

## **The Australasian Report on CFS**

*Compiled by Margaret Williams on 2 December 2001 from various critiques posted on Co-Cure*

In 1996 Dr Michael Wooldridge, Minister for Health and Family Services, approved an application to Medicare to provide funding of \$130,000 to the Royal Australasian College of Physicians (RACP) to produce Guidelines on the most clinically relevant and cost effective methods of diagnosing and treating CFS.

The first draft report was released in December 1997 and was heavily criticised.

The second draft was released in June 2001 (this four year delay achieved nothing).

As in the UK CMO's report, the guidelines focused on the (psychiatric) management of symptoms, not on discovering their cause. They ignore the substantial evidence of organic disease.

Excerpts from published critiques include:

**Dr Abhijit Chaudhuri, DM, MD, MRCP (UK); Clinical Senior Lecturer in Neurology, University of Glasgow; Consultant Neurologist, Institute of Neurological Sciences, Glasgow.**

(Introduction). The last sentence is seriously misleading (and) should be deleted. The RACP seems to suggest that cognitive behaviour therapy (CBT) provides a clear understanding of CFS. This claim is unfounded and lacks evidence...CBT is not a specific strategy for CFS where its claimed benefit is still questionable....no long-term study has established that graded exercise programmes can significantly improve aerobic capacity in CFS....It appears that the RACP has failed to recognise that post-exertional malaise is a valid CFS symptom. There is no evidence that patients with CFS demonstrate avoidance behaviour to physical activity as claimed.....the second paragraph of this section is a mixture of imagination and half-truths and should be entirely deleted. The UK experience of graded exercise in CFS has shown that as a single intervention, graded exercise was associated with the highest negative grading for its effect on fatigue by the patients.

(What is CFS?). Patients with myalgic encephalomyelitis (ME) fulfil the modified CDC criteria for CFS. Both neuromyasthenia and ME are classified as neurological diseases by the World Health Organisation in the International Classification of Diseases (ICD-10).

If ME is accepted by the RACP to be the same as CFS (page 18), then ME/CFS is a neurological disease according to the WHO classification. ....RACP appears to be making a subtle attempt to suggest that patients with CFS have a subjective problem or

an illness behaviour (problem). (This) should be deleted. RACP is confusing the issues of CFS and unevaluated chronic fatigue.

(What other terms are commonly used for CFS?). It is incorrect to propose that neurasthenia is the same as CFS: it is neuromyasthenia (and not neurasthenia) that is similar to CFS. the discussion on neurasthenia ( a psychiatric disorder in ICD-10) should be replaced by a note on neuromyasthenia ( a neurological disorder in ICD-10)...The suggestion that neurasthenia was an alternative term for CFS is to be found largely in the psychiatric literature. Most neurological texts of the 19<sup>th</sup> century make it clear that neurasthenia was an inaccurate and confusing term and should not be used in clinical practice.....The RACP must clarify the diagnostic definition used...the higher prevalence of CFS in primary care was based on a broader diagnostic definition for CFS (the Oxford criteria) that would be inappropriate.

(Does chronic fatigue overlap with other illnesses?). While the document takes care to mention somatoform disorders and chronic fatigue, it does not mention the following diseases with overlap symptoms of chronic fatigue, e.g. post-polio syndrome, multiple sclerosis, dysautonomic states, orthostatic intolerance or postural tachycardia syndrome, cardiological syndrome X, post-Guillain Barre syndrome, chronic hepatitis and so on.

The reader of the document may be lead to believe that the overlap of chronic fatigue is only restricted to the functional disorders. The number of psychiatric references cited to support the psychiatric co-morbidity in CFS is the highest in the entire document. However, analysis of these references shows how uncritical and biased the selections are.

The most recent reviews which clearly show that psychiatric co-morbidity in CFS has been over-exaggerated are omitted...the psychiatric co-morbidity in CFS is comparable with that seen in other chronic medical illnesses (MS, diabetes or cancer)...The document confuses the issue of somatoform disorders and CFS. Fewer than 5% of CDC-defined CFS population would fulfil the DSM-IV diagnostic criteria for somatoform disorder as shown in a published study. However, this study has not been referred to.....Only psychiatrists may find this distinction difficult, as appears from the cited references....In my opinion, this entire section should be scrapped for its abysmal quality of potentially misleading information.

(What are the outcome of fatigue states?). The fact that complete recovery of CFS in adults is uncommon should be clearly stated.

(What is known about the pathophysiology of CFS?). This subsection is confusing, poorly written and is an inappropriate reflection...I find it strange that the latest reference cited is dated 1995. This suffices to show that the authors of the RACP document have not desired to look beyond 1995 for the pathophysiology of CFS (because the earlier papers) support the psychological hypothesis. Non-psychological hypotheses have been largely ignored.

(What psychological evaluation is required?). The document states that evaluation by a specialist psychologist or psychiatrist “may be useful for the diagnostic and treatment purposes”. This is inappropriate advice and should be reviewed. Referral to a psychologist or psychiatrist in CFS is only indicated for concurrent or suspected psychological problems...furthermore, psychiatric intervention for CFS has been shown to be ineffective in the long-term.

(Managing CFS). I am surprised by reading “ This is in sharp contrast to the widely held but inappropriate belief that prolonged rest and social withdrawal should be advocated”.

Where did the RACP discover this “widely held belief”?...I believe this is a good example where the authors of the RACP guidelines have made an erroneous statement based solely on their personal belief rather than on the evidence-based science....At the very least, this sentence should be deleted as a mark of respect to the intelligence of the CFS patients.

(Overview). Sadly, this document contains many flawed statements and observations. In some areas, as already pointed out, the accounts appear biased and inaccurate. In addition, I have deep concerns about the selectivity of the literature review....as an example, while great effort has been taken to discuss the psychiatric co-morbidity in CFS, (the guidelines) do not bring home the point that the rate of psychiatric co-morbidity in CFS is comparable to many other medical and neurological conditions and that as a group, CFS patients can be reliably distinguished from depressed patients by clinical assessment using widely-validated neuroendocrine tests....The document has over-emphasised the psychologically-driven cognitive behaviour model of CFS and has failed to review the appropriate literature on the neurology, neuroendocrinology and neuropsychiatric changes in CFS. This is rather surprising given the fact that “ME” (an alternative term for CFS) is a neurological disease in the current classification of the WHO.....The paper has devoted much of its clinical discussion on the comparison of psychiatric disorders with CFS....The quality of references and review on the neurobiological aspect of CFS is very poor, with several important omissions of research carried out by the international groups in the past three or four years....The cited references show a skewed representation of a group of psychiatrists (notably Wessely and Hickie). These features clearly undermine not only the quality of science but also the quality of advice presented in the guidelines.

The guidelines also show a preference for CBT and graded exercise therapy and ignore criticisms and the flawed designs of the trials upon which their success has been claimed.

CBT as an intervention is no more effective than a purposeful physician-patient relationship.

(Conclusion). The RACP guidelines on CFS have several shortcomings. Many areas of the text appear highly opinionated in favour of the psycho-behavioural model of CFS. In its current form, this document cannot be recommended for acceptance since it does not reflect the cumulative base of knowledge on CFS.

**Dr Eleanor Stein, MD FRCP ( C ) Psychiatrist (Calgary, Alberta, Canada)**

The failure to mention any of the evidence of physiological and neuropsychological deficits in CFS is disappointing in a document sponsored by an authoritative body who would presumably wish to present an accurate and unbiased view of current medical knowledge.....The authors could hardly be unaware of the repeated findings by unaffiliated groups of autonomic dysfunction (and) immune dysfunction in CFS.... In conclusion, this document...will ensure that most persons with CFS in Australia will continue to be inadequately treated.

**Dr Peter del Fante, BSc, Dip Comp Sci, MBBS (Hons,) MSc, FAFPHM (RACP), FRACGP, MRACMA; Medical Director, Adelaide Western Division of General Practice**

“These guidelines have been sitting around for years awaiting a revision because they were considered biased and incomplete. A revised version is suddenly thrust upon us...and then we are given a short time-frame to respond...Is this how the RACP (of which I am a Fellow) undertakes rigorous peer review of guidelines?.....The content has hardly advanced from the biases and incompleteness of the initial draft guidelines....This only confirms the perceived lack of professionalism and integrity in creating a balanced and unbiased set of guidelines for CFS....Too much emphasis is placed on fatigue and sleep disturbance at the expense of the other key symptoms of CFS.... CFS is a heterogeneous, complex, multi-system and multi factorial illness; the recent State of the Science Conference (October 2000, Arlington, Virginia, which was organised by the US Department of Health and Human Sciences) acknowledges the need for CFS patient populations to be sub-grouped / stratified (and) this should equally apply to the management of CFS. All the CBT studies to date ignore the above fact and some even modify the CDC criteria (Judith Prins et al, Lancet 2001:357:841-847). Clearly, all the studies are methodologically flawed and their conclusions biased. Some of the studies even admit this fact. (CBT) does not treat the underlying (as yet unidentified) disease process in CFS.

You also completely ignore the growing evidence from neuro-imaging (both SPECT and PET) of significant, localised reductions in blood flow to areas of the limbic system and brain stem regions. The areas affected are different from those seen in patients with depression. These areas correlate well with many of the CFS symptoms....even if the disease process cannot be defined, there is objective evidence of disturbed brain function --- this is a fact.

You appear to completely ignore Level IV evidence on consensus opinions of respected authorities (in Australia and overseas) based on clinical experience (which) should form the backbone of management strategies. In your Introduction you emphasize clinical judgment, yet this is downplayed considerably in your guidelines.

There is no mention of dietary aspects to management.

My experience with using SSRIs in CFS patients is that the majority can only tolerate low doses. Their CFS actually worsens with usual doses used to treat depression.

Fortunately, the ME/CFS groups have very professionally developed patient information and self-management guidelines to use while we (the medical profession) get our act together.

**Peter C Rowe, MD., Professor of Paediatrics, Johns Hopkins Hospital, Baltimore**

I am disappointed by the complete failure to integrate the scientific evidence regarding circulatory abnormalities in CFS. In a detailed letter on the draft guidelines written to Dr Loblay in April of 1998, I discussed ways in which the guidelines might better acknowledge the association between CFS and syndromes of orthostatic intolerance.

Despite the fact that many more scientific studies have emerged on this topic in the past three years, the current revision of the guidelines contains even less on orthostatic intolerance....the failure to integrate literature from many sources perpetuates pre-existing disciplinary biases in reviews on CFS.

The evidence for an association between CFS and orthostatic intolerance is strongest in adolescents but there is no mention of this association in the guidelines.

The revised draft has recommended “active approaches to the control of key symptoms”, focusing primarily on analgesics and antidepressants as a means of improving daily function.....few physicians would withhold therapy from those with serious orthostatic symptoms. I don't think the guidelines should ignore treatment of persistent orthostatic symptoms in those with CFS...symptoms of orthostatic intolerance include chronic or severe lightheadedness with upright posture, exercise intolerance, recurrent syncope and palpitations or excessive tachycardia with standing (other symptoms include chronic fatigue, difficulty thinking and concentrating, headaches, myalgias and chest wall pain, and nausea).

In closing, I feel the debate about the optimal treatment for patients with CFS is not advanced by ignoring a substantial body of the current evidence. Guidelines that do not even acknowledge the research findings in this area will risk being dismissed as hopelessly biased.

**Laurence E Budd MB BS, Consultant Paediatrician, Coffs Harbour, NSW (Australia)**

In my view (this document) epitomises limitations with the scientific methodology and the application of “evidence-based-medicine”....conclusions have been reached that represent opinion or consensus view rather than a statement of the obvious that insufficient evidence exists to allow an accurate and definitive conclusion to be reached. That a number of similar opinions can be assembled from published sources is not in itself “evidence” that an opinion or point of view is correct. The history of medical practices and opinions is littered with consensus points of view that eventually have been shown to be incorrect.

There are some specific issues, in my view, that cause concern.

Proscribed pathology testing: novel and innovative testing procedures are essential in trying to determine an understanding of aetiology as well as pathophysiology.

“Science” surely, is by definition the application of novel and innovative strategies to reach understanding in exactly this situation. How can the “recommended” tests progress the process of understanding CFS?...to restrict testing to a range of tests that cannot define the aetiology or pathophysiology of CFS is anti-scientific.

Multiple chemical sensitivity is barely mentioned, and when mention is dismissed as irrelevant. This is an unfortunate position for the committee preparing the Guidelines, suggesting adoption of consensus opinion rather than due consideration of all possible aetiological factors. The omission of MCS raises serious questions as to the scientific credentials of the document. Perhaps MCS is a politically uncomfortable concept...but political sensitivity is not a valid scientific reason to ignore the obvious cross-over of symptoms with CFS. I believe it is unfortunate that MCS is ignored in this document. I don't believe that any Guidelines document will have validity if MCS is not given due consideration and recognition.

Some concern is expressed about attempts to manage CFS by dietary and nutritional means....Unfortunately similar concern regarding adverse events from common pharmaceuticals, especially the neuropsychiatric compounds, are ignored....The inference in the document that diet and nutrition strategies are inherently wrong is not a fair representation of such strategies, particularly when there can be significant and, worryingly, unpredictable adverse reactions to orthodox treatments.

What confidence is there that the Guidelines will remain “guidelines” and not become dogma?

CFS is a complex disorder that can have a devastating impact on those affected and their families. My personal experience with CFS clearly indicates that the medical profession has an obligation to provide professional support of the highest integrity.

**Dr Nicole Phillips, Medical Editor (Australia)**

I am a psychiatrist, medical educator, writer and medical editor.

The term neurasthenia is an outdated English psychiatric term which some CFS researchers are trying to revive. The DSM psychiatric classification system used in America and Australia has not used this term for many years on the basis of its lack of validity. It has no place in a section on “other terms for CFS” other than to be mentioned and dismissed.

If a sound psychiatric and physical history is taken, (somatisation disorder) can, in most cases, be clearly distinguished from CFS.

The study by Wilson in which 19% of patients followed up developed “other psychological disorders” does not state the important point that in any chronic illness, co-existent depression is common --- in fact, most studies provide figures in other medical illnesses of greater than 19%.

There has been more than enough evidence, including HPA axis work, to dispel Wessely’s “depression hypothesis” as invalid. The references about (CFS) being a “psychological” response in “vulnerable individuals” are out-dated and this purely psychological hypothesis has no validity in 2001.

In generalised anxiety, fatigue is not a core feature. In DSM IV, fatigue is not even mentioned in the diagnosis of panic disorder.

In reality, people with depression can present in many ways. Fatigue and / or pain is not the most likely presentation at all.

In summary, the document shows bias from certain psychiatric researchers.

**Dorothy I.W. Morris TSTC, HDT(Sec), B Voc Ed & Train, Dip RBM (Australia)**

The cognitive problems of ME/CFS typically include poor concentration and short-term memory, word-finding difficulty, and inability to cope with multiple stimuli (with) fragile retrieval. 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. My research also found that there is objective evidence of deterioration of physical and mental fatigue after exertion, and yet this report has not mentioned the nature of cognitive impairment in CFS.

Other symptoms which this RACP report has not addressed include orthostatic intolerance (neurally mediated hypotension), the muscle lactate response, and the high incidence of new onset asthma and / or allergy after CFS where (patients) are affected by environmental allergens / chemicals.

These RACP Guidelines ignore the cognitive dysfunction of ME/CFS and also the other physical symptoms altogether.

**Maureen A Stephenson, BA, Dip School Admin, MACE (Australia)**

Areas of concern

Presentation and Format: inconsistency in labelling the document; the need for further editing in terms of content to correct imbalance; noticeable repetition of content; bias to one school of thought (ie. an approach which is parochial rather than global); narrow research base; no details re literature search.

Content: minimum consideration of sub-groups with the CFS population; stereo-typing of patients, with emphasis on those who recover; exclusion of those patients whose condition is stabilising but not improving and those who continue to deteriorate; application of negative symptoms to CFS alone when indeed they are common to many illnesses and disabilities; highlighting factors which are seen by the writing team as impeding recovery and minimising patients own coping strategies; minimum inclusion of patient experience and maximum emphasis on opinions held by the writing team; advice to doctors which is disempowering to patients (authoritative statements which are not supported by longitudinal studies); emphasis on physical exercise.

To conclude: Today, both medical personnel and their patients have quick access to worldwide information via the internet and are quick to identify bias, omissions and filtering of information. In today's social climate, input from clients (be they consumers, patients, shareholders) is considered a legal right (and) an important part of any guidelines document.

By contrast, medicine's sole emphasis on an evidence-based approach appears out of touch with reality.

A Guidelines document on any medical condition needs to pursue balance rather than create division.

No medical writing team can ignore the diversity of worldwide research into CFS and expect credibility.

**Judy Lovett, President, National Body, ME/CFS Association of Australia (submitted on behalf of the Board)**

I do not believe that our organisation, representing consumers around Australia, can support the current version....Surely CFS patients are entitled to the very best outcome possible from a guidelines document.



(re) Investigations: Please refer to the papers presented at the Brussels Conference and at the (AACFS) Fifth International Research and Clinical Conference (Seattle) January 2001.

“Sleep hygiene” has little relevance in an illness such as CFS. I can cite clinical experience that states that sleep hygiene is of no benefit. Have you ever watched a very ill CFS patient trying to stay awake? It is a pathetic sight. They simply cannot do it, no matter how strong willed they may be. Please delete “sleep hygiene” as a management strategy.

In our view, this paper overlooks the severe end of the spectrum. Many people with CFS are housebound; however, the severely (affected) end is far worse. At the severe end, they will be bed-ridden, unable to feed properly and unable to attend to personal care. It is very important that this is recognised because access to care will only be available if this recognition is given.

(What laboratory tests are appropriate?). Again there is a blurring between fatigue states and CFS. This paper should refer to CFS only.

(Management). It should be noted that some patients with CFS have very bad reactions to (pharmacological interventions). CBT is too inflexible to work for CFS patients. This illness of unknown origin takes its course. Social withdrawal is not a widely advocated treatment and we suggest that reference to this be removed. Are you really suggesting that sick people keep working and performing at their “normal” well pace? You fail to address the issue of food intolerance.

(What are the disadvantages of a diagnosis of CFS?). Please remove this section. If a patient has any other illness, the doctor will tell them so. Why is CFS different?

(The role of patient support groups). You again ignore the role of the support groups in providing information to the medical community and providing money for research. This is self-help at its very best.

In conclusion, I must state that our organisation no longer supports the guidelines. We originally co-operated in every way possible. It should be written after extensive, current literature searches have been evaluated. The content should stand up to rigorous debate and peer review. To accept anything less is totally unjust to the CFS patients. In the light of the vast array of information put before you, please do not continue with the publication of these guidelines.

**Frances B Sandbach on behalf of the Committee, ACT ME/CFS Society Inc (Australia)**

The literature review presented in the guidelines is incomplete and biased. Information reporting the organic view of CFS is under-represented or substantially absent, whereas

that involving psychiatric opinion and psychological aspects is over-represented. There is evidence of specific organic abnormalities in significant numbers of people with CFS, and credible information representing the entire range of studies should be presented for completeness.

There is concern that application of the requirements of evidence-based medicine gives credibility to subjective judgment which would not be granted by the stricter requirements of empirical evidence within organic medicine.

The routine screening tests recommended in the guidelines are insufficient for the reliable diagnosis of CFS.

There is no adequate clinical description of CFS.

Inflexible graded exercise programmes are inappropriate. Patients should not be pushed to physical or mental exhaustion.

CBT is recommended for all patients with no acknowledgment that it is inappropriate (indeed potentially harmful) for some patients....it is unlikely that a single treatment would help everyone. There are people at different stages of illness and different degrees of severity.

The guidelines do not fully acknowledge the especially difficult and vulnerable position of children and adolescents with CFS....there are too many stories of children's separation from their families because of mislabelling of CFS as psychiatric and disagreements over appropriate treatment.

This draft of the guidelines is still considered inadequate and potentially damaging. It is recommended that they be withdrawn and redrafted ab initio.

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