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In February 2004 Margaret Williams was asked to comment on the entries on "CFS/ME on the King's College website material

A few quick comments (all made --- and ignored --- many times before) on the King's College website material

16 February 2004

What's in a name? CFS or ME?

- **"some of the descriptions…..aren't entirely the same as what we see now"**

That's because no-one is looking. The descriptions / symptoms / signs of ME ***are*** still the same as in the early literature; the problem is that under the psychiatrists' own re-definition (Oxford 1991), such symptoms and signs have been specifically excluded, therefore studies based on the re-defined criteria automatically exclude from study those with such symptoms and signs, yet this is called "evidence-based medicine"

- **"we know now that (a specific neuropathological process) is not present in "ME"**

Not true at all --- there is such evidence but it is only found ***when specifically looked for*** (and that is rarely). How can it be known, when ME patients are not being studied or investigated?

- **The 1988 name-change**

The 1988 US label was designed to protect the giant insurance companies from having to pay out on claims by those with a devastating disorder that was known to be chronic and often of life-long duration, the incidence and prevalence of which were known to be rising rapidly. (Osler's Web by Hillary Johnson; Crown Publishers Inc, New York 1996). If one looks at the documented discussions of that group of experts, it is quite clear that

Gary Holmes (from the Holmes et al 1988 criteria) wanted to keep the name ME, and this was supported by the two members with the most experience of ME (Shelakov from the US and Parish from the UK) but they were over-ruled, causing them to withdraw in protest: they could not in conscience condone the deliberate dumbing-down of what they knew to be a very serious and incapacitating disorder.

- **<u>The 1991 (Oxford) criteria for "CFS"</u>**

The UK psychiatrists changed the criteria by specifically including mental illness and by specifically excluding neurological disorders: what was left was a catch-all situation which embraced ***anyone*** who complained of "medically unexplained" tiredness (ie. "fatigue") for more than six months (many psychiatric disorders have "fatigue" as a cardinal feature), so as a screening measure for study inclusion, it was an absolute gift to those same ambitious psychiatrists who were hungry for ever more control over ever more patients (which brought ever more ***money and status and power***). Let no-one tell you otherwise.

- **<u>"In the real world, CFS has not really got such wide acceptance"</u>**

In the real world of clinical medicine and patient experience, "CFS" has not got "wide acceptance" for one reason: it has been high-jacked to mean what the Wessely School psychiatrists want it to mean (and ***not*** to mean that it is one of terms listed in the ICD-10 as being synonymous with ME); as such, the psychiatric interpretation of it does not accord with patients' experience, so naturally they reject it. The relentless determination of those supporting the vested interests contingent to dumb-down what is so plainly an organic disorder has caused years of unnecessary suffering for patients and has been allowed to take precedence over supposed Government policy of support for "the patient as expert" in chronic and disabling disorders (*see* "The Expert Patient: A New Approach to Chronic Disease Management for the 21st Century"; Department of Health, September 2001: available from NHS Response Line: 08701-555-455 *and also* "The Expert Patient" written by John Illman for The Association of the British Pharmaceutical Industry (ABPI), March 2000; tel: 0207-930-3477).

- **<u>"Both the CMO's report and the MRC report suggest that the two terms (CFS/ME) are interchangeable. Not everyone agrees"</u>**

It is ***the Wessely School psychiatrists*** who don't agree that the terms are interchangeable, not the patients: many patients know that the two terms are ***supposed to be synonymous in the ICD-10***. It is the psychiatrists who have insisted that "CFS" is a

"mental and behavioural disorder" that should be classified at F48.0 along with neurasthenia, which Wessely claims "would readily suffice for ME" (Chronic fatigue, ME and the ICD-10. David A, Wessely S, Lancet 1993:342:1247-1248). No amount of slippery semantics can deny what has been published --- time and again --- since 1987. It's all there for the looking.

- **"at King's we favour the CMO/MRC view……."**

Hardly surprising, since they were so instrumental in both those reports, but in the light of the letter dated 11th February 2004 from Lord Warner to the Countess of Mar which unequivocally sets out the position of the Department of Health (and that includes Wessely as an NHS employee), Wessely's wings have been publicly clipped --- it is no longer an option for him to claim that CFS = ME = a somatisation / behavioural disorder = a psychiatric disorder over which he calls the shots: it is now cast in tablets of stone in the UK (as it has been by the WHO since 1992) that CFS = ME = a ***neurological*** (ie. physical, organic) disorder, so on what basis will he continue to run a psychiatric clinic at Kings for those with CFS/ME? Will those with multiple sclerosis, motor neurone disease and Parkinson's Disease be compulsorily referred to his unit so that they can be told they suffer from an "aberrant illness belief" that is amenable to his own version of CBT (and unless they comply, their State benefits will be withdrawn and they may be sectioned under the Mental Health Act)?

"What's in a classification?"

The official position of the DoH has formally superseded most of this particular piece of propaganda, but a few points may be worth considering.

- **"For most professionals, ICD codes barely enter into their lives"**

That may be so for "most professionals" but it is not the case at all for ***patients*** for whom those professionals are supposed to be caring. If those professionals were actually "caring" for their patients (and for medical and scientific accuracy), they would realise (and be concerned about) the fact that if a disorder is wrongly coded, the consequences for the patient may be catastrophic in terms of loss of financial survival, loss of freedom, loss of appropriate health service provision and management, and even loss of life itself. It is worth recalling that in 1995 Wessely wrote a lengthy Editorial in the Journal of Psychosomatic Research called "Liability for Psychiatric Illness" (J Psychosom Res 1995:39:6:659-669) in which he stated that the ICD is "*an arbiter of psychiatric compensation, since if your illness is not in the Manual, you will certainly not be able to claim (compensation in the Courts)"*, so he obviously thought then that the ICD was extremely important.

- **<u>"What is important to grasp is that … what was being described was almost identical clinical conditions"</u>**

This would appear to be a misperception by these psychiatrists, whose vested interests in the maintenance of such obfuscation have now been exposed (for example, their long-time and intimate involvement with the disability insurance industry and with a healthcare company --- PRISMA --- that is now providing the NHS with their own version of "rehabilitation programmes" of CBT and graded exercise for those with "CFS/ME". The reality is that only certain symptoms are "almost identical", but the totality of the disability is not in any way "almost identical". Despite the evidence to the contrary (the importance and significance of which these psychiatrists invariably attempt to dismiss), they have fought for ***years*** to convince the world that "what was being described was almost identical clinical conditions", and they have refused to accept that the recorded abnormalities between "chronic fatigue" and "ME/CFS" are legion.

Because not only symptoms but ***causation*** are different, it is likely that ***management and future treatment*** will be different. For example, haematuria (blood in the urine) is found in relatively minor infections of the genito-urinary tract, in TB of the bladder and in carcinoma of the bladder, but it is still the same symptom. Since treatment approaches differ according to causation of the symptom, it is vital to ascertain causation. It is the same with the symptoms shared by neurological and psychiatric disorders: it is imperative to discover the ***cause*** of the "fatigue", not just to assume and assert that because the cause has so far resisted discovery, it must be psychiatric in origin.

- **<u>"nearly all accept that there are important psychological and social issues surrounding CFS"</u>**

Of ***course*** there are, and they result from the years of abuse by these psychiatrists who have so influenced almost the entire medical, scientific and research communities, which has resulted in clinicians no longer ***listening to patients***.

- **<u>"The WHO Primary Care Mental Health Guide…is an ideal opportunity to disseminate high quality, evidence-based advice on management (of CFS)"</u>**

It ***ought*** to be, but the reality is that it has been shown to be seriously flawed and that it does not reflect an unbiased evidence-base at all. Patients and carers know this to be so, and it was they (not those whose job it ought to be) who challenged the erroneous information promulgated in that Guide and who exposed the deceit. It is thanks to the

very few individuals who would not give up that the errors have finally been conceded by Government.

- **"The WHO Manual makes it clear that CFS can be classified under neurology and/or under mental health"**

This has now been shown --- finally and comprehensively --- by the WHO headquarters in Geneva to be completely wrong and those responsible for this misinformation should be compelled to apologise publicly on the same website.

- **"The question of classification and the WHO is a storm in a teacup"**

Those who are responsible for this situation may wish it to be (and may try to diminish their own culpability by down-playing it as) nothing more than "a storm in a teacup", but it is nothing of the kind. There has been a deliberate and successful strategy to deceive that has led to incalculable and life-wreaking but unnecessary suffering for patients already crushed by a devastating illness, the ramifications of which will continue for an indefinite period. The harm done cannot be undone.

- **"(Classification) excites no division, controversy or even discussion in the medical literature…….it has not surfaced in the literature for over a decade"**

This is untrue: classification depends on correct criteria and the two are inseparable -- see for example what Fred Friedberg, Clinical Professor in the Department of Psychiatry at the State University, New York published in 1999:

"Several studies of graded activity-orientated cognitive behavioural treatment for CFS, all conducted in England, have reported dramatic improvement in functioning and subsequent reductions in symptomatology. On the other hand, cognitive interventions conducted in Australia and the United States have not found significant improvements in functioning or CFS symptoms. Furthermore, descriptive studies of CFS patients in England, the US and Australia suggest that the CFS population studied in England shows substantial similarities to depression, somatization or phobia patients, while the US and Australian research samples have been clearly distinguished from depression patients and more closely resemble fatiguing neurological diseases"

The reference for this is A Subgroup Analysis of Cognitive Behavioural Treatment Studies". Fred Friedberg, JCFS 1999:5:3-4:149-159.

Correct identification and classification are vital and that is why there has been so much published disquiet about the efficacy of the 1994 CDC criteria (it is generally accepted that, like the Oxford 1991 criteria, it is far too inclusive to be useful) and why the Canadian case definition was published (ref: Myalgic Encephalomyelitis / Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols Bruce M Carruthers, Kenny de Meirleir, Nancy Klimas et al JCFS 2003:11(1):7-115).

More recently there have been other relevant papers, including Variability in Diagnostic Criteria for CFS may result in substantial differences in patterns of symptoms and disability Leonard Jason et al Evaluation and the Health Professions 2003:26:1:3-22 (with another in press).

Another is The Specificity of the CDC 1994 criteria for chronic fatigue syndrome: comparisons of health status in three groups of patients who fulfil the criteria Gwen Kennedy, Vance Spence et al Annals of Epidemiology 2004:14:2:95-100.

There is a significant body of evidence that "CFS" is too heterogeneous and (despite the denial in the CMO's report) that there is an urgent need for subgroups (which would then allow for correct classification). See the following (taken from a submission to the CMO's Working Group):

Where is the evidence that there is a need for careful subgrouping within "CFS"?

There is now an unmistakable recognition that sound research has strengthened the need
for consideration of subgroups. [1] [2] [3] [4] [5] [6] [7] [8]

[1] A Subgroup Analysis of Cognitive Behavioural Treatment Studies. Fred Friedberg. *JCFS 1999:5:3-4:149-159*

[2] Estimating rates of chronic fatigue syndrome from a community-based sample: a pilot study. Jason LA et al. *Am J Community Psychol 1995:23(4):557-568*

[3] Politics, Science and the Emergence of a New Disease. The case of Chronic Fatigue Syndrome. Jason LA et al. *Am Psychol 1997:52:9:973-983*

[4] Chronic fatigue syndrome, Fibromyalgia and Multiple Chemical Sensitivities in a community-based sample of chronic fatigue syndrome - like symptoms. Jason LA et al. *Psychsom Med 2000:62(5):655-663*

[5] Brain MRI abnormalities exist in a subset of patients with chronic fatigue syndrome. John DeLuca, Benjamin H Natelson et al. *J Neurol Sciences 1999:171:3-7*

[6] Fatigue 2000 Conference Proceedings. The National ME Centre in conjunction with The Essex Neurosciences Unit. 23-25 April 1999

[7] Severe and very severe patients with chronic fatigue syndrome: perceived outcome following an inpatient programme. DL Cox LJ Findley. *JCFS 2000:7(3):33-47*

[8] Symptom patterns in long-duration chronic fatigue syndrome. Fred Friedberg et al. J *Psychsom Res 2000:48:59-68*

A recent Editorial in the Journal of Chronic Fatigue Syndrome [9] makes the point that *"the sorting of patients into subpopulations….is helping in the design and interpretation of clinical trials for therapeutic interventions aimed at particular disease manifestations".*

The 1994 CDC criteria for CFS (whilst referring only to CFS) themselves recommend that researchers use stratification techniques to identify subgroups of patients. [10]

One clear message which emerged from the National Institutes of Health (NIH) State of the Science Conference on CFS held on 23-24 October 2000 in Arlington, Vancouver was that CFS is heterogeneous and researchers ***must*** subgroup patients by features including chronicity, immunology and neuroendocrinology. [11] Conference participants included Dr David Bell, Professor Dedra Buchwald and Professor Nancy Klimas, all world-renowned experts on CFS.

Roberto Patarca-Montero, Assistant Professor of Medicine and Director of the Laboratory of Clinical Immunology, University of Miami School of Medicine (as well as Editor of The Journal of Chronic Fatigue Syndrome) emphasises the importance of subsets of patients in his paper "Directions in Immunotherapy". [12]

Experienced researchers and clinicians presented evidence at the Fifth International AACFS Conference held in Seattle, 27-29 January 2001 about the need for subgrouping. Some examples include the following:

--- Professor Leonard Jason from De Paul University, Chicago, concluded that *"Subtype differences detected may account for some of the inconsistencies in findings across prior studies that have grouped CFS patients into one category. Subtyping patients according to more homogeneous groups may result in more consistent findings which can then be used to more appropriately and sensitively treat the wide range of illness experience reported by different types of individuals with CFS"* [13]

--- Professor Kenny De Meirleir from Brussels compared immunological profiles in three different subgroups of CFS patients; he found significant differences between the groups. [14]

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[9] Editoral. Roberto Patarca-Montero. *JCFS 2000:7(4):1*

[10] The Chronic Fatigue Syndrome: A Comprehensive Approach to its Definition and Study. Keiji Kukuda, Michael C Sharpe, Simon Wessely et al. *Ann Int Med 1994:121:12:953-9*

[11] Conference calls for Serious Research. T.Lupton. *CFIDS Chronicle 2001:14:1:12-13*

[12] Directions in Immunotherapy. Roberto Patarca-Montero. *The CFS Research Review 2001:2:1*

[13] Subtyping patients with Chronic Fatigue Syndrome in a Community Based Sample. Leonard A Jason et al. Presented at AACFS, January 2001 # 011

[14] Cytokine Levels in CFS Patients with a Different Immunological Profile. Kenny De Meirleir et al. Presented at AACFS, January 2001 # 017

--- Dr Pascale de Becker from Brussels presented evidence that there is a need to assess the homogeneity of a large CFS population in order to establish those symptoms which can improve differentiation of CFS patients. [15]

--- Dr Paul Levine from Washington demonstrated that factor analysis is an important tool for separating subgroups of CFS; he showed that it should be utilised in future attempts to develop case definitions for CFS to identify discrete patient groups, which may have different pathogeneses and responses to treatment. [16]

--- Dr Katherine Rowe from Australia presented evidence showing that at least three distinct subgroups can be identified within the CFS syndrome. [17]

--- A large international multicentre study of autoimmunity was presented by E.Tan (with, amongst others, participants from The Scripps Research Institute, La Jolla, California; the University of Washington; Harvard Medical School, Boston; State University of New York and George Washington University,Washington DC. Of interest is that another participant was Simon Wessely from Kings College, London). This large study reflected the heterogeneity from one CFS centre to another; it emphasised the importance of subcategorising CFS studies. [18]

In the light of current awareness of the overriding need for consideration of subgroups within CFS (including that which has emerged from Seattle), there is concern that if some of the content of chapter 3 of the present draft is incorporated into the final version, then the UK CMO's Report may be immediately dismissed and be held in derision by well-informed clinicians and patients alike.

The various views of the WG on the need for subgroups

In February 1999 a member of the CMO's Key Group (Dr Derek Pheby of The Unit of Applied Epidemiology, Frenchay Campus, Bristol) produced a discussion document [19] for the Working Group to consider. In that document, the author is unequivocal about the need for attention to be given to the existence of subgroups and he quotes from the

[15] A Definition Based Analysis of Symptoms in a Large Cohort of Patients with Chronic Fatigue Syndrome. Pascale De Becker et al. Presented at AACFS January 2001 # 019

[16] Use of Factor Analysis in Detecting Subgroups (of CFS patients). Paul H Levine et al Presented at AACFS January 2001 # 052

[17] Symptoms Patterns of CFS in Adolescents. Katherine Rowe et al. AACFS Jan 2001 # 064

[18] A multicenter study of autoimmunity in CFS. K.Sugiura, D Buchwald, A Komaroff, P Levine, S Wessely, EM Tan et al. Presented at AACFS 2001 # 037

[19] Discussion Document: an overview of the recent research literature. Dr Derek Pheby.Feb 1999

Report of the UK National Task Force on CFS / PVFS / ME. [20] The Task Force Report states unequivocally that ***"Although both the terms "CFS" and "ME" have a range of applications, they do not represent the same populations".***

It is a matter of record that those who favour a psychiatric aetiology (and who wish to eradicate the classification and even the existence of ME [21]) were unhappy about the Report from the Task Force; indeed, the Report itself acknowledges this, stating *" People who gave us their much-valued help are not necessarily in agreement with the opinions expressed".* Being known to be in disagreement with the Report from the National Task Force (which did not have a psychiatric bias), the proponents of the psychiatric view responded to the Task Force Report by producing their own report (that of the Joint Royal Colleges 1996, in the Preface to which it confirms that the authors of the Joint Royal Colleges' Report are not in agreement with all the findings of the National Task Force report).

In his discussion document for the CMO's Working Group, Dr Pheby explicitly states (emphasis added):

" The National Task Force recommended that five main sets of issues should be addressed, i.e. ***Clarify the difference between the various chronic fatigue syndromes…*** *areas where in the view of the Task Force research needed to be encouraged included:* ***clear definition of the various chronic fatigue syndromes****"*

" CFS is a ***spectrum*** *of disease"* i.e. not a disease entity in itself and quoting Levine [22] who is emphatic that *"It is clear that CFS is not a single entity"*

"Variations in prognosis may be attributable once again to the heterogeneity of the condition, ***with different subgroups having different prognoses"***

"The heterogeneity of CFS has made it very difficult to interpret research results from different studies which may have been conducted in very dissimilar populations"

"If progress is to be made, it is necessary to consider…the possible existence of subgroups within the population of patients with CFS / ME"

"The increasing knowledge of pathological processes occurring in CFS / ME has led to a belief that it should be possible to define subgroups on the basis of biomarkers and thus to draw a distinction between CFS and ME"

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[20] Report from The National Task Force on Chronic Fatigue Syndrome, Postviral Fatigue Syndrome, Myalgic Encephalomyelitis. Westcare, Bristol 1994

[21] Eradicating ME. Report of a lecture given by Simon Wessely on 15 April 1992 at Belfast Castle,Belfast. Pfizer / Invicta Pharmaceuticals 1992: 4-5

[22] Epidemiologic advances in chronic fatigue syndrome. Levine PH. *Journal of Psychiatric Research 1997:31:1:7-18*

"It has been argued by many that not only can ME be differentiated from CFS by biological markers, but that its clinical features also differ"

Under "Priority Areas for Research", the author concludes: *"Certain areas for research have been identified as being important in enabling the Working Group to achieve its objectives. These include…systematic reviews to consider* ***subgroups****"*

On 24th August 2000 Helen Wiggins of the NHS Executive (who co-compiled chapters 1 and 2 of version 6) e-mailed a correspondent as follows:

" I would also like to assure you that the CFS/ME Working Group is aware that treatment that works for one person does not necessarily work for another. Hence the fact that the team undertaking the Systematic Review will look at evidence that subgroups of patients respond differently to treatment".

On 18th August 2000 Professor Pinching wrote to Mrs Anne Crocker of Okehampton as follows:

"…. there is no doubt in my mind that the CMO's Group is well aware of the heterogeneity of CFS/ME….obviously "one size" will not fit all….I hope very much that the final product will adequately address these issues".

In an e-mail to a correspondent dated 11th December 2000 Professor Pinching wrote:

" I am all too well aware of the fact that current treatment options are unsatisfactory and that there is a significant group of patients where our current very limited armamentarium is either ineffective or worse".

On 11th January 2001 he e-mailed a correspondent as follows:

" It may be that we can define subgroups that are useful and I would have no problem with the concept (I have done this on other disease entities (when) subgrouping has also been helpful), recognising that a broad spectrum of related things can be seen as a useful grouping…."

<u>The apparent change of mind by the authors of chapter 3 of the draft regarding the need for subgroups</u>

Chapter 3 was compiled by Dr Derek Pheby, Professor Anthony Pinching and Dr Tim Chambers. From what had earlier been made known of the WG's intentions (examples of which are set out above), many people were hopeful that the matter of subgroups

would be addressed, especially given their importance in relation to the implications for treatment outcomes.

Regrettably this was not to be, because it did not accord with the aims and beliefs of the dominant psychiatric lobby.