



# ME/CHRONIC FATIGUE SYNDROME ASSOCIATION OF AUSTRALIA LIMITED

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Friday 24th May 2002

Dear Sir or Madam,

This submission is made on behalf of The ME/Chronic Fatigue Syndrome Association of Australia Limited in relation to the:

### **“Inquiry into the education of students with disabilities”**

#### **Introduction to CFS and implications for learning**

Chronic Fatigue Syndrome (CFS) sometimes known as ME (Myalgic Encephalopathy or Myalgic Encephalomyelitis) is a serious, disabling condition, which can affect people of all ages. Classified by the World Health Organisation as a neurological disorder (International Classification of Diseases ICD 10.G.93.3), CFS simultaneously affects many systems of the body giving rise to numerous symptoms including persistent profound exhaustion, post exertional fatigue, cognitive impairment, sleep disturbance, muscle and joint pain, headaches, digestive disorders, sensory dysfunction, flu-like feelings, mild fevers, sore throat, irritability, sensitive to foods and chemicals, painful lymph nodes, heart palpitations, disturbance of balance and night sweats.

The level of incapacity experienced varies from individual to individual but CFS is not diagnosed unless previous functional capacity has been reduced by at least 50% for more than six months. Many people remain ambulatory but are often unable to manage steps, prolonged standing or carry bags and require extended sleep and rest periods. However the more severely affected are confined to wheelchairs and/ or bed.

The symptoms fluctuate from day to day and hour to hour and are exacerbated by physical and/ or mental exertion. For some, the level of exertion required before symptoms worsen is minimal. Moreover, recovery from overexertion is delayed and prolonged.

Therefore CFS can severely affect the learning capacity of students living with the illness and can limit their ability to take part in educational programmes that require regular attendance and sustained performance.

There is no known cure for the disease. However, by careful self-management of the illness, people with CFS can maximise their functional capacity without causing serious symptom deterioration. Some people make a reasonable recovery from CFS after a number of years but for others the condition follows a relapsing path or remains chronic.

It is critical, therefore, that educators understand not only the nature of the illness but also the adjustments that students need to make to realise their full educational potential.

There is much that can be done by educational organisations to assist students with CFS.

## **In relation to the Terms of Reference of the Inquiry, the Association presents the following:**

### **a) Comments on the adequacy of current policies and programs for students with CFS.**

#### **i) Lack of recognition of CFS as a disability under the Disability Services Act 1991**

The attached document *“Recognition of CFS/ME as a Disability: a submission to Government”* describes the problems associated with the lack of recognition of CFS as a disability under the definition of the Disability Services Act 1991 in Victoria. The Victorian Act is but one example amongst similar State and Territory legislation in Australia of a common approach to the definition of disability that discriminates against and disadvantages those suffering CFS in Australia. It is presumed that this common difficulty across Australia reflects in part the influence of the definition of people with a disability contained in the *Commonwealth-State Disability Agreement (CSDA) 1998-2000*.

The fact that CFS is not classified as a disability is out of step with international recognition of the illness. In the U.S. the National Institute of Health, The Centres for Disease Control, Food and Drug Administration and Social Security Administration all recognise CFS as a serious, often disabling illness and the level of funding of tens of millions of dollars recognises this. In Australia the National Health and Medical Research Council recognises CFS as an organic physical disease affecting up to 150,000 Australians.

It is submitted that, in the context of the similar and unacceptable definitions of disability in legislation across the States and Territories, in as much as it relates to the common failure to recognise CFS as a serious and disabling illness for a prolonged period of person’s life if not permanently, there is an urgent need to amend legislation across Australia. The Senate Committee ought recommend that the Commonwealth lead, perhaps through the Council of Health Ministers and/or Community Services Ministers, an initiative to review and then reform the definitions of “disability” across the Nation so that there is a uniform acceptance that CFS is a real disability. Such recognition in legislation that CFS is a real disability, will improve the opportunities or chances of persons, especially students, with CFS and their carers to have access to the essential support services which they so often require.

#### **ii) Variation in accuracy with which students’ disability-related needs are met.**

There is still much misunderstanding of CFS by many medical practitioners and educators in Australia. The recent publication in the *Medical Journal of Australia of CFS Clinical Practice Guidelines-2002* (sponsored by Commonwealth funding) has not reduced this

problem. The Association believes that the *Guidelines* misrepresent the illness and may lead to misdiagnosis, misunderstanding and inappropriate treatment.

The inadequacy of accurate information on CFS in the community combined with the lack of its recognition as a disability means there is wide variation in the degree to which the disability-related needs of students with CFS are accurately assessed.

### **iii) Inadequacy in and inequity between support in rural and urban areas**

In a recent report written in by Lesley-Anne Elbourne, “*Just a Lazy Teenager*”, (attached) in her capacity as a member of the National Youth Roundtable, has revealed inadequacy in and inequity between rural and Metropolitan Victoria in support for students with CFS. In rural and remote areas of Victoria, 78% of young people who had left school because of CFS and were not in any form of education stated that their schools had not provided the support they needed and 11% stated they were supported only some of the time. In Metropolitan Victoria comparable statistics showed that 20% of similar students had not received the support they needed and 40% stated they were supported some of the time.

This study indicates that there is much scope for improvement in the level of provision of support for students with CFS in Victoria. It is anticipated that a similar situation is likely to occur in other parts of Australia.

It is respectfully submitted that the Senate Committee ought recognize the particular difficulties of and the additional disadvantages of students with disabilities residing in rural communities – especially a disability such as CFS which is widely misunderstood. The Commonwealth is responsible for a wide range of rural community support programs. The problems experienced by students with CFS in rural communities cross the areas of responsibilities of a number Commonwealth departments: Health and Education in particular but in respect to rural communities other departments have relevance. It is recommended that a co-ordinated approach to redress these particular problems facing students with CFS in rural communities ought be led by the Commonwealth – ideally encouraging the States and Territories to become partners in implementing the initiative.

### **iv) and vi) Provision for full or partial learning opportunities with mainstream students.**

Some students with CFS are able to take part in mainstream education with the support of individually designed adjustments to the regular programme. Arrangements that have been found to be beneficial include: flexibility in attendance, part-time study, provision of on-campus rest rooms, extensions for assignments, special examination conditions, provision of note takers, taped lessons, exemption from physical education activities, access to lifts, transport to and from school/college. For those able to drive, preferential parking arrangements are desirable. Of critical value for many students is the appointment in the school or college of a counsellor or understanding educator to act as an advocate/mediator for the student in negotiating special arrangements for learning.

The earlier such special provisions are made, the less the likelihood of deterioration in the health of the student and a decline in educational achievement.

For many students however, attendance at school or college on a regular basis is impossible and for these students access to high quality distance education and/or a visiting teacher service is essential. Such services should be available to all students with CFS whether they are in the private or the public sector. A visiting teacher service provides a valuable link between school and home. Visiting teachers are well able to assess a

student's needs as they see the student at various stages of the fluctuating illness. Classroom teachers only see the student when he or she is well enough to attend class and therefore may consider the student less incapacitated than is the case.

**v) Access to funding for students with CFS and the need for funding for provision of appropriate support.**

Statistics from attached Elbourne study show that 59% of 16-18 year olds with CFS who reported that they were too ill to study or work were receiving no financial assistance. 32% of these people were not aware that they may be entitled to government assistance. 60% were from rural centres and had been ill for over two years.

Of the respondents who were aged 16+ and studying less than eight hours per week or via distance education and had been ill for over two years, 36% were not receiving any form of government assistance.

Thus there is a need for greater awareness of the availability of financial support for students with CFS.

There is also a need for funds to be made available to finance the various types support mentioned under a) iv), a) vi), a) vii) and b i) and b ii)

**vii) Teacher training and professional development.**

The attitude of teachers to CFS can dramatically influence the educational success or otherwise of students with CFS and the degree to which the students are socially integrated. When a teacher does not understand the nature of CFS a student can experience unreasonable pressure to perform and this can exacerbate symptoms. For example teachers may insist on a full workload and strict assignment deadlines, which are difficult for a student to achieve when living with a fluctuating illness.

If a teacher understands the illness and treats a student with CFS with respect, this can have a great impact on the student's self-esteem and peer relations. If a teacher gives credibility to the illness then other students generally do likewise. This facilitates normal student interactions and helps to make a student with CFS feel comfortable in the school environment. For a student with CFS, getting to school itself can be an ordeal even prior to the commencement of class. It is beneficial if teachers can acknowledge this.

There is much scope for the improvement of educators' knowledge and understanding of CFS.

**b) The role of the Commonwealth and states and territories in supporting the education of students with disabilities.**

**i) Preparation and dissemination of up to date information to doctors on the diagnosis and characteristics of CFS.**

Accurate diagnosis and understanding of CFS by medical practitioners is an essential prerequisite for designing appropriate educational support for students with CFS because access to special support usually requires a medical certificate. Therefore the Commonwealth and states and territories should make it a priority to prepare and disseminate accurate, up to date information to doctors on the diagnosis and characteristics

of CFS and the likely impact of the illness on a student's learning capacity. The Association would welcome the opportunity to work with the Government on such a project.

**ii) Preparation and dissemination to educators of information on CFS and the special educational needs of students with CFS**

The ME/Chronic Fatigue Syndrome Association of Australia Ltd. is an association comprising representatives of each of the State and Territory ME/CFS Societies in Australia (there being one or more in each Australian jurisdiction). The Association represents at least 150,000 patients and carers in Australia who are experiencing the challenges of CFS on a daily basis.

The Association has a critically important role to play in Australia in stimulating and coordinating nationwide efforts to achieve greater awareness of CFS and better support services for those with the condition.

The Association proposes that a partnership be established between the Commonwealth Department of Education and the ME/Chronic Fatigue Syndrome Association of Australia Limited to develop an information package on CFS for educators and counsellors. It is proposed that the package be distributed to all educational institutions in Australia and be accompanied, when possible, by seminars, workshops and other support services and personnel to enable teachers to better understand CFS and its impact on the learning capacity of students with the condition.

In the context of the Association being a private charitable organization with no staff and so entirely dependent upon the voluntary contribution of its members and supporters, the Senate Committee will understand that any such initiatives will need to be externally funded, most probably underpinned by grant funding from appropriate quarters within the Commonwealth Government. It is essential that such an initiative be seen as a nationwide priority rather than a State by State by Territory exercise which would most probably involve extensive delays, a patchy response (perhaps with some States or Territories not involved) and greater funding uncertainty.

The Association requests the opportunity to address the Senate Employment, Workplace Relations and Education References Committee to present these and other information relevant to the enquiry.

Yours faithfully,

Simon R. Molesworth AM, QC

Honorary Chairman,  
ME/Chronic Fatigue Syndrome Association of Australia Ltd.

**Attachments:**

1. Elbourne L.A. "*Just a lazy teenager*", National Youth RoundTable, 2001.
2. Miles, N. "*Recognition of CFS/ME as a Disability: a submission to Government*", ME/Chronic Fatigue Syndrome Society of Victoria, 2002