Education of Students with the Chronic Illness Disability of

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

(ME/CFS.

Attachment 2.

Morris, D. (2001), "Report on the findings of 'The Lived Experiences of tertiary students with ME/CFS" to the ME/CFS Society of South Australia and SAYME2001, 18 February 2001 as guest speaker.

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ME/CFS Society of South Australia and SAYME2001

"A Report on 'The Lived Experiences of tertiary students with ME/CFS'".

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Abstract.

The research analysis into the lived stories of Australian tertiary students with ME/CFS has revealed that there are four major areas of concern which have arisen. These are the effects of the illness experience, especially the cognitive dysfunction; accommodations: rules, practical access issues, equity issues weighed against the Federal Disability Discrimination Act (1992) and the Students with Disabilities: Code of Practice for Australian Tertiary Institutions (O'Connor et al.,1998); the disempowerment through the political/medical/psychiatric constructs and the name; and the emotional and social effects on the ME/CFS tertiary student which arise from the first three issues. These become important quality of life issues for the ME/CFS students, as well as impinging on their student life and academic success.

Keywords. ME/CFS, discrimination, Federal Disability Discrimination Act 1992, human rights, equity, academic assessment, indirect discrimination, symptom research, resources for ME/CFS students.

Introduction.

My research is into *"The lived experience of ME/CFS students: A study into human rights and equity in tertiary education'*. This is of necessity a brief summary of some of my research findings, and in these short summary papers I shall draw attention to the areas where, according to the research stories of the ME/CFS participants they experience the most difficulty. This presentation, has four parts:

Part 1: The Conduct of the Research and Preliminary Findings and Discussion.

This is a discussion of the motivation to conduct this research, the conduct of the research and details about the participants, and a discussion of some of the findings which have emerged from out the stories of the participants..

Part 2: Standards for education practice in Australia.

This gives references to the Federal Disability Discrimination Act (1992), the Draft Education Guidelines for Disability (2000) , and the Code of Practice for tertiary students in Australia. It also explains Section 6 of the Federal Disability Discrimination Act (1992) and what Indirect Discrimination means in practice. Since the implementation of the Federal Disability Discrimination Act in 1992, most academics and institutions are aware of the implications of Section 22, dealing with education specifically, but have remain blinded to Indirect Discrimination, and how this impacts on students.

Part 3: A brief review of related literature.

This is a brief list of references which are used in the area of accommodations for students with a disability. There are general references which do not address the needs of the ME/CFS student at all, but are general interpretations of the Federal Disability Discrimination Act (1992) and how it should be applied. Then there are more specific references, which are utilised by disability advisors, to obtain information on specific conditions and appropriate accommodations. Here there is concern at the types of recommendations which are made for ME/CFS, and presumptions are made that fatigue is the one symptom which has to be considered, even ignoring the existence of other symptoms, such as cognitive dysfunction. There is also a list of helpful Australian references applicable to ME/CFS tertiary and other students, and a list of overseas references which is particularly applicable to ME/CFS primary school children.

Part 4: The symptomatology of ME/CFS.

This is a very brief list of some of the more common symptoms of ME/CFS, along with a list of research paper findings regarding these symptoms. This has been included because ME/CFS is a multifactoral condition with variable symptoms, and it is most likely preferable to negotiate an appropriate accommodation on the basis of a specific symptom.

Part 5: Stories of ME/CFS (not included)

"A Report on 'The Lived Experiences of tertiary students with ME/CFS'".
Part 1:
The Conduct of the Research and Preliminary Findings and Discussion.

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Introduction
This is a discussion of the motivation to conduct this research, the conduct of the research and details about the participants, and a discussion of some of the findings which have emerged from out the stories of the participants..

Research Topic:
The research topic which I have chosen for my Doctor of Philosophy at Deakin University is *"The Lived Educational Experiences with ME/CFS: A Study in Human Rights and Equity in Tertiary Education",*

My motivation
In 1997 I had my own enrolment cancelled at University, because of incorrect knowledge about my capabilities as a student with ME/CFS. In my fight back to be reinstated in my course, I discovered that there was no literature nor resources which I could access. As other students or their support persons have accessed me for details of my fight back, as they had also suffered traumatic experiences during the course of their tertiary studies, I became aware that my experiences were not unique.

The purpose of my research
The purpose of my research is to investigate the lived experience of tertiary students with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and to present the findings from the perspective of human rights and equity.

ME/CFS students had mentioned their own problems, experiences and difficulties, and even subsequent withdrawal or exclusion from their courses in conversation. Mungovan and England (1998) found that there were discriminatory attitudes and other difficulties which students with ME/CFS had to cope with when endeavouring to negotiate better understanding and conditions in their educational institution.

The aim of the research.
The aim of this research has been to obtain a greater understanding and accommodations for ME/CFS tertiary students, through the gaining of this information from the lived experiences of the ME/CFS students. This research could assist the empowerment of the ME/CFS students to negotiate study conditions appropriate to their health limitations, thereby enabling these students to continue their education successfully, in a less stressful and more accommodating environment. This in turn, could also lead to the higher retention of ME/CFS tertiary students and perhaps fewer suicides amongst ME/CFS tertiary students in Australia as the needs ME/CFS students are made known and accommodations made to obtain the same human rights and equity of access enjoyed by all other students (King, M.1999, Morris 1999; Mungovan & England 1998).

Research Methodology.

Qualitative research methods were considered to be the most appropriate method of conducting this research, as there had been no previously known research into this area of the lived experience of the ME/CFS tertiary students. The perspectives of Fay, Carr and Kemmis, and members of the Frankfurt School, such as Habermas, Gadamer, Horkheimer and others have been investigated (Carr & Kemmis 1983; Fay 1975). Kemmis (1998) has said critical theory is also social theory, and Oliver (1990) has positioned research into disability as being political research. The research has been interpreted through narrative analysis from a critical perspective. This research is therefore critical narrative case study research. This research shares with other disability researchers, such as Oliver (1990), Morris, J. (1991)and others, the desire of the emancipation of the participants from the burden of the medical model of disability, and moving towards the enabling social model.

Case study research was decided to be the most appropriate method of research which would reveal the lived experiences of the participants There were difficulties with access to the participants due the large scale of the research covering the whole of Australia, and face to face interviewing and telephone interviewing were deemed to be inappropriate. Further the medical condition circumscribed the access to the participants. Email was therefore selected as a cost effective, and accessible means of access to the participants, and the participants stories were written, mainly in emails, and as email attachments.

The Conduct of the Research

The criteria for selection and limitations on participants:

This research was limited to present and past Australian tertiary students, who either concurrently had ME/CFS as a student, or who succumbed to the illness during the course of their studies.

A further limitation was made, that the students would had to have been enrolled in tertiary studies in 1995 or later, so that their experiences would be as current as possible, and their experiences could also reflect the impact of the Disability Discrimination Act(1992) on student study conditions.

Age groups and institutions

The student participants came from various age groups, and a variety of different tertiary institutions, which could reflect different campus experiences. University and TAFE students were included.

ME/CFS research definition criteria

There is no diagnostic test and there is misdiagnosis of up to 40% (Hickie & Parker 1990). Presently, the diagnosis of ME/CFS is made by a medical practitioner only on the subjective answers of the person with the condition, using various medical definitions of the syndrome, and this diagnosis further rests on the opinions of the doctor who may have very variable knowledge of this syndrome.

All participants in this case study research were therefore asked to assess their illness against the Ramsay (1988) ME Criteria with the inclusion of the six month’s criteria of Fukuda (1994). A shortened version of the Fukuda CDC Definition of the Chronic Fatigue Syndrome was also included for information (Komaroff & Buchwald 1998). This helped to add confidence that the research participants conformed to a standardised, common definition (Hyde 1992).

Preparation of the participants.

As there had been no known research to find out what has really been happening in regards to human rights and equity for ME/CFS students, my study accessed the tertiary students to learn their stories: to find out exactly what the experience of being a student in a tertiary institution with ME/CFS is really like from a student's perspective (Morris 2000c). The research invitation stated that

> *This research involves you writing out your own stories, in your own words, about your experiences during your tertiary studies. I am particularly interested in learning about the understanding of your ME/CFS which you have received, and accommodations made for you while a tertiary student. Areas which you might like to consider writing about may include assessment, dealing with academic and other staff, attendance, mobility on campus, access to facilities, or other issues which you feel are relevant. There is no set length to the documentation of your experiences, and I shall not be looking for expertise in grammar or expression."*

The participants were not told that this research was into human rights and equity, as this could have pre-empted the kind of stories which they would write - I wanted to ascertain if the issues of human rights and equity would emerge.

Research Phase

The research phase of my research commenced 1st July 1999, and concluded on 31st October, 1999.

Size of Research

Participants were invited to participate through mail and emails, a general appeal through Ozme Listserv, and there was also some snowballing, through persons who knew of my research. The Disability Support officers in the tertiary institutions were not approached, nor were the state ME/CFS Societies, nor local support groups.

Forty students consented to participate, and completed the questionnaire, and all but five participants wrote of their experience as a tertiary student for the research (although in some cases this amounted to less than half a page, as some were just too ill to write more and apologised for this). No-one formally withdrew. Seven persons wrote their stories by standard postal mail, so participants, who did not have access to a computer nor email, were not debarred from participating.

A participant wrote, when returning her consent form and questionnaire

> *I am looking forward to writing down my experiences, I am so glad you are doing this research, it gives so many of us a voice. Most of the time no one wants to know.*

And this may be a reason for the high rate of participation.

Representativeness of the Research

All forty participants have been enrolled at an Australian University in 1995 or since, so this has allowed for the implementation of the Federal Disability Discrimination Act (1992) in the tertiary institutions. There were twenty-nine female students (72.5%), and eleven male students (27.5%), which reflects the gender composition of the disease in the general community (Hyde 1992). All participants conformed to the Ramsay (1988)/Fukuda (1992) definition of ME/CFS.

The forty participants were from all states and territories of Australia. Twenty-five Australian Universities are represented, and eight TAFE/OTEN institutions are also in the sample. Six students have had enrolments at more than one institution in the applicable period since 1995.

There are eighteen students enrolled in New South Wales Universities, seven from Victoria, South Australia and Queensland each has six, Tasmania has four, the Australian Capital Territory has two, and one each from Western Australian and the Northern Territory. It was interesting to find that there were six participants who were enrolled at a University which was not located in their home state: two from South Australian, and one from Victoria, Queensland, and Tasmania were enrolled at New South Wales Universities, and one participant from the Australian Capital Territory was enrolled in Tasmania (some of these interstate enrolments may reflect distance education availability at the under-graduate level).

There were eight enrolments at TAFE Colleges/OTEN, and of these two were in New South Wales, four in Victoria, and one each in Queensland and South Australia.

Findings and Discussion

Questionnaire

This information is still not fully assessed but information was on the types of courses studied and mode of study, duration of the illness have provided a valuable source of information. The average (mean) duration of ME/CFS for the forty participants was 8.6 years, with a median of 7 years, and the range was from 6 months to 25 years.

A preliminary scattergram showed that the level of academic study was not of importance, but rather the duration of the disease, and the mode of study. Full-time students (on-campus) in the early years of this disease were the ones with the greatest difficulty, and were most of the people who had to withdraw from the tertiary studies. It would be interesting to compare with this with the research of Jason *et al.* (1999) into the phasing of ME/CFS as this could then maybe become a predictive tool to assess the likelihood of academic success.

Assessment of Stories

The preliminary research analysis into the lived stories has revealed that there are four major areas of concern. These are the effects of the illness experience, especially the cognitive dysfunction; physical accommodations; the politico/medico/psychiatric constructs, and the name; and the flow on of the emotional and social effects on the lives of ME/CFS tertiary students.

Illness experiences.

All participants wrote of their illness experience of being a student with ME/CFS and many wrote of their struggle with limited energy and pain, but it was the cognitive dysfunction which attracted the most comment with thirty two/thirty five participants volunteering information regarding their cognitive dysfunction. Yet the primary resource books by Lockhart (1997) used by the Disability Liaison Officers in Australian Universities does not even refer to cognitive dysfunction at all! Further, Rowe (n.d.) and Rowe *et al.*(1993), al Mahmood *et al.* (1998) all ignore these phenomena of "brain fog", short-term memory, memory encoding, and recall difficulties (Goldstein 1993, 1996).

Accommodations: Rules, practical access, equity issues.

The stories of the participants have been weighed against the FDDA (1992) and the Students with Disabilities: Code of Practice for Australian Tertiary Institutions (O'Connor *et al.* 1998) and are being analysed with a view to finding physical examples of a lack of human rights and equal opportunity issues.

All thirty-five participants mentioned difficulties in some areas, and library access, and examination and assessment provisions seemed to cause the most problems. There seemed to be little understanding of how the cognitive dysfunction and fatigue affected the performance of students in examinations in most universities.

There has also been other issues raised, such as physical access on campus such as stairs, difficulties attending lectures and tutorials, library accommodations. Many of the issues, such as mobility, are not specific to ME/CFS and could also affect students with other similar medical conditions

The issues of university requirements have also been raised, which although not intended to discriminate against the ME/CFS student, nevertheless the experience is that when these rules and regulations are applied, they do discriminate, with deep repercussions in many cases (FDDA 1992).

One issue, which was mentioned on a number of occasions is that it was not thought ME/CFS students needed special accommodations as they are not disabled, and the thinking of disability in many universities seemed confined to wheelchair access and accommodation of blind students (O'Connor 1998). Indeed many of the ME/CFS students did not categorise themselves to be disabled and had the same perceptions of disability, further this was often suggested as a reason why the participants did not access the Disability Support Unit. Many Disability Officers were reported as not understanding that ME/CFS is a physical long term debilitating illness. Additionally, many of the participants were also in denial of the realities of their condition, hoping it was only a temporary aberration in their health, and so did not ask for help (and this idea was often fuelled by their doctors who were erroneously predicting a quick recovery.

The loss of human rights and equity, in many cases, are a result of Indirect Discrimination, as defined by Section 6 of the Federal Disability Discrimination Act 1992. So while there is the *Federal Disability Discrimination Act* (1992), and *Students with Disabilities: Code of Practice for Australian Tertiary Institutions*

(O'Connor *et al*., 1998), which are designed to meet the needs of students with disabilities, the reality is that they are failing to meet the needs of the ME/CFS student. In addition, many participants had been unaware of their rights contained in these documents,, but when they discovered this information have felt empowered to fight further.

The effects of the Political/Medical/Psychiatric constructs of ME/CFS on participants.

Comments in this area was not solicited from the participants, as can be seen from the extract from the research invitation yet 33/35 students drew attention to how they feel discredited, trivialised, disbelieved and disempowered due to the beliefs and misunderstanding of those with whom they have had to deal. This has affected negotiations with lecturers, disability support officers, as well as peer acceptance. The psychiatric paradigm versus the physical reality of the disease caused problems.

Media misrepresentations, such as the use of headings like "Yuppie flu real illness" (Sunday World 1998) and also advertisements, such as the Shell radio advertisement for the Australia Day weekend (1999), and the recent Hamilton Island advertisements (1999), and trivialised and even 'vilified the condition' (Lawrence 1999). The media reports of the two Sydney ME/CFS conferences did help in getting some credibility out in to the general public that students are not putting on an act, nor are attention seeking malingerers.

To avoid discrimination and misperceptions caused by the "f" word, some students said they did not use the name chronic fatigue syndrome at all. Some used the name ME, and others said that they used another condition they had, or they described their symptoms, such as a 'muscular-neurological condition with cognitive dysfunction', without giving it a name! Many have mentioned being perceived as lazy, malingering, and not having a real disease -after all 'everyone gets tired'. This is certainly the biggest and most problematical area for students with ME/CFS especially while they are faced with the psychiatric paradigms of this disease as propounded in the Draft Guidelines (RACP1997. A new name may in time help with more credibility in this area (Jason 1999).

Emotional and Social Affects.

The stories of the participants have been influenced by the socio/political environment of ME/CFS. Millen (1997) has written about the strategies which many persons with ME/CFS use to keep up appearances, the problems with stigma, the lack of credibility, which delegitimatises the person with the condition (Komaroff & Buchwald 1998; Mungovan & England 1998; Wittenberg 1996). Hence these stories which were told in this research have been written by stigmatised participants, or as Frank (1995) puts it "wounded storytellers".

The disbelief, trivialisation, and the physical reality of the disease itself, meant that there were strong emotional effects mentioned. Thirty-five of the thirty-six participants mentioned their frustration, emotions and disempowerment (the only one who did not had only been diagnosed six weeks before writing their research story).

Many participants mentioned the isolation on campus, the inability to socialise with other students, the barriers created as other students perceived them to be lazy and malingering, and not having a real illness. Students in the health fields and psychology fields seemed to feel, on preliminary analysis, that they had less credibility with their peers, as well as with their faculty staff, so this could be a direct result of the erroneous psychiatric paradigms.

These issues of emotional stress and social isolation must only make the burden greater for the ME/CFS student, and improvements will only occur when there is a better understanding of the condition. It has been interesting that the students mention that the staff and peers, who had the most understanding, were those who had already had family or close friends with ME/CFS.

The psychological, somatisation medical arguments on the reality of this condition, and the very name itself imposed by CDC in 1988 (Holmes *et al* 1988), has meant that the patriarchal medical/psychiatric model is affecting the human rights and equity of tertiary students in Australian universities and TAFE/OTEN colleges.

Other issues which have arisen from the research and will be further analysed are the differing experiences through different academic level analysis, duration of the disease and how this may be equated to academic success; whether "phasing" is an explanation for the types of experiences (Jason *et al.* 1999); types of enrolments and areas of enrolment, such as the male/female area; the patriarchal constructs of the condition affecting empowerment; and the impact of the politico/medical dominance on the lived experiences of tertiary students with ME/CFS. Also the analysis of the constructs and situation of the student writing the story (placing the story in context) should also reveal more balance when the issues of human rights and equity are assessed. It should be possible, with the exploration of these additional areas that recommendations which will assist the ME/CFS students, will be able to be made with more confidence.

It is apparent that ME/CFS students are being seriously disadvantages, both academically and in physical health, when being placed in the same category as other students with chronic illnesses, or being placed along side students with writing difficulties, who need additional time (Morris 2000b). In fact, the very use of examinations as a means of assessment must be called into question. They certainly are precluding any chance of any equity for ME/CFS students according to the *Draft Guidelines for Education* (2000)(Morris 2000a).

Alternative assessment procedures must therefore be investigated. It would seem to me (arising out of my research findings) that the writing of small essay/exercises during the course of the semester may be an appropriate method of accommodating ME/CFS students, who would then work in their 'window of opportunity' on their, hopefully, better days. Yet this suggestion of mine may not be appropriate for all students with ME/CFS, so therefore I would recommend that any decisions which are made regarding the form of assessment be made with the ME/CFS student, after they have had explained to them what *all* of their assessment options are, and *after* they have had time to weigh up these options, and discuss it with other experienced

ME/CFS students. Flexibility will be important if the equity spirit of the Draft Guidelines for Education is to be achieved for ME/CFS students.

My research will add substantially to the knowledge of the lived experience of the ME/CFS student, where presently there are is no known information available in Australia or overseas. The information produced from this research will inform and empower tertiary students with ME/CFS, as well as assist Disability Liaison Officers in universities, and also assist school counsellors and parents to advise secondary school students in their decision making when considerations are given to tertiary study with this disability.

These are preliminary conclusions only, and I have only been able to draw attention to the major areas of difficulty which have emerged.

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Part 2:
Standards for education practice in Australia.

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There is now substantive literature which has been written to explain the requirements of the Disability Discrimination Act (1992), and the *Students with Disabilities: Code of Practice for Australian Tertiary Institutions* (1998); and the *Consultations on the Draft Disability Standards for Education* (2000) are examples.

This gives references to the *Disability Discrimination Act* (1992), the *Draft Education Guidelines for Disability* (2000) , and the *Students with Disabilities: Code of Practice for Australian Tertiary Institutions* (O'Connor *et al*. 1998). It also explains Section 6 of the Disability Discrimination Act (1992) and what Indirect Discrimination means in practice. Since the implementation of the Federal Disability Discrimination Act in 1992, most academics and institutions are aware of the implications of Section 22, dealing with education specifically, but have remain blinded to Indirect Discrimination, and how this impacts on students.

1. The Disability Discrimination Act (DDA, 1992).

The *Disability Discrimination Act* (DDA, 1992), is the Australian standard for assessing disability discrimination and in education sections 6 and 22 are particularly applicable. Section 22 is written to explain direct discrimination in the field of education.

2. Indirect Discrimination.

The *Federal Disability Discrimination Act* (FDDA, 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. It is easier if we look at a hypothetical situation to explain this.

Imagine that there is a group of students who have been studying Fine Arts, and a part of their assessment includes an appraisal of an oil painting. The examiner, presuming that all students are the same in their capabilities to perform the task, sets the exam question, asking students to appraise the painting, with particular attention to content, colour and texture.

There is though a student in the group who happens to be severely visually impaired. The student is unable to see the painting, but does go an feel the painting to ascertain the texture. The student writes about the texture in the painting but cannot write about the content nor the colours though. The paper is sent off to an external examiner to assess. Although the visually impaired student has written a superior answer in regards to the texture, the student is failed as the student has not addressed the content nor the colours of the painting.

This constitutes Indirect Discrimination. The examiner did not intend to discriminate against the visually impaired student when setting the examination question. But when a visually impaired student is confronted with the question, there is the inability, caused by the disability, to answer the question. Without taking into account that the visually disabled student is unable to meet the requirements of the question, the visually impaired student experiences discrimination.

Many ME/CFS students will also acknowledge that many rules and regulations, when applied to them, in reality do discriminate against them. And thus they are experiencing Indirect discrimination, as defined in Section 6 of the Federal Disability Discrimination Act.

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(February 2001)

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<http://www.austlii.edu.au/legis/cth/consol_act/ddaa992264/S22.html>

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<http://www.austlii.edu.au/legis/cth/consol_act/ddaa992264/S6.html>

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Morris, D. (2000), 'Submission to the Draft Disability Standards for Education from the perspective of ME/CFS.' November, 2000.
http://www.ozemail.com.au/~ddasp/Submissions.htm

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Also at http://www2.deakin.edu.au/edu_research/default.htm
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http://www.gut.edu.au/pubs/disabilities/national_code/code.html

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"A Report on 'The Lived Experiences of tertiary students with ME/CFS'".
Part 3:

A brief review of related literature.

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This is a brief list of references which are used in the area of accommodations for students with a disability. There are general references which do not address the needs of the ME/CFS student at all, but are general interpretations of the Federal Disability Discrimination Act (1992) and how it should be applied. Then there are more specific references, which are utilised by disability advisers, to obtain information on specific conditions and appropriate accommodations. Here there is concern at the types of recommendations which are made for ME/CFS, and presumptions are made that fatigue is the one symptom which has to be considered, even ignoring the existence of other symptoms, such as cognitive dysfunction. There is also a list of helpful Australian references applicable to ME/CFS tertiary and other students, and a list of overseas references which is particularly applicable to ME/CFS primary school children.

The following publications, used in the area of disability in tertiary education, omit all reference to ME/CFS concentrating on physical disability, such as blindness, deafness, wheelchair mobility. It would be presumed that the issues of ME/CFS learning and cognitive dysfunction should have been addressed, as they cover chronic illness and/or other areas of learning disabilities:

Guidelines for Working Effectively with Students with Learning Disabilities (ANU May 1994), http://anu.edu/disabilitities/altass.html

The Regional Disability Liaison Unit Information Series *No. 10 Chronic illness and university* and *No.11 Learning disability and university.* http://www.deakin.edu.au/extern/rdlu/appsl.html

Publications, such as those listed below, which specifically mention ME/CFS have all reiterated that fatigue is the main consideration to be considered in ME/CFS. This demonstrates a poor understanding of the condition, most likely arising out the inappropriate name of ‘Chronic Fatigue Syndrome”. All of these publications, emphasising only the fatigue symptom, state that this may be accommodated for in examinations with additional time:

al-Mahmood, R., McLean, P., Powell, E. & Ryan, J. 1998, *Towards Success in Tertiary Study with ongoing medical conditions,* University of Melbourne, Melbourne

Commissioned Report No. 29, 1994, *Guidelines for Disability Services in Higher Education Commissioned Report no. 29 : National Board of Employment, Education and Training Aug. 1994,* Australian Government Publishing Service: Canberra

Jordan, M. & Rodgers, N. (n.d.) *Alternative Assessment for Students with Disabilities*, The Disabilities Office, Griffith University Qld. hhtp://www.anu.edu.au/disabilities/altass.html#19

Lawrence, A. (2000),*Inclusive Practices For Students with Disabilities: a guide for academic staff,* University Disabilities Cooperative project (NSW).

Lockhart, A. (ed) 1993, ‘*Reasonable Accommodations: Strategies for Teaching University Students with Disabilities’* : for Macquarie University, University of New South Wales, University of Sydney and University of Technology from *Reasonable Accommodations: Teaching College Students With Disabilities: The President’s Commission On Disability Issues,(1990)* University of Maryland at College Park, USA, Lockhart Darby: Macquarie University *et al*, Sydney.

Also at < http://www.anu.edu.au/secretary/disabilities/book4.html>
http://www.anu.edu.au/disabilities/reaacc.html#25

Mungovan, A. & England, H. (1998), *Bridging the Gap: Understanding the issues and needs of students and staff with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) within Tertiary Education: A NSW Regional Disability Liaison Officer Initiative,* Paper presented at the Pathways Conference, Perth 1998.
Also at <http://www.nepean.uws.edu.au/sserv/ed_emp/> (accessed 4 January 1999)

Mungovan and England (1998) in their questionnaire still focussed on fatigue as the main area of concern, and also made the presumption that longer time for examinations is an appropriate accommodation for ME/CFS tertiary students. The original questionnaire asked the participants the question "7.7 What disability support services were provided to you by your education institution? (Please tick one or more boxes.)" and listed here was 'Extended time for exams" without even a chance for the ME/CFS participant to make a comment on whether this was an appropriate accommodation, and met the needs of the student. And so the myth has been perpetuated that additional time at examinations is an appropriate accommodation for ME/CFS students.

Jennings, R. (1994) Joint Equity Project for Students with a Disability Deakin University Victoria University of Technology, *Resources for Students With a Disability in Higher Education*
http://www.deakin.edu.au/extern/rdlu/disresource.html

may be of assistance for students to find out about disability resources at various Australian Universities.

Publications and internet sites which may be helpful to the ME/CFS Student.

Australian:

Beasley, L 1995, Possible Areas of Difficulty for University Students with Chronic Fatigue Syndrome Paper presented at Canberra, ACT 1995.

Stephenson, M., Hunter C., & Leggo, A. (1999) Educational Guidelines - Understanding and Accommodating Myalgic Encephalopathy/Chronic Fatigue Syndrome, Clinical Management of ME/CFS, Allison Hunter Memorial Foundation, NSW.
<http://www.ahmf.org/Manage.htm>

SAYME (2001) South Australian Youth with ME
sayme.org.au

Tate, F. (2001) Information for Students with Chronic Fatigue Syndrome (CFS)
http://www.geocities.com/farrah_j_tate/Cfs/cfs.htm

Villis, S. (1998) "Studying with CFS/ME" in *Talking Point,* Journal of the ME/CFS Society (SA) Inc. March 1998, Adelaide.

Overseas:

Colby, J. 1997, *Action for ME Children's Charter MJC Online,*
<http://www.jafc.demon.co.uk/charter.htm>

Colby, J. 1999, 'Ten points on organizing care for children with ME., *General Practitioner Magazine,* reprinted *The CFIDS Chronicle,* September/October 1999, pp.17-18.

Colby, J. (2000) 'Ten points on the education of children with ME', Special Children Magazine, November/December 2000.
<http://www.education-quest.com>

Colby, J., Franklin, A., Macintyre, A., Michell, L., Moss, J., Siner, J. & Speight, N. 1999, *Childhood ME,*
<http://www.jafc.demon.co.uk/yaonline/docs/chldhdme.htm>

Colby, J. & Jacobs, G. 1997, 'ME and Learning : Problems and Solutions', *MJC Online* <http://www.jafc.demon.co.uk/melearn.htm>

National CFIDS Foundation, Inc. !997, *Guidelines for Schools : Understanding and Accommodating CFIDS/FMS Chronic Fatigue and immune Dysfunction Syndrome and Fibromyalgia Syndrome,* National CFIDS Foundation, Needham, Massachusetts

Speight, N., Siner, J., Moss, J., Michell, L., Macintyre, A., Franklin, A. & Colby, J. 1999, *Children With M.E.*
<http://www.ayme.org.uk/theme2/children.html>
<http://www.ayme.org.uk/theme2/chiildren.html#effects>

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Part 4:
The symptomatology of ME/CFS.

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This is a very brief list of some of the more common symptoms of ME/CFS, along with a list of research paper findings regarding these symptoms. This has been included because ME/CFS is a multifactoral condition with variable symptoms, and it is most likely preferable to negotiate an appropriate accommodation on the basis of a specific symptom. Many persons with whom the student will have to negotiate will not have heard of many of the symptoms of ME/CFS, and students will be faced with the presumption that fatigue is their only problem which needs to be accommodated. If standing is a problem, or mobility on campus presents difficulties, then negotiating on the basis of neurally-mediated hypotension, low blood volume and orthostatic intolerance would be appropriate. But the student needs to make sure that they are well informed about how they are affected by these symptoms, and it would therefore be advisable to assist in negotiations that they have accessed some research papers on the topic. Internet access is probably the easiest way to gain access although some resource references would be available from the ME/CFS Society. Co-cure is an excellent source for obtaining additional research information on many of the symptoms.

Cognitive Difficulties.

Physical or mental exertion can affect brain function. Memory is seriously impaired and retrieval of information is virtually impossible. This phenomena is known colloquially by ME/CFS persons as 'brain fog' and it has a variable duration, often lasting into the next day (AYME 1998; Colby, 2000; USDHHS CFSCC, 2000). Most students, when 'brain fog' sets in, call it a day, and know that it is no use to try and persist with the examination. In fact, they find that paradoxically that trying to persist will mean that they are only exacerbating the problem - as they are faced with no other alternative but to hand in their paper and depart the examination room: additional time does not allow for this phenomena. According to Friedberg *et al.* (2000) this is the most common and disabling symptom of ME/CFS. Scoley *et al.* (1999) found that persons with ME/CFS fell between mild and moderate Alzheimers' patients on most tasks

1. Neurocognitive Impairment in ME/CFS (AYME 1998; DeLuca 2000; USDHHS CFSCC, 2000)
2. Brainwaves, without warning, may shift out of beta activity (associated with thinking) into delta and theta activity (associated with sleep and pre-sleep states in healthy people) during cognitive challenge. (Preston, 2000; Sieverling, 2000)
3. Quantifiable difficulties in encoding information into short term memory (Grace *et al.* 1999; Goldstein 1992, 1993; USDHHS CFSCC, 2000)
4. Fragile retrieval (Friedberg *et al.* 2000; Goldstein, 1996).

Other Symptoms:

1. Reduced total blood volume in persons with ME/CFS, which means that there is less blood flow to the brain when sitting or standing, therefore poor brain function and syncope feelings (AYME 1998; Streeten & Bell 1998)
2. Orthostatic Intolerance in ME/CFS, and this could also affect the blood flow to the brain. (AYME 1998; Klimas 2000; USDHHS CFSCC, 2000)
3. Neurally Mediated Hypotension (Calkins &Rowe, 1998; Stewart, Gewitz *et al.* 1998; USDHHS CFSCC, 2000).

Pain Symptoms:

1. Migraines and vascular headaches often arise from this situation for the student (Evengard *et al.*1999).
2. The pain of myalgia (muscle pain) (Klimas, 2000; McGregor et. al. 2000; USDHHS CFSCC, 2000), which can be so intolerable that it may mean that the student may leave the examination early. One student described the pain as being akin to medieval torture. The pain in the affected muscles may take many months to resolve.

Further Symptoms which may cause problems.

1. Vision difficulties, such as blurring and scotopia (AYME 1998; Friedberg *et al.* 2000; Macintyre 1992).
2. Noise and hearing difficulties - hypercussis (so sensitive to loud noise it hurts) or alternatively, at another time, deafness (Friedberg *et al.* 2000)
3. Irritable Bowel Syndrome and Food Chemical Sensitivities (Friedberg *et al.* 2000).
4. Chemical sensitivities and environmental chemical exposures - which may affect brain function, pain levels, etc. (Friedberg *et al.*, 2000)
5. EMR Sensitivities (e.g from computers)(Friedberg *et al.*, 2000).
6. Hypoglycaemia (low blood sugar).
7. Sleep disorders (Lapp, 1996; Le Bon *et al.*, 2000)
8. Utter exhausting fatigue.
9. And anything else which is a symptom of ME/CFS not listed above!

Some general overviews of the physical nature of ME/CFS may be found in the following articles and books:

AYME (1998) Notes on Dr. David Bell's talk on 25 August 1998, given at the invitation of AYME (Association for youth with ME) http://www.chsresearch.org./cfs/research/treatment/5.htm

Hyde, B. (ed.) (1992) *The Clinical and Scientific Basis of Myalgic Encephalopmyelitis/Chronic Fatigue Syndrome*, The Nightingale Research Foundation, Ottawa.

Komaroff, A. (2000) 'The biology of chronic fatigue syndrome', *American Journal of Medicine*, 108:169-71, February 2000.

Macintyre, A. 1992, *M.E. : How to Live with it: Post-Viral Fatigue Syndrome,* Thorsons, London

Pleby, D. (2000) Management and Treatment of M.E. , Positive Health, (also in archives of <http://www.meactionuk.org.uk> November 2000.

USDHHS CFSCC (2000) Chronic Fatigue Syndrome State of the Science Conference Report, The U.S. Department of Health and Human Services Chronic Fatigue Syndrome Coordinating Committee held October 23-24, 2000 DHHS CFSCC website: http://www4.od.nih.gov/cfs/reports.html

Excellent internet site is < http://www.co-cure.org/> where the archives may be accessed for information on nearly all ME/CFS research over the past four to five years.

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