From: Professor Malcolm Hooper

To: The Guardian in response to their recent article

The Editor

The growing understanding of ME shown in the recent article (The trouble with ME 14/05/10) by your medical correspondent, Sarah Boseley, is most welcome. However, there are a number of significant errors and omissions in the article.

ME is Myalgic Encephalomyelitis, which signifies muscle pain with inflammation of the brain and spinal cord (inflammation has been shown to occur, in three recent UK*post-mortems)* and the disorder has been classified by the WHO as a neurological disorder since 1969. The correct terminology is NOT myalgic encephalopathy, which is not classified and is a much less specific clinical term. The alternative term Chronic Fatigue Syndrome, CFS, was introduced in 1988. Its use is restricted by the WHO to ICD-10 G93.3 and excluded from use elsewhere, particularly in somatoform, fatigue, chronic fatigue, and fatigue syndromes which are classified at F48.0. The similarities in these words used in F48.0 and in G93.3 have led to much confusion, and some deception, by those seeking to reclassify ME as a somatoform disorder.

The identification of people with ME relies on accurate terminology and case definition which are essential for well designed research studies. The CDC-Fukuda 1994 definition has been shown to be non-specific, whilst the 1991 Oxford definition developed and favoured by certain influential psychiatrists who work for the medical insurance industry, excludes neurological conditions. Studies with such heterogeneous cohorts of patients cannot provide any meaningful data for interpretation. The current Medical Research Council PACE Trial on “CFS/ME” is seriously flawed in this way since it uses the Oxford definition which embraces all states of “medically unexplained fatigue” but by definition excludes those with ME, a situation that defies logic.

The 2003 Canadian Criteria were produced by very experienced clinicians who, between them have diagnosed and treated over 20,000 patients with ME. They provide comprehensive clinical signs associated with ME, from which any competent physician should be able to make a diagnosis with the use of appropriate investigative tests many of which are restricted or proscribed in the UK by NICE.

Although the recent judicial review did find against the ME plaintiffs, the decision is the subject of a legal challenge due to the alleged failure of due legal process.

The undeclared vested interest of doctors associated with insurance companies was critically exposed in the report by senior Parliamentarians chaired by Dr Ian Gibson which exposed the severe difficulties experienced by patients with ME when they seek benefits and support. This is not conspiracy theory or paranoia but a daily reality for many patients, families and carers.

Over many years it has been demonstrated that numerous viruses are associated with ME, the most common being enteroviruses with herpes viruses (glandular fever etc) coming second.

People do die from the illness (Jason et al. Health Care for Women International 2006:27:615-626). The tragic story of Sophia Mirza, who died aged 32 from ME, has been published, together with her medical records. These demonstrate the ideological commitment of some clinicians to the somatoform model of the illness and the ignorance and inhumanity of some members of the medical profession, including sectioning of a very sick woman and accusations, in this and other cases, of MSBP (Munschausen's syndrome by proxy) with parents having only limited access to their children or even banned from any contact.

The offer of only behavioural modification and incremental aerobic exercise (CBT and GET, upon which the payment of benefits is contingent), which are management techniques and in no way curative, as allegedly effective treatments for people with a severe neurological disorder is unethical, and a betrayal of doctor's Hippocratic oath. Many surveys by ME charities, including the 25% ME Group for the Severely Affected that represents the most severely ill have shown that CBT has no lasting value and that GET is positively harmful. The most severely affected are almost totally excluded from any research studies since they are housebound or bedbound.

The recent discovery in the US of the retrovirus, XMRV, in ME/CFS patients emphasises the urgent need for biomedical studies. The acclamation of the three subsequent studies that failed to find XMRV by those who subscribe to the behavioural model of ME (which did not attempt to replicate the US study) serve merely as vehicles to discredit any suggestion that ME/CFS is a serious organic disease.

Following the demonstrated association of a retrovirus with ME/CFS, the Canadian and New Zealand governments have banned patients with ME from serving as blood donors. This accords with the current UK position that people with ME must refrain from donating blood.

If Sarah Boseley attends the forthcoming Invest in ME conference on 24th May at 1, Birdcage Walk, Westminster, she will hear international experts addressing most of the above topics. She will be one of the few medical journalists who appear willing to listen and learn in order to understand more fully the complexities of the chronic multi-system illness that is ME. I look forward to meeting her there.

Malcolm Hooper (Professor)