

Action for ME and its latest links to the Insurance Industry

Margaret Williams 9th May 2011

Disturbing evidence exists that the charity Action for ME (AfME) seems to be strengthening its links to the insurance industry, which may be to the potential detriment of people with ME/CFS (whose best interests the charity is required by The Charity Commission to represent).

1. The appointment of Alan Cook CBE as Chairman of AfME

On 8th February 2010 AfME announced that Alan Cook CBE was the charity's new Chairman. Sir Peter Spencer, CEO of AfME, said: *"It's great news that Alan is coming on board to contribute his experience to this forward thinking organisation. We will benefit hugely as he extends his fantastic track record for achieving success in all that he does"*.

Alan Cook also happens to be Chairman of the insurance group that includes Irish Life & Permanent Group Holdings plc.

An Occupational Health doctor who works for Irish Life is Dr Deidre Gleeson, and there is mounting evidence that she is recommending termination of benefit payments to Irish Life policy holders with severe ME/CFS who make claims on their income protection policies because they are simply unable to work.

Can AfME not comprehend that it is not appropriate for it to have a Chairman with such an obvious conflict of interest, whose company is responsible for denying insurance benefits to people with ME/CFS?

For AfME to be so closely linked to the insurance industry that has done so much harm to people with a devastating multi-system disorder must surely be a matter of concern.

2. Allen & Overy LLP

AfME has announced that it is to hold its Annual General Meeting and Open Conference on 22nd October 2011, and that this will take place at the London offices of the law firm Allen & Overy LLP.

Allen & Overy is an international law firm that claims insurance law as one of its areas of expertise: *"Our International Insurance Group...advises many of the world's leading insurers (and) financial institutions....The group consists of lawyers with specialist insurance expertise, some of whom have spent part of their careers in the industry or with insurance regulators. This practical industry experience ensures that we are able to provide commercially driven legal advice. Our insurance lawyers work...with specialists from other market leading practices, such as corporate, capital markets, banking (and) litigation....As a result, our clients receive the best possible technical and commercial legal advice at both a domestic and international level....Practices within Insurance (include) Insurance advice for corporates (and) Insurance disputes"*.

3. Professor Michael Sharpe

Although not listed publicly, it is a matter of record that the charity secured the services of psychiatrist Professor Michael Sharpe as a medical advisor, and that he is deeply involved with the insurance industry (particularly with UNUMProvident) in the dismissal of income protection claims submitted by people with ME/CFS.

In February 2000 a Conference on Insurance Medicine was held at The Royal College of Physicians in London, attended by Professors Simon Wessely and Michael Sharpe, at which it is believed Sharpe advised that he was recommending to insurance companies that claimants with ME/CFS should be subject to covert video surveillance.

On 9th May 2001 Michael Sharpe appeared before the Cross Party Group on ME of Members of the Scottish Parliament in Edinburgh, where he informed the meeting that the disorder is not a neurological disorder.

Despite denials from Professor Sharpe that he has ever harmed “CFS” patients, there is evidence that such may not be the case; documented and detailed evidence of the consequences of inappropriate psychiatric intervention has been put before the Chief Medical Officer and is also variously recorded in Hansard. Patients with ME/CFS have been threatened with being sectioned under the Mental Health Act unless they agree to psychiatric interventions, and other kinds of harm include the refusal and/or withdrawal of state benefits; difficulty amounting to the impossibility of obtaining insurance payments, with policy holders being refused benefits; the withdrawal of cover by private health companies for those with ME/CFS (often on the grounds that no cover is available for ‘psychiatric’ illness); an almost total lack of suitable provision or care by the NHS, with no facilities for specialist referral other than to a psychiatrist; an overtly hostile and unfavourable attitude being shown by doctors and other health professionals to those with ME/CFS and special problems for children and adolescents, with increasing numbers of young people being threatened with being removed from their parents and put into care (which has led to litigation).

Perhaps a unique form of harm is to be found in the persistent recommendation by Wessely School psychiatrists that no investigations (or only limited investigations) are necessary and appropriate in patients with ME/CFS. Why are these psychiatrists so insistent that patients should not be medically investigated? As the Countess of Mar asked, where is their natural curiosity about this condition? Why should sufferers and those doctors who *observe* their suffering accept the limitations of scientific knowledge? These psychiatrists refer to a lack of proven causality, yet they actively advise that no investigations should be performed on patients with ME/CFS and that no research into its organic nature should be undertaken. Is it because they do not wish to know? (Hansard, Lords, 19 December 1998:1011-1024).

AfME must surely be aware that Sharpe was one of the authors of the 1994 (CDC) Fukuda case definition and that the 1994 CDC case definition was unambiguous: ***“The use of tests to diagnose the chronic fatigue syndrome should be done only in the setting of protocol-based research. In clinical practice, no additional tests, including laboratory tests and neuro-imaging studies, can be recommended. Examples of specific tests (which should not be done) include serologic tests for enteroviruses; tests of immunologic function, and imaging studies, including magnetic resonance imaging scans and radionuclide scans (such as***

single photon emission computed tomography (SPECT) and positron emission tomography (PET) of the head. We consider a mental status examination to be the minimal acceptable level of assessment” (Ann Int Med 1994;121:12:953-959).

Professor Sharpe was one of the Principal Investigators of the notorious PACE Trial, and AfME was intimately involved with that trial and with the production of the Manuals used in the trial.

It may be recalled that AfME received substantial Section 64 funding (Health Services Act 1968) in return for supporting Department of Health policy priorities (which currently include managing “CFS/ME” as a behavioural disorder).

AfME members and those who fund-raise for it may wish to consider in whose best interest the charity is acting.