

Attachment 4

Education of Students with the Chronic Illness Disability of

**Myalgic Encephalomyelitis/Chronic Fatigue Syndrome**

**(ME/CFS).**

**Attachment 4.**

Morris, D. (2001) 'Analysis from the Perspective of Education of the Chronic Fatigue Syndrome Guidelines (Revised Draft 2001) of the Royal Australian College of Physicians, Sydney NSW 2001, submitted to the Royal Australian College of Physicians, Sydney, NSW 30<sup>th</sup> July and also to the Allison Hunter Memorial Foundation for inclusion with the other critiques of the Revised Draft 2001. <http://www.ahmf.org/>

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**ANALYSIS FROM THE PERSPECTIVE OF EDUCATION  
OF THE  
THE CHRONIC FATIGUE SYNDROME GUIDELINES  
(Revised Draft 2001)  
OF THE ROYAL AUSTRALIAN COLLEGE OF PHYSICIANS,  
SYDNEY NSW 2001**

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**Introduction:**

The publication of the RACP document, “Chronic Fatigue Syndrome Guidelines” was welcomed. I believed that this document could have been of much assistance to doctors, disability officers in the universities and the tertiary students themselves. But I have been sadly disappointed.

My doctoral research area has been into equity and human rights in tertiary education for Australian ME/CFS tertiary students (Morris 2001a). I shall discuss some issues which have arisen out of this research and how this relates to the Chronic Fatigue Syndrome Guidelines (Revised Draft 2001) of the Royal Australian College of Physicians.

**Research background:**

All participants’ symptoms met the CDC research definition (Fukuda et al. 1994; Jason, King *et al*, 1999). The forty participants (twenty-nine females and eleven males) have been enrolled post-1994, at twenty-four Australian universities and eight TAFE/OTEN institutions. All states and territories of Australia are represented. No participants formally withdrew, although illness limited the full participation of some of the severely ill.

My research found that ME/CFS is now the most common disability condition in Australian Universities. My research also found that there are problems with human rights and equity in tertiary education in Australia arising from the lived experience of tertiary students with the chronic illness of Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (Morris 2000, 2001b, 2001c). This study also investigated the degree of empowerment of ME/CFS students in negotiating study conditions and accommodations appropriate to their health limitations. Higher retention rates of ME/CFS tertiary students and fewer suicides amongst ME/CFS tertiary students in

Australia when they obtain the same human rights and equity of access as enjoyed by other students is another expected long term research outcome (King 1999; Mungovan & England 1998).

### **Discussion:**

With the advent of the new name for ME, coined in 1988 by the Centers for Disease Control, USA, (Holmes, *et al.* 1988) the focus changed away from the encephalitic features of ME, to emphasis on the less serious, but statistically more common symptom of fatigue. In the public perceptions thereafter ME was thought to be merely chronic fatigue. The encephalitic features have been ignored or relegated to a secondary position

*Many report difficulty in saying the right word and are conscious of the fact that they continue to say the wrong one, for example 'cold' when they mean 'hot'. Others find that they start a sentence but cannot complete it, while some others have difficulty comprehending the written or spoken word (Ramsay 1986).*

The cognitive problems of ME/CFS typically include poor concentration and short-term memory, word-finding difficulty, and inability to cope with multiple stimuli and then there is fragile retrieval (Bastien, 1992; Grace, 1999; Goldstein, 1993, 1996; Pinching, 2000; Ramsay, 1986; Scoley, et al.1999). Bastien (1992 p. 454) found almost a decade ago that:

*The patient sample had the following neuropsychological impairments: word finding problems; subtle problems with receptive and expressive aphasia, including intermittent dysnomias; decreased concentration; distractability, problems in recall, verbal more than visual, including remote memory disturbance; dyscalculia ...; both gross and fine motor problems; spatial-perceptual dysfunction, including losing their way while driving; some abstract reasoning disturbance, primarily non-verbal; decreased visual discrimination; and problems in sequencing.*

More time has to be spent in encoding this new information, yet on the day of an academic examination there can be no assurance that this information will be able to

be retrieved and utilised, as mental fatigue will mean that the brain has apparently shut down. Brainwaves, without warning, may change from beta (thinking) to delta and theta waves, (associated with sleep and pre-sleep states in healthy people) as sudden inexplicable “power drains” during cognitive challenge (Preston 2000). My research also found that there objective evidence of deterioration of physical and mental fatigue after exertion, such as academic assessment, and yet this report again has not mentioned this.

My research found that there were profound difficulties experienced by all forty participants with cognitive dysfunction. And yet this report of the RACP has not mentioned the nature of cognitive impairment in CFS. My own research findings have been consistent with the research which used the CDC definitions (DeLuca, Johnson *et al.* 1993; Johnson, DeLuca 1994; Krupp, Sliwinski *et al.* 1994; Lange, DeLuca *et al.* 1999; Marcel, Komaroff *et al.* (1996); Marshall, Forstot, *et al.* 1997, and others using this same definition). Other research in this area which has not used the CDC research definition and has used broader or alternative definitions or has not stated their research definition has not come up with similar findings (DiPino & Kane 1996; Kane, Gantz *et al.* 1996; Scheffers, Johnson *et al.* 1992; Schmaling, DiClementi *et al.* 1994 and Voller-Conna, Wakefield *et al.* 1997).

The Disability Discrimination Act (DDA, 1992), and Code of Practice for Tertiary Students With Disabilities.(O’Connor *et al.*, 1998), are designed to meet the needs of students with disabilities however the reality is that they are failing to meet the needs of the ME/CFS student. My research has found that currently, there is the dilemma in accommodating the needs of ME/CFS tertiary students. There seems to a huge chasm between the medical knowledge of a condition, and how it impinges on academic progress. The complexity of the medical symptoms, and their far-reaching impact on the ME/CFS student, has meant that there has been many complaints amongst tertiary ME/CFS students that their needs for suitable accommodations are not being met, especially in the area of academic assessment and attendance. Other symptoms which this RACP report has not addressed has included orthostatic intolerance (neurally mediated hypotension), the muscle lactate response which affected students when writing (especially in examinations) and their mobility, and the higher incidence of

new-onset asthma and/allergy after CFS where students are affected by environmental allergens/chemicals.

Academics, teachers and lecturers are confined by the educational requirements of their institutions, especially in the areas of assessment and attendance. Yet at the same time they need to address and meet the requirements of the *Disability Discrimination Act* (1992), especially Section 6 which deals with Indirect Discrimination.

The *Disability Discrimination Act* (DDA, 1992), Section 6 says:

***Indirect disability discrimination***

*For the purposes of this Act, a person (“discriminator”) discriminates against another person (“aggrieved person”) on the ground of a disability of the aggrieved person if the discriminator requires the aggrieved person to comply with a requirement or condition:*

*(a) with which a substantially higher proportion of persons without the disability comply or are unable to comply; and*

*(b) which is not reasonable having regard to the circumstances of the case; and*

*with which the aggrieved person does not or is not able to comply*

Indirect Discrimination occurs when ‘normal’ students are able to comply with a regulation/situation whereas the student with the disability cannot due to the nature of their impairment. Further the act does not allow for the ‘discriminator’ to plead that they did not understand they were discriminating. This therefore leaves academics and teachers in a very difficult position as they face the task of finding academic assessment procedures which are appropriate for their ME/CFS students.

Medical practitioners are writing medical certificates requesting accommodation for their patients Chronic Fatigue Syndrome, and the only symptom therefore, which the lecturers, teachers and disability support persons can negotiate on this basis is the fatigue, a non-definable entity which is assumed to equate to mere tiredness. It is acknowledged that medical practitioners are not trained educators and thus would find it difficult to comment on the cognitive difficulties which is

experienced by ME/CFS tertiary students, and it is here that these guidelines could have assisted medical practitioners in writing recommendations for academic accommodations for their patients.

These RACP Guidelines ignore the cognitive dysfunction of ME/CFS and also the other physical symptoms altogether. A very serious omission, and one which leaves those involved in making appropriate accommodations in the area of education at much risk of infringing the Federal Disability Discrimination Act 1992, especially Section 6, Indirect Discrimination. And the only defence which the educator, lecturer and academic will have if legally challenged, is that they acted on the advice of the students treating medical practitioner!

### **Summary:**

The serious omission of the effects of cognitive dysfunction is not consistent with my research findings of the effects of ME/CFS in tertiary education in Australia. Further these guidelines will not assist medical practitioners to advise educators on the necessary accommodations required for their ME/CFS students, and this will leave educators open to legal action under Section 6, Indirect Discrimination, Disability Discrimination Act 1992.

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