

## More Zombification of ME/CFS?

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17th August 2008

Not only is NICE facing a judicial review of its Guideline on “CFS/ME”, it has also come under fire from other quarters, with calls for it to be abolished after “*a series of ‘barbaric’ and ‘crazy’ decisions*” (“Call to abolish NICE over ‘crazy’ decisions”; Daily Telegraph, 14<sup>th</sup> August 2008). The article quoted Jonathan Waxman, Professor of Oncology at Imperial College, London: “*Professor Jonathan Waxman said NICE was bureaucratic, unaccountable and run by economists, not doctors*”. The article also said: “*There were concerns that some of its processes were not transparent*” and it quoted Professor Waxman verbatim: “*NICE should be abolished. It is an unaccountable body that has made some barbaric decisions and is preventing patients getting the care they need*”.

Four days earlier, in an article entitled “NICE distinctions may save money but they don’t save lives” (Sunday Telegraph, 10<sup>th</sup> August 2008), Professor Karol Sikora said: “*A conspiracy theorist would think that the conclusion was given to NICE by the Government and that data was found to justify the outcome. Current policy-making is reminiscent of the line in one of the Indiana Jones movies where the heroine asks Indiana at a point of crisis: ‘What shall we do next?’ He responds: ‘I don’t know. I’m making this up as we go’*”.

The ME/CFS community is well aware that evidence continues to mount showing that in the production of its Guideline on “CFS/ME”, the conclusion may indeed have been given to NICE and that “data was found to justify the outcome”.

It cannot be denied that powerful forces are at work to deny the validity of ME/CFS.

It is irrefutable that certain UK psychiatrists, all deeply involved with the medical insurance industry, have worked unceasingly to deny the nature of ME/CFS. The three key players are Professor Simon Wessely, Professor Peter White and Professor Michael Sharpe, but there are others with undue influence such as Dr William Hamilton, a member of the NICE Guideline Development Group, who for the past 15 years has been Chief Medical Officer of a medical insurance company (Exeter Friendly Society) and who drew up that company’s policy to exclude ME/CFS from benefit cover as long as it remains categorised as a “behavioural” problem.

Following publication of the Chief Medical Officer’s Working Group Report on “CFS/ME” in January 2002, the medical insurance company was alarmed and set about tightening control of such claims with heightened self-preservation. The following quotations come from an article by Peter Pallot:

*“Official recognition has not brought clarity for insurers. Insurers see the devil in the long-term nature of CFS. Take for instance a 30-year-old City high flier who succumbed aged 30 when earning £75,000 a year. (He) might be in line to get two-thirds salary -- £50,000. Over 35 years, if the condition never resolved, the insurer would be paying out £1.75 million”.*

***“Renaming the condition CFS and discarding earlier labels, including myalgic encephalomyelitis (ME), was helpful”.***

*“ ‘Syndrome’ implies a range of causes and symptoms, rather than a specific reaction to an organism”.*

*“Sun Life Financial of Canada managing director Paul Davies thinks the condition could account for as much as ten per cent of claims by value”.*

*“Norwich Union’s Louise Zucchi says this accounts for a considerable part of the gamut of mental illnesses which make up a third of all claims”.*

*“Friends Provident technical claims manager Andy Parkinson says: ‘Mental health and chronic fatigue claims comprise round about a quarter of all the claims we have’.*

James Vallender, benefits operations manager of the largest company, UNUM, said: *“We experienced a big rise in the 1990s but in the last 18 months or so it’s got quieter. In 2000, cases accounted for 1.5 per cent of the caseload but increased last year to two per cent’.* According to Vallender, some claims that formerly might have been classified as chronic fatigue are today examined more thoroughly. ***To this end, it is becoming standard practice for insurers to pay for medical interventions such as cognitive behaviour therapy in CFS cases”.***

*“Norwich Union uses neurologists (and) psychiatrists. Zucchi recalls: ‘We had our first claims 12 years ago and they have continued to grow. We send trained people to their homes. We have put more and more emphasis on home visits and rehabilitation over the past five or six years’ ”.*

***“A typical rehabilitation programme could be designed to entail exercise in a gym (and) this might be paid for by the insurer”.***

***“Sun Life Financial of Canada has co-opted the German occupational health company PRISMA Health to help. At the insurer’s Basingstoke offices, Davies says insurers need just such a specialist company. The company’s exposure to chronic fatigue claims has pushed it into a very proactive approach. Davies explains: ‘We are probably a little more expensive but we have put a lot greater effort into getting people back to work. We’ve been looking at cases that have been on the books a couple of years. The crux is that if you did not apply rigorous medical attention and rehab programmes you really would have very long- term claims. We get PRISMA to talk to the family and also the partner and PRISMA will work out a programme to get that person’s life back”.***

*“PRISMA’s assessment costs ‘a significant sum’ says Davies. The group insurer could spend £50,000 on one rehabilitation”.*

*“Until recently, the role of IP (income protection) providers stopped at paying claims. Now they are initiating intervention in a way that seems to help all parties”.*

The article can be accessed at <http://www.hi-mag.com/healthinsurance/article.do?articleid=20000081634>

This confirms what the ME/CFS community has known for many years, namely, the influence of the medical insurance industry on the management of people with ME/CFS, which is reflected in the NICE Guideline.

It would seem to be proof that medicine has been commandeered by industry and that the only outcome measure regarded as important is company profits.

As one comment on an ME internet group so aptly noted, it is an unmitigated disaster *“when the basic definition of the disease is wrong, when the guidelines for treatment are not grounded in credible evidence or in science at all, and the guidelines misinform health professionals so badly. We need another word for what we mean by ‘multidisciplinary’, because we mean relevant immunology, cardiology, neurology (and) endocrinology, and the psychosocial school don’t”* (16<sup>th</sup> August 2008; [MEActionUK@yahoo.com](mailto:MEActionUK@yahoo.com)).

Of course they don’t – the paymaster of the psychosocial school is the medical insurance industry, which for the most part excludes “mental” disorders from eligibility for income protection payments.

On the fees known to be charged by these psychiatrists for reports for the insurers on “CFS/ME” patients advising against the payment of insurance benefit, it has been calculated that each psychiatrist could easily earn an additional £4,000 per week on top of their NHS and academic remuneration.

Many ME/CFS patients have to fight – in future, likely to be every three months -- for the right to exist on £84.50 per week.