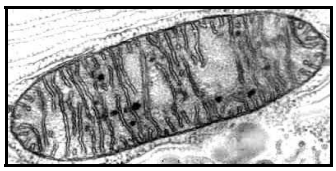
Leger-ME:

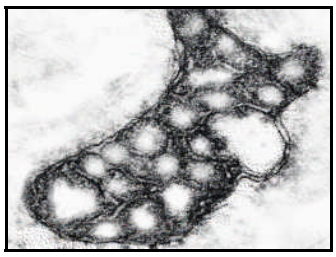
Supporting Myalgic Encephalopathy or Encephalomyelitis (ME),
Chronic Fatigue Syndrome (CFS),
Post Viral Fatigue Syndrome (PVFS),
Fibromyalgia Syndrome (FMS), Patients & Carers

ME/CFS in 2006.

With the Chief Medical Officers Report and the imminent NICE report, ME/CFS is at long last receiving the long awaited focus. The regional clinic is now based in Sheffield, from which we welcome Mark Adams, Clinical Network Lead for CFS/ME for South Yorkshire and North Derbyshire CFS/ME Service*. In this pack we have included information we believe will be of interest to all medical staff. The one management strategy that applies to all ME\CFS patients is Pacing, for which Action for ME have published a useful booklet. Budgets prohibit us from including one this in this information pack. However, it is included as a PDF file on the resource CD with this pack.



Normal



ME/CFS Patient

There are a number of exciting new developments in ME/CFS Research. Gene expression studies have confirmed that different genes are active in Insidious and Acute onset versions of ME\CFS, confirming clinical observations that there are a least two subs types. ME/CFS patients have about 8% less grey matter than controls explaining the cognitive problems experienced by many patients. Studies currently indecate that there are abnormalities in neutrophil mitochondria. A lab test is being trialled, and early indications indecate a high degree of correlation between the level of observed fatigue and measured abnormalities. A biochemical model explaining observed fatigue has been postulated. Much more research is needed before the significance of these findings can be verified.

As for ME/CFS treatments, while behavioural strategies predominate, e.g. CBT and GET, they are unpopular with many patients e.g., (Cognitive Bullying Therapy). Nationally, they have fragmented availability and consistency. Pharmaceutical treatments are gradually making in roads. Items readily available e.g. fatty acid products (MaxEPA, EPO), and nicotinamide derivatives (Hexopal) help some patients markedly. A strategy being tried in the private sector is ribose, a pentose sugar, used by some sports enthusiasts. The old mainstay of ME/CFS management, low dose TCAD's have not been reviewed by NICE, which I believe is a serious omission on their part. Melatonin and B12 work very well for some patients, but not others.

On the ward ME/CFS can complicate what otherwise would be simple cases. In common with arthritis, many ME/CFS patients experience morning stiffness. A number of pharmacists including myself believe that Statins are contra indicated in ME/CFS patients. Mental health patients with ME/CFS very often cannot get the needed stabilisation though interacting socially and physically. ME/CFS very often severely restricts therapies in terminal patients. CFS/ME patients with diabetes have more problems with hypo's due to impaired HPA axis activation. HPA problems have implications for anaesthetists. Autonomic dysfunction is common, as in one recent case, a ME/CFS patient crashed due to vagal dysfunction.

ME/CFS like many other diseases is incurable. Unlike with e.g. MS, there is no intervention proven control the disease process. This means the only treatment strategy is management and palliation. While about 25%-33% of patients, mainly younger ones ultimately recover, the remainder have a degree of disability for life. About 25% are severely disabled, many more than with MS. Leger ME exist to help Patients are Carers get all the available help. If you want any further information or to refer patients, we have a helpline (01302) 787353 or website: www.leger.me.uk.

Mike Valentine, Leger ME Chairman.

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The Finley Grading System. This the grading scale used by Professor Findley et al at the National ME Centre. Romford, Essex. It is similar to the grading of many other diseases.

Grad	Description	Ability of Patient	Proportion
0.	Normal	Lives a 'normal' life.	
1.	Mild	Mobile and self caring and able to manage light domestic and work tasks, with difficulty	25-33%
2.	Moderate	Reduced mobility and restricted in all activities of daily living, often having peaks and troughs of ability, dependent on degree of symptoms. Usually stopped work or limited capacity, requiring many rest periods.	50–60%
3.	Severe	Will be able to carry out minimal daily tasks, i.e. face-washing, cleaning teeth, has severe cognitive difficulties and is wheelchair-dependent for mobility. Often unable to leave the house except rarely.	25%
4.	Very Severe	Unable to mobilize or carry out any daily task for themselves. Bed-ridden the majority of the time.	1-2%

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For the gene stuff http://www.meresearch.org.uk/research/sponsored/genesig.html

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