Alice Green (UK) versus the CDC (USA)?

Eileen Marshall Margaret Williams 26th April 2006

It is generally accepted that a sign of maturity is the ability to learn by experience. Why is this ability so lacking in the field of myalgic encephalomyelitis (ME) but not in other areas of medicine?

In her power-point presentation entitled "Cognitive Behavioural Therapy in Chronic Fatigue Syndrome / ME" (available online at http://www.meactionuk.org.uk/Alice_Green_Powerpoint_Presentation.html), Alice E. Green describes herself as "Highly Specialist Counselling Psychologist – Oldchurch Hospital CFS Team". The CFS Team's address is given as Essex Centre for Neurosciences, Oldchurch Hospital, Romford, Essex RM7 0BE. (The National ME Centre / Centre for Fatigue Syndromes is connected with the Oldchurch Hospital CFS Team: it was set up in the early 1990s by neurologist Professor Leslie Findley, who works in both centres).

The National ME Centre / Centre for Fatigue Syndromes representative (Karen Walsh) was scheduled to give evidence to the Gibson Inquiry first Oral Evidence Session on 18th April 2006 but failed to appear.

In an open letter to Ms Green (MEActionUK@yahoogroups.com / 26th April 2006), a stalwart campaigner for ME patients --- Gurli Bagnall from New Zealand --- writes: "I would like to make a couple of comments. The first point is your qualification which you have described as a Highly Specialist Counselling Psychologist. From a grammatical point of view, the wording is questionable and suggests the self-awarding of a non-existent qualification. Your presentation belies anything vaguely resembling specialist knowledge of the ME field. The inability to read and understand the scientific literature has been demonstrated repeatedly by those who push the 'mental disorder' barrow, and while I do not suggest that you have conflicts of interest, your presentation does demonstrate the same lack of intellectual acumen which plagues all who do".

It is said elsewhere that Professor Findley now endorses the Canadian Guidelines: this is difficult to reconcile with the views of Alice Green, who apparently works in Findley's own unit.

Some illustrations from Ms Green's presentation include the following:

"Illness beliefs and coping strategies are key factors in the onset and perpetuation of CFS/ME"

"Cycle of Avoidance: Pain symptoms are misinterpreted by patient as due to a physical disease / illness"

"Perpetuators: personality traits, beliefs"

"CFS/ME patients are more Hypervigilant to symptoms"

“Attribution of CFS/ME to external factors may help protect patients from a sense of failure”

“Patients attribute symptoms control to biological factors and not so much to their own behaviour”

“Catastrophising thinking styles increase CFS/ME symptoms”

“Negative beliefs lead to helplessness”

“CBT interventions (include) Reinterpreting symptoms; reducing symptom-focusing behaviours; Re-education re CFS precipitators and perpetuators and treatment programmes”.

Having read Ms Green’s presentation, one practising clinician who specialises in ME commented: “The logic presented is very flawed (and) the concepts and diagrams are facile” (personal communication).

By comparison, in the real world there is increasingly unassailable evidence that ME/CFS is a multi-system biological disorder: the US Centres for Disease Control (the principal agency in the US for protecting the health of all Americans) has recently invested about $2 million in order to unravel the enigma that is ME/CFS. The results have appeared in 14 research papers published in the April 2006 special edition of Pharmacogenomics, a journal dedicated to the rapid publication of original research on basic pharmacogenomics and its clinical applications. These papers analyze the most detailed and comprehensive clinical study on (ME)CFS to date. The message is that there is “a clear biologic basis for (ME)CFS” and that genetic and environmental factors have a combined impact upon such patients.

For convenient comparison with the beliefs of Alice Green of the Oldchurch Hospital CFS Team, here are some of the findings and comments relating to the CDC results:

“People who suffer from (ME)CFS have a genetic make-up that affects the body’s ability to adapt to change”

“Over the past year, CDC scientists have worked with experts in medicine, molecular biology, epidemiology, genomics, mathematics, engineering and physics to interpret information (including) an assessment of the activity of 20,000 genes (of (ME)CFS patients)”

“The CDC’s Dr Suzanne Vernon, Molecular Epidemiology Team Leader for the CFS Research Laboratory, said: ‘There is a clear biological basis for (ME)CFS’ ”

“The condition takes a tremendous personal and social toll and can be as disabling as multiple sclerosis and chronic obstructive pulmonary disease”

(The above quotations are taken from the CDC Press Release of 20th April 2006).

“An intense battery of medical and psychological tests of people with (ME)CFS has strengthened the idea that (it) is actually a collection of five or more conditions with varying genetic and environmental causes”

“The new work points to an important common feature: the brains and immune systems of affected people do not respond normally to physical and psychological stresses”

" 'This is a very important step forward in the field of (ME)CFS research' said Julie L Gerberding, director of the CDC in Atlanta, which sponsored the project"

"The new findings come from the largest clinical trial ever to focus on people with the syndrome"

" 'CFS is very heterogeneous' said William C Reeves, who oversaw the project with CDC co-worker Suzanne D Vernon. It will take time to identify all the biological pathways involved, Reeves said, but the growing evidence of genetic links should put to rest the idea that the syndrome is a made-up diagnosis for 'a bunch of hysterical, upper-class white women' "

(Notably, it was on 20th April 2006 in a BBC Radio 4 programme called "Questions, Questions" that Elaine Showalter – not a clinician or medical scientist but an American Associate Professor of English – repeated her infamous view that (ME)CFS is the modern-day equivalent of hysteria).

"Several hundred (genes) were found to be over- or under-active in various subgroups of patients"

"In one analysis, the activity of just 26 genes did accurately predict which of six categories of chronic fatigue a patient had on the basis of symptoms and other clinical tests. That is a powerful hint that those genes – many of them involved in immune system regulation, the adrenal gland and the hypothalamus, which are involved in the body's response to stress – may hold clues to the disease variants"

" 'Everybody's finding the same five genes to be involved, which is pretty cool' (said Vernon)"

(The above quotations come from " Chronic Fatigue's Genetic Component: Study clarifies predisposition to syndrome" by Rick Weiss; Washington Post; April 21st, 2006).

"Chronic fatigue syndrome is caused by genetic mutations that impair the central nervous system's ability to adapt to stressful situations, according to a major new study by the CDC"

" 'This is the first credible evidence for a biological basis' for the syndrome, said CDC Director Dr Julie L Gerberding"

"The findings will provide immediate help in diagnosing the disorder, which often puzzles physicians because of the broad spectrum of symptoms"

"It should also lead to the development of effective treatments for patients, who receive only therapy to mitigate symptoms – or are scoffed at as slackers"

" 'It is very hard to treat an illness until you understand what it is physiologically' said Dr Lucinda Bateman of the Fatigue Consultation Clinic in Salt Lake City. 'This is a very important foundation' for developing new treatments"

(This contrasts markedly with the view of Wessely School psychiatrists and adherents -- including immunologist Professor Tony Pinching -- who persist in their advice to the UK

Government that it is not necessary to carry out any tests other than the most basic screening, nor is it necessary to understand the aetiology of ME/CFS. It also diverges from Pinching's well-known view as published in the UK Chief Medical Officer's Working Group Report of January 2002 that sub-grouping is unnecessary and is simply a matter of "semantics").

"Over the last two decades, most physicians have come to recognise (ME)CFS as a valid illness (Reeves) said"

" '(Patients) are as impaired as people with multiple sclerosis or AIDS or who are undergoing chemotherapy for cancer' Reeves said".

"The CDC assembled four independent teams. Each team produced two or three new papers, and their results were surprisingly consistent"

"The teams found that there were at least four distinct forms of the disease, each with its own genetic profile and symptoms, but all including disabling fatigue"

"All forms shared genetic mutations related to brain activity that mediated the response to stress"

"In particular, five polymorphisms in three genes were 'very important' said Dr Suzanne Vernon of the CDC. Those polymorphisms alone were sufficient to diagnose about 75% of cases".

(These quotations come from "Chronic Fatigue is in the Genes, Study Finds. Mutations are to blame for a syndrome often scoffed at as imaginary, researchers say" by Thomas Maugh; Los Angeles Times, April 21st, 2006).

It would seem that Wessely School proponents of the psychosocial model of what they term "medically unexplained" illnesses urgently need to reconsider their unproven and iatrogenic theories, not only about the cause and perpetuation of ME/CFS, but also about the 1988 Camelford disaster, in which 20 tonnes of aluminium sulphate were inadvertently pumped into the drinking water. At the time, seven people died, 25,000 suffered serious health effects and 40,000 animals were affected, but Wessely et al decreed that "mass hysteria was largely responsible for the furore". As with ME/CFS, Wessely et al asserted that "the perception of normal and benign somatic symptoms was heightened and subsequently attributed to an external cause, such as poisoning" and that "sensational reporting" by the media was held to be a significant factor. It has now been proven that victims were indeed poisoned and that they had high levels (5,000 times the safety limit) of aluminium in their brain. The catastrophy itself was compounded by the official cover-up, which Michael Meacher MP (a member of the Gibson Parliamentary Inquiry into ME) has called an "unbelievable scandal" (see The Independent on Sunday: "Poisoned: The Camelford scandal" by Geoffrey Lean; 16th April 2006).

Wessely is still on the record as asserting that ME is simply a belief that one has an illness called ME.

Once again, Wessely has been shown to be comprehensively wrong.

Having for years promoted himself as a “world expert” on (ME)CFS (for example, in the PRISMA literature), in the light of this latest scientific evidence from the CDC, for how much longer can Wessely’s claims about ME be accorded credibility, and for how much longer can his influence --- described by Professor Malcolm Hooper as “malign” http://www.meactionuk.org.uk/Organic_evidence_for_Gibson.htm --- remain paramount throughout UK Government bodies?