and CFS can be confused with chronic tiredness, 'burn-out' and depression.

HISTORY OF ME/CFS

ME has been around for centuries, and has had many names, including:

- neurasthenia (1800s)
- post-viral fatigue syndrome (PVFS)
- Royal Free Disease (a major outbreak in London's Royal Free Hospital 1955).

ME used to occur in mini-epidemics, but since 1956 it is more usually seen in isolated cases, sometimes 'clusters' in schools or villages.

At present there is no cure for ME, and no specific diagnostic test.

DIAGNOSING ME/CFS

Diagnosis is made from recognising the main symptoms, and the ruling out of other illnesses. ME probably affects about 2 per thousand people in the UK, and affects all social, ethnic and economic groups.

The onset is commonest between ages 20 to 40, and women are more affected than men. However ME is increasingly recognised in children, with the peak onset in young people around puberty.

ME can vary in severity, the worst affected may become unable to walk, even too weak to eat. The less severely affected may be able to attend school or hold down a job, but only if they avoid sports and rest a lot.

PROGNOSIS IS IMPOSSIBLE TO PREDICT

After onset of ME, about 20% make a nearly complete recovery within 2 years. 60% partially recover over several years to 70-80% of their pre-illness level of activities.

However the progress is erratic, with relapses and remissions. About 20% remain seriously disabled, and of these some unfortunately steadily deteriorate, with no remissions, and become bed-bound.

ME is predominantly a brain illness - the brain controls all body functions and sensations, so patients may experience many apparently unrelated and bizarre symptoms.

MAIN FEATURES OF ME/CFS

- Severe fatigue of muscles and/or the brain, developing 24-48 hours after relatively minor exertion, with recovery taking days or weeks. There may also be muscle pain and/or twitching. The exhaustion is much more severe than ordinary tiredness, and is unrelieved by a night's rest.
- A variety of neuropsychiatric (brain) symptoms, most prominent being loss of memory, concentration and comprehension, and disturbances of sensation.
- Unpredictable variation in severity from week to week, or day to day.
- A tendency to become chronic over many months or years.

TYPICAL MUSCLE SYMPTOMS

- Muscle weakness after minimal effort, with long recovery time.
- Difficulty standing - rapid onset of aching legs and feeling light-headed, causing problems queuing or cooking!
- Difficulty holding the arms up, carrying bags or holding a telephone.
- Intermittent blurring of vision - due to fatigue of eye muscles
- Muscles painful to touch, sometimes visible muscle twitching.

[All problems arise from sustained use of a muscle, which may work normally to begin with, but becomes weak and painful after a relatively short time]

BRAIN SYMPTOMS

- neurological & psychological

- Poor concentration - problems following TV or a conversation. Difficulty learning new information. [Significant for schoolchildren and students]

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- Poor memory - losing names of familiar people, disorientated and lost in a familiar place, loss of words for things.
- Muddled or slurred speech when tired.
- Loss of arithmetic skills - e.g. cannot count money.
- Hypersensitive to light and especially sound.
- Poor balance, feeling unsteady, clumsiness, dropping things
- Altered skin sensation - painful to touch, numbness, or 'pins and needles' in arms or legs.
- Transient blurred or double vision.
- Nightmares, sleep disturbance
- Exaggerated emotions - weepiness, irritability, panic attacks, mood changes.

AUTONOMIC NERVOUS SYSTEM DISTURBANCE

- also part of brain disturbance

- Sudden rapid heart beat, palpitations.
- Profuse sweating, even when cold.
- Pallor - often ashen grey - at onset of feeling ill.
- Poor temperature control
- Hands or feet icy cold, or hot and flushed.
- Alternating diarrhoea or constipation
- Dizziness on standing ['postural hypotension']
- Poor blood sugar control
- Bladder symptoms

IMMUNE SYSTEM OVERACTIVITY

- Persistent or recurrent sore [but not septic] throat.
- Tender lymph nodes.
- Low grade fever [under 38.6C]
- Aching joints

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- Development of new allergies - particularly to chemicals and some foods

Another typical symptom is almost total intolerance to alcohol.

TREATMENT

There is no curative treatment; the best management is based on:

- Plenty of rest, pacing activities, managing energy carefully
- Treating specific symptoms - pain, insomnia, depression
- Avoiding emotional and physical stress where possible
- Patience, allowing time for gradual recovery!

Other conditions may develop over time, so a regular check with a doctor is important, especially if there are new symptoms.

FURTHER INFORMATION

For further information please visit our website where you can also buy a copy of Dr Anne MacIntyre's Book by going to the following link. It is also in the Group library.

Website: <http://www.eastlancsme.org.uk/shtml/buyonline>

Title: ME/Chronic Fatigue Syndrome: A Practical Guide

Publisher: Thorsons Health (Harpercollins)

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