

101 Good Reasons: Why it is wrong to provide CBT and GET to ME Patients.

By Greg Crowhurst (with special thanks to Clara Valverde)

2nd March 2010

Originally posted on <http://selsius.wordpress.com/2010/03/03/101-good-reasons-why-it-is-wrong-to-provide-cbt-and-get-to-me-patients/> (Blog has since been deleted; reproduced by ME/CFS Victoria, 17/8/10.)

From the literature , here are 101 good reasons why services are wrong to provide Cognitive Behaviour Therapy (CBT) and Graded Exercise Therapy (GET) for ME patients:

1. Malcolm Hooper

CBT is based on the idea that somatoform disorders are maintained by abnormal or unhelpful illness beliefs which lead to abnormal or unhelpful behaviour. The first requirement for a somatoform diagnosis is that there be no physical cause for the symptoms. This is not the case in ME/CFS”

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

2. Dr William Weir

“Two forms of treatment...are CBT and GET. CBT is a psychological treatment. Its application in what is certainly an organic disorder is basically irrational....

Its application is counter-intuitive, particularly when one of the most debilitating and well recognised symptoms of ME/CFS is post-exertional malaise which can put some patients in bed for days after relatively trivial exertion”

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

3. Dr Irving Spurr

I consider that the recommendation of CBT and GET as blanket treatments of ‘clinically excellent’ first choice is extremely dangerous to patients.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

4. Dr Eleanor Stein

A close read of the literature reveals that none of the core symptoms of ME/CFS improve with CBT or GET.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

5. Dr Byron Hyde

“(Graded exercise therapy) is not therapy – it is simply the enforcement of an opinion rather than a treatment based upon any scientific examination of a patient’s pathology and treatment of that pathology.

.....Graded exercise programmes may be significantly dangerous to many of these ME patients”

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

6. Dr Derek Enlander

“(The GDG) produced a Guideline that recommends CBT and GET as the prime treatment yet there is in fact published evidence of contra-indication / potential harm with GET.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

7. Dr Bruce Carruthers

It is when a therapy such as CBT begins to interfere with the natural warning systems, of which both pain and fatigue are a part, that the increased risks arise. In particular, musculo-skeletal pain and fatigue have essential function in modulating activity when the body is in a state of disease as in ME/CFS.

NICE, however, recommends over-riding this essential safety-net, thus the risk of serious harm is increased in this situation of simultaneous activity and symptoms denial. This will become a more serious risk in patients with more severe ME/CFS.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

8. Dr Neil Abbot

“There have been only five trials of CBT with a validity score greater than 10, one of which was negative for the intervention; and only three RCTs of GET with a validity score greater than 10.Until the limitations of the evidence base for CBT are recognised, there is a risk that psychological treatments in the NHS will be guided by research that is not relevant to actual clinical practice and is less robust than is claimed’.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

9. Dr Charles Shepherd

“In some cases people are now being given little more than a ‘therapist-led’ management assessment followed by an offer of CBT and/or GET.

<http://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.htm>

10. Susanna Agardy

Studies of GET do not ensure that the participants included suffer from serious symptoms of ME/CFS such as post-exertional malaise and mostly use loose, fatigue-based criteria, allowing mixed groups of fatigued participants to be included. ... Recommendations for GET ignore the risk of harm indicated by other research and the frequent worsening of symptoms following exercise reported by people with ME/CFS.

http://sacfs.asn.au/news/2009/12/12_10_exercise_guidance_note.htm

11. JK Rowbery

There is real concern that not only is CBT (Cognitive Behavioural Therapy, the other “treatment” provided by the NHS) ineffective, but that GET is potentially harmful to patients with ME/CFS. It is known that GET may leave up to 82% of ME/CFS patients who have undertaken it irreversibly house or bed-bound.

<http://www.jkrowbery.co.uk/about-me/>

12. A Chaudhuri

“Whilst no one would question that physical exercise improves quality of life both in health and diseases in general, recommending graded exercise as a specific prescription for complex disorders like fibromyalgia and CFS is a gross oversimplification of science.” – A Chaudhuri

“Missing data and compliance with oversimplification” - letter to the British Medical Journal by A Chaudhuri, Clinical Senior Lecturer in Neurology at the University of Glasgow, 1 August 2002, commenting on the study “..Prescribed exercise in people with fibromyalgia: parallel group randomised controlled trial...”,

Richards SC, Scott DL., published in BMJ 2002 Jul 27;325(7357)

13. Canberra Fibromyalgia and CFS

Graded exercise therapy (GE or GET) – sometimes referred to as “graded aerobic exercise” (GAE) – is often included as part of a cognitive behavioural therapy (CBT) program. It is recommended by those who follow the biopsychosocial model. The fundamental philosophy underlying this kind of treatment is that deconditioning, depression and believing one is ill are at the root of CFS.

<http://www.mecfscanberra.org.au/docs/pacing.htm>

14. Carruthers et al.

The question arises whether a formal CBT or GET program adds anything to what is available in the ordinary medical setting. A well informed physician empowers the patient by respecting their experiences, counsels the patients in coping strategies, and helps them achieve optimal exercise and activity levels within their limits in a common sense, non-ideological manner, which is not tied to deadlines or other hidden agenda. Physicians must take as much care in prescribing appropriate exercise as in prescribing medications to ME/CFS patients.

This excerpt is taken from pages 46-49 of the article “Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols” which appeared in the Journal of Chronic Fatigue Syndrome, Vol. 11(1) 2003, pp. 7-115, written by Carruthers et al.

<http://cfids-cab.org/MESA/ccpc-1.html>

15. Frank N.M. Twisk and Michael Maes

ME/CFS is considered to be a rather harmless condition by most physicians, but patients with ME/CFS are often more functionally impaired than those suffering from type 2 diabetes, congestive heart failure, multiple sclerosis, and end-stage renal disease a) the evidence-based success claim for CBT/GET is unjust, since the evidence base is lacking and CBT/GET is not significantly more effective than usual care; and b) the exertion, and thus GET, can have numerous potential damaging physical effects on ME/CFS patients. The (bio)psychosocial model (CBT/GET) has been invalidated by research.

A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS, Frank N.M. Twisk and Michael Maes.

<http://forums.aboutmecfs.org/showthread.php?947-CBT-GET-potentially-harmful-to-ME-CFS-patients>

16. Horace Reid

In 2006 Chalder and others claimed that “Cognitive behavioural therapy and graded exercise therapy have been shown to be effective in restoring the ability to work in those who are currently absent from work.”[10] In 2007 NICE demurred: “There is a lack of studies in this area ... More information is needed on functional outcomes such as return to work or education.” (CG53 p 61)

Santhouse et al. describe CBT and GET as “treatments” for CFS/ME. As defined by NICE they are much less than that. They are merely techniques to help patients cope with an intractable and so far untreatable condition. In the words of NICE: “The GDG did not regard CBT or other behavioural therapies as curative or directed at the underlying disease process, which remains unknown. Rather, such interventions can help some patients cope with the condition”; (CG53 p 252).

<http://niceguidelines.blogspot.com/>

17. Margaret Williams

Not only did NICE ignore the fact that the recommended interventions (CBT/GET) are not effective, it ignored the evidence that subsuming all states of “chronic fatigue” into one functional somatic syndrome is contra-indicated, as well as evidence that most of the randomised controlled trials (RCTs) on CBT on which the GDG relied are seriously flawed.

In most of the ten trials of CBT upon which the GDG relied, the methodology does not meet even the most minimally acceptable standards. The trials used give a total of 480 patients out of an alleged UK total of 240,000 patients and is insufficient data upon which to recommend a national strategy.

Patients with pre-existing psychiatric co-morbidity were not excluded from the studies relied upon.

Nowhere is there any evidence that patients fully recovered.

The behavioural model of “CFS/ME” offers relatively little; it is supported only by researchers with a professional interest in psychosocial aspects of illness. This model dominates the NICE management regime.

There is no credible evidence to support the GDG's claim that the best practice evidence-base is the nationwide implementation of CBT/GET for patients with "CFS/ME".

Background information and illustrations of evidence that CBT cannot improve ME/CFS which NICE disregarded.
Margaret Williams, 25th July 2008

http://www.meactionuk.org.uk/Background_Information_re_CBT.htm

18. ME Research UK

... the management strategies making up the bulk of the 'treatments' on offer by the National Health Service in the UK — "CBT and Graded Exercise" — seem absurd to patients and carers given the problem on the ground.

ME/CFS Research: What do patients want? Why isn't it happening?

<http://www.mereseach.org.uk/information/publications/rsmtalk.html>

19. NICE Guidelines Blog

A thorough analysis of the current medical scientific literature and international patient surveys,...shows that CBT/GET is not only ineffective for the majority of the ME/CFS patients, but also potentially very harmful.

Scientific studies and large-scaled patient surveys have shown that treatments with CBT/GET seriously deteriorate the condition of many patients with ME/CFS.

<http://niceguidelines.blogspot.com/2009/11/get-and-cbt-harmful-for-mecfs.html>

20. 25% Severe ME Group

ME/CFS is not "cured" by Cognitive Behavioural Therapy (CBT) and Graded Exercise (GET). CBT and GET are not accepted in the British Formulary for ME and therefore cannot be considered automatically to be within the legal framework for treatment, especially for the severely affected (25% Group 2005) CBT and GET are potentially harmful to anyone with neurological ME.

25% Group: 25% ME Group Response to the DWP Guidance Document on CFS/ME APRIL 2006

<http://www.25megroup.org/.../25%20Group%20response%206.04.06.doc>

21. Margaret Williams

The UK definition of CBT is contained in the Chief Medical Officer's Working Group Report of January 2002: "Cognitive behavioural therapy is a tool for constructively modifying attitude and behaviour".

The UK definition of GET is contained in the NHS Plus National Guideline on Occupational Aspects of CFS of October 2006: "GET involves structured activity management that aims for a gradual increase in aerobic activities".

According to Cheney, aerobic exercise may kill the patient with (ME)CFS, so patients are rightly wary, because for almost 20 years Wessely School psychiatrists have claimed that ME does not exist except as an aberrant belief, and that "CFS" is a psychiatric disorder in which patients refuse to confront their "faulty illness beliefs"

(ie. that they have a physical, not a mental, illness).

Margaret Williams : Kilmas, Wessely and NICE, Redefining CBT? Invest in ME

<http://www.investinme.org/Article-075%20Margaret%20Williams%20Redefining%20CBT.htm>

22. Jodi Bassett

No evidence exists which shows that cognitive behavioural therapy (CBT) or graded exercise therapy (GET) are appropriate, useful or safe treatments for Myalgic Encephalomyelitis (M.E.) patients. Studies involving miscellaneous psychiatric and non-psychiatric 'fatigue' sufferers, and their response to these treatments, have no

more relevance to M.E. sufferers than they do to diabetes patients, cancer patients, patients with multiple sclerosis or any other illness.

Jodi Bassett, The effects of CBT and GET on patients with M.E. - Condensed version

[www.hfme.org/CBT and GET/Effects of CBT and GET Condensed.doc](http://www.hfme.org/CBT_and_GET/Effects_of_CBT_and_GET_Condensed.doc)

23. Professor Malcolm Hooper

(CBT, GET):

- (i) is not remotely curative;
- (ii) modest gains may be transient and even illusory;
- (iii) these interventions are not the answer to ME/CFS;
- (iv) patients have a tendency to relapse; and
- (v) evidence from randomised trials bears no guarantee for treatment success

ref: www.meactionuk.org.uk/Concerns_re_NICE_Draft.pdf).

For a detailed review of Wessely School indoctrination of State agencies, and the impact of this on social and welfare policy, see www.meactionuk.org.uk/Proof_Positive.htm. Evidence submitted by Professor Malcolm Hooper (NICE 07).

<http://www.publications.parliament.uk/pa/cm200607/cmselect/cmhealth/503/503we79.htm>

24. Norfolk and Suffolk ME/CFS Service Development

Latest scientific studies find GET and CBT ineffective and harmful The two therapies which the NHS here in the UK remains committed to (under the 2007 NICE guidelines) for the clinical treatment of ME/CFS are Graded Exercise Therapy (GET) and Cognitive Behavioural Therapy (CBT). NICE recommends CBT/GET as the first line of intervention and as key therapeutic strategies. Two recent scientific reviews of CBT and GET by medical research departments in the UK and Europe have condemned the use of both treatments in light of overwhelming evidence of the biological abnormalities present in ME/CFS.

A collaborative review by Frank Twisk and Michael Maes from research centres in the Netherlands and Belgium says: "... we invalidate the (bio)psychosocial model for ME/CFS and demonstrate that the success claim for CBT/GET to treat ME/CFS is unjust." They go on to conclude: "it is unethical to treat patients with ME/CFS with ineffective, non-evidence-based and potentially harmful "rehabilitation therapies", such as CBT/GET."

This evidence brings into question a High Court judgement from the Judicial Review of the NICE Guidelines in March 2009 where the judge dismissed allegations that current therapies are harmful to some with myalgic encephalomyelitis. The latest scientific evidence clearly supports the defendants, ME sufferers Kevin Short from Norwich, and Douglas Fraser from London.

The study on Graded Exercise Therapy by Pierce and Pierce (UK/Italy) concludes that "... it is difficult to conceive of a more inappropriate therapy for ME".

Norfolk and Suffolk ME/CFS Service Development

<http://www.norfolkandsuffolk.me.uk/latest.html#cbtget>

25. Tom Kinlon

Kinlon (Do CBT and GET really work for Chronic Fatigue Syndrome?)pointed out that : "Santhouse and colleagues (1) claim that treatments such as cognitive behavioural therapy (CBT) and graded exercise therapy (GET) "have been shown to work" in Chronic Fatigue Syndrome (CFS)/Myalgic Encephalomyelitis (ME).i However, what the literature actually shows is that such therapies have an effect, which is not necessarily the same thing as

“working”: a meta-analysis calculated the average Cohen’s d effect size across various CBT and GET studies to be 0.48, which would generally be described as a small effect size.

http://www.bmj.com/cgi/eletters/340/feb11_1/c738

26. Charles Shepherd

It is disingenuous to claim that the use of CBT and GET “in a group of patients who cannot normally travel to hospital to access them, is going to produce a ‘dramatic recovery’”. A considerable amount of accumulating patient evidence indicates that a significant proportion of people with ME/CFS find that the two behavioural treatments being recommended – cognitive behaviour therapy (CBT) and graded exercise therapy (GET) – are either ineffective (ie CBT) or harmful (ie GET).

And the only research so far to investigate potential risk factors which are involved in the development of severe ME/CFS (4) has concluded that there is no evidence to implicate personality or neurotic traits.

Do CBT and GET really work for Chronic Fatigue Syndrome?

http://www.bmj.com/cgi/eletters/340/feb11_1/c738

27. Northern Irish ME Association

Current NHS recommended treatments for ME are ineffective, and often have serious side-effects. CBT and GET are unpopular with patients, and face client resistance. GET has complication rates ranging from 37% – 50%, and should never have been approved for general use in the NHS. The use of psychotherapy as a first-line treatment perpetuates the myth that ME is a psychiatric illness.

<http://www.nimea.org/presentation1.html>

27. Kathelijne A Hugaerts

In Belgium, during 5 years, the Belgian Government subsidized 5 “CFS Reference Centers” who treated patients solely with CBT/GET. They used the Fukuda criteria for selection. Every year, 1.5 million Euro was distributed to the 5 centers. This makes a total of 7.5 million Euro during 5 years. 800 patients were treated during this period.

The Belgian Health Care Knowledge Centre (KCE) reviewed the result after 5 years (2009) (The KCE is a semi-governmental institution which produces analyses and studies in different research of health topics).

Conclusion :

Patients feeling better: 6 %

Patients feeling worse: 38 %

Patients with no result, not better nor worse: the remaining 56 %

The ultimate goal of the Reference Centers and their CBT/GET therapy was not met: NOT ONE PATIENT RESUMED WORK. This confirms that CBT/GET is ineffectively and possibly harmful.”

The Belgian experiment with CBT and GET

http://www.bmj.com/cgi/eletters/340/feb11_1/c738

28. Vance Spence

In the context of ME/CFS, cognitive–behavioural approaches are not evidence-based to a level where they can be claimed to be specific “treatments” – an unsurprising observation given that this “syndrome” diagnosis delivers a heterogeneous population widely believed to contain distinct clinical sub-groups (15). The systematic review underpinning NICE Guideline 53 found 10 randomized clinical trials on adults, 3 of these negative with the remainder showing mild to modest positive, though non-curative, results.

Recent overviews have confirmed this; a recent Cochrane review (16) found 15 studies of CBT (including controlled clinical trials) for ME/CFS and took a more cautious view of the evidence and its limitations than the

authors of the BMJ Editorial, as did a second recent review (17). This latter meta-analysis of 13 clinical trials (representing 1371 patients) found a very mixed bag of studies and reported an overall effect size that was small–moderate by usual standards. Not for nothing did NICE Guideline 53 (Full Guidelines, section 6.3.8, pp 252) state that it did “not regard CBT or other behavioural therapies as curative or directed at the underlying disease process”.

Not the Answer to the Biomedical Enigma

http://www.bmj.com/cgi/eletters/340/feb11_1/c738

29. Theresa L Heath

“I undertook the course of CBT offered by King’s College Hospital with an open mind and a degree of optimism. I finished the course feeling depressed and like a failure. I now view CBT as akin to other quack ‘therapies’ such as the Lightning Process. Your recovery is in your hands. If you don’t improve, you’re a failure. My therapist seemed genuinely confused when I did not make any improvement, and in fact suffered my worst relapse to date whilst endeavouring, against my better instincts, to adhere to their GET and sleep programme. I completed the course doing less physical activity than when I had started, and feeling guilty for my own ‘unhelpful illness beliefs’.

CBT and GET taking up valuable funds

http://www.bmj.com/cgi/eletters/340/feb11_1/c738

30. A.F. Andrew

“The basis of CBT for ME/CFS is fantastic. First, you blame the patient for his illness, and then when CBT doesn’t cure him, you blame him for not being motivated. When I’m fit and well again, I will use this same principle when I see a patient with for example, a severe infection. If the antibiotic I have prescribed, doesn’t solve the problem, then I will blame the patient. That the culture has shown that I prescribed the wrong treatment, is something I will ignore. “

I Adore CBT http://www.bmj.com/cgi/eletters/340/feb11_1/c738

31. Richard Simpson

To use NICE as an example for promoting the use of CBT and GET is risible and perverse, yet entirely predictable as biomedical research was ignored. The fact that 90% percent of ME support groups opposed NICE, the fact that ME patients took NICE to a judicial review in protest at their guidelines for ME, the fact that the only support that NICE could muster from those supposedly supporting the ME community were from organisations that accept government money and who themselves organise “psychosocial conferences” on ME – all of this illustrates the lack of confidence which people with ME and their families have for NICE. “

Education the Key to http://www.bmj.com/cgi/eletters/340/feb11_1/c738

32. Tanya Harrison

...any recommendation of CBT is based on flawed research, and goes against patient, and research, evidence:

...any recommendation of GET is based on flawed research, and goes against patient, and research, evidence:

There are multiple research papers showing that people with ME react adversely to exercise, and that increasing the cardiac rate, in particular, is extremely dangerous.

...patient evidence has shown that the majority of patients find GET unhelpful/harmful, with more than one patient survey showing over half of patients undertaking GET are made worse.

BRAME: Personal Response from Tanya Harrison to NICE guideline on CFS/ME

<http://meagenda.wordpress.com/2007/08/22/brame-personal-response-from-tanya-harrison-to-nice-guideline-on-cfsme/>

33. Linda Crowhurst

What is omittedis a warning of the very real dangers of imposing CBT and GET on very frail, vulnerable, ill people for whom exercise is contra-indicated and who suffer such devastating levels of cognitive dysfunction, as a result of their disease, that CBT becomes equally as dangerous as physical exercise. Mental exertion can have an equally disastrous impact upon the body , leading to an increase in already severe symptoms and a deterioration that can be permanent and may lead to death.

Patients with severe ME do not want CBT and GET. What they want is biomedical research, significant biomedical testing and new tests and treatments available on the NHS. What they need is the psychiatric interpretation and powerful influence out of ME altogether. It is long overdue.

A Dangerous Path to take

http://www.bmj.com/cgi/eletters/340/feb11_1/c738#231540

34. Clara Valverde RN BSc and Dr Iñaki Markez MD, PhD

"CBT is being used in ME/CFS to forward governments' political and economic agendas...

The proponents of CBT are mistaken when they define the patient with ME/CFS as someone whose way of thinking has to be changed. The sociological literature shows that people who have his illness, more than those with any other chronic illnesses , use, within their enormous limitations, their meagre energy to help others who are in the same situation as themselves.

Despite of being mostly housebound, these patients dedicate their few able moments to support and encourage on, especially through internet, other patients with ME/CFS, and to share useful information for their self-care. They also work to try to improve the limited services provided for this illness.

Not only is that a lesson in generosity for society, also all the knowledge on how to live with this new and difficult illness, which is on the increase, it is a great richness for all which this society cannot afford to waste".

http://www.ome-aen.org/NORTE/35/NORTE_35_110_89-106.pdf

35. Maryann Spurgin, Ph.D.

According to this thesis, some 2 million people across the country, people whom the book (A Review of Mark Demitrack's and Susan Abbey's Chronic Fatigue Syndrome: An Integrative Approach) theorizes were often of above-average intelligence before they got sick, developed a viral infection or some other bodily stressor and then, suddenly, their interpretation became skewed. Suddenly they began imagining that their symptoms continued beyond the acute, infectious stage and that those symptoms were severe. Such "attributions" and "cognitions" perpetuate the illness, as does the "attributional bias" of the physicians who take them seriously. The cure, according to the book, is Cognitive Behavioural Therapy, which alters the faulty cognitions and leads to new behaviors such as exercise. Exercise, according to the book, restores the patient to normal. Elegant prose and cool, clinical language provide the book with an aura of scientific objectivity. Careful examination, however, reveals the book to contain more value-laden rhetoric than logic, more religion than science.

Critical Analysis of the CBT/GET Model www.cfids-cab.org/MESA/

36. Drs. M.P. Koolhaas, H. de Boorder, Prof. dr. E. van Hoof

A recent pilot study (Koolhaas, et al., 2008, Netherlands) reports that only 2% of ME/CFS patients are cured by CBT, while the greatest share (38%) are adversely affected – most reporting substantial deterioration. It is especially notable that employment and education are negatively affected. This is in sharp contrast to the claims of psychiatrists and the Dutch Health Council that 70% of patients improve. Previous studies have also ignored or denied the negative affects of CBT on ME/CFS patients. The pilot study, recently published in the Dutch Medical Magazine, Medisch Contact, concludes that the previously reported claims of 70% improvement in ME/CFS patients receiving CBT are vastly overstated and misleading.

Drs. M.P. Koolhaas, H. de Boorder, prof. dr. E. van Hoof

Date: February 2008

ISBN: 978-90-812658-1-2 Cognitieve gedragstherapie bij het chronische vermoeidheidssyndroom (ME/CVS) vanuit het perspectief van de patiënt

37. Frank N.M. Twisk and Michael Maes

“In this review we invalidate the (bio)psychosocial model for ME/CFS and demonstrate that the success claim for CBT/GET to treat ME/CFS is unjust. CBT/GET is not only hardly more effective than non-interventions or standard medical care, but many patients report that the therapy had affected them adversely, the majority of them even reporting substantial deterioration.

Moreover, this review shows that exertion and thus GET most likely have a negative impact on many ME/CFS patients.”

Neuroendocrinol Lett 2009;30(3): 284–299 .A review on cognitive behavioral therapy (CBT) and graded exercise therapy (GET) in myalgic encephalomyelitis (ME) / chronic fatigue syndrome (CFS): CBT/GET is not only ineffective and not evidence-based, but also potentially harmful for many patients with ME/CFS. NEL300309R02 ©2009

Neuroendocrinology Letters

www.nel.edu

38. Paul Moloney

The supposedly sound evidence base for the effectiveness of the psychological therapies may be far more questionable than is widely supposed.

The trouble with psychotherapy CoCure Monday, February 25, 2008, Clinical Psychology Forum 162 – June 2006

<http://tinyurl.com/2yI9ji>

39. Boudewijn Van Houdenhove and Patrick Luyten

In this issue of Patient Education and Counseling, two interesting papers challenge current evidence-based treatments of chronic fatigue syndrome (CFS). In the first study Goudsmit et al. [1] show that a brief multi-component programme aimed at helping CFS patients cope with their illness, may be as effective as cognitive behavior therapy (CBT). In the second study Jason et al. [2] demonstrate that CFS patients who carefully stayed within their ‘energy envelope’ (measured by a self-monitoring strategy) did better than patients who were less successful in keeping expended energy close to available energy – a finding that challenges basic assumptions of graded exercise therapy (GET)

[1] Goudsmit EM, Ho-Yen Do, Dancey CP. Learning to cope with chronic illness. Efficacy of a multi-component treatment for people with chronic fatigue syndrome. Patient Educ. Couns. 2009; doi:10.1016/j.pec.2009.05.015.

[2] Jason L, Benton M, Torres-Harding S, Muldowney K. The impact of energy modulation on physical functioning and fatigue severity among patients with ME/CFS. Patient Educ. Couns. 2009; doi:10.1016/j.pec.2009.02.015.

Commentary: Treatment of chronic fatigue syndrome: How to find a ‘new equilibrium’?

Journal: Patient Educ Couns. 2009 Sep 19

40. Malcolm Hooper

Despite the vast amount of biomedical literature (some 5000 papers) going back to 1934 and the classification of ME as a neurological illness by the WHO (ICD-10 G93.3) since 1969, the official UK attitudes as demonstrated = by the MRC, DWP, Department of Health, and to some extent your own organisation NICE: ignore all this evidence, show an ideological commitment to a psychosomatic/behavioural model of the illness which is no longer tenable recommend only cognitive restructuring techniques (CBT and GET) = that are not remotely curative and

have been shown to be of no lasting value and in the case of GET to be positively harmful (Peter White's assertion that this is because the interventions have been incorrectly administered has been shown to lack credibility)

From Professor Malcolm Hooper to Sir Michael Rawlings 19 February 2010

<http://www.meactionuk.org.uk/Hooper-signed-letter-to-Rawlins.htm>

41. Simon Lawrence

I am also extremely worried where this (25% ME Group Response to the ruling concerning the NICE Judicial Review into ME/CFS Guidelines) will lead in relation to the so called treatment therapies of Cognitive Behavioural Therapy and Graded Exercise Therapy. These treatments in many cases have caused wide spread problems for ME sufferers. Our Report from 2004 (<http://tinyurl.com/25megroupanalysis> see last page) reported serious flaws in the therapies and also the fact that many were not helped and a great deal more were harmed by undertaking these programs. Many of these sufferers were not even severely affected patients before undertaking the therapies!

We have previously quoted that these therapies are flawed when the NICE Guidelines were released: "Patient experience of this serious neurological illness, which affects up to 240,000 people in the UK has been all but ignored in favour of a psychological approach. The illness affects many body systems and their functions, and an estimated 60,000 develop M.E. so severely they become bed or house bound, with others needing to be tube fed".

13 March 2009

<http://stanford.wellsphere.com/chronic-fatigue-syndrome-article/statements-from-major-me-cfs-charities-over-court-ruling/624754>

42. ME Association

The legal challenge to the NICE Guideline on ME/CFS was lost in the High Court today – when it was dismissed by Mr Justice Simon. More details later. Please find The ME Association's immediate response below.

People with ME/CFS now face a situation where doctors will continue to recommend two forms of treatments that many people with the illness find ineffective or even harmful.

The ME Association is disappointed that the High Court Judicial Review of the NICE Guideline on ME/CFS found in favour of NICE.

Recommendations that two controversial treatments – cognitive behaviour therapy (CBT) and graded exercise treatment (GET) – be offered as front-line treatments for those with mild to moderate forms of the illness remain unchanged.

This is despite the findings of the largest-ever survey of ME patient opinion carried out by The ME Association last year which found that only 26% were helped by CBT – while 56% reported that GET made them feel worse.

The ME Association believe that the two people with ME who took up the legal challenge were fully justified in seeking a court hearing into the processes used by NICE to draw up the Guideline.

Despite the Judicial Review failing to result in withdrawal of these potentially dangerous guidelines, The ME Association maintains that the evidence relating to both clinical and cost effectiveness does not justify the emphasis and optimism being given to these two treatments.

NICE's recommendations cannot be justified by the evidence.

<http://stanford.wellsphere.com/chronic-fatigue-syndrome-article/statements-from-major-me-cfs-charities-over-court-ruling/624754>

43. Professor Malcolm Hooper

Referring to (ME)CFS and fibromyalgia as somatoform disorders, and citing an article by Wessely et al, a 2005 paper from Norway (Biological sensitisation and psychological amplification: Gateways to subjective health complaints and somatoform disorders. Ingvard Wilhelmsen. Psychoneuroendocrinology 2005;30:990-995) fuelled the “CFS/ME is a somatoform disorder” controversy:

“What messages do we want to convey to the public? I will propose three slogans:

1. Do not listen to your body’s signals! In other words, don’t amplify.
2. Do not trust your feelings!
3. Do not trust your thoughts!

“This is the central theme of CBT. It is an important message to the public that subjective health complaints are common and seldom an indicator of serious disease. Cognitive, emotional and behavioural factors have the capacity to relieve symptoms and even change the brain. These facts should be highlighted in our message to the public”.

Such a message could prove fatal for some ME/CFS sufferers. It runs directly counter to the advice given fifteen years earlier by Dr Darrel Ho-Yen about CBT/GET: “It has been suggested that a new approach to the treatment of patients with postviral fatigue syndrome would be the adoption of a cognitive behavioural model (Wessely S, David A, Butler S, Chalder T: Management of chronic (postviral) fatigue syndrome. JRCGP 1989;39:26-29). Those who are chronically ill have recognised the folly of the approach and, far from being maladaptive, their behaviour shows that they have insight into their illness” (JRCGP 1990:40:37-39).

Magical Medicine <http://www.meactionuk.org.uk/magical-medicine.htm>

43. Professor Malcolm Hooper

“A CBT model of CFS/ME” The Trial Manual for Participants who were allocated to the cognitive behavioural therapy (CBT) arm of the (PACE) trial refers to a “CBT model of understanding CFS/ME” which in the next line has become a “CBT model of CFS/ME”.

There is no “CBT model of understanding” in respect of understanding any disorder: people either understand something or they do not.

How offensive it would be if psychiatrists talked about a “CBT model of understanding” HIV/AIDS, or a “CBT model of understanding” breast cancer, or a “CBT model of understanding” multiple sclerosis, or diabetes (which seems to be already happening – see above).

Medical knowledge does not rely on a “CBT model of understanding” a disease but relies on the science of medicine. To impose such a false doctrine upon patients with ME/CFS seems tantamount to psychological abuse of defenceless sick people.

Magical Medicine <http://www.meactionuk.org.uk/magical-medicine.htm>

44. Professor Malcolm Hooper

Sharpe describes the “cognitive model of CFS/ME” as follows: “A cognitive model of CFS ,based on systematic observation of over 100 patients meeting criteria for CFS, has been proposed.

The model as a whole attempts to explain how early life experiences lead to the formation of assumptions that, combined with certain life stressors, may precipitate CFS in predisposed individuals.

The model then attempts to explain how cognitive , behavioural, biological and social factors interact in a vicious circle to perpetuate or maintain the illness. According to this model, the interpretation of symptoms predominantly in terms of physical illness, and not in terms of negative emotional states, plays a particularly important role in the maintenance of the disorder.”

To base a theoretical model on around 100 patients, whilst subsequently ignoring the extensive biomedical evidence obtained on over 20 000 patients showing on going viral activity and a disrupted immune system as perpetuating factors in ME/CFS, thereby wasting millions of pounds sterling trying to prove the validity of their non-existent “CFS/ME” model, is something for which many people believe the Wessely School ought to be held to account.

Magical Medicine <http://www.meactionuk.org.uk/magical-medicine.htm>

45. MP Koolhass

Conclusions:

This pilot study, based on subjective experiences of ME/CFS sufferers, does not confirm the high success rates regularly claimed by research into the effectiveness of CBT for ME/CFS.

Overall, CBT for ME/CFS does not improve patients’ well-being: More patients report deterioration of their condition rather than improvement.

Our conclusion is that the claims in scientific publications about the effectiveness of this therapy, based on trials in strictly controlled settings within universities, has been overstated and are therefore misleading. The findings of a subgroup analysis also contradict reported findings from research in strictly regulated settings.

[Cognitive behavior therapy for chronic fatigue syndrome from the patient’s perspective] [Article in Dutch]- Source: Medisch Contact, Feb 2008 Source: Medisch Contact, February 2008, ISBN: 978-90-812658-1-2, by Koolhaas MP, de Boorder H, van Hoof E. The Netherlands.

http://www.prohealth.com/library/showarticle.cfm?id=8724&t=CFIDS_FM

46. Paul Cheney

“The most important thing about exercise is not to have (patients with ME / CFS) do aerobic exercise. I believe that even progressive aerobic exercise is counter-productive. If you have a defect in mitochondrial function and you push the mitochondria by exercise, you kill the DNA”

Cheney P (1999) Lecture given in Orlando, Florida at the International Congress of Bioenergetic Medicine, 5th-7th February 1999 <http://www.cfsresearch.org/cfs/cheney/2.htm>

47. e van de Sande

It takes the ME sufferer an inordinate amount of time to recover from exercise.

e van de Sande M.(2003) ME/CFS Post-Exertional Malaise / Fatigue and Exercise

<http://www.mefmaction.net/default.aspx?Page=selectedarticlesmedical>

Quest #60, June/July, 2003

48. Charles Shepherd

As much care should be taken in prescribing exercise as in prescribing pharmaceuticals. ME/CFS patients do not respond to exercise in a manner that is expected of healthy people.

Sheperd C. (2001) Pacing and exercise in chronic fatigue syndrome.

Physiotherapy 2001 Aug;87(8):395-396.

49. Severe ME patient

A sufferer recounts the often horrifying impact of this “treatment” regime on those with severe ME:

“All of my ‘help’ is useless:

I am offered anti-depressants (I am not depressed).

I am offered ‘Behavioural Therapy’ (I have no incorrect illness beliefs).

I am offered 'Graded Exercise' (Which even in small moderation, relapses me).

EVEN WHEN I DO THESE ALL AGAINST MY WILL. As an inpatient in Hospital, my medical records are falsified, and it claims I am 'obstructive' to my own recovery, as these psychosomatic principles have no effect on me. This is then claimed to be MY fault, not the fact that I am not mentally ill, and therefore do not 'recover' from M.E via mental illness interventions".

<http://mesite.dk/UKGibsonInquiry25Group.htm>

50. 25% Group

In a 2004 survey, members of the 25 % Group found:

- * Cognitive behavioural therapy (93% unhelpful) and psychotherapy (90% unhelpful)
- * Worsening of condition with graded exercise therapy (tried by 39% of members, and 82% made worse by it)

These results are confirmed by this latest survey in which only one person who had tried CBT and GET reported that it was helpful.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

51. Greg Crowhurst

According to Loveless the ME/CFS patients whom he saw had far lower scores on the Karnofsky performance scale than HIV patients even in the last week of their life, indicating a probable functional ability of between 10 and 20 % of normal. This figure is highly significant for as Ho-Yen (1994) states, a patient "with (ME/CFS) should be advised not to increase their activities gradually until they feel 80% of normal".

<http://mesite.dk/UKGibsonInquiry25Group.htm>

52. Severe ME patient

"I was an in-patient in a psychiatric ward of a London hospital. I was the only patient who did not have a mental health problem, and although my CBT therapist had had plenty of experience of working with M.E. patients, I was the first to be admitted as an in-patient. I only saw my therapist once a week, and the psychiatric nurses had no understanding of my illness at all. There was a huge amount of stress, and I was treated very badly by some of them. I received both CBT and GET, but the graded exercise seemed to be given priority. I worked with a physiotherapist, who also had no experience of M.E. I began to seriously deteriorate, and 4 months in, suffered a major relapse. I had a kind of undiagnosed 'stroke', collapsed, and became incapable of looking after myself.

When I went to the hospital I could walk 100 yd., feed, wash and dress myself. When I left I could not weight bear at all, had no leg muscles to speak of, and needed two people to transfer me on and off the toilet and in and out of bed. I had little use of my hands and was totally bed bound. I could not tolerate sitting upright against the pillows, conversation was beyond me, and I could barely manage to feed myself by picking up food in my hands — cutlery was out of the question. Nine years later I have improved, but I'm still bed bound".

<http://mesite.dk/UKGibsonInquiry25Group.htm>

53. Severe ME patient

Giving GET and CBT to people with ME is like trying to prescribe treatment without first investigating the disease – madness! We need proper biomedical research to find out the cause(s) of this illness and to investigate fully what it does to the body. GET and CBT have been found to be at best unhelpful to those with ME at worse, harmful.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

54. Severe ME patient

After I came home from the hospital where I received CBT/GET therapy, a physio came to see me once a week. The first one was absolutely appalling, and used to drag me up off the bed and hold me upright, even though I

was too ill to cope with this, and my body was collapsing under me. It was a 'fight' really, with her believing that if I wasn't allowed to sit down, the muscles in my legs would improve, and I would gradually begin to weight-bear.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

55. Severe ME patient

"I have been ill in different phases for 15 years. I have worked it out for myself that you can only "exercise" within very narrow limits. It is simply not the case that you can exercise your way out of this illness. If it were that simple most people with ME who were previously very fit and active, would have long since recovered."

<http://mesite.dk/UKGibsonInquiry25Group.htm>

56. Severe ME patient

Another sufferer describes how, despite an "extensive psychiatric evaluation" which resulted in a report saying 'she is severely physically disabled', 'has no mood or behavioural problems' and 'is coping remarkably well given very difficult circumstances', she was still offered "CBT and counselling and my symptoms of severe nerve pain, nausea, difficulties with speaking, sight, swallowing and eating, seizure like brain activity, intermittent paralysis, contractures in hands and feet etc were left un-investigated and untreated."

<http://mesite.dk/UKGibsonInquiry25Group.htm>

57. Severe ME patient

This sufferer states how: "I could see the sense in graded exercise and how it could help someone to come back from an illness and aid in their recovery but unfortunately with ME this treatment does not work and just sets you back".

<http://mesite.dk/UKGibsonInquiry25Group.htm>

58. Severe ME patient

I participated in Graded Exercise therapy via the 'National M.E Centre', Romford, Essex. This led to a relapse, at home, and made me unable to sit upright for 1 year due to pressure in my head, and chest pain. I then relapsed and ended up in my local NHS Hospital in a cardiac care unit.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

59. 25% Group

44% of respondents were offered Graded Exercise Therapy: Of the 44% who were offered GET 64% tried it and 95% reported that GET had a negative impact on them; 67% of respondents were offered Cognitive Behaviour Therapy; of the 67% who were offered CBT 42% tried it and 96% reported that CBT had a negative impact on them; the one sufferer who found GET and CBT helpful, heavily qualified their supporting statement.

This (CBT & GET) had a positive effect in that it helped me develop coping strategies to deal with the day to day problems of ME. In no way was it put forward as a cure & I have never had the impression the therapist very firmly believes I have a genuine physical illness.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

60. Severe ME patient

Please, please, please start funding research into the physical side of the illness instead of flogging a dead horse by continuing to research CBT and GET. The evidence is already there that CBT and GET don't work but there are research projects around that look very promising and they badly need funding.

<http://mesite.dk/UKGibsonInquiry25Group.htm>

61. Malcolm Hooper

It (Action for ME) reported a survey of >2000 people and some analysis of their data. 25% were housebound, 75% had lost their jobs, 77% had very much reduced social contacts and 92% were not helped by GET.

Gibson Inquiry – Day 1, April 18th 2006 – Group Testimonies.

<http://mesite.dk/HooperCommentDay1GibsonInquiry.htm>

62. Malcolm Hooper

Beth Llewelyn gave a very moving account of her own illness and the commonly experienced failures of the medical and benefits system.

- * Her GP refused to follow up the many medical reports associated with her illness, which was not recognised.
- * The family had been accused of all sorts of things because she did not get better.
- * 62% of GPs in Wales do not believe in ME.
- * She collapsed on the second day of GET.

Gibson Inquiry – Day 1, April 18th 2006 – Group Testimonies.

<http://mesite.dk/HooperCommentDay1GibsonInquiry.htm>

63. Greg Crowhurst

The number of patients who actually benefit from CBT and GET (Graded Exercise Therapy) in trials, is less than 10% and a large number of patients get significantly worse [1]. If anyone benefited from one of these trials they probably had some form of Chronic fatigue, but they did not have ME [2]. In reality virtually no research has been carried out on those who are most severely affected by ME.

What few trials there have been, tend not to deal with the house and bed-bound. As Neil Abbot (2004) points out: “very few studies exist, and all define “severe illness” in different ways, complicating interpretation of the findings. And specific laboratory-based or experimental studies on severe sufferers are as rare as hens’ teeth.”

[3]. The relevance of the psychiatric approach to the severely affected, now being rolled-out as a nationwide programme, is based on only one report in the scientific literature, [4], and that involved two wheelchair-bound participants who were actually able to attend a clinic in the first place.

1. Text of speech by Alex Fergusson to the Scottish Parliament June 9 2005

2. ibid

3. Abbot N (2004) Severely Overlooked by Science — An Overview of Research on Severely-ill People with ME, MERGE www.mererearch.org.uk/publications/severe.html

4. ibid

Issues related to severe ME and the involvement of the UK Psychiatric lobby

<http://mesite.dk/IssuesRelatingSevereME.htm>

64. Lajla Marks

The difference between pacing and Graded Exercise Therapy is well described by the pacing expert Ellen Goudsmit C. Psychol. AFBPsS, UK:

“GET as understood by psychologists and doctors would encourage patients to keep to the plan. Some therapists see the deterioration and allow patients to stop and rest. But that’s not standard GET and not mentioned in any publication I ever read. It’s certainly not in the trials cited in the draft [NICE Guidelines]). The idea is to plod on and complete the plan.. As discussed, Stulemeijer kicked out all those who could not keep the

plan. Prins et al excluded those they felt might not be able to stick to the plan at the intake. Wessely allowed patients to reduce but not stop If people can stop when they begin to feel unwell, it's pacing. It's the patient listening to their body. That's anathema in the CBT lit on CFS.

Pacing is about hour-to-hour management. There's no agreeing plans a fortnight earlier. It requires more self-discipline than GET or GA. It's an easy principle but not an easy option."

Treatment <http://www.mesite.dk/Treatment.htm#Exercise>

65. Countess of Mar

"During the Committee Stage of the Welfare Reform Bill – debates from Clause 9 onwards in the Lords, I managed to extract from the Minister statements to the effect that people with CFS/ME would not be forced to do CBT/GET in order to continue to get their benefits".

That debate is recorded in Hansard (Lords) on 28th February 2007, column GC198: Countess of Mar: "If a group of people refuses graded exercise and cognitive behaviour therapy, on the basis either that they are afraid or that they know it will not help them, will they be penalised?"

Lord McKenzie of Luton (Parliamentary Under-Secretary, Department for Work and Pensions; Labour Peer): "there is no requirement for individuals to carry out any specific type of activity or treatment. That cannot be sanctioned".

<http://www.investinme.org/IIME%20Campaigning-CBT-GET-002.htm>

66. The Grace Charity for ME

SAYING NO CAN BE POSITIVE

Those who wish to refuse psychological therapies for M.E. can be supported by the following facts:-

- 1) The law protects patients from unwanted treatments Medical practitioners cannot give a treatment to a patient without the patient's consent.
- 2) Private Health Insurers cannot force an M.E. client to undergo unwanted treatment before making a payment, unless those treatments are specified in the contract. Unless the contract of a company states clearly that M.E. clients must undergo CBT and/or graded exercise before a payment is made, the company could well be in breach of contract. Also, every individual has freedom to express views as stated by The Human Rights Act 1998. If an insurance company ignores a client's reasons for refusing CBT and/or graded exercise, a client could claim their 'freedom of expression' has been violated [i].
- 3) An M.E. patient cannot have their state benefits withdrawn for refusing CBT and graded exercise. U.K. law says that if a patient refuses suitable treatment without good cause, benefits can be withdrawn [ii]. However, CBT and graded exercise could be argued as unsuitable treatments for M.E. sufferers (see facts below).
- 4) M.E. is a neurological disorder; it has been classified as such by the World Health Organisation in the International Classification of Diseases since 1969 [iii]. Therefore psychological therapies could well be inappropriate.
- 5) M.E. has a strong medical history of being an organic disease. Dr.Gordon Parish is the curator of the Ramsey Archive, which is possibly the world's largest collection of medical papers on M.E. [iv]. It includes detailed world-wide epidemics of M.E. since 1934 and the viruses which triggered the disease.
- 6) Many tests exist in aiding a diagnosis for M.E. Therefore, using psychological therapies for 'unexplained fatigue' is inappropriate. Although diagnostic tests for M.E. are still being worked upon with promise, nevertheless many tests and procedures can be administered in aiding a diagnosis of M.E. These include the use of SPECT, MRI and PET scans, test for NK cell activity and endocrine abnormalities, Tilt Table Test, viral tests and many more [v]. Although these tests aren't always offered by the NHS for M.E., they have nevertheless shown evidence of physical abnormalities.

7) "Patients who improve after physical exercise programmes do not have M.E./CFS.," says Dr. Byron Hyde, M.D. of the Nightingale Research Foundation for M.E. in Canada, who has studied M.E. since 1984 [vi]. Dr. Hyde stresses that M.E. is primarily a disease of the Central Nervous System [vii].

8) Patients who respond well to CBT and graded exercise might not have M.E. due to the diverse criteria used. Some criteria focus on unexplained chronic fatigue only, omitting symptoms showing central nervous system involvement. There are at least ten definitions of Chronic Fatigue Syndrome [viii]. In the U.K., a frequently used case definition is the Oxford Criteria which includes patients with no physical signs and selects subgroups of patients with high levels of psychiatric diagnoses. [ix] The PACE and FINE trials use the Oxford Criteria. [x]

9) The assumption that an M.E. patient can always do more is an erroneous one. There are overwhelming international research findings on M.E., which support multi-system involvement particularly of the immune, endocrine, cardiovascular and neurological systems. [xi]

Also, there is evidence indicating pathology of the central nervous system and immune system [xii] and evidence of metabolic dysfunction in the exercising muscle. [xiii] Also, Dr. Jay Goldstein has demonstrated through SPECT scans the severely decreased brain perfusion of an M.E. patient 24 hours after physical exercise. [xiv] The Canadian Criteria (2003) states that the worsening of symptoms after exertion is a principal symptom of M.E. [xv] Raised levels of noxious by-products of abnormal cell membrane metabolism, associated with exercise and correlating with patients' symptoms have been demonstrated. [xvi]

10) CBT and Graded Exercise can worsen M.E. symptoms. In a survey of 3074 M.E./CFS patients conducted between 1998 – 2001, 55% of patients said that CBT had made no difference to their illness, whilst 22% said CBT had made their illness worse. 16% of patients said that Graded Exercise had made no difference to their illness whilst 48% said it had made their illness worse [xvii] A survey by the 25% ME Group (for severe sufferers) of 437 patients, demonstrated that of the 39% of group members who had used graded exercise, 95% had found this therapy unhelpful, whilst – 82% reported their condition had been made worse by graded exercise. Some patients were not severely ill with M.E. until after graded exercise. In the same survey – 93% of those who had undergone Cognitive Behavioural Therapy had found it unhelpful [xviii] See also the ME Conference 2006 DVD.

11) The CMO's Report recommended CBT and graded exercise despite the objection of two patient support groups. The patient support groups of BRAME (Blue Ribbon for the Awareness of ME) and the 25% ME Group refused to endorse the CMO's Report of 2002 based on its recommended treatments of CBT and graded exercise. These support groups mainly represent the needs of severe M.E. sufferers and were part of the CMO's Working Group.

12) Medical Concerns have been raised about the CMO's Report. The Journal of Chronic Fatigue Syndrome, [xix] mentions criticism by health professionals and the public of both the British and the Australian M.E./CFS guidelines.

"These criticisms included claims of bias in the recommendations toward a psychiatric outcome and failure to understand the limitations of patients to perform exercise programs as well as many others."

References :

1 The Human Rights Act 1998, European Convention for the Protection of Human Rights and Fundamental Freedoms, Section 1, Article 10, no.1

2 U.K. law on state benefits, Regulation 18 Social Security (Incapacity For Work) Regulations. A similar law applies to other state benefits for sickness and disability.

3 World Health Organisation – International Classification of Diseases 10-G93.3

4 What is ME? What is CFS? Information For Clinicians and Lawyers, Dec. 2001, Marshall, Williams, Hooper, page 11, available from Prof. Malcolm Hooper, Dept. of Life Sciences, University of Sunderland SR2, 7EE 5 Leaflet, A Physician's Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, The Nightingale Research Foundation,

Vol.1, Issue 7, revised, 1992, page 17. Also, Journal of Chronic Fatigue Syndrome Vol. II, No.1, 2003, Canadian Criteria, page 25, The Haworth Press Inc.

6 Ibid., A Physician's Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, page 25

7 Clinical Observations of Central Nervous System Dysfunction in Post-Infectious, Acute Onset M.E./CFS, page 38, The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome 1992, Byron Marshall Hyde, M.D., The Nightingale Research Foundation.

8 Report from the National Task Force on Chronic Fatigue Syndrome, Westcare, Bristol 1994. This states nine definitions: the recent Canadian definition in 2003 makes ten.

9 Katon & Russo, 1992; Freiberg, 1999, Unhelpful Counsel? MERGE's response to the CMO report on CFS/ME, 2002, p15.

10 See the website of the Medical Research Council at www.mrc.ac.uk

11 ME and/or CFS paper, September 2001, page 1, V.A. Spence PhD, Chairman of MERGE (ME Research Group for Education and Support). This paper quotes from several published findings. Available from MERGE, The Gateway, North Methven Street, Perth PH1 5PP

12 The Biology of the Chronic Fatigue Syndrome, Prof. Anthony Komaroff, The American Journal of Medicine 2000: 108: 99-105.

13 Mitochondrial abnormalities in the postviral fatigue syndrome, Behan, W.M.H. et al., Acta Neuropathologica 83, 1991, pages 61-65.

14 The Negative Effects of Exercise on an M.E./CFS Dysfunctional Brain, page vii, The Clinical and Scientific Basis of Myalgic Encephalomyelitis Chronic Fatigue Syndrome 1992, Byron Marshall Hyde, M.D., The Nightingale Research Foundation.

15 Journal of Chronic Fatigue Syndrome Vol. 11, No.1, 2003, Canadian Criteria, page 22, The Haworth Press Inc.

16 Oxidative stress levels are raised in Chronic Fatigue Syndrome and are associated with clinical symptoms, Kennedy, Spence, Belch, Free Radical Biology & Medicine 2005:39:584-589

17 Directly from the Horses' Mouths, Doris M. Jones MSc, Reference Group Member, CMO's Working Group. This survey was part of the Working Group on ME/CFS set up by the Chief Medical Officer Sir Kenneth Calman in 1998.

18 Analysis Report by 25% ME Group March 2004 www.25megroup.org

19 see footnote 15, page 2 of the Editorial .

'Saying No Can Be Positive' has been produced by The Grace Charity for M.E.

<http://www.thegracecharityforme.org/documents.asp>

67. Sussex

The Sussex CFS referral criteria consists of the presence of unexplained fatigue, and gives emphasis to "illness beliefs", and so does not even identify the hallmarks of Neurological/Immunological ME G93.3, but instead identifies chronic fatigue, a common symptom of a wide range of conditions including many psychiatric disorders. In the ICD Chronic Fatigue is listed as a completely different disorder to ME, CF is in ICD F48 Neurasthenia, in the psychiatric section.

The Sussex referral criteria also requires that the patient agrees to have a Biopsychosocial and management assessment, and then offers "management" with CBT and GET which does not have the evidence base to justify such expenditure of millions and 11 wasted years since the CMO's Working Group was convened in 1998, not to mention wasted lives of patients with Neurological, Immunological ME....

Selected Emails/Letters to Dr Turner for May 5 Deadline

<http://www.rime.me.uk/Inquiry%20Letters.doc>.

68. North London

... Re. the APPG on ME Inquiry into NHS Services, will you be asking the CNCC at Barts London for evidence?

Please note (1) the patients' leaflet is entitled 'The Chronic Fatigue Service' (2) the Referral Criteria says, 'A primary complaint of unexplained fatigue' (3) the unit offers GET and CBT.

Is this consistent with the illness described by WHO ICD G93.3 (which the APPG recognises) and Canadian Criteria? Selected Emails/Letters to Dr Turner for May 5 Deadline

<http://www.rime.me.uk/Inquiry%20Letters.doc>

69. ME Research UK

Indeed, when Clinical Guideline 53 is placed side by side with other Clinical Guidelines in the NICE pantheon, representing 19 different clinical conditions (see the table in "The NICE Guideline: what's the problem?" in the Spring 2008 issue of Breakthrough, pdf 53 KB), it can be seen that while CBT is postulated to be a main intervention for a range of psychological conditions, ME/CFS is the only physical condition in this list for which the therapy is flagged up as a primary specialist management approach in a NICE guideline. This is a rum business, particularly since Clinical Guideline 53 (full version, page 252) is clear in stating: "The [Guideline Development Group] did not regard CBT or other behavioural therapies as curative or directed at the underlying disease process, which remains unknown. Rather, such interventions can help some patients cope with the condition and experience improved functioning, and consequently a improved quality of life."

The NICE Clinical Guideline: from content to clinic

<http://www.mereseach.org.uk/information/publications/niceguideline.html>

70. Margaret Williams

In contrast to Cleare's assertions about the "favourable evidence" for the "long-term benefit" of CBT international attempts in Australia and America to replicate the claimed success of the Wessely School psychiatrists for those with ME/CFS have not been successful.

By analogy, is Cleare claiming that the physical symptoms of multiple sclerosis can also be reversed by psychiatrically "corrected" cognition processes and exercise? Does Cleare believe that the established laboratory abnormalities seen in ME/CFS are simply inconsequential epiphenomena? Is he confident that in terms of restoring ME/CFS patients to asymptomatic pre-morbid levels of functioning, CBT/GET can restore damaged mitochondria; that CBT/GET can address the confirmed (published) vascular abnormalities- specifically the blood vessel sensitivity to acetylcholine which affects only those with ME/CFS and not other groups (such as Gulf War Syndrome and those with Organophosphate-exposed illness) who are equally disabled and who fulfil criteria for chronic fatigue syndrome; that CBT/GET can restore a leaky gut and a non-intact blood brain barrier; that CBT/GET can prevent the prominent immune derangements seen in ME/CFS such as humoral autoimmunity against polypeptides of the nuclear envelope (the occurrence of autoantibodies to an intracellular protein like lamin β 1 provides laboratory evidence for an autoimmune component in ME/CFS); that CBT/GET can modulate increased neutrophil apoptosis; that CBT/GET can restore maximum oxygen delivery and optimum lung function tests; that CBT/GET can restore an increased CD4-CD8 ratio; that CBT/GET can restore an up-regulated antiviral pathway and that CBT/GET can reverse recurrent pancreatitis, cardiomyopathy and hair loss and that it can control vertigo and observable nystagmus, double vision, nausea, bladder and bowel dysfunction, neuromuscular incoordination and intractable pain, all of which may occur in ME/CFS?

Dysfunctional Beliefs In ME/CFS? www.hfme.org/wmarshallandwilliams.htm

71. Jeannie Carson

Mill Crescent resident Jeannie Carson suffers from ME, and has criticised the NHS's view of the illness which looks at it as a psychiatric condition, with treatment including cognitive behavioural therapy (CBT).

The former Pembury Hospital midwife feels the healthcare system is wrong for labelling it in this way, and says it should be treated as a neurological illness. The 67-year-old spends most of the day bed-bound and as well as the overwhelming tiredness, she suffers muscular pain, difficulty walking, and feelings of isolation and loneliness.

She has shunned her treatment through psychiatric methods and now gets by with the help of a carer.

"I was very active, I didn't want this ME," she said. "There are times when I get angry and frustrated because I am unable to be as active as I want to be. I feel they are being unfair.

"How dare they say it is a psychological illness? I did not ask for this."

Miss Carson is a member of The Grace Charity for ME which sends treatment guidelines to all surgeries in Kent and Medway. 'NHS must not treat ME as a mental illness'

http://www.meassociation.org.uk/index.php?option=com_content&view=article&id=1060%3Anhs-must-not-treat-me-as-a-mental-illness&Itemid=219

72. Mary M. Schweitzer, Ph.D.

Kings College, London, follows the theory that patients with CFS hold "inappropriate illness beliefs,"

and they have to re-learn that (1) they are well, through cognitive behaviour therapy (CBT), and (2) they can be reconditioned, through graded exercise therapy (GET) – and then they can happily go back to work and family.

These theories have sent children and even adults to foster care or psychiatric hospitals for the sin of having "chronic fatigue syndrome."

Simon Wessely: Pay Attention GIGO ... Pay Attention To The Data Set

<http://niceguidelines.blogspot.com/2010/01/simon-wessely-pay-attention-gigo.html>

73. Maryann Spurgin, Ph.D.

In 1994, a group of government propagandists and psychiatrists on the take from insurance companies created one of the most damaging documents in the fifty-year history of ME/CFS: the 1994 Centers for Disease Control Case Definition. Hillary Johnson was one of the first harshly to criticize the document in her book *Osler's Web*, stating that the criteria were too broad and failed to describe the disease with which she and so many of us had been stricken, the disease that caused post-exertional sickness and neurological problems. Instead, it selected heterogeneous fatigue states under the CFS umbrella. This led to inconsistent research results and inappropriate treatment protocols like cognitive behavioral therapy (CBT) and graded exercise therapy (GET), which caused many patients to become worse.

Review of : "Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols," *J of Chronic Fatigue Syndrome*, Vol. 11 (1) 2003, pp. 7-116. Bruce M. Carruthers, MD, CM, FRCP(C); Anil Kumar Jain, BSc, MD; Kenny L. De Meirleir, MD, PhD; Daniel L. Peterson, MD; Nancy G. Klimas, MD; A. Martin Lerner, MD, PC, MACP et al.

<http://www.cfids-cab.org/MESA/cccd-1.html>

74. Countess of MAR

"What are we doing to our teenage ME suffers when we force them back to school, deny home tuition, and tell them to exercise as form of therapy ? What will happen in 30 years time to children now getting ME in a climate where they are disbelieved and told to pull themselves together?"

Countess of Mar's address in the House of Lords, 22 Jan 2004

75. Greg Crowhurst

The UK Government has spent millions of pounds setting up clinics across the country which offer a common treatment programme of Pacing, CBT (cognitive behavioural therapy) and GET (graded exercise therapy).

According to one job description (2005) : “severely disabled, fatigued patients and relatives (will be required) to change perpetuating illness behaviour and perform a self-managed activity programme, regulate disturbed sleep patterns and modify predisposing personality style.”

Royal Liverpool & Broadgreen University Hospitals NHS Trust , Job title: Trainee Clinical Fatigue Therapist, Chronic Fatigue Treatment Service Ref: 2570, January 2005

76. Eleanor Stein

Stein E (2007) points out how when measured objectively the CBT trials delivered no statistical change. Regarding the graded exercise therapy (GET) trials , Stein states that only two RCT’s had positive results, but after 24 weeks there were no benefits at all. Another study had no control group, and its conclusion was that “exercise capacity should not be used as an outcome criterion – the reason is because they could not find any change”. A Belgium study concluded that “the results are less robust than expected and it was noted that complete recovery was never recorded”.

Stein E (2007) Behavioural Interventions in ME/CFS New Horizons International Conference on ME/CFS Research, ME Research UK and the Irish ME Trust DVD

77. Elsie Owing

It is very important to note that internationally CBT and exercise are viewed as a coping strategy, to help people to “adjust to the limitations of the disease. It does not attempt to convince them (as in the UK, where it is used as a “treatment”) that there is nothing physically wrong with them.”

Elsie Owing in Eileen Marshall and Margaret Williams Deliberate Dichotomy? 10th November 2004

[www.meactionuk.org.uk/Deliberate Dichotomy.htm](http://www.meactionuk.org.uk/Deliberate_Dichotomy.htm)

78. Severe ME patient

Graded Exercise Therapy worsened me dramatically and I have no doubt had been a large factor in my being severely affected after 20 years. Cognitive Behavioural Therapy – this did not make me worse but I feel was completely inappropriate and didn’t have any relevance to my day to day life.

Greg Crowhurst East Anglia ME patients (EAME) Survey of the Severely Affected 2007

79. Severe ME patient

I’ve had CBT and GET. Both of these made me extremely worse for a number of years and from which I am still recovering from and which has still affected me.”

Greg Crowhurst East Anglia ME patients (EAME) Survey of the Severely Affected 2007

80. Severe ME patient

“Hydrotherapy, using a form of GET, made me more and more ill and I developed spasms.”

“Common sense helps with pacing and graded exercise etc. CBT and GET I don’t think are helpful, as often any course is very draining and I cannot concentrate anyway”

Greg Crowhurst East Anglia ME patients (EAME) Survey of the Severely Affected 2007

81. Catherine Ashenfelter

Ashenfelter (2007) , for example, describes how one ME sufferer, referred in May 2007 to the National Hospital for help in managing their illness and pain control, was placed in a mental ward, alongside suicidal patients and “immediately put on a Cognitive Behaviour Therapy and Graded Exercise programme and was denied pain relief..... Her privately employed carer was phoned up at home and told to no longer care for her in the future. “

Ashenfelter C (2007) Hospital Warning, The Quarterly, 25% Severe ME Group, Newsletter, Issue 24, Winter 2007, p. 19

82. Ruth Nolan

Nolan (2007) outlines how in submissions to NICE, The British Psychological Society said that “there is no evidence that GET (with or without CBT) actually increases activity levels”, the Royal College of Physicians said “Clinical evidence and patient experience suggests strongly that some patients may be worsened with GET”, while the Association for British Neurologists said that “the guideline needs to be thoroughly revised to reflect our current understanding of this condition rather than the supposition of the psychiatrists”.

Nolan R (2007) A serious lack of evidence for NICE guidelines BMJ Rapid Responses to R Baker and E J Shaw
Diagnosis and management of chronic fatigue syndrome or myalgic encephalomyelitis (or encephalopathy):
summary of NICE guidance

BMJ 2007; 335: 446-448

<http://www.bmj.com/cgi/eletters/335/7617/446>

83. Chief Medical Officer

The Chief Medical Officer (2002) has warned that exercise-based regimes advocated for less severely affected patients tend not to have been studied among those most severely affected.

Department of Health (2002a) , A Report of the CFS/ME Working Group.

Report to the Chief Medical Officer of an Independent Working Group, London, The Stationary Office.

84. Dr Speedy

...the “revalidation therapies” for patients with ME/CFS, which are monopolized by the governmental institutions for example in the UK, Belgium and the Netherlands, are not only not efficient, but also aggravate the condition of many patients.

Despite several major scientific breakthroughs, ME/CFS is still described in the popular media as a medically unexplained disorder. Psychotherapy (cognitive behavioral therapy) and graded exercise therapy (GET) are declared to be the only possible therapies. A thorough analysis of the current medical scientific literature and international patient surveys, however, shows that CBT/GET is not only ineffective for the majority of the ME/CFS patients, but also potentially very harmful.

Scientific studies and large-scaled patient surveys have shown that treatments with CBT/GET seriously deteriorate the condition of many patients with ME/CFS. The work capacity decreased as well!

The review also explains why GET and exercise do aggravate characteristic complaints, like “fatigue”, pain, neurocognitive problems (e.g. concentration and memory).

Pre-existing biological aberrations, e.g. inflammation, oxidative stress, and dysfunctional ion channels, will be amplified by a minor exertion, like walking or reading a book ... and by “rehabilitation therapies” like CBT/GET.

GET and CBT HARMFUL FOR ME/CFS

<http://niceguidelines.blogspot.com/2009/11/get-and-cbt-harmful-for-mecfs.html>

85. Frank NM Twisk, Michael Maes

We conclude that it is unethical to treat patients with ME/CFS with ineffective, non-evidence-based and potentially harmful “rehabilitation therapies”, such as CBT/GET. [A review on CBT and GET in ME/CFS: Not only ineffective and not evidence-based, but also potentially harmful] – Source: NeuroEndocrinology Letters, Sep 15, 2009

<http://www.prohealth.com/library/showarticle.cfm?LIBID=14964>

86. 25% Group

The July 2007 document 'Defiance of Science' by M Hooper et al (www.meactionuk.org) provides details of studies and references which showed that prescribed exercise programmes for ME/CFS patients not only cannot be complied with by them, but also results in worsening of ME/CFS symptomatology (p3/4). In addition a number of references are given of statements made by some of the very UK psychiatrists who advocate these regimes, especially also CBT. For instance: At the American Association for CFS (AACFS, now the IACFS/ME) International Conference at Cambridge, Mass., on 10-11th October 1998, Wessely-School psychiatrist Michael Sharpe went on record stating that the benefits of CBT faded with time.

On 3.11.2000, Sharpe again confirmed "There is a tendency for the difference between those receiving CBT and those receiving comparison treatment to diminish with time due to a tendency to relapse in the former" (www.cfs.inform.dk).

Wessely himself is on record stating that CBT doesn't work for all: in his Editorial (JAMA 19.9.2001:286:11) he stated that CBT + GET are only "modestly effective" and that neither is "remotely curative". Wessely is also on record as stating: "It should be kept in mind that evidence for randomised trials bears no guarantee for treatment success in routine practice. In fact, many CFS patients, in specialised treatment centres and the wider world, do not benefit from these interventions." (The art of diagnosis: pros and cons of labelling chronic fatigue syndrome. Marcus JH Huibers + Simon Wessely. (Psychological Medicine, 2006:36(7):895-900).

<http://www.25megroup.org/Campaigning/NICE/ADDITIONAL%20MEMORANDUM%20TO%20THE%20HEALTH%20SELECT%20COMMITTEE.doc>.

87. Dr Speedy

CBT is just as effective for a neurological illness as watching grass grow....which is a lot cheaper actually...

http://www.mecfswa.org.au/News_and_Media/News_Details/Letter_to_Royal_Society_of_Medicine/Default.asp
[X](#)

88. Susan Wenger

CBT may help people with garden-variety chronic fatigue. It does NOT reduce the severity of symptoms of chronic fatigue SYNDROME, which is an organic disease.

Put it this way: sending a CFS patient to a therapist is much like sending someone with multiple sclerosis to a therapist. At best, it can help the person cope with the emotional difficulties of living with a (so far) incurable disease. It's not going to ameliorate the physical symptoms.

<http://www.nursingtimes.net/whats-new-in-nursing/cbt-could-be-treatment-option-for-chronic-fatigue/1733803.article>

89. Terri Smith

M.E./CFS is not a mental condition, it is a neurological illness & CBT has been repeatedly found by patient group surveys to worsen the already debilitating symptoms. There is overwhelming research evidence proving it is a physical illness. 80% of sufferers never recover, & some live their lives in darkened rooms unable to speak or swallow. It is time that the nursing profession stopped colluding with the powerful psychiatric lobby that have redefined M.E. as a somatisation disorder to their own personal gain. This redefinition makes sufferers already difficult lives impossible. It is not acceptable enough in 2008 for the nursing profession to 'just follow orders' in the treatment of M.E. patients as if they have a mental illness.

WORLD HEALTH ORGANISATION (W.H.O.) DEFINITION OF M.E.

ME/CFS is an acquired organic, pathophysiological, multi-systemic illness that occurs in both sporadic and epidemic forms. Myalgic Encephalomyelitis (ICD 10 G93.3), which includes CFS, is classified as a neurological disease in the World Health Organization's International Classification of Diseases (ICD). Chronic fatigue must not be confused with ME/CFS because the "fatigue" of ME/CFS represents pathophysiological exhaustion and is only

one of many symptoms. Compelling research evidence of physiological and biochemical abnormalities identifies ME/CFS as a distinct, biological clinical disorder.

www.nursingtimes.net/whats-new-in-nursing/cbt-could-be-treatment-option-for-chronic-fatigue/1733803.article

90. Dr John Greensmith

When therapists – or, sometimes, the patients themselves -claim that CBT has helped their CFS, there are always other possible explanations, such as improvement with time, resting or pacing, which CBT advocates choose to ignore or overrule.

This month, at a Conference at the University of East Anglia, Professors Mick Cooper & Robert Elliott from Strathclyde University showed that the efficacy of CBT is a ‘myth’ and we are probably wasting millions of pounds.

www.nursingtimes.net/whats-new-in-nursing/cbt-could-be-treatment-option-for-chronic-fatigue/1733803.article

91. Joanna Ko

My daughter who has severe ME has attended 25 CBT sessions. It has helped her to deal with the depression caused by this awful disease but it has definitely caused deterioration in her ME symptoms which in turn brought the depression back, as strong as ever. Overall-drawbacks outweigh the benefits manifold.

www.nursingtimes.net/whats-new-in-nursing/cbt-could-be-treatment-option-for-chronic-fatigue/1733803.article

92. Dr John Greensmith

The spectacular results claimed for CBT and GET depend on the say-so of advocates and practitioners, unsupported by any independent evidence. The latest review (Twisk & Maes, September 2009) confirms that all the research to date shows that CBT is ineffective and GET makes matters worse for M.E. sufferers. Yet, astonishingly, there are calls for even more funding to expand the service.

Few, if any, voices are heard in opposition. Government ministers are perhaps relieved that they can be said to be offering something rather than nothing. Busy GPs may assume that the NICE guidelines are firmly scientifically based and not even check the literature. Those with any concerns may be remain silent rather than question the medical establishment and patients who have been hurt may be reluctant to say so for fear of being left even more isolated. The wailing and gnashing of teeth is still audible for all but deaf ears.

Open letter to Professor Sir Liam Donaldson, Chief Medical Officer

[http://www.dailyecho.co.uk/yoursay/letters/4856745.Open letter to Professor Sir Liam Donaldson Chief Medical Officer/](http://www.dailyecho.co.uk/yoursay/letters/4856745.Open_letter_to_Professor_Sir_Liam_Donaldson_Chief_Medical_Officer/)

93. RIME

RiME is particularly concerned about the plight of severely affected PWME. Most mail comes from the latter. These people are desperate for hope. One person wrote recently: “I don’t want more GE/CBT/Pacing...

I’m sick of it. I just want someone to investigate what is going wrong with my body. It’s as simple as that.”

<http://erythos.com/RiME/Docs/NL0305.rtf>

94. Patricia Sanders and Jakob Korf, PhD

Chronic fatigue syndrome (CFS) is now recognized as a medical disorder. In contrast to recent related reports, the present review focuses primarily on aetiological aspects of CFS. Four major hypotheses are reviewed. (1) Although CFS is often associated with viral infection, the presence of viruses has as yet not consistently been detected. (2) It is not clear whether anomalies of the HPA axis often observed in CFS, are cause or the consequences of the disorder. (3) Immune dysfunction as the cause of CFS is thus far the weakest hypothesis.

(4) The psychiatric and psychosocial hypothesis denies the existence of CFS as a disease entity. Accordingly, the fatigue symptoms are assumed to be the consequence of other (somatic) diseases. Other possible causes of CFS

are oxidative stress and genetic predisposition. In CFS cognitive behavioural therapy is most commonly used. This therapy, however, appears to be ineffective in many patients. The suggested causes of CFS and the divergent reactions to therapy may be explained by the lack of recognition of subgroups. Identification of subtypes may lead to more effective therapeutic interventions.

Summary Neuroaetiology of chronic fatigue syndrome: An overview World Journal of Biological Psychiatry 2008, Vol. 9, No. 3, Pages 165-171 , DOI 10.1080/15622970701310971

<http://informahealthcare.com/doi/abs/10.1080/15622970701310971?cookieSet=1&journalCode=wbp>

95. velogubbed

People with M.E don't want sympathy – they just want the nonsense to stop. They want proper biomedical research to be funded at government level, they want the patronising, arrogant approach of the champions of CBT to stop. CBT and graded exercise will not cure M.E – it may cure other things but it will not cure M.E. People with ME are no more mentally ill than the rest of the population. There is in fact NO evidence that CBT and graded exercise help people with genuine M.E.

There *is* however evidence that graded exercise can make people with M.E worse. Testimonies of people with M.E were actually ignored in the NICE studies.

<http://www.guardian.co.uk/commentisfree/2007/nov/16/sickmadorbad>

96. MerkinOnParis

“At present there is no convincing evidence that any treatments work except CBT and graded exercise.’Nonsense. In fact, as has been pointed out this may actually make matters worse.The reason that CBT is touted for ME and Depression is that the Government is basing Pathways to Work on the American welfare system where the Insurance companies involved are allowed carte blanche in efforts to get people off welfare.This includes fitting the illness to the desired cost outcome regardless of clinical need.

<http://www.guardian.co.uk/commentisfree/2007/nov/16/sickmadorbad>

97. Yamila Samsun

Why are there millions of CBT studies but no psychologist has ever done one in patients with (very) severe ME? Just think about it. If CBT would be the solution and the wonder therapy why is there no study showing that patients who are tube fed can eat again because they had CBT? Or they don't need washing in bed or a bottle for urinating because they now can walk again. The reason is very simple. Of the patients with (very) severe ME, almost all of them have ME.

They don't have psychiatric illnesses or fall in the category, we are all a bit tired at times. It would be really nice if CBT would help/cure them but that is just as likely as it would help patients walk again if they are wheelchair bound due to MS or a spinal cord injury after an RTA. And that is the real reason why there are no CBT studies in patients where there is no doubt that they have ME. And don't say we can't find those patients with (very) severe ME, because estimates say there are 50-60,000 of them in the UK alone.

Back to Basics <http://www.bmj.com/cgi/eletters/335/7617/446#175606>

98. Dr Derek Englander

I decided to attempt to determine the effectiveness of the Graded Exercise Therapy (GET) protocol in a known patient group suffering from Myalgic Encephalomyelitis (ME). The protocol was tested in a simple manner without double blinding but the original research was also subjective. Twenty patients with Myalgic Encephalomyelitis (ME) diagnosed according to the Fukuda criteria (3) were started on the GET protocol. After 24-48 hours of the onset of GET, twelve of the patients succumbed to relapse in their symptoms: massive fatigue, increased muscle pain, pains in joints, brain “fog”.

During the following week seventeen of the twenty patients suffered from increased symptoms as delineated above. The protocol was continued for three weeks. There was no improvement. Some patients were so severely affected that they were bedridden for four weeks following the protocol.

GET was pronounced as the most effective method of treatment of ME by NICE. From this short but rather apparent review of the GET protocol, it is obvious that either the study group used initially by the NICE research did not suffer from ME or the results were not adequately analysed. It is apparent that this treatment is not the treatment of choice, in fact it is detrimental to the well being of the ME patient.

The psychiatric psychopolitical group have used GET as a lever to support their theory, GET is unhelpful and unhinges their theory. NICE and ineffective GET Therapy

<http://www.bmj.com/cgi/eletters/335/7617/446#175606>

99. Dr Andrew Ashley

I have been going through the responses and in Belgium 18% worked before CBT and Nijmegen claims 69% gets cured by CBT than 18 plus 69 = 87%, so 87% should be back at work after CBT. But apparently it is only 14.9%; so what is the evidence for treating ME with CBT?

CBT makes you more ill <http://www.bmj.com/cgi/eletters/335/7617/446#175606>

100. Tom Kinlon

On the issue of group CBT, which is available in many NHS CFS services around the UK, St Bartholomew's Hospital Chronic Fatigue Services gave the following research information: "The only RCT of CBT using a group approach showed that the treatment was no better than either usual medical care or supportive listening in improving physical function, one of its two primary outcomes, which it was designed to improve (O'Dowd H, Gladwell P, Rogers CA, Hollinghurst S, Gregory A. Cognitive behavioural therapy in chronic fatigue syndrome: a randomised controlled trial of an outpatient group programme. Journal: Health Technol Assess. 2006 Oct;10(37):1-140). A non-randomised waiting list control trial of group delivered CBT found only modest effects on fatigue and negative effects on function (Bazelmans E, Prins JB, Lulofs R, van der Meer JWM, Bleijenberg G. Cognitive behaviour group therapy for chronic fatigue syndrome: a non-randomised waiting list controlled study. Psychotherapy & Psychosomatics 2005;74:218-24)."

Stakeholders comments on Draft Guidelines make for interesting reading

<http://www.bmj.com/cgi/eletters/335/7617/446#175606>

101. Dr Peter Saunders

Tip FIVE: discuss CBT, if it cures the patient your diagnosis of ME was wrong.

Tip SIX: ME patients have the so called threshold phenomenon, meaning that they can't increase their stamina like healthy people. If they can or if GET helps to improve their stamina then again, the diagnosis of ME was wrong.

Quick guideline to ME for busy GPs.

<http://www.bmj.com/cgi/eletters/335/7617/446#175606>