Twenty-five years of the Barts Fatigue Service

Margaret Williams 1st December 2010

The Barts "Fatigue Service" 25th birthday party held on 29th November 2010 was proclaimed by the Wessely School as being a mile-stone achievement in their "service" for people with ME/CFS (known by them "CFS/ME").

Their celebrations gave rise to numerous critical appraisals of exactly what has been achieved by them in those 25 years from ME/CFS sufferers' perspective (this being the disorder in which the Wessely School profess to be the experts and which they are allegedly studying in the £5 million MRC PACE Trial, even though on 12th May 2004 the Parliamentary Under Secretary of State at the Department of Health, Dr Stephen Ladyman, confirmed that GPs were offered financial inducements – a more refined term than "bribes" – to persuade patients who do not suffer from ME/CFS to agree to be entered into the trial, which would seem to indicate that something is seriously wrong with the PACE trial).

Given that behavioural interventions may help some people with fatigue-inducing somatoform disorders, the self-congratulations and obvious pride of Professor Peter White's "Fatigue Service" staff and others in the Wessely School would not matter but for one cardinal consideration, which is that they insist on asserting that, amongst those suffering from chronic "fatigue", they are studying and helping patients with ME/CFS. There is substantial evidence to the contrary, because they continue in their belief that "CFS/ME" is a continuum of on-going tiredness perpetuated by deconditioning and false illness beliefs, whereas ME/CFS is a chronic inflammatory neuroimmune disorder in which the following have all been demonstrated (ie. not simply hypothesised):

- evidence of disrupted biology at cell membrane level
- evidence of abnormal brain metabolism
- evidence of a reduction in grey matter
- evidence of widespread abnormal cerebral perfusion (hypoperfusion)
- evidence of central nervous system / immune dysfunction
- evidence of central nervous system inflammation and demyelination
- evidence of hypomyelination
- evidence of spatial disorientation
- evidence that ME/CFS is a complex, serious multi-system autoimmune disorder (in Belgium, the disorder has now been placed between MS and lupus)
- evidence of significant neutrophil apoptosis
- evidence that the immune system is chronically activated (eg. the CD4:CD8 ratio may be grossly elevated, as seen in multiple hypersensitivities)
- evidence that NK cell activity is impaired (ie. drastically diminished)
- evidence of hair loss in ME/CFS
- evidence that the vascular biology is abnormal, with disrupted endothelial function
- novel evidence of significantly elevated levels of isoprostanes (a marker for oxidative stress, which in ME/CFS rises with exercise intolerance)
- evidence of impaired proton removal from muscle during exercise
- **evidence of cardiac insufficiency and that patients are in a form of heart failure**
- evidence of autonomic dysfunction (especially thermo-dysregulation; frequency of micturition with nocturia; haemodynamic instability with labile blood pressure; pooling of blood in the lower limbs; reduced blood volume (with orthostatic tachycardia and orthostatic hypotension)
- evidence of respiratory dysfunction, with reduced lung function in all parameters tested
- evidence of neuroendocrine dysfunction (notably HPA axis dysfunction)
- **evidence of recovery rates for oxygen saturation that are 60% lower than those in normal controls**

- evidence that the average maximal oxygen uptake is only 15.2 ml/kg/min, whilst for controls it was 66.6 ml/kg/min
- **conclusive evidence of delayed recovery of muscles after exercise**, with ME/CFS patients reaching exhaustion more rapidly than controls, with this failure to recover being more pronounced 24 hours after exercise (note: there is no evidence of de-conditioning)
- evidence of mitochondrial metabolic dysfunction
- evidence of inability to sustain muscle power
- evidence of greatly increased REE (resting energy expenditure)
- evidence of enteroviral particles in muscle biopsies
- **evidence of a sensitive marker of muscle inflammation (inflamed tissues should not be exercised)**
- evidence of on-going infection
- evidence that the size of the adrenal glands is reduced by up to 50% (with reduced cortisol levels)
- evidence that up to 92% of ME/CFS patients also have irritable bowel syndrome (80% of the immune system is located in the gut)
- evidence of abnormal gene expression (at least 35 abnormal genes -- acquired, not hereditary), specifically those that are important in energy metabolism; **there are more abnormal genes in ME/CFS than there are in cancer**
- evidence of profound cognitive impairment (worse than occurs in AIDS dementia)
- evidence of adverse reactions to medicinal drugs, especially those acting on the central nervous system, such as anaesthetics
- evidence that symptoms fluctuate from day to day and even from hour to hour
- there is no evidence that ME/CFS is a psychiatric or behavioural disorder.

Over a decade ago, Dr Elizabeth Dowsett, a former President of the ME Association and a member of the Chief Medical Officer's Working Group on CFS/ME, was clear:

"*There is ample evidence that ME is primarily a neurological illness, although non-neurological complications affecting the liver, cardiac and skeletal muscle, endocrine and lymphoid tissues are also recognised…**The commonest causes of relapse are physical or mental over-exertion…. The prescription of increasing exercise can only be counter-productive…. Some 20% have progressive and frequently undiagnosed degeneration of cardiac muscle which has led, in several cases, to sudden death following exercise**…. Neurological problems include **exhaustion, weakness and collapse following mental or physical exertion beyond the patient's capacity….** This arises from metabolic damage…. **Problems with balance are common in ME due to involvement of spinal nerve tracts in the damaged brain stem**…. Over 70% of ME patients suffer from significant bone and muscle pain (a further consequence of brain stem damage which seriously affects their mobility)…. Other patients have in addition metabolic damage to muscle fibres…. 30% of patients with abnormal exercise tests have evidence of persistent infection in the muscles, and evidence of muscle infarcts…. (Patients with ME exhibit) jitter due to incoordinated muscle fibre action, following damage to the neuromuscular junction…. Patients with ME suffer a variety of symptoms arising from autonomic nervous system dysfunction, including liability to a dangerous drop in blood pressure on standing for more than a few minutes"* (http://www.25megroup.org).

It seems increasingly apparent that, no matter the calibre and quantity of evidence that has long ago shown the Wessely School to be wrong about ME/CFS, their 25-year old mind-set remains set in stone.