Professor Wessely over a Barrel?

Margaret Williams 24th September 2011

On 23rd September 2011 in its "News Focus", the journal *Science* published a chronology of events surrounding the putative relationship of a retrovirus with ME/CFS (False Positive;www.sciencemag.org), in which psychiatrist Simon Wessely was quoted: *"People will rather go over Niagara in a barrel than ever getting involved in CFS again".*

His statement is clearly contemptuous about everyone suffering from ME (known by him and his colleagues as "CFS") and it seems designed to ensure that biomedical research into the disorder will not proceed. Such overt discouragement of urgently-needed research into ME is contrary to the basic tenet of medicine, which used to be: "First do no harm".

Professor Wessely's latest jibe illustrates exactly what should not occur when clinicians are dealing with sick and vulnerable people: "*The most shameful behaviour is to engage in a contest of meanings with a patient, denigrating or ridiculing what one does not agree with"* (Healing beyond the body – Medicine and the Infinite Reach of the Mind; Dr Larry Dossey; Piatkus Books, 2002).

Wessely certainly does not agree that biomedical research into ME is needed; he is well-known for his belief that ME/CFS is "*somatisation par excellence"* (J Psychosom Res 1994:38:2:89-98) and for his British Medical Journal podcast on 5th March 2010: *"We're not going to go doing more and more tests to find out what the virus was because, frankly, even if we found it there's nothing we're going to do about it. We're in the business of rehabilitation"* (http://podcasts.bmj/2010/03/05.chronic-fatigue-syndrome).

It is not surprising that Professors Wessely, Peter White and Michael Sharpe, all of whom were involved with the PACE Trial, are held in deep disregard by those whose lives have been wrecked by ME/CFS and who – rightly – are both exasperated and infuriated at repeatedly reading the inane description of their disease as fatigue, with some cognitive impairment, and perhaps a bit of depression thrown in for good measure.

Each and every time that Wessely makes yet another denigratory attack on people with ME, there is a need for attention to be drawn to the reality of ME, which cannot be repeated too often. ME is not

“fatigue”, accompanied by a few memory problems and depression, nor is it an aberrant illness belief that has resulted in reversible deconditioning, as the Wessely School maintain.

ME is a devastating multi-system inflammatory neuroimmune disorder, with extreme malaise; nausea; abdominal pain and diarrhoea; frequency of micturition with nocturia; post-exertional exhaustion almost to the point of collapse; inability to stand unsupported for more than a few moments, sometimes being too weak and painful to walk; inability to walk upstairs or to maintain sustained muscle strength, as in brushing one’s hair; inability to carry a shopping bag, or dry oneself after a bath, peel vegetables or prepare a meal, with recurrent mouth ulcers that make speaking and eating difficult.

ME is neuromuscular in-coordination, not only of fine finger movement with clumsiness and inability to control a pen and to write legibly, but also of the larynx and oesophagus – there is a need to swallow carefully to avoid choking, with oesophageal spasm and pain.

ME is constant danger of falling because of balance disturbance (ie. dysequilibrium or loss of balance); staggering gait (ataxia); dizziness on moving, with episodic incapacitating vertigo; difficulty with voice production, especially if speaking is sustained; expressive dysphasia (inability to find the right word); muscle cramps, spasms and twitching and spasmodic trembling of arms, legs and hands.

ME is frequent episodes of angor animi (brought about by abrupt vasomotor changes, when the heart stops beating then crashes furiously, causing difficulty breathing and uncontrollable shaking, and feeling that death is imminent); there may be an urgent need for oxygen.

ME is photophobia; difficulty in focusing and in visual accommodation, with rapid changes in visual acuity; blurred and double vision; sometimes actual loss of vision; eye pain; swollen and painful eyelids, with inability to keep the eyelids open.

ME is tinnitus and hyperacusis, for example the noise of a lawnmower can cause acute distress and nausea; heightened sensory perception (eg. acute sensitivity to being patted on the back; inability to tolerate lights, echoes, smells, movement, noise and confusion such as found in a shopping mall or supermarket without being reduced to near-collapse).

ME is peripheral neuropathy; numbness in the face; parasthesias; altered sleep patterns, with hypersomnia and insomnia.

ME is severe dysautonomia, including alternate sweats and shivers; temperature dysregulation, with intolerance of heat and cold; tightness of the chest alternating with a moist chest; breathing problems -- shortness of breath on minimal exertion; the need to sleep upright because of weakness of the intercostal muscles; pronounced cardiac arrhythmias; lack of bladder and bowel control; orthostatic tachycardia; orthostatic hypotension, with extremely labile blood pressure that is not amenable to therapeutic drugs.

ME is intermittent palindromic nerve pains; muscle tenderness and myalgia, sometimes burning or vice-like; typically shoulder and pelvic girdle pain, with neck pain and sometimes an inability to hold the head up.

ME is hypovolaemia, with blood pooling in the legs and feeling faint due to insufficient blood supply to the brain; there may be swollen feet and ankles.

ME is intermittent crushing chest pain akin to a myocardial infarct; segmental chest wall pain; subcostal pain; vasculitic spasms, including headaches; cold and discoloured extremities, with secondary Raynaud's Disease; easy bruising; peri-articular bleeds, especially in the fingers; leaking blood vessels; cutaneous vasculitis with rashes; flushing of the face (sometime just on one side); flushing and swelling of fingers and hands, with vasculitis of feet and (in females) the breasts.

ME is pancreatic exocrine dysfunction leading to malabsorption; reduced liver function and demonstrable adrenal insufficiency.

How Wessely could possibly justify encouraging scientists not to engage with such a devastating disorder is incomprehensible, yet he has been taunting and ridiculing patients with ME for years, denying their illness (Susanna Agardy; Co-Cure EDU: 25th August 2011).

The first tenet of medical research used to be that it was necessary to have as homogeneous a cohort as possible, this being another tenet that seems to have vanished – witness the moving of goal posts by the Wessely School.

For example, contrary to accepted scientific practice, the PACE Trial Investigators deliberately chose broad entry criteria which included people with psychogenic fatigue, idiopathic fatigue and fibromyalgia – quite different disorders – claiming that they were all manifestations of medically unexplained fatigue, despite the fact that the trial purported to be studying those with the discrete disorder "CFS/ME".

Deliberately to broaden entry criteria for a clinical trial to include patients who do not have the disorder allegedly being studied contravenes elementary rules of scientific procedure.

As noted by others: "*Mixing in people who do not have a disease with patients who do confounds the results and conclusions of any study regardless of the disease or disorder being studied"*(Kelly Latta; Co-Cure RES; 15th September 2011).

However, having claimed for many years that ME, CFS, irritable bowel syndrome, fibromyalgia, hyperventilation syndrome, "atypical" chest pain, tension headache, pre-menstrual syndrome, globus hystericus and multiple chemical sensitivity are all one single functional somatic syndrome, those same PACE Investigators are now on record saying something rather different.

A recent article by BBC News health reporter James Gallagher says: "*There is emerging consensus that CFS/ME is not one illness";* Professor Peter White is on record in the article stating: "*Most specialist doctors* (there are no specialist NHS doctors in the UK apart from psychiatrists) *and scientists agree that it is more than one illness. It may be three to five separate illnesses"*, whilst his co-Principal Investigator, Michael Sharpe, is now saying: *"The concepts of CFS and ME have been conflated as CFS/ME. That may be right but it may be a bit like an apple/banana – we need to be clearer what we are talking about"* (http://www.bbc.co.uk/news/health-14883651).

That is precisely what biomedical scientists and patients with ME have been saying for decades. The PACE and FINE Trials have shown that "*the business of rehabilitation"* is unsuccessful. Is it not time for the Wessely School to leave the field entirely and encourage new approaches based on hard science rather than psycho-speculation?