

SAYING NO CAN BE POSITIVE Spring 2006 (updated 2007)

The following has been designed to support M.E. sufferers who choose to **not** attend the current NHS Chronic Fatigue Syndrome/Myalgic Encephalomyelitis clinics recently set up across the country. These clinics have been based upon the Chief Medical Officer's report from 2002 and consist mainly of psychological therapies such as Cognitive Behavioural Therapy and graded exercise. This document may also support M.E. patients who refuse to participate in the PACE and FINE trials recently set up by the Medical Research Council, which also endorse psychological therapies. Bedbound/housebound sufferers who are advised to have these therapies on domiciliary visits may also find this document helpful. It may also help those pressurised to undertake CBT and graded exercise by Private Health Insurers.

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 if the patient is deemed to be mentally competent. Medical practitioners cannot give a treatment to a patient without the patient's consent.¹ Scientifically, M.E. is NOT in Mental Health, see below.

2) An M.E. patient who is in a comatose/semi comatose state cannot by law be forced into psychological treatment just because they have M.E.²

3) 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.³ The following organisation may offer help, including a free telephone appointment for legal advice:

Disability Law Service
Ground Floor
39-45 Cavell Street
London
E1 2BP

Tel: 020 7791 9800
Email: advice@dls.org.uk

4) An M.E. patient cannot have their state benefits withdrawn for refusing CBT and graded exercise. U.K. law says that if a patient refuses suitable treatment without good cause, benefits can be withdrawn.⁴ However, CBT and graded exercise could be argued as unsuitable treatments for M.E. sufferers (see facts below).

5) M.E. is a neurological disorder. It has been classified as such by the World Health Organisation in the International Classification of Diseases since 1969.⁵ Therefore psychological therapies could well be inappropriate.

6) 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.⁶ It includes detailed world-wide epidemics of M.E. since 1934 and the viruses which triggered the disease.

7) There are over 2,000 papers showing that M.E. is an organic disorder, according to Prof. Anthony Komaroff (Professor of Medicine at Harvard).⁷

8) 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.⁸ Although these tests aren't always offered by the NHS for M.E., they have nevertheless shown evidence of physical abnormalities.

9) "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 1984.⁹ Dr. Hyde stresses that M.E. is primarily a disease of the Central Nervous System.¹⁰

10) 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, *all of them different.*¹¹ ***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.***¹² ***The PACE and FINE trials use the Oxford Criteria.***¹³

11) 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.¹⁴ Also, there is evidence indicating pathology of the central nervous system and immune system¹⁵ and evidence of metabolic dysfunction in the exercising muscle.¹⁶ Also, Dr. Jay Goldstein has demonstrated through SPECT scans the severely decreased brain perfusion of an M.E. patient 24 hours after physical exercise.¹⁷ The Canadian Criteria (2003) states that ***the worsening of symptoms after exertion is a principal symptom of M.E.***¹⁸ Raised levels of noxious by-products of abnormal cell membrane metabolism, associated with exercise and correlating with patients' symptoms have been demonstrated.¹⁹

12) 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.***²⁰ 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.***²¹

13) 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.

14) Medical Concerns have been raised about the CMO's Report. The *Journal of Chronic Fatigue Syndrome*,²² 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.”*** (Quote)

References

- ¹ See the case of St.George's Healthcare NHS Trust v S (1998) 3 All ER 673 (Court of Appeal), p.758 of Hepple, Howarth and Matthews Tort, Cases and Materials, 5th Edition by DR Howarth and JA O'Sullivan, ISBN 0 406 063265 (Butterworths, 2000)
- ² Ibid., see section attributed to Lord Brandon of Oakbrook, pp.744, 745
- ³ The Human Rights Act 1998, European Convention for the Protection of Human Rights and Fundamental Freedoms, Section 1, Article 10, no.1
- ⁴ 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.
- ⁵ World Health Organisation - International Classification of Diseases 10-G93.3
- ⁶ 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
- ⁷ See the paper 'Illustrations of Clinical Observations and International Research Findings from 1955 – 2005 that demonstrate the organic aetiology of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome' by Hooper, Marshall, Williams, 2005, page 6
- ⁸ 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.
- ⁹ Ibid., A Physician's Guide to Myalgic Encephalomyelitis Chronic Fatigue Syndrome, page 25
- ¹⁰ 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.
- ¹¹ 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.
- ¹² Katon & Russo, 1992; Freiberg, 1999, Unhelpful Counsel? MERGE's response to the CMO report on CFS/ME, 2002, p15.
- ¹³ See the website of the Medical Research Council at www.mrc.ac.uk
- ¹⁴ 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
- ¹⁵ The Biology of the Chronic Fatigue Syndrome, Prof. Anthony Komaroff, The American Journal of Medicine 2000: 108: 99-105.
- ¹⁶ Mitochondrial abnormalities in the postviral fatigue syndrome, Behan, W.M.H. et al., Acta Neuropathologica 83, 1991, pages 61-65.
- ¹⁷ 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.
- ¹⁸ Journal of Chronic Fatigue Syndrome Vol. 11, No.1, 2003, Canadian Criteria, page 22, The Haworth Press Inc.
- ¹⁹ 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
- ²⁰ 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.
- ²¹ Analysis Report by 25% ME Group March 2004 www.25megroup.org
- ²² See footnote 18, page 2 of the Editorial

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

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