

ME: who is attacking whom?

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5th March 2005

Following various postings about Dr Peter Manu's recent book, there have been comments on some lists from both patients and clinicians (including one on Co-Cure on 3rd March 2005 from Alan Gurwitt MD) noting that "attacks" on all psychiatrists are inappropriate and insulting. We agree.

We wonder if Gurwitt's concern was referring to quotations from former psychiatrist John Diamond contained in our submission "More Medical Malfeasance" (published on Co-Cure on 2nd March 2005) in which Diamond addressed the issue of cruelty by psychiatrists, even though Diamond was at pains to state: "I do not mean to say that all psychiatrists are cruel".

Gurwitt himself referred to the harm he believes Manu to have caused and as Gurwitt also noted: "Questions can be raised about certain well-known – perhaps infamous— psychiatrists but it is destructive to paint them all with the same brush ...many psychiatrists are poorly informed and misinformed but they are not evil by nature".

Indeed not, but we would suggest that (i) before pronouncing on ME/ICD-CFS patients, practising physicians in all medical disciplines (including psychiatry) have a duty to keep themselves up-to-date with current medical knowledge so that they are not "poorly informed" and (ii) it is the work of a small group of "infamous" psychiatrists whose disproportionate influence is relied upon and widely quoted by those in authority (who have power over ME sufferers) that brings "infamy" upon the entire discipline of psychiatry.

Neither of these situations is the fault of any patient.

The time has surely come for non-"infamous" psychiatrists who do not wish to be painted with the same brush to ask themselves why they do not unite and speak out against their "infamous" colleagues.

It is a matter of record that in relation to ME/ICD-CFS, most of the "attacks" are on *patients* and have come from doctors, including psychiatrists; indeed, Professor Michael Sharpe (now of Edinburgh) teaches about ME/ICD-CFS that "Those who cannot be fitted into a scheme of objective bodily illness yet refuse to be placed into and accept the stigma of mental illness remain the undeserving sick of our society and health service" (ref: ME: what do we know (real illness or all in the mind?): October 1999: University of Strathclyde). Does this not constitute an "attack" on those with ME/ICD-CFS, not only on patients' quality of life but on their very right to life?

It may be worth briefly reconsidering how doctors have effectively "attacked" those with ME/ICD-CFS.

ME/ICD-CFS sufferers are not “malingerers”: they cannot be malingerers because ME is not classified by the World Health Organisation as a mental disorder, yet on 17th May 1995 at a symposium entitled “Occupational Health Issues for Employers” held at the London Business School, ME was described as “the malingerer’s excuse”. Speakers included psychiatrist Simon Wessely (who spoke on the “myths” of ME); psychiatrist Michael Sharpe (who spoke about cognitive behavioural therapy for ME/CFS) and Trudie Chalder (close colleague and co-author of Wessely who spoke about “selling the treatment to the patient”). Also present was Dr John LoCascio, Vice President of the largest disability insurer UNUM (known for its view that ME/CFS is “neurosis with a new banner” as set out in UNUM’s “CFS Management Plan”, 4th April 1995).

Six years later, on 6th-8th November 2001, a collection of influential people from the UK, Australia, the US and Canada attended a conference held at Woodstock, Oxford; the title of the conference was “Malingering and Illness Deception Meeting”.

Participants included Professor Mansel Aylward (then medical director of the UK Department for Work and Pensions); Dr Christopher Bass (a psychiatrist previously of Kings College Hospital, who has published on ME/CFS and whose articles support the “Wessely School” model of ME/CFS); Professor Anthony David from the Institute of Psychiatry, who has co-authored with Wessely on ME/CFS); Professor (then Dr) Michael Sharpe, well known for his “attacks” upon the ME/CFS community and for his close association with the medical insurance industry); Professor Simon Wessely (“infamous” for his belief that ME is nothing but dysfunctional thinking by those who aberrantly believe they suffer from it) and psychiatrist Dr Peter White from St Bartholomew’s Hospital, London (likewise known for his close association with the medical insurance company). Two other notable participants were Mrs Diana Brahams (known for her active membership of HealthWatch) and Dr John LoCascio from UNUMProvident.

At an International Congress on Somatoform Disorders – New Approaches to Classification and Treatment held on 21st-24th February 2002 in Marburg, Germany (sponsored by the drug companies Novartis and Pfizer), Simon Wessely gave the Keynote Lecture (“The chronic fatigue syndrome and the ‘S’ word”); Michael Sharpe’s topic was “Management of somatic disorders in primary care”; Peter White’s topic was “Studies of biopsychosocial factors in two alleged somatoform disorders” and Trudie Chalder’s topic was “Treatment of chronic fatigue syndrome”.

Bearing in mind the volume of published evidence of multi-system organic dysfunction that since 1934 has been known to exist in ME/ICD-CFS, do such blatant, repeated and deliberate misrepresentations of the facts not amount to “attacks” upon those with this disorder?

Is it not bizarre that so much credible and available evidence is so consistently disregarded or dismissed and that on the dictat of these psychiatrists state benefits necessary for basic survival are denied to those with this disorder? Does this not constitute an “attack” upon severely sick people?

Because this is an important issue, we provide specific illustrations of “attacks” upon ME/ICD-CFS patients by doctors to whom those patients turned for help.

In 1989, when the UK charity ME Action Campaign (now “Action for ME”) represented those with ME as distinct from those with chronic fatigue, its’ journal Interaction carried the results of 1500 professionally conducted questionnaires that had been sent out and some of the responses are provided here.

Comments of doctors to ME patients:

- “Throw away your crutches – it’s your head that needs them, not your legs”
- “Women of your age imagine aches and pains – are you sure you’re not attention-seeking?”
- “I’m not prepared to do any tests, they cost money”
- “Shut up and sit down”
- “You are a menace to society – a pest. I wish you’d take yourself away from me”
- “You middle class women have nothing else to worry about”
- “Its one of those thing you silly young women get”
- “Hypochondriac, menopausal, you have the audacity to come here and demand treatment for this self-diagnosed illness which does not exist”
- “Stop feeling sorry for yourself – I have patients with real illnesses, patients who are dying from cancer”
- “ME is a malingerer’s meal ticket”
- “Your inability to walk is in your mind”
- “I’m not going to further your career of twenty years of being ill”
- “Nothing at all wrong with this woman – Put her on valium” (to GP from Consultant).

Comments of ME patients about their doctors:

- “I was told I was lazy and laughed at”
- “(he said) the illness was a load of trollop, he laughed me out of the surgery”
- “(he) laughed when I told him I could only visit him if I felt fit enough”
- “I was called ‘stupid’ and shouted at on more occasions than I care to mention...one neurologist said he ‘couldn’t care less’ whether I ever got better”
- “I was told I was a disgrace”
- “My illness started with a sudden, severe collapse. The doctor said that it was due to ‘attention seeking’”
- “(I was) told that I was a nutter”
- (I was) told I was selfish and introverted and it was nothing but hysteria”
- “(the) doctors said to me ‘if you go on like this you will be struck off the register””
- “(the doctor) said my symptoms / signs ‘didn’t exist””
- “It was suggested ‘a good man’ was all I needed”.

That same year, a severely affected female patient was informed by her GP that ME “is a condition developed by the patient for what they can get out of it”.

In 1991, researchers at Southampton University asked 140 local GPs to refer patients with ME/CFS to take part in a trial; only 60 bothered to reply, of which 40 made it clear that they did not believe in ME/CFS (“GP doubts hamper new treatment”: GP Magazine, 6th April 1991).

In April 1994, GP magazine carried an article entitled “GPs despise the ME generation” and the article stated that nationwide, only 10 to 30% of GPs believe that ME is a real disease.

Perhaps GPs are not entirely to blame for such an attitude when the information digest that is so readily provided for them in the medical trade publications (such as Pulse, GP and Doctor) and the BMJ is provided virtually exclusively by the “infamous” psychiatrists.

In Doctor magazine on 12th January 1995 in the section entitled “Bluffer’s Guide”, Dr Douglas Carnall wrote about chronic fatigue as “Yesteryear’s neurasthenias: Investigations have their own hazards – it is possible to reinforce the patient’s somatising behaviour. This has all kinds of risks, especially that the patient will run off to join a self-help group, membership of which is itself an adverse prognostic factor. Modern bluffers prefer the term chronic fatigue syndrome. If they insist on a physical diagnosis tell them chronic fatigue syndrome is a complex disorder in which multiple biopsychosocial factors are mediated via the anterior hypothalamus – in other words, it’s all in the mind”.

On 5th May 1996, in the section on America (Foreign News), the Sunday Express published a piece by Jonathan Miller, who stated: “the absolutely most fashionable disease here is Chronic Fatigue Syndrome – CFS for the initiated”. The headline was “Chronic Bandwagon Disease”.

Despite considerable advances in biomedical understanding of the disorder, ten years after the ME Action Campaign questionnaire, professional perception had not changed much.

On 18th February 1999, Adrian Furnham, Professor of Psychology at University College, London, wrote an article in the Daily Telegraph in which he suggested that there was “a wealth of conditions that can be fashionable excuses for lack of success” in which he included ME/CFS. In the ME Association’s Newsletter (Perspectives, Summer 1999, page 3), Dr Charles Shepherd, the Association’s Medical Adviser wrote: “Professor Furnham’s view that ME/CFS is nothing more than a fashionable medical excuse for people who are otherwise lazy, mediocre or incompetent is not only insulting, but totally inconsistent with published scientific findings”. Dr Shepherd made a formal complaint to Disciplinary Committee of the British Psychological Society, claiming that Professor Furnham had broken the Society’s Code of Conduct given that their Code of Conduct required that members “shall value and have respect for scientific evidence when making public statements”. After four months, the Investigatory Committee of the BPS concluded that Professor Furnham had not committed any form of professional misconduct.

Commenting on a paper in the Journal of the Royal Society of Medicine about children with ME/CFS, Dr Keith Hopcroft, a GP in Basildon, Essex wrote in Update,

6th April 2000, page 522: “In more than three-quarters of a group of children with chronic fatigue syndrome, the illness began at the start of the school year. An adult version of this – recurrent brief chronic fatigue—affects me every Monday morning”.

On 28th August that same year, Dr Hopcroft wrote in the Scotsman: “There is great debate among the medical profession and in the media about what causes CFS and how it should be treated. Those who specialise in this area reckon it’s futile to look for the cause”.

In 2001, Dr Tony Copperfield (known to be a pseudonym of a GP in Essex who writes a regular column in Doctor magazine) posed a question: “What would be your initial response to a patient presenting with self-diagnosed ME?” Out of four possible answers, the correct one was stated to be: “For God’s sake pull yourself together, you piece of pond life”.

On 23rd March 2001 in an article entitled “Top 100: the many faces of fatigue”, GP magazine afforded Dr Marko Bogdanovic (research registrar, Merton College, Oxford, and a Wessely School psychiatrist) a platform to “attack” ME/ICD-CFS sufferers: “The provision of disability services and benefit payments is controversial because illness beliefs may be reinforced (and) services and benefits constitute a secondary gain”.

Also in 2001 on 20th October, in the section called “Choices for the new generation of GPs”, Pulse magazine (sent to GPs and to hospital libraries) carried a prominent feature giving three GPs’ views on what was described as a “tricky situation”. The subject for discussion was: “ME patient with litigation history demands inappropriate therapy”. The response by Dr Mary Church (real name), a full-time Principal in a GP practice near Glasgow at 64, Victoria Street, Blantyre, Lanarkshire, Scotland, was particularly disturbing: “Never let patients know you think ME doesn’t exist and is a disease of malingerers. Frustrating though it is...certain members of the profession are true believers. Never advise an ME patient to make a review appointment. At the end of the consultation, I say goodbye, not au revoir. Always refer ME patients to a local expert. It’s a wonderful way of passing the buck”. Almost more disturbing than her response is the fact that Dr Mary Church is a member of the British Medical Association’s Medical Ethics Committee.

As recently as this month, Dr Mike Jones (Senior Physician at Edinburgh International Health Centre, Musselburgh and Associate Specialist, Regional Infectious Diseases Unit, Western General Hospital, Crewe Road, Edinburgh) states: “In at least some cases of CFS, and possibly most, there are psychological factors. Occasionally CFS is a clear benefit to the CFS patient. Rational discussion is often hampered by polarisation by those who dislike psychological hypotheses of causation into ‘believers’ and ‘non-believers’. Believers can then dismiss the views that they do not like on the grounds that the person who holds those views ‘does not believe in ME’”.

The option for medical practitioners of whether or not to “believe” in ME no longer exists, as was made plain by the Chief Medical Officer himself in January 2002. Three years later, this seems to have escaped Dr Mike Jones.

The tradition of shameful diatribes and invective against ME sufferers still abounds. Doctors seem to vie amongst themselves to produce jibes at ME sufferers' expense. Why do they not jibe with equal disdain and offence at those with other classified chronic conditions such as lupus or multiple sclerosis?

It is abhorrent that vulnerable and desperate patients should still be forced to justify their illness because of ill-informed but influential doctors who so persistently dismiss the reality and severity of ME/ICD-CFS.

The incidence of psychiatric co-morbidity in ME/ICD-CFS has been greatly over-emphasised: a study in the Journal of the Royal Society of Medicine (2000:93:310-312) found that of patients in a tertiary referral centre who had received a psychiatric diagnosis, 68% had been misdiagnosed, with no evidence of past or current psychiatric illness.

This refers to just one study: if the findings of such a high percentage of psychiatric misdiagnosis in ME/ICD-CFS were to be investigated nationwide, the results might be phenomenal.

Until such a study is undertaken (and vested interests may ensure that it will never be undertaken), does the now nationwide compulsory but inappropriate psychiatric management regime not constitute an "attack" on physically sick people, especially in the light of the recent study by Black, O'Connor and McCully (Dyn Med 2005: March 3: 4(1):3)?

This study aimed to sustain an increase in daily physical activity in ME/ICD-CFS patients for four weeks and to assess the effects on fatigue, muscle pain and mood. At baseline, patients reported significantly higher fatigue and muscle pain intensity but patients and controls did not differ in overall mood. Subjects increased their daily activity over the four week period but with the increased activity, mood and muscle pain worsened in patients. The study concluded that the results suggest that a daily "activity limit" may exist in this population.

This being so, is it acceptable for the national programme to continue to "attack" those with ME/ICD-CFS by forcing them to undergo damaging psychiatric interventions, the only NHS alternative being no help or support whatever?

In the light of the published evidence, such denigratory "attacks" by doctors on those with ME/ICD-CFS are a travesty, so let there not be too much sympathy for the "infamous" psychiatrists who are responsible for this travesty.

Many of the perjorative "attacks" on ME/ICD-CFS patients would be dispelled if patients were permitted to undergo at least some of the appropriate testing that is now available, which although not definitive, does confirm the organic pathoaetiology of ME/ICD-CFS and would filter out the majority with a primary psychiatric disorder who are currently included within the heterogeneous label "CFS/ME" that was created by the "infamous" psychiatrists.