

Education of Students with the Chronic Illness Disability of
Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
(ME/CFS).

Attachment 1.

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Research into ME/CFS and tertiary education

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Abstract:

My research with tertiary students with Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome (ME/CFS), has gathered the stories of forty participants, enrolled since 1995, at thirty-three Australian Universities and TAFE Institutions. The expected themes of difficulties meeting the physical demands of the institutions and of illness experience appeared, but another theme emerged - of the political struggle of the participants with credibility, disbelief, and disempowerment of a newer poorly understood, badly named and defined invisible disability. It is no coincidence that, when named, females comprised ninety-eight percent of diagnosed sufferers. The name conjures up images of tiredness, malingering, hypochondria and shirker: persons with this condition are trivialised and so discredited that they are unable to negotiate for social justice, which leads in turn to emotional distress. This is the story of my research: the political constructs, the actions endeavouring to empower, gain justice, equity and human rights in tertiary education with a stigmatising chronic illness.

Introduction:

This is a research report on 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.

Myalgic Encephalomyelitis (ME), also known as Chronic Fatigue Syndrome (CFS), is a neurological illness, generally regarded as cognate with Parkinson's and MS (Multiple Sclerosis), with well documented encephalitic features, and variable involvement of all other body systems for which there is presently no cure. It is likely to be life long for the person with the condition (Hyde 1992; Komaroff 2000). The female incidence is seventy-five to eighty per cent and all age groups may be affected. Diagnosis is made through the medical practitioner's clinical judgement as there is no diagnostic test. Successive research definitions have been written with ever widening generalisations, now stressing the non-specific fatigue symptom (Hyde 1992). Quality of life for persons with the condition maybe severely affected (Anderson & Ferrans 1997). Mathers *et al.* (1999) found ME/CFS to be a serious illness and placed it along side of pre-terminal AIDS.

The Federal Disability Discrimination Act (FDDA, 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. In addition, many students are still unaware of their rights.

This study is therefore aimed to investigate the degree of empowerment of ME/CFS students in negotiating study conditions and accommodations appropriate to their health limitations. My findings could lead to higher retention rates of ME/CFS tertiary students as well as 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 (King 1999; Mungovan & England 1998).

Method:

All participants' symptoms complied with Ramsay's definition, as well as satisfying Fukuda's 'six month ill' criterion (Jason, King *et al*, 1999). The forty participants (twenty-nine females and eleven males) have been enrolled in 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. Participants completed an introductory questionnaire and then wrote their stories of their lived experiences as a tertiary student with ME/CFS. Most of these forty personal stories were collected via email.

Findings:

Participants' stories of their lived experience reflected their frustration, sadness and poignancy but also, in most cases, their determination. Narrative analysis of the lived stories revealed that four major themes.

Theme one: illness experiences.

Ramsay (1986) details a triad of physical symptoms drawing particular attention to ME's characteristic profound fatigue with severely delayed slow muscle recovery, the circulatory disorder and the universal cerebral difficulties which include impairment of memory, inability to concentrate, aphasia, diplopia, acute hyperacusis. All participants wrote of their illness experience of being a student with ME/CFS and many wrote of their struggle with limited energy and constant or intermittent pain.

Note taking pre-illness was a task I performed easily, efficiently and effectively. However after the onset of CFS note taking became a constant struggle. The muscular and joint pain through my shoulders and upper back would and still does escalate when writing or typing and this would distract my concentration from the task of listening to the lecturer and noting the information provided (Student A).

Theme two: difficulties on campus.

All thirty-five participants, who proved able to complete their stories, mentioned difficulties in some areas where they felt that they were at a disadvantage. The invisibility of their condition, as well as the lack of acceptance of ME/CFS, created many problems. Issues cited included on-campus access problems such as stairs, difficulties attending lectures and tutorials, library access and access to rest rooms and student catering facilities. Poor architectural design and layout of university campuses (built on hill sides) were cited as major problems.

If I were blind, a scribe and a braille typewriter would be provided for me. If I were in a wheelchair, lectures would be held in rooms that were accessible. But because CFS cannot be seen, it tends to be ignored. The concessions required for students with CFS only serve to give us the same opportunities to succeed as other students (Student B).

I found I had to leave supplementary exams after 2 hours of a 3 hour exam. I was just not well enough to stay for the duration. ...Exams had become a nightmarish experience as I tolerated vertigo, dizziness, feeling faint, nausea, muscle aches, soreness and exhaustion that still hasn't been relieved by rest (Student C).

Theme three: political constructs and name of condition.

Fitzgerald and Paterson (1995, p.16) point out that disbelief by both the medical professionals and by family, friends and the community 'can have a profound affect (sic) on their concept of self, even on their sense of legitimisation of self'. Although comments were not solicited from the participants, 33/35 students volunteered comments about being belittled through misunderstanding of the condition and the by the name 'chronic fatigue syndrome'.

I was always terrified that my credibility and my 'usefulness' as a person would be called into question as a student, which was probably why I did not approach the Uni. I also did not want to feel the pity of my peers or face their attitudes about the illness. Nor did I feel I was strong enough to justify myself and struggle to try and educate them or the Uni. (Student D). Unfortunately I have found that a certain ignorance and intolerance exists within various departments of the universities that we have to deal with. I believe that these beliefs and attitudes have at times made study and achieving my goals more difficult (Student G).

Theme four: emotional, social and quality of life.

Thirty-five of the thirty-six participants mentioned their frustration, emotions and disempowerment. Many participants mentioned their isolation on campus, their inability to socialise with other students, the barriers created as other students perceived them to be lazy malingerers and as not having a real illness.

Through the handling by certain university staff of particular situations I have felt at times angry, frustrated and disempowered (Student F).

In fact, once they heard the name, they didn't even want to hear me try and explain..., they just shot off, as if all their initial assessments of me had been confirmed and I was just a bludger. It was awful (Student E)

Discussion:

This discussion addresses the third theme of the research: the medical and political constructs and the flow on effects into the community which reveal more than the physical illness experience (Holloway & Pinikahana 1999; Jason *et al.* 1997).

Grbich (1996 p.30) has espoused that 'Medicine is seen as a male-dominate system of social control which operates to maintain the subordinate position of women in society', a viewpoint endorsed by Broom (1989). Historically ME/CFS has been considered a 'disease of white middle class women', but Jason, Richman *et al.* (1999) have conducted

research which found an even greater frequency in Hispanic and Afro-American women although the Centers for Disease Control, USA, still persist with the white middle class woman myth.

In 1988, when the name chronic fatigue syndrome was coined by The Centers for Disease Control, USA, by an overwhelmingly medical male dominated committee, (Holmes *et al.* 1988), ninety-eight per cent of persons diagnosed with the condition were white, middle class, and female. It would seem to be no coincidence that the patriarchal medical profession came up with this name for this condition, which may be called a feminine condition, without a diagnostic test, which relegated this condition to a 'soft' status, whereas other conditions with a diagnostic test were considered 'hard' and quantifiable (Richman *et al.* 2000). Johnson (1996, p.219) has succinctly summarised this:

the euphemistic, benign-sounding name suggested a trivial, volitional disability, one that could be shrugged off with vitamins, aerobic exercise, stress reduction, a good night's sleep, or sheer will power. By casting its victims in the role of shirkers who chose to defy the nation's Protestant work ethic, the name, in addition, had the subtle effect of inspiring hostility toward the victim. As one psychologist ... evaluating the psychological impact of words notes, 'Chronic fatigue syndrome' has a real negative impact. The word 'chronic' is associated with chronic complainers chronic whiners. And 'fatigue' is even worse. More profoundly, the name camouflaged the nature of the illness itself; the fatigue in 'chronic fatigue syndrome' was merely a symptom and, compared to the neurologic dysfunction resulting from the structural damage to the brain in the early phases of the disease, a sometimes unimportant one at that.

This patriarchal bias led to the labelling of many of the organic physical symptoms as psychosomatisation (David 1999). The original narrow exclusive neurological ME with disproportionate post-exertion delayed recovery of Ramsay and London ME research definitions has become broadly defined as inclusive of non-specific fatiguing conditions (CFS) by Fukuda and Oxford (Jason, King *et al.* 1999) and Royal Colleges (Lancet 1996).

Fatigue is referred to as the "F Word" by persons with ME/CFS as people consider that this condition is merely fatigue, and that as everyone has been fatigued at some time or other, fatigue is unimportant and often people will say "I think I must be getting that, I've been feeling a bit tired lately."

But when people learned the name of the illness - chronic fatigue syndrome - the general attitude was (and this isn't limited to my class mates, but most members of the general public) "well, I get tired too, you know". There was complete misunderstanding (Student E).

The ambiguity caused by interchangeability of the name Chronic Fatigue Syndrome with chronic fatigue within the community, and even used by some Australian researchers and Royal Australian College of Physicians (Hickie 2000; RACP 1997; 2001) has added to the confusion about this physical medical condition. With the emphasis on the word fatigue, there has been many presumptions that fatigue is the overwhelming symptom of this condition, and non-medical research has been carried out on this presumption (Hart & Grace 2000). Jason decided to test medical practitioner and student perceptions of the

name of the condition and used three names by which ME/CFS is known: Chronic Fatigue Syndrome, Florence Nightingale Disease and Myalgic Encephalopathy (Jason 1999). Jason found that first two names were perceived as not serious conditions, whereas Myalgic Encephalopathy was a serious condition.

Research has been carried out with a ME/CFS definition which will select a participant cohort most likely to give the desired finding (Goudsmit 1998a). Many psychological tests have been used without subjecting the measuring instrument to close scrutiny to see if their instrument is capable of differentiating between physical chronic illness symptomatology and somatisation symptoms (White & Schweitzer 2000). Some psychologists have been most critical of this lack of scientific rigour in research into ME/CFS (Jason *et al.* 1997). It has been impossible to compare much of the research as each side discredits or ignores research findings that does not endorse their own particular scientific discipline (Pheby 1999). Inappropriate treatments, such as Cognitive Behavioural Therapy, have been recommended for persons with ME/CFS based on research where only 10% of the participants met the ME definition (Fisher 1998).

White (2000 p.283) made the following comment in his peer-reviewed scientific research findings that his research had

a significantly greater proportion of female CFS patients than healthy controls. This is important since women are in general less physically active than men... It is therefore likely that this study underestimated the prevalence of pervasive passivity...

This demonstrates a dismissive male perception of women's work loads.

The Australian medical situation.

Lloyd (1994) at the Seminar on Chronic Fatigue Syndrome for physicians held in Sydney, satirised the stereotypical professional overstressed female with CFS in his workshop presentation of the 'Hypothetical of Anita Bleating' and called into question her subjective experience of living with this condition. In 1996, the president of the Australian Medical Association called on the medical profession to take ME seriously (Nelson 1996). Draft Clinical Guidelines for Chronic Fatigue Syndrome have been written by the Royal Australian College of Physicians (RACP 1997, 2001). The RACP appointed only their members to this committee hence no gynaecologists, scientists nor outside researchers were included. This committee had only male membership to make recommendations on a predominantly female condition and it was only through vehement female lobbying of the chairman that one token female was appointed to this committee - a paediatrician. The only consumer representative was male and appointed by the Australian Consumer Health Forum, the ME/CFS societies membership were not consulted. No-one on this committee represents the overwhelming majority of mature woman with ME/CFS. Further the RACP Draft Clinical Guidelines further disregard women by completely ignoring the dysfunctional female hormonal symptomatology not experienced by males with ME/CFS.

Community attitudes

The medical credibility of this condition has in turn been reflected in community attitudes to persons with ME/CFS.

Government and Insurance

The Victorian Taxi Directorate, (a state government directorate) have expressly denied access to taxi travel concessions to persons with chronic fatigue syndrome, yet ME is listed, under four different categories, as an allowable condition (VTD n.d.). There has been evidence that insurance companies have been denying persons with ME/CFS access to their insurance benefits and Pearce raised this in Parliament (Hansard, Qld 1999).

Media

The ME/CFS has been frequently referred to by the term 'Yuppie Flu' in the media which stands for 'Young Upcoming Professional Illness' (Sunday World, 1998). The Wall Street Journal, owned by Dow-Jones, has carried the editorials "The Actively Sick" and "Chronic Disability Payments" (Bartley, 1997,1998). Shell Oil Company had a radio advertisement for the Australia Day weekend 1999 saying: 'You are as relaxed as a mattress tester with chronic fatigue syndrome'. Hamilton Island billboards outside of the Brisbane, Melbourne and Sydney airports carried the caption 'Chronic Fatigue Syndrome: Hamilton Island - Spoiling Australia.' picturing a couple lazing in a dinghy. The Advertising Standards Board (ASB) said 'Ads should not discriminate or vilify a section of the community. In this particular case, the ASB felt it vilified sufferers of Chronic Fatigue Syndrome and felt it tended to demean or belittle those people' (Lawrence, 1999). Baskett (2000) maintained that with any other medical condition there would have been a public outcry, but the name chronic fatigue syndrome does not evoke public wrath.

Academics

Many academics have passed opinions regarding the legitimacy of ME/CFS (or under the aegis of an alternative name for the condition - and these include Goffman (1963, p.10), Hymes (1996 p.55), Ware and Kleinman (1992), and Showalter (1997). Many of these non-medical academics have taken extreme positions as exemplified by the feminist Showalter, a professor of English literature and not medically trained, aligned ME/CFS as hysteria, alongside of alien abduction and satanic ritual abuse, admitting she did not bother to access any medical research material (Goudsmit 1998b). Morris (1996) has pointed out that the majority of mainstream feminists ignore the needs and recognition of their disabled sisters, so persons with ME/CFS also experience denigration from those who purport to support the feminist cause.

General public

The lay community have become 'instant experts' on ME/CFS. As soon as chronic fatigue syndrome is mentioned all kinds of treatments/behaviours are promoted to the person with the condition, as they all know someone who has been completely cured of their illness. The medical reality is that ME/CFS may go into voluntary remissions, but there is presently no proven treatment nor cure.

Conclusion:

Woodward *et al.*(1996) found that for persons with ME/CFS the diagnosis was enabling. Yet the name chronic fatigue syndrome creates false impressions of what this condition is, and there is currently official and government meetings which have been convened in USA, Canada, UK, and Europe, to find a new name for this condition (Schweitzer 1998).

Above all, the name of 'chronic fatigue syndrome' is a patriarchal name which expresses disdain and may be literally translated into 'chronic whining, tired all the time female with a collection of non-quantifiable symptoms'. For creditability and equity we need to reclaim the name Myalgic Encephalomyelitis, or wear a completely new name for this condition.

This paper presents research findings which have emerged from the political and patriarchal construction of ME/CFS. It is hoped that this activist research into the lived experiences of ME/CFS tertiary students using critical narrative inquiry will lead to respect and willingness to address their needs within the Australian tertiary education system. The empowerment of students with ME/CFS to negotiate for appropriate accommodations to meet their needs is also a goal of this research.

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