

What sort of people get M.E?

Mostly age 30-40. Cases occur between 5-80 years. Health workers & those stressed dealing with many people seem worst affected. Women are prone. M.E does not acknowledge income, marital status, social status or lifestyle & may complicate other major illness e.g. diabetes, asthma & coeliac disease.

Are there any famous people with M.E?

Clare Francis, around the world yacht woman.
Florence Nightingale, the nursing pioneer.
T.V. personality Esther Rantzen's daughter.

Can I attend school or college with M.E?

No one should be forced who is ill. Games & physical activity are out. Attendance may be limited or a home tutor may be needed. Co-operation of the school, teachers, doctor & parents is essential.

Can I continue to work with M.E?

In some cases light work may be possible with reduced hours, but it needs a protected environment supervised to avoid a relapse as stress of any kind hinders recovery. In many cases, the unpredictability is incompatible with what an employer would reasonably expect, as no guarantee can be given about fitness to work at any one time or the quality of work that can be expected.

Employers are firstly sympathetic, but when it becomes clear that the illness may last a long term problems occur. Take careful advice from your union, solicitor and doctor. No one should resign or accept an offer without professional guidance. In most cases an occupational pension

How can I best help myself now?

- Keep a diary of your problems (useful later).
- Ask your doctor to consult a specialist.
- Give an 'Information for Doctors' sheet to the doctor yourself.
- Consider multivitamins as your G.P. advises.
- Avoid known stressors, foods & chemicals.
- Apply for state benefits e.g. D.L.A., or A.A.
- Check with your G.P. about any alternative therapies before starting them.

What should I not do?

- Expose yourself to any form of stress.
- Graded exercise often used for 'depression' treatment if it makes you worse.
- Expose yourself to chemicals e.g. paint fumes.

How can LEGER ME help?

- CFS/ME Assessment Service
- Helpline for information and guidance.
- Meetings.
- 'Pathways', our newsletter.
- Guidance with Welfare Benefits.
- Website: www.leger.me.uk.
- Social events.
- Linking Up service to other members.

Further information:

Ring our group contact, Mike, on:
(01302) 787353 (afternoons & evenings).



Leger-ME:

*Supporting Myalgic Encephalopathy or Encephalomyelitis (ME),
Chronic Fatigue Syndrome (CFS),
Post Viral Fatigue Syndrome (PVFS),
Fibromyalgia Syndrome (FMS), Patients & Carers*

Members' Information Leaflet

*This leaflet is intended to supplement
guidance from the group helpline*

Welcome to **LEGER ME**

What does CFS/ME mean?

CFS/ME is a mnemonic used for all the conditions we support (ME.CFS,PVFS, FMS). Doctors use all these terms.

How does CFS/ME start?

- a) Triggered by a viral infection and/or other life trauma incident or stress. e.g. vaccinations, accidents, environmental poisons
- b) By gradual onset, unnoticed until a specific event makes someone realise something is wrong.

How is CFS/ME classified?

CFS/ME is a multi system illness. The nervous & immune systems are mainly involved. The WHO classification is 'Neurological Conditions'. More conservative medical opinion classifies ME/CFS as 'Fatigue Syndromes'.

What are the main symptoms of CFS/ME?

Muscle Fatigue: Abnormal muscle fatigue brought on by normal activity. All symptoms are made worse by over-exertion, even minimal activity, and are disproportionate to the effort expended. After activity, the onset of 'rebound fatigue' may be delayed by up to 72 hours. Recovery from ME/CFS may take many months or years.

Pain sensation may change from day to day. Severe headache, abdominal pains, back, neck or facial pain, joint pain and swelling, muscle pain and tenderness and paraesthesia are all common.

Neurological problems: Poor concentration, short term memory loss, disturbances of sensation, poor co-ordination, balance problems, impaired or confused speech, tinnitus, blurred or distorted vision may be experienced.

Autonomic Nervous System Palpitations, rapid pulse, sudden pallor, poor circulation and poor temperature control, constipation, diarrhoea and bladder dysfunction may occur..

Sleep Disturbance: Initially over-sleeping then insomnia, early wakening, morning stiffness, vivid, unpleasant dreams and abnormal sleeping patterns ('Night Owls') are all reported by sufferers.

Emotional: ME/CFS leads to reactive depression, low mood being directly related to the severity of the illness.

How is CFS/ME diagnosed?

There is no single specific NHS test, however there are tests within the private sector. Doctors take a careful history, make an examination and exclude other conditions which could cause the symptoms. The presence of symptoms in varying degrees for 6 months or more is often treated as diagnostic, along with fatigue sufficient to reduce daily activities by at least 50%.

What has gone wrong ?

Opinions differ greatly. There are at least six subtypes of CFS/ME. One or more of the following is true in most cases:-

- a) The immune system behaves as though a persistent virus is present, but is not. Cytokines are produced by the immune system causing 'flu like' symptoms affecting nerve & muscle tissue.
- b) SPECT scans show reduced blood flow to the brain stem. There are hypothalamic & pituitary disturbances causing hormone & neurological changes which lead to further symptoms..
- c) There are disturbances in the mitochondria (cell power station) & A.T.P. production.
- d) Abnormalities have been found in immune system T cell & NK subsets.

What are the chances of recovery?

- a) In 20-25% of cases recovery takes place within a year and is complete. Children have the best chance, but recovery can take 3-5 years.
- b) In 50-60% of cases partial recovery occurs over several years only with major lifestyle changes.
- c) 25-30% remain permanently disabled.
- d) About 1% are bed bound.
- e) Relapses are common.

Are there Myths about M.E?

'M.E. is all in the mind' is a popular myth among some doctors. Any doctor holding this view is mistaken and should be avoided. The Chief Medical Officer's Report makes it quite clear that CFS/ME is a bona fide medical condition. This was further confirmed by the recent establishment of a network of NHS clinics.

Are there any treatments for M.E?

The only effective treatment is complete rest in the early stages followed by pacing. The sooner started the better the chances of recovery. Most of the symptoms except fatigue can be controlled by medicines, nutritional and other interventions..

Are there any common complications?

- a) 'Reactive depression', technically different from clinical depression and related to the severity of the illness, is common. This may or may not co-exist with clinical depression. Both problems usually respond to low doses of tricyclic antidepressants.
- b) Patients experience gut fermentation and Dysfunctional Gut Syndrome (D.G.S.), similar to Irritable Bowel Syndrome. (IBS). Central Nervous System & immune system dysfunction leads to abnormal gut flora, causing food & chemical intolerance. Small amounts of irritants can cause a major relapse. These problems can be tested for and treated with medicines & dietary modifications.

How many people are affected in the U.K?

About 1-1½ in every 1000. For Doncaster there will be between 300-450 of which we know of about 200. There are estimated 150,000 in the U.K. Many may not know they have ME/CFS.