

National Institute for Health and Clinical Excellence  
 CFS/ME consultation draft  
 29 September – 24 November 2006  
 Comments on the Appendices

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Status	SH organisation	Order no.	Document	Page No.	Line no.	Comments	Response
SH	Action for M.E.	3	FULL, Appendix 1	17		It is stated that, "No studies were able to establish the superiority of one existing case definition over another". Our constituents have queried the omission of the Canadian guidelines in the development of diagnostic criteria.	We will feed these comments to the team who completed the review.  Please also see the discussion of diagnosis in Chapter 5.
SH	ME Research UK (formerly MERGE)	35	References Consulted			References (in alphabetical order)  25% ME Group. 2004. Severely affected ME (myalgic encephalomyelitis) analysis report on a questionnaire issued January 2004. 25% ME Group, Troon, Ayrshire, UK. <a href="http://www.25megroup.org/">http://www.25megroup.org/</a>  Acheson ED. The clinical syndrome variously called benign myalgic encephalomyelitis, Icelandic disease and	Noted – thanks.

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						<p>epidemic neuromyasthenia. American Journal of Medicine 1959; 569: 595.</p> <p>Andersen MM, Permin H, Albrecht F. Illness and disability in Danish Chronic Fatigue Syndrome patients at diagnosis and 5-year follow-up. J Psychosom Res 2004 ;56(2): 217-29.</p> <p>Bolsover N. Commentary: the evidence is weaker than claimed. British Medical Journal 2002; 384: 294.</p> <p>Baraniuk JN et al. A chronic fatigue syndrome – related proteome in human cerebrospinal fluid. BMC Neurology 2005; 5: 22.</p> <p>Bazelmans E, Bleijenberg G, Van Der Meer JW, Folgering H. Is physical deconditioning a perpetuating factor in chronic fatigue syndrome? A controlled study on maximal exercise performance and relations with fatigue, impairment and physical activity. Psychol Med. 2001</p>	

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						<p>Jan;31(1):107-14.</p> <p>Cairns R, Hotopf M. A systematic review describing the prognosis of chronic fatigue syndrome. <i>Occup Med (Lond)</i>. 2005 Jan;55(1):20-31.</p> <p>Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM, Bsted AC, Flor-Henry P, Joshi P, Powles ACP, Sherkey JA, van de Sande MI. Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Clinical Working Case Definition, Diagnostic and Treatment Protocols. <i>Journal of Chronic Fatigue Syndrome</i> 2003; 11 (1): 7-116.</p> <p>Chalder et al. Inpatient treatment of CFS. <i>Behav Cognit Psych</i> 1996; 24: 351-365.</p> <p>Chambers D, Bagnall AM, Hempel S, Forbes C. Interventions for the treatment, management and rehabilitation of patients with chronic fatigue syndrome/myalgic</p>	

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						<p>encephalomyelitis: an updated systematic review. J R Soc Med 2006; 99(10): 506-20.</p> <p>Chia JKS. The role of enterovirus in chronic fatigue syndrome", Journal of Clinical Pathology, 2005; 58: 1126-1132.</p> <p>Chief Medical Officer. A Report of the CFS/ME Working Group. Report to the Chief Medical Officer of an Independent Working Group. February 2002.</p> <p>Crowhurst G. Supporting people with severe myalgic encephalomyelitis. Nurs Stand 2005; 19(21): 38-43.</p> <p>De Becker et al. A definition based analysis of symptoms in a large cohort of patients with CFS. Journal of Internal Medicine 2001; 250: 334-40.</p> <p>De Meirleir K, Bisbal C, Campine I, De Becker P, Salehzada T, Demettre E, Lebleu B. A 37 kDa 2-5A binding protein as a potential biochemical marker for</p>	

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						<p>chronic fatigue syndrome. Am J Med 2000; 108(2): 99-105.</p> <p>Deale A, Husain K, Chalder T, Wessely S. Long-term outcome of cognitive behavior therapy versus relaxation therapy for chronic fatigue syndrome: a 5-year follow-up study. Am J Psychiatry 2001; 158(12): 2038-42.</p> <p>Devanur LD, Kerr JR. Chronic fatigue syndrome. J Clin Virol 2006; 37(3): 139-50.</p> <p>De Lange FP, Kalkman JS, Bleijenberg G, Hagoort P, van der Meer JW, Toni I. Gray matter volume reduction in the chronic fatigue syndrome. Neuroimage 2005; 26(3): 777-81.</p> <p>Dowsett EG et al. Myalgic encephalitis - a persistent enteroviral infection? Postgraduate Medical Journal 1990; 66: 526-30.</p> <p>Essame CS, et al. Pilot study of a</p>	

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						<p>multidisciplinary inpatient rehabilitation of severely incapacitated patients with CFS. JCFS 1998; 4(2): 51-60.</p> <p>Freiberg F. A subgroup analysis of cognitive behavioural treatment studies. Journal of Chronic Fatigue Syndrome 1999; 5: 3-4 &amp; 149-59.</p> <p>Fukuda K et al. The chronic fatigue syndrome: A comprehensive approach to its definition and study. Annals of Internal Medicine 1994; 121: 953-9.</p> <p>Fulcher KY &amp; White PD. 2000. Strength and physiological response to exercise in patients with chronic fatigue syndrome. Journal of Neurology, Neurosurgery, and Psychiatry 69: 302-307.</p> <p>FULLe S, Belia S, Vecchiet J, Morabito C, Vecchiet L, Fano G. Modification of the functional capacity of sarcoplasmic reticulum membranes in patients suffering from chronic fatigue syndrome.</p>	

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						<p>Neuromuscul Disord 2003; 13(6): 479-84.</p> <p>Holmes J. All you need is cognitive behavioural therapy? British Medical Journal 2002; 384: 288-90.</p> <p>Huibers MJ, Wessely S. The act of diagnosis: pros and cons of labelling chronic fatigue syndrome. Psychol Med 2006; 36(7): 895-900.</p> <p>Jason LA et al. Politics, Science, and the Emergence of a New Disease: The Case of Chronic Fatigue Syndrome. American Psychologist 1997; 52(9): 973-83.</p> <p>Jason LA et al. Chronic Fatigue Syndrome: The Need for Subtypes. Neuropsychology Review 2005; 15(1): 29-58.</p> <p>Katon W, Russo J. Chronic fatigue syndrome criteria. A critique of the requirement for multiple physical complaints. Archives of Internal Medicine</p>	

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						<p>1992; 152: 1604-9.</p> <p>Kaushik N, Fear D, Richards SC, McDermott CR, Nuwaysir EF, Kellam P, Harrison TJ, Wilkinson RJ, Tyrrell DA, Holgate ST, Kerr JR. Gene expression in peripheral blood mononuclear cells from patients with chronic fatigue syndrome. <i>J Clin Pathol</i> 2005; 58(8): 826-32.</p> <p>Kennedy G, Spence VA, McLaren M, Hill A, Underwood C, Belch JJ. Oxidative stress levels are raised in chronic fatigue syndrome and are associated with clinical symptoms. <i>Free Radic Biol Med</i> 2005; 39(5): 584-9.</p> <p>Kennedy G, Abbot NC, Spence V, Underwood C, Belch JJ. The specificity of the CDC-1994 criteria for chronic fatigue syndrome: comparison of health status in three groups of patients who fulfill the criteria. <i>Ann Epidemiol</i> 2004; 14(2): 95-100.</p> <p>Khan F, Kennedy G, Spence VA,</p>	



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						<p>Newton DJ, Belch JJ. Peripheral cholinergic function in humans with chronic fatigue syndrome, Gulf War syndrome and with illness following organophosphate exposure. Clin Sci (Lond) 2004; 106(2): 183-9.</p> <p>Lane RJ et al. Muscle fibre characteristics and lactate responses to exercise in chronic fatigue syndrome. Journal of Neurology, Neurosurgery and Psychiatry 1998; 64: 362-7.</p> <p>Lane RJ. Chronic fatigue syndrome: is it physical? Journal of Neurology, Neurosurgery and Psychiatry 2000; 69: 280.</p> <p>Lane RJM, Soteriou BA, Zhang H, Archard LC. Enterovirus related metabolic myopathy: a postviral fatigue syndrome. Journal of Neurology, Neurosurgery, and Psychiatry 2003; 74: 1382-1386.</p> <p>Lange G, Steffener J, Cook DB, Bly BM,</p>	

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						<p>Christodoulou C, Liu WC, Deluca J, Natelson BH. "Objective evidence of cognitive complaints in Chronic Fatigue Syndrome: a BOLD fMRI study of verbal working memory." Neuroimage. 2005 Jun;26(2):513-24.[PDF Format]</p> <p>Lerner AM, Dworkin HJ, Sayyed T, et al. Prevalence of abnormal cardiac wall motion in the cardiomyopathy associated with incomplete multiplication of Epstein-barr Virus and/or cytomegalovirus in patients with chronic fatigue syndrome. In Vivo 2004; 18(4): 417-24.</p> <p>McCully KK, Smith S, Rajaei S, Leigh JS Jr, Natelson BH. Muscle metabolism with blood flow restriction in chronic fatigue syndrome. J Appl Physiol 2004; 96(3): 871-8.</p> <p>Mulrow CD, Ramirez G, Cornell JE, et al. Defining and Managing Chronic Fatigue Syndrome. Evidence Report/Technology Assessment No. 42. AHRQ Publication</p>	

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						<p>No. 02-E001. Rockville (MD): Agency for Healthcare Research and Quality: October 2001. Available from: <a href="http://www.ahrq.gov">www.ahrq.gov</a>.</p> <p>Natelson BH, Weaver SA, Chin-Lin Tseng, and Ottenweller, JE. "Spinal Fluid Abnormalities in Patients with Chronic Fatigue Syndrome" <i>Clinical and Diagnostic Immunology</i>. Jan. 2005. p. 562-55. [PDF Format]</p> <p>Nijs J, Meeus M, McGregor NR, Meeusen R, De Schutter G, Van Hoof E, De Meirleir K. Chronic fatigue syndrome: exercise performance related to immune dysfunction. <i>Medicine and Science in Sports and Exercise</i> 2005; 37(10): 1647-1654.</p> <p>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.</p>	

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						<p>Health Technol Assess 2006; 10(37): 1-140.</p> <p>Paul L, Wood L, Behan WM, Maclaren WM. Demonstration of delayed recovery from fatiguing exercise in chronic fatigue syndrome. <i>European Journal of Neurology</i> 1999; 6(1): 63-9.</p> <p>Pierce S and Pierce PW. The physiology of exercise intolerance in patients with myalgic encephalomyelitis (ME) and the utility of graded exercise therapy. In Press. 2006.</p> <p>Pinching AJ. Chronic Fatigue Syndrome. <i>Prescriber's Journal</i> 2000; 40; 99-106.</p> <p>Powell et al. The treatment of wheelchair-bound chronic fatigue syndrome patients: two case studies of a pragmatic rehabilitation approach. <i>Behavioural and Cognitive Psychotherapy</i> 1999; 27: 249-60.</p> <p>Powell P, Bentall RP, Nye FJ, Edwards</p>	

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						<p>RH. Randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome. <i>BMJ</i> 2001;322:387–90</p> <p>Prins JB et al. Cognitive behaviour therapy for chronic fatigue syndrome: a multicentre randomised controlled trial. <i>Lancet</i> 2001; 357: 841-7.</p> <p>Reeves WC, Wagner D, Nisenbaum R, Jones JF, Gurbaxani B, Solomon L, Papanicolaou DA, Unger ER, Vernon SD, Heim C. Chronic fatigue syndrome - a clinically empirical approach to its definition and study. <i>BMC Med</i> 2005 15; 3: 19.</p> <p>Ridsdale L, Godfrey E, Chalder T, Seed P, King M, et al. Chronic fatigue in General practice: is counseling as good as cognitive behaviour therapy? A UK randomised trial. <i>Br J Gener Pract</i>, Jan. 2001;51:19-24.</p> <p>Sharpe MC, Archard LC, Banatvala JE,</p>	

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						<p>Tan EM et al. The case definition of chronic fatigue syndrome. Journal of Clinical Immunology 2002; 22: 8-12.</p> <p>Tirelli U, Chierichetti F, Tavio M, Simonelli C, Bianchin G, Zanco P, Ferlin G. Brain positron emission tomography (PET) in chronic fatigue syndrome: preliminary data. Am J Med 1998; 105(3A): 54S-58S.</p> <p>Van der Werf et al. Identifying physical activity patterns in chronic fatigue syndrome using actigraphic assessment. Journal of Psychomotor Research 2000; 49: 373-9.</p> <p>Wearden AJ, Morriss RK, Mullis R, Strickland PL, Pearson DJ, Appleby L, Campbell IT, Morris JA. Randomised, double-blind, placebo-controlled treatment trial of fluoxetine and graded exercise for chronic fatigue syndrome. Br J Psychiatry 1998; 172: 485-90.</p> <p>Wessely S. Chronic fatigue syndrome-</p>	

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						<p>trials and tribulations. Journal of the American Medical Association 2001; 286: 1378.</p> <p>Whiting P, Bagnall A-M, Sowden AJ, et al. Interventions for the treatment and management of chronic fatigue syndrome: a systematic review. Journal of the American Medical Association. 2001;286:1360-8.</p>	
SH	The British Psychological Society	58	Appendix	16	Table	The London criteria. The details are based on incomplete information. There are exclusions e.g. all psychiatric disorders. These are listed on the complete photocopy, available from AFME.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	59	Appendix	17	Para 2	The London criteria were used in at least one study in the review (Perrin), the Dowsett criteria of 1990 were not. Did the authors confuse the Dowsett criteria 1990 with the London criteria (Dowsett et al 1994) as Jason et al 2003 did?	We will feed these comments to the team who completed



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							the review.
SH	The British Psychological Society	60	Appendix	18	Para 2	It's not clear from the article by Jason et al if they used the Dowsett criteria 1990 or just one of the criteria common to both the Dowsett and London criteria (i.e. post-exertional fatigue). In one place, they refer to the 'Dowsett London criteria 1990'. This is clearly an error. One solution may be to refer to the criteria for ME.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	61	Appendix	50	Para 1	One would expect the Ridsdale et al study on counselling to be included here. It was included in the original review.	The Ridsdale study included people with chronic fatigue, not CFS.
SH	The British Psychological Society	62	Appendix	54	Table	Friedberg and Krupp. This study combined CBT with pacing. That is possible. Results indicated an improvement in the subgroup with higher	We will feed these comments to the team

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Status	SH organisation	Order no.	Document	Page No.	Line no.	Comments	Response
						depression scores. This is not clear from the summary.	who completed the review.
SH	The British Psychological Society	63	Appendix	General	Table	Ridsdale et al 2004 compared CBT and GET in a sample with fatigue and CFS. Like Prins et al. Prins et al was included in the CRD review, though not everyone met criteria for CFS. Why did the CRD not include Ridsdale et al 2004 when mixed samples are acceptable?	Prins 2001 included people who met the CFS 1994 criteria.
SH	The British Psychological Society	64	Appendix	81	Para 2	This broad-based programme included medical care, drugs, and pacing. To describe it as “information and advice” is misleading. Validity score should be 3, not 2 (factual error).	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	65	Appendix	88	Para 2	Again, no mention that CBT is as effective as counselling. Also, the CBT trial which showed no effect (Lloyd et al) did not have a low validity score, but did use a strictly-defined, severely-affected	We will feed these comments to the team who

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						sample. This is significant. Studies using strictly-defined samples do not show the same benefits as trials involving more broadly-defined patients (see also Friedberg and Krupp). This may explain the discrepancy between research findings and the reports from patients. The summaries clearly favour CBT and GET, and do not take account of some of the serious flaws, e.g. failure to measure activity levels objectively (e.g. with actometer), no assessment of somatic symptoms, inclusion of the less affected (Sharpe et al) etc.	completed the review.
SH	The British Psychological Society	66	Appendix	94	Table	Re combination, ref 211. Treatment was judged to have no overall effect, despite significant differences on five outcome measures (somatic symptoms, fatigue, self-efficacy, anxiety and depression), 23% completely or virtually recovered within 6 months and the fact that 82% felt better or ‘much better’. Improvements were maintained at 12	We will feed these comments to the team who completed the review.  Please also see the

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						months follow-up. The judgement of no overall effect seems very odd.  This is one of the few studies assessing an alternative rehabilitation programme to CBT/GET. It deserves an objective and accurate evaluation. Information about this trial elsewhere in the document also reveals a number of errors. Although obviously a coincidence, it adds to the impression that the CRD favours the CBT and GET trials, and appears less interested in alternative rehabilitation programmes.	response to comments in Chapter 2.
SH	The British Psychological Society	67	Appendix	112	Ref 13	Reference is incorrect. Dowsett EG, Gouldsmit E, MacIntyre A. Should read Dowsett, E, Goudsmit, E, Macintyre, A and Shepherd, C.	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	68	Appendix	170	Table	Jason et al 2003. Did they use the Dowsett criteria 1990? This just isn't	We will feed these

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						clear from their paper. They appear to have studied patients with post-exertional malaise.	comments to the team who completed the review.
SH	The British Psychological Society	69	Appendix	420	Table	Perrin. This paper mentions using the London criteria as well as the CDC criteria (1998, p.2).	We will feed these comments to the team who completed the review.
SH	The British Psychological Society	70	Appendix	426	Table	Re Goudsmit. There is no Hamilton Anxiety and depression scale. Do they mean the Hospital Anxiety and Depression Scale. Re Self-efficacy, if there was a significant difference, $p=.013$ , not .13? (Outcome 2)  Significant difference in depression and anxiety scores ( $p=.04$ ). Table states no significant differences. (This study comes from a member of the British	We will feed these comments to the team who completed the review.

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						Psychological Society, hence the detailed knowledge).	
SH	The British Psychological Society	71	FULL	442	Table B	Validity score Goudsmit is 3, not 2. It was 2 in the original review, since changed to 3 (2005).	We will feed these comments to the team who completed the review.