

# The fruits of unbelief

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On a recent trip to Malaysia, I was asked to suggest some topics for talks to interested doctors in Ipoh and Kuala Lumpur. Near the top of the list was chronic fatigue syndrome (CFS) in view of our recent book.<sup>1</sup>

The reply was quickly received that the topic was unacceptable because *'we don't believe in that over here.'* A further trip to the eastern states of Australia for a day conference on CFS included a meeting in the evening for local general practitioners. None of them turned up and the reason given, you guessed it, the CEO of the local Division of General Practice *'doesn't believe in CFS.'* The conference for patients during the day was well attended by patients and the media, and the remark, which drew spontaneous applause, was that every person with CFS needs a GP and that GPs are the core of the health system. So why do we still have this problem about making care and attention to the patient conditional on the diagnosis and its acceptability to the medical profession?

In New Zealand there is historical evidence that strong belief in a certain pathophysiology can lead to grave error. The unfortunate experiment at National Women's Hospital was based on the firm conviction that carcinoma-in-situ of the cervix did not lead to invasive cancer. Presumably there are still some doctors who do not believe in therapeutic termination of pregnancy, but if they hold such views they are ethically and morally required to share these beliefs with the patient and invite them to consult with another doctor who has no such scruples. One wonders

whether all the doctors who 'don't believe in' ME/CFS, feel duty bound to reveal their unbelief to those who consult them with fatigue and all the other problems associated with the illness.

It is now nearly twenty years since Peter Snow observed the rising prevalence of a fatigue in his community, which led to the name of 'Tapanui flu' for the illness.<sup>2</sup> Shortly after that I also became involved in the long battle to ensure that such people were identified, understood and managed appropriately. Much has happened in the meantime which has alleviated their situation but management is still very difficult. Such people only ever have two questions to ask of their doctor, the first is about diagnosis (*Have I got it?*) and the second is about treatment (*How do I get rid of it?*).

The first question is more easily answered now that the condition is internationally recognised. While there are still many professionals and patients who pour disdain on the term 'chronic fatigue syndrome', there is no doubt that the work of international researchers in produc-

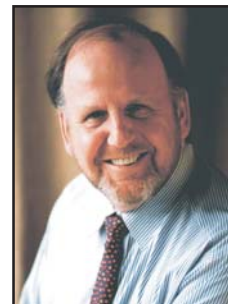
ing criteria for the illness has greatly helped research into the problem. New Zealand was early (1986) in producing national criteria, thanks to the Roy Mackenzie Founda-

tion<sup>3</sup> and in some ways the Mackenzie criteria are more sensible than the CDC criteria which are now the gold standard for diagnosis.<sup>4</sup> The important thing is, however, that there are criteria and that they can be applied to exclude other causes and to give a diagnosis of either CFS or idiopathic

chronic fatigue (ICF.) One of the major misunderstandings associated with the application of

these criteria is that it is only psychosis which serves as an exclusion criteria. Depression is often present as a comorbidity in CFS and its presence in the same person should be expected. The fact that antidepressants have not been shown to be effective in CFS is an interesting piece of evidence which points to the fact that they are two separate illnesses. Prevalence studies have now demonstrated that CFS is among the most common health problems, six times more common than multiple sclerosis and thirty times more common than HIV<sup>5</sup> so it should be diagnosed fairly smartly by all general practitioners. There is now no excuse for delay in diagnosis.

The second question is much more difficult and the conclusions of systematic reviews is that there is little evidence of benefit from any of the myriad treatments which have been applied to these unfortunate people. People with CFS are questions in search of answers and there are many purveyors of doubtful therapies around. The only positive evidence from treatment in a systematic review<sup>6</sup> came from studies involving cognitive behavioural therapy and graded exercise programmes. Two RCTs found that a graded exercise programme could produce substantial improvements in measures of fatigue and physical functioning for people with chronic fatigue syndrome, but one had a withdrawal rate of 37% and it is difficult to devise a



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placebo for exercise. The same systematic review found that cognitive behaviour therapy was effective in patients with chronic fatigue syndrome in secondary care, but a recent systematic review has suggested that such mental health interventions may not

apply to primary care.<sup>7</sup> Their conclusions were that it cannot be assumed that results from secondary

care can be extrapolated to primary care and that the quality and amount of evidence on mental health interventions for back pain, chronic fatigue syndrome, and irritable bowel syndrome is sometimes poor.

This reminds me of a significant paper by Ian McWhinney<sup>8</sup> when he quotes William James who said that sometimes a large acquaintance with par-

ticulars about a person is better than a knowledge of generalities. In this case the generalities of treatment of CFS are unknown but this is far from saying that there is no effective treatment for CFS. In my experience (Level IV evidence admittedly) the majority of individuals with CFS recover slowly over a two to three year period. The role of the personal doctor in being there, supporting the person and the family and assisting in healing is absolutely key. But then I would say that, I'm a believer and we wrote the book.

## **The role of the personal doctor in being there, supporting the person and the family and assisting in healing is absolutely key**

### References

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