

Treating Chronic Fatigue Syndrome: What Works? What Doesn't?

What constitutes effective treatment for chronic fatigue syndrome (also referred to as myalgic encephalomyelitis and chronic fatigue and immune dysfunction syndrome) has been a matter of considerable debate and dispute.

Several systematic reviews of the literature in the last 10 years have concluded that cognitive behavioural therapy and graded exercise have been the only treatments with demonstrated efficacy to both improve function and decrease symptoms in patients diagnosed with chronic fatigue syndrome¹.

Most unfortunately, these treatments have not been well received by patient support groups, and alternatives have been advocated in various publications in spite of the lack of empirical evidence supporting these alternative recommendations.

As an example, a paper was published by Carruthers et al² (referred to as 'Canadian Consensus Document') presenting a variety of suggestions, described in the paper as the clinical opinions of the authors, with regard to treatment. These suggestions did not represent empirically supported treatments.

One of the most significant points of contention and controversy between the mainstream, empirically-supported literature and the opinions reflected in this document had to do with whether increases in function and exercise should be progressed in a carefully graduated fashion but independent of the patient's experience of their symptoms, or whether the patient's level of activity needed to be actively modulated based upon their experience of fatigue and other symptoms.

It is quite well established in the chronic pain literature that activities should be quota-based rather than symptomatically-based.³ Indeed it is well established that basing activity upon the symptom of pain will reinforce fear and avoidance and result in

¹ Whiting, P.; Bagnall, A.; Sowden, A., Cornell, J., Mulrow, C. and Ramirez, G.: Interventions for the Treatment and Management of Chronic Fatigue Syndrome: a Systematic Review, Journal of the American Medical Association, September 19, 2001, Volume 286, Number 11; Chambers, D., Bagnall, A., Hempel, S. and Forbes, C. (2006) Interventions for the Treatment, Management and Rehabilitation of Patients with Chronic Fatigue Syndrome/Myalgic encephalomyelitis: an Updated Systematic Review. Journal of the Royal Society of Medicine, 99, 506-520; Prins, J., van der Meer, J. and Bleijen, G. (2006) Chronic Fatigue Syndrome. Lancet January 28, 2006.

² Carruthers, B.M., Jain, A.K., DeMeirleir, K.L. et al (2003) Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. Journal of Chronic Fatigue Syndrome, 11 7-97

³ See Flor and Turk in Melzack and Wall's Textbook of Pain, 5th Edition, pp 241-258.

diminished function and an increased experience of pain.

The authors of the Carruthers et al paper argued that pursuing such a strategy with chronic fatigue syndrome, in their clinical experience, produced a significant number of untoward adverse events and might indeed be harmful to patients. Once again the authors acknowledge that such concerns and predictions were based upon their clinical experience and not upon well-controlled published studies.

Fortunately, White, Goldsmith, Johnson et al recently completed a multicentre comparison of Cognitive Behaviour Therapy, Graded Exercise Therapy, Specialist Medical Care, and what they characterize as Adaptive Pacing Therapy (designed to formally implement the kinds of recommendations outlined in the Carruthers et al paper).

The White et al paper was very recently published on-line (February 18th, 2011) in the prestigious British medical journal Lancet.

White et al reported on the outcome of 641 patients, 160 of whom were assigned to the Adaptive Pacing Therapy, 161 to the Cognitive Behaviour Therapy, 160 to the Graded Exercise Therapy and 160 to the Specialist Medical Care group.

When the 3 active therapies were compared to Specialist Medical Care alone, both Cognitive Behaviour Therapy and Graded Exercise Therapy produced an improvement in self-reported fatigue scores, 52 weeks after starting treatment, as well as improvement in self-reported functioning. No such difference was noted between Adaptive Pacing Therapy and Specialist Medical Care alone.

When Cognitive Behaviour Therapy and Graded Exercise Therapy were compared directly to Adaptive Pacing Therapy, patients receiving Cognitive Behaviour Therapy and Graded Exercise Therapy again reported less fatigue and better physical functioning overall.

Furthermore, there were no significant differences in the frequency of serious adverse reactions between many of the groups, with 2 adverse reactions reported in the Adaptive Pacing Therapy Group, 3 adverse reactions in the Cognitive Behaviour Therapy, 2 adverse reactions in the Graded Exercise Therapy group and 2 adverse reactions in the Specialist Medical Care alone group.

Review of the demographic data showed that patients averaged 38 years of age, were 77% female, and had an average duration of illness of 32 months (range 16 to 68 months). None of these demographic variables differed between groups of patients. Patients were randomly assigned to treatment.

It is of interest to note that when patients were asked about their confidence about treatment (prior to commencing treatment) only 57% of patients in the Cognitive Behaviour Therapy reported being confident compared to 72% of patients in the Adaptive Pacing Therapy group and 70% in the Graded Exercise Therapy group. For Specialist Medical Care alone, only 41% of patient reported feeling confident.

However, after treatment, 82% of patients in the Cognitive Behaviour Therapy group reported they were satisfied with treatment compared to 88% in the Graded Exercise Therapy group and 84% in the Adaptive Pacing Therapy group. A much lower level of satisfaction (50%) was reported in the Specialist Medical Care alone.

Thus, when put to a multicentre, randomly assigned, carefully controlled empirical test, Cognitive Behavioural Therapy and Graded Exercise Therapy were both demonstrated to be superior to Adaptive Pacing Therapy, similar to the advice recommended in Carruthers et al, as well as the advice recommended by Bested, Logan and Howe⁴ for the treatment of chronic fatigue syndrome as well as fibromyalgia.

An accompanying editorial⁵ noted that while the White et al study clearly demonstrated (as had previous studies) that Cognitive Behaviour Therapy and Graded Exercise Therapy demonstrated that patients could recover from chronic fatigue syndrome, further study was required to isolate the effective elements of therapy and to further understand why the Adaptive Pacing Therapy was ineffective.

Odyssey Health Services has treated many patients with chronic fatigue syndrome as well as patients with fibromyalgia and other chronic pain syndromes. Our therapy has always been individualized, modeled after the empirically supported therapies but customized to individual patients and implemented with patients in the field.

Our therapy is combined aspects of cognitive behavioural therapy with graded exercise therapy and insured concomitant treatment of other physical and mental health difficulties. I published a study with my colleagues in the *American Journal of Medicine*⁶ demonstrating the effectiveness of this particular methodology with chronic fatigue patients.

Unfortunately, as Simon Wessely⁷ speculated in a commentary accompanying the systematic review of the evidence-based treatment for chronic fatigue syndrome reported by Whiting et al in the *Journal of the American Medical Association*, the empirical evidence does not always persuade patient support groups and others with strongly entrenched beliefs about the nature of the illness and appropriate treatment.

Thus it can be expected that this recent study will generate considerable debate and criticism. Nonetheless, the study adds significantly to the weight of evidence supporting

⁴ Bested, A., Logan, A. and Howe, R. (2006) [Hope and Help for Chronic Fatigue Syndrome and Fibromyalgia](#). Cumberland House (a handbook not subject to peer review as in a major journal)

⁵ Bleijenberg, G. and Knoop, H. (2011) Chronic Fatigue Syndrome: Where to PACE from here? [Lancet](#). Published on-line February 18, 2011.

⁶ Marlin, Anchel, Gibson, Goldberg and Swinton. (1998). An Evaluation of Multidisciplinary Intervention for Chronic Fatigue Syndrome with Long-Term Follow-Up, and a Comparison with Untreated Controls. [American Journal of Medicine](#), 105 (3A), 1105-1145.

⁷ Wessely, S. (2001) Chronic Fatigue Syndrome – Trials and Tribulations. [Journal of the American Medical Association](#). 286, 11, 1378-1379.

cognitive behavioural therapy and graded exercise, and clearly fails to demonstrate effectiveness of what the author's term adaptive pacing therapy.

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